

REVIEW

Body image and cancer-related lymphoedema: A systematic review

Emma Byrne | Jane Gaffey | Lucy Hayden | Adam Daly | Pamela Gallagher |
Simon Dunne 

School of Psychology, Dublin City University,
Dublin, Ireland

Correspondence

Simon Dunne.
Email: simon.dunne@dcu.ie

Funding information

Irish Cancer Society

Abstract

Objective: Cancer-related lymphoedema is a common side effect of cancer, affecting 24%–49% of people with cancer. Body image contributes to the well-being of individuals with this condition. This systematic review aimed to explore, for the first time, the state of the science concerning body image in cancer-related lymphoedema, including how body image is measured and variables associated with body image concerns.

Methods: Six databases were systematically searched for peer-reviewed articles describing empirical quantitative studies where body image was measured with a reliable and valid measurement tool in adults with cancer-related lymphoedema.

Results: Nine studies with 977 participants were included. The studies involved individuals who had experienced breast, head and neck, melanoma, and urogenital cancers and developed lymphoedema. There was considerable heterogeneity in body image measures used, precluding meta-analysis. The following variables were associated with increased body image concern: higher body integrity beliefs, experience of physical changes (e.g. pain) and differences in sensation and function, including changes in appearance related thoughts, feelings and emotions. Several studies described behavioural and psychological interventions which positively impacted body image outcomes in individuals with lymphoedema relating to specific cancers.

Conclusion: Regular screening for body image concerns could encourage more positive body image awareness in individuals with cancer-related lymphoedema and lessen some of its associated negative consequences. Future longitudinal and individual differences research in this area is important to inform intervention development. There is also need for a more standardised approach to the study and measurement of body image in people with cancer-related lymphoedema.

KEYWORDS

body image, cancer, cancer survivorship, cancer-related lymphoedema, neoplasms, quantitative research, systematic review

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *Psycho-Oncology* published by John Wiley & Sons Ltd.

1 | BACKGROUND

Advances in treatment have increased cancer survival rates worldwide.¹ Depending on the type of cancer, approximately 50% of people will live for 10 years or more after diagnosis.² Following treatment, it is estimated that 25% of cancer survivors will experience one or more physical or psychological consequences every day.³ One such consequence, cancer-related lymphoedema, is a progressive long-term condition involving swelling or oedema due to excess accumulation of lymphatic fluid in the body.⁴ Lymphoedema can be congenital or acquired and cancer-related lymphoedema is one of the most common consequences of many cancers and their treatment.^{5,6} Between 24% and 49% of individuals who have experienced cancer develop secondary lymphoedema.⁷ Cancer-related lymphoedema accounts for most incidences of acquired lymphoedema and stems from a wide range of cancers, including, but not limited to: breast cancer, melanoma, gynaecologic cancer, lymphoma, sarcoma and genitourinary cancer.^{8,9} Typically cancer-related lymphoedema occurs up to 2 years after surgery; however, at risk individuals remain vulnerable for the duration of their lives.^{8,10} Despite its prevalence, some healthcare providers continue to overlook, under-diagnose or late diagnose, and/or undertreat, individuals with cancer-related lymphoedema.¹⁰⁻¹²

Due to the nature of the condition, body image issues have a substantial impact on the physical, psychological and social well-being of individuals with cancer-related lymphoedema. Body image is a person's perceptions, thoughts and feeling about their body, which can also incorporate the perspectives of other people and society, or personal, mental and emotional representations of one's body.^{13,14} Physical issues arising from bodily changes in lymphoedema can include pain, discomfort and increased susceptibility to skin infections; psychological issues can incorporate decreased self-confidence, loss of, or diminished sexual function, distress and anger; and social issues can include social isolation due to embarrassment and shame about a changed body.^{8,15} These often profound consequences can lead to lifelong appearance and body function changes. The associated psychological impact of which can complicate and further burden the mental health of those affected.^{11,16} Furthermore, any of these issues can have a considerable, sustained impact on the quality of life of the individual and the self-management of their condition.¹⁷⁻¹⁹ Body image disturbance may also be of particular concern among individuals with cancer-related lymphoedema, as swelling of the limbs and associated appearance changes have been found to impact upon individuals' perceptions of their sexual desirability or attractiveness and their abilities to perform simple daily functions such as looking in the mirror, or buying clothing.¹⁵

Despite broader recognition of the importance of body image issues in cancer-related lymphoedema,¹⁵ to our knowledge, there has been no systematic examination of the literature on this topic to date. With this in mind, we undertook a systematic review to examine the state of the science regarding body image in cancer-related lymphoedema. Specifically, we were interested in looking at the variables associated with body image concerns among people with cancer-related lymphoedema, and how body image is measured in extant

literature on the topic. We anticipate that the findings will help highlight and promote awareness of body image issues for practitioners and inform the development and delivery of interventions to promote positive body image in cancer-related lymphoedema.

2 | MATERIALS AND METHODS

This systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines.²⁰ It was registered with the following PROSPERO protocol registration number: CRD42021235584.

2.1 | Search strategy

Initial searches were conducted on 19 January 2021 on the following databases, using a combination of free text and controlled vocabulary terms (Supplementary Online Appendix A outlines the search terms used on each database) relating to body image and lymphoedema: Medline, PsycINFO, PubMed, CINAHL, Embase, and Web of Science (Social Sciences Citation Index only). An updated search was conducted on 19 March 2023 using the same search terms and databases.

2.2 | Selection criteria

A full list of inclusion and exclusion criteria is outlined in Table 1 below. We used Grogan, Cash and colleagues'^{15,16} definition of body image as described above. There were no date limiters.

Following the removal of duplicates from the initial database searches, titles and abstracts were independently screened for eligibility by two reviewers (E.B & L.H). L.H and A.D screened the studies from the updated searches as E.B was unavailable. Papers sourced from the updated search that were deemed as eligible were sourced as full texts and independently assessed for inclusion by L.H. and A.D. Full texts were obtained and examined independently using the previously outlined inclusion and exclusion criteria.

In both the initial and updated search, any inconsistencies between the reviewers were resolved through discussion and a third author (S. D.) was available to resolve disputes/facilitate discussion as necessary. The following information was extracted from the included studies: (1) author name(s), (2) country of origin, (3) study design used, (4) sample size, (5) number and type of data collection sites, (6) participant gender and age, (7) cancer type if specified, (6) body image measurement tool used, (7) findings relating to variables associated with body image concerns in individuals with cancer-related lymphoedema.

2.3 | Quality assessment

A quality assessment was undertaken to evaluate the risk of bias of the studies. Included articles were assessed by two reviewers (E.B and L.H)

TABLE 1 Article inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
1. Peer reviewed articles describing empirical studies involving individuals with a diagnosis of cancer-related lymphoedema.	1. Articles describing body image concerns which are not specifically related to lymphoedema.
2. Body image was measured with a reliable and valid body image specific measurement tool.	2. Editorials, reviews, notes, letters to the editor, guidelines, conference proceedings, continuing education units, theoretical papers, unpublished theses.
3. Participants were at least 18 years old.	3. Non-English language studies.
4. Quantitative studies.	4. Primary aim of the studies is body image/QoL measurement tool validation.
	5. Qualitative studies.

using a 12 item checklist from previous research.^{21,22} L.H and A.D repeated this process for studies obtained from the updated search. Each checklist item was scored as follows: 2 for 'Yes', 1 for 'Partial' and 0 for 'No'. Articles which scored 17 or over were deemed to be of good quality (maximum score was 24), those with a score of between 9 and 16 were considered acceptable quality and articles that scored 8 and under were of poor quality. Any differences of appraisal were resolved by discussion between the two reviewers. A third author (S.D.) was available to resolve disputes/facilitate discussion as necessary.

2.4 | Statistical analysis

Due to the heterogeneity of the measurement tools used, a meta-analysis was not possible to conduct in this instance. Consequently, we undertook a narrative synthesis of the included studies.

3 | RESULTS

Following database searching, 3068 articles were identified for possible inclusion (See Figure 1). Of these articles, 1226 were duplicates and were subsequently excluded. The titles and abstracts of the remaining 1842 articles were screened, resulting in 147 full texts identified for review. Nine articles identified met the inclusion criteria and were included in the review. Table 2 below summarises the main characteristics of the included articles.

3.1 | Study characteristics

The nine articles²³⁻³¹ included data from 997 participants from the following regions: Europe ($n = 2$),^{29,31} America ($n = 4$),^{25,26,28,30} Australia ($n = 2$)^{24,27} and Canada ($n = 1$).²³ Study sample sizes ranged from 9 - 304 participants and involved people who had experienced the following types of cancer: breast,^{24,26-28,30} head and neck,^{23,25} gynaecological,³¹ melanoma or urogenital.²⁹ The majority of studies included female participants only^{24,26-28,30,31} with three including both male and female individuals.^{23,25,29} Participants' ages ranged from 20 to 85 in two studies where only age range was reported.^{26,29}

Six studies outlined participants' mean age, ranging from 52.18-64.9^{23-25,27,28,30} and a final study identified participants' median age and accompanying age range (58.5 ± 13.9 for individuals with lymphedema and 55.7 ± 8.6 for individuals without lymphedema).³¹

Four studies recruited participants from multiple settings,^{24,27-29} including hospital and national cancer registries, treatment clinics, advocacy organisations and through general media. The remaining five articles included participants recruited from single sites.^{23,25,26,30,31}

3.2 | Body image measurement tools

Body image was assessed using a diverse range of tools across the nine studies. Table 3 below outlines the included measures, only two of which were specifically developed for use among cancer survivors.^{35,37} Three of the included measures did not contain separate domains relating to body image, and simply provide an overarching body image score; Modified Blepharoplasty outcome evaluation (MBOE),³² BIS³⁴ and BAS-2.³⁶ Of the remaining scales, the DAS59³³ and the MBSRQ³⁵ tap into five and four general body image domains respectively that are not specific to cancer, while the BIRS³⁷ taps into six body image domains, developed specifically for women diagnosed and treated for breast cancer (Appearance; health; physical strength; sexuality; relationships; and social functioning).

3.3 | Findings by study design

Four articles described longitudinal randomised controlled trials,^{23,27-29} four of the included studies were cross-sectional in nature^{24,26,30,31} and one was prospective.²⁵

3.3.1 | Intervention studies

The four RCT's described different interventions (submental liposuction, therapeutic, strength training exercise programme, wearing compression garments) and tested the body image of participants in the intervention group compared to a control group who did not receive the intervention. Those who received these interventions

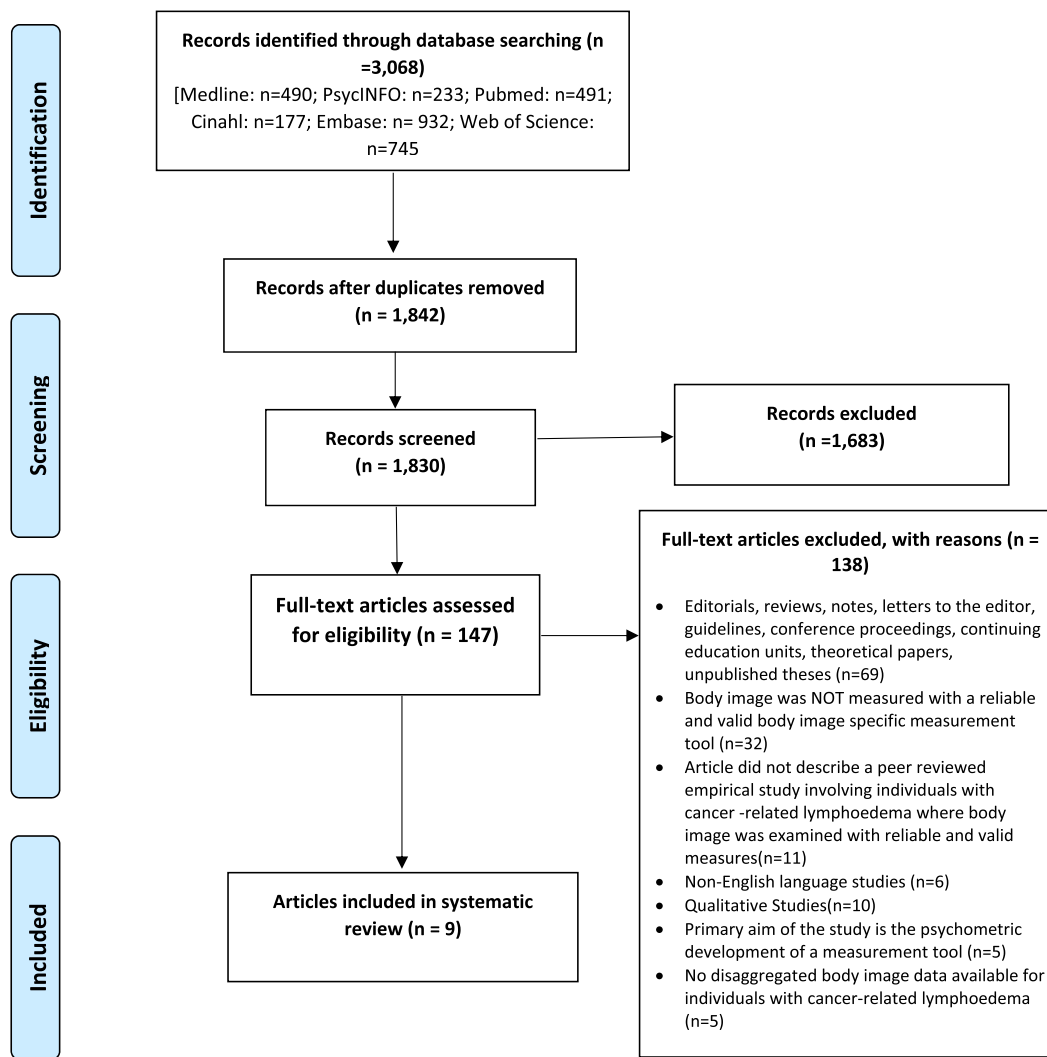


FIGURE 1 Number of articles screened, assessed and included in the review.

reported improved body image perception following liposuction, participating in a therapeutic writing group and strength training.^{23,27,28} In the first of these studies,²³ head and neck cancer patients with post-treatment cervical lymphoedema who were treated with submental liposuction and had been disease-free for a year were found to have significantly improved body image in total scores, and individual domain scores for all subscales, on the DAS-59 ($p < 0.05$) compared to similar patients who had a 6 months waiting period without surgery. In another study with a sample of women with breast cancer,²⁷ women with lymphoedema from the intervention group, who received a web-based psychological intervention comprising a structured writing exercise plus usual care, were found to have lower body image distress (assessed by the Body Image Scale (BIS)) at 1 week and 1-month post-intervention ($p < 0.05$, $d_s = 0.43-0.46$) but not at 3-months post-intervention compared to women with lymphoedema from a control group who received an unstructured expressive writing task plus usual care. Women with lymphoedema from the intervention group also had higher scores on body appreciation compared to controls at 1-week, 1-month and 3-months post-intervention ($p < 0.01$, $d_s = 0.61-0.70$). In the third

study,²⁸ women with lymphoedema following breast cancer treatment who received a twice-weekly strength training intervention administered over a year had significantly improved change scores (calculated by the difference in % change pre- and post-treatment) compared to equivalent controls who were put on a waiting list for treatment in total scores on the Body image and relationships scale (BIRS) ($p < 0.001$) and its *strength and health* and *appearance and sexuality* sub-scales ($p < 0.05$) but not on the *social barriers* sub-scale. In the fourth included study, use of graduated compression garments in individuals with melanoma and/or urogenital cancer, following groin lymph node dissection did not reduce lymphoedema occurrence or severity or lead to improvements in body image.²⁹

3.3.2 | Observational studies

Cross-sectional In the first of the four included cross-sectional studies,²⁴ body image disturbance in women with breast cancer-related lymphoedema was significantly positively associated with depression, anxiety, stress and scores on the personal control,

TABLE 2 Characteristics of included articles.

Authors	Country	Study design	Number and type of setting	Sample size, gender split	Cancer type	Body image measurement tool	Body image related findings	Quality assessment rating
Alamoudi et al. ²³	Canada	Longitudinal RCT	1 site	20 (17 males; 3 females)	Head and neck	Modified Blepharoplasty outcome evaluation Derriford appearance scale (DAS)	The receipt of submental liposuction significantly improved body image concerns.	Good quality
Alcorso & Sherman ²⁴	Australia	Cross-sectional	Multiple sites: Community based cancer organisation and 3 lymphoedema clinics	166 females	Breast	Modified body image scale (BIS)	Body image disturbance was significantly positively associated with depression, anxiety, stress and scores on the personal control, and perceived treatment effectiveness.	Good quality
Brake et al. ²⁵	USA	Prospective	1 site	9 (6 males; 3 females)	Head and neck	Derriford appearance Scale Modified Blepharoplasty outcome evaluation	Submental liposuction was found to significantly improve the appearance and quality of life of patients with lymphoedema, improving self-perception and self-confidence.	Good quality
Martin and Hanson ²⁶	USA	Cross-sectional	1 site	27 female	Breast	Multidimensional body-self relations questionnaire	A higher percentage of participants with lymphoedema were dissatisfied with the mid and upper torso than participants without lymphoedema.	Good quality
Sherman et al. ²⁷	Australia	Longitudinal RCT	Multiple sites: breast cancer consumer organisations, hospitals and lymphoedema clinics	304 female	Breast	Body image scale Body appreciation scale	Women with/without breast cancer-related lymphoedema in the My changed body writing group demonstrated lower body image disturbance and higher body appreciation compared to women with/without breast cancer-related lymphoedema in unstructured expressive writing alone group.	Good quality
Speck et al. ²⁸	USA	Longitudinal RCT	Multiple sites-State/hospital cancer registries and general media	234 female	Breast	Body image and relationships scale	Progressive strength training improved elements of body image, such as self-perception of appearance, health, physical strength, sexuality, relationships, and social functioning for participants with and without lymphoedema	Good quality

(Continues)

TABLE 2 (Continued)

Authors	Country	Study design	Number and type of setting	Sample size, gender split	Cancer type	Body image measurement tool	Body image related findings	Quality assessment rating
Stuiver et al. ²⁹	The Netherlands	Longitudinal RCT	2 cancer treatment centres	80 (43 males; 37 females)	Melanoma and urogenital	Body image scale	The use of graduated compression stockings did not reduce the incidence of lymphoedema or body image issues.	Good quality
Teo et al. ³⁰	USA	Cross-sectional	1 site	54 female	Breast	Body image scale	In participants with lymphoedema, pain was a predictor of depressive symptoms and body image dissatisfaction mediated the relationship between pain intensity and depressive symptoms.	Good quality
Abakay et al., ³¹	Turkey	Cross-sectional, between groups	1 site	103 female	Uterine and Ovarian	Body image scale	An increase in lymphoedema symptoms lead to lower body image scores; however, the lymphoedema group had higher overall body image compared to the non-lymphoedema group	Good quality

perceived treatment effectiveness and consequences subscales of the Revised Illness Perception Questionnaire (all p s < 0.01, r s = 0.36–0.55) but negatively associated with self-regulation of affect (p < 0.01, r = –0.25). In the same study, a series of hierarchical multiple linear regressions were conducted to determine factors predictive of psychological depression, anxiety and stress respectively among women with breast cancer-related lymphoedema; in these analyses, body image disturbance was a significant predictor of each outcome at step 1 (p s \leq 0.01) and an interaction effect was found between age and body disturbance in relation to depression and anxiety only at step 2 (p s < 0.05), indicating that older women with greater body image disturbance were more distressed.

The second cross sectional study²⁶ described differences between women with breast cancer with respect to their body image depending on whether or not they presented with lymphoedema. The authors found no significant differences between the lymphoedema (n = 10) and non-lymphoedema (n = 17) group with respect to all ten subscales of the Multidimensional Body-Self Relations Questionnaire (MBSRQ; p s > 0.005). They also reported a descriptive analyses of participants' scores on each item of the Body Areas Satisfaction Subscale of the MBSRQ, highlighting that a higher percentage of participants with lymphoedema were more dissatisfied with the following aspects of their bodies compared to participants without lymphoedema: mid-torso (90% dissatisfied compared to 58% dissatisfied) and upper torso (60% dissatisfied compared to 40% dissatisfied). The authors also highlighted differences in participants' scores on the Appearance Evaluation and Appearance Orientation subscales of the MBSRQ; 47% of the no lymphoedema group reported dissatisfaction in their overall appearance compared with 40% of the lymphoedema group, while 29% of the no lymphoedema group rated low scores on their appearance orientation compared to 10% of the lymphoedema group. The authors suggested the latter results indicated that the lymphoedema group expended a lot of time and/or energy on their appearance.

The third cross-sectional study on women with lymphoedema secondary to breast cancer³⁰ found that participants who were married had lower body integrity beliefs (p < 0.05, r = –0.312). In a series of hierarchical multiple regression analyses, body image dissatisfaction significantly predicted depressive symptomatology when entered at a second block (p < 0.01) following pain intensity, and body integrity beliefs respectively; in both cases, the presence of body image dissatisfaction at the second step meant that pain intensity and body integrity beliefs no longer predicted depressive symptomatology. Upon further analysis of these relationships, the authors found that body image dissatisfaction fully mediated the relationship between pain intensity and depressive symptomatology (μ = 0.2, σ = 0.09) and body integrity beliefs and depressive symptomatology (μ = 0.82, σ = 0.32).

In the remaining cross-sectional study,³¹ an increase in lymphoedema symptoms negatively affected body image scores in gynaecological cancer patients. In turn, decreased levels of body image resulted in increased kinesiphobia. BIS scores were higher for patients with lymphoedema in comparison to patients without

TABLE 3 Body image measurement tools.

Measurement tool	No. of items	Brief description	Domains relating to body image	Validated with a sample of cancer patients/survivors	Included in articles
Modified Blepharoplasty outcome evaluation (MBOE) ³²	6	Items tap into appearance (personal/others perspective), function and surgical modification of problem area, which are not specific to cancer	No separate domains	No	Alamoudi et al. ²³ Brake et al. ²⁵
Derriford appearance scale (DAS59) ³³	59	Items tap into five domains of appearance concern, which are not specific to cancer, but validated for use in oncology settings	Five: General self-consciousness; social self-consciousness; negative self-concept; sexual and bodily self-consciousness of appearance; facial self-consciousness of appearance.	Yes	Alamoudi et al. ²³ Brake et al. ²⁵
Body image scale (BIS) ³⁴	10	Items tap into thoughts, feelings and behaviour and how it relates to one's body after cancer and/or treatment.	No separate domains	Yes	Alcorso & Sherman ²⁴ Sherman et al. ²⁷ Stuiver et al. ²⁹ Teo et al. ³⁰ Abakay et al. ³¹
Multidimensional body-self relations Questionnaire (MBSRQ) ³⁵	69	Items tap into four domains of body image that focus on cognitive, behavioural and affective components, which are not specific to cancer	Four: Appearance evaluation and orientation; fitness evaluation and orientation; health evaluation and orientation; and illness orientation.	No	Martin & Hanson ²⁸
Body appreciation scale (BAS-2) ³⁶	13	Items tap into acceptance of, and/or favourable opinions about, one's body, which are not specific to cancer	No separate domains	No	Sherman et al. ²⁷
Body image and relationships scale (BIRS) ³⁷	32	Items tap into six body image domains, developed specifically for women diagnosed and treated for breast cancer	Six: Appearance; health; physical strength; sexuality; relationships; and social functioning	Yes	Speck et al. ²⁸

lymphoedema ($p < 0.08$ ($t = 2.69$)). In the same study, Spearman correlation was used to analyse the relationship between BIS scores and GPFBQ1-4-8 (Global Pelvic Floor Bother Questionnaire) scores, revealing a negative correlation between body image and stress urinary incontinence, urinary urge incontinence, and faecal incontinence.

Prospective Cohort Study Only one article was included describing a prospective cohort study²⁵ relating to the use of submental liposuction in individuals who had experienced head and neck cancer ($n = 10$). Participants with lymphoedema demonstrated improvements in their appearance after submental liposuction treatment on four out of five questions on the MBOE scale. Specifically, participants reported increases in their overall satisfaction with the appearance of their chin, their social networks' satisfaction with its appearance and their confidence that its appearance is the best it can be, and a decrease in their desire to surgically alter the appearance of their chin, in postoperative versus preoperative ratings (all $ps < 0.01$). The authors also reported a statistically significant improvement on the General Self-Consciousness of Appearance subsection of the

DAS95 and three questions from the Social Self-Consciousness of Appearance and the Negative Self-Concept subsections of the DAS95 (all $ps < 0.05$) following submental liposuction treatment. However, there were no statistically significant differences before and after liposuction treatment on overall scores for Social Self-Consciousness of Appearance or Negative Self-Concept subsections, nor were there statistically significant responses within the Sexual and Bodily Self-Consciousness of Appearance or the Facial Self-Consciousness of Appearance subsections of the DAS95. Finally, the authors reported significant improvements in "objective ratings" of appearance from two independent reviewers in relation to pre- and post-liposuction photographs of the participants ($p < 0.05$).

3.4 | Quality assessment

The quality assessment is summarised in Table 3 (with further details in Supplementary Online Table S1). Following the quality review, all articles were deemed to be of good quality. Key areas where studies

scored well included: having clearly stated aims, describing the main features of the population/design of the study, no evidence of selective reporting of and adequately discussed results, appropriate statistical method(s) used and relevant and the use of validated and well described measures. Key areas where studies were downgraded included: insufficient clearly documented participant eligibility and recruitment strategy and description of responders (and non-participants), the absence of a control group and the lack of justification of a sample size.

4 | DISCUSSION

To our knowledge, this is the first review to synthesise the extant published evidence on body image in cancer-related lymphoedema. Nine studies with 997 participants met the inclusion criteria and were included. The studies involved individuals with cancer-related lymphoedema who had experienced breast, head and neck, melanoma, gynaecological or urogenital cancers. Each article looked at body image in conjunction with one or more other variables ranging from a variety of interventions to psychological distress and depression. A wide range of body image measures were reported among studies ($n = 6$). Depression and Body Image Dissatisfaction were frequently reported as having strong associations with higher body integrity beliefs, experience of physical changes such as pain and differences in sensation and function, including changes in appearance-related thoughts, feelings and emotions.

The findings of the systematic review highlighted the potential positive association between negative affect and body image for people with cancer-related lymphoedema in two studies. In these studies, body image disturbance was positively associated with psychological distress, depression, anxiety and stress and body image dissatisfaction was reported to mediate the relationship between pain and symptoms of depression in women with breast cancer-related lymphoedema.^{24,30} As well as recognising the impact body image can have, these studies demonstrate the association between body image concerns, distress and disturbance and other psychological issues for individuals with cancer-related lymphoedema.

Some of the included studies also indicated that certain individuals with cancer-related lymphoedema may be more susceptible to body image concerns. Specifically, individuals with stronger body integrity beliefs, and those who encounter physical changes such as pain and differences in sensation and function including changes in appearance related thoughts, feelings and emotions experienced increased body image concerns.^{30,31} These issues indicates how body image changes can be linked to physical and psychological well-being. Considering body image issues are more than aesthetics, encompassing one's perceptions, emotions, and thoughts about one's body,³⁸ it may be useful to conduct further research to better understand the mechanisms behind these individual differences in body image concerns in individuals with cancer-related lymphoedema. In particular, it may be useful to understand the extent to which these differences relate to physical differences in the extent or visibility of

lymphoedema symptoms and/or individuals' pre-existing values and beliefs relating to their bodies as a means of identifying potential at-risk groups to target for body image interventions.

Articles included in the review also highlighted how behavioural and surgical interventions can have wide-ranging and positive impacts on body image in individuals with cancer-related lymphoedema. Regular physical activity in the form of strength training improved scores across all scales of the BIRS.²⁸ Women with breast cancer-related lymphoedema who participated in a study specific therapeutic creative writing course reported improvements in body perception scores overall and positive changes in depression, anxiety and self-compassion scores.²⁷ Individuals with head and neck cancer-related lymphoedema who received submental liposuction demonstrated an improvement in perception of appearance, self-confidence and quality of life.^{23,25} These studies highlight how such interventions positively affect body image perceptions of individuals with lymphoedema arising from specific cancers. However, future research among is required to ensure the utility of these interventions among the broader population of individuals with cancer-related lymphoedema, or their efficacy among individuals with lymphoedema arising from other cancers.

Many included articles involved women who had experienced breast cancer ($n = 5$). This is to be expected given the high incidence of breast cancer and an estimated 60% chance of lymphoedema development in breast cancer survivors.^{39,40} Whilst this is important, given the high incidence of breast cancer and women living with breast cancer related lymphoedema, there is need to undertake research with other cancer groups particularly those that are harder to reach (e.g. those affecting older men). Comparisons of body image scores across multiple cancer-related lymphoedema groups may be an important area for future research in order to establish the differential impact of cancer type on body image disturbances in cancer-related lymphoedema.

The measurement of body image concerns varied significantly across the included studies, precluding the ability to conduct a meta-analysis. Furthermore, studies which did not include a validated measure of body image/concerns were excluded from the review. Although some of these excluded studies reported relationships between body image and various aspects of cancer-related lymphoedema, they used other scales related to other constructs as proxy measures of body image, for example, the Lymphoedema Symptom Intensity and Distress Scale - Arm (LSIDS-A)⁴¹ and the Lymphoedema quality of life questionnaire (LYMQOL).^{42,43} Such approaches to reporting body image concerns in cancer-related lymphoedema are problematic as they employ sub-components of other constructs (e.g. quality of life) that have not been explicitly validated as body image measures. As indicated in Table 3, there were also a number of scales in the included studies that have either not been validated with a cancer-related sample, or do not contain cancer-specific items. Only the BIS³⁴ and BIRS³⁷ contained cancer/cancer-treatment-specific items; the former of these scales has been validated in a range of different cancer populations but only provides a total score for body image based on ten generic items, while the latter was specifically

developed for female breast cancer survivors only and contains six specific domains related to body image concerns in breast cancer. None of the body image measures included were specifically developed for individuals with cancer-related lymphoedema who may experience unique issues relating to their body image. For instance, while the BIS³⁴ and BIRS³⁷ contain some items that are specifically related to cancer treatment (e.g. relating to the appearance of one's scar or appearance changes arising from cancer treatment), none of the included scales contain items or domains that relate to body image issues arising from swelling limbs, skin infections or wearing compression garments. Considering these issues, and the heterogeneity in body image measurement across the included studies, there appears to be a need for a gold-standard approach to body image measurement in cancer-related lymphoedema, and potentially in the cancer survivorship literature more broadly. More specifically, there is a need for robust measures of body image that are validated specifically for cancer survivors, and which contain specific domains that are deliberately constructed to be relevant to salient body image concerns in cancer-related lymphoedema.

4.1 | Study limitations

This review has a number of limitations. Firstly, the studies included are published in English; there may be additional relevant research published in other languages. The findings of this review are also not applicable to individuals with primary lymphoedema; the review focussed solely on individuals who acquired lymphoedema as a result of cancer and or its treatment. Furthermore, in many included studies, body image was not a primary outcome of interest or the target of intervention; there is a need for more comprehensive programmes of future research and intervention with individuals with cancer-related lymphoedema which specifically target body image concerns as a primary outcome. Only three studies included male participants, and neither gender nor socio-demographic factors were used to compare body image scores in individuals with cancer-related lymphoedema in the included studies; further research is needed to elucidate the extent to which body image concerns in cancer-related lymphoedema may vary by age, gender or other socio-demographic factors. Finally, the considerable heterogeneity among body image measures used in the included studies prevented meta-analysis.

4.2 | Clinical implications

This review indicates that regular screening for body image concerns could encourage more positive body image awareness in individuals with cancer-related lymphoedema and lessen some of its associated negative consequences. Therefore, clinicians (e.g. oncologists, psycho-oncologists, and clinical nurses) should frequently screen for such concerns as part of their clinical practise. However, before this can be implemented, there is a need to develop a gold standard

approach to Body Image measurement for use among individuals with cancer-related lymphoedema.

By examining the effectiveness of previous interventions used to address body image issues, this review also has the potential to specifically inform clinicians and intervention developers in this area, as findings from included studies support the use of various pre-existing interventions whilst providing directions for future research. When body image concerns are detected, it may be useful for clinicians to refer patients to specific interventions that have been shown to reduce body image concerns among individuals with lymphoedema arising from specific cancers, such as liposuction,^{23,25} strength training,²⁸ and writing groups.²⁷ However, there is a need to understand the efficacy of such interventions across individuals with cancer-related lymphoedema more broadly. Furthermore, there may be specific individuals with cancer-related lymphoedema who are more susceptible to body image concerns (e.g. those with higher body integrity beliefs); future research and intervention-development in this area should consider whether supports to improve body image need to be more specifically tailored, or targeted, towards these potentially at-risk groups.

5 | CONCLUSIONS

To our knowledge, this is the first systematic examination of literature relating to body image and cancer-related lymphoedema. The review emphasises the importance of body image in the study of cancer-related lymphoedema. The review has identified a small body of high-quality extant research and intervention studies on this subject. The included studies identify some key variables that were found to be associated with body image disturbance and interventions which may be useful for improving body image outcomes in individuals with lymphoedema relating to specific cancers. The limited extant research also highlights the need for a more standardised approach to the measurement of body image, the need for greater comparison studies examining body image concerns among people with different types of cancer-related lymphoedema and the need for more longitudinal body image research in this area. It also identifies the necessity for further research looking at body image concerns among hard-to-reach groups of individuals with cancer-related lymphoedema (e.g. older men), where there are physical differences in the extent or visibility of lymphoedema symptoms and/or where individuals may hold pre-existing values and beliefs relating to their bodies, as a means of identifying potential at-risk groups to target for body image interventions.

AUTHOR CONTRIBUTIONS

Emma Byrne: Conceptualization; data curation and design; data analysis and interpretation; original manuscript preparation; writing, review and editing. **Jane Gaffey:** Data analysis and interpretation; original manuscript preparation; writing, review and editing. **Lucy Hayden:** Data curation; data analysis and interpretation. **Adam Daly:** Data curation; data analysis and interpretation. **Pamela Gallagher:**

Conceptualization; data curation and design; supervision; interpretation; manuscript review and editing. **Simon Dunne**: Conceptualization; data curation and design; supervision; interpretation; manuscript review and editing.

ACKNOWLEDGEMENTS

This research was supported by the Irish Cancer Society, through a Social and Allied Health Research PhD Scholarship grant to the first author (CRS19BYR). The authors would like to thank subject librarians Ellen Breen and Celine Campbell for their guidance and assistance, without which this research would not have been possible.

Open access funding provided by IReL.

CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest for any of the authors of this manuscript.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

ORCID

Simon Dunne  <https://orcid.org/0000-0003-3655-7647>

REFERENCES

- Hoffman MA, Lent RW, Raque-Bogdan TL. A social cognitive perspective on coping with cancer: theory, research, and intervention. *Couns Psychol*. 2013;41(2):240-267. <https://doi.org/10.1177/0011000012461378>
- Lagergren P, Schandl A, Aaronson NK, et al. Cancer survivorship: an integral part of Europe's research agenda. *Mol Oncol*. 2018;13(3):624-635. <https://doi.org/10.1002/1878-0261.12428>
- Department of Health. National Cancer Strategy 2017-2026 [Internet]; 2017. <https://health.gov.ie/blog/publications/national-cancer-strategy-2017-2026/>
- Moffatt CJ, Franks PJ, Doherty DC, et al. Lymphoedema: an underestimated health problem. *QJM*. 2003;96(10):731-738. <https://doi.org/10.1093/qjmed/hcg126>
- Girgis A, Stacey F, Lee T, Black D, Kilbreath S. Priorities for women with lymphoedema after treatment for breast cancer: population based cohort study. *BMJ*. 2011;342. <http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L606955008>
- Gjorup CA, Groenvold M, Hendel HW, et al. Health-related quality of life in melanoma patients: impact of melanoma-related limb lymphoedema. *Eur J Cancer*. 2017;85:122-132. <https://doi.org/10.1016/j.ejca.2017.07.052>
- Azhar SH, Lim HY, Tan BK, Angeli V. The unresolved pathophysiology of lymphedema. *Front Physiol*. 2020;11:137. <https://doi.org/10.3389/fphys.2020.00137>
- DeSnyder SM, Shaitelman SF, Schaverien MV. Lymphedema and body image disturbance. In: Fingeret MC, Teo I, eds. *Body image care for cancer patients: Principles and practices*. Oxford University Press; 2018:213-230. <http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2018-25953-010&site=ehost-live>
- Lyons O, Modarai B. Lymphoedema. *Surg Oxf*. 2019;37(2):81-87. <https://doi.org/10.1016/j.mpsur.2018.12.004>
- Schulze H, Nacke M, Gutenbrunner C, Hadamitzky C. Worldwide assessment of healthcare personnel dealing with lymphoedema. *Health Econ Rev*. 2018;8.
- Cormier JN, Askew RL, Mungovan KS, Xing Y, Ross MI, Armer JM. Lymphedema beyond breast cancer: a systematic review and meta-analysis of cancer-related secondary lymphedema. *Cancer*. 2010;116(22):5138-5149. <https://doi.org/10.1002/cncr.25458>
- Lymphoedema Ireland. Frequently Asked Questions; 2019. <https://www.lymphireland.com/faq/>
- Cash TF, Smolak L, eds. *Body image: a handbook of science, practice, and prevention*. 2nd ed. Guilford Press; 2011:490.
- Grogan S. *Body Image: Understanding Body Dissatisfaction in Men, Women, and Children*. Routledge; 1999:225.
- Fu MR, Ridner SH, Hu SH, Stewart BR, Cormier JN, Armer JM. Psychosocial impact of lymphedema: a systematic review of literature from 2004 to 2011. *Psycho Oncol*. 2013;22(7):1466-1484. <https://doi.org/10.1002/pon.3201>
- Burney S. Psychological issues in cancer survivorship. *Climacteric*. 2019;22(6):584-588. <https://doi.org/10.1080/13697137.2019.1606795>
- Fingeret MC, Teo I, Epner DE. Managing body image difficulties of adult cancer patients: lessons from available research: body Image in Adult Cancer Patients. *Cancer*. 2014;120(5):633-641. <https://doi.org/10.1002/cncr.28469>
- Health Service Executive. Lymphoedema and Lipoedema Treatment in Ireland: A Model of Care for Ireland - A Working Group Report [Internet]; 2018. <https://www.hse.ie/eng/services/publications/lymphoedema-model-of-care.pdf>
- Sherman KA, Kilby CJ, Elder E, Ridner SH. Factors associated with professional healthcare advice seeking in women at risk for developing breast cancer-related lymphedema. *Patient Educ Couns*. 2018;101(3):445-451. <https://doi.org/10.1016/j.pec.2017.10.010>
- Shamseer L, Moher D, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ*. 2015;349(jan02 1):g7647. <https://doi.org/10.1136/bmj.g7647>
- Jefferies P, Gallagher P, Dunne S. The Paralympic athlete: a systematic review of the psychosocial literature. *Prosthet Orthot Int*. 2012;36(3):278-289. <https://doi.org/10.1177/0309364612450184>
- Dunne S, Mooney O, Coffey L, et al. Psychological variables associated with quality of life following primary treatment for head and neck cancer: a systematic review of the literature from 2004 to 2015: psychological variables associated with QoL in head and neck cancer. *Psycho Oncol*. 2017;26(2):149-160. <https://doi.org/10.1002/pon.4109>
- Alamoudi U, Taylor B, MacKay C, et al. Submental liposuction for the management of lymphedema following head and neck cancer treatment: a randomized controlled trial. *J Otolaryngol - Head Neck Surg J Oto-Rhino-Laryngol Chir Cervico-Faciale*. 2018;47(1):22. <https://doi.org/10.1186/s40463-018-0263-1>
- Alcorso J, Sherman KA. Factors associated with psychological distress in women with breast cancer-related lymphoedema. *Psycho Oncol*. 2016;25(7):865-872. <https://doi.org/10.1002/pon.4021>
- Brake MK, Jain L, Hart RD, Trites JRB, Rigby M, Taylor SM. Liposuction for submental lymphedema improves appearance and self-perception in the head and neck cancer patient. *Otolaryngol-Head Neck Surg Off J Am Acad Otolaryngol-Head Neck Surg*. 2014;151(2):221-225. <https://doi.org/10.1177/0194599814529401>
- Martin SM, Hanson C. The differences in body image between patients with and without lymphedema following breast cancer treatment. *Occup Ther Ment Health*. 2000;15(2):49-67. https://doi.org/10.1300/j004v15n02_04
- Sherman KA, Przewdziecki A, Alcorso J, et al. Reducing body image-related distress in women with breast cancer using a structured online writing exercise: results from the my changed body randomized controlled trial. *J Clin Oncol Off J Am Soc Clin Oncol*. 2018;36(19):1930-1940. <https://doi.org/10.1200/jco.2017.76.3318>
- Speck RM, Gross CR, Hormes JM, et al. Changes in the Body Image and Relationship Scale following a one-year strength training trial

- for breast cancer survivors with or at risk for lymphedema. *Breast Cancer Res Treat.* 2010;121(2):421-430. <https://doi.org/10.1007/s10549-009-0550-7>
29. Stuijver MM, de Rooij JD, Lucas C, et al. No evidence of benefit from class-II compression stockings in the prevention of lower-limb lymphedema after inguinal lymph node dissection: results of a randomized controlled trial. *Lymphology.* 2013;46(3):120-131.
 30. Teo I, Novy DM, Chang DW, Cox MG, Fingeret MC. Examining pain, body image, and depressive symptoms in patients with lymphedema secondary to breast cancer. *Psycho Oncol.* 2015;24(11):1377-1383. <https://doi.org/10.1002/pon.3745>
 31. Abakay H, Dogan H, Atilabey Güç A, Talay Çalış H. Association of lower extremity lymphedema with pelvic floor functions, sleep quality, kinesiophobia, body image in patients with gynecological cancers. *Women Health.* 2023;63(1):27-34. <https://doi.org/10.1080/03630242.2022.2155900>
 32. Alsarraf R. Outcomes research in facial plastic surgery: a review and new directions. *Aesthetic Plast Surg.* 2000;24(3):192-197. <https://doi.org/10.1007/s002660010031>
 33. Carr T, Harris D, James C. The Derriford Appearance Scale (DAS-59): a new scale to measure individual responses to living with problems of appearance. *Br J Health Psychol.* 2000;5(2):201-215. <https://doi.org/10.1348/135910700168865>
 34. Hopwood P, Fletcher I, Lee A, Al Ghazal S. A body image scale for use with cancer patients. *Eur J Cancer.* 2001;37(2):189-197. [https://doi.org/10.1016/s0959-8049\(00\)00353-1](https://doi.org/10.1016/s0959-8049(00)00353-1)
 35. Cash TF. *The Multidimensional Body-self Relations Questionnaire Users' Manual (Third Revision)*. Department of Psychology, Old Dominion University; 2000.
 36. Avalos L, Tylka TL, Wood-Barcalow N. The body appreciation scale: development and psychometric evaluation. *Body Image.* 2005;2(3):285-297. <https://doi.org/10.1016/j.bodyim.2005.06.002>
 37. Hormes JM, Lytle LA, Gross CR, Ahmed RL, Troxel AB, Schmitz KH. The body image and relationships scale: development and validation of a measure of body image in female breast cancer survivors. *J Clin Oncol.* 2008;26(8):1269-1274. <https://doi.org/10.1200/jco.2007.14.2661>
 38. Alebachew F, Ashagrie M. The Body-Image concept analysis of youth and adolescent. *Am J Biomed Life Sci.* 2017;5(6):130-134. <https://doi.org/10.11648/j.ajbls.20170506.14>
 39. Michael S, Charikleia S, Konstantinos K. Lymphedema and breast cancer: a review of the literature. *Breast Cancer.* 2011;18(3):174-180. <https://doi.org/10.1007/s12282-010-0246-1>
 40. Paskett ED, Stark N. Lymphedema: knowledge, treatment, and impact among breast cancer survivors. *Breast J.* 2000;6(6):373-378. <https://doi.org/10.1046/j.1524-4741.2000.99072.x>
 41. Ridner SH, Deng J, Doersam JK, Dietrich MS. Lymphedema symptom intensity and distress surveys-truncal and head and neck, version 2.0. *Lymphat Res Biol.* 2021;19(3):240-248. <https://doi.org/10.1089/lrb.2020.0071>
 42. Keeley VL, Veigas D, Crooks S, et al. The development of a condition-specific quality of life measure for lymphoedema(LYM-QOL). *Eur J Lymphol.* 2004;12(41):36.
 43. Keeley V, Crooks S, Locke J, et al. A quality of life measure for limb lymphoedema (LYMQOL). *J Lymphoedema.* 2010;5:26-37.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Byrne E, Gaffey J, Hayden L, Daly A, Gallagher P, Dunne S. Body image and cancer-related lymphoedema: a systematic review. *Psychooncology.* 2023;1-11. <https://doi.org/10.1002/pon.6215>