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ORIGINAL ARTICLE

Online information and support needs of women with advanced breast cancer: a qualitative analysis

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Abstract

Purpose Women with advanced breast cancer (ABC) face significant adjustment challenges, yet few resources provide them with information and support, and attendance barriers can preclude access to face-to-face psychosocial support. This paper reports on two qualitative studies examining (i) whether information and support-seeking preferences of women with ABC could be addressed in an online intervention, and (ii) how an existing intervention for patients with early stage cancer could be adapted for women with ABC.

Methods Women with ABC participated in telephone interviews about their information and support-seeking preferences ($N = 21$) and evaluated an online intervention focused on early-stage cancer ($N = 15$). Interviews were transcribed and underwent thematic analysis using the framework method to identify salient themes.

Results Participants most commonly sought medical, lifestyle-related, and practical information/support; however, when presented with an online intervention, participants most commonly gave positive feedback on content on coping with emotional distress. Difficulty finding information and barriers to using common sources of information/support including health professionals, family and friends, and peers were reported; however, some women also reported not wanting information or support. All participants evaluating the existing intervention gave positive feedback on various components, with results suggesting an online intervention could be an effective means of providing information/support to women with ABC, given improved specificity/relevance to ABC and increased tailoring to individual circumstances and preferences.

Conclusions Adaptation of an existing online intervention for early stage cancer appears to be a promising avenue to address the information and support needs of women with ABC.

Keywords Advanced breast cancer · Information and support needs · Internet use · eHealth intervention

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Despite evidence of high distress [1, 2] and high support needs [3], women with advanced breast cancer (ABC) report frequent unmet needs. A 2015 Breast Cancer Network Australia (BCNA) online survey of 582 individuals with ABC [4] found unmet needs in up to 68% of participants, with five of the top 10 domains relating to psychosocial needs, and recommended addressing these needs through development of specific resources for women with ABC [4].

A 2013 Cochrane Review found only 10 randomised controlled trials (RCTs) of interventions for women with ABC [5]; these predominantly evaluated intensive face-to-face group therapy programmes requiring weekly participation [5]. Our subsequent systematic review found a strong evidence base for efficacy of face-to-face group therapy for ABC but lower accessibility and/or acceptability [6], consistent with previously documented low uptake of face-to-face mental health services among women with ABC [7, 8]. Both reviews recommended future research should focus on accessible low-intensity, home-based interventions, such as tele- or Internet-based counselling, specifically to meet the needs of women with ABC [5, 6].

While Web-based therapy is yet to be tested in ABC, our group developed and extensively tested a Web-based psychological intervention for *early-stage* cancer patients [9]. This has consistently demonstrated improvements in quality of life and psychological distress, with a multi-site RCT finding reduced health service utilisation [9–12]. While designed for the curative setting, this programme may offer a useful basis for developing an ABC-tailored adaptation.

Co-design of an online programme tailored to women with ABC requires exploration of information and support needs of women with ABC *that may be met via an Internet intervention*. Thus, women's preferences for Internet use, and experiences of the Internet intervention format, require examination.

Cross-sectional surveys have found frequently reported unmet needs of women with ABC include psychological, informational, and practical needs (e.g. [4, 13–16]). Qualitative studies highlight concerns about treatment side effects, body image, sexuality, fear of disease progression and dying, lack of social support, ambivalence over support group use, and preferences for seeking alternative means of support [17, 18]. However, few studies examine whether such needs and concerns can be addressed via the Internet.

Studies of Internet use by women with *breast cancer* report predictors of Internet use (e.g. younger age, higher education [19–21]); reasons for not using the Internet (e.g. lack of computer/Internet access, satisfaction with provided information, and fear of what Internet information might say [20]); no association of Internet use with coping [22]; and reasons for discussing Internet-obtained information with doctors (e.g. becoming more educated [23]). Studies reporting types of information sought are rare; one study reported women with breast cancer most commonly seek medical information [21], and one indicated women with ABC sometimes used the Internet to check whether symptoms were normal but preferred other information sources [18]. To our knowledge, no other study has specifically explored patterns of Internet use among women with ABC to meet information and support needs, nor has any study examined perspectives of women with ABC regarding development of an ABC-specific Internet intervention, nor obtained evaluative feedback of an existing Internet intervention.

This paper summarises two related qualitative interview studies that investigate this unexplored area by examining information and support needs of women with ABC that could be addressed in an online intervention, and preferences for the content and format of such an intervention (study 1), and exploring the views of women with ABC on the existing *Finding My Way* (*FMW*) programme, to identify whether it is broadly applicable to this setting and identify how content might require revision (study 2).

Method

Participants

Participants were 21 women with ABC, aged 34 to 78 years ($M = 59.71$, $SD = 10.50$), recruited via clinicians at Flinders Centre for Innovation in Cancer ($N = 16$) or online promotion through Breast Cancer Network Australia ($N = 5$) (study 1); and 15 women with ABC and Internet access, aged 42 to 69 years ($M = 58.80$, $SD = 7.50$), recruited via study 1 ($N = 9$) or subsequent BCNA promotion ($N = 6$) (study 2).

Materials

Study 1 participants were sent a semi-structured interview guide to allow them to consider their information and support-seeking preferences prior to participating in interviews. The guide consisted of nine questions regarding current information and support-seeking, how successful participants found their efforts to seek information/support, and attitudes towards using the Internet to seek information and/or support for ABC. The interviewer version of the guide included additional prompts to facilitate responses where required.

Study 2 participants received access to *FMW*, a six-module online psychological intervention designed for individuals with curatively treated cancer of any type [9], with all modules simultaneously available for review. Prior to interviews, they were also sent a semi-structured interview topic guide comprising two sections: (1) general programme feedback (11 questions), and (2) specific feedback on the user home screen and each of the six modules (Appendix 2).

Procedure

Ethics approval was obtained from Southern Adelaide Clinical Human Research Ethics Committee. All interviews occurred via telephone and were audio-recorded, then transcribed. Saturation was determined through an iterative process: after completing the 20th–21st interviews (study 1) and 14th–15th interviews (study 2), no additional issues were being identified and no new themes were emerging; collection of further data was therefore determined redundant.

Analysis

Transcripts were thematically analysed using the software program NVivo 11 to identify salient themes and subthemes. Due to the pragmatic objective of informing future development/adaptation of an online intervention, themes were developed as per the framework method of thematic analysis [24] in response to the specific objectives of the study. While themes were qualitatively developed, they were summarised according to prevalence (how many participants raised a theme) and frequency (how many times in total a theme was raised).

Results

Numerous themes were identified for both studies, therefore only the most prevalent are reported here. For a detailed summary of all themes and subthemes (including frequency and prevalence), please refer to Appendices 3 and 4.

Information and support needs (study 1)

Themes clustered under five broad areas of information/support sought, sources, barriers to information and support seeking, content, and attitudes to Internet (Fig. 1; see Appendix 3).

Participants most commonly reported seeking medical information, particularly on treatment and side effects, diagnosis/prognosis, and new interventions. For example:

> ‘For me, it was more about the longevity. How long was the median life, you know?’ (Participant 16)

Approximately one third sought information or support for lifestyle choices, including diet and other lifestyle choices; and one third sought practical information/support, including financial and functional information/support.

A small minority of participants (14–19%) sought others’ experiences of ABC, information or support for end-of-life decisions/arrangements, or emotional/psychological support.

Most commonly reported information/support sources included family and friends, medical/health professionals, and print resources. Peer support from others with ABC or other cancers was a source of support for almost half of the participants and included informal peer support and traditional or online support groups. Additional information and/or support sources included cancer support organisations, with professional psychology or counselling reported by a small minority. In addition to those reporting online support group use, *almost half of the participants reported using the Internet to seek information and/or support for ABC.*

The most commonly cited barrier to obtaining information/support was difficulty finding information and/or support, reported by two thirds of participants, often due to a reported lack of ABC-specific information/support or difficulty meeting information/support needs through medical professionals. For example:

> ‘There’s lot about…early stages, but not a lot for stage four.’ (Participant 16)

Almost 25% of participants reported difficulty accessing services. Three participants noted difficulty finding information/support for partners/families while two noted particular challenges for rural patients in finding accessible information and/or support.

However, almost two thirds of participants reported not wanting some types of information/support. Specific reasons for this included not looking for emotional/psychological support, not liking psychology or counselling, and finding ABC-related information too confronting.

Over one third of participants reported the barrier of family and friends not meeting support needs; most experiencing this barrier had difficulty even discussing cancer with family and friends, which exacerbated limitations to information/support. For instance:

> ‘I wanted to keep it to myself, to protect my family, so I didn’t get the help I should have gotten for a long time.’ (Participant 18)

Participants also identified barriers to obtaining peer support. The majority reported not using a support group, with barriers including the sentiment that support groups were not ‘their thing’, lack of availability/access, not ‘fitting in’ due to most or all other women in the group having an early stage rather than advanced diagnosis, and the potential to be distressed by such groups. Differences between early and advanced breast cancer were also experienced as affecting the relevance of peer support more generally (including informal support).

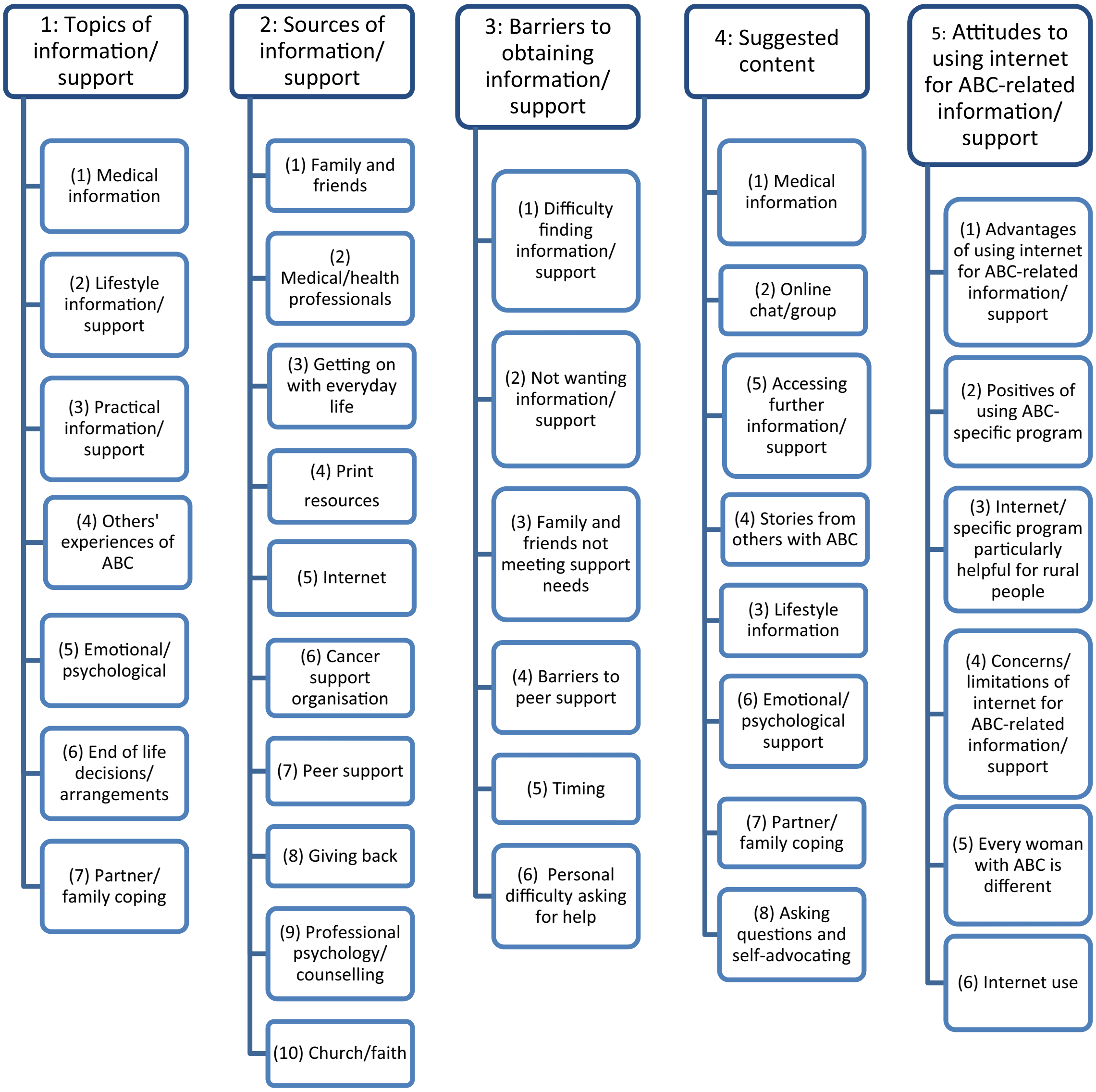


Fig. 1 Summary of study 1 themes

Further barriers included challenges of timing with other life events/stressors and with cancer diagnosis and treatment.

The most commonly suggested content was medical information, including information on treatments and side effects and on prognosis and ‘what to expect’.

One third of participants wanted advice on accessing support, including up-to-date Web links.

Almost one third wanted lifestyle-related information/support.

One third suggested an online group and one third suggested content on others’ experiences of ABC. Small minorities suggested emotional/psychological support, resources for/about partners and families, or information and support for asking questions and self-advocating.

Participants recognised several advantages of using the Internet for ABC information and support, including general helpfulness of the Internet, access to information/support in one’s own time, and convenience of access. Over one third recognised potential advantages of an ABC-specific programme, including centralisation of ABC-specific information and/or support, legitimacy of content, and convenience.

Several participants also noted that accessibility of the Internet and of a specific programme would be particularly helpful for rural people:

> ‘Oh, country people just live on the internet. You see, that’s the other thing, I think country people or rural people are more likely to use it than someone from the city.’ (Participant 3)

Despite recognising advantages, almost two thirds of participants expressed concerns about using the Internet for ABC information/support, including concerns over legitimacy/currency of information, that information could be too confronting (including specific concerns over sensitive provision of palliative care information), and privacy. Frequently, participants saw some advantages as well as disadvantages to use. However, over a third of the sample reported they would not have concerns about using a specific programme for ABC information and support.

Participants noted individual differences in information- and support-seeking preferences between women with ABC, including a minority who stated preference for face-to-face support. Several participants reflected that information/support needs could vary according to differences in prognosis, progression, and response to treatment; thus, how to maintain relevance to all was a concern for some.

While a third of participants reported they were comfortable using the Internet/computers, nearly as many stated they did not use the Internet much.

Feedback on existing online resource (study 2)

Themes in participant's evaluations of *FMW* are summarised in Fig. 2 (for a detailed description, see Appendix 4).

Positive feedback on FMW content included participants' reflections that *FMW* is generally helpful or relevant.

Participants gave positive feedback on specific content areas, most commonly content on emotional distress, worksheets/exercises, and meditation/relaxation, but also content on clarifying questions, supporting partners and families, physical symptoms, and self and identity, along with video content and anecdotes. Over one third of participants commented that some content was relevant to ABC despite the early-stage cancer focus.

The most common recommended change to content was increasing relevance to ABC. Specifically, participants indicated a need for content to address issues of ongoing/progressing treatment (instead of treatment completion), and recommended this content address both end-of-life treatment decisions and care, and coping psychologically with mortality, for example:

> 'When you reach stage 4, the biggest thing on your mind is the fear of dying. You know, that fear hits you like a brick wall. That's really, *really*, hard, to get through… and that is really what I would call a top lying thing that needs to be addressed, the mortality.' (Participant 5)

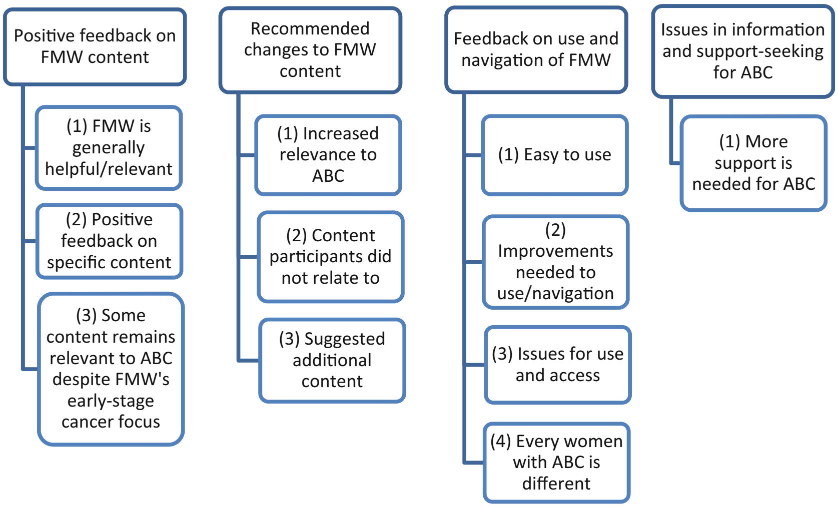
More than half commented that women with ABC who have previously had early-stage disease are already familiar with *FMW* content, thus reducing relevance to ABC. While one participant with a de novo diagnosis of ABC reported experiencing a knowledge gap compared to women who had progressed after early-stage diagnosis, two participants raised the potential for women with a de novo ABC diagnosis to be overwhelmed by too much information.

Specific content that participants did not relate to most commonly included worksheets/activities, for example:

> 'The thing that put me off was the homework, the exercises and homework.' (Participant 12)

However, recommended changes more commonly involved suggested additional content, most often on accessing available resources and coping with partner, family, and friend responses, along with treatment and side effects, exercise, and managing pain.

Fig. 2 Summary of study 2 themes



Feedback on use included themes reflecting finding the intervention easy to use, improvements needed to use/navigation, issues for use and access, and issues in information and support seeking for women with ABC.

Almost all participants found *FMW* easy to use. Specific factors identified as facilitating ease of use included appropriate language, sufficient flexibility/self-pacing, appropriate module length, a well set-up home screen, and ease of the Internet format.

Comments on improvements related to *FMW* needing general improvement to ease-of-use or specific navigation/layout issues, or evaluations that the programme/modules were too long, needed more flexibility for self-pacing, needed better indexing, or were too complicated. Four participants noted difficulty focusing after recent treatment or being informed of progression.

Issues for use and access included participants' recognition that the intervention would need to be well-promoted and would need to be kept relevant and up to date.

Participants' recognition that every woman with ABC was different included recognition of varying preferences for information and support seeking among women with ABC, with three participants reporting preference for face-to-face support; and recognising that some women with ABC may have difficulty using technology. One participant commented on varying disease-related needs and (response to) treatment, and on coping with guilt on comparing oneself with others' needs or responses.

Finally, participants' evaluations revealed the general but pervasive issue in information and support seeking for women with ABC, that more support is needed for ABC. This included reports of feeling unsupported with ABC, the need for more studies of women with ABC, issues around terminology reflecting ABC status (e.g. 'palliative', 'survivor'), and the need for more public awareness of ABC.

Discussion

The present studies found information and support commonly sought by women with ABC to include medical, lifestyle, and practical information/support, consistent with findings indicating the highest levels of unmet need in women with ABC include health system and information domains [14–16] and use of Internet among women with breast cancer to seek medical information [21].

Only a minority of study 1 participants reported seeking psychological/emotional information/support despite unmet needs in the psychological domain being commonly identified in previous studies [14, 15]. Participants may have had these needs met informally, and therefore may not have considered themselves as actively seeking psychological/emotional support. On the other hand, participants may have perceived psychological information/support as involving a traditional support group or face-to-face therapy, or did not expect to find relevant psychological/emotional support for ABC, and therefore did not look despite their need.

It may be the case that psychological distress and unmet needs in women with ABC could be addressed by meeting their information needs, and providing greater opportunities to learn from peers, or that the Internet is not perceived as the medium through which women address emotional needs.

Interestingly, when presented with an example intervention, the majority of study 2 participants gave positive feedback on content concerning emotional distress and worksheets/activities, and more than one third gave positive feedback on meditation and relaxation content; these three content areas were the top three that received specific positive feedback. One third also suggested relevance to ABC would be increased by addressing coping psychologically with mortality. Therefore, it appears women with ABC respond positively to an *online* avenue for addressing psychological/emotional needs but may not be aware of the potential of the Internet in addressing that need.

Together, these findings offer new insights into how women with ABC perceive the role of the Internet in addressing their support needs in terms of preferred content and pattern of use. The study offers some suggestion that women may not realise the full potential of what the Internet may offer, or may have particular preferences regarding content or type of support obtained via the Internet. These observations warrant further research.

Notably, participants drew on family support but reported a lack of resources available to families, consistent with research indicating high levels of burden and low levels of available support for cancer caregivers/significant others [25]. At times, participants attempted to fulfil partner/family support needs or prioritised family needs over their own. Concern for families and friends also contributed to difficulty obtaining support due to reluctance to discuss cancer with them.

Difficulty finding ABC-specific information/support and feeling unsupported in comparison to available information and support for early stage breast cancer corroborate other recent findings that women with ABC believe ABC-related information is inadequate and frequently feel isolated [13].

Findings suggest women with ABC could see benefits of a specific Internet programme, *provided* it was legitimate, up-to-date, and ABC-specific. Most study 2 participants noted FMW needed more specificity to ABC, and several suggested tailored sections for women who received a de novo diagnosis of ABC, reflecting BCNA recommendations [4]. Variation in specific content areas participants related to and concerns over whether ABC-related information may be confronting or stressful also highlighted the importance of personalising the intervention to address varying needs of women with different disease-related and other circumstances, consistent with literature indicating benefits of tailored Web-based interventions [26].

Limitations and directions for future research

While each study achieved saturation of themes, recruitment through BCNA online promotion and the study 2 requirement of Internet access may mean findings are biased towards perspectives of women with BCNA support and Internet access. However, study 1 included several women without Internet access, and study 2 included women who did not consider themselves technologically adept despite Internet access. Furthermore, these studies are likely to represent perspectives of women most likely to access a future Internet intervention.

Future research is required to develop and evaluate an ABC-specific Internet intervention as a promising avenue for addressing the information and support needs of women with ABC, while also addressing how to provide accessible interventions to women who cannot, or are reluctant to, access the Internet.

Conclusions

These studies confirmed that while many women with ABC are positive about an online intervention and would potentially use such an intervention to meet information and support needs, content of such an intervention needs to be ABC-specific, user-friendly, and personalised to suit users with a range of disease characteristics, treatments, personal circumstances, topics of interest, and information and support-seeking preferences.

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Compliance with ethical standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethical approval All procedures in studies involving human participants were conducted in accordance with the ethical standards of the Southern Adelaide Clinical Human Research Ethics Committee, and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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