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## Overview

### Helping Patients to Help Themselves after Breast Cancer Treatment

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#### Abstract

There is a rise in the number of women living with the long-term consequences of cancer and continuing to suffer unmet need as breast cancer survival improves. This paper includes an introduction to self-management and a discussion of the evidence around the effectiveness of the key intervention types that could help patients to help themselves after treatment. Self-management interventions are particularly beneficial in reducing bother from symptoms, without patients having to take on the additional burden of more unwanted side-effects frequently seen with pharmacological interventions. There is a need to prioritise the funding of these financially viable self-management strategies to ensure equity of access and that these interventions are available for those in need.

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*Key words:* Cancer survivors; confidence; self-efficacy; self-management

#### Statement of Search Strategies Used and Sources of Information

The search strategies used and sources of information are in line with this being an overview paper.

#### Introduction

As survival from breast cancer improves, there is a corresponding rise in the number of women living with the long-term consequences of cancer [1]. These can be physical and functional or psychosocial and may have a significant effect on women's lives. They include joint pain [2], fatigue [3], sexual problems [4], cognitive problems [5], anxiety [6], fear of recurrence [1], lymphoedema [7] and vasomotor symptoms [8]. Many can be a serious problem, having a significant effect on daily life: physically, psychologically and socially [9].

The consequences of living with and managing breast cancer can affect relationships, social activities and work

[10]. As a consequence of cancer and the imposition of this range of iatrogenic conditions, people experience a biographical disruption. Disruptions in biography include changes to social relationships and the structures of everyday life [11]. Therefore, women's needs at the end of cancer treatment often include a focus on more existential concerns, such as reflecting on what they have experienced, feelings of loss and the pursuit of restoration of a 'normal' way of life [12].

There is evidence of effective interventions, yet there is a lack of consistent provision of these interventions due to changes in follow-up care being passed from secondary to primary health care providers [13]. Furthermore, current patient follow-up tends to adopt a biomedical model, which may not adequately address psychological and social concerns [12]. Without this kind of support, many women with breast cancer turn to complementary and alternative medicines, and search for other non-pharmacological strategies, particularly to help with hot flushes or fatigue [14]. There is evidence that people want to help themselves and have a preference to do this using non-medical approaches, as well as an emerging evidence base for supported self-management [15,16]. Feedback from people who have had cancer has highlighted a call for more support from clinicians so that they can facilitate their own self-care [17]. It is

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timely, therefore, to explore self-management. Here we explore the evidence around a variety of interventions that have been shown to help in the self-management of cancer-related problems.

## Self-management

Self-management has been identified as an important way of managing the burden of long-term health conditions [18]. It entails patients and families being given support to manage their own health [19]. There is a need for support to facilitate self-management strategies to enable women at the end of treatment to process what has happened and move on. Enabling people to self-manage their aftercare can help patients benefit from an enhanced ability to effect change [20]. Patients have identified a need for strategies to do this [12]. These strategies include complementary therapies, psychological interventions, diet, nutrition and exercise [12].

Self-management support is what health services can offer to encourage people living with long-term conditions to improve or maintain their health [17]. Fenlon and Foster [21] presented an adapted definition of self-management support specifically in relation to cancer. It can be understood as (i) a portfolio of techniques and tools and (ii) as a transformation of the patient–caregiver relationship into a collaborative partnership. In the case of cancer, the self-management goals for survivors include health promotion and managing the long-term effects of disease and treatment [21].

Foster and Fenlon [22] applied Lent's [23] model of restorative emotional well-being to a conceptual framework to inform areas of self-management support to facilitate the recovery of people after cancer treatment. Lent's model has been expanded to include wider domains that could affect health recovery. The model shows that a number of factors, including the perception of problems as well as demographic factors, influence how disruptive cancer and its treatment are. There is a process of appraising the situation (coping appraisal) and appraisal of cancer-related self-efficacy (confidence) to manage the situation. How a survivor appraises the situation and how equipped they feel to deal with it are influenced by factors like self-efficacy, personality and environmental factors. Foster and Fenlon [22] hypothesised that appropriate and specific support designed to help survivors feel more confident to manage cancer-related problems can facilitate a more rapid recovery.

Foster *et al.* [24] conducted a cross-sectional online survey to assess perceived self-efficacy to manage problems in the 12 months after cancer treatment. The results showed that levels of self-efficacy varied between individuals and according to specific tasks. Although survey respondents were most confident in accessing information, they were least confident in managing fatigue. This highlights the importance of considering variation in self-efficacy. Domain-specific cancer-related self-efficacy measures will probably be valuable for identifying survivors who lack self-

efficacy for particular tasks. The identification of low self-efficacy in specific behaviours could facilitate targeted support.

## Interventions to Support Self-management

Interventions take many forms and can be delivered in different ways. They include programmes specifically targeted at increasing people's ability to self-manage or training in specific techniques. Examples include coaching, relaxation, cognitive behavioural therapy (CBT), mindfulness and self-delivered acupuncture. Programmes such as the Expert Patient Programme [25], Taking CHARGE [20], RESTORE [26], PRO-SELF [27] often build on behavioural techniques, such as CBT or relaxation. These interventions can be delivered online, through one to one support and group support. For example, the Taking CHARGE intervention included group and telephone sessions, whereas the RESTORE intervention for fatigue in survivors was entirely delivered online without any one to one support.

The Expert Patient Programme is a central element of chronic disease management policy in the UK aiming to deliver self-management support and improve the quality of life of people with long-term conditions by developing generic self-management skills to take more control over their illnesses [25]. This was used as the basis for a cancer-specific expert patient programme led by the UK charity Macmillan Cancer Support, although the evidence for the benefit of this programme is unclear.

Taking CHARGE is an intervention developed to facilitate successful transitions to survivorship after breast cancer treatment [20]. This particular self-management intervention was designed on the basis of social cognitive theory through self-regulation principles. These included equipping survivors with skills to address concerns and construct an understanding of their experience of illness to guide self-care. The intervention consisted of a blended delivery approach, which involved group sessions (peer support) and individual telephone sessions (individualised education). The content covered psychological well-being, managing symptoms and achieving functional wellness. Participants can use processes of self-regulation to prevent, identify and resolve problems. This process has also been successfully applied in interventions for women who have experienced illnesses other than cancer [20].

These group-based programmes can be resource intensive and inaccessible. There is therefore a need for evidence-based support tools to be delivered in different ways. The use of the internet as an important source for support is increasing. The RESTORE intervention is a first in terms of online exploratory randomised controlled trials, designed to support the self-management of cancer-related fatigue. Participants included 125 cancer survivors experiencing fatigue within 5 years of primary treatment completion with curative intent. The results from this study are yet to be published. The authors hope that the pilot nature of the study will allow for refinement of the intervention and also provide information on whether a mostly

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