

REVIEW OPEN ACCESS

Impact of Lymphedema on Women's Lives After Gynaecological Cancer: An Integrative Review

Pernille Dehn^{1,2}  | Anette Rasmussen³ | Lene Seibæk⁴  | Ragnhild Johanne Tveit Sekse^{5,6}  | Anne Marie Thimm^{3,7}  | Mette Linnet Olesen^{3,7,8} 

¹Department of Gynaecology and Obstetrics, Aarhus University Hospital, Aarhus, Denmark | ²Department of Social Education, Research & Development, Faculty of Social Education, University College Copenhagen, Copenhagen, Denmark | ³Department of Gynaecology, Fertility and Births, Copenhagen University Hospital – Rigshospitalet, Copenhagen, Denmark | ⁴Institute of Health and Nature, University of Greenland, Nuuk, Greenland | ⁵Faculty of Health Studies, VID Specialized University, Bergen, Norway | ⁶Department of Obstetrics and Gynecology, Haukeland University Hospital, Bergen, Norway | ⁷The Interdisciplinary Research Unit of Women's, Children's and Families' Health, Copenhagen, Denmark | ⁸Institute of Clinical Medicine, Faculty of Health Sciences, University of Copenhagen, Copenhagen, Denmark

Correspondence: Mette Linnet Olesen (mette.linnet.olesen@regionh.dk)

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ABSTRACT

Background: Secondary Lower-Limb Lymphedema (LLL) is a frequent, progressive late effect affecting women after gynaecological cancer treatment, causing swelling due to fluid accumulation in the interstitial spaces in the lower extremities, the lower abdomen, hips and genitals. There is no consensus on how to define and quantify LLL, which makes research on treatment effect difficult. A negative relation between LLL and quality of life has been reported.

Aim: To review the literature concerning the identification and impact of LLL on women's lives after gynaecological cancer, including physical, psycho-social and existential aspects.

Methods: In an integrative review, as described by Whittemore & Knafl, data were thematically analysed.

Results: Forty-one papers published between 2003 and 2024, encompassing a total of 11,488 participants, were included. The overarching theme was limited knowledge of LLL among healthcare professionals and patients and identification discrepancies. It highlighted a widespread lack of awareness among healthcare professionals and the absence of a standardised approach to LLL assessment. This was further substantiated by the considerable heterogeneity in both diagnostic and measurement methods. Consequently, women received minimal information, experienced delayed diagnoses and had restricted access to treatment. These shortcomings had a negative impact on daily life, affecting physical and psychosocial wellbeing, as well as sexual health. The women reported unmet needs, which led them to adopt proactive approaches and various coping strategies.

Conclusion: LLL profoundly affects women's quality of life, physical and psychosocial health and existential well-being. Lack of standardised assessment and diagnostic criteria and clear care pathways creates knowledge gaps, delays diagnosis and fragments care, while its 'homeless' status leaves responsibility unclear. Urgent systemic change is needed: research must define evidence-based strategies and policy makers should prioritise multidisciplinary centres and education, with healthcare adopting patient-centred, multidisciplinary practices to ensure timely diagnosis, referral and self-management support.

Trial Registration: <https://osf.io/jrh6c>

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1 | Background

Lower-Limb Lymphedema (LLL) is a frequent late effect after especially radiation therapy and lymph node dissection as part of treatment for gynaecological cancer [1]. The condition presents as a progressive swelling of one or both legs, the abdomen and/or vulva, causing protein-rich fluid to accumulate in the interstitial spaces. LLL may occur months or even years after treatment, but most cases appear within the first year [2, 3]. Although the condition also includes the abdomen and vulva, it is referred to most commonly as lower extremity lymphedema (LEL) or lower-limb lymphedema (LLL).

Every year approximately 8600 women are treated for gynaecological cancer in the Nordic countries [4]. Historic data have reported that up to 70% of gynaecological cancer patients may have been affected by lymphedema [1, 5] involving bilateral legs, feet, the lower abdomen, bilateral hips and genitals [6], indicating that the condition is rather frequent after gynaecological cancer disease. Adding to the treatment-related factors, risk factors are age, body mass index, ethnicity and primary lymphedema [6]. In addition, Hayes et al. [7] identified insufficient physical activity and a vulva cancer diagnosis as risk factors.

There is no consensus on how to define and quantify LLL in a standardised way [6], which makes research on lymphedema itself and the treatment of it very difficult. In a Swedish observational study [8] assessing lymphedema at four occasions with systematic measurement of leg circumferences, clinical grading and patient's perception measured by a lymphedema-specific questionnaire, Wedin et al. found considerable variation in incidence, depending on mode of measurement [8]. This was supported by Hayes et al. and Pigott et al., who both found variation between self-reported and objectively measured lymphedema [7] at 24 months post-diagnosis [9].

It is known that there is a negative relationship between cancer related LLL and quality of life (QoL). Women with LLL have reported reductions in their physical and mental QoL up to three to 5 years past treatment [10]. These are mainly in physical domains [11, 12] but include sleep disturbances, a decrease in daily activities and fear of recurrence [13]. The presence of LLL has been found to negatively affect the lymphedema-specific health related QoL (HRQoL), mainly in physical domains [10]. Further, serious body image-related, psycho-sexual concerns have been reported in qualitative studies [14–18].

Taken together, lymphedema is a frequent complication following gynaecological cancer treatment, affecting QoL, physical functioning and interfering with everyday life. Overall gynaecological cancer patients request further attention to LLL, including thorough examination at onset of symptoms [10, 15]. However, research is sparse, fragmented and methodologically weak in lack of a clear LLL definition.

Given this gap of knowledge, we identified a need to gather the existing evidence across methodologies on how LLL is identified, its influence on various aspects of women's daily lives and the coping strategies women employ. Understanding these

interconnected aspects of women's post-cancer treatment experiences holistically is essential to inform improved clinical care, supportive interventions and health policies including future research. Additionally, identifying cancer-related LLL is crucial to provide a comprehensive view of women's health needs after gynaecological cancer.

2 | Aim

To review the literature concerning the identification and impact of LLL after gynaecological cancer on women's lives understood as a complexity that includes physical, psycho-social and existential aspects.

2.1 | Research Questions

1. How Are Women with Cancer-Related LLL Identified?
2. How Does Cancer-Related LLL Impact Women's Everyday Lives, Including Physical, Psycho-Social and Existential Aspects?
3. What Coping Strategies Do Women Apply to Overcome Cancer-Related LLL in Their Everyday Lives?

3 | Design and Method

As we wished to achieve a comprehensive and nuanced synthesis across multiple evidence types on the topic to reconceptualise rather than only summarise data, we conducted an integrated review ad modum Whitemore & Knafl, in five stages; (1) Problem identification, (2) Literature search, (3) Data evaluation, (4) Data analysis and (5) Presentation [19].

3.1 | Search Strategy

During September 2022 search strings in Medline, Embase, Cinahl and Psycinfo were developed in collaboration with a health professional librarian at Copenhagen University Hospital—Rigshospitalet, Denmark, using both keywords and relevant MESH terms and Cinahl headings combined with AND and OR (Table 1). We ensured that a set of relevant studies was included in the Medline search. Due to a limited number of results, we did not add the concept of 'lower extremity' in Cinahl and Psycinfo. This primary search was updated on October 25th, 2024, in the same databases using the similar search strings.

3.2 | Selection of Studies

The result was imported to the online systematic review management platform Covidence [20]. Titles and abstracts were independently assessed for eligibility by at least two authors according to the in- and exclusion criteria (Table 2). Likewise, in a second phase, full text versions of the included abstracts were assessed for eligibility. In case of discrepancy, inclusion was discussed with a third author until agreement was reached. The results of the two searches can be seen in the PRISMA flow chart (Figure 1).

TABLE 1 | Literature search.

Ovid MEDLINE(R)		
1	Lymphedema/	676
2	(lymphedema* or lymphoedema* or edema* or oedema*).ab,kf,ti.	
3	1 or 2	
4	exp Genital Neoplasms, Female/	
5	((gyn?ecologic* or cervix or cervical or myometrial or endometrial or uterine* or corpus or ovarian* or vulva*) adj3 (cancer* or neoplasm* or malignan* or tumo?r*)).ti,ab,kf.	
6	4 or 5	
7	3 and 6	
8	exp Lower Extremity/or Vulva/	
9	(lower extremit* or lower bod* or lower limb* or leg* or ankle* or buttock* or foot* or feet or toe* or hip* or knee* or thigh* or vulva*).ti,ab,kf.	
10	8 or 9	
11	3 and 6 and 10	
Ebsco CINAHL		
S1	(MH "Lymphedema")	351
S2	TI (Lymphedema* or lymphoedema* or edema* or oedema*)	
S3	AB (Lymphedema* or lymphoedema* or edema* or oedema*)	
S4	S1 OR S2 OR S3	
S5	(MH "Genital Neoplasms, Female+")	
S6	TI ((gynecologic* or gynaecologic* or cervix or cervical or myometrial or endometrial or uterine* or corpus or ovarian* or vulva*) N3 (cancer* or neoplasm* or malignan* or tumour* or tumour*))	
S7	AB ((gynecologic* or gynaecologic* or cervix or cervical or myometrial or endometrial or uterine* or corpus or ovarian* or vulva*) N3 (cancer* or neoplasm* or malignan* or tumour* or tumour*))	
S8	S5 OR S6 OR S7	
S9	S4 AND S8	
Embase < 1974 to 2022 September 28>		
1	lymphedema/	1.422
2	(lymphedema* or lymphoedema* or edema* or oedema*).ti,ab,kw.	
3	1 or 2	
4	exp female genital tract tumour/	
5	((gyn?ecologic* or cervix or cervical or myometrial or endometrial or uterine* or corpus or ovarian* or vulva*) adj3 (cancer* or neoplasm* or malignan* or tumo?r*)).ti,ab,kw.	
6	4 or 5	
7	3 and 6	
8	exp lower limb/or Vulva/	
9	(lower extremit* or lower bod* or lower limb* or leg* or ankle* or buttock* or foot* or feet or toe* or hip* or knee* or thigh* or vulva*).ti,ab,kw.	
10	8 or 9	
11	3 and 6 and 10	

(Continues)

Psycinfo via APA (Association Psychologist Association)	
43 Results for (Any Field: lymphoedema* OR Any Field: lymphedema* OR Any Field: oedema* OR Any Field: edema*) AND (Any Field: gynecologic* OR Any Field: gynaecologic* OR Any Field: cervix OR Any Field: cervical OR Any Field: myometrial OR Any Field: endometrial OR Any Field: uterine* OR Any Field: corpus OR Any Field: ovarian* OR Any Field: vulva*) AND (Any Field: cancer* OR Any Field: neoplasm* OR Any Field: malignan* OR Any Field: tumour* OR Any Field: tumour*)	
PubMed	
(lower extremit* or lower body or lower bodies or lower limb* or leg or ankle* or buttock* or foot* or feet* or toe or hip or knee* or thigh* or vulva*) OR (“Lower extremity”[Mesh]) OR “Vulva”[Mesh])) AND (((gynecologic OR Gynaecologic OR Cervix OR cervical OR myometrial OR endometrial OR uterine* OR corpus OR ovarian OR vulva*) AND (cancer* OR neoplasm* OR malignan* OR tumour* OR tumour*)) OR (“Genital Neoplasm, Female”[Mesh])) AND ((lymphedema*[Title/Abstract] OR Lymphoedema*[Title/Abstract] OR edema*[Title/Abstract] OR oedema*[Title/Abstract] OR (“Lymphedema”[Mesh:NoExp])))	

49

TABLE 2 | Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> All types of studies investigating the identification and impact of lymphedema on women’s lives after gynaecological cancer, and which contained independent analyses on LLL in this specific population Peer-reviewed publications Language: English, Swedish, Danish, or Norwegian 	<ul style="list-style-type: none"> Studies that exclusively measured incidence Reviews, protocols, abstracts, or conference contributions

4 | Analysis

Initially, data was extracted from the included papers and organised into a matrix containing authors, year, title, country, aim, design and number of participants, cancer type, treatment and time since treatment, outcome measures and results to provide an overview of all included studies (Table 3). All papers were quality assessed independently by two of the authors using the Mixed Methods appraisal tool (MMAT) [21] (Supporting Information).

The analysis of data was inspired by the six steps in thematic analysis [22]. First, all papers were re-read to become familiar with data. Second, initial codes were noted and discussed by all authors, then all ‘result sections’ in the included papers were transferred to NVivo [23]. Third, two authors (AMT, MLO) coded the initial codes into preliminary themes. The analysis was primarily inductive. Given the nature of the research question, a convergent integrated approach was applied by transforming quantitative data into qualitative to enable integration [24]. While the research question provided an initial orientation, patterns and relationships between themes were identified through iterative engagement with the data. Fourth, the themes and interrelationships were discussed and

reviewed by all authors. Fifth, themes were named, and their interrelatedness defined and finally presented in this paper.

5 | Results

The search generated 1774 papers, with abstracts screened against the inclusion and exclusion criteria. One hundred and twenty-two studies were assessed in full text, of which 81 were excluded for not meeting the inclusion criteria. Finally, 41 papers (39 studies) were included in the review (Figure 1).

5.1 | Quality Assessment

The quality of the included papers was not high, as only 19.5% met all the screening criteria in the MMAT [21]. Further details of the assessment can be found in Supporting Information.

5.2 | Characteristics of Included Studies

Of the included studies, six were qualitative (N=487), 35 had a quantitative design of which two used a mixed methods approach (N=11,001). The studies originated from many different countries, with a predominance from Australia (n=10) and the USA (n=9). Additionally, there were studies from Korea (n=3), Sweden (N=3), Japan (n=2), Denmark (n=2), Taiwan (n=2), Germany (n=1), the UK (n=1), Norway (n=1), Turkey (n=1), Brazil (n=1), Singapore (n=1), Italy (n=1), South Africa (n=1), Denmark/Netherlands (n=1), and finally a collaboration between 20 countries (n=1). Eighteen studies investigated lymphedema related to various gynaecological cancers, 13 focused exclusively on endometrial cancer, six on vulvar cancer, three on cervical cancer and one on ovarian cancer, see Table 3 for more details of the included studies.

Throughout this review, the term prevalence will be used to also encompass frequency and occurrence, as reported in the included studies. For a detailed overview of these findings, including studies that conducted baseline pretreatment assessment, please refer to Table 3 in the Results section.

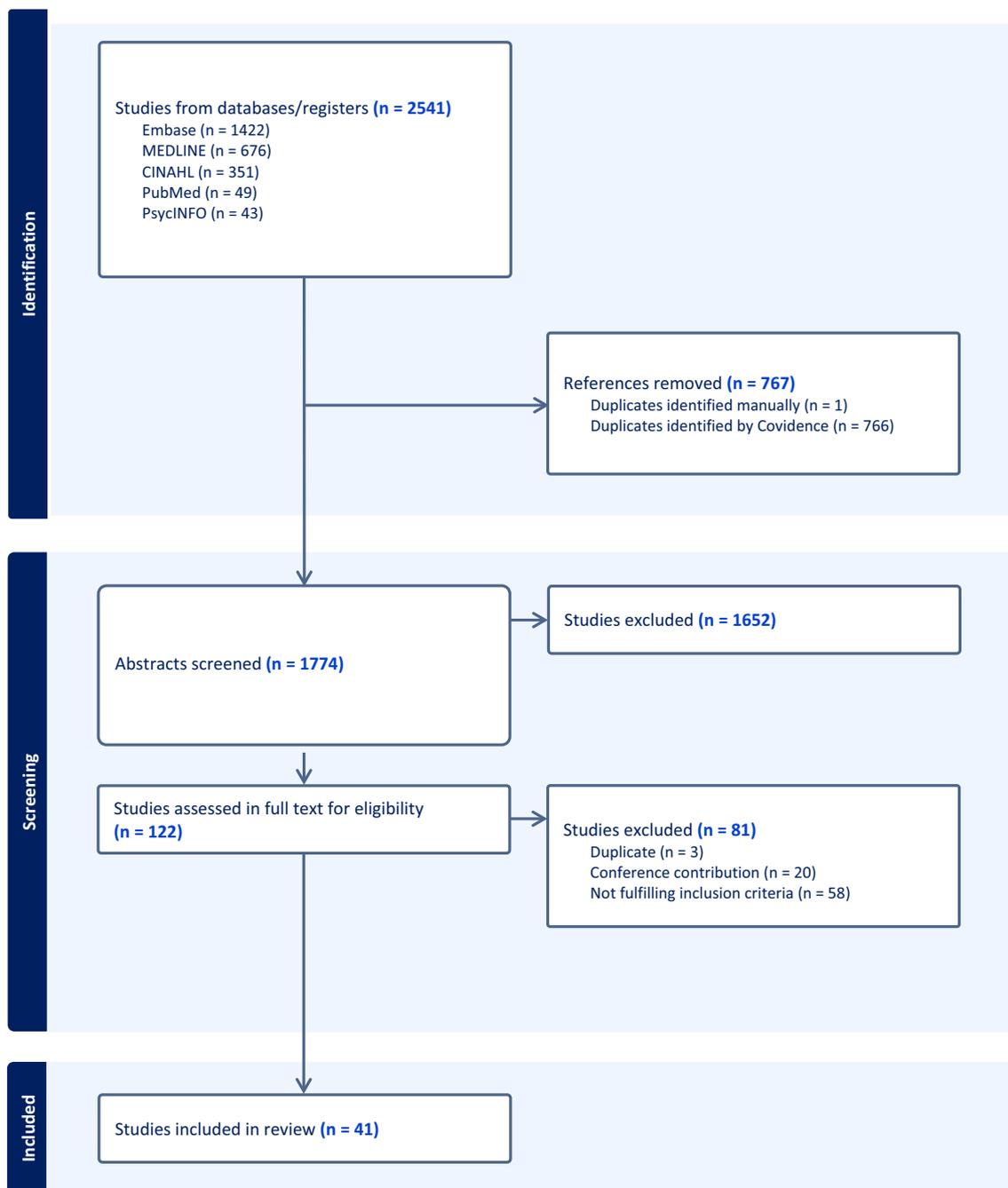


FIGURE 1 | PRISMA flowchart.

5.3 | Themes

We identified an overarching theme (Table 4): Lack of knowledge of LLL among healthcare professionals and patients and identification discrepancies, comprising four subthemes: *Inconsistent assessment of lymphedema*, *Limited knowledge leading to limited awareness and patient information*, *Delayed and inaccurate diagnosis* and *Limited access to treatment and diversity of treatment options*. The impact of LLL and the circumstances described in the first theme are unfolded in the second theme: Consequences for women's everyday life, encompassing the subthemes: *Physical symptoms and sensations*, *Psychosocial impact*, *Affected sexual health & Body image*, *Affected QoL and Economic and financial burden*. Management experiences are

finally unfolded in the theme Needs, unmet needs & coping strategies covering the subthemes *Needs and unmet needs* and *Coping strategies*.

6 | Limited Knowledge of LLL Among Healthcare Professionals and Patients and Identification Discrepancies

6.1 | Inconsistent Assessment of Lymphedema

When mapping the different methods to measure and assess LLL, it became evident that no consensus existed. In most studies, various objective and subjective methods were employed for

TABLE 3 | Overview of included studies.

Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Qualitative <i>n</i> = 6 Barlow EL, 2013 Sexuality and body image following treatment for early-stage vulvar cancer: a qualitative study Australia	To describe women's experiences of sexuality and body image following treatment for early-stage vulvar cancer Qualitative (<i>N</i> = 10)	Vulvar cancer	Primary surgery, with or without groin node dissection > 1 year	Semi-structured interviews	Findings indicated that most women experienced little to no long-term disruption to sexuality and body image following conservative treatment for early-stage vulvar cancer The factors that contributed to women experiencing negative emotions were radical vulvar excision, multiple vulvar procedures and/or the development of lymphedema
Chan EJ, 2018 Living with lymphoedema after treatment for breast and gynaecological cancers in Singapore Singapore	To explore the experience of Singaporean women living and coping with lymphoedema in the following key areas: 1. Their perceptions of lymphoedema 2. How they are managing their lymphoedema 3. What makes them take care of their lymphoedema Qualitative (<i>N</i> = 12)	Breast + Gynecologic cancers	Surgery and/or radiotherapy > 3 months	Semi-structured interviews	Women with gynecologic cancer were more affected by adjustments in attire and footwear. Maintaining mobility motivated treatment adherence. Breast cancer participants preferred pre-operative education while those with gynecologic cancer felt information should be regulated There is a longing for normalcy as women adjusted their lives to manage with lymphedema
Philp S, 2017 The road less travelled: Australian women's experiences with vulval cancer Australia	To explore the women's experience of diagnosis, treatment for, and recovery from vulvar cancer. Specifically, to describe the physical, practical, and emotional needs of the women and describe strategies women have found effective in maximising recovery Qualitative (<i>N</i> = 12)	Vulvar cancer	All participants underwent surgery < 5 years	Semi-structured interviews	The experience of having a vulval cancer diagnosis was an isolating and difficult experience. They felt unprepared with no roadmap and no support. The women experienced numerous physical consequences—among other lymphedema. Many women experienced issues with clothing and a medically driven follow-up The majority experienced a major impact on intimacy and relationships

(Continues)

TABLE 3 | (Continued)

Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Ryan M, 2003 The Experience of Lower Limb Lymphedema for Women After Treatment for Gynecologic Cancer Australia	To describe women's experience with lower limb lymphedema (LLL) and to determine the physical and emotional impact that LLL has on the lives of women who had gynaecologic cancer surgery Retrospective survey (N = 487) and interviewed (N = 82)	Gynecologic cancers	Surgical and radiation treatment > 0–5 years	Structured interviews	Prevalence/frequency: 36% reported lower limb swelling, 18% had a clinical diagnosis of LLL. Developing lymphedema affected the women's lives in a variety of ways Women identified changes in appearance and sensation in the legs and the triggers that both preceded and exacerbated symptoms. Women described seeking help and receiving inappropriate advice with as many as three assessments prior to referral to lymphedema specialists. Many implemented self-management strategies. LLL had an impact on appearance, mobility, finances, and self-image
Seki K, 2023 Suffering of patients developing lymphedema following gynaecological cancer surgery Japan	To concretize the suffering of patients who develop lymphedema and enhance the understanding of nurses Qualitative (N = 13)	Cervical, uterine, and ovarian cancers	Surgery and radiation therapy and/or chemotherapy Time since treatment unknown	Semi-structured interviews	Two core categories were created: 1. <i>Suffering of Lymphedema Developing in Lower Extremities</i> covering 7 categories and 2. <i>Supports that allow patients to face the suffering of lymphedema in lower extremities</i> covering 4 categories
Winch CJ, 2016 'You're naked, you're vulnerable': Sexual well-being and body image of women with lower limb lymphedema Australia	To understand the sexual concerns of women with lower limb lymphedema, both primary and secondary to gynaecologic cancer Qualitative (Primary LLL N = 11) (Secondary LLL N = 8)	Women with primary (congenital) LLL and women with LLL after Gynaecologic cancers (ovarian, cervical, endometrial)	Women with gynaecologic cancers had surgery Year since gynaecological cancer related lymphedema diagnosis 0–18 years	Semi-structured interviews	Serious lymphedema related sexual challenges were revealed Lymphedema-related pain, heaviness, and immobility in sexual situations Most women with secondary LLL reported that gynaecological cancer had caused the more distressing functional concerns The sample overall downplayed lymphedema related functional concerns, instead reporting lymphedema related treats to their appearance and confidence, that is body image. Their relationship, sexual role, and coping strategies were linked with body image

(Continues)

TABLE 3 | (Continued)

Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Other methodology <i>n</i> = 35					
Abakay H, 2022 Association of lower extremity lymphedema with pelvic floor functions, sleep quality, kinesiophobia, body image in patients with gynaecological cancers Turkey	To investigate the relationship between lymphedema and pelvic floor functions, sleep quality, kinesiophobia, and body image in women with gynaecological cancer. Patients were divided into two groups, – with and without LLL Observational comparative study (<i>N</i> = 103; 52 participants with LLL and 51 without)	Ovary, cervix, endometrial cancers	Surgery Time since treatment: > 6 months	GCLQ GPFBQ PSQI TSK BIS	Increase in lower extremity lymphedema (LEE) symptoms negatively affected kinesiophobia, pelvic floor dysfunction and body image
Bae HS, 2016 Postoperative Lower Extremity Edema in Patients with Primary Endometrial Cancer Korea	To investigate clinical manifestations of lower extremity edema (LEE) after lymph node dissection Cross-sectional study with a retrospective component (<i>N</i> = 154)	Endometrial cancer	Surgery between 2001 and 2011 Time since treatment not specified, but patients reported recurrent LLE up to 115 months after surgery (9.6 years)	Medical records (2001 to 2011) Telephone interviews GCLQ	The most frequent GCLQ responses were experienced ‘swelling’ (35.7%), ‘numbness’ (30.5%), ‘heaviness’ (29.9%), and ‘aching’ (29.9%) Prevalence/frequency: LEE developed in more than one-third after surgery 42% (1 symptom) and 33% (4–6 symptoms), and LEE lasted for more than 12 months in most patients A high number of dissected pelvic lymph nodes and postoperative radiotherapy was associated with LEE
Beesley, 2007 Lymphedema After Gynaecological Cancer Treatment. Prevalence, Correlates, and Supportive Care Needs Australia	To establish prevalence, correlates, and supportive care needs of gynaecological cancer survivors who develop lymphedema Cross-sectional survey (<i>N</i> = 802)	Gynaecologic cancers	Surgery, chemotherapy, and radiotherapy 3 months–5 years after diagnosis	SCNS-SF34 Supplementary needs module developed to measure 11 support-need items of women with lymphedema Lymphedema-specific items—questions developed to determine lymphedema status and capture the experience of having LLL	Prevalence/frequency: Twenty-five percent reported swelling of their legs—only 10% were clinically diagnosed with LLL—across cancer type and survival phase 5%–36% depending on diagnosis Diagnosed lymphedema was more prevalent (36%) among vulva cancer survivors Undiagnosed LLL swelling prevalence was similar across main cancer types Gynaecological cancer survivors with lymphedema had higher supportive care needs in the information and symptom management domain compared to those who had no swelling

(Continues)

TABLE 3 | (Continued)

Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Beesley, 2015 Incidence, risk factors and estimates of a woman's risk of developing secondary lower limb lymphedema and lymphedema-specific supportive care needs in women treated for endometrial cancer Australia	To assess lymphedema incidence and key personal, behavioural, and clinical risk factors of post-treatment lymphedema among women with endometrial cancer and to estimate absolute risk for individuals Further, to report the proportion of women with unmet needs for help with lymphedema-specific issues Population based survey ($N = 1243$) A subset of 643 completed a follow-up survey that asked about lymphedema and lymphedema-related support needs	Endometrial cancer	All participants had surgery, fewer chemotherapy, and radiation therapy 3–5 years after diagnosis	Medical records Lymphedema status, lymphedema-specific supportive care needs Potential lymphedema risk factor variables measures: Information on personal and behavioural factors, clinical variables	Prevalence/frequency: One in eight women (13%) developed lymphedema, most within 2 years after surgery Risk varied markedly with the number of lymph nodes removed, which was the strongest predictor for lymphedema. To a lesser extent, receipt of adjuvant radiation or chemotherapy treatment, and use of non-steroidal anti-inflammatory drugs (pre-diagnosis) 55% of those who developed lymphedema reported unmet care needs particularly with costs and pain
Beesley V, 2008 Unmet needs of gynaecological cancer survivors: implications for developing community support services Australia	To determine the prevalence of unmet support needs, and to evaluate the correlates associated with higher levels of unmet need across multiple need domains, using a broader, social-ecological perspective Cross-sectional survey ($N = 802$)	Cervical, Uterine, Ovarian, and other	Surgery, chemotherapy, radiation 3 months to 5 years post diagnosis	SCNS-SF34 QGCR The Duke-UNC Functional Social Support Questionnaire	Prevalence/frequency: 10% with a lymphoedema diagnosis, 13% with undiagnosed lower limb swelling Forty-three per cent of respondents reported having at least one moderate- or high-level unmet need The five highest included needing help with fear about the cancer spreading (17%), concerns about the worries of those close to them (15%), uncertainty about the future (14%), lack of energy/tiredness (14%), and not being able to do things they used to do (14%) Subgroups of women with higher odds of reporting 'some' unmet needs across multiple supportive care domains include those who are not in remission, live with lymphoedema or are unable to work due to illness

(Continues)

TABLE 3 | (Continued)

Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Bjerre Trent PK, 2023 Self-reported lower extremity lymphedema and quality of life after surgical staging of endometrial carcinoma: A population based cross-sectional study Norway	To explore the prevalence of self-reported lymphedema, identify factors associated with LEL, compare quality of life (QoL) scores using thresholds of clinical importance, and assess correlation between different questionnaires Multicenter, population based cross sectional study (N = 1226)	Endometrial carcinoma	Surgery, chemotherapy, and radiation Median 71 months	LELSQ EORTC QLQ-C30 QLQ-EN24 EQ-5D-5L	Prevalence/frequency: 51%, 36% and 40% after lymphadenectomy, SLN and hysterectomy The prevalence of self-reported LEL was significantly lower for women without musculoskeletal complaints when compared to women with musculoskeletal complaints Sentinel lymph node implementation is not associated with increased LEL prevalence compared to hysterectomy alone but is associated with a significantly lower prevalence compared to lymphadenectomy LEL is associated with lower QoL. Our study demonstrates moderate to strong correlation between self-reported LEL and QoL
Bjornholt SM, 2024 Patient-reported lymphedema after sentinel lymph node mapping in women with low-grade endometrial cancer Denmark	To investigate the risk of patient reported lymphedema after sentinel lymph node mapping in women with low-grade endometrial cancer. Also, to evaluate risk factors for lymphedema and the condition-specific quality of life (QoL) among women who reported lymphedema 12 months after surgery National prospective longitudinal cohort study (N = 486)	Low-grade endometrial cancer	Surgery and 9.6% received adjuvant treatment (not specified) Before surgery, 3 and 12 months after surgery	EORTC QLQC30 EORTC QLQ-EN24 Items from the EORTC item library assessing additional locations of potential lymphedema and symptomatology related to leg lymphedema; tightness and pain LYMQOL	Prevalence/frequency not reported. The mean difference score of leg lymphedema from baseline to 12 months was 5.0, that is below the threshold for clinical importance Baseline leg lymphedema score and body mass index were positively associated with the leg lymphedema score at 12 months Leg lymphedema score at 3 months was associated with a higher 12-month score High scores of lymphedema at 12 months were negatively associated with the women's daily activities, appearance, emotional functioning, and global quality of life and increased their subjective symptom burden
Brown JC, 2014 Physical Activity, Daily Walking, and Lower Limb Lymphedema Associate with Physical Function among Uterine Cancer Survivors USA	To quantify the association of poor physical function with physical activity, walking, and LLL Survey (N = 213)	Uterine cancers	Surgery, chemotherapy, radiation 0-6 years	SF-12 PPAQ GCLQ	Prevalence/frequency: Thirty-six percent were classified with LLL The odds of reporting poor physical function were increased in the presence of LLL. Compared with participants without LLL, participants with LLL had an OR of 5.25 Participants with LLL were more likely to have poor physical function compared to participants without LLL

(Continues)

TABLE 3 | (Continued)

Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Carter J, 2021 GOG 244—The Lymphedema and Gynaecologic cancer (LeG) study: The impact of lower-extremity lymphedema on quality of life, psychological adjustment, physical disability, and function USA	To assess QoL in patients who developed lower-extremity lymphedema after radical gynaecologic cancer surgery including lymphadenectomy Prospective multi-institutional study (N = 768)	Endometrial, cervical, vulvar cancers	Surgery Data collected 14 days before surgery and 6, 12, 18 and 24 months after surgery	FACT general FACT-Cx FACT-En FACT-V PROMIS-SexFS IES LEFS GCLQ	Prevalence/frequency: approximately 8% at year 1. From 34% (4–6 months from baseline) to 2% at year 2.768 evaluable patients, those with a GCLQ score change ≥ 4 from baseline had significantly worse QoL, body image, sexual and vaginal function, limb function, and cancer distress There were no significant differences in sexual activity rates between those with and without LLE-symptoms LLE is significantly detrimental to QoL, daily function, and body image
Carter J, 2019 GOG 244—The LymphEdema and Gynaecologic cancer (LEG) study: The association between the gynaecologic cancer lymphedema questionnaire (GCLQ) and lymphedema of the lower extremity (LLE) USA	To explore whether patient-reported lymphedema-related symptoms, are associated with a patient-reported diagnosis of lymphedema of the lower extremity and limb volume change (LVC) in patients who have undergone radical surgery, including lymphadenectomy Prospective multi-institutional study (N = 894)	Endometrial, cervical, or vulvar cancer	Surgery, +/- radiation, +/-chemotherapy Baseline (14 days prior to surgery), 4–6 weeks, and 3, 6, 9, 12-, 18-, and 24-months post-surgery	GCLQ LVC	Prevalence/frequency: Fourteen percent reported an LLE diagnosis (endometrial, 11%; cervical, 18%; vulvar, 38%) Significantly more patients diagnosed versus not diagnosed with LLE reported ≥ 4 -point increase from baseline on the GCLQ total score Changes from baseline were significantly larger on all GCLQ-symptom cluster scores in patients with LLE compared to those without LLE An LVC increment of $> 10\%$ was significantly associated with reported general swelling, heaviness, infection-related symptoms, and physical function
Cho K, 2023 Factors associated with health-related quality of life in gynaecologic cancer survivors with lower limb lymphedema: a cross-sectional study in Taiwan Taiwan	To assess the levels of symptom distress, depression, body image, and health-related quality of life (HRQoL) To recognise factors associated with HRQoL in gynaecologic cancer survivors with lower limb lymphoedema Cross-sectional study (N = 85) convenience sampling of participants with lower limb lymphoedema	Cervical, endometrial, ovarian, and other cancers	Surgery, radiation, chemotherapy Time since surgery 13.50 years (mean)	SDS POMS-Depression and dejection subscale BIS Lymph- ICF-LL Cheng's lymphedema grading system KPS	The most common symptoms of distress in survivors with lower limb lymphedema were lower extremity oedema, lower extremity tightness, and lower extremity stiffness Worse HRQoL was associated with higher levels of symptom distress, less satisfaction with body image, a high grade of lymphoedema, and a longer duration of lower limb lymphedema

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
De melo Ferreira, 2012 Quality of life in women with vulvar cancer submitted to surgical treatment: a comparative study Brazil	To investigate the occurrence and severity of lymphoedema of the lower extremities, QoL, and urinary and sexual dysfunction (cases $N=28$, controls $N=28$) Case-control	Vulvar cancer	Surgery, chemotherapy, and radiotherapy > 6 months	Miller's clinical evaluation EORTC QLQ-C30	Occurrence of LLL: 67% in case group, 10.7% in control group There was a significant correlation between the severity of LLL and worse QoL in the following domains: physical, cognitive, emotional, social, fatigue, pain, sleep, and financial questions
Dunberger G, 2013 Lower limb lymphedema in gynaecological cancer survivors—effect on daily life functioning Sweden	To investigate the impact of LLL on the overall quality of life, sleep, sexuality, and daily life activities Cohort study (cases $N=616$, controls $N=486$)	Gynaecologic cancer survivors	Pelvic radiotherapy alone or as part of combined treatment of gynaecological cancer, from 1991 to 2003	A self-constructed validated study-specific questionnaire covering QoL and questions in relation to the lymph system Medical records reviewed to confirm diagnosis and treatment	Prevalence/frequency: Thirty-six percent of the survivors reported LLL Overall quality of life was significantly lower among cancer survivors with LLL. They were also less satisfied with their sleep, more worried about recurrence of cancer, and more likely to interpret symptoms from the body as recurrence Satisfaction with sexuality and the prevalence of feeling attractive as a woman did not differ between the two groups Concomitant symptoms such as urinary- and faecal incontinence were more prevalent among the gynaecological cancer survivors with LLL LLL kept them from physical activity (45%) and housework (29%) and affected their ability to partake in social activities (27%) or to meet friends (20%) Thirty-one percent had actively sought health care due to lymphedema
Ekdahl L, 2021 Quality of life and long-term clinical outcome following robot-assisted radical trachelectomy Sweden	To evaluate QoL and long-term clinical outcome following robot-assisted radical trachelectomy (RRT) Cohort study ($N=49$, 42 finalised RRT, 33 completed questionnaires)	Early-stage cervical cancer	Surgery—RRT Median follow-up time 54 months, but 33 of the 42 who finalised RRT had a median time of follow-up at 85 months	EORTC QLQ-C30 QLQ-CX24 Swedish LYMQOL	Prevalence/frequency: Fifteen of 33 responders (45%) reported symptoms of lymphedema Nine (27%) had bilateral lymphedema and three (9%) rated their symptoms as severe with an impact on QoL Fourteen reported that the lymphedema affected their body image to some extent

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Gane EM, 2018 The Prevalence, Incidence, and Quality-of-Life Impact of Lymphedema After Treatment for Vulvar or Vaginal Cancer Australia	To determine point prevalence and incidence of lymphedema in women with vulvar/vaginal cancer To describe symptom burden and QoL Prospective longitudinal cohort study (vulvar cancer N=20, vaginal cancer N=2)	Vulvar and vaginal cancer	All underwent surgery between 2008 and 2011. Some received radiation and chemotherapy Baseline (prior to surgery), 3 weeks—3 months (n = 19), 6–12 months (n = 17) and 15–24 months (n = 15)	SRS Clinical diagnosis Rate of severity (inspired by the questionnaires FACT-Breast version and Disabilities of the Arm, Shoulder, and Hand) FACT-G	Prevalence/frequency: 2 years post-surgery; 50% had a clinical diagnosis of lymphedema and 91% had self-reported swelling. By 2 years post-surgery, about 9 of 10 self-reported swelling in 1 or more regions of the lower body The majority reported multiple lower limb symptoms such as pain, tingling, or weakness of moderate or severe intensity throughout the 2-year observation and the presence of these symptoms (even if only mild in nature) was associated with lower quality of life
Haidopoulos D, 2024 Lower limb lymphedema awareness among gynaecological cancer patients: An international survey supported by the European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) Group 20 countries	To capture and document the awareness among gynaecological cancer survivors about postoperative lymphedema, including aspects such as the adequacy of perioperative counselling, management, and quality of life Web based survey (N= 386)	Gynaecological cancers	Surgery, radiotherapy, and chemotherapy Assessed long term impact of lymphedema (not specified)	25 multiple-choice questions that targeted patients' perceptions concerning: (i) their preoperative education about the possibility of developing lymphedema; (ii) knowledge of lymphedema symptoms; (iii) physician response to their symptomatology; and (iv) treatment alternatives for lymphedema prevention and treatment; as well as one open question	Prevalence/frequency: 44% at had signs of lymphedema Only half of the patients knew what lymphedema is, whereas 52% of the respondents stated that they were never informed pre-operatively about the potential risk of developing lymphedema Fifty-three percent of those women who were informed about the risk and management of lymphedema received information through self-initiative, connecting mainly with patient groups or online Approximately 84% of patients with lymphedema reported that they informed their doctor about their symptoms Ninety-four patients were treated for lymphedema Forty-five women out of 136 reported that lymphedema significantly affected their everyday lives
Hsu YY, 2023 Determinants of quality of life related to lower limb lymphedema in women with gynaecological cancer surgery Taiwan	To identify the predictors of QoL related to lower limb lymphedema among women who had undergone gynaecological cancer surgery and examine the association between fatigue and QoL Cross sectional, survey (N = 200)	Ovarian endometrial, cervical, vulvar and vaginal cancer	Surgery, chemotherapy, radiotherapy Median time since surgery: 15 months	Lymph-ICF-LL-C C-LFS-SF	Prevalence/frequency: Sixty percent of the participants reported a mild to severe impact on QoL related to LLL with main impact on the function of mobility and physical symptoms Fatigue explained 11% of the variance in the QoL

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Jeppesen, MM, 2015 Needs and priorities of women with endometrial and cervical cancer Danish	To identify short-term rehabilitative needs Exploratory questionnaire study (N = 96) including focus group interviews (N = 16)	Endometrial and cervical cancer	Surgery, radiation therapy Needs were assessed pre-treatment and 3 months later	EORTC QLQ-C30 QLQ-CX24 QLQ-EN24 3LNQ	61% of women with cervical cancer reported any degree of lymphoedema. Women with endometrial and cervical cancer experience emotional problems prior to therapy and lymphoedema, and urological and sexual problems following treatment An awareness of these problems may facilitate early identification of women with unmet needs and enable individualised follow-up adjusted for such patient's needs
Jones GL, 2016 The impact of surgery for vulvar cancer upon health-related quality of life and pelvic floor outcomes during the first year of treatment: a longitudinal, mixed methods study UK	To measure the long-term impact of surgical treatment for vulvar cancer upon HRQoL and pelvic floor outcomes during the first year of therapy Prospective longitudinal mixed-methods study (survey and qualitative) N = 23 (11 were interviewed)	Vulvar cancer	Surgery, radiotherapy, chemotherapy Questionnaires 3, 6, 9 and 12 months post-surgery Interviews around 3 months after surgery	EORTC QLQ C30 SF-36 ePAQ-PF Semi-structured interviews	Prevalence/frequency not reported Physical functioning (especially the ability to carry out daily activities and walking) appeared most affected by lymphoedema and urinary incontinence For some women pain was also the consequence of lymphoedema and radiotherapy (where administered) with women describing their skin as burnt or blistered
Khutjwe JW, 2020 The incidence and effects of lower-limb lymphoedema in women treated with radiotherapy for gynaecological cancer in South Africa South Africa	This study will report the incidence of lymphoedema, compare the symptoms experienced by women with and without lymphoedema and highlight the effects lymphoedema has on women treated for gynaecological cancer in South Africa Cross sectional design (N = 155)	Cervical, uterus and vulva cancers	All received radiotherapy, +/- chemotherapy Time since treatment: 1-2 years	GCLQ	Prevalence/frequency: 30% percent of women treated for gynaecological cancer with radiotherapy developed lower limb lymphoedema between 12 and 24 months after completing treatment; the majority had Stage I lymphoedema Swelling mostly influenced the lifestyle and resulted in being miserable

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Koehler L, 2023 Functional and Psychosocial Quality of Life in Gynaecologic Cancer Survivors with and without Lymphedema Symptoms USA	To compare function, quality of life, body image and distress levels between gynaecologic cancer survivors with and without lymphedema symptoms as well as to determine how many individuals received rehabilitation treatment following treatment for gynaecological malignancy Cross sectional design, 105 + 80 (N = 185)	Cervical, endometrial, ovarian, vaginal/vulvar cancers	Surgery, radiation The average time since cancer diagnosis was 4.7 years for symptomatic participants and 5.0 for asymptomatic	GCLQ FACT-G LEFS DT	We found lower extremity lymphedema to be associated with lower quality of life, lower limb function, greater distress, and negative body image
Kusters I, 2015 Women with self-reported lower limb lymphedema after treatment for gynaecological cancers: are they more likely to self-report psychosocial symptoms and less likely to use services? Australia	To assess self-reported lower limb lymphoedema (LLL), depression, anxiety, quality of life, unmet supportive care needs, and service use among gynaecological cancer survivors Cross-sectional survey (N = 160)	Gynaecologic cancers	Surgery, chemotherapy, radiotherapy 5–30 months post-diagnosis	GCLQ HADS SCNS-SF34 The needs for service module of the SCNS FACT-G	The prevalence of self-reported LLL was 30% Twenty-one percent and 24% self-reported symptoms of depression or anxiety, respectively. Women with LLL were more likely to also report symptoms of depression or anxiety and had higher unmet supportive care needs Women with LLL or high distress were less likely to use services they needed
Leitao MM, 2020 Patient-reported outcomes after surgery for endometrial carcinoma: Prevalence of lower-extremity lymphedema after sentinel lymph node mapping versus lymphadenectomy USA	To compare the prevalence of patient-reported lower-extremity lymphedema (LEL) with sentinel lymph node (SLN) mapping versus comprehensive lymph node dissection (LND) for the surgical management of newly diagnosed endometrial carcinoma Survey (N = 599) 180 SLN, 352 LND and 67 HYST (hysterectomy alone) cohorts	Endometrial cancer	Surgery + a small number also received external beam radiotherapy Minimum 44 months after surgery	A validated 13-item LEL screening survey EORTC QOL-C30 (items 22–49) EORTC QOL-EN24 (items 50–75)	Prevalence/frequency: 27% SLN cohort, 41% in the LND cohort and 40% in the HYST cohort High BMI was associated with increased prevalence of LEL After controlling for external beam radiotherapy and BMI, lymph node dissection retained independent associated with an increased prevalence of LEL over sentinel lymph node mapping (SLN) Patients with self-reported LEL had significantly worse QoL compared to those without self-reported LEL

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Kim SI, 2015 Impact of lower limb lymphedema on quality of life in gynaecologic cancer survivors after pelvic lymph node dissection Korea	To evaluate the impact of lower limb lymphedema (LLL) on QOL in gynaecologic cancer patients after pelvic lymph node dissection Cross-sectional case-control study (LLL group N=25, controls N=28)	Cervical, ovarian, endometrial cancer	Surgery only, chemotherapy, radiation therapy or concurrent chemoradiation therapy 1 to at least 5 years from diagnosis to survey	The Korean version of GCLQ-K EORTC QLQ-C30	The GCLQ-K total symptom score and scores for swelling-general, swelling-limb, and heaviness were significantly higher in the LLL group than in the control group In the EORTC QLQ-C30, the LLL group reported more financial difficulties compared to the control group Global health status was poorer in the LLL group with borderline statistical significance Global health status in the EORTC QLQ-C30 correlated with the GCLQ-K total symptom score
Lim MC, 2014 Lower extremity edema in patients with early ovarian cancer Korea	To investigate clinical manifestations of lower extremity edema (LEE) Survey (N=71)	Ovarian cancer	All patients underwent surgery, chemotherapy Not specified but some had LEE longer than 60 months	GCLQ Medical records	Prevalence/frequency: Twenty-nine patients (40.8%) had past (13 patients, 44.8%) and/or current patient-reported LEE (16 patients, 55.2%) Symptoms in over 20% of respondents were numbness, firmness/tightness, swelling, heaviness, limited movement of knee, and aching GCLQ total symptom score was significantly higher in patients with current LEE. Most of the LEE (25/29), developed within 12 months after surgery and LEE lasted more than 6 months in approximately two-thirds of the patients Only half of the patients indicated knowledge of lymphedema Although a significant proportion of patients with ovarian cancer have LEE after surgery, most are not aware of lymphedema until it develops. Education and analyses for LEE and lymphedema are needed in patients with ovarian cancer

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Mantegna G, 2013 Long-term prospective longitudinal evaluation of emotional distress and quality of life in cervical cancer patients who remained disease-free 2-years from diagnosis	To evaluate emotional distress and QoL in early stage (ECC) and locally advanced cervical cancer (LACC) patients who remained disease-free 2-years from diagnosis A prospective, longitudinal study, ECC (N=92) and LACC (N=77)	Cervical cancer	Treated with radical surgery or chemoradiation followed by radical surgery, respectively Baseline and 3, 6, 12 and 24 months from surgery	HADS GHS items of EORTC QLQ-C30 & EORTC QLQ-CX24	Prevalence/frequency not reported. Body Image mean scores were significantly impaired by chemoradiation administration in LACC patients, without long-term recovery In both groups, lymphedema and menopausal symptoms showed an early worsening which persisted 2-year after surgery Despite a significant improvement over time, elevated anxiety levels were still detectable at 24 months after surgery in approximately 10% of cervical cancer patients. Much more attention should be focused on surgical/medical approaches able to minimise the negative impact of lymphedema and menopausal symptoms on QoL
Omichi C, 2018 The Influence of Adverse Effects on Quality of Life of Survivors of Gynaecologic Cancer Japan	To investigate correlations between adverse effects (lower-extremity lymphedema LEL, dysuria, and severe gastrointestinal symptoms) and QoL (physical well-being, social well-being, emotional well-being, and functional well-being) Observational study (N=75)	Cervical, endometrial, ovarian cancer	Surgery, chemotherapy, Radiotherapy Before treatment, at least 6 weeks after treatment (posttreatment1), and 3 or 6 months after treatment (posttreatment2)	FACT-G Clinical data from medical records	Prevalence/frequency: Lymphedema occurred in 9 out of 75 participants (12%) Participants with LEL had significantly poorer QoL than did those without it in the domains of physical well-being at posttreatment1 and emotional well-being at posttreatment2 Moreover, patients with 2 adverse effects (LEL plus dysuria or severe gastrointestinal symptoms) had significantly poorer QoL than did those with no or single adverse effect in the domains of physical well-being at posttreatment1 and posttreatment2 and poorer QoL compared with those with no adverse effect in the domain of emotional well-being at posttreatment1 Poorer QoL in emotional and physical domains is associated with adverse effects of treatment. It is important to consider the effects of radical therapy not only on survival but also on the QoL of survivors

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Rowlands I, 2014 Quality of life of women with lower limb swelling or lymphedema 3–5 years following endometrial cancer Australia	To assess and compare QoL of women with a self-reported diagnosis of lower limb lymphedema (LLL), to women with lower limb swelling (LLS), and to women without LLL or LLS following treatment for endometrial cancer Mail survey 3 groups: Without lymphedema or lower limb swelling: N = 394 LLL (told by a doctor or health professional they had lymphedema): N = 68 LLS (self-reported): N = 177 N in total = 639	Endometrial cancer	Surgery, Chemotherapy, radiotherapy, brachytherapy 3–5 years after diagnosis	Questions regarding lymphedema Clinical and demographic variables SF 12	Prevalence/frequency Overall, 39% of women experienced either LLL (11%) or LLS (28%) Women with LLL and LLS had lower QoL Scores, compared to those without LLL and LLS Women with LLL had clinically lower physical QoL than women without LLL or LLS, however their mental QoL was within the normative range Women with LLS had significantly lower physical and mental QoL than women without LLL or LLS
Salani R, 2014 Swelling among women who need education about leg lymphedema (SWELL): A descriptive study of lymphedema in women undergoing surgery for endometrial cancer USA	To obtain a subjective assessment for the presence of LLS (lower limb swelling) and LLL (Lower limb lymphedema) and its impact on women who underwent surgical treatment for endometrial cancer Descriptive cross-sectional survey (N = 305)	Endometrial cancer	All participants underwent surgery for between 2006 and 2008 Survey conducted in 2011, at least 3 years after diagnosis	Self-administered survey developed from previously validated questionnaires and input from locally conducted user focus groups (patients and professionals) Participants were asked to rate a series of concerns about the effect of their LLL and LLS on their QoL (on a Likert scale) Self-rated health and health behaviour	Prevalence/frequency Swelling was the most common symptom (35%), but only 22% stated they had received a clinical diagnosis of LLL. Complaints included pain/tenderness (23%), numbness (21%), tightness (16%), heaviness (15%), tingling sensation (15%), and warmth/redness (13%) The presence of symptoms associated with sexual dysfunction, was similar between those that reported swelling and those that did not. However, responders who reported swelling were significantly more likely to report concurrent pain symptoms (back pain, abdominal pain, constipation, pelvic cramping) Approximately 60% of LLL responders reported impact on the ability to perform activities of daily living; 23% noted impact on their employment and 46% appearance of their legs had required a change in type of clothing 13% reported that they received information regarding the risk for LLL

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Sponholtz SE, 2022 SENTIREC—The sentinel node mapping in women with cervical cancer study—Patient-reported early lymphedema and its impact on quality of life Denmark/Holland	To evaluate patient-reported incidence and severity of early lymphedema and if the presence of early lymphedema affects the quality of life (QoL) after sentinel lymph node (SLN) mapping only and after SLN and pelvic lymphadenectomy (PL) A national multicenter prospective cohort study (N = 200)	Early-stage cervical cancer	Surgery: SLN only SLN + PL Preoperatively and 3, 12, 24, and 36 months postoperatively—this paper focuses on the baseline and three-month postoperative responses	Nine items on lymphedema (IL76) from the EORTC QLQ-VU34 LYMQOL EORTC QLQ-C30 QLQ-CX24 IL76	Incidence: 6% (SNL only)-32% (SLN + PL) Women who undergo SLN mapping rarely develop lymphedema, while women who undergo SLN + PL have a higher incidence and more severe early lymphedema Lymphedema symptoms in the legs, genitals, and groins increased in both groups postoperatively, but three times more in women who underwent PL Lymphedema symptoms after SLN + PL significantly impaired physical performance and appearance e.g., the ability to find shoes and clothes that fit Early lymphedema was associated with significant impairment regarding body image, global health status, physical-, role-, cognitive-, and social functioning, as well as a higher level of fatigue, pain, dyspnea and symptom experience
Trott S, 2020 Quality of life and associated factors after surgical treatment of vulvar cancer by vulvar field resection (VFR) Germany	To investigate patient-reported quality of life (QoL) and associated factors in vulvar cancer patients treated surgically by vulvar field resection without adjuvant radiation Retrospective post hoc analysis in patients who had participated in a previous prospective observational trial (N = 43)	Vulvar cancer	All patients underwent surgery (vulvar field resection) 38/43 (88%) had received inguinal lymph-node dissection in addition to VFR All patients who were still alive were contacted in 2017 Time since treatment ≤ 8 years	EORTC QLQ-C30 supplemented by self-developed question assessing sexual activity GCLQ	Prevalence/frequency: 40%, much higher risk with total inguinal LND Mean global QoL (global health status) rating among all patients was 66.1 on a scale from 0 to 100 with higher scores indicating better QoL. Higher GCLQ scores (lymphedema) were significantly associated with lower global QoL scores The presence of preoperative co-morbidities and postoperative wound-healing complications were also linked to reduced global QoL

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Watson CH, 2019 A pilot study of lower extremity lymphoedema, lower extremity function, and quality of life in women after minimally invasive endometrial cancer staging surgery USA	To pilot the use of an objective measurement technique to prospectively evaluate the incidence of LEL after minimally invasive staging surgery Secondary objectives included observation of changes in lower extremity function and OoL in this patient population Longitudinal, prospective pilot study (N = 97)	Endometrial cancer	All women underwent minimally invasive staging surgery Participants were evaluated at 4–6 weeks, 6–9 months and 12–18 months postoperatively	CCV LEFS FACT-G	Prevalence/frequency the rate of LLL was 25% at 4–6-weeks postoperative period, 19% 6–9 months, 27% at 12–18 months postoperatively Presence of LLL was associated with a significant worsening from baseline LEFS scores at 4–6 weeks and 6–9 months Lower extremity lymphoedema was not associated with a change in patient reported global QoL
Wedin M, 2021 Impact of lymphadenectomy and lymphoedema on health-related quality of life 1 year after surgery for endometrial cancer. A prospective longitudinal multicentre study Sweden	To determine whether lymphadenectomy influenced generic HRQoL 1 year after surgery for endometrial cancer To analyse the HRQoL in women with and without LLL to determine the impact of LLL on generic and lymphoedema specific HRQoL domains Prospective longitudinal cohort multicenter study (N = 235)	Early- stage endometrial cancer	All participants had surgery +/- radiation, +/-chemotherapy Preoperatively, at 4–6 weeks, 6 months and 1 year postoperatively	SF-36 EQ-5D-3L LYMQOL Leg circumference measurement Clinical grading of lymphoedema Perceived swelling of legs	Prevalence/frequency Leg volume determination: 22 (9.5%) were found to have lymphoedema Clinical evaluation: 51 (22.2%) had lymphoedema at the 1-year assessment Patient's perception of leg swelling: 92 (40%) reported leg swelling after 1 year Irrespective of method of determining LLL, women with LLL were significantly more affected in the LYMQOL domains Function, Appearance/body image and Physical symptoms than women without LLL, but not in the domain Emotion/mood No such differences were seen in the generic HRQoL or in the LYMQOL global score between the groups with and without LLL

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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Yost KJ, 2014 Lymphedema After Surgery for Endometrial Cancer: Prevalence, Risk Factors, and Quality of Life USA	To estimate lower-extremity lymphedema prevalence in patients surgically treated for endometrial cancer, identify predictors of lymphedema, and evaluate the effects of lymphedema on quality of life Mailed survey (N= 591)	Endometrial cancer	Surgery Median 6.2 years	Self-reported history of clinically diagnosed LLL EORTC QLQ-C30 EORTC EN-24 A 13-item lower-extremity lymphedema screening questionnaire	Prevalence/frequency A previous self-reported lymphedema diagnosis was reported by 103 (17%) patients and identified undiagnosed lymphedema in 175 (30%) Obesity, congestive heart failure, performance of lymphadenectomy, and use of external beam irradiation therapy were identified as significantly associated with prevalent lymphedema Multiple QoL scores were worse in women with lymphedema Patients with lymphedema reported worse lymphedema symptoms, urological symptoms, body image, back/pelvic pain and sexual functioning A total of 454 patients (77%) responded that their surgeon had not discussed the possibility of developing lymphedema because of their endometrial cancer surgery

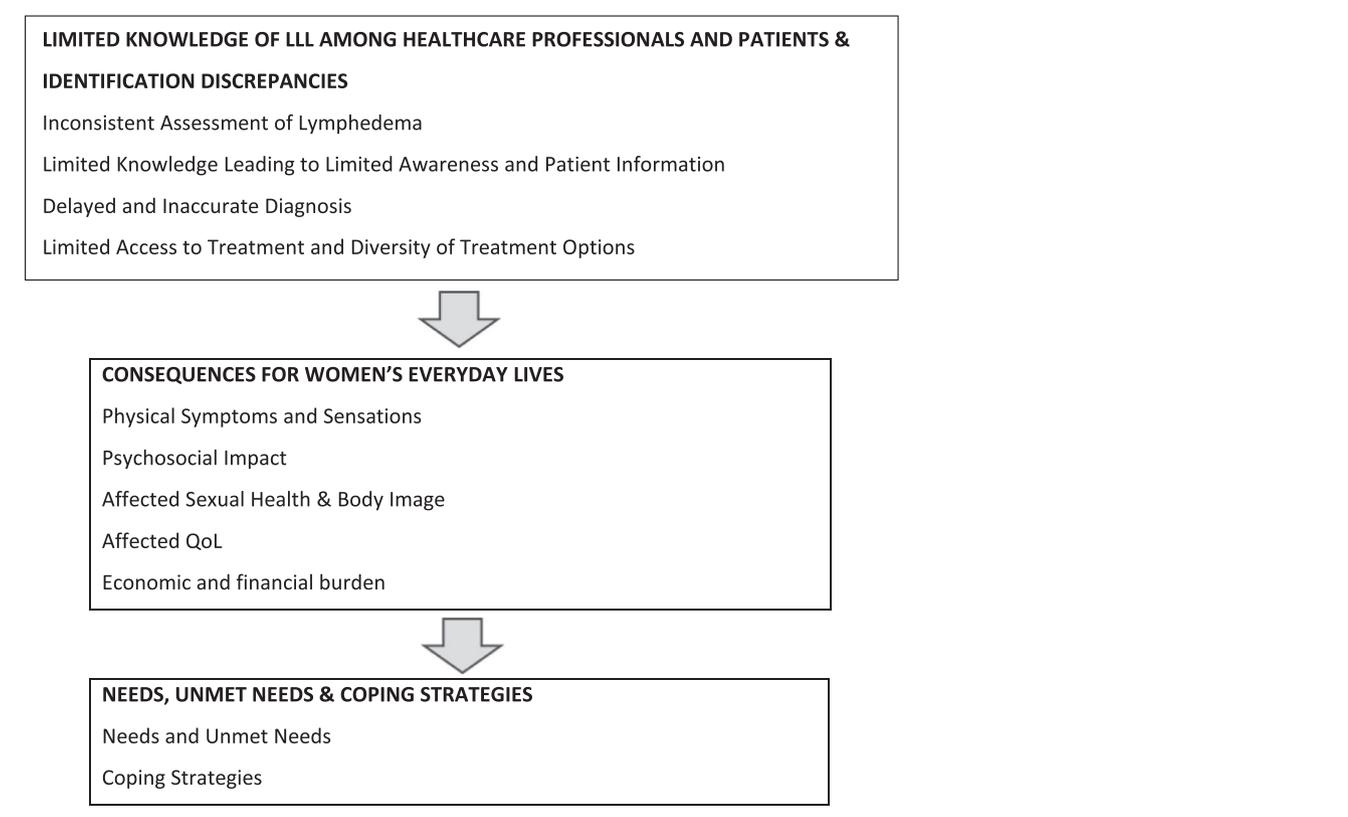
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Author, year, title, country	Aim, design, and number of participants	Cancer type	Treatment and time since treatment	Outcome measures	Results
Zhang X, 2022 Association of Lower Extremity Lymphedema With Physical Functioning and Activities of Daily Living Among Older Survivors of Colorectal, Endometrial, and Ovarian Cancer	To examine LEL among older female survivors of colorectal, endometrial, or ovarian cancer and investigate the association of LEL with physical functioning and activities of daily living (ADL) limitations Cohort study Secondary analysis of The Life and longevity after cancer (LILAC) Study (N = 900)	Colorectal, endometria and ovarian cancers	Surgery, radiation therapy, chemotherapy, hormone therapy The mean time since cancer diagnosis was 8.75 years	The 13-item Lower Extremity Lymphedema Screening Questionnaire 10 item PF assessment—the PF subscale of the RAND 36-item Health Survey 6 item ADL scale—derived from the Lawton Instrumental Activities of Daily Living & Katz Index of Independence in Activities of Daily Living	Prevalence/frequency Overall, 292 (32.4%) women reported lower extremity lymphedema, with the highest prevalence among ovarian cancer survivors (38 of 104 women- 36.5%), followed by endometrial cancer survivors (122 of 375 women—32.5%) Compared with women without LEL, women with LEL had a PF score that was lower and higher odds of needing help with ADLs In the association of LEL with PF, the mean decrease in PF score was greatest among survivors of colorectal cancer compared with survivors of endometrial cancer and ovarian cancer Additionally, among survivors of colorectal cancer, LEL was associated with increased odds of needing help with ADLs, while there was no such association among survivors of endometrial cancer or ovarian cancer The overall mean difference in PF between women with and without LEL was greater among those aged 80 years and older vs. those aged 65 to 79 years. However, among survivors of colorectal cancer, the mean difference in PF score was greater among women aged 65 to 79 years vs. those aged 80 years or older

Abbreviations: 3LNO, The Three-Levels-of-Needs Questionnaire; ADL, activities of daily living; BIS, The Body Image Scale; C-LFS-SF, The Chinese Version of the Lee Fatigue Scale-Short; DT, The National Comprehensive Cancer Network's Distress thermometer; EORTC QLQ-C30, The European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire—generic core module; ePAQ-PF, Personal Assessment Questionnaire-Pelvic Floor; EQ-5D-5L, Three-level version of the EuroQoL group five-dimension form; FACT-Breast, Functional Assessment of Cancer Therapy—Breast; CCV, Comparative Circumferential Volume; FACT-Cx, Functional Assessment of Cancer Therapy—Cervix; FACT-En, Functional Assessment of Cancer Therapy—Endometrial; FACT-G, Functional Assessment of Cancer Therapy General; FACT-V, Functional Assessment of Cancer Therapy—Vulva; GCLQ, The Gynecologic Cancer Lymphedema Questionnaire; GHS, Global health status; GPFBQ, The Global Pelvic Floor Bothers Questionnaire; HADS, The Hospital Anxiety and Depression Scale; HRQoL, health-related quality of life; IES, Impact of Event Scale; IL76, The hypothesized provisional scale structure of the IL76 as part of the EORTC QOL VU34, includes three separate domains on leg lymphedema, groin, lymphedema, and vulva swelling; KFS, Karnofsky Performance Status index; LEE, Lower Extremity Edema; LEFS, Lower Extremity Functional Scale; LEL, Lower Extremity Lymphedema; LELSQ, The Lower Extremity Lymphedema Screening Questionnaire; LLL, Lower Limb Lymphedema; LVC, limb volume change; Lymph-ICF-JL, Lymphoedema Functioning, disability, and Health Questionnaire for Lower Limb Lymphoedema; Lymph-ICF-LL-C, A Chinese version of the Lymphedema Functioning, Disability, and Health Questionnaire for Lower Limb Lymphedema; LYMQOL, The lymphedema Quality of Life Tool; PF, Physical functioning; POMS—Depression and dejection subscale, Profile of Mood States—Depression and Dejection Subscale; PPAQ, The Paffenbarger PA Questionnaire; PROMIS-SexFS, Sexual Function and Satisfaction screener items; PSQI, The Pittsburgh Sleep Quality Index; QGCR, The Queensland Gynaecological Cancer Registry; QLQ-EN24, The European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire—the endometrial cancer specific module; QLQ-VU34, The European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire—Vulva Cancer Module; QoL, Quality of Life; RRT, Robot-assisted Radical Trachelectomy; SCNS-SF34, Supportive Care Needs Survey Short Form; SCNS-SF34, The short form of the supportive care needs survey; SDS, Symptom Distress Scale; SF-12, Short -Form Health Survey; SF-36, Short form 36; SRS, Self-Reported Swelling; TSK, The Tampa Scale of Kinesiophobia.

TABLE 4 | Themes, subthemes, and interconnections.



the identification of lymphedema, often involving a combination of several approaches.

Three studies [25–27] used retrospective medical records and seven studies [12, 18, 26, 28–31] referred to a ‘physical examination/clinical evaluation’. Neither the medical records nor the clinical assessment provided detailed documentation beyond noting that an HCP had informed the woman of her lymphedema diagnosis. Nine studies [12, 32–39] used measurements such as ‘Limb Volume Change (LVC)’ or ‘Comparative Circumferential Volume (CCV)’, which were mostly well described in terms of how to perform them. The different measurements included for example: (a) ≥ 200 mL volume discrepancy between the limbs; (b) $\geq 10\%$ discrepancy between the limbs; (c) defined as equal to or greater than 7% of the relative circumference difference; (d) a LVC $\geq 10\%$ above baseline or (e) Cheng’s Lymphedema Grading System, a method of measuring and classification. Comparison of measurement were therefore not possible. However, three studies [12, 18, 27] applied the more well-known stages 0-III, defined by the ‘International Society of Lymphology’ in addition to a physical examination. Only two studies [30, 36] employed imaging techniques, including options such like limb volume measurement by various methods (e.g., perometry, lymphoscintigraphy, magnetic resonance imaging and computed tomography).

Analysis of self-reported data for evaluating and identifying LLL also revealed significant variation in methods, some of which consisted of self-constructed questions. Most frequent, eight studies [3, 33–35, 40–43] used the ‘Lymphedema symptoms

Gynecological Cancer Lymphedema Questionnaire (GCLQ)’. Four studies [28, 44–46] used the ‘13-item LEL screening survey and validated QOL assessment tool’, four studies [12, 47–49] used the ‘Limb Lymphedema Quality of Life Questionnaire LYMQoL’ and two studies [36, 37] used the ‘28 item Lymph-ICF-LL (Lymphoedema Functioning Disability and health questionnaire)’, all validated questionnaires.

Further, five studies [10, 25, 50–52] used an ostensibly validated questionnaire, though the authors did not provide further details. Eleven studies [3, 13, 17, 18, 26, 43, 53–57] utilised various self-reported measures or interviews developed by the researchers themselves. Four studies [47, 56, 58, 59] applied the EORTC *Vulva (QLQ-VU34)* or *Cervix (QLQ-CX 24) Cancer Modules*.

An accumulation of more than 4–5 symptoms typically corresponded to a diagnosis of lymphedema in the questionnaires. However, no defined cut-off value existed. Some questionnaires included additional questions such as ‘Have you been diagnosed with Lymphedema (in your leg)?’ and ‘Are you undergoing, or have you received treatment for Lymphedema?’ Some studies incorporated both questionnaires and measurement methods, while others identified women with LLL either through questionnaires or measurement. Many studies reported incidence and prevalence of lymphedema in populations undergoing surgery for cancers such as cervical, endometrial and vulvar. These studies often detailed disease extent and surgical scope, particularly lymph node removal.

6.2 | Limited Knowledge Leading to Limited Awareness and Patient Information

As outlined above, there was a lack of methodological rigour in the assessment and diagnosis of LLL, accompanied by substantial heterogeneity in the approaches used to measure its presence and impact. Several studies highlighted a lack of provided information regarding LLL as a possible late effect.

LLL was found to be a surprising and unknown symptom to some women [17, 60], and that health care professionals (HCPs) often lacked knowledge about the condition [31, 55]. Two studies on endometrial cancer patients found that most of the women did not receive preoperative information about the risk of LLL and only five to 7% were informed post-operatively [45, 52]. Lim [3] found that slightly more than half of early ovarian cancer patients were familiar with LLL, primarily those who had experienced it. A recent survey of gynaecological cancer patients in 20 countries revealed that 45% were unaware of lymphedema secondary to treatment [55]. Seventy-eight women of 142 complained about inadequate perioperative information on the side effects of lymphadenectomy and 53 women felt they were not given sufficient information to choose treatment alternatives that could reduce the risk of lymphedema [55]. The authors noted that the significant lack of appropriate counselling seemed to be driven by insufficient physician training [55]. Women described seeking information from various sources on their own [52, 55]. Ryan et al. [17] found that 34% of women who developed LLL after treatment for gynaecological cancers experienced considerable delays in finding appropriate information and treatment. Beesley et al. [51] found that out of 81 women diagnosed with lymphedema, 34% did not recall being informed about LLL until the time of the diagnosis. In contrast, a qualitative study by Barlow [53] found that five women who had groin nodes removed all reported being well-informed about the possible development of lymphedema and preventive strategies.

6.3 | Delayed and Inaccurate Diagnosis

Lack of knowledge about LLL may delay diagnosis of the condition. In a survey of 800 gynaecological cancer survivors [51], 25% reported leg swelling, but only 10% were clinically diagnosed with LLL. Of these, 75% were diagnosed within the first year after cancer diagnosis, 19% the following year and the rest up to 5 years later. Ryan et al. [17] found that only half of the women who experienced swelling (36%) were diagnosed with LLL (18%). Ninety-eight percent sought professional advice as symptoms appeared, mainly through their GPs. Before referral to a lymphedema specialist, 83% needed two or three consultations with an HCP. Few HCPs discussed LLL as a chronic condition [17].

Some women sought help on their own as their physicians did not refer them to treatment [55]. Others blamed themselves for not detecting lymphedema due to sparse information provided about LLL [31]. One of the participants described: *‘When I developed LLL, it was in an era when even the doctors in the hospital didn’t know about support socks. There was next to no*

information about that. I had been dealing with LLL for 6 whole years. I didn’t ask, and because of that, I didn’t have any internal sense of what it involved’ [31].

6.4 | Limited Access to Treatment and Diversity of Treatment Options

Symptoms of lymphedema did not always lead to treatment. Koehler et al. compared gynaecological cancer patients with and without lymphedema symptoms and found that 22.9% of symptomatic women had received treatment while 11.3% in the asymptomatic group [41]. Treatment was for 46.7% of the symptomatic patients physical and/or occupational therapy.

Patients diagnosed with LLL were offered treatments or recommendations for self-initiated activities to relieve their symptoms. A common form of prescribed treatment across studies was compression garments [13, 17, 18, 52, 54, 55]. However, some patients found them uncomfortable [17, 54] and unattractive, leading some to discontinue their use [17]. Dunberger et al. reported that the three most common treatments were limb elevation (75%), compression (50%) and diuretics (27%) [13]. Beesley et al. [51] also found frequent use of compression, with most patients treated with compression garments (64%) followed by lymphatic massage (62%) and lymphatic exercises (42%).

Ryan et al. [17] reported that 93% of the women treated by lymphedema therapists received a combination of education, skin care, lymphatic massage and exercises, routine bandages and compression garments tailored to their condition. Table 5 shows the variety of treatments prescribed and self-management strategies.

7 | Consequences for Women’s Everyday Lives

7.1 | Physical Symptoms and Sensations

Women with LLL experienced a range of physical symptoms that significantly impacted their daily activities and physical functioning. This included swelling [12], aching, tightness, heaviness, numbness, pain, tingling sensation and warmth/redness [3, 17, 31, 40, 51, 52]. Additional symptoms included leg swelling combined with abdominal and back pain, constipation and pelvic cramping [52], lower extremity stiffness [36], increased fatigue [49], stress and urge urinary incontinence, the latter in combination with faecal incontinence [13, 32].

Compared to women without LLL, those suffering from LLL had increased odds of reporting poor physical function [33, 35]. The negative consequences of LLL on physical function were also identified by others [36, 39, 41]. In a qualitative study by Seki et al. [31] women described limited ability to walk, move and exercise due to pain from swollen legs. Physical symptoms and function, measured by the condition-specific LYMQOL questionnaire 1 year postoperatively, were found to differ significantly between those with perceived swelling and those without [12].

TABLE 5 | Prescribed treatments and self-management strategies.

Treatment/study	Dunberger G, 2013 (N=616)	Ryan M, 2003 (N=82)	Beesley V, 2007 (N=802)	Salani R, 2014 (N=305)	Winch CJ, 2016 (N=8)	Seki K, 2023 (N=13)	Lim MC, 2014 (N=71)	Haidopoulos D, 2024 (N=386) ^c
Prescribed treatment								
Unspecified lymphedema treatment	9%					54% (7)		25% (43)
Compression stockings	50%	72% ^b	64%	64%	75% (6)			
Self-care programs (Multilayer) bandaging	12%	+		26%	87.5% (7)			14% (23)
Physiotherapy	9%							
Massage			62%	36%	100% (8)			26% (44)
Skin care					75% (6)			
Laser therapy					50% (4)			
Complex physical therapy ^a		93%						
Medication								9% (15)
Diuretics				46%				
Anti-inflammatory medications				36%				
Surgery								2% (4)
Other								8% (13)
Self-management strategies								
Exercise			42%	35%				33% (56)
Elevated limb/leg elevation	75%			93%			28% (8/29)	
Tai-Chi, gentle walking, and line dancing				73%			14% (4/29)	
Self-care only (not specified)						46% (6)		

^aCombination of education, skin care, lymphatic massage and exercises, routine bandages and compression garments regulated to their state of illness.

^bOf the 72% (n = 55) who had compression garments prescribed, 20% were unable to continue wearing them because they found them uncomfortable and difficult to use.

^c170 respondents.

LLL impacted the ability to carry out daily activities such as household chores, social activities, or sports to such an extent that these activities were altered or even stopped [13, 17, 57]. The decline in physical functioning among women reporting LLL increased with age [36, 46]. Furthermore, the ability to rest and the length and quality of sleep were disturbed [13, 46]. However, Akabay et al. did not find any differences in sleep quality between women with or without lymphedema [32].

Symptoms were triggered by walking, heat and stasis from standing or sitting still for long periods [13, 17, 51, 52]. Exercise, excessive drinking and infections worsened LLL [13, 17]. Infection could result from falls, ascitic tap, sunburn, injections, or mosquito bites [17]. The most common cause of worsening symptoms was keeping the legs in one position for a long time, followed by heat, trauma, infection and overactivity [17].

7.2 | Psychosocial Impact

Some women with swelling reported mood changes, feeling miserable and irritable, needing more time to complete tasks and a desire to be alone [38]. However, other findings showed no difference in mood between endometrial cancer survivors with or without LLL/self-reported leg swelling [12].

Women with self-reported LLL/lymphedema symptoms experienced increased cancer distress and worry about recurrence [13, 34, 41]. Gynaecologic cancer survivors with lymphedema symptoms had higher rates of clinically significant cancer distress compared to those without [41]. Women with LLL often interpreted bodily signals as signs of recurrence [13]. Gynaecologic cancer survivors with late-grade LLL experienced higher levels of symptom distress than those with early grade lymphedema [36].

Gynaecological cancer survivors with LLL, especially late grade LLL, were more likely to report symptoms of depression and anxiety compared to those without LLL or early-grade lymphedema [36, 42]. Qualitative research highlighted feelings of resignation and despair [31, 54] in response to LLL being a chronic condition requiring lifelong treatment. Furthermore, survivors reported feeling misunderstood and unable to discuss their symptoms and challenges with HCP's, friends, or family members, leading to feelings of isolation [31].

7.3 | Affected Sexual Health and Body Image

LLL has been reported to cause loss of sexual desire [38]. Winch et al. found that lymphedema affected women's sexual function and activity by impacting desire, arousal and pain [18]. Studies have associated lymphedema symptoms with worse sexual and/or vaginal function [34, 45]. However, Carter et al. found no differences in sexual activity between having lymphedema symptoms or not [34]. This aligns with Dunberger et al., who found no differences in satisfaction with sexuality and present sexual life [13] and with Salani et al. [52], who reported symptoms associated with sexual dysfunction to be similar in those reporting swelling and those without. However, women with swelling

were significantly more likely to report pain, including abdominal pain and pelvic cramping, which might impact sexual life negatively.

The sexual impact of lymphedema-related pain, immobility and compression garments was described in a qualitative study: *'If you talk about sex, positions will be quite affected by it, because you just 'can't do anything because you 'can't move'* [18]. Some women managed to overcome these challenges, while others did not. Having a supportive partner who helped manage the lymphedema, such as by providing lymphatic massage, was valued by some women, as it established intimacy. Others felt distressed and guilty of not fulfilling the sexual role expected in their relationships and appreciated their partner's support. For single women, exposing lymphedema to a new partner involved significant fear of lack of acceptance [18].

LLL negatively impacted body image [12, 18, 32, 38, 41, 45, 48, 52–54]. Increased LLE symptoms and distress were associated with a more negative body image [32, 34]. Survivors with late-grade lymphedema reported worse body image than those with early-grade lymphedema [36]. However, one study found no difference in feeling attractive between survivors with and without LLL [13].

Qualitative studies revealed that visible symptoms of lymphedema made some women feel vulnerable, threatening their femininity and body image, as it affected their physical appearance and self-confidence [18, 31] and limited clothing, shoe and fashion choices [17, 18, 31, 49, 52–54].

7.4 | Affected QoL

Studies using various psychometric scales measuring QoL confirmed the negative impact of LLL on QoL [10, 26, 28–30, 34, 37, 41, 45, 47, 48, 55, 58]. Early LLL was associated with self-reported impairment in body image, global health status, physical, role, cognitive and social functioning, as well as higher levels of fatigue, pain, dyspnoea and overall symptom experience [12, 13, 27, 44]. Women with late-onset LLL had significantly worse scores for symptom distress, depression, body image and health-related QoL compared to those with early LLL [36].

A recent study among low grade endometrial cancer patients found that high scores of lymphedema at 12 months were negatively associated with daily activities, emotional functioning, global QoL and subjective symptom burden [47]. Likewise, Trott et al. found the presence of lymphedema to be associated with reduced QoL after surgical treatment of vulvar cancer by vulvar field resection [43]. However, a prospective evaluation of postoperative endometrial cancer patients undergoing minimally invasive staging surgery found no significant change in QoL from baseline to long-term follow-up, despite 27% developing LLL [39].

7.5 | Economic and Financial Burden

The decline in physical functioning also impacted professional employment and financial situations [30, 31, 38, 52, 60]. Lifelong

treatment for LLL entailed expenses for hospitalizations, transport costs and costs for support stockings and other preventive treatments [31].

8 | Needs, Unmet Needs and Coping Strategies

8.1 | Needs and Unmet Needs

As presented, a significant number of women received insufficient guidance and support regarding preoperative counselling, preventive strategies, referral and access to treatment for lymphedema. This lack of support impacted their lives in multiple ways. Jeppesen et al. unfolds this in their study of women with cervical and endometrial cancer three months post-treatment, reporting that lymphedema was among the top five prioritised problems [56]. Another study reported that 25% of women with symptomatic or diagnosed LLL had a moderate to high need for support and information on its causes, prevention and treatment [51]. This aligns with findings that found early knowledge to be crucial for better prevention and management of LLL [54].

Furthermore, gynaecological cancer survivors diagnosed with lymphedema had higher relative odds of psychological, physical, daily living and sexual needs compared to those without [50, 51]. Beesley et al. [51] found that a fifth of the women diagnosed with lymphedema experienced moderate or high-level needs for assistance with leg discomfort, pain and managing lymphedema symptoms. These findings are supported by a smaller survey [42] which found that gynaecological cancer survivors with self-reported lower limb swelling, or lymphedema had significantly higher unmet supportive care needs related to psychological, physical, daily living, health and patient care [42].

Later, Beesley et al. [25] investigated lymphedema-specific supportive care needs among endometrial cancer patients three to 5 years post-diagnosis. More than half of those with self-reported lymphedema had either met or unmet needs for assistance with lymphedema-related issues and 29% had at least one unmet moderate or high-level need, particularly regarding pain and costs [25]. Qualitative research highlighted the need for peer support groups to share experiences and support each other [54].

8.2 | Coping Strategies

Living with lymphedema-related challenges left women feeling resigned [17, 31, 54]. Coping strategies included reframing the problem by emphasising being alive, thinking ‘it could have been worse’ or ‘others are worse off’, using humour, or adopting a pragmatic approach to the lymphedema-related problems [17, 18, 54]. Seki et al. found that one of the most empowering factors was the ‘existence of therapists and doctors who would accept, encourage, understand and treat the patient no matter the circumstances’ [31]. Women discussed coming to terms with or partially accepting lymphedema-related problems [18]. Other coping strategies to prevent exacerbation included time-consuming daily massage and exercise routines, as well as self-management techniques like gentle walking and leg elevation to reduce swelling and provide comfort [3, 52, 54].

9 | Discussion

Women with LLL faced significant unmet needs due to insufficient knowledge and inconsistent identification, leaving them unprepared and inadequately treated. Most studies in this review used disease-specific QoL questionnaires to examine women’s symptoms of lymphedema. While they mapped many multidimensional symptoms, only six qualitative studies allowed women to elaborate on their lives with lymphedema. Similarly, one study argued that few studies assessed benefits of lymphedema treatment from the patient’s perspective [61]. Seventy-two percent of their participants rated ‘To find a clear diagnosis and therapy’ to be the most important expectation and need, which aligns with our findings of diagnostic delay and women struggling to receive timely and adequate treatment.

Our results also highlight a significant lack of consensus regarding the definition, assessment and diagnosis of LLL. It was not an objective of this review to examine prevalence; however, it is reported where possible. The prevalence estimates vary widely, likely due to factors such as disease type and stage, surgical techniques, healthcare access and diagnostic criteria. Changes in treatment, including less aggressive approaches, may influence future prevalence of LLL. The absence of standardised diagnostic tools—both objective and self-reported—complicates accurate identification. Current methods face challenges with reliability, measurement error and symptom overlap with other conditions. Known risk factors (e.g., BMI, infections, immobility) might improve screening if applied systematically. Overall, robust diagnostic standards are urgently needed to ensure timely detection and treatment of lymphoedema. Others have also argued that no accepted standard for the definition of lymphedema is largely responsible for the wide variation in the reported incidence of lymphedema [62, 63]. This is a problem because early detection and onset of lymphedema treatment is of utmost importance as the disease will otherwise slowly progress, causing tissue damage and advancing to the later stages of lymphedema [62]. Lack of knowledge, education, standards and access to treatment were also reported 15 years ago by Hodgson et al. [64], where stakeholders, including patients, HCPs, industry representatives and policymakers, identified the main barriers, challenges and issues regarding lymphedema. Consensus was reached on five priority areas: education, standards, research, reimbursement and access to treatment, with the overall issue being the lack of clear responsibility for lymphedema care within the healthcare system.

Lack of knowledge is also found within breast cancer-related lymphedema (BCRL), where a study investigating clinician awareness and knowledge of BCRL found that only 44% had ever made a referral and where clinicians who had a higher BCRL knowledge score were more likely to make referrals [65]. This was also the case among oncology nurses, where 70% lacked knowledge about BCRL assessment and examination and 96% reported that they did not receive any education regarding BCRL [66]. Comparable conclusions were drawn by Keast et al. [67] noticing that recognition of the seriousness of this chronic disease in healthcare is scarce, even though untreated lymphedema is progressive and can lead to infection, disfigurement, disability and even death. All of which have severe consequences for the patient and significant expenses for society [67].

The lack of knowledge among HCPs creates an ethical dilemma, too, because patients expect them to be experts and trust their guidance. It also raises the question of whether lymphedema is described as a risk factor in the treatment decisions patients make with HCPs. A survey covering long-term cancer survivors at risk of developing LEL found 78% being unsure or having never heard about LLL [68]. The lack of knowledge among HCPs may be due to the lack of systematic research on diagnostics and management of LLL. A systematic review from 2017 that examined evidence-based practice in the management of LLL after gynaecological cancer found no randomised studies and included only three retrospective studies [69]. This is supported by participants in the study by Hodgson et al., who referred to the global lack of awareness as 'the vicious circle of lacks'. When there is a lack of research on lymphedema, it also becomes difficult to convince policymakers of the problem and its costs, secure reimbursement and access to treatment, establish standards for the assessment and diagnosis of lymphedema and develop guidelines [64].

As part of an enhanced treatment approach, it is highly relevant to consider how women's coping strategies can be supported and strengthened. We found that women employed a range of coping mechanisms including emotion-focused coping such as reframing and acceptance, as well as problem-focused coping, which involved the use of various self-management strategies aimed at reducing or alleviating the LLL [70]. Admoun et al. [71] examined an extended range of coping mechanisms including how patients themselves assessed the effectiveness of these strategies. Particularly, support from therapists and family members was evaluated positively. Fu et al. described how a patient-centred, mobile, learning- and behaviour-supportive tool, designed for women experiencing lymphedema following breast cancer, assisted patients in monitoring and responding to lymphedema symptoms as part of their development of self-care skills [72]. Learning to balance exercising without impacting recovery after surgery negatively was a skill to learn according to Hsu et al. [73]. Alsaratee et al. promoted a comprehensive approach to strengthen the treatment of LLL covering accurate examination, designated support from lymphedema specialists and recommendations for self-management techniques such as gentle exercise, weight management, skin care and use of compression garments [74].

With severe consequences for patients and society, it seems paradoxical that there is sparse attention on this condition. Secondary lymphedema seems historically understood as a symptom caused by various diseases and therefore not belonging to a single medical specialty. Lymphedema thus being 'homeless' and falling between different siloes of specialties leads to fragmented care and treatment, as demonstrated in our findings. This is supported by others describing no defined medical domain responsible for lymphedema diagnosis and treatment being a barrier [64]. However, lymphedema is recognised as a disease in the WHO International Classification of Diseases (ICD) system [75]. This is important because the diagnostic coding system is used for quality assurance, monitoring and documentation of resource utilisation within the healthcare system, thereby legitimising the treatment of the condition.

When research and standards for LLL are lacking, HCPs struggle to prevent, educate and treat patients effectively. Systematic

educational initiatives are needed to improve prevention, assessment and management. Education should be integrated and thoroughly addressed in undergraduate nursing and medical curricula. This is supported by HCPs in a study where the majority did not receive teaching on lymphedema as undergraduate medical students [76].

Our findings indicate that women face a healthcare system unable to effectively prevent, diagnose, or treat lymphedema, nor provide adequate education for self-management to reduce complications such as infections. Previous research comparing symptom burden in upper versus lower limb lymphedema found that individuals with LLL experienced significantly more frequent and severe symptoms, infection episodes and infection-related hospitalisations [77].

The study by Bowman et al. [76] investigated both HCPs and patients' perspectives on lymphedema to develop a model for quality lymphedema care. Their model encompasses important factors such as HCP education and knowledge, formalised cancer-related lymphedema programs, screening and diagnosis, LEL resource awareness, clinical referral and resource accessibility, holistic psychosocial patient support and finally referral to lymphedema clinics to facilitate continued supportive care [76].

There is an urgent need for policy makers to prioritise multidisciplinary lymphedema centres or programs and clear pathways to follow when experiencing symptoms. Another paper evaluates a model of care for all types of lymphedemas covering a multidisciplinary specialist lymphedema clinic in primary care along with early detection centres in all oncology centres to improve education, early diagnosis and intervention [78]. One-year data showed a significant reduction in GP and public health nurses visits, along with a reduction in infections and hospital admissions. QOL was improved on all areas of LymQoL [78].

Future research is therefore needed on most aspects of LLL, including development and testing the effect of multidisciplinary lymphedema centres. These centres would have the potential to centralise knowledge, improve diagnostic procedures, implement standardised treatment plans and enhance education and research. Knowledge must be effectively disseminated to HCPs so that it can benefit patients and inform policy makers, enabling them to change health policies and prioritise all aspects of lymphedema care in the future. This is important not only from a single patient perspective, but also because the number of cancer survivors with lymphedema is increasing [79]. Concurrently, research incorporating patients' perspectives is essential to guide the development of clinically relevant treatment approaches.

9.1 | Limitations

This review has several limitations, primarily stemming from the nature of the available evidence. Whilst the study was well designed, it cannot make up for studies of generally low methodological quality, with only 19.5% meeting all MMAT screening criteria [21], and many studies had small sample sizes. Restricting inclusion to English and Scandinavian languages may have introduced language bias, potentially overlooking

relevant studies published in other languages. Interpretive bias may also have occurred due to preconceptions influencing how our findings were analysed [80].

Substantial heterogeneity regarding the definition and assessment of LLL also complicated the synthesis and comparison of findings. The patient-centred insights that could be integrated into the review were sparse due to a scarcity of qualitative research. Some studies may also be affected by recall bias [81]. The generalisability of the findings is limited, as they reflect specific healthcare systems, cultural contexts and practices within the included countries and within a specific period.

9.2 | Strengths

The review also possesses key strengths that enhance the robustness of its findings. A protocol was published prior to initiating the review, ensuring transparency. The integrative design allows for inclusion and synthesis of all research methodologies, providing a more comprehensive and holistic understanding of LLL. The review successfully integrated 39 studies (41 papers) from a wide range of countries, providing a broad evidence base to support its conclusions. Finally, the review was conducted systematically and rigorously, adhering to the stages described by Whittemore & Knafl [19]. Two authors independently screened abstracts and full texts against inclusion and exclusion criteria and the quality of the included studies was assessed by all authors.

10 | Conclusions

LLL have a profound impact on women's daily life, affecting their QoL, their physical and psycho-social health and their existential well-being. The lack of standardised diagnostic criteria and clear care pathways creates major knowledge gaps, delays diagnosis and fragments care. LLL 'homeless' status across medical specialties further obstructs management and leaves responsibility unclear. Urgent systemic change is needed. Research must define evidence-based strategies for prevention, assessment and treatment to support robust clinical guidelines. Policymakers should prioritise multidisciplinary centres, education of HCPs and healthcare should ideally adopt patient-centred, multidisciplinary practices to ensure timely diagnosis, referral and self-management support.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Data S1:** scs70189-sup-0001-Supinfo01.docx.