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ORIGINAL ARTICLE

Qualitative assessment of information and decision support needs for managing menopausal symptoms after breast cancer

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Abstract

Purpose For breast cancer (BrCa) survivors, premature menopause can result from conventional cancer treatment. Due to limited treatment options, survivors often turn to complementary therapies (CTs), but struggle to make informed decisions. In this study, we identified BrCa survivors' CT and general information and decision-making needs related to menopausal symptoms.

Methods The needs assessment was informed by interpretive descriptive methodology. Focus groups with survivors (n = 22) and interviews with conventional (n = 12) and CT (n = 5) healthcare professionals (HCPs) were conducted at two Canadian urban cancer centers. Thematic, inductive analysis was conducted on the data.

Results Menopausal symptoms have significant negative impact on BrCa survivors. Close to 70 % of the sample were currently using CTs, including mind-body therapies (45.5 %), natural health products (NHPs) and dietary therapies (31.8 %), and lifestyle interventions (36.4 %). However, BrCa survivors reported inadequate access to information on the safety and efficacy of CT options. Survivors also struggled in their efforts to discuss CT with HCPs, who had limited time and information to support women in their CT decisions. Concise and credible information about CTs was required by BrCa survivors to support them in making informed and safe decisions about using CTs for menopausal symptom management.

Conclusions High quality research is needed on the efficacy and safety of CTs in managing menopausal symptoms following BrCa treatment. Decision support strategies, such as patient decision aids (DAs), may help synthesize and translate evidence on CTs and promote shared decision-making between BrCa survivors and HCPs about the role of CTs in coping with menopause following cancer treatment.

Keywords Breast cancer · Menopause · Information needs · Decision support · Complementary therapy

Introduction

At least 50 % of women with breast cancer (BrCa) will experience menopause as a consequence of cancer treatments [1–4]. The abrupt onset of menopause is particularly problematic for women with BrCa because they have not had an opportunity to acclimatize to waning levels of hormones in the same way that occurs for women in the general population [4]. The resulting symptoms of menopause can be extremely disruptive [5, 6] and significantly reduce BrCa survivors' quality of life [2, 7].

Treatment options for BrCa survivors experiencing menopausal symptoms are limited. Hormone replacement therapy

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(HRT) is typically avoided because of the potential risk of recurrence for hormone-sensitive cancer [8], despite recent research that suggests that it should be considered on a case-by-case basis [9]. Lifestyle changes, such as exercise and stress management, lack strong evidence of efficacy [10–12] and have been reported by BrCa survivors to have limited utility [13]. While some women may consider pharmaceutical options, such as antidepressants (e.g., venlafaxine), anti-seizures (e.g., gabapentin), or anti-hypertensives (e.g., clonidine), these medications can have significant and unwanted side effects.

Frustrated by the limited conventional treatment options available, BrCa survivors are motivated to search for alternatives, including such complementary therapies (CTs) as acupuncture or natural health products (NHPs) [14–16], with at least 25 % of survivors using NHPs to address menopausal symptoms [17, 18]. BrCa survivors, however, have reported difficulty finding reliable, balanced information on CT options [19]. Information drawn from the Internet often lacks credibility and validity [20], is overwhelming in volume and rife with contradictory opinions [13, 21, 22]. Survivors are also frustrated by the lack of knowledge held by many conventional healthcare providers (HCPs) about CTs, despite the growing literature on the efficacy of CTs in managing menopausal symptoms both in the general [23, 24] and BrCa [25–27] populations. The limited time and resources available within conventional healthcare settings to support shared decision-making about CTs have posed further challenges for BrCa survivors considering CTs for menopausal symptom management [28].

These challenges highlight the need for decision support interventions, such as patient decision aids, that will support BrCa survivors to make informed decisions about CTs. Decision aids (DAs) are designed to increase patient involvement in the treatment decision-making process and reduce their decisional conflict by translating clinically relevant evidence into a patient-friendly format, while clarifying personal values relevant to the decision [2, 29–31]. DAs are not meant to “replace the human element in facilitating informed choice” [32] (p. 293), but rather aim to enhance dialogue about options between a patient and their HCP. Without such decision support, survivors are at risk for making uninformed decisions that can seriously impact their BrCa treatment and outcomes [33].

While DAs are available to inform menopausal [30, 34] and cancer treatment decisions [31], an aid specific for BrCa survivors considering CT options for menopausal symptom management has yet to be developed. The purpose of this study was to develop and evaluate the impact of a DA on BrCa survivors’ decision-making behaviors and outcomes. However, the first step in developing a DA according to the International Patient Decision Aid Standards (IPDAS) [29] is to conduct a needs assessment to accurately capture the treatment options of interest and the information required by the target population.

Aims of the study

The aim of this needs assessment was to identify the CTs and related information to be included in a DA (called MyChoices™) for BrCa survivors experiencing menopausal symptoms. The specific objectives were to (1) identify the most problematic menopausal symptoms experienced by BrCa survivors, (2) assess the CT and general information needs of BrCa survivors experiencing menopausal symptoms, and (3) understand what BrCa survivors were currently doing to manage menopausal symptoms.

Methods

The needs assessment was informed by qualitative descriptive methodology [35], which privileges the simple description of the phenomena under study.

Sample and sampling

Six focus groups were conducted with BrCa survivors recruited through the CAMEO Program[1] [36], a survivorship clinic, and support groups located in two urban cancer centers in British Columbia and Ontario. A total of 22 women who met the eligibility criteria participated. Eligibility included the following: a diagnosis of stages I to IIIb BrCa in the past 5 years without recurrence, completion of primary cancer treatment, fluency in English, and considering CTs for menopausal symptom management. One woman unable to attend a focus group participated in a one-on-one interview.

Purposeful sampling with regard to timing of diagnosis, experience with CTs, and estrogen receptor status maximized sample size and diversity. Women who were diagnosed with estrogen receptor positive (ER+) BrCa were also purposefully sampled due to the controversy that exists regarding the potential role of select NHPs in stimulating a recurrence of ER+ BrCa [37, 38].

Key informant interviews were conducted with a purposeful sample of 17 HCPs, including dietitians, pharmacists, nurses, general practitioners in oncology, and medical and radiation oncologists. Naturopathic doctors and natural health pharmacy personnel were also interviewed as they are often consulted by BrCa survivors about CT options [39, 40].

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[1] *CAMEO (Complementary Medicine Education and Outcomes) is a research program that studies the CT decision support needs of people living with cancer, their support persons, and HCPs, and develops programs and resources to help address those needs. CAMEO offers the latest CT research to the conventional cancer care setting through education courses and lectures, published documents, and individualized information and decision support consultations.

Data collection

The focus groups were conducted by two trained facilitators using a structured interview guide (Table 1) informed by the Ottawa Health Decision Centre needs assessment workbook [41]. The focus groups encouraged BrCa survivors to discuss their menopausal symptoms and concerns, treatment options they had tried or were interested in, and the type of information they needed to make informed CT decisions. The focus groups and single interview were digitally recorded and transcribed verbatim. Survivors also completed a demographic form and the Menopausal Rating Scale (MRS) [42].

The key informants participated in 30-min interviews that focused on how they supported BrCa survivors in managing menopausal symptoms, including which therapies they recommended, how they addressed the use of conventional and complementary therapies, and what information they perceived to be important in making treatment decisions. The interviews were digitally recorded and transcribed verbatim.

Data analysis

Inductive thematic analysis [35] of the focus group and key informant interview data was conducted. The transcripts were read twice to develop a preliminary overview of key themes. An initial coding scheme was developed, which was used by two research team members (AB, LL) to separately code two transcripts to determine if the key concepts within the data were adequately captured. All transcripts were coded using the qualitative software, NVivo™. Following coding, key concepts and themes in the data were further refined and compared across focus groups and participants. Memoing captured coding decisions, relationships among concepts and themes and questions to be posed in analyzing the data.

Table 1 Survivor focus group interview guide

1. Understanding menopausal symptoms and concerns
    a. What are the menopausal symptoms or concerns you are dealing with or anticipating struggling with?
2. Menopausal treatment options and information received
    a. What treatments, including complementary therapies, have you tried or are considering?
    b. What information have you been given about these options?
    c. Where have you sought information?
    d. Do you feel you need different information?
    e. Has there been conflict in the information you have been given?
    f. What has the decision been like for you?
3. Information preferences
    a. What kind of information would you like about managing menopause?
    b. How would you like this information presented to you?

Findings

Demographics

The sample of women ($n = 22$) was diagnosed between 2008 and 2010, the majority ($n = 13$) with ER+ stage II BrCa (Table 2). All women had an education level greater than high school, most self-identified as Caucasian (63.6 %), and the majority had annual household incomes greater than $70,000 (63.6 %).

Approximately two thirds of the HCPs had 10 years or more oncology experience, and just over half had some training or education related to CT (52.9 %) (Table 3).

Table 2 Characteristics of the women with breast cancer ($n = 22$)

Characteristic	Frequency (%)
Age	
30–39 years	2 (9.1)
40–49 years	9 (40.9)
50+ years	11 (50.0)
Study site	
British Columbia	17 (77.2)
Ontario	5 (22.8)
Marital status	
Married/common law	18 (81.8)
Not married	4 (18.2)
Education	
Some college/college diploma	11 (50.0)
Bachelor degree	5 (22.7)
Graduate degree	6 (27.3)
Ethnicity/race	
Caucasian	14 (63.6)
Asian	4 (18.2)
South Asian	1 (4.5)
Missing	3 (13.6)
Household income (CDN$)	
<$30,000	3 (13.6)
$30,000–$70,000	5 (22.7)
>$70,000	14 (63.6)
Stage of BrCa	
Stage I	3 (13.6)
Stage II	13 (59.1)
Stage III	5 (22.7)
Missing	1 (4.5)
Receptor status	
Estrogen positive (ER+)	16 (72.7)
Progesterone positive (PR+)	7 (31.8)
HER2+	5 (22.7)
Menopausal Rating Scale symptoms (moderate/severe rating)	
Hot flushes, sweating	19 (86.4)
Sexual problems	19 (86.4)
Sleep problems	18 (81.8)
Depressive mood	16 (72.7)
Physical and mental exhaustion	16 (72.7)
Mean total menopausal rating (s.d.)	19.6 (7.4)

Therapy choices

The majority of women (68.2 %) were currently using a variety of CTs to manage their menopausal symptoms (Table 4). The most popular was mind-body therapies, which were used by 45.5 % of the sample, followed by NHPs, which were utilized by close to 40 % of the sample. Lifestyle interventions were also popular with 36.4 % of the sample mentioning exercise or dietary changes. Just fewer than 20 % of the women were using prescription or over-the-counter medications, such as anti-depressants, hormonal cream, and even HRT. Several women were hesitant to use pharmaceutical options due to concerns about side effects and the desire to avoid using additional medication following their cancer treatment.

Perceptions about menopausal symptoms

A key finding was that some women were not aware their symptoms were menopause, induced by their cancer treatment—and not a temporary, remediable effect. Although many of the women were informed that their menstrual cycles would end following treatment, they did not fully realize the implications and meaning of the associated physiological changes. The women were surprised by the sudden onset and intensity of their menopausal symptoms. A woman with stage III BrCa described her experience:

> I didn't know I was having menopausal symptoms frankly... I didn't really know what to expect of chemo, and was just talking to a friend who is about 10 years older than me. I said, "Well, it's bearable, but I'm doing this and I'm doing that, you'll never believe this!" And she goes, "Oh, I've got all that." And it made me realize that what I was experiencing wasn't just solely because I was going through chemo…."

Both the survivors and HCPs indicated that the most bothersome symptom was hot flashes, throughout the day and night, which interrupted work and sleep, and caused significant social anxiety. The women struggled to hide the lengthy, uncomfortable flushing and associated sweating. A woman diagnosed over 5 years ago shared her experience:

> I started chemo and it threw me into immediate menopause…I have extreme hot flashes. And during the summer I would have dozens every day and all night and to the point that I just wanted to cry. I was exhausted from just trying to get through one after another.

The reported impact of hot flashes was corroborated by survivors' responses to the MRS, with over 85 % of women rating hot flashes and sweating as moderate to severe. Although other symptoms, such as sexual problems and sleep deprivation, were

Table 3 Key informant demographics ($n = 17$)

Characteristic	Frequency (%)
Profession	
Medical oncologist	2 (11.8)
Radiation oncologist	1 (5.9)
General practitioner in oncology	2 (11.8)
Pharmacist	3 (17.6)
Dietician	2 (11.8)
Nurse	1 (5.9)
Nurse practitioner	1 (5.9)
Naturopathic doctor	3 (17.6)
Other	2 (11.8)
Study site	
British Columbia	10 (58.8)
Ontario	7 (41.2)
Years worked in oncology	
Less than 10 years	6 (35.3)
+10 years	11 (64.7)
Education in CT	
No	8 (47.1)
Yes	9 (52.9)

Table 4 Treatments currently used to manage menopausal symptoms ($n = 22$)

Type of treatment	Frequency (%)
Pharmaceutical options	4 (18.2)
Hormone replacement therapy	1 (4.5)
Hormone creams	2 (9.1)
Anti-depressants	4 (18.2)
Gabapentin	1 (4.5)
Vaginal moisturizer	2 (9.1)
Natural health products/food	7 (31.8)
Black cohosh	3 (13.6)
Vitamin E	2 (9.1)
Flaxseed	5 (22.7)
Soy	1 (4.5)
Passion flower	1 (4.5)
Homeopathic remedy	1 (4.5)
Traditional Chinese medicine	1 (4.5)
Reishi mushroom	1 (4.5)
Mind-body therapies	10 (45.5)
Lifestyle therapies	8 (36.4)
Other therapies	2 (9.1)
Acupuncture	1 (4.5)
Environmental changes (e.g., fan)	1 (4.5)

also reported to be extremely disruptive, many of these symptoms were directly attributed to hot flashes.

Seeking treatment information

Once women recognized their symptoms were menopause-related and not a short-term side effect of their cancer treatment, many expressed uncertainty regarding which HCPs could best answer their questions: "Do I see my oncologist? Do I see my general practitioner (GP)?" Several expressed frustration with the scarcity of information about menopause management after BrCa and the lack of knowledge among HCPs. Some of the women who consulted their oncologist stated their menopausal symptoms were perceived as a relatively inconsequential outcome. A woman shared: "…their purpose [oncologists] was to keep you alive, but not give you that extra quality of life that you needed."

Many of the HCPs described their role in helping women make informed decisions about treating menopausal symptoms. They presented as having the knowledge and training necessary to understand the latest evidence and effectively translate that information without, as one naturopathic doctor framed it, "bamboozling" individuals. However, many felt ill equipped to recommend specific interventions due to the lack of clinical guidelines for menopausal symptom management following BrCa treatment. A medical oncologist explained:

> There are many review articles on the topic so I would base my decision on the most recent literature review that I can find. We don't have guidelines that I have seen within the group on the management of menopausal symptoms.

Both the survivors and HCPs commented on the inconsistency among professionals regarding the management of menopause following BrCa. According to a pharmacist, "It's really going to be dependent on which physician they're seeing in the community." A lack of consistency was also perceived among health disciplines, which left women confused and frustrated. A naturopath shared:

> Coming to see somebody like me and getting a different story than what they're getting from their oncologist and from their [general practitioner]…they [survivors] feel like they're getting three different stories and they don't know who to believe.

Acknowledging this confusion and lack of consistency, several HCPs confirmed that having a tool that summarized the evidence related to different menopausal treatment options, particularly CTs, would increase their ability to support women in the decision-making process. A general practitioner shared:

> I think it's important for patients, but also for us because sometimes we don't know about these products [NHPs] and it would be nice if we had something that we could easily go to and say 'Okay, this is safe…don't worry about that one' and then you can [speak] with more confidence to the patient…

Information needs related to menopausal symptom management

Lacking decisional support from conventional HCPs, the women became resourceful in seeking information. They consulted friends and family members, other BrCa survivors, the Internet, as well as pamphlets, books, journals, and medical textbooks about the various treatment options available to manage menopausal symptoms. Foremost in women's minds was the safety of therapies in the context of a BrCa diagnosis. They had serious concerns that using a CT could interfere with their cancer treatment or promote the growth of their cancer. This concern overrode any possible benefit offered by a therapy, even when faced with highly disruptive menopausal symptoms. A pharmacist noted, "As soon as we really explain to them the distant possibility that you may actually do some harm for the BrCa, they just back off. To them that's more frightful."

For the most part, however, it was the tentative and contradictory nature of the available information on the efficacy and safety of CTs that frustrated the women. A woman shared:

> I was reading what they were saying on flaxseed, going, 'Can you just stop waffling?' Whoever had drafted it didn't want to take a position, but it left you not knowing what the hell you should do!"

In addition to being inundated by the large volume of information, the women were frustrated by the lack of conclusive information, particularly regarding CTs. Another woman commented:

> I get scared because you hear soy is bad and you hear soy might not be bad… You think something's good, and then you know next week it's going to be bad so I've just sort of done nothing. I'm doing acupuncture and I find that helps and other than that I'm kind of scared to venture into it. There's so much information. You get overwhelmed. Like flaxseed is supposed to be good for BrCa, but too much can promote BrCa so you sort of throw up your arms!

The majority of women were also frustrated by their inability to differentiate between credible and non-credible information sources. They struggled to determine the trustworthiness of information, particularly sources from the media, the Internet, and for some, even HCPs.

> I experienced a growing distrust of the whole system. One person says something, one person says another and [I'm] just not trusting information to the point where I get really anxious going to see a doctor…

CT decision-making experience

The women had difficulty making definitive treatment decisions, as a consequence of unmet information needs, a perceived lack of decisional support, and inconsistent information about the efficacy and safety of therapy options in managing menopausal symptoms after BrCa. Some of the survivors described feeling "paralyzed" in the decision-making process, fearing that a CT could result in the progression or recurrence of cancer. A woman described her decision-making impasse:

> …I'm frozen and I don't know what to do, what not to do, and honestly there are so many professionals and practitioners who you can turn to. But at the end of the day I just find everybody so confusing because nobody gives you the same answers as the next person…

Other survivors described themselves as making the conscious decision to "do nothing" after an independent search for information about CTs. Faced with limited and contradictory evidence on the efficacy and safety, these women were uncomfortable with the degree of uncertainty and potential risk associated with many CTs. Instead, they pursued lifestyle interventions, such as exercise or dietary changes, as a way of coping with their menopausal symptoms. Many of the women expressed hesitancy about using pharmaceutical drugs to manage their symptoms; most preferred to avoid further conventional treatment after such intensive cancer treatment.

Those BrCa survivors who did use CTs to manage their hot flashes and other menopausal symptoms engaged in a complex process of seeking and confirming information about the possible risks and benefits. These women valued not only the advice of HCPs but also the information obtained from other trusted individuals, such as family members. Fellow survivors were seen as especially helpful in providing advice about the timing of CT use, such as "do one thing at a time," and "finish [conventional] treatment first." These women ultimately chose a CT that they could afford, readily incorporate into their lives, and employ over an extended period of time.

Despite the differences among the BrCa survivors regarding their CT decision, all of them expressed a need for concise and credible information about CT options to support an informed decision. They wanted to be active participants in the decision-making process and avoid a "paternalistic" relationship with HCPs in which their values and beliefs were not respected.

Discussion

Our findings highlight the profound impact of menopausal symptoms, particularly hot flashes, on the lives of BrCa survivors. The women in this study shared stories of how hot flashes and related symptoms disrupted their daily activities, caused significant embarrassment and discomfort, and negatively impacted their quality of life. Because many survivors were hesitant to use HRT due to their BrCa diagnosis and avoided pharmaceutical drugs because of the potential side effects, these women tried a variety of CT options, including NHPs and mind-body therapies, as well as lifestyle interventions. Many of the survivors, however, found the decision-making process challenging. Not only was it difficult to obtain information from HCPs about CTs, the information they did receive was often contradictory in nature. Another barrier that hampered BrCa survivors' decision-making was the confusion around which HCP was responsible for informing survivors of the various treatment strategies. In the end, the women expressed the need for concise and credible information about the efficacy and safety of using CTs to managing menopausal symptoms to support them in participating in a shared decision-making process with their HCPs.

Previous research has confirmed the significant effect menopausal symptoms have on women following BrCa treatment [2, 15] as well as the popularity of CTs among BrCa survivors, particularly within the context of menopausal symptom management [17, 18, 43]. Similar to our findings, prior qualitative research has reported BrCa survivors' interest in CTs to arise, in part, from their concerns about the potential side effects of pharmaceutical treatment options [43]. Mao et al. also highlighted the important role that physicians and family members play in BrCa survivors' decision-making process related to CTs [43]. To our knowledge, however, our study is the first to uncover the confusion experienced by women regarding which physician to consult about their menopausal symptoms (i.e., oncologist versus primary care physician), as well as their frustration with the limited and contradictory information available in conventional care settings related to CTs. The fear expressed by women related to using a CT that could lead to a recurrence of cancer highlights the need for evidence-based information about the safety of CTs in the context of BrCa survivorship. Further, our study adds to the existing literature by including the perspective of HCPs, who struggled to provide recommendations about menopausal treatment options in the absence of established guidelines for BrCa survivors. The HCPs involved in our study identified the need for a resource that synthesized the latest research on CTs to allow them to provide consistent, evidence-based advice to survivors about the efficacy and safety of various therapies in managing menopausal symptoms.

Our study findings reflect a larger issue in the literature regarding the long-term management of cancer survivors and where survivorship care is best located [44]. The lack of national or international clinical guidelines regarding menopausal symptom management in women with BrCa is a significant gap that requires immediate attention. Rigorous, well-designed clinical research focused on CTs and menopausal symptom management in BrCa populations is also needed to address the growing interest by BrCa survivors in CTs. As this body of clinical research expands, decision support interventions will be required that summarize the latest evidence related to the efficacy and safety of these therapies and translate this knowledge to the bedside [36]. From BrCa survivors' perspective, such interventions must provide clear treatment recommendations to help alleviate their fear and uncertainty and to support their participation in shared decision-making with HCPs.

Implications for CT decision support

The challenges experienced by BrCa survivors and HCPs to engage in informed, evidence-based discussions about CT options for menopausal symptom management point to the need for effective and tailored knowledge translation and decision support strategies that can be easily implemented within varied clinical settings. Patient DAs are one strategy that efficiently translates evidence-based health information and support shared decision-making between individuals and their HCP, as well as acknowledging patients' unique beliefs and values [31]. A patient DA would address BrCa survivors' information needs related to CT and menopausal symptom management by concisely summarizing what is currently known and unknown about conventional and complementary treatment options, account for survivors' health and healthcare experiences (e.g., diagnosis, severity of menopausal symptoms, treatment preferences), and be utilized in both oncology and primary care settings.

Limitations

Although efforts to ensure survivor diversity within the sampling process were undertaken, the composition of a largely Caucasian, well educated, early stage (I and II) BrCa sample limits broad applicability of the study findings. For example, women with later stage disease (>II) may assess risk and make decisions about the use of CTs differently than those with earlier stage disease [45]. Purposeful sampling from two different urban centers, while adding some diversity, does not include perspectives of women living in rural and remote settings, where access to CTs and the influence of sociocultural practices may differentially influence menopause management strategies and CT choices. Patient DAs tailored to women's unique menopause-related CT needs and accounting for their social context may provide an accessible and feasible form of decision support.

Conclusion

BrCa survivors suffer profoundly from hot flashes and other menopausal symptoms associated with cancer treatment. Faced with limited treatment options, many women consider CTs for relief of their symptoms. Survivors and HCPs, however, lack credible and concise information about the efficacy and safety of CTs. High-quality clinical trials are needed that expand the evidence base regarding the efficacy and safety of CTs in the management of menopausal symptoms following BrCa treatment. Patient DAs are one decision support strategy that may help synthesize and translate research on CTs as well as empower BrCa survivors and HCPs to engage in shared decision-making about the full range of therapeutic options for managing menopausal symptoms.

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