

What Male Caregivers of Women With Breast Cancer Want in an Online Intervention: A Qualitative Study

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Abstract

The diversity in cancer caregiver responsibilities often leaves caregivers feeling ill-prepared for their role. To inform the development of an online caregiver training intervention, we examined the views of men caring for a woman with breast cancer on intervention mode, timing, and content preferences. Thirteen men participated in a qualitative interview. The findings reveal that an online intervention should include educational content and psychological support, be interactive and personalized, and be available from the point of diagnosis. There is encouraging support for an online caregiver training intervention that covers numerous topics and is available for men to tailor how they use the content based on their individual needs.

Keywords

male caregivers, supportive care, self-management, online intervention, breast cancer, smartphone apps, website

Introduction

In Australia, approximately 19 000 women were diagnosed with breast cancer (BC) in 2019 (1). Supporting a loved one with cancer impacts caregivers' physical health (2,3) mental health (4,5) and financial status (6,7). Many caregivers feel ill-prepared, particularly when required to address complex medical needs while supporting their loved one with the psychological challenges patients experience following a cancer diagnosis (5). Specifically, male caregivers of women with BC experience high levels of psychological stress in relation to their caregiving role (8,9). Carers seldom utilize potentially beneficial face-to-face services such as support groups and training due to caregiving demands, time restrictions, long distance travel, and prioritizing the patient (10,11). These services are also usually limited to metropolitan areas, highlighting the importance of accessible interventions such as online resources (12) which are more acceptable to men in particular (13,14).

A review of 17 studies on online interventions for family caregivers found positive impacts on depression, anxiety, and stress/distress but also numerous null findings and variable research quality (15). Similarly, a review and meta-analysis of 13 studies examining the impact of online interventions on caregiver mental health outcomes revealed

small to medium beneficial effect sizes on depression and anxiety noting that many studies were of poor quality with high risk of bias (16). A review of 6 web-based interventions for cancer caregivers (17) reported that these online interventions may reduce caregiver burden, negative mood, and cancer-specific distress and increase quality of life and emotional functioning. However, study reporting quality was again judged as weak, and studies predominantly included female caregivers (17).

As such, it is currently unclear how such interventions may aid male caregivers, particularly those caring for women with BC. Consistent with the "person-based" approach to intervention development, which highlights the

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Table 1. Participant Characteristics.

Code	Age	Marital status	Relationship to patient being cared for	Stage of patient's breast cancer	Time since diagnosis
P009	68	Married or partnered	Husband or partner	Early stage	Between 3 and 5 years
P015	33	Married or partnered	Husband or partner	Early stage	More than 5 years ago
P030	54	Married or partnered	Husband or partner	Early stage	Between 12 months and 3 years
P031	55	Divorced or separated	Husband or partner	Early stage	Between 3 and 5 years
P033	59	Married or partnered	Husband or partner	Early stage	More than 5 years ago
P044	65	Married or partnered	Husband or partner	Secondary stage	More than 5 years ago
P045	–	Married or partnered	Husband or partner	Early stage	More than 5 years ago
P060	52	Married or partnered	Husband or partner	Secondary stage	More than 5 years ago
P067	65	Married or partnered	Husband or partner	Early stage	Between 3 and 5 years
P068	71	Married or partnered	Father	Don't know	Between 12 months and 3 years
P072	67	Widowed	Husband or partner	Secondary stage	More than 5 years ago
P077	66	Married or partnered	Husband or partner	Early stage	More than 5 years ago
P091	53	Married or partnered	Husband or partner	–	More than 5 years ago

importance of eliciting and incorporating the views of the end users (18), this study explored men's views regarding suitable content, timing, and delivery mode for an online caregiver intervention to improve their well-being and caregiving skills.

Methods

This article reports the qualitative results from a mixed methodology study of male caregivers of women diagnosed with BC, previously described in detail (19). The study was approved by the Human Research Ethics Committees of South Western Sydney Local Health District (reference number: HREC/16/LPOOL/34) and Monash University (reference number: 2016-1007).

Participants

Eligibility criteria include caregivers who are (1) male, (2) currently caring or had previously cared for a woman with BC (unpaid, eg, relative, spouse, friend), (3) aged 18+ years, and (4) mentally and cognitively able to participate. Refer to Table 1 for participant characteristics.

Recruitment

Recruitment was conducted through Breast Cancer Network Australia (BCNA) (20) and Register4 (21) organizations with databases of members interested in cancer-related research opportunities. The organizations promoted the study through their digital media; members were invited to read the participant information sheet, and if interested, consent and complete an online survey (results presented at a conference (22) and reported elsewhere). Fifteen of the survey (n = 89) participants expressed interest in a subsequent

interview with n = 13 completing the interview, and n = 2 could not be reached by the research team.

Sample size in qualitative research is variable, influenced by sample characteristics, analytic technique, and reflexive engagement with the data. Braun and Clarke (23) contend that large sample sizes in qualitative work can be problematic as it can limit the nuance that can be found in smaller data sets and hence fail to do justice to the participants' accounts of their experiences. In the current study, n = 13 participants provided us with a manageable volume of rich data that allowed complex and sustained engagement with the data to construct themes that reflected participants' views regarding suitable content, timing, and delivery mode for an online caregiver intervention to improve their well-being and caregiving skills.

Telephone Interviews

The interview guide explored views about the content, format, and timing of a male caregiver intervention (see Supplemental Appendix A), including their interest in a caregiver support intervention, information they believed should be included, preferred intervention delivery method, and the timing of intervention availability. The mean duration of interviews was 31:38 minutes (standard deviation = 15:03 minutes, range = 20.1-68.4 minutes); they were recorded and transcribed verbatim.

Data Analysis

An inductive thematic analysis was conducted following the 6 phases outlined by Braun and Clarke (24): (1) data familiarization; (2) creating initial codes; (3-5) searching for, reviewing, and defining themes; and (6) report production. Two researchers (JVL and MG) conducted initial coding to establish a consistent system of coding. Subsequently, one

researcher (AB) completed the coding following the system established by authors JVL and MG, with regular consultation with the senior author (AG). Codes were reviewed by AG and AB and subsequently organized into themes, with disagreements resolved through discussion. Analysis was inductive and conducted iteratively.

To demonstrate the scientific rigor of this study, trustworthiness was achieved as follows: (1) for credibility, a proportion of the interviews were reviewed, with coding and theme review processes discussed with a second team member; (2) for dependability, we have reported our study in detail to facilitate future researchers repeating our work; (3) we have incorporated peer-debriefing by presenting our findings at conferences (22,25) to demonstrate that the findings and data are clearly linked and to enhance the confirmability, credibility, and trustworthiness of our study; and (4) our study findings may be applicable in, and transferable to, other cancer tumor groups as long as the patient is a female and the caregiver is a male, thus demonstrating transferability.

Results

Four themes emerged: educational content, psychological needs, an interactive and personalized intervention, and intervention timing, which provide an overview of requirements of an online caregiver intervention from the perspective of men caring for women with BC.

Educational Content

Participants reported limitations in received information and expressed a strong desire for information on what to expect, questions to ask at each stage of the diagnosis, treatment and survivorship continuum, treatment options, and associated side effects.

And then sort of setting up and saying, “Well, these are the potential [steps] that you will be going through, these are the times in between. So, expect that if you go and do a test, it’s gonna take a few weeks to get a result and things like that.” Just so you got an overview of what are the things that will be coming up, how many appointments and things that you might be going to, so you can start planning out your time. (P067)

And taking another step sideways, one of the bits of information on the website should be the questions at each stage that you should ask the specialist, because I think trying to understand what questions we had to ask upfront were difficult. (P077)

Participants also wanted information regarding physical and/or practical care such as wound management, practical support, and how to manage multiple caring responsibilities. They raised the importance of being prepared for physical caring and knowing how to juggle caring responsibilities particularly in situations where one caregiver is caring for 2 or more family members.

... when she did have the radiation, she was very, very badly burned and all her skin was really cracking, it was literally black, and so we didn’t know how to treat it at first... but then for next month or so, I had to help dress it every morning for her. So, little things like that when you’re not used to looking at wounds and things like that... (P067)

when my wife she had her operation, I couldn’t go and see my dad because he’s in an infectious disease ward. So, I had to make certain decisions, so I obviously stuck with my wife, at the same time, that just sort of confused things... (P060)

Participants also mentioned the need for information on employment and legal rights and on financial support options.

[what would] be very practical would be to have a very quick synopsis of, like, what the legal position is for employment and so on, as what you can or can’t do with your employer, because—I know I worried about it. (P009)

we’d actually gone to Centrelink before that to say—earlier to see what she—I mean, she had a sort of critical disease in that respect and whether she could go into pension or whatever. And they said, “Well, not while you’re working,” and that sort of thing... although we found out we could get a carer’s allowance or something like that, which we hadn’t known about—I mean, I could’ve been—we could’ve been getting this sort of [support for] four or five years, I suppose, and we only found out about it at the last 12 months or so. (P044)

Psychological Needs

This theme reveals the often hidden but salient psychological issues and needs of caregivers, including self-doubt and inability to cope mentally.

Might be just need was for something brief, just something to keep me on track. Something to let me know I was doing okay to remove a lot of self-doubt... I want to be able to say my wife’s being a bitch... To be able to say stuff like that I think it helps to—just to be able to and also for men to know certainly about coming forward if you need help. People often say let me know what you need, ... but often you don’t know what you need. (P091)

Relevant to this theme is participants’ needs to have some form of support to encourage caregivers to accept the situation at hand and deal with it accordingly.

Well, I think the first thing is to come to grips with reality. My feeling probably is that the first reaction of somebody is, “Oh, this can’t be true. There isn’t a record of it in my family,” or “What have I done wrong?” (P045)

Participants also reported how their relationship with health-care professionals (HCPs) influenced their experience and the importance of trust.

I think the second thing is to have confidence in all the medical backups that you have . . . we've always gone to the same doctor . . . So I think it's important to make sure that you have a regular medical doctor who you've been seeing for some time and that you've had some confidence in. Then you also have to have faith in the doctors' referrals, referral to the oncologist, or the hospital, or the other specialist, and so on. (P045)

Another important aspect men raised was the need to know how to prepare for, and cope with, the loss of their loved one. Besides pictures, it was suggested that caregivers should know the importance of recording audio messages and videos, even if eventual loss is not expected to occur.

And my wife's had a message on my mobile which said, "We're not here at the moment. Can you leave a message and ring back?" Now, I was just about to delete that, but we sort of realised that that's about the only sort of actual voice message I had. And I ring up my phone every now and again just to hear the message. (P044)

An Interactive and Personalized Intervention

Participants confirmed the value of existing resources, face-to-face caregiver information, and support services but they expressed an overwhelming need for an online intervention, delivered through websites and/or smartphones.

And smart phone is probably the go-to thing that people would prefer to do it on, or especially if they're on the go, or they're busy . . . Sometimes sitting down on a computer and actually dedicating the time to do something is a bit cumbersome and not really effective. (P033)

I think if you have a dynamic—I mean, if you got a website there where you can sort of dip in to the places you need at that particular time, whether you're sort of—maybe it's the first time you're going to the chemo and you need some information on that or you're going into radiotherapy or something like that. (P044)

Participants wanted the intervention to be multimodal, with text, audios, graphics, and videos.

And then I guess in terms of like a book or whatnot, I—yeah, at the time, I definitely didn't feel like reading a whole book about it. So, I don't know. I probably would be more willing to know, but still, I think most people would struggle to deal with the whole presentation as just written text. So, yeah—yes, the smart phone or internet site could make it much more interactive as well. (P033)

Videos . . . even people's experiences. That could be a good way to learn things. (P031)

Participants expressed value in information tailoring as a user experience intervention feature, so that only information that is relevant to their current diagnosis, treatment, and survivorship stage is accessed when needed.

I think you just wanna be careful that [the intervention is] not too generic . . . Because I think what we've found—it's really disturbing the amount of women that have been diagnosed since—around our neighbourhood since [my wife] was, and they've all got different variations of breast cancer. So, all the treatments are quite different. (P077)

Perhaps the most important feature nominated was the need for interactivity through an online group chat feature for men who are essentially experiencing the same issue. They thought this might facilitate them asking questions and receiving peer responses.

I mean, just to maybe even if you got sort of online forums or something like that, you might sort of specify that next Friday we're gonna have a talk about such and such or something like that, and if you wanna sort of—I don't know—Skype in or text in or do whatever, but make some sort of—and it sort of gives you the opportunity to participate then because I think when you know that there's other people in exactly the same bone as you or whatever, it makes things a lot easier. (P044)

I also think it would pay to have someone that could be rung up for specific questions or you could lodge a specific question to, on email or something. (P077)

Intervention Timing

The general consensus was that the support intervention should be provided from the moment of diagnosis, while ensuring the resource is available throughout the milestones along the diagnosis–treatment–survivorship continuum.

Oh, I suggest soon as the diagnosis when things are—now, there is a problem. Now, you just need to work these things out—once the diagnosis—you need to be able to know just where you're going to be in a month's time and what's going to happen, type of thing. Yeah. (P015)

. . . once the caring regime starts that's when they're gonna start needing support within a week or two, they're gonna need to know—'cause pretty soon they're gonna start experience the self-incrimination and the self-doubt and not knowing if they're doing a good job and they're gonna start feeling over stretched and emotionally battered. (P091)

Discussion

The interviews provided important insights to inform the content and timing of an online intervention for male caregivers of women with BC. Caregivers acknowledged the support of HCPs and value of existing resources but identified the need for important issues to be addressed to optimize their support. These include personalized educational information regarding what to expect at each stage of the diagnosis, treatment, and survivorship continuum, including tailored information on treatment types and side effects, physical care, financial support options, practical support, managing multiple caring responsibilities, and employment

and legal rights. Existing online caregiver interventions mostly focus on female caregivers and typically provide only some of the desired information, with and studies of their efficacy characterized by poor attrition rates, high risk of bias, and poor reporting quality (17). Hence, there is a need for a new comprehensive and personalized online intervention addressing these issues that target male caregivers.

The need for psychological support for caregivers was a major theme, with men raising psychological issues such as self-doubt, trust in HCPs, communication, acceptance, and preparing for and coping with loss. These issues are consistent with existing literature (4,5,26) and have been well-documented as unmet needs and challenges experienced by caregivers more broadly, though accessible psychological support for this subgroup of male caregivers has received comparatively little attention. Current psychological support is predominantly face-to-face, often inaccessible to caregivers with time restrictions, long-distance travel, lack of respite, and who prioritize the patient (10,11) thus highlighting the importance of accessible alternatives such as online interventions. Our study reinforces the importance of incorporating psychological support in any newly developed comprehensive and personalized online intervention for male caregivers of women with BC.

Also, it was noted that the development of a new online intervention should be multi-modal (text, audios, pictures, videos) and delivered through a website and/or a smartphone app to maximize accessibility and availability. Specifically, smartphone apps are highly portable and mobile (27) offering convenience at any location and time. Both websites and smartphone apps provide technological features supporting personalization and interactivity, thereby also supporting an online group forum through the intervention. Nonetheless, the choice of one or both channels should be based on their potential reach across the target population.

Limitations

This study was limited to English-speaking male caregivers, hence not reflecting the perspectives of culturally and linguistically diverse (CALD) caregivers, with CALD communities known to have difficulty accessing cancer information and navigating the health system for psychological support (28). We also acknowledge our relatively small sample size and that recruiting participants online through BCNA and Register4 may have limited our ability to capture the needs and perspectives of caregivers not included in these organizational databases or who do not have access to online resources. However, this recruitment approach ensured that participation was not limited by geographical location; and telephone interviews also facilitated participation from across Australia. In addition, participants were recruited at any time after the care recipient's diagnosis, with many participants several years postdiagnosis, possibly impacting their recall bias. However, this decision was made to elicit

the insights from male caregivers of women with BC at all points of the diagnosis–treatment–survivorship continuum.

Based on the limitations associated with our study, we suggest that future works should target at risk/high risk demographics to provide more in-depth and generalizable insights into the perceptions of male caregivers of women with BC.

Conclusion and Practical Implications

It is evident that male caregivers experience numerous challenges that are primarily psychosocial in nature and impact on both their relationship with the care recipient and their everyday functioning. There is encouraging support for an online caregiver training intervention that covers numerous topics, is easily accessible and flexible, allowing men to tailor their content use based on individual needs, and to interact with other caregivers. The practical implications are that psychosocial support should be the top priority for supporting male caregivers, alongside managing symptoms, which is often viewed to be of the utmost importance for caregivers' supportive care needs. The clinical teams addressing these priorities will enable caregivers to be better equipped to support the women diagnosed with BC.

Thus, opportunities for the development and pilot testing of an intervention addressing the psychosocial needs of this subgroup of caregivers warrant immediate attention. Future studies may aim to explore the balance of modalities (text, audios, pictures, and videos) in addition to testing the accessibility of the intervention at specific time points (all content available at once vs sections released on a time basis). However, in a technologically advanced age, it is recommended that future studies aim at exploring the optimal delivery of a personalized online intervention to ensure adherence, rather than experimenting with paper-based and online interventions.

Authors' Note

The study was approved by the Human Research Ethics Committees of South Western Sydney Local Health District (reference number: HREC/16/LPOOL/34) and Monash University (reference number: 2016-1007). Informed consent was obtained from all participants in our study.

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Supplemental Material

Supplemental material for this article is available online.

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Martha Gerges is undertaking a research masters degree, with a specific focus on health literacy in immigrant populations affected by cancer.

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