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Quality of life issues in patients with ductal carcinoma in situ: A systematic review

Thenugaa Rajeswaran BSc(C)[1*], Milena Gojsevic BSc(C)[1*], Adrian Wai Chan MBBS[1,2], Henry CY Wong MBBS[3], Shing-Fung Lee MBBS, MSc[2,4], Rhys Bernard BSc(C)[5], Gustavo Nader Marta MD, PhD[6], Katarzyna Pogoda MD, PhD[7], Jennifer YY Kwan MD, PhD[8,9], Olivia Kuszaj BSc(C)[1], Marley Day BSc(C)[1], Tara Behroozian MD(C)[10], Eveline MA Bleiker PhD[11], Cindy Wong MBBS[12], Yuichiro Kikawa MD, PhD[13], Kaori Tane MD[14], Galina Velikova BMBS, PhD[15,16], Yiola Marcou MRCP, FRCR[17], Vesna Bjelic-Radisic MD, PhD[18], Irene Karam MD[1,9], Muna Al-Khaifi MD, CCFP, MPH[1], Samantha KF Kennedy BSc[1], Edward Chow MBBS[1,9]

[1] Odette Cancer Centre, Sunnybrook Health Sciences Centre, University of Toronto, Toronto, Ontario, Canada

[2] Department of Clinical Oncology, Tuen Mun Hospital, Hospital Authority, Hong Kong

[3] Department of Oncology, Princess Margaret Hospital, Hospital Authority, Hong Kong

[4] Department of Radiation Oncology, National University Cancer Institute, National University Hospital, Singapore

[5] Faculty of Health Sciences, McMaster University, Hamilton, ON, Canada

[6] Department of Radiation Oncology, Hospital Sírio-Libanês, Sao Paulo, Brazil

[7] Department of Breast Cancer and Reconstructive Surgery, Maria Sklodowska-Curie National Research Institute of Oncology, Warsaw, Poland

[8] Radiation Medicine Program, Princess Margaret Cancer Centre, Toronto, Canada

[9] Department of Radiation Oncology, University of Toronto, Toronto, Canada

[10] Michael G. DeGroote School of Medicine, McMaster University, Hamilton, ON, Canada

[11] Netherlands Cancer Institute, Amsterdam, the Netherlands

[12] Union Oncology Centre, Kowloon, Hong Kong

[13] Department of Breast Surgery, Kansai Medical University Hospital, Hirakata, Japan

[14] Department of Breast Surgery, Hyogo Cancer Center, Hyogo, Japan

[15] Leeds Institute of Medical Research at St James's, University of Leeds, Leeds, UK

[16] Leeds Cancer Centre, St James's University Hospital, Leeds

[17] Department of Medical Oncology, Bank of Cyprus Oncology Centre, Nicosia, Cyprus

[18] Breast Unit, Helios University Hospital Wuppertal, University Witten–Herdecke, Wuppertal, Germany

[*] TR and MG are joint first authors

Correspondence:
Dr. Edward Chow
Department of Radiation Oncology, Odette Cancer Centre
2075 Bayview Avenue
Toronto, Ontario, Canada M4N 3M5
E-mail: edward.chow@sunnybrook.ca

Abstract

Purpose: Ductal carcinoma in situ (DCIS) of the breast is one of the most common pre-invasive cancers diagnosed in women. Quality of life (QoL) is extremely important to assess in studies including these patients due to the favourable prognosis of the disease. The primary objective of this systematic review was to compile a comprehensive list of QoL issues, all existing QoL assessment tools and patient-reported outcome measures used to assess DCIS.

Methods: A search was conducted on Ovid MEDLINE, EMBASE, and Cochrane Central Register of Controlled Trials databases from inception to August 2023, using keywords such as "ductal carcinoma in-situ", "quality of life", and "patient reported outcomes." QoL issues and QoL tools in primary research studies were extracted.

Results: A total of 67 articles identified issues pertaining to patients with DCIS spanning physical, functional, and psychosocial QoL domains. Physical and functional issues observed in patients included pain, fatigue, and impaired sexual functioning. Psychosocial issues such as anxiety, depression and confusion about one's disease were also common. QoL tools included those that assessed general QoL, breast-cancer specific tools, and issue-specific questionnaires.

Conclusion: The current instruments available to assess QoL in patients with DCIS do not comprehensively capture the issues that are pertinent to patients. Thus, the modification of existing tools or the creation of a DCIS-specific QoL tool is recommended to ensure that future research will be sensitive towards challenges faced by patients with DCIS.

Keywords: Ductal carcinoma in situ, quality of life, patient-reported outcome, pre-invasive cancer, breast, systematic review

Introduction

Ductal carcinoma in situ (DCIS) of the breast is a disease where malignant epithelial cells are confined within the ductal system of the breast [1]. DCIS stands apart from invasive breast cancer in several key aspects. DCIS is usually detected by screening, is typically asymptomatic, and does not have regional or distant metastases [1,2]. As a precursor for invasive breast cancer, DCIS has seen an increase in incidence globally due to the widespread adoption of breast cancer screening, and the mean age of detection of DCIS is earlier when compared to invasive breast cancer [3]. Understanding the prognosis of DCIS is paramount, particularly in relation to risk stratification using tools such as the Van Nuys Prognostic Index [4]. Low-risk DCIS is characterized by an excellent prognosis, while high-risk disease presents an increased likelihood of progressing into invasive breast cancer [4].

The management of DCIS involves a delicate balance between preventing progression to invasive disease and minimizing potential overtreatment [2]. While DCIS is confined to the ducts of the breast and is non-invasive, it carries a risk of local relapse if not adequately treated [1]. This local recurrence can evolve into invasive breast cancer, which may increase the risk of regional or distant metastases, thereby significantly impacting patient prognosis and quality of life [1]. Consequently, there is a critical need to exercise caution in the treatment approach, avoiding overtreatment for those with low-risk disease and considering multimodality treatment for individuals classified as high risk [4]. Treatments for DCIS typically include surgery, radiation therapy (RT), hormonal therapy and a combination of these modalities, which can help to prevent local or contralateral relapse [4,5]. These treatments may lead to adverse physical side effects, such as acute or chronic pain, fatigue, hot flashes, and sensory disturbances [3]. Additionally, clinical trials have shown limited improvement in overall survival with adjuvant treatments, such as RT or endocrine treatment, in patients diagnosed with DCIS [5,6]. Active surveillance is gaining prominence as a prudent option for managing low-risk DCIS, aiming to minimize treatment-related toxicities [7]. However, the adoption of active surveillance should be approached judiciously, recognizing its potential association with heightened patient worry and anxiety [7]. These patients, unlike those with invasive breast cancer, are uniquely worried about the progression of their disease into an invasive disease [8]. The diagnosis and treatment journey for patients with DCIS can result in a wide variety of physical, functional, and psychosocial quality of life issues (QoL).

With an earlier detection age and positive prognosis, short- and long-term impacts on QoL is of the utmost importance to consider when treating patients with DCIS. This extends beyond conventional clinical endpoints, and requires exploration of the psychosocial implications, treatment-related challenges, and long-term survivorship experiences unique to this patient population. Thus, the primary objectives of this systematic review are to (1) compile a comprehensive list of QoL issues and (2) compile all existing QoL assessment tools and patient-reported outcome measures (PROMs) used to assess DCIS.

Methods

This systematic review was conducted as guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [9].

Search strategy

Three electronic databases were searched: Ovid MEDLINE, EMBASE, and Cochrane Register for Controlled Trials from inception to August 2023. The search strategy utilized keywords such as “ductal carcinoma in-situ”, “quality of life”, and “patient reported outcomes” among others as shown in Appendix 1. The search was limited to adult human populations and studies available in English.

Article selection

Results were screened using Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia (available at www.covidence.org) [10]. Two independent reviewers (TR and MG) screened the titles and abstracts and full texts according to the eligibility criteria. Conflicts were resolved by discussion between the authors. Qualitative and quantitative studies were included if they (1) discussed patients with DCIS and (2) reported QoL issues or toxicities in patients. Studies that recruited both patients with DCIS and invasive breast cancer were included if there was a separate analysis done on the patients with DCIS. We considered prospective trials and retrospective studies. Secondary literature such as review articles were excluded, however, the citations of such articles were used to identify additional relevant articles.

Data collection and analysis

The year of publication, country, study design, number of patients with DCIS, any QoL issues discussed, and QoL assessment tools were extracted from all the studies. The QoL issues extracted were sorted by frequency and categorized into three domains: (1) physical, (2) functional, and (3) psychosocial, following the European

Organization for Research and Treatment of Cancer (EORTC) Quality of Life Group module development guidelines [11].

Results

Literature search

The literature search yielded 2225 results from Medline (n=932), Embase (n=1107), and Cochrane Central Register for Controlled Trials (n=186). After 362 duplicates were removed, 1863 papers remained for title and abstract screening, and after the initial screening, 298 articles were screened by their full texts. Of these articles, 67 met the inclusion criteria and were included in this systematic review as reported in the PRISMA diagram (Figure 1) [8, 12-77]. This included 10 qualitative studies using semi-structured interview format and 57 quantitative studies using a variety of PROMs . Table 1 presents the study characteristics of the 67 studies included. These studies had a range of 10 to 3046 patients with DCIS involved. The most common treatments were surgery, RT, and hormonal therapy.

DCIS-related QoL issues

Tables 2 and 3 show the extracted QoL issues and tools, respectively, and summarize the frequency that these QoL issues and tools are mentioned in the literature. A few selected studies with the largest and/or the most representative patient populations are discussed.

Physical

The physical QoL issues reported in this systematic review were found to be caused by the treatments for DCIS. A cross-sectional study by Mertz et al. on the QoL of DCIS patients showed that one third (33%, n=154/473) of patients had persistent pain over the breast, chest wall, axilla, or arm at a median of 24 months after diagnosis, and 12% (n=57/473) reported moderate to severe pain [54]. Accordingly, within the physical QoL domain, pain was the most reported issue, with studies additionally reporting pain in the abdomen, bones, joints, and muscles [34,65]. Fatigue was also a commonly reported issue by patients, and another cross-sectional study conducted in the Netherlands found there to be severe fatigue in 23% (n=20/88) of patients with DCIS, compared to 6% (n=11/178) of healthy women [12]. In the study by Mertz et al., sensory disturbances were reported by 63% (n=299/473) of patients, where patients reported experiencing a “pins and needles” sensation (33%, n=156/473), electric shock (20%, n=95/473), burning hot sensations (12%, n=57/473), and numbness (37%, n=175/473) [54]. Hormonal therapies, such as anastrozole and tamoxifen, also caused several physical QoL issues, such as gynaecological symptoms, hot flashes, hair thinning, headaches, weight gain, indigestion, reduced appetite, sweating, and dizziness [34,65,69]. RT was commonly associated with issues such as erythema, pigmentation, and itchiness over the irradiated area [36].

Functional

Alongside physical symptoms caused by treatments, functional QoL issues were reported by patients with DCIS. Bluman et al. found in a study of 122 women with DCIS that half of the women who had been sexually active experienced decreased interest in sex and decreased sexual activity since the diagnosis of DCIS [16]. In addition, 33% of the sexually active women reported feelings of sexual unattractiveness, and 19% experienced pain/difficulty with intercourse [16]. Worse physical function was also reported in several studies that impacted their daily activities such as an inability to breastfeed, a loss of range of motion, back problems, general weakness, and difficulty in performing strenuous activities [34,52,53,65,67]. Less commonly reported functional QoL issues included issues with memory and a need for physical rehabilitation [34].

Psychosocial

Anxiety and depression were the most common QoL issues identified in this review, and Mertz et al. found that 20% (n=94/473) and 6% (n=26/473) of Danish women with DCIS had anxiety and depression, respectively, as measured by the Hospital Anxiety and Depression Scale (HADS) [54]. In an exploratory study by Rosenberg et al., more than 1100 responses also reported concerns of the recurrence and/or progression of DCIS into invasive cancer, and other concerns included what their DCIS diagnosis meant in terms of risk to family members having cancer [65]. Additionally, over 1100 responses showed concern about surgery and/or RT side effects, such as the loss of a breast/nipple, uneven breasts, and scarring/disfiguration [65]. Emotions ranged from depression and suicidal thoughts to lower levels of fear, anxiety, embarrassment and the feeling of being overwhelmed [65]. Some respondents also questioned whether the level of treatment was appropriate and expressed treatment regret [65]. Other DCIS-specific psychosocial QoL issues included a perceived lack of support, in the form of emotional support, professional support services, clinician-patient communication and social support in comparison to those with invasive breast cancer [21,22,39].

Additionally, a few studies mentioned QoL issues such as impacts on one's body image, confidence, relationships, ability to enjoy life, and satisfaction with cosmetic outcomes [42,52,63,77]. Body image is a significant concern for some women with DCIS, especially those who had mastectomy and immediate breast reconstruction [40,67]. In a study of 43 participants by Kennedy et al., 56% (n=5/9) of women with reconstruction reported body image scores that were regarded as high enough to be priority for help, even at 9 months post-diagnosis [40]. In a qualitative study on Chinese women with DCIS, some patients talked about their difficulty accepting their changed body image describing how they felt "imbalanced" after surgery [77].

Information needs

Of the psychosocial issues identified, information needs were unique to patients with DCIS. In a large quantitative exploratory study by Rosenberg et al. including 1832 patients diagnosed with DCIS, most responses (n=1432) reflected confusion surrounding the DCIS diagnosis, with many patients describing the diagnosis of DCIS as a “gray zone” and stated they were unsure about whether DCIS was cancer or not [65]. The diverse terms used by health care professionals including, “breast cancer,” “early cancer,” “in situ,” “pre-malignant,” “ductal carcinoma in situ,” “DCIS,” “abnormal cells,” “non-invasive” and “pre-cancer(ous)” contributed to the confusion many patients faced [39]. Confusion was often accompanied in studies by other QoL issues, such as a lack of prior knowledge about DCIS, a lack of information received about one's disease/treatment, and shock due to the diagnosis [8,21,22]. In a study by Davey et al., 30% (n=69/231) of women reported feeling shocked or overwhelmed by the DCIS diagnosis, enhanced by their lack of physical symptoms and the invisibility of DCIS [21].

QoL tools and assessments

A range of QoL tools and PROMs were used to assess the patient-reported outcomes of patients with DCIS (Table 3), and no validated DCIS specific QoL measurement tools were identified in our review. These tools covered various and specific domains of QoL, and many studies used these scales in conjunction with one another. Investigator designed assessment tools were commonly used for the purpose of evaluating DCIS patients. These questionnaires either combined various domains of QoL, such as physical, psychosocial, and functional domains, or focused on DCIS-specific issues of QoL, such as knowledge about the disease, symptoms from treatments, or psychosocial issues.

The most frequently used scale was the Medical Outcomes Study (MOS) 36-Item Short Form Health Survey (SF-36), which is a non-cancer specific measure that evaluates a patients' physical and mental health-related QoL [78]. Variations of this scale were also utilized, such as the MOS SF-8 and the MOS SF-12. Another common QoL assessment used was the EORTC Quality of Life Questionnaire (QLQ)-Core 30, which is a general cancer QoL tool assessing five functioning scales including physical, social, emotional, cognitive, and role functioning [79]. Other instruments that assessed general QoL included the Edmonton Symptom Assessment System, EuroQol-5 Dimensions, and the Patient-Reported Outcomes Measurement Information System-10.

Aside from these PROMs, issue-specific assessment tools were also utilized. This included the HADS, which is a validated tool used to screen for anxiety and depression in patients [80], and the Central for Epidemiology Studies Depression Scale, which is similarly used to quantify depression [81]. Other tools used included the Beck Anxiety Inventory, Visual Analog Scales and Numeric Rating Scales for pain, the MOS Social Support Survey, and the MOS Sexual Problems Survey.

Breast-cancer specific QoL questionnaires were also identified to assess patients with DCIS in this systematic review. The most frequently used was the BREAST-Q, a validated tool for evaluating patient reported outcomes in patients having undergone surgery [82]. In the studies extracted, patients were given the corresponding BREAST-Q module for breast conserving therapy or mastectomy, depending on the surgery they received. Additionally, the EORTC QLQ-BR23 and the EORTC QLQ-BRECON 23, which are breast cancer specific extensions of the EORTC QLQ-C30 were identified in this review [83,84]. Another questionnaire identified was the Functional Assessment of Cancer Therapy (FACT)-Breast, which is a validated instrument with five domains including: physical, social, emotional, functional, and a breast-specific subscale [85]. Other breast-cancer specific QoL tools included in this review were the Breast Cancer Prevention Trial Symptom Checklist and the Consequences of Screening - Breast Cancer questionnaire. While these tools cover breast cancer-related QoL issues, none covered the information needs specific to patients with DCIS.

Discussion

Our literature review comprehensively summarizes all potential QoL issues related to the physical, functional, and psychosocial domains for patients with DCIS recorded in the literature. One notable aspect is the heightened confusion about diagnosis experienced by DCIS patients, which stems from the unique nature of this non-invasive condition and its distinct implications. Unlike invasive breast cancer, where the diagnosis is often more straightforward, DCIS may perplex individuals due to its pre-invasive status, potential variability in treatment approaches, and implications for future health. Additionally, the informational needs of DCIS patients present a distinctive set of challenges. DCIS patients may require tailored information regarding the nature of their condition, potential treatment trajectories, and long-term implications.

Randomized controlled clinical trials studying these patients often incorporated QoL questionnaires as an important secondary endpoint [28,34,42,44]. Many of the clinical studies included often used either multiple tools [22,34,44], or more frequently, an investigator-designed questionnaire [13,16,63,59] to measure one or more of these QoL domains, due to the lack of a single comprehensive tool for DCIS patients. Potential problems of using multiple tools include creating inconvenience for patients and researchers, reducing comparability across trials, and failing to capture the full range of QoL issues faced by this population. Breast-cancer specific tools, such as the EORTC QLQ-BR45 or BREAST-Q, either do not comprehensively capture prominent issues for patients with DCIS, such as shock/confusion about their diagnosis, or include QoL issues which are often irrelevant, such as the side effects of chemotherapy. The lack of specificity in generic or breast cancer specific QoL tools may neglect these critical components, impacting the assessment of QoL in DCIS patients.

There have been review articles previously published on the QoL of patients with DCIS [86,87]. In alignment with the review by King et al., this review identified the physical QoL issues caused by treatments and the exaggerated risk perceptions of breast cancer progression/recurrence and death within DCIS patients [86]. A review by Dominici and Rosenberg also highlighted the prevalence of anxiety and depression and the lack of knowledge about their disease faced by patients with DCIS [87]. These issues were frequently reported in the literature, and accordingly captured by our systematic review. Compared to these reviews, our study had particular focus on creating a comprehensive list of QoL issues and additionally evaluating the QoL assessment tools currently used in studies. Additionally, we excluded studies which grouped together patients with DCIS and early invasive breast cancer, to ensure issues pertinent to women with DCIS were captured.

Strengths and limitations

A strength of this systematic review lies in its comprehensive evaluation of various study types, such as randomized controlled trials, qualitative studies, and case reports. Additionally, the inclusion of studies with structured interviews allowed for new issues pertinent to patients with DCIS that are not currently covered by existing tools to be captured. However, a limitation of this review is that the QoL issues identified are restricted to the specific aims and questions examined in the included studies. Additionally, some of the studies included in our review did not have a healthy control group and QoL issues related to other factors besides DCIS, such as concomitant illnesses or ageing, could have been recorded. Finally, most of the physical QoL items in women with DCIS are related to side effects of treatments, such as surgery or RT, which are employed in many patients with either non-invasive or invasive breast cancer.

Future directions

The findings of this systematic review underscore the multidimensional nature of QoL issues in individuals with DCIS, necessitating a comprehensive and tailored approach to assessment. The absence of validated DCIS-specific QoL measurement tools signals a critical gap in the field, urging future research endeavors to develop instruments that capture the nuanced experiences of individuals with DCIS. Clinicians and researchers alike can leverage the insights provided herein to inform patient care, prioritize areas of intervention, and guide the development of targeted interventions to enhance the QoL of individuals navigating the complexities of DCIS diagnosis and treatment. Thus, based on the results of this review, we advocate for either the development of a new tool that is specific to women with DCIS, or the modification of an existing breast cancer-specific tool. These tools can cater towards patients with DCIS, by removing items related to side effects of chemotherapy and adding new items related to shock and confusion about the diagnosis or the risk of recurrence. By refining QoL assessment tools, future research endeavors can capture the comprehensive experience of patients, allowing for a more accurate evaluation of the impact of DCIS on various aspects of patients' lives.

Conclusion

This systematic review explored the QoL issues described by patients with DCIS and compiled a comprehensive list of such issues and the tools used to assess them. With DCIS impacting patients across physical, functional, and psychosocial domains, the importance of considering such effects when treating patients was highlighted. Additionally, no validated tool identified captured all QoL issues discussed, emphasizing the gap in measuring outcomes. The creation of a DCIS-specific QoL tool or the modification of an existing QoL tool is recommended to ensure that future research will be sensitive towards specific challenges faced by patients.

Figure 1. PRISMA Flow Diagram of Study Selection

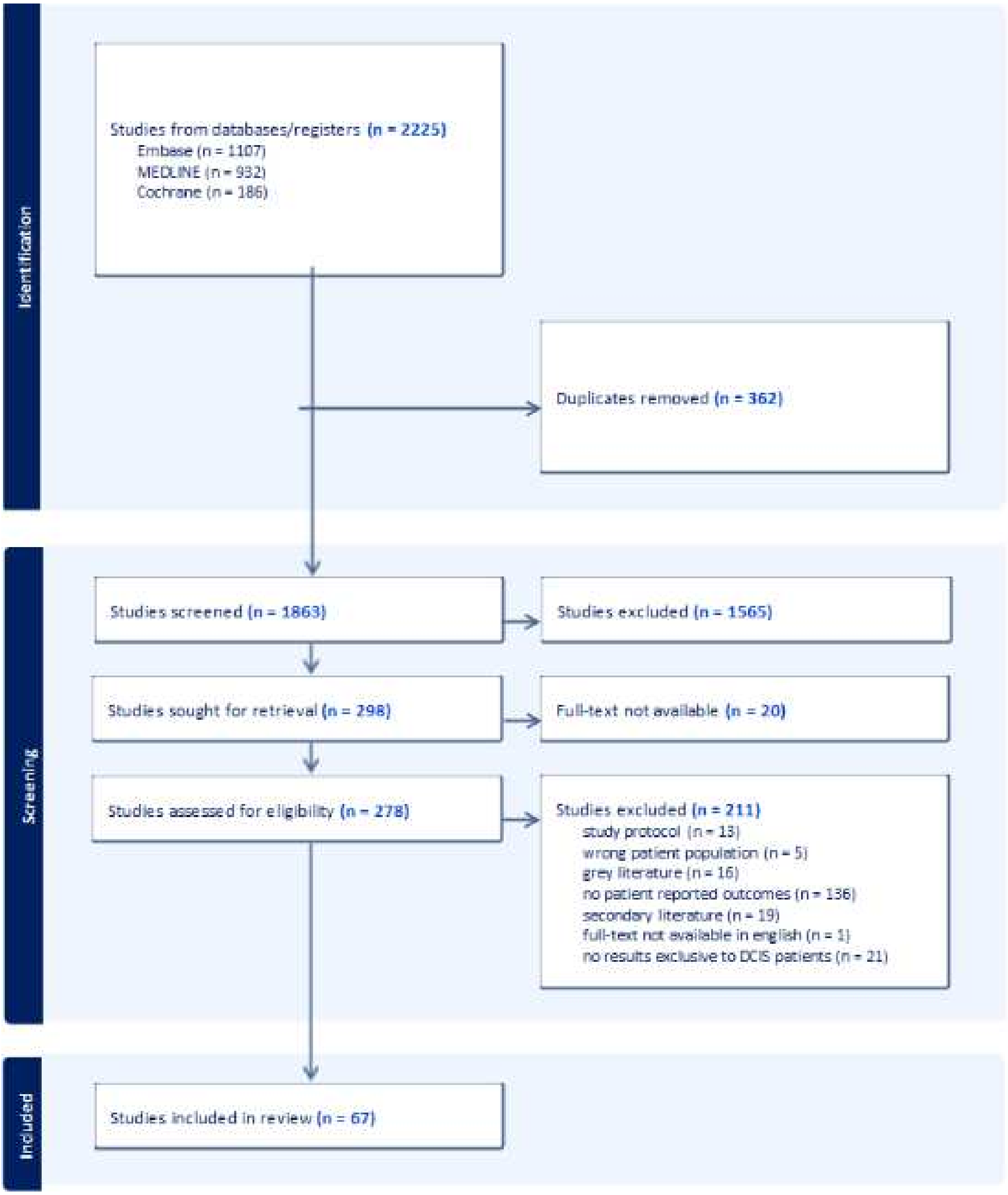

Table 1. Characteristics of included articles (n=67)

Study characteristics	*Number of studies (%)*
Study location	
Europe (Denmark, Germany, Italy, Netherlands, Spain, Sweden, United Kingdom)	15 (22.4%)
North America (Canada, United States of America, Mexico)	39 (58.2%)
South America (Chile)	
Australia/Oceania (Australia)	1 (1.5%)
Others	12 (17.9%)
Patient population size	
Studies with <250 patients	43 (64.2%)
Studies with 250-499 patients	10 (14.9%)
Studies with 500-750 patients	5 (7.5%)
Studies with >750 patients	9 (13.4%)
Year conducted	
Before 2000	2 (3.0%)
2000-2010	18 (26.9%)
After 2010	47 (70.1%)
Study design	
Prospective (unspecified design)	13 (19.4%)
Randomized controlled trial	5 (7.5%)
Longitudinal Study	7 (10.4%)
Cohort Study	13 (19.4%)
Cross-Sectional Study	6 (9.0%)
Retrospective study	14 (20.9%)
Case series	1 (1.5%)
Qualitative Study	8 (11.9%)

Table 2. DCIS-related quality of life issues

Number of articles discussing the issue	Physical Symptoms (treatment-related)	Functional	Psychosocial
20+	-	-	Anxiety Depression Worry about recurrence/progression of DCIS
15-19	-	-	Lack of information received about treatment/disease
10-14	Fatigue General pain	-	Body image Cosmetic outcome satisfaction Confusion about diagnosis/disease Treatment regret
5-9	Breast/chest pain Gynaecological symptoms (vaginal bleeding, vaginal dryness, impact on menstruation, etc.) Joint pain Sensory disturbance (numbness, etc.) Sleep disturbance (insomnia, etc.) Hot flashes	Impact on sexual function (pain, difficulty, arousal) Worse physical function	Concerns about treatment (side effects, uncertainty, etc.) Difficulty in decision-making about treatment Lack of doctor-patient communication/support Lack of prior knowledge about DCIS Lack of support services Impact on relationships (family, partner, etc.) Shock Worry about dying from DCIS
1-4	Abdominal pain Arm pain Axilla pain Bone pain Dizziness/light-headedness General discomfort Erythema Hair thinning Headache Indigestion Itchiness Lymphedema Muscle pain Nausea Pigmentation/discolouration Reduced appetite Skin contour changes	Impact on sexual enjoyment/satisfaction Memory issues Need for physical rehabilitation Weakness	Avoidance of activities Embarrassment Financial burden due to treatment Impact on confidence Lack of emotional support Perceived lack of social support Unable to enjoy life Worry about being a burden on others due to treatment

	Stiffness Sweating Weight gain		

Table 3. Patient-reported quality of life tools used to assess patients with DCIS by frequency

Number of articles	*Quality of life tool*
10+	Medical Outcomes Study (MOS) 36-Item Short Form (SF) Health Survey Investigator-designed QoL tool
5-10	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ)-Core 30 Central for Epidemiology Studies Depression Scale Hospital Anxiety and Depression Scale MOS Social Support Survey
1-4	Assessment of Survivor Concerns Breast Cancer Prevention Trial Symptom Checklist Breast Cancer Treatment Outcome Scale Beck Anxiety Inventory Body Image Scale BREAST-Q Cognitive and Behavioral Responses to Symptoms Questionnaire Concern about Recurrence Scale Consequences of Screening – Breast Cancer Decisional Conflict Scale Distress Thermometer EORTC QLQ-Breast 23 EORTC QLQ-Breast Reconstruction 23 Edmonton Symptom Assessment System EuroQol-5 Dimensions Checklist Individual Strength-20 Functional Assessment of Cancer Therapy Breast Functional Assessment of Chronic Illness Therapy Harvard Cosmesis Evaluation Health Literacy Questionnaire Illness Management Questionnaire Impact of Event Scale MOS Sexual Problems Survey MOS SF-8 Multidimensional Body-Self Relations Questionnaire Numerical Rating Scale for Pain Patient-Reported Outcomes Measurement Information System-10 Psychiatric Symptom Index Self-Administered Comorbidity Questionnaire General Self-Efficacy Scale MOS SF-12 Sickness Impact Profile-8 Social Network Index Social Support List Discrepancy State-Trait Anxiety Inventory Testing Morbidity Index Interpersonal Processes of Care Survey Veterans Rand-12 Visual Analog Scale

	Watts Sexual Function Questionnaire World Health Organization-5 Well-Being Index

Statements and Declarations

Competing interests

K Pogoda acted as consultant/speaker for AstraZeneca, MSD, Roche, Novartis, Lilly, Pfizer, Gilead outside the submitted work.

G Velikova has acquired honoraria from Pfizer, Novartis, Eisai, Lilly; is on advisory boards and has received consultancy fees from AstraZeneca, Roche, Novartis, Pfizer, Seagen, Eisai; and has acquired an institutional grant from Pfizer outside of the submitted work.

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Appendix 1. Search Strategy

All Ovid MEDLINE(R) <1946 to Present>

1	exp Carcinoma, Intraductal, Noninfiltrating/	11246
2	ductal carcinoma in situ.mp.	7984
3	dcis.mp.	5886
4	intraductal carcinoma.mp.	1078
5	or/1-4	16616
6	exp "quality of life"/	271403
7	quality of life.mp.	446768
8	exp patient reported outcome measures/	13864
9	patient reported outcome*.mp.	39257
10	exp patient satisfaction/	99682
11	patient satisfaction.mp.	114340
12	(QoL or HRQoL or PROM).mp.	77153
13	exp "surveys and questionnaires"/	1215282
14	or/6-13	1643362
15	5 and 14	996
16	limit 15 to english	932

EMBASE <1974 to 2023 August 23>	1107
Cochrane Central Register for Controlled Trials <1974 to 2023 August 23>	186