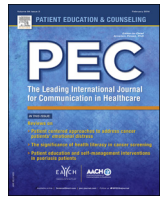




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Research paper

Factors associated with professional healthcare advice seeking in women at risk for developing breast cancer-related lymphedema

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ABSTRACT

Objectives: Approximately 6–20% of breast cancer patients undergoing lymph node surgery will develop lymphedema. At-risk individuals are encouraged to seek professional healthcare advice if symptoms arise. This study aimed to identify cognitive and affective factors associated with professional healthcare advice (PHCA) seeking behavior in women with heightened lymphedema risk.

Methods: Women with increased lymphedema risk ($N=462$) completed an online survey measuring cognitive and affective responses to lymphedema risk, including the Illness Perception Questionnaire (Revised), and adherence to seeking PHCA.

Results: Overall, 62% of women reported seeking professional healthcare advice if symptoms arose. Logistic regression analysis indicated that adherence to seeking PHCA if lymphedema symptoms arise was associated with greater illness coherence, belief in the efficacy of seeking PHCA, and lymphedema risk-related emotional distress.

Conclusion: Women were more likely to seek PHCA if symptoms arose if they held a coherent understanding of lymphedema and believed in the usefulness of seeking PHCA. For these women, psychological distress associated with lymphedema risk was associated with enhanced adherence to seeking PHCA.

Practice implications: Health professionals should target lymphedema education to ensure at-risk women have a coherent understanding of lymphedema and that they believe in the effectiveness of seeking PHCA to help manage lymphedema symptoms.

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1. Introduction

Breast cancer-related lymphedema is characterised by swelling of the arm, breast, or axilla and affects between 6% and 20% of breast cancer survivors who undergo some form breast cancer-related lymph node surgery [1]. Surgical removal of lymph nodes from the axilla is a key risk factor, with axillary lymph node dissection (≥ 5 nodes removed) presenting much higher risk than sentinel node biopsy (< 5 nodes removed) [2,3]. Other risk factors include axilla-focused radiotherapy [4], Taxane chemotherapy [5], and obesity [6]. Lymphedema is a lifetime risk, potentially developing any time following breast cancer treatment [7,8]. Loss of sensation, pain, and impaired arm mobility are common physical symptoms [9–11], and from a psychosocial perspective impaired

quality of life, heightened psychological distress, body image and sexuality concerns, and interpersonal difficulties [12–17] are frequently experienced. Without an available cure, early detection of lymphedema symptoms is vital for timely administration of effective treatments to manage these symptoms [18–20]. It is therefore paramount that at-risk woman seek immediate professional healthcare advice (PHCA) should early signs and symptoms of this condition emerge [21]. Women's adherence to this recommendation is less than optimal [11,22], with one study reporting non-adherence to seeking PHCA between 18 and 28% [22].

The decision to seek PHCA, generally, is influenced by a myriad of psychosocial factors [23]. Two self-regulatory theories that provide insight into these factors include the Common-Sense model of illness representation (CSM) [24] and the Cognitive-Social Health Information Processing (C-SHIP) model [25]. The CSM suggests that the mental representation an individual holds of a particular chronic illness [26] reflects how they process and interpret information about the chronic illness, which in turn

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influences the initiation of protective health behaviors, such as seeking healthcare advice [27,28]. The C-SHIP model proposes that an individual's adherence to a particular protective health behavior for a chronic illness, such as lymphedema, will be influenced by a number of cognitive and affective factors [25,29]. These factors include the way an individual encodes information about the chronic illness (e.g., perceived risk and knowledge of the illness), their beliefs and expectancies about the chronic illness (e.g., response efficacy; the belief that they can do something to prevent or reduce the chronic illness), as well as self-regulatory competency (e.g., the perceived ability to manage distress that arises from the chronic illness) [25,29,30]. Each individual will uniquely encode information, hold unique beliefs and expectancies, and will have unique levels of self-regulatory competency. These differences in illness representation in turn are proposed to lead to interpersonal differences in health behaviors [25].

Together these models suggest a combination of cognitive and affective factors that encapsulate a woman's perceived risk of developing lymphedema [24], and her cognitive representations of lymphedema. Each model contributes a unique range of factors that are considered important for understanding one's intentions to engage in protective health behaviors [25,26]. Within these combined theoretical frameworks, and in the lymphedema context, cognitive factors that may influence risk management approaches include the woman's perceived level of risk for developing breast cancer-related lymphedema, her understanding of lymphedema, and the extent to which it makes "sense" (i.e., illness coherence), her perceived ability to action these recommendations (i.e., self-efficacy), and her beliefs about the effectiveness of the recommendations to manage lymphedema risk (i.e., response efficacy) [24,25,31]. The woman's beliefs about her ability to control lymphedema risk, the perceived chronicity and consequences of lymphedema are also important cognitive factors [24]. Regarding affective factors, these models identify both the level of negative affect aroused by the woman's lymphedema risk, as well as her perceived ability to control this negative affect (i.e., emotional self-regulation), as factors that may influence lymphedema-related health behaviours [24]. In particular, prior research suggests that moderate levels of health-threat related psychological distress may facilitate health protective actions, whereas very low and high levels of emotional distress may inhibit these actions [32].

Previous studies applying CSM [26] and C-SHIP [25] approaches in the lymphedema context have identified that being knowledgeable about lymphedema risk is a necessary step in promoting lymphedema risk management amongst at-risk women, including being aware of the need to seek prompt healthcare advice [11,22]. Breast care nurses and lymphedema therapists are key sources of influence in imparting information for promoting this behavior [22]. However, being knowledgeable about lymphedema risk management alone does not guarantee women will seek professional healthcare advice if any lymphedema symptoms arise. One longitudinal study assessed adherence rates for a range of risk management behaviours, including seeking prompt medical advice, following the provision of detailed information about lymphedema [22]. Professional healthcare advice seeking increased after education on the importance of this risk management strategy, but dropped off by the 12-month follow-up, suggesting that factors, in addition to knowledge, influence ongoing adherence. Other studies have further identified self-efficacy, response efficacy, emotional self-regulation, and decreased lymphedema risk-related negative affect as factors associated with overall adherence to lymphedema management self-care behaviours, included in which is the recommendation to seek PHCA [11,29].

Previous research [11,29] into the influence of these self-regulatory theories on lymphedema risk management has focused on overall adherence to all lymphedema risk management recommendations (including avoiding lifting heavy weights, and avoiding cuts and abrasions to the at-risk arm), rather than focusing on specific recommendations. Furthermore, emerging evidence has questioned the efficacy of many existing lymphedema risk management behaviors, such as limiting physical activity [33]. This highlights the need to understand the association between these cognitive and affective factors with the one recommended strategy that will always remain, namely seeking PHCA in light of early signs and symptoms of lymphedema.

By adopting the self-regulatory perspective [25,34], we aimed to extend previous lymphedema research by identifying cognitive and affective factors associated with PHCA seeking in breast cancer survivors. Consistent with prior research [11,22,29], we predicted that greater knowledge, perceived risk, illness coherence, self-efficacy, and response efficacy would be associated with greater adherence to seek PHCA. It was expected that individuals who report perceiving lymphedema as being a chronic but controllable condition with negative consequences would be more likely to seek PHCA. The association between negative affect associated with lymphedema risk and emotional self-regulation with adherence was also explored. Given the difference in lymphedema incidence in women who have axillary lymph node dissection compared with sentinel node biopsy [2,3], we assessed whether type of lymph node surgery moderated any of the above associations.

2. Method

2.1. Participants and Procedure

Women were eligible for this online study if they were over 18 years of age; and had: 1) a breast cancer diagnosis \geq 12-months ago; 2) completed active treatment (i.e., surgery, radiotherapy, chemotherapy); 3) undergone lymph node surgery (axillary lymph node dissection or sentinel node biopsy); and, 4) were at risk but otherwise asymptomatic for lymphedema. Participants were recruited by emailed invitation through the nationwide Breast Cancer Network Australia research participant pool. Of the 1200 women invited to participate, 548 Australian women consented to this study (46% response rate). Women self-identified their eligibility, provided online consent, and completed an online survey containing self-report measures of cognitive-affective factors, physical quality of life, adherence to PHCA seeking, and demographic and medical information. This study was approved by the Macquarie University Human Research Ethics Committee.

2.2. Measures

2.2.1. Self-regulatory factors

The cognitive representations of, and affective factors related to, breast cancer-related lymphedema were assessed with the Revised Illness Perception Questionnaire (IPQ) [31], and previously published items derived from the CSM and C-SHIP models [11,29]. The IPQ is an established measure comprising subscales assessing all domains of the CSM. All IPQ measures were on a 5-point Likert-type scale (0 "Not at all" to 4 "Very much"). Previously published additional items evaluated cognitive and affective factors identified by the C-SHIP model that were not otherwise included in the IPQ (e.g., response-efficacy). These items were on a different 5-point Likert-type scale (1 "Not at all" to 5 "Very much"), unless otherwise specified. Higher scores on all subscales represent stronger endorsement. All subscales demonstrated

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