

Professional education on breast-cancer-related lymphoedema and its relation to patient wellbeing

KEY WORDS

- ▶▶ Breast cancer-related lymphoedema
- ▶▶ Education
- ▶▶ Healthcare professionals
- ▶▶ Patient perceptions

This systematic review uses qualitative research to establish how education on breast-cancer-related lymphoedema (BCRL) impacts patient perspectives and experiences of lymphoedema. A comprehensive literature and hand search of papers published in English between January 2000 and September 2012 (Cochrane Library, Medline, CINAHL and Science Direct), and (updated March 2016) between October 2012 and June 2015 (Google and Google Scholar) was carried out. Of the 31 potentially relevant papers, four met the inclusion criteria including a total of 88 patients and ten healthcare professionals (HCPs). Most patients received little or no information on the development of BCRL and many got conflicting advice from HCPs. A total of 43 patients had never been given any information on the 'risks' of developing lymphoedema and seven doctors did not discuss BCRL with patients. On its development, patients expressed 'shock' at diagnosis, felt unprepared and neglected by the lack of HCPs' knowledge. Patients who had received information coped better with BCRL than those who had not. Patients who did not get sufficient information believed doctors 'underestimated' BCRL, some wished their doctors had given more information on its avoidance, and many would liked to have been informed of the risks before surgery or at discharge, as they believed BCRL was avoidable. Patients are not receiving adequate information on the triggers and risks of developing BCRL. There is a lack of awareness of lymphoedema among HCPs in general, and those who are working closely with breast cancer patients need to educate themselves on the potential triggers and risk factors associated with BCRL.

The most common cancer diagnosed in the UK is breast cancer, which is the most common cancer among women (Deo et al, 2004). The risks of developing lymphoedema are greater when both surgery and radiotherapy are used; there is a higher incidence of lymphoedema in these patients (Gilbert and Mortimer, 2001). Breast-cancer-related lymphoedema (BCRL) is a chronic progressive condition and is the precursor to a lifetime of on-going management and attention, which can be disruptive to daily living and activities (Harmer, 2009). An important part of the care of breast cancer survivors is the provision of advice on precautions and lifestyle modification to reduce the lifelong risk of developing BCRL (Nielsen et al, 2008).

Patients' ability to manage and cope with their illness depends on their understanding of the experience (Johnson et al, 1997). Healthcare professionals (HCPs) should provide breast cancer patients with both written and oral information at every follow-up appointment to help reduce the risk of developing lymphoedema. The purpose of this systematic review was to explore whether knowledge about BCRL is adequate among patients and whether HCPs are assisting in reducing the risks of developing this condition.

BACKGROUND

Lymphoedema is defined as oedema or swelling consisting of fluids and proteins in the extravascular and interstitial spaces of the

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affected area (Rockson, 2001). A decrease in the ability of the lymphatic system to drain fluid from the interstitial spaces and return it to the bloodstream can lead to a build-up of fluid in the skin and subcutaneous tissues of the affected area (Preston et al, 2009). BCRL characteristically presents as swelling of the affected arm, although oedema can also occur in the chest wall, breast, hand and trunk region. The amount of swelling can range from mild to severe and can occur at any time, even years after the treatment for breast cancer (Mortimer et al, 1996). Patients present with symptoms such as pain, discomfort, heaviness, and distortion in limb shape and size, which can lead to impaired function and a reduction in mobility (Todd, 1998; Morrell et al, 2005). Tissues become thickened and fibrotic, giving a solid element to the swelling (Földi et al, 1985; Mortimer, 1995). Fibrosis reduces the immune response in the affected area, which compounds the problem of recurrent cellulitis and inflammation (Mortimer, 1995).

Various authors have supported the theory that lymphoedema has physical, psychosocial, functional, occupational, cognitive, lifestyle and financial aspects (Carter, 1997; Passik and McDonald, 1998). Changes in physical appearance and capabilities can result in psychological debility, leading to increased anxiety, depression and difficulty adjusting to the condition (Woods, 1993). Having a swollen arm is a constant reminder that the patient has had cancer, as is concealing the swollen limb or getting clothes to fit (Carter, 1997; Ganz, 1999; Petrek et al, 2000). Lymphoedema is incurable and therefore it can be an overwhelming blow, both physically and emotionally, for those who have already undergone treatment for breast cancer (Passik and McDonald, 1998).

A practitioner with experience working with BCRL patients reported that many patients presented with physical and emotional problems as a result of their condition. Delayed presentation meant that patients had difficulty with activities of daily living and were unable to perform simple tasks by the time they were seen by a HCP. A therapist working in the area of lymphoedema management had observed an information gap regarding the development of lymphoedema

prior to and following treatment for breast cancer, prompting research on the question: “Is knowledge on BCRL adequate/sufficient amongst patients and HCPs in improving patient well-being?” In an area where there is a high risk of developing this condition, it is crucial that if the patient is to give informed consent they are equipped with information. A significant part of breast cancer survivor care involves supplying them with advice on ‘risk reduction’ precautions and lifestyle modifications targeted at reducing the lifelong risk of developing BCRL (Nielsen et al, 2008). This systematic review examines the information delivered to breast cancer patients on the risks of developing lymphoedema.

METHOD

Narrative synthesis of qualitative research was used to establish whether knowledge of BCRL is adequate/sufficient among patients and HCPs. Narrative synthesis examines the amount of knowledge, when information is provided, and who should inform the patients on their risk of developing BCRL. ‘Grounded theory’ has been used as it is “a systematic qualitative research methodology in the social sciences emphasising generation of theory from data in the process of conducting research” (Martin and Turner, 1986) and “a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in a study” (Cresswell, 2009). It suggests that patients’ ability to cope with their illness depends on their understanding of the experience (Johnson et al, 1997). Patients require adequate information to gain knowledge and understanding of a particular health-related condition — in this case lymphoedema — permitting them to make decisions and plan preventative strategies, such as ‘risk reduction’ behaviours (Johnson et al, 1997).

Qualitative research papers published in English between 2000 and 2015 were included if they included women over the age of 18 years who had been diagnosed with and treated for breast cancer and had developed lymphoedema. Papers were not included if they considered women with active cancer.

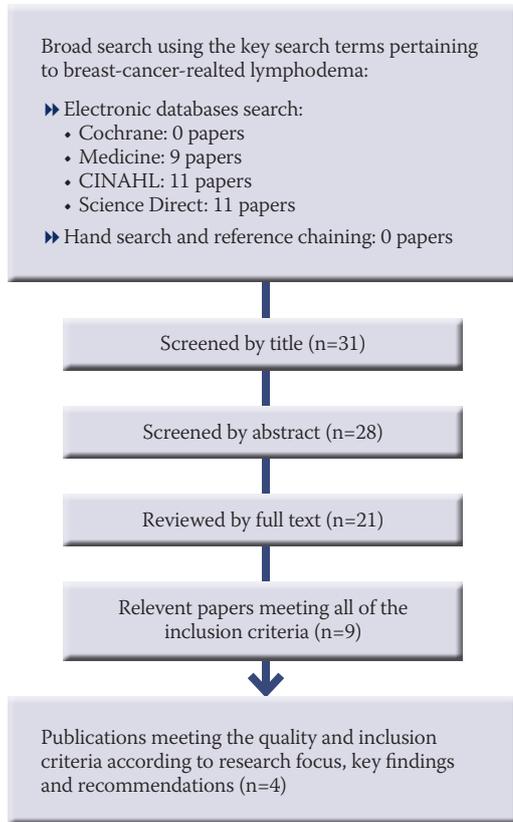


Figure 1. PRISMA flow chart showing how the research papers were selected

A comprehensive search of the Cochrane Library was conducted to eliminate the possibility that the review question – “Is knowledge on BCRL adequate/sufficient amongst patients and HCPs in improving patient well-being?” – had already been addressed (Thomas and Harden, 2008). Medline, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane Library and Science Direct online databases were searched. Secondary reference lists in the papers selected through these databases were traced. Relevant journals were hand-searched, including *Lymphology*, *Journal of Lymphoedema* and *Phlebology*. The National Lymphoedema Network (www.lymphnet.org) and Lymphoedema Support Network (www.lymphoedema.org/bls) websites were searched. The search terms used were ‘lymphoedema/lymphedema’, ‘breast cancer’, ‘breast neoplasms’, ‘education’, ‘knowledge’, ‘information’, and ‘awareness’. The initial searches

were carried out in October 2011 and September 2012 covering the period 2000–2012. The literature search was updated using Google and Google Scholar in March 2016 using the same search terms to include publications between October 2012 and June 2015.

Thirty-one potentially-relevant primary research papers were identified. Twenty-one had non-duplicate abstracts and of these, nine abstracts met the inclusion criteria after the full texts were analysed using the extraction form (see *Figure 1*). Possibly noteworthy papers were read and summarised methodically using the data extraction form. They were measured in relation to the inclusion/exclusion criteria and methodological quality. They were then organised into groups according to the focus of the research, key findings and recommendations. Finally, four papers met the quality and inclusion criteria and therefore merited inclusion in the systematic review: Paskett and Stark, 2000; Thomas-MacLean et al, 2005; Honnor, 2009 and Tsuchiya et al, 2011. These research papers mostly examined patients’ experiences of the psychological and physical effects of being diagnosed and living with lymphoedema and examined the level of information given to them either before or after treatment for breast cancer. HCPs’ knowledge of lymphoedema was investigated, who patients received their information from and when they would like to obtain information.

Quality assessment

Cullen (1994) claims that some problems may be encountered with a literature review, such as studies being scientifically unsound, failure to identify strengths and weaknesses in empirical research appraisals, and overlooking of methodology and rigor, leading to “reviews with simplistic, erroneous and inaccurate conclusions, which can be problematic in practice”. Evidence-based medicine uses the best scientific evidence that has been appraised systematically and expertly, without bias. The Best Evidence Topics (BETs) appraisal tool enables researchers to determine whether primary research papers are robust enough to guide treatment, prevention, diagnostic or policy decisions (Centre for Reviews and Dissemination,

Table 1. Identification of common themes in the four papers meeting the inclusion criteria

Lymphoedema theme	Tsuchiya et al, 2011	Honnor, 2009	Thomas-MacLean et al, 2005	Paskett and Stark, 2000
Lack of information provided	Y	Y	Y	Y
Patients' existing knowledge	Y	Y	N	Y
Physical effects	Y	Y	N	Y
Psychological effects	Y	Y	N	Y
Acceptance of living with lymphoedema	Y	Y	Y	N
Healthcare professional's knowledge	Y	Y	Y	Y
Information sought from sources other than healthcare professionals, e.g. voluntary organisations	Y	N	Y	Y
Ethical approval	Y	Y	Y	Consent obtained

2009). According to Popay et al (2006), BestBETs deals with the robustness of evaluation of studies in terms of methodological quality and aims to identify and synthesise sources of evidence, no matter how diverse. It builds on the principle of evidence-based medicine by providing answers to specific clinical problems while using the best available evidence. Using a structured approach, BETs seeks to answer a three-part specific question in each topic. This can be reviewed regularly to ensure evidence is the best available. The use of the BETs tool in this study ensured that critical analysis of the primary literature was rigorous and valid, identifying strengths, highlighting weaknesses and ensuring that the process was robust and conducted using a systematic approach.

Data extraction

To minimise bias, two researchers independently extracted the data using a specifically-designed form. Using the review question for guidance, data were extracted from each individual study. The specific information or data extracted and recorded are those that may influence the interpretation of the study results or be helpful in evaluating how appropriate the results are to different population groups or other settings (Popay et al, 2006).

RESULTS

A total of 88 patients and ten doctors were involved in the research. Eighty-one patients

were interviewed using a semi-structured method and seven were in a focus group. The homogeneity of the selected papers was explored. All four studies reviewed contain similar themes (*Table 1*) and their combination was found to be acceptable. Patients were recruited through physical therapists, lymphoedema specialist practitioners, civic facilities and lymphoedema support groups, via advertising in newspapers, through physicians treating breast cancer patients and the 'snowball effect'. Patients ranged in ages from 39 to 79 years old. The research was conducted in Canada, Japan, United Kingdom and United States, giving a good global representation of the phenomenon.

A thematic analysis approach was undertaken that highlighted important and recurring themes, thus allowing for the development of a structured tabulation format to display the information, see *Table 2* (Centre for Reviews and Dissemination, 2009). This method has evolved into what is now known as 'thematic synthesis' (Thomas and Harden, 2008). The 'theory of change' described as "the chain of causal assumption that links programme resources, activities, intermediate outcomes and ultimate goals" (Popay et al, 2006), was used to assist in the interpretation of a reviews' findings and was valuable in assessing how appropriate those findings were.

The second element involved the development of a preliminary synthesis using groupings, and building a common measure. Organising the

Table 2. Characteristics of papers included in the systematic review

Name of study	Aim	Education	Knowledge	Treatment	Impact of lymphoedema
The information needs of patients with therapy-related lymphoedema (Honor, 2009)	Explore the information needs of breast cancer patients	Healthcare professional knowledge of lymphoedema	Healthcare professional, participants and other people's knowledge	Psychological effects of lymphoedema	How lymphoedema affected breast cancer patients psychologically and physically
Information provision and problem-solving processes in Japanese breast cancer survivors with lymphoedema symptoms (Tsuchiya et al, 2011)	How perceptions on medical information affected Japanese breast cancer survivors	Perceptions of those who got information and those who did not get information	Healthcare professionals' provision of knowledge	Help-seeking	Effects on patients' daily lives
Lymphedema: Knowledge, treatment, and impact among breast cancer survivors (Paskett and Stark, 2000)	What patients and physicians know about lymphoedema	What information they received	What caused the lymphoedema and what made it worse	What treatment patients received	How lymphoedema affected patients' lives
Breast cancer-related lymphedema: women's experiences with an underestimated condition (Thomas-MacLean et al, 2005)	Breast cancer patients' experience of lymphoedema	The triggers of lymphoedema	Lack of information	Accessibility of treatment	Effects on patients' daily lives

findings from the studies included allowed the authors to explore the relationship within and between the primary research papers. It also assisted in identifying and listing facilitators and barriers to implementation (Popay et al, 2006).

The main themes that were identified and explored in this systematic review were:

- ▶ Lack of information — the patient's perspective
- ▶ HCPs' lack of knowledge
- ▶ Perceived risks and triggers of BCRL due to a lack of information
- ▶ Information provision: what, when and by whom
- ▶ The impact of a lack of knowledge on outcomes for BCRL patients.

Lack of information

The first key finding is that breast cancer patients appear to receive inadequate information regarding lymphoedema following cancer treatment, even though the condition is a considerable encumbrance on their lives (Woods, 1993; Carter, 1997; Runowicz, 1998). Importantly, the rationale underpinning this problem must be established: whether it is due to a lack of HCP knowledge or patients receiving inadequate information at the time of cancer diagnosis, treatment or during follow-up visits must be determined.

All four papers articulate the lack of information given to breast cancer patients at the time of surgery, post-surgery and at follow-up appointments during and after treatment (Paskett and Stark, 2000; Thomas-MacLean et al, 2005; Honor, 2009; Tsuchiya et al, 2011). Many patients said that they were not informed of the cause of lymphoedema, self-care or treatment options. Most did not remember or did not receive information. A small minority were given information by voluntary organisations and other groups after requesting it (Thomas-MacLean et al, 2005). Some patients obtained information on BCRL from the internet, books or cancer support groups.

HCPs' lack of knowledge

According to Thomas-MacLean et al (2005), lack of knowledge among HCPs is common, and is evident across a wide sphere of disciplines, including the surgeon, oncology department staff and family physician. According to Paskett and Stark (2000), when physicians were asked about the prevention of lymphoedema, five stated the avoidance of medical treatments such as surgical procedures and radiotherapy, while two focused on the behaviour of patients, for example adhering to prescribed exercises. They also encountered seven

physicians who stated that they do not routinely counsel women in the prevention of lymphoedema because so few patients present with the condition, there is no way of preventing it, or they do not see patients during the 'at risk' periods due to their medical specialty. Many patients believed that HCPs, including breast care nurses, surgeons and family physicians, lacked appropriate knowledge about lymphoedema (Honnor, 2009; Tsuchiya et al, 2011); consequently, these patients sought help from books, the internet and self-help groups.

Perceived risks and triggers of BCRL

Lack of information and knowledge of risk reduction behaviour has an influence on the psychological impact BCRL has on patients. When BCRL develops it is often accompanied by fear the cancer has reoccurred, and self-blame is a common phenomenon (Honnor, 2009; Tsuchiya et al, 2011). Some patients believe repetitive and extreme physical activities were the principal cause of the development of their lymphoedema (Thomas-MacLean et al, 2005). Physicians often cite patient behaviour as the precipitating factor in developing lymphoedema (Paskett and Stark, 2000).

Information provision

According to patients, information should be given at various times during the journey from breast cancer diagnosis through treatment and beyond. In all four papers, patients declare that they rely on HCPs for the provision of information on BCRL (Thomas-Paskett and Stark, 2000; MacLean et al, 2005; Honnor, 2009; Tsuchiya et al, 2011). Some believe information should be given before surgery; more say information is needed both before and after surgery, from the physical therapist and breast care nurse (Honnor, 2009). In Paskett and Stark's (2000) and Honnor's (2009) research, patients expressed that written information in the form of leaflets should be given repeatedly.

Impact of lack of knowledge on outcomes

Patients expressed 'shock' and fear on the diagnosis of lymphoedema (Paskett and Stark, 2000; Honnor, 2009) and both the emotional and physical impact that BCRL has on their daily lives. Some felt embarrassed having to purchase larger clothes to

accommodate the swollen arm; more cited the pain and discomfort of such swelling (Honnor, 2009). These findings were further confirmed by Thomas-MacLean et al (2005), in whose study women expressed their inability to engage in ordinary activities like household chores, sports and leisure activities, thus leading to a reduction in their quality of life.

DISCUSSION

A common theme in all four studies is that patients expect to get information on BCRL from one of the extensive team of HCPs involved in their care. Findings suggest that doctors, oncologists, breast care nurses and physical therapists need to give both written and verbal information on the risks of BCRL before and after treatment and repeatedly during follow-up visits.

Self-blame, fear and an inability to engage in ordinary activities are common consequences of BCRL that are expressed by patients. Breast cancer patients who receive early education/information have an improved wellbeing compared to those who do not. Breast cancer patients have in the past reported dissatisfaction with the pre-treatment education concerning lymphoedema. They have expressed disappointment with HCPs, whom they sense as being ill-informed about the condition. Many patients maintain they are not told about the risks of developing lymphoedema or provided with 'risk reduction' approaches either before or after their treatment for breast cancer, and they express feelings of being neglected by the HCPs who manage their condition. All of these factors impact on patients' acceptance of BCRL.

This review of the literature demonstrates that there is a lack of knowledge on the 'risks' of developing BCRL and the 'perceived triggers' in HCPs from all disciplines, including surgeons, oncologists, breast care nurses, physical therapists and family physicians. Family physicians need to be educated on the signs, symptoms and risks of developing lymphoedema. The lack of education provided by HCPs is exacerbated by the disparity that exists between patient expectations and how doctors view their role as an information and counselling resource. This issue also needs to be addressed.

Limitations

Limitations of this review include the restriction to English language publications only, due to cost constraints regarding translation. The numbers of participants in each study were small, but this is consistent with most research pertaining to lymphoedema. Only two researchers participated in the quality assessment and inclusion/exclusion criteria stage, as this study was part of an MSc. This may be construed as a further limitation.

CONCLUSION

Patients are seriously lacking information regarding the development and management of BCRL. Even though patients from three continents were included in this analysis, the patterns were very similar, indicating that lack of patient education and poor knowledge among HCPs is a global problem. The education of patients and HCPs is essential to raise awareness of lymphoedema and promote research into this potentially debilitating condition. Adequate information provided in a timely manner may help prevent associated risk behaviours.

More research needs to be done on this subject and this systematic review should guide policy makers within the healthcare sector on the importance of information provision and education on BCRL.



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