Experiences of Parenting Following Breast Cancer

Jodie Scott

This thesis is submitted in partial fulfilment of the

Honours degree of Bachelor of Psychology

School of Psychology

University of Adelaide

October 2018

Word count: 8,987

Table of Contents

List of Tables and Figures

Tables

Figures

Abstract

Whilst a body of research exists detailing the negative psychological effects of a life crisis such as a breast cancer diagnosis, few have explored the positive outcomes of such an event. It is known that trauma can also serve as a powerful catalyst for posttraumatic growth. This qualitative study aimed to explore the parenting experiences of women diagnosed with breast cancer in the last 2 to 10 years, with at least one child under the age of 18 at the time of diagnosis. Open-ended questions about parenting their dependent child in the context of cancer were posed to the 15 participants, guided by the relevant literature. Thematic analysis was used to identify patterns in the data, reflecting both the positive and negative emotional parenting experiences. While most participants reported experiencing at least some negative impacts on their parenting, all reported positive impacts. Two negative themes were identified: difficulty maintaining role; and fear for the future. Seven positive themes were identified: generativity; maintaining normality; togetherness; altered priorities; mutual empowerment; gratitude; and supportive others. Novel findings of the study include generativity – qualities the mother's cancer experience had instilled in her children, or character traits she was able to role model. Physical and emotional support was identified as being integral to the growth process. Whilst cancer should not be viewed as simply a precursor to growth, it is clear that it can prompt positive change including enhancing the parent-child relationship.

Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

Jodie Scott

October 2018

Acknowledgements

I would sincerely like to thank my supervisors on this project – Professor Deborah Turnbull and Dr Jeneva Ohan, for their generosity in sharing their time and expertise. I feel fortunate to have worked with you both this year and value the mentorship, guidance and constructive feedback you have given.

A very special thanks goes to my husband, David, for his love, support and belief in me, and for all the sacrifices he has made to enable me to study. I am truly grateful. To my daughters, Eliza and Clementine, who inspire me everyday – thank you for giving me some perspective. Thank you also to my family, for your support and interest in my research. To my friends who I have neglected for the past few months – I am sorry, and I thank you for your patience and support. Now we can drink all the coffee and have all the lunches!

I am also grateful to Julia for her recruitment and interview advice during the initial stages of the study, to Belinda and Nicole for their advice on phrasing of questions, and to Katrina for helping to promote the study. Many thanks also to fellow student Chevaun for offering to promote the study in her workplace, and Ella for reciprocal encoding of transcripts. Also to my fellow thesis group and honours students, whose friendship, advice and encouragement I value. Many thanks to Lisa and Breast Cancer Network Australia (BCNA)* for their invaluable support in recruiting participants for this research. Last but not least, I would like to thank all the participants in this study, for their meaningful contribution in sharing their thoughts and experiences on the topic.

* Participants in this research were recruited from Breast Cancer Network Australia's (BCNA) Review and Survey Group, a national, online group of Australian women living with breast cancer who are interested in receiving invitations to participate in research. We acknowledge the contribution of the women involved in the Review and Survey Group who participated in this project.

CHAPTER 1

Introduction

1.1 Overview

Adverse life experiences, such as a cancer diagnosis, can have a high psychological impact (Ochoa, Casellas-Grau, Vives, Font, & Borràs, 2017). Previously, much attention has focused on research detailing the negative psychological effects of trauma, yet these powerful negative consequences can also serve as catalysts for positive personal growth (Janoff-Bulman, 2004). The term ‘posttraumatic growth’ refers to the positive psychological changes that can occur after suffering a traumatic event (Tedeschi & Calhoun, 1995). Positive psychological outcomes include changes in self-perception, in interpersonal relationships and in life philosophy (Tedeschi & Calhoun, 1996).

It is thought that positive and negative effects of trauma often co-exist within the same person (Aldwin, 1994). In their study on trauma survivors, this was apparent when almost all participants reported negative effects, yet 60% also perceived positive outcomes. It appears that when people perceive benefits, they do not deny the difficulties (Aldwin, 1994). Respondents often do not expect a positive personal change to co-occur with their cancer (Skeath et al., 2013), but discover personal abilities and resources that, whilst not anticipated, became highly useful in facing other challenges unrelated to their cancer. It should be emphasised that traumatic events should not be viewed as simply precursors to growth, but as circumstances that typically produce psychological distress and anguish in sufferers.

Whilst there is some evidence of the existence of posttraumatic growth in cancer sufferers, few studies have explored how this growth may influence a mother’s relationship with her children. Undoubtedly, a diagnosis of breast cancer can prompt a mixture of emotions. Within parenting, previous research suggests that the experience may initiate changes in thinking and behavior that enhance the closeness and authenticity of relationships with their children (Bekteshi & Kayser, 2013), or change a woman’s perception of herself as a mother. Many cancer sufferers report that the experience drew them closer to their children (Bekteshi & Kayser, 2013) and, as they considered their own survival, often emphasised the need to make every moment count (Walsh, Manuel & Avis, 2005). Some mothers reported becoming more emotionally available to their children, more positive, and more oriented in the present. Many were able to transform the stressful cancer experience into one from which they grew emotionally in the relationship with their children (Bekteshi & Kayser, 2013). Whilst many experienced positive outcomes with regard to their relationships, emotions such as fear, anger or guilt were often expressed (Bekteshi & Kayser, 2013). It is also clear that many experience a huge loss of quality time with their children during their cancer treatment, and grieve the loss of their maternal role (Walsh et al., 2005).

1.2 Experiencing Posttraumatic Growth

Whilst the concept of positive personal growth has begun to be researched in the last three decades, the idea is not new. Philosophical and religious literature from ancient Hebrews and Greeks discussed the transformative power of suffering (Tedeschi & Calhoun, 2004). In the mid-20th century, scientists and psychology clinicians began writing about the processes whereby suffering life crises may create possibilities for positive personal change.

In 1995 Tedeschi and Calhoun developed the theory of ‘posttraumatic growth’. Their model described positive personal growth across five domains – relating to others; new possibilities; personal strength; spiritual change; and appreciation of life (Tedeschi & Calhoun, 1995). Growth is thought to stem from the coping process in the aftermath of a traumatic event, whereby an individual strives to find meaning in the experience, achieve control over it, or maintain self-esteem (Steffens & Andrykowski, 2016). Research has suggested that the more traumatic the crisis, the more powerful the potential for growth (Stutts, Calhoun, Tedeschi, & Cann, 1994). It is thought an event so extreme it “shatters” (p. 53) fundamental assumptions (Janoff-Bulman, 1992) may produce greater positive change than less challenging crises (Tedeschi & Calhoun, 1996). However, it appears most people perceive at least some positive change as having occurred, regardless of the circumstances.

The positive psychological, social and spiritual outcomes reported can take many different forms and are experienced within many constructs (Skeath et al, 2013) – variously described in previous literature as “benefit-finding”, “life-transforming change process” and “meaning-making”. It is thought that posttraumatic growth has a more distinct focus on the outcomes of major life crises, rather than lower level stressors (Tedeschi & Calhoun, 2004). The Tedeschi and Calhoun (1995) model is currently the dominant one used in trauma research, with their related assessment tool – the Posttraumatic Growth Inventory (PTGI) (Tedeschi & Calhoun, 1995) widely used.

Whilst the negative reactions to trauma, such as anxiety and depression, often appear immediately after the crisis, posttraumatic growth tends to become evident over time, stemming from the process of coping with, and finding meaning in, the event (Steffens & Andrykowski, 2016). Whilst some researchers believe there is no specific timeframe for posttraumatic growth to develop (Tedeschi & Calhoun, 1996), a review of correlates of growth in cancer patients (Shand, Cowlishaw, Brooker, Burney, & Ricciardelli, 2015) found it may increase over time as individuals process the traumatic event. However, it is thought that variables such as individual character differences and personal circumstances as survivors recover, are more important in determining any perceived benefits than simply the passage of time (Tedeschi & Calhoun, 1996). A meta-analytic study found that growth outcomes may reflect a variety of processes (Helgeson, Reynolds, & Tomich, 2006) and further research is required to capture the distinction between actual life changes, the coping process and the cognitive manipulations one may conduct to ease distress.

It is clear that posttraumatic growth is multi-dimensional (Tedeschi & Calhoun, 1996). The five domains of growth tend to have different correlates (McMillen, 2004), suggesting there are aspects of personality, environment or coping processes that lead to each of the domains of growth. Empirical evidence from the PTGI validity study found that pre-trauma personality characteristics of extraversion, openness and optimism are positively correlated with perceived growth (Tedeschi & Calhoun, 1996), and are thought to allow individuals to transition more easily towards growth (Calhoun & Tedeschi, 1998). The lack of a relationship between the character trait neuroticism and posttraumatic growth suggests that personal growth is not related to psychological health (Tedeschi & Calhoun, 1996), but represents a different construct. Conversely, a systematic review of seventy-two studies on the psychological correlates of posttraumatic growth in cancer offers an alternate perspective – that growth is inversely related to depressive and anxious symptoms and directly associated with hope, optimism and meaning (Casellas-Grau, Ochoa, & Ruini, 2017).

One of the criticisms of the Tedeschi and Calhoun (1995) theory is that it fails to include culture in its explanatory model (McMillen, 2004), with researchers citing cultural bias (Tennen & Affleck, 2009). Much of the previous literature originated in the United States – a culture that embraces what is described by one researcher as the “tyranny of the positive attitude” (Held, 2002, p. 965) – a pressure to accentuate the positive and eliminate the negative. One theorist believes the positive and negative are inextricably linked – with one model of growth described as “strength through suffering” (Janoff-Bulman, 2004, p. 30).

Empirical research has shown that women experience greater growth than men (Tedeschi & Calhoun, 1996) and it is thought the two genders differ in their response to trauma, in that women may be more capable of learning or benefiting from difficult life experiences. The greatest gender differences exist across the domain of ‘relating to others’ (Tedeschi & Calhoun, 1996), suggesting that women may rely on their relationships more as a coping strategy, enabling these experiences to have a greater effect.

It is known that social support plays a large part in the process of growth. The quality of relationships – both before and after the crisis – have a role in determining the likelihood of growth occurring (Tedeschi & Calhoun, 1995). The importance lies in the ability to promote rumination of the event, thereby enabling the revision of schemas (Tedeschi & Calhoun, 1995). Social support can be grouped into four categories: instrumental, emotional, role modelling, and advice (Fitch, Bunston, & Elliot, 1999). Supportive others may communicate positive messages, promote increased personal strength, and may remind sufferers of the importance of family and friends, or of the goodness of others (McMillen, 2004). The modelling of compassionate responses may allow the survivor to call on these skills if required.

It has been reported that some cancer patients experience profound positive changes – within themselves, their relationships and other life domains, after their cancer diagnosis (Stanton, Bower, & Low, 2006). Evidence within a controlled comparison study supports the view that cancer is a psychosocial transition with the potential to induce growth along with distress (Cordova, Cunningham, Carlson, & Andrykowski, 2001). Literature on posttraumatic growth amongst cancer sufferers shows a prevalence rate of between 59% and 83% (Stanton et al., 2006).

1.3 Parenting with Cancer

Being a mother with breast cancer can be an extraordinary challenge. Traumatic events, such as a cancer diagnosis, can challenge fundamental assumptions about ourselves, our world (Janoff-Bulman, 1992) and the relationships within it. Mothers with cancer often expressed anguish in wanting to be available for their children, yet acknowledged the possibility of not existing at all (Billhult & Segesten, 2003).

Facing a diagnosis of breast cancer can create a fundamental shift in the way a family functions (Elmberger, Bolund, Magnusson, Lützen, & Andershed, 2008). Of primary concern for the cancer sufferer is how their diagnosis and treatment will impact their children. The experience is described as a transition process – of mothers attempting to balance the demands imposed on them by their illness and treatment, with their own efforts to maintain their responsibilities as mothers (Elmberger et al., 2008). Mothers with cancer often feel torn between their own care needs and those of their children (Helseth & Ulfsæt, 2004) and find their life situation incompatible with the demands of being both a ‘good’ mother and patient. Yet while cancer often consumed all their energy both physically and emotionally, some sufferers also report a shift in priorities that brought their family closer together.

Many women expressed using the “strength of motherhood” (Billhult & Segesten, 2003, p. 122) to balance out the conflicting forces and continue living with a positive perspective. A systematic review of studies involving the impact of cancer on the parent-child relationship found that mothers used a variety of strategies for coping with a cancer diagnosis whilst still maintaining their parenting roles (Tavares, Brandão, & Mena Matos, 2017). These included making use of any physical or emotional support available to conserve strength for coping with their illness, maintaining routines, focusing on the positive experiences that have been triggered by the illness, and involving themselves in distracting activities to decrease negative thoughts. Many mothers increased availability to their children, included them in family problem-solving, encouraged open communication about their illness and valued spending more time with their children. However, many also reported difficulties maintaining their parental responsibilities during treatment due to side-effects – leading to feelings of loss, sadness and guilt – and prompting some to consider themselves bad mothers (Tavares et al., 2017).

1.4 Challenges for Breast Cancer Sufferers

In recent years, substantial advances have been made in the prevention, diagnosis and treatment of breast cancer, with a 5-year survival rate of 87% (Australian Institute of Health and Welfare, 2018). Yet it remains Australia’s most prevalent cancer in women, accounting for 28% of all new cancer cases in females, with projections for 2017 estimating over 17,000 new diagnoses countrywide (Australian Institute of Health and Welfare, 2018). The incidence of breast cancer in Australia is twice the world average (after age adjustment) – reflecting both increased risk and higher rates of detection (Roder et al., 2017). In South Australia, 23%

of breast cancers occur in women under the age of 50 (Roder et al., 2017) – the prime parenting years.

Those affected by breast cancer can face many physical, psychological and social issues – as noted in the following recent review of breast cancer impacts (Jefford, Mann, Nolte, Russell, & Brennan, 2014). They often suffer long-term consequences of treatment, such as neuropathic pain and alterations in body image due to surgery; fatigue, weight gain and early menopause due to chemotherapy; and ongoing pain from radiotherapy. The psychological impact of a breast cancer diagnosis varies widely, but for most, involves a period of readjustment to cope with changed relationships, or to manage expectations of family and friends. This can prompt some to reassess their life priorities and develop strategies to continue to live well against a future of uncertainty. Some women will have more complex psychological needs and experience depression or high levels of anxiety, often prompted by fear of the cancer returning. There may also be direct social impacts on work, study and finances, as well as indirect impacts on those who are physically, psychologically, or financially dependent on them.

1.5 The Current Study

The previous research on the experiences of parenting following breast cancer is limited. Some studies focus on the child's perspective when their parent has cancer, the parenting impacts when a child has cancer, or the growth experienced by the adult children of cancer sufferers. Some explore posttraumatic growth in cancer sufferers unrelated to their parenting experiences. However, few examine the psychological impact of a mother's breast cancer diagnosis on her parenting practices.

The current study addresses critical gaps in the literature by providing an in-depth qualitative exploration of both the positive and negative psychological impacts of a breast cancer diagnosis on parenting experiences, and exploring the existence of posttraumatic growth in this group. Many previous studies make the assumption that positive growth *will* occur in these groups (Baker, Kelly, Calhoun, Cann, & Tedeschi, 2008), yet it is not always experienced (Harbin, 2015). For this reason, the current study explores the mothers' experiences after breast cancer, without priming explicitly for positive growth. The research also aims to provide an understanding of the factors that may support personal growth and the impact of peer support. It is hoped this will advance our knowledge of how a mother's breast cancer diagnosis may positively and negatively affect her parenting.

CHAPTER 2

Method

2.1 Theoretical Framework

Given the limited previous research on the topic and exploratory nature of the current study, qualitative analysis methods were chosen for their ability to promote a deep understanding of the topic, and yield rich data (Green & Thorogood, 2009). Qualitative research attempts to understand the experience from the participant’s perspective – consistent with the aims of the study (Green & Thorogood, 2009). A quantitative component enables the researcher to adequately describe the sample.

Through its freedom from theoretical constraints, thematic analysis provides a flexible approach to gaining a rich, detailed description of the data (Braun & Clarke, 2006). Whilst the current study is informed by theories of posttraumatic growth, the intent was to reflect the lived experiences of mothers with breast cancer, without trying to fit the data into pre-determined theories. The inherent flexibility of this approach is particularly suited to studies exploring sensitive issues such as cancer (Dickson-Swift, James, & Liamputtong, 2008).

2.2 Participants

A purposive sampling framework was adopted, with participation restricted to those with a breast cancer diagnosis of stage 0–III in the last 2 to 10 years, with at least one child under the age of 18 at the time of diagnosis. The reason for the strict criteria was two-fold. Firstly, in ethical consideration for those with a later stage of the disease who are likely to be more traumatised. Secondly, the post-diagnosis timeframe was put in place to provide some scope through which to consider the mother’s experience, and sufficient time to have passed for any growth to occur. Participants were restricted to mothers with a breast cancer diagnosis, since this is the most common cancer in Australian women (Australian Institute of Health and Welfare, 2018), and often occurs in younger women of childbearing age (Roder et al., 2017).

Three participants were recruited through personal networks, one via a radiology clinic poster, whilst a further 11 were recruited through the Breast Cancer Network Australia (BCNA) Review and Survey Group – an Australia-wide support network for breast cancer sufferers, who receive invitations to participate in research. In all cases, participants contacted the researcher to volunteer, or directly accessed the study online. A further five participants were excluded from the research as they either did not meet the criteria, or did not respond to the open-ended questions in the online study.

2.3 Measures

It is considered best practice to collect demographic information in qualitative research. Under the belief that knowledge is situated (Tracy, 2010), this allows the researcher to reflect on the relationship between the results and the sample (Braun & Clarke, 2013). Information was gathered regarding participants' age, gender and age of children, cancer stage and type, time elapsed since diagnosis, and treatment regime (see Appendix F). In addition to this descriptive information, participants completed two self-report quantitative inventories, using validated measures to ascertain current mood states, and any perceived growth that may have occurred. They were then asked open-ended interview questions, to understand their own lived experience since their diagnosis.

2.31 Depression, Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1995).

The Depression, Anxiety and Stress Scales 21 (DASS-21) is the short-form version of Lovibond and Lovibond's (1995) self-report measure of depression, anxiety and stress. The scale measures the three inter-related negative emotional states across a dimensional construct of psychological disorder. Each item is rated along a four-point Likert scale from 0 (*Did not apply to me at all*) to 3 (*Applied to me very much or most of the time*), with higher scores indicating higher levels of psychological distress. Scores are multiplied by two to calculate the final score for each subscale, enabling comparison with normative data and clinical severity ratings (Lovibond & Lovibond, 1995). The total of these subscale scores gives a General Psychological Distress (GPD) score. The DASS-21 is known to have high internal consistency, with a Cronbach's alpha level of .94 for the total scale, with the subscales ranging from .79 to .90, within a population of 497 Australian adults (Crawford, Cayley, Lovibond, Wilson, & Hartley, 2011). Within the current study, the DASS-21 has a Cronbach's alpha level of .92 for the total scale.

2.32 The Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1995).

The Posttraumatic Growth Inventory (PTGI) assesses positive changes experienced after trauma. The 21-item scale assesses growth and change across five factors: new possibilities (5 items), relating to others (7 items), personal strengths (4 items), spiritual change (2 items) and appreciation of life (3 items). For each item, respondents indicate, along a six-point Likert scale, the degree to which they experienced a change in their lives as a result of their breast cancer, ranging from 1 (*I did not experience this change*) to 6 (*I experienced this change to a very great degree*). The sum of the 21 items yields a total growth score, which can range from 21 to 126 – with higher scores indicating greater growth. The PTGI has shown high internal consistency, with a Cronbach's alpha level of .90, whilst the factors themselves ranged from .67 to .85 – reported within an adult population in the United States who had experienced a traumatic event in the past 5 years (Tedeschi & Calhoun, 1995). In the current study, the PTGI was found to have a Cronbach's alpha level of .96 for the total scale. It has been reported that the PTGI is not related to social desirability (Steffens & Andrykowski, 2016), eliminating the concern with false positive reports of growth.

2.33 Open-ended survey questions.

In order to explore these women's lived experience of breast cancer within the context of their parenting, six open-ended questions were posed, based on the relevant parenting, breast cancer and posttraumatic growth literature. Within these, prompt and emergent questions were added where appropriate (see Appendix G). Careful consideration was given to the phrasing of questions, with the word “growth” deliberately omitted, so as not to prime participants to respond in a certain way. Questions were asked regarding how their mothering roles and relationships with children were impacted by the illness, how their experience of parenting has changed, how perceptions of themselves as mothers changed, and the role of any support in allowing them to continue parenting.

The initial open-ended questions were developed and piloted with a test group to ensure they met the research aims. After the first interview, the questions were modified to broaden the scope for response. This is accepted as best practice within qualitative interviewing (Britten, 2006). The researcher also consulted with a research advisor – a cancer survivor and parent herself – who advised on phrasing of questions and prompts. For those who completed the research via SurveyMonkey (SurveyMonkey Inc., 1999), where emergent questions could not be tailored based on previous responses, short prompts were added to questions, enabling respondents to elaborate on an issue or describe a particular instance when change occurred (see Appendix G).

2.4 Procedure

The research study was approved by the University of Adelaide Human Research Ethics Committee (H-2018-113). Participants were then recruited through personal networks and via posters (see Appendix C, D), with interested participants asked to email the researcher in the first instance. To minimise participant burden, they were offered the choice of completing the research via face-to-face interview, phone interview, or online via SurveyMonkey. Participants were also recruited via the BCNA Review and Survey Group, who completed the research online. BCNA sent an email requesting participation to their database (see Appendix E) – which contained a direct link to the survey. The interviews and online research was conducted over a three-month period, from June to September 2018. The process for each method of completion will be described below.

For those who completed the research either in-person (*n* = 2) or via phone (*n* = 1) – the researcher (JS) conducted semi-structured interviews, whereby participants were first emailed an information sheet containing an outline of the research, with confidentiality explained and consent obtained (see Appendix A, B). Interviews ranged from 34 to 50 minutes and took place at a time and location convenient to them. Participants were given a hard copy of the demographic questions and the two quantitative scales to complete (see Appendix F), with the participant interviewed via phone completing these online. A series of open-ended questions were asked, with emergent questions added based on responses, to prompt the participant to elaborate on points raised (see Appendix G). Interviews were digitally recorded with participants' consent and transcribed verbatim.

For participants (*n* = 12) who chose to complete the research online, one was emailed the link by the researcher, with the remainder directly accessing the SurveyMonkey link via the BCNA email (see Appendix E). An information sheet formed part of the SurveyMonkey preamble, with consent given via a tick box (see Appendix H).

Within each method of participation, the information sheet contained details on confidentiality and the use of de-identified information. Whilst it was not anticipated to cause an adverse psychological response, it was acknowledged that reliving their cancer diagnosis and how the experience has affected their family may cause distress to some. Participants were provided with information for psychosocial support agencies should they become distressed by the experience.

2.5 Analytic Approach

Thematic analysis (TA) as outlined in Braun and Clarke (2006) was used to analyse the data. Their approach comprises six phases. The first is familiarisation with the data, involving transcription of interviews and repeated reading of the data, taking note of initial ideas and preliminary themes. Lines were numbered so that extracts can be linked back to the data. Phase two involved generation of initial codes, systematically collating interesting features of the data into groups. In the third phase, codes were collated into potential themes, with these reviewed and refined to ensure they were meaningful against both the coded extracts and the entire dataset. Themes were then defined and named in relation to the overall analysis. The final stage is to produce the report, selecting compelling extracts to demonstrate their association to the research aims and relevant literature. It should be noted that, consistent with the view of Braun & Clarke (2006), greater prevalence does not always indicate greater importance of a theme – more crucial is whether it captured an interesting aspect in relation to the research aims. A thematic network was then created, in order to improve rigour and transparency, and provide a visual map of broad and sub-themes (see Figure 1).

A data saturation table was used to establish the point at which saturation was reached (see Appendix I). Data saturation is described as the point at which no new themes are identified in the data (Braun & Clarke, 2013). Despite data saturation being reached at twelve participants, it was decided to include three more participants to capture a greater range of experiences.

A recursive approach was taken with the research, whereby the researcher moved back and forth between sampling, data collection and analysis, in order to improve the richness of the findings (Braun & Clarke, 2006). Research questions were revised according to preliminary themes identified and answers on the previous interview, as discussed earlier. This process of constant comparison allowed the point of saturation to be more easily identified (Braun & Clarke, 2006).

The analysis was conducted within an essentialist/realist framework, whereby participant descriptions of their experiences were assessed as direct insights into the experience (Braun & Clarke, 2006), rather than socially constructed. The analysis combined elements of both inductive and deductive coding. Within an inductive, or ‘bottom-up’ approach, data are coded without trying to fit them into a pre-existing frame (Braun & Clarke, 2006). In this way, themes are strongly linked to the data themselves. Within a deductive or ‘top down’ approach, analysis is driven by the researchers theoretical interest in an area – in this case, determined by posttraumatic growth theory.

2.6 Quality Criteria

Efforts were made to adhere to Tracy’s (2010) eight “big-tent” criteria for excellence in qualitative research. Within each participation method (face-to-face, via phone and online), transcripts were de-identified using pseudonyms and emailed to participants within one week of the interview, or receipt of online responses. This allows for the process of participant validation or “member reflections” (p. 844), whereby participants are able to review the transcript, should they wish to verify accuracy or provide clarification (Tracy, 2010). This is accepted best practice to ensure credibility in the research and mutual understanding on the topic, as well as allowing the participant an opportunity to provide additional comment. Participants were also sent a summary of the findings at the conclusion of the study.

An audit trail was maintained throughout data collection and analysis, in an effort to maintain transparency and enhance rigour in the research process (Tracy, 2010) by documenting all research decisions and activities. These notes captured the logistics of interviews or receipt of SurveyMonkey responses, and outlined any preliminary themes that the researcher thought interesting.

Within this method of analysis, it should be noted that the researcher takes an active role in identifying themes in the data – selecting those that are interesting from our own theoretical positions and understandings (Braun & Clarke, 2006). For this reason, one transcript was coded by a second researcher (EM) and cross-checked with identified themes to ensure rigour and trustworthiness, with any discrepancies resolved through discussion (Pope, Ziebland, & Mays, 2006). Likewise, the data were analysed in conjunction, and ongoing discussion with, the project supervisors (DT, JO) to maximise reliability (Green & Thorogood, 2009). It is thought that selecting a range of analysts may negate the subjective judgments displayed by an individual researcher (Pope et al., 2006).

Reflexivity regarding the researchers position in relation to the study is one of the primary criteria for excellence in qualitative research (Tracy, 2010). Researchers must be introspective in appraising their own motivations and biases in order to enhance the sincerity of the findings. It is acknowledged that, although the researcher has not experienced breast cancer herself, she has experienced several parental cancer diagnoses and their impact on the family. The researcher is also a mother of two children, with an understanding of the challenges and rewards of parenting. However, cross-checking of themes with another researcher (EM) was expected to reduce the impact of any biases (Pope et al., 2006), as noted above.

Due to the sensitive nature of the topic, procedural ethics were followed in accordance with guidelines set out by Tracy (2010). This includes ensuring the privacy and confidentiality of participants – with all identifying material removed, data stored on a password-protected laptop and audio recordings destroyed after transcription. This is thought to lead to more credible data, as participants feel protected and trust the intentions of the researcher (Tracy, 2010).

CHAPTER 3

Results

3.1 Participant Characteristics

For the present study, the data corpus consisted of demographic information, quantitative psychological and personal growth inventories, and transcripts of open-ended interview questions. A total of 15 women, aged between 41 and 60 (*M* = 50, *SD* = 4.54) participated in the study. Each had experienced a breast cancer diagnosis of stage I to III, with the time elapsed since their diagnosis ranging from 2 to 10 years. Their families consisted of between one and six children, and each had at least one child under the age of 18 at diagnosis. Three mothers also had other children over the age of 18 at diagnosis – who were included in the analysis. All were biological parents, with one participant also a mother to two foster children and one adopted child. In regards to family characteristics, both dual-parent (*n* = 12) and single-parent families were represented (*n* = 3), with all children residing with their mothers. Seven women had completed post-graduate education, six had completed a degree or diploma, with two completing high school qualifications. Demographic and medical characteristics of the participants can be seen in Table 1 below.

Table 1.

Demographic and Medical Characteristics of Participants (N = 15)

Participant*	Current age	Years post-diagnosis	Cancer stage	Mastectomy	Number of children	Gender and current age of children
Sarah	45	5	II	Yes	3	Boy 11 Girl 10 Boy 10
Jane	41	5	Early	Yes	1	Boy 9
Emma	53	3	I	Yes	3	Boy 22 Boy 20 Boy 18
Mary	53	3	Early	No	2	Girl 21 Girl 18
Annie	49	3	I	Yes	2	Boy 13 Girl 13
Maggie	50	8	II	Yes	2	Boy 20 Girl 13
Julia	51	6	Early	Yes	2	Girl 14 Boy 12
Miranda	56	4	II	Yes	6	Girl 35 Girl 32 Boy 29 Boy 20 Girl 17 Boy 12
Lily	52	9	II	Yes	2	Boy 18 Girl 14
Elizabeth	50	5	IIIa	Yes	4	Girl 19 Girl 17 Girl 13 Girl 13
Alice	49	4	III	Yes	6	Boy 21 Girl 19 Girl 16 Boy 14 Boy 12 Boy 8
Grace	47	5	I	Yes	2	Girl 15 Boy 11
Eve	60	10	Early	Yes	1	Boy 21
Fran	48	3	III	Yes	2	Boy 14 Boy 10
Rose	47	2	II-III	Yes	3	Boy 24 Girl 21 Girl 19

Note. * Pseudonyms used.

In the current study, DASS-21 scores were categorised in accordance with the clinical severity criteria for qualitative comparison (Lovibond & Lovibond, 2005). Scores ranged from normal to severe, with one participant scoring in the ‘extremely severe’ category for depression. Table 2 below reports the individual clinical characteristics for each participant. Mean scores on the DASS-21 were found to be higher than normative scores for the general Australian population (Crawford et al., 2011), across each dimension of the scale. Notable was the mean anxiety score for the current sample, which was reported at close to twice that stated in the normative sample.

Table 2.

Clinical Characteristics of Participants (N = 15)

Participant	Depression score / severity	Anxiety score / severity	Stress score / severity	GPD score	PTGI score
Sarah	0 / normal	12 / moderate	10 / normal	22	88
Jane	6 / normal	6 / normal	24 / moderate	36	85
Emma	30 / extremely severe	12 / moderate	16 / mild	58	37
Mary	0 / normal	0 / normal	0 / normal	0	27
Annie	4 / normal	4 / normal	4 / normal	12	81
Maggie	2 / normal	0 / normal	0 / normal	2	120
Julia	0 / normal	4 / normal	8 / normal	12	28
Miranda	2 / normal	2 / normal	6 / normal	10	101
Lily	2 / normal	6 / normal	0 / normal	8	81
Elizabeth	20 / moderate	16 / severe	18 / mild	54	65
Alice	0 / normal	16 / severe	10 / normal	26	104
Grace	14 / moderate	4 / normal	20 / moderate	38	67
Eve	0 / normal	4 / normal	2 / normal	6	47
Fran	0 / normal	0 / normal	14 / normal	14	89
Rose	0 / normal	8 / mild	8 / normal	16	89

Note. Measure abbreviations:
DASS-21: Depression, Anxiety and Stress Scale (abbreviated version of the 42-item self-report measure).
GPD: General Psychological Distress.
PTGI: Posttraumatic Growth Inventory.
DASS-21 raw scores were doubled to render them comparable to full-length DASS scores.
Clinical severity ratings are included (Lovibond & Lovibond, 2005).

The mean scores on the PTGI were only slightly higher than normative data for females, suggesting moderate levels of growth amongst the current sample, given the high general psychological distress scores reported. Descriptive statistics of the various psychological dimensions can be seen in Table 3.

Table 3.

Descriptive Statistics of Each Psychological Dimension (N = 15)

Measure	Subscale	Normative scores	*M*	*SD*	Scale range
DASS-21	Depression	5.14	5.33	8.99	0-30
	Anxiety	3.48	6.27	5.44	0-16
	Stress	7.98	9.33	7.69	0-24
	GPD	16.6	20.93	18.03	0-58
PTGI	Factor I: New possibilities	18.26	14.2	6.04	5-24
	Factor II: Relating to others	23.94	27.27	8.61	10-42
	Factor III: Personal strength	14.65	16.13	5.82	4-24
	Factor IV: Appreciation of life	10.16	12.73	3.99	3-18
	Factor V: Spiritual change	6.48	5.47	3.64	2-12
	Total	73.49	73.93	28.24	27-120

Note. Measure abbreviations:
DASS-21: Depression, Anxiety and Stress Scale (abbreviated version of the 42-item self-report measure).
GPD: General Psychological Distress.
PTGI: Posttraumatic Growth Inventory.
Normative Scores:
(DASS-21): Normative sample scores from general Australian adult population for comparison (Crawford et al., 2011).
(PTGI): Normative sample scores from female population for comparison (Tedeschi & Calhoun, 1996).
Total DASS-21 raw scores were doubled to render them comparable to full-length DASS scores.

3.2 Overview

The themes identified in the data reflected the emotional experiences resulting from the mother’s cancer diagnosis in relation to her parenting – consistent with the aims of the research. These can be split into two key domains – those that were considered negative outcomes and those considered positive. Although most participants reported at least some negative impacts (*n* = 13), all experienced positive impacts in relation to their parenting.

Two overall negative themes were identified: difficulty maintaining role; and fear for the future. Seven positive themes were identified: generativity; maintaining normality;

togetherness; altered priorities; mutual empowerment; gratitude; and supportive others. Figure 1 below illustrates the domains and themes within them.

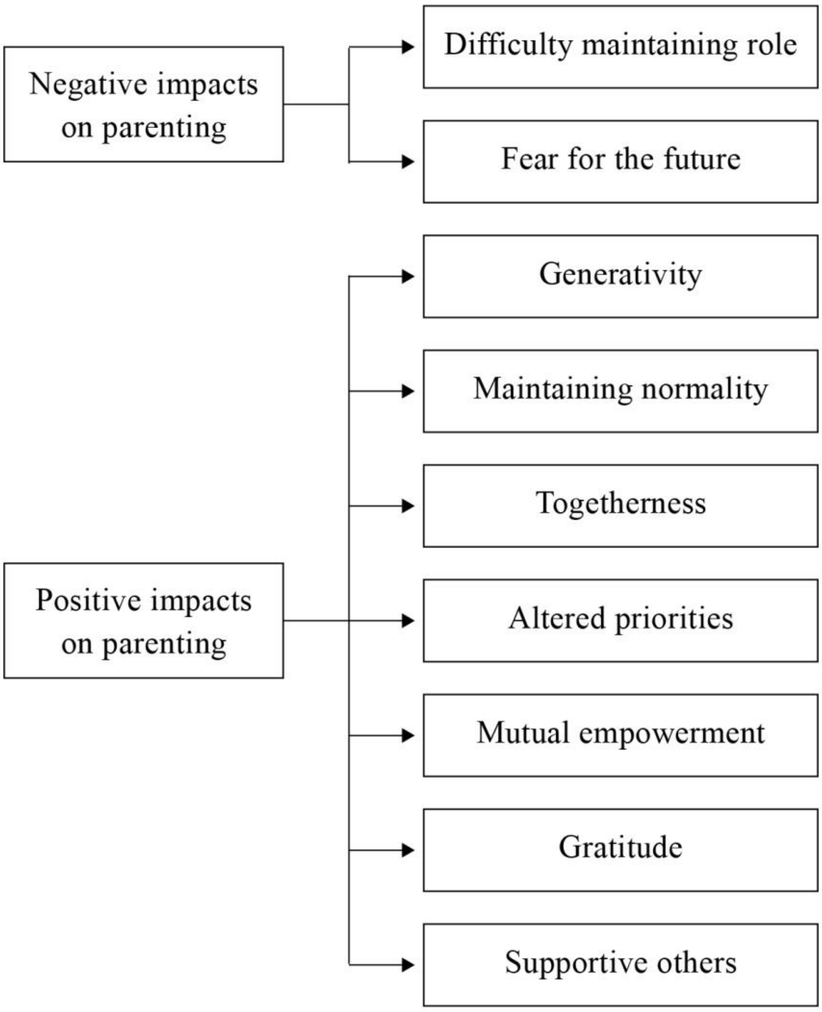


Figure 1. Thematic map of identified domains and themes.

3.3 Themes

3.31 Difficulty maintaining role.

The majority of participants expressed some degree of difficulty in maintaining their mothering roles during and after their diagnosis and treatment (*n* = 12). In particular, the hospital stays proved problematic, with some finding it hard to rely on others for parenting responsibilities during this time. Some found difficulty in adjusting to others taking on their parenting role in a different manner, or considered the help intrusive – while one expressed feeling a poorer parent for the cancer experience. One participant expressed feelings of loss at not being available physically or emotionally when her young son most needed it.

> *I had quite a few set backs in treatment which had me hospitalised and impacted greatly on my son, one time was for 16 days, and this is in addition to the surgeries. This impacted the most and stressed me the most, as I couldn't be there for him and he knew something was wrong and was fretting and upset. My role was affected as I needed to rely on others, mainly my mother (who is also a breast cancer survivor), to be there physically and emotionally for him when I couldn't. It was probably the hardest part - not letting someone else do it, as I want him to be filled with love always, but knowing it was me he wanted, and I couldn't meet his basic needs of love, warmth and cuddles every day.* (Jane, lines 11-20)

Of the participants, four expressed guilt at the impact their illness and absences had on their children. One mother described an incident with her daughter, and the ongoing consequences for their relationship.

> *My second oldest – she doesn't like relying on me. A pivotal moment with her was that I didn't pick her up one afternoon from school – I just forgot her. It was tragic – I was picking up her older sister unexpectantly from 2* [sic] *suburbs away and then just forgot to ring the school to tell them. Someone walked her into the office as she was sitting outside waiting for ages. I'll never forgive myself. But I think also she was scared of losing me.* (Elizabeth, lines 81-87)

Another was overwhelmed with guilt about the negative impacts on her children, which she attributes to her own inability to support them.

> *I still feel overwhelmed with guilt about their life pathways and depression that 2* [sic] *sons have. I feel I haven't been there to support them as I was just hanging in there myself.* (Emma, lines 22-24)

Guilt and anguish was also expressed over missing major milestones in their children's lives, such as a first day of school. Participants described the treatment cycles as dictating how much energy they had available for their children, and the resulting sadness over time lost to the illness. Managing both the physical and emotional impact of the illness and children's concern for their mother, highlighted the dual burdens that parents experiencing cancer must contend with. One participant noted "it was challenging to try and meet the needs of everyone else when my reserves were low" (Miranda, lines 10-12). One participant with teenage children expressed that her view of herself as a mother was challenged when she realised that she did not have to do it all, she can take time for herself and her children took on extra responsibility without being asked. While most participants were disappointed at their diminished role as mothers, they also realised that they must balance that with a focus on getting well.

> *At first it really bothered me that I couldn't do all the "mom" things I wanted to do, but as things progressed I realized* [sic] *I had to pull back and focus my energy on getting through it all.* (Alice, lines 8-10)

3.32 Fear for the future.

A dominant pattern that became clear in the research was an uncertainty about the future. Just over half of participants (*n* = 8) expressed that their fear of the cancer recurring permeated their thoughts and their lives. Several participants described it a looming threat always hanging over them.

> *The relationship with my children is weakened probably because of the constant threat of cancer coming back, metastasising – and that always being in the back of my mind. But then that impacts on making it stronger and having more quality time with my children, and um hoping to do the best I can, while I am still here. It's not…I mean, I might still be here in another 50 years, but, in the back of your mind, it's always*

> *something that's looming and impacting on your every day, pretty much.* (Sarah, lines 33-39)

Similarly, another participant also expressed that this fear had a strengthening effect on her parenting practices and the relationship with her children. It functioned as a constant reminder to live in the moment.

> *…my biggest worry still is that I'll be taken away from him, because I know what it's like to seriously consider you may die. This has impacted my parenting good and bad. Good in that I do live for the day, go on the holidays, cuddle him often, try and be 'present'. Bad in that it sits there, the worry, and hangs over me, and I never actually feel free.* (Jane, lines 36-40)

Participants highlighted the greatest fear was not being around to see their children grow up. For some, the fear prompted them to value their children's milestone even more, as they initially believed they may not survive. One participant noted that the fear had brought everything into sharper focus.

> *I guess it started there, when you just go… this could be the last book week that my kids do, this could be the last, you know,* […] *it was more just sort of that confronting phase… I was so scared that it was the end, that just everything was very sharp, and very, um, yeah what if… this is the last time we get to do this…* (Fran, lines 21-26)

Several respondents highlighted that, upon receiving their cancer diagnosis, the immediate thought was that her children would be without a mother:

> *When I was diagnosed I was petrified my children wouldn't have a mother and that's what was the most worrying part. My first thought was for them.* (Sarah, lines 60-61)

Conversely, one participant, when asked how her view of herself as a mother had changed, noted that she accepts that life goes on with or without her in it. Some mothers were conscious of their children also carrying the burden of fear that the cancer will return.

> *…they always have to deal with a certain amount of apprehension about whether the cancer will return. I see this on their faces whenever I have a doctor's appointment (even if it is not a cancer checkup).* (Alice, lines 30-32)

One participant expressed that she would give up the growth she experienced, to not have that fear of the cancer recurring.

> *I've come to think of cancer as the gift no-one wants, because it has changed me… it definitely without a doubt has changed my life for the better… now, um, certain aspects of my life, but if I know I'm not going to have a recurrence, or it's... you know, then I would say yeah, absolutely, I wouldn't have my life any other way. But, I just want to be around a bit longer… yeah… that's a good question. I probably would. I probably would want to not have it.* (Fran, lines 207–215).

3.33 Generativity.

Of the themes conveying a positive impact on the parent-child relationship, generativity was one of the strongest. Most of the participants (*n* = 10) reported at least some dimension of generativity with regard to their parenting. The term generativity (Erikson, 1950) was coined by Erik Erikson in 1950 and refers to contributions that benefit or guide the next generation. In the current study, this manifested in qualities the mothers' cancer experience had instilled in her children, or character traits she was able to role model.

One mother considered a positive aspect of her breast cancer diagnosis was the opportunity to educate her teenage daughters about taking control of their own health, and instilling a sense of compassion for those who are experiencing difficulties.

> *A positive has been teaching them about taking responsibility for their own health and well being and to show compassion to people going through difficult times.* (Mary, lines 19-21)

Several of the participants highlighted the need to model positive coping skills to their children and encourage resilience against the events that may occur in one's life. Many of the women, who live with an element of uncertainty about their own futures, felt compelled to prepare their children for what is ahead of them, as well as a moral responsibility to ensure their children grow up to be good people.

> *I probably try to not shape their future, but I, I have this feeling that I must make sure in that whatever time I have with them, that I prepare them best for what's ahead in this world for them. So it's added responsibility but I feel a bit of an added pressure to make sure that the time I have with them I've used really well, to make sure I see them off into the world as good little citiz… you know…good little, good boys, good young men, one day hopefully… hopefully they are old men by the time I go.* (Fran, lines 114-120)

Another mother sought to convey the importance of kindness to her children – since "no-one is promised tomorrow" (Lily, lines 27-28). Several of the women expressed that their children became more sensitive and empathic to others, and, having had these values instilled in them, had become more self-reliant in response to their mother's illness.

A large part of generativity involves caring for others and efforts to make the world a better place. One participant noted how the impact of her illness on her son made her reflect on other children without parents and those who needed support.

> *During my time in hospital thinking about my son all the time, it made me think of all the children doing it tough without parents, who need and deserve love and support, and so from my hospital bed I sponsored a child with World Vision, and still have him to this day. I probably wouldn't have done so otherwise.* (Jane, lines 63-67)

Several of the participants became involved in breast cancer charities and fundraisers, with the motivation often driven by their children. Some expressed that their children were proud to support them at these events.

My children are proud of me. They want to attend breast cancer fund raising events with me and stand beside me. (Mary, lines 25-26)

3.34 Maintaining normality.

Many respondents (*n* = 10) expressed their desire to maintain a physical and emotional presence in their children's lives, and to continue their regular routines and activities – both during and after diagnosis and treatment. For some, it was one of their main parenting goals during treatment.

> *I made sure that my children's sporting activities, because it was mainly sporting back then, um, were unchanged, so they still continued their activities and their life as much as normal, that was my goal.* (Sarah, lines 9-11)

While the type of activities and rituals varied, some mothers expressed wanting to maintain simple everyday routines of cooking and eating family meals together, with these providing an added incentive to get well. Some went to great efforts to maintain special family birthdays and celebrations, despite feeling unwell or having to fit them around treatments.

> *I became sentimental. Their birthdays were around my surgery. It was extremely important to me to have a parties* [sic] *despite leaving for appts or surgeries the following days. I travelled away to see the son who was working away despite being unwell. The first xmas* [sic] *after my treatment and it was very important we have a normal small family Xmas…* (Emma, lines 12-16)

Several participants mentioned the importance of minimising the impact of their illness on their children.

> *I worked hard at keeping everything as normal as possible. I didn't want treatment to define me. I was still as capable at doing everything I did before diagnosis. I felt ok but worked hard both physically and mentally at doing everything I always did… I was determined not to let it have a big impact on their lives.* (Mary, lines 3-6; 18-19)

Maintaining structure in their lives also provided a way for the mothers to allay the children's fears of the illness. In lessening the impact on their children, the mothers often put the children first, despite feeling poorly. For others, some responsibilities were passed on to their partners to avoid disruption to the children's lives and ensure there was always at least one parent available to them.

> *I don't think my role was overly impacted. I had treatment on Monday's* [sic] *so by the weekend I was pretty good and made sure I got to every soccer and cricket game!... I was very sensitive to their fears so just tried to keep things as normal as possible… my husband is hands on working from home whist I work outside the home. They always have a parent available.* (Lily, lines 8-10; 16-17; 44-46)
>
> *Although my husband stepped up I still found myself putting my kids first and trying to do things for them, despite how sick I felt.* (Grace, lines 3-5)

3.35 Togetherness.

All of the participants (*n* = 15) expressed the importance of togetherness or described a sense of enhanced connection with their children following their cancer experience. Most respondents placed a higher value on the quality time they could spend with their children and felt that a strengthened relationship resulted.

> *I think I just wanted to spend every minute that I could with them. So, you know,* […] *we didn't change, ah, big things like you know, they didn't start sleeping in our bedroom, or… you know we didn't change the fundamentals of, you know, you still need to do your homework, you still have no computers during the week. Those sorts of things carried on, but I just wanted to be with them. I didn't want them to go on play dates, I didn't want them to go and watch movies with friends, I just wanted to be home. And I just wanted to be with them.* (Fran, lines 38-45)

One participant highlighted that, whilst the relationship with her young son is extremely strong, she is conscious that he still contemplates her illness and their bond is somewhat confined by fear, not freedom. Of their relationship, she notes:

> *Definitely strengthened. But I do worry at what cost to him, as I feel he saw too much… So the bond is strong, but from a place of fear and love, not freedom and love.* (Jane, lines 44-54)

Open communication was identified as a key feature of the sense of togetherness that participants felt. One mother emphasised the closeness she enjoyed with her sons, but concedes she is unsure if it can be completely attributed to her illness.

> *Definitely strengthened in every* [emphasised] *way I think. Um, I think we talk really openly about things, I'm really comfortable talking to my kids and they're really comfortable talking to me. Um, I love* [emphasised] *spending time with them, I think they quite like being around. Um, and yeah I…. yeah, I think we are much closer and yeah it's difficult because I don't have a comparison… there's no control group, so I don't know what it's…what it would have been like otherwise.* (Fran, lines 78-84)

Others explicitly knew that their tight bond was due to that experience.

> *To this day my son and I have an extremely tight bond (tighter than any other Mum/son I have seen) and I think it's due to that time, and that it was in main just us…* (Jane, lines 31-33)

Many highlighted an increase in physical and emotional displays of affection both from and towards their children. Open and honest communication also manifested in increased expressions of love from children that were quite unexpected.

> *I think the relationship has been strengthened. Whenever it is my birthday or Mother's Day, the children write very poignant messages to me. The girls have also expressed their love for me through poetry and song.* (Alice, lines 36-38)

Some mothers noted they made changes to the family schedule to accommodate spending more time together and highlighted the desire to be more involved in their children's lives. For some, the children also appreciated the extra time they had with their mother, even if the reason was not desirable.

> *I have very good relationships with my children and I always have. I appreciated their love and support throughout and since my treatment. They gave me terrific incentive to get up and out of bed whenever possible. I had been working full-time prior to diagnosis and it was so beautiful when they said, 'Mummy we don't like the reason you're home, but we love you being home.'* (Julia, lines 14-19)

Whilst one mother noted her breast cancer experience had made the family closer, she also indicated that the physical impacts of the disease impacted their togetherness.

> *My relationship stayed the same, although I was upset to see my children scared because of cancer* […] *I don't feel my parenting has changed, but tiredness has had a negative impact on how much I feel like doing with the kids.* (Annie, lines 7-8, 12-13)

3.36 Altered priorities.

For most women, their breast cancer experience forced them to re-evaluate their lives in terms of what was most important. Many highlighted that their illness had prompted them to change their priorities in life (*n* = 7), with less focus on work or finances and more on living in the moment and enjoying their children. One participant also noted the high importance she placed on her role as a mother.

> *…it's made me, um, want to spend more time with them, and maybe, I mean I work three days a week now, so, um, it's made me want to enjoy the few days that I can with them, and not focus all my energy to working… it's given me that want to spend some time with them, to be able to pick them up from school, and not be at work all the time, in that sense. The financial aspect was difficult – I just wanted to be a mum.* (Sarah, lines 50-57)

Some stressed the importance of creating memories with their children while they could, and that the window of opportunity for experiences together was closing as their children grew up.

> *I think I've realized* [sic] *we are all vulnerable. And I only have my kids for a short time and want to enjoy this time as much as possible. Do more memorable things with them. Try and be more patient as well.* (Grace, lines 30-32)
>
> *We did a few things that we'd talked about for a while – putting in a pool and going on overseas holidays. We figured there's only a small window of time to have these experiences with the kids.* (Sarah, lines 27-29)

Some women noted the financial implications of both parents taking time out from work due to the illness, yet it became less of a priority in comparison to their children and health. One highlighted a desire to eliminate stress from her life – an aspect she thought contributed to her cancer. Several respondents noted they no longer "sweat the small stuff". One mother expressed that she was not willing to burden the relationship with her children for the sake of inconsequential matters.

> *I don't sweat the small stuff, that's really the biggest thing I, um, I don't get too worked up about whether they do their homework or not… where now I just go, is this going to matter next year this time… what's more important?* […] *it's almost as if I'm thinking… is the stress this is going to cause my relationship with my child worth the outcome of what I'm trying to accomplish?… I don't want to ruin my relationship with my kids of the sake of "you must go to hockey practice tonight, or you must enjoy your swimming lesson" so I definitely am more… is it that important, is it that important? And if it isn't, then I'm a bit more… lenient.* (Fran, lines 55-69)

It was also highlighted that, whilst priorities had changed with regards to life and parenting, this was often reassessed once again as time went by. After the initial angst subsided and life returned to normal some years on, some mothers suggested their parenting resumed in a new, yet more positive, way. They gained a new perspective that allowed them to adapt their parenting style and still maintain what they considered 'good' parenting.

> *In that first um, period right after diagnosis, it's like, you know nothing matters, nothing matters,* […] *and life kind of returns, and now three years on, you have those little irritations that you never thought would come back because you were so… um, caught up in… that emotion of treatment, and, am I going to live? And, yeah, that rushed anxiety has gone, and it's more like, well, this is the new… this is just the way it is.* (Fran, lines 128-130; 132-136)

Although many participants concede that their cancer diagnosis had a positive effect on their parenting, this in itself could cause friction for those family members who hadn't experienced it in the same way.

> *…the changes that I've noticed in the way I parent now, um, you see my husbands' way he parents hasn't changed, and the… you know it does generate a bit of conflict in my house… I don't feel like the same person, and I know I don't parent the same way, and that's difficult. That's difficult.* (Fran, lines 167–176).

3.37 Mutual empowerment.

Most of the participants (*n* = 11) mentioned some element of reciprocal empowerment between themselves and their children. Often, the children provided a powerful incentive to get through the cancer experience, and fuelled the mother's desire to get well. One participant, a single mother, used a warrior metaphor to emphasise the powerful will she developed to protect, and get well, for her son.

> *…I feel strong, like a lion protecting its cub, and a warrior, there is power in that. I feel proud of getting through it, and of protecting him as much as I could, and knowing I have this internal fire to survive. It makes me a strong woman and mother.* (Jane, lines 59-62)

Another mother expressed her children's pride in her ability to be strong and resilient in the face of cancer. The powerful role that mothers play in their children's lives was also highlighted.

> *I know that, as their mother, I am the key figure in their lives. I know the strength we get from each other. I know we appreciate each other.* (Julia, lines 45-47)

One mother expressed that the unique experience she had shared with her children, although unpleasant, had undoubtedly strengthened their relationship.

> *I think it's you know it's in a way that something special that we have, as awful as it is, it's something special that we have that I think has made us closer, it has strengthened our relationship.* (Fran, lines 90-93)

Some keenly felt the weight of responsibility to be strong for their children, which in turn, gave them a greater insight into their children's strengths and weaknesses, with one participant noting:

> *I felt the responsibility to be 'strong' and 'brave' for my youngest son who was adopted from Ethiopia and was scared of losing another mother… I have learned a lot about my own strengths and weaknesses as well as those of my children. This gives me more insight into their own needs.* (Miranda, lines 5-6, 26-28).

It was highlighted throughout that this mutual learning empowered the women to want to be better, stronger, and more patient mothers, with several noting an improved view of themselves as a result. In turn, some noted their children are more sensitive and empathic to the needs of others.

3.38 Gratitude.

Gratitude was highlighted by participants (*n* = 9) as one quality that their breast cancer diagnosis had prompted with regard to their parenting. Some identified that they tried to look at the positives of having family and children whilst dealing with a life crisis. One mother expressed how blessed she felt to be alive to celebrate Christmas with her family. Several highlighted how appreciative they were of their children's love and support throughout their cancer experience, and the incentive they provided to remain positive.

Participants expressed gratitude in being able to celebrate both their own milestones such as completing treatment, and their children's major life milestones – initially unsure if they would be alive to celebrate them.

> *I truly cherished seeing my elder son graduate from school last year because when you're told you have cancer you initially think you're not going to be here to see your children grow up.* (Lily, lines 28-30)

The gratitude was often reciprocal, with two participants expressing that their children no longer took their mother for granted. Another was touched by the thoughtful, yet unexpected, everyday gestures her son showed toward her.

> *… I love it when my 14 year old sends me a little text message at 10 o'clock in the morning from school saying "hi mum, how are you, how's your day going?" and I think, oh, that is really lovely to get that, yeah, to get … from a teenager to hear "hi mum, how is your day going?" for no reason. You know, no reason at all.* (Fran, lines 97-102)

3.39 Supportive others.

Support was identified as a significant factor in enabling the women to fulfill their parenting roles, maintain routines and promote recovery. Most of the women (n = 14) indicated that they had both physical and emotional support from various sources, some quite unexpected. The type of support offered included meal preparation, transport – especially with regard to taking the children to and from school or sporting activities, child care and entertainment, appointment support and household chores. Whilst a few mentioned professional psychological support, many expressed that their surgeon, oncologist or health care nurse were very supportive of their situation.

> *I had absolutely amazing support! My ex husband and mother balanced the responsibility of my son when I couldn't. My friends cooked for me, brought me gifts, came over for coffee, or just cried with me. My work paid me the whole time, 9 months,*

> *that I wasn't there, and all donated gifts and time and cards that were amazing! I'll never forget being taken to a car boot, opening it and it was just full of gifts! And so much was for* [my son]. *So much support also came from a couple of older ladies I met in chemo (I was 36 and they were in their 60s, and just took me under their wing). The doctors, nurses and specialists, were sent from heaven. I couldn't have had better treatment or care. They saved my life and my sons Mum.* (Jane, lines 71-82)

Employers were identified as being particularly supportive in offering the women, and their partners, time off when they needed it, enabling the family to manage the care of both the mother and the children. Several expressed appreciation for the financial support they received, enabling them to spend more time with their children without the burden of worry for lost income.

> *I was employed by a large corporate company so had accumulated some sick leave, I was also granted special paid leave prior to my income insurance being paid and I was able to be off work for 10 months which enabled me to relax and recover. When I returned to work it was through a special rehabilitation program where I initially worked shorter hours.* (Lily, lines 55-49)

Those in rural areas identified the wonderful community support they received, with some local groups raising money to support both the cancer-affected family, and breast cancer charities. Several noted they had to manage the lack of convenience in rural areas, yet still were offered kind support from friends and the children's school.

> *I had support from everywhere, it was amazing. Um, financial support, um, food, wood, you know wood for our fire, transport, um, emotional support,* […] *for example the* [rural town] *golf club, our community organised a pink pig day, so they had a pig on a spit, and they organised a* [sic] *auction, so all the businesses, every business in* [rural town] *barr one, donated to this auction and um, they raised $21,000 for the* [rural town] *hospital, um the McGrath Foundation and our family.* […] *the coach said to* [eldest

> son] *"we want to do something for your family", um, so they organised a pink day as well. And the players donated their player match fee um, to our family, which is unbelievable. Like, we hardly knew them but they loved* [eldest son] *so much that they did that.* (Rose, lines 142-148, 152-156)

Conversely, one mother indicated she received no support at all from family or friends, and support was denied even when she initiated it from government agencies.

> *My son had difficulties going to school as a direct result of my illness. I had difficulties assisting him to overcome this and communicate with the school as I was feeling overwhelmed. He subsequently never returned to school despite connecting with child mental health services as they provided me with zilch support.* (Emma, lines 3-7)

Overall, most identified that they felt very supported during their illness and recovery, which often allowed them to spend more time with their children. Respondents also expressed that soft support, such as the expression of love and encouragement from those close – even via text or email – enabled them to cope day by day.

CHAPTER 4

Discussion

4.1 Overview

This study employed qualitative methods to explore the parenting experiences of women with breast cancer. The themes identified were: difficulty maintaining role; fear for the future; generativity; maintaining normality; togetherness; altered priorities; mutual empowerment; gratitude; and supportive others.

Consistent with previous research (Barrington & Shakespeare-Finch, 2013; Aldwin, 1994), respondents reported both growth and depreciation, in the form of negative impacts on their parenting – indicating that negative and positive changes can co-exist.

Many of the themes identified were consistent with previous research of a similar nature. However, to the best of the author's knowledge, the finding of generativity was a unique aspect found in the current study – in the context of parenting after a cancer diagnosis. The psychological construct of 'generativity' was introduced by Erik Erikson (1950) as the seventh of eight stages in his theory of psychosocial development – believed to take place between ages 40 and 65. It is thought that people who have positive relationships with others are more likely to experience feelings of generativity (Snow, 2015), and family and community involvement are the major focal points. McAdams and Guo (2015), note that a generative person is able to transform negative scenarios into positive outcomes, and shows sensitivity to the suffering of others – redemptive narratives that many of the participants in the current study displayed toward their children and others. A subsequent review of studies involving generativity in cancer survivors noted that, while Erikson (1950) described the psychological construct as a developmental hallmark of middle age in guiding and caring for the next generation, he failed to take into account unexpected life events, such as a cancer diagnosis, which can prompt the sufferer to consider issues of mortality and their legacy at an earlier stage than expected (Bellizzi, 2004). As Erikson (1968) noted: “I am what survives me” (p. 141).

As with previous studies of a similar nature, a difficulty in maintaining the parental role (Tavares et al., 2017), and fear for the future (Billhult & Segesten, 2003), were identified as ongoing challenges for the women, both during, and after, the cancer diagnosis. Interestingly, many participants who feared the return of their cancer spoke of this fear as prompting positive changes in their parenting. However, one participant noted that she would give up the growth she experienced, to not have that looming fear of the cancer returning.

Consistent with previous studies, support was considered integral to enabling the women to spend time with their children. It is thought that instances where help is offered in a collaborative framework may provide for the most growth (Tedeschi & Calhoun, 1995). These collaborations demonstrate to the sufferer that a traumatic event can be managed, and that others around them can be relied upon to provide help – changing their schemas about others in a positive direction. Discovering that one can use the traumatic event to help others is a powerful way to find meaning – as demonstrated by mothers receiving support to enable them to maintain and enhance relationships with their children.

Maintaining normality, indicated as an important factor for most of the respondents, fulfilled another function – that of creating a link between the present situation and their pre-cancer lives, to retain their identity as mothers first and foremost (Fisher & O’Connor, 2012). In line with previous findings by (Billhult & Segesten, 2003), mothers thoughts were dominated by becoming strong and well for her children.

Consistent with systematic review findings (Tavares, et al., 2017), motherhood functions as a protective factor, as the children’s care needs provide an important positive motivation to cope with the disease. Corresponding with the study by Billhult and Segesten (2003), mothers often combine their own strength with support from others to enable them to maintain a positive perspective. In a study on relational growth between mothers with cancer and daughters (Bekteshi & Kayser, 2013) mutual empowerment was cited as a relational competency linked to caring for and supporting each other's wellbeing, yet developing autonomy. In the current study, empowerment inspired their children to help not only their own mothers, but also others facing a cancer diagnosis.

It is clear that the transition to positive growth in relationships does not always follow a linear upward path (Bekteshi & Kayser, 2013). The authors who originally developed the construct of posttraumatic growth do concede that growth may not always be accompanied by less distress and increased wellbeing (Calhoun & Tedeschi, 2006). However, their data suggest that those who do experience it, from their own viewpoint at least, lead lives that are richer, fuller and more meaningful. This life, of course, comes at the expense of the distress that trauma almost always causes.

4.2 Strengths

The strengths of this research included the development of questions that enhanced the scope for both positive and negative responses, to gain rich insights into the spectrum of experiences. In addition, Calhoun and Tedeschi (2006) noted that those having experienced trauma can gain emotional relief by self-disclosing their experiences, promoting positive rumination.

Rigour was maintained throughout, as was sincerity through the use of self-reflexivity and an audit trail (Tracy, 2010). Data saturation was also achieved, suggesting that sufficient data were captured to support claims made in the research (Tracy, 2010). Likewise, credibility was enhanced through member reflections and a detailed analysis of the data.

4.3 Limitations

The findings from this study need to be viewed in the context of its limitations. Ideally, face-to-face interviews would be conducted with all participants. However, time constraints of the project and consideration for the busy lives that mothers have, meant that most of the participants responded online. Given the sensitive nature of the topic, one respondent expressed that the online method seemed less confrontational, whilst one participant noted she felt quite intimidated by the recording device in the face-to-face interview. However, the use of both online and offline methods enhanced the response rate.

It has been suggested that the PTGI may in fact measure illusory growth rather than actual growth (Christiansen, Iversen, Ambrosi, & Elklit, 2016). However, studies using significant others to corroborate the growth provide validation of the posttraumatic growth construct (Shakespeare-Finch & Barrington, 2012). A limitation of the current study is therefore an inability, due to time restraints, to triangulate the data through a comparison with growth experiences reported by the women’s partners and children.

Being exploratory in nature, the present study included participants with a variety of cancer stages and years post-diagnosis, and more importantly, children of differing developmental stages. It is thought that the level of growth, or negative impacts, may differ depending on the age and needs of their children.

Another potential limitation is that those who were motivated to take the study may be more likely to report positive effects. It is possible that participants in the current study may be more self-reflecting or engaged than the wider population, with research by Tennen (2009) noting that respondents may be motivated to claim personal progress. It should be noted that the study concerns *accounts* of experiences, rather than direct evidence of these experiences, and the findings should be viewed within this context.

The restrospective nature of the study, up to 10 years in some instances, may be considered a limitation. Research suggests that people often do not reliably recall their pre-trauma beliefs on growth issues and cannot accurately attribute the changes specifically to the traumatic event (Tennen & Affleck, 2009).

A limitation common in all self-report scales of positive growth is that they rely on retrospective accounts of perceived changes. It is thought that asking people explicitly about positive change may prompt defensive posttraumatic growth – a process thought to maintain the self-esteem of the sufferer (Scrignaro, Marini, Magrin, & Borreani, 2018). Another criticism of the PTGI is that it does not allow respondents to report negative experiences, which may increase the likelihood of a positive response bias (Park & Lechner, 2006). A possible solution is to make each item bipolar, allowing them to be rated in either a negative or positive direction, so as to better represent the change due to the crisis. However, this would force the respondent to evaluate each area as resulting in *either* positive growth, or negative depreciation – which ignores the fact that gains and losses may co-exist within the same domain (Baker et al., 2008).

4.4 Recommendations for Future

Given that there is concern of posttraumatic growth being an illusory concept, it may be of benefit to enable any potential growth to be corroborated by a partner or the children themselves – should they be of sufficient age to observe and describe changes.

Previous research has suggested that interventions may be useful to help the parent-child relationship remain stable under crisis situations (Davis Kirsch, Brandt, & Lewis, 2003). Future studies could help understand ways to prompt a positive reaction to the diagnosis, by way of personal growth in parenting.

4.5 Implications

It is hoped that this research can provide further understanding of the nature of both growth and negative experiences related to parenting after breast cancer. The evaluation of posttraumatic growth may promote an easier adaptation and transition through the cancer experience (Casellas-Grau et al., 2017) and aid in assessing future support needs. It is hoped it may inform future clinical work to initiate growth in those experiencing a cancer diagnosis, in an effort to reduce emotional distress and enhance the parent-child relationship.

4.6 Conclusions

The present study contributes to the literature by identifying both the positive and negative impacts of a mother’s breast cancer diagnosis on her experiences of parenting. It is clear that the losses and gains can co-exist, whereby one can act as a catalyst for the other. Generativity within parenting was displayed as a unique, positive and lasting outcome in the growth process, while physical and emotional support from others was identified as being integral in enabling growth experiences between mother and child. Whilst breast cancer should not be viewed as simply a precursor to growth, it is clear that it can prompt positive change including enhancing the parent-child relationship.

References

Aldwin, C. (1994). *Stress, coping, and development*. New York, NY: Guilford Press.

Australian Institute of Health and Welfare (2018). Cancer in Australia: Actual incidence data from 1982 to 2013 and mortality data from 1982 to 2014 with projections to 2017. *Asia-Pacific journal of clinical oncology, 14*, 5–15. DOI: 10.1111/ajco.12761

Baker, J., Kelly, C., Calhoun, L., Cann, A., & Tedeschi, R. (2008). An examination of posttraumatic growth and posttraumatic depreciation: Two exploratory studies. *Journal of Loss and Trauma, 13,* 450–465. DOI: 10.1080/15325020802171367

Barrington, A., & Shakespeare-Finch, J. (2013). Posttraumatic growth and posttraumatic depreciation as predictors of psychological adjustment. *Journal of Loss and Trauma, 18*, 429–443. DOI: 10.1080/15325024.2012.714210

Bekteshi, V., & Kayser, K. (2013). When a mother has cancer: Pathways to relational growth for mothers and daughters coping with cancer. *Psycho-Oncology, 22*, 2379–2385. DOI: 10.1002/pon.3299

Bellizzi, K. (2004). Expressions of generativity and posttraumatic growth in adult cancer survivors. *International Journal of Aging and Human Development, 58,* 267–287. DOI: 10.2190/DC07-CPVW-4UVE-5GK0

Billhult, A., & Segesten, K. (2003). Strength of motherhood: Nonrecurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Sciences, 17,* 122–128. DOI: 10.1046/j.1471-6712.2003.00219.x

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–101. DOI: 10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* London, UK: Sage Publications Ltd.

Britten, N. (2006). Qualitative interviews. In C. Pope & N. Mays (Eds.), *Qualitative research in health care* (3rd ed. pp. 12–20). Carlton, Vic: Blackwell.

Calhoun, L., Tedeschi, R. (1998). Posttraumatic growth: Future directions. In R. Tedeschi, C. Park, & L. Calhoun (Eds.) *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 215–238). Mahwah, NJ: Lawrence Erlbaum Associates.

Calhoun, L., & Tedeschi, R. (2006). The foundations of posttraumatic growth: An expanded framework. In L. Calhoun & R. Tedeschi (Eds.) *Handbook of posttraumatic growth: Research & practice* (pp. 3–23). Mahwah, NJ: Lawrence Erlbaum Associates.

Casellas‐Grau, A., Ochoa, C., & Ruini, C. (2017). Psychological and clinical correlates of posttraumatic growth in cancer: A systematic and critical review. *Psycho‐Oncology, 26,* 2007–2018. DOI: 10.1002/pon.4426

Christiansen, D., Iversen, T., Ambrosi, S., & Elklit, A. (2016). Post-traumatic growth: Critical review of problems with the current measurement of the term. In C. Martin, V. Preedy, & V. Patel (Eds.), *Comprehensive Guide to Post-Traumatic Stress Disorders,* (pp. 1797–1812). Cham, Switzerland: Springer. DOI 10.1007/978-3-319-08359-9_5

Cordova, M., Cunningham, L., Carlson, C., & Andrykowski, M. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology, 20,* 176–185. DOI: 10.1037//0278-6133.20.3.176

Crawford, J., Cayley, C., Lovibond, P., Wilson, P., & Hartley, C. (2011). Percentile norms and accompanying interval estimates from an Australian general adult population sample for self-report mood scales (BAI, BDI, CRSD, CES-D, DASS, DASS-21, STAI-X, STAI-Y, SRDS, and SRAS). *Australian Psychologist, 46,* 3-14. DOI:10.1111/j.1742-9544.2010.00003.x

Davis Kirsch, S., Brandt, P., & Lewis, F. (2003). Making the most of the moment: When a child's mother has breast cancer. *Cancer Nursing, 26,* 47–54.

Dickson-Swift, V., James, E., & Liamputtong, P. (2008). *Undertaking sensitive research in the health and social sciences: Managing boundaries, emotions and risks.* New York, NY: Cambridge University Press. DOI:10.1017/CBO9780511545481

Elmberger, E., Bolund, C., Magnusson, A., Lützen, K., & Andershed, B. (2008). Being a mother with cancer: Achieving a sense of balance in the transition process. *Cancer Nursing, 31*, 58-66. DOI: 10.1097/01.NCC.0000305677.90963.67

Erikson, E. (1950). *Childhood and society*. New York, NY: Norton.

Erikson, E. (1968). *Identity: Youth and crisis.* New York, NY: Norton.

Fisher, C., & O'Connor, M. (2012). "Motherhood" in the context of living with breast cancer. *Cancer Nursing, 35*, 157–163. DOI: 10.1097/NCC.0b013e31821cadde

Fitch, M., Bunston, T., & Elliot, M. (1999). When mom's sick: Changes in a mother's role and in the family after her diagnosis of cancer. *Cancer Nursing, 22*, 58–63. DOI: 10.1097/00002820-199902000-00011

Green, J., & Thorogood, N. (2009). *Qualitative methods for health research* (2nd ed.). London, UK: Sage Publications Ltd.

Harbin, A. (2015). Prescribing posttraumatic growth. *Bioethics, 29,* 671–679. DOI:10.1111/bioe.12164

Held, B. (2002). The tyranny of the positive attitude in America: Observation and speculation. *Journal of Clinical Psychology, 58*, 965–991. DOI: 10.1002/jclp.10093

Helgeson, V., Reynolds, K., & Tomich, P. (2006). A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology, 74*, 797–816. DOI: 10.1037/0022-006X.74.5.797

Helseth, S., & Ulfsæt, N. (2004). Parenting experiences during cancer. *Journal of Advanced Nursing, 52,* 38–46. DOI: 10.1111/j.1365-2648.2005.03562.x

Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York, NY: Free Press.

Janoff-Bulman, R. (2004). Posttraumatic growth: Three explanatory models. *Psychological Inquiry, 15*, 30–34.

Jefford, M., Mann, G., Nolte, L., Russell, L., Brennan, M. (2014). Follow-up of women with early stage breast cancer. *Current Breast Cancer Reports, 6,* 183–192. DOI 10.1007/s12609-014-0150-3

Lovibond, S., & Lovibond, P. (1995). Manual for the depression anxiety stress scales. Sydney: Psychology Foundation Monograph.

McAdams, D., & Guo, J. (2015). Narrating the generative life. *Psychological Science*, 26, 475–483. DOI: 10.1177/0956797614568318

McMillen, J. (2004). Posttraumatic growth: What's it all about? *Psychological Inquiry, 15,* 48–52.

Ochoa, C., Casellas-Grau, A., Vives, J., Font, A., & Borràs, J. (2017). Positive psychotherapy for distressed cancer survivors: Posttraumatic growth facilitation reduces posttraumatic stress. *International Journal of Clinical and Health Psychology, 17,* 28–37. DOI: 10.1016/j.ijchp.2016.09.002

Park, C., & Lechner, S. (2006). Measurement issues in assessing growth following stressful life experiences. In L. Calhoun & R. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research and practice* (pp. 47–67). Mahwah, NJ: Lawrence Erlbaum Associates.

Pope, C., Ziebland, S., & Mays, N. (2006). Analysing qualitative data. In C. Pope & N. Mays (Eds.), *Qualitative research in health care* (3rd ed., pp. 63–81). Oxford, UK: Blackwell Publishing.

Roder D., Farshid G., Kollias, J., Koczwara B., Karapetis C., Adams J., … Price, T. (2017). Female breast cancer management and survival: The experience of major public hospitals in South Australia over 3 decades – trends by age and in the elderly. *Journal of Evaluation in Clinical Practice, 23,* 1433–1443. DOI: 10.1111/jep.12819

Scrignaro, M., Marini, E., Magrin, M., Borreani, C. (2018). Emotive and cognitive processes in cancer patients: Linguistic profiles of post-traumatic growth. *European Journal of Cancer Care, 27*. DOI: 10.1111/ecc.12620

Shakespeare-Finch, J., & Barrington, A. (2012). Behavioural changes add validity to the construct of posttraumatic growth. *Journal of Traumatic Stress 25*, 433–439. DOI: 10.1002/jts.21730

Shand, L., Cowlishaw, S., Brooker, J., Burney, S., & Ricciardelli, L. (2015). Correlates of post-traumatic stress symptoms and growth in cancer patients: A systematic review and meta-analysis. *Psycho-Oncology, 24*, 624–634. DOI: 10.1002/pon.3719

Skeath, P., Norris, S., Katheria, V., White, J., Baker, K., Handel, D., … Berger, A. (2013). The Nature of Life-Transforming Changes Among Cancer Survivors. *Qualitative Health Research, 23*, 1155–1167. DOI: 10.1177/1049732313499074

Snow, N. (2015). Generativity and flourishing. *Journal of Moral Education, 44*, 263–277. DOI: 10.1080/03057240.2015.1043876

Stanton, A., Bower, J., & Low, C. (2006). Posttraumatic growth after cancer. In L. Calhoun & R. Tedeschi (Eds.) *Handbook of posttraumatic growth: Research & practice* (pp. 138–175). Mahwah, NJ: Lawrence Erlbaum Associates.

Steffens, R., & Andrykowski, M. (2016). Post-traumatic growth inventory: Overview. In C. R. Martin, V. R. Preedy, & V. B. Patel (Eds.) *Comprehensive guide to post-traumatic stress disorders*, (pp.2203–2219). Basel, Switzerland: Springer International. DOI 10.1007/978-3-319-08359-9_12

Stutts, W., Calhoun. L., Tedeschi. R., & Cann, A. (1994). Religion, assumptive worlds, and the aftermath of trauma: What changes? Paper presented at the Annual Convention of the American Psychological Association, Los Angeles.

SurveyMonkey Inc. (1999). San Mateo, California, USA www.surveymonkey.com

Tavares, R., Brandão, T., & Mena Matos, P. (2017). Mothers with breast cancer: A mixed-method systematic review on the impact on the parent-child relationship. *Psycho-Oncology, 27*, 367–375. DOI: 10.1002/pon.4451

Tedeschi, R., & Calhoun, L. (1995). *Trauma & transformation: Growing in the aftermath of suffering.* Thousand Oaks, CA: Sage Publications Ltd.

Tedeschi, R., & Calhoun, L. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*, 455–471. DOI: 10.1002/jts.2490090305

Tedeschi, R., & Calhoun, L. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry, 15.* 1–18.

Tennen, H., & Affleck, G. (2009). Assessing positive life change: In search of meticulous methods. In C. Park, S. Lechner, M. Antoni, & A. Stanton (Eds.), *Medical illness and positive life change: Can crisis lead to personal transformation* (pp. 31–49). Washington, DC: American Psychological Association. DOI: 10.1037/11854-002

Tracy, S. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry 16,* 837–851. DOI: 10.1177/1077800410383121

Walsh, S., Manuel, J., & Avis, N. (2005). The Impact of Breast Cancer on Younger Women’s Relationships With Their Partner and Children. *Families, Systems, & Health, 23,* 80–93. DOI: 10.1037/1091-7527.23.1.80

Appendix A: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Project Title: Experiences of Parenting Following Breast Cancer
Supervisor: Professor Deborah Turnbull
Student Researcher: Xxxxx Xxxxxxxxxx
Human Research Ethics Committee approval number: [redacted]

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?
The aim of the research is to explore the positive and negative parenting experiences of mothers with early stage breast cancer. It is hoped the research will provide a greater understanding of the impact their illness has on the relationship with their children.

Who is undertaking the project?
This research is being conducted by Professor Deborah Turnbull and Honours student Xxxxx Xxxxxxxxxx – both of the University of Adelaide, alongside Dr Jeneva Ohan from the University of Western Australia. This research will form part of the Honours degree of Bachelor of Psychological Science at the University of Adelaide under the supervision of Professor Deborah Turnbull.

Why am I being invited to participate?
You are being invited to take part in the study as you meet the eligibility criteria of being a mother who has had a breast cancer diagnosis of stage 0-II[1] in the last 2 to 10 years, with at least one child under the age of 18 at the time of diagnosis.

What am I being invited to do?
You are being invited to complete a number of questions relating to your own emotions and stress, along with any psychological change that may have occurred after this difficult life event. Open-ended questions will also be posed, so as to gather a personal perspective on how your diagnosis and treatment may have changed your experience of parenting.
If you choose to participate, you will be asked to complete the survey and open-ended interview questions in the manner most convenient to you – either online (via Survey Monkey), via phone, or in person (at a date, time and public venue suitable to you). In the interview, you will be asked to discuss your experiences of parenting after your cancer diagnosis.
If you choose to complete the research via phone or in-person, you will be asked permission for the interview to be audio recorded. If you do consent, the audiotape will be destroyed after your interview has been transcribed. If you wish, a copy of the transcript will be forwarded to you, and/or a summary of the project's findings. You will have the opportunity to review the transcript – should you wish to verify accuracy, correct errors or provide clarification.

How much time will my involvement in the project take?
It is anticipated the research will take no longer than one hour. There is no ongoing commitment.

Are there any risks associated with participating in this project?
We recognise that the interview may make you feel upset when talking about your experiences. If you do experience emotional distress during or after the research the following services are available:
Breast Cancer Network Australia Helpline: 1800 500 258
Lifeline 24 hour crisis support services: 13 11 14
[redacted]

What are the potential benefits of the research project?
Whilst this study will further our understanding of the parenting experiences of mothers who have experienced breast cancer, it should be understood that you may not directly benefit from the research.

Can I withdraw from the project?
Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time before submission of the survey.

What will happen to my information?
Please be assured that all information collected will be treated in the strictest confidence. Information will be de-identified with individual codes after data collection, to remove any information that might identify you in the final report. Audio tapes will be destroyed after the interviews have been transcribed. Participant data will be stored in digital format on the researchers private password-protected laptop during the study, with access given only to the fellow researchers on this project. A copy will also be stored on the University of Adelaide servers for a period of 12 months from completion, or up to 5 years if the research is published. The results of this study will form the basis of an Honours thesis and will not be used for other purposes.

We will not use your name in the written interview and publications will not contain any information that could identify you in any way.

Who do I contact if I have questions about the project?
If you have any queries about the study, please contact one of the researchers listed below:
Student Researcher: Xxxxx Xxxxxxxxxx at *xxxxx xxxxxx*@student.adelaide.edu.au or XXXX XXX XXX
[redacted]

What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-113). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:
Phone: +61 8 8313 6028
Email: hrec@adelaide.edu.au
Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000
Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?
If you wish to participate in this study, please contact Xxxxx Xxxxxxxxxx xxxxx.xxxxxxx@student.adelaide.edu.au or XXXX XXX XXX in the first instance. A consent form is attached – you may give verbal consent at the time of the interview, or via the Survey Monkey link provided to you.

Thank you for your time and consideration.

Yours sincerely,
Xxxxx Xxxxxxxxxx – Honours student, School of Psychology, University of Adelaide
Professor Deborah Turnbull, Supervisor, School of Psychology, University of Adelaide
Dr Jeneva Ohan, Co-researcher, School of Psychology, University of Western Australia

---

[1] With participation originally restricted to those with stage 0–II breast cancer, the Human Research Ethics Committee was further consulted on the inclusion of three respondents with diagnoses of stage III (pre-cancerous) and stage IIIa breast cancer, with approval granted to include these participants.

Appendix B: Consent Form

Human Research Ethics Committee (HREC)

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	**Experiences of Parenting Following Breast Cancer**
Ethics Approval Number:	[redacted]

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

4. Although I understand the purpose of the research project, it has also been explained that my involvement may not be of any direct benefit to me.

5. I agree to participate in the activities as outlined in the participant information sheet.
   ☐ Self-report survey ☐ Interview questions

6. I agree to the interview being audio-recorded Yes ☐ No ☐

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I have been informed that the information gained in the project may be published in a thesis and/or journal article. I have been informed that in the published materials I will not be identified and my personal results will not be divulged.

9. I agree to my non-identifiable datasets and interview transcript being shared on an online digital repository.
   Yes ☐ No ☐

10. My information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.

11. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ________________________ Signature:___________________________ Date: ____________

Researcher/Witness to complete:

I have described the nature of the research to ____
(print name of participant)

and in my opinion she/he understood the explanation.

Signature: _____________________ Position: ____________________________ Date: ____________

Appendix C: Online Post

Seeking Research Participants

STUDY TITLE:

Experiences of Parenting Following Breast Cancer

Researchers at the University of Adelaide are seeking volunteer research participants to explore the parenting experiences of mothers with early stage breast cancer. It is hoped the research will provide a greater understanding of the impact their illness has on the relationship with their children.

You may be eligible if you:

- Have experienced an early stage breast cancer diagnosis (stage 0-II)[1] in the past 2-10 years
- Are a mother with at least one child under the age of 18 at the time of diagnosis
- Are a fluent English speaker

The study may be of particular interest if you feel your diagnosis and treatment has changed your experience of parenting

What am I being invited to do?

If you choose to participate, you will be asked to complete a short survey and several open-ended interview questions in the manner most convenient to you – either online (via Survey Monkey), via phone, or in person (at a date, time and public venue suitable to you).

In the interview questions, you will be asked to discuss your experiences of parenting after your cancer diagnosis and treatment.

For further information, please contact the researcher Xxxxxx Xxxxx at xxxxxxx.xxxxxxxx@student.adelaide.edu.au

This research is being conducted by Professor Deborah Turnbull (deborah.turnbull@adelaide.edu.au) and Honours student Xxxxx Xxxxxxx – both of the University of Adelaide, alongside Dr Jeneva Ohan from the University of Western Australia.

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number [redacted]).

---

[1] With participation originally restricted to those with stage 0–II breast cancer, the Human Research Ethics Committee was further consulted on the inclusion of three respondents with diagnoses of stage III (pre-cancerous) and stage IIIa breast cancer, with approval granted to include these participants.

Appendix D: Recruitment Poster

THE UNIVERSITY
of ADELAIDE

Seeking Research Participants

STUDY TITLE:

Experiences of Parenting Following Breast Cancer

Being a mother with breast cancer can be an extraordinary challenge. Researchers at the University of Adelaide are seeking volunteer research participants to explore the parenting experiences of mothers with early stage breast cancer. It is hoped the research will provide a greater understanding of the impact their illness has on the relationship with their children.

You may be eligible if you:

- Have experienced an early stage breast cancer diagnosis (stage 0-II)[1] in the past 2-10 years
- Are a mother with at least one child under 18 at the time of diagnosis.
- Are a fluent English speaker

The study may be of particular interest if you feel your diagnosis has changed your experience of parenting.

For further information, please contact the researcher Xxxxx Xxxxxxxx at xxxxxxxx.xxxxxxxx@student.adelaide.edu.au
This research is being conducted by Professor Deborah Turnbull (deborah.turnbull@adelaide.edu.au) and Honours student Xxxxxxx Xxxxxx – both of the University of Adelaide, alongside Dr Jeneva Ohan from the University of Western Australia.

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number [redacted].

---

[1] With participation originally restricted to those with stage 0–II breast cancer, the Human Research Ethics Committee was further consulted on the inclusion of three respondents with diagnoses of stage III (pre-cancerous) and stage IIIa breast cancer, with approval granted to include these participants.

Appendix E: BCNA Email to Potential Participants

Research opportunity: Study exploring the experiences of parenting following breast cancer

Dear

Researchers at the University of Adelaide are conducting a study exploring the experiences of parents diagnosed with early breast cancer. The research will explore how a breast cancer diagnosis may change women's experience of parenting.

Who can participate?
You can participate in this study if you:

- have been diagnosed with early breast cancer (stage 0-II)[1] in the last 2 to 10 years
- Have (at least) one child under the age of 18 years when diagnosed with cancer

What does the study involve?
You will be asked to participate in a survey, comprising some questions about yourself and your diagnosis of breast cancer, as well as some open-ended and multiple choice questions about how your diagnosis may have changed or impacted your experience of parenting.

How do I take part?
If you wish to participate in this study, please access via the Survey Monkey link https://www.surveymonkey.com/r/ParentingAfterBreastCancer_BCNA
Please note you will be able to go back and edit responses if you wish, or complete a portion of the survey and return later to finish the rest (it will save up to the last full page completed).
If you have any queries, please contact Xxxxx Xxxxxxxxxx, Honours student, School of Psychology, University of Adelaide, by emailing xxxx.xxxxxxx@student.adelaide.edu.au or calling XXXX XXX XXX.
More information is also available via the Participant Information Statement, which forms part of the survey preamble with consent given via a tick box.
The researchers make sure that the information you provide is kept confidential (your information will be kept securely and only used for the purpose it was collected for). By taking this survey you are providing your consent (agreement) for the researchers to collect and store your answers on Survey Monkey's overseas server (large computer).
Your name and email address are collected only to enable a transcript to be forwarded to you, should you wish to verify accuracy or provide clarification – and/or to receive a summary of the project's findings at the conclusion of the study. Personal information will be de-identified with individual codes after data collection, to remove any information that might identify you in the final report.
Thanks very much for taking the time to consider this opportunity.

Warm regards,

Lisa Morstyn
Senior Policy Officer

---

[1] With participation originally restricted to those with stage 0–II breast cancer, the Human Research Ethics Committee was further consulted on the inclusion of three respondents with diagnoses of stage III (pre-cancerous) and stage IIIa breast cancer, with approval granted to include these participants.

Appendix F: Participant Demographics and Scales

PARTICIPANT SURVEY

Experiences of Parenting Following Breast Cancer

Thank you for taking the time to participate in this study exploring the parenting experiences of mothers with early stage breast cancer.

Section 1: Demographic Information:

Name:________________________________ Age: ____________________

When was your breast cancer diagnosed? ________________________________

What stage is/was your cancer? ____

Type of breast cancer: ____

Node involvement: Yes ☐ No ☐ Metastasis: Yes ☐ No ☐

Please provide a description of your treatment:_______________________________

____

____

____

____

Which best describes you? Biological parent ☐ Adoptive parent ☐ Step parent ☐

How many children do you have, and what are their ages and genders?

____

____

____

____

Which best describes your family situation? Single parent family ☐ Two-parent family ☐

Do your children reside with you? Yes ☐ No ☐

Which best describes your highest level of education?
High school ☐ Degree or diploma ☐ Postgraduate degree ☐

How often do you have difficulty meeting basic living costs, bills etc?
Daily ☐ Weekly ☐ Monthly ☐ Never ☐

Continued over…

Section 2:

Please read each statement and select the response that best indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 = ***Did not apply*** to me at all ***(NEVER)***

1 = Applied to me to ***some degree***, or ***some*** of the time ***(SOMETIMES)***

2 = Applied to me to a ***considerable degree*** or a ***good part*** of the time ***(OFTEN)***

3 = Applied to me ***very much*** or ***most*** of the time ***(ALMOST ALWAYS)***

1.	I found it hard to wind down	0	1	2	3
2.	I was aware of dryness of my mouth	0	1	2	3
3.	I couldn’t seem to experience any positive feeling at all	0	1	2	3
4.	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5.	I found it difficult to work up the initiative to do things	0	1	2	3
6.	I tended to over-react to situations	0	1	2	3
7.	I experienced trembling (e.g. in the hands)	0	1	2	3
8.	I felt that I was using a lot of nervous energy	0	1	2	3
9.	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10.	I felt that I had nothing to look forward to	0	1	2	3
11.	I found myself getting agitated	0	1	2	3
12.	I found it difficult to relax	0	1	2	3
13.	I felt down-hearted and blue	0	1	2	3
14.	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15.	I felt I was close to panic	0	1	2	3
16.	I was unable to become enthusiastic about anything	0	1	2	3
17.	I felt I wasn’t worth much as a person	0	1	2	3
18.	I felt that I was rather touchy	0	1	2	3
19.	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20.	I felt scared without any good reason	0	1	2	3
21.	I felt that life was meaningless	0	1	2	3

Section 3:

Indicate for each of the statements below the degree to which this change occurred in your life *as a result of your breast cancer*, using the following scale:

1 = I ***did not experience*** this change as a result of my crisis

2 = I experienced this change to a ***very small degree*** as a result of my crisis

3 = I experienced this change to a ***small degree*** as a result of my crisis

4 = I experienced this change to a ***moderate degree*** as a result of my crisis

5 = I experienced this change to a ***great degree*** as a result of my crisis

6 = I experienced this change to a ***very great degree*** as a result of my crisis

1.	My priorities about what is important in life	1	2	3	4	5	6
2.	I'm more likely to try to change things that need changing	1	2	3	4	5	6
3.	An appreciation for the value of my own life	1	2	3	4	5	6
4.	A feeling of self-reliance	1	2	3	4	5	6
5.	A better understanding of spiritual matters	1	2	3	4	5	6
6.	Knowing that I can count on people in times of trouble	1	2	3	4	5	6
7.	A sense of closeness with others	1	2	3	4	5	6
8.	Knowing I can handle difficulties	1	2	3	4	5	6
9.	A willingness to express my emotions	1	2	3	4	5	6
10.	Being able to accept the way things work out	1	2	3	4	5	6
11.	Appreciating each day	1	2	3	4	5	6
12.	Having compassion for others	1	2	3	4	5	6
13.	I'm able to do better things with my life	1	2	3	4	5	6
14.	New opportunities are available which wouldn't have been otherwise	1	2	3	4	5	6
15.	Putting effort into my relationships	1	2	3	4	5	6
16.	I have a stronger religious faith	1	2	3	4	5	6
17.	I discovered that I'm stronger than I thought I was	1	2	3	4	5	6
18.	I learned a great deal about how wonderful people are	1	2	3	4	5	6
19.	I developed new interests	1	2	3	4	5	6
20.	I accept needing others	1	2	3	4	5	6
21.	I established a new path for my life	1	2	3	4	5	6

Appendix G: Interview Guide

PARTICIPANT INTERVIEW:

[FACE-TO-FACE / PHONE INTERVIEW VERSION]

Experiences of Parenting Following Breast Cancer

Section 4:

We would like you to be as open as you can regarding the following questions. Remember that you cannot be identified in the final thesis.

1. How were your roles and responsibilities as a mother impacted by your illness?
   - *How did you feel about this? Was it welcomed or did you feel any resentment or loss because of this change?*
   - *Have these changes (if any) been redefined once again as time moves forward?*

2. How did your relationship or interaction with your children change throughout your diagnosis and treatment?
   - *If so, can you describe a defining moment in which you noticed the changing relationship with your children?*

3. How has your experience of parenting changed as a result of your breast cancer experience?
   - *Has it been both positively and negatively impacted?*
   - *What do you feel you have learned about parenting through this experience?*

4. In what ways do you feel the relationship between you and your children has been strengthened or weakened as a result of your breast cancer experience?
   - *If a strengthened relationship is expressed:* Can you suggest an example of a time when your bond was very strong?
   - *Can you describe an instance when this occurred?*

5. In what ways has your view of yourself as a mother changed?
   - *Has this changed over time, since your diagnosis?*

6. Can you describe the kind of support from your family, community, employer or medical team that made it easier for you to parent your children?
   - *Were there any barriers?*

PARTICIPANT INTERVIEW

[SURVEYMONKEY ONLINE VERSION]

Experiences of Parenting Following Breast Cancer

Section 4:

We would like you to be as open as you can regarding the following questions. Remember that you cannot be identified in the final thesis.

1. How were your roles and responsibilities as a mother impacted by your illness? How did you feel about this?
2. How did your relationship or interaction with your children change throughout your diagnosis and treatment? Can you describe a defining moment?
3. How has your experience of parenting changed as a result of your breast cancer experience? Has it been both positively and negatively impacted?
4. In what ways do you feel the relationship between you and your children has been strengthened or weakened as a result of your breast cancer experience? Can you describe an instance when this occurred?
5. In what ways has your view of yourself as a mother changed?
6. Can you describe the kind of support from your family, community, employer or medical team that made it easier for you to parent your children?

Appendix H: Sample of SurveyMonkey Online Version

Experiences of Parenting following Breast Cancer

PARTICIPANT INFORMATION SHEET

THE UNIVERSITY of ADELAIDE

Project Title: Experiences of Parenting Following Breast Cancer
Supervisor: Professor Deborah Turnbull
Student Researcher: [redacted]
Human Research Ethics Committee approval number [redacted]

Dear Participant,
You are invited to participate in the research project described below.

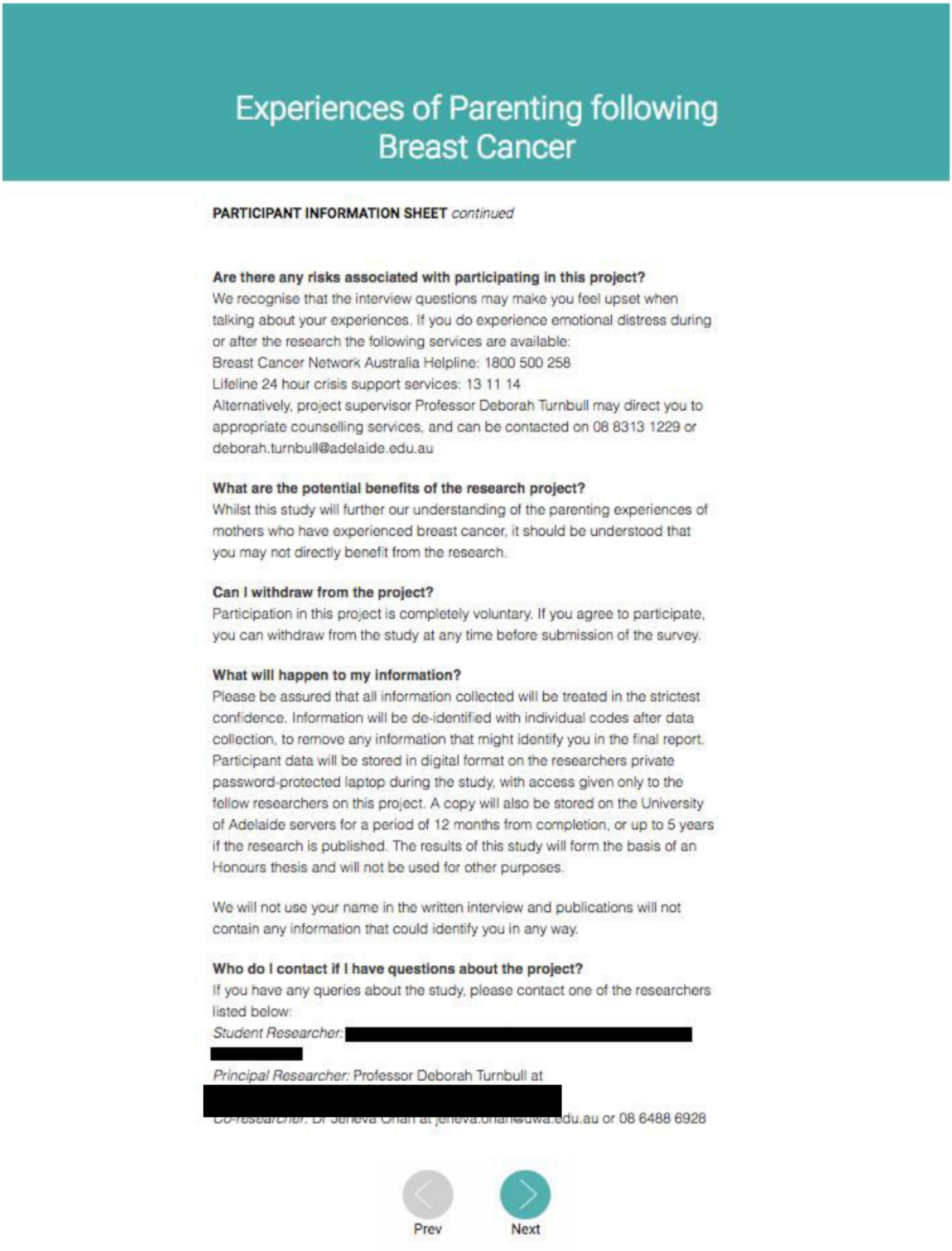
What is the project about?
The aim of the research is to explore the positive and negative parenting experiences of mothers with early stage breast cancer. It is hoped the research will provide a greater understanding of the impact their illness has on the relationship with their children.

Who is undertaking the project?
This research is being conducted by Professor Deborah Turnbull and Honours student [redacted] - both of the University of Adelaide, alongside Dr Jeneva Ohan from the University of Western Australia. This research will form part of the Honours degree of Bachelor of Psychological Science at the University of Adelaide under the supervision of Professor Deborah Turnbull.

Why am I being invited to participate?
You are being invited to take part in the study as you meet the eligibility criteria of being a mother who has had a breast cancer diagnosis of stage 0-II in the last 2 to 10 years, with at least one child under the age of 18 at the time of diagnosis.

What am I being invited to do?
You are being invited to complete a number of questions relating to your own emotions and stress, along with any psychological change that may have occurred after this difficult life event. Open-ended questions will also be posed, so as to gather a personal perspective on how your diagnosis and treatment may have changed your experience of parenting.
If you choose to participate, you will be asked to complete the survey and open-ended questions both online.
If you wish, a copy of the open-ended question transcript will be forwarded to you, and/or a summary of the project's findings. You will have the opportunity to review the transcript – should you wish to verify accuracy, correct errors or provide clarification.

How much time will my involvement in the project take?
It is anticipated the research will take no longer than one hour. There is no ongoing commitment.



Experiences of Parenting following Breast Cancer

PARTICIPANT INFORMATION SHEET *continued*

Are there any risks associated with participating in this project?
We recognise that the interview questions may make you feel upset when talking about your experiences. If you do experience emotional distress during or after the research the following services are available:
Breast Cancer Network Australia Helpline: 1800 500 258
Lifeline 24 hour crisis support services: 13 11 14
Alternatively, project supervisor Professor Deborah Turnbull may direct you to appropriate counselling services, and can be contacted on 08 8313 1229 or deborah.turnbull@adelaide.edu.au

What are the potential benefits of the research project?
Whilst this study will further our understanding of the parenting experiences of mothers who have experienced breast cancer, it should be understood that you may not directly benefit from the research.

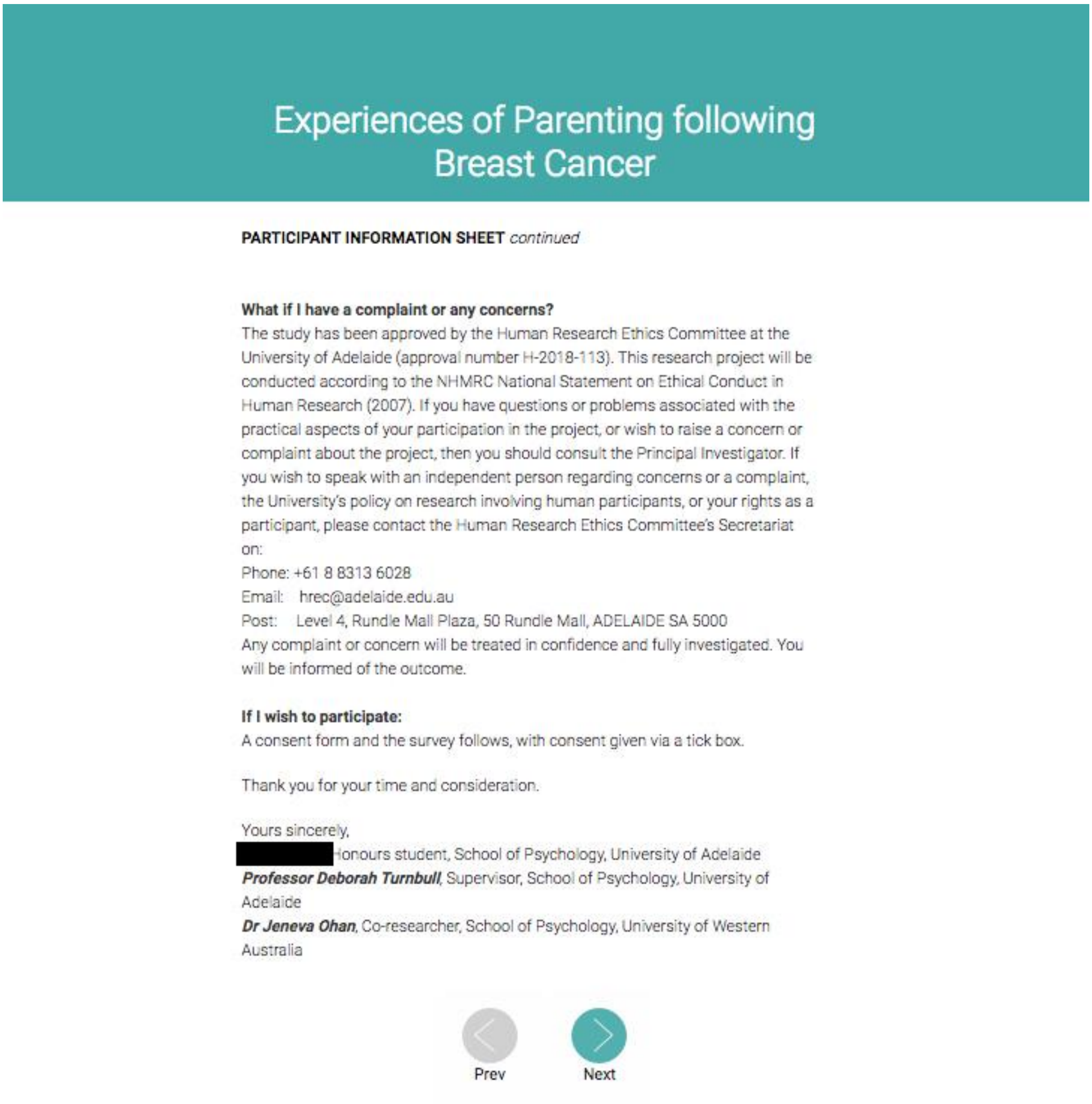
Can I withdraw from the project?
Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time before submission of the survey.

What will happen to my information?
Please be assured that all information collected will be treated in the strictest confidence. Information will be de-identified with individual codes after data collection, to remove any information that might identify you in the final report. Participant data will be stored in digital format on the researchers private password-protected laptop during the study, with access given only to the fellow researchers on this project. A copy will also be stored on the University of Adelaide servers for a period of 12 months from completion, or up to 5 years if the research is published. The results of this study will form the basis of an Honours thesis and will not be used for other purposes.

We will not use your name in the written interview and publications will not contain any information that could identify you in any way.

Who do I contact if I have questions about the project?
If you have any queries about the study, please contact one of the researchers listed below:
Student Researcher: [redacted]

Principal Researcher: Professor Deborah Turnbull at
[redacted]edu.au or 08 6488 6928



Experiences of Parenting following Breast Cancer

PARTICIPANT INFORMATION SHEET *continued*

What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-113). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (2007). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

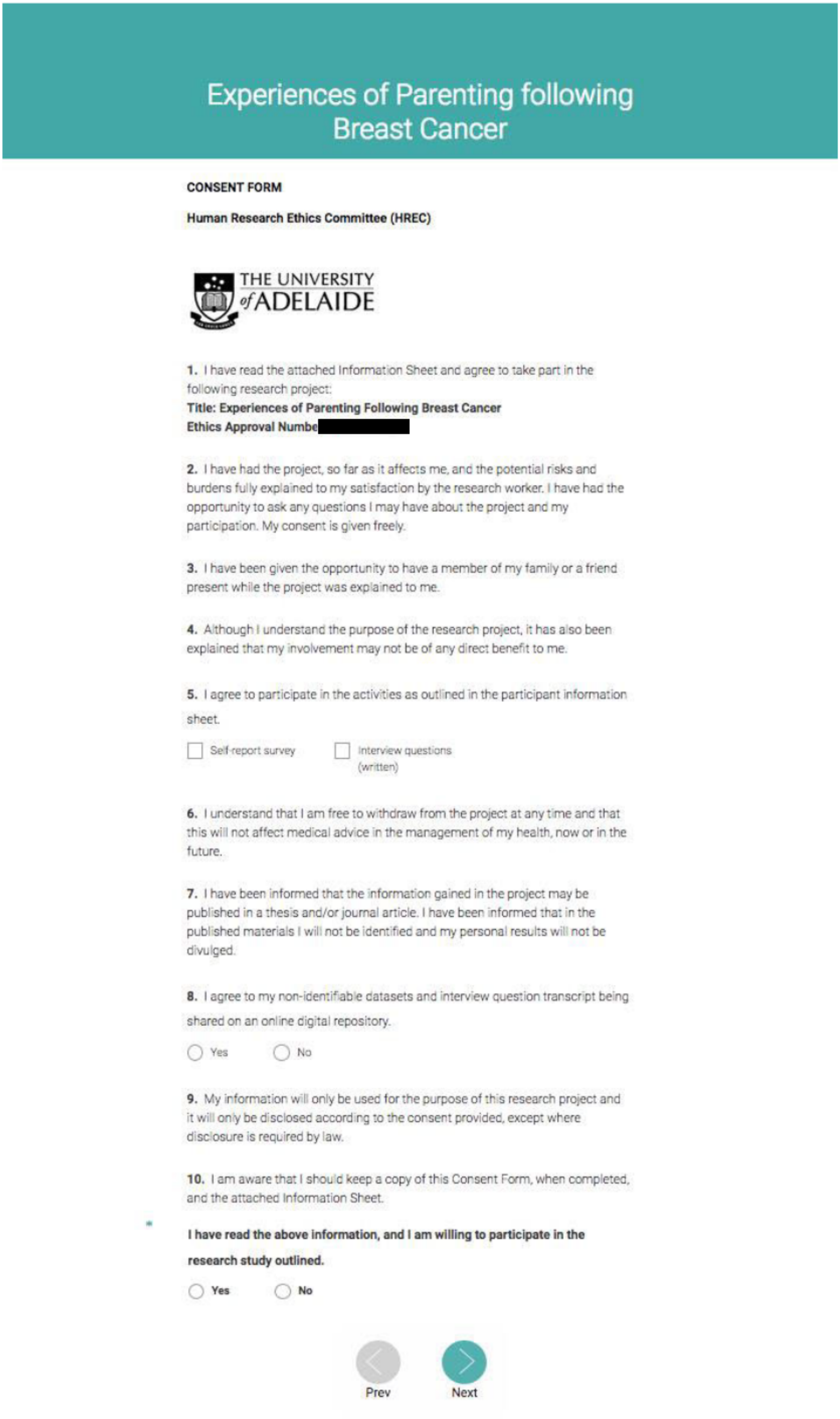
Phone: +61 8 8313 6028
Email: hrec@adelaide.edu.au
Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I wish to participate:
A consent form and the survey follows, with consent given via a tick box.

Thank you for your time and consideration.

Yours sincerely,
[redacted]onours student, School of Psychology, University of Adelaide
Professor Deborah Turnbull, Supervisor, School of Psychology, University of Adelaide
Dr Jeneva Ohan, Co-researcher, School of Psychology, University of Western Australia



Experiences of Parenting following Breast Cancer

CONSENT FORM

Human Research Ethics Committee (HREC)

THE UNIVERSITY *of* ADELAIDE

1. I have read the attached Information Sheet and agree to take part in the following research project:
Title: Experiences of Parenting Following Breast Cancer
Ethics Approval Numbe[redacted]

2. I have had the project, so far as it affects me, and the potential risks and burdens fully explained to my satisfaction by the research worker. I have had the opportunity to ask any questions I may have about the project and my participation. My consent is given freely.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

4. Although I understand the purpose of the research project, it has also been explained that my involvement may not be of any direct benefit to me.

5. I agree to participate in the activities as outlined in the participant information sheet.

☐ Self-report survey ☐ Interview questions (written)

6. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

7. I have been informed that the information gained in the project may be published in a thesis and/or journal article. I have been informed that in the published materials I will not be identified and my personal results will not be divulged.

8. I agree to my non-identifiable datasets and interview question transcript being shared on an online digital repository.

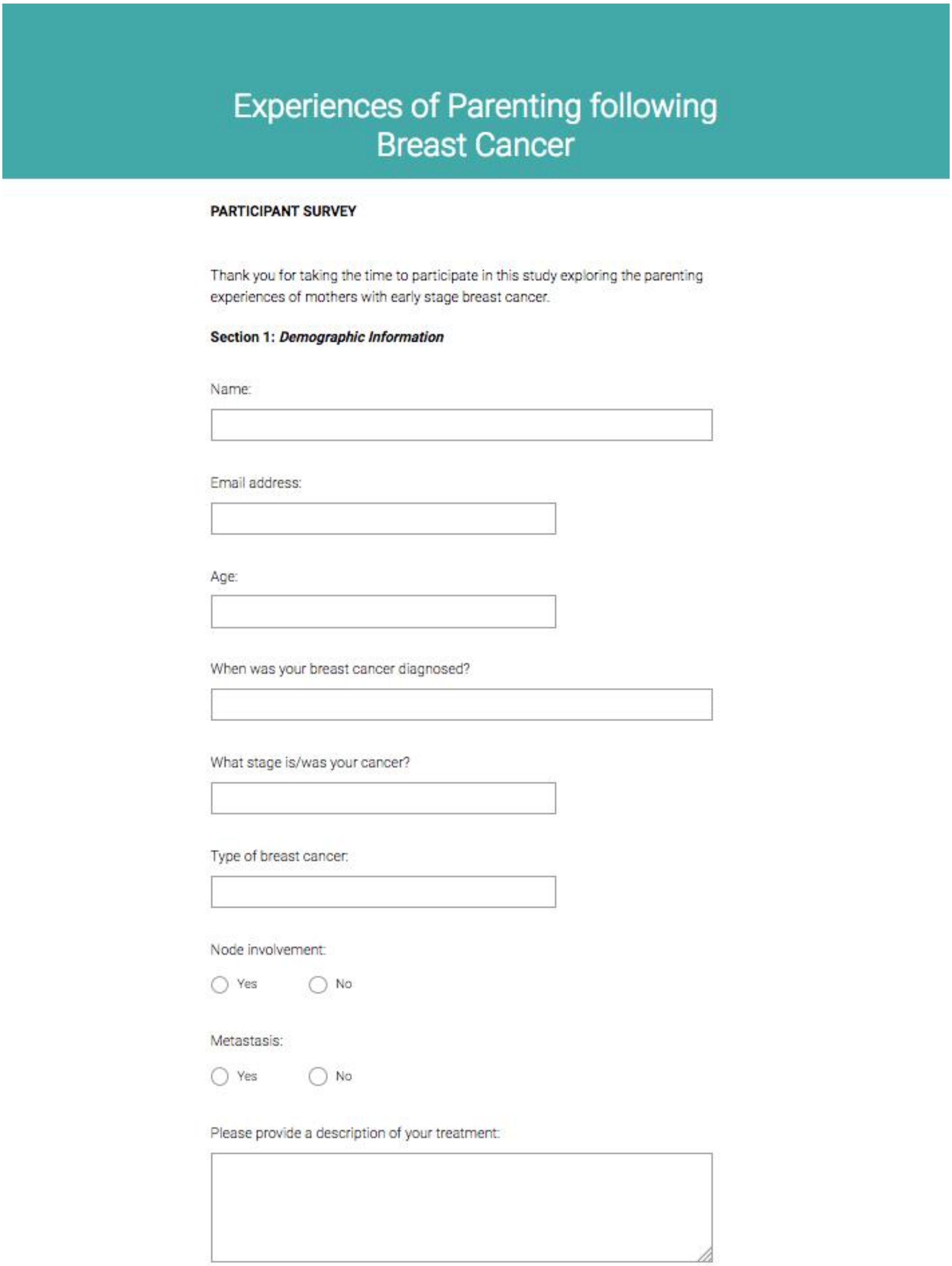
○ Yes ○ No

9. My information will only be used for the purpose of this research project and it will only be disclosed according to the consent provided, except where disclosure is required by law.

10. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

* **I have read the above information, and I am willing to participate in the research study outlined.**

○ **Yes** ○ **No**



Experiences of Parenting following Breast Cancer

PARTICIPANT SURVEY

Thank you for taking the time to participate in this study exploring the parenting experiences of mothers with early stage breast cancer.

Section 1: *Demographic Information*

Name:

Email address:

Age:

When was your breast cancer diagnosed?

What stage is/was your cancer?

Type of breast cancer:

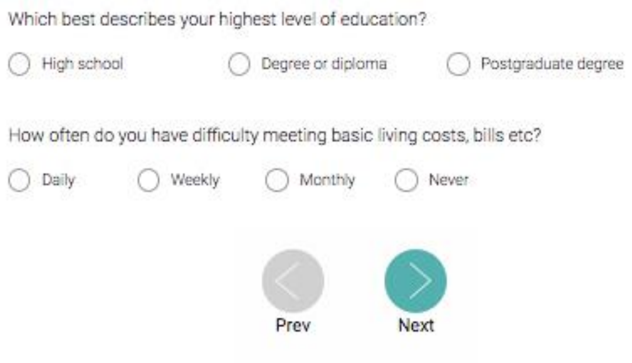
Node involvement:

○ Yes ○ No

Metastasis:

○ Yes ○ No

Please provide a description of your treatment:

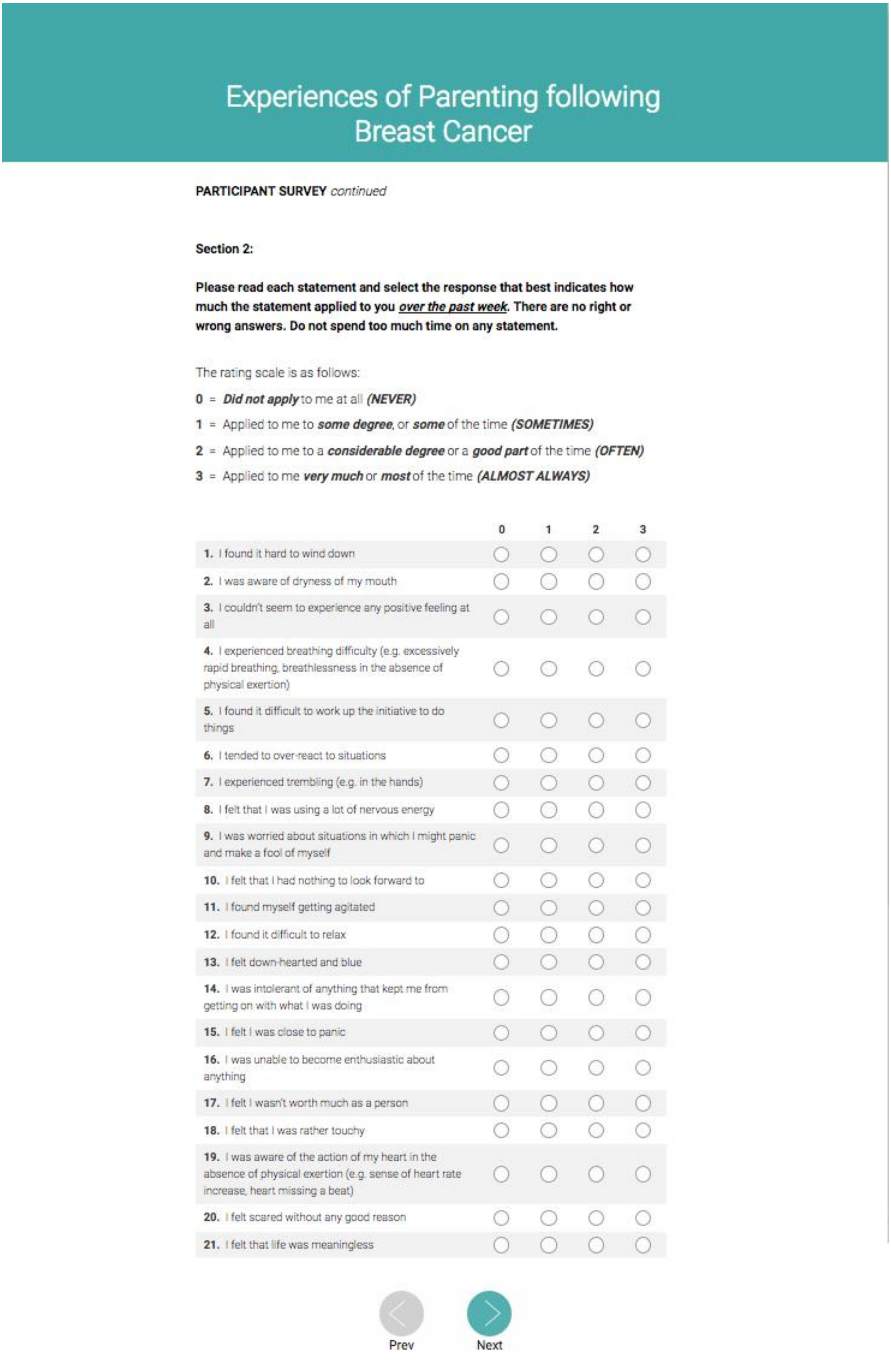


Which best describes your highest level of education?

○ High school ○ Degree or diploma ○ Postgraduate degree

How often do you have difficulty meeting basic living costs, bills etc?

○ Daily ○ Weekly ○ Monthly ○ Never



Experiences of Parenting following Breast Cancer

PARTICIPANT SURVEY *continued*

Section 2:

Please read each statement and select the response that best indicates how much the statement applied to you *<u>over the past week</u>*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

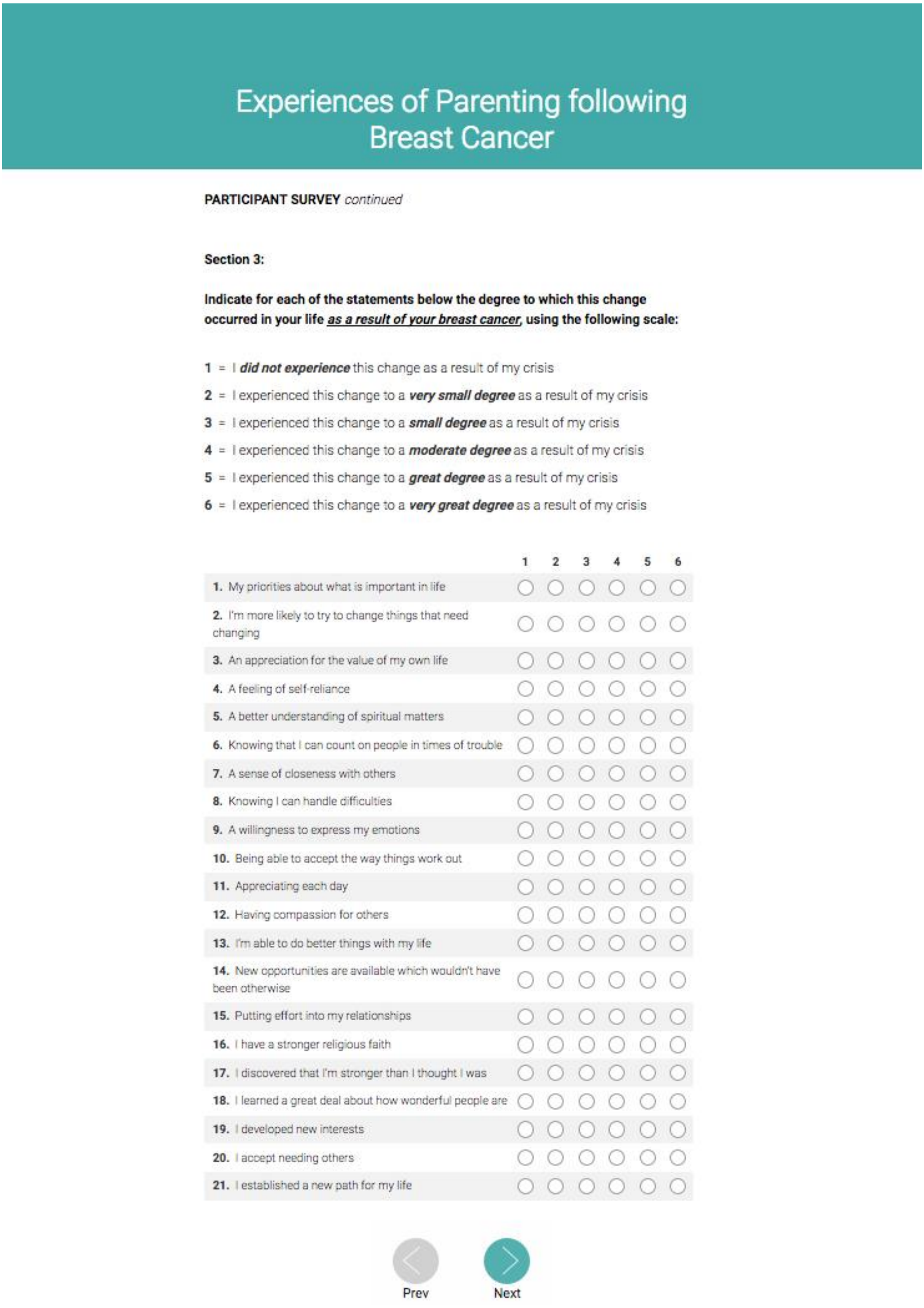
0 = ***Did not apply*** to me at all ***(NEVER)***

1 = Applied to me to ***some degree***, or ***some*** of the time ***(SOMETIMES)***

2 = Applied to me to a ***considerable degree*** or a ***good part*** of the time ***(OFTEN)***

3 = Applied to me ***very much*** or ***most*** of the time ***(ALMOST ALWAYS)***

	0	1	2	3
1. I found it hard to wind down	○	○	○	○
2. I was aware of dryness of my mouth	○	○	○	○
3. I couldn't seem to experience any positive feeling at all	○	○	○	○
4. I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	○	○	○	○
5. I found it difficult to work up the initiative to do things	○	○	○	○
6. I tended to over-react to situations	○	○	○	○
7. I experienced trembling (e.g. in the hands)	○	○	○	○
8. I felt that I was using a lot of nervous energy	○	○	○	○
9. I was worried about situations in which I might panic and make a fool of myself	○	○	○	○
10. I felt that I had nothing to look forward to	○	○	○	○
11. I found myself getting agitated	○	○	○	○
12. I found it difficult to relax	○	○	○	○
13. I felt down-hearted and blue	○	○	○	○
14. I was intolerant of anything that kept me from getting on with what I was doing	○	○	○	○
15. I felt I was close to panic	○	○	○	○
16. I was unable to become enthusiastic about anything	○	○	○	○
17. I felt I wasn't worth much as a person	○	○	○	○
18. I felt that I was rather touchy	○	○	○	○
19. I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	○	○	○	○
20. I felt scared without any good reason	○	○	○	○
21. I felt that life was meaningless	○	○	○	○



Experiences of Parenting following Breast Cancer

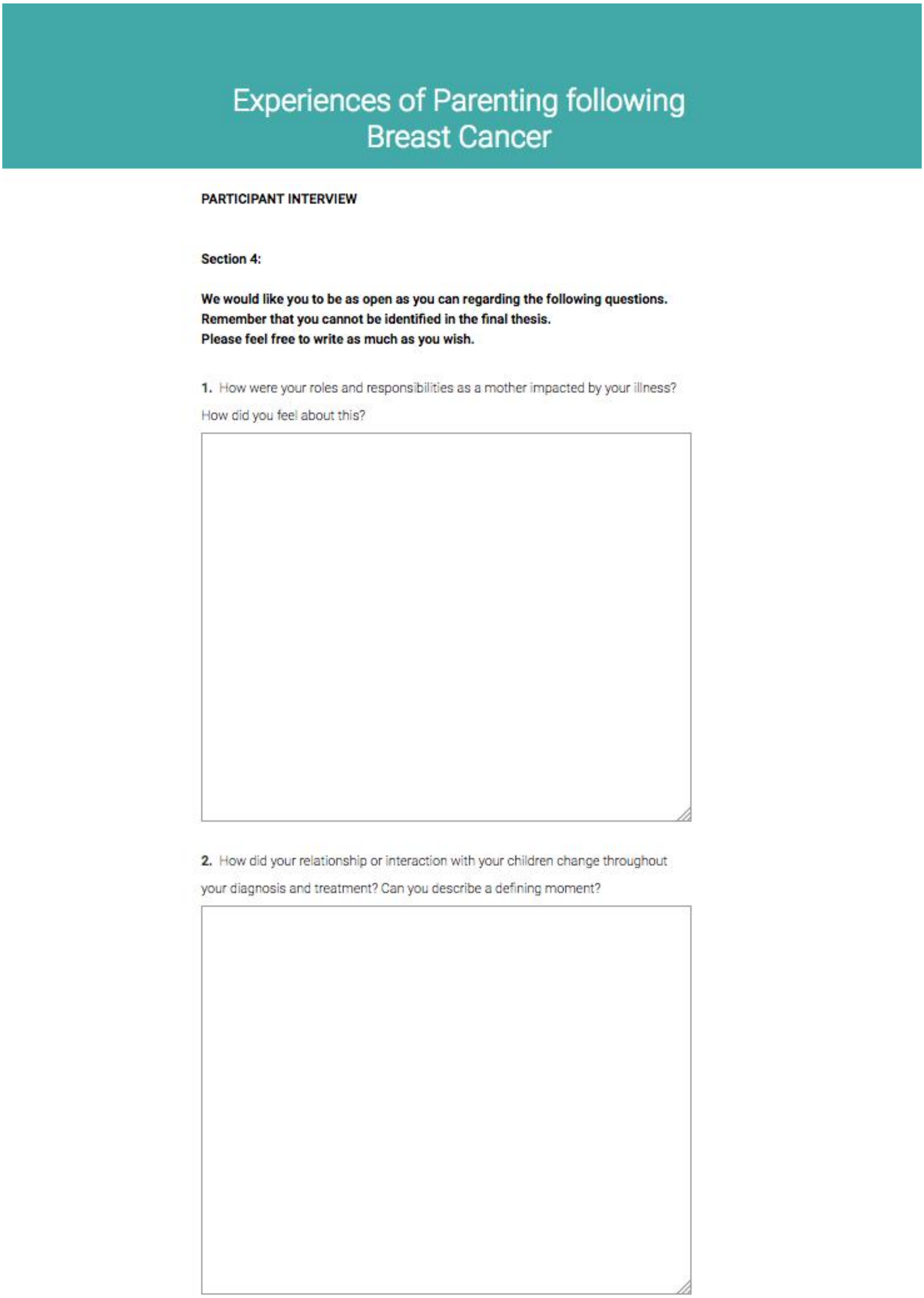
PARTICIPANT SURVEY *continued*

Section 3:

Indicate for each of the statements below the degree to which this change occurred in your life *as a result of your breast cancer*, using the following scale:

1 = I ***did not experience*** this change as a result of my crisis
2 = I experienced this change to a ***very small degree*** as a result of my crisis
3 = I experienced this change to a ***small degree*** as a result of my crisis
4 = I experienced this change to a ***moderate degree*** as a result of my crisis
5 = I experienced this change to a ***great degree*** as a result of my crisis
6 = I experienced this change to a ***very great degree*** as a result of my crisis

	1	2	3	4	5	6
1. My priorities about what is important in life	○	○	○	○	○	○
2. I'm more likely to try to change things that need changing	○	○	○	○	○	○
3. An appreciation for the value of my own life	○	○	○	○	○	○
4. A feeling of self-reliance	○	○	○	○	○	○
5. A better understanding of spiritual matters	○	○	○	○	○	○
6. Knowing that I can count on people in times of trouble	○	○	○	○	○	○
7. A sense of closeness with others	○	○	○	○	○	○
8. Knowing I can handle difficulties	○	○	○	○	○	○
9. A willingness to express my emotions	○	○	○	○	○	○
10. Being able to accept the way things work out	○	○	○	○	○	○
11. Appreciating each day	○	○	○	○	○	○
12. Having compassion for others	○	○	○	○	○	○
13. I'm able to do better things with my life	○	○	○	○	○	○
14. New opportunities are available which wouldn't have been otherwise	○	○	○	○	○	○
15. Putting effort into my relationships	○	○	○	○	○	○
16. I have a stronger religious faith	○	○	○	○	○	○
17. I discovered that I'm stronger than I thought I was	○	○	○	○	○	○
18. I learned a great deal about how wonderful people are	○	○	○	○	○	○
19. I developed new interests	○	○	○	○	○	○
20. I accept needing others	○	○	○	○	○	○
21. I established a new path for my life	○	○	○	○	○	○



Experiences of Parenting following Breast Cancer

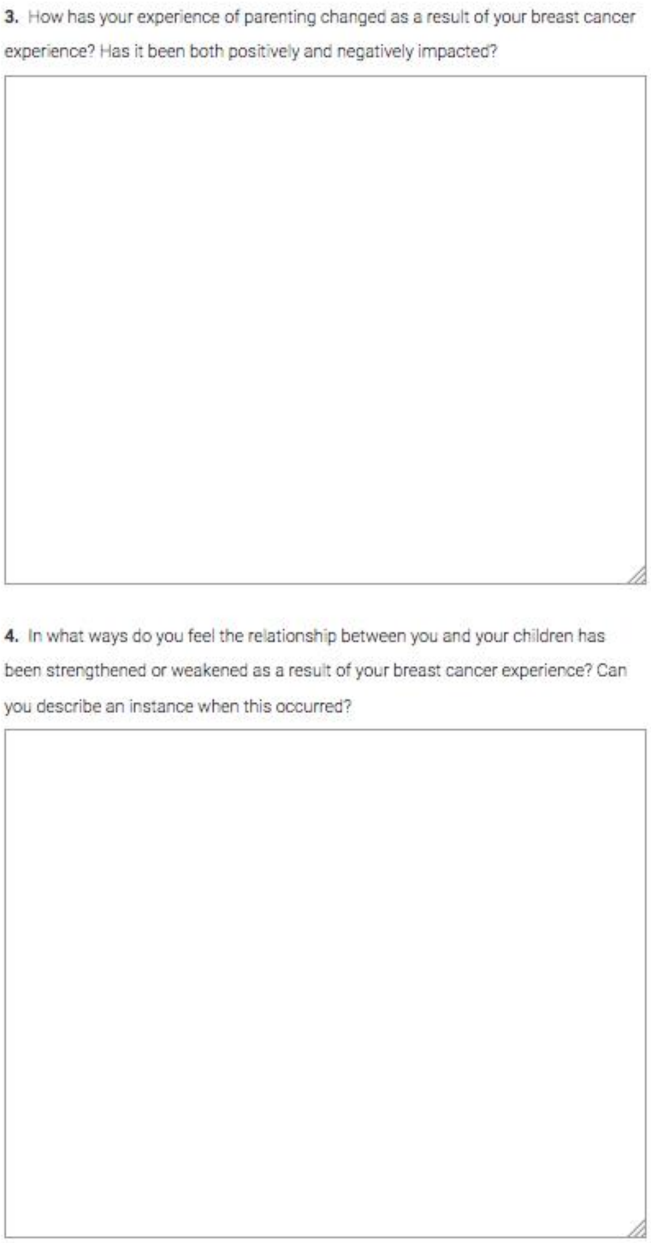
PARTICIPANT INTERVIEW

Section 4:

We would like you to be as open as you can regarding the following questions.
Remember that you cannot be identified in the final thesis.
Please feel free to write as much as you wish.

1. How were your roles and responsibilities as a mother impacted by your illness? How did you feel about this?

2. How did your relationship or interaction with your children change throughout your diagnosis and treatment? Can you describe a defining moment?



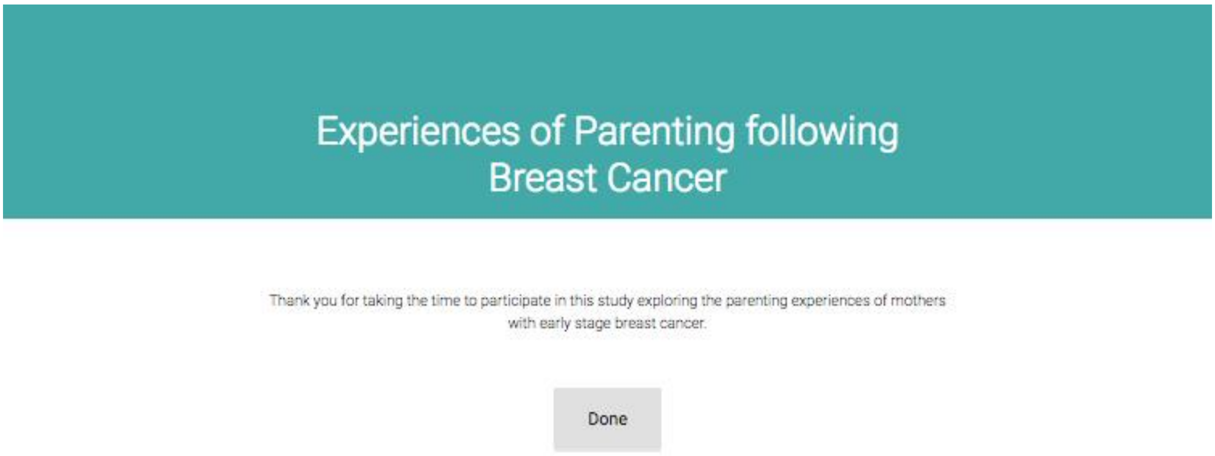
3. How has your experience of parenting changed as a result of your breast cancer experience? Has it been both positively and negatively impacted?

4. In what ways do you feel the relationship between you and your children has been strengthened or weakened as a result of your breast cancer experience? Can you describe an instance when this occurred?

5. In what ways has your view of yourself as a mother changed?

6. Can you describe the kind of support from your family, community, employer or medical team that made it easier for you to parent your children?

Thank you for your generosity in sharing your thoughts and experiences.



Experiences of Parenting following Breast Cancer

Thank you for taking the time to participate in this study exploring the parenting experiences of mothers with early stage breast cancer.

Appendix I: Saturation Table

	Interviewee														
Theme	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Negative impacts															
Difficulty maintaining role (12)	X	X	X		X	X	X	X		X	X	X		X	X
Fear for the future (8)	X	X	X						X	X	X	X		X	
Positive impacts															
Generativity (10)		X		X	X	X		X	X	X		X		X	X
Maintaining normality (10)	X	X	X	X			X		X	X	X	X		X	
Togetherness (15)	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Altered priorities (7)	X	X						X		X			X	X	X
Mutual empowerment (11)	X	X	X	X	X		X	X		X		X	X		X
Gratitude (9)	X		X				X	X	X		X		X	X	X
Supportive others (14)	X	X		X	X	X	X	X	X	X	X	X	X	X	X