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Qualitatively Understanding Patients' and Health Professionals' Experiences of the *BRECONDA* Breast Reconstruction Decision Aid

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Abstract

Objective. Women diagnosed with breast cancer or ductal carcinoma *in situ* (DCIS), and those with a genetic susceptibility to developing this disease, face the challenging decision of whether or not to undergo breast reconstruction following mastectomy. As part of a large randomized controlled trial, this qualitative study examined women's experiences of using the *Breast RECONstruction Decision Aid (BRECONDA)*, and health professionals' feedback regarding the impact of this resource on patients' knowledge and decision-making about breast reconstruction.

Method. Semi-structured interviews were conducted with women who accessed the *BRECONDA* intervention (N=36), and with their healthcare providers (N=6). All interviews were transcribed verbatim and subjected to thematic analysis by three independent coders.

Results. Participants reported an overall positive impression, with all interviewees endorsing this decision aid as a useful resource for women considering reconstructive surgery. Thematic analysis of patient interviews revealed four themes: Overall impressions and aesthetics; Personal relevance and utility; Introducing *BRECONDA*; and, Advantages and suggested improvements. Analysis of health professionals' interviews also revealed four themes: Need

for *BRECONDA*, Impact of *BRECONDA*, Potential difficulties that may arise in using the decision aid, and Recommending *BRECONDA* to patients. Patients indicated that they derived benefit from this resource at all stages of their decision-making process, with the greatest perceived benefit being for those early in their breast reconstruction journey.

Conclusion. These findings support the use of *BRECONDA* as an adjunct to clinical consultation and other information sources.

Women diagnosed with breast cancer or ductal carcinoma *in situ* (DCIS), and those with genetic susceptibility to developing this disease, often face challenging decisions regarding whether to undergo breast reconstruction following mastectomy. Decision-making is complicated by the myriad of reconstruction options available, each with unique benefits and costs (1-9). Women contemplating breast reconstruction at the same time as their mastectomy must often make their reconstruction decision within days of cancer diagnosis and during a time fraught with anxiety and decisional conflict (6, 10).

To help counteract negative psychosocial outcomes, women need sufficient information to make an informed decision about breast reconstruction, as well as opportunities to fully process and consider all available options. We therefore developed an online, interactive decisional support tool, *Breast RECONstruction Decision Aid (BRECONDA)* to facilitate informed decision making regarding whether or not to have breast reconstruction (see breconda.bcna.org.au) *BRECONDA* (11) contains modules concerning reconstruction options and potential risks and benefits, incorporating values clarification exercises (12) enabling users to see how other women weighed up their options, and then undergo this process themselves. Stress-management guidance and videos of women describing their experiences of reconstruction decision-making are also included. Individual log-in passwords ensure privacy. Core screens provide basic reconstruction information, with

optional detailed material (e.g., photo galleries) allowing users to tailor their use of *BRECONDA* to match their information processing style (13, 14). See Table 1 for more details.

Pilot testing indicated high user-acceptability and ease-of-use, enabling women to feel secure in their reconstruction decisions and well prepared for surgical consultations (11). Findings from a randomized controlled trial (RCT) demonstrated that women accessing *BRECONDA* were more satisfied with information and experienced less decisional conflict over a 6-month period, compared with women receiving standard breast reconstruction information (15). When evaluating patient resources it is important that along with patient reported outcomes (e.g., decisional conflict), all users' *experiences of using the resource* are documented. Accordingly, we conducted semi-structured interviews on women's experiences of *BRECONDA*, and health professionals' feedback regarding its impact on patient knowledge and assistance with breast reconstruction decision making.

Methods

Participants

36 women [19 diagnosed with breast cancer, 3 with DCIS (BC); 14 at high risk (HR)] were recruited into this study following participation in the *BRECONDA* RCT (15). Eligible women were: 1) *either* diagnosed with breast cancer or DCIS *or* at high risk for breast cancer; 2) considering undergoing breast reconstruction following mastectomy; 3) over 18 years old; 4) English language competent; 5) had internet access. Additionally, six health professionals (HPs) based at three RCT recruitment sites (two breast surgeons, three breast care nurses, one breast physician) participated. Pseudonyms are used in reporting all interview data in this study.

Procedure

Women who accessed *BRECONDA* within the RCT were invited to participate in a 30-minute semi-structured telephone interview assessing their experiences using the intervention (e.g., ‘What were your initial impressions of *BRECONDA*?’); 36 women agreed and were contacted for interviews. Health professionals were invited via email to participate in 30-minute telephone interviews about the impact of *BRECONDA* on women’s knowledge and breast reconstruction decision-making. Following consent, all telephone interviews conducted by LKS were audio-recorded and transcribed verbatim. See online supplementary material for full interview schedules. Ethical approval for this study was granted by the relevant institutional human research ethics committees.

Data Analysis

Transcribed interviews were independently coded by researchers LKS, LJ, and KS using thematic analysis (Braun & Clarke, 2006). Within-case codes were initially developed for each interviewee to capture information that was either salient for that particular participant, or relevant to the research question. These codes were then categorised into sub-themes, and subsequently grouped into themes. The three coders discussed similarities and differences in coding, reaching 100% overall agreement.

Results

Patients

Patient participants ranged in age from 28-68 years ($M=48.31$; $SD=10.77$); and were mostly educated at vocational (27%) or tertiary (57%) levels. At the time of interviews, five patients had already undergone breast reconstruction (Recon), 13 indicated strong intentions to undergo reconstruction (ReconIntent), and 18 had opted not to have reconstruction (NoRecon). Four overarching themes were identified: Overall impressions and aesthetics;

Personal relevance and utility; Introducing *BRECONDA*; and, Advantages and suggested improvements (see Table 2 for example quotes). Pseudonyms are used to protect participants' identity.

Overall Impressions and Aesthetics

Patients' initial impressions were positive, describing *BRECONDA* as 'valuable' (Shona-BC-NoRecon), 'a useful starting point' (Melanie-HR-ReconIntent), and 'helpful' for making reconstruction decisions (Grace-BC-NoRecon). Content was described as 'very informative' (Jo-HR-ReconIntent), easy to read and understand, and providing a 'balanced' view (Ashley-HR-ReconIntent). Participants commended the opportunity to personally tailor information, noting how 'you can choose what information you want to take' (Joyce-BC-NoRecon) and the 'simple' (Katrina-HR-ReconIntent) and 'straightforward' (Judy-BC-NoRecon) format, being 'well laid out' and 'easy to navigate' (Katrina-HR-ReconIntent), 'professional' (Mia-HR-ReconIntent), and 'friendly, not medically scary' (Marion-BC-NoRecon).

Personal Relevance and Utility

Personal Benefits and Irrelevancies

Participants reported that *BRECONDA* facilitated their decision making, providing reassurance that they had made the 'right decision' (Cathy-BC-Recon). Beneficial aspects included: 'evidenced information' (Eliza-HR-ReconIntent), 'details of...different surgical approaches' (Kristy-HR-NoRecon), 'advantages and disadvantages' of each surgical option (Ros-BC-NoRecon, Georgie-BC-NoRecon, Adele-HR-(NoRecon), 'photos' (Claire-HR-ReconIntent, Anne-HR-NoRecon) and 'visual aids' (Peta-HR-NoRecon), the other women's 'stories' (Kristy-HR-NoRecon, Millie-HR-ReconIntent, Joyce-BC-NoRecon), and values clarification components (Meredith-BC-Recon, Kristy-HR-NoRecon).

Some women thought they had access to *BRECONDA* 'too late' in their decision making process (e.g., Cathy-BC-Recon) and that it would have been most beneficial at an

earlier stage, before sourcing information elsewhere. Two HR women found the section about discussing feelings less relevant because they had been aware of their genetic status for years and, therefore, had already contemplated their feelings. Nonetheless, most women agreed that 'anything that was [irrelevant] I skipped over anyway' (Jo-HR-ReconIntent) due to the modular layout.

Appropriateness of Information

Most patients found that *BRECONDA* clarified the reconstruction options available, commending the information concerning the associated benefits and limitations (including aesthetics), case studies, recovery time, and the mental and emotional aspects of surgery.

Use of Values Clarification

Many women reported positively on the *BRECONDA* decision sheets, finding them 'useful' (Ros-BC-NoRecon), 'novel' (Sarah-BC-NoRecon), and 'scientific' (Gail-BC-Recon) in helping them clarify their thoughts about reconstruction. Some noted that the sheets facilitated their decision-making, whereas for others this section confirmed their original breast reconstruction decision.

Relaxation and Video Modules

Ten women reported using *BRECONDA*'s relaxation module, finding it 'useful' (Jo-HR-ReconIntent), 'relevant' (Grace-BC-NoRecon), and 'calming' (Sarah-BC-NoRecon). Reasons for not finding it helpful ranged from already using similar stress-management strategies or not feeling stressed (especially those considering delayed reconstruction, who were less time-pressured in making their decision). Many commented that the relaxation module may be useful for other women.

The 'Other women's stories' videos were considered 'helpful' (e.g., Katrina-HR-ReconIntent, Gail-BC-Recon) and 'valuable' (Judy-BC-NoRecon), feeling that the stories resonated with their own experiences of the reconstruction process. Those not finding them

helpful considered them too confronting, not personally relevant, and were more interested in ‘facts’ than other women’s opinions and ‘emotional baggage’ (Meredith-BC-Recon, Jenny-HR-NoRecon).

Introducing *BRECONDA*

Suitability for Target Population

All patients believed that *BRECONDA* is a useful resource for women considering breast reconstruction, emphasizing its importance in the provision of care for this population as an adjunct to, rather than replacement of, face-to-face consultation with HPs.

Recommend to Whom and When?

Patients ranged in their beliefs regarding which HPs should introduce *BRECONDA*, citing breast surgeons, general practitioners, and breast cancer nurses, and for HR women, genetic counselors. One woman suggested promoting *BRECONDA* through breast cancer consumer organisations, and two participants noted the importance of ensuring that women have access to it, irrespective of how it is distributed. Most reported that *BRECONDA* was beneficial to them either by helping them arrive at their decision and instilling them with confidence to speak to their doctor about surgical preferences, or confirming a previous reconstruction-related choice. All participants voiced a clear preference for *BRECONDA* to be introduced early in the treatment process, either upon initial cancer diagnosis or during the genetic testing process, to focus women’s attention towards reliable information and help deter them from browsing the ‘wrong sort of websites’ (Eliza-HR-ReconIntent).

Advantages and Suggested Improvements

*Advantages of *BRECONDA**

Participants valued having comprehensive information about breast reconstruction in one place, and felt reassured that the information is evidence-based, ‘backed by medical professionals’ (Jenny-HR-NoRecon). Patients commended the ‘interactive’ components of

the website (e.g., Kira-BC-NoRecon), such as the decision sheets, describing how these facilitated their decision-making. They remarked positively on the ‘holistic’ approach (Trudy-BC-NoRecon) providing information about emotions and coping strategies, in addition to surgical options.

Women noted that *BRECONDA* is easily accessible, a resource that can be used at home and accessed as often as required. It usefully encourages patients to prepare for time-limited surgeon consultations by formulating questions in advance.

Suggested Improvements

Most women did not report any disadvantages to using *BRECONDA*, however, some suggested that women may find the content confronting, or use the website as a substitute for face-to-face consultations. Others were wary that women may have difficulty setting aside time to complete the modules, or reading the content when fatigued during cancer treatment. A final concern was whether the website would be kept up-to-date. Suggested future improvements included further information about all reconstruction options available nationwide, the timeframe of the reconstruction options and the associated costs involved, and a broader range of women’s experiences.

Health Professionals

Four over-arching themes were identified from the HPs interviews: The need for *BRECONDA*; The impact of *BRECONDA*; Potential difficulties; and, Recommending *BRECONDA* to patients.

The Need for *BRECONDA*

All HPs were positive about *BRECONDA*, describing it as a ‘very useful tool’ (Natalie) that ‘covers the important issues’ (Jeff) and educates women about the different options available: ‘it helps them to make their decision about [whether and] what reconstruction was best for them’ (Sharon). HPs described how *BRECONDA* helps patients to ‘hone in on their options’

(Sharon), reducing feelings of being overwhelmed and confusion. None of the HPs were aware of any similar resource, and considered the interactive nature of the website particularly unique. They all voiced a need for a resource like *BRECONDA* for both cancer and genetic testing patients, as an adjunct to medical consultations. They noted it would be particularly useful in helping patients prepare questions about reconstruction that they could then bring to consultations, thus deriving benefit from medical appointments. One HP noted that *BRECONDA* had helped to reduce consultation times, allowing focused time to speak specifically about topics including recovery and expectations.

Impact of *BRECONDA*

Patient Feedback to Health Professionals

Four HPs received positive feedback from patients about their experiences of using *BRECONDA* during consultations, with patients indicating that it was 'really helpful' (Patricia) and 'useful' (Natalie). Women indicated that it 'made decisions a bit easier' and those who had already arrived at their decision noted that it 'reconfirmed' their decisions (Natalie). Some patients had commented positively on the other women's stories, while others noted the benefits of the website being tailored to the individual.

Observed Impact

Some of the HPs found it difficult to distinguish the specific impact of *BRECONDA*, yet others commented that their patients were 'happier' (Stephanie), 'definitely more informed' (Sharon), 'more knowledgeable' (Stephanie), and more advanced in their decision making. One HP observed that *BRECONDA* helped patients better prepare for consultations, that they asked more questions, and the session was more 'valuable' (Marina).

Potential Difficulties

None of the HPs foresaw any difficulties with making *BRECONDA* available to women considering whether or not to have breast reconstruction, but emphasized the importance of

maintaining current content that is relevant for different medical institutions. One HP (Jeff) acknowledged that it is the woman's personal decision regarding whether or not to view the website.

Recommending *BRECONDA*

All HPs would recommend *BRECONDA*, and stated that surgeons, breast care nurses, and other specialists are well-placed to recommend the website. Some believed it would be most appropriate to provide *BRECONDA* early in the woman's cancer journey to help them prepare for their initial consultation, whereas others advocated the time between cancer diagnosis and reconstructive consults as most suitable. One HP noted that timing should be tailored to each patient, given the potential for the images to be 'confronting' for some women (Patricia), and that for some patients *BRECONDA* may be less useful, particularly those without internet access or who are not 'technologically savvy' (Patricia).

Discussion

This qualitative study reported on women's experiences of using *BRECONDA* (11), and HPs' feedback regarding its impact on patient knowledge and decision-making about breast reconstruction. All interviewees endorsed *BRECONDA* as a useful resource for women considering whether or not to have reconstructive surgery. This is consistent with the findings of an RCT whereby *BRECONDA* led to women experiencing greater satisfaction with information and less decisional conflict (15).

Importantly, although women voiced a clear preference for receiving access to *BRECONDA* early in their breast cancer journey, they derived benefit irrespective of their decision-making stage. Those considering reconstruction reported that *BRECONDA* facilitated their decision-making, whereas those who had already made their choice stated that it confirmed their decision, supporting the broad suitability of *BRECONDA* for HR

women considering prophylactic mastectomy and those diagnosed with breast cancer. Both patients and HPs emphasized *BRECONDA*'s as an adjunct to clinical consultations. This is important as patients often feel poorly equipped to initiate breast reconstruction conversations with their health care team, and do not believe that credible reconstruction-related information is readily accessible (16).

A significant perceived benefit was that *BRECONDA* is accessible anywhere, including in the comfort and privacy of patients' homes, consistent with the benefits of web-based interventions generally (17-20). With approximately 90% of adult Australians having internet access (21), the web-based *BRECONDA* minimizes geographic and financial barriers to breast reconstruction information. By late 2016 *BRECONDA* will be publically available from the consumer organization Breast Cancer Network Australia, ensuring easy access to women and health professionals alike. The intervention content has been revised by an expert panel to reflect recent developments in breast reconstruction surgery. The expert panel will undertake regular reviews and updates to *BRECONDA* to ensure ongoing currency of the content. Suggestions by interviewees to provide more information about likely timeframes and costs of breast reconstruction have also now been incorporated.

Women responded positively to many *BRECONDA* components, including the photographs depicting different reconstruction outcomes. As these galleries are optional, users can tailor the website to match their information processing style (13), thus deriving maximum benefit from the decision aid. Many women commended the inclusion of 'Other women's stories'. Patient narratives have been shown to encourage greater information searching, and decision aids incorporating narratives have been perceived as more trustworthy, which may lead to greater use of the resource during decision making (22-24). The values clarification exercises facilitated women's decision making and the relaxation segments helped in managing stress during a process that is often fraught with anxiety and

uncertainty (6, 10). Prior research indicates that values clarification components lead to decisions in agreement with personal values (25), reduced decisional uncertainty (26), and perceptions that one is better prepared for decision making (27).

Study Limitations

Notwithstanding these findings, certain limitations should be considered. Participants self-selected to participate in interviews, and were relatively well-educated, which may have biased responses. However, the results are consistent with the RCT findings (15), demonstrating that *BRECONDA* is beneficial to many women considering reconstruction. The limited number of HPs who agreed to participate may represent a biased sample, and although participants were recruited nationwide, the generalisability of findings to non-Australian participants should be addressed in future research.

Clinical implications

These findings strongly support the use of *BRECONDA* as an adjunct to clinical consultations. It provides current, evidence-based information about breast reconstruction options, and exercises to promote stress management, values clarification, and guidelines for communication with family and health professionals.

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decision is actually made: evidence from a randomized controlled trial. *Med Decis Making*.

2012;32(4):616-26.

Accepted Article

Table 1. *BRECONDA* module content.

Module	Content
Introduction	Defining reconstruction.
Making decisions	How <i>BRECONDA</i> may facilitate decision-making.
Hints for making a decision	Questions women should ask themselves to aid decision-making.
What reconstruction choices do I have?	Reconstruction options including implant, flap, contraindications, eligibility.
When can I have reconstruction?	Immediate versus delayed considerations.
What to expect	Likely look and feel of reconstructed breast, recovery time.
What else should I know before making a decision?	Perceived advantages/disadvantages: reconstruction versus no reconstruction, implant versus flap, immediate versus delayed.
What might go wrong?	Possible complications.
My feelings about the reconstruction decision/ Tips for managing my feelings	Strategies for recognising and reducing stress
Family issues	Strategies for communicating with family members about reconstruction decisions.
Other people's stories	Video interviews of other women's experiences of deciding whether or not to undergo reconstruction

What do I think about
reconstruction?/What type of
reconstruction do I prefer?

Interactive values clarification activities

Who to contact for more
information/Conclusion

Contact information for healthcare professionals, support services.

Table 2. Experiences Using *BRECONDA*

	Theme	Subtheme	Illustrative Quotation
Patients	Overall impressions/aesthetics		I thought it was fantastic and I wish I had seen it a lot sooner. I was really impressed because it reinforced to me that the decision I made was the right one (Laura-BC-NoRecon).
			A useful starting point, good at the beginning of your journey (Melanie-HR-ReconIntent).
	Personal relevance/utility	Personal benefits and irrelevancies	It really did confirm my decision...it's a huge decision to make, and by asking the questions...it really focused on what was important to me and what wasn't so important (Laura-BC-NoRecon).
			There was something there about how it can affect thought and feelings...this wasn't really relevant to me...because I grew up knowing that there was a risk of breast cancer (Mia-HR-ReconIntent).
		Appropriateness	I thought I would just be interested in the implant, but the other options that were

of information	presented I thought they sound just as good. I didn't know there were other options (Ashley-HR-ReconIntent).
Use of values clarification	<p>I found those really quite useful...it helped me get all the different bits of information clear...and my own feelings clear in my head (Meredith-BC-Recon).</p> <p>I was surprised...at first I wrote down it's too personal a thing to be decided mathematically. And then when I did go through those [values clarification] sheets I found that it was quite good the way you presented back the information- you took the question and then you presented back what I was saying when I answered that question (Georgie-BC-NoRecon).</p>
Relaxation and videos modules	<p>I don't know how I would have coped without having gone away and done the relaxation (Meredith-BC-Recon).</p> <p>Getting information scares me...That's why I liked the videos because you can select the information you want to listen to, because it was all broken down into little questions (Joyce-BC-NoRecon).</p>

		It's how somebody would speak to you...totally unscripted, just very nice (Isla-BC-NoRecon).
Introducing <i>BRECONDA</i>	Suitability for target population	It's a good information source because you go on the internet and there's stuff that's all over the place...something like this is a bit more reputable and you can trust the information (Peta-HR-NoRecon).
	Who and when to recommend	I think having access to all the information up front is better...If you're not ready to deal with it then you can say "I'm not ready to deal with it", but if you want to deal with it at least the information's available (Katrina-HR-ReconIntent).
Advantages/suggested improvements	Advantages	Knowledge is power...to have as much knowledge about something that relates to their body without having to filter through Google...nonsense where you don't know the source...that's a huge thing. That's the uniqueness about your program. It's the information, it's medically based and research based at university standard and yet it's about real people and real situations (Millie-HR-ReconIntent). Certainly the primary one is information gathering because it's a big hole – you're

wonderfully filling a big void with that information (Isla-BC-NoRecon).

It helps you to make an informed decision at a time when there's a lot of emotions involved...it just really focuses on what really is important in your life (Laura-BC-NoRecon).

You can go through it in your own time (Peta-HR-NoRecon).

The advantages is its accessibility to anyone anywhere... the privacy is there, people can....educate themselves so they can walk into their surgeons room knowledgeable and knowing what questions they want to ask (Judy-BC-NoRecon).

Suggested
improvements

I can't see any disadvantages unless people use it and don't speak to their doctors (Eileen-BC-ReconIntent).

There's a lot of information on there and I was personally going through chemo at the time and had 'chemo brain'...but I would say that the pros outweigh the cons (Meredith-BC-Recon).

Health The need for
Professionals *BRECONDA*

It's almost like a consultation with the doctor to...help them make their decision about what reconstruction was best for them. Or to confirm...the way they were already thinking was the best for them (Sharon).

If they've heard something about it [reconstruction] before and it's not a totally new concept they can get much more out of my consultation –otherwise everything is so new and a bit frightening' (Jeff).

Impact of
BRECONDA

Patient feedback

They usually say it's been really helpful (Patricia).

They mentioned it's a very useful tool (Stephanie).

They really comment that it's good to be able to see the bigger picture of the choice that you've got (Patricia).

Observed impact It helped reconfirm to a lady what she might have already been thinking was right for her (Sharon).

Potential difficulties

Constantly evolving surgeries, need to keep up-to-date (Natalie).

Recommending

I think fairly early on. Women who may be looking at a delayed reconstruction may look at it later but the fact that is there as an option for them to look at early (Sharon).

BRECONDA
