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"I just googled and read everything": Exploring breast cancer survivors' use of the internet to find information on complementary medicine



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ABSTRACT

Objective: Breast cancer survivors often turn to the internet as an information resource when deciding whether to use complementary and alternative medicine (CAM) but their use of online CAM-related resources is poorly understood. The objective was to explore breast cancer survivors' use of the internet when making decisions about CAM use.

Design: A purposive sample of 11 breast cancer survivors (mean age = 56) completed a quantitative questionnaire and a qualitative telephone interview. The theory of planned behaviour (TPB) was used to guide interview questions. Framework analysis and descriptive statistics were used.

Setting: United Kingdom.

Results: All participants found information on CAM using the internet and used some form of CAM after their diagnosis. Themes from the interviews went beyond the standard definitions of the TPB areas. Despite the lack of approval from their social network and healthcare team, participants used the internet to find information on CAM. Further, participants' cancer diagnosis changed their needs, transforming how they perceived and experienced the internet

Conclusions: Participants' use of the internet was more complex than can easily be explained by the TPB and was inherently connected to the experience of self-management for the consequences of cancer and its treatment. As breast cancer survivors may not disclose their use of the internet to their healthcare team, healthcare professionals need to be aware that the information available on the internet plays a factor in the decision-making process to use CAM.

1. Introduction

There are approximately two million people living with or beyond cancer in the UK, ¹ these individuals are described as 'cancer survivors'. ² Breast cancer is currently the most commonly diagnosed cancer in the UK; approximately 49,900 women and 350 men were diagnosed with breast cancer in the UK in 2011. ³ Throughout the disease trajectory breast cancer survivors can experience a range of physical and psychological problems such as anxiety, breathlessness, depression, fatigue, lymphedema, nausea, pain and stress; these effects may also develop into long-term issues. ^{4–8}

As a way of living with the effects of cancer, cancer survivors may use a range of self-management techniques. Self-management is any activity and behaviour undertaken by individuals to control their health and deal with disease. Self-management is now an embedded component of care for cancer survivors; the National Cancer Survivorship Initiative supported the development of a care pathway called the

'recovery package' which includes providing information and support to individuals to manage the consequences of cancer.² In the UK, NHS Improvement and the Department of Health worked together with the National Cancer Survivorship Initiative to provide resources and support to encourage self-management activity amongst cancer survivors.^{10,11} Research indicates that many cancer survivors already use a wide range of resources to self-manage the problems associated with cancer, such as visiting healthcare professionals and services, support networks, and using the internet for information.¹²

The literature suggests that many cancer survivors also use Complementary and Alternative Medicine (CAM) as a form of self-management. CAM can be defined as: 'a group of diverse medical health care systems, practices, and products that are not generally considered to be part of conventional medicine'. ¹³ The National Institute for Clinical Excellence (2004) suggest that CAM therapies are being used by up to one third of patients with cancer. Cancer survivors' motivation for using CAM includes: increasing treatment options, reducing the

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side-effects of conventional treatment, coping with the psychological impact of cancer, and dissatisfaction with conventional medicine. $^{14-17}$

A review of self-management activities by people affected by cancer found that using the internet to find information was common among women with breast cancer. ¹⁵ One of the topics commonly searched for on the internet is CAM; a questionnaire evaluating internet use by breast cancer patients found that 37% of participants used the internet to seek information on CAM. ¹⁸ Evidence suggests that women use the internet particularly to gather and evaluate information on CAM in the initial stages of deciding whether to use CAM. ^{19–21} However, there is little evidence-based, officially-sanctioned guidance on CAM for cancer survivors, despite recommendations that supportive resources are provided for any form of self-management. ^{12,22} CAM information that is available to cancer survivors online has been heavily criticised: patients using such information may be misinformed and unknowingly taking risks with their health. ^{23,24}

There is currently little research exploring the relationship between cancer survivors' internet use and their decision-making processes for CAM use. Therefore, this qualitative study aimed to explore how breast cancer survivors use the internet to inform decisions about CAM use. The research objectives were to: examine the barriers and facilitators to using the internet as a self-management resource, and explore the experiences of breast cancer survivors in using the internet to make decisions on CAM treatment.

The theory of planned behaviour (TPB) was used as a guiding

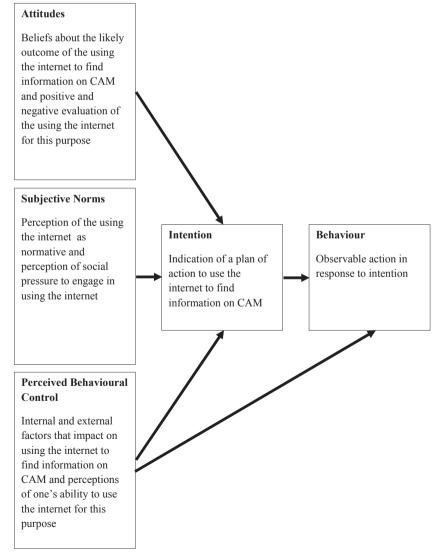
framework. The TPB is an established model of the psychological predictors associated with intentional human actions (see Fig. 1). ^{25,26} Within this research context, the TPB suggests that the following factors influence breast cancer survivors' intention to get information on CAM via the internet: a) a positive attitude towards using the internet, b) the view that using the internet for this purpose is a normal behaviour, and c) a belief that they have the ability and resources to use the internet for this purpose. Ultimately, a better understanding of how and why women use the internet when making decisions about CAM use could inform the future development of web-based resources to support informed decision-making. ¹⁹

2. Methods

2.1. Participants

The inclusion criteria were: breast cancer survivors who were 18 years of age or older who had completed active cancer treatment (chemotherapy, radiotherapy and/or surgery) in the last five years, were internet users and had considered using some form of CAM. Participants who were taking long-term oral chemotherapy or hormone therapy were also eligible. The study was advertised in regional newspapers, on the Macmillan Cancer Support Cancer Voices Network and posters were put up locally around the community. There was no previous relationship between the research team and participants.

Fig. 1. The theory of planned behaviour.



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