

Short communication

My Changed Body: Background, development and acceptability of a self-compassion based writing activity for female survivors of breast cancer

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ABSTRACT

Objective: To assess consumer and health professional user acceptability of a web-based self-compassion writing activity to minimize psychological distress related to the negative impact of breast cancer on body image.

Methods: “My Changed Body” is a web-based writing activity that combines expressive writing with a self-compassionate approach that focuses on cancer-related adverse body image alterations. Breast cancer survivors ($n = 15$) and health professionals ($n = 20$) provided feedback via a survey regarding the appearance, organization and content of the website and writing activity.

Results: Both breast cancer survivors and health professionals rated the website highly in terms of design, layout and content. Participants commented positively on the website's clear wording, appealing design and ease of navigation. Suggestions for improving the website included simplifying the instructions for the writing activity and allowing participants' writing to be saved.

Conclusion: Results from both breast cancer survivors and health professionals suggest a moderate to high level of user acceptability and positive ratings for the overall impression of the website.

Practice implications: Self-compassion based writing interventions can be translated to a web-based self-administered activity for body image difficulties after breast cancer treatment in a format that is acceptable to consumers and health professionals.

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1. Introduction

Breast cancer treatment can bring negative body changes, poor adjustment and ongoing psychological distress [1,2]. Central to this is the reality of change and loss regarding certain aspects of a woman's appearance and function. In addition, some women develop lymphoedema as a consequence of their treatment, characterized by severe swelling of the affected area, resulting in the need to wear visible compression garments [3], and consequently, further challenging the woman's body image [4–6]. The Cash theoretical model suggests that adverse appearance changes will increase the discrepancy between an individual's ideal and perceived body image, making her more likely to experience body image-related distress [7]. Unfortunately, body

image problems are not always adequately recognized or addressed, with evidence of unmet needs [1,2,7–9].

Many existing interventions designed to address body image difficulties after breast cancer treatment focus on couple or group formats within clinic settings [7], and have limited effectiveness for younger women [10]. Such approaches can be limited by demand for staff, cost, and the need to attend in-person, potentially resulting in poor accessibility [11]. There is a need for more interventions addressing body image distress that employ novel approaches, such as writing activities [7], that can be delivered in an individual, accessible format [12,13] which may especially benefit those with an increased reliance on online materials [14].

Expressive, unstructured writing has been used in the field of psychology [15] and oncology [16] to assist individuals who are experiencing distress. Writing interventions are a simple and inexpensive way to provide support, with evidence of physical and psychological benefits [15–17]. To date, unstructured writing has not been used to address cancer-related body image disturbances,

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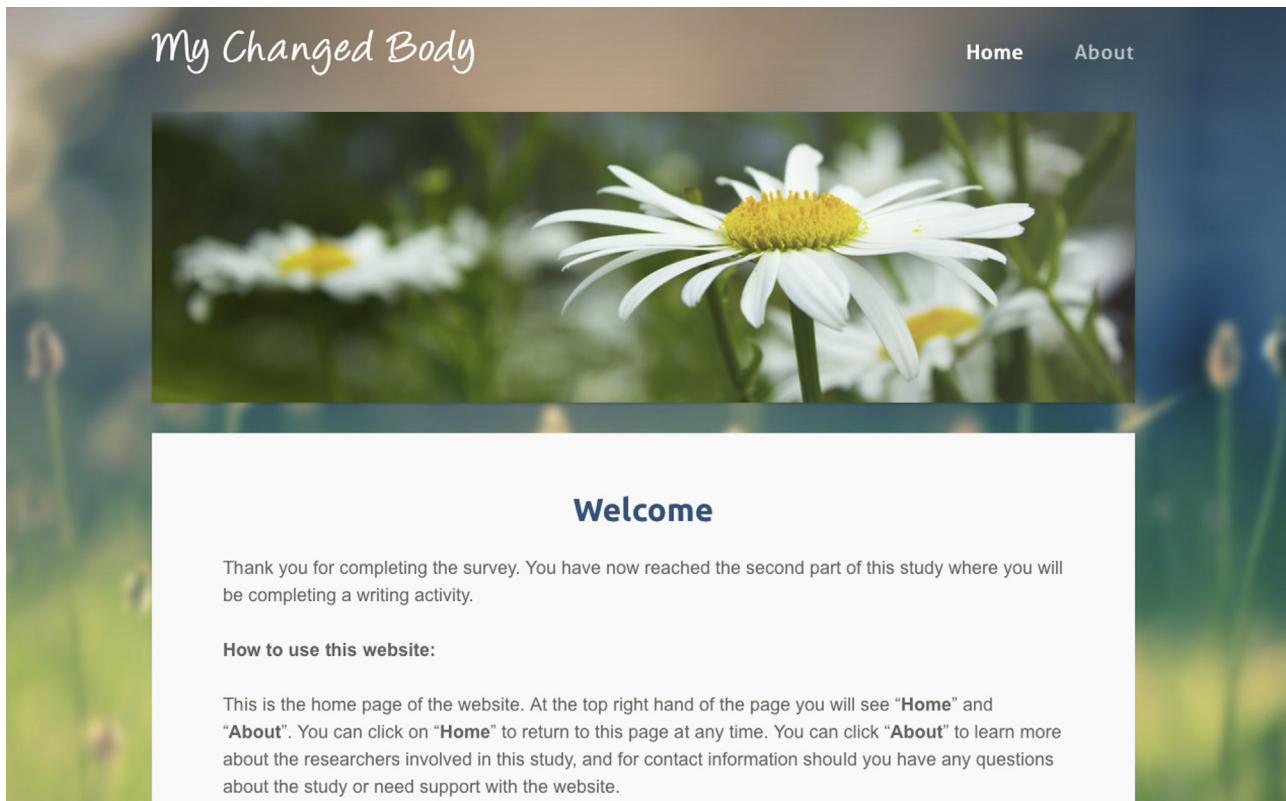


Fig. 1. Screenshot of the My Changed Body website 'Welcome' page.

possibly as despite its many strengths, limited effectiveness in addressing body image concerns has been demonstrated by unstructured expressive writing in a variety of contexts [18–22]. Alternatively, self-compassion based approaches may be uniquely placed to address the difficulties associated with body image disturbance [23]. Thus, a need to investigate this possibility in the cancer context is indicated.

Self-compassion is a promising approach to assist with difficult life experiences, and has been linked to lower psychopathology [24]. It relates to a woman's ability to approach herself with kindness, a sense of mindful awareness about her circumstances, within a context of common humanity (i.e., knowing difficulties and loss are normal part of human life) [25]. A woman who is higher in self-compassion is likely to display less self-criticism, a more accurate appraisal of her losses, as well as the ability to place her problems within the broader context of life [25,26]. Furthermore, there is evidence that self-compassion is associated with decreased body image disturbance and psychological distress in breast cancer survivors [2], therefore making it a potentially valuable aspect to address.

In sum, combining unstructured writing with self-compassion-based prompts may provide dual benefits of decreasing distress and body image disturbance related to breast cancer treatment and its outcomes in a single intervention.

2. Methods

2.1. My Changed Body intervention development

2.1.1. Website and content development

My Changed Body is a web-based writing intervention designed to address body image concerns arising from breast cancer and lymphedema. It entails a self-paced writing activity that is

estimated to take approximately 30 min to complete. The website provides "Welcome" page user instructions (Fig. 1) followed by information about the developers of the website. The remaining section comprises the intervention writing activity instructions, prompts and writing text boxes (Fig. 2). Six writing prompts are provided: (1) an introductory unstructured writing section where individuals write about a negative body image experience according to a modified Pennebaker [15] writing prompt; (2) treatment of one's body with kindness; (3) kind advice to oneself; (4) connection with others who experience difficulties with body image; (5) awareness of one's circumstances and reactions in a broader context; and, (6) a self-compassionate letter to the writer that acts as a summary of the most salient points of self-compassion as applied to one's own situation. Thus, the intervention user addresses self-kindness, common humanity and mindful awareness, as outlined by self-compassion research [25].

2.1.2. Consultation with consumers and health care professionals and assessment of user acceptability

Following website development, consumers (breast cancer survivors) and health professionals experienced in breast cancer were given access to the website and provided feedback via an online survey regarding their perceptions of the website. Consumers and health professionals were recruited to ensure that we gathered perspectives from the population of women who would be using the intervention, as well as from health professionals who would be referring women to the intervention. Health professionals were recruited from the researchers' networks via an online advertisement. Consumers were recruited via the consumer-based breast cancer organization, the Breast Cancer Network Australia.

Participants were sent a link to the study website and asked to interact with all web pages before completing the online user

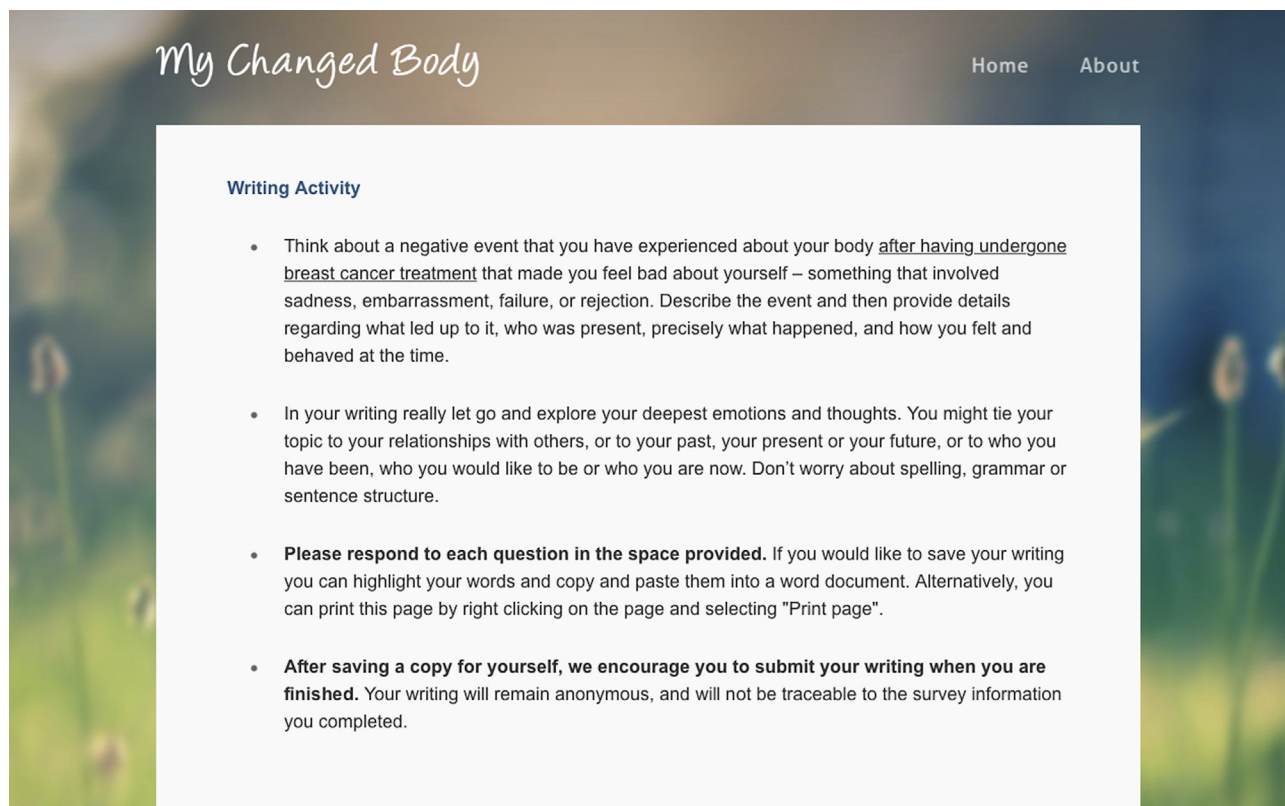


Fig. 2. Screenshot of the My Changed Body website writing activity page.

acceptability survey (both activities were estimated to take 20 min to complete). Feedback was provided for 18 statements regarding the overall impression of the website (e.g., “The website appeals to me”), website layout and design (e.g., “The website is easy to navigate”) and website information and content (e.g., “The information contained in the website is clear”) on a 5-point Likert-type scale (1 “strongly disagree” to 5 “strongly agree”). Demographic information and self-rated experience with websites was also collected, as well as providing free text sections for qualitative comments. In addition, the health professional survey collected the area of professional expertise, while the consumer survey collected information on the participants’ breast cancer diagnosis, treatment and diagnosis of lymphedema.

3. Results

A total of 20 consumers and 15 health professionals participated in this study. Participant characteristics are displayed in Table 1. The mean rating for the overall impression of the website (5 items; $\alpha = 0.81$) was 3.97 (SD = 0.78) for consumers and 3.96 (SD = 0.69) for health professionals. The mean rating for the website layout and design (7 items; $\alpha = 0.95$) was 4.05 (SD = 0.69) for consumers and 3.98 (SD = 0.57) for health professionals. The mean rating for the website information and content (6 items; $\alpha = 0.89$) was 3.96 (SD = 0.81) for consumers and 3.86 (SD = 0.56) for health professionals. A series of *t*-tests indicated that there were no significant differences between consumers’ and health professionals’ ratings of the website user acceptability ($p = 0.100$ – 0.900).

Thematic analysis was used to analyze the qualitative feedback provided by participants (Table 2). To achieve inter-rater agreement two researchers first independently coded participants’ responses, and then together discussed and refined identified themes.

Table 1
Participant characteristics.

Consumers (n = 20)	M (SD) or %
Age	58.22 (9.01)
Breast cancer diagnosis	
Early breast cancer	65%
Secondary breast cancer	0%
Ductal carcinoma in situ (DCIS)	30%
Lobular carcinoma in situ (LCIS)	5%
Breast cancer treatment	
Surgery	96%
Chemotherapy	57%
Radiation therapy	78%
Hormonal treatments	91%
Breast reconstruction surgery	30%
Lymphoedema diagnosis	22%
Level of experience using online activities provided through a website	
None or very low level of experience	0%
Low level of experience	9%
Neutral – neither high nor low level of experience	65%
High level of experience	26%
Very high level of experience	0%
Health Professionals (n = 15)	
Age	47.07 (8.63)
Number of years working in oncology	12.93 (8.06)
Occupation	
Nursing	27%
Physiotherapy	20%
Occupational therapy	20%
Psychology	7%
Other	26%
Level of experience using online activities provided through a website	
None or very low level of experience	7%
Low level of experience	0%
Neutral – Neither high nor low level of experience	33%
High level of experience	53%
Very high level of experience	7%

Table 2

User acceptability themes and supporting quotations from thematic analysis of qualitative feedback.

Theme	Supporting quotations from health professionals (HP) and consumers (C)	Response to feedback
Comments on what participants liked about the website.		
Clear wording	HP The text was clear. C Straightforward explanations.	No changes.
Appealing design	HP I really liked the color scheme and design – felt really warm and inviting. C Appealing, user friendly and a useful platform to express ideas, thoughts, emotions encountered on the BC journey.	No changes.
Easy to navigate	HP The website is easy to navigate and not too cluttered or busy looking. C I liked that the website was simple and easy to navigate.	No changes.
Participants' suggestions for improvements to the website.		
Allow writing to be saved.	HP: It would be so great if after the women completed the sections of the writing task, 'print' button would be available, so they can print/save their answers for later use. C: Also I was confused by the message that the text written wouldn't be saved . . . However, it does seem somewhat pointless for people to write/type/spend time on that for the words not to be considered important.	Option provided to participants to print their writing and/or save it to their desktop computer.
Simplify the instructions	HP: I found the instructions somewhat wordy and confusing. C: The instructions are a bit wordy.	Instructions simplified and bullet points were used to break up the text to make it easier to read.
Negative focus	HP: I found it confronting being asked to write about negative experiences upfront for both the non-lymphedema and lymphedema clients. C: I found the early and repeated emphasis on negative feelings really off putting.	Invitations to participate in the pilot evaluation study will specify that the writing intervention includes discussing "negative events" to ensure that women have accurate expectations of what participation will involve.

4. Discussion and conclusion

4.1. Discussion

My Changed Body is a theoretically-based [7,15,16] web-based writing intervention developed to assist breast cancer survivors with body image disturbance resulting from cancer treatment. Results from both breast cancer survivors and health professionals suggest a moderate to high level of user acceptability and positive ratings. Participants reported favorably on the website's clear wording, appealing design and ease of navigation. Suggestions were made by study participants for improving the website, including simplifying the instructions and allowing participants to save or print their writing.

4.2. Limitations

These findings provide preliminary support for the use of this body image-focused intervention. However, a few limitations should be noted. Two participants expressed concerns about the principally negative focus of the writing activity. It is possible that they were expecting positively-focused cognitive-behavioral self-esteem enhancing activities [7]. To ensure that participants have accurate expectations of the My Changed Body intervention, information about the activity has been revised to include the discussion of negative events and body image concerns. Body image disturbance, self-compassion and distress were not measured in this study, so it is not possible to determine if these factors influenced participants' feedback. Finally, consumers were recruited from an online organization; therefore, women in this study may be more experienced with websites and more motivated to participate in research compared with the general breast cancer population.

4.3. Conclusion

Results suggest a moderate to high level of user acceptability for the overall impression of the website as well as layout, design and

content. A randomized controlled evaluation study is now underway to assess the impact of the intervention on self-compassion and body image disturbance in breast cancer survivors.

4.4. Practice implications

Self-compassion based writing interventions can be translated to a web-based, self administered activity for body image difficulties after breast cancer treatment in a format that is acceptable to consumers. This approach may also be considered for other situations where psychological distress, particularly for body image, is problematic and a self-paced, non-therapist delivered intervention is indicated.

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Conflict of interest statement

All authors declare no conflict of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institution: Macquarie University Human Research Ethics Committee (Medical Sciences), Reference No. 5201401083, Title "Online Self-Compassion Activity for Body Image in Breast Cancer Survivors".

Informed consent: Informed consent was obtained from all individual participants included in the study.

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