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

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Finding
My Way

Advanced

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

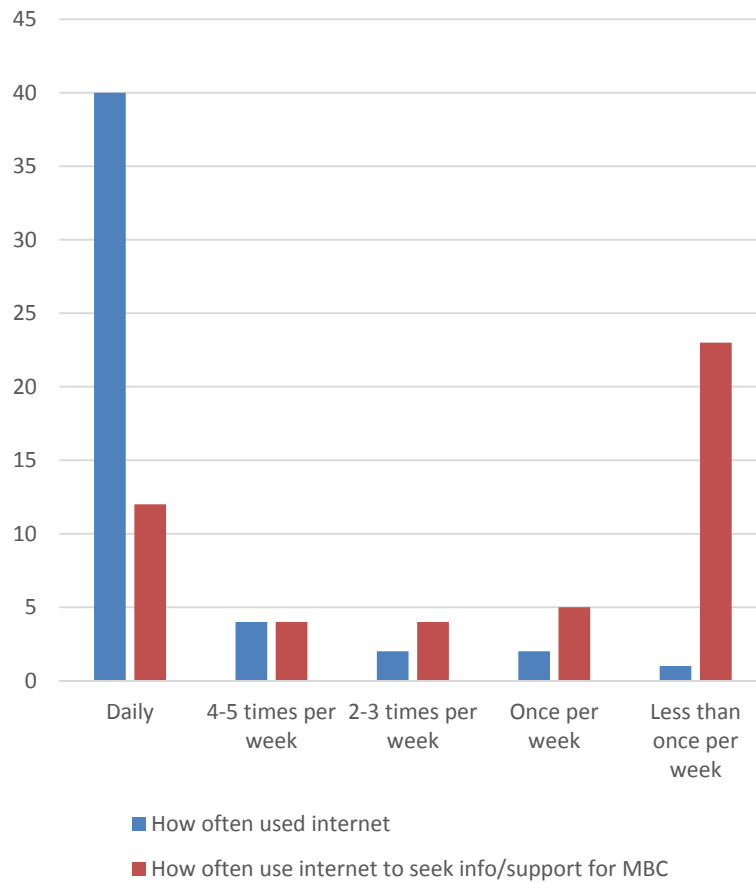
- III. **Review of existing early stage intervention** (*Finding My Way*) via telephone interview (N = 15, aged 42-69 years, M=58.8, SD=7.5)
 - I. Qualitative (thematic) analysis



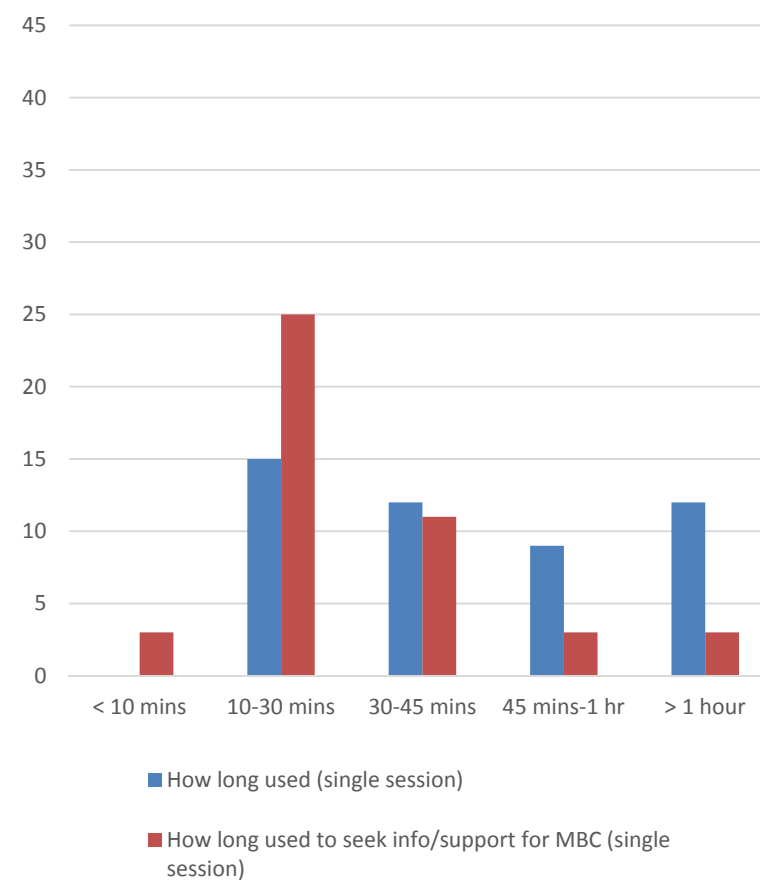
I. Results – Online survey

Internet use

Frequency of internet use in women diagnosed with MBC

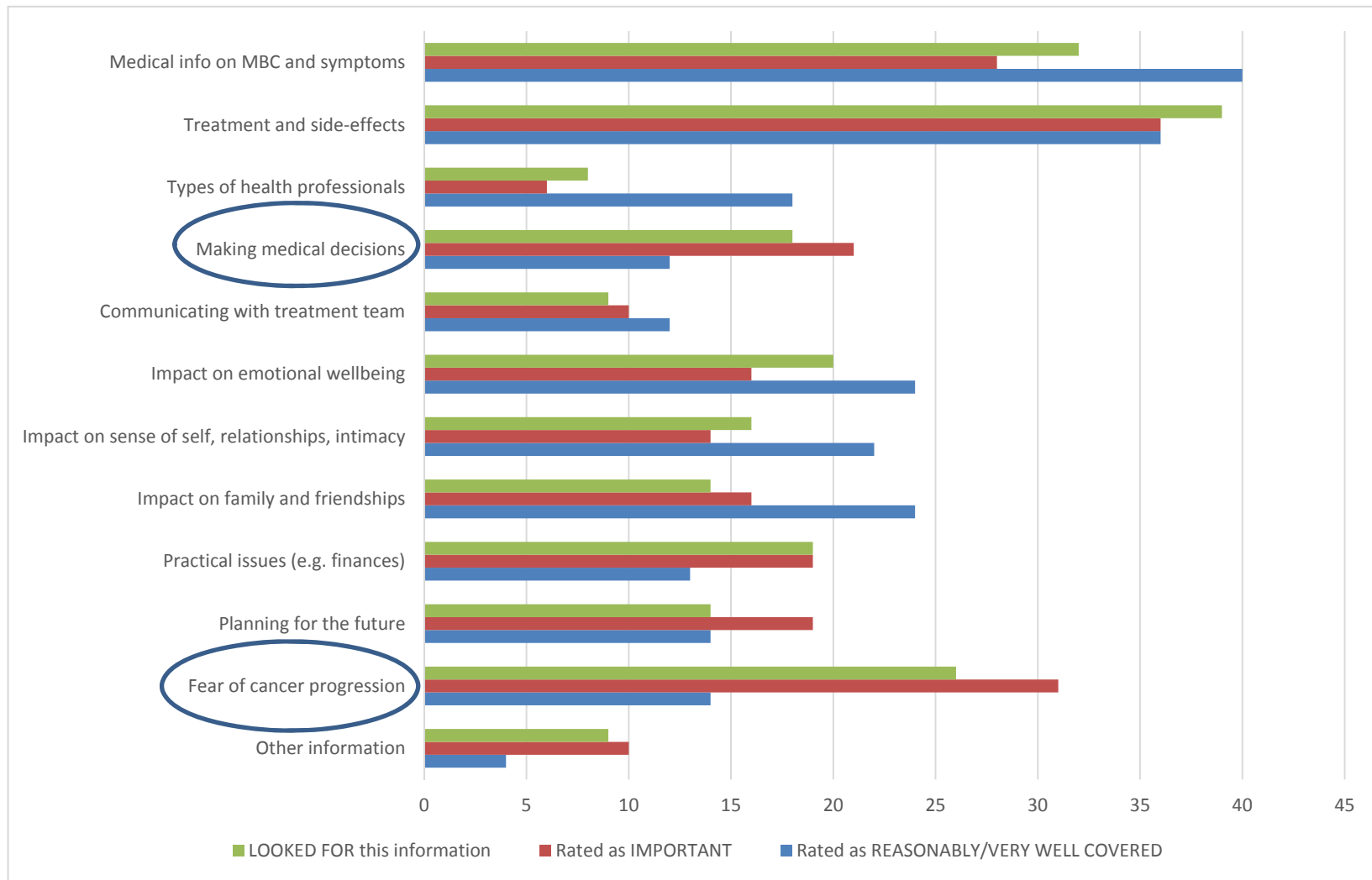


Duration of internet use in women diagnosed with MBC



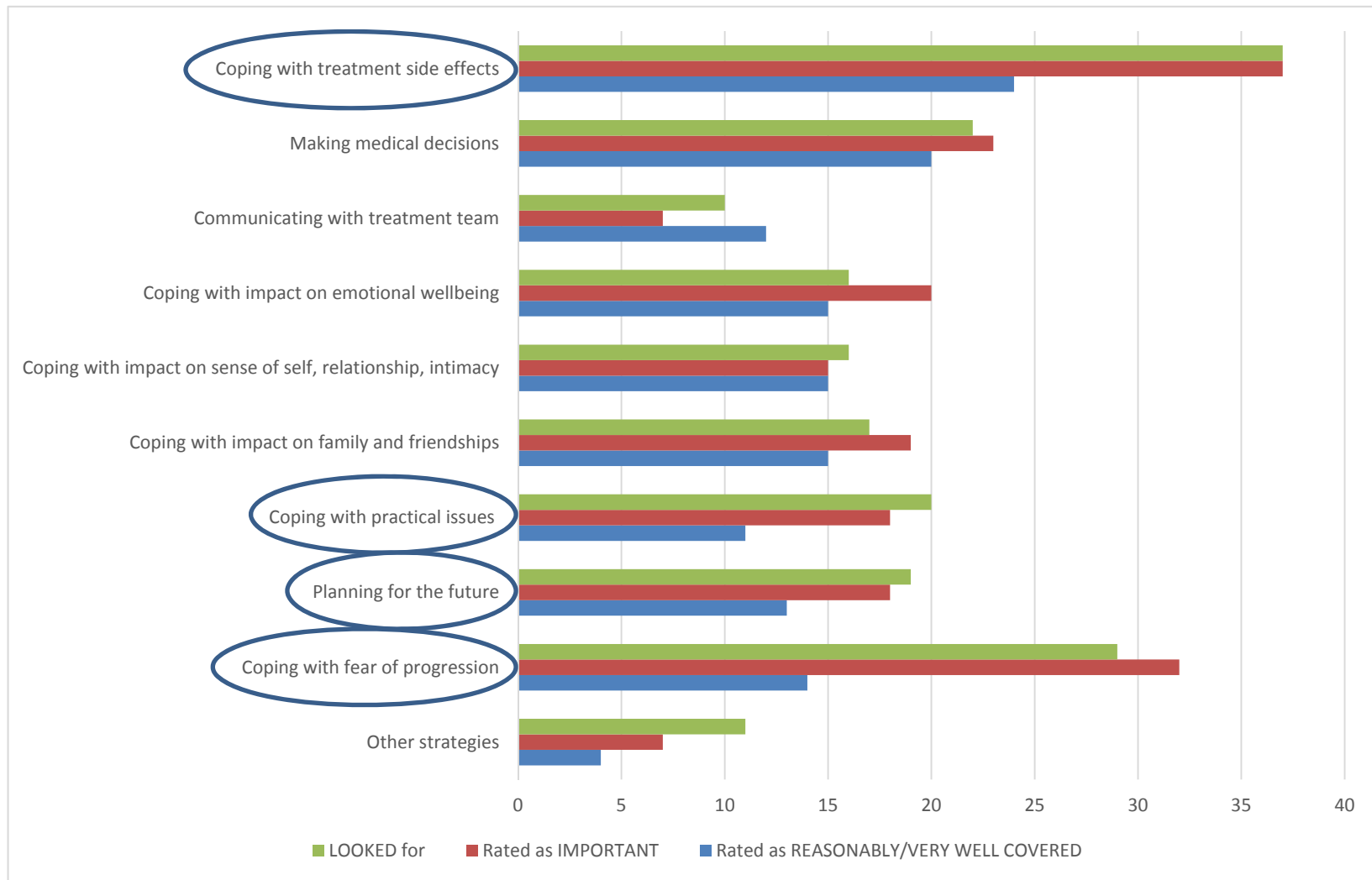
I. Results – Online survey

Use and ratings of MBC *information* on the internet



I. Results – Online survey

Use and ratings of MBC *support/strategies* on the internet



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 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



Acknowledgements



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