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Title: Development and usability testing of a web-based psychosocial intervention for women living with metastatic breast cancer: *Finding My Way-Advanced*

Short Title: Development of *Finding My Way-Advanced* development

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Development and usability testing of a web-based psychosocial
intervention for women living with metastatic breast cancer: *Finding*

My Way-Advanced

Abstract

Purpose: Women living with metastatic breast cancer (MBC) face significant distress and unmet needs, yet few resources have been developed for this population. The current study aimed to develop and evaluate the usability of *Finding My Way-Advanced (FMW-A)*, a web-based self-guided psychosocial program for women with MBC.

Methods: FMW-A was co-designed through (a) adapting an efficacious online program for people with curatively treated cancer, and (b) receiving iterative rounds of input and feedback from a multidisciplinary co-design team including consumers, clinicians and academics. A think-aloud protocol was then implemented to test the usability of the resulting 6-module prototype, with women living with MBC accessing up to three modules with an interviewer sitting along-side. Participants were recruited until saturation of themes occurred. Data were analysed thematically.

Results: Participants (n=8) were, on average, 65.3 years old, mostly partnered (n=5), retired (n=6), post-secondary school educated (n=6), with non-dependent children (n=7). Feedback fell into 6 themes. *Positive feedback* about FMW-A summarised the supportive and informative nature of the programme, supplemented by comments about broadly *relatable content*. However, one size clearly did not fit all: within themes, diverging experiences emerged regarding *navigability*, *worksheets* and *layout*. Participants noted that *having/making time* for the intervention would be important to program engagement.

Conclusions: Usability testing indicated participants found content helpful and relatable, and identified significant pragmatic improvements to be made prior to further testing.

Implications for cancer survivors: The development of FMW-A represents an important step in providing acceptable resources to support women living with MBC.

Key terms: metastatic breast cancer; psychosocial intervention; digital health

Declarations

This project has been produced with financial and other support of Cancer Council SA's Beat Cancer Project on behalf of its donors and the State Government of South Australia through the Department of Health. The first author is supported by a Cancer Council SA Postdoctoral Fellowship (Cancer Support).

This study was approved by the Southern Adelaide Clinical Human Research Ethics Committee (No. 258.18). Informed consent was obtained for all participants.

The authors have no conflicts of interest to declare.

1 | Introduction

A diagnosis of metastatic breast cancer (MBC) brings significant adjustment challenges, as women face a future of progressing illness, physical symptoms, functional limitations, and existential concerns about mortality [1]. Despite evidence of high distress and support needs [2], a 2015 Breast Cancer Network Australia (BCNA) online survey of 582 individuals with MBC found 68% of participants had unmet needs, with the top three being (i) fear of progression; (ii) fatigue, and (iii) uncertainty about the future [3]. ‘Self-care’ was the preferred management strategy for the latter two needs, and second-preferred option (after oncologist-involvement) for managing fear of progression.

However, few resources have been developed for this population, particularly resources that utilise self-care. Our 2018 systematic review of interventions for women with MBC [4] found only 15 randomised controlled trials (RCTs). Group therapy had the strongest evidence base with seven published trials, but also poorest uptake/adherence. In contrast, low-intensity interventions had the weakest evidence base (only four trials published: two telephone-based, two expressive writing), but highest uptake/adherence, highlighting the importance of further research [4].

No published study has yet investigated web-based interventions [4], despite findings that women with MBC use the internet for their health [5], are receptive to the online provision of a psychosocial program [6], and are optimistic about the potential of an existing intervention being adapted to meet their needs [6]. Building on these early findings, this study aimed to develop and usability-test an online program to support women with MBC: *Finding My Way-Advanced (FMW-A)*.

2 | Methods

2.1 | FMW-A co-design

FMW-A was iteratively developed using a person-based co-design approach [7], with content initially sourced and adapted from our FMW web-program, an evidence-based program applying Cognitive Behavioural principles, designed for people with curatively treated cancers [8]. Content was

authored by a senior clinical psychologist with expertise in psycho-oncology [LB], with numerous rounds of input and feedback provided by the multidisciplinary co-design team comprised of three psycho-oncology researchers; three clinical psychologists; one medical oncologist; one psychiatrist; one woman living with MBC; one breast cancer advocacy group representative, and one cancer charity representative.

The program is comprised of six psychosocial modules (table 1). Five modules were retained from the original FMW, with language and content revised based on feedback from interviews with women with MBC [6]. One additional module was co-created based on this feedback, to replace a module about 'cancer survivorship' with 'the unique challenges' of living well with MBC, to ensure the program's relevance to this population. Each module includes videos and written accounts from women living with MBC, educational videos from health care professionals, psychoeducation, quizzes, and interactive exercises based on cognitive behaviour therapy.

Website development was guided by Ritterband's internet interventions behaviour change model [9]. Two key strategies were implemented to facilitate usage: (a) *personalisation and tunnelling*: module access is limited to one per week, but participants can personalise content by rearranging the module order, to prioritise topics according to their needs; and (b) *engagement/interactivity*: the program provides (i) worksheets, activities, and quizzes with immediate feedback and recommendations; (ii) a 'favourites' and 'notes feature' to encourage participants to highlight and reflect on relevant content, a 'where you left off' feature to enable participants to immediately return to their last accessed page, and (iii) automated weekly email reminders. For more program detail, see Online Resource 1.

2.2 | Usability evaluation

2.2.1 | Participants

Women were recruited by oncology clinicians at a tertiary public hospital and purposively sampled for diversity in age. Eligibility criteria included: (a) diagnosis of MBC; (b) age 18 or older; (c) sufficient

English for informed consent and program comprehension; and (d) no medical history of dementia or cognitive impairment.

2.2.2 | Procedure

The Southern Adelaide Clinical Human Research Ethics Committee provided approval (ref: 258.18). Individual think-aloud interviews were conducted in person. Consistent with the person-based approach [7], participants were asked to share their perspectives on content and usability by verbalising their thoughts as they worked through FMW-A, with occasional prompts by the interviewer for clarification. All modules were assessed by at least two participants. Interviews were recorded using digital audio recorders, and transcribed verbatim. Saturation was determined through an iterative process. After completing the eighth interview, no additional changes or issues were identified, and no new themes were emerging; rather, identified usability issues were frequently repeated and a wide range of perspectives on subjective aspects (e.g., layout, illustrations) had been recorded. Given that this study built on previous scoping studies examining usability via at-home access to a previous iteration of the program[5, 6], and that similar studies using a think-aloud procedure to evaluate online programs have achieved saturation with equally small samples [7], collection of further data was therefore deemed redundant.

2.2.3 | Data Analysis

Transcripts were thematically analysed following established guidelines [10], using the software program NVivo 12. One author (EK) conducted initial coding, with regular consultation with the first author (LB). Final codes were then reviewed by the two authors, organised into themes and sub-themes, with disagreements resolved through discussion. While themes were qualitatively developed, they were summarised according to frequency (how many times in total a theme was raised).

3 | Results

Participants (n=8) ranged in age from 47 to 76 years (M = 65.25). Most identified as Australian (7) and were retired (6), without dependent children (6), partnered (5), and tertiary educated (5). Participants accessed the website landing page, user dashboard, and two to three *FMW-A* modules during the interview (duration range: 94-117 minutes).

Participants' feedback on the program was coded into six themes and 28 subthemes, summarised below and in Table 2.

Theme 1: Positive feedback

All participants gave positive feedback, indicating the program was *informative or helpful, supportive*, used appropriate *language and tone*, and/or that they would *recommend it to others*.

Theme 2: Relatable content

All participants indicated they related to some program *information*, with the majority relating to *quotes and videos*. Relatable content was identified as helpful/relieving and likely to improve engagement. While participants also *did not relate* to some content, this was partly attributable to variation in personal circumstances (e.g. not having a partner, not having lymphoedema or sleeping difficulty). Participants recognised the *diversity* of circumstances addressed by the program, including in consumer videos.

Theme 3: Navigation

All participants commented on aspects of *navigation*, with many finding it *easy or simple*, particularly *once they were used to it*. Several participants gave positive feedback on the *default order of modules*. Participants identified that effective navigation of the program could be affected by the user's *digital literacy*; for example, some required (minimal) support to overcome *technological challenges* (scrolling, clicking).

Each participant experienced some *navigation difficulty or confusion*, most commonly relating to a function intended for participants to use a 'plus symbol' (+) to expand sections of the program which was often missed or interpreted as a 'dot point'. Other specific difficulties related to accessing linked pages via *hyperlinks*, then being unable to return to the original page without direction.

Theme 4: Worksheets

All participants gave some *positive feedback about worksheet content* and most were *positive about worksheet instructions or process*. Some had some *difficulty following worksheet instructions or process*, or identified specific worksheets that were '*not for them*'. Some participants made suggestions to improve worksheets (e.g., providing time estimate for completion).

Theme 5: Layout

Most participants gave *positive feedback* on program layout, but some identified *improvements needed* (e.g. amount of text). Feedback on layout varied substantially according to participants' personal preferences (e.g. colour scheme, illustrations).

Theme 6: Having time

All participants commented on the time commitment needed to engage with the program. Some considered they *would have or make time*, whereas others felt they would be *unlikely to have or make time*. Several participants commented that competing priorities, such as work or family commitments, could make engagement more challenging.

4 | Discussion & Conclusion

The development and usability testing of *Finding My Way – Advanced* represents an important step in meeting the unmet need of providing tailored self-management resources, which aims to improve quality of life and decrease distress among women living with MBC [1-4]. While participants gave positive feedback on helpful, and relevant/relatable content, usability testing identified significant improvements required to navigation and layout. However, this process highlighted that the content

or navigation functions that suit one participant do not necessarily suit another's preferences, underscoring the challenges of developing a program to meet diverse needs. These findings, along with feedback relating to time commitments, emphasise the importance of building flexibility into digital programs [7, 9].

Strengths of this study included our person-based co-design methodology [7], which enabled modifications to address most usability concerns, thus increasing the likelihood of future engagement and benefit [7]. These considerations are particularly important considering: (a) the potential for internet-based resources to partially address the needs of women with MBC [4-6]; and (b) improve the uptake and adherence difficulties identified in this population [4].

Additional strengths include the representation of diversity in age and digital literacy levels.

However, limitations include small sample size and minimal diversity in participants' cultural and educational backgrounds. Even so, this study enabled consideration of diverse perspectives and preferences, including those of younger women with school age children, older women with adult children, women without children, women who were partnered, women who were unpartnered, women who were employed in paid work and those who were no longer employed, while simultaneously enabling identification of common themes. Furthermore, usability testing currently applies only to the Australian population. As Australia is an island nation with a small population geographically spread, this modality is particularly well suited to Australian women living with MBC. It may however be transferable and helpful for women in other developed countries, especially for similarly geographically dispersed populations.

Identification of navigation and layout issues using the think-aloud process has enabled these pragmatic issues to be corrected prior to feasibility testing, which is currently underway in the form of a pilot RCT. Further evaluation of the program (helpfulness, user satisfaction) will therefore occur prior to testing for efficacy in a planned larger RCT. In conclusion, co-designing *Finding My Way-Advanced* with a multidisciplinary team of stakeholders and end-users has resulted in a tailored,

relevant, and meaningful web-based program with exciting potential to improve outcomes for this overlooked population. Future research will aim to establish feasibility and efficacy of FMW-A.

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Table 1. *Finding My Way-Advanced* program

Module	Content and Features
1: Navigating Diagnosis	<ul style="list-style-type: none"> • Covers issues women face when first diagnosed, including who is in their treatment team, communication, and making treatment decisions • Activities: Assertive Communication; Decision Making
2: The Unique Challenges	<ul style="list-style-type: none"> • Covers some of the biggest challenges of living with advanced breast cancer: coping with fear of progression, living with uncertainty, and living well • Activities: Values clarification; Goal setting; Mindfulness; Worry postponement; Therapeutic Writing; Distress Tolerance
3: Physical Symptoms	<ul style="list-style-type: none"> • Covers common cancer-related and treatment side effects that women may experience, and how they can cope with these • Activities: Fatigue and Pain Activity Pacing; Relaxation
4: Emotional Distress	<ul style="list-style-type: none"> • Covers common emotional reactions, including anxiety, depression, stress, and anger, and ways to cope with these emotions. • Activities: Behaviour Activation; Cognitive Restructuring; Mindfulness; Therapeutic Writing
5: How You See Yourself	<ul style="list-style-type: none"> • Examines some of the very personal challenges of advanced breast cancer, such as changes to body image, intimacy, and identity • Activities: Reducing body dissatisfaction; Acceptance; Exploring Intimacy; Core Attributes Exploration
6: Your Family and Friends	<ul style="list-style-type: none"> • Covers some common concerns women have for their family and friends, and coping with social changes that may occur • Activities: Needs exploration; Assertive Communication; Social Support Exploration

Table 2. Usability Themes

Theme 1: Positive overall feedback <i>(124 references)</i>	
Subtheme	Example quote
Program informative/helpful <i>(51 references)</i>	"Now I've already learned something and can read something that I didn't know about" (P3)
Program supportive <i>(6 references)</i>	"I think it would be comforting to have it there to go back if you were, you know, experiencing something, or just needing to refresh or just need a bit of support" (P6)
Positive/clear language/tone <i>(17 references)</i>	"I like how easy it is to read" (P2)
Would recommend to others <i>(3 references)</i>	"I'd recommend it to anybody" (P4)
Theme 2: Relatability <i>(186 references)</i>	
Subtheme	Example quote
Found content relatable	
<i>Information</i> <i>(66 references)</i>	"I like the bit about washing dishes and cleaning your house, because sometimes I need to do that to calm down. That's one of the weird ones... but it's on there. A lot of my friends and family don't understand it." (P2)
<i>Quotes</i> <i>(22 references)</i>	"You look so well - they have no idea. Yeah, it's lovely to hear people actually say things what you're going through." (P3)
<i>Videos</i> <i>(31 references)</i>	"I think they all actually touch on real things that at some stage or another I've felt myself" (P1)
Doesn't relate <i>(45 references)</i>	"Yeah, the values and all that stuff, that's not relevant, to me. Whether it's relevant to other people, I don't know." (P8)
Diversity, range <i>(20 references)</i>	"And it helps to show the broadness of the people. The number of people, and the ages of people, there have been some rather younger women, but there have certainly been some older women, and the subtleness of that is, it can happen to anyone" (P7)
Theme 3: Navigation <i>(134 references)</i>	
Subtheme	Example
Navigation difficulty/confusion <i>(76 references)</i>	
<i>General navigation difficulty</i> <i>(22 references)</i>	"Now why is this in here? Is this, something I click on or is it just, emphasizing something...?" (P5)
<i>'Plus' symbol</i> <i>(25 references)</i>	"No, I wouldn't have known to do that...I was just thinking it was a dot point." (P2)
<i>YouTube videos</i> <i>(5 references)</i>	"Now, what are these ones here?" (P7)
<i>Hyperlinks</i> <i>(12 references)</i>	"So, I was interested in barriers to obtaining support, and when I selected that it just went straight back to that one" (P6)

Navigation easy/simple (31 references)	“Oh, you just go here. Yeah, that’s quite easy.” (P5)
Navigation easy once ‘used to it’ (18 references)	“I felt as we moved through it and quite quickly I was getting used to it and I felt comfortable.” (P6)
Positive: default module sequence (3 references)	“The sequence it’s in actually really makes sense - a really good way that you actually go through it” (P1)
Digital literacy (12 references)	“The literate people will enjoy it, and it will be a help. I’m not so sure, people who have... a lower educational level could do it on their own.... ‘Cause not everyone nowadays is computer literate, either.” (P7)
Technological challenges (6 references)	“I didn’t click the right thing. Oh, do I click it twice?” (P7)
Changes implemented:	<ul style="list-style-type: none"> • Simplification of module introduction pages • Moving videos from introduction pages • Changes to flow/order of some pages • Expanding sections and corresponding ‘plus symbols’ removed) • Hyperlinks clarified, total number of hyperlinks reduced
Changes planned for future iteration:	<ul style="list-style-type: none"> • Tutorial to assist familiarity • Alternative video platform (to avoid promotion of unrelated videos)
Theme 4: Worksheets (144 references)	
Subtheme	Example
Positive: worksheet content (35 references)	“That’s good. It’s a good worksheet, makes you think about if you do have an actual plan, an actual goal, how you’re going to do it” (P1)
Positive: instructions/process (25 references)	“That’s nice, yeah, coz it’s highlighted and everything in the right situation, it’s explaining and then giving, what they will do.” (P3)
Difficulty following worksheet instructions/process (51 references)	“I’m still trying to work out what the point of it is, why am I doing this? I don’t know what this information...is this all examples? A lot of examples. I’m trying to work out how it works. So, I have to do each option separately...so I haven’t done it right.” (P1)
Worksheet ‘not for them’ (12 references)	“I sort of work one day a week if I’m feeling OK. My kids and my friends and all that sort of stuff still do the same, I’m not going to be returning to study, so a lot of that’s not really, you know, I don’t feel like I need to do that” (P8)
Suggested improvements (14 references)	“That might be an aspect to put in here, to say that it will change all the time and you could look back and go, ‘Oh, I’ve got better at that’, or ‘that’s not bothering me anymore” (P5)
Changes implemented:	<ul style="list-style-type: none"> • Revised worksheet instructions for clarity and inclusivity (e.g. using ‘partner or support person’ rather than ‘partner’) • Clearer delineation of example entries
Changes planned for future iteration:	<ul style="list-style-type: none"> • More complex changes to flow/functionality of worksheets (catalogued to inform future iterations where not possible in current platform)

Theme 5: Layout

Positive: layout
(42 references) “They’re very cute little pictures.”

Negative feedback/ improvements needed
(26 references) “I thought they [pictures] didn't really do a lot for me. I didn't see their relevance, like what is the relevance of that person sitting down... It'd be just as meaningful without it, I think.” (P8)

Changes implemented:

- Reduced amount of text, increased spacing on some pages

Theme 6: Having the time

Making/having the time
(19 references) “Instead of reading you might feel, 'no, I want to have a look at that'. And if I want to know something to do with cancer or my health, that comes before anything.” (P3)

Unlikely to make or have time for this
(9 references) “I also think there are some things in there that are a bit of a waste of time.” (P8)

Competing priorities
(6 references) “If you were working, you know, you were a young person then it might be difficult to be able to - and if you’re continuing to work, then, you know, that might difficult, maybe, fitting everything in.” (P6)

Changes planned for future iteration:

- Longer total time for program use between baseline and post-treatment assessments
- Module release to be adjusted to allow flexible access to any module at any timepoint once enrolled