Internet support needs and preferences of women living with advanced cancer.

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Background

- Advanced/metastatic breast cancer (MBC) is associated with significant distress
  - Psychological morbidity for women with MBC ranges 35-43% (up to 54% if aged under 55 at diagnosis)
- Accessible psychological interventions for those diagnosed with MBC are lacking
  - Few interventions exist (compared with those for early stage breast cancer)
  - Attendance barriers to face-to-face therapy
    - Compromised health status
    - Intensive medical treatment schedules
    - Inability to commit to future appointments
- There is a need for novel/home-based interventions
  - Tele-counselling or internet-based counselling
Aim

To examine internet support needs and preferences of women with MBC including

(a) internet use

(b) information and support-seeking preferences and needs and

(c) preferences for an internet-intervention to meet these needs
The **Finding My Way** intervention  
(Existing intervention for early stage cancer)

An online psychotherapeutic self-help program for individuals affected by early stage cancer (developed with support from the NHMRC)

Tested for efficacy via RCT (online attention-control)

No significant group differences in distress BUT

- Significantly better emotional functioning (3 months)
  - Managing distress better
  - Less impact of distress

- Trends for better Global QoL
- Significantly lower total health service use and supportive care practitioner use post-treatment
Methods

Mixed methods
Women with MBC recruited via clinicians at FCIC or via Breast Cancer Network Australia participated in any of three sub-studies:

I. Online survey examining internet use to seek cancer-related information and/or support (N = 49, aged 34-76 years (M=57.7, SD =11.1)
   I. Quantitative (descriptive) analysis

II. Telephone interview on current information and support needs (N = 21, aged 34-78 years, M=59.7, SD=10.5)
   I. Qualitative (thematic) analysis

III. Review of existing early stage intervention (Finding My Way) via telephone interview (N = 15, aged 42-69 years, M=58.8, SD=7.5)
   I. Qualitative (thematic) analysis
I. Results – Online survey

Internet use

Frequency of internet use in women diagnosed with MBC

Duration of internet use in women diagnosed with MBC

- How often used internet
- How often use internet to seek info/support for MBC

- How long used (single session)
- How long used to seek info/support for MBC (single session)
I. Results – Online survey

Use and ratings of MBC information on the internet

- Medical info on MBC and symptoms
- Treatment and side-effects
- Types of health professionals
- Making medical decisions
- Communicating with treatment team
- Impact on emotional wellbeing
- Impact on sense of self, relationships, intimacy
- Impact on family and friendships
- Practical issues (e.g. finances)
- Planning for the future
- Fear of cancer progression
- Other information

[Bar chart showing results]

- Green: LOOKED FOR this information
- Red: Rated as IMPORTANT
- Blue: Rated as REASONABLY/VERY WELL COVERED
I. Results – Online survey
Use and ratings of MBC support/strategies on the internet

- Coping with treatment side effects
- Making medical decisions
- Communicating with treatment team
- Coping with impact on emotional wellbeing
- Coping with impact on sense of self, relationship, intimacy
- Coping with impact on family and friendships
- Coping with practical issues
- Planning for the future
- Coping with fear of progression
- Other strategies

Green bars: LOOKED for
Red bars: Rated as IMPORTANT
Blue bars: Rated as REASONABLY/VERY WELL COVERED
I. Results – Online survey

Preferred use of an internet program

- Participants rated existing MBC information/support on the internet as ‘quite helpful’ (N = 18, 38.3%) or ‘somewhat helpful’ (N = 15, 31.9%) 

- However, they thought an internet program designed specifically to provide information and support for MBC would be ‘very helpful’ (N = 29, 59.2%) or ‘quite helpful’ (N = 11, 22.9%) 

- Participants indicated they would access such a program at least once per week (N = 39, 81.3%), most commonly for 10-30 minutes per session (N = 31, 64.6%). 

- Preferred content for such a program included fact sheets, an online forum, short quizzes, videos or written stories sharing women’s MBC experiences, and relaxation/meditation audio clips.
II. Results – interviews

Topics of information and support to provide via an internet program

Participants were interested in several areas of information and support that could be received via an internet program, including:

**Medical information** (19, 90.5%);
Diagnosis/prognosis, terminology, treatments and side-effects

**Sharing/connecting with others with MBC** (10, 47.6%)
“If there was some sort of online chat group that would be fantastic…I would definitely use that” (Participant 16, age 34)

**Coping with practical/system challenges** (8, 38.1%)
Accessing financial support, travel from rural areas, coping with physical challenges
II. Results – interviews

Concerns about seeking information via an internet program

*Most common concern was legitimacy of the information/program* (12; 57.1%):

“It has to be very obvious that this is a legitimate site. It’s not just some joke site that someone made up…. [A specific program] would be really good because we would know that we could trust it.” (Participant 9, age 50)

*Less common concerns included*

**Usability:** Several participants thought other women may have trouble using an internet program (4, 19.0%), but only one was concerned about her own ability to use such a program

**Privacy/security** (4, 19.0%)

Potential to find the program **confronting/stressful** (4, 19.0%)
III. Results – feedback on existing intervention

Theme 1: Content is generally helpful/relevant
(14/15 participants)

“I think that it just makes it easier to negotiate the whole process and I think it’s a wonderful tool. And it’s very comprehensive. You know, it covers just about everything you can think of, doesn’t it really?” (Participant 13, 61 years)

Theme 2: Program is easy to use
(14/15 participants)

“I liked the presentation of the website. It was very friendly. It was very easy to work out” (Participant 14, 58 years)
III. Results – feedback on existing intervention

Theme 3: Program needs more general relevance to MBC (10/15 participants)

“I think you need to have two entirely different programs…it’s got to be something that would appeal to a woman with secondary breast cancer, as a source of information, and a source of perhaps finding out things that she may not already know about” (Participant 6, 60 years)

Theme 4: ‘Completing treatment’ needs to be changed to ‘coping with ongoing treatment/progression’

(9/15 participants)

“…that was quite important. I mean with metastatic breast cancer… there’s no end to the treatment and it’s more a succession of progressions and how you deal with, you know, different treatments and so on.” (Participant 10, 63 years old)
Conclusions

Many women with MBC use the internet to seek MBC-related information and support, but identify gaps in information and support and raise concerns re legitimacy of some information.

Women with MBC are interested in a specifically developed, credible internet program to meet their information and support needs.

Women with MBC were generally positive about the existing intervention, but prefer tailoring of the future program to meet specific needs of women with MBC.
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