Psycho-Oncology
Psycho-Oncology **23**: 835–838 (2014)
Published online 6 February 2014 in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.3498

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BRECONDA: Development and acceptability of an interactive decisional support tool for women considering breast reconstruction†

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Received: 13 August 2013
Revised: 12 January 2014
Accepted: 15 January 2014

†Some of the findings of this study have been presented at the 9th International Psycho-Oncology Society (IPOS) World Congress, London, UK (16–20 September 2007), Appearance Matters 3 Conference, Bristol, UK (1–2 July 2008) and the 46th APS Annual Conference, Canberra, Australia (4–8 October 2011).

Dear Editor,

Many women diagnosed with breast cancer or ductal carcinoma *in situ* (DCIS), and those at hereditary breast cancer risk, face the decision of whether to restore their breast shape following mastectomy. Increasingly, women are considering immediate or delayed breast reconstructive surgery. Reconstruction can lessen the negative psychosocial impact of mastectomy; however, it is not universally beneficial (1), with many women experiencing decisional regret following surgery (2).

Deciding whether to undergo reconstruction can be difficult and relies on personal preferences (1). Patient support typically focuses on information provision, which alone is relatively passive, may not encourage women to actively process information and identify their personal preferences, and may increase indecision, particularly for women experiencing distress prior to commencing breast cancer treatment (3). Existing educational aids detailing reconstruction options have been shown to increase knowledge and patient satisfaction. However, these are limited in that they do not focus specifically on the complex reconstruction decision, have an underlying theoretical basis, account for individual information processing preferences, detail the outcomes of reconstruction options, and address the role of emotions in decision making (e.g. 2, 4, and 5). Therefore, a rigorously developed, theoretically guided, interactive intervention that accounts for cognitive and emotional dimensions of decisions about breast reconstruction is warranted (4).

Because computer usage can enhance active involvement in making decisions, and most women considering breast reconstruction are computer users (3), we developed a computer-based interactive decisional support tool, *b*reast *recon*struction *d*ecision *a*id (*BRECONDA*). This paper outlines the development and user acceptability of *BRECONDA*. All investigations were approved by the relevant institutional Human Research Ethics Committee.

BRECONDA development

Needs analysis

The development of *BRECONDA* incorporated International Patient Decision Aids Standards criteria (5) and was underpinned by psychological theoretical models (6,7) focussing on the role of cognitive and affective representations held by women as determinants of their health-related decision making. Decision aid content was informed by research (2) highlighting the need for more information about available options and possible consequences of these alternatives, the broader breast cancer literature, and from consultations with a multidisciplinary advisory team (representing surgery, radiation oncology, medical oncology, nursing and women with breast cancer). Feedback from these consultations informed storyboard creation, which addressed site structure, navigation, aesthetics and content, as described in the following text. *BRECONDA* is optimised for use with either PC or Macintosh computer formats, including compatibility with personal tablet-type devices.

Table 1. *BRECONDA* module content

Module	Content description
Introduction	What reconstruction is and who can undergo this procedure.
Making decisions	*BRECONDA* content and how it 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-based reconstruction (tissue expanders and types of implants), autologous flap reconstruction (latissimus dorsi muscle flap, transverse rectus abdominis myocutaneous pedicle and free flaps, deep inferior epigastric perforator flap), and skin-sparing and nipple-sparing mastectomy (one-stage and two-stage procedures). Also, contraindications and general eligibility criteria.
When can I have reconstruction?	Immediate versus delayed reconstruction and factors influencing the type and timing of reconstruction offered.
What to expect?	How the reconstructed breast will look and feel, reconstruction results and expected recovery time.
What else should I know before making a decision?	Perceived advantages and disadvantages of reconstruction versus no reconstruction, implant versus flap and immediate versus delayed reconstruction.
What might go wrong?	Possible complications for implant (e.g. wrinkled appearance of breast, capsular contracture following radiation therapy and possible need to replace implant over time) and flap-based (e.g. muscle weakness and flap failure) reconstruction options and estimated complication rates.
My feelings about the reconstruction decision/tips for managing my feelings	Emotions the user may experience and strategies for recognising and reducing stress (e.g. progressive muscle relaxation and imagery techniques).
Family issues	Strategies for communicating with family members about reconstruction decisions.
Other people's stories	Video segments of other women's experiences of deciding whether or not to undergo reconstruction. Each interviewee represents a different experience (i.e. diagnosis, reconstruction versus no reconstruction, type of reconstruction, and post-surgical complications), to minimise biassed responses to decision making.
What do I think about reconstruction?/ What type of reconstruction do I prefer?	Presents user with a value and asks them to indicate the relative importance of this value. A summary is presented in tabular format, colour coded to reflect the personal importance of each value.
Who to contact for more information?	Contact information for healthcare professionals and support services. Provides additional websites for further information.
Conclusion	Reminder to make decisions about reconstruction in consultation with a doctor/healthcare professional.

BRECONDA, breast reconstruction decision aid.

Module development

BRECONDA is organised in a menu-driven modular format, with each module addressing an identified area of need for women considering breast reconstruction (see Table 1 for module content). A glossary is provided to explain technical terms, and the overall readability of *BRECONDA* is 8th grade level. Animations illustrate surgical techniques, and photographs depicting outcomes from various breast reconstruction procedures are shown in separate links. Interviews with a plastic surgeon specialising in breast reconstruction (TL) are also included via separate links to provide expert commentary about surgical options. Institutional ethics approval was obtained for the conduct of all videotaped interviews and use of patient photographs for galleries.

BRECONDA is self-paced, and it is estimated to take the average user 45 min to review all sections. Following initial development, consumers in two focus groups representing women who previously had ($n = 8$) or had not ($n = 7$) undergone reconstruction provided feedback on the content and presentation of the decision aid. Minor adjustments were then made, including additional detail about flap-based options. These women also provided feedback using Likert-type scale ratings (5 = high; 1 = low), which indicated the decision aid to be very useful ($M = 4.82$, $SD = 0.41$), relevant ($M = 4.36$, $SD = 0.53$) and providing high quality information ($M = 4.36$, $SD = 0.67$). *BRECONDA* was then reviewed, edited and tested by the researchers, and audio narration was incorporated into the final version that was subjected to the pilot feasibility and acceptability study outlined in the succeeding texts.

Preliminary assessment of user acceptability

Following *BRECONDA* development, a mixed-methods pilot study was conducted to determine user acceptability. Women who were (1) diagnosed with invasive breast cancer or DCIS and scheduled to undergo mastectomy, (2) eligible for breast reconstruction, (3) English literate, (4) over 18 years of age, and (5) had computer access were identified through the Westmead Breast Cancer Institute and invited to participate in the study. Participants ($N = 28$) received access to the *BRECONDA* programme for 6 weeks following completion of an initial demographic/medical characteristics questionnaire, in addition to standard clinic care entailing consultations with medical staff. Six weeks after accessing *BRECONDA*, participants responded to eight user acceptability questions (e.g. 'How useful was the decision aid?') using a 5-point scale.

Participants were also invited to participate in a telephone interview (approximately 30 min) to discuss their experiences using *BRECONDA*. Interviews were audiotaped and transcribed verbatim, and final transcriptions were reviewed

DOI: 10.1002/pon

for accuracy. Content analysis (9) was used to analyse the transcripts. Inter-rater agreement was achieved by having two researchers first independently code participants' responses, then meet to discuss, specify and refine identified categories. Each researcher then independently reread responses, using specified codes to identify themes, and then met to discuss potential discrepancies in coding outcomes, and to obtain consensus. Finally, the lead investigator (KS) independently reviewed the transcripts, with no new themes identified from this analysis.

Pilot study quantitative measures

Demographics and Medical History including age, education level, marital status, country of birth, cancer stage, treatment and breast reconstruction status, and breast cancer family history were documented.

User Acceptability of BRECONDA was assessed at follow-up using eight statements rated on a 5-point Likert scale (1 = strongly agree to 5 = strongly disagree), with a higher score indicating greater user acceptability ($\alpha = .93$).

Results

Participants who ranged in age from 31 to 64 years ($M = 47$, $SD = 7.90$) were mostly Australian born (57%), married (86%) and high school level educated (69%). The most commonly reported tumour type was Grade III (39%), with 25% Grade II, 15% Grade I and 7% DCIS. At baseline, two women anticipated needing adjuvant radiation and 12 women anticipated undergoing chemotherapy.

All participants accessed the intervention and reviewed all modules. Participants' ratings of *BRECONDA* demonstrated very high user acceptability ($M = 4.10$, $SD = 0.79$), as well as high rating of usefulness ($M = 3.97$, $SD = 0.80$), ease of use ($M = 4.58$, SD = 0.81) and sufficient information ($M = 3.89$, $SD = 0.59$).

Thirteen women (four of whom had chosen breast reconstruction) opted to participate in a telephone interview. Interview data resulted in two themes (Table 2). The first referred to *BRECONDA* as 'a useful resource'. Women described how they benefitted from reading about reconstruction options and viewing the testimonials and photo galleries. They commended the 'clear' and 'professional' layout and described the ability to tailor the resource to their own preferences as 'invaluable'. The second theme referred to *BRECONDA* providing 'support for a difficult decision'. Women who had not finalised their decision explained how *BRECONDA* helped them to consider what was personally important, and those who already preferred reconstruction described how it made them feel more secure in their decision. Support was maximised by listening to patient testimonials and accessing *BRECONDA* at diagnosis.

Discussion

The *BRECONDA* theoretically guided, interactive decision aid builds upon other available tools in the breast reconstruction context (2,8,10) in that it is the first to address the role of cognitions *and* affect in the reconstruction decision-making process. Results suggest a high level

Table 2. User acceptability themes and supporting quotations from thematic analysis of semi-structured interviews

Theme	Subtheme	Supporting quotations (Participant ID)	Decision outcome
A useful resource	Reconstruction options	Good balance between different choices (4)	No reconstruction
		Very enlightening and an eye opener (2)	Reconstruction
	Visual layout and accessibility	It was very professional (9)	No reconstruction
		There's a lot of very good information and it was presented very clearly (6)	Reconstruction
	Tailored use	Being able to review it in my own time, when the time is right is invaluable (12)	No reconstruction
		I picked what was appropriate for me out of it (11)	Reconstruction
	Testimonials	Its' very good to hear normal ladies who have gone through the same thing (3)	No reconstruction
		Liked the really personal experience from the women and how they felt about it (6)	Reconstruction
	Photo galleries	Can see what people have gone through (5)	No reconstruction
		The information was concise, the photographs were good (2)	Reconstruction
Support for a difficult decision	A starting point for considering options	Sometimes… you don't know where to start, so those focus questions did assist (6)	Reconstruction
	Support through testimonials	I felt better about myself after hearing the other women's stories… I felt more positive (1)	No reconstruction
	Support maximised by accessing *BRECONDA* at diagnosis	It would be good to give it to the patient and say 'this is here for you to look at when you're ready' (10)	No reconstruction

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DOI: 10.1002/pon

of user acceptability and ease of-use of the intervention; these are critical features that will determine the likely translation of *BRECONDA* into clinical practice and home-use settings. Interview data indicated participants perceived *BRECONDA* to be well-balanced, informative and beneficial to the decision-making process. The values clarification components, patient testimonials and photo galleries were highly valued by all interviewees. *BRECONDA* was perceived as being helpful by assisting the women to prepare questions for their surgeon and making them feel more secure in their decisions. The capacity to weigh up the benefits and costs of available options, and to clearly understand this comparison of options, is a key aspect of informed decision making (5). These findings indicate the potential for *BRECONDA* to facilitate decision making amongst women considering breast reconstruction.

Although this research presents preliminary support for what appears to be a promising breast reconstruction decision aid, some limitations should be considered. First, some participants cautioned that consideration should be given to the timing of when the tool is made available to women. This is a valid point, but one which should be weighed against the importance of making information available to women eligible for immediate reconstruction. Second, while this study focused on women scheduled for mastectomy, *BRECONDA* has been designed to be equally applicable to those women who are undergoing a lumpectomy who may also require a mastectomy in the future. Third, baseline levels of anxiety and depression were not monitored in this sample; future studies will need to assess these at baseline and follow-up to assess the efficacy of the intervention. Finally, the sample was drawn from one large multidisciplinary clinic; *BRECONDA* should be assessed across various breast clinics to determine its applicability. A multicentre randomised controlled trial (ACTRN 12609000363280) is underway to explore the longer-term impact of *BRECONDA* across women from a range of specific surgical situations and clinic types.

Acknowledgement

This research was co-funded by the National Breast Cancer Foundation and Cancer Australia, and Macquarie University. The Westmead Breast Cancer Institute receives funding from the NSW Department of Health.

Key points

- Deciding whether or not to undergo breast reconstruction after mastectomy can be very difficult.
- *BRECONDA* is a new theory-guided, computer-based interactive intervention to help women make this choice.
- Participants in a mixed-methods acceptability study (n = 24) rated *BRECONDA* very highly in terms of acceptability and ease of use. Interview data indicated that they perceived it to be well-balanced, informative and beneficial to the decision-making process and that it helped them feel more secure in their decision and to prepare for consultations.
- *BRECONDA* has potential to assist mastectomy patients in their decisions regarding breast reconstruction.
- A randomised controlled trial is now exploring the longer-term impact of *BRECONDA* across a wide range of breast surgical clinics, to delineate the specific components of this intervention that provide greatest benefit.

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