BODY IMAGE FOLLOWING CANCER TREATMENT

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BODY IMAGE FOLLOWING CANCER TREATMENT

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Table of Contents

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Editorial: Body image following cancer treatment

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Editorial on the Research Topic
Body image following cancer treatment

Significant medical advances in screening, prevention, and successful treatment in recent decades have increased the number of people living with and beyond cancer worldwide every year (Hulvat, 2020). Many of these people are recommended to receive aggressive treatments in order to prevent metastasis and improve survival (Shrestha et al., 2019). The aggressive nature of these treatments can often lead to significant changes to an individual's body. This includes, but is not limited to, changes to their appearance (e.g., surgical scars, removal of individual body parts, limb swelling, anorexia, and hair loss), sensory changes (e.g., pain, numbness, tingling, burning), functional changes (e.g., changes to speech, swallowing, hearing, eyesight, bowel/bladder incontinence), sexuality/fertility effects, weight gain or weight loss, loss of mobility, and the need to use of prosthetic devices (Fingeret, 2011). These changes to an individual's body resulting from cancer treatment can have a substantial impact on their everyday life, particularly in relation to their body image.

Body image is a multidimensional construct describing an individual's mental representation of their body, including their total concept of conscious and unconscious feelings, thoughts, and perceptions about their bodies, as well as their awareness of how others perceive them (Alebachew and Ashagrie, 2017). In the context of cancer treatment, it has become common to examine body image as it relates to body image disturbances and associated distress. For instance (Rhoten, 2016) has identified the following core attributes of body image disturbance in adults who have undergone cancer treatment: (1) dissatisfaction with a perceived change in appearance resulting from cancer treatment; (2) decline in function relating to some aspect of one's body; and (3) psychological distress regarding these changes.

Body image disturbance and distress are known to affect a range of psychosocial factors for individuals following cancer treatment. In particular, heightened concerns relating to a changed appearance following cancer treatment may lead some individuals to avoid contact with others altogether and become isolated (Fingeret et al., 2014; Fingeret and Teo, 2018). Changes in body image resulting from cancer and its treatment may also have deleterious effects on other aspects of a person's daily life, such as their experiences of sexuality and relationships (Pelusi, 2006; Sacerdoti et al., 2010; Faria et al., 2021). However, while some studies have shown a direct relationship between self-reported dissatisfaction with body image and emotional, functional, physical, and social wellbeing following cancer treatment, such findings have been inconsistent in the literature, particularly in relation to cancers such as head and neck cancer (Howren et al., 2013).

The potential complexity of the relationship between body image and wellbeing following cancer treatment has been underscored by a diverse literature which has examined how socio-demographic and clinical factors can influence this relationship. For instance, a recent systematic review of older breast cancer survivors found that older women, particularly those who are post-menopausal, may be less affected by changes to their appearance following breast cancer treatment (Davis et al., 2020). In addition to these variables, other socio-demographic and clinical factors which have been demonstrated to affect the relationship between body image and wellbeing following cancer treatment, include gender, marital status, income, education level, cancer stage, treatment type, and many other such variables (Rezaei et al., 2016; Albert et al., 2022). This demonstrates the need for a nuanced understanding of the complex inter-relationship between body image and clinical, demographic, functional, and psychosocial variables. However, there is still a limited literature base examining the impact of such relationships longitudinally.

The inherent subjectivity in the experience of body image following cancer treatment has also been noted in the literature. It is increasingly recognized that sensitivity toward bodily changes following cancer treatment varies among those affected and is not necessarily proportional to the amount of change experienced (Rhoten, 2016). A growing body of research has begun to examine the differential subjective impact of body changes following cancer treatment by investigating the mediating or moderating influence of particular variables on the relationship between body image and wellbeing. For instance, investment in appearance has been identified as a variable that may have a particularly important moderating effect on the relationship between body image and emotional wellbeing (Helms et al., 2008; Sherman et al., 2017). There is a need to continue this work of disambiguating the subjective experience of body image following cancer treatment through examining possible mediating and moderating variables, and through qualitative research examining the subjective experience of living with a changed body following cancer treatment.

The increasing use of body image screening and interventions in oncology settings also underscores the importance of this topic. Body image measurement and screening is particularly important to allow health professionals and intervention developers to identify at-risk individuals who may be targeted for tailored interventions that ameliorate the deleterious effects of cancer treatment on body image among cancer survivors. However, there is a growing recognition of the lack of gold standard approaches to body image screening and measurement (Covrig et al., 2021). In relation to body image interventions, systematic reviews have highlighted the potential usefulness of cognitive-behavioral therapy, social interaction skills training, and physical activity interventions in promoting positive body image (Lewis-Smith et al., 2018). Nevertheless, there are inherent methodological limitations and limited use of randomized controlled trials in this work, which make it difficult to draw definitive conclusions about the efficacy of such interventions (Lewis-Smith et al., 2018). There is also a need for more tailored interventions that focus on developing positive body image in relation to men or for cancer populations beyond breast cancer (Esplen and Fingeret, 2021).

The articles presented in the current collection go some way to addressing core issues in the literature base, which we have identified above. The collection brings together quantitative research exploring the longitudinal relationship between body image and wellbeing and mediating factors involved in this relationship, qualitative research, and patient-driven perspectives which spotlights cancer survivors' body image needs and intervention preferences following cancer treatment, and reviews of the literature and commentaries which synthesize important learnings from research on body image in specific cancer groups. We also present some exciting new work, involving the validation of novel scales addressing body image and formal evaluations of interventions designed to improve outcomes among cancer survivors who are impacted by body image changes.

Author contributions

SD: conceptualization, original manuscript preparation, and writing—review and editing. MF and CS: conceptualization, manuscript review, and editing. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Mediator Roles of Social Support and Hope in the Relationship Between Body Image Distress and Resilience in Breast Cancer Patients Undergoing Treatment: A Modeling Analysis

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Breast cancer and its treatment are particularly distressing for patients because of their potential impacts on body image. The most difficult phase of cancer treatment is usually the first year after a diagnosis. Cancer patients with strong resilience have the positive attitude, internal strength and external resources needed to cope with the disease and its treatment. This cross-sectional study investigated the mediator roles of hope and social support in the association between body image distress and resilience. A structured questionnaire was used to collect data for a convenience sample of 141 breast cancer patients undergoing treatment in southern Taiwan. Structural equation modeling was used for data analysis. The results showed that the final model had a good fit to the data and accounted for 51% of the total variance in resilience. The model of multiple parallel mediators of resilience revealed that hope and social support had mediator roles in the effect of body image distress on resilience. Hope had an important partial mediating role in the association between body image distress and resilience. Social support also had a partial mediating role in the relationship between body image distress and resilience. Social support did not directly affect resilience and indirectly affected resilience through hope. Psychosocial interventions aimed at reducing the impact of body image distress and increasing resilience in breast cancer patients should focus on cultivating hope and increasing social support, particularly support from family members and health professionals.

Keywords: resilience, hope, social support, breast cancer, body image distress

INTRODUCTION

Breast cancer is the most common cancer in women worldwide (Gradishar et al., 2020). In Taiwan, the incidence of breast cancer in women exceeds that of all other cancer types (Hsu et al., 2017). Statistically, breast cancer is rare in women younger than 25 years, but the incidence increases with age until age 50 years and then plateaus at ages 50–69 years (Health Promotion Administration Ministry of Health Welfare, 2018). Current treatment for stage I-III breast cancer is mainly surgical treatment combined with adjuvant therapy. Stage IV breast cancer is mainly treated with systemic therapy, including chemotherapy, hormone therapy, targeted therapy, immunotherapy or some combination of these (Gradishar et al., 2020). Although these treatments improve survival, breast cancer patients face many challenges during treatment, including the physical impacts of the disease, its treatment, and treatment side effects as well as psychological and social impacts of the cancer experience such as loss of hope and a sense of lost control over life (Hsu et al., 2017; Li et al., 2018). These experiences have strong associations with body image distress (Rezaei et al., 2016).

For patients, the most difficult phase of cancer treatment is usually the first year after a diagnosis (Park et al., 2017), in which patients experience the diagnosis, symptoms, treatment, and side effects. Breast cancer and its treatment are highly distressing because of their potentially large impacts on body image. Promoting resilience is an essential component of psychological and social care for these patients, and the role of resilience in cancer recovery has recently attracted the attention of researchers. For example, researchers have established a significant positive association between resilience and quality of life (QOL) in breast cancer patients (Zhang et al., 2017). Factors that reportedly contribute to resilience in diverse cancer populations include social support and hope (Li et al., 2016). Each phase of the cancer experience profoundly affects the life of the patient, and the role of resilience differs in each phase. Therefore, the current study investigated the association between body image distress and resilience in breast cancer patients undergoing treatment as well as the roles of hope and social support in this association.

Body Image Distress

Body image can be defined as a mental image of one's body as well as an attitude about one's appearance, state of health, and sexual functioning (Rezaei et al., 2016). Thus, a negative body image can cause body image distress. Surgery can negatively affect body image by causing physical changes such as post-operative scarring, swelling, redness or lymphedema. Tumors, scars, and disfigurement can contribute to body image distress by causing a loss of identity and a sense of lost control over the body (Yamani Ardakani et al., 2020). Additionally, chemotherapy and hormone therapy can cause body changes such as hair loss, weight gain, vaginal dryness, etc. These changes can diminish self-perceived sexual attractiveness, libido, and even fertility (Kołodziejczyk and Pawłowski, 2019). Patients may also experience emotional distress caused by a sense of lost control over their bodies, impaired body image, and the fear of cancer recurrence (Yamani Ardakani et al., 2020). In breast cancer patients, body image distress has been linked to late cancer stage and increased time since diagnosis (Mcclelland et al., 2015). Therefore, we hypothesized the following:

Hypothesis 1 (H1): Cancer stage is significantly associated with body image distress.
Hypothesis 2 (H2): Time since diagnosis is significantly associated with body image distress.

Resilience

Resilience can be defined as the ability of an individual to maintain or restore relatively stable psychological and physical functioning even when living under adverse conditions or circumstances (Seiler and Jenewein, 2019). That is, resilience is not a personality trait, but a dynamic process in which life changes motivate an individual to restore balance or establish a new balance in life and to evolve positively. Such changes can include changes in life circumstances, in the environment, and in situational or contextual factors (Sisto et al., 2019). For an individual with high resilience, these destabilizing life changes can have positive outcomes by providing opportunities for in-depth self-reflection and opportunities to redefine the self through positive changes in self-perception, outlook, and emotional stability. The insight gained from this experience and the search for inner resources needed to address and overcome these challenges further reinforce the features of resilience. Consequently, individuals with high resilience actively apply adaptive strategies, e.g., seeking social support, that help them cope with and overcome adversity and restore life balance (Rabenu and Tziner, 2016; Sisto et al., 2019). This study defined resilience as the process of adapting to difficult life circumstances.

Therefore, promoting resilience is an essential component of psychological and social care for breast cancer patients. Cancer patients with strong resilience have the positive attitude and internal strength needed to cope with the disease and its treatment. Patients with high resilience tend to have a positive emotionality, a sense of purpose in life, spirituality, and ability to find a life meaning. Factors that affect resilience include individual factors, family factors, and environmental factors. According to the resilience model developed by Kumpfer (Kumpfer, 1999), the overall resilience of an individual depends on the balance between risk factors and protective factors against low resilience. In adverse life circumstances, highly resilient individuals exhibit positive adaptation behaviors that maximize protective factors and minimize risk factors (Kumpfer, 1999). Risk factors for low resilience in cancer patients include the stress caused by the disease and its treatment as well as emotional and psychological distress such as body image distress. Protective factors in the resilience of these patients include social support, and hope. Women rely on various internal resources (e.g., hope) and external resources (e.g., social support) to cope with their breast cancer.

Hope

Hope is defined as a positive expectation of a good future. Hope is a complex multifaceted motive for life and a prerequisite for effective coping and decision-making (Ye et al., 2018). For breast cancer patients, hope is an important quality because it provides the internal strength needed to fight with the disease (Li et al., 2018). Notably, hope protects cancer patients against physical and mental stress by giving meaning to the cancer experience and by giving a reason for survival. Thus, hope is a positive psychological resource that helps patients adapt to cancer and helps them maintain and improve their well-being and QOL (Seiler and Jenewein, 2019).

Social Support

Social support, which is a subjective perception of meaningful caring and concern in others, also promotes the formation of resilience and gives individuals the courage to face adversity, which improves their adaptability and QOL (Spatuzzi et al., 2016). Cohen and Syme (1985) identified four forms of social support from family and friends: 1) emotional support, i.e., care and support that induces trust and a sense of belonging and love; 2) esteem support, i.e., support that increases self-esteem; 3) information support, i.e., knowledge, information and advice; and 4) tangible support, i.e., financial assistance, material goods, or services (Cohen and Syme, 1985). Support from health professionals, family and friends reportedly protects against poor body image (Cohen and Syme, 1985).

Relationship Between Body Image Distress and Resilience

Body image distress has been negatively linked to resilience in cancer patients. For example, Ristevska-Dimitrovska et al. (2015) surveyed resilience and quality of life in 218 patients (average age, 60.2 years) who had received treatment for breast cancer. Their results revealed that poor body image was associated with low resilience and poor quality of life. Another review of 12 qualitative studies in Sun et al. (2018) revealed that, in breast cancer patients, loss of the breasts and the perceived loss of integrity of the body structure caused a loss of the sense of overall harmony and symmetry of the body (Sun et al., 2018). Therefore, we hypothesized the following:

> Hypothesis 3(H3): Body image distress has a significant negative association with resilience.

Mediating Role of Hope in The Relationship Between Body Image Distress and Resilience

Body image distress is well-documented in patients with breast cancer (Rezaei et al., 2016), but little is known about the link between body image distress and hope in the breast cancer context (Liu et al., 2017; Todorov et al., 2019). Hope provides the internal strength needed to maintain emotional stability and a positive outlook while undergoing breast cancer treatment, which is often painful and disfiguring (Hatamipour et al., 2015). Studies of cancer patients have identified a strong positive relationship between body image distress and emotional distress (Liu et al., 2017; Li et al., 2018) and have identified protective effects of hope against emotional distress, including anxiety and depression (Peh et al., 2017). Hope also provides a buffer against the stress of the cancer experience and its negative impacts (Todorov et al., 2019). For cancer patients under acute and chronic stress, hope is an essential internal resource because it increases resilience, which then improves quality of life (Li et al., 2016; Solano et al., 2016). Thus, the literature suggests that hope confers a protective effect in cancer patients by reducing body image distress and by increasing resilience. Therefore, we hypothesized the following:

> Hypothesis 4(H4): Body image distress has a significant negative association with hope.
> Hypothesis 5(H5): Hope has a significant positive association with resilience.
> Hypothesis 6(H6): Hope mediates the association between body image distress and resilience.

Mediating Role of Social Support in the Relationship Between Body Image Distress and Resilience

In breast cancer patients, body image distress has been linked to lack of social support (Spatuzzi et al., 2016). Social support is an important external resource for coping with breast cancer. Specifically, support from health professionals, family and friends has important protective effects against body image distress. Lugton (1997) interviewed 29 women with breast cancer and found that social support reduced their stress by making the cancer threat seem less overwhelming. Specifically, social support helped them to address the challenges of living with breast cancer by enabling them to accept identity changes, uncertainty about the future, and mortality. Studies also show that social support increases hope in women who receive a new diagnosis of breast cancer after undergoing mastectomy (Denewer et al., 2011). Cancer patients who have strong social support can effectively manage the distress of body image changes (Spatuzzi et al., 2016) and tend to have high resilience (Alizadeh et al., 2018). Therefore, we hypothesized the following:

> Hypothesis 7(H7): Body image distress has a significant negative association with social support.
> Hypothesis 8 (H8): Social support has a significant positive association with resilience.
> Hypothesis 9(H9): Social support mediates the association between body image distress and resilience.

Relationship Between Social Support and Hope

In patients with high hope, social support reportedly exerts a positive effect on resilience. For example, low severity of symptoms and high hope were positively associated with resilience in 204 South Korea breast cancer patients undergoing chemotherapy (Yang and Kim, 2016). Although social support did not directly influence resilience, patients with strong social support tended to have decreased severity of symptoms and increased hope. Therefore, the authors inferred that social support indirectly influences resilience through hope. Another study by Ye et al. (2018) performed a questionnaire survey of resilience in 342 Chinese women undergoing breast cancer treatment. Although both hope and social support positively affected resilience, hope had a direct effect on resilience whereas social support had an indirect effect (Ye et al., 2018). Additionally, in a qualitative study by Bergqvist and Strang (2019), interviews with 20 breast cancer patients found that two forms of social support were important sources of hope: patient-doctor communication about treatment and patient-family interaction. For these patients, detailed information about their cancer treatment and reassurance that they would continue to receive treatment were essential for hope. Hope tends to be high in patients who refuse to be defined by their disease, e.g., patients who continue to participate in their daily life activities and who are willing to discuss matters other than their illness with family and friends maintaining relationships and continuing daily life activities provide the life meaning needed to maintain hope (Bergqvist and Strang, 2019). Therefore, we hypothesized the following:

> Hypothesis 10 (H10): Social support has a significant positive association with hope.

In a review of the literature on body image distress and resilience in women with breast cancer, Rezaei et al. (2016) retrieved 14 relevant articles published during 1993-2016. According to their review, age and education were related to body image distress in women with breast cancer. Additionally, young age and high education level revealed strong relationships with high resilience in women with breast cancer (Wu et al., 2016; Seiler and Jenewein, 2019). Since age and education correlate with body image distress and resilience, our hypothesized model included both age and education as controlled variables.

Mediating effects are conferred by intervening variables or mechanisms that transmit the effects of antecedent variables (e.g., body image distress) to outcomes (e.g., resilience) (Aguinis et al., 2017). Baron and Kenny (1986) observed that, in the stimulus-organism-response model proposed by Woodworth (1928), “an active organism intervenes between stimulus and response” and is “perhaps the most generic for stimulation of a mediation hypothesis” (p. 1176). The mediator variable is the middle variable between an independent variable (IV) and a dependent variable (DV). The purpose of including a mediator variable is to explain the relationship between an IV and a DV, e.g., to explain the relationship between a stimulus and a response. Whereas a moderator variable affects the strength and direction of this relationship, a mediator variable explains the process through which two variables are related, i.e., a mediator variable represents the generative mechanism through which the focal independent variable is able to influence the dependent variable of interest (Baron and Kenny, 1986). However, no studies have investigated the mediating roles of social support and hope in the relationship between body image distress and resilience in breast cancer patients currently undergoing treatment. Previous studies of resilience in cancer patients have investigated resilience at the time of a new diagnosis, 1 week after initiation of treatment, or after completion of treatment (Eicher et al., 2015). Therefore, the objectives of this study were to investigate mediating roles of social support and hope in the relationship between body image distress and resilience during the first year of treatment after a breast cancer diagnosis. Clarifying these mediating roles would provide medical personnel with guidelines for developing appropriate and effective interventions for increasing resilience. **Figure 1** presents the conceptual model developed and tested in this study, which was based on the resilience model developed by Kumpfer (1999).

MATERIALS AND METHODS

Participants and Setting

This cross-sectional descriptive correlation study was performed from March, 2017, to November, 2018. Factors in resilience were investigated in a convenience sample of breast cancer patients currently undergoing treatment. The recruitment sites were one outpatient oncology/ infusion department of a Medical Center and two outpatient clinics of regional hospitals in southern Taiwan. The inclusion criteria were (1) diagnosis of stage 0 to IV female breast cancer within the past 1 year; (2) current cancer treatment, i.e., chemotherapy, hormone therapy, targeted therapy, immunotherapy, bone metastasis treatment or some combination of these; and (3) ability to communicate in Mandarin Chinese. The exclusion criterion was any psychiatric or addictive disorder.

Out of 160 patients who were contacted for the study and were asked to participate, six did not complete the questionnaires due to time constraints, three declined because they felt “overwhelmed” by their cancer diagnoses, and 10 did not meet the criterion of current treatment. A “complete” questionnaire was defined as a questionnaire in which at least 80% of questions had been answered. Consent and completed questionnaires were obtained from 141 subjects (response rate = 88.1%).

The study protocol was reviewed and approved by the institutional review board of the participating hospital [KMUHIRB-E(I)-20170055], and the administrative director of each recruitment site gave approval before data collection. The researchers attended the cancer centers or outpatient clinics daily and met with eligible patients in a private room. After explaining the study objectives and methods to patients that met the enrolment criteria, the researchers obtained their consent, collected signed informed consent forms, and then asked the patients to complete a structured questionnaire. The patients were also assured that participation in the study would not affect their rights to receive medical care. Each participant completed hard copies of the demographic and structured questionnaires on the same day they gave consent to participate. The data collection procedure took 15–20 min to complete.

Materials

Body Image and Relationships Scale (BIRS). Hormes et al. (2008) developed the 32-item BIRS by conducting focus group interviews with female breast cancer survivors. The questionnaire has three dimensions: a 12-item “health and strength” dimension for assessing perceived physical impairment related to treatment (including perceived loss of energy, health, and strength and perceived loss of control over health and strength; an example of the questionnaire items in this dimension is, “I feel physically

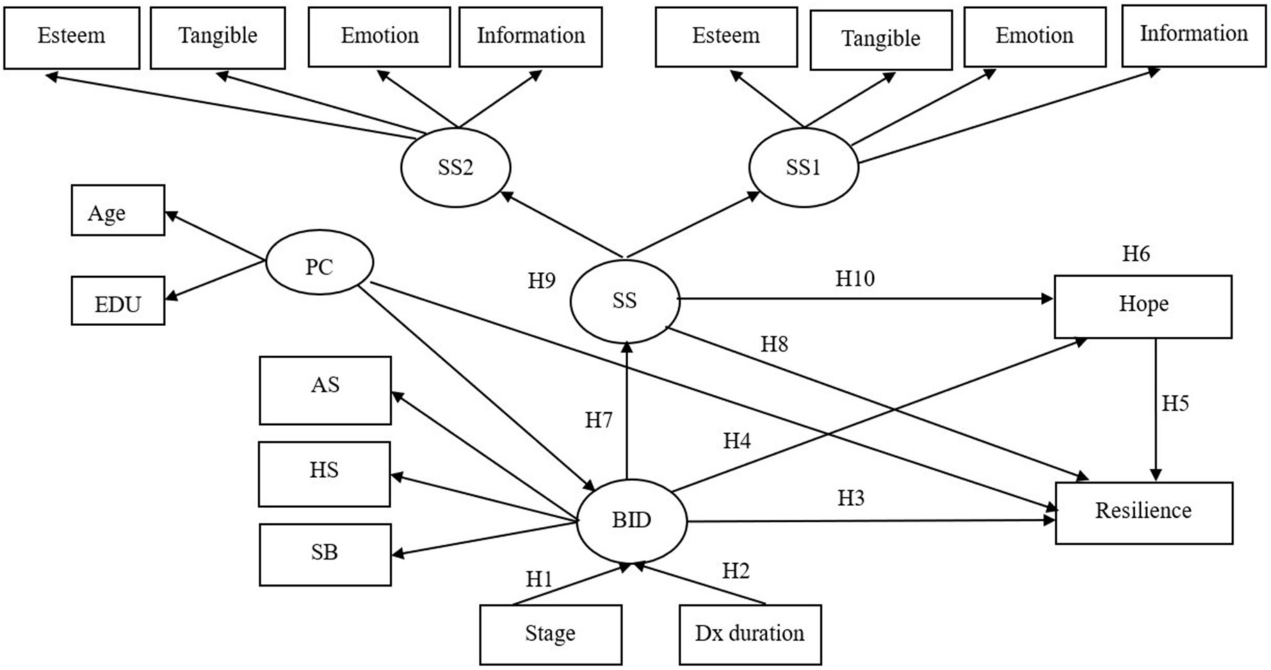

FIGURE 1 | Conceptual framework of hypothesized model. PC, personal characteristic; EDU, education; BID, body image distress; SB, social barriers; AS, physical appearance and sexual life; HS, Health and strength; Stage, disease stage; Dx duration, time since breast cancer diagnosis; SS, social support; SS1, social support from family and friends; SS2, social support from health professionals; ⬭ = latent variable; □ = measured variable; → = unidirectional path.

powerful"), a 9-item "social barriers" dimension for assessing perceived impairment in social interactions (including perceived impairment of social interaction and social activity caused by embarrassment about physical or psychological symptoms; an example of the questionnaire items in this dimension is, "My concerns about my physical appearance limit my social activities"), and an 11-item "physical appearance and sexual life" dimension for assessing satisfaction with perceived changes in physical appearance and with sexual activity (including decreased enjoyment of and satisfaction with sexual activity, embarrassment about physical appearance, and altered perception that the body is "whole" and "natural"; an example of the questionnaire items in this dimension is, "I feel sexually attractive"). Each item is rated on a 5–point Likert scale from 1 point (strongly disagree) to 5 points (strongly agree). The total score ranges from 32 to 160 points, and a higher score indicates greater impairment of body image (Hormes et al., 2008). In factor analysis, the 32-item BIRS had acceptable results for the Bartlett Test of Sphericity ($\chi^2 = 2361.04$; $p < 0.001$). In reliability tests, the overall scale had a Cronbach α-value of 0.94 and a test-retest reliability correlation coefficient of 0.41–0.80 (Hormes et al., 2008). In the BIRS-C used in this study, the Cronbach α-values for health and strength, social barriers, and physical appearance and sexual life were 0.80, 0.91, and 0.84, respectively.

Herth Hope Index (HHI). The HHI (Herth, 1992) has 12 questions, and questions 3 and 6 are reverse-scored. Examples of questionnaire items are, "I look forward to the future," "I have a faith that gives me comfort," and "I feel time heals." Each item is answered on a Likert-type scale from 1 ("strongly disagree") to 4 ("strongly agree"). The score range is 12–48, and a high score indicates a high degree of hope. The good reliability and validity of the 12-item HHI have been established in numerous studies (Mahendran et al., 2016). The Cronbach α-values for the Chinese version of the 12-item HHI were 0.87 in Zhang et al. (2010) and 0.89 in this study.

Social Support Scale (SSS). The Chinese version of the SSS contains 31 questions for evaluating social support as perceived by breast cancer patients in Taiwan. It measures social support from family members (19 items) and from health professionals (22 items). The four SSS subscales are emotion (5 items, e.g., "They care about my breast cancer"), esteem (5 items, e.g., "They make me feel important"), information (4 items, e.g., "They take the initiative to remind me of precautions for breast cancer self-care"), and tangible support (5 items for family support and 7 items for health professional support, e.g., "When I am unwell, they give me the assistance and care I need"). Each item is answered using a 5-point Likert scale from 0 to 4. The total score ranges from 0 to76 points for family members and 0 to 88 points for health professionals, and a higher score indicates higher perceived social support. The Cronbach alpha value for the overall reliability of the SSS was 0.97 in Chu (2010) and 0.95 in the current study. In this study, the Cronbach α-values for the emotion, esteem, information and tangible support dimensions of the family support subscale were 0.93, 0.83, 0.88, and 0.77, respectively. The Cronbach α-values for these four dimensions of the health professional support subscale were 0.81, 0.90, 0.94, and 0.88, respectively.

Chinese Version of 14-item Simplified Resilience Scale (RS-14). The Chinese version of the RS-14 developed by Wagnild (2009) and translated by Tian and Hong (2013) was used to survey the resilience of the participants in this study. Each item is rated on a 7-point Likert scale from 1 (strongly disagree) to 7 (strongly agree). Examples of questionnaire items are, "I usually manage one way or another," "My life has meaning," "When I'm in a difficult situation, I can usually find my way out of it," etc. The total score ranges from 14 to 98 points with a higher score indicating greater resilience. The RS-14 classifies resilience into 6 levels: very low (14–56 points), low (57–64 points), moderately low (65–73 points), moderate (74–81 points), moderately high (82–90 points) and high (91–98 points). In reliability tests of the RS-14 in Chinese cancer patients, the scale had a Cronbach α of 0.93 and a test-retest reliability correlation coefficient of 0.82 (Tian and Hong, 2013). The Cronbach alpha value for the overall reliability of the RS-14 was 0.94 in this study.

Statistical Analysis

Statistical analysis was performed using SPSS software (version 26.0, IBM Corp., Armonk). A p-value < 0.05 was considered statistically significant. For demographic characteristics and disease characteristics, categorical variables were presented as frequency and percentage whereas continuous variables were described as the mean and standard deviation for each questionnaire. Analysis of Variance (ANOVA) was used to determine whether body image distress differed by cancer stage. Spearman correlation and Pearson correlation analysis were used to investigate relationships among time since diagnosis, body image distress, social support (from health professionals and from family members), hope and resilience.

The overall fit of the hypothesized model was tested by structural equation modeling (SEM), which is considered reasonably reliable for models with 75 to 200 cases (Bollen and Long, 1993). For data analysis and hypothesis testing, IBM-SPSS-AMOS package 25.0 was used in two phases: a measurement phase and a structural phase. The factorial structures of the BIRS (3 subscales) and the SSS (4 dimensions, 2 subscales) were verified in confirmatory factor analysis (CFA). In CFA of the initial measurement model, five latent factors (personal characteristics, social support, social support from family and friends, social support from health professionals, and body image distress) of 13 indicators and four measured variables were allowed to covary. Maximum likelihood method was used for data fitting. The recommended cutoffs for a good model fit are χ^2/degree of freedom(df) < 3, goodness-of-fit index (GFI) > 0.9, adjusted goodness-of-fit index (AGFI) > 0.9, normed-fit index (NFI) > 0.9, comparative fit index (CFI) > 0.9 and root mean square error of approximation (RMSEA) < 0.05 (Schermelleh-Engel et al., 2003). If the model did not meet the recommended cut-offs for a good fit, maximum modification indices were used to adjust the fit to the ideal indices (Whittaker, 2012). Structural relationships among variables were tested as established in the theoretical model (**Figure 1**). Bootstrapping, which is already implemented in SEM software, was based on 2,000 resamples and was used in model fitting to determine each of the total direct and indirect path parameters and their standard errors (Leth-Steensen and Gallitto, 2016). Bias-corrected bootstrapped confidence intervals for both total and specific indirect effects within such models were also obtained (Leth-Steensen and Gallitto, 2016). If zero is not between the lower and upper bound, it can be assumed with 95% confidence to have a significant total effect or specific indirect effect.

RESULTS

The data analysis included 141 valid and complete questionnaires. **Table 1** shows the relevant demographic and disease characteristics. The mean scores for BIRS, HHI, SSS (family), SSS (health professionals), and RS-14 were 81.62 (±16.36), 37.40 (±4.68), 59.16 (±13.85), 63.15 (±18.18), 70.86 (±13.82), respectively. The patients in this study generally revealed moderate scores for body image distress, hope, and social support and moderate-to-low scores for resilience. Differences or associations among these factors were identified by ANOVA or by Spearman or Pearson correlational analysis (**Table 2**). Resilience had a significant negative association with body image distress ($r = -0.50$, $p < 0.001$) and significant positive associations with education ($r = 0.18$, $p = 0.035$), hope ($r = 0.66$, $p < 0.001$), family social support ($r = 0.28$, $p = 0.001$), and health professional support ($r = 0.26$, $p = 0.002$). Resilience was not significantly associated with age (r =-0.071, $p = 0.406$). Hope had significant positive associations with health professional support ($r = 0.295$, $p < 0.001$) and family social support ($r = 0.285$, $p = 0.001$) but had a significant negative association with body image distress ($r = -0.402$, $p < 0.001$). Body image distress had significant negative associations with education ($r = -0.26$, $p = 0.002$), health professional support ($r = -0.099$, $p < 0.001$) and family social support ($r = -0.166$, $p = 0.05$). Body image distress did not significantly differ by cancer stage ($F_{4.136,0.05} = 1.406$, $p = 0.235$). Finally, body image distress was not significantly associated with age ($r = 0.16$, $p = 0.062$) or with time since cancer diagnosis ($r = 0.12$, $p = 0.144$).

SEM Analysis

Measurement Phase

In the initial measurement model, CFA was used to verify the factor structures of the SSS and BIRS. In the original SSS, factor loading exceeded 0.4 within each dimension. However, the SSS did not meet the criteria for a good model fit (χ^2/df = 4.794, GFI = 0.886, AGFI = 0.783, RMSEA = 0.165). Maximum modification indices were used to adjust the fit to the ideal indices. For the best fit of the CFA model, "information support" and "esteem support" were dropped from SSS results for the family and friend's domain, and "esteem support" and "tangible support" were dropped from SSS results for the health professional's domain (χ^2/df = 1.382, GFI = 0.995, AGFI = 0.951, RMSEA =0.050). Factor loadings exceeded 0.4 in three BIRS domains: health and strength (0.93), social barriers (0.67), and physical appearance and sexual life (0.81). The BIRS data had a good fit to the original model (χ^2/df = 1.210, GFI = 0.941, AGFI = 0.905, RMSEA =0.039).

TABLE 1 | Demographic and disease characteristics of subjects (*n* = 141).

Characteristic	**Subgroups**	**Mean ± SD**	***n***	**%**
Age		53.61 ± 10.27	141	
Time (days) since cancer diagnosis		39.66 ± 43.33		
Age	30–39		15	10.6
	40–49		34	24.1
	50–59		54	38.3
	60–69		30	21.3
	70 or more		8	5.7
Education level	Lower than junior high school (lower than grade 6)		10	7.1
	Junior high school (grades 7–9)		19	13.5
	High school (grades 10–12)		52	36.9
	University/college		45	31.9
	Graduate school		15	10.6
Marital status	Unmarried		27	19.1
	Married		94	66.7
	Separated, divorced, or widowed		20	14.2
Religion	None		32	22.7
	Buddhist		62	44.0
	Christian or Catholic		23	16.3
	Taoist		22	15.6
	Other		2	1.4
Employment	Unemployed		46	32.6
	Employed full time		58	41.1
	Employed part time		12	8.5
	Retired		25	17.7
Average monthly income (NT$[a])	<NT$20,000 (<US$625)		18	12.8
	NT$20,000∼39,999 (US$625∼1249)		45	31.9
	NT$40,000∼59,999 (US$1250∼1874)		25	17.7
	NT$60,000∼79,999 (US$1875∼2499)		16	11.3
	NT$80,000∼99,999 (US$2500∼3125)		19	13.5
	>NT$100,000 (>US$3125		18	12.8
Cancer stage				
	In situ and I		74	52.4
	II		49	34.8
	III and IV		18	12.8
Surgery type	MRM[b]		3	2.1
	TM[c]		32	22.7
	SSM[d]		2	1.4
	NPSSM[e]		31	22.0
	Partial M[f] (formerly BCS[g])		65	46.1
	None		8	5.7
Treatment type	ct[h]		7	5.0
	rt[i]		1	0.7
	ht[j]		97	68.8
	tt[k]		7	5.0
	ct + tt		5	3.5
	ct + ht		2	1.4
	ht + tt		5	3.5
	rt + ht		10	7.1

(Continued)

TABLE 1 | Continued

Characteristic	Subgroups	Mean ± SD	*n*	%
	Zometa (bone metastasis)		1	0.7
	ht + Zometa (bone metastasis)		2	1.4
	ht + Xgeva (bone metastasis)		1	0.7
	ct + rt		1	0.7
	ct + ht + tt		1	0.7
	tt + Xgeva (bone metastasis)		1	0.7

[a] *The New Taiwan Dollar (NT$) is the official currency used in Taiwan. The average exchange rate in year 2019 was US$1 = NT$31.*
[b] *Modified radical mastectomy.*
[c] *Total mastectomy.*
[d] *Skin-sparing mastectomy.*
[e] *Nipple sparing mastectomy.*
[f] *Partial mastectomy.*
[g] *Breast-conserving surgery.*
[h] *Chemotherapy.*
[i] *Radiotherapy.*
[j] *Hormone therapy.*
[k] *Targeted therapy.*

TABLE 2 | Spearman's/Pearson's correlations between the study variables.

Variables	1	2	3	4	5	6	7	8
1. Education	1.00							
2. Time since diagnosis	−0.54**	1.00						
3. Age	−0.21*	0.27**	1.00					
4. Body image distress	−0.26**	0.12	0.16	1.00				
5. Family SS	0.09	−0.04	0.01	−0.17*	1.00			
6. Health professional SS	0.02	−0.08	0.14	−0.10	0.55**	1.00		
7. Hope	0.05	−0.12	−0.09	−0.40**	0.29**	0.30**	1.00	
8. Resilience	0.18*	−0.17*	−0.07	−0.50**	0.28**	0.26**	0.66**	1.00

*SS, social support; *p < 0.05; **p < 0.01.*

Structural Phase

The original hypothesized model had a poor fit to the data (χ^2/degree of freedom = 1.917, GFI = 0.863, AGFI = 0.812, NFI = 0.903, CFI = 0.921, RMSEA = 0.081) (**Figure 2**). Therefore, maximum modification indices were used to adjust the fit to the ideal indices. The "age," "education," "stage of cancer," "time since diagnosis," and "health and strength" domains of body image were removed from the model. Next, the fit analysis of the revised structural equation model confirmed a good data fit (χ^2/df = 1.242, GFI = 0.971, AGFI = 0.925, NFI = 0.984, CFI = 0.992, RMSEA = 0.042) (**Figure 3**). The body image scale retained two dimensions: "social barriers" and "physical appearance and sexual life." **Figure 3** presents the structural relationships and standardized coefficients, which show that significant paths identified in the analysis included paths from body image distress to hope (β = −0.37, $p < 0.001$), from hope to resilience (β = 0.50, $p < 0.001$), from body image distress to social support (β = −0.24, $p = 0.046$), from social support to hope (β = 0.27, $p = 0.011$), and from body image distress to resilience (β = −0.30, $p = 0.002$). The bias-corrected bootstrapping results further revealed that hope had a partial mediating effect on the relationship between body image distress and resilience (95% CI: −1.019 to −0.161, with a point estimate of −0.497, $p = 0.002$) (**Table 3**). Social support had a partial mediating effect on the relationship between body image distress and hope (95% CI: −0.181 to −0.001, with a point estimate of −0.059). Social support indirectly affected resilience through hope in the absence of an association between social support and resilience (95% CI: −0.235 to 0.029, with a point estimate of −0.045, $p = 0.172$). Therefore, another full mediating pathway was from body image distress to social support to hope to resilience (95% CI: −0.315 to −0.006, with a point estimate of −0.088, $p = 0.041$) (**Table 3**). In the final model, body image distress, hope, and social support accounted for 51% of the total variance in resilience.

DISCUSSION

This study is the first in Taiwan to analyze the mediator roles of social support and hope in the relationship between body image distress and resilience in breast cancer patients undergoing treatment. The patients in this study generally revealed moderately low resilience. In univariate analysis,

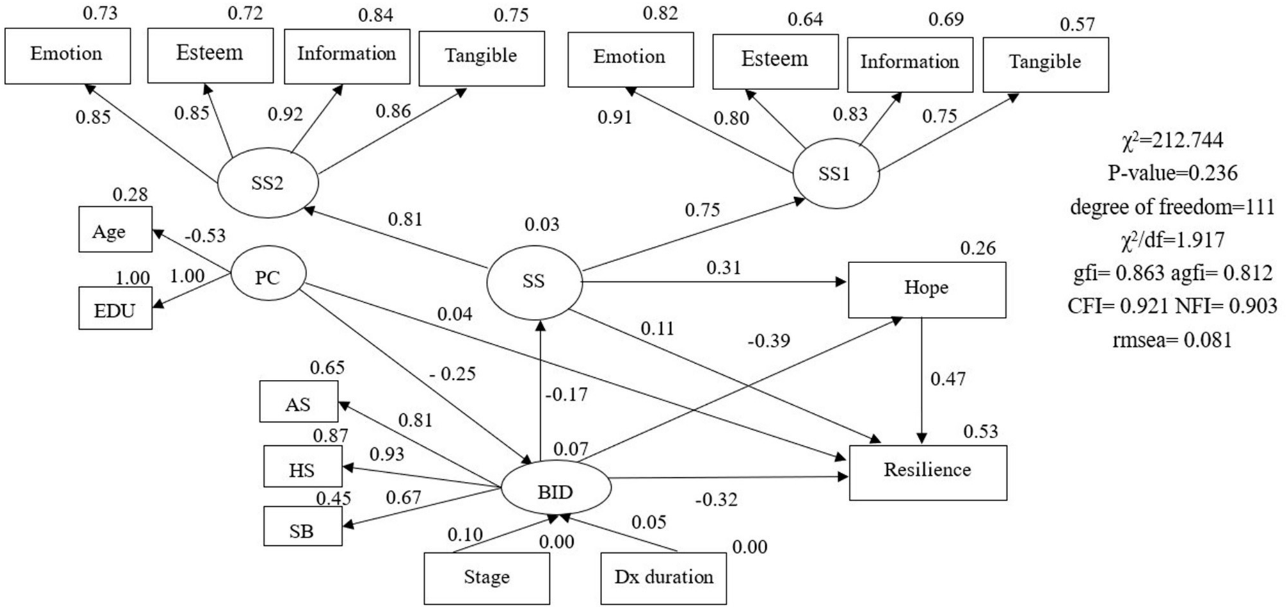

FIGURE 2 | Hypothesized model with standardized estimates. PC, personal characteristic; EDU, education; BID, body image distress; SB, social barriers; AS, physical appearance and sexual life; HS, health and strength; Stage, disease stage; Dx duration, time since breast cancer diagnosis; SS, social support; SS1, social support from family and friends; SS2, social support from health professionals; ◯ = latent variable; ☐ = measured variable; → = unidirectional path; *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

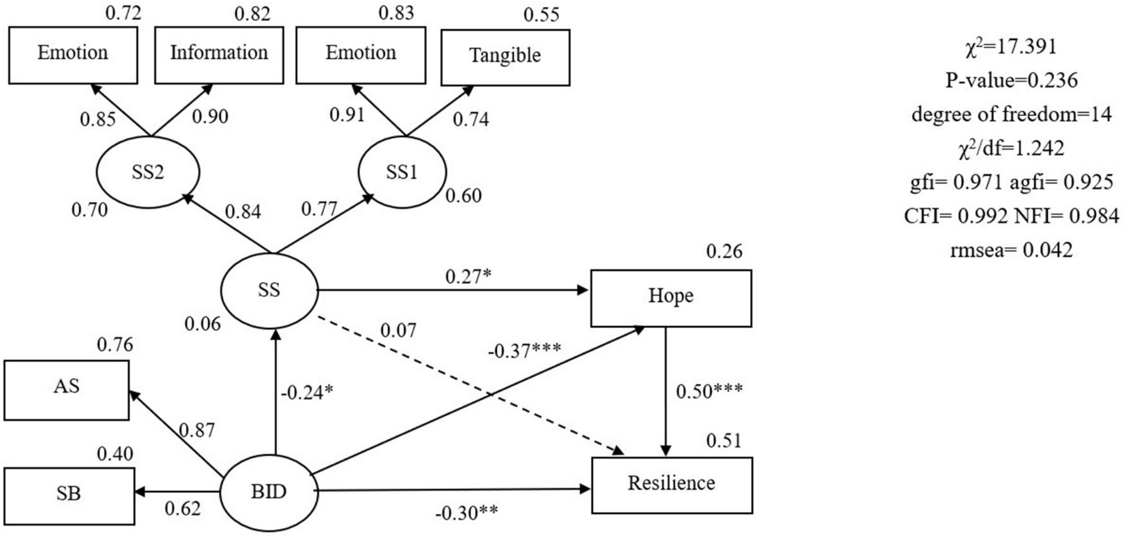

FIGURE 3 | The final model with standardized estimates. BID, body image distress; SB, social barriers; AS, physical appearance and sexual life; SS, social support; SSl, social support from family and friends; SS2, social support from health professionals; ◯ = latent variable; ☐ = measured variable; → = unidirectional path; *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

body image distress had significant negative associations with resilience, hope and social support (supported H3, H4, H7). Social support had significant positive associations with hope (supported H10). Hope had a significant positive association with resilience (supported H5). In SEM analysis, hope and social support were significant mediators of the association between body image distress and resilience (supported H6 and H9). Social support had a partial mediating role in the relationship between body image distress and hope. Additionally, hope had a full mediating role in the relationship between social support and resilience. Although social support did not directly affect resilience (did not support H8), it indirectly affected resilience

TABLE 3 | Direct and indirect effects of hope and social support on association between body image distress and resilience.

Relationship	Point estimate	SE	95% CI		p
			Lower	Upper	
Total indirect effects	−0.630	0.220	−1.224	−0.290	0.001
BID[a] → Hope → Resilience	−0.497	0.208	−1.019	−0.161	0.002
BID → Support → Resilience	−0.045	0.058	−0.235	0.029	0.172
BID → Support → Hope → Resilience	−0.088	0.063	−0.315	−0.006	0.041
Total direct effects	2.338	0.882	0.357	3.821	0.027
BID → Hope	−0.334	0.098	−0.601	−0.075	0.004
Hope → Resilience	1.490	0.224	0.969	1.947	0.002
BID → Support	−0.161	0.081	−0.375	−0.025	0.039
Support → Resilience	0.280	0.317	−0.299	1.022	0.284
Support → Hope	0.366	0.187	0.080	0.754	0.025
BID → Resilience	−0.793	0.330	−1.568	−0.215	0.002
Total effects					
BID → Resilience	−1.423	0.440	−2.338	−0.559	0.002

[a] *Body Image Distress.*

through hope (supported H6). Together, body image distress, hope, and social support accounted for 51% of the total variance in resilience.

Body image distress has been linked to low resilience in cancer patients. For example, a survey of resilience and QOL in 218 patients treated for breast cancer revealed that poor body image distress was associated with low resilience and poor QOL (Ristevska-Dimitrovska et al., 2015). Another review of 12 qualitative studies revealed that loss of the breasts and the perceived loss of structural integrity of the body caused a loss of the sense of overall harmony and symmetry of the body in breast cancer patients (Sun et al., 2018). Therefore, women rely on various internal and external resources to cope with breast cancer. Hope, which is an internal resource, provides the internal strength needed to fight breast cancer (Liu et al., 2017). In our patients, hope was a very important mediating factor in the relationship between body image distress and resilience, which has not been reported previously. Hope had a partial mediating effect on the relationship between body image distress and resilience, and social support indirectly affected resilience through hope. Previous studies have only reported that hope is the best predictor of resilience in breast cancer patients (e.g., Wu et al., 2016, in a study of 213 newly diagnosed breast cancer patients), which is consistent with our findings. Body image impairment is well-documented in patients with breast cancer, but little is known about the link between body image distress and hope in this context (Todorov et al., 2019). Prior works have identified a strong positive relationship between body image distress and emotional distress (Li et al., 2018). Hope is a buffer against negative and stressful events in the cancer experience. Thus, the literature suggest that hope confers a protective effect in cancer patients by reducing body image distress and by increasing resilience, which is consistent with our results.

In addition to hope, another factor that revealed a full mediating role in this study was social support, which is an external resource. Social support positively affected resilience by increasing hope. For example, a low symptom experience and high hope were positively associated with resilience in 204 South Korea breast cancer patients undergoing chemotherapy (Yang and Kim, 2016). Although social support did not directly influence resilience, it decreased symptom experience and increased hope. The authors inferred that social support indirectly influences resilience through hope (Yang and Kim, 2016). Another study by Ye et al. (2018) performed a questionnaire survey of resilience in 342 Chinese women undergoing breast cancer treatment. Hope had significant direct effects on their resilience whereas social support had significant indirect effects on their resilience.

Emotional and tangible support were retained in the family and friends support subscale of the proposed model. Family and friends mainly provide emotional support (Lugton, 1997). Support from partners and loved ones is a particularly important social support. Partners and loved ones must have the sensitivity to broach the topic at an appropriate time and manner, and the woman must feel free to discuss her anxieties. Work colleagues can give emotional support to women with breast cancer by expressing concern and by minimizing anxiety about taking time off from work (Lugton, 1997). Tangible support is physical support, e.g., assistance with household chores, cooking, bathing and other self-care activities, childcare, and even simple tasks such as noting the date of a doctor appointment (Hirschman and Bourjolly, 2005). Family and friends usually provide tangible support in their primary and secondary roles. For women with breast cancer, tangible support is usually provided by a partner or by the mother (Hirschman and Bourjolly, 2005).

Information support and emotional support were retained in the health professional support subscale of the proposed model. Women with breast cancer often seek support in the form of information about appearance, e.g., the most suitable protheses or clothing. Health professionals must consider the information needs of the patient, i.e., current knowledge related to breast cancer and its treatment, including self-care. Notably, assessment of information needs of patients with breast cancer should account for cultural factors. For example, in Nair et al. (2018), an assessment of information needs in Chinese women with breast cancer revealed an unmet need for information related to sexuality and negative body image. However, the low need for this information may have been related to the tendency to avoid discussion of issues related to sexuality and body image in Asian culture. Even if patients are willing to discuss issues of sexuality and negative body image, health professionals in Asian countries rarely provide useful information relevant to these issues because they lack skills in identifying and managing these issues. Most breast cancer patients have an ongoing need for information, which must be delivered with sensitivity, honesty, and patience. A multidisciplinary approach to addressing psychosexual issues can improve their sexual well-being, which would then enhance their QOL.

Although family and health professionals have important roles in the development of individual resilience, most studies of resilience have only investigated western populations (Eicher et al., 2015). In traditional eastern culture, ethical and philosophical systems (e.g., Confucianism) and religious systems (e.g., Buddhism) tend to emphasize the importance of family and social groups whereas analogous systems in western culture tend to emphasize the importance of the individual. Asian culture de-emphasizes the importance of the individual by encouraging self-reflection and suppression of emotional displays (Schouten et al., 2020). Cultural factors such as these should be considered when assessing body image distress, hope and resilience and when designing and implementing interventions for increasing resilience, particularly during face-to-face sessions. Additionally, cancer stage and time since diagnosis had no significant association with body image distress. However, the numbers of patients with stage III and IV breast cancer in this study were small, and time since diagnosis varied widely. The roles of cancer stage and in body image distress need further study in a larger sample.

The effectiveness of breast cancer treatment can be increased by identifying and supporting patients who are prone to high body image distress. Therefore, we suggest that, in routine clinical assessments of breast cancer patients, two dimensions of the 32-item BIRS should be administered to assess body image distress: the "social barriers" dimension and the "physical appearance and sexual life" dimension. Health professionals can also refer patients for psychological counseling or other interventions to address body image distress. Since this study also revealed that hope had a buffering effect against the negative psychological and social effects of body image distress in women with breast cancer, interventions for increasing hope should include providing resources to increase the ability to manage and cope with emotional distress, encouraging participation in social networks, and suggesting strategies for finding new meaning in life. Finally, cognitive behavioral therapy has proven effective for inducing a constructive perception of breast cancer.

Acknowledged limitations of this study are the use of convenience sampling and the somewhat small sample size for an analysis of this type, which limited the representativeness of the investigated breast cancer population. The cross-sectional design of this study also limited the ability to infer causality. Although this study provides some insight into the mediator roles of hope and social support in the association between body image distress and resilience in breast cancer patients undergoing treatment, further studies are needed to collect additional qualitative and longitudinal data in a larger cancer population.

SUMMARY

Hope and social support were important mediating factors in the resilience of breast cancer patients currently receiving treatment. Health professionals can improve their care quality by understanding how hope, social support, and other mediating variables affect the relationship between body image distress and resilience and by applying a conceptual framework that increases resilience by minimizing risk factors and maximizing protective factors.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Requests to access the datasets should be directed to hthsu@kmu.edu.tw.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Kaohsiung Medical University Hospital Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

H-TH and H-FH conceived and designed the study, involved in title selection, data analysis, drafting of the manuscript, and approved the final manuscript. C-HJ and H-TH analyzed the data, recruited the study participants, evaluated them, and collected the data. H-TH wrote the manuscript. H-TH and J-LC were involved in the interpretation of the data and contributed to the manuscript preparation. All authors read and approved the final manuscript.

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Women's Preferences for Body Image Programming: A Qualitative Study to Inform Future Programs Targeting Women Diagnosed With Breast Cancer

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Purpose: This paper describes women's opinions of the attributes of the ideal body image program to inform the design, development, and implementation of future programs for those diagnosed with breast cancer.

Methods: Deductive-inductive content analysis of semi-structured interviews with 26 women diagnosed with breast cancer (mean age = 55.96 years; mean time since diagnosis = 2.79 years) was performed.

Findings: Participants' opinions regarding the ideal body image program are summarized into five themes, mapping the *where* (community-based, hospital-based, or online), *when* (across the cancer continuum or at specific points), *how* (peer-led programs, professional help, events, presentations/workshops, resources, support groups), *what* (self-care, counseling and education for one self, education for others, support for addressing sexuality/sexual health concerns, and concealing treatment-related changes), and *who* (team approach or delivered by women, health professionals, make-up artists).

Conclusion: This study provides useful data on what women believe are the attributes of the ideal body image program, which can contribute to efforts aimed at developing and delivering body image programs for women diagnosed with breast cancer that prioritize their needs and preferences.

Keywords: breast cancer, survivorship, body image, qualitative, content analysis

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INTRODUCTION

Worldwide, there are more than 2.1 million women diagnosed with breast cancer each year, making it the most common type of cancer diagnosed in women (Sung et al., 2021). Conventional treatments for breast cancer include surgery, chemotherapy, radiation, and hormone therapy (Senkus et al., 2015). Unfortunately, complete removal or changes to the size/shape/symmetry/sensation of one/both breast(s), hair loss, skin or fingernail discoloration, scaring, hot flashes, vaginal dryness, and weight gain/fluctuations are common side effects of these treatments (Ewertz and Jensen, 2011; Brunet et al., 2013). Such physical changes can have an enduring negative impact on women's body image during and after treatment for breast cancer (Brunet et al., 2013). Approximately 17–33% of women recently diagnosed with breast cancer (Fobair et al., 2006) and 15–30% of women who have completed treatment for breast cancer experience some degree of body image concern (Anagnostopoulos and Myrgianni, 2009; Falk Dahl et al., 2010; Lyngholm et al., 2013), causing significant distress, impairing quality of life, and damaging sexual functioning (Fobair et al., 2006; Falk Dahl et al., 2010; Moreira and Canavarro, 2010; Lam et al., 2012). Consequently, body image has been deemed a "critical psychosocial issue for patients with cancer" (Esplen et al., 2021) and there has been a surge in research focused on developing programs for women to improve their body image and psychosocial adjustment during the course of the illness (Lewis-Smith et al., 2018b; Esplen and Trachtenberg, 2020; Esplen et al., 2020; Brunet and Price, 2021).

Two recent systematic reviews of studies with women diagnosed with breast cancer showed that body image programs comprised of psychotherapy, psychoeducation, or physical activity can have positive effects on body image (ds = 0.15–1.43, Lewis-Smith et al., 2018a; $g = 0.50$, 95% CI [0.08; 0.93], Sebri et al., 2021). Generally, programs reviewed with positive findings were delivered at different times during the course of the illness and adopted a multi-session, face-to-face, group format, though some online interventions have been shown to be effective in addressing body image distress among women diagnosed with breast cancer (Esplen and Trachtenberg, 2020). Although the studies reviewed are promising and support the importance of body image programs, there is insufficient applied evidence available to make recommendations at present for the type of body image program women diagnosed with breast cancer prefer. This is, in part, because there is a significant gap in the literature regarding the opinions of women toward body image programs.

Typically, body image programs are developed based on researchers' opinions and available resources (e.g., time, financial), resulting in a variety of modes, formats, and content, and potentially programs that are not likely to match women's needs and preferences (Arch et al., 2018). As such, it may be a challenging task for authorities and health professionals to discern what, how, and when to offer body image programs. Moreover, researchers have not consistently summarized the key methods and processes used to design body image programs based on women's preferences (e.g., Hamzehgardeshi et al., 2017). Rather, the focus has often been on describing the mode, format, and content of programs to allow for replicability (e.g., Pinto et al., 2005). Thus, it remains unclear whether (and to what extent) researchers have involved women diagnosed with breast cancer in the creation of their programs. However, the potential of body image programs is likely to only be fully exploited when using an approach that takes women's opinions and preferences regarding the mode and content, as well as the delivery format (e.g., face-to-face vs. online, individual vs. group-based, single- vs. multi-session) into account to enhance relevance, accessibility, and quality of implementation. Otherwise, a mismatch between what is designed and what women want can lead to poor usability, which can directly affect program efficacy. This issue can be resolved by conducting formative research to understand women's opinions of the attributes of the ideal body image program.

Public involvement in the development, design, and delivery of programs is highly promoted (Mead and Bower, 2000; Kitson et al., 2013) and is vital to guide successful translation of the promising research findings of the benefits of body image programs into practice. Indeed, there is growing recognition of the need for researchers to adopt a user- or patient-centered design approach. A patient-centered approach to care typically involves identifying intended end-users of a program (e.g., women diagnosed with breast cancer) and then ascertaining and prioritizing their needs and requirements (Mead and Bower, 2000; Kitson et al., 2013). This can be done by consulting with end-users and involving them at specific points during the design process. To this end, researchers could employ qualitative methods to determine what women diagnosed with breast cancer seek from a body image program and explore their perceptions of the *what*, *when*, *where*, *who*, and *how* of the ideal body image program. The aim of the present qualitative study was therefore to explore women's opinions of the attributes of the ideal body image program. This manuscript describes their opinions and presents implications for future program design, development, and delivery.

MATERIALS AND METHODS

Participants and Procedures

This study used a qualitative interview design and adopted a constructivist paradigm approach wherein knowledge is considered introspective and co-developed based on individuals' unique perspectives (Crotty, 1998). Ethics approval was obtained from the authors' institutions, and the data reported in this paper were collected within a larger grounded theory study that aimed to explore the meaning of body image for women diagnosed with breast cancer and how they see their breast cancer experience as influencing their body image to develop a grounded theory of body image for this population (Brunet et al., 2021b). Adult women (18 years or older) who were fluent in English and had undergone treatment for breast cancer within the past 5 years were eligible to participate. No stipulations were made in terms of age limit or treatment type to ensure the inclusion of women with different opinions. Women were recruited from The Ottawa Hospital (Ontario, Canada) and through various Canadian-based cancer charities and organizations via their online forums, newsletters, bulletins, websites, and social media. Additionally, women were recruited through social networking sites and word of mouth. Women were provided with a monetary incentive of $25 CAD upon completion of the interview.

Twenty-seven women provided consent prior to completing the interview; one was removed from this study because she

TABLE 1 | Participants' characteristics and treatment details ($n = 26$).

Variables	Descriptives
Age (years), M ± *SD*; range[a]	55.96 ± 16.21; 25–81
Married, *n* (%)[a]	18 (69.2)
White, *n* (%)[a]	22 (84.6)
Completed university/college/graduate school, *n* (%)[a]	20 (77)
Annual household income > $100,000 CAD, *n* (%)[a]	15 (53.8)
Body mass index (kg/m^2), M ± *SD*; range[b]	28.08 ± 7.57; 18.95–57.24
Cancer stage, *n* (%)[a]	
0	1 (3.8)
I–III	20 (80.8)
IV	1 (3.8)
Do not remember	3 (11.5)
Time since diagnosis (years), M ± *SD*; range[a]	2.79 ± 1.64; 0.42–5.83
Treatments received, *n* (%)	
Surgery[a]	25 (96.2)
Chemotherapy[a]	15 (57.7)
Radiotherapy[a]	16 (61.5)
Hormonal[a]	16 (61.5)
Other[c]	8 (30.8)
Comorbidities	
Diabetes[a]	3 (11.5)
High blood pressure[a]	11 (42.3)
High cholesterol[a]	4 (15.4)
Arthritis[a]	8 (30.8)
Lung disease[a]	2 (7.7)
Osteoporosis[a]	6 (23.1)
Hip/joint replacement[a]	3 (11.5)
Perceived physical health, *n* (%)[c]	
Poor to fair	4 (15.3)
Good to very good	17 (65.4)
Excellent	3 (11.5)
Perceived mental health, *n* (%)[a]	
Fair	1 (3.8)
Good to very good	16 (61.6)
Excellent	8 (30.8)

[a]$n = 25$; [b]$n = 23$; [c]$n = 24$.

did not answer questions pertaining to the current aim due to time constraints. Data from the remaining 26 women (mean age = 55.96 ± 16.21 years; range = 25–81) were analyzed; **Table 1** displays their characteristics and treatment details. All participants had their names replaced with an ID number (e.g., P1) to maintain confidentiality.

Data Collection

Semi-structured interviews were conducted by a female research assistant in her 20's with a Master's degree, either in-person ($n = 10$), by telephone ($n = 11$), or via videoconferencing ($n = 5$). The latter two means were done to reduce barriers for participation (e.g., constrictive schedules) and permit interviews with women from a broader geographic area (Sedgwick and Spiers, 2009; Janghorban et al., 2014). An interview guide was created to facilitate discussion during the interviews regarding the research aim, while affording participants flexibility to elaborate on their opinions based on personal experiences (Denzin and Lincoln, 2011). A pilot interview was conducted with one woman diagnosed with breast cancer, who had expressed interest in the study after seeing it advertised on social media and met eligibility criteria, to trial and refine the interview guide. The wording of some questions was edited as a result to reduce the length of some of the questions, make questions as simple as possible, and remove jargon. Core questions that covered women's opinions on what an ideal body image program would look like were: "*How do you envision the ideal body image workshop/intervention/program for women diagnosed with breast cancer?*" and "*What should be the aims, topics covered, settings/context, format, etc.?*" Based on women's responses, the interviewer posed follow-up questions, including "*What should be the topics covered in a body image workshop/intervention/program?*", "*What should be the format of a body image workshop/intervention/program?*", "*What should be the setting/context of a body image workshop/intervention/program?*", "*Who should deliver a body image workshop/intervention/program?*", and "*When would be the ideal time to deliver a body image workshop/intervention/program?*". She also probed for depth and clarity. Of note, the interviewer did not to provide participants with a definition of body image during the interview; rather, she was to encourage participants to interpret the meaning of body image for themselves and answer questions accordingly. Interviews were audio recorded and transcribed verbatim.

Data Analysis

Transcripts of participants' interviews were uploaded to NVivo and analyzed using deductive-inductive latent qualitative content analysis (Graneheim and Lundman, 2004) by two independent researchers. Both researchers (1) read each interview to acquire an overall understanding of content related to the research aim; (2) read each interview again while noting repeated viewpoints that could represent meaning units; (3) created and discussed a coding scheme to support subsequent coding of meaning units; (4) coded each interview based on these meaning units; and (5) extracted condensed meaning units out of meaning units with regard to the context. Those condensed meaning units that were related in terms of their meaning and content were then merged and abstracted into themes.

Reflexivity

The research team (i.e., authors, research coordinator, and the interviewer) reflected on their positions throughout the research process. They acknowledge that none had been diagnosed with breast cancer at the time of this study. As such, they were keenly aware of the differences between themselves and the interviewed women, especially in terms of disease history and age. Nonetheless, they had empathy for the interviewed women and the challenges they had faced as a result of having been diagnosed with breast cancer. Moreover, the interviewer felt compelled at times to reassure women and struggled to curb her urge to offer support in a matter that would take her beyond her role. To avoid this and protect against biases, she spent time debriefing with the first author after interviews.

RESULTS

Participants clearly had an overwhelming desire to access a body image program. Yet, the data collected in this study suggest they had a range of opinions regarding the attributes of the ideal body image program. Participants' opinions were summarized into five themes reflecting their preferences for the *where*, *when*, *how*, *what*, and *who* of the ideal body image program. Themes are summarized in **Table 2** (with a selection of representative quotes from participants) and outlined below.

Where We Want to Attend a Program

This theme refers to participants' preferred location for a body image program. Based on participants' collective accounts, body image programs should be delivered across different locations because "*there's never going to be a convenient place for everyone at different times*." Of the 26 participants, two expressed interest in a body image program that could be undertaken within the community (i.e., public spaces close to home) for convenience. Four expressed interest in a body image program that could be delivered online to obtain easily accessible information at convenient times at their preferred location. Three mentioned that a body image program could be delivered in-hospital because it "*makes more sense*" and because they had "*become accustomed to medical settings*." However, they did not necessarily feel it was the most appropriate setting. Moreover, five participants voiced concerns about having to go to the hospital for a body image program because they thought of the hospital as "*such a sterile place that nobody wants to go to*" and added that parking would likely deter participation.

When We Want a Program

This theme describes participants' preferences for the timing of a body image program. Participants had a variety of opinions, highlighting that differential timing may be needed for different women. Only three participants were interested in accessing a body image program across the cancer continuum, suggesting there should be "*several sections. There would be a newly diagnosed section, then there'd be the treatment time, then there'd be the post-treatment time, and then there'd be the rest of your life*." Only one participant was of the opinion that a program offered pre-diagnosis would be of interest because "*if you're coming from a place of negative body image and then you have breast cancer, I mean, you would need a lot of help*." However, similar to two others, she also believed post-surgery would be good timing. Others described a preference for a program at diagnosis or immediately after ($n = 4$), during treatment ($n = 3$), or post-treatment ($n = 6$). Further supporting post-treatment timing, two participants expressed a negative opinion about having a body image program during treatment because they believed women would have other priorities (e.g., completing treatment). Thus, overall, participants were of the opinion that women should be able to undertake a body image program when they are comfortable doing so.

How We Want a Program

This theme refers to the format participants were interested in for a body image program. Ten participants were interested in attending presentations or workshops focused on body image, and an additional five suggested special events. Whilst different terms were used by participants, they described presentations, workshops, and special events as one-time occurrences wherein information pertaining to body image (e.g., self-care, strategies for self-acceptance) could be shared with attendees to facilitate knowledge. Yet, it is unclear what the size of the audience should be as "*there's safety in small groups but sometimes there's anonymity in big groups. So you might be doing the same things, but have two different kinds of workshops and you give them the option of what ones they would rather [attend]*." Another option mentioned was to have a peer-led program ($n = 7$) or support group for women that facilitates discussion and encourages friendly relationships ($n = 8$). This was driven by participants' belief that camaraderie would be built with other women diagnosed with breast cancer and that peer social support would be facilitated. Others, however, were more interested in receiving individual guidance or support such as through one-on-one counseling ($n = 1$) or by receiving a compilation of resources women can access on their own ($n = 2$). Whilst divergent opinions were shared by participants, they generally agreed that, regardless of the format, a one-size fits all approach would not work as "*you'd probably have to cover quite a wide range because everybody has different problems depending on your age, your situation, and things are different*."

What We Want in a Program

This theme describes what topics participants would like to see covered in a body image program. Participants identified 13 topics, none of which were unanimously recommended, highlighting the personal nature of body image and the potential need for tailoring. Despite the diversity in participants' preferred topics, these could be organized into five areas: self-care, counseling and education for oneself, education for others, support for addressing sexuality/sexual health concerns, and concealing treatment-related changes. Of the 26 participants, 14 mentioned an interest in self-care, including promoting healthy eating ($n = 3$), encouraging physical activity for improved health and wellbeing ($n = 6$), giving sleep advice ($n = 3$), and discussing body size, shape, and weight management ($n = 2$). Of note, many of these participants expressed interest in multiple aspects of self-care. Within the realm of counseling and education, two key topics prevailed. Twenty-five participants expressed a desire for a program aimed at accepting and embracing their new normal, either by promoting self-compassion ($n = 12$), focusing on inner strength more so than appearance ($n = 5$), building resistance to body-based stereotypes/prejudices ($n = 4$), supporting spiritual growth – which can exist within or independent of religion – to feel more connected with life ($n = 3$), and building confidence

TABLE 2 | Summary of attributes for the ideal body image program.

Attributes	Program specifics	Quotations	Divergences
Where we want to attend a program	• Community-based (*n* = 2) • Online (*n* = 4) • Hospital-based (*n* = 3)	*People don't really want to have to come to the city. They want to be able to do it in their community. [. . .] You don't want to have to travel and I think that's a big, big thing*. P2 *Everybody has such a busy life. It would be great to have some help online. With the younger women, more and more, everybody needs that. And between treatments and work and everything, you would like to have something at your fingertips*. P10 *Just a website that someone could say go a have a look at what you could hope for or what happened to other people and you could have an idea of what you're facing*. P19 *It would make more sense if it happened at the hospital.* P18	Non-hospital (*n* = 5) *I'd have a room that's not sterile because you've been in these sterile situations over and over and over again. Something that's like warm and inviting and cozy. [. . .] Not in a hospital*. P16 *It costs $13 every time you go. [. . .] People have to then travel from wherever they live to come to the hospital and fight to find parking, and have to pay for parking, and it's just wrong. As a patient, you pay so much for parking already, so people aren't going to go*. P2
When we want a program	• Across the cancer continuum (*n* = 3) • Pre-diagnosis (*n* = 1) • At or immediately post-diagnosis (*n* = 4) • Post-surgery (*n* = 3) • During treatment (*n* = 3) • Post-treatment (*n* = 6)	*I think before treatment starts is a good one. [. . .] Then part way through, a check-up with women. [. . .] And then at the end of treatment.* P21 *If after surgery you're in the hospital [. . .] just having somebody that's engaging you on this topic*. P26 *While going through treatment.* P17 *Stopping treatment also is a huge up hill. It's like "now what?" That would be a good time for the workshop*. P14	Not during treatment (*n* = 2) *Personally, as a breast cancer patient, if you organize a workshop on body image, I would laugh. It's just not where I'm at. I'm not going willingly go to a workshop while I'm in treatment.* P26
How we want a program (i.e., format)	• Peer-led program (*n* = 7) • One-on-one counseling (*n* = 1) • Special events (*n* = 5), presentations/workshops (*n* = 10) • A compilation of resources women can access on their own (*n* = 2) • Support groups for women that facilitate discussion and encourage friendly relationships (*n* = 8)	*I feel like everybody diagnosed with cancer should have a one-on-one mentor with someone who went through it*. P18 *If the hospital were to put on something about breast cancer, like body image, I think women would come out of the woodwork to do that.* P23 *Maybe some lectures with subjects [where] I don't have to open my mouth, I just listen and learn.* P17 *I wish there was a sort of formal class*. P9 *A workshop that essentially helps you to restore your physical self, your appearance, and helps to promote feeling good about yourself*. P1 *I'm a literature person*. P15 *I think support group would be a really important part. [. . .] Different support groups for different needs, for different women*. P13	
What we want in a program	• Self-care: – Promoting healthy eating (*n* = 3) – Encouraging physical activity for improved health and wellbeing (*n* = 6) – Giving sleep advice (*n* = 3) – Discussing body size, shape, and weight management (*n* = 2) • Counseling and education for oneself: – Promoting self-compassion (*n* = 12) – Focusing on inner strength more so than appearance (*n* = 5) – Building resistance to body-based stereotypes/prejudices (*n* = 4) – Supporting spiritual growth – which can exist within or independent of religion – to feel more connected with life (*n* = 3) – Building confidence (*n* = 1) – Discussing typical physical changes (*n* = 6) – Learning to deal with stress and mental health issues (*n* = 2) – Discussing sexuality/sexual health (*n* = 5)	*The male part of the equation really needs some help and understanding. Understanding how a female feels, what she's going through, and what she might want as well*. P13 *I think eating properly, sleeping properly, keeping your body weight within a good range of what it should be*. P12 *Having a makeup artist, having beautiful clothes that you can wear [. . .]. Wearing that piece of clothing, that beautiful dress, that makes you feel good. [. . .] So doing that type of workshop, that self-care workshop*. P17 *I wish there was a sort of formal class or something that I could have gone to that was designed for strength, stretching, and movement. You still need that strength to move and to be engaged in your life. [. . .] I think that's a critical piece of accepting your body*. P9 *I would try to tell them to be happy with themselves and that really how you look is not that important to other people*. P11 *If a workshop were to focus on strategies of accepting yourself and maybe strategies of dealing with messaging or pressures, whether that be, at large, sort of media and public images, or from friends or family. That could be helpful*. P3	Do not focus on make-up and clothing (*n* = 2) *Do you know the Look Good, Feel Better? I had a really hard time with that. I didn't enjoy it and part of me gets it, but another part of me doesn't. I guess it's because I've never been a big make-up person and all that kind of stuff. So it wouldn't be like that is what I'm saying*. P14

(Continued)

TABLE 2 | (Continued)

Attributes	Program specifics	Quotations	Divergences
	• Education for others ($n = 3$) • Support for addressing sexuality/sexual health concerns ($n = 3$) • Concealing treatment-related changes ($n = 4$)	*Downgrading those stereotypes and letting the participants know that they have control over how they see their body and what they can do and that they don't have to fit in that mold that's been set by society*. P5 *I guess just allow people to know that "Here's 10 ladies who had lumpectomies and here's what their breasts look like afterward" so when you get your lumpectomy and you look and see what you've got you can think well that's about average. If you look at it without knowing what other lumpectomies look like, you might think "Oh shit that looks like crap." But when you can compare it to other women, you might get a sense of well that's as good as they can do I guess*. P19 *A workshop that focuses on women really working on self-acceptance and not judging. Finding their own strengths and beauty, their own natural beauty, and defining it in different terms*. P13 *Focus on inner strength. How do we make a person feel to how do we make a person to accept these difficult circumstances and how to make that person feel that no you have not lost anything*. P27 *I would definitely start with a mental health component, that would be number one for me*. P14 *Maybe you have somebody who is a body image specialist who helps improve sexual awareness for instance, because that's a very big topic around women my age who have breast cancer, but where do we find those resources? Between ourselves, we get our own speakers, we get people to talk to us, we go for talks and stuff like that, but having somebody organize something like that for us, so if there's a professional that you can also ask those tough questions to would be helpful*. P26 *My main issue is weight so if I want to optimize my body image, I do have to work toward losing a little bit of weight and firming up the arms, the legs, and the abdomen area*. P5	
Who we think should deliver a program	Team approach – women diagnosed with breast cancer and health professionals ($n = 4$) Women diagnosed with breast cancer ($n = 16$) Health professionals ($n = 11$) Make-up artists and/or clothing stylists ($n = 1$)	*I think your best bet is a mix of medical professionals and peers; people who have been through it themselves. I would say both*. P14 *For me, it would be helpful if I heard it from people who have gone through it. It touches me more from people who have experienced what I have experienced and who have overcome their insecurities and have back their self-confidence because that's what you strive to be like.* P25 *A nurse or a doctor could talk about health or the issues about the body image*. P5	
		I think a nurse. [. . .] They're really helpful, very knowledge, and really a little bit more in tune with the patients and their emotional needs. P16 *Have somebody who is a body image specialist*. P26 *Having a professional makeup artist there. [. . .] Someone from a prosthetics or a mastectomy store who's worked with women in fitting bras and undergarments and bathing suits and gowns and stuff like that*. P7	Non-health professionals ($n = 5$) *Not a healthcare professional because healthcare professionals are not, in my opinion, exposed to these things*. P27 *Surgeons are technical. So I would say no*. P7

($n = 1$). Another 13 mentioned counseling and education related to addressing the side-effects of cancer treatment, including discussing typical physical changes ($n = 6$), learning to deal with stress and mental health issues ($n = 2$), and discussing sexuality/sexual health ($n = 5$). Raising awareness of how body image affects women ($n = 3$), especially with partners, was also mentioned and thus necessary to "*focus on the people around, the support system, and yes, educate men. [. . .] Like have him attend a meeting, educate him, this is how your wife is feeling*." In addition to discussing sexuality/sexual health, three participants mentioned wanting help addressing sexuality/sexual health concerns to help improve their body image. Finally, four participants expressed interest in receiving make-up and clothing tips for coping with body image changes, though two others held negative opinions toward make-up and clothing-oriented topics.

Who We Think Should Deliver a Program

This theme refers to the person(s) who participants felt should deliver a body image program to women diagnosed with breast cancer. Because the person(s) delivering the program is central to what and how the content is delivered, most participants ($n = 16$) preferred that women previously treated for breast cancer be involved in delivering the program because "*you need somebody that's been in the trenches*." Similarly, four said that a promising option could be to have women previously treated for breast cancer partner with a health professional to deliver the program. The rationale provided was that "*some people really like having the authority of having a medical degree behind the person speaking. Some people really like that and have difficulty if they don't have that. Other people prefer a more peer type interaction with the person presenting. So those are dichotomies. How are you going to do that unless you have two people speaking, which obviously might work*." Generally, participants who desired that women diagnosed with breast cancer be involved in delivering the program were driven by the belief that having a shared experience was an essential component of a body image program. Eleven participants expressed an interest in having health professionals such as doctors ($n = 6$), nurses ($n = 5$), dieticians/nutritionists ($n = 2$), psychologists ($n = 3$), social workers ($n = 4$), fitness professional or physiotherapists ($n = 3$), or sex therapists ($n = 2$) deliver the program. Only one participant mentioned having a make-up artist and/or clothing stylist deliver the program. Given this diversity, delivering a body image program may require a multi-disciplinary team approach, whereby women previously treated for breast cancer partner with health professionals to design and deliver programs to meet an assortment of needs and preferences.

DISCUSSION

Previous research indicates that it is not uncommon for differences to exist between end-users' needs and preferences and existing programs/interventions (Short et al., 2014; Cadmus-Bertram et al., 2020). The aim of the present qualitative study was to gain insight into the attributes of the ideal body image program for women diagnosed with breast cancer from their perspective. Through a series of open-ended questions, participants shared their opinions on the *where*, *when*, *how*, *what*, and *who* of the ideal body image program, which has implications for future program design, development, and delivery. Most notably, participants' accounts confirm that topics covered in previous body image programs are of relevance, though there are other topics that should be covered as well. Moreover, participants indicated that the ideal body image program would be offered across the cancer continuum so that women can attend when they are ready. Finally, participants suggested that alternatives for when, where, who, and how be considered rather than having a standard program. Indeed, they underscored the need for diverse programs in terms of content and delivery to cater to different audiences and contexts.

Within the "*What* we want in a program" theme, participants identified 13 topics they wished a body image program would cover, which could be grouped into self-care, counseling and education for oneself, education for others, support for addressing sexuality/sexual health concerns, and concealing treatment-related changes. It was encouraging to find that participants were interested in topics previously covered in existing body image programs comprised of psychotherapy, psychoeducation, or physical activity (Esplen et al., 2018; Esplen and Trachtenberg, 2020; Lewis-Smith et al., 2018b). It is, perhaps, not surprising because psychotherapy and psychoeducation have been shown to help women challenge negative thinking and self-talk, modify unhealthy thoughts, feelings, and behaviors (i.e., cognitive restructuring), receive empathetic and non-judgmental support, while also exploring and addressing factors that contribute to negative body image (Neff, 2003). Whereas physical activity, while often promoted as a strategy for weight management due to its effects on body weight and shape (Zhu et al., 2016), can help women appreciate their bodies' strength and respect it as it is despite weight, shape, and perceived imperfections (Lewis-Smith et al., 2018b). Nevertheless, the relationship between physical activity and body image is tricky because women may withdraw if they do not see changes in their body composition and because appearance-based physical activity motivation (i.e., the extent to which physical activity is pursued to influence weight or shape) weakens the association between physical activity and positive body image (Homan and Tylka, 2014). Thus, emphasis within a body image program should be placed on building women's awareness of their physical capabilities by helping them focus on what their body can do, learn new physical activities, appreciate what they can do with their body and enjoy being active, and accept that healthy bodies come in different shapes and sizes in order to reduce focus on physical appearance. As well, it may be helpful to emphasize non-appearance-based physical activity motivation (e.g., health, enjoyment) and encourage women to attend to the sensations that can result from physical activity (e.g., improved mood, Homan and Tylka, 2014). Still, one topic identified by participants seems to have received relatively little attention despite mounting evidence on its importance – sexuality/sexual health post-treatment (Male et al., 2016). The extant literature and the diversity of topics identified in this study underscores the personal nature of body image and the potential need for tailoring. Accordingly, greater improvements in body image may be seen if women are provided with a program covering a topic (or topics) that align with their needs and preferences such as those mentioned with in the "*What* we want in a program" theme (Kwan et al., 2010).

Surprisingly, little is known about the effectiveness of body image programs based on *who* delivers the program. In this study, within the "*Who* we think should deliver a program" theme, participants mostly suggested a multi-disciplinary team approach whereby women diagnosed with breast cancer and health professionals co-facilitate the program. In comparison, most published body image programs have been delivered by trained researchers or health professionals (Lewis-Smith et al., 2018b). This is not unexpected as women diagnosed with breast cancer have expressed interest in programs guided by experts such as fitness professionals or healthcare providers

(Wong et al., 2018), and the current findings are partly consistent with this observation. However, it may be beneficial to involve more women diagnosed with breast cancer in the delivery of body image programs. A clear benefit of doing so is that these women have first-hand experience. This said, the instructor/facilitator is central to how the content of a program is delivered which further has the potential to influence how it is received by end-users. In fact, researchers have called attention to the interpersonal style of the facilitator as important to the receptiveness of participants to information presented in an intervention (Hagger and Hardcastle, 2014; Hardcastle et al., 2017). Moreover, participants in this study highlighted the importance of credibility and knowledge about the topic alongside the importance of developing rapport and being able to speak simply without relying on technical language or jargon to explain concepts. As such, when designing body image programs in the future, it is important to not just be mindful of *who* is delivering the program, but also their capacity to connect with and convey information to the audience. Indeed, if employing a multi-disciplinary team approach, it would be necessary to ensure all involved parties respect the individual expertise and experience that each instructor/facilitator brings to the program, are comfortable interacting with other instructors/facilitators and participants, and are prepared and not overburden by participation in the program. As a systematic review of the impact of patient and public involvement on those involved in health and social care illustrated (Brett et al., 2014), this can be a challenge, though it is typically worthwhile for participants as multiple instructors/facilitators provide more diverse perspectives and knowledge.

The physical environment and setting are also important components to consider when designing a body image program. Within the "*Where* we want to attend a program" theme, some participants suggested a community-based setting. The participants placed importance on creating a welcoming setting that was comfortable and convenient. Although the hospital was considered a suitable location to some because of familiarity with the location, the expensive parking and clinical environment reduced the appeal of the location. Indeed, as researchers have previously noted (Blaney et al., 2013; Browall et al., 2018; Clifford et al., 2018), appropriate locations for supportive care programs and services are those located in close proximity to potential participants' homes to enhance program attendance because home, work, and family obligations, particularly for women (Mailey et al., 2014; Browall et al., 2018), may limit their ability to attend programs. To maintain a free or low-cost program, familiar community spaces (e.g., local churches, libraries, public schools, community centers) might be potentially suitable locations. However, not all participants desired for a body image program to be delivered in-person as the added travel time may make it difficult to attend. This concern is echoed in the extant literature (Brunet et al., 2021a), which has resulted in alternative modes of delivery for body image programs, such as online programs (Esplen and Trachtenberg, 2020). In line with previous research (Phillips et al., 2017, 2019), online was identified as a favorable mode of delivery among some participants. The use of technology as a mode of delivery could provide an opportunity to reach a larger target population (Prutzman et al., 2021) and may open the door for a more diverse crowd of participants and instructors/facilitators.

Regardless of the mode of delivery (e.g., in-person, online), participants expressed a desire for group discussions and interactive activities that facilitate peer engagement, print or digital materials (e.g., books, fact sheets, or pamphlets), and one-on-one counseling. In particular, a large proportion of participants expressed a desire to interact with other women diagnosed with breast cancer in order to have opportunities to ask questions and share experiences. Notably, interaction with others has been highlighted as an important component of creating an optimal experience in psychological and behavioral interventions for adults diagnosed with cancer (Cavallo et al., 2014; Lee and Suh, 2018; Lewis-Smith et al., 2018b). As research expands to examine the acceptability and effectiveness of digital delivery methods, such as telehealth, as means to offer accessible programs, it will be critical to maintain social interaction opportunities for participants.

Limitations and Strengths

The limitations of this study should be acknowledged. It only included English-speaking women living in a high-income country. Relatedly, the high education and lack of racial and ethnic diversity in the sample is another limitation. It is possible that women living in lower income countries, women with lower education, or women from different racial or ethnic groups may have different opinions and preferences. Also, participants were post-treatment. By interviewing women post-treatment, it is possible that certain opinions were influenced by reduced recall. Prospective, longitudinal studies are warranted to understand women's opinions at different points in time. Similarly, participants had completed treatment within the past 5 years. Accordingly, it will be necessary to determine if the opinions and preferences expressed by participants in this study are echoed by women further away from treatment completion. Additionally, data were analyzed to aid in the development, design, and delivery of future body image programs for women diagnosed with breast cancer that meet their needs and align with their interests and preferences. It remains to be seen if such programs are just as effective as others tested in the literature. However, the strengths of this study were its sample size, inclusion of women with a range of ages and cancer experiences to support a diversity of perspectives, and analysis conducted by two researchers experienced in qualitative methodology.

CONCLUSION

The objective of this study was to investigate women's perspectives of the ideal body image program for women diagnosed with breast cancer. Participants' accounts suggest that a body image program may be an effective way to help them feel better about their bodies in a world that constantly makes them focus on their perceived flaws, personal inadequacies, and failures. Although one specific formula for how to design, develop, and deliver a body image program to women diagnosed with breast cancer may not exist, the findings of this study lay the foundation for the development, design, and delivery of a more diverse and tailored approach to such programs. Specifically, findings provide a starting point for *what* (self-care, counseling and education for oneself, education for others, support for addressing sexuality/sexual health concerns, and concealing treatment-related changes), *when* (across the cancer continuum or at specific points), *where* (community-based, hospital-based, or online), *who* (team approach or delivered by other women, health professionals, make-up artists or stylists), and *how* (peer-led programs, professional help, events, presentations/workshops, resources, support groups) that should be considered when developing, designing, and delivering body image programs targeting women diagnosed with breast cancer. It is hoped this information will help in the creation of more meaningful, relevant, useful, and usable programs for this growing segment of the population.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the data cannot be shared as participants were assured that their data would be kept private and confidential to the extent permitted by law and that only the research team would have access to the data. Requests to access the datasets should be directed to JB, Jennifer.Brunet@uottawa.ca.

ETHICS STATEMENT

This study involving human participants was reviewed and approved by the Ottawa Health Science Network Research and the University of Ottawa Ethics Boards. Participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

JB conceptualized and designed the study, oversaw the acquisition of the data, contributed to the interpretation of the data, and drafted the manuscript. JP led the analysis and interpretation of the data, helped draft sections of the manuscript, and critically revised the manuscript. CH assisted with the conceptualization of the study, participant recruitment, and revised the manuscript. All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

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OPINION
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The Psychosocial Consequences of Prostate Cancer Treatments on Body Image, Sexuality, and Relationships

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INTRODUCTION

Body image can have an important impact on quality of life, particularly in the context of cancer. Body image is considered the "*attitudes and perceptions about the body, particularly its appearance*" (Tylka, 2018) including "*thoughts, beliefs, feelings, and behaviors*" pertaining to one's body (Cash, 2004). Body image is often impacted by cancer and its treatment.

In the context of prostate cancer (PCa), how men view their body can change as a result of treatment side effects. The impact of PCa treatments on men vary with cancer stage and treatment. Localized PCa is regularly treated with radical prostatectomy (surgical removal of the prostate, seminal vesicles, and proximal lymph nodes) or radiation therapy. Such treatments are known to have side effects that significantly impact sexual function, urinary and even bowel control (Sun et al., 2014; Downing et al., 2019). In the case of cancer recurrence, patients with systemic or locally advanced PCa are regularly treated with androgen deprivation therapy (ADT). ADT is also used as neo-adjuvant therapy along with radiotherapy.

ADT controls PCa growth by greatly suppressing testosterone in the body and therefore has profound physical, sexual, and psychological side effects (Smith, 2007; Downing et al., 2019; Wibowo et al., 2019). Considering the low mortality rate of PCa (Lu-Yao et al., 2008; Hamdy et al., 2016), many patients endure treatment side effects for years and sometimes decades. Some of these side effects, including physical and sexual effects, can directly affect body image and can have negative psychological and social implications.

EFFECTS OF PRIMARY PROSTATE CANCER TREATMENTS ON BODY IMAGE

How PCa treatments affect the body and bodily functions depends on the focal nature of the treatment and impact on neighboring structures. For example, due to the proximity of the bladder to the prostate, incontinence and urine leakage are common side effects of a prostatectomy and, to a lesser extent, radiation therapy (Sun et al., 2014). Incontinence can be humiliating and can decrease men's quality of life (Stewart et al., 2003; Powel and Clark, 2005; Downing et al., 2019); as can management strategies that include the use of pads and other absorbent undergarments (Palmer et al., 2003). These lifestyle changes may in turn lower patients' self-confidence and make them withdraw socially (Bowie et al., 2021).

Climacturia (urination during orgasm) is a side effect mainly associated with prostatectomy (Lee et al., 2006). Climacturia has substantial negative effects on men's sexual lives and overall quality of life (Nilsson et al., 2011). Urinary leakage during sexual activity can be bothersome to both patient and partner, resulting in embarrassment, and act as a significant deterrent to willingness to engage in sexual activity (Mendez et al., 2018).

Erectile dysfunction due to PCa treatment has a profound impact on sexual satisfaction and reduces sexual confidence and positive feelings about one's body. Other PCa treatment side effects that are common but often neglected by healthcare providers include reduced ejaculation (Akbal et al., 2008), anorgasmia (Hollenbeck et al., 2003), and decreased orgasm intensity (Koeman et al., 1996; Frey et al., 2017). Various management strategies are available for erectile dysfunction (Sherer and Levine, 2014; Elliott and Matthew, 2017; Salonia et al., 2017; Wassersug and Wibowo, 2017). Nevertheless, many men report feeling less manly due to erectile dysfunction following PCa treatment (Tsang et al., 2018b), and need to find new ways to be sexually intimate that are not erection-dependent (Gray et al., 2002; Wassersug et al., 2016; Duthie et al., 2020).

A significant weakness of the literature on PCa and masculinity is that many authors have reported that PCa treatments result in a loss of "masculinity" without rigorously defining what masculinity is. Still, most recent reports suggest that patients perceive that loss of "masculinity" as a result of impairment in bodily functions; i.e., in erectile function and overall physical strength (Tsang et al., 2018a,b).

EFFECTS OF ANDROGEN DEPRIVATION THERAPY ON BODY IMAGE

Patients who are treated with ADT are known to have poorer body image than ADT-naïve patients (Harrington et al., 2009), and this may be for a variety of reasons. Perhaps most significantly, side effects associated with the loss of testosterone include a vast array of physical changes such as fatigue, weight gain, muscle loss, breast enlargement, genital shrinkage, and body hair loss (Nguyen et al., 2015; Wibowo et al., 2019). Many of these effects can be perceived as emasculating for men (Gentili et al., 2019), with erectile function being definitional to most PCa patients' understanding of what it means to be "a man" (Muermann and Wassersug, 2021). While the magnitude of many of the adverse side effects of PCa treatment that impact body image can be reduced with physical exercise, the challenge remains that poor body image following treatment can conversely be a barrier for exercise, especially exercise with others (Gentili et al., 2019).

Sexual implications of ADT can also impact body image. ADT commonly leads to a loss of sexual desire (Fode and Sonksen, 2014). If patients had not received a primary treatment for localized disease before ADT, they would now experience substantial and abrupt sexual changes including erectile dysfunction, reduced orgasmic capability if not total anorgasmia, diminished ejaculation, and reduced sexual interest, which can lower their body image (Tsang et al., 2018b). Data from healthy young men demonstrate a relationship between negative genital self-image and sexual dissatisfaction (Van Den Brink et al., 2018). The genital shrinkage associated with prolonged ADT can be very distressing to patients and further impact genital and overall self-image. While patients on ADT have less frequent sexual activity (Walker et al., 2018), the precise relationship between body image and sexual activity in men on ADT remains to be determined.

ADT may also lead to psychological changes in PCa patients' mood. ADT is associated with an increased risk of depression (Nead et al., 2017), anxiety (Dinh et al., 2017), and emotional lability (Donovan et al., 2015) as exemplified typically by increased spontaneous tearfulness (Galvin et al., 2019). Currently, it is unclear how psychological changes following ADT influences patient's body image. In the general population, depression and higher body weight are associated with poor body image (Silva et al., 2019). ADT patients are at elevated risk for sarcopenic obesity, and their increase in weight may potentially be a contributing factor to their depression and poor body image.

Not unexpectedly, the psychological implications of altered body form and function following ADT can vary with gender identity. Previously, Wassersug and Gray (2011) reported that some male-to-female transgender do not perceive changes induced by testosterone suppression for gender affirmation as negatives. For example, some of the distressing changes that cis-gendered males experience as emasculating—notably loss of muscle mass, gynecomastia, loss of body hair—are experienced as gender affirming and thus may enhance the body image of some transgender women.

BODY IMAGE CONCERNS OF GAY AND BISEXUAL MEN TREATED FOR PROSTATE CANCER

The burden of PCa treatments on gay and bisexual men (GBM) has received substantial research in recent years (Dowsett et al., 2014; Ussher et al., 2016a, 2019; Wassersug et al., 2016), however body image has not yet been rigorously studied in the GBM PCa population. GBM without PCa are likely to have poorer body image (Gil, 2007) and more body dissatisfaction (Kaminski et al., 2005; Tiggemann et al., 2007) than straight men. As such, PCa side effects may differentially affect GBM. GBM with PCa are also less likely than straight patients to be in a committed relationship (Wassersug et al., 2016) and more likely to have casual sexual relationships (Ussher et al., 2019). Thus, the impact of changes in body image induced by PCa treatment may be particularly burdensome for GBM when it comes to dating and seeking new sexual relationships. Sexual dysfunction has been identified as a major deterrent for attempting to establish new intimate relationships for single PCa patients in general (Mathew et al., 2020). It remains to be determined if this problem is more severe for non-heterosexual men.

To date, only one study (Thomas et al., 2018) has explored body image in GBM and straight men using a validated scale, namely the Multidimensional Body-Self Relations Questionnaire (Cash, 2000). On three subscales of this survey instrument, no differences were observed in appearance evaluation, health evaluation, or health orientation. However, the authors excluded several subscales from this questionnaire (e.g., overweight preoccupation, body area satisfaction, fitness evaluation, appearance orientation) which may vary between GBM and straight PCa patients, especially given the profound bodily changes associated with ADT (Elliott et al., 2010). Given the research on GBM without PCa, it may be reasonable to assume that many components of body image are more affected in GBM than in straight men.

Overall, sexual changes due to PCa treatment are comparable between GBM and straight men (Ussher et al., 2016a; Thomas et al., 2018). However, GBM tend to be more distressed by sexual dysfunction than straight men (Ussher et al., 2016a). This may in part be due to the inability to engage in anal sex among GBM when erectile dysfunction is present. Firmer erections are needed for anal than vaginal penetration (Goldstone, 2005; Ussher et al., 2016b), thus even minor reductions in erectile rigidity may make anal penetration impossible for GBM burdened by PCa sexual side effects. GBM with PCa conversely may also be concerned about rectal bleeding and rectal pain following radiation treatment if they take on the receptive role (Blank, 2005; Ussher et al., 2016b). Furthermore, the loss of ejaculation has been noted to be more bothersome to GBM than straight men (Wassersug et al., 2013). In sum, reduced sexual capacity, loss of sexual function and bodily discomfort amongst PCa survivors, may differentially affect GBM even more than straight men.

ASSESSMENT AND IMPROVEMENT OF BODY IMAGE

More studies directly assessing body image as a treatment outcome in PCa patients are warranted. A standard, concise, well-validated, and commonly used assessment instrument is the Body Image Scale, developed by Hopwood et al. (2001) and modified by Mcdermott et al. (2014). This is a 9-item self-report questionnaire that could easily be added to questionnaire batteries assessing psychological or relational outcomes among PCa patients.

Although we have briefly reviewed the potential impacts of sexual and physical affects from PCa treatments on body image, the relationships between body image and sexuality—specifically for men treated for PCa—is a topic worth more in-depth study. Relevant to the PCa population, which is largely made up of older men, is the fact that aging itself can erode body image and that in turn can undermine the experience of sexual pleasure (Schwartz et al., 2014). Body image is known to have a significant negative relationship with sexual satisfaction and sexual function for women (Afshari et al., 2016; Quinn-Nilas et al., 2016), but this has been under-investigated for men and, to our knowledge, not studied within men treated for PCa.

Interventions to improve body image are available, but require evaluation in the context of PCa. For example, moderate-to-vigorous aerobic exercise has been reported to improve PCa patients' sense of their manhood [assessed *via* the Personal Attributes Questionnaire (Helmreich et al., 1981)] and body image [assessed *via* the Body Image Scale (Langelier et al., 2018)]. However, the association between exercise and body image was found only in patients not undergoing ADT. It remains unclear why this was not the case for men on ADT. Psychosocial counseling may also be a promising strategy to improve body image. Though we are not aware of any studies specific to PCa, psychosocial counseling and psycho-education have been shown to improve body image in women with breast cancer (Lewis-Smith et al., 2018).

CONCLUSION

In conclusion, the physical and sexual side effects of PCa treatments may lower men's body image. This change may affect patients' sexual intimacy with their partners, as well as the confidence of unpartnered patients in forming a new relationship.

It remains to be determined whether PCa treatment causes more profound changes in the body image of GBM than straight men. While research in this area is limited, exercise programs and psychosocial counseling may potentially benefit PCa patients who have concerns about their body image.

AUTHOR CONTRIBUTIONS

JM and EW: writing first draft of the manuscript. JM, LW, JR, RW, and EW: manuscript editing and concept and discussion. All authors contributed to the article and approved the submitted version.

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Association of Inventory to Measure and Assess imaGe Disturbance – Head and Neck Scores With Clinically Meaningful Body Image-Related Distress Among Head and Neck Cancer Survivors

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Objective: The Inventory to Measure and Assess imaGe disturbance – Head and Neck (IMAGE-HN) is a validated patient-reported outcome measure of head and neck cancer-related body image-related distress (BID). However, the IMAGE-HN score corresponding to clinically relevant BID is unknown. The study objective is to determine the IMAGE-HN cutoff score that identifies head and neck cancer patients with clinically relevant BID.

Methods: We conducted a cross-sectional study at six academic medical centers. Individuals $\geq$18 years old with a history of head and neck cancer treated with definitive intent were included. The primary outcome measure was the IMAGE-HN. A Receiver Operating Characteristic curve analysis was performed to identify the IMAGE-HN score that maximized sensitivity and specificity relative to a Body Image Scale score of $\geq$10 (which indicates clinically relevant BID in a general oncology population). To confirm the validity of the IMAGE-HN cutoff score, we compared the severity of depressive [Patient Health Questionnaire-9 (PHQ-9)] and anxiety symptoms [Generalized Anxiety Disorder-7 (GAD-7)], and quality of life [University of Washington-QOL (UW-QOL)] in patients with IMAGE-HN scores above and below the cutoff.

Results: Of the 250 patients, 70.4% were male and the mean age was 62.3 years. An IMAGE-HN score of ≥22 was the optimal cutoff score relative to a Body Image Scale score of ≥10 and represents a clinically relevant level of head and neck cancer-related BID. Relative to those with an IMAGE-HN score of <22, patients with IMAGE-HN scores of ≥22 had a clinically meaningful increase in symptoms of depression (mean PHQ-9 score difference = 5.8) and anxiety (mean GAD-7 score difference = 4.1) as well as worse physical (mean UW-QOL score difference = 18.9) and social-emotional QOL (mean UW-QOL score difference = 21.5). Using an IMAGE-HN cutoff score ≥22, 28% of patients had clinically relevant BID.

Conclusion: An IMAGE-HN score of ≥22 identifies patients with clinically relevant head and neck cancer-related BID. This score may be used to detect patients who could benefit from strategies to manage their distress, select patients for studies evaluating interventions to manage head and neck cancer-related BID, and improve our understanding of the underlying epidemiology of the disorder.

Keywords: body image distress, disfigurement, head and neck cancer, depression, anxiety, quality of life, patient-reported outcome measure (PROM), survivorship

INTRODUCTION

There are nearly 500,000 head and neck cancer (HNC) survivors in the United States (US) and this population is growing exponentially (Tota et al., 2019; Howlader et al., 2020). Because HNC arises in cosmetically and functionally critical areas, such as the tongue, jaw, throat, and face, patients with HNC experience substantial life-altering morbidity related to disfigurement, difficulty swallowing, impaired smiling, and speaking challenges. As a result, 75% of patients with HNC express body image concerns (Fingeret et al., 2012), and it is estimated that up to 20% meet criteria for body image-related distress (BID) (Melissant et al., 2021a), a disorder characterized by a distressing self-perceived change in appearance and function (Fingeret et al., 2012; Rhoten, 2016; Teo et al., 2016; Ellis et al., 2019b). BID is associated with devastating psychosocial morbidity, such as social isolation, stigmatization, depression, and decreased quality of life (QOL) (Fingeret et al., 2012, 2015; Rhoten et al., 2013). BID, in addition to a number of other factors, contributes to HNC survivors dying from suicide at 2 times the rate of other cancer types and 4 times that of the US general population (Osazuwa-Peters et al., 2018, 2021).

Due to its subjective nature and poor correlation with objective measures of disfigurement (Manier et al., 2018; Graboyes et al., 2020a), BID is best measured using patient-reported outcome measures (PROMs). Unfortunately, the PROMs that have been used to assess BID in patients with HNC have been limited by concerns about construct validity and psychometric performance (Ellis et al., 2019a). The Inventory to Measure and Assess imaGe disturbance – Head and Neck (IMAGE-HN) was created to fill this gap (Graboyes, 2021). IMAGE-HN is a psychometrically valid 24-item PROM developed in accordance with the Patient Reported Outcomes Measurement Information System (PROMIS) guidelines (PROMIS, 2013) to comprehensively assess HNC-related BID (Graboyes et al., 2020a). Although IMAGE-HN underwent rigorous validation in a multi-institutional cohort, the IMAGE-HN score that corresponds to clinically relevant BID remains unknown. As a result, clinicians and researchers are limited in their ability to identify patients with HNC-related BID, preventing appropriate referrals for management of this devastating disorder and enrollment into clinical trials to test the efficacy of novel interventions. Therefore, the objective of this study is to determine the IMAGE-HN score that identifies clinically relevant BID in patients with HNC.

MATERIALS AND METHODS

Study Design and Patients

A cross-sectional study was conducted at six academic medical centers in the US (Medical University of South Carolina, Washington University School of Medicine, the University of Pittsburgh School of Medicine, Vanderbilt University Medical Center, Henry Ford Health System, and the Medical College of Wisconsin). This study was approved by the institutional review board at each institution. Individuals ≥18 years old with a history of HNC (i.e., oral cavity, pharynx, larynx, nose/paranasal sinuses, major salivary gland, or cutaneous structures of the head and neck) who had undergone definitive treatment and were free of known active disease were eligible for the study. Patients were excluded if they were unable to read English. Patients were recruited during routine follow-up or survivorship visits at multidisciplinary head and neck oncology clinics from November 2020 to August 2021 and enrolled face-to-face by a study team member following provision of written informed consent. Following enrollment, patients completed study assessments using an electronic tablet. Of 284 patients approached for participation, 23 declined and 11 did not provide demographic or oncologic data, leaving a sample of 250. Patients were compensated $10 for participation. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline (von Elm et al., 2014).

Outcome Measures

Head and Neck Cancer-Related Body Image-Related Distress

The primary outcome measure was the IMAGE-HN global score. The IMAGE-HN is a 24-item PROM that assesses multiple domains of HNC-related BID including other-oriented appearance concerns, personal dissatisfaction with appearance, distress with functional impairments, and social avoidance and isolation. Global IMAGE-HN scores range from 0 to 84, with higher scores indicating more severe HNC-related BID (Graboyes et al., 2020a). The IMAGE-HN instrument and scoring manual are publicly available (Graboyes, 2021).

Legacy Measure of Body Image-Related Distress

The Body Image Scale (BIS) is a 10-item PROM that assesses the affective, cognitive, and emotional aspects of body image due to cancer or its treatment over the prior 7 days (Hopwood et al., 2001). Initially developed for breast cancer patients, the BIS has been widely used to study BID in patients with HNC although it has not been specifically validated in this population (Fingeret et al., 2012; Ellis et al., 2019a). Higher scores indicate greater body image concerns and a BIS score of ≥10 corresponds to clinically relevant BID in general oncology patients (Chopra et al., 2020).

Depression

Depression was measured using the Patient Health Questionnaire-9 (PHQ-9), a reliable and validated 9-item measure of depressive symptoms (Kroenke et al., 2001). The PHQ-9 was selected because of its performance in patients with HNC (Shunmugasundaram et al., 2020) and because it is among the measures recommended by the American Cancer Society (ACS) and American Society of Clinical Oncology (ASCO) to screen for depressive symptoms (Andersen et al., 2014; Cohen et al., 2016). Scores range from 0 to 27, with higher scores reflecting more severe depressive symptoms. Established cutoff scores of 5, 10, 15, and 20 indicate mild, moderate, moderately severe, and severe depressive symptoms, respectively. A difference of ≥3–4 points between groups on the PHQ-9 is considered clinically important (Kroenke et al., 2020).

Anxiety

The Generalized Anxiety Disorder-7 (GAD-7) is a validated 7-item measure of anxiety symptoms. The GAD-7 was chosen because it is the recommended tool to screen for anxiety symptoms in patients with cancer by the ACS and ASCO (Andersen et al., 2014; Cohen et al., 2016). Scores range from 0 to 21, with higher scores indicating more severe anxiety symptoms. Cutoff scores of 5, 10, and 15 are indicative of mild, moderate, and severe anxiety symptoms, respectively (Spitzer et al., 2006). A difference of ≥3 points between groups on the GAD-7 is considered clinically important (Kroenke et al., 2019).

Quality of Life

The fourth version of the University of Washington-QOL (UW-QOL) is an HNC-specific questionnaire with 12 domains (pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder, taste, saliva, mood, and anxiety) that assesses QOL within the past 7 days (Rogers et al., 2002). This tool was chosen as it is one of the most widely used HNC-specific measures of QOL (Pateman et al., 2017). Individual domain questions have between 3 and 6 response options scaled evenly from 0 (worst) to 100 (best), according to the hierarchy of response (Rogers et al., 2002). The global UW-QOL score can be broken into two subscale scores, physical function (domains chewing, swallowing, speech, taste, saliva, and appearance) and social-emotional function (domains anxiety, mood, pain, activity, recreation, and shoulder function) (Rogers et al., 2010). Established cutoff scores are not known. A difference of ≥7 points between groups on the UW-QOL composite score is considered clinically important (Vartanian et al., 2004).

Other Study Variables

Self-reported sociodemographic characteristics include age, gender, race, ethnicity, marital status, living situation, education, employment, rurality, and insurance coverage. Self-reported oncologic characteristics include tumor subsite, cancer treatment, and type of reconstructive surgery. Time since completion of treatment was collected in months.

Statistical Analysis

Descriptive statistics (e.g., frequencies and percent for categorical variables, mean, and standard deviation for continuous variables) were used to characterize the sample. To determine the IMAGE-HN cutoff score that represents clinically meaningful HNC-related BID, we performed a Receiver Operating Characteristic (ROC) curve analysis to identify the IMAGE-HN score that maximized sensitivity and specificity relative to a BIS score of ≥10 (which indicates clinically relevant BID in a general oncology population) (Chopra et al., 2020). We did this by selecting the point on the ROC curve that minimized the Euclidean distance to the (0,1) point. To examine the clinical validity of our newly defined IMAGE-HN cutoff score, we compared the severity of associated symptoms of depression and anxiety, and QOL (mean PHQ-9, GAD-7, and UW-QOL scores, respectively) in those with and without HNC-related BID, using independent samples t-tests. We used Fisher's Exact tests to compare these subgroups on the proportions of patients with moderate depressive symptoms (defined as PHQ-9 score of ≥10) and anxiety symptoms (defined as GAD-7 score of ≥10) (Spitzer et al., 2006; Hinz et al., 2016). Statistical analyses were performed using SAS. A two-sided $P < 0.05$ was considered statistically significant.

RESULTS

Sample Characteristics

A total of 250 patients were included in the study. **Table 1** demonstrates the demographic and clinical characteristics of

TABLE 1 | Participant characteristics.

Variable	N (%)	IMAGE-HN Mean ± SD
Years of age, Mean ± SD	62.3 ± 11.9	
Sex		
Female	74 (29.6)	20.9 ± 20.9
Male	176 (70.4)	13.4 ± 13.4
Race		
White	224 (89.6)	15.0 ± 15.0
African American	20 (8.0)	16.6 ± 16.6
Other	6 (2.4)	34.0 ± 25.8
Ethnicity		
Hispanic	2 (0.8)	2.0 ± 2.8
Non-hispanic	237 (94.8)	15.0 ± 16.4
Prefer not to answer	11 (4.4)	31.0 ± 26.6
Marital status		
Married/current partner	174 (69.6)	13.6 ± 15.6
Single	34 (13.6)	22.4 ± 21.0
Separated/divorced/widowed	42 (16.8)	18.5 ± 18.6
Living situation		
Spouse	167 (66.8)	13.9 ± 15.7
Parents/children/friends/other	45 (18.2)	19.9 ± 22.0
Self	38 (15.0)	17.8 ± 16.0
Educational attainment		
Less than high school	11 (4.4)	22.9 ± 24.7
High school graduate	73 (29.2)	17.8 ± 17.9
Some college	68 (27.2)	16.7 ± 17.4
College graduate	56 (22.4)	14.4 ± 17.3
Graduate school	42 (16.8)	9.6 ± 10.9
Employment		
Employed (either part or full-time or homemaker)	94 (37.6)	15.5 ± 17.7
Not employed (disability or unemployed)	48 (19.2)	26.3 ± 19.3
Retired	108 (43.2)	10.9 ± 13.4
Rurality		
Rural	103 (41.2)	15.8 ± 17.5
Suburban	112 (44.8)	15.0 ± 16.6
Urban	35 (14.0)	17.2 ± 18.2
Insurance		
Private	96 (38.4)	14.5 ± 16.6
Medicare	116 (46.4)	14.9 ± 17.3
Medicaid/self-pay/other	38 (15.2)	20.5 ± 17.6
Tumor location		
Oral cavity	88 (35.2)	17.6 ± 18.8
Oropharynx	76 (30.4)	10.5 ± 14.4
Larynx/hypopharynx	37 (14.8)	20.5 ± 18.0
Nasal cavity/paranasal sinuses/nasopharynx	13 (5.2)	22.3 ± 11.3
Major salivary gland	12 (4.8)	17.3 ± 13.0
Facial cutaneous malignancy	16 (6.4)	11.7 ± 17.9
Other or unknown	8 (3.2)	14.4 ± 21.9
Cancer treatment		
Surgery	68 (27.2)	12.5 ± 16.9
Surgery and adjuvant radiation	77 (30.8)	17.9 ± 18.2
Surgery and adjuvant chemoradiation	56 (22.4)	19.4 ± 18.5
Nonsurgical treatment[a]	49 (19.6)	12.0 ± 12.7
Reconstructive surgery		
None	80 (39.8)	10.1 ± 15.3
Other (including local or regional flap)	25 (12.4)	18.3 ± 18.2
Microvascular free flap	96 (47.8)	21.3 ± 18.6
Osseous microvascular free flap reconstruction		
No	66 (68.8)	18.7 ± 17.1
Yes	30 (31.2)	26.7 ± 20.6
Time since completion of treatment		
0–11 months	111 (43.7)	15.9 ± 16.0
1–5 years	106 (41.7)	15.6 ± 19.0
>5 years	22 (8.7)	12.3 ± 13.9
Unknown	15 (5.9)	19.3 ± 16.8
Academic medical center		
Medical University of South Carolina	63 (25.2)	18.7 ± 20.9
Washington University School of Medicine	62 (24.8)	15.0 ± 17.0
University of Pittsburgh School of Medicine	50 (20.0)	13.0 ± 16.1
Vanderbilt Ingram Cancer Center	10 (4.0)	16.2 ± 14.6
Medical College of Wisconsin	50 (20.0)	15.5 ± 14.1
Henry Ford Health System	15 (6.0)	13.3 ± 14.6

[a] *Includes radiation and/or chemotherapy.*

the cohort as well as the mean IMAGE-HN scores (and SD) for each sociodemographic and treatment-related variable. The mean age (SD) was 62.3 (11.9) years; 94.8% (237/250) were non-Hispanic white, and 70.4% (176/250) were male. The most common HNC subsites were oral cavity (35.2%; 88/250), oropharynx (30.4%; 76/250), and larynx/hypopharynx (14.8%; 37/250). Eighty percent of patients were treated with a surgical-based paradigm (201/250) and 47.8% (96/201) underwent free flap reconstruction. The mean (SD) duration since completion of treatment was 22.5 (26.0) months. Of the study patients, 25.2% (63/250) were from the Medical University of South Carolina; 24.8% (62/250) from the Washington University School of Medicine, and 20.0% (50/250) each from the University of Pittsburgh School of Medicine and Medical College of Wisconsin.

Clinically Relevant Inventory to Measure and Assess imaGe Disturbance – Head and Neck Score

An IMAGE-HN score of ≥22 was the optimal dichotomization value relative to a BIS score of ≥10 and represents a clinically relevant level of HNC-related BID (**Figure 1**). Relative to a BIS ≥10, an IMAGE-HN cutoff score ≥22 was highly sensitive at identifying patients with HNC-related BID (area under curve = 0.96). Overall, 28% of patients with HNC in the cohort (70/250) had clinically relevant BID as determined by an IMAGE-HN score ≥22. An IMAGE-HN score of ≥22 identified 28 additional patients (11% of the study sample) as having clinically

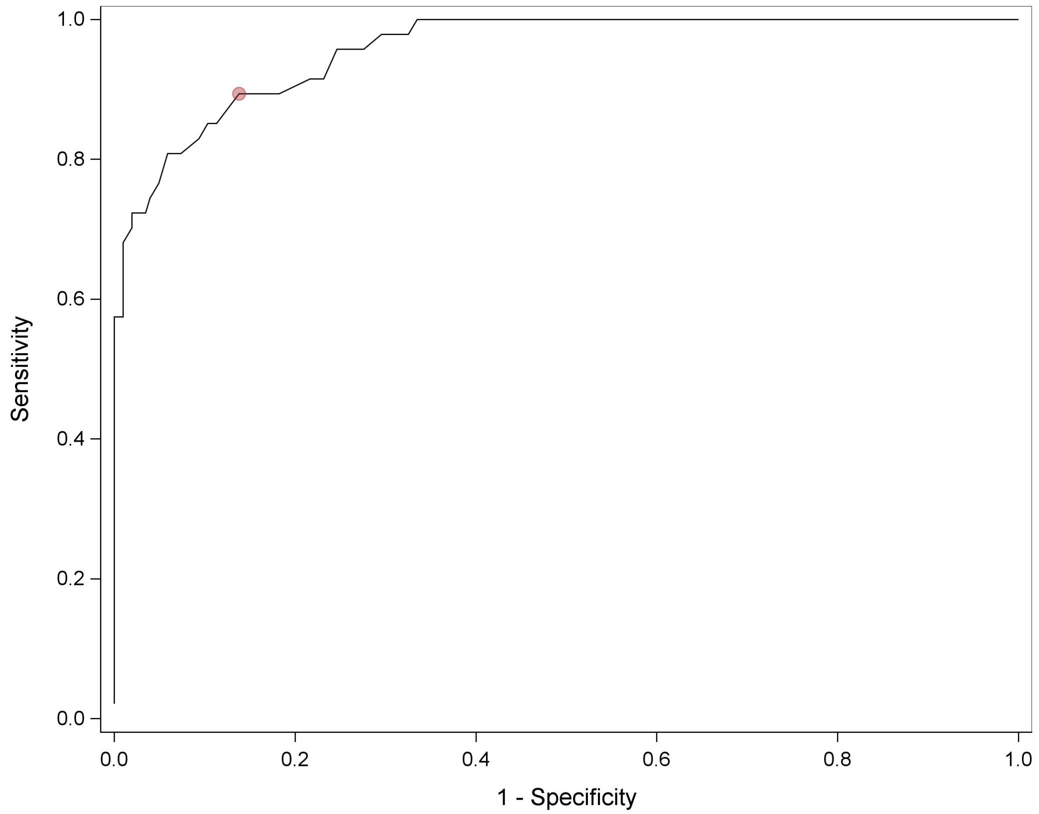

FIGURE 1 | Receiver operating characteristic curve for the IMAGE-HN for identifying clinically relevant HNC-related BID. Area under the curve = 0.96. The red dot represents the IMAGE-HN score that maximized sensitivity and specificity relative to a BIS score of ≥10.

relevant BID who would not have been diagnosed with HNC-related BID using the legacy measure (BIS ≥10) (**Figure 2**; patients in the top left quadrant).

Association of Clinically Relevant Inventory to Measure and Assess imaGe Disturbance – Head and Neck Scores With Depression, Anxiety, and Head and Neck Quality of Life

Because of the strong association of HNC-related BID with psychological well-being and QOL, we evaluated the association of clinically relevant IMAGE-HN scores with symptoms of depression and anxiety and QOL (**Table 2**). Relative to those with an IMAGE-HN score of <22, patients with an IMAGE-HN score of ≥22 were more likely to experience more severe depressive symptoms [mean PHQ-9 score = 8.3 (*SD* = 6.2) vs. 2.5 (*SD* = 3.4); mean difference = 5.8] and more severe anxiety symptoms [mean GAD-7 = 6.7 (*SD* = 6.0) vs. 2.6 (*SD* = 3.1); mean difference = 4.1]. These differences between those with and without HNC-related BID are both clinically and statistically significant. Patients were also more likely to experience worse physical QOL [mean UW-QOL physical sub-score = 60.1 (*SD* = 16.8) vs. 79.0 (*SD* = 16.3); mean difference = 18.9] and worse social-emotional QOL [mean UW-QOL social-emotional score = 62.4 (*SD* = 20.6) vs. 83.9 (*SD* = 13.8); mean difference = 21.5; $p < 0.01$ for each]. These differences were also clinically and statistically significant between those with and without HNC-related BID. When analyzed using established cutoff scores for moderate depressive symptoms (PHQ ≥ 10) and moderate anxiety symptoms (GAD ≥ 10), patients with an IMAGE-HN score of ≥22 were more likely to have moderate or severe depressive symptoms (30.0% vs. 5.0%) and moderate or severe anxiety symptoms (24.3% vs. 3.0%; $p < 0.001$ for each) relative to patients with an IMAGE-HN score of <22.

DISCUSSION

Contribution to the Assessment of Head and Neck Cancer-Related Body Image-Related Distress

Although BID has profound consequences in terms of psychosocial well-being and QOL for patients with HNC, HNC-related BID remains poorly understood in large part due to limitations in our ability to measure HNC-related BID and identify patients with this disorder (Rodriguez et al., 2019; Graboyes et al., 2020a). The BIS has been used frequently to assess BID in patients with HNC (Ellis et al., 2019a) and a clinically relevant cutoff score for the BIS was recently determined

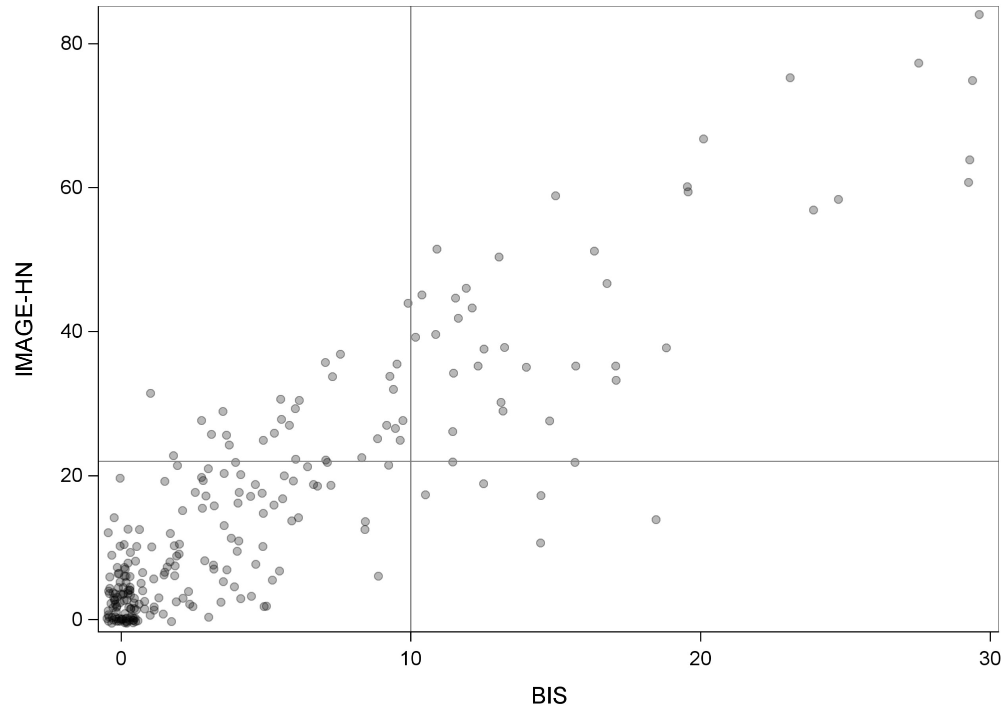

FIGURE 2 | IMAGE-HN vs. BIS scores. Scatterplot showing the distribution of IMAGE-HN and BIS scores for our study sample. Circles represent the IMAGE-HN and BIS scores of each patient, with a jitter (small amount of random noise) applied to minimize overlap of observations. Any remaining overlapping observations are indicated by darker shaded circles. Twenty-eight patients (11% of the cohort) have clinically relevant HNC-related BID as measured by IMAGE-HN score ≥22 who would not be identified using the BIS (BIS < 10; circles in the upper left quadrant). Forty-two patients (17% of the cohort) have clinically relevant HNC-related BID as measured by IMAGE-HN score ≥22 who would have been identified by the BIS (BIS > 10; circles in the right upper quadrant). One hundred seventy-five patients (70% of the cohort) do not have clinically relevant HNC-related BID as measured by IMAGE-HN score < 22, who also have BIS < 10 (bottom left quadrant). Five patients (2% of the cohort) would not be identified as having clinically relevant HNC-related BID as measured by an IMAGE-HN score < 22 who would have been identified using a BIS score > 10 (bottom right quadrant).

TABLE 2 | Association of clinically relevant IMAGE-HN scores with depression, anxiety, and head and neck quality of life.

Scale	**Full sample (*n* = 250)**		**IMAGE-HN < 22 (*n* = 180)**		**IMAGE-HN ≥ 22 (*n* = 70)**		***p*-value**
	Mean	***SD***	**Mean**	***SD***	**Mean**	***SD***	
IMAGE-HN[1] Global (raw sum)	15.6	17.2	6.8	6.5	38.2	15.3	<0.001
PHQ-9[2]	4.1	5.1	2.5	3.4	8.3	6.2	<0.001
GAD-7[3]	3.4	4.6	2.6	3.1	6.7	6.0	<0.01
UW QOL v4[4]							
Physical	73.7	18.5	79.0	16.3	60.1	16.8	<0.001
Social-Emotional	77.9	18.6	83.9	13.8	62.4	20.6	<0.001

[1] *The Patient Health Questionnaire-9 is a validated measure of depression. Scores range from 0 to 27 with higher scores reflecting more severe depressive symptoms. The minimal important difference is ≥3 to 4 points.*

[2] *The Generalized Anxiety Disorder-7 is a validated measure of anxiety. Scores range from 0 to 21 with higher scores indicating worse anxiety symptoms. The minimal important difference is ≥3 points.*

[3] *The fourth version of the University of Washington-QOL is a HNC-specific questionnaire with 12 domains that assesses quality of life within the last 7 days. Domains are scaled from 0 (worst) to 100 (best) according to the hierarchy of response. The minimal important difference is ≥7 points.*

(Rhondali et al., 2015; Chopra et al., 2020). However, the BIS lacks content validity for HNC-related BID through its (1) omission of key appearance (e.g., drooling and facial asymmetry) and functional (e.g., eating in public and speaking challenges) concerns and (2) inclusion of items not relevant to patients with HNC (e.g., "Did you find it difficult to look at yourself naked?") (Ellis et al., 2019b). Recently, a number of PROMs have been developed for, and validated among, patients with HNC including the IMAGE-HN, FACE-Q, and McGill Body Image Concerns Scale-Head and Neck Cancer (Cracchiolo et al., 2019; Rodriguez et al., 2019; Graboyes et al., 2020a). The development and validation of each of these HNC-specific PROMs represents significant progress. However, the clinical application of these PROMs to distinguish between HNC patients with and without clinically relevant BID remains uncertain (Macias et al., 2021). The current study addresses this key measurement gap. In a large, multi-institutional cohort, we demonstrated that an IMAGE-HN score of ≥22 represents a clinically relevant threshold and can distinguish between those with and without HNC-related BID.

There are two important caveats to interpreting the optimal IMAGE-HN cutoff score. First, there is no gold standard for the diagnosis of HNC-related BID [e.g., Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnosis] against which to compare the diagnostic accuracy of IMAGE-HN. As a result, the process for determining score thresholds for HNC-related BID is not straightforward. However, the approach to IMAGE-HN development (Ellis et al., 2019b) ensured that we captured relevant conceptual constructs of HNC-related BID (Rhoten, 2016; Melissant et al., 2021a) as well as the associated social, functional, and QOL impairments that are critical to DSM-based diagnoses. Second, our method of determining an IMAGE-HN cutoff score aimed to maximize the sensitivity and specificity of IMAGE-HN relative to the legacy measure (BIS). Another approach would have been to maximize statistical power, or the IMAGE-HN score that maximizes the effect size between those with and without HNC-related BID. Our selected method was optimized to meet the study objective of most accurately identifying patients with clinically relevant BID.

Epidemiology of Head and Neck Cancer-Related Body Image-Related Distress

Findings from the current study can be applied to better characterize the epidemiology of HNC-related BID. A recent study by Melissant et al. (2021a) estimated that 13–20% of HNC survivors had clinically relevant BID as measured by the BIS. The current study using a HNC-specific measure of BID (IMAGE-HN) shows that (1) 28% of HNC survivors have clinically relevant HNC-related BID and (2) 11% of HNC patients with clinically relevant BID would not have been identified by the BIS. To our knowledge, this is the first study to estimate the prevalence of HNC-related BID utilizing a tool created for and validated in patients with HNC. Future research should utilize the IMAGE-HN and its cutoff score to refine our understanding of the trajectory of HNC-related BID throughout HNC survivorship and better characterize the prevalence of HNC-related BID in relation to demographic, oncologic, and treatment characteristics (Graboyes et al., 2019; Macias et al., 2021).

Clinical and Research Implications of an Inventory to Measure and Assess imaGe Disturbance – Head and Neck Cutoff Score

A second implication of our study is that the IMAGE-HN cutoff score can now be used in clinical practice and research studies to identify patients with clinically relevant HNC-related BID who might benefit from interventions to manage their distress. A recent national survey showed that body and self-image-related distress was the least likely of all survivorship topics to be addressed by head and neck oncology providers (Cognetti et al., 2020). Prior to this study, clinicians were limited in their ability to identify those with clinically relevant HNC-related BID, inhibiting referrals for further management. Despite the high prevalence of BID in patients with HNC, evidence-based interventions to manage HNC-related BID are lacking (Ellis et al., 2019a; Richardson et al., 2019). Preliminary data from a few recent small studies highlight the promise of a virtually delivered cognitive behavioral intervention (Graboyes et al., 2020b) or a structured expressive writing activity as novel treatments for HNC-related BID (Melissant et al., 2021b). Future research should utilize validated measures of HNC-related BID (e.g., IMAGE-HN) to test interventions aimed at reducing BID in patients with HNC. Furthermore, an IMAGE-HN cutoff score of ≥22 should be utilized as an inclusion criterion for accrual into clinical trials to test the efficacy of interventions intended to decrease HNC-related BID.

Future Directions

As part of a comprehensive and patient-oriented approach to managing HNC-related BID, the IMAGE-HN can be a powerful tool to help clinicians and patients identify unmet needs. However, there are several areas that still need to be addressed to enhance the clinical relevance of IMAGE-HN. First, the minimal important difference in IMAGE-HN scores over time and between groups are unknown; these values are necessary to evaluate the effectiveness of treatment (Kallogjeri et al., 2020). Second, while a cutoff score for clinically relevant HNC-related BID is an important benchmark, BID likely exists on a continuum and score ranges or thresholds defining disease severity are lacking. Score thresholds can be ascertained using innovative techniques such as bookmarking (Cook et al., 2019) and could guide clinicians and researchers to utilize stepped-therapy approaches that match treatment intensity to severity of BID.

Moreover, factors affecting the clinical implementation of IMAGE-HN are not known. HNC-related BID may be difficult to detect in the clinical setting as symptoms overlap with the adverse effects of cancer-related treatment. In addition, head and neck oncology providers are not readily trained to identify psychosocial concerns, and patients with HNC may be hesitant to express body image-related concerns (Lydiatt et al., 2013). Lessening the shame and embarrassment associated with HNC-related BID is vital to providing high-quality, patient-centered oncology care, which is associated with improved outcomes, including survival, and is prioritized by organizations involved in oncology funding, policy making, and regulation (Basch et al., 2012; Rotenstein et al., 2017). Routine use of IMAGE-HN may help normalize the assessment and treatment of body image concerns in patients with HNC. While the widespread utilization of the IMAGE-HN in busy oncology practices is perhaps unrealistic, adequately screening for and addressing psychosocial concerns in patients with HNC is likely to decrease the overall burden on healthcare resources in the long term by prevention of mental health complications. To improve the clinical implementation of BID screening among patients with HNC, additional research is necessary. This may include studies to identify high-risk groups for targeted screening, leveraging alternative screening tools for distress that assess body image and are already routinely used in the clinical oncology setting (e.g., NCCN Distress Thermometer), or developing a short-form of IMAGE-HN. Finally, even if patients with HNC-related BID are identified in the clinical realm through appropriate screening tools, significant barriers to the delivery and provision of appropriate psychosocial oncology care remains (Pirl et al., 2020). Future research is therefore necessary to investigate the most thoughtful and balanced approach to diagnosing and treating HNC-related BID within our current healthcare delivery models.

Strengths and Limitations

This study has several strengths. It was conducted with a large sample size from 6 academic medical centers and captured a sample of patients diverse by certain demographic and oncologic characteristics, which enhances the generalizability of study findings. We also used validated PROMs of BID, depression, anxiety, and health related QOL. Finally, we used rigorous statistical methods and incorporated findings from recent advancements in the field of measuring BID among cancer patients to ensure that our cutoff score optimally identifies HNC patients with clinically relevant BID. Despite its strengths, several important limitations should be discussed. Most patients included in this study were white and non-Hispanic, limiting the external validity of the newly defined cutoff score for other races and ethnicities. We only included patients who had completed HNC treatment and were free of active disease. We are thus unable to account for the effect of body image concerns prior to cancer diagnosis and further study of the normative values of IMAGE-HN scores across the trajectory of HNC from diagnosis through treatment should be prioritized. This study relied on self-reported patient characteristics susceptible to recall or response bias. We did not confirm the optimal IMAGE-HN cutoff score in a separate validation cohort. However, this is not expected to be a concern because the study was not attempting to fit a model to our specific sample. Lastly, although no gold standard (e.g., DSM diagnosis) for HNC-related BID exists, the rigorous study methodology we employed ensures the diagnostic accuracy of the IMAGE-HN.

CONCLUSION

In this multi-institutional study, an IMAGE-HN score of $\geq$22 identified patients with clinically relevant HNC-related BID. Furthermore, we found HNC patients with clinically relevant BID suffered clinically meaningful increases in symptoms of depression and anxiety and worse QOL when compared to HNC patients without clinically relevant BID. This score may be used in clinical practice to identify patients with HNC-related BID who may benefit from interventions to manage their distress. Researchers may use the IMAGE-HN cutoff score to improve our understanding of the underlying epidemiology of the disorder and better stratify patients for accrual into clinical trials evaluating novel strategies to manage HNC-related BID.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Medical University of South Carolina Institutional Review Board, Washington University School of Medicine Institutional Review Board, University of Pittsburgh School of Medicine Institutional Review Board, Vanderbilt-Ingram Cancer Center Institutional Review Board, Henry Ford Health System Institutional Review Board, and Medical College of Wisconsin Institutional Review Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

DM, BH, and EG: full access to the data in the study and take responsibility for the integrity of the data and accuracy of the data analysis. DM and EG: concept and design and obtained funding. DM, BH, PP, AW, SC, JZ, MN, BR, AH, NO-P, SM, WB, HL, KR, KS, and EG: acquisition, analysis, or interpretation of data and critical revision of the manuscript for important intellectual content. DM and BH: drafting of the manuscript. BH and HL: statistical analysis. All authors contributed to the article and approved the submitted version.

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MINI REVIEW
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Body Image in BRCA-Positive Young Women Following Bilateral Risk-Reducing Mastectomy: A Review of the Literature

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Background/Significance: The presence of a breast cancer (BRCA) gene mutation increases a woman's lifetime risk of developing breast cancer. Bilateral risk-reducing mastectomy is a proactive treatment option which lowers that risk. However, breast removal can create a change in physical appearance. It is unclear if BRCA-positive women undergoing this surgery in young adulthood, a life stage where intimate relationships, families, and careers are being established, have the same experience with body image as women in later stages of life.

Purpose: The aim of this literature review is to assess how bilateral risk-reducing mastectomy impacts body image in young BRCA-positive women less than 40 years of age, with no history of breast cancer.

Methods: Database searches were performed, yielding 402 results. Studies were considered if participants had an increased lifetime breast cancer risk/BRCA-positive diagnosis and history of bilateral risk-reducing mastectomy, body image was evaluated, and mean age was less than 40 years. A total of three qualitative studies and three quantitative studies were identified as relevant for this review.

Results: A dearth of information exists on body image in young women following bilateral risk-reducing mastectomy. It was found in this review that some women experienced a decline in body image following surgery, while in others body image was maintained or improved.

Conclusion: Understanding factors that impact body image following this risk-reducing surgery will allow clinicians to support this unique population. Open and informative discussion should be encouraged with young women considering, or who have undergone, bilateral risk-reducing mastectomy.

Keywords: body image, BRCA, risk-reducing mastectomy, prophylactic mastectomy, young adult, risk-reducing surgery

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INTRODUCTION

The presence of a breast cancer (BRCA) gene mutation is predicted to increase a woman's lifetime risk of developing breast cancer to 72%, compared to the 12% lifetime risk of a woman without this gene mutation (Kuchenbaecker et al., 2017; McCarthy et al., 2017). Approximately, 1 in 400 people in the United States have a BRCA 1 or 2 mutation (National Cancer Institute, 2020). Women less than 40 years of age have accounted for a 15% increase in BRCA testing between 2003 and 2016 (Guo et al., 2020), emphasizing the importance of knowing and managing risk to this population.

Bilateral risk-reducing mastectomy (BRRM), a surgical procedure in which healthy breasts are removed to prevent breast carcinoma, is the most effective proactive treatment option available for BRCA-positive women. Lifetime breast cancer risk is reduced by 90% following BRRM (Rebbeck et al., 2004). This procedure continues to increase in prevalence, with insurance claims database surveys between 2003 and 2016 displaying that BRCA-positive women undergoing BRRM had increased between 1.2 and 1.6% per month (Liede et al., 2018).

Younger women who undergo BRRM note having a close family member diagnosed with breast cancer and the reduction of breast cancer-related worry as common reasons for seeking this surgery (Hoskins and Greene, 2012; Borreani et al., 2014; Hunt et al., 2017; Long et al., 2017; Henry et al., 2019), despite its potential to cause a significant change in appearance. Body image, defined as a person's attitudes, thoughts, beliefs, and behaviors regarding their physical appearance (Cash, 2004), has been negatively impacted by mastectomy in young breast cancer survivors (Iddrisu et al., 2020; Rosenberg et al., 2020). Body image has been both positively and negatively affected following BRRM in studies comprised of women across the lifespan (Metcalfe et al., 2015; Razdan et al., 2016; Bai et al., 2019). Younger women are undergoing this surgery during a stage in life where commitments to careers, families, and/or monogamous relationships are being established (Scheck, 2005), and may be affected differently than women 40 years of age or older. The aim of this review of the literature is to examine how BRRM effects body image in BRCA-positive women less than 40 years of age.

MATERIALS AND METHODS

Search Strategy

Searches were performed 06/16/2021, and 08/22/2021 utilizing a combination of the key terms of "risk-reducing mastectomy," "BRCA," "body image," and "young." CINAHL, PubMed, and Scopus databases were utilized in the review of literature. No limits were placed on geographic location or length of time for follow up. Studies were limited to those published in peer reviewed journals from 2011 and onward, and in the English language. This timeframe for article selection was chosen as the use of prophylactic breast surgery to reduce lifetime breast cancer risk in young women is a relatively new concept.

Eligibility Criteria

Studies selected for this review included those in which participants had previously undergone BRRM, were BRCA-positive or had an increased familial risk of breast cancer, and those in which body image was addressed within the study. Articles were included if body image broadly met the definition provided in this review. Due to the paucity of studies comprised solely of participants less than 40 years of age, studies were considered for inclusion if the mean age of study participants was less than 40 years. Studies were also included if data on women who had undergone BRRM were reported separately from women undergoing other risk-reducing surgery or who were breast cancer survivors. Two qualitative articles used data collected from semi-structured interviews in the same sample of participants. From this study, both articles were included as each pursued different research questions and aims (Glassey et al., 2018a,b). Ineligible studies were those in which mean age of participants was greater than 40 years and were comprised of, or did not separately report data from, women with a breast cancer diagnosis.

Study Selection

Searches yielded 402 results, with 316 articles remaining after duplicates were removed. Titles and abstracts of these results were then screened for relevance, with 34 articles identified for full text review. The articles were then read in their entirety and were excluded for the following reasons: three contained participants that were only breast cancer survivors; 17 had a mean age greater than 40 years; three did not provide a mean age for study participants; two did not address body image; and two did not differentiate participants with and without breast cancer. Seven articles were identified as meeting inclusion criteria for this literature review (see **Figure 1**).

RESULTS

General Characteristics of Included Studies

Table 1 displays study characteristics for the seven articles included in this review. While all studies had a mean age of less than 40 years, only two studies contained participants who were all less than 40 years of age at the time of BRRM (Glassey et al., 2018a,b; Salibian et al., 2020). Studies were located across Europe (*n* = 3), Australia and New Zealand (*n* = 2), and the United States (*n* = 1). In all studies participants underwent some form of reconstruction following mastectomy, though details on reporting reconstruction type(s) varied widely across studies. Three quantitative articles were included in this review. All are observational, with participants completing surveys. Of the three qualitative studies included in this review, all conducted semi-structured interviews to obtain data. In analyzing this data, two articles, which used the same sample population, utilized interpretative phenomenological analysis theory (Glassey et al., 2018a,b), one study used thematic

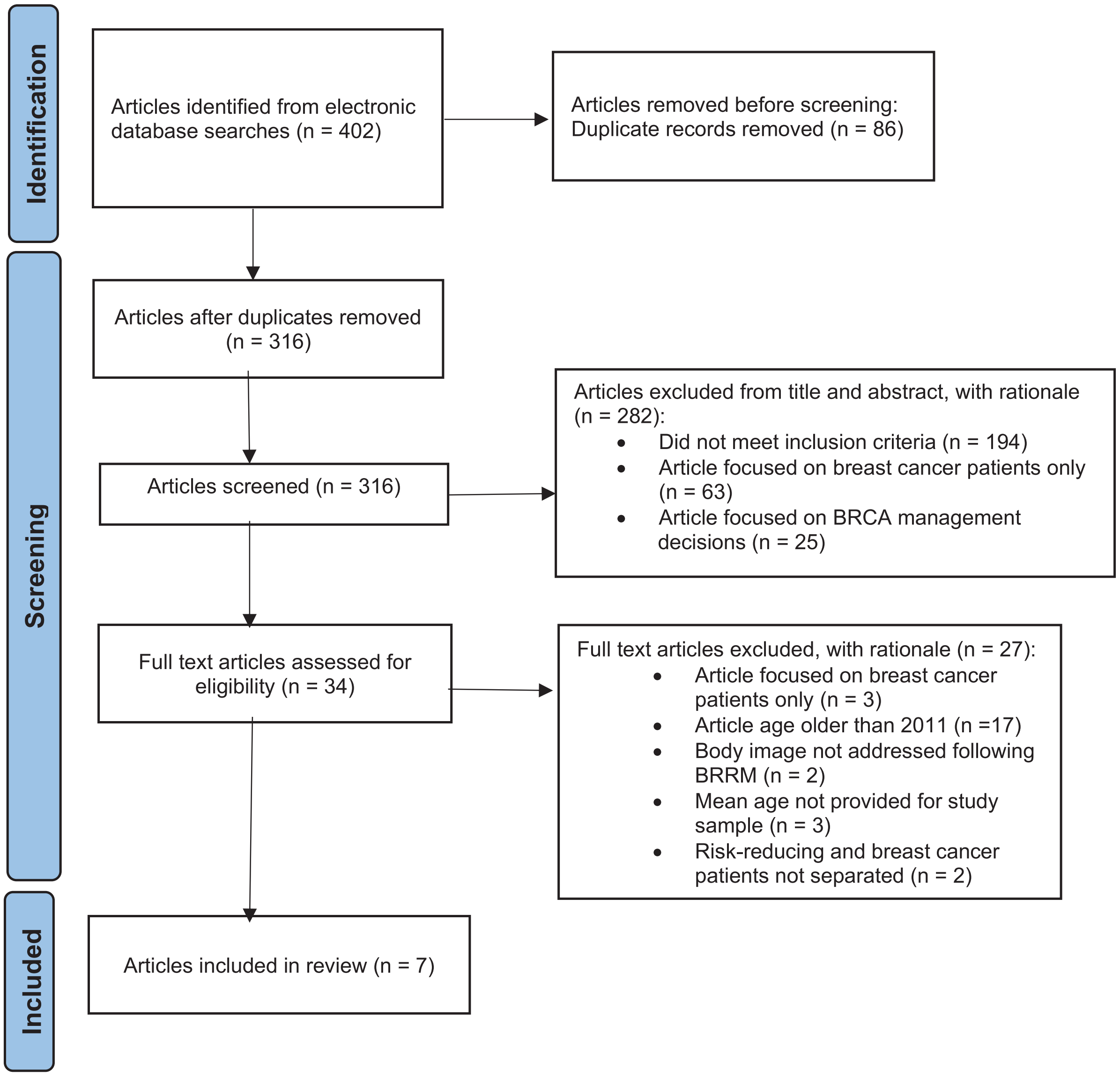

FIGURE 1 | PRISMA flow diagram for article inclusion.

qualitative analysis (Hallowell et al., 2012), and one used content analysis (Wasteson et al., 2011).

Body Image Findings in Quantitative Literature

The BREAST-Q Reconstruction Module was used to evaluate body image in two studies in this review (Salibian et al., 2020; Gandhi et al., 2021). This instrument is a validated patient-reported outcome measure designed to evaluate outcomes in women who have undergone breast reconstruction. It generates a numerical score on a scale from 0 (worst) to 100 (best), with a higher score indicating a more positive outcome (Mundy et al., 2017). In the BREAST-Q, body image is measured through the satisfaction with breasts and psychosocial well-being domains (Pusic et al., 2017). Participants in both studies expressed high breast satisfaction and psychosocial well-being scores on the BREAST-Q (see **Table 1**), including a study in which women (*n* = 12) underwent nipple-sparing BRRM before the age of 30 (Salibian et al., 2020). Gandhi et al. (2021) found that women undergoing BRRM (*n* = 241) had higher BREAST-Q scores than the group with breast cancer (*n* = 56). On the satisfaction with breasts scale the BRRM group scored 62 compared to a score of 56 in the cancer group, and on the psychosocial well-being scale the BRRM group score 73, compared to a score of 60 in the cancer group.

In the third study, body image was measured over time with a 31 item study-specific body image scale. It found that satisfaction with breast appearance at the preoperative baseline level was 82.9%. A decline in body image occurred 6

TABLE 1 | Table of studies.

First author/Study type (Year)	Design/Method	Sample/Setting	Inclusion criteria	Body image instrument/Items	Analysis/Results	Findings addressing body image
Gandhi et al. (2021)/Quantitative (2021)	• Observational, multi-site (2) • Data collected between 2015 and 2016 • The BREAST-Q reconstruction module was completed after BRRM to measure satisfaction with breasts	• *N* = 241 women without breast cancer • x̄ age of women without breast cancer at BRRM: 39.6 years • Location: United Kingdom	• Increased familial breast cancer risk • BRRM	• BREAST-Q reconstruction module/99 items	• Satisfaction with breasts score: 62 • Psychosocial well-being score: 73	• The BREAST-Q displayed high breast satisfaction and psychosocial well-being scores (out of 100) following BRRM
Glassey et al., 2018a,b/Qualitative (2018 and 2018)	• Interpretive phenomenological analysis • Data collected between 2015 and 2016 • One semi-structured interview was conducted per participant to explore whether psychological consultation prior to BRRM was beneficial to women • One semi-structured interview was conducted per participant to explore the influences on satisfaction with reconstructed breasts	• *N* = 26 • x̄ age at time of study = 31 years (range 23–38 years) • Location: Australia and New Zealand	• BRCA-positive diagnosis or strong family history of breast cancer • Age under 35 at time of BRRM	Semi-structured interview guide	Interpretative phenomenological analysis/3 themes surrounding psychological consult: psychological well-being and adjustment, intimacy, and body image and 4 themes surrounding breast satisfaction: satisfaction with breasts before surgery, outcome expectations, type of mastectomy, and open communication	• Women who underwent psychological evaluation (38%) prior to BRRM upheld their confidence and self-esteem following surgery; body image was maintained • Women who were satisfied with breast appearance prior to BRRM were less satisfied after • Unrealistic surgical expectations caused a decline in body image • Loss of nipples caused a decline in body image
Gopie et al., 2013/Quantitative (2013)	• Observational, multi-site, prospective • Data collected between 2007 and 2010 • Women filled out a study-specific body image survey preoperatively, 6 months postoperatively, and after reconstruction to determine the psychological impact of breast reconstruction	• *N* = 73 • x̄ age at time of BRRM = 37.1 years (range at time of BRRM: 21–65 years) • Location: Netherlands	• BRCA-positive diagnosis or increased familiar breast cancer risk	• Study specific Body Image Scale (BIS)/31 items • Impact of Event Scale (IES)/15 items	Cohen's $d = -0.63$ at 6 months Cohen's $d = -0.83$ at 21 months	• A high preoperative cancer distress score led to a more negative body image at long term follow-up in 25% ($n = 12$) of the women • Discussion of outcomes is important for expectation management
Hallowell et al. (2012)/Qualitative (2012)	• Thematic Analysis • Data collected between 2006 and 2009 • One semi-structured interview was conducted per participant to explore the experiences of women 3 years after risk-reducing surgery, including BRRM	• *N* = 8 • x̄ age at time of BRRM: 34 years (range at time of BRRM: 28–41 years) • Location: Australia and New Zealand	• No previous breast cancer diagnosis • BRCA-positive diagnosis or increased familial risk of breast cancer	Semi-structured interview guide	Thematic analysis/2 themes: looking different, feeling different	• Positive and negative impressions were experienced by women following BRRM • BRRM offered cosmetic improvement to some participants who were unhappy with their appearance prior to surgery
Salibian et al. (2020)/Quantitative (2019)	• Observational, retrospective chart review • Data collected from charts between 2006 and 2018 • The BREAST-Q reconstruction module was completed after BRRM to measure satisfaction with breasts	• *N* = 12 • x̄ age at time of BRRM: 26.9 years (range at time of BRRM: 23–29 years) • Location: United States	• BRCA-positive diagnosis • Age under 30 at time of BRRM • Six month since breast reconstruction completed	BREAST-Q reconstruction module/99 items	• Satisfaction with breasts score: 73 • Psychosocial well-being score: 78.2	The BREAST-Q displayed high breast satisfaction and psychosocial well-being scores (out of 100) following BRRM in young patients undergoing nipple-sparing mastectomy
Wasteson et al. (2011)/Qualitative (2011)	• Content analysis • Data originally collected 1993–1997 • One semi-structured interview was conducted per participant to determine long-term consequences of BRRM approximately 10 years after surgery	• *N* = 13 • x̄ age at time of BRRM: 35 years • Location: Sweden	• BRCA-positive diagnosis or increased familiar breast cancer risk • Previous BRRM and study participation	Semi-structured interview guide	Content analysis/6 categories: risk perception, activities after BRRM, spousal bond, recreational activities, cosmetic results, other	• 66% of participants considered cosmetic results to be positive following BRRM • Women would benefit from psychological support after BRRM

months after BRRM, with only 45.7% of participants reporting satisfaction with breast appearance. At the 21 month follow up body image had improved but remained lower than baseline with 71.4% of women satisfied with breast appearance (Gopie et al., 2013).

Breast Cancer Worry and Body Image

Women with a BRCA-positive diagnosis have been found to experience breast cancer- related worry and uncertainty surrounding if and when a breast cancer diagnosis might occur (McQuirter et al., 2010; Hoskins and Greene, 2012; Dean, 2016). Increased breast cancer-related worry was found to lower body image in one study in this review. A study by Gopie et al. (2013) examined if body image could be predicted from breast cancer-related distress using the Impact Event Scale. This scale measures subjective distress related to a specific life event (Horowitz et al., 1979). The study found that a high preoperative cancer distress score led to a more negative body image at long-term follow-up in 25% of study participants (n = 12), with a higher preoperative cancer distress score (−0.33) associated with decreased body image at 6 months (Cohen's d = −0.63), and a higher preoperative cancer distress score (0.10) associated with decreased body image at 21 months (Cohen's d = −0.83) (Gopie et al., 2013).

Body Image Findings in Qualitative Literature

The Impact of Psychological Evaluation on Body Image

Braude et al. (2017) have noted that psychologists provide advantages to women considering BRRM, including decision-making and adjustment-preparation pre-operatively and support with adjustment post-operatively. In this review, two qualitative studies also noted the importance of psychological evaluation on the psychosocial outcomes of women in the time surrounding BRRM (Wasteson et al., 2011; Glassey et al., 2018a,b). In a study where participants underwent BRRM before age 35, those who are able to speak with a psychologist before surgery upheld their confidence, were more satisfied with cosmetic outcomes, and did not develop negative self-esteem postoperatively (Glassey et al., 2018a). However, women who did not undergo evaluation experienced psychosocial adjustment and body image issues after surgery (Glassey et al., 2018a).

Unrealistic Expectations

The importance of knowledge and understanding to the change in physical appearance following BRRM appeared to be a key factor in participants forming realistic expectations of breast appearance following surgery (Wasteson et al., 2011; Hallowell et al., 2012; Gopie et al., 2013; Glassey et al., 2018b). One study noted that body image declined postoperatively when women did not receive adequate preparation from their healthcare team on how their reconstructed breasts could appear; to facilitate understanding participants suggested photographs as a helpful medium for visualizing breast reconstruction (Glassey et al., 2018b).

Factors Which Improved or Maintained Body Image Following Bilateral Risk-Reducing Mastectomy

Two studies demonstrated that reconstruction following BRRM did not negatively impact body image. In one study, women who were unhappy with their breast appearance preoperatively experienced an improvement in body image due to change in breast shape and size following reconstruction (Glassey et al., 2018b). In a second study, some participants noted a more appealing breast shape, youthful figure, and fit of clothing as positives following reconstruction after BRRM (Hallowell et al., 2012). Nipple preservation appeared to sustain body image as well, with participants who had had nipple-sparing mastectomies reporting their satisfaction through the maintenance of breast appearance (Glassey et al., 2018b).

DISCUSSION

This literature review aimed to evaluate how body image was impacted following BRRM in young BRCA-positive women. Findings from both quantitative and qualitative studies indicate that body image can be affected both positively and negatively following this risk-reducing surgery. In quantitative studies, body image was measured through both validated and study-specific instruments. A decline in body image was experienced by some women due to breast cancer-related worry, and persisted for many months (Gopie et al., 2013). However, other women were either satisfied with their physical appearance following BRRM or experienced some improvement in body image with the passage of time (Gopie et al., 2013; Salibian et al., 2020; Gandhi et al., 2021).

Qualitative studies in this review found that some participants noted body image decline following BRRM due to insufficient education from their medical team (Glassey et al., 2018b). Information from healthcare providers was necessary to assist women in forming a realistic understanding of physical appearance after surgery. It was also understood that body image declined among some participants when women did not undergo psychological evaluation prior to BRRM (Glassey et al., 2018a). Body image was also found to be sustained or improved following BRRM. This was noted to occur when women were able to preserve their nipples (Glassey et al., 2018b) and in women who were unhappy with their breast appearance preoperatively. These participants expressed improvement in body image BRRM due to reconstruction (Hallowell et al., 2012).

As a weakness in this review, it should be noted that only three articles included samples comprised solely of women less than 40 years of age at the time of BRRM (Glassey et al., 2018a,b; Salibian et al., 2020). All other studies also included women older than 40 years of age, making it difficult to generalize findings to younger women. Additionally, the body image outcomes in young women who elected not to undergo reconstruction following BRRM were not well-represented in this review. As a limitation of this review, the author had the sole responsibility for the literature search strategy, review of retrieved studies, data elicitation from included studies, and summary of findings. Finally, as the majority of study participants in this review were

Caucasian, the homogeneity of the samples should be viewed as a limitation.

Further investigation is needed following BRRM in BRCA-positive young women to further elucidate factors effecting body image. Such efforts are needed to ultimately develop interventions that would improve a negative body image following BRRM in this population. A strength of this review is the discovery of a gap in the literature, with few studies offering the perspective of body image following this risk-reducing surgery in BRCA-positive women less than 40 years of age.

CONCLUSION

While a dearth of information exists that focuses exclusively on how young BRCA-positive women perceive their physical appearance after undergoing BRRM, this literature review has identified that younger women experience both positive and negative impacts to body image following this risk-reducing surgery. This echoes findings from studies of body image after BRRM comprised of women across the lifespan (Metcalfe et al., 2015; Razdan et al., 2016; Bai et al., 2019). For clinicians, it is important to appreciate both the positive and negative consequences of BRRM identified in this review when treating young women who are considering, or who have undergone, this risk-reducing surgery to lower lifetime breast cancer risk.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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Testing the Associations Between Body Image, Social Support, and Physical Activity Among Adolescents and Young Adults Diagnosed With Cancer

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Physical activity (PA) is important for managing the side effects and long-term outcomes of cancer treatment, yet many adolescents and young adults diagnosed with cancer (AYAs) are not meeting PA guidelines. Body image and social support are two factors that can influence PA behavior and require further attention in this population. The purpose of this study was to examine the associations between body image, social support, and PA among AYAs. An online cross-sectional survey administered through the Research Electronic Data Capture platform was used to assess self-reported body image (body-related self-conscious emotions of appearance and fitness shame, guilt, authentic pride, and hubristic pride), social support (general and cancer-specific), and PA (mild, moderate-to-vigorous, and resistance exercise) in AYAs (N = 119; M_{age} = 34.5 ± 5.5 years). Based on findings from path analyses, body image and social support were directly associated with PA (R^2 = 0.09–0.33). Social support was also directly associated with body image. However, there were no indirect effects. These findings provide preliminary support for the influential role of appearance and fitness body-related emotions and cancer-specific social support on PA. The results have important implications for the development of targeted strategies aimed at improving body image (e.g., cognitive dissonance and compassion-focused interventions) and social support (e.g., facilitating the provision of cancer-specific support), with the overall goal of increasing AYAs' PA.

Keywords: body image, cancer, adolescents, young adults, physical activity, social support, quantitative, oncology

INTRODUCTION

Cancer in adolescents and young adults (AYAs; diagnosed between 15 and 39 years) accounts for approximately 5% of all new cases of cancer diagnosed each year in North America (American Cancer Society, 2019; Canadian Cancer Statistics Advisory Committee, 2019). With improvements in early screening and treatment, many AYAs are living 50–60 years after diagnosis (Lewis et al., 2014; Canadian Partnership Against Cancer, 2017). However, cancer treatment can have significant acute and long-term effects on AYAs' physical, psychological, and social health and well-being

(Tai et al., 2012; Patterson et al., 2015). Identifying strategies to help offset these detrimental outcomes of cancer is needed.

Physical activity (PA) during and after cancer treatment is associated with many benefits including reduced adverse effects, mortality, and cancer recurrence (Bélanger et al., 2011; Baumann et al., 2013; Cormie et al., 2017; Brunet et al., 2018). The consistent well-documented benefits of PA are reflected in PA guidelines for cancer survivors, with the most recent recommendations described as at least 90 min of aerobic activity and two sessions of resistance exercise per week (Campbell et al., 2019). Yet, about half of AYAs are inactive or insufficiently active, with PA levels declining from pre-diagnosis to during and post-treatment (Bélanger et al., 2011; Murnane et al., 2015). Therefore, it is important to identify potential intervening factors that may help to improve AYAs' PA levels and overall health and well-being.

Social support is likely an important factor that can affect PA. Social support can be conceptualized as a multidimensional construct that involves interpersonal interactions from support networks (Bianco and Eklund, 2001). Even though AYAs are in a developmental stage marked by fostering social connections, a cancer diagnosis impedes their ability to create and maintain social relationships (Patterson et al., 2015). Social disconnect may undermine perceptions of physical skills and abilities (Feeney and Collins, 2015). AYAs report that perceptions of low social support for PA limit their interest in participating in activity (Wu et al., 2015). Further, AYAs describe that holding discordant PA goals when compared to others challenges their willingness to engage in activity (Wu et al., 2015). Meanwhile, group-based PA increases AYAs' PA engagement and maintenance (Gill et al., 2016). As such, social support may be an important factor related to PA among AYAs.

Body image is another key factor that can impact PA behavior. Body image is a multidimensional construct that involves positive and negative perceptions, cognitions, feelings, and behaviors toward the body's appearance and function (Cash and Smolak, 2011). Although appearance has been widely studied in previous research with AYAs, there is a paucity of studies examining functional body image (Vani et al., 2021). Up to 88% of AYAs report changes to their body's appearance and physical function as a consequence of cancer and related treatment (Vani et al., 2021). Body image theories within oncology (White, 2000) posit that cancer-related body changes (e.g., scarring, hair loss, weight change, and physical functioning issues) can negatively impact body image perceptions, cognitions, affect, and behaviors. Particularly related to body image affect, AYAs have described feelings of self-consciousness, shame, and guilt associated with body changes resulting from cancer (Williamson et al., 2010; Pounders et al., 2017). Self-consciousness is often measured *via* body-related shame and guilt (Castonguay et al., 2014, 2016). Body-related shame occurs when an individual feels they have a flaw related to their sense of self, while body-related guilt occurs when an individual has a negative evaluation of their behavior (Tracy and Robins, 2007). Meanwhile, some AYAs have reported body-related pride, a positive self-conscious emotion (Wallace et al., 2007; Grogan and Mechan, 2017). Pride is experienced when an individual evaluates their engagement in socially valued behaviors or their social presentation of their body in a positive manner (Tracy and Robins, 2007). Pride can be further divided into two facets: authentic (i.e., positively evaluating one's appearance- or fitness-related achievements) and hubristic (i.e., evaluating body appearance or function as superior to others) pride (Tracy and Robins, 2007; Castonguay et al., 2013, 2014, 2016). Positive and negative appearance- and fitness-related self-conscious emotions have been associated with PA among AYAs who have not been diagnosed with cancer (Sabiston et al., 2010; Castonguay et al., 2015; Gilchrist et al., 2018; Pila et al., 2020), yet these relationships have not been tested among AYAs.

In addition to the plausible direct association between body-related emotions and PA, body image may indirectly influence the relationship between social support and PA. Although these associations are likely to be similar to the general population, the relationships may be more pronounced among AYAs due to the unique social disconnect, body-related changes, and difficulties with PA engagement that AYAs may experience (Murnane et al., 2015; Patterson et al., 2015; Vani et al., 2021). Supportive others are central to helping AYAs feel more positively and less negatively about their bodies and provide protection against negative body commentary from others (Larouche and Chin-Peuckert, 2006; Williamson et al., 2010; Vani et al., 2021). As such, social support may be positively associated with body-related pride and negatively associated with body-related shame and guilt. These associations are consistent with sociocultural perspectives (Petrie and Greenleaf, 2012), wherein social influences (e.g., peers, parents) are often implicated in the development of thoughts and feelings about the body and exercise behaviors. AYAs' body-related perceptions and feelings have been reported as a barrier to PA engagement after treatment (Wu et al., 2015). Further, AYAs who hold negative body perceptions avoid physical activities that emphasize the body's appearance (e.g., swimming) and communal changing spaces that are common in fitness facilities (Larouche and Chin-Peuckert, 2006; Vani et al., 2021). Interpreting this evidence, positive body-related emotions may enhance PA participation whereas negative body-related emotions may impede PA participation (Sabiston et al., 2010; Gilchrist et al., 2018; Pila et al., 2020). However, body-related guilt can also be reparative and increase PA (Sabiston et al., 2010; Castonguay et al., 2017). Furthermore, these emotions may be uniquely associated with different PA intensities and types. To promote PA among AYAs, it is important to better understand the associations among social support, body image, and PA after a cancer diagnosis.

Drawing on sociocultural perspectives (Petrie and Greenleaf, 2012) and White's (2000) body image model in oncology social support and body image may be factors associated with PA and body image may indirectly influence the relationship between social support and PA. The aim of this study was to test the pathways of social support, appearance- and fitness-related self-conscious emotions of shame, guilt, authentic pride, hubristic pride, and PA. Given the PA recommendations for participation in both aerobic and resistance-based exercise, both types of PA were examined. Based on existing literature (Vani et al., 2021) and conceptual underpinnings (Petrie and Greenleaf, 2012), it was expected that social support would be negatively associated with shame and guilt and positively associated with authentic and hubristic pride. Shame was expected to demonstrate a negative relationship with PA. The reparative nature of guilt (Tangney and Dearing, 2002) suggested that guilt would be positively tied to PA. Authentic and hubristic pride and social support were also expected to demonstrate a positive relationship with PA. Finally, it was hypothesized that self-conscious emotions would indirectly influence the relationship between social support and PA.

MATERIALS AND METHODS

Participants and Procedure

Following university research ethics board approval (#39245), AYAs were recruited by emailing cancer organizations and survivorship programs in Canada and the United States. Supporting organizations and programs contacted the AYAs via email and/or social media. A recruitment poster was also shared on the research team's social media accounts. AYAs were eligible to participate if they (i) were diagnosed with cancer between the ages of 15 and 39 years, regardless of cancer type, stage, time since diagnosis, treatment status, and treatments received; and (ii) were able to read and respond to questions in English. The selected age range is aligned with the standard for cancer organizations in Canada and the United States (American Cancer Society, 2019; Canadian Cancer Statistics Advisory Committee, 2019). Interested eligible AYAs used the provided link or QR code to directly access the electronic consent form. Once consent was complete, participants were redirected to the secure online survey using the Research Electronic Data Capture platform. Upon completion, participants were entered into a draw to win one of twenty $25 gift cards. Surveys were completed between January and June, 2021. Based on this timing, data collection mainly occurred during public health restrictions pertaining to the COVID-19 pandemic. Standard sample size estimate protocols for path analyses suggest 10–20 participants per main parameter (Nunnally, 1967; Stevens, 2012; Kline, 2015). Based on these recommendations, the target sample size was 120 AYAs.

Measures

Demographics

Participants completed a sociodemographic questionnaire containing personal (e.g., age, self-identified gender, sexuality, and ethnicity) and cancer-related (e.g., cancer type, treatment status, and time since diagnosis) questions.

Social Support

Social support was measured using the Social Support Survey (Richman et al., 1993), which was modified to include a cancer-specific support type. Participants were provided with the definition of each of the following support types: listening, task challenge, emotional, reality confirmation, tangible assistance, and based on previous literature, a cancer-specific support type (i.e., "people who support you by letting you know that they understand what it is like to have gone through cancer"; McDonough et al., 2014). For each support type, participants completed two items assessing the (i) quantity (i.e., "how many individuals provided you with this type of support") on a 5-point Likert-type scale from 0 (*none*) to 4 (*8 or more*), and (ii) quality (i.e., "in general, how satisfied are you with the overall quality of support you receive?") on a 5-point Likert-type scale from 0 (*very dissatisfied*) to 4 (*very satisfied*). A total general social support score was calculated by averaging the quantity and quality items across the five general support types. Aligning with research practice (McDonough et al., 2014), a total cancer-specific social support score was calculated by averaging the quantity and quality items. Evidence of validity and reliability were previously reported with non-cancer AYAs (Richman et al., 1993; Rees et al., 2007) and adult breast cancer survivors (McDonough et al., 2014).

Body Image

Body image was operationalized as appearance- and fitness-related self-conscious emotions (Castonguay et al., 2014, 2016).

Appearance-Related Self-Conscious Emotions

Participants completed the 16-item Body and Appearance Self-Conscious Emotions Scale (BASES; Castonguay et al., 2014) to assess appearance-related shame, guilt, authentic pride, and hubristic pride (four-items per emotion). Participants were asked to indicate how often, on average, they experienced appearance-related shame (e.g., "ashamed of the way I look"), guilt (e.g., "guilty that I do not do enough to improve the way I look"), authentic pride (e.g., "proud of the effort I place on maintaining my appearance"), and hubristic pride (e.g., "proud that I am an attractive person") on a 5-point Likert-type scale ranging from 1 (*never*) to 5 (*always*). Subscales were computed by averaging responses across the four items for each emotion, with higher scores reflecting higher levels of the emotion. Evidence of validity and reliability has been reported previously with non-cancer AYAs (Castonguay et al., 2014; Chiminazzo et al., 2021).

Fitness-Related Self-Conscious Emotions

Participants completed the 16-item Body-Related Emotions in Fitness Instrument (BSE-FIT; Castonguay et al., 2016) to assess fitness-related shame, guilt, authentic pride, and hubristic pride. Participants were asked to indicate how often, on average, they experienced fitness-related shame (e.g., "ashamed that I am a person who is unfit"), guilt (e.g., "guilty that I do not do enough for my fitness"), authentic pride (e.g., "proud of my fitness efforts"), and hubristic pride (e.g., "proud of myself when I compare my fitness to others") on a 5-point Likert-type scale ranging from 1 (*never*) to 5 (*always*). Subscales were computed by averaging responses across the four items for each emotion, with higher scores reflecting higher levels of the emotion. Evidence of validity and reliability has been reported previously with non-cancer AYAs (Castonguay et al., 2016; Pila et al., 2020).

Physical Activity

Self-reported PA was assessed using a modified version of the Godin Leisure-Time Exercise Questionnaire (GLTEQ; Godin and Shephard, 1985). Participants indicated how many times on average they engaged in mild (e.g., yoga, golf), moderate (e.g., fast walking, baseball), and vigorous (e.g., running, soccer) exercise for more than 15 min in a typical week. Aligned with the PA guidelines for cancer survivors [i.e., 90 min of moderate-to-vigorous PA (MVPA) per week; Campbell et al., 2019], we included the common modification of assessing the average duration (in hours and minutes) per session of each intensity category of PA. Aligning with previous research among non-cancer AYAs (Murray et al., 2021), respondents were asked to report the frequency and average duration of resistance exercise (e.g., free weights, bodyweight training). Resistance training was important since AYAs report a preference for resistance exercise (Adams et al., 2021) and qualitative evidence suggests AYAs may have unique experiences engaging in resistance training compared to aerobic PA (Vani et al., under review). Total scores for mild, moderate, and vigorous activity and resistance exercise were calculated by multiplying self-reported times per week by average duration of sessions for each type. In addition, moderate and vigorous scores were summed to yield a total MVPA score. This scale has been used in studies with AYAs (Brunet et al., 2018), has shown convergent validity with accelerometer measures in samples of cancer survivors (Amireault et al., 2015), and has demonstrated test-retest reliability (i.e., α-coefficient ranges from 0.46 to 0.96 in adolescent and adult samples; Godin and Shephard, 1985; Sallis et al., 1993).

Data Analysis

Data were screened for outliers, missing data, and regression analysis assumptions prior to analyses (Tabachnick and Fidell, 2013). Preliminary analyses included descriptive statistics (e.g., mean, frequencies) to characterize the sample and the main study variables. Bivariate Pearson *r* and Spearman rho correlations were computed to test the relationships between variables using SPSS (Version 21).

To test the hypothesized associations among social support, body image, and PA, path analysis with maximum likelihood estimation was conducted using MPlus (Muthén and Muthén, 1998-2011). Two models were computed to examine appearance- and fitness-related emotions separately. The models were tested separately to examine the distinct influence of appearance and fitness contextualized emotions and to avoid measurement overlap and furthering model complexity. The models tested the direct path coefficients of: (i) social support (general and cancer-specific), *appearance*-related self-conscious emotions (shame, guilt, authentic pride, and hubristic pride), and PA (mild PA, MVPA, and resistance exercise); and (ii) social support, *fitness*-related self-conscious emotions, and PA. Indirect path coefficients of each model were computed for the effects of social support on PA through body-related emotions in both models. The following variables were set to correlate: (i) general and cancer-specific social support; (ii) shame, guilt, authentic pride, and hubristic pride; and (iii) mild PA, MVPA, and resistance exercise. Age, gender, and time since diagnosis were included as covariates in the models. Model goodness of fit was established using non-significant chi-square, and the accepted fit indices (Hu and Bentler, 1999) of: (i) Standardized Root Mean Square Residual (SRMR; values $\leq$0.08); (ii) Root Mean Square Error of Approximation (RMSEA; values close to 0.06); and (iii) Comparative Fit Index (CFI; values $\geq$0.90). Statistical significance was set to $p < 0.05$.

RESULTS

Data cleaning led to the removal of 85 records; some individuals opened the link but did not complete the consent form ($n = 23$), completed informed consent but did not begin the survey ($n = 34$), were identified as Bots[1] ($n = 20$), began the survey multiple times ($n = 4$), or were not diagnosed with cancer between 15 and 39 years ($n = 4$). The remaining sample ($n = 119$) completed the electronic consent and survey, and was screened for missing data. Data were missing at the item level, and no item was missing greater than 5% of responses. Missing data were determined to be missing completely at random (MCAR $\chi^2 = 703.42$, $df = 661$, $p > 0.05$). Incomplete data were imputed using an Expectation Maximization algorithm (Dempster et al., 1977). Outliers were classified as values that deviated beyond ± 3 standard deviations from the mean and detected univariate outliers were winsorized (Osborne, 2010).

Descriptive Results

Descriptive statistics for the analytical sample ($N = 119$) are presented in **Table 1**. AYAs were an average of 34.5 ± 5.5 years of age (range = 21–47), predominantly identified as White (82.4%), women (84.0%), married or living with a life partner (56.3%), diagnosed with stage II or III cancer (48.9%), and had completed cancer treatment (78.2%). Based on PA guidelines for cancer survivors (Campbell et al., 2019), 27.7% of AYAs reported meeting guidelines of both MVPA and resistance training. Descriptive statistics, bivariate correlations, and internal consistency for the main study variables and covariates are presented in **Table 2**. In general, participants reported social support and body-related emotion scores around the mid-point of the respective scales. Overall, higher scores for shame and guilt were reported compared to authentic and hubristic pride, and fitness emotion scores were generally higher than appearance emotions.

Main Results

Preliminary models produced spurious relationships involving appearance- and fitness-related shame and guilt, and the correlations between shame and guilt were significant ($r = 0.76$–0.82, $p < 0.001$). To address a potential model misfit, revised models using guilt-free shame (GFS) and shame-free guilt (SFG) were tested. Based on previous research (Sabiston et al., 2010), GFS was assessed as the standardized residual associated with predicting shame from guilt (operationalized as maladaptive negative emotion focused on the self; Tangney and Dearing, 2002), while SFG was assessed as the standardized residual associated with predicting guilt from shame (operationalized as a behavior-focused and often adaptive negative emotion without conflating the negative value of the self; Tangney and Dearing, 2002). Significant ($p < 0.05$) bivariate correlations for GFS, SFG, and the remaining model variables are presented under **Table 2**.

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[1] Bots were identified in consultation with the Information Technology department at the authors' university. Identification occurred using a combination of email address, time to complete the survey, and responses provided. Using the same approach, the remaining participants were deemed genuine.

TABLE 1 | Participant descriptive characteristics (*n* = 119).

Descriptive and study variables	*M* ± *SD* or *n* (%)
Age, years	34.5 ± 5.5
Gender	
Man	16 (13.4%)
Woman	100 (84.0%)
Other[a]	3 (2.5%)
Sexual orientation*	
Bisexual	7 (5.9%)
Gay	3 (2.5%)
Heterosexual	91 (76.5%)
Lesbian	1 (0.8%)
Pansexual	3 (2.5%)
Other[b]	8 (6.7%)
Prefer not to answer	5 (4.2%)
Ethnicity[‡]	
Arab	1 (0.8%)
Black	3 (2.5%)
Chinese	2 (1.7%)
Filipino	2 (1.7%)
Latin American/Hispanic	3 (2.5%)
South Asian	7 (5.9%)
White	98 (82.4%)
Education[†]	
High school	4 (3.4%)
College/Technical	12 (10.1%)
University undergraduate	53 (44.5%)
Post-graduate	47 (39.5%)
None of the above	1 (0.8%)
Relationship status*	
Single	33 (27.7%)
In a relationship, not living with partner	12 (10.1%)
Married/living with life partner	67 (56.3%)
Separated/Divorced	4 (3.4%)
Widowed	2 (1.7%)
Children (*n*, % yes at least one)	40 (33.6%)
Population size*	
Small (1,000–29,999)	15 (12.6%)
Medium (30,000–99,999)	25 (21.0%)
Large (100,000 +)	78 (66.1%)
Socioeconomic status (income)[§]	94,910 ± 63,839
Cancer type[c]	
Breast	39 (32.8%)
Hodgkin lymphoma	15 (12.6%)
Non-Hodgkin lymphoma	12 (10.1%)
Colorectal	7 (5.9%)
Ovarian	6 (5.0%)
Acute lymphoblastic leukemia	5 (4.2%)
Stage of cancer at diagnosis[d]	
0	3 (2.5%)
I	22 (18.5%)
II	33 (27.7%)
III	24 (20.2%)
IV	16 (13.4%)
Currently on treatment (*n*, % yes)*	26 (21.8%)
Number of treatments received	2.3 ± 1.0
Type of treatment (*n*, % yes)[e]	
Chemotherapy	94 (79.0%)
Surgery	79 (66.4%)
Radiation	60 (50.4%)
Hormone therapy	15 (12.6%)
Stem cell transplant	8 (6.7%)
Immunotherapy	7 (5.9%)
Time since diagnosis, years	4.2 ± 3.7
Time since treatment, years	3.0 ± 3.8
Met aerobic physical activity guidelines[f]	84 (70.6%)
Met resistance exercise guidelines[f]	41 (34.5%)
Met aerobic and resistance guidelines[f]	33 (27.7%)

(Continued)

TABLE 1 | (Continued)

[a] *Other consists of the following self-identified genders: transgender (n = 1), gender fluid (n = 1), and gender queer (n = 1). These individuals (n = 3) were removed from gender in the model.*

[b] *Other consists of the following self-identified sexual orientations: queer (n = 4), asexual (n = 2), questioning (n = 1), did not specify their sexual orientation (n = 1).*

[c] *Other cancer types included n = 4: thyroid, skin, and brain; n = 3: Ewing sarcoma; n = 2: acute myeloid leukemia, chronic myelogenous leukemia, and kidney; n = 1: appendix, bladder, cervical, laryngeal, lung, multiple myeloma, sarcoma, testicular, tongue, and uterine.*

[d] *Remaining 17.6% of AYAs did not know their cancer stage or reported that stage was not applicable.*

[e] *Multiple responses given.*

[f] *Meeting combined physical activity guidelines is defined as 90 min of at least moderate-intensity aerobic activity per week and two sessions of resistance exercise per week (Campbell et al., 2019). Using prior physical activity guidelines (i.e., 150 min of at least moderate-intensity aerobic activity per week; Schmitz et al., 2010), 48.7% met aerobic guidelines and 18.5% met aerobic and resistance guidelines.*

**n = 118. [†]n = 117. [‡]n = 116. [§]n = 106.*

Appearance-Related Emotions Model

The results of the path analysis are presented in **Figure 1**. Goodness-of-fit statistics were: $\chi^2(21) = 30.28$, $p = 0.09$, RMSEA = 0.06 (90% CI = 0.00–0.11), CFI = 0.97, and SRMR = 0.06. Significant ($p < 0.05$) direct path coefficients included: general social support to appearance shame, authentic pride, and hubristic pride, appearance guilt to MVPA and resistance exercise, and appearance authentic pride to MVPA and resistance exercise (standardized coefficients presented in **Figure 1**). In addition, cancer-specific social support was positively associated with mild PA ($\beta = 0.19$, $p < 0.05$) and MVPA ($\beta = 0.29$, $p < 0.001$). Overall, the model predicted 10% of the variance in mild PA, 25% in MVPA, and 28% in resistance exercise.

Fitness-Related Emotions Model

The results of the path analysis are presented in **Figure 2**. Goodness-of-fit statistics were: $\chi^2(21) = 28.89$, $p = 0.12$, RMSEA = 0.06 (90% CI = 0.00–0.10), CFI = 0.98, and SRMR = 0.05. Significant ($p < 0.05$) direct path coefficients included: general social support to fitness shame and guilt, cancer-specific social support to fitness guilt, fitness shame and authentic pride to MVPA, and fitness guilt and hubristic pride to resistance exercise (standardized coefficients presented

TABLE 2 | Descriptive statistics, bivariate correlations, and internal consistency for the main study variables (*n* = 119).

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Appearance shame[a]	–															
2. Appearance guilt[a]	0.76**	–														
3. Appearance authentic pride	–0.39**	–0.40**	–													
4. Appearance hubristic pride	–0.37**	–0.34**	0.61**	–												
5. Fitness shame[a]	0.74**	0.79**	–0.42**	–0.33**	–											
6. Fitness guilt[a]	0.58**	0.78**	–0.41**	–0.26**	0.82**	–										
7. Fitness authentic pride	–0.44**	–0.55**	0.57**	0.37**	–0.62**	–0.64**	–									
8. Fitness hubristic pride	–0.42**	–0.51**	0.55**	0.59**	–0.54**	–0.50**	0.79**	–								
9. General social support	–0.32**	–0.20*	0.19*	0.27**	–0.31**	–0.12	0.17	0.22*	–							
10. Cancer social support	–0.17	–0.10	0.01	0.07	–0.13	–0.16	0.21*	0.22*	0.37**	–						
11. Mild PA	–0.03	–0.15	0.07	0.04	–0.21*	–0.19*	0.08	0.11	0.17	0.22*	–					
12. MVPA	–0.12	–0.32**	0.24**	0.06	–0.36**	–0.37**	0.40**	0.30*	0.04	0.25**	0.25**	–				
13. Resistance exercise	–0.19*	–0.40**	0.39**	0.29**	–0.33**	–0.48**	0.48**	0.46**	0.02	0.05	0.10	0.28**	–			
14. Age	0.01	–0.00	–0.18	–0.17	–0.07	–0.09	0.02	0.00	–0.09	0.26**	0.13	0.06	–0.10	–		
15. Time since diagnosis[b]	–0.11	–0.18	–0.03	–0.04	–0.16	–0.19*	0.09	0.08	–0.19*	–0.02	0.04	0.14	0.04	0.20*	–	
16. Gender[c]	0.22*	0.30**	–0.07	–0.23*	0.19*	0.25**	–0.11	–0.18	0.04	–0.01	0.12	–0.11	–0.09	0.11	0.07	–
Mean	2.7	2.8	2.2	1.9	2.9	3.1	2.6	2.0	2.1	2.2	139.3	174.8	36.9	34.5	4.2	–
Standard deviation	1.1	0.9	0.8	0.8	1.0	1.1	1.1	1.0	0.7	1.2	125.5	152.4	57.7	5.5	3.7	–
Score range[d]	1–5	1–5	1–5	1–4	1–5	1–5	1–5	1–5	0–4	0–4	0–483	0–587	0–240	21–47	0–19	–
Internal consistency (α)	0.92	0.84	0.86	0.88	0.87	0.94	0.94	0.90	0.87	0.74	–	–	–	–	–	–

PA = physical activity; MVPA = moderate-to-vigorous physical activity; α = Cronbach's alpha.

[a] *Significant ($p < 0.05$) bivariate correlations for guilt-free shame (GFS), shame-free guilt (SFG), and the remaining model variables included: (i) appearance GFS with general social support (r = –0.26) and MVPA (r = 0.19), (ii) fitness GFS with appearance hubristic pride (r = –0.21), fitness hubristic pride (r = –0.23), and general social support (r = –0.37), (iii) appearance SFG with fitness authentic pride (r = –0.33) and hubristic pride (r = –0.30), mild PA (r = –0.19), MVPA (r = –0.35), resistance exercise (r = –0.39), and gender (r_s = 0.21), and (iv) fitness SFG with fitness authentic pride (r = –0.24), general social support (r = 0.24), and resistance exercise (r = –0.36).*

[b] *Time since diagnosis measured in years.*

[c] *Spearman rho correlation coefficients; coded as 1 = man; 2 = woman; n = 116.*

[d] *Scale range for body-related emotions is 1–5 and social support is 0–4.*

*$p < 0.05$, **$p < 0.001$.

in **Figure 2**). In addition, cancer-specific social support was positively associated with mild PA (β = 0.18, $p < 0.05$) and MVPA (β = 0.22, $p < 0.05$). Overall, the model predicted 9% of the variance in mild PA, 23% in MVPA, and 33% in resistance exercise.

DISCUSSION

The aim of this study was to test the relationships between social support, appearance- and fitness-related self-conscious emotions, and PA. Findings demonstrate that social support is associated with mild PA and MVPA, body-related emotions are associated with MVPA and resistance exercise, and social support is directly related to body-related emotions. However, there were no indirect effects of body-related emotions and the relationship between social support and PA. To further provide context to the findings, just over one quarter of the sample were meeting PA guidelines (Campbell et al., 2019) of 90 or more minutes of MVPA and at least two resistance-training sessions per week. The results have implications for further testing these relationships over time and provide preliminary support for developing strategies aimed at increasing social support and improving body image for AYAs during and after treatment for cancer.

In partial support of the hypothesis, greater perception of cancer-specific social support was associated with increased levels of mild PA and MVPA. Although AYAs reported similar levels of general and cancer-specific social support, general social support was not associated with PA. Previous literature with AYAs found that support group involvement, but not general social support, moderated the association between stress and PA (Brunet et al., 2014). Given that group PA with other cancer survivors has shown to be useful in increasing PA confidence (Zebrack et al., 2017; Pugh et al., 2021) and behavior (Gill et al., 2016), it may be important to further examine the aspects of cancer-specific support that may be most beneficial for increasing PA levels among AYAs. It may be valuable to explore the (i) types of cancer-specific support (e.g., emotional, informational), (ii) characteristics of individual(s) involved (e.g., similar-aged/-life stage peer(s), mentor(s) further out from treatment), (iii) methods of connecting (e.g., virtual, in-person), and (iv) contexts (e.g., conversations, exercising together). Further, age was positively associated with cancer-specific social support, indicating that those who are older have higher perceptions that others understand what they are going through. And so, particular attention toward adolescents and the provision of cancer-specific support may be needed.

Aligned with sociocultural perspectives (Petrie and Greenleaf, 2012) and previous literature

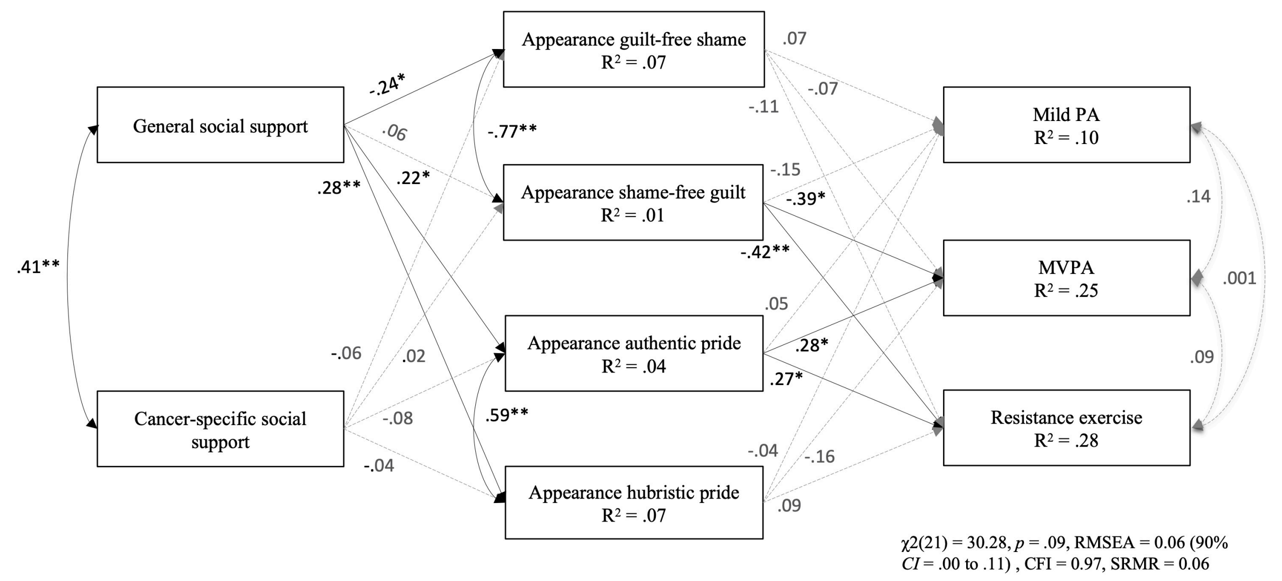

FIGURE 1 | Standardized path coefficients and explained variance of the model in predicting social support, appearance-related emotions, and physical activity. Note. Covariates included in the model are age, gender, and time since diagnosis. Variance explained for each endogenous variable are reported within the observed variable boxes. None of the indirect effects were significant. PA = physical activity; MVPA = moderate-to-vigorous physical activity. *$p < 0.05$; **$p < 0.001$.

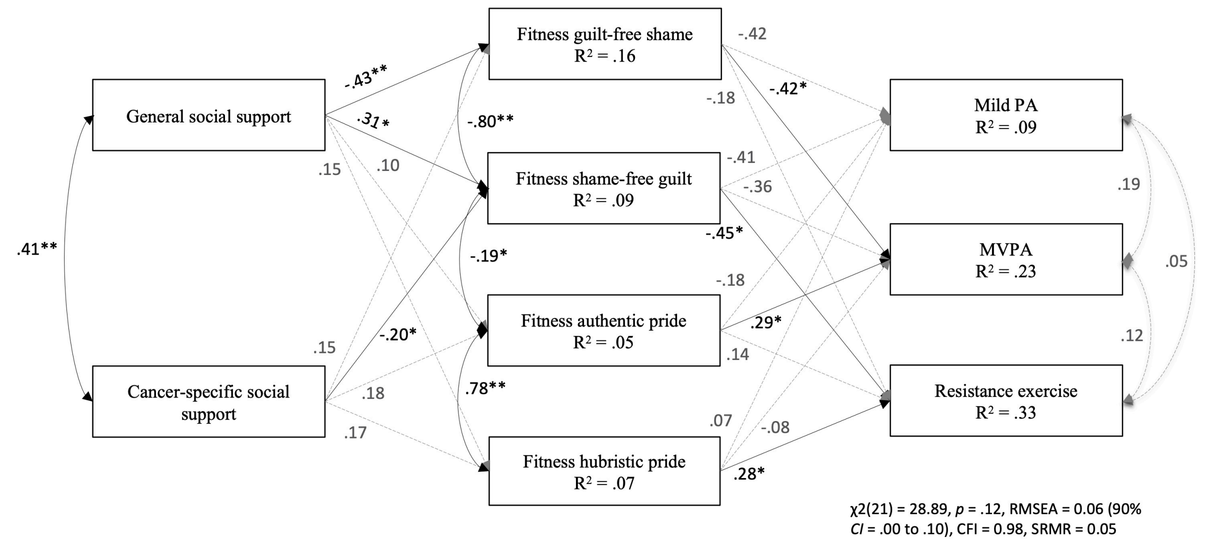

FIGURE 2 | Standardized path coefficients and explained variance of the model in predicting social support, fitness-related emotions, and physical activity. Note. Covariates included in the model are age, gender, and time since diagnosis. Variance explained for each endogenous variable are reported within the observed variable boxes. None of the indirect effects were significant. PA = physical activity; MVPA = moderate-to-vigorous physical activity. *$p < 0.05$; **$p < 0.001$.

(Larouche and Chin-Peuckert, 2006; Williamson et al., 2010) and consistent with hypotheses, social support was associated with numerous body-related emotions. The current findings suggest that those who perceive high general support from others report experiencing higher appearance-related authentic and hubristic pride, and lower appearance and fitness GFS, yet higher fitness SFG. Given that literature demonstrates that shame thwarts PA, while guilt can encourage individuals to initiate PA (Sabiston et al., 2010; Castonguay et al., 2015, 2017), these latter findings are not entirely troubling. However, it is important to understand the aspects of general social support (e.g., types, individuals providing support) that increase feelings of fitness-related guilt. Further, greater perception of cancer-specific social support was associated with lower fitness-related SFG, indicating that receiving support from those who validate one's cancer experience may make AYAs feel less alone in their challenges with fitness, and therefore, reduces one's guilt toward their fitness. Taken together, these results suggest that a positive perception of a supportive social network can help AYAs to feel more positive and less negative body-related self-conscious emotions. Thus, it may be important to ensure AYAs feel socially supported during and after treatment. Given that time since diagnosis was negatively associated with general social support, those who are further out from diagnosis may require additional ongoing supportive care.

In support of hypotheses, appearance- and fitness- related emotions were associated with PA. These findings are generally consistent with other cross-sectional studies among women (Sabiston et al., 2010; Castonguay et al., 2017; Pila et al., 2020) and men (Castonguay et al., 2015; Gilchrist et al., 2018). Overall, the fitness-related emotions were more consistently related to MVPA and resistance exercise, while only appearance-related guilt and authentic pride were related to PA. Intervening on fitness-related emotions may be ideal for enhancing PA among AYAs. More attention on fitness-related emotions in research, theory, and practice is needed. Notably, however, the body-related emotions were not related to mild PA, which may indicate that body-related feelings may not play a role in engagement in light and lifestyle activities (e.g., walking). Previous work in this area does not tease out PA into different intensities, yet some qualitative evidence suggests that different types of PA may be important outcomes of body image (Vani et al., under review) and should be further explored in future research.

Higher reports of body appearance and fitness-related guilt and shame were related to lower levels of MVPA and resistance exercise. These findings are consistent with theoretical tenets (e.g., self-objectification theory; Fredrickson and Roberts, 1997) and general body image literature among AYAs (Wu et al., 2015; Vani et al., 2021) wherein negative body image can be a barrier for PA engagement. The results extend previous findings by exploring appearance and functional facets of affective body image among AYAs. Although prior research with adult breast cancer survivors found appearance-related shame was related to MVPA (Castonguay et al., 2017), the current study's findings demonstrated that fitness-related, but not appearance-related, GFS was related to MVPA. Therefore, AYAs who blame themselves for their fitness may have an especially difficult time engaging in activity after a cancer diagnosis. Given that shame is a particularly painful self-conscious emotion (Tracy and Robins, 2007), strategies to reduce fitness-related shame are needed. Cognitive dissonance-based psychoeducation related to challenging societal expectations for fitness and body ideals may help to minimize fitness-related shame (Smith and Petrie, 2008).

In contrast to previous work that demonstrates guilt as a reparative emotion with positive effects on PA (Sabiston et al., 2010; Castonguay et al., 2017), appearance-related SFG was negatively associated with MVPA and resistance exercise, and fitness-related SFG was negatively associated with resistance exercise. These results are aligned with descriptions of the maladaptive aspects of this emotion (Tangney and Tracy, 2012). AYAs who express guilt over their appearance and fitness efforts are less likely to engage in intentional aerobic and resistance activities, indicating a need for the use of guilt-reducing strategies. Self-compassion approaches, such as journal prompts or expressing gratitude to the self and body-related efforts, may be useful to express emotions and alleviate feelings of body shame and guilt (Mosewich et al., 2011). Future research is needed to examine these relationships over time.

Experiencing positive body-related emotions was related to engagement in greater levels of aerobic activity and resistance exercise. Overall, these findings support the important role of positive body image in facilitating health-promoting behavior (Tylka and Wood-Barcalow, 2015; Gilchrist et al., 2018). In particular and aligned with previous literature (Sabiston et al., 2010; Castonguay et al., 2015), appearance- and fitness-related authentic pride were associated with MVPA, while appearance-related authentic pride was also related to resistance exercise. AYAs may use PA as a way of achieving their appearance- and fitness-related goals (Castonguay et al., 2013). Given these findings, it would be advantageous to enhance AYAs' appearance- and fitness-related authentic pride. Strategies to achieve this may include facilitated interventions wherein AYAs are prompted to connect their effort, competence, and manageable goal setting to their PA achievements (Castonguay et al., 2015).

Furthermore, aligned with previous research (Gilchrist et al., 2018), fitness-related, but not appearance-related, hubristic pride (related to feeling superior to others' fitness), translated to higher engagement in resistance exercise. AYAs may use resistance exercise to display their superior fitness to others (Castonguay et al., 2013). Although fitness-related hubristic pride is associated with health-enhancing behavior, it should be noted that hubristic pride has been related to worsened mental health (Tracy et al., 2009), and therefore should not be promoted to foster PA maintenance with AYAs. It would be worthwhile to explore these relationships over time and uncover the mechanisms through which the facets of pride facilitate increased aerobic and resistance activity.

Contrary to our hypotheses, there were no indirect effects of body-related emotions and the relationship between social support and PA. The tested direction of effects is supported by conceptual and theoretical notions and prior research (Sabiston et al., 2010; Petrie and Greenleaf, 2012; Castonguay et al., 2015), however, there are no specific models within the oncology context to link social support, body image, and PA. Based on the current cross-sectional findings, future research efforts could focus on a more nuanced understanding of cancer-related support, assess other dimensions of body image (perceptual, cognitive, and behavioral) and body image affect indicators (envy, embarrassment), and test the relationships over time.

Study Limitations and Future Directions

Findings should be interpreted in context with the following limitations. The cross-sectional nature of this study precludes our understanding of directionality of the associations, and causal inferences cannot be made. Although there is conceptual and empirical evidence for the direction of relationships tested and discussed (Sabiston et al., 2010; Petrie and Greenleaf, 2012; Castonguay et al., 2015, 2017), reverse or bidirectional associations may also be reasonable and should therefore be tested in future research. Further, measurement and structural models were not tested due to sample size, and so future research should examine these relationships using structural equation modeling. In addition, due to the homogeneity of the sample (e.g., mainly educated, White women), generalizability is limited. Future research efforts should be aimed at recruiting a larger and more diverse sample of AYAs. Moreover, body image may differ based on demographic considerations. Whilst the current study controlled for age and time since diagnosis in the path models, the range of age and time since diagnosis were broad. Thus, future research should consider assessing body image differences based on age groups, developmental stages, and cancer trajectory. Further, the survey was collected during the COVID-19 pandemic, and with widespread restrictions, engagement in PA and social support and body image scores may have been affected. Future research should explore these relationships among AYAs post-pandemic. Finally, PA was assessed using a self-report measure, which can have measurement limitations (Schmidt et al., 2008). Assessing the associations using an objective PA measure (e.g., accelerometers) warrants future investigation.

CONCLUSION

The current study uniquely explored appearance- and fitness-related body image emotions and examined both aerobic activity and resistance exercise among AYAs. The findings underscore the importance of assessing appearance- and fitness-related self-conscious emotions. This study is strengthened by the inclusion of cancer-specific social support, mild PA, and resistance exercise, which are not well understood among AYAs. The results underscore the importance of the development and use of supportive care initiatives and strategies aimed at improving social support (e.g., facilitate the provision of general and cancer-specific social support) and body image (e.g., psychoeducation, compassion-focused, and goal-achievement interventions) for potential increases in PA participation.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the University of Toronto Research Ethics Board. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

CS, DS, LT, and MV: conception and design and reviewing the manuscript. MV and CS: acquisition and interpretation of the data. MV: drafting the manuscript. All authors contributed to the article and approved the submitted version.

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Body Image Concerns in Patients With Head and Neck Cancer: A Longitudinal Study

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Objective: Head and neck cancer (HNC) treatments are known to significantly affect functionality and appearance, leading to an increased risk for body image disturbances. Yet, few longitudinal studies exist to examine body image in these patients. Based on a conceptual model, the current study aimed to determine, in patients newly diagnosed with HNC: (1) the prevalence, level, and course of body image concerns; (2) correlates of upon cancer diagnosis (pre-treatment) body image concerns; (3) predictors of immediate post-treatment body image concerns; and (4) association between body image concerns and levels of anxiety, depression, suicidal ideation, support (i.e., satisfaction with support from physician, social/family wellbeing, and unmet support needs), and alcohol and drug misuse.

Methods: Two hundred and twenty-three (participation rate = 72%), newly diagnosed with a primary HNC were assessed using structured clinical interviews and psychometric measures at three, and 6 months after diagnosis. Primary outcome was 3-month, as it was most salient to body image disturbance. Multiple linear regression analyses were conducted on the potential body image predictors, based on the model.

Results: Sixty-eight percent of patients with HNC (*n* = 148 of 218) presented some level of body image concerns. Body image concerns at baseline (i.e., upon cancer diagnosis, pre-treatment) and post-treatment were significantly related and significantly increased from pre- to post-treatment. Immediately post-treatment (i.e., at 3 month follow-up), 89% (*n* = 132 of 148) presented some level of body image concerns. Correlates of body image concerns in patients with HNC at baseline included: physical symptom burden, difficulties with communication and eating, coping with the cancer diagnosis using denial, suicidal ideation, and having had a past anxiety diagnosis. When controlling for sociodemographic and medical variables, body image concerns in patients with

HNC in the immediate post-treatment were predicted by: baseline body image, physical symptom burden, and neuroticism.

Conclusion: This longitudinal study helps identify patients more susceptible to experience body image disturbance following head and neck cancer. Clinicians ought to pay special attention to body image concerns upon cancer diagnosis, physical symptom burden, and neuroticism, and may want to target these factors in future preventive interventions.

Keywords: body image, cancer, oncology, psycho-oncology, head and neck cancer

INTRODUCTION

Body image is a complex and multifaceted term commonly defined as the subjective perceptions, views, and thoughts of an individual's own physical appearance (Falk Dahl et al., 2010; Rhoten et al., 2013; Paterson et al., 2016; Shunmuga Sundaram et al., 2019). Body image occurs through both self-observation and noticing how others react to oneself (Falk Dahl et al., 2010; Rhoten et al., 2013; Shunmuga Sundaram et al., 2019). An individual's attitude toward their body is affected by one's investment in appearance, meaning the importance of appearance to the individual and self-evaluation relating to the cultural ideals for physical appearance, and the discrepancy they feel between these ideals and their perceived body (Falk Dahl et al., 2010).

Body image disturbance in the cancer context is defined as an individual's perceived change in appearance and the displeasure and psychological distress felt as a result of this change (White, 2000; Shunmuga Sundaram et al., 2019). As stated by White (2000), "cancer and cancer treatments are, by their very definition, destructive" as the disease and treatments may lead to the loss of body parts, scarring, hair loss, disfigurement, weight changes, and functional limitations that can affect a patient's self-perceptions and lead to body image disturbance (Vani et al., 2021). The physical changes that occur due to cancer affect patients of all ages and genders and although there are services available to help restore physical appearance, the rates of patients with cancer suffering body image disturbance remains high (between 25 and 77%) (Fingeret et al., 2010; Rhoten et al., 2013; Melissant et al., 2020). Body image concerns have found to be prevalent in many cancer patient demographics particularly in adolescents and young adults diagnosed with cancer (Barakat et al., 2016; Vani et al., 2021). Not only are body image concerns seen in patients of many ages but past research also suggests that patients of a variety of cancers are at risk for developing body image concern including head and neck cancer, colorectal cancer, testicular cancer, gynecological cancer, and breast cancers (Li and Rew, 2010; Sacerdoti et al., 2010; Rossen et al., 2012; Latifi et al., 2020; Song et al., 2021).

Despite the many cancers that have been found to be associated with body image concerns, the majority of research on body image to date in the oncological context has been conducted on patients with breast cancer (Falk Dahl et al., 2010; Paterson et al., 2016; Davis et al., 2020). According to a systematic review conducted by Paterson et al. (2016), in the breast cancer context, cancer patients are highly susceptible to body image concerns due to changes in their physical appearance post-treatment, including the loss or disfigurement of their breasts, scars from surgery, skin changes, hair loss, and chemotherapy induced hormone imbalance leading to weight gain. Overall, body image concerns have been found to be moderated by psychological, social, and environmental factors. In the context of cancer, specifically breast cancer, body image concerns have been found to be impacted by several factors including age, menopausal status, mental health, treatment modality and exercise (Davis et al., 2020). Poorer body image in patients with cancer has been linked to poorer physical and mental health, chronic fatigue, and a reduced quality of life (Falk Dahl et al., 2010; Paterson et al., 2016). Moreover, body image concerns often lead to poor self-esteem, low sexual functioning, depression, and social anxiety and can impact an individual's quality of life (QoL), personal identity, and self-confidence (White, 2000; Cash, 2012; Rhoten et al., 2013; Juhl et al., 2017; Shunmuga Sundaram et al., 2019). In view of this, it is no surprise that studies have found that individuals with a better conceptualization of their body image tend to cope better with cancer and cancer related treatments as improved mental health and QoL has been consistently found to lead to better treatment and disease outcomes (Carlson and Bultz, 2003; Han et al., 2009; Paterson et al., 2016; Mausbach et al., 2020). Considering the negative health-related outcomes that can occur as a result of the body image concerns held by patients it is important to identify specific moderators or predictors for body image concerns in patients with specific cancers that are most often associated with body image disturbance.

With this in mind, head and neck cancers (HNC) have been found to be particularly associated with body image disturbances (Rhoten et al., 2013). HNC is characterized by malignant tumours originating at the lining surfaces of the oral cavity, sinuses and nasal cavity, pharynx, larynx, and salivary glands (Shunmuga Sundaram et al., 2019). Despite the advances in treatments, HNCs are predominantly diagnosed in advanced stages and often necessitate invasive treatments that involve pain, altered facial appearance (e.g., removal of parts of the face with radial arm free-flap reconstruction, temporary or permanent tracheostomy, visible scars on the face and/or neck), and compromised function in vital and visible areas of eating, speech, and breathing (White, 2000; Rhoten et al., 2013; Nakarada-Kordic et al., 2017; Shunmuga Sundaram et al., 2019; Melissant et al., 2020).

Treatment recovery for patients with HNC takes an average of 12 to 36 months and frequently includes long term sequelae (Neilson et al., 2012). These treatment side-effects require major readjustments in physical function, activities of daily living and life roles, particularly affecting one's identity, social and interpersonal relationships, and often leading to high levels of distress and body image disturbances (Alias and Henry, 2018; Melissant et al., 2020).

Despite the prevalence of body image concerns in patients with HNC, there has been a paucity of studies examining predictors of body image concerns in this population, and a limited number of studies using longitudinal designs (Muzzatti and Annunziata, 2016; Paterson et al., 2016; Vani et al., 2021). In a recent systematic review by Ellis et al. (2019) including only studies examining body image in HNC using psychometric measures, only 2 out of the 17 studies used a longitudinal methodology. The majority of past HNC body image research is cross-sectional, limiting the examination of predictors of body image effects through survivorship, which is detrimental as the few longitudinal studies analyzed by Paterson et al. (2016) found that body image concerns can be present for as long as 12-months post-treatment (Paterson et al., 2016; Vani et al., 2021). The literature suggests that more longitudinal studies are needed to see which characteristics upon diagnosis (baseline) predict body image concerns into survivorship immediately post-treatment or long after (Paterson et al., 2016; Vani et al., 2021).

Furthermore, research in patients with HNC have identified mostly sociodemographic and medical predictors of body image concerns including being female, younger age, a single relationship status, cancer stage, reconstructive surgery, surgical treatments, adjuvant therapies, dysfunction in eating and speech, cognitive difficulties, and lymphedema (Fingeret et al., 2011; Chang et al., 2019; Ellis et al., 2019; Melissant et al., 2020). Additional longitudinal research on body image concerns in patients with HNC using a larger framework of psychosocial variables can help the creation and implementation of effective, timely, and targeted psychosocial interventions that can potentially alleviate body image concerns in patients (Zimmermann et al., 2009; Rhoten et al., 2013; Ellis et al., 2019). In addition to using a longitudinal design as stated above it is essential that research is guided by a framework including a variety of relevant variables. Considering the utility of a HNC specific model for the current study we created a conceptual model specific to HNC.

The conceptual model used in this study is based on the Diathesis-Stress Model (Ingram et al., 1998, 2011) in combination with the Wilson and Cleary Model (Wilson and Cleary, 1995). Wilson and Cleary proposed a conceptual model of health-related quality of life that includes both psychological and biological determinants of outcomes; while the Diathesis-Stress Model posits mental health outcomes as the resultant of an interaction between an individual's diathesis (i.e., vulnerability) and levels of environmental stress. Our conceptual model includes seven main components: sociodemographic, cancer- and treatment-related variables, other medical variables, physical symptoms / function, pre-existing and upon cancer psychological vulnerability, and social support (see **Figure 1**). Based on this conceptual model, the current longitudinal study aimed to determine, in patients newly diagnosed with HNC: (1) the prevalence, level, and course of body image concerns from cancer diagnosis to 1-year follow-up; (2) predictors of immediate post-treatment body image concerns (i.e., 3-month post-cancer diagnosis); (3) correlates of baseline (i.e., upon cancer diagnosis, pre-treatment) body image concerns; and (4) association between body image concerns and levels of anxiety, depression, suicidal ideation, support (i.e., satisfaction with support received by physician, social/family wellbeing, and unmet needs for support), and alcohol and drug misuse. We hypothesized that psychosocial vulnerabilities would be early determinants of body image concerns when controlling for sociodemographic and medical variables. We will be analyzing predictors of levels of body image concerns at 3-months post-cancer diagnosis as this is the timeframe when distress is known to be at the highest (Henry et al., 2018a,b).

MATERIALS AND METHODS

Design

This longitudinal prospective study included use of Structured Clinical Interviews for DSM-IV Diagnoses (SCID-I) (First et al., 2002), observer-rated disfigurement measured at baseline (i.e., upon cancer diagnosis, pre-treatment) and post-head and neck cancer treatment, and self-administered questionnaires completed upon cancer diagnosis and at 3-month follow-up. The Structured Clinical Interviews for DSM-IV Diagnoses (SCID-I) were conducted in person by either the research coordinator trained in the approach or the principal investigator (MH; a psychologist with extensive training and experience conducting SCID interviews). The self-administered questionnaires took 60 min to complete at baseline and 45 min at 3 months follow-up. The study received full ethics approval from McGill University Faculty of Medicine's Institutional Review Board #A05-B24-10B.

Eligibility and Exclusion Criteria

Eligible patients were adults 18-years and older diagnosed within 2 weeks of a first occurrence of primary head and neck cancer (TNM Classification System), based on tumour board case discussions. Patients diagnosed in the community were re-diagnosed within the recruiting treatment centres and the date of diagnosis was considered from that moment for these patients. All patients were recruited pre-treatment. They needed to be cognitively capable of giving free and informed consent according to physicians, and present a score of 60 or more on the Karnofsky Performance Scale (KPS) upon enrolment and/or an expected survival of at least 6 months according to medical judgement.

Recruitment

Eligible patients were identified by physicians and nurses of the Department of Otolaryngology – Head and Neck Surgery at McGill University-affiliated hospitals (Jewish General Hospital and McGill University Health Centre – Montreal General Hospital and Royal Victoria Hospital sites). Identified patients were then presented to the research coordinator or contacted by telephone to verify eligibility. The research coordinator arranged

FIGURE 1 | Conceptual model of predictors of body image concerns in patients with HNC.

for a face-to-face meeting with identified participants in which consent was obtained. A list was kept of patients to follow enrolment and attrition over time. Questionnaires were sent by email and the participants had a 7-day period for completion at each time-point.

Measures – Outcome

The Body Image Scale (BIS) is the most commonly used measure in body image research (Ellis et al., 2019). It has 10 items measuring general perceptions of bodily appearance in patients with cancer. Respondents indicate their levels of body image concerns on a 4-point Likert type scale: whereby 0 = not at all, 1 = a little, 2 = quite a bit, and 3 = very much (internal consistency 0.93; test-retest reliability 0.70) (Hopwood et al., 2001). A cut-off score of ≥ 8 on the scale is considered to be clinically significant (Hopwood et al., 2001; Melissant et al., 2018, 2020). Body image scores were characterized as low, low to medium and medium to high based on the mean score of items juxtaposed to the Likert scale anchors (i.e., mild range > 0–0.99, mild to medium 1–1.99, medium to severe 2–3) (Hopwood et al., 2001).

Predictors

Sociodemographic data were collected through self-administered questionnaires and medical data through chart review. Sociodemographic questions included age, sex, marital status, education, work status, individual and family income, and living alone. Medical variables included cancer stage, cancer type, tumour site, HPV-status, comorbid medical conditions, performance status (ECOG Status) (Oken et al., 1982), and treatments received (surgery, radiation therapy, chemotherapy) with radial forearm free-flap treated as a marker of surgery extent. Other medical variables included use of psychiatric medication and counselling/therapy. Disfigurement was rated using the Observer-Rated Disfigurement Scale for Head and Neck Cancer (Katz et al., 2000).

Physical symptoms were measured by the Functional Assessment of Cancer Therapy – General (FACT-G) (Cella et al., 1993), the Physical Wellbeing subscale (7-items, score range 0–28, internal consistency: >0.70), and item F5 concerning sleep, as well as the FACT-Head and Neck Module (rated on a Likert-scale from 0 to 4 where higher scores represent a better quality of life) (D'Antonio et al., 1996). Function was measured by the Eastern Cooperative Oncology Group (ECOG) scale (Oken et al., 1982), the FACT-HN Module items #7, #11 (swallowing), and #10 (speaking) (D'Antonio et al., 1996).

Pre-existing psychosocial vulnerabilities were examined through the Structured Clinical Interview for DSM-IV diagnoses (First et al., 2002) covering past and upon cancer diagnosis Major Depressive Disorder, Anxiety Disorder, or Substance Use Disorder (inter-rater reliability 0.75 on symptoms and 0.90 on diagnoses). The Eysenck Personality Inventory – Neuroticism Subscale measured neuroticism. The measure includes 12-items with a total score ranging from 0 to 36 and higher scores indicating higher levels of neuroticism (internal consistency: 0.80–0.84) (Barrett et al., 1998). The Rosenberg Self-Esteem Scale measured self-esteem. The measure includes a 10-item scale, with a total score ranging from 0 to 40 and higher scores indicating higher self-esteem (internal consistency: 0.92; test-retest reliability: 0.85–0.88) (Rosenberg, 2016). The Social Support Questionnaire measured social support. The measure includes a 12-item scale, with a total score ranging from 0 to 90 and higher scores indicating higher social support (internal consistency: 0.90–0.93, test-retest reliability: 0.90) (Sarason et al., 1987). Childhood abuse was measured using the Statistics Canadian incidence study of reported child abuse and neglect - 2008 (2010). The Hospital Anxiety and Depression Scale measured anxiety and depression. The scale incudes 14-items with the total score ranging from 0 to 42 and higher scores indicating higher levels of anxiety and depression (internal consistency: 0.78–0.93; test-retest reliability >0.80) (Zigmond and Snaith, 1983). The Beck Scale for Suicidal Ideation measured past and current suicidal ideation. The measure includes 21-items, with the total score ranging from 0 to 42 and higher scores indicating higher levels of suicidal ideation (internal reliability: 0.94) (Beck and Steer, 1991). The Drug Abuse Screening Test and the Rapid Alcohol Problems Screen measured drug and alcohol misuse, respectively. The Drug Abuse Screening Test includes 10 dichotomous items, with the total score ranging from 0 to 10 and higher scores indicating higher level of drug misuse (internal consistency reliability: 0.92) (Skinner, 1982). The Rapid Alcohol Problems Screen includes 5-items with higher scores indicating higher level of alcohol misuse (Cherpitel, 2005). The Brief COPE denial subscale measured coping with a cancer diagnosis using denial and avoidance and includes 2-items ranging from 2 to 8 where higher scores indicate higher denial-based coping (internal consistency: 0.54) (Carver, 1997). Finally, the Supportive Care Needs Survey – Short Form SCNS-SF34 includes 34-items, with the total score ranging from 34 to 170, and higher scores indicating higher levels of unmet needs (internal consistency: 0.86–0.96) (Boyes et al., 2009).

Statistical Analyses

Analyses were carried out using SPSS Statistics 28. Descriptive statistics were generated for sociodemographic and clinical characteristics, as well as determine prevalence and level of body image concerns at each timepoint. We compared baseline (i.e., upon cancer diagnosis, pre-treatment) and post-levels of body image concerns between time-points (i.e., baseline to 3-months, 3–6 months, and 6–12 months) using paired-sample t-tests. Independent sample t-tests and correlations were used to measure the association between our identified predictors and outcome (**Figure 1**). Significant variables were included in a multiple linear regression analysis used to investigate baseline predictors of body image concerns immediately post-treatment. A second multiple regression analysis was used to identify correlates of upon HNC diagnosis levels of body image concerns. Correlations were used to measure association between body image concerns and levels of anxiety, depression, suicidal ideation, support (i.e., satisfaction with support received by physician, social/family wellbeing, and unmet needs for support), and alcohol and drug misuse. For all analyses, a standard alpha level of 0.05 was used.

RESULTS

Out of the 313 eligible patients with HNC, 223 (71.5%) accepted to participate between September 2012 and September 2015, of which 219 completed the BIS outcome at baseline and 149 at 3-month follow-up see **Table 1** for sociodemographic, medical, and clinical characteristics of our sample. Eighty-six percent of participants completed baseline SCID-I interviews and 67.9% at 3 months. Participants who did not complete the follow-up questionnaire at 3 months were not shown to differ on sociodemographic, medical, and psychological variables; except those patients who dropped out presented with significantly lower ECOG functioning ($p < 0.05$).

Of the participants, 68% ($n = 148$) presented some level of body image concerns at baseline, including 53.7% ($n = 117$) mild, 9.2% ($n = 20$) mild to moderate and 5.0% ($n = 11$) moderate to severe levels. Body image concerns at baseline and post-treatment were significantly related ($r = 0.55$, $p < 0.001$); and significantly increased from baseline to immediately post-treatment ($t(146) = -7.22$, $p < 0.001$; baseline $x = 4.5$, $s.d. = 5.7$; post- $x = 7.5$, $s.d. = 7.3$). Immediately post-treatment, 89% ($n = 132$ of 148) presented some level of body image concerns, including 60.1% ($n = 89$) mild, 20.3% ($n = 30$) mild to moderate and 8.7% ($n = 13$) moderate to severe levels. Body image concerns significantly decreased from immediately post-treatment to 6-month follow-up ($t(118) = 2.41$, $p = 0.02$; immediately $x = 7.0$, $s.d. = 6.8$, 6-month $x = 5.8$, $s.d. = 6.5$), and then stayed the same from 6- to 12-month follow-up ($t(94) = 0.88$, $p = 0.38$; 6-month $x = 5.6$, $s.d. = 6.4$, 12-month $x = 5.1$, $s.d. = 6.2$) (see **Figures 2, 3**).

When controlling for sociodemographic and medical variables, body image concerns in patients with HNC in the immediate post-treatment (i.e., at 3 months) were predicted by: upon HNC diagnosis body image concerns ($p < 0.001$); physical symptom burden ($p = 0.003$); neuroticism ($p = 0.01$); and difficulties with communication (trend) ($p = 0.07$). These variables accounted 47% of variance in levels of body image concerns ($r = 0.75$; $Adj.r2 = 0.47$, $p < 0.001$) (see **Table 2**).

Correlates of body image concerns in patients with HNC at baseline (i.e., upon cancer diagnosis, pre-treatment) included: physical symptom burden ($p = 0.002$), difficulties with

TABLE 1 | Sociodemographic, medical, and clinical characteristics of patients newly diagnosed with a first occurrence of head and neck cancer.

Variable	**Mean (SD)/ n (%)** ***n* = 219**
Age	63.0 (11.6) range 30–101
Sex: male	151.0 (68.9)
Living alone	71.0 (32.4)
Advanced stage (III/IV)	156.0 (71.2)
Cancer sites	
Oropharynx	80.0 (36.5)
Oral	44.0 (20.1)
Larynx	37.0 (16.9)
Skin	15.0 (6.8)
Nasopharynx	18.0 (8.2)
Unknown primary	12.0 (5.5)
Other (salivary glands, paranasal sinuses, and nasal cavity)	13.0 (5.9)
Cancer type: HPV+	107.0 (54.0)
Treatment: 3 months	
Surgery alone	37.0 (17.2)
Radiotherapy alone	21.0 (9.8)
Chemotherapy alone	5.0 (2.3)
Surgery and radiotherapy	23.0 (10.7)
Radiation and chemotherapy	99.0 (46.0)
Surgery and radiotherapy and chemotherapy	30.0 (14.0)
Major depressive disorder (SCID-I)	
Baseline	13.0 (8.3)
Prior to diagnosis	42.0 (26.9)
Anxiety disorder (SCID-I)	
Baseline	37.0 (23.7)
Prior to diagnosis	47.0 (30.1)
Alcohol use disorder (SCID-I)	
Baseline	8.0 (5.12)
Prior to diagnosis	45.0 (28.8)
Psychological distress (HADS) at baseline	
Anxiety subscale	6.0 (4.6); range 0–20
Depression subscale	3.7 (4.0); range 0–18
Past suicidal ideation	25.0 (11.3)
Neuroticism (Eysenck Personality Inventory) at baseline	7.5 (3.5)
Avoidance coping (Brief COPE) at baseline	
Denial	3.0 (1.4)
Childhood mistreatment < 12 years old	24.0 (13.6)
Parental care in childhood and adolescence (PBI Care)	13.3 (7.9)
Concomitant life stressors < 12 months (SRRS)	3.4 (1.9)
Level of social support (SSQ-6) at baseline	55.3 (26.7)

communication ($p < 0.001$) and eating ($p = 0.05$), coping with the cancer diagnosis using denial ($p = 0.005$), suicidal ideation prior to diagnosis ($p = 0.009$), and having had a past anxiety diagnosis (trend) ($p = 0.058$). These variables accounted 47.1% of variance in levels of body image concerns ($r = 0.74$; $Adj.r2 = 0.471$, $p < 0.001$) (see **Table 3**).

Body image concerns in the immediate post-treatment were significantly associated with post-treatment levels of depression ($r = 0.58$, $p < 0.001$), anxiety ($r = 0.51$, $p < 0.001$), suicidal ideation ($r = 0.39$, $p < 0.001$), and unmet needs for support (satisfaction with support received by physician, $r = -0.17$, $p = 0.049$, social/family wellbeing, $r = 0.30$, $p < 0.001$ and unmet needs on the SCNS-SF34, $r = 0.46$, $p < 0.001$). All domains of unmet needs on the SCNS-SF34 were affected, with highest association in the psychological and sexuality domains ($r = 0.53$, $p < 0.001$ and $r = 0.41$, $p < 0.001$, respectively), followed by daily living needs ($r = 0.38$, $p < 0.001$), health system and information needs ($r = 0.27$, $p < 0.001$), and patient care and support ($r = 0.24$, $p = 0.004$). Levels of body image concerns immediately post-treatment were not significantly associated with post-treatment alcohol ($p = 0.43$) or drug misuse ($p = 0.85$).

DISCUSSION

This study contributes to the existing literature in several ways. First, it underlines that concerns around body image are highly prevalent (i.e., in 89% of patients) immediately post-treatment and persistent over time in patients with HNC. Second, most patients present with low levels of body image concerns (60.1%) post-treatment, and clinical levels are present in 29% (20.3% mild to moderate, 8.7% moderate to severe). Third, 68% of patients presented with body image concerns even before treatments commenced, including 53.7% mild, 9.2% mild to moderate and 5% moderate to severe levels.

Body image concerns upon being diagnosed with cancer were associated with physical symptom burden, difficulties with speech/communication and eating, coping with the cancer diagnosis using denial, past suicidal ideation, and having had a past anxiety diagnosis. Immediately post-treatment, levels of body image concerns were predicted by upon HNC diagnosis body image concerns, physical symptom burden, and neuroticism. Furthermore, body image concerns immediately post-treatment were significantly related to post-treatment levels of depression, anxiety, suicidal ideation, and unmet supportive care needs. They were not significantly related to alcohol or drug misuse.

It appears that people diagnosed with HNC may already present with body image concerns even before treatments begin. This may be partly due to physical changes in their bodies, especially physical symptoms and functional changes in speech, communication and eating. This finding is in accordance with past research having found disturbance in speech and eating impairments to be a predictor of body image concern (Fingeret et al., 2011; Chen et al., 2016; Ellis et al., 2019). The mechanisms for this association would need further clarification as it pertains to actual or perceived physical changes, as these changes were measured through patient-reported outcomes in our study. It is unclear if patients more vulnerable to body image concerns would from the start place more emphasis on or be more aware of changes in their bodies. It also becomes clear from this study that one needs to pay attention to patients' historical background beyond physical changes in appearance, function, and symptom-burden. As such, it appears important to test current models of body image which illustrate interrelated dimensions preceding physical changes such as degree of appearance investment, emotions of self-consciousness

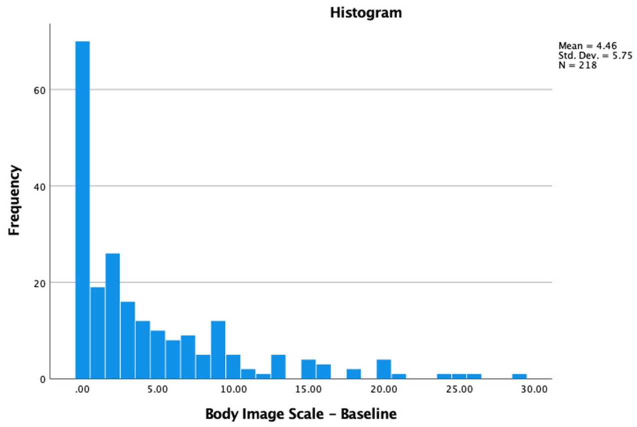

FIGURE 2 | Levels of body image concerns upon HNC diagnosis.

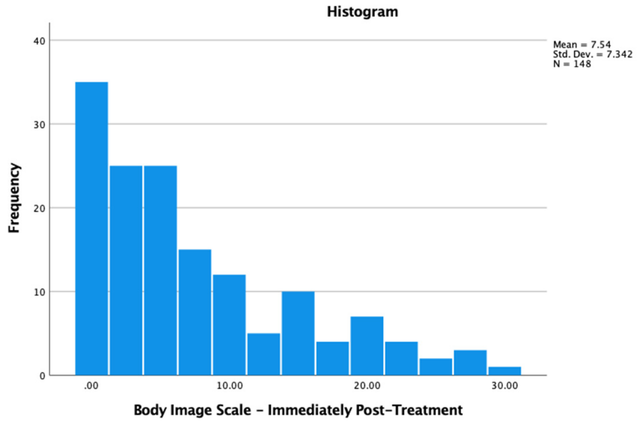

FIGURE 3 | Levels of body image concerns immediately post-treatment in patients with HNC.

or shame and compensatory behaviours (Falk Dahl et al., 2010). Issues around speech would merit further investigation in interfacing with the ability to communicate and social skills, with its implicit working out of issues around stigma and shame (Fingeret et al., 2011; Chen et al., 2016; Ellis et al., 2019). This study also highlights other predisposing historical factors to be investigated in this model such as coping with the cancer diagnosis using denial, past suicidal ideation, and a past anxiety diagnosis.

Neuroticism in particular has been associated with body image concerns in non-HNC populations (Allen and Walter, 2016). Past studies have found that people who exhibit neuroticism (one's susceptibility to emotional instability) tend to be more self-conscious, care more about how they look, compare themselves to more attractive people, and are often sensitive to rejection causing them to strive for an ideal body (Costa and McCrae, 1992; Davis et al., 2001; Roberts and Good, 2010; Benford and Swami, 2014; Allen and Walter, 2016).

Denial is defined as an unconscious defence against painful aspects of reality in patients with cancer, identified in 4 to 47% and found to be associated with distress and poorer psychological functioning (Vos and de Haes, 2006). Despite research on denial in the cancer context, only one study identified examined denial and its association with body image concerns within the context of patients presenting an eating disorder (Túry et al., 2010). Considering the lack of research on denial and body image and the association found in the current study, future research should examine different coping styles and their association with body image concerns. This is particularly important in patients with head and neck cancer, as use of denial may prevent them from digesting the preparatory information as part of consent for treatments and avoidance may no longer be a helpful coping strategy when reality of treatment impacts hits.

Suicidal ideation and a past anxiety diagnosis as predictors for body image concerns is congruent with past research findings (Fingeret et al., 2011; Rhoten et al., 2013; Paterson et al., 2016; Shunmuga Sundaram et al., 2019). A study examining body image concerns after bariatric surgery, found that patients who scored high on suicidal ideation were more likely to report body image concerns 3 months after bariatric surgery

TABLE 2 | Predictors of body image concerns immediately post-treatment in patients with HNC.

Measure	B	β	95% CI	*P* value
Body Image Scale – Baseline	0.49	0.36	0.27 – 0.70	<0.001***
FACT physical wellbeing	−0.37	−0.33	−0.61 – −0.13	0.003**
FACT-G sleep	−0.42	−0.07	−1.51 – 0.66	0.44
FACT H&N Module at 3-months	−0.08	−0.09	−0.35 – 0.18	0.55
Patient satisfaction with emotional support from physician	0.11	0.03	−0.39 – 0.60	0.68
FACT functional wellbeing 3 months	0.04	0.04	−0.21 – 0.30	0.74
FACT-G speech 3 months	1.02	0.14	−0.12 – 2.17	0.078†
FACT-G eating 3 months	−0.30	−0.06	−1.33 – 0.74	0.57
Coping with denial (COPE denial)	0.36	0.08	−0.39 – 1.11	0.34
Neuroticism	0.33	0.31	0.07 – 0.59	0.012*
Professional counselling 3 months	1.48	0.09	−1.17 – 4.13	0.27
Cancer stage	−0.43	−0.03	−2.35 – 1.48	0.66
Past suicidal ideation	0.91	0.04	−3.09 – 4.92	0.65
HADS anxiety	−0.49	−0.03	−0.43 – 0.33	0.80
HADS depression	−0.06	−0.03	−0.50 – 0.38	0.79
Beck scale for suicidal ideation	−0.04	−0.01	−0.52 – 0.45	0.89
Age (years)	0.03	0.05	−0.09 – 0.15	0.57
Marital status	−0.07	−0.02	−0.68 – 0.53	0.82
Work status	−0.18	−0.07	−0.60 – 0.250	0.41
FACT social/family wellbeing	0.02	0.01	−0.24 – 0.27	0.91

FACT, Functional Assessment of Cancer Therapy; FACT-G, Functional Assessment of Cancer Therapy-General; FACT-HN, Functional Assessment of Cancer Therapy-Head & Neck Module; HADS, Hospital Anxiety and Depression Scale. *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$, †$0.10 > p > 0.05$.

TABLE 3 | Correlates of body image concerns upon HNC diagnosis.

Measure	B	β	95% CI	Value
FACT physical wellbeing	−0.33	−0.29	−0.53 – −0.12	0.002**
FACT sleep	−0.50	−0.10	−1.41 – 0.40	0.28
FACT H&N module	0.09	0.12	−0.09 – 0.26	0.33
Patient satisfaction with emotional support from physician	0.02	0.007	−0.34 – 0.38	0.91
FACT functional wellbeing	0.20	0.22	−0.008 – 0.40	0.060†
Difficulties with communication (FACT-G speech)	−2.00	−0.28	−3.08 – −0.91	<0.001***
Difficulties with eating (FACT-G eating)	−1.15	−0.21	−2.17 – −0.12	0.029*
Counselling	−1.43	−0.10	−3.43 – 0.57	0.16
Cancer stage	0.55	0.047	−1.04 – 2.14	0.49
EQPS neuroticism	−0.10	−0.10	−0.28 – 0.09	0.32
FACT family/social wellbeing	−0.07	−0.07	−0.23 – 0.09	0.40
Coping with denial (COPE denial)	0.66	0.19	0.20 – 1.12	0.005**
Past suicidal ideation	−0.46	−0.02	−3.07 – 2.15	0.73
Beck scale for suicidal ideation	0.53	0.19	0.13 – 0.92	0.009**
Past anxiety diagnosis (SCID)	1.85	0.13	−0.06 – 3.77	0.058*
HADS anxiety	0.21	0.16	−0.05 – 0.47	0.11
HADS depression	0.17	0.11	−0.14 – 0.48	0.27
Age (years)	−0.07	−0.12	−0.15 – 0.02	0.13
Sex	1.33	0.11	−0.35 – 3.01	0.12
Marital status	0.03	0.006	−0.46 – 0.51	0.92
Working	0.22	0.11	−0.08 – 0.51	0.15
Social support questionnaire	0.01	0.04	−0.03 – 0.05	0.50

FACT, Functional Assessment of Cancer Therapy; FACT-G, Functional Assessment of Cancer Therapy-General; H&N, Head & Neck; HADS, Hospital Anxiety and Depression Scale; SCID, Structured Clinical Interview for DSM; *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$, †$0.10 > p > 0.05$.

(Pona et al., 2016). Suicidal ideation has been associated with body image concerns in many studies, however, from our review of the literature, suicidal ideation has never been found as a precursor to body image concerns but rather a consequence (Brausch and Muehlenkamp, 2007). Based on our findings, suicidal ideation may be more interconnected to body image concern than previously thought. One may want to investigate how people with past suicidal ideation may present certain features in the face of adversity that would contribute to body image concerns, such as those from theoretical frameworks as the Integrated Motivational–Volitional Model of Suicidal Behaviour (i.e., defeat, humiliation, and entrapment) (O'Connor, 2011), the Attention Mediated Hopelessness (AMH) Theory (i.e., propensity toward depressogenic thinking, ruminative response style, and pessimistic or hopelessness outlook on the future) (Smith et al., 2006), and the Interpersonal Theory of Suicide (i.e., thwarted belongingness and burdensomeness) (Van Orden et al., 2010). The constructs of demoralization and dignity may also merit further attention (Hack et al., 2004; Robinson et al., 2015).

Physical symptom burden was found to predict body image concerns at baseline and immediately post-treatment. In general body image research, having a positive body image often means placing less value on physical appearance and more on physical ability and functionality. This brings up a concern for people who are less physically able due to physical pain or other symptoms associated with a disease as it may change how they experience their bodies (Alleva et al., 2018; Markey et al., 2020). Perceiving something to be "wrong" with one's body has been associated with poor body image in a study by Markey et al. (2020) which focused on chronic pain. Additionally, Jolly (2011) highlights how symptoms such as pain may leave individuals feeling more uncomfortable and self-conscious based on physical limitations as well as their appearance changes. In addition to pain, fatigue has also been associated with body image concerns in past research, however, very few studies have examined fatigue in the cancer context (Cantarero-Villanueva et al., 2011; Fingeret et al., 2011; Rosenberg et al., 2012). In view of the findings on physical symptom burden and body image, more research is needed to explore the specific symptoms in head and neck cancer that are most associated with body image concerns in order to provide earlier and more effective interventions.

Finally, body image concerns immediately post-treatment were significantly related to levels of depression, anxiety, suicidal ideation, and unmet needs for support in the same time period. They were not significantly related to alcohol or drug misuse. As previously discussed, past research has found depression, anxiety, and suicidal ideation to predict and be associated with body image concerns (Moreira and Canavarro, 2010; Rhoten et al., 2014; Chang et al., 2019; Ellis et al., 2019; Melissant et al., 2020). There may be different pathways to discover in directionality of the relationship between depression, anxiety, and body image, with treatment of depression and anxiety having the potential to alleviate body image concerns and allowing a more nuanced perception of oneself and perhaps of interactions with others.

The findings of this study highlight the importance of using a Diathesis-Stress Model in body image research and a larger set of predictors, including biological, psychological, and environmental factors associated with body image concerns (Wilson and Cleary, 1995; Ingram et al., 1998, 2011).

Clinical Implications

Patients should be screened upon a HNC diagnosis for baseline body image concerns (BIS), physical symptoms (FACT-G), and neuroticism (Eysenck Personality Inventory – Neuroticism Subscale). Further studies could further explore these dimensions as they relate to body image in order to uncover mechanisms on which to build appropriate interventions.

One can foresee patients identified as having baseline body image concerns be offered an online therapist led intervention covering topics associated with reconnecting to the body, adjusting to post-cancer identity, improving psychosexual functioning, and aspects of cognitive behavioural therapy (Esplen and Trachtenberg, 2020). Patients identified as exhibiting neuroticism may be presented with mindfulness-based cognitive therapy focusing on emotional regulation, flexibility, and the strengthening of social engagements and supports either by family or non-family members (Armstrong and Rimes, 2016; Olawa and Idemudia, 2020). Another intervention can focus on a balance between optimizing physical symptom management (Markey et al., 2020) and function (Chen et al., 2016) before and after treatment, all the while helping patients to change their focus from a preoccupation with their bodies to their adaptation to a new temporary or permanent normal. Patients using denial may be targeted to help improve their capacity to tolerate difficult affect and develop other more adaptive coping such as approach-oriented coping, emotional expression and acceptance (Stanton et al., 2018). Clinicians may want to use the teach-back method (Talevski et al., 2020) with these patients to help better prepare their expectations as to treatment impacts on their body. Improved psychosocial interventions for patients with HNC based on a solid conceptualization of body image disturbance will necessarily improve distress and quality of life (Rhoten et al., 2013).

Limitations

While this study is the first to investigate body image concerns prospectively in a large cohort of patients with HNC, several limitations are noteworthy. First, patients having dropped-out of the study were more susceptible to have had lower physical function, which may have minimized the prevalence of body image concerns in our sample. Second, while the Body Image Scale was the best measure to use at the time of the study, it was initially developed for patients with breast cancer and includes items that may not be representative of the head and neck cancer experience. In future studies, one may want to use a body image concern measure more specific to HNC such as the recently developed and validated FACT/McGill Body Image Scale – Head & Neck (FACT-MBIS) (Rodriguez et al., 2019a,b). Finally, recruitment in large university settings may limit result generalizability to less resourced contexts.

CONCLUSION

Head and neck cancer has significant sequela to functionality and appearance leading to body image disturbance in many. The current study helps clinicians better predict body image disturbance based on upon cancer diagnosis factors such as degree of pre-treatment body image preoccupations, physical symptom burden, and neuroticism. Better understanding how these early determinants interface with later body image concerns would be of merit to tailor interventions addressing this often-neglected component of HNC. Until then, screening for distress, collaborative care models, and patient-health care provider communication skills training (Barth and Lannen, 2011; Alias and Henry, 2018; Deleemans et al., 2020) remain mainstays in HNC oncology clinics.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the study received full ethics approval from

McGill University Faculty of Medicine's Institutional Review Board #A05-B24-10B. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

MH contributed to the conception, design, and analysis of the study as well as supervised the entire project. Along with MH, JA built the model, assisted with study design, and wrote sections of the manuscript. SF, MiH, AZ, KK, AM, MB, CM, KR, MM, GM, GC, NS, CL, and ZR contributed to the conception, design, manuscript revision, and read and approved the submitted version.

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'Weighing' Losses and Gains: Evaluation of the Healthy Lifestyle Modification After Breast Cancer Pilot Program

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Objectives: This pilot study sought to develop and evaluate a novel online group-based intervention (Healthy Lifestyle Modification after Breast Cancer; HLM-ABC) to help breast cancer survivors (BCSs) make healthy lifestyle changes intended to yield not only beneficial physical outcomes (i.e., weight loss, reduced body mass index) but also greater behavioral (e.g., increased physical activity, healthier eating), and psychosocial well-being (e.g., self-efficacy, motivation, body image).

Methods: An exploratory single-arm, mixed-method triangulation design was employed to evaluate the feasibility and preliminary effectiveness of the HLM-ABC intervention for overweight BCSs. Fourteen women participated in the 10-week intervention and completed quantitative measures of the above-mentioned outcomes at baseline, post-treatment, 6-month, and 12-month follow-up time points. Qualitative data were obtained post-treatment via semi-structured interviews and a treatment satisfaction questionnaire.

Results: Participants lost an average of 2.83% of their baseline weight (M = 196.65; SD = 38.59) by 1-year follow-up (M = 191.29; SD = 33.91), equal to a small effect size (d = –0.37). Despite achieving only modest weight loss, participants achieved meaningful gains in the form of increased physical activity (d = 0.2), discovery of gratifying movement, more intuitive eating habits (d = 1.12), greater bodily and emotional awareness, and positive shifts in beliefs about being able to make healthy choices regarding food (d = 0.63) and physical activity (d = 0.38). Furthermore, they demonstrated a slight improvement in body image (d = 0.36) and described feeling more self-compassionate, empowered, and acknowledging of variables beyond control (i.e., hormonal therapy, unsatisfactory surgery) that can present barriers to change.

Conclusion: After completing a 10-week online program, participants achieved meaningful and lasting changes on a number of healthful indicators, even when this did not correspond with a significant reduction in weight. Findings highlight the

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complex, multifaceted nature of "health" and lend support for promotion of healthier lifestyle following cancer treatment that encompasses not only physical weight, but also behavior, psychosocial well-being, and (often unmodifiable) circumstances such as life-preserving hormonal treatments.

Keywords: breast cancer, survivorship, online intervention, group, health behavior change, holistic, psychosocial oncology

INTRODUCTION

The overall 5-year net survival for BC is 87%, varying from 22% for stage IV to nearly 100% for stage I (Canadian Cancer Society [CCS], 2022a). In light of advances in early detection and increased survival rates, there remain numerous long-term challenges for women following BC treatment. Weight gain is one of the most prevalent yet less commonly discussed survivorship concerns, with a reported 50–96% of women who gain weight after diagnosis and treatment of BC (Wang et al., 2022). The most recent data available from a nation-wide American health survey (Greenlee et al., 2016) reported that approximately 30–35% of breast cancer survivors sampled were obese.

Possible explanations for treatment-related weight gain are a combination of type and length of chemotherapy, increased fatigue, reduced physical activity (PA) and resting energy expenditure, increase in energy intake, and development of amenorrhea and/or menopause (Campbell et al., 2007). Excess weight and body fat distribution have been identified as important modifiable risk factors for BC survivors, given their association with other health conditions (e.g., type II diabetes, heart disease, stroke), as well as increased risk for cancer recurrence and mortality (Protani et al., 2010; Ligibel, 2011; Ligibel and Strickler, 2013). In the case of BC specifically, increased fat results in greater production of estrogen, insulin, leptin and pro-inflammatory cytokines, and lesser production of sex hormone binding globulin, all of which have been linked to the promotion of BC and tumor growth (Rock et al., 2013). Being overweight is also associated with a range of psychological difficulties including low self-esteem, mood disorders, eating disorders, chronic pain, sleep disturbances, and reduced quality of life (QoL) (Collins et al., 2016). Psychological issues can underlie the development of unhealthy behaviors and excess weight; they can also occur as a result of ongoing weight struggles.

Physical Activity and Eating Habits

Along with obesity, lack of PA is considered to be one of the most important health determinants in breast cancer survivors (BCSs) who have completed adjuvant treatment (Sinicrope et al., 2010). BCSs experience severe side effects during and following treatment that can directly limit mobility and engagement in PA (Whitehead and Lavelle, 2009; Schmidt et al., 2017).

Research consistently demonstrates the importance of PA during BC survivorship. The health benefits of PA appear to be true for BCSs regardless of tumor stage, cancer treatment, smoking habits, menopausal status, body composition, and weight and have been demonstrated in large and small sample-sizes alike, across various cultures (Schmid and Leitzmann, 2014). Guidelines of 30 min per day of moderate to vigorous daily activity or 150 min of moderate (or 75 min of vigorous) activity per week have been published by the Canadian (Canadian Cancer Society [CCS], 2022b) and American (American Cancer Society [ACS], 2020). Cancer Societies, respectively. Dietary guidelines for BCSs have also been developed (e.g., intake of fruits of vegetables, limited intake of foods high in fat and sugar, limited alcohol consumption) (Gandini et al., 2000; Rock et al., 2012; Hamer and Warner, 2017) and represent an important modifiable part of a woman's overall lifestyle that can contribute to healthy weight management.

Despite research demonstrating that diet and exercise interventions can lead to improvements in physical and mental health, there remains a lack of consistent evidence that these changes are maintained over time (Campbell et al., 2012; Greenlee et al., 2012). Studies investigating the benefits of moderate-to-vigorous physical activity (MVPA) following diagnosis of BC reveal that such benefits seem to only be maintained for as long as exercise behaviors continue (Ritvo et al., 2017). Therefore, the maintenance of healthy behaviors over time following active completion of such interventions is paramount. Furthermore, evidence suggests that interventions that account for psychosocial factors and include self-directed professionally guided PA, follow-up behavioral prompts, and at least four sessions of related counseling are associated with successful promotion of PA (Ritvo et al., 2017).

Self-Concept

BCSs undergo a variety of physical and functional changes that impact their self-image (Male et al., 2016). Thirty-one to 58% of BCSs consider themselves to be less attractive and more dissatisfied with their bodies than they were before treatment (Andrzejczak et al., 2013), 73% report feeling less desired, 44% uncomfortable exposing their body, and 38% less confident (Ussher et al., 2012). Not surprisingly, BCSs score relatively worse on measures of body satisfaction than do women in the general population (Raggio et al., 2014) and, in fact, score similarly to obese women seeking weight-loss treatment (Foster et al., 1997), implying especially low body satisfaction among obese BCSs. The literature suggests that body image concerns amongst BCSs persist over time (Brunet et al., 2013; Raggio et al., 2014; Male et al., 2016; Kang et al., 2018). One study found that women felt similarly about their body image 3 years following mastectomy as they did 10 months after surgery (Fallbjörk et al., 2012). Another study found that 31% of stage

II-III breast cancer survivors struggled with body image 4 years after surgery, and 27% continued to struggle 7 years post-surgery (Falk Dahl et al., 2010).

Theoretical and Applied Underpinnings of Program Development

Self-Determination Theory

Self-determination theory (SDT) (Ryan and Deci, 2017) posits that human beings have inherent tendencies to explore, engage, and understand the world around them, and to internalize social norms and rules; these strivings are reliably driven by basic needs of feeling competent, autonomous, and related. SDT in the context of weight loss and healthy eating indicates autonomous motivation predicts greater treatment adherence and weight loss, as well as sustained exercise and weight loss at follow-up (Williams et al., 1996). Conversely, research demonstrates that when people are extrinsically motivated to engage in healthy eating and exercise (i.e., for financial incentive), they enjoy these activities less and have poorer weight loss outcomes (Moller et al., 2014).

Mindfulness and Self-Awareness

The concept of mindfulness has been applied to health behavior change in the practice of behavioral self-monitoring. Self-monitoring of diet and PA is a well-established part of effective weight loss interventions, and those who track their eating habits more regularly and completely seem to have the most successful outcomes (Burke et al., 2011). Mindfulness can also be practiced in the form of "mindful" (Kristeller and Lieberstein, 2016; Wnuk and Du, 2017) or "intuitive" eating (Tribole and Resch, 2012). This practice involves non-judgmental awareness of physical and emotional sensations (e.g., hunger and satiety cues) related to eating and intentional choices regarding the same. A systematic review of mindfulness-based interventions for obesity found that 86% of studies demonstrated improvements in eating habits (O'Reilly et al., 2014).

Motivational Interviewing

Motivational interviewing (MI) is "a collaborative conversation style for strengthening a person's own motivation and commitment to change" (Rollnick and Miller, 2013, p. 23). MI places emphasis on individuals' inherent tendency toward growth, which can be optimized through various psychological processes. MI has been adapted (Clifford and Curtis, 2016) and successfully implemented in health behavior change interventions with patient and non-patient samples (Pudkasam et al., 2018). It has been demonstrated to be a promising approach to promoting PA among BC patients and survivors (e.g., Sheppard et al., 2016).

General Systems Theory

General systems theory (GST) (von Bertalanffy, 1950, 1968) provides a framework to understand phenomena from a holistic approach—that is, how distinct parts of a complex, organized system interrelate and operate as a whole toward a broader purpose (Mele et al., 2010). Through a systems lens, a person's weight or body composition represents only one aspect of their broader health, comprised of a multitude of personal behaviors, emotions, physiological sensations, and thoughts that function together within a larger social context to achieve a state of homeostasis, or what may be referred to as health status. From this view, there are a variety of adaptable ways in which a person (and their environment) can influence the state of their health. In order to achieve sustained change, such as weight loss or other physical health benefits, one must consider how, to what extent, and at what pace, a person's broader lifestyle and context is likely to accommodate, or reject, such a shift in the system's homeostasis.

National Institute for Health and Care Excellence Guidelines

The National Institute for Health and Care Excellence (NICE) is aimed at improving health and social care by providing evidence-based recommendations, development of standards for health care providers, and provision of information services. The following guidelines were developed by NICE for providers of lifestyle weight management programs based on effective weight loss strategies, and were incorporated into the Healthy Lifestyle Modification After Breast Cancer (HLM-ABC) intervention protocol: incorporate multiple lifestyle components including diet, PA, and other behavior changes; develop by a multidisciplinary team (e.g., dietitian, psychologist); focus on long-term lifestyle change; establish specific and agreed-upon dietary targets tailored to individual needs and goals without "banning" foods or food groups; consider individual input from a registered dietitian; discuss reduction of sedentary behavior and types of PA that can easily be integrated into everyday life and maintained over time (e.g., walking); integrate a number of different behavior-change strategies that involve education, problem solving, goal-setting, social support or changes in one's environment that can facilitate lifestyle change, self-monitoring, and individualized feedback; tailor to the needs of participants so that the program is accessible and convenient to all; monitor indicators of behavior change and participants' personal goals throughout the course of the intervention; and adopt a respectful, non-judgmental approach (National Institute for Health and Care Excellence, 2014).

Cognitive Behavior Therapy

Cognitive behavior therapy (CBT) formulates problems in living (e.g., obesity, sedentariness) according to a model of how cognitions, emotions, physical sensations, and behaviors reciprocally influence one another (Padesky and Greenberger, 1995) and seeks to improve functioning by modifying thoughts and behaviors. CBT has been demonstrated to be an effective weight loss treatment (Munsch et al., 2007; Cooper et al., 2010; Leal and Ramos, 2012), and particularly with BCSs (Mefferd et al., 2007). The research suggests that the efficacy of CBT for weight management may be increased when delivered in a group format due to the suspected benefits of mutual support, and when combined with individualized nutritional and PA strategies (Leal and Ramos, 2012).

MATERIALS AND METHODS

Study Aims

There is a need to develop holistic health interventions that address the deleterious physical effects of BC treatment as well as the disturbances in self-and body-image arising from these, which are unlikely to resolve naturally. Albeit there are exceptions (e.g., Cohen and Narayanan, 2021), the relative dearth of comprehensive, sustainable health promoting programs for women recovering from BC led to the development of the HLM-ABC intervention (Yufe et al., 2019). The aim of this study was to evaluate the feasibility and preliminary effectiveness of the HLM-ABC program in order to determine the potential justification for further development and larger-scale investigation. From March to July 2017 the program was piloted in an asynchronous online format and employed an exploratory single-arm, mixed-method concurrent triangulation design for the purposes of evaluating the preliminary effectiveness of the HLM-ABC program. Given the small sample size and exploratory nature of this pilot, qualitative and quantitative methods were triangulated in such a way to increase "comprehensiveness" and "confidence" (O'Cathain, 2010, p. 577) in the findings.

Research Question

Does this intervention demonstrate promise in terms of helping BCSs achieve and maintain greater physical (weight, body mass index (BMI), and waist circumference), behavioral (intuitive eating and PA levels), and psychosocial (attitudes toward change, psychological distress, QoL, and body image) health?

Hypothesis

This program demonstrates feasibility and preliminary effectiveness in terms of improving and maintaining participants' physical, behavioral, and psychosocial health as indicated by quantitative and qualitative indicators assessed at baseline, post-treatment, 6-months follow-up, and 12-months follow-up.

Recruitment

Staff oncologists, nurses, dieticians, and physiotherapists at the study site (i.e., cancer center) were informed about the study through internal email and presentations delivered at interprofessional rounds by the primary investigator/first author. These healthcare professionals actively informed patients of the study and obtained their verbal consent to be contacted by a member of the research team for a telephone screening interview. The study was also advertised to patients through flyers posted at the cancer center, as well as through community-based organizations.

Prospective participants were contacted by a Research Coordinator (third author, then a clinical psychology graduate trainee) who scheduled a screening interview. During this interview, the Research Coordinator detailed information about the purpose and procedures of the study, obtained informed consent, and determined eligibility based on the following inclusion criteria: (1) be female; (2) be 21 years or older, (3) have been diagnosed with primary BC (stages I-III), (4) completed active treatment within the previous 5 years, (5) have a BMI above 25 ("overweight" category) or report a weight increase of 10 pounds or more post-treatment, (6) be comfortable using, and have access to, a computer and secure Internet connection, and (7) can read and write in English. Exclusion criteria included: (1) current diagnosis of metastatic cancer, (2) diagnosis of a mental health condition that would interfere with their own, or another group members' ability to benefit from group (e.g., psychosis), (3) diagnosis of an additional unmanaged/untreated medical condition, (4) plans to undergo a medical procedure within the next year, and (5) plans to participate in another structured weight loss program or take weight loss medication within the next year. **Figure 1** provides a visual diagram of participant recruitment and retention.

Procedures

Research Ethics Board Approval

Ethics approval was obtained from Sunnybrook Health Sciences Centre (SHSC)'s Research Ethics Office (339-2014) and York University's Office of Research Ethics (Sunnybrook Approval – 339-2014). The trial has also been registered at clinicaltrials.gov, under the ID CBCF-092014.

Baseline and Repeated Outcome Measures Data Collection

Participants ($n = 12$) were scheduled by one of the co-investigators (first author) to visit the cancer center to complete baseline data and repeated outcome measures. During the baseline visit (T0), participants reviewed and signed the informed consent form (verbal consent was already obtained during the phone intakes), as well as completed a one-time demographic/medical questionnaire. Repeated measurements were collected at pre-treatment (T0), post-treatment (T1), 6-months follow-up (T2), and 12-months follow-up (T3) and involved measurement of body weight, height, and waist circumference by a registered dietician on site, and completion of a questionnaire package including behavioral and psychosocial self-report measures. Upon completion of the program (T1), in addition to completing the standard repeated measures, participants also completed a one-time Treatment Satisfaction Questionnaire (TSQ).

Two ($n = 2$) of the participants resided rurally and were unable to attend the central cancer center for data collection. These women were emailed password-protected copies of the self-report measures to be completed anonymously and returned electronically via email. These participants solicited the involvement of their primary care provider (i.e., family physician, nurse practitioner) to collect their anthropometric measurements remotely, according to the same written instructions used by the dietitians at the local study site.

Post-treatment Interview

Upon completion of the intervention, participants engaged in a post-treatment interview (PTI) conducted over the telephone by a research assistant who was unknown to the participants. The interviews were semi-structured according to an interview protocol (see **Supplemental Material**), approximately 60 min in duration, audio-recorded, and intended to solicit individualized,

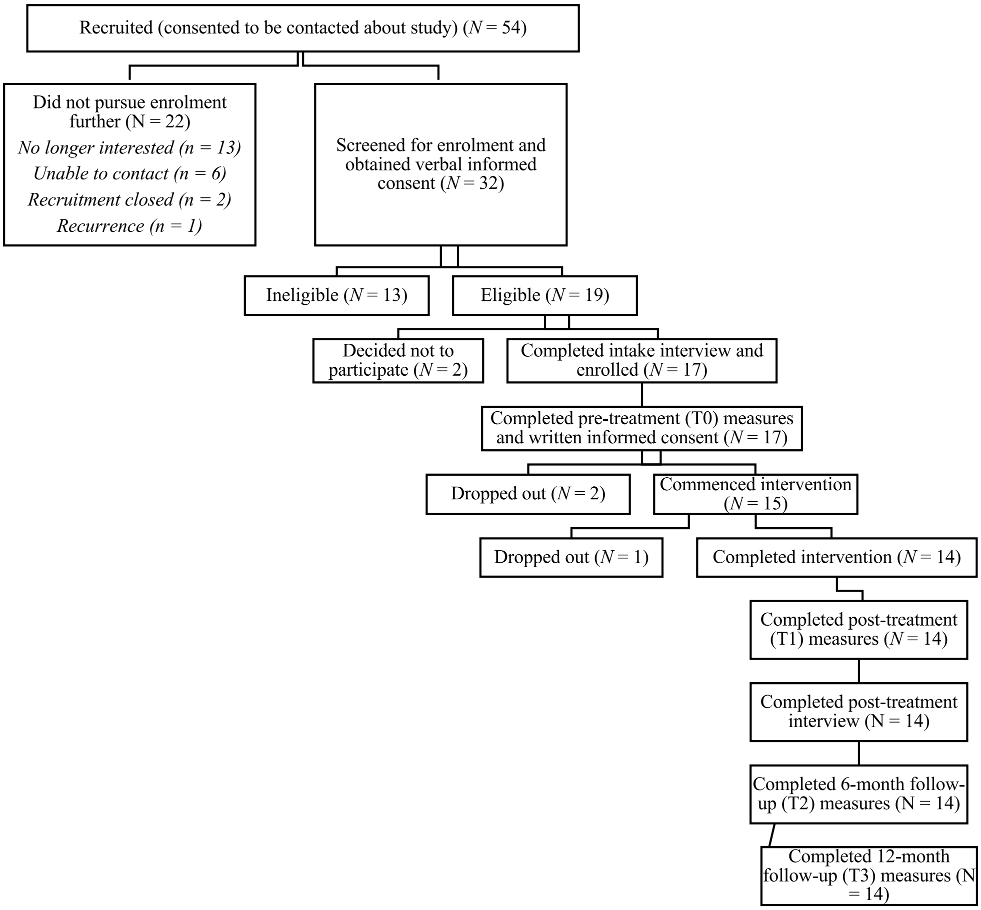

FIGURE 1 | Participant recruitment and retention flowchart.

open-ended feedback from participants about their experiences in the HLM-ABC intervention.

Program Delivery

The HLM-ABC program is a 10-week at-home, group-format lifestyle intervention that was delivered entirely online using "Moodle," an open-source "learning management system." The platform features interactive, closed-access exchange of information via sharing and uploading of documents, as well as asynchronous communication via discussion forums. Participants were expected to log in, at least once each week but ideally more often, to the secure website using a personal identification and password. They were expected to review and discuss weekly psychoeducational material (i.e., videos) geared at teaching and promoting new and healthier ways of thinking, feeling, and behaving. Discussion forum about the program content and participants' reactions to it were posted asynchronously on the website's discussion board. Participants were able to access the group at any time, from any personal computer or device, for the duration of the intervention.

At the beginning of each week, the two co-facilitators (who also occupied roles of co-investigators) alternated posting a message on the discussion forum to introduce that week's topic, upload the relevant psychoeducational material, and pose questions to facilitate group discussion. They provided clear instructions about the weekly homework and managed the discussion forum daily to respond to questions and promote group interaction. At the end of the week, participants were expected to submit their homework assignments online (which were reviewed by the facilitators who returned individualized feedback), and comment on their experience on the discussion board. **Table 1** provides a summary of the educational content and homework assignments delivered over the course of the 10-week intervention.

Measures

Preliminary effectiveness was assessed by triangulating qualitative findings from the PTI data with quantitative change scores on a number of standardized outcome measures. These outcome measures, summarized below, assessed a range of anthropometric (weight, waist circumference, BMI), behavioral (intuitive eating, PA habits), and psychosocial (motivation, self-efficacy, QoL, body image). Repeated measures were collected at pre-treatment (T0), post-treatment (T1), 6-months follow-up (T2), and 12-months follow-up (T3).

TABLE 1 | Healthy lifestyle modification after breast cancer (HLM-ABC) intervention weekly outline.

Week	Topic	Educational Content	Practice Homework
Initial log-in	Welcome/Practice	Introduction to facilitators, group format and responsibilities, general topics to be covered	(1) Practice assignment (2) Introductions
1	Getting Started	Foundational principles and conceptual framework Behaviors, Emotions, Sensations, Thoughts (BEST), balanced "blue zones, systemic balance, 80–20% rule, shifting from external to internal focus, daily planning"	(1) Food List (2) Weekly diary
2	Eating Consciously/Intuitively	"What" and "How" of eating Plate method (proportions, Canada Food Guide recommendations) Snacks as bridge between meals Hunger scale and hunger type	(1) Daily diaries (2) Pause, distract, check-in (3) My danger zones
3	Let's Get Moving	Tips for increasing and maintaining activity Behavioral activation Steady climb vs. final destination	(1) Diaries (2) My Satisfying Movements (3) Putting my Movements to the Satisfaction Test
4	Barriers to Staying on Course	Planning for inevitability of 'falling "off track" Triggers and barriers 3 saboteurs (Drill Sergeant, Rebel, Quitter) S.U.R.E. thinking (sudden, unrealistic, rigid, extreme)	(1) Diaries (2) Reviewing the play
5	Overcoming Barriers (Staying on Course)	Cultivating your Inner Coach G.R.A.B. principles (gradual, realistic, adaptable, balanced) Coach's tips: set schedule, show up prepared, realistic standards, check in often, recognize your efforts	(1) Diaries (2) Call in the Coach
6	Getting Emotionally Aware and Practicing Self-Care	Reasons for eating The dangerous cycle of emotional eating Basic emotion states and triggers Eating as a "Band-Aid" for emotional discomfort/pain Interrupting the emotional eating cycle: Take C.A.R.E. (Catch, Acknowledge, Recognize, Engage) Emotions and corresponding needs and action tendencies Proactive self-care ("oxygen mask" metaphor)	(1) Diaries (2) Taking C.A.R.E. with emotional "falls" (in-the-moment self-care) (3) Investing in Me (proactive self-care)
7	Body Image and Self Esteem	Defining body image How breast cancer relates to body image Respecting/accepting your body The Body Bully vs. Self-Compassion/Coach	(1) Diaries (2) Strengthening your self-compassion reflex (3) Check the checking
8	Reviewing the Journey	Review of major principles and strategies B.E.S.T. "Road Map" B.E.S.T. Players	(1) Review and practice exercises from "Repertoire of B.E.S.T. practices"
9	Looking Ahead	Anticipation of set-backs, relapse prevention, troubleshooting for maintenance Focus on group discussion, consolidation, and support	(1) Repetition and practice of homework for feedback
10	Take-aways and goodbyes	Reflect upon progress and mutual support Consolidate gains Group discussion, consolidation, and support (no video)	(1) Repetition and practice of homework for feedback

Physical/Anthropometric Health

Weight was measured using a physician's scale. Waist circumference was measured by aligning the bottom edge of a non-elastic measuring tape with the top of the hip bone and wrapping around the waist. BMI was calculated by dividing participant weight (kg) by their height (m^2).

Behavioral Health

Eating habits were measured using the Intuitive Eating Scale—2 (IES-2; Tylka and Kroon Van Diest, 2013). The IES-2 is a 23-item questionnaire that assesses an individual's degree of intuitive eating, which has been described as an adaptive way of eating, with strong connections to our internal physiological hunger and satiety cues (Tribole and Resch, 2012). The IES-2 has been found to be internally consistent, with Cronbach's coefficient alpha of 0.87 for the total 23-item IES-2 and similarly high for the subscales (Tylka and Kroon Van Diest, 2013) and total and subscale scores have demonstrated good test-retest reliability (Tylka and Kroon Van Diest, 2013). Cronbach's alpha for the total IES-2 has been found to be very reliable according to a validation study with a sample of 762 BCSs who were overweight or obese (Cronbach's alpha of 0.93 for entire IES-2 (Nejati et al., 2020).

Physical activity was measured using the Godin Leisure-Time Exercise Questionnaire (GLTEQ; Godin, 2011). The GLTEQ is a self-report measure consisting of three questions about the frequency and duration of mild, moderate, and strenuous exercise that one typically engages in during a week. The

GTLEQ is a commonly used and validated questionnaire among cancer survivors. It has demonstrated adequate construct validity (ranging from $r = 0.32$ to 0.45 when compared to accelerometry) and reliability (intraclass correlation coefficient of 0.74 over a two-week interval) (van Poppel et al., 2010).

Psychosocial Health

Psychosocial well-being was assessed according to measures of motivation/attitudes toward change and emotional well-being. The Change Questionnaire (CQ; Miller and Johnson, 2008) asks respondents to identify what they are considering changing (e.g., living a healthier lifestyle) and responding to 12-items about their intentions and motivation to make this particular change. The CQ has demonstrated good internal consistency and test–retest reliability (Miller and Johnson, 2008).

The Exercise Self-Efficacy Scale (E-SES) is a 5-item questionnaire measuring one's personal agency and optimistic self-beliefs about being capable of adopting healthy exercise behaviors. The scale has an internal consistency (Cronbach's alpha) of 0.88 and has been found to have satisfactory construct validity, as it is significantly correlated with healthy exercise intentions ($r = 0.33$) and behaviors ($r = 0.39$) (Schwarzer and Renner, 2009).

The Nutrition Self-Efficacy Scale (N-SES) is a 5-item questionnaire measuring one's perception of their own personal agency or control over eating. This scale has an internal consistency (Cronbach's alpha) of 0.87 and test-retest correlation of $r = 0.59$. The scale has been found to have satisfactory construct validity, as it is significantly correlated with healthy eating intentions ($r = 0.22$) and behaviors ($r = 0.34$) (Schwarzer and Renner, 2009).

The Functional Assessment of Cancer Therapy – For Patients with Breast Cancer (FACT-B; Brady et al., 1997) is designed to measure QoL in BC patients across various dimensions of physical, social, functional and emotional well-being as well as additional breast-cancer specific concerns. Internal consistency is high ($\alpha = 0.90$, $N = 295$), and subscale alpha coefficients range from 0.63 to 0.86. The scale has also demonstrated test–retest reliability, convergent validity, divergent validity, and known-groups validity (Brady et al., 1997).

Body image was measured using the Body Image Scale (BIS; Hopwood et al., 2001). The BIS was designed to measure body image concerns that cancer patients/survivors may have experienced during the past week, as experienced in the form of negative thoughts, feelings, or behaviors. The total scale and individual items have demonstrated high reliability when tested with BC samples, with Cronbach's alpha coefficients equal to 0.93, and ranging between 0.92 and 0.93, respectively (Hopwood et al., 2001).

Analysis

Qualitative Analysis

This study employed a thematic analysis (Graneheim and Lundman, 2004; Braun and Clarke, 2006) of the qualitative PTI data. Firstly, audio recordings of the PTIs were transcribed verbatim and uploaded into NVivo 12 software. Each transcript was read through several times by the first author (DM) to develop an overall sense of each participant's experience in the program. Subsequently, the text was organized into meaning units (segments of text that together represent a distinct thought, idea, or meaning), which were then assigned a "code." All codes were compared against one another for similarities and differences in meaning, and organized according to higher-order categories. At this stage, codes and categories were analyzed inductively, in that they very closely reflected the manifest data (Braun and Clarke, 2006). Subsequently, categories were examined against one another and as a whole, and through a process of deductively applying the broader research questions, were grouped into higher-order themes. The themes and organizational structure were subjected to a second independent audit by the second author (KF) and a subsequent dialogue and consensus building where differences existed to ensure validity and reliability of findings.

The researchers in this study were themselves instrumental in delivery of the intervention and analysis of the data. As such, it is important to provide the following background information. DM was a Doctoral Candidate in Clinical Psychology and was familiar with the processes and facilitation of online support groups through her master's thesis research, for which she conducted an in-depth qualitative analysis of archived transcripts of online group discussion (Male et al., 2015, 2017). She also possessed previous clinical experience facilitating several in-person therapy and psycho-educational groups. KF was DM's academic supervisor as well as a licensed Clinical Psychologist working as a Scientist-Practitioner at SHSC. KF has extensive (i.e., 20 years) research and clinical experience with online and in-person group facilitation in the area of psychosocial oncology.

The epistemological paradigm of this mixed-method study is a combination of both postpositivism-realism and constructivism-interpretivism (Ponterotto, 2005). The quantitative element of investigation acknowledges that the researchers and participants interact and have an influence on one another (especially because the PI/author occupied additional roles of clinician and research coordinator); however, this approach emphasizes independent and objective measurement of the phenomena under quantitative inquiry (e.g., the impact of the HLM-ABC intervention on overweight/obese BCSs' health, according to various quantifiable indices).

By combining qualitative and quantitative methodology, this study also integrates a constructivist-interpretivist lens. Therefore, this paradigm also assumes that the phenomena being investigated are determined by multiple, different and equally valid experiences of those individuals who participated in the study. Additionally, this approach does not presume that the researchers and participants are independent of one another; it is believed that "truth" is best discovered through joint pursuit and creation, by means of the researcher interacting with participants and interpreting the multiple meanings of reality they bring forth (Ponterotto, 2005).

Quantitative Analyses

In order to investigate whether the HLM-ABC intervention was effective at helping breast cancer survivors achieve (and maintain) healthy changes, sample means and standard deviations of the various outcome measures were calculated for each of the four time points. Given this study's small sample size and the intention of estimating power and sample size for a possible later-phase trial, the main statistic of interest reported is that of effect size (Cohen's *d*). The magnitude of effect sizes was interpreted according to Cohen's thresholds of $d < 0.2$ defined as negligible, $d < 0.5$ defined as small, $d < 0.8$ defined as medium, and $d \geq 0.8$ defined as large.

Pearson's chi-squared comparisons were conducted to explore the relationships between weight change (classified as less than 5% change in body weight, 5% greater reduction in body weight, or 5% or greater increase in body weight between baseline and 12-months follow-up), and a number of independent variables, including change in motivation (no change, increase; or decrease from baseline to 12-months follow-up). In addition, Fisher's exact test was conducted to identify the exact probability that the chi-squared statistics were accurate, given that the data violates the chi-square assumption that the expected frequencies in each cell not be below five (significance level set at $p < 0.05$). All statistical *analyses* were conducted using IBM SPSS Statistics 26 software.

Mixed-Method Triangulation

A mixed-methods concurrent triangulation design (Gonzalez Castro et al., 2011) was employed to evaluate changes in domains of physical, behavioral, and psychosocial health. Quantitative and qualitative data were collected and analyzed, separately, with a goal of obtaining multiple viewpoints of the phenomena under study (feasibility and preliminary-effectiveness of the program). Subsequently, the independent yet complementary results of these two data sets were merged at the phase of interpretation and discussion to create a cohesive and comprehensive conclusion to the research questions. A mixed-method triangulation approach was deemed especially appropriate for this pilot study given its small sample size and exploratory nature; this method illuminated convergence amongst findings and therefore increased confidence in such, while also revealing variability or exceptions amidst the multiple methods that could not be captured using a quantitative or qualitative method alone. Triangulation of mixed methods has also been established as especially suitable for social sciences and health research (O'Cathain, 2010). In the present study, preliminary effectiveness was assessed by interpreting the quantitative results (i.e., outcome change scores) in light of the converging and/or diverging thematic findings from the qualitative PTI data. The results presented herein represent those findings that are most relevant to the focus of this paper and are part of a broader dataset that is presented in full elsewhere (Male, 2020).

RESULTS

Demographics

Demographic information is summarized in **Table 2**. This pilot study sample consisted of fourteen ($N = 14$) women, with an average age of 52.07 years (*SD* = 9.75, range 29–71 years). The average age at time of diagnosis was 49.21 years (*SD* = 10.56, range 24–70 years), and the average amount of time that had lapsed since the last active treatment (e.g., surgery, chemotherapy, or radiation) was 26.57 months (*SD* = 20.21 months, range 7–64 months). The majority of women ($n = 9$) were married, three were single, and two identified as being in a common-law partnership (one heterosexual and one same-sex relationship).

Preliminary Effectiveness

This study sought to determine whether the HLM-ABC intervention demonstrates promise in terms of helping BCSs achieve and maintain greater physical, behavioral, and psychosocial health. This was assessed by comparing quantitative measures of such at baseline to those repeated at post-treatment, 6-month follow-up, and 12-month follow-up, and triangulating these results with participants' qualitative reports of perceived change (**Table 3**).

Physical Health

The preliminary effectiveness of the HLM-ABC intervention program on physical health was assessed by measuring weight, BMI, and waist circumference. Pairwise comparisons were performed for each of the outcome measures at T0 to T1, T2, and T3, to determine preliminary effectiveness of the intervention. Effect sizes for each of these values are presented in **Table 4**.

Weight

Weight (lbs) decreased from pre-intervention (T0) (*M* = 196.65; *SD* = 38.59; range = 159.83–300.49) to post-intervention (T1) (*M* = 194.50; *SD* = 35.24; range = 159.39–279.50). This represents a 1.09% reduction in baseline weight and a small effect. Weight did not change from pre-intervention to 6-months follow-up (T2) (*M* = 193.63; *SD* = 33.29; range = 157.85-264.55). Weight decreased from pre-intervention to 12-months follow-up (T3) (*M* = 191.29; *SD* = 33.91; range = 156.31–260.15), which is a 2.73% reduction in baseline weight and a small effect.

In order to explore individual variability within the sample and determine whether this mean trend in weight change was representative of individuals' change trajectories, descriptive statistics were examined for each individual participant across all four time points. Using the recommended guideline in the literature of at least 5% reduction in weight from baseline as the cut-off for clinically meaningfully weight loss (Swift et al., 2016), this analysis revealed that five participants in this study lost a clinically significant amount of weight at 12-months follow-up. Weight loss amongst these participants varied from 9.7 pounds (5.33% reduction in baseline weight) to 40.34 pounds (13.42% reduction in baseline weight) between T1 and T4.

Weight, Body Mass Index

BMI decreased minimally from pre-intervention (T0) (*M* = 33.51; *SD* = 5.32; range = 27.82–46.84) to post-intervention (T1) (*M* = 33.14; *SD* = 4.75; range = 27.74–43.57). BMI did not change from pre-intervention to 6-months follow-up (T2) (*M* = 33.11; *SD* = 4.59; range = 27.54–41.24). BMI decreased from pre-intervention to 12-months follow-up (T3) (*M* = 32.62; *SD* = 4.71; range = 26.65–40.55), with five participants moving down a BMI category (four went from "class I obese" to "overweight" and one went from "class II obese" to "class I obese"), one participant went up a BMI category from "overweight" to "class I obese," and the

TABLE 2 | Demographic characteristics (N = 14).

Variable	n	%
Ethnicity		
White/Caucasian	11	78.57
Eastern European	1	7.14
Italian	1	7.14
South African Jewish	1	7.14
Education		
High school	1	7.14
College	4	28.57
University	9	64.29
Employment status – missing data (*n* = 12)		
Working	11	91.67
Retired	1	8.33
Annual income – missing data (*n* = 13)		
$0-$9,999	2	15.38
$25,000-$49,000	2	15.38
$50,000-$74,000	3	23.08
$75,000-$99,000	2	15.38
$100,000+	4	30.77
Number of children		
None	3	21.42
1	2	14.29
2	7	50.00
3	2	14.29
Stage of cancer		
I	5	35.71
II	6	42.86
III	3	21.43
Surgery		
Single lumpectomy	6	42.86
Single lumpectomy followed by revision to clean margins	1	7.14
More than one lumpectomy	1	7.14
Unilateral mastectomy (followed by reconstruction)	5 (2*)	21.43 (14.30*)
Single lumpectomy followed by bilateral mastectomy followed by reconstruction	1	7.14
Other treatment		
Chemotherapy	9	64.29
Radiation	13	92.86
Hormonal Therapy	12	85.71
Herceptin Therapy	5	35.7

*n, Refers to the number of participants who endorsed each category. *, Refers to a subset of participants from a category.*

TABLE 3 | Qualitative themes and sub-themes regarding preliminary effectiveness outcomes.

Category	n	%
Theme 1: Behavioral Health Changes		
(1.1) Eating habits	11	79
How they were eating (i.e., mindfully)	10	71
What they were eating	4	29
When they were eating	6	43
More planful	5	36
Eating when hungry (as opposed to emotional)	3	21
(1.2) Moving habits	8	57
Increasing overall amount of movement	6	43
Engaging in more enjoyable and diverse forms of movement	5	36
Approaching movement more flexibly	5	36
Increased importance placed on movement and its inherent benefits	3	21
Increasing movement in little informal ways that add up	3	21
Creating greater accountability through structure	3	21
Theme 2: Psychosocial Changes		
(2.1) Mentality/attitudes toward health behavior change		
Adopting a more gradual and continuous approach to change	10	71
Feeling efficacious	11	79
Efforts sustainable over time	9	64
Empowered through increased self-awareness	9	64
More flexible and self-compassionate	9	64
Greater value and prioritization of self-care and nurturance	5	36
(2.2) Self-concept		
Some degree of change	5	36
Unchanged	1	7

n Refers to the number of participants who endorsed each category. % Refer to the percentage of participants from the overall sample who endorsed each category.

eight others remained in the same BMI category (two remained "overweight," two remained "class I obese," three remained "class II obese," and one remained "class III obese").

Waist Circumference

Waist circumference (cm) increased from pre-intervention (T0) (M = 105.15; SD = 11.58; range = 88.00–124.00) to post-intervention (T1) (M = 105.31; SD = 11.61; range = 86.00–124.00), with a small effect. There was essentially no difference in waist circumference from pre-intervention to 6-months follow-up (T2) (M = 104.18; SD = 12.47; range = 84.50–124.46) or from pre-intervention to 12-months follow-up (T3) (M = 105.58; SD = 11.06; range = 91.44–124.46).

Behavioral Health

Pairwise comparisons of intuitive eating scores and PA scores were calculated at T0 to T1, T2, and T3, and effect sizes are presented in **Table 4**. These quantitative results were triangulated with qualitative descriptions of altered patterns of eating and moving (**Table 3**, items 1.1 and 1.2).

Eating Habits

Intuitive eating (according to the total IES score), increased from pre-intervention (T0) (M = 2.90; SD = 0.61; range = 1.91–4.09) to post-intervention (T1) (M = 3.25; SD = 0.52; range = 2.26–4.22). Intuitive eating also increased from pre-intervention to 6-months follow-up (T2) (M = 3.28; SD = 0.64; range = 2.43–4.52) and from pre-intervention to 12-months follow-up (T3) (M = 3.25; SD = 0.56; range = 2.39–4.30). There were large effect sizes for each of these pairwise comparisons.

Participants (n = 11; 79%) described a number of *changes made to their eating habits* that they ascribed to the HLM-ABC program (**Table 3**, item 1.1). These changes corresponded with modifications in (1) *how they were eating* (i.e., more mindfully) (n = 10; 71%), (2) *what they were eating* (n = 4; 29%), and (3) *when they were eating* (n = 5; 36%). With respect to the first of these changes, some of the women described being more thoughtful

TABLE 4 | Pairwise comparisons of anthropometric, behavioral, and psychosocial outcome scores at baseline (T0) with post-treatment (T1), 6-month follow-up (T2), and 12-month follow- up (T3).

Health domain	**Variable**	**T0-T1** *d* **[95% CI]**	**T0-T2** *d* **[95% CI]**	**T0-T3** *d* **[95% CI]**
Anthropometric	Weight	0.30 + [–0.48, 1.09]	–0.007 [–0.82, 0.80]	0.37 + [–0.42, 1.15]
	BMI	0.32 + [–0.46, 1.10]	–0.019 [–0.83, 0.79]	0.37 + [–0.41, 1.16]
	Waist circumference	0.39 + [–0.43, 1.21]	–0.052 [–0.86, 0.76]	–0.073 [–0.85, 0.70]
Behavioral	Total IES	–0.91+++[–1.73, –0.097]	–0.81+++[–1.65, 0.037]	–1.12+++[–1.96, –0.29]
	GLTEQ	–0.72++[–1.52, 0.08]	–0.27+[–1.046, 0.51]	–0.21+[–1.02, 0.61]
Psychosocial	MCQ	–0.18 [–0.96, 0.60]	–0.23+[–1.04, 0.59]	–0.42+[–1.21, 0.36]
	N-SES	–0.18 [–0.96, 0.60]	0.072 [–0.74, 0.88]	–0.63++[–1.43, 0.16]
	E–SES	0.23+[–0.55, 1.0050]	0.63++[–0.21, 1.46]	0.38+[–0.41, 1.16]
	FACT-B	–0.01 [–0.79, 0.77]	0.36+[–0.46, 1.17]	–0.06 [–0.83, 0.72]
	BIS	0.38+[–0.40, 1.16]	0.11 [–0.74, 0.95]	0.36+[–0.43, 1.14]

d, Cohen's d; CI, 95% confidence interval; +, small effect; ++, medium effect; +++, large effect; IES, intuitive eating scale; GLTEQ, Godin Leisure-Time Exercise Questionnaire; MCQ, Motivational Change Questionnaire; N-SES, Nutritional Self-Efficacy; E-SES, Exercise Self-Efficacy; FACT-B, Functional Assessment of Cancer Therapy – for Patients with Breast Cancer; BIS, Body Image Scale.

about their reasons for eating (*n* = 6; 43%). One participant (P14) explained:

> . . .we had to rate the type of hunger we were having— is it bored hunger, is it biological hunger, is it emotional hunger? Like that kind of stuff. I found having to actually stop and keep track of that kind of thing really helped in terms of thinking about why I'm eating, what I'm eating, when I'm eating. And I find, even though I don't submit that to anybody anymore, I find it still comes to mind when I'm making choices about what I'm eating. . .

A number of women (*n* = 3; 21%) also spoke about how they developed greater consciousness of their internal bodily sensations around eating and relatedly, their unique eating preferences, which led to more intentional choices. One woman (P04) stated:

> . . .It was actually the first time, I mean it seems obvious that you shouldn't eat when you're not hungry. . .I heard that [laughing], but it didn't really ever actually sink in. And in this program, I started to realize I ate dinner because dinner was ready. Because everyone else was hungry. And that I don't overeat massively, but I eat more than I need to. And, you know, instead of feeling just full, sometimes I'm a little too full. . .I'm thinking about what I'm eating and how I feel [now]. . . I've never ever focused on how food made me feel. Seems so crazy.

In terms of reported changes in *what they were eating*, participants described eating a better balance or proportion of 'healthy' foods to 'unhealthy' foods (*n* = 3; 21%). They spoke of having changed their eating habits in terms of *when they ate* (*n* = 6; 43%); for example, being more planful to reduce feelings of extreme hunger (*n* = 5; 36%).

Moving Habits

The average level of PA across the sample (as assessed using the GLTEQ) increased from "moderately active" at pre-intervention (T0) (*M* = 21.57; *SD* = 19.05; range = 0.00–74.00) to "active" at post-intervention (T1) (*M* = 33.36; *SD* = 18.26; range = 6.00–64.00). This was a medium effect. The level of PA remained essentially the same from pre-intervention to 6-months follow-up (T2) (*M* = 21.38; *SD* = 10.98; range = 6.00–44.00), and increased from "moderately active" at pre-intervention to "active" at 12-months follow-up (T3) (*M* = 25.92; *SD* = 17.10; range = 3.00–60.00). This was a small effect.

Participants (*n* = 8; 57%) described a number of *changes made to patterns of physical activity* (**Table 3**, item 1.2). Five participants described *approaching movement more flexibly*, adjusting their expectations to be more realistic and thus achievable. For instance, one woman (P02) explained:

> I think this is just a more realistic approach to a life change—like a lifestyle change. But I think that, just thinking of it that way- that any kind of movement is valuable, that really helped me because I used to put a lot of pressure on myself that I wasn't going to the gym for an hour. If I wasn't doing this much cardio or that much strength training, then it really wasn't worth it. And so that's kind of shifted in me; I'm a little more laid back about what I do and how long, as long as I'm doing something.

The other way participants (*n* = 3; 21%) seemed to change their way of thinking about PA was in terms of the *increased importance placed on movement and its inherent benefits*, as opposed to it being a means toward the end of weight loss:

> Okay, so in my mind before was that exercise isn't really going to take weight off, it's the eating. But now, they've changed it to *moving*, which I like way better than *exercise*. And so even though I still feel moving isn't going to take your weight off, moving is going to give you health (P06).

Several participants also described *increasing their overall amount of movement* (*n* = 6; 43%) and *engaging in more enjoyable and diverse forms of movement* (*n* = 5; 36%). A number of participants (*n* = 3; 21%) described changing the way they move in terms of *increasing movement in little informal ways that add up* over time, such as "making a choice to park my car further away when I go into a store" (P14). Three women described *creating greater accountability through structure*.

Psychosocial Health

The HLM-ABC program's potential to improve participants' psychosocial functioning was evaluated by triangulating quantitative and qualitative measures of motivation and attitudes toward change, and psychological well-being. Motivation and attitudes toward change was assessed according to scores on the MCQ, N-SES, E-SES, as well as qualitative feedback that emerged from the PTIs. Emotional well-being was assessed based on QoL (FACT-B), body image distress (BIS), and relevant qualitative findings. Pairwise comparisons were performed for each of the repeated outcomes at T0 to T1, T2, and T3. Effect sizes are presented in **Table 4**. Qualitative themes are summarized in **Table 3** (items 2.1 and 2.2).

Motivation and Attitudes Toward Change

Motivation for change did not change from pre-intervention (T0) (*M* = 8.92; *SD* = 0.52; range = 7.92–9.75) to post-intervention (T1) (*M* = 9.21; *SD* = 1.44; range = 4.75–10.00). Motivation increased from pre-intervention to 6-months follow-up (T2) (*M* = 9.15; *SD* = 0.87; range = 7.42–10.00) and from pre-intervention to 12-months follow-up (T3) (*M* = 9.40; *SD* = 0.83; range = 7.33–10.00). These effects were small.

According to the Pearson's chi-squared comparisons analysis, a significant relationship was found between weight and change in motivation, with Fisher's exact test = 7.94, $p < 0.05$. Participants who experienced a decrease in motivation over the course of the intervention were more likely to have gained weight, those who did not experience a shift in motivation were more likely to also not have experienced a significant change (defined as 5% or more) in weight, and those who experienced an increase in motivation were more likely to have either lost an insignificant (less than 5%) or significant (5% or greater) amount of weight, but not to have gained weight.

Participants' self-efficacy regarding nutrition (N-SES) essentially remained the same from pre-intervention (T0) (*M* = 14.14; *SD* = 2.69; range = 10.00–20.00) to post-intervention (T1) (*M* = 15.00; *SD* = 3.94; range = 7.00–20.00) and from pre-intervention to 6-months follow-up (T2) (*M* = 14.23; *SD* = 3.61; range = 9.00–20.00). N-SES increased, however, from pre-intervention to 12-months follow-up (T3) (*M* = 15.79; *SD* = 2.83; range = 10.00–20.00). This was a medium effect suggestive that between the time prior to participating in the HLM-ABC and 12-months following completion of this program, participants' perception of their own personal agency or control over their eating increased.

Participants' self-efficacy regarding exercise (E-SES) decreased from pre-intervention (T0) (*M* = 12.93; *SD* = 3.27; range = 8.00–20.00) to post-intervention (T1) (*M* = 12.21; *SD* = 4.92; range = 5.00–20.00). E-SES decreased from pre-intervention to 6-months follow-up (T2) (*M* = 11.39; *SD* = 4.79; range = 5.00–20.00). E-SES decreased from pre-intervention to 12-months follow-up (T3) (*M* = 11.79; *SD* = 4.08; range = 6.00–20.00). These effects were small, medium, and small, respectively. Findings suggest that between the time prior to participating in the HLM-ABC program and 6- and 12-months following completion, participants' perception of their personal agency or control over their exercise habits decreased slightly.

Participants described a number of specific *changes in their mentality or attitudes toward health behavior change* during the PTIs (**Table 3**, item 2.1). The first of these changes was *adopting a more gradual and continuous approach to change* (as opposed to sudden) (*n* = 10; 71%), as illustrated by the following quote:

> I wanted to lose some weight, and, get some exercise, get back on track. And you know. . .I thought it would come off faster. But that's okay too. That's okay. It's, you know, if I can do a few more pounds in the next 10 weeks, if I just sort of look at it that way. . . I think we all said that in the first place though, you know, if you look over a year, if you can lose, you know seven or eight pounds in 10 weeks and you stay with it, maybe you lose 20 over a year. And then in 3 years you would have lost 60 pounds.

Several (*n* = 9; 64%) participants spoke about how the program helped them develop a *more flexible and self-compassionate* (as opposed to rigid, extreme and critical) attitude toward accomplishing and maintaining their health goals. Another theme that emerged through the PTIs regarding motivation and attitude toward change was that of *feeling efficacious* (*n* = 11; 79%). This finding seemed to be related to participants' belief that their efforts to live healthier would be *sustainable over time* (*n* = 9; 64%). Another sub-theme that emerged was that of feeling *empowered through increased self-awareness* (*n* = 9; 64%). One participant (P07) described how the program helped increase her awareness of her internal dialogue and how doing so positioned her to feel more confident in making healthier choices:

> I definitely [feel that I am living a healthier lifestyle] . . . when I go out and it's like "oh, you know what, I deserve a treat," I kind of double think. I have had. . . a bad day where I did buy a bag of potato chips, but it was okay. "Now you've done it, you've got it over with. Let's move on, let's get back." Whereas before, I'd be all, "You know, who cares? I'm going to be this way, and screw it anyway." So yeah, it's helped. . . I kind of feel more it is in my hands to deal with. Whereas before I would just not be happy and it got to the point where it was like "Okay, I'm just going to keep eating because. . . I don't care because I don't know what the hell to do.". . . I feel good that it's in my hands, I know there is a solution, and. . . I know what the block is.

Finally, participants (*n* = 5; 36%) spoke of the program shifting their attitude toward health behavior change was in the way it promoted *placing greater value and prioritization on self-care*.

Psychological Well-Being

Quality of life, as measured by the FACT-B, remained essentially the same from pre-intervention (T0) (*M* = 104.99; *SD* = 16.36; range = 77.00–128.00) to post-intervention (T1) (*M* = 105.10; *SD* = 18.22; range = 64.00–131.00). QoL decreased from pre-intervention to 6-months follow-up (T2) (*M* = 101.14; *SD* = 21.22; range = 63.00–139.00), and was essentially the same at pre-intervention as 12-months follow-up (T3) (*M* = 105.88; *SD* = 21.71; range = 61.00–133.00). These results reveal that QoL remained generally unchanged, except for a temporary decrease 6-months after treatment, before returning to baseline level.

Body image distress was measured using the BIS, where a lower score is indicative of better body image (i.e., less distress). On average, BIS decreased from pre-intervention (T0) (*M* = 14.48.99; *SD* = 6.66; range = 2.00–25.00) to post-intervention (T1) (*M* = 13.07; *SD* = 7.54; range = 3.00–26.00). This effect was small. Body image distress remained essentially the same from pre-intervention to 6-months follow-up (T2) (*M* = 13.50; *SD* = 7.81; range = 1.00–26.00). Body image distress decreased from pre-intervention to 12-months follow-up (T3) (*M* = 13.14; *SD* = 7.13; range = 3.00–26.00). This effect was small, and suggests that on average, women in this sample were slightly less distressed about their bodies immediately after participating in the HLM-ABC program, and still 1 year following their participation.

Six of the participants spoke about their relationship with their body, which revealed two broad themes regarding self-concept: *some degree of change* (*n* = 5; 36%), *and unchanged* (*n* = 1; 7%). Only one of the participants (P02) described an unchanged, entirely negative experience of her body:

> I kind of found that I wasn't too open to [discussing body image]. I kind of was, I don't know, I think I have a bit of a barrier. . . I mean it's been a while since I've gone through reconstruction and I'm just not happy with, you know the way that I look and I don't know if that's ever going to change. So, it's just a topic that makes me feel really angry and kind of bitter. . . So that's a big part of my frustration, you know? Like I shouldn't be 159 pounds.

The other five women described at least some element of their self-concept as having shifted, or being in the process of shifting. Two women described feeling better about their bodies in direct relation to perceiving that they had achieved some tangible physical change (i.e., weight loss, desired change in body shape, size, and/or strength). For example:

> Let's just say I feel better in terms of feeling stronger. I feel like I have more energy, I feel like my mobility is better, I just feel a bit more normal in terms of that aspect instead of before, which was really bad. But because of that, I would say I feel leaner. I don't actually know if I've lost weight. . . I think may have lost inches maybe but I feel better than when I started. (P19)

The other three women appeared to have "reframed" their experience of their body, regardless of having achieved a desirable amount of weight or feeling as though they directly improved their body image. One woman (P07) described that while she still felt "not good about [her body]," she also felt more "empowered" in terms of recognizing her barriers to weight loss (e.g., medications, unhelpful extreme thinking) and that "finally after all these years, it's in perspective. It's not going to be a quick hit."

DISCUSSION

Participants in the HLM-ABC program evidenced trends in achievement and maintenance of healthier lifestyle habits up to 1 year following completion, based on a number of physical (i.e., modest but sustained weight loss, downward trend in BMI), behavioral (i.e., higher levels of PA and intuitive/mindful eating), and psychosocial (i.e., slight yet sustained improvements in motivation, self-efficacy regarding eating habits, and body image) outcomes.

Physical Health

On average, participants in the current sample lost 2.15 pounds between pre-treatment and the time that they completed the HLM-ABC program, approximately 10 weeks later. At 1-year follow-up, the sample weighed an average of 5.36 pounds less than at pre-treatment, meaning that, on average, participants maintained a 2.73% reduction in baseline weight up to 12 months after completing the program.

A minimum of five percent reduction in body weight has been associated with significant health benefits and has been suggested as the cut-off for clinically meaningful weight loss (Rock et al., 2012; Swift et al., 2016; Borek et al., 2018). According to this guideline, five participants (36%) in the current sample maintained a clinically significant amount of weight loss at 1-year follow-up, with one participant having maintained a 40-pound (13.42%) weight reduction. At 12-months follow-up, seven (50%) participants' weight had not changed significantly (less than 5% reduction) and two (14%) had gained a clinically significant amount weight. In comparison, Christian et al. (2010) found in their review of "low intensity" lifestyle modification interventions that at 12-months follow-up, 29% of participants maintained a weight loss of 5% or greater, 27% lost less than 5% weight, and 43.6% lost no weight or gained weight. A large meta-analysis of 24 randomized controlled trials (*N* = 6,042) of group-based diet and/or exercise interventions for overweight/obese men and women reported an average reduction of 7.58 pounds at 12 months follow-up, varying from 0 to 21.16 pounds. Percent reduction in baseline weight for 23 of the studies revealed an average of 4.83% weight loss. Only 14 of these interventions yielded a minimum of 5% weight loss.

Goode et al. (2015) conducted a systematic review of 27 exercise, diet, and/or weight management interventions for cancer survivors that were delivered via non-face-to-face methods (telephone, short-message service, print, and/or Internet). These researchers found that of those interventions that measured weight loss from pre- to post-treatment, effect sizes varied between 0.09 and 0.75, representing a 1.3–10.6% reduction in baseline weight. In comparison, the current study yielded results similar to or within this range, with effect sizes of 0.30 and 0.37 at post-treatment and 12-months follow-up, and 1.09 and 2.73% reduction in weight at post-treatment and 12-months follow-up.

Weight loss maintenance is very difficult to achieve, with an estimated 10–20% of formerly obese individuals being able to maintain significant weight loss long-term, and rapid weight gain being common (Uhley and Jen, 2007; Tylka et al., 2014). Researchers who have investigated the rapid-cycling of weight loss and regain (often referred to as "yo-yoing") have found that such weight cycling is associated with insulin resistance (Lu et al., 1995), which may explain why some individuals experience great difficulty losing weight despite making changes in eating and activity that would otherwise be expected to generate weight loss. The study of weight-cycling in rats has found that such a pattern is associated with increased levels of 5-hydroxymethyl-2′-deoxyuridine, which is a marker of oxidized DNA damage and a risk factor of breast cancer (Djuric et al., 1996; Uhley and Jen, 2007). Thus, a history of repeated weight loss-gain cycling may place some women at increased risk of developing breast cancer (Uhley and Jen, 2007). Anecdotally, several of the women in the current sample described a longstanding history of repeated weight loss attempts via a number of various programs; further exploration of this theory may be warranted.

Behavioral Health

Intuitive eating improved from pre- to post-intervention ($d = 0.91$) and this large effect was maintained at 12-months follow-up ($d = 1.12$). These results can be interpreted in comparison to other non-face-to-face lifestyle interventions for cancer survivors (Goode et al., 2015), which found that most ($n = 9$) of these sorts of interventions had a small effect on diet at post-treatment ($d = 0.2–0.49$), while four had a large effect ($d \geq 0.8$), another four had a negligible effect, and two studies had a moderate effect ($d = 0.5–0.79$).

The HLM-ABC program demonstrated a medium effect ($d = 0.72$) on movement, with the sample increasing from an average level of "moderately active" at pre-treatment to a level of "active" at post-treatment. This effect, albeit small ($d = 0.21$), was maintained at 12-months follow-up. Goode et al. (2015) meta-analysis of non-face-to-face lifestyle interventions for BCSs concluded that when it comes to longer-term maintenance of PA and diet outcomes, effects are small ($d < 0.49$) or not reported at all. Therefore, it is a strength of the current study to have collected this follow-up data, and to have yielded a large sustained effect on eating habits; the small sustained effect on PA is consistent with other non-face-to-face lifestyle interventions for this population.

Psychosocial Health

Participants' level of motivation increased from pre-intervention to 6-months and 12-months follow-up. According to categorical analysis, the extent to which a person's motivation changed from pre-intervention to 12-months follow-up also appeared to be associated with how much their weight changed during this time; those women whose motivation decreased during this time were more likely to have also gained weight, those who did not experience a change in motivation were also more likely to have not experienced a significant change in weight (<5% reduction in baseline weight), and those women whose motivation increased were more likely to have lost weight of a significant (>5% reduction in baseline weight) or insignificant (<5% reduction in baseline weight) amount.

The qualitative findings also converge to illustrate a positive change in motivation and general attitudes toward change. Participants described adopting an approach to change that is more gradual and continuous, and being more committed to prioritizing self-care (including through healthy eating and moving).

Contrary to expectations, exercise self-efficacy scores (E-SES) decreased between baseline and all subsequent time points. This quantitative result suggests that participants' confidence in their ability to be in control of their exercise habits decreased slightly, which deviates from the qualitative themes regarding *feeling efficacious* (**Table 3**, item 2.1). Furthermore, a decrease in exercise self-efficacy seems to contradict the finding that self-reported levels of exercise (as measured by the GLTEQ) increased, on average. It is possible that self-efficacy may not have mediated or been directly related to actual levels of activity, which is a finding that has been reported by other studies of remotely delivered PA interventions for BCSs (Rabin et al., 2006; Vallance et al., 2007; Valle et al., 2015; Forbes et al., 2017).

Another possible explanation for this unexpected decrease in E-SES is that the HLM-ABC program was developed and implemented in close collaboration with two dieticians. Participants were provided guidelines regarding healthy eating and were given individualized feedback on their food diaries from one of the dieticians. However, the program did not include a similar degree of integration of PA guidelines or collaboration with an exercise or rehabilitation specialist. Therefore, as a result of the program's relative emphasis on eating and dietetic influence, the women in the HLM-ABC program may have felt more confident in their abilities to persist in their eating goals than in their movement goals, which might explain the observed discrepancy between changes in nutrition versus exercise self-efficacy.

Psychological Well-Being

The current sample's QoL did not change from pre-treatment to post-treatment, but decreased slightly between pre-treatment and 6-months follow-up, with a small effect. By 12-months follow-up, QoL had returned to a baseline level. A minimum change of 6 points on the FACT-B total score has been identified as clinically meaningful (Eton et al., 2004), and therefore, this temporary reduction (of 3.85 points) at 6-months is not likely to have been significant. This transient increase in distress may be explained by the fact that the intervention promoted increased self-awareness of (maladaptive) emotions and thoughts, and as described by a number of participants, unveiled longstanding and/or sensitive issues (e.g., feelings of low self-worth, neglect of one's needs/values). Such insight was encouraged while simultaneously encouraging participants to refrain from engaging in familiar yet problematic coping behaviors (e.g., emotional eating, inactivity) and experiment with new, healthier strategies (e.g., increased self-care, greater movement, mindful eating), which may have understandably generated temporary feelings of discomfort or distress.

Self-Concept

Women in this sample were slightly less distressed about their bodies upon completing the HLM-ABC program and still 1 year beyond, compared to before starting the program. This increase in self-acceptance occurred in light of perceived physical change for some, and *despite the absence* of perceived physical change for others. This finding is consistent with evidence that engaging in PA for pleasure rather than for weight loss is associated with well-being and improved body image (Homan and Tylka, 2014). This outcome suggests that in the absence of quantifiable weight loss, BCSs can improve their self-concept and still achieve an overall sense of feeling healthier.

Summary and Implications

The aim of this research was to evaluate the potential health impacts of the HLM-ABC program, across a number of biopsychosocial health indicators. Although participants in the current study achieved varying degrees of weight loss (and two gained weight), they also demonstrated improvements (varying from small to large magnitude) in other domains of health and well-being, including intuitive eating, PA level, motivation, nutrition self-efficacy, and BIS. In addition to these quantitative outcomes, the women reported themes of increased self-awareness, feelings of empowerment and self-efficacy, increased skillfulness in approaching their health goals, and enhanced self-acceptance. These mixed-method findings suggest that positive behavioral, emotional, and attitudinal health changes can occur even when physical outcomes (i.e., weight loss) are modest and in spite of very real, unmodifiable barriers to weight loss (hormonal treatments, metabolic/insulin resistance related to chronic dieting, genetics).

Mainstream research and health care tend to conceptualize health according to quantifiable outcomes (e.g., BMI, muscle mass, measures of body circumference, biomarkers), with weight often being the primary indicator. However, this medicalized approach to health has been criticized by proponents of a "weight-inclusive" (versus "weight-normative") approach to health (Tylka et al., 2014). Among the problems associated with a weight-centric system are: weight-cycling and its related adverse health impacts (e.g., heightened risk of bone fractures and gallstones, muscle atrophy, hypertension, chronic inflammation; Rzehak et al., 2007; Nilsson, 2008; Tylka et al., 2014); failure to diagnose legitimate health conditions in individuals whose weight appears 'normal; false diagnosis and prescription of weight loss interventions for individuals who are considered "overweight" but are otherwise healthy (Tylka et al., 2014); establishment of weight goals that are often unrealistic and generate chronic feelings of failure (Jeffery et al., 2000; Bacon et al., 2005; Wing and Phelan, 2005); absence of empirical evidence that a higher BMI actually *causes* poor health (Bruno, 2017); and harmful stigma presenting within oneself, between individuals and their health care providers, and amidst society at large. Furthermore, a weight-normative approach to health fails to account for the range of factors that can influence a woman's body weight and shape that are beyond her control (e.g., genetics, age, hormonal status, metabolic functioning, disease- and/or treatment-related weight gain, surgical body changes) and can therefore impede her sense of autonomy and competence with respect to managing her own health—experiences that are considered fundamental to motivation and self-efficacy (Ryan and Deci, 2017).

The findings of this study suggest that women with a history of BC are capable of modifying one or various aspects of their well-being (e.g., improved body image, increased physical activity) and that such changes may or may not coincide with clinically significant weight loss. The findings from this study and developing sociocultural and academic perspectives around "weight inclusivity" invite us to reflexively and critically examine the validity of assigning body weight as the primary (best) measure to evaluate success/change when it comes to helping BCSs create meaningful and lasting improvements to their health. Future research in this area is warranted, including investigation of potential correlations between long-term health outcomes (e.g., cancer recurrence, mortality) with psychosocial and behavioral variables (e.g., body image, self-efficacy, intuitive eating habits) irrespective of weight loss.

Study Limitations

A major limitation of this study is its small sample size. Although the sample represented a wide age range (29–71 years), time elapsed since treatment (ranging from 6 to 64 months) and annual income, the majority self-identified as White/Caucasian (nearly 79%) and as having a university-level education (64%). Results cannot be assumed to reflect the experiences of all BCSs who are seeking to make changes to their weight and/or lifestyle, especially those with various cultural and educational backgrounds.

Although an exclusion criterion for this research was participation in other types of health-promoting programs during their involvement in the study, actual data about this, or other potentially confounding variables (e.g., changes in health/illness), that could have influenced the results was not collected.

Furthermore, the small sample data were not amenable to statistical analyses that carry assumptions of normality and adequate power, thus were limited to exploratory analyses and reporting of effect sizes to estimate the magnitude of the HLM-ABC intervention's potential. Notwithstanding these limits, a small sample size was appropriate given the aim of this study, which was to pilot the feasibility and acceptability of a novel intervention and estimate effect sizes, power, and sample size for later-phase trials.

CONCLUSION

This study evaluated the HLM-ABC program's preliminary effectiveness through triangulation of various physical, behavioral, and psychosocial outcome data to determine whether the intervention was successful in supporting sustained (i.e., 1-year follow-up) improvements in a number of health indicators rather than relying exclusively or unduly on weight. Results demonstrated quantitative and qualitative trends of sustained but modest weight loss, increased intuitive eating, higher levels of PA, increased motivation and self-efficacy (regarding eating habits), and improved body image.

The preliminary effectiveness of the HLM-ABC pilot program is quite promising in light of the fact that it was a relatively self-directive, at-home intervention that did not impose restrictions or strict prescriptions. In other words, the HLM-ABC program did not so much instruct participants on *what* to do to establish a healthy lifestyle, but rather taught principles and practices for how to develop healthier lifestyle habits that suit each woman's unique situation, needs and preferences. Furthermore, considering that this online intervention was implemented entirely through text-based interaction (i.e., no in-person or video meetings), it is interesting to think how much greater the impacts of the program could be in the future with the incorporation of additional opportunities for human connection, accountability and external structure especially in the current context where video-conferencing is ubiquitous. Additionally, future implementations of the program could be improved by incorporating greater guidelines (i.e., 30 min per day of moderate to vigorous daily activity) and direct clinical input from collaborators with a background in exercise/physiology to compliment the relative degree of eating guidelines and involvement of dieticians in this intervention. Overall, the results herein suggest that the HLM-ABC program, and holistic person-centered interventions more broadly, have potential to help BCSs adopt and maintain a healthier lifestyle following treatment.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author/s.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Sunnybrook Health Sciences Centre (SHSC)'s Research Ethics Office (339-2014) and York University's Office of Research Ethics (Sunnybrook Approval –339-2014). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

DM, KF, and SY contributed to conception and design of the study, recruitment, intervention implementation and data collection. DM organized the database and conducted analyses in collaboration with KF. DM wrote the first draft of the manuscript. KF contributed written sections. All the authors contributed to manuscript revision, read, and approved the submitted version.

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SUPPLEMENTARY MATERIAL

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Body Image Scale: Evaluation of the Psychometric Properties in Three Indian Head and Neck Cancer Language Groups

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Background: Body image is a subjective concept encompassing a person's views and emotions about their body. Head and neck cancer (HNC) diagnosis and treatment affects several psychosocial concepts including body image. Large numbers of HNC patients are diagnosed each year in India but there are no suitable measures in regional languages to assess their body image. This study assessed the psychometric properties of the Body Image Scale (BIS), a measure suitable for clinical and research use in HNC populations, translated into Tamil, Telugu and Hindi and compared body image distress between language groups.

Methods: Translated versions of BIS were completed by HNC patients recruited from three cancer centers across India one time only. Psychometric evaluation was conducted including factor analysis using principal component analysis and internal consistency reliability using Cronbach's alpha. Patients completed the EORTC Quality of Life Questionnaire (QLQ) C-30 and EORTC QLQ HN-35 measures to enable exploration of convergent and discriminant validity. ANOVA was used to calculate difference in mean values for body image.

Results: Our sample included 621 HNC patients (Tamil = 205, Telugu = 216, Hindi = 200). Factor analysis revealed a one-factor solution and Cronbach's alpha coefficients ranged between 0.891 and 0.969 indicating good reliability. Hypothesized correlations between similar and different constructs were as expected, supporting construct validity. On the BIS, we found a statistically significant difference ($F = 11.0954$, $P < 0.05$) between means of Tamil, Telugu, and Hindi groups, with higher body image scores in Telugu ($M = 12.86$; $SD = 7.65$) and Hindi groups ($M = 12.52$; $SD = 7.36$)

indicating more symptoms/body image distress, when compared to Tamil population (*M* = 9.28; *SD* = 10.04).

Conclusion: The reliability and validity of the three translated Indian versions of the BIS were maintained, providing a method for assessing body image of HNC population worldwide speaking Tamil, Telugu, and Hindi across the illness trajectory.

Keywords: validation, cross-cultural adaptation, body image, head and neck cancer, Indian languages

INTRODUCTION

Head and neck cancers (HNC) in India are a major health problem, constituting about one-third of all cancers (Shah et al., 2016). According to Global Cancer Incidence, Mortality, and Prevalence (GLOBOCAN), over 100,000 cases of oral malignancies are registered in India each year (Johnson and Amarasinghe, 2016; Bray et al., 2018). Main causes of HNC in India are chewing tobacco, smoking bidis and cigarettes, and alcohol consumption. Regardless of clinical advances in early diagnosis and treatment, HNCs result in significant functional, physical, and psychosocial effects and affect mortality rates (Gupta et al., 2016). Treatment toxicity is common and can lead to scarring, appearance changes or disfigurement, difficulties in talking, eating and swallowing, sticky saliva, weight loss, and dental problems (Semple et al., 2008). People treated for HNC most commonly report body image concerns from disfigurement and scarring. Studies have shown poorer body image in HNC patients post-surgery compared to before surgery (Hung et al., 2017) and that reduced body image is associated with a decline in general health-related quality of life (HRQoL) (Nayak et al., 2016; Manier et al., 2018).

Physical appearance and attractiveness are highly valued by individuals (Sharma et al., 2018) but influenced by various psychosocial factors such as personality, interpersonal factors (family and peers), and social factors (values and norms) (Sharma et al., 2018). Generally, when a person is diagnosed with a life-threatening disease such as cancer, they may initially perceive their physical appearance and body image as less important than concerns about survival (Page and Adler, 2008). Some individuals may continue to perceive disfigurement positively, reporting gratitude for being alive and surviving cancer, and self-confidence in dealing with body changes (Manier et al., 2018). While others may come to perceive disfigurement as an embarrassment resulting in social withdrawal, isolation, feelings of inadequacy, anxiety, and low self-esteem, all consequently contributing to poor HRQoL (Sundaram et al., 2019). Addressing body image issues may prevent these negative outcomes (Sharma et al., 2018). Therefore, in a population susceptible to disfigurement or appearance related changes, it is crucial to assess patient-reported outcomes (PROs) such as body image throughout the HNC disease and treatment journey to identify concerns and provide appropriate supportive care (Hopwood et al., 2001).

Many patient-reported outcome measures (PROMs) have been developed in English and are not suitable for use in countries where people do not speak English, or in immigrant populations or minority groups who also may not speak English (Guillemin et al., 1993; Saxena et al., 1998). Furthermore, with increased global immigration, an individual country can have inhabitants whose linguistic and cultural origins vary widely (Castles, 2000). With increasing transnational research involving multiple countries, including diverse patient groups in research is crucial as without adequate representation, the generalizability of study results to all segments of the population is questionable. There is potential for systematic bias in studies if whole sections of a population are excluded because they do not speak English or measures are not appropriate for them (Anderson et al., 1993; Beaton et al., 2000). Therefore, culturally relevant, valid, and reliable PRO measures are essential.

Translating existing valid and reliable patient-reported outcome measures (PROMs), rather than developing new ones, reduces effort, saves time, and speeds up the acquisition of knowledge related to cultural differences (Guillemin et al., 1993). To use a PROM across cultures, the items in the measure should be translated, their content validity and cultural appropriateness assessed (Sperber, 2004), and psychometric properties such as reliability, validity, and responsiveness tested. Such cross-cultural adaptation helps achieve equivalence between the original and translated versions of a measure (Guillemin et al., 1993).

India being a large, culturally diverse country, has an increasing number of clinical trials being conducted because of its potential to recruit large patient samples (Saxena et al., 1998; Gupta and Padhy, 2011). However, primary reasons reported for excluding Indian populations from participation in research are illiteracy and language barriers, with the main concern being lack of psychometrically robust PROs. Some PRO measures specific to HNC have been translated into few Indian languages and are cross culturally validated (Pandey et al., 2004; Thomas et al., 2004; Chaukar et al., 2005, 2009). For example, HNC-specific measures of quality of life developed by the European Organization for Research and treatment of Cancer Quality (e.g., EORTC QLQ-HN35) and the Functional Assessment of Cancer Therapy (FACT – Head and Neck) have been translated into several regional Indian languages (Chaukar et al., 2005). However, those assessing body image are not currently available in common Indian languages (Sundaram et al., 2019). Our earlier work found the Body Image Scale (BIS) to be the most appropriate measure for assessing body image in HNC populations following appraisal of its content and psychometric properties (Sundaram et al., 2019).

Our team recently translated the BIS into the Indian languages Tamil, Telugu, and Hindi, and demonstrated their cultural appropriateness and conceptual equivalence with the English original (Shunmugasundaram et al., 2021). The purpose of this study was to analyze the psychometric properties of the translated

Indian versions of the BIS in HNC patients who speak Tamil, Telugu, and Hindi.

MATERIALS AND METHODS

This study is a part of a larger study evaluating the psychometric properties of several translated PROMs assessing body image, unmet needs, anxiety, and depression in Indian HNC patients (Shunmugasundaram et al., 2020, 2021).

Sample Eligibility

Patients were eligible if aged 18 years or above, any gender, diagnosed with any type of HNC except thyroid cancer (irrespective of cancer stage or treatment phase), treated by surgery, radiotherapy, chemotherapy, or a combination of these, could read and write in one or more of the target languages: Tamil, Telugu, and Hindi, and gave informed consent.

Study Sites

This study was carried out in three regional cancer centers in Tamil Nadu (Cancer Institute, WIA in Chennai for Tamil speaking patients), Andhra Pradesh and Telengana (MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad for Telugu speaking patients) and the Nanavati Super Specialty Hospital, Mumbai (for Hindi speaking patients) between August 2019 and February 2020.

Recruitment and Consent Process

Eligible patients in participating cancer hospitals were informed about the study by a member of their clinical team (oncologist, psycho-oncologist, nurse, or ward assistant). Patients who expressed interest in the study were then approached by trained researchers who explained the study in detail and obtained participants' written consent. A minimum of 600 patients (200 from each language group) meeting the eligibility criteria were approached by researchers. We sampled purposively but broadly to ensure representation of a wide range of HNC types, treatment types, disease stages, and impacts. Recruitment was periodically monitored for these variables.

Sample Size

Sample size was estimated based on recommendations in the literature (Tabachnick and Fidell, 1996; Pallant, 2013), suggesting 5–10 participants per item in the measure being evaluated. Hence, a sample size of 50–100 participants would be required. However, larger samples are required for factor analyses (Comrey and Lee, 1992; Thompson, 2004). Therefore, we considered 200 participants per language group fulfilling the criteria and would provide an adequate sample to evaluate standard psychometric properties.

Ethics

Ethics approvals were obtained from The University of Sydney Human Research Ethics Committee (Sydney, Australia), Scientific Advisory Committee and Ethical Committee of Cancer Institute, WIA (Chennai, India), Ethical Committees of MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad and Nanavati Super Specialty Hospital, Mumbai, India.

Data Collection

Participants self-completed hard-copy questionnaire booklets that included demographic information as well as three PROMs. Participants were asked to return their booklets to the researcher on completion of the PROMs. Data were entered into a REDCap (Harris et al., 2009) database by one researcher and manually checked for errors by a second researcher to ensure accuracy.

Patient-Reported Outcome Measures

Body Image Scale

The 10-item BIS was developed to assess changes in body image in patients diagnosed with cancer, irrespective of their diagnosis, assessed with a four-point scale from "not at all" to "very much." High scores indicate higher body image. The BIS has been shown to be reliable (Cronbach's alpha 0.93), and valid (Hopwood et al., 2001). The BIS was translated from English to three Indian languages (Tamil, Telugu, and Hindi) following internationally accepted methods, ensuring conceptual and linguistic equivalence was maintained between versions (Shunmugasundaram et al., 2021).

Health-Related Quality of Life

The European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30) is a 30-item measure of cancer-specific symptoms and quality of life relevant to a broad range of cancer populations (Aaronson et al., 1993). It includes five functional domains (physical, role, cognitive, emotional, and social), eight symptom domains (fatigue, pain, appetite loss, constipation, sleep, dyspnea, diarrhea, nausea, and vomiting) and a global health/quality of life and financial impact domain. Items 1 to 28 are assessed with a four-point scale from "not at all" to "very much" and items 29 and 30 are assessed with a 7-point Likert scale from "very poor" to "excellent". Raw scores are transformed to a 0–100 scale and higher scores represent better functioning and greater symptom burden. The EORTC QLQ-C30 has been shown to be reliable (Cronbach's alpha $\geq$0.70) and valid (Aaronson et al., 1993), and is available in several languages including Tamil, Telugu, and Hindi, which were used in this study.

The EORTC QLQ Head and Neck 35 (EORTC QLQ-HN35) is a 35-item measure of HNC-specific symptoms (Bjordal et al., 1999). It includes 18 symptom domains (pain, swallowing, teeth, opening mouth, dry mouth, sticky saliva, senses, coughing, felt ill, speech, social eating, social contact, sexuality, pain killers, nutritional supplements, feeding tube, weight loss, and weight gain). Items 31–60 are assessed on a 4-point scale from "not at all" to "very much" and items 61–65 are assessed on a yes or no scale. Raw scores are transformed to a 0–100 scale and higher scores represent greater symptom burden or problems (Bjordal et al., 1999). The EORTC QLQ-HN35 has been shown to be reliable (Cronbach's alpha $\geq$0.70) and valid (Bjordal et al., 1999; Bjordal et al., 2000). EORTC QLQ-HN35 is also available in several languages including Tamil, Telugu, and Hindi.

All PROMs in our study have previously been used in other studies of HNC patients (Chaukar et al., 2005).

Data Analysis

The psychometric analyses of the BIS were undertaken using Statistical Package for the Social Sciences Version 25.0 (IBM Corporation Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY, United States: IBM Corporation). Descriptive statistics (number and percentage of total sample) reported sample characteristics across three languages. Data quality and completeness were assessed based on percentage of computable scale scores (>50% completed items).

Exploratory factor analysis using principal component analysis with varimax rotation was performed to identify the underlying factor structure of the BIS. Factors with eigen value <1 and items with loading of minimum 0.3 were retained. Missing values were managed using pairwise deletion. The suitability of the data for factor analysis was assessed using the Kaiser–Myer–Olkin (KMO) measure of sampling adequacy and the Bartlett test of sphericity. Criteria for suitability are KMO 0.6 and a *P*-value for Bartlett's $\chi 2$ of less than 0.01 (Moreira et al., 2010; Pallant, 2013). Confirmatory factor analysis (CFA) was carried out using Lavaan and Structural equation modeling (SEM) Package in R Commander. The goodness-of-fit indices were examined without any limitations or adding new connections (Hu and Bentler, 1999).

Internal consistency reliability was assessed using the Cronbach's alpha coefficient for each of the language groups. A Cronbach's alpha coefficient of 0.7 or greater was considered acceptable (Gorecki, 2011).

Scale-to-sample targeting was determined by investigating whether scale scores spanned the entire scale range; floor (proportion of the sample at the maximum scale range) and ceiling (proportion of the sample at the minimum scale range) effects were low (<15%). Scaling assumptions were assessed based on item-total correlations (ITC) where ITC $\geq$0.3.

Construct validity of the BIS was explored through correlations between body image (assessed with BIS) and other constructs (similar and dissimilar) assessed by the EORTC QLQ-C30 and EORTC QLQ-HN35. Pearson's correlation coefficient (>0.3 considered adequate) was calculated between BIS and appearance scale of the EORTC QLQ-C30 to test convergent validity and pain, financial difficulties, pain killer, swallowing and/coughing scales of the EORTC QLQ-C30 and EORTC QLQ-HN35 measures to test discriminant validity (Gorecki, 2011). Criteria were used as guides to the magnitude of correlations, as opposed to pass/fail benchmarks (high correlation $r > 0.7$; moderate correlation $r = 0.3–0.7$; low correlation <0.3).

An analysis of variance (ANOVA) was used to estimate mean differences between Tamil, Telugu, and Hindi speaking HNC patients, on body image.

RESULTS

Participants

A total of 621 participants, of which 205 were Tamil speaking, 216 Telugu speaking, and 200 Hindi speaking, completed all PROMs. **Table 1** presents participants' demographics for all three languages. The overall mean age of respondents was 50 years (range 19–89) and most were male (81.5%), married (86.3%), and employed (64.4%). About 84.9% reported substance use: either tobacco (chewing and/or smoking) and/or alcohol.

Data Quality

The criteria were satisfied for most psychometric properties evaluated. Data quality was generally high (scale scores were computable for 98–100% of respondents). Scale-to-sample targeting was good (scale scores spanned the scale range, were not skewed and values were within ±1.0); mean scores were near the scale mid-point for Hindi and Telugu but not the Tamil version, and floor effects exceeded the 15% criterion for Tamil version (see **Table 2**). The lowest and highest scores for BIS across all three languages were 0 and 30, respectively.

Factor Structure

The suitability of data for EFA were assessed and confirmed: Tamil (KMO = 0.950; Bartlett's $\chi 2 = 2561.939$, *P* = 0.000); Telugu (KMO = 0.837; Bartlett's $\chi 2 = 1275.547$, *P* = 0.000); Hindi (KMO = 0.863; Bartlett's $\chi 2 = 1747.382$, *P* = 0.000). Correlation matrices revealed all the correlation coefficients were above 0.3, suggesting the EFA results could be considered.

The EFA results (**Supplementary Table 1**) revealed the presence of only one component with eigenvalue exceeding 1, explaining cumulative variances of 78.66, 65.91, and 71.42% for Tamil, Telugu, and Hindi versions, respectively. Hence, this one-factor was retained across all three languages as it was practically relevant and conceptually equivalent to the factor analysis of the original measure (Hopwood et al., 2001).

Scale Reliability

The reliability coefficients (Cronbach's alpha) for the BIS across all three languages were within the satisfactory range (>0.70) with values of 0.969 (Tamil), 0.919 (Telugu), and 0.891 (Hindi) (**Table 3**).

Validity

Scaling assumptions were satisfied. Corrected ITC ranged from 0.722 to 0.941 for Tamil BIS, 0.433 to 0.743 for Telugu BIS, and 0.611 to 0.753 for Hindi BIS; see **Table 3**. Convergent and discriminant validity of the translated versions of the BIS were demonstrated.

Convergent Validity

Correlations between BIS and the hypothesized item in EORTC QLQ HN-35 on appearance "*has your appearance bothered you?*" were consistent with the predicted moderate positive correlations ($r > 0.30$) across all three languages (see **Table 4**).

TABLE 1 | Socio demographics for 621 patients across all languages.

Socio demographics	Tamil (n = 205)	Telugu (n = 216)	Hindi (n = 200)	Total (n = 621)
Age: Mean, Median (Range)	52.83, 54 (19–82)	50.5, 49 (21–89)	45.98, 45 (21–75)	49.77, 49 (19–89)
Missing	1	3	0	4
Gender *n* (%)				
Male	163 (79.5)	170 (78.7)	173 (86.5)	506 (81.5)
Female	41 (20)	42 (19.4)	26 (13)	108 (17.5)
Missing	1 (0.5)	4 (1.9)	1 (0.5)	6 (1)
Marital Status *n* (%)				
Married/De facto	183 (89.2)	169 (78.2)	184 (92)	536 (86.3)
Divorced/Separated	3 (1.5)	7 (3.2)	1 (0.5)	11 (1.7)
Single	6 (2.9)	8 (3.7)	13 (6.5)	27 (4.4)
Widowed	11 (5.4)	27 (12.5)	2 (1)	40 (6.4)
Missing	2 (1)	5 (2.3)	0	7 (1.1)
Education qualification *n* (%)				
Primary level	60 (29.3)	127 (58.8)	74 (37)	261 (42)
Intermediate level	78 (38)	28 (13)	46 (23)	152 (24.5)
Higher secondary level	39 (19)	27 (12.5)	26 (13)	92 (14.8)
Diploma	10 (4.9)	21 (9.7)	0 (0)	31 (5)
University degree	14 (6.8)	10 (4.6)	44 (22)	68 (11)
Post-graduate degree	1 (0.5)	3 (1.4)	9 (4.5)	13 (2.1)
Missing	3 (1.5)	0	1 (0.5)	4 (0.6)
Employment *n* (%)				
Employed	141 (68.7)	106 (49.07)	153 (76.5)	400 (64.4)
Unemployed	23 (11.2)	80 (37)	20 (10)	123 (19.8)
Homemaker	23 (11.2)	20 (9.2)	17 (8.5)	60 (9.7)
Training/education	1 (0.5)	2 (0.9)	4 (2)	7 (1.1)
Retired	1 (0.5)	1 (0.5)	5 (2.5)	7 (1.1)
Unable to work	13 (6.3)	1 (0.5)	0 (0)	14 (2.2)
Other	0	1 (0.5)	1 (0.5)	2 (0.3)
Missing	3 (1.5)	5 (2.3)	0	8 (1.3)
Type of Cancer *n* (%)				
Oral Cavity	94 (45.8)	108 (50)	181 (90.5)	383 (61.7)
Salivary Gland	2 (0.9)	6 (2.8)	1 (0.5)	9 (1.4)
Oropharynx	26 (12.6)	3 (1.4)	2 (1)	31 (5)
Larynx + Hypopharynx	35 (17.1)	9 (4.2)	0 (0)	44 (7.1)
Sinus gland	2 (0.9)	1 (0.5)	0 (0)	3 (0.5)
Tongue	35 (17.1)	35 (16.2)	9 (4.5)	79 (12.7)
Nasopharynx	9 (4.4)	7 (3.2)	0 (0)	16 (2.6)
Nasal Cavity	0	29 (13.4)	4 (2)	33 (5.3)
Unknown primary	1 (0.5)	11 (5.1)	0 (0)	12 (1.9)
Missing	1 (0.5)	7 (3.2)	3 (1.5)	11 (1.8)
Stage of disease *n* (%)				
I	3 (1.4)	8 (3.7)	14 (7)	25 (4)
II	34 (16.5)	24 (11.1)	63 (31.5)	121 (19.5)
III	114 (55.6)	69 (31.9)	84 (42)	267 (42.9)
IV	43 (20.9)	19 (8.8)	31 (15.5)	93 (14.9)
Missing	11 (5.3)	96 (44.4)	8 (4)	115 (18.5)
Treatment offered *n* (%)				
Radiation	205 (100)	177 (81.9)	199 (99.5)	581 (93.6)
Chemotherapy	198 (96.6)	121 (56)	33 (16.5)	352 (56.7)
Surgery	29 (14.1)	32 (14.8)	115 (57.5)	176 (28.3)
Treatment status *n* (%)				
Undergoing treatment	104 (50.7)	177 (81.9)	189 (94.5)	470 (75.7)
Survivor	97 (47.3)	39 (18.1)	11 (5.5)	150 (24.1)
Substance usage *n* (%)				
Yes	150 (73.2)	187 (86.5)	190 (95)	527 (84.8)
No	54 (26.3)	20 (9.2)	9 (4.5)	83 (13.3)
Missing	1 (0.5)	9 (4.1)	1 (0.5)	11 (1.7)
ECOG Performance Status *n* (%)				
0	51 (24.8)	25 (11.6)	99 (49.5)	175 (28.1)
1	110 (53.6)	75 (34.7)	77 (38.5)	262 (42.2)
2	23 (11.2)	71 (32.9)	17 (8.5)	111 (17.9)
3	16 (7.8)	26 (12)	5 (2.5)	47 (7.6)
4	4 (1.9)	13 (6.0)	1 (0.5)	18 (2.9)
Missing	1 (0.4)	6 (2.8)	1 (0.5)	8 (1.3)

Discriminant Validity

Correlations between BIS and the scales of EORTC QLQ-HN35 (pain, swallowing, pain killers, and coughing) and EORTC QLQ-C30 (pain and financial difficulties) across all three languages were consistent with predictions ($r < 0.30$); see **Table 4**, thus supporting those responses to BIS are not biased by pain, coughing, swallowing, or financial difficulties.

Body Image Between Different Language Groups

The effect of different language groups and their respective cultures on body image were statistically tested with one-way ANOVA. We found a statistically significant difference (F = 11.0954, $P < 0.05$) between means of Tamil, Telugu, and Hindi groups, with higher body image scores in Telugu (M = 12.86; SD = 7.65) and Hindi groups (M = 12.52; SD = 7.36) indicating more symptoms/body image distress, when compared to Tamil speaking population (M = 9.28; SD = 10.04) (see **Table 5**).

DISCUSSION

The incidence of HNCs is increasing in global regions such as India. Treatment for HNCs commonly leads to significant changes to appearance and negative effects to one's body image. The BIS is a reliable and valid PROM for measuring body image in cancer patients. Studies have reported BIS has content appropriate to patients with breast cancer, HNC, colorectal cancer, and benign gynecological conditions (Brédart et al., 2007). However, it is a screening measure, that does not indicates a specific diagnosis related to body image disturbance. We recently translated the BIS into three common Indian languages (Shunmugasundaram et al., 2021). This study assessed the psychometric properties of the translated Indian versions of the BIS in a large sample of HNC patients.

TABLE 2 | Scale level analyses–data completeness and targeting of BIS across Tamil, Telugu, and Hindi (*n* = 621).

Scale	Data completeness–Computable scale score (%)	Targeting						
		Possible score range*	Observed score range	Range mid-point	Mean score	SD	F/C effect (%)	Skewness
Tamil								
BIS	99.0	0–30	0–30	15	9.28	10.066	32.0/5.4	0.808
Telugu								
BIS	100	0–30	0–30	15	12.756	7.685	2.9/6.7	0.583
Hindi								
BIS	98.0	0–30	0–30	15	12.41	7.363	1.5/4.6	0.757

**High scores indicate great bother/impact; SD standard deviation; F/C floor/ceiling–floor effect = % scoring 100 (greatest bother/impact); ceiling effect = % scoring 0 (least bother/impact); BIS, Body image scale.*

TABLE 3 | Body image scale level analyses–reliability and scaling assumptions: validity within-scale analysis of measures across Tamil, Telugu, and Hindi (*n* = 621).

Scale	Cronbach's alpha	Mean IIC	IIC range	Scaling assumptions–Corrected ITC range
Tamil BIS (*n* = 203)	0.969	0.928	0.530–0.913	0.722–0.941
Telugu BIS (*n* = 216)	0.891	0.449	0.220–0.840	0.433–0.743
Hindi BIS (*n* = 196)	0.916	0.528	0.348–0.983	0.611–0.753

CI, confidence interval; IIC, inter-item correlation; ITC, item-total correlation (corrected for overlap); BIS, Body image scale.

The Tamil, Telugu, and Hindi versions of the BIS satisfy criteria for reliability and validity in line with recommended Food and Drug Administration guidelines for PRO instruments (Speight and Barendse, 2010). Thus, these translated versions can be used to assess body image in Indian HNC populations' in future clinical research and in clinical practice.

In general, our findings are comparable with the original BIS validation results and other studies of language translations (Hopwood et al., 2001; Moreira et al., 2010; Karayurt et al., 2015). For construct validity of the Indian versions of the BIS, we found support for the factor structure (Hopwood et al., 2001; Karayurt et al., 2015). Kaiser's criterion was used to determine the number of factors extracted. A one-factor solution for the BIS has emerged in both EFA and CFA, explaining 57.55, 61.8, and 68.11% of the total variance, respectively, consistent with other studies (Hopwood et al., 2001; Karayurt et al., 2015).

Our scaling findings were within acceptable criteria and convergent and discriminant validity was demonstrated from confirmed hypotheses about constructs expected to be related or unrelated. These findings are consistent with the original validation study, and also with the Portuguese and Turkish translation studies (Hopwood et al., 2001; Moreira et al., 2010; Karayurt et al., 2015). A BIS Portuguese validation study evaluated convergent validity and found moderate to high correlations between the Experience of Shame Scale's body shame scale and Derriford Appearance Scale–24 consciousness of appearance scale with BIS (Moreira et al., 2010). In the same study, discriminant validity was supported by low correlations between BIS and WHOQOL (Physical, Environmental, General facet) scales (Moreira et al., 2010).

Reliability is the overall consistency of a PROM which can be calculated either by internal consistency of the items or test–retest reliability. High levels of internal consistency reliability provide greater confidence when using a measure to compare different groups (for example, those undergoing different treatments or those with different diagnoses). The reliability coefficients for all three Indian language versions were supported, with all Cronbach Alpha's >0.89. These findings are consistent with those reported for the original BIS (0.93), Portuguese version (0.92–0.93), and Turkish version (0.94) (Moreira et al., 2010; Karayurt et al., 2015). These findings suggest the Indian versions of the BIS are equivalent with the original and other language translations in terms of content (Shunmugasundaram et al., 2021), reliability, and validity.

Data completeness was high for all three Indian language groups indicating there were no items to which a high proportion of participants did not respond. This is important as high levels of non-response can indicate problems with an item such as difficult to understand, or the measure contains distressing or irrelevant content. Generally, a total of <30% respondents selecting "not at all" or "very much" indicates an item does not show significant "floor" or "ceiling" effects, respectively. Analysis of response distributions showed all response categories were used for all items with no significant floor or ceiling effects in Telugu and Hindi populations. However, floor effects (32%) were found in the Tamil population. These results may be a reflection of the sample as only 50% of the Tamil samples were undergoing treatment, unlike Telugu (82%) or Hindi (94.5%) sample, and subsequently experiencing less impact on body image. Cognitive debriefing interviews conducted during the translation and linguistic validation phase with a diverse HNC patient population found the BIS was relevant, comprehensive, and unambiguous (Shunmugasundaram et al., 2021).

Our findings suggest Tamil speaking HNC population have fewer body image concerns than Telugu and Hindi speaking groups. Previous literature reports body image concerns were significantly higher among HNC patients with speech and

TABLE 4 | Scale level analyses–convergent and divergent validity across Tamil, Telugu, and Hindi.

Scale	Convergent validity	Discriminant validity					
	QLQ-HN35 Appearance item r^1	QLQ-HN35 Pain scale r^1	QLQ-HN35 Swallowing scale r^1	QLQ-HN35 Pain killers scale r^1	QLQ-HN35 Coughing scale r^1	QLQ-C30 Pain scale r^1	QLQ-C30 Financial difficulties scale r^1
Tamil BIS (n = 203)	0.425*	0.380*	0.129	0.140*	−0.006	0.275	0.151*
Telugu BIS (n = 216)	0.466*	0.061	0.158*	0.045	0.104	0.268*	0.245*
Hindi BIS (n = 196)	0.437*	0.121	0.140	0.083	0.214	0.183*	0.041

**p = 0.05; BIS, Body image scale.*

TABLE 5 | Body image between Tamil, Telugu, and Hindi language groups.

Language groups	*n*	Mean	SD	*F*	*p*-value
Tamil	203	9.28	10.04	11.0954	0.00001854*
Telugu	216	12.86	7.65		
Hindi	196	12.52	7.36		

**p-value < 0.05; SD, Standard deviation; F = ANOVA.*

eating concerns (Rhoten et al., 2013). Since, 81.9 and 94.5% of our Telugu and Hindi speaking groups were undergoing treatment, they may have been experiencing these concerns during their participation in the study. Studies have also found non-surgically treated patients with HNC have a better body image outcome than surgically treated patients (Rhoten et al., 2013; Ellis et al., 2019; Sundaram et al., 2019). Since 57.5% of the Hindi speaking population reported undergoing surgery for their HNC treatment, their body image dissatisfaction could be associated to visible disfigurement from surgery. Few studies have examined body image in Indian populations treated for HNC. Qualitative studies in the future should explore experiences of patients with HNC in India, with a focus on body image.

Body image is an important area of HRQoL research and about 75% of HNC patients treated surgically experience some level of bodily changes, often resulting in psychosocial challenges (Nayak et al., 2016). Although most common reactions to bodily changes are poorer body image and self-esteem and increased distress, self-consciousness and anxiety, some patients experience positive impacts such as regained confidence from their scars and view their scars as a reminder to be grateful for being alive and surviving cancer (Manier et al., 2018). India is a culturally diverse country and the floor effects in this study reflect that. Hence, it is possible that sample demographics and culture contribute to Tamil speaking participants low score on body image (low scores indicate no appearance related concerns).

Current globalization trends and the increasing importance of multinational clinical trials highlight the need for PROMs in languages other than English. PROMs developed in western countries may not be applicable to other cultures and require cross-cultural and linguistic validation. Although adapting a PROM for a different cultural group can be arduous and requires considerable investment of time and resources, unless this process is undertaken, the results of research using that PROM may be questionable. This is because language and culture have an impact on the way people respond to questions (Halliday and Hasan, 1989; Shunmugasundaram et al., 2021). If a non-English speaker answered a PROM in English, their responses may be biased or inaccurate, limiting the quality of the data. We need multilingual PROMs, suitable for routine clinical and research use, which are brief and inflict minimal patient burden to enable assessment of important outcomes and possibly improving study participation rates among ethnic groups in English speaking countries (Gupta and Padhy, 2011).

There is strong evidence that psychosocial interventions improve outcomes in cancer patients. However, for interventions to be effective, they need to be tailored to disease-specific outcomes. Using disease-specific measures will capture outcomes appropriately, particularly if they are translated and validated across languages and cultures. Assessing important outcomes could be used in clinical practice to help healthcare professionals identify concerns and address them directly. Although substantial efforts with regards to PROM development and validation have been made in the western literature to ensure robust measures are available, less has been studied and found available in the Indian literature (Saxena et al., 1998; Shah et al., 2016). This work serves as a model for ensuring future cultural relevance of measures for use in multinational trials.

This study had a number of strengths such as large samples across the three language groups, representative of different HNC types, disease stages and treatment phases, from multiple centers across India, and psychometric analyses to test the reliability and validity of the BIS according to internationally accepted standards. Future work will evaluate clinical validity (known groups) and responsiveness of the Indian versions of the BIS in longitudinal studies and the psychometric properties of the Tamil, Telugu, and Hindi versions of BIS among Indian immigrant populations with HNC living abroad. As India is a diverse country with a range of cultures and languages, more language translations or cross-cultural adaptations may be required to ensure inclusion of the entire Indian population in multinational trials.

CONCLUSION

The Tamil, Telugu, and Hindi versions of the BIS are valid and reliable measures of body image, with equivalent content and psychometrics as the original version as well as other language translations. The Indian BIS versions can be used in both clinical research and in healthcare settings to assess body image disturbances across HNC disease and treatments in Indian HNC patients in India and abroad.

AUTHOR'S NOTE

This study formed part of CS's PhD work.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

Ethics approvals were obtained from the University of Sydney Human Research Ethics Committee (Sydney, Australia; Ref: 2019/202), Scientific Advisory Committee and Ethical Committee of Cancer Institute, WIA (Ref: IEC/2019/Sep 02), Ethical Committees of MNJ Institute of Oncology and Regional Cancer Centre (Regd No: ECR/Inst/AP/2013/RR-16 dated 18/04/2019; no reference number was provided in the letter of approval), and Nanavati Super Specialty Hospital. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

CS recruited participants and collected data (in one site) and supervised recruitment and data collection in the other sites, entered and managed data, checked for accuracy, analysed, and interpreted the findings, drafted, and wrote the manuscript. CR, HD, PB, and PS conceived the presented idea, developed the study design, helped plan the study and contributed to the preparation including ethics and data collection and supervised the overall study. MC, SV, NA, and NH contributed to ethics, recruitment, data collection, and discussed the results and contributed to the final manuscript. CR and HD verified the analytical methods and supervised the findings of this work. All authors contributed to the article and approved the submitted version.

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Every Story Is Different: Experiences With Body Changes Related to Cancer

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One of the important aspects of stakeholder engagement in cancer care and system planning is hearing from individuals who have been diagnosed with cancer about the impact of the diagnosis and treatment on their lives. Hearing stories from the perspectives of cancer survivors offers opportunity to gain new insight and understanding about experiences of being diagnosed and treated for cancer. This article presents ten short narratives about survivors' perspectives on body image and cancer. Each story is unique but, taken together, the picture they create is one of facing challenges, discovering personal resilience, and moving forward to engage in living. The stories emphasize the importance of communication and support from healthcare providers and understanding needs for a person-centered cancer care system.

Keywords: body image, cancer, patient/survivor perspectives, survivorship, quality of life

INTRODUCTION

A significant development over the past decade in the cancer care system has been the growth in engagement with stakeholders (Lowe et al., 2021) and understanding more from them about what it means to have a person-centered philosophy driving care delivery (American Geriatrics Society Expert Panel on Person-Centered Care, 2015; Sharma et al., 2016; Eklund et al., 2019). One of the important aspects of stakeholder engagement is hearing from individuals who have been diagnosed with a disease, and experienced its treatment, about their perspectives and the impact of the diagnosis and treatment on their lives (Nolte et al., 2020; Fares et al., 2021). As the cadre of survivors has grown, an increasing number of individuals are coming forward and expressing a desire to help improve care provision and support for people facing cancer (Stover et al., 2019; LeClair et al., 2020). Hearing the stories from survivors offers an avenue to continue the journey as health care providers toward truly providing person-centered care (Frank, 2018).

Stories are vital to human experience. They are vehicles for connecting, offering a means of sharing, and interpreting experiences (Calman, 2001; Woods, 2011). They help us understand the world around us and are universal bridges for building relationships and sharing cultures. Hearing stories can enhance understanding of the experiences of others and aid in linking our thoughts and feelings. Stories can capture attention, invite conversations, and inspire the imagination for change. This article was written from a stance of valuing stories, of listening to the narrative of one, and embracing the importance of hearing stories directly from the voice of a person who has lived through an experience.

The series of stories or short narrations below are from cancer survivors about living with body image changes following cancer treatment. The stories were contributed by each of the authors working collaboratively to produce this perspectives manuscript. The stories illustrate various types of bodily changes these individuals experienced from their cancer treatment and what it has been like to live with the changes. Some changes have been temporary, and some are permanent, some visible and some concealed. The short narrations do not include all cancer types, all ages, or attention to every type of change or characteristics which might influence reactions or coping. The short narrations cannot tell the whole story for each person, but they offer a vantage point for gaining a deeper understanding about living with changes in body image. Collectively, they offer an emergent picture of the complexity inherent in the wholeness of human response. Individuals have more than one way to be in the world and to cope with its realities.

Collectively the stories paint a picture which can help us appreciate how body image is not a unidimensional concept. Living with bodily changes following cancer or its treatment is challenging and not easily separated from other aspects of life. The changes have impacts beyond the physical and are intermingled with emotional, practical, and spiritual aspects of human response.

THE STORIES

Amelia

I was diagnosed with breast cancer in August 2020, 2 days after turning 36. I had a single mastectomy and, luckily, didn't undergo chemotherapy or radiation. In my situation, the negative long-term effects of them outweighed the benefits. I'm also doing hormone therapy to help prevent a recurrence and that has affected me significantly. I'm in medically induced menopause, which has been really tough physically and emotionally. I get hot flashes, migraines, insomnia, joint pain—it makes me feel older than I am. It's such a big change. My joint pain, for example, can get very painful. If I'm out in the cold for too long, my hands can feel swollen. The hot flashes are brutal—they happen all day and are uncomfortable and make me feel clammy and sticky. And having insomnia has been physically and mentally draining.

Along with my single mastectomy, I had 3 lymph nodes removed. That has left my arm and chest weak and numb. It makes it hard to exercise and I find that I'm nervous to do so. I'm definitely not exercising as vigorously or often as I should. I'm worried about hurting my arm even though I know it needs to be strengthened.

I decided to stay flat on the one side after my mastectomy. Although I'm so glad about my choice, I find having one breast can feel weird. I have to wear a bra for the other side and clothes don't fit right. I am very conscious of only having one. When I'm out, I wonder if people will notice and what they'll think. But I've learned to tune that out and do my best not to care. I give myself pep talks a lot about it—who cares what they think? My body is amazing!

My husband is totally fine with however I look; he is very supportive and has told me on numerous occasions that he doesn't love me because of my breasts. I'm so lucky to have that support. But my daughters, who are 7 and 5, have struggled, which can be hard on me. They see my body and tend to be uncomfortable because it looks so different. I tell them it's just my body; everyone has a different body and that's what makes us beautiful. I explained that I was sick and needed to have my breast removed. They understand that, but it's taking them time to adjust.

I have decided to have my ovaries and my other breast removed as a preventive step. I am going to stay flat afterwards. When I was first diagnosed, I wanted a bilateral mastectomy with reconstruction. After finding the lump, my breasts felt totally foreign to me, and I just wanted them both gone. Unfortunately, I didn't have time to have reconstruction right away. I would need to have my breast removed and reconstruction at a later date. With that in mind, I had to decide on surgery. To help with my decision, I looked at Google images to see what the scars might look like, and the photos were just too much; I was so scared of the scars and worried I wouldn't be me if I didn't look like me. The surgeon didn't think a double mastectomy was necessary; he said I was overreacting and that I just needed a lumpectomy. But it was ultimately my decision—my body!

In the end, my surgeon and I agreed that I would have a single mastectomy and have the other side removed later. I am so glad I went with that decision. Now, I am totally comfortable with the scars and the idea of being flat. I actually feel more confident now, which is a huge surprise.

What helped me, and what I would suggest to others, is to take photos. I wanted to share photos of myself and my scar for other women going through a similar diagnosis. I wanted them to have better photos than the ones on Google. So, my friend did a photo session with me 4 weeks post-operation. I truly thought I was going to hate the photos; they were simply for others, not for me. But when I saw the photos, I cried. They were so beautiful. It was such a healing experience for me.

I've taken lots of photos since that session and have found it empowering. I'm honoring my body and what it's gone through and continues to go through.

This experience has taught me the importance of advocating for yourself. Breast cancer can happen at any age. Young women need to know the signs and be taught proper breast health. So often when young women do find a lump and seek help, they're told, "You're too young; it's just a cyst or a blocked milk duct" (which is initially what I was told). It's so frustrating. These women go home thinking they're fine, and then down the road have a delayed diagnosis and precious time wasted. So you have to push: demand tests and investigation. It's always better to know than not know. And remember that whatever decision you make is the right one for you. It's your body and you have to live with it. Do what's best for you.

Emily

I was diagnosed with stage 3, triple positive breast cancer with lymph node involvement, the summer after I graduated from law school. I was 27, and on August 26, 2015, I had to put my career on hold to endure a year of grueling treatments. I had 5 months of chemotherapy, a double mastectomy with immediate reconstruction, 25 radiation treatments, a year of Herceptin treatments, three other surgeries to fix my reconstruction, and am currently still doing hormone therapy for another 5 years.

My cancer treatment started with chemotherapy. Chemo took all of my hair (who knew nose hair had a purpose), made me physically weak, and gain weight to the point that a different person was staring back at me in the mirror. When I look back at photos during this time, I don't recognize myself because I am so swollen from the steroids. The day before my last chemo session I finally lost my eyebrows and eyelashes, which made me really look like a cancer patient. This was a hard day for me because I had beautiful, long eyelashes which became a part of my identity. They still haven't grown back in the way they used to be.

During my double mastectomy, tissue expanders were inserted to create space for my eventual implants. After two more reconstructive surgeries, my implants failed because the skin had died from the radiation. My plastic surgeon tried cutting the dead skin and stitching it back together, hoping the skin would heal, but it never did. Once the stitches came out, I had a hole in my breast and every day it would get bigger and you could see the implant. I had an open wound for months and had to clean and bandage it up daily. I had to monitor myself for signs of infection (which happened a couple times), so a thermometer became my most important accessory. This led me to have the DIEP Flap surgery.

Those 4 months, when my implants had failed and I was weighing my options on next steps, were very hard emotionally. We were no longer dealing with actual cancer in my body and my support system didn't understand why I kept having surgeries. I'm as happy as I can be with reconstructed breasts without nipples. I now have so many scars—huge round scars around my whole breasts, a scar from literally hip to hip that looks like my stomach is always smiling, a port scar just underneath my collarbone and a concave scar in my armpit from where my lymph nodes were taken out.

After my mastectomy it took me a long time to be able to even look at myself in the mirror, let alone touch my scars. A few months after my mastectomy I started radiation and from day one you are supposed to moisturize the radiated area a few times a day. I had to get my husband to do it for me because touching myself made me feel sick. Eventually, I mustered up the courage to do it myself, but it took a bit of time.

Dealing with body image is a daily process. Most of the time I'm proud of my body and everything it has been through, but I wish I didn't have a forever "muffin top" that will be there no matter how much I exercise or such misshapen breasts. Every time I look in the mirror without my clothes on, it is a reminder that I am not a "normal" 33-year-old anymore. I've lived so long without nipples that sometimes I forget breasts are supposed to have nipples. It took me a while to be intimate with my husband without a shirt on and I still haven't felt sexy in this new body. I am also unable to do things physically that I was able to do before cancer and surgeries. For instance, I was really proud of my push-up abilities and was able to do over twenty with my feet elevated. Now, I'm lucky if I'm able to do three from my feet instead of my knees.

I'm now 6 years from my cancer diagnosis and cancer still has a huge impact on the decisions I make in my life, like fertility. I still have five more years of hormone therapy. Do I pause it to have a baby? What about my fear of recurrence and leaving my future child without a mother? Or what about passing it on to my child?

Sometimes I still have trouble trusting my body and see myself as the weak cancer patient. I'm still working through my fears and anxieties with a psychologist which really helps. And I know that most of the time I am a strong and resilient person, but I miss the days when things weren't as complicated. But, through my cancer diagnosis I have found what I'm good at—using my experience as an AYA with breast cancer to help others going through it. One thing I would say to others diagnosed with cancer is, "With time, cancer won't be the first thing you think about when you wake up."

Ellil

I was diagnosed 10 years ago when I was 52. I had two primary cancers—rectal and testicular. I had surgery (laparoscopic abdominoperineal resection), radiotherapy (28 cycles), and chemotherapy (8 cycles). In the beginning I was shocked and did not believe this was happening to me. I felt despair, anger, and anxiety—all of these reactions. I was worried about how I was going to live day-to-day and go to work and socialize or play any sports. I could not imagine how I was going to be able to live a normal life. I was active in sports and used to box, fence, and play squash. I could not imagine how I would be able to keep doing these.

After my surgery I had an ostomy—a permanent colostomy—and that changed the way I passed stool. So, I had to learn how to manage that—change the bag, care for the stoma itself. Because it was an end colostomy, I do not have any dietary restrictions, so that made it a lot easier. It was explained to me before the surgery that I would have an ostomy, so I expected it.

I did feel differently about my body afterwards, and I did not want to show the ostomy to anyone else, perhaps for about the first 6 months. I was actually ashamed, having to collect my stool in a bag, and didn't want anyone else to know about it. After that, I accepted that the stoma was necessary because of the surgery needed to treat my cancer, and acceptance came with it. Also, I checked all the boxes when it came to risk factors for colorectal cancer, so I couldn't really ask why me. It was more a case of why not. That made me realize it was no use dwelling on the past and decided to move forward with my life with my new friend, my stoma. And so, I adjusted quickly, and got on with it. Subsequently, I had no qualms about showing my body with my stoma bag. I guess you could say I adjusted quickly and felt acceptance about my situation. I do not feel it was a major impact on me. Now I am able to do a brisk walk, do Zumba, and dragon boating. For other people who know about the situation, having the ostomy, they have been very accepting. I think because I manage it quite well in most situations and surroundings, they have no problems with it.

For the entire first year, I only had support online, and from Colostomy UK. They sent me a postage-paid package all the way from the UK. And I joined their online support group, which I found very useful. I especially liked the positive patient stories, which lifted the doom and gloom which I was under when recovering at home. Also, the sheer number of products and accessories available for living with a stoma reassured me that I could manage my condition. And after that, I was introduced to a support group in one of the major hospitals here. Since then, I have been very involved in setting up support groups in other hospitals and co-founded the Ostomy Association of Singapore to provide psychosocial and other kinds of support to help improve the quality of life for ostomates in Singapore.

The advice I would share with others who are facing this situation would be to seek out a support group. It is possible to live a near normal life with a stoma and the conversations you have at the support group and the advice the others have to share is very helpful.

People are wired differently. Not everyone will be quick to accept having an ostomy and get on with their lives. We need to let them know it is OK and allow them to take as long as they need to come to terms with it. But in the meantime, we need to help them with the areas that are important to them—directly or indirectly through other agencies. There is always hope and there is a lot of life after a cancer diagnosis.

Julie

I was diagnosed just over 20 years ago, when I was 23, with Hodgkin's lymphoma. I had chemo, radiation and surgery to remove lymph nodes. I feel so fortunate to be here as a 20-year survivor, but I would say my feelings and my relationship with my body have changed over time.

The moment I was told my diagnosis, my very first thought was, "I am going to lose my hair!" It seems so silly to me now. It was not about potentially dying, it was about my hair. I'm not a vain person, but at that time my hair was my identity. I had a head full of ringlets and was always known as "the girl with the curly hair." Losing hair was a visible sign of cancer and for me a loss of who I was.

The hair came out after my second chemo and it was so messy. I decided to have a head shaving party and invited everyone who I thought would be shocked seeing me without hair. I did it in an almost ceremonial way. My biggest fear was how others would feel and react. Later, I always kept my hat on and would ask them, "Are you ready?," before I took it off. Not that I was ashamed, but I did not want to see the look of shock and sadness in their eyes. I felt so lost at first. I was no longer "the girl with the curly hair," I became "the young girl with cancer."

I also had scars, but I could hide them under my clothes. I was self-conscious about them and thought they were ugly, a constant reminder of cancer. I thought if people saw them, they'd comment, and I did not want to talk about them. I did not want to stand out any more than I already did.

But now, my feelings have changed about those scars. As much as the scars have healed and softened over time, so have my feelings toward them. I embrace them as a sign of empowerment, a sign of strength. I am proud to be here, for my resilience through all of this. I would say my view of my body is more positive now than it was at the time of the diagnosis. I am proud of my body for persevering. I am proud of my scars. But that attitude took time and effort to work through over the years.

At the time, there was no one else my age with cancer in my area and very few supports. I went to see about wigs, and it was "just a wall of gray wigs." I went to a support group and all the women were older, they had already gone through so much of their lives and the things I had yet to experience. I couldn't relate to anyone. Not the people with cancer, and not the friends my age without cancer.

When I was first diagnosed, I was so naïve and did not know a thing about cancer. I had never even set foot in a hospital before. I had no idea what to expect. I discovered there were many other issues I had to face—like loss of fertility, menopause, finances, and social isolation. Losing my hair became the least of my worries. There were even times when I didn't mind being bald, particularly in the heat of summer. I'll never forget the amazing feeling of the cool rush of water on my scalp when I would swim in the river. For the first time in my life people noticed other things about me, not just my hair.

In the end, I had braced myself for the physical changes, but not really for the emotional changes and the ever-changing relationship with my body. I had to learn to trust my body again. My diagnosis was delayed, so I feared every new lump or cough. I had to learn to be well again. Long term, I am now going through a new phase. Some new side effects from treatment seem to be emerging. It's eye opening. I feel so far removed from the original experience and have not thought about recurrence for a while. I don't know what's normal any more for someone my age, after years of being monitored and on such high alert about my health. I feel I am walking a fine line between trusting my body and not wanting to miss something again.

It's big hill to climb, dealing with the changes to your body, but my feelings about them, the scars, the different hair that grew back, have shifted. I am still known to some as "the girl who had cancer"—but now I am proud of it and the way I coped. I am not saying it was not a struggle, but what I have learned, the power I feel now, I feel I can use for good.

Karen

I was diagnosed 5 years ago with cancer at the base of my tongue on the right side, with spread to the lymph nodes on both sides. It really was devastating when I heard, and I was only 63. I had treatment with chemotherapy and radiation for 6 weeks, which really was the worst thing ever. I was really sick from the side effects of radiation and eventually could not eat.

I do not have any permanent physical changes. But during the treatment I had a PEG tube for nutrition, and redness and peeling of my skin on my lower face and neck because of the radiation. I had hair loss on the lower part of my head and noticeable weight loss, though not to the point of me being fragile.

Because I could not eat, I ended up with a PEG tube, and the nausea was so bad I could hardly stand the smell of food. I really had decreased energy and my endurance was way down. It all gradually came back after treatment finished, but at the time it meant I was not able to do what I enjoyed in my life. I would say, though, there was one permanent change, and that was my mental state. My priorities changed in what as important or not, the values in life, and a more "self" centered attitude.

During the treatment, with the fatigue and little endurance, I really could not do anything I enjoyed. I was not able to travel from the city to our permanent home (which is a 4-h drive away) and enjoy it. I had little energy to be with my young grandchildren. So, I was not able to be where *I Wanted* to be. With the low energy I could not go golfing or hiking. And of course, I could not eat—and I love eating and trying different foods.

I was upset about all the changes, but I knew I had to have them. I expected them because the team had told me about them. I knew there was a good chance of recovery, as I was healthy to begin with, but I knew that changes could happen with the treatment I had to have. I suppose if I had to have extensive surgery and had a lot of changes to my face, it would be different. I am a physiotherapist by profession and remember treating a lot of head and neck cancer patients with extensive facial changes. That was the way it was then with the available treatments. And I even remember saying, "I do not know what I would do if I got head and neck cancer." And here we are!

I really did not think too much about how I looked, I am not that type of person. But I did wonder if I would ever get back to doing what I loved after my body failed me. I knew what I needed to do, what was likely to happen, and I was doing all I needed to do to get better. I really did not dwell on thoughts about the physical changes. I guess, though, it did cross my mind to wonder how I would deal with things if speech and swallowing issues turned out to be permanent. But I also thought if that turned out to be the case, I would deal with it because of the type of person I am. I mean, after all, the alternative is not great.

I was really sick at one point and needed the PEG tube, but it was not obvious to others. I suppose others might have reacted to the redness and peeling skin. But I really was not out socially then as I was guarding my immunity. I guess I would have just explained it to them, if they reacted, so they would be comfortable.

My body is different now. I am back to golf, but I have to watch too much arm movement because it hurts my neck. I have limited range of motion in my head and neck because of fibrosis from the radiation; swallowing is somewhat of a challenge, and I have to be careful. But no one really sees it. It is not visible. I keep thinking these things are not as big a concern as they could have been, and I am alive. I look fine on the outside. I have just accepted it all. But then that is the type of person I am—logical, concrete, deal with what happens, do what I have to do.

And I learned I am far more resilient than I thought I was before this diagnosis. That was a surprise to me.

As far as advice to other patients I would just say, we all make choices. You can choose treatment and living, or you can choose not to have treatment. But treatment will mean there are things that will happen, and you will have to deal with them. You will have to almost disassociate yourself from your body at times.

Linda

I'm 58 now and I was diagnosed with Stage 4 tongue cancer. November 2015 was when I was told I had cancer. January 14, 2016, I had surgery. I had a total glossectomy, reconstruction of my tongue, tracheotomy and a feeding tube. Five days after my first surgery I developed an infection and was brought back into surgery. This infection affected my new tongue and eventually it died.

I went through radiation and chemotherapy March 2016. Because I had radiation, I had to wait a year and a half before my doctor could attempt another reconstruction. So, for a year and a half I had no tongue. With all these changes I really had a lot of adjusting to do in my life.

I went back to work full time after 7 months. It definitely was an adjustment period for myself and my co-workers. I still had my tracheotomy in, so people at work were very curious of this.

I really didn't have problems communicating, I did a lot of writing, texting, and emailing. I was a Grocery Manager at our main store, and I did the ordering for one of our smaller stores. I had lots of interaction with suppliers and venders with no problems.

In September 2017 I had my second surgery to attempt reconstruction again. It was a success. After I healed, I spent a year and a half going to speech therapy. I am now able to have a conversation without writing on a piece of paper and I'm able to talk on the phone. My speech isn't 100% and it never will be; my speech is about 50%.

When I meet someone for the first time, I always try and put them at ease because some people are uncomfortable around people with disabilities. So, I always say to them, "If at any time during our conversation you don't understand me, please let me know." This way they don't feel uncomfortable asking me to repeat myself. So many people say they understand what I'm saying but they don't, and that's very frustrating for me because they are nodding their heads but don't have a clue what I said. So that's why I always tell them upfront, just ask me to repeat myself if you don't understand.

One struggle for me at work was feeding. It was very awkward for me. This isn't something you see every day. Like, how many people do you know that are on a feeding tube? It was hard, but it got easier as time went by. I just said to myself, “I can’t worry about what other people think.” So, when people would ask me about it, I would educate them.

My other struggle is how I look; I have no teeth. I have denture implants, but I can’t wear them. I only use them for pictures. My tongue is very big, when I wear my dentures, I am not able to speak. So, with that being said, when people see me, they think I am a lot older than what I really am. My mouth is sunken, so I really struggle with how I look. I know that sounds vain, but your looks play a big part in getting a job in our society. So, my speech and no teeth are my struggles.

When the pandemic hit, like a lot of people, I lost my job. I have been applying for jobs for over a year now. I have over 30 years’ experience in the grocery business. This is the one industry that thrived during pandemic. So, you would think that I wouldn’t have a problem getting a job. Well, sad to say, no luck. They hear me speak and I never get a call. They aren’t looking at my experience, they just hear me and see me. A lot of people think I’m deaf. They would be advertising that they are hiring right in front of store, but when I would ask them when I would drop off my resume, they would say, “No.” You don’t realize how much discrimination there is until you are in that situation. I am definitely experiencing a lot of discrimination now.

One thing I’m proud of is I was able to help someone that was diagnosed with tongue cancer. He was struggling with if he should have the operation. We spoke and he was really worried about how he would sound. But once we spoke and he heard me, he decided to get the operation; he lost 50% of his tongue.

I wish I had been able to meet someone that went through this before I did, so I could ask questions about what to expect and how my life was going to change. It would put you at ease and you wouldn’t feel like you were alone.

Stubbornness and attitude have gotten me through this. My goal was being able to carry on a conversation and I have accomplished this. You always go through some self-doubt. But that’s when you get the attitude and stubbornness coming through, and have that “I don’t care what anybody thinks; if they don’t like me, that’s their problem.” If I didn’t tell myself this, I wouldn’t be where I am today. It takes a long time to accept how you are, it’s hard. But if you don’t accept who you are, then it will be even harder to go through life.

Leslie

Eighteen months after surgery for head and neck cancer, my face was still swollen. The scar, beginning behind my right ear and ending under my chin, was obvious to me. The skin was puckered and slightly red. I had no feeling on the right side of my face and neck with some muscle stiffness and range of motion difficulties. Facial nerve damage and numbness of my chin was juxtaposed with exaggerated pain at points on my lip. My voice sounded like that of a stranger. It was weak and lacked the intonation and diction necessary for conversation. When I tried to force my voice, it quickly became a whisper and then disappeared. I tolerated one brief activity only in a day. My physical condition made me feel even more isolated. Well-meaning acquaintances told me that I looked good or that radiation therapy was so much easier than chemotherapy. I felt wounded, weak and fragile. My face was completely different. I bought many scarves and collared shirts to hide my neck. But each evening I faced a mirror completing a teeth protocol that took 30–45 min. I had ample time to note the changes that cancer treatment had wrought. The mantra that reverberated constantly inside me was “damaged goods.”

I had lost 40 pounds. Physicians encouraged me to eat as much as I could. The radiation treatments destroyed my salivary glands meaning a painfully dry mouth, chronic irritation of oral tissues and difficulty swallowing with choking episodes from both liquids and solids. Baby pureed apple sauce added moisture to enable me to swallow more easily as liquids were simply swallowed and were ineffective. I had to physically work to swallow which quickly caused muscle fatigue and more difficulties. I would choke on dried saliva in my throat. It sounded like I was a heavy smoker. These episodes occurred frequently when I was trying to speak and eat at the same time. Do you ever get together socially when there is no food or drink? Each time I had to explain to strangers that cancer treatment caused my problems with speech, eating and the reason for carrying apple sauce. I could see they thought I was an alcoholic smoker, the typical head and neck patient profile, if they were health care professionals. For example, 9 years post my cancer a senior resident informed me a first diagnostic step was to determine my level of alcoholic liver damage. I was so diminished I could not respond before the resident left the room.

At a restaurant, I would search the menu for an item I might be able to eat. I then became one of those people querying the server about ingredients and asking for changes as I could not tolerate spices such as salt, pepper, ginger, or curry. Many spices created an overwhelming burning sensation in my mouth. Then, I had to ask about changing menu choices. “Could I have the fish with mashed potatoes as the rice it comes with is hard to swallow and makes me choke?” I would display my applesauce to back up my claims. These requests required a consultation with the chef, so my food was frequently delayed. The others had to then wait for me as I tried to eat. Food also stuck to my teeth without the lubrication of saliva. I would discover, for example, the food in my teeth when I went to the Ladies Room or returned home. I could hear “damaged goods” as I attempted to eat and tried to join the conversations. I quickly realized I could not do both so I would add an apology about my inability to speak when I was trying to eat. I would tell people I had already eaten or would eat later or would just order soup. The problem was the salt or spices that were already added made it more difficult to consume. I still felt it made others uncomfortable.

Fifteen years later, I struggle with many of the same issues. I could no longer meet the physical demands of work. I try to participate in a few team sport activities. My inability to speak clearly and to project my voice disadvantages our team. I feel bad about the extra work it creates for everyone in attempting to overcome my deficits. I continue one activity per day due to muscle fatigue of my neck and body. Thick tenacious secretions result in spontaneous choking episodes irrespective of food or drink intake. I must double swallow and ensure there are no crumbs in my mouth to ensure I don’t choke if I look up. Again, my lack of saliva means everything sticks to my teeth.

My swallowing difficulties are worse. I choke at least once during every meal. This disrupts all conversations and makes me the center of attention when I want to fade away. Added to this my lip numbness has progressed to drooling when attempting to swallow or spontaneously if I look down. This is hard to conceal from people around me. There is no quip from me to fix it. I will sometimes just say, "welcome to my world" but am mortified.

Head and neck cancer treatment changes everything, I feel. These changes are impossible to hide. They are literally in your face every moment of the day and night.

Nancy

I was diagnosed with breast cancer 26 years ago when I was 36. It was a genetic cancer, but they had not yet found the marker at that time. They found it 7 years ago. It is BRCA 1, deletion of exons 18 and 19. I lost my mother, my grandmother, and a cousin, all within a two-year period to breast cancer.

Diagnosing my cancer was like looking for a needle in a haystack. When I went for a baseline mammogram, the technicians found something and called the radiologist. In a very short time, I was connected with a surgeon. In 2 weeks, he had done the biopsy and removed the tumor, and booked me for a double mastectomy. They took lymph nodes and one-third of the chest muscle, and fortunately nothing showed up in the nodes. I then had 6 months of chemo but no radiation.

We were worried that my chest would be concave with such radical surgery, so I was connected with a plastic surgeon about reconstruction. Temporary implants were put in during the surgery and I had regular appointments over the next year to expand the implants and tissue around them. Then permanent implants were put in at the end of that year. The two surgeons really worked well together and understood each other's goals—one to get all the margins clear and the other wanting as much tissue as possible to be left for the reconstruction. I was actually the first women to have implants put in at the time of the surgery in my province—my claim to fame!

A big worry was my arm and being able to move it afterwards. So, 10 days after surgery, I started physiotherapy and exercising to gain the best possible range of motion. I have not had lymphedema, although I have to be careful because I do not want it to develop—and that could happen anytime.

I had mouth sores as a result of the chemo and ended up losing the pigment on my upper and lower lips. Also, my eyelashes and half of one eyebrow did not grow back. But this was all easily resolved. I had tattoos done—and no one would ever know! It is amazing what can be done and looks so natural.

I also went through the change of life. I was on hormone replacements at the time of my diagnosis, as I had a hysterectomy because of endometriosis. This turned out to be an unknown lifesaving procedure as my ovaries were removed, thus eliminating the risk of ovarian cancer. I had real challenges with hot flashes. But thank goodness it was wintertime and all I did was open the back door!

One of the biggest problems was shaving under my arms. It is really hard to do when you can't feel it. I talked with a woman who had gone through the same thing, and she said, "You stand in front of a mirror and just make yourself do it." It was good advice.

My husband was very supportive throughout. He said it made no difference to him how I looked after and that was important for me to hear. But my young daughter struggled, wondering if this was her future. I have lots of scars, but no one sees them. She really struggled with it all and that was hard, but we had amazing family support. The compassion and caring of my community made a real difference. That's what it is like in a small town.

I am happy my hair grew back in because I was told there was a 50% chance it would not. Although it is half as thick, that's OK, I had a lot before anyway. At the time, I wore a wig and got a special bra. But you have to laugh sometimes. I remember 1 day I was going into the post office, which is always busy. And it was windy. And the wind blew my wig backwards! What could you do but laugh and straighten it!

Reconstruction was not about getting back what I lost but more to do with looking and feeling normal again. Sure, they do a better job of the surgery now, but I am satisfied with the way I look. I tell other women when asked, it takes time to come to terms with a cancer diagnosis. It is a process and does not happen easily. Everyone's journey is their own and how they cope is unique. But we are strong, and the lucky ones survive.

Sharon

I was diagnosed with uterine cancer. The D&C diagnostic was in September 2003, a hysterectomy in early January 2004, followed by an extended course of radiation therapy, and a hernia repair the next September. So, three general anesthetics in just under a year. I think the hernia started from throwing suitcases onto an airplane baggage belt. I realized later that probably was in the same category as the cautions not to vacuum or lift shopping bags after surgery, but that didn't occur to me at the time.

For me, physical changes from the surgery weren't the main issue. Friends and colleagues with medical experience remarked on how my mind was clearer and I had more energy than they expected. I had a desperate need to be back to normal and to get back to work. Granted I am self-employed, so there was the financial piece, but it was also about who I am and my personality. I had obligations to clients, and I was already frustrated. After the diagnosis I never was able to get a specific surgery date, or even a range of dates, so I could make plans with clients and family members who needed to make arrangements for international travel. And I was never able to get a clear sense of where the process was at—different parts of the system kept pointing the finger at other parts of the system to explain the delay or inability to tell me where things were at. Really makes you feel irrelevant.

I don't see how body image is separate from sense of identity as a whole person, and how I engage with the world. The main part of the puzzle for me was about sorting out my place in the world and way of being—more spiritual. And sorting through how I live confidently in the world afterwards—having had this kind of experience brings it home that life can change in an instant.

The loss of a uterus was not a big issue for me. People said the worst would be that it would catapult me into menopause and losing my identity as a woman, but I didn't find that to be the case. I had already seen a waning of my hormonal cycle where periods were few and scant. A lot I attributed to job stress. So, I felt I had sort of already gone through menopause. And I was at peace at being finished with my childbearing capacity.

In fact, there was one big blessing! A few months after surgery I was noticing a marked reduction in stamina, and sort of a generalized fatigue—maybe the benefit of the oxygen therapy I had after surgery was waning? It brought into focus a collection of cues and a diagnosis of sleep apnea. From the first night with a CPAP, my quality of sleep hugely improved!

For me the experience doesn't end with the time around the event. About 15 years later I became involved in some advocacy for patient-centered care and I found that all the recounting stories of my cancer experiences brought back so much. Once I realized what was happening, I think it really helped to process some of the emotions that I buried at the time.

One possible physical aspect was the gradual onset of incontinence I experienced. I learned recently that incontinence can be an after effect of having had a hysterectomy. No one had mentioned that before, and I was taken aback when I heard. I felt a sense of betrayal—why didn't' anyone tell me years ago? It would have been most beneficial to have known earlier, so I could take some action to slow or stop the progression. Maybe if it was a common thing, there'd be some research going on to develop something that could be done as a part of the surgical procedure to correct it. Maybe not, but I'd have liked to have that chance.

My orientation is pretty pragmatic. I like to have information. I understand life has challenges, and I expect to get quality information and a consistent story from skilled professionals, so I don't have to do all my own research. For many of us, it's part of feeling confident in the health care system. Examples like these erode our confidence in the health care system and in individual professionals.

In sum I'd say body image and identify is a lifelong affair one has with oneself. Information is influential and feeds into our identity, our sense of control. It is constantly in flux as we go through life. Each change helps us know more about who we are and how we engage with the world.

Richard

I am a research scientist, who was diagnosed with prostate cancer 23 years ago when I was 52 years old. I promptly had surgery to remove my cancerous gland, followed by salvage radiotherapy to try and destroy residual cancer cells in the neighborhood where my prostate gland used to reside. For over 20 years I've been almost continuously on hormonal therapy, which is more properly called androgen deprivation therapy (ADT). ADT retards the growth of prostate cancer cells but doesn't necessarily kill them. Blood tests indicate that I have many quiescent cancer cells hiding in my body right now.

Before getting treated for prostate cancer, most of my research was with amphibians and had nothing to do with cancer. After going on ADT, I was so surprised by the side effects that I changed the direction of my research. Much of my work now relates to strategies for improving the quality of life of men treated for prostate cancer.

It was the impact of ADT on my body form and function which initiated the shift in my research. Indeed, it was the morphological effects that I experienced from ADT that led me to study the impact of cancer treatment on men's quality of life.

ADT has a slew of side effects, some of which are serious, but not seen. Others are seen, but not necessarily of medical concern. One of the most common side effects is increased adiposity, which is both serious and easy to see. It typically presents as increased fat in the abdominal region and thighs. Indeed, in my first 2 years on ADT, I experienced a ∼10% increase in my body mass, all as fat.

Dr. Matthew Smith, who is an oncologist at Harvard, told me that when he asks his patients on ADT, "How are you doing?," they often respond by saying, "Fine, except for this." The "this" here is a specific gesture where they grab that new abdominal fat fold with both hands and jiggle it up and down. This action confirms the patients' awareness of how that additional abdominal fat has changed their body image.

That jiggle gesture is common among men on ADT, when discussing the side effects of their cancer treatment. I've made that gesture myself. Dr. Smith now calls the two-handed, abdominal jiggle a "positive Lupron sign" in reference to the historically most commonly prescribed drug for ADT.

One can gain weight as fat and not necessarily be distracted by it. My belly fat was not something that I constantly saw, sensed, and obsessed about. But after a year or so my ADT, I found myself very conscious of, and distracted by, the fact that the medial sides of my enlarged thighs were touching each other when I walked. This was a body image issue that was not necessarily conspicuous to others. But I felt it with every step I took after gaining that much weight on ADT. I have adapted to it now, and don't notice it as much. But after 20 years, I still struggle with keeping my BMI in a normal and healthy range.

And then there is gynecomastia. About 15% of the patients on ADT experience some breast development, which is influenced by the particular drugs they are on and how fat they are overall.

Some men are indifferent or unconcerned by gynecomastia, whereas others find it intolerable. One of my colleagues, who experienced it on ADT, had a mastectomy to remove the extra tissue. I alluded to how it affected me in an earlier essay (Wassersug, 2014), but, as a scientist I'm particularly interested in understanding why men vary so greatly in their tolerance for breast development. A colleague and I have previously suggested that gynecomastia may be more problematic for men who hold to a rigid gender hierarchy, with men dominant to women (Wassersug and Oliffe, 2009). That hypothesis has not been tested, but it might be helpful to know in advance of starting ADT, what are predictors of distress from gynecomastia. This could open the way to developing educational programs that might help reduce the distress and improve patients' quality of life in the long run.

There is one impact of ADT on body image that I do not believe has had much, if any, discussion in the literature. It's ADT's impact on one's hair. ADT causes a loss of body hair from the limbs and torso, but that doesn't seem to be of great concern to most patients on ADT, nor for that matter to their oncologists as it has no clinical significance. I've talked with patients, who were totally unaware of it. [However, one patient thought it malpractice that his doctor had not warned him about that.]

Hair on adult men's faces and head persists even when we are androgen-deprived. The persistence of hair of my head has had an unexpected impact on my body image—it makes me appear younger than my age. I know that to be true having asked many folks to guess my age. As long as I stay on ADT, I am unlikely to go bald.

Of course, how old one looks and how old one feels are not the same. I mention the topic of hair, however, just as a note that not all the ways the cancer treatments can impact body image are invariably negative.

CONCLUDING REMARKS

The short narrations are personal reflections from the authors about their experiences with body image changes and the impact and challenges of living with those changes. There is a totality about the situations that defies "breaking it into pieces and isolating factors." Experiencing and responding to bodily changes happens within, and is influenced by and intermingled with, the person's whole life. No two individuals have the exact same reaction and response, and the context of their daily living is an important influence. For some, there is a decided focus on the physical itself while others focus primarily on the emotionality which emerges in the situation; others simply focus on getting through each day with the demands the changes bring. There is a clear sense that body image is challenging for individuals to describe in isolation of its links with self-concept, self-identity, and self-esteem. Living with the day-to-day changes means living with the intermingled messiness—it is not about staying with strict conceptual definitions.

This article is offered as a way of illustrating a range of insights from individuals who have gone through an experience of cancer treatment and coped with bodily changes. The intention was to offer an avenue to reflect upon the individuality and the complexity of confronting body image changes resulting from that treatment. The personal descriptions present the voices of survivors and a glimpse into living with bodily changes. By reading the stories together, like looking at individual puzzle pieces and then putting the puzzle together, a picture emerges of the variation and complexity of living with body image changes from cancer and its treatment.

The changes and the responses to them range widely. For some the changes are profound and long lasting; for others, the body image concerns fade into the background and other issues take predominance. But what crosses the narratives, is evidence of a dynamic process unfolding as individuals live with the changes. We can see threads or storylines unfolding about how perspectives can change over time, the influence of information, the importance of relationships and support, and the personal discovery of resilience. There is an emphasis on the value of being alerted to possible changes ahead of time and learning what can be done about them. And there is illustration of how support from family, friends, and health care providers is significant and can make a difference for the individual coping with the change.

The notion of embracing storytelling to improve cancer care has been gaining ground in recent years (Atkinson and Rubindli, 2012). Perspectives from patients, survivors and family caregivers offer a rich base on which to launch conversations about necessary change within cancer care. Health care professionals and cancer system planners have begun to design and implement strategies to draw on patient stories for the purpose of incorporating them into all levels of health care including practice, education, research, and system planning (Bird et al., 2020).

At the practice or care delivery level, the individual practitioner can gain insight from hearing patient narratives which can be used in their own interaction with patients and families, enhancing their understanding of what is important to the individual and could be of assistance at the point of care. Two strategies leaders in clinical facilities have utilized to bring patient perspectives to the forefront of care delivery for health care professionals include implementing a person-centered philosophy across a health care facility (Health Quality Ontario, 2017) and introducing programs to screen for symptom and emotional distress (6th vital sign) (Bultz et al., 2011).

A person-centered philosophy challenges health care professionals to prioritize notions of dignity and respect, share information of relevance to the individual, engage with patients as partners, and facilitate patient collaboration in their own care (Throarinsdottir and Kristjansson, 2014; Calisi et al., 2016). Providing information and resource tools which enables individuals to be effective self-care agents is a growing expectation in practice (Howell et al., 2020) as cancer becomes more of a chronic type of illness and the number of survivors is increasing (McGeechan et al., 2018; Miller et al., 2019). Screening for distress programs introduce triage strategies using standardized distress screening tools at regular patient visits or specific points of transition in care when vulnerability may be more pronounced (Howell et al., 2012). The resulting information from patients can facilitate identification of any concerns which are of importance to patients and focus on those concerns as priorities for meaningful intervention (Howell and Olsen, 2011).

In the arena of education, patient narratives have been used to help students learn about patient and family experiences and health care professionals to gain insight about needed change in their care settings. Ultimately, the aim is to have practitioners be opened to listening to patients, giving time for individuals to share their stories, and being responsive to individualized concerns. Often, what is of concern or priority to a patient is not necessarily the same priority for the health care professional. As an example, a program designed by the Canadian Ovarian Cancer Association, entitled "Survivors Teaching Students," was utilized at the University of Toronto to teach medical and nursing students about survivors' experiences (Fitch et al., 2011). Survivors were prepared to share their stories with classes of undergraduate students and respond to the student questions in small groups following the presentation. In another example, a theater play was designed for health care professionals to share the stories of cancer patients and family members and challenge their perspectives about the experience of being a cancer patient. The script was written as a series of vignettes based on results from qualitative research regarding living with breast cancer (Gray et al., 2000). The play was performed by survivors and delivered in cancer centers across Canada (Gray et al., 2003).

In terms of research, there is a growing trend toward embracing participatory action strategies or engaging patients and family members in research activities beyond being subjects in a trial or respondents to a survey (Canadian Institutes of Health Research, 2014; Hamilton et al., 2018). Engaging patients and family members as research team members or embracing approaches where patient advisory panels inform a research project design and measurement approaches have been utilized with success (Puts et al., 2017; Fitch et al., 2019). The participation aims to ensure the research focuses on questions of importance to patients and families, data collection approaches are respectful and appropriate, interpretation of results is done within a context of patient experiences, and dissemination reaches relevant audiences beyond health care professionals (Johnson et al., 2016; Bombak and Hanson, 2017).

Finally, use of strategies to engage patients and families as stakeholders in cancer system planning has been unfolding in some countries (International Alliance of Patients' Organizations (IAPO), 2007; National Health Service Department of Health, 2012; Staniszewska et al., 2014; Moody et al., 2016; Canadian Partnership Against Cancer, 2022). These strategies focus on intentionally hearing and using patient narratives in decision-making about new developments. The strategies have included analysis of both quantitative and qualitative data about what patients see as "quality" in cancer care (Institute of Medicine (United States) - Committee on Quality of Health Care in America, 2001; Darzi, 2008; Corner et al., 2013; Fitch et al., 2020) or suggestions they have about needed improvements (Nicoll et al., 2020; Fitch et al., 2021). Engaging individuals in co-design approaches (e.g., workshops, conferences, planning committees) and incorporating storytelling reflection has also been helpful for exploring patient perspectives and identifying priorities for improvement. Co-design approaches can be useful in planning new programs, developing new interventions, and developing survivor roles in communication and implementation of new approaches (Bethell et al., 2019).

In summary, hearing unique patient stories on an individual basis offers a variety of pictures and focus on various events and reactions. The stories offer the possibility of gaining new insights and understanding, new ideas for assessment or research, and new illustrations for professional, provider and/or patient education. Collectively they begin to illuminate underlying patterns that require change in moving toward a person-centric system that enables person-centered care (Cornish, 2020). Stories can be useful in the process of transforming an organization and gathering and mobilizing people for a common purpose. They can set the stage for co-creating or co-designing innovations in cancer care and finding meaningful ways to achieve a truly person-centered approach throughout the cancer care system.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author at marg.i.fitch@gmail.com.

ETHICS STATEMENT

Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

AUTHOR CONTRIBUTIONS

Each author contributed a story for inclusion. MF produced the initial draft and all authors edited until a final version was reached. All authors approved the final version.

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The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Breast Cancer Stigma Scale: A Reliable and Valid Stigma Measure for Patients With Breast Cancer

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Purpose: This study aims to develop and validate a stigma scale for Chinese patients with breast cancer.

Methods: Patients admitted to the Affiliated Cancer Hospital of Xiangya School of Medicine, Central South University, for breast cancer treatment participated in this study. Development of the Breast Cancer Stigma Scale involved the following procedures: literature review, interview, and applying a theoretical model to generate items; the Breast Cancer Stigma Scale's content validity was assessed by a Delphi study ($n = 15$) and feedback from patients with breast cancer ($n = 10$); exploratory factor analysis ($n = 200$) was used to assess the construct validity; convergent validity was assessed with the Social Impact Scale ($n = 50$); internal consistency Cronbach's α ($n = 200$), split-half reliability ($n = 200$), and test–retest reliability ($N = 50$) were used to identify the reliability of the scale.

Results: The final version of the Breast Cancer Stigma Scale consisted of 15 items and showed positive correlations with the Social Impact Scale ($\rho = 0.641$, $P < 0.001$). Exploratory factor analysis (EFA) revealed four components of the Breast Cancer Stigma Scale: self-image impairment, social isolation, discrimination, and internalized stigma, which were strongly related to our perceived breast cancer stigma model and accounted for 69.443% of the total variance. Cronbach's α for the total scale was 0.86, and each subscale was 0.75–0.882. The test–retest reliability with intra-class correlation coefficients of the total scale was 0.947 ($P < 0.001$), and split-half reliability with intra-class correlation coefficients of the total scale was 0.911 ($P < 0.001$). The content validity index (CVI) was 0.73–1.0.

Conclusion: The newly developed Breast Cancer Stigma Scale offers a valid and reliable instrument for assessing the perceived stigma of patients with breast cancer in clinical and research settings. It may be helpful for stigma prevention in China.

Keywords: breast cancer, stigma, scale, development, validation, reliability

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INTRODUCTION

Breast cancer is currently the most common cancer type experienced by women worldwide, with an estimated 2.3 million new cases in 2020 (Sung et al., 2021). Approximately 11% of all breast cancer cases worldwide occur in China, and the incidence has increased rapidly in recent decades (Li et al., 2016). The 5-year relative survival rate for individuals with breast cancer is approximately 82% (Zeng et al., 2018). Despite the improved prognosis, adverse effects (e.g., loss of breasts, visible scarring, hair loss, and lymphedema) from surgery, chemotherapy, and radiotherapy can be significantly disfiguring and can negatively affect patients' lives (Suwankhong and Liamputtong, 2016). In addition, psychological stressors from adverse effects cause them to experience stigma and limit their social interactions due to changes in body image and others' perception of them as "abnormal" (Rajasooriyar et al., 2021).

Stigma is typically a social process, experienced or anticipated, and is characterized by exclusion, rejection, blame, or devaluation that results from experience, perception, or reasonable anticipation of an adverse social judgment regarding a person or group (Lebel and Devins, 2008). The prevalence rate of perceived cancer-related stigma ranges from 5 to 90% (Ohaeri et al., 1998; Cho et al., 2013; Phelan et al., 2013; Fujisawa et al., 2020). Approximately 76.7 and 8.7% of the breast cancer survivors report moderate and high stigma levels, respectively (Jin et al., 2021). Perceptions related to one's own body may impact the sense of identity, self-esteem, acceptance, sexuality, and perceived stigma of women (Tripathi et al., 2017). The main factors influencing stigma in China were personal acceptance of the disease and body image (Jin et al., 2021). Physical appearance impacts self-esteem, depression, and a tendency toward social isolation.

Breasts are considered a symbol of physical and sexual attractiveness and femininity. The psychological ramifications of a mastectomy can be substantial for women. They face distress and disfigurement due to missing or asymmetric breasts (Fang et al., 2013). Moreira and Canavarro (2010) reported that those treated with mastectomy were more dissatisfied and felt more ashamed of their appearance than those who had undergone breast-conserving surgery. Breast reconstruction offers an alternative opportunity for those who require mastectomy and improves women's wellbeing and quality of life (Fang et al., 2013). A meta-analysis also indicated that women undergoing mastectomy alone perceived higher levels of distress than those undergoing mastectomy with immediate reconstruction or delayed reconstruction (Fang et al., 2013). Permanent changes (e.g., scars or loss of breasts) in a woman's body resulting from breast surgery contribute to the perception of stigma.

Chemotherapy-induced alopecia (CIA) is a distressing side effect for those undergoing adjuvant chemotherapy. Chemotherapy does improve the survival rate of the cancer population; however, severe adverse effects of chemotherapy limit the dose and treatment continuation. Certain classes of chemotherapy agents (e.g., alkylating agents, anthracyclines, antibiotics, antimetabolites, vinca alkaloids, and taxanes) for breast cancer are known to cause alopecia more readily (Chon et al., 2012). CIA causes physical and psychological distress to patients and attracts unwanted attention, significantly affecting self-esteem and social interactions. For some women, losing hair was found to be even more distressing than losing their breasts (Trusson and Pilnick, 2017). The inability to conceal a negative body image is possible for this disparity. While they can wear prosthetic breasts or particular clothes to shape their body image, breast is an integral part of physical appearance and symbolizes health, femininity, and attractiveness, and influences body image and identity.

A series of existing measures could be used to assess breast cancer-related stigma. The Perceived Devaluation-Discrimination Scale was developed for individuals with mental illness to measure the subjective feelings of failure and the feeling of being less intelligent than others or for individuals whose opinions need not be taken seriously (Link et al., 1991, 2001). The Social Impact Scale, a 24-item instrument developed by Fife in 2000 (Fife and Wright, 2000), was used to evaluate the feelings of stigma in persons with HIV/AIDS and cancer. The Internalized Stigma of Mental Illness Scale, developed by Ritsher et al. (2003) in collaboration with people with mental illnesses in 2003, was used to measure the subjective experience of stigma, with subscales measuring alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance. The Consumer Experiences of Stigma Questionnaire was developed by Wahl (1999) to measure the stigma of patients with mental illness. The translation and measurement properties of these four scales have provided a framework to create a scale for measuring the stigma of patients with breast cancer in China. However, their items may be too broad to reflect the stigma attached to a single illness. As breast cancer survivors have much higher rates of anxiety, depression, cognition impairment, and adverse effects, it is necessary to explore in-depth stigma among patients with breast cancer and develop a tool that contains items specifically associated with the assessment of breast cancer-related impairments. Undoubtedly, universal measurements lack sensitivity to patients who are coping with breast cancer, who undergo a major disruption in their life course that leads to changes in their concept of self. In order to understand the stigma status of these patients and try to develop interventions to help these stigmatized individuals, the initial step is to create an effective evaluation measurement specifically for women with breast cancer. Therefore, this study aimed to develop and validate a measurement tool that is sensitive to the stigma experienced by women with breast cancer.

MATERIALS AND METHODS

Part 1: Conceptualization and Development of an Initial Item Pool

We referred to a published method of examining the construct validity of newly developed instruments for creating objective measurements (Clark and Watson, 2019). We constructed a model of the perceived stigma associated with breast cancer based on the conceptual model of perceived lung cancer-related stigma developed by Cataldo et al. (2011), as well as conducted a literature search and qualitative interviews. We extracted the question items, conducted two rounds of Delphi study, pilot testing, and made corrections. Thus, the main themes and item pool of the stigma scale for patients with breast cancer were generated through a multi-step process, described in the following sections.

Literature Search

Conducting a comprehensive literature review enables a clear articulation of how the proposed scale will either be a theoretical or an empirical improvement over existing measures or will fill a vital measurement gap (Clark and Watson, 2019). Therefore, we performed a thorough literature review to understand the dimensions of self-stigma unique to patients with breast cancer. PubMed, Web of Science, Embase, CINAHL for full text, CNKI, Wanfang, VIP, and CBM were systematically searched from each database's inception to March 2020 to explore dimensions of self-stigma in patients with breast cancer. The final search strategy combined the terms breast cancer or its related words and also stigma or its related words.

Applying a Theoretical Model

Some studies have researched perceived stigma among patients with cancer. However, early research only focused on discovering the self-stigma in their families. We developed a model of the perceived stigma associated with breast cancer based on the conceptual model of perceived lung cancer-related stigma developed by Cataldo et al. (2011). **Figure 1** guided the development of items in the Breast Cancer Stigma Scale and described the process of perceived stigma among patients with breast cancer.

Qualitative Interviews to Explore Sub-Dimensions

The participant sample size depended on any beneficial information gleaned from the semi-structured interviews. Data collection ended once no further information was extracted. We conducted semi-structured interviews with 14 patients with breast cancer whose age, marital status, educational level, residence, stage of cancer, and surgery type varied to explore the appropriate sub-dimensions. The second author performed the interviews, which lasted 15–30 min per participant. Furthermore, the interviews were conducted face-to-face in a private and quiet room. All interviews were recorded by a digital voice recorder and subsequently transcribed verbatim within 24 h. The interviews were analyzed deductively, applying Colaizzi's method of phenomenological analysis (Sanders, 2003). Four structural concepts were extracted related to the stigma process revealed through these interviews.

Self-image impairment, social isolation, discrimination, and internalized stigma were considered constructs of the stigma of patients with breast cancer.

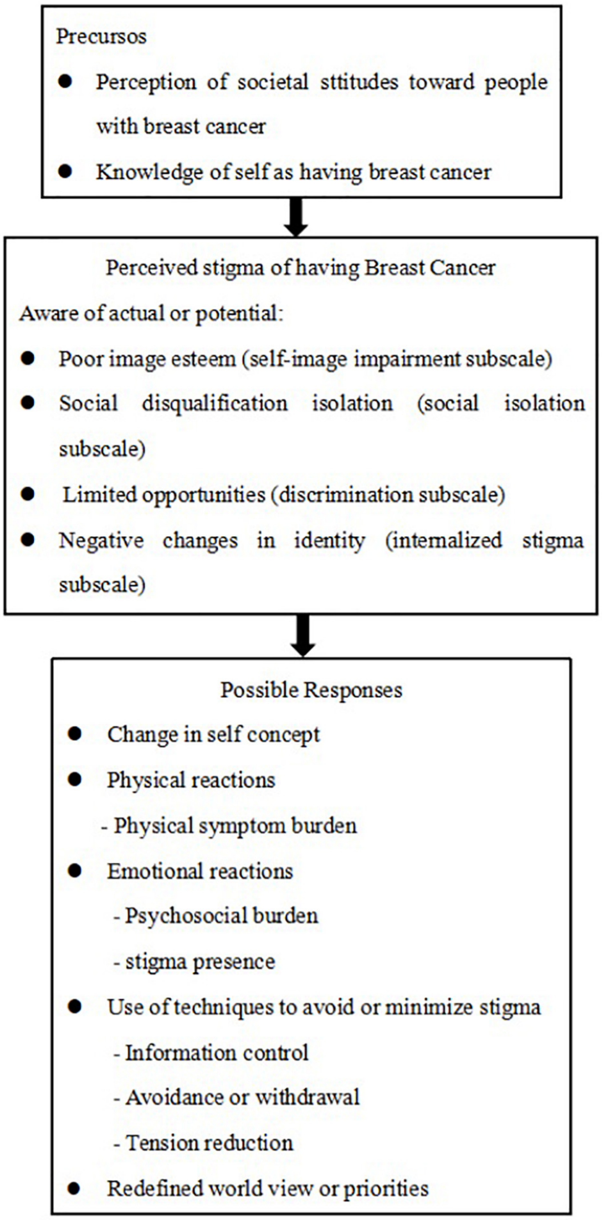

FIGURE 1 | A model of perceived stigma in patients with breast cancer.

Validating the Scale and Pilot Testing

We examined the initial items while using the Delphi method to explore the content validity of the Breast Cancer Stigma Scale. The Delphi method is an approach used to gain the most reliable consensus among a panel of experts by using a range of questionnaires (Keeney et al., 2001; Powell, 2003). We listed dimensions and the item pool during each Delphi round. Between each round, we revised the content based on the experts' feedback. An invitation to participate in the consultation and a content description was sent by WeChat, email, or through in-person meetings to identified experts. Inclusion criteria for experts were those (1) with more than 10 years of working experience related to breast cancer nursing or psychology, (2) those with at least a professional title of associate professor, intermediate title, or above, and (3) experts who mastered in the psychometric assessment of a scale and who were willing to offer advice. Finally, 15 experts from nine provinces in China participated in the consultation. In total, eleven of these experts were in clinical nursing and nursing management in tertiary A general hospitals, two were psychologists, and two were nursing education experts in colleges. They reviewed the content and evaluated each item's score independently using a 5-point Likert-type scale (ranging from "not important" to "very important"). A pilot test was performed on 10 participants by completing the 24-item questionnaire of scale items and it was with good validation.

Phase II: Scale Validation

Participants

Patients who received treatment in the breast internal medicine department or breast surgery department in the Hunan Cancer Hospital were conveniently and consecutively recruited from September 2020 to February 2021. The ethical committees of the Hunan Cancer Hospital, approved this study. All the participants provided their informed consent. The inclusion criteria were those (1) $\geqslant$18 years old, (2) whose clinical manifestations and pathologic biopsies were consistent with patients diagnosed with breast cancer, (3) with clear consciousness and could complete the questionnaire, and (4) who provided consent to participate in this study. Participants were excluded if they had been diagnosed with another illness or with psychiatric diseases.

Participants were asked to complete the sociodemographic questionnaire, the Chinese version of the Social Impact Scale, and the stigma items individually. The process lasted 15–25 min. A total of 50 patients completed the same items again, 2 weeks after the first test, to assess test–retest reliability. The sample size was at least 100 to ensure stability of the variance–covariance matrix (Terwee et al., 2007). Furthermore, the exploratory factor analysis requires a sample of 200 (Horne et al., 2017). Hence, we had to recruit more than 200 participants.

Measures

Questionnaires with basic demographic information included age, gender, ethnicity, religion, place of residence, marital status, occupation, employment status, education level, family income status, medicare coverage, stage of cancer, and surgery type.

The 24-item Breast Cancer Scale contained 24 items. Participants rated their experiences of stigma by using a 4-point Likert-type scale (1 = "strongly disagree," 4 = "strongly agree"). Scores ranged from 24 to 96. A higher score indicated a more significant stigma.

The Social Impact Scale (SIS) is a 24-item instrument (Fife and Wright, 2000) used to assess people's stigma with HIV/AIDS and cancer. The responses to each item were based on a 4-point scale ("strongly disagree" to "strongly agree"). The score obtained on this scale was used as a criterion for the Breast Cancer Stigma Scale validity. The Chinese SIS is a widely used scale with good reliability (Pan et al., 2007). The separation reliability was 0.99, representing good internal consistency (Pan et al., 2007).

Statistical Analyses

All statistical analyses were performed using the IBM SPSS 26.0 software, with an α of 0.05 for significance. General and disease-related characteristics were presented as numbers, mean, and *SD*. The validity evaluation of the scale included content, criterion, and construct validity, while the reliability evaluation comprised internal consistency and test–retest reliability.

Validity

Content Validity

The item-level content validity index (I–CVI) was calculated for each item by dividing the number of experts who rated the item as reasonably necessary or highly important (i.e., a rating of 4 and 5 given by experts) by the total number of experts taking part in the rating (Polit et al., 2007). Cs represented experts' familiarity with the research field, and Ca represented the judging criteria based on the experts. CV was defined as the SD divided by the mean, which is used to describe the relative dispersion degree of the item's importance evaluation from experts (Reed et al., 2002; Chen et al., 2020). The Kendall coefficient W- test evaluated the consensus on agreement among the experts. It refers to the level of intra-expert understanding of all of the indicators (Xing et al., 2019). A two-tailed p-value of less than 0.05 was considered statistically significant (Chen et al., 2020). Therefore, we predefined a mean score of no less than 4, a CV of no more than 0.2, and a two-tailed p-value of Kendall coefficient W-test of no more than 0.05 among experts for the items to be included.

Discriminant Validity

Discriminant validity refers to a scale's ability to distinguish between two or more groups (Li et al., 2019). Every participant received a total score after completing the questionnaire. Participants' total scores on each item were listed in a sequence of numeric values from the lowest to highest for the assessment of internal criterion validity. The difference between the lower 27% and the upper 27% of the distribution was analyzed by an independent two-sample t-test. We deleted items that had a two-tailed p-value of ≥ 0.05 or $t < 3$.

Criterion Validity

The relationships between the Breast Cancer Stigma Scale scores and the Chinese version of the Social Impact Scale were examined to assess criterion validity. Pearson's correlation coefficients (ρ) were considered no less than 0.3 (Salter et al., 2004).

Substantive Validity

Qualitative interviews, a literature review, and a theoretical model were used to explore subdimensions.

Construct Validity

Exploratory factor analysis (EFA) was used to assess the construct validity. The Kaiser–Meyer–Olkin index and Bartlett's sphericity test were performed to determine the data suitability for EFA. Components were selected if eigenvalues were greater than 1. Items were considered for removal when their loading was less than 0.4 (Fu et al., 2015).

Reliability

Internal Consistency

Internal consistency was assessed using Cronbach's α. A Cronbach's α of 0.7 or above was considered good internal reliability (Hendriks et al., 2013).

Split-Half Reliability

The split-half reliability of the scale was tested using the odd–even method. A correlation coefficient of 0.7 or above was considered good internal reliability.

Test–Retest Reliability

Test–retest reliability was examined through intra-class correlation coefficients (ICCs), represented by calculating Pearson's ρ of two assessments for the same participant with an interval of 2 weeks in between assessments. An ICC greater than 0.70 suggests that the two tests had excellent test–retest reliability.

RESULTS

Qualitative Interviews

Our sample consisted of 14 patients with breast cancer who sought treatment at the Hunan Cancer Hospital from July to September 2020. The characteristics of the participants are shown in **Table 1**. The authors analyzed the transcripts independently by bracketing data on preconceived ideas and strictly following the adapted Colaizzi's method. Findings were then compared and discussed by the team until consensus on themes, theme clusters, and categories were achieved.

Theme 1: Self-Image Disorder

Interview responses revealed that the body image of patients with breast cancer is damaged due to symptoms such as mass ulceration and breast asymmetry, and feeling of attraction decreases:

- Weight change—N1: "I used to be so thin. After taking hormone drugs, I gained 10 kg."
- Hair loss—N1: "[after shaving her hair following chemotherapy since it resulted in alopecia] I bought a wig and brought it up; I am annoyed due to hair loss."
  N2: "I always wear a wig at home."
  N4: "I want to buy a beautiful wig."
  N6: "I must wear a wig when I go out."
  N10: "I care about hair loss since I am still young. I am a little troubled when I wear a wig."
  N13: "My hair was badly lost after the second chemotherapy, I cried loudly when I shaved my hair because it is unacceptable. [My] chest is not integrated after the operation. I didn't dare to go out a few days ago. I felt that shaving my head looks ugly; I heard that the eyebrows will fall out, although they haven't fallen out yet, so I hurried to buy some eyebrow pens."
- Image impairment—N1: "I don't look as beautiful as before after dressing. I always pay attention to my image."
- N5: "I'm still afraid to see my wound right now. Maybe the breast on the surgical side is like a man."
- N6: "The breast is cut and becomes ugly; I regret not getting breast reconstruction surgery. The breast is really beautiful after reconstruction. Although it is painful, it just lasts for three months; otherwise, this (breast) will be gone for a lifetime. I thought that [it was good enough] as long as I was alive at first, but later, I found it ugly. The breast has been cut. The artificial breast is not as good-looking as the one on the other side. Additionally, it is hard. I want to make my breast more good-looking after I recover. Last time, a person [who underwent] breast reconstruction surgery showed her breast to me. It's rather beautiful without a big scar. She can also wear a swimsuit." [envious expression]
  N8: "I feel a little uncomfortable after cutting the breast. Everyone has breasts, but not me."
  N10: "A little concerned about the lack of breasts." [awkward smile]
  N12: "A little bit? [excited] So big! My wound is so big."
  N13: "I care about the lack of breasts." [raises the tone]

TABLE 1 | Participant characteristics.

ID	Age	Place of residence	Marital status	Occupation	Education level	Payment	Stage of breast cancer	Approach of surgery
N1	48	Village	Married	–	Secondary school	Medical insurance	I	Modified radical mastectomy
N2	38	Village	Married	Worker	Primary school	New rural cooperative medical insurance	III	Modified radical mastectomy
N3	41	Township	Married	–	Secondary school	New rural cooperative medical insurance	II	Extensive radical surgery
N4	42	City	Married	Self-employed	University	New rural cooperative medical insurance	II	Breast reconstruction
N5	55	City	Married	Engineer	Technical secondary school	Medical insurance	III	Modified radical mastectomy
N6	41	City	Married	Worker	High school	Medical insurance	I	Modified radical mastectomy
N7	53	Township	Single	Worker	High school	New rural cooperative medical insurance	IV	Modified radical mastectomy
N8	47	Village	Married	Farmer	Primary school	New rural cooperative medical insurance	I	Modified radical mastectomy
N9	49	Village	Married	–	Primary school	New rural cooperative medical insurance	II	Modified radical mastectomy
N10	37	Village	Married	–	Secondary school	New rural cooperative medical insurance	IV	Modified radical mastectomy
N11	46	Village	Married	Civil servants	University	Medical insurance	III	Breast reconstruction
N12	41	Village	Married	Farmer	Secondary school	New rural cooperative medical insurance	I	Breast conservative operation
N13	36	Village	Married	Worker	Secondary school	New rural cooperative medical insurance	II	Modified radical mastectomy
N14	38	Township	Married	Housewife	Secondary school	Medical insurance	I	Modified radical mastectomy

- Wear artificial breast—N1: "I bought an artificial breast online."
- N6: "I have to wear a bra with an artificial breast; otherwise, I still feel a little bit strange."

Theme 2: Social Isolation

Responses further revealed that patients with breast cancer avoid social contact due to their illness:

- N1: "I used to dance and go shopping, but now, I seldom go out. Some friends do not know I had breast cancer and asked me why I do not go out with them. I said that I work in Guangdong." [angry and impatient]
- N2: "I do not want to work anymore. My family also does not want me to go to work [after my illness]. I rarely go out, even if I am invited out to play."
- N6: "I am a patient now, not a healthy person. I haven't gone back to work, and I do not want to go back to work. I wear a mask when I go out and do not want others to see me. I do not want to talk to others."
- N10: "I have less contact with my friends. I can't go to work anymore. I have to take good care of myself."

Theme 3: Discrimination

Patients with breast cancer face discrimination because of changes in their social and family roles:

- N1: "A friend immediately blocked my WeChat after knowing that I had breast cancer. Some people will say, 'Why you wear that hat? You look like a 70-year-old woman"'.
- N2: "My neighbor is rather boring. He went to my workplace inquiring about my illness."
- N8: "Why is no one gossiping? Of course some people talk. 'She had cancer."'
- N13: "As soon as others hear about that cancer, they feel a little queer."
- N14: "My husband asked me to get reconstruction surgery."

Theme 4: Self-Perception

Patients with breast cancer experience humiliation and shame because they belittle their value or think they cannot achieve their goals:

- Depression and fear—N1: "I wish the tumor [had been] benign. My breast was cut off. I have no fun to live."
  N2: "It has been diagnosed for so long, but I still feel more or less uncomfortable." [wry smile]
  N3: "[At the time of diagnosis] I did not know much about the disease at that time. I was in a relatively low mood. I thought I would not have lived for long. It's like I was sentenced to death."
  N4: "When I was diagnosed, I felt like my life was over; it was like I was sentenced to death. Then, I was very flustered."
  N7: "I did not believe the diagnosis."
  N8: "I must be in a bad mood [sad]. It must be sad to be diagnosed. In the beginning, I could not accept it. I felt very miserable."
  N10: "I could not believe and accept the diagnosis at the beginning."
  N11: "I was confused when I was diagnosed."
  N12: "Then, I broke down. At that time [when I was diagnosed], my tears flowed out. After the doctor left, I ran to the toilet crying for a while."
  N13: "I cannot believe it. I just wonder how this disease must be on me. It is like a dream. I am still a little sad to say."
  N14: "Diagnosis is a little unacceptable at first."
- Conceal illness—N2: "My neighbor know [about] my disease. Many people do not know [about] my disease yet, and I do not want others know."
  N4: "Because there were a lot of people [who] did not want to let others know [about] their disease."
  N10: "Only family members and relatives knew [about the disease]; others did not."
  N12: "I do not tell others. Only my friends and relatives know; others did not know. Anyway, I cannot let them know and do not want them to see me."
  N13: "Few people know. My relatives know it. I cannot accept the disease, so I do not want to talk."
- Hope to be a healthy person—N4: "I do not want others consider me as a patient. My breast was cut off; I do not want others to look at my breast intentionally or unintentionally to see what my breast looks like after it was cut off. Notably, it will still be a little uncomfortable and a little embarrassed. Only my relatives, the closest relatives, and immediate relatives know. Others do not know, and I do not want others to visit me or care about me. To have family members accompanying me is enough. It is meaningless, and I have to deal with them."
- Worry about recurrence—N2: "Fear of recurrence; there is more or less a feeling of fear of recurrence."
  N14: "Fear of proliferation."
- Burden—N3: "I am still a little worried about the economic burden because it is long-term. My husband is busy. Additionally, if the treatment takes one year, I do not have much time to take care of the children and the elderly psychologically and physically. I'm a little worried."
  N4: "My child is still young. If something happen to me, I will be a little stressed."
  N6: "I feel that I am no longer as capable as before and have become a patient. Now, I'm sick. They have to take care of me and help me take care of my children."
  N8: "I'm afraid of getting my family in trouble. I cannot do anything now. My family members have to take care of me."
  N10: "It is inconvenient for me to move. I need someone else to take care of me." [embarrassed] "I hope I can move by myself. My mother-in-law takes care of many things, which is very troublesome for my family members. I hope to recover as soon as possible without bothering them so that I can feel better. I spend less time accompanying and mentoring my child. I also feel sorry for my child."
  N12: "Worry about the cost! I am afraid I cannot afford it; I feel remorseful because I have this disease."
  N14: "The family is still a little burdened financially."

Delphi Study

Cs and Ca were, calculated to be 0.793 and 0.939, respectively. The mean value of the expert authority coefficient (Cr) was 0.866. The Kendall's coefficient of concordance (W) was calculated to be 0.133–0.452 ($p < 0.05$). After two rounds of consultations, nine items were deleted, 19 were modified, and seven were merged. The initial 24-item scale was developed. I–CVI was calculated to be 0.73–1.0, and S–CVI/Ave was estimated to be 0.92.

Sample Characteristics

A total of 218 questionnaires were distributed, and 200 valid questionnaires were recovered. The valid recovery rate was 91.74%. Respondents were between 29 and 62 years of age. Furthermore, the mean age was 45.405 years ($SD = 6.55$). Details are shown in **Table 2**.

Two items ("My social activities have decreased because of my illness"[t = -2.881, p = 0.005] and "I felt miserable and emotionally devastated when diagnosed"[t = -1.373; p = 0.173]) were eliminated as they did not meet the criteria of discriminative validity. The participants' total scores for each item were listed sequentially by numeric value (from the lowest to highest) for the assessment of internal criterion validity. The difference between the total scores of the lower 27% and the upper 27% of the distribution was analyzed by an independent two-sample t-test. We deleted items with a two-tailed $p \geq 0.05$ or $t < 3$. Three items ("I feel bothered by chemotherapy-induced hair loss, pigmentation, and weight changes [$r = 0.271$, $p < 0.01$]," "My social activities have decreased because of my illness [$r = 0.284$, $p < 0.01$]," and "I felt miserable and emotionally devastated when diagnosed [$r = 0.108$, $p < 0.01$]") were eliminated since there was a higher α on both the total scale and subscales. All p of inter-scale and inter-subscale correlation coefficients were < 0.01. The relationships between the scores of the Breast Cancer Stigma Scale and the Chinese version of the Social Impact Scale were examined to assess criterion validity. Pearson's correlation coefficients were considered no less than 0.3. Therefore, we deleted items that were less than 0.3. Four items ("If I do not wear prosthetic breasts or take other measures, body asymmetry caused by surgery will make my center of gravity unstable," "I feel bothered by chemotherapy-induced hair loss, pigmentation, and weight changes," "My social activities have decreased because of my illness," and "I felt miserable and emotionally devastated when diagnosed") were eliminated. The Cronbach's α coefficient method aims to observe the change in the reliability coefficient of the total quantity table after deleting an item. If the Cronbach's coefficient of the total quantity table increases significantly after deleting an item compared with the original coefficient, it indicates that the item has low homogeneity with other items, and is deleted. In this study, the Cronbach's coefficient of the total amount table was calculated first and then calculated after deleting an item. If the latter was greater than the former, the item was

TABLE 2 | Sample characteristics.

Variable	Group	n	(%)
Age	18–44	99	49.5%
	45–54	86	43.0%
	≥55	15	7.5
Ethnicity	Ethnic Han	198	99.0
	Minority	2	1.0
Religion	Yes	2	1.0
	No	198	99.0
Place of residence	City	46	23.0
	Township	71	35.5
	Village	83	41.5
Marital status	Married	192	96.0
	Single	8	4.0
Occupation	Farmer	62	31.0
	Worker	36	18.0
	Civil servants	7	3.5
	Teachers	13	6.5
	Freelance professional	34	17.0
	Others	48	24.0
Employment status	Unemployed	86	43.0
	Employed	79	39.5
	Retired	13	6.5
	Others	22	11.0
Education level	Secondary school or below	125	62.5
	High school or technical secondary school	26	13.0
	College	27	13.5
	University or above	22	11
Family income status (RMB/month/per person)	≤1,000	48	24.0
	1,000–2,000	59	29.5
	2,000–5,000	80	40.0
	≥5,000	13	6.5
Medical insurance	Urban basic health insurance	1	0.5
	New rural cooperatives medical service	26	13.0
	Self-paying	113	56.5
	Others	60	30.0
Family history	Yes	13	6.5
	No	187	93.5
Stage of breast cancer	I	48	24.0
	II	95	47.5
	III	50	25.0
	IV	7	3.5
Type of surgery	Standard radical surgery	16	8.0
	modified radical mastectomy	112	56.0
	Extended radical surgery	19	9.5
	Mastectomy+breast reconstruction	43	21.5
	breast-conserving surgery	10	5.0
Adjuvant therapy	Chemotherapy	79	39.5
	Chemotherapy+Radiation therapy	15	7.5

(Continued)

TABLE 2 | (Continued)

Variable	Group	n	(%)
	Chemotherapy+Hormone therapy	17	8.5
	Chemotherapy+ Targeted therapy	25	12.5
	Radiation therapy+Hormone therapy	1	0.5
	Hormone therapy	2	1.0
	Comprehensive therapy	49	24.5
	None	12	6.0
Time since diagnosis (months)	<1	1	0.5
	1–11	24	12
	12∼23	23	11.5
	24–35	139	69.5
	≥36	13	6.5
Time since surgery (months)	0∼	4	2
	1∼	30	15
	12’	19	9.5
	24∼	142	71
	36∼	5	2.5
Psychological counseling	Yes	5	2.5
	No	195	97.5

deleted. Hence, four items were deleted, resulting in a final scale of 20 items.

Structural Validity

To identify the underlying components of the Breast Cancer Stigma Scale items, we performed two rounds of EFA. The data were suitable for EFA with a Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy with a value of 0.789 and a highly statistically significant Bartlett Test of Sphericity ($P < 0.0001$). EFA revealed six eigenvalues greater than 1, explaining 67.50% of the variance. A Scree plot was used to examine changes in the eigenvalue. We explored changes in the eigenvalues by using the scree plot to determine the number of factors to be retained. A sharp drop was shown in the plotline slope after four factors. In addition, we considered the clinical significance, and deemed it inappropriate to exclude these items as they were all significant for the construct. Two eigenvalues and their items were deleted due to lesser theoretical correlation, and the items with loading below 0.40 (“My life and work were affected after my illness,” “If one looked down on me knowing that I was sick, I would hide him,” “I think the treatment makes my body incomplete,” “I feel self-blame because of the economic pressure and care pressure caused by my illness,” and “I was unable to take care of my family due to my illness”). The remaining 15 items were retained for further EFA. The KMO measure of sampling adequacy was 0.792 and was highly statistically significant. Bartlett Test of Sphericity suggested that the data were still suitable for EFA. Four factors were retained according to the inspection of the scree plot and contributed 69.443% to the explained variance. Details of the results of EFA are shown in **Table 3**.

Reliability Assessment: Internal Consistency, Split-Half Reliability, and Test–Retest Reliability

As shown in **Table 4**, the Cronbach’s α coefficient, the split-half reliability coefficient, and the test-retest reliability coefficient for the 15-item Breast Cancer Stigma Scale and that of factors were all above 0.75. **Table 4** elaborates on the reliability correlations of the Breast Cancer Stigma Scale.

External Validity

Concerning external validity, we examined criterion validity. The correlation coefficient between the Breast Cancer Stigma Scale’s 15-item total score and the Chinese version of SIS’s 24-item average score was 0.641 ($p < 0.001$). There were significant correlations between the Breast Cancer Stigma Scale’s 15-items and all of the Chinese versions of SIS domains.

DISCUSSION

This study aimed to develop and verify the construct validity of the newly created the Breast Cancer Stigma Scale. The 15-item scale comprises four factors: self-image impairment, social isolation, discrimination, and internalized stigma. The scores of the expert consultation indicated that the scale has adequate content validity. Factor analysis findings suggest that the scale has an acceptable component construct. Other findings indicated highly estimated internal consistency, split-half reliability, and test–retest reliability. These results indicate that the 15-item Breast Cancer Stigma Scale is a valid and reliable instrument to assess stigma status in patients with breast cancer. Therefore, this Breast Cancer Stigma Scale can serve as a unique instrument for the assessment of perceived stigma among patients with breast cancer in China and potentially abroad.

Interviews revealed that stigma might emerge at different stages of a patient’s illness. Stigma is a significant contributor to low self-esteem, depression, and a tendency toward social isolation, which may hinder recovery at any stage of the illness, resulting in changes in social roles, acceptance, and challenges related to employment. Therefore, an accurate assessment of the stigma associated with breast cancer is in the patient’s best interest.

There is a strong linear correlation between the Breast Cancer Stigma Scale and the Social Impact Scale. The Social Impact Scale is a broad scale used for patients with all types of chronic illness, while the Breast Cancer Stigma Scale is used specifically for patients with breast cancer and is more unique in evaluating breast cancer-related stigma. Factor analysis indicated that a 15-item scale with four factors is optimal. Of the four factors of the Breast Cancer Stigma Scale, factors 1 (self-image impairment) and 4 (internalized stigma) were used to evaluate the self-stigma of patients with breast cancer. When coping with breast cancer, perceived stigma was assessed by factors 2 (social isolation) and 3 (discrimination). These findings were consistent with the definition of the stigma that we expounded in the Introduction. Furthermore, compared to 24 items on the Social Impact Scale,

TABLE 3 | Item factor loadings (*n* = 200).

Items	Factor 1 Body-image impairment	Factor 2 Social isolation	Factor 3 Discrimination	Factor 4 Internalized stigma
1. I care about the changes to my breasts.	0.781			
2. I feel I am imperfect after surgery.	0.857			
3. I do not want to see or touch the scars left by surgery.	0.743			
4. After the surgery, I feel more anxious and less confident about my appearance than before.	0.849			
5. I feel the treatment has made me less physically attractive and less feminine.	0.846			
6. I do not think I am a healthy person.	0.428			
7. I cover my breasts when I am intimate with my partner.		0.767		
8. I am afraid of intimate physical contact, such as hugging.		0.845		
9. People usually sympathize with me because of my illness.			0.717	
10. I often feel people staring at me after my diagnosis.			0.951	
11. After my illness, I often hear people secretly talking about me after my diagnosis.			0.937	
12. I was ridiculed for wearing a hat due to the loss of hair caused by chemotherapy.			0.477	
13. I do not want anyone other than those closest to me to know I have been diagnosed with breast cancer.				0.834
14. I feel unnatural when someone looks at my chest.				0.729
15. I do not want anyone to see how I look after my illness.				0.841

there are only 15 items on the Breast Cancer Stigma Scale. The shorter length of the new scale may improve completion rates with acceptable reliability and validity.

To the best of our knowledge, only one scale has been developed recently to assess stigma in patients with breast cancer. The Breast Cancer Stigma Scale for use with Arab patient populations (BCSS-A), consisting of a 12-item questionnaire, was using a sample of 59 women (Dewan et al., 2020). The Cronbach's alpha coefficient of the BCSS-A was 0.79, the content validity of S-CVI was 1.0, and the item-CVI ranged from 0.85 to 1.0. The BCSS-A predominantly focuses on health-related stigma: perceived danger, blame, concealability, disruptiveness, esthetics, and shaming and devaluation of patients or their families. However, the total number of participants was 59, most of whom were married and on hormonal therapy. Therefore, it is difficult to generalize their findings to patients undergoing other treatments or single women. In this study, the total variance explained was 69.443%, and it was higher than the total variance of other cancer-related stigma scales.

Our study has several strengths. First, a significant strength of this research was that the scale was developed based on Chinese patients' cultural context and experiences with breast cancer. Second, to ensure the integrity of the information and the scale, patients' stigma status, conceptualization, and development of an initial item pool were based on various methods. Through a rigorous instrument development process and iterative scale validation, a reliable instrument has been tested for patients with breast cancer with a potentially stigmatized condition. Third, stigma was directly associated with patients' mental health. Shame and embarrassment stemming from stigmatization may compromise patients' body image and lead to psychological distress. The Breast Cancer Stigma Scale may provide a useful screening measure for identifying patients with a potentially stigmatized condition and provide those affected patients with appropriate psychological support.

TABLE 4 | Reliability correlations for the Breast Cancer Stigma Scale (*N* = 200).

	Cronbach's α	Split-half reliability	Test–retest reliability
Body-image impairment	0.882	0.903	0.919*
Social isolation	0.849	0.855	0.904*
Discrimination	0.750	0.803	0.884*
Internalized stigma	0.785	0.767	0.941*
Total	0.860	0.911	0.947*

**P < 0.01 (2-tailed).*

There are some limitations to this study. First, we did not examine the confirmatory factor analysis of the Breast Cancer Stigma Scale. Therefore, it is important to confirm the factor structure in future studies. Second, the Breast Cancer Stigma Scale was developed based on the theory of perceived stigma. Focusing on perceived stigma only in patients with breast cancer was considered one of the strengths of the Breast Cancer Stigma Scale compared with the Social Impact Scale. However, more studies with larger sample sizes are needed to confirm this advantage. In addition, our study recruited participants conveniently and only from one hospital.

CONCLUSION

The newly developed Breast Cancer Stigma Scale offers a valid and reliable instrument for assessing the stigma of patients with breast cancer in clinical and research settings. To the best of our knowledge, there has been no specific measurement of breast cancer-related stigma in China. The scale was tested and modified after a literature review, two rounds of Delphi panels, and qualitative interviews, thus capturing the spectrum of stigma relevant to patients with breast cancer. This study is a step forward for breast cancer stigma-related studies and provides a reference for developing effective interventions for those with potentially stigmatized conditions.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available from the corresponding author on reasonable request.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Hunan Cancer Hospital Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

XB, SL, AC, PN, XX, YX, and XL wrote the first draft of the manuscript. XB, SL, and XL involved in the data collection and statistical analysis. All authors reviewed the manuscript, contributed to critical changes, and approved the final version of the manuscript.

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SUPPLEMENTARY MATERIAL

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Research on body image cognition, social support and illness perception in breast cancer patients with different surgical methods

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In parallel with the rapid rise in breast cancer incidence, there is also a noticeable rise in the number of patients who experience persistent negative body image cognition after breast cancer surgery. This study aimed to explore the differences in illness perception, social support, and body image cognition among breast cancer patients with different surgical methods, and the correlation, regression, and mediation among the three variables. The Brief Illness Perception Questionnaire (BIPQ), the Social Support Rating Scale (SSRS) and the Body Image Cognition after Breast Cancer Questionnaire (BIBCQ) were used to evaluate breast cancer patients' illness perception, social support and body image cognition. Data analyses were performed by descriptive statistics, independent samples t-test, analysis of variance (ANOVA), Pearson correlation, and linear regression. The mediation was explored by the PROCESS V3.3. The study found that breast cancer patients undergoing radical mastectomy (RM) and modified radical mastectomy (MRM) demonstrated more negative illness perception, body image cognition, and lower social support compared with the patients receiving nipple-sparing mastectomy (NSM; $p<0.05$). The subscale cognitive representation (CR) of BIPQ was strongly positively correlated with BIBCQ ($p<0.05$). Illness perception positively predicted body image cognition ($p<0.01$), while social support negatively predicted body image cognition. Social support partially mediated illness perception and body image cognition, exhibiting a positive role in post-operative body image cognition.

KEYWORDS

breast cancer, illness perception, social support, breast conservation, body image cognition

Introduction

According to the World Cancer Report released by the WHO International Agency for Research on Cancer (IARC), breast cancer has become the world-leading cancer in 2020, and it ranks first among Chinese women, accounting for 17.1% of all female malignancies. Surgery is the first choice for patients with early-stage breast cancer (Burstein et al., 2021). At present, about 70% of breast cancer patients in China have received the modified radical mastectomy (MRM) named Auchincloss surgery. Compared with the radical mastectomy (RM) named Patey surgery that removes the pectoralis minor, MRM preserves the pectoralis minor. The MRM reduces the scope of surgery and the size of the scar. It also improves patients' quality of life after surgery. The diseased breast is removed in the process of RM and MRM. The nipple-sparing mastectomy (NSM) preserves the appearance of the breast and guarantees adequate skin coverage for subsequent breast reconstruction (He et al., 2021). Though clinical trials have demonstrated that the survival outcomes have no significant difference in patients who received NSM or MRM (He et al., 2021), the prevalence of NSM in China remains lower than that in developed countries (Kummerow et al., 2015), especially in northern China (Yu et al., 2020).

Breasts, as an external organ and symbol of women, are subject to long-term external gazes and comments (Li et al., 2017). In the absence of breast tissue, patients' femininity is undermined (Jabłoński et al., 2018), generating a sense of shame and affecting their body image cognition (Saeed et al., 2021). In 1935, Schilder pointed out that body image cognition was an impression of the body formed by self-observation and others' evaluations (Schilder, 1999). Female breast cancer patients are particularly susceptible to body image disturbances in response to the breast deficiency caused by breast surgery, especially in the first year after the operation (Rosenberg et al., 2020). Although breast conservation is crucial to a patient's post-operative body image cognition (Rosenberg et al., 2020), Chinese breast cancer patients are more concerned with the treatment outcomes (Yu et al., 2020). A complete cure of cancer is more important for them, thus they would rather suffer more psychological damage to guarantee the treatment effect. It can be supported by the fact that Chinese women preferred MRM and RM to treat breast cancer, even if they were eligible for breast conservation surgery (Kummerow et al., 2015). This is closely related to the high implementation rate of MRM in China (He et al., 2021). Hence, it is worth investigating the impact of mastectomy and breast conservation surgery on Chinese patients' body image cognition. On the other hand, an emerging number of psychosocial oncology research mainly focused on the relationship between body image cognition and emotional reaction (Rosenberg et al., 2020; Zamanian et al., 2021), shame (Trindade et al., 2018) and quality of life (Aydın Sayılan and Demir, 2020; Rosenberg et al., 2020) whereas the influence of illness perception on body image cognition has rarely been explored.

Illness perception is defined as a patient's understanding of the disease after combining professional advice, past experiences, family opinions, communications among patients and the various reactions after treatment. It is based on a theory proposed by Leventhal et al. in the 1980s (Leventhal and Contrada, 1998). When patients feel less control over the disease, they are inclined to believe that this disease will result in serious consequences. It incurs the incidence of negative attitude and poor treatment adherence in chronic diseases such as chronic kidney disease (CKD; Xiong et al., 2018), heart disease (Mosleh and Almalik, 2016) as well as tumors (Czerw et al., 2020). It is common for patients with advanced stages of cancer to suffer more physical and mental pain. However, the breast cancer perception varied across cultures and individual backgrounds. A Korean study found no significant relationship between illness perception and breast cancer stage. Since Asian women tended to avoid being informed of their own disease, they obtained less medical condition about themselves (Lee et al., 2019). In contrast to Dutch breast cancer patients, early-stage breast cancer patients in Japan were more pessimistic about their illness perception (van der Kloot et al., 2016). In addition, the post-operative appearance of breasts caused by different surgical methods influenced illness perception. There is a study showing that the breast reconstruction surgery restored the appearance of the breast and reduced the patient's perceived sense of threat from breast cancer (Fanakidou et al., 2018). Therefore, it is necessary to investigate the breast cancer perception of patients who underwent different surgical methods in China.

Social support refers to a social network that provides any type of help to an individual in distress. Various individuals and social groups such as family members, friends, neighbors and colleagues can be sources of support (Hou et al., 2020). Patients diagnosed with cancer are under considerable stress (Eckerling et al., 2021). As a mediation factor of stress and multiple psychosomatic disorders (Usta, 2012), social support is considered to modulate the cognition of cancer patients (Zamanian et al., 2021). The previous literature documented some relationships between social support, illness perception and body image cognition. A negative correlation between social support and illness perception was revealed (Aydın Sayılan and Demir, 2020). Further analysis identified social support as an important mediator of psychological changes in breast cancer patients. In the mediation effect of social support, patients' psychological resilience indirectly affected the quality of life (Zhang et al., 2017). Social support toward breast cancer patients developed them adaptive coping styles, which reduced the symptoms of depression and anxiety (Zamanian et al., 2021). Family is an indispensable unit of social support in Chinese culture. Post-operative women coped better with changes in body image cognition when they received positive social support from their families (Liu et al., 2021). Intimate support from spouses was also highly associated with the recovery of body image cognition (Jabłoński et al., 2018).

Patients after breast conservation surgery had higher social support than the patients after MRM. This difference further affected the patient's quality of life (Zhang et al., 2017). These evidences show that social support combined between hospital and family will enhance the effectiveness of breast cancer post-operative rehabilitation (Li et al., 2019).

Accordingly, the present study recruited patients diagnosed with breast cancer, with a first focus on the differences in illness perception, social support and body image cognition among patients receiving NSM, MRM, and RM. After different surgical procedures, we hypothesized that patients undergoing NSM would exhibit the most positive illness perception, body image cognition and the highest social support. Patients undergoing RM would report the most negative illness perception, body image cognition and the lowest social support. Secondly, the correlations among illness perception, social support and body image cognition would be investigated. In order to analyze the relationship between illness perception, social support and body image cognition, the surgical method and other demographic variables were set as control variables. The regression from illness perception to social support and body image cognition would be explored, also the regression from social support to body image cognition. In the mediation model, illness perception would be assumed as the independent variable, social support would be assumed as the mediator variable, and body image cognition would be assumed as the dependent variable. We hypothesized that social support would play a protective role in mediating the relationship between illness perception and body image cognition in post-operative breast cancer patients.

Materials and methods

Source of data

During October 2021 and January 2022, purposive sampling was undertaken from the medical recorded system in the oncology department and breast surgery department of Binzhou Medical University Hospital, using a convenience sampling strategy. The hospital was a governmental three-grade hospital located in Shandong Province, a province in eastern China with better economic conditions.

Participants

The inclusion criteria for participation were that patients:

1. Female; 2. Were at least 18 years of age; 3. Had been diagnosed with breast cancer; 4. Received surgery for breast cancer; 5. Voluntarily participated in this study and gave written informed consent. The study excluded patients with concomitant diseases and active psychiatric disorders.

Study design

Participants were provided with paper questionnaires including a demographic and clinical form, BIPQ, SSRS and BIBCQ. The author of the study, who is specialized in medical psychology, conducted face-to-face interviews in private rooms with the patients to understand their psychological situation. After explaining the purpose of this research to the participants, they were asked to fill out the questionnaires based on their most recent reality. Data collection took 20–30 min on average. During the interview, patients could withdraw if they so desired. The questionnaire scores were used to assess patients' psychological status.

Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Binzhou Medical University (no. 2021-271). Informed consent was obtained from all individual participants included in the study.

Measurements

Demographic and clinical form

The form was designed by the researchers. Demographic form included age, education level, marital status, residence, family income and occupation. Patients completed this part themselves. Clinical form included time since diagnosis, cancer stage, surgical method and current therapy. The current therapy referred to the therapy the patient was receiving at the time the investigator recruited them. The author filled out this section based on the patient's medical records.

Illness perception

The Brief Illness Perception Questionnaire (BIPQ) consisted of nine items (Broadbent et al., 2006). The first eight items (consequences, timeline, personal control, treatment control, identity, concern, understanding, emotional response) were rated by a Ten-point Likert-type scale (0 = not at all, 10 = severely affected my life), ranging from 0 to 80. The last item (causes) was an open-ended question that asked patients to list three contributing factors to the disease. The eight items could be regrouped into three subscales: cognitive representation (consequences, timeline, personal control, treatment control, identity), emotional representation (concern and emotional response), and illness comprehensibility (understanding). To determine the extent to which the illness was considered harmful or harmless, an overall score was calculated. When the total scores were higher, the illness was perceived as more threatening.

Social support

The Social Support Rating Scale (SSRS) was used to measure the level of social support an individual received (Hou et al., 2020). It had 10 items in total, including three subscales that measured objective social support, subjective social support and availability. Objective social support (OSS) consisted of the material assistance an individual received, as well as the presence and participation of their social networks. Subjective social support (SSS) represented the emotional support experienced by the individual. It referred to the emotional experience and satisfaction that the individual was supported in society. Availability (AVL) meant the use of social resources by an individual. Respondents were assessed by a Four-point Likert-type scale (1 = poor social support to 4 = rich social support). The aggregate score indicated the degree of social support.

Body image cognition

The Body Image after the Breast Cancer Questionnaire (BIBCQ; Baxter et al., 2006) is a 53-item questionnaire that measured body image cognition along six dimensions: vulnerability (*VS*; to breast cancer), body stigma (BSS; impairment of femininity and attractiveness), limitations (LS; daily functioning), body concerns (BCS; satisfaction with body image), transparency (TS; appearance after breast surgery) and arm concerns (ACS; any discomfort in the arm) in the context of breast cancer. Both questions 1–28 (1 = strongly disagree to 5 = strongly agree) and questions 29–53 (1 = never to 5 = always) were scored on a Five-point Likert-type scale. Negative responses to body image cognition contributed to higher scores.

Data analysis

The Statistical Package for Social Sciences (SPSS) 20.0 was used for data analysis. Measurement data was described as mean ± standard deviation. To examine the effects of different surgical methods and demographic-clinical characteristics on social support, illness perception, and body image cognition, independent samples *t*-tests and ANOVA were used. The effects of the variables on each other were examined by means of Pearson correlation. A *p*-value of 0.05 was considered statistically significant.

Taking illness perception as the independent variable (X), social support as the mediator variable (M), and body image cognition as the dependent variable (Y), the mediation analysis was based on Model 4 in SPSS PROCESS V3.3(by Andrew F. Hayes; Igartua and Hayes, 2021) with bootstrapping (5,000 bootstrapped samples) using 95% confidence intervals (CI). Both demographic and clinical factors involved in this study were set as covariates. The effect was termed significant when the 95% CI excluded 0. The bootstrap test was devised into three steps. First, test the significance of a for model $X \rightarrow M$. Second, test the significance of b, c' for model $X \rightarrow Y$ and $M \rightarrow Y$. Third, if c' was not significant, then there was a complete mediation. If c', a and b were significant, plus $c' < c$, there was a partial mediation. a*b/c denoted a mathematical interpretation for the mediation effect.

Results

Participants

A total of 173 breast cancer patients initially participated in the study, of which 157 eventually completed all questionnaires, with an effective response rate of 90.75%. Participants included patients who underwent RM (Patey operation), MRM (Auchincloss operation) and NSM (nipple-sparing mastectomy). The mean age of participants was 49.9 years (range = 31–76 years, SD = 8.65). More detailed demographic and clinical characteristics are presented in Table 1.

TABLE 1 Demographic and clinical characteristics (*n*=157).

Variable		Number (%)
Age (years)	≤45	55 (35.03%)
	>45	102 (64.97%)
Education level	Below junior high school	116 (73.89%)
	High school	22 (14.01%)
	University or above	19 (12.10%)
Marital status	Married	140 (89.17%)
	Divorced/widowed	17 (10.69%)
Residence	Urban area	75 (47.77%)
	Rural area	82 (52.22%)
Family income	≤3,000	73 (46.50%)
	>3,000	84 (53.50%)
Occupation	Fixed job	37 (23.57%)
	No fixed job	120 (76.43%)
Time since diagnosis	<1 month	36 (22.93%)
	1–3 months	36 (22.93%)
	3–6 months	48 (30.57%)
	>6 months	37 (23.57%)
Cancer stage	I	9 (5.57%)
	II	110 (70.06%)
	III	35 (22.29%)
	IV	3 (1.19%)
Surgical method	NSM	21 (13.38%)
	MRM	112 (71.34%)
	RM	24 (15.29%)
Current therapy	Chemotherapy	117 (74.52%)
	Chemotherapy and others (radiation, targeted therapy or endocrine therapy)	40 (25.48%)

NSM, nipple-sparing mastectomy; MRM, Modified radical mastectomy (Auchincloss operation); RM, Radical mastectomy (Patey operation).

The comparison of illness perception, social support, and body image cognition under different demographic and clinical characteristics

The scores of the SSRS were statistically different in age ($p < 0.01$), marital status ($p < 0.01$), residence ($p < 0.05$), family income ($p < 0.01$) and occupation ($p < 0.01$). The scores of the BIPQ differed significantly in age ($p < 0.05$), marital status ($p < 0.01$) and family income ($p < 0.05$). More data are given in Table 2.

Body image cognition, social support and illness perception in patients with different surgical methods

As shown in Table 3, compared with the MRM group and the RM group, the NSM group scored lower on three subscales of the BIBCQ: body stigma (BSS; $p < 0.01$), body concerns (BCS; $p < 0.01$), transparency (TS; $p < 0.01$), and the total score ($p < 0.01$). The NSM group had the highest score

TABLE 2 The differences in social support and illness perception among different sample characteristics groups (n=157).

Variable	Social support			Illness perception		
	Mean ($x \pm s$)	t/F	p	Mean ($x \pm s$)	t/F	p
Age		4.33**	<0.001		2.32*	0.022
≤45	33.82 ± 7.07			32.60 ± 9.90		
>45	28.95 ± 6.52			36.42 ± 9.84		
Education level		1.05	0.352		0.93	0.396
Below junior high school	30.24 ± 7.13			35.66 ± 10.47		
High school	31.05 ± 7.40			34.32 ± 7.99		
University or above	32.74 ± 6.38			32.42 ± 9.00		
Marital status		3.99**	<0.001		4.48**	<0.001
Married	31.41 ± 6.56			33.91 ± 9.51		
Divorced/widowed	24.47 ± 8.38			44.76 ± 8.76		
Residence		2.35*	0.020		1.09	0.277
Urban area	32.03 ± 7.44			34.17 ± 10.42		
Rural area	29.40 ± 6.55			35.91 ± 9.58		
Family income		3.63**	<0.001		2.00*	0.047
≤3,000	28.53 ± 6.29			36.78 ± 9.38		
>3,000	32.50 ± 7.26			33.61 ± 10.34		
Occupation		3.01**	0.003		1.53	0.128
Fixed job	33.65 ± 8.25			32.89 ± 9.67		
Unfixed job	29.73 ± 6.45			35.76 ± 10.04		
Time since diagnosis		0.69	0.559		1.56	2.02
<1 month	30.22 ± 6.74			35.28 ± 8.12		
1–3 months	29.47 ± 7.76			37.64 ± 10.77		
3–6 months	31.60 ± 6.92			32.92 ± 9.38		
>6 months	31.00 ± 7.05			35.22 ± 11.35		
Cancer stage		1.80	0.149		1.44	0.233
I	32.78 ± 6.69			32.89 ± 7.15		
II	30.77 ± 7.35			35.08 ± 10.10		
III	30.49 ± 6.24			34.69 ± 9.99		
IV	22.00 ± 1.73			46.33 ± 11.37		
Current therapy		1.13	0.260		0.92	0.358
Chemotherapy	30.28 ± 7.21			35.51 ± 9.86		
Chemotherapy and others (radiation, targeted therapy or endocrine therapy)	31.75 ± 6.68			33.28 ± 7.21		

*$p < 0.05$; **$p < 0.01$.

TABLE 3 The body image cognition, social support and illness perception scores after different surgical methods (n=157).

	NSM① ($n=21$)	MRM②($n=112$)	RM③ ($n=24$)	F	p	LSD
Body image cognition	93.57 ± 17.04	111.62 ± 20.20	120.21 ± 22.02	10.41**	<0.001	①<②<③
Vulnerability	24.86 ± 7.68	26.98 ± 8.00	27.13 ± 7.94	0.67	0.514	/
Body stigma	21.29 ± 6.57	28.14 ± 7.61	32.79 ± 9.51	12.31**	<0.001	①<②<③
Limitations	18.24 ± 3.10	19.91 ± 4.39	21.04 ± 5.30	2.30	0.104	/
Body concerns	12.52 ± 2.89	15.09 ± 3.34	15.21 ± 3.72	5.44**	0.005	①<②<③
Transparency	9.71 ± 4.20	13.35 ± 3.52	15.00 ± 3.60	12.69**	<0.001	①<②<③
Arm concerns	6.95 ± 2.31	8.14 ± 2.86	9.04 ± 2.96	3.11*	0.047	①<②<③
Social support	35.38 ± 6.51	30.11 ± 7.12	29.08 ± 5.83	5.95**	0.003	③<②<①
Objective support	9.76 ± 1.30	8.32 ± 1.71	8.72 ± 1.98	6.32**	0.002	③<②<①
Subjective support	18.24 ± 4.72	15.13 ± 4.32	14.63 ± 3.84	5.14**	0.007	③<②<①
Availability	7.38 ± 2.50	6.65 ± 2.82	5.71 ± 2.00	2.26	0.108	/
Illness perception	31.05 ± 7.87	34.96 ± 9.92	39.17 ± 10.83	3.86*	0.023	①<②<③
Cognitive representation	18.14 ± 4.59	20.81 ± 6.35	22.83 ± 7.17	3.13*	0.046	①<②<③
Emotional representation	9.52 ± 4.91	9.96 ± 5.04	10.63 ± 4.95	0.29	0.753	/
Illness comprehensibility	3.38 ± 2.71	4.19 ± 2.98	5.71 ± 3.18	3.76*	0.025	①<②<③

*$p < 0.05$; **$p < 0.01$.

of the SSRS ($p < 0.01$) and the lowest score of the BIPQ ($p < 0.05$).

Correlations between illness perception, social support and body image cognition

There was a significant positive correlation between the BIPQ and the BIBCQ ($p < 0.01$) as well as their subscales. Both BIPQ and BIBCQ were negatively correlated with the SSRS and its subscales ($p < 0.05$). Other correlation coefficients are shown in Figure 1.

Regressions between illness perception, social support and body image cognition

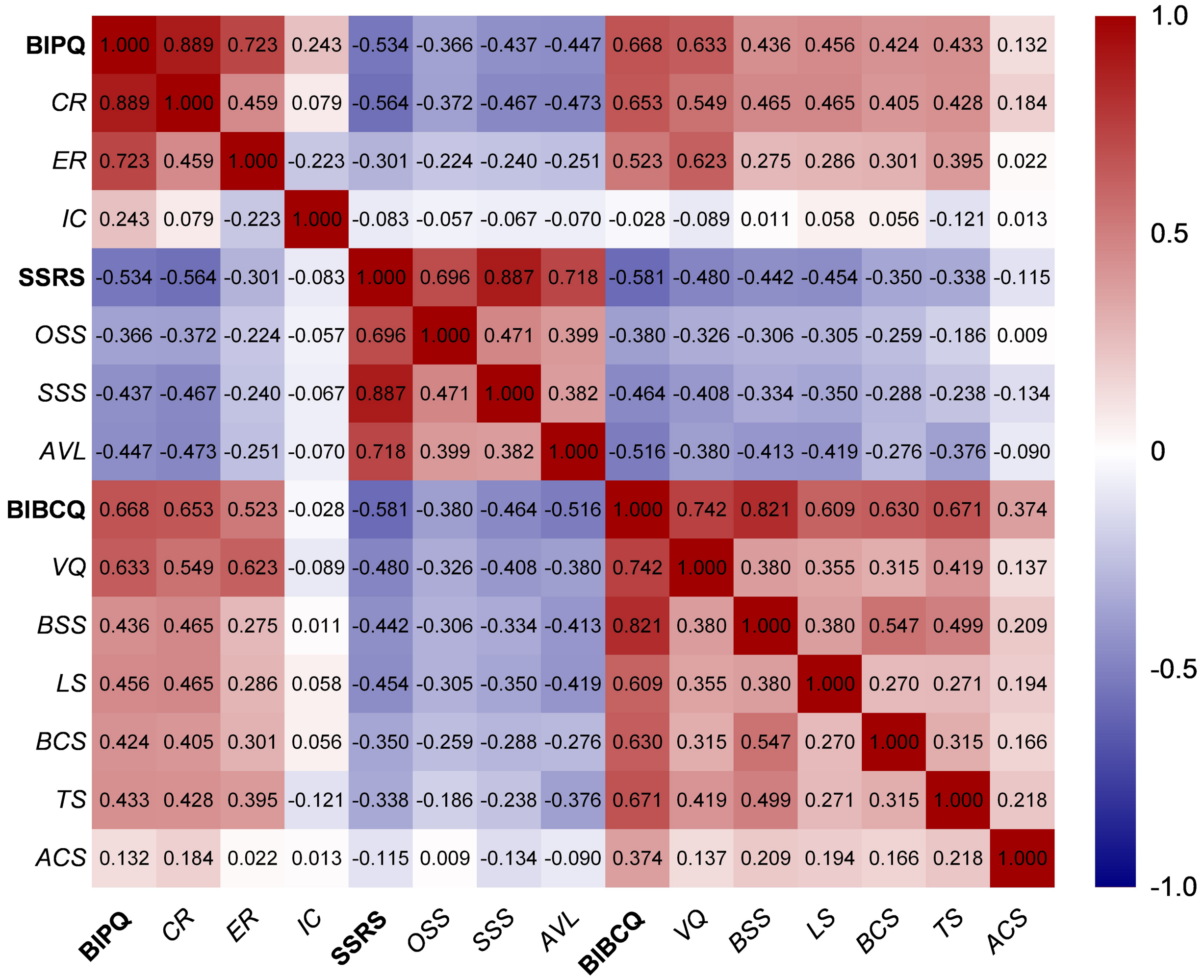
Age, education level, marital status, residence, family income, occupation, time of diagnosis, cancer stage, surgical method and current therapy were set as covariate. The regression analysis results are shown in Table 4. It revealed that illness perception positively predicted body image cognition ($\beta = 0.582$, $p < 0.01$), 51.7% of body image cognition could be effectively explained by illness perception. Illness perception negatively predicted social support ($\beta = -0.401$, $p < 0.01$), 38.8% of social support could be effectively explained by illness perception. Illness perception and social support negatively predicted body image cognition ($\beta = -0.304$, $p < 0.01$), 57.3% of body image cognition could be effectively explained by illness perception and social support.

The mediation effect of social support on the relationship between illness perception and body image cognition

In the mediation model, illness perception was set as the predictor variable, body image cognition was set as the outcome variable, and social support was set as the mediator variable. Age, education level, marital status, residence, family income, occupation, time of diagnosis, cancer stage, surgical method and current therapy were set as covariate, with repeated sampling up to 5,000 times. The direct effect of illness perception on body image cognition was 0.581, with a 95% CI of [0.4553, 0.7067], excluding 0, indicating that the direct effect was significant. Illness perception influenced body image cognition through an indirect pathway partially mediated by social support, resulting in an indirect effect of 0.123, with a 95% CI of [0.0609, 0.2001], excluding 0, indicating that the indirect effect was significant (Table 5). The effect size of mediation was $a*b/c = 20.14\%$. Figure 2 illustrates the mediation effect among illness perception, social support and body image cognition.

Discussion

In this study, patients undergoing NSM had more positive illness perception, body image cognition, and higher social support than patients undergoing MRM and RM. Illness perception negatively predicted patients' social support while it positively predicted patients' body image cognition. In the mediation effect, social support came out to be a partial mediator. In the presence of social support, the positive predictive effect of illness perception on body image perception is diminished.



	BIPQ	CR	ER	IC	SSRS	OSS	SSS	AVL	BIBCQ	VQ	BSS	LS	BCS	TS	ACS
BIPQ	1.000	0.889	0.723	0.243	-0.534	-0.366	-0.437	-0.447	0.668	0.633	0.436	0.456	0.424	0.433	0.132
CR	0.889	1.000	0.459	0.079	-0.564	-0.372	-0.467	-0.473	0.653	0.549	0.465	0.465	0.405	0.428	0.184
ER	0.723	0.459	1.000	-0.223	-0.301	-0.224	-0.240	-0.251	0.523	0.623	0.275	0.286	0.301	0.395	0.022
IC	0.243	0.079	-0.223	1.000	-0.083	-0.057	-0.067	-0.070	-0.028	-0.089	0.011	0.058	0.056	-0.121	0.013
SSRS	-0.534	-0.564	-0.301	-0.083	1.000	0.696	0.887	0.718	-0.581	-0.480	-0.442	-0.454	-0.350	-0.338	-0.115
OSS	-0.366	-0.372	-0.224	-0.057	0.696	1.000	0.471	0.399	-0.380	-0.326	-0.306	-0.305	-0.259	-0.186	0.009
SSS	-0.437	-0.467	-0.240	-0.067	0.887	0.471	1.000	0.382	-0.464	-0.408	-0.334	-0.350	-0.288	-0.238	-0.134
AVL	-0.447	-0.473	-0.251	-0.070	0.718	0.399	0.382	1.000	-0.516	-0.380	-0.413	-0.419	-0.276	-0.376	-0.090
BIBCQ	0.668	0.653	0.523	-0.028	-0.581	-0.380	-0.464	-0.516	1.000	0.742	0.821	0.609	0.630	0.671	0.374
VQ	0.633	0.549	0.623	-0.089	-0.480	-0.326	-0.408	-0.380	0.742	1.000	0.380	0.355	0.315	0.419	0.137
BSS	0.436	0.465	0.275	0.011	-0.442	-0.306	-0.334	-0.413	0.821	0.380	1.000	0.380	0.547	0.499	0.209
LS	0.456	0.465	0.286	0.058	-0.454	-0.305	-0.350	-0.419	0.609	0.355	0.380	1.000	0.270	0.271	0.194
BCS	0.424	0.405	0.301	0.056	-0.350	-0.259	-0.288	-0.276	0.630	0.315	0.547	0.270	1.000	0.315	0.166
TS	0.433	0.428	0.395	-0.121	-0.338	-0.186	-0.238	-0.376	0.671	0.419	0.499	0.271	0.315	1.000	0.218
ACS	0.132	0.184	0.022	0.013	-0.115	0.009	-0.134	-0.090	0.374	0.137	0.209	0.194	0.166	0.218	1.000

FIGURE 1
Heatmap of Pearson correlations in BIPQ, SSRS and BIBCQ. Figure represents the coefficients of the correlation analysis of illness perception, social support, and body image cognition. BIPQ, the brief illness perception questionnaire; CR, cognitive representation; ER, emotional representation; IC, illness comprehensibility; SSRS, social support rating scale; OSS, objective social support; AVL, availability; BIBCQ, the body image after the breast cancer questionnaire; VQ, vulnerability scale; BSS, body stigma scale; LS, limitation scale; BCS, body concerns scale; TS, transparency scale; ACS, arm concerns scale.

As a threatening stressor, cancer and cancer related treatment interfere with patients' cognitive function, resulting in hypersensitivity and sensory distortion (Eckerling et al., 2021). Surgical methods played a significant role in patients' post-operative illness perception. For one thing, this study found that the cognitive representation (CR) in BIPQ had different outcomes in the groups of NSM, MRM and RM. Patients receiving NSM had lower CR scores in BIPQ, indicating that those patients perceived less threat from breast cancer. Different surgical methods, including the size of the incision, the preservation of the breast, and the degree of muscle and nerve damage, can affect the patient's breast cancer perception after surgery. For another, there was no significant difference in the emotional representation (ER) in patients receiving NSM, MRM, and RM. It was explained that a diagnosis of breast cancer put patients' health at risk (Liu et al., 2021), therefore, a pervasive negative impact will be exerted on the patients emotion regardless of the type of surgery.

Breasts are often regarded as an intimate part of a woman's body. As a result of a breast surgery, women typically experience cosmetic impairment and body image concerns (Rosenberg et al., 2020). It is possible for patients to maintain their natural breast shape and structure after NSM (Zehra et al., 2020), thereby patients receiving NSM in this study experienced more positive body image cognition related to their appearance. On the other hand, an absent breast causing by MRM and RM seriously affected the breast's appearance. Patients who underwent MRM or RM developed more negative body image cognition (Zehra et al., 2020), exhibiting the higher scores of body stigma (BSS), body concerns (BCS) and transparency (TS) in the BIBCQ. Since the patients were worried about that others would notice their absent breast after surgery, they felt more concerned about their bodies,

TABLE 4 Regressions of illness perception, social support and body image cognition.

Dependent variable		**Independent variable**	***β***	***t***	***p***
Body image cognition ($R^2 = 0.517$)	c	Illness perception	0.582	9.06**	<0.001
Social support ($R^2 = 0.388$)	a	Illness perception	−0.401	−5.55**	<0.001
Body image cognition ($R^2 = 0.573$)	b	Social support	−0.304	−4.37**	<0.001
	c′	Illness perception	0.460	6.90**	<0.001

**$p < 0.01$.

TABLE 5 Results of mediation effect.

Mediation		***β***	**Boot SE**	**95%CI**	
				LLCI	**ULCI**
Direct effect	Illness perception ➛ Social support	−0.418	0.073	−0.5613	−0.2744
	Social support ➛ Body image cognition	−0.294	0.069	−0.4293	−0.1581
	Illness perception ➛ Body image cognition	0.581	0.636	0.4553	0.7067
Indirect effect	Illness perception ➛ Social support ➛ Body image cognition	0.123	0.036	0.0609	0.2001

Boot SE, standard error; Boot LLCI, lower limit of 95%; Boot ULCL, upper limit of 95%.

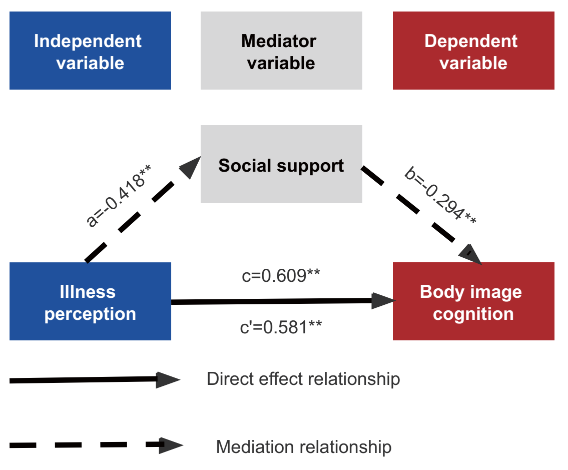


FIGURE 2
The diagram of the mediation effect of social support (***p*<0.01).

thus the senses of shame and transparency increased. The most negative body image cognition was observed in patients after RM. The diseased breast was removed in the process of RM and MRM, but RM caused wider tumor dissection, more damage of the muscle and the nerve, and larger scars. These surgical injuries led to further deterioration of body image cognition.

There are two sources of explanation for the body image cognition after surgery. In the aftermath of breast surgery, patients' self-consciousness about appearance was worse than expected, this discrepancy left them ashamed of their bodies (Rosenberg et al., 2020). In east Asia, inferiority and embarrassment imposed by social culture and prejudice were also responsible for body image cognitive impairment (Amini-Tehrani et al., 2021). The stigma of breast cancer has been rooted in cultural beliefs concerning bad luck, karma, and other traditional practices. Despite emigration to western countries, Chinese-American women were unable to reduce the stigmatization of breast cancer after surgery (Warmoth et al., 2017). In the long run, these changes led to the social isolation and poor quality of life in breast cancer patients (Liu et al., 2021), suggesting the importance of presurgical counseling to help patients understand body image changes rationally (Rosenberg et al., 2020), and to prevent self-devaluation through breast prosthesis, reconstruction and cognitive therapy (Zehra et al., 2020).

There was no significant difference in limitation scale (LS) in BIBCQ among patients undergoing NSM, MRM, and RM. This is because there is a standardization process for the daily care of patients in the three-grade hospitals (Lovelace et al., 2019), including the guidance of restoration of various physical functions. Professional nursing staff ensured the rehabilitation of patients' physical functions during hospitalization. Nevertheless, the high scores of emotional representation (ER) in BIPQ and vulnerability (VL) in BIBCQ shows that there were negative emotions among breast cancer patients during their hospitalization, attributed to the lacking of high-quality cancer related psychological support (Li et al., 2019). Consequently, psychosocial support in addition to medical social support is rather crucial for breast cancer patients.

Patients undergoing NSM required higher medical costs and more time for the subsequent therapy (Yu et al., 2020). With more material support, these patients scored higher in the objective social support (OSS) in the SSRS. In addition, patients with NSM experienced little appearance change, leading to less social isolation of their social network (Liu et al., 2021). Therefore, they had a better emotional experience with their family members, friends and other groups. Since a stable spouse meant easier access to a reliable source of livelihood and ongoing emotional support (Ghizzani et al., 2018), married patients scored higher in SSRS. These reasons led to higher subjective social support (SSS) scores in patients after NSM. Among the patients undergoing different surgery, there was no significant difference in availability (AVL) in SSRS, indicating that all breast cancer patients had strong need for social support after surgery.

In the mediating effect model, the positive predictive effect of illness perception on body image cognition was lessened in the presence of social support. As such, it has been speculated that a sense of belonging to a social group or community may moderate the adverse cognition in breast cancer patients. Furthermore, there is psychobiological evidence that in groups with high social support, the neurohypophysis released more oxytocin to strengthen the bonds between individuals (Riem et al., 2021). Inhibition of the HPA axis reduced the stress-induced adverse health conditions (Iob et al., 2018). The mediating effect ratio of social support accounted for 20.14% of the total effect, implying other potential mediators such as hope (Hsu et al., 2021) and shame (Amini-Tehrani et al., 2021).

In this study, in comparison with the elderly patients, empathy and support were more easily accessible to younger patients because of the mismatch between age and the life-threatening disease (Champion et al., 2014). Thus the younger patients with early-onset cancer had higher social support and less negative illness perception. Rural patients face challenges such as financial problems, transportation barriers and limited opportunities for clinical trials (Charlton et al., 2015). The choices of treatment regimens and nutritional status of patients are largely determined by financial status (Sun et al., 2021), increasing a sense of control over breast cancer (Rosenberg et al., 2020). Similar studies have also found correlations between education deficiency, less income and lower social support (Coughlin, 2020).

This study showed that post-operative breast cancer patients exhibited lower social support. The cultural reluctance of Asian women and the suppression of negative emotions commonly prevent them from seeking psychological and emotional assistance (Warmoth et al., 2017). Inadequate patient-doctor communication and the cost of specialized psychotherapy are impediments to cancer psychosomatic recovery in China, calling for improvements in the doctor-patient relationship, from authorization to collaboration, as well as more health insurance coverage for cancer psychological care (Amini-Tehrani et al., 2021).

In conclusion, there is an urgent need for individualized treatment of cancer patients based on demographics and personality characteristics. If a patient is eligible, Chinese surgeons should recommend breast conservation for the breast cancer patient to ensure more positive illness perception and body image cognition and higher social support after surgery. Oncologists, psychiatrists, psychotherapists, social workers and relatives together constitute the social support network for breast cancer patients, which can accommodate patients' postoperative cognitive change in a supportive manner.

Limitations

Several limitations may affect the generalizability of this study. First, this study has limited sample cases. The subsequent study will collect more patients with different surgical methods. It will also be supplemented with the surgical methods that account for a smaller proportion in China, such as the breast conservation surgery, to verify the generalizability of the current study. Second, the causality of a patient's psychological status cannot always be determined by cross-sectional studies. A wider selection of breast cancer patients will be studied in the future, including multicenter longitudinal studies in different hospitals and regions, to further investigate the influence of surgical methods on patients' physical and mental recovery. Third, given that the participants in this study were all cancer patients, we minimized their fatigue in completing the questionnaire. Therefore, there are many more variables that could be incorporated in the future studies to explore their impact on the psychological status of breast cancer patients, such as medical insurance, breast cancer genotype, and patients past experience.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Binzhou Medical University. The patients/participants provided their written informed consent to participate in this study.

Author contributions

YL and SS contributed to the study's conception and design and wrote the first draft of the manuscript. Material preparation, data collection and analysis were performed by YL, WL, YM, XY, and HZ. All authors commented on previous versions of the manuscript and read and approved the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articless/10.3389/fpsyg.2022.931679/full#supplementary-material

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