EXPERIENTIAL AVOIDANCE: ASSOCIATIONS WITH QUALITY OF LIFE, DISTRESS, AND FEAR OF RECURRENCE AMONG EARLY BREAST CANCER SURVIVORS LIVING IN REGIONAL AUSTRALIA

A Thesis submitted by

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ABSTRACT

Women survivors of early breast cancer living in regional Australia experience unique challenges to their wellbeing starting with treatment choices as patients, to accessibility of practical and psychological services to address unmet needs as survivors. Targeting psychological interventions to the mechanisms of change proposed for quality of life, psychological distress, and fear of cancer recurrence is especially required in regional settings where resources are scarce. Preliminary information suggests that acceptance and commitment therapy (ACT) may be a theoretical and practical fit for improving quality of life in regional breast cancer survivors through targeting of experiential avoidance to increase adaptive coping. Study 1 was a pilot, unblinded, three-arm crossover randomised control trial of 20 women within two years of completing primary treatment for early breast cancer. In this study, experiential avoidance correlated negatively with quality of life, and positively with fear of cancer recurrence. Results indicated that there were individual differences in how ACT intervention impacted distress, fear, and avoidance. Not all improvements could be attributed to a reduction in experiential avoidance. A second study sought to clarify these variables and current quality of life for women in regional Australia. Study 2 was a cross-sectional survey of 538 participants that considered the role of experiential avoidance in quality of life for regional women survivors of early breast cancer. The survey included established demographic, social, psychological, and disease characteristic predictors of quality of life. Experiential avoidance was a significant predictor in a model that contained these established and strong predictors, which included chemotherapy, financial strain, exercise, social support, and time since treatment. The practical implications of this research are the improved targeting of variables that improve quality of life outcomes specific to regional breast cancer survivors, in a context where there is health and resource disparity. The main limitations were sampling biases and lack of representativeness of certain marginalised groups such as Aboriginal and Torres Strait Islanders Australians. Strengths of this research were the focus on clinical utility and the understanding of quality of life holistically. Future research directions include targeted recruitment of marginalised groups and the use of measures that capture more processes of ACT to explore avenues other than experiential avoidance through which ACT may improve quality of life for regional breast cancer survivors.

CERTIFICATION OF THESIS

I, Ing-Chen May Chi, declare that the PhD Thesis entitled Experiential Avoidance: Associations With Quality Of Life, Distress, And Fear Of Recurrence Among Early Breast Cancer Survivors Living In Regional Australia is not more than 100,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references, and footnotes. The thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signed:  Date: 15 May 2022

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Student and supervisors' signatures of endorsement are held at the University.

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CHAPTER 1 - INTRODUCTION

An Overview of Wellbeing After Breast Cancer

To be in a position where we can ask 'what's next?' following breast cancer treatment is the result of investment into breast cancer medical treatment with more women now expected to survive the disease long term. An ongoing survey conducted by the Australian National Cancer Control Indicators (2019) estimates the relative survival for women with breast cancer in Australia is at 91.3% percent overall over five years. Survivorship is more promising in breast cancer at Stage 1 to 3, collectively known as early breast cancer, where the five-year survival rate compared to someone without breast cancer is 100.8% for Stage 1, 94.6% for Stage 2, and 80.6% for Stage 3. At Stage 4, where the cancer has spread beyond the breast to other parts of the body, the 5-year survival rate is 32%. Yu et al. (2015) conducted a population study in the state of New South Wales, Australia to estimate the prevalence and the needs of breast cancer survivors. They estimate that most breast cancer survivors from 2017 will become long-term survivors and require post-treatment monitoring, with a majority aged between 50 – 69 years. They projected that the number of women living with breast cancer in New South Wales alone would increase by more than 40% from 2007 to 2017, to a total of 68,620 women in 2017. Extrapolated to the population of Australia, this number would total 209,200. The care of this growing population becomes an important focus of cancer care due to the chronic conditions experienced in the years to come.

In Australia, cancer service providers across metropolitan, rural, and remote areas identify survivorship services and supportive care as the biggest service gap in cancer services (Hunter et al., 2019). There is a body of literature on breast cancer treatment and recovery that documents the impairment and distress of cancer patients during and following their primary medical intervention and the need for continued care, with an updated review by Nardin et al. (2020) highlighting a number of issues from cardiotoxicity after adjuvant therapy, to psychosocial changes and distress, to health issues in long-term survivorship. The issues experienced by patients that impact their quality of life are diverse. Examples range from lymphedema, which is swelling in the lymph nodes (Cormier et al., 2010), impaired cognition (Wieneke & Dienst, 1995), and fatigue following chemotherapy (Jacobsen & Stein, 1999), to

chronic pain following surgery (Poleshuck et al., 2006), sexual difficulties and menopausal symptoms (Ganz et al., 1998), and body image issues (Helms et al., 2008). The difficulties of psychological adjustment to these diverse, aversive and painful experiences is often associated with poorer quality of life (Brandão et al., 2017) and fear of cancer recurrence (Simonelli et al., 2016). There may also be divergent experiences of breast cancer patients due to, for example, age, life experiences, and socio-economic status (Mandelblatt et al., 1991). Therefore, improving the quality of life for breast cancer survivors is multi-faceted. Dealing with these issues effectively requires the development of coping strategies that work across domains to promote wellbeing despite potential stressors or fluctuating changes to functioning.

Issues specific to Regional Australia

Regional Australia is a term that can broadly refer to any area in Australia outside of a metropolitan city (Regional Australia Institute, 2022), however, there are also specific guides that distinguish remoteness levels, such as from the Australian Institute of Health and Welfare (2004), which further differentiate regional from remote areas of Australia based on a number of geographic and population characteristics. In discussing issues specific to regional Australia, the former definition of areas outside of a metropolitan city is used. Living in regional Australia further affects breast cancer survivor wellbeing, starting from the point women first experience breast cancer and its treatment.

Treatment choices, such as access to certain hospitals or health facilities, or the feasibility of breast conserving surgery versus mastectomy, are significantly impacted by geographic location (Spilsbury et al., 2005). Patients and survivors in regional areas face unique psychosocial challenges including psychological distress and financial burden (Butow et al., 2012). In the years following cancer treatment, survivors in regional and rural Australia areas continue to report unmet needs, including information and psychological needs (Girgis et al., 2000). Efforts are required, starting with regionally based clinical, translational, and health services research (Murphy et al., 2015) that considers a tailored approach to the process of psychological support to improve wellbeing for regional women through treatment into long term survivorship.

The differences in quality-of-life outcomes for women begins with treatment decisions available to them in regional areas. Spilsbury et al. (2005) conducted a review of hospital morbidity records, cancer registrations, and death notifications for women diagnosed with breast cancer in Western Australia between 1982 – 2000. Using a sample of 11,445 women, they found that living in regional Western Australia was associated with poorer five-year relative survival compared to living in the state's capital city of Perth. Women who underwent breast cancer surgery who lived in metropolitan Perth (survival proportion = .86) were more likely to survive than women who lived in a regional location (survival proportion = .82), a difference that was significant (p <.01). Women that accessed metropolitan public hospitals (survival proportion = .84) or private hospitals (survival proportion = .88) for their initial surgery were significantly (p <.01) more likely to survive than women who accessed regional public hospitals (survival proportion = .79). For women who accessed regional private hospitals for their first surgery, the survival proportion was .87. Other factors associated with poor survival for women with breast cancer included diagnosis at ≤35 years or ≥80 years, diagnosis in early calendar periods, lower socioeconomic status, being an Aboriginal or Torres Strait Islander Australian, having a mastectomy as the initial surgical procedure, chemotherapy, and having comorbid health conditions at the time of surgery. The authors calculated a hazard ratio using regression models that adjusted for these significant co-variates. They found that accessing a regional public hospital had a hazard ratio of 1.5, which was significant in this model (p <.05). Metropolitan public (hazard ratio = 1.0), metropolitan private (hazard ratio = 1.1) and regional private hospitals (hazard ration = 1.1) were not significant. Other significant variables were treatment or health related variables such as additional breast cancer surgeries, mastectomy as first surgery, co-morbid health conditions, and chemotherapy. As women who live in regional areas are more likely to access regional hospitals, this is one example of the unique challenges women face regarding breast cancer survivorship in regional Australia. This study demonstrates that women living in regional areas may experience poorer survivorship outcomes due to options for treatment.

When considering outcomes for regional Australia, the geography itself, particularly distance, is a factor. Collins et al. (2018) examined the socio-economic and distance-related considerations for women's access to breast conserving surgery which required follow-up radiotherapy, versus mastectomy which avoids

radiotherapy. This study was conducted on a sample of 1,213 women across metropolitan and regional areas of the state of Victoria, Australia, zoning regionality as 0 to 100km, >100 to 200 km, and >200 to 300 km from a major Victorian city such as Melbourne or Geelong. They found no significant differences between socioeconomic status and access to type of treatment. However, distance to a radiotherapy centre was strongly associated with increased rates of mastectomies if women had to travel more than 100km for radiotherapy treatment (74.1% mastectomy in this area, compared to the average of 40.7%, $p = .01$). These disparities are more evident as remoteness increases, including that of socioeconomic status. Roder et al. (2013) distinguished between major city, inner regional, outer regional, and more remote areas of residence for an Australian national cohort of 30,299 women treated for breast cancer between 1998 – 2010. They found that women living in outer regional and more remote areas were 33 and 17 times respectively more likely to have lower socio-economic status. Women in outer regional and more remote areas were significantly less likely to have breast conserving surgery compared to major city areas (relative odds compared to major cities = .89, $p = .03$), and more likely to have adjuvant chemotherapy (relative odds compared to major cities = 1.13, $p = .04$). Not only do these sorts of factors affect the survival of women in regional and rural Australia, but they also affect the quality of life in survivorship. If a program is not imbedded within the community where women live, then they are less likely to access that particular option.

The characteristic of remoteness, and the flow-on effects of treatment choices and access, including access to allied health services, creates differences in psychosocial wellbeing and supportive care needs of regional women accessing breast cancer care. Butow et al. (2012) conducted a systematic review of these needs using 37 studies that combined quantitative and qualitative methods from the United Kingdom, United States, and Australia. The review indicated that rural patients in the United States had poorer mental health functioning, and higher levels of anxiety, depression, distress and emotional problems. The effect sizes for these issues, calculated as the difference between group means divided by the standard deviation of the entire sample, ranged from .41 to .70. An Australian study contained in the review also highlighted psychological needs one-month post diagnosis, which included worries for those closest to the patient, fear of cancer spreading, fear of cancer returning, and anxiety about treatment. Later in the treatment process,

sexuality needs, physical and daily living issues, lack of energy, and tiredness became common themes. Studies from all countries in this review highlighted financial struggles related to travel, treatment, and accommodation, with Australian women who were eligible for financial assistance struggling to claim the money. The burden of treatment and difficulties accessing treatment continue to impact regional women's survivorship following the conclusion of medical management.

Regional Australian women's quality of life continues to be impacted long after the primary treatment for breast cancer has concluded. As part of a larger population study conducted in the state of Queensland, Australia, DiSipio et al. (2010) compared the quality of life of urban breast cancer survivors living in the state's capital city of Brisbane (n = 277), to non-urban breast cancer survivors in inner regional, remote, and very remote areas of the state (n = 323). There was significant quality of life differences between urban and non-urban survivors, with non-urban survivors reporting poorer physical wellbeing (p <.01) and emotional wellbeing (p <.01), with more breast cancer related concerns (p <.01), and additional questions related to arm morbidity (p <.01). DiSipio et al. (2010) additionally specified whether these differences were clinically meaningful, using the guidelines for defining minimally important differences by Webster et al. (2003). Of the statistically significant differences, only breast cancer concerns showed a clinically meaningful difference. Another part of the DiSipio et al. (2010) study included comparisons with the general population stratified by residential location. When compared to the general population, non-urban breast cancer survivors had poorer physical wellbeing (p <.01) and emotional well-being (p <.01), but better social wellbeing (p <.01) and functional wellbeing (p <.01). Of these statistically significant differences, only poorer physical wellbeing and better social wellbeing showed clinically meaningful difference. Given the limits of treatment access posed by remoteness, it is no surprise that regional women continue to experience poorer physical wellbeing compared to the general population, and more breast-cancer specific difficulties compared to their urban peers.

Access to intervention would assist regional women to meet their needs in survivorship. Girgis et al. (2000) conducted a survey that included 52 needs items to assess the frequency of unmet needs in urban (n = 100) and rural (n = 129) breast cancer survivors living in the state of New South Wales, Australia. This paper did not discuss how remoteness was defined. Top needs for both urban and rural women

included mostly needs in the information and psychological domains. The most expressed moderate or high unmet need for urban and regional women was for help with dealing with fears about cancer spreading or returning. This need was expressed in significantly higher proportions by rural survivors (70%) compared to their urban counterparts (40%; $\chi^2 = 4.24$, $p = .04$). While not statistically significant, a higher proportion of rural survivors tended to endorse psychological needs as unmet. These included dealing with anxiety or stress (rural sample 50% compared to urban sample 33%) and dealing with feeling down or depressed (rural sample 41% compared to urban sample 28%). Rural survivors also reported more unmet needs specific to breast cancer in every category compared to urban counterparts, though these differences were not subjected to statistical analysis. Some of these needs related to coping with practical and medical issues such as breast prostheses and lymphoedema, psychological issues such as self-image and shock with the amount of breast removed, and social issues such as implications for daughters or sisters and fears about reactions from future partners. Age was a predictor of reporting unmet psychological needs, with survivors across urban and rural settings between 30 – 49 years old reporting more unmet needs in this area ($\beta = 1.86$, $p < .01$). The rate of unmet information and psychological needs for regional breast cancer survivors suggests that more supports in these areas is required in long term survivorship.

However, the implementation of these supports for breast cancer survivors in regional Australia is not without challenges. Murphy et al. (2015) outline a number of challenges facing oncology services initiatives and research in regional Australia. The authors note that differences in intervention leading to poorer cancer outcomes in regional Australia require clinical, translational, and health services research that considers the barriers and opportunities in growth and implementation of rural medicine. The study reviews current initiatives and barriers to oncology research and practice in regional New South Wales, Australia. Novel challenges to achieving outcomes for patients include the co-ordination of many services across different care settings, geographic isolation with complexities delivering psychosocial care, and limited data available to inform treatments for the health and wellbeing of Aboriginal and Torres Strait Islander peoples. There are also challenges with clinical research, with a relative dearth of clinical trials in regional areas due to barriers such as difficulties recruiting health care workers and researchers to regional areas and funding for trials due to relatively lower participants available to recruit within

geographical areas. This affects translational research in regional Australia. Cancer patients and survivors may have different preferences for the access of care, such as the preference for care at home or in the community, and there are currently large gaps in the understanding of how to deliver the interventions required. This review by Murphy et al. (2015) highlights the challenges and need for regionally tailored services to provide the most effective support with limited human resources.

Due to the rising number of long-term breast cancer survivors, and the disparities in unmet informational and psychological needs for regional women, outcomes for women's wellbeing in survivorship will likely include psychosocial outcomes. A systematic review of these psychosocial outcomes by Youl et al. (2016), which included both the Girgis et al. (2000) and DiSipio et al. (2010) studies in a total of 16 Australian studies, found differences in regional outcomes related to quality of life, psychological distress, and psychosocial support. A limitation noted is the comparative scarcity of studies in regional Australia compared to urban settings, with no studies found to include outcomes for Indigenous Australians. This review found that while broadly no studies showed significant differences in the psychological distress of women in regional areas compared to urban counterparts, there were some differences in terms of support and need. Specifically, regional women reported more fear of cancer recurrence and financial worries, had comparative difficulty accessing information related to breast cancer research including the psychological impact of cancer, and a sense of isolation and vulnerability associated with the lack of regular follow-up with allied health professionals such as psychologists, dieticians, and physiotherapists. The lack of community-based programs, despite the availability of national outreach counselling from a breast cancer support service, was identified as a concern for rural women. The additional burdens to quality of life such as traveling for treatment, fear of cancer recurrence, and lack of psychological care were consistently reported. This review again highlights the need for targeted regional services. Specifically, psychological support addressing the wellbeing of regional breast cancer survivors, focusing on the unique challenges to quality of life, the prevalence of fear of cancer recurrence, and access to local psychosocial support, is needed.

Despite attempts to implement initiatives to address service gaps in regional and remote Australia, options for cancer survivor wellbeing services remain limited. There are continued gaps, despite updated initiatives, due to the sustainability of

these services across remote regions of Australia, such as access to psychosocial support (Platt et al., 2015), that continue to create differences in survivorship outcomes (Chen et al., 2015). What is lacking in an approach to survivorship wellbeing in regional Australia is the forefront consideration of geographic, demographic, and health workforce characteristics of regional and remote areas in psychosocial intervention for breast cancer survivorship. In the abovementioned studies, the adaption of approaches convenient in the dense population of urban areas frames regions with a deficit lens, dismissing possibilities arising from region centric research methodology and clinical practice.

As more women become long-term survivors of early breast cancer, survivorship needs, including psychosocial needs, are increasingly a focus of wellbeing related support for this growing group. Given the varied health, social, and life stage circumstances of this cohort, and ongoing functional concerns, addressing women's quality of life will require the development of strategies that help women navigate across wellbeing domains. Additionally, women survivors in regional Australia face a shortage of local services including psychological services and face higher unmet needs with lower quality of life compared to their urban counterparts. Addressing the needs of regional Australian breast cancer survivors will require a focus on these unique challenges from research to applied approaches.

Structure of the research project

The current research project aims to combine a practical approach to community-based research, with exploration into theoretical treatment variables. The overall aim is to both address (1) the immediate needs of a regional community and (2) the gaps in the literature related to how the proposed targets of treatment relate to therapeutic outcomes in improving the wellbeing of women breast cancer survivors. To this end, Chapter 2 begins with a literature review of the constructs most relevant to psychological intervention for survivorship wellbeing in regional Australia, and the type of approach that may address these. Specifically, the constructs are quality of life, psychological distress, and fear of cancer recurrence. Chapter 3 considers the targets of intervention for breast cancer survivors, proposing the use of acceptance and commitment therapy (ACT), and presents experiential avoidance as an additional construct of interest to survivors. Chapter 4 outlines a randomised control pilot study conducted in a regional town in the state of Queensland, Australia. The aim of this pilot study was to consider the feasibility of a community needs driven

study, using group-based ACT to improve quality of life, and reduce psychological distress and fear of cancer recurrence, for women survivors of early breast cancer. To follow up on some of the gaps in the literature identified from the pilot study, Chapter 5 updates and further explores the literature on quality of life for breast cancer survivors to clarify targets of intervention for quality of life, including the role of experiential avoidance. Chapter 6 is a survey study of current quality of life factors for regional Australian women survivors of early breast cancer. The survey included demographic, psychological and health related variables to consider a complete model of quality of life in regional Australia. Chapter 7 provides a discussion of the findings of the research project as a whole, and how the findings inform support for women following primary breast cancer care.

CHAPTER 2 – QUALITY OF LIFE, PSYCHOLOGICAL DISTRESS, AND FEAR OF CANCER RECURRENCE

Health-related quality of life

The use of the term 'quality of life' in this thesis refers to health-related quality of life, which has targets that differ with population and illness characteristics, but generally focuses on a person's health. Definitions and models of health-related quality of life in cancer survivorship need to be well constructed, specific to the characteristics of the illness, and have a practical component such as a measure, in order for the definition to have clinical utility (Taillefer et al., 2003). Explicitly defining the components of quality of life and the variables that affect these components helps target interventions, including psychological intervention, towards addressing a specific health improvement (Wilson & Cleary, 1995). Instead of a narrow focus on symptom reduction, targets of quality of life intervention may include physical, functional, emotional, and social wellbeing, (Cella, 1994). Additionally, models of quality of life provide some support for targeting subjective experiences, increasing survivor's ability to process their experiences, and harness this in creating new goals focusing on long term wellbeing (Naus et al., 2009). Definition of quality of life, measurement of this construct, and the targeting of related components and processes are relevant to consider when operationalizing this variable for the purpose of intervention.

An issue in the application of quality of life as a construct with clinical utility is that quality of life is at times defined too broadly, if at all. A review of 68 health related quality of life models published between 1965 to 2001 by Taillefer et al. (2003) found that a quarter of health related quality of life models did not contain a definition of quality of life or factors that may influence it. This review used two raters to judge the quality of the articles based on the four criteria: 1) the type of model such as a conceptual model, conceptual framework, or theoretical framework; 2) the frame of definition for quality of life such as happiness, wellbeing, satisfaction, performance, functioning, goal attainment, needs satisfaction, or health factors; 3) any distinction between definition and contributors to quality of life; and 4) whether the model is associated with a measure. A limitation of this method identified by the authors was that quality of life had different focuses depending on

the reason it was being measured. For example, the aspects of quality of life relevant to cancer survivors were different from those experiencing dementia. Therefore, although quality of life appears to be a broadly researched construct, definitions, models, and frameworks may only be understood within the context of each disease. Another limitation of this study is that it reviewed the papers in isolation, not in context. For example, the author of one paper reviewed, Cella (1994), also wrote about how quality of life can be measured in cancer care (Cella & Tulsky, 1993), and was involved in developing a series of measures for quality of life in cancer broadly (Cella et al., 1993) and specifically (Webster et al., 2003). The same was true for work from Ferrell et al. (1991) and Ferrans (1996) when considering their bodies of work as a whole. However, the work of Taillefer et al. (2003) does assist researchers and clinicians to consider the importance of definitions and how these inform measurement and practice.

One broad quality of life definition and model from the Taillefer et al. (2003) review that met criteria for model, definition, and instrument was proposed by Wilson and Cleary (1995). Wilson and Cleary (1995) focused on the importance of explicit conceptualization of the relationship between clinical variables involved in health related quality of life to target intervention. In this model, quality of life was defined as a dimension of functional and overall wellbeing that is distinct but related to health. It included physical, social, and role functioning, as well as mental and general health perceptions. The conceptual model captured a flow of causes and possible points of intervention starting from biological and physical variables (cells, organs, and organ systems) to symptom status (the perception or belief about the state of the body), to functional status (ability to perform particular tasks), to general health perceptions (the integration of previous variables, including mental health), and to overall quality of life (a subjective wellbeing or happiness and satisfaction with life as a whole). This model included characteristics of the individual and environment that influence most of these areas, and provided possible entry points and flow on effects of intervention. For example, a characteristic of the environment that affects quality of life is psychological supports. Wilson and Cleary (1995) proposed that psychological supports improved quality of life through intervention that impacted symptom status, general health perceptions, and directly on overall quality of life. This model supports the use of psychological strategies in specific and general perceptions of health, and the subjective wellbeing, happiness, and

satisfaction with life. There is continued interest in using this model for research in chronic diseases, for example in Ferrans et al. (2005) and recently a review of the model and its contemporary uses in Ojelabi et al. (2017). However, while Taillefer et al.'s (2003) review identified Wilson and Cleary's (1995) model to include a measurement of quality of life, the paper did not include mention of a measurement instrument either in the construction or measurement of the model. In contrast, the work of David F. Cella considered jointly did provide as broad definition of quality of life (Cella, 1994), with specified measurement of constructs as applied in cancer care (Cella & Tulsky, 1993), and a validation for a measurement instrument (Cella et al., 1993).

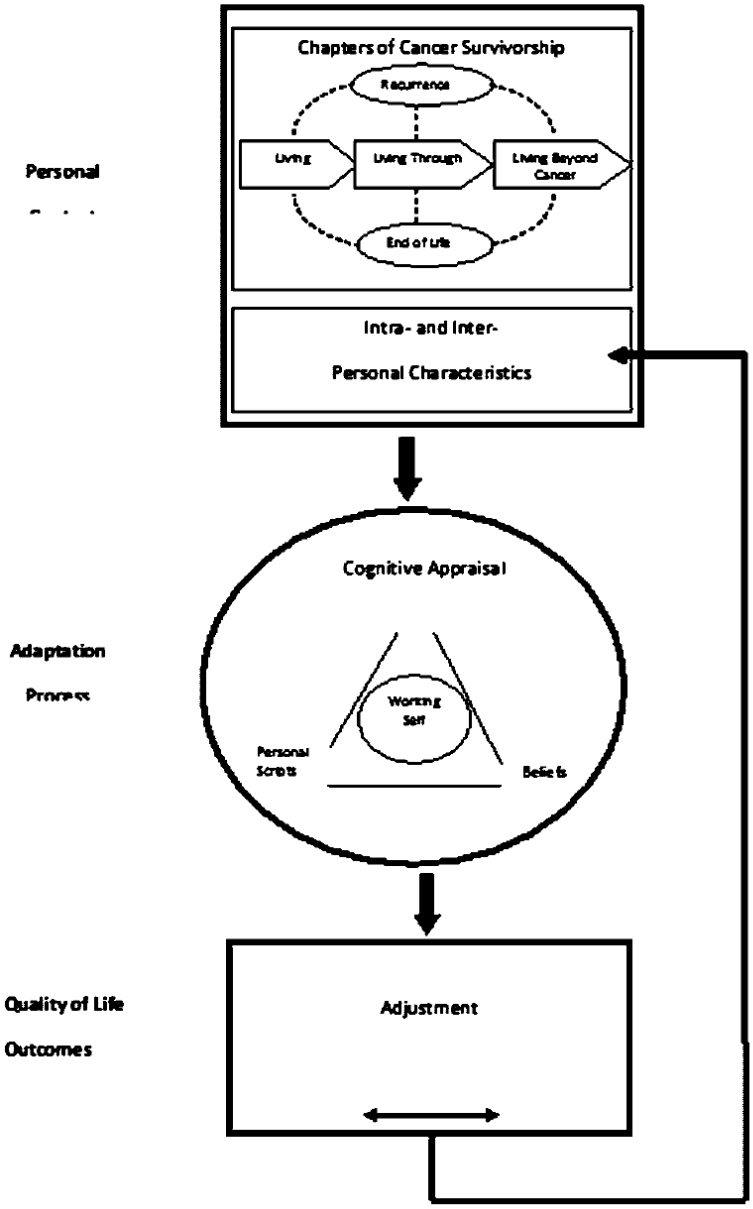
Cella and Tulsky (1993) defined quality of life in cancer care as the patient's appraisal and satisfaction with their current functioning, compared to what they perceive is possible or ideal, across domains such as physical, functional, emotional, and social functioning. Cella's (1994) work does not specify possible entry-points to psychological intervention on quality of life, however, does highlight the importance of considering quality of life in interventions where decisions regarding treatment effects and treatment toxicity must be made with the patient. He emphasized the importance of a multidimensional conceptualization of quality of life that includes physical, functional, emotional, and social wellbeing. Physical wellbeing was defined as perceived and observable body functions and disruption. Functional wellbeing was defined as the self-perceived ability to meet personal needs, ambitions, and social role. Emotional wellbeing was defined by positive affect and negative affect. Social wellbeing was defined as the self-perception of social, leisure, and family functioning. Cella (1994) proposed that quality of life was considered subjectively within these dimensions, and a patient's values and subjective experiences were valid. He proposed several assumptions in the inclusion of quality of life measures in cancer treatment. The first assumption was the possibility of different relationships between symptom intensity and quality of life, for example, constant, linear, or curvilinear relationships. The second assumption was that the amount of time living with a symptom was unrelated to the symptom's impact on quality of life, and time may result in adaption, or have no relationship with the impact of symptoms on quality of life. These assumptions account for the possibility of treatment to remedy aspects of quality of life, regardless of cancer symptom severity. These assumptions changed the focus of cancer intervention for quality of

life from symptom reduction to a focus on increasing aspects of wellbeing. Cella and Tulsky (1993) were interested in comparing outcomes across competing treatments and to predict responses to future treatment. Cella's work provides an approach to quality of life that is useful in informing and measuring quality of life interventions by defining constructs for measurement, valuing of patient subjective experience, and explicitly outlining assumptions that are relevant to treatment.

The valuing of patient subjective experience and assumptions on the relationship between symptoms and quality of life is compatible with the dimensions of Wilson and Cleary's (1995) model, and relevant when considering adaption in survivorship. The idea of adaption in survivorship and its impact to quality of life is extended in the cancer survivor adaption model by Naus et al. (2009), shown in Figure 2.1.

Figure 2.1:

Cancer Survivor Adaption Model



Cancer Survivor Adaption Model with three components: personal context, adaption process, and quality of life outcomes. Used with permission from publisher.

This conceptual model involves three components: the personal context, adaption process, and quality of life outcomes. Broadly, the model proposes that personal context impacts adaption process, which affects quality of life. An example of this is that a patient's coping style pre-cancer (personal context) informs their perception, appraisal, and response to cancer-related symptoms. This includes perceived threats and coping (adaption process), leading to life decisions that impact

on health and wellbeing (quality of life outcomes). There is an additional direct impact of personal context on quality of life that bypasses the adaption process. An example is that, if a survivor's support network perceives the person as completely recovered following primary treatment, they may not be as supportive or considerate of the survivor's needs following this time. This conceptual model of quality of life features cognitive processing in adaption to cancer survivorship, proposing that adaption requires new goals and world assumptions within the framework of the personal context, and influencing quality of life. As an example of the possible effects of cognitive processing in survivorship, Naus et al. (2009) references an unpublished work by Naus and Baker from 2009 on the psychological growth of breast cancer survivors. They found that survivors who could recall memories at the time of diagnosis experienced high levels of psychological growth. If these survivors were also able to articulate new goals established through their identity changes during cancer, they also experienced high levels of posttraumatic growth. However, details about this study are scant, with no further discussion about how psychological and post traumatic growth were measured. Nevertheless, the authors emphasize the role of adaptive, goal directed behaviour towards quality of life outcomes, within a sense of self that can encompass the experience of cancer in survivorship. Naus' (2009) model for quality of life in survivorship presents targets for psychological intervention; if survivors are assisted to accept a sense of self that includes difficult cancer experiences, while using experience and acceptance to direct new goals in their lives, there may be an increase in specific domains of quality of life where this process is applied.

While Naus (2009) provides a model of adaption to cancer survivorship focusing on subjective experience with entry points into supporting women's quality of life in breast cancer survivorship, the model does not capture how subjective experience then contributes to self-rated functional outcomes of quality of life, which is the focus of many self-report quality of life measures in cancer care. It also does not capture how illness and treatment characteristics interact with personal context. A review of literature reviews by Mokhtari-Hessari & Montazeri (2020) indicated that quality of life was still under-considered in treatment decisions of patients, and there was limited information focused on understanding quality of life through stages of survivorship from patient to survivor, to long term survivor. Furthermore, care for these survivors long term in the primary health setting is usually not wholistic or

proactive (Lovelace et al., 2019). These issue may be exacerbated for women living in regional areas, and there is a gap in the literature that starts at patient care co-ordination (Anbari et al., 2020).

Measure of Quality of Life

A measure of quality of life specific to cancer and breast cancer, driven by an acceptable conceptual model, would be ideal in capturing outcomes in psychological intervention. The Functional Assessment of Cancer Therapy – General (FACT-G; Cella et al., 1993) was developed to measure quality of life as the combined impact of cancer and cancer treatment from the patient's perspective. In a synopsis article, Tamburini (2001) noted the FACT-G as one of three most frequently used measures in cancer research. In addition to providing definition and targets for quality of life, Tamburini (2001) discussed additional merits in measure construction that included patient involvement, acceptable psychometric qualities, and the adaption of cancer-specific scales for breadth and specificity.

The steps in instrument construction consisted of comparisons to existing measures for convergent validity; patient, oncology professionals, and researcher input and consensus on items; and reduction of item pool with factor analysis; and re-iterations based on usability of the measure. Cella et al. (1993) generated the initial questionnaire items following semi structured patient interviews. An initial group of 45 participants completed a brief Profile of Mood States (Cella et al., 1987), the Functional Living Index-Cancer (Schipper et al., 1984), and the Quality of Life Index (Spitzer et al., 1981) for convergent validity. This initial group were also asked to generate any items that they believed related to quality of life. These responses were endorsed by 15 oncology doctors and nurses, who were then in turn asked to generate any additional items that they did not see in the list. A review of these items was completed by an independent sample of patients and specialists. As retained responses lacked comment on the physical and sexual aspect of quality of life, items emphasizing these were added to form a final pool of 38 items, constituting Version 1 of FACT-G. Following a factor analysis, the original item pool was reduced to 28 items, which loaded onto six factors, combined to make five categories: Physical, functional, social, emotional, and relationship with doctor. These categories were combined for an overall quality of life score, constituting Version 2 of FACT-G. A third sample of 316 patients with different cancers and stages was recruited for an initial evaluation of this measure. It was found that the measure differentiated known

groups such as stage of cancer, had good test-retest reliability over three to seven days (α=.82 to .84 for subscales, and total measure α=.92), and was sensitive to change over a period of two months (F = 11.90, p <.01). The current version, Version 4, does not include questions related to the relationship with doctor, likely due to changes based on usability, such as item reduction, clarity, and precision (Webster et al., 2003). Version 4 of the FACT-G consists of 27 items, grouped into four subscales: Physical wellbeing, social/family wellbeing, emotional wellbeing, and functional wellbeing. Higher scores indicate better wellbeing, with a highest possible score of 108.

As part of the Queensland Cancer Risk Study, Janda et al. (2009) conducted a study to obtain Queensland population norms for the FACT-G. They used random sampling phone interviews of 2727 participants representative of Queensland, Australia norms that covered metropolitan, regional, and remote areas. These phone interviews were followed by a mail-out questionnaire for participants that provided contact details. Janda et al. (2009) used a version of the questionnaire with six cancer specific items removed, as these were not relevant to the general population of non-cancer patients, and a variation on scoring to maintain comparability with the 27-item full FACT-G Version 4 scale. A confirmatory factor analysis was performed, with the four factors of the questionnaire maintained with this sample. Additionally, the authors noted that the Australian sample was comparable to the United States sample that was recruited to create the FACT-G, except that Australians tended to report a higher quality of life. They considered this difference to be an artifact of the recruitment method; studies that used internet versus mail out and phone call. There is also a difference between health systems, with a federal public health system in Australia. For this normative sample, the mean FACT-G summary score was 85.9, with a standard deviation of 15.1.

The Functional Assessment of Cancer Therapy – Breast (FACT-B; Brady et al., 1997)

Cella et al. (1993) noted that generalised measures for use in clinical trials may not capture cancer region and type-specific quality of life items. For example, women breast cancer (cancer region) survivors may experience quality of life concerns related to womanhood (type-specific). An additional scale was developed by Brady et al. (1997) to capture the unique characteristics of quality of life for breast cancer survivorship. The Breast Cancer Scale was added to the FACT-G to

create the Functional Assessment of Cancer Therapy – Breast (FACT-B). The process of item generation and validation for the Breast Cancer Scale was similar to the FACT-G, refining descriptive information from patients and oncology professionals. It added an additional 10 items to the questionnaire, bringing the total highest possible score to 148. The FACT-B was assessed for internal consistency with the target population of breast cancer patients, and Cronbach's alpha for the full scale was high at $\alpha = .90$, except for the breast subscale, at $\alpha = .63$, which Taber (2018) describes as having moderate internal consistency. While the breast cancer subscale's internal consistency was lower than the other subscales, the process used to create the subscale the was true to the ideology of capturing patient experiences. Test-retest reliability was high for the breast subscale and FACT-B total scale ($\alpha = .89$ and .85, respectively).

There is a version of the FACT-B that includes four additional questions regarding lymphedema, the FACT-B+4 (Coster et al., 2001), validated for use to monitor additional arms problems using a similar methodology as the other FACT measures. The additional scale of four items related to commonly reported arm problems in women with breast cancer had a good internal validity ($\alpha = .83$) on a sample of 279 breast cancer patients, test-retest reliability ($r = .93$) on a group of 29 women with chronic arm morbidity, and was sensitive to change when readministered at four weeks ($t = 15.37$, $p < .01$) and 12 weeks ($t = 7.39$, $p < .01$) on a subscale of 66 breast cancer patients. While lymphoedema is reported by survivors of breast cancer (Cormier et al., 2010), this measure was not considered for use as a measure of quality of life for this study as lymphedema was not a symptom experienced by all breast cancer survivors.

Psychological Distress

As it was with quality of life, psychological distress in breast cancer survivorship is not a well-defined construct, though it is often included in quality of life outcomes because mental disorders are known to impact quality of life (Evans et al., 2007). In the broader field of cancer survivorship, psychological distress is most commonly reported as the experience of symptoms of anxiety and depression (Mitchell et al., 2013), and stress (Green et al., 1998). Psychological distress in longer term cancer survivors was associated with cancer and non-cancer related stressors (Deimling et al., 2002), as well as coping style (Boyes et al., 2009). The actual prevalence of psychological distress, and thus need for intervention, in long

term survivors is disputed, with mixed results from studies; some report that women breast cancer survivors have comparable or lower distress to a non-cancer population, for example, Boyes et al. (2009), whereas others report a distinct subset of women who continue to experience high distress, for example, Bleiker et al. (2000). Despite discrepancies, a review and inclusion of this construct as a focus of study is warranted due to increased prevalence of psychological distress found in some studies, and also due to the higher unmet need for psychological support regarding anxiety, stress, and depression symptoms reported by regional Australian survivors of early breast cancer in the Girgis et al. (2000) study.

A tested conceptual model of psychological distress in cancer survivors was put forward by Deimling et al. (2002) to explain psychological distress in long-term survivorship. This model defined psychological distress as consisting of bi-directional distress symptoms (anxiety, hostility, and depression) and post-traumatic stress disorder symptoms (hyperarousal, avoidance, intrusiveness). Contributing to psychologial distress were three categories of stressors; cancer-related stressors, non-cancer related stressors, and temporal factors. Deimling et al. (2002) used a cross sectional sample of 180 cancer survivors, of which 41% had breast cancer. The largest group of participants (38.3%) were between 65 – 74 years old. Distress was measured by the Profile of Mood States (POMS; McNair et al., 1971) and the Centre for Epidemiology Studies Depression Scale (Radloff, 1977). Post-traumatic stress disorder was measured by the Post Traumatic Stress Disorder Checklist Civilian Version (Weathers et al., 1993). Deimling et al. (2002) first conducted bivariate correlations, followed by multiple regression analysis of distress and stress disorder symptoms. They found a modest goodness of fit for inter-relatedness of anxiety (R^2 = .28), hostility (R^2 = .20), and hyperarousal (R^2 = .19), but poor fit for depression (R^2 = .13) and intrusiveness (R^2 = .10). Overall, the model explained less than 20% of the variance, which suggests that the bi-directional link between types of distress does not explain most of the distress reported. Their study found several cancer related stressors predictive of distress. In particular, survivor's current condition was most related to psychological distress, with significant predictive value for hostility (β = .39), depression (β = .27), and hyper-arousal (β = .37). Additionally, chemotherapy was shown to be significantly predictive of hostility (β = .30), depression (β = .24), as was current cancer-related illness symptoms (β = .39 and .27 respectively). Number of treatment types predicted anxiety (β = .-.24), past cancer-related illness

symptoms predicted hostility (β = .-.31), and cancer-related functional limitations predicted avoidance (β = .25). Non cancer-related stressors with the most impact to current psychological distress were recent life events, which predicted anxiety (β = .29) and hostility (β = .24). Temporal factors with the most impact to current psychological distress was age on anxiety (β = -.16) and hostility (β = -.19). These findings provide support for a model of wellbeing that includes cancer related stressors, non-cancer related stressors, and temporal factors when considering women's wellbeing in long term survivorship. Intervention for psychological distress in survivors may benefit from targeting response to present stressors including cancer and non-cancer related issues, as these are most predictive of psychological distress in survivors.

While post-traumatic stress disorder (PTSD) is discussed in Deimling et al.'s (2002) model, Green et al. (1998) cautions against the use of the term for women with early stage breast cancer because their experience and symptoms of stress does not fit the diagnostic criteria for the disorders. Green et al. (1998) recruited 160 women from Washington, DC, in the United States who had completed treatment for Stage 1 or 2 breast cancer within the past four to 12 months. Participants underwent a Structured Clinical Interview for DSM-III-R (Spitzer et al., 1990) which the authors matched to diagnoses based on the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (American Psychiatric Association, 1994). The participants also completed the Impact of Events Scale (Horowitz et al., 1979) and the Stressful Illness Experiences measure developed by the investigators for the study as an intrusive thoughts measure. While the women did experience high levels of intrusive (M = 8.55, SD = 7.80) and avoidance (M = 9.81, SD = 8.57) symptoms associated with post traumatic stress, their stress was more related to waiting for a diagnosis from their doctor rather than aspects of the treatment, which is an abstract and future-oriented stressor as the women were not physically ill at the stage pre-diagnosis. Conceptualising this sort of stress experienced by survivors as post traumatic stress disorder may misrepresent women's experiences. Later, this chapter will discuss a separate construct that is relevant in breast cancer survivors termed fear of cancer recurrence, which may be a more fitting conceptualisation for a type of distress experienced by this population.

The actual prevalence of psychological distress in breast cancer survivors is disputed, and likely depends on the characteristics of women and their contexts. This

has important implications for assigning resources to treatment. If psychological distress is not a relevant target for breast cancer survivors, then the scant allied health resources in regional Australia may benefit from use elsewhere. Boyes et al. (2009) conducted a study of anxiety and depression in a sample of 846 participants from the state of New South Wales, Australia, 26% of whom were breast cancer survivors. They used the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) , the Medical Outcomes Study Social Support Scale (Sherbourne & Stewart, 1991), and the Mini-Mental Adjustment to Cancer Scale (Watson et al., 1994), in a cross-sectional survey to explore the prevalence and predictors of clinical or borderline levels of anxiety and depression in survivors. Their results indicated that the prevalence of clinically-important levels of anxiety and depression were equal to or lower than the normative data for Australian adults five years into survivorship, with the median anxiety score of three with a possible range of 0 – 20, and a median depression score of two with a possible range of 0 – 21. This was comparable or lower than the HADS normative data and sample of Australian adults in 1998. Helplessness and hopelessness as coping styles were related to anxiety and depression; those who reported these styles of coping were three times more likely to report clinical or borderline levels of symptoms. An avoidance coping style was associated with depression (odds ratio = 2.56, p <.01), and anxious preoccupation style was associated with anxiety (odds ratio = 8.87, p <.01). Social participation was also a factor in survivor wellbeing with low levels of overall support associated with anxiety (odds ratio = 2.45, p <.01) and low levels of positive social interaction associated with depression (odds ratio = 3.10, p <.01).

While the Boyes et al. (2009) study is useful in considering local prevalence of anxiety and depression in Australia, the approach of other studies that stratify length of time into survivorship tend to find differences in psychological distress. A study on the trajectory of distress for breast cancer survivors in the Netherlands from diagnosis to one-year survivorship by Henselmans et al. (2010) indicated four types of trajectories. They used the General Health Questionnaire (Goldberg, 1978) as a measure of psychological distress and analysed a final sample of 171 women. They found that 36% of women did not experience distress; 33% of women only experienced distress after diagnosis and in the active treatment phase; 15% of women showed a late increase in distress at the transition period from patient to survivor; and 15% experienced chronically elevated levels of distress within the first

12 months. Another study specific to breast cancer survivors, of which 170 participants from the National Health Service in London were followed up over five years, found different prevalence of depression and anxiety over five years. This study by Burgess et al. (2005) found that 50% of participants had depression and/or anxiety within the first year of diagnosis, 25% in the second to fourth years, and 15% in the fifth year. If the women experienced a recurrence of cancer, the prevalence of depression and/or anxiety was 45%. Risk factors for depression and anxiety in midterm survivorship of four months to two years included past psychological treatment (hazard ratio = 1.38, p <.01), lack of intimate confiding relationship (hazard ratio = 1.38, p <.01), and severely stressful non-cancer life events (hazard ratio = 1.36, p = .02). Risk factors in long term survivorship of two years to five years again included lack of intimate confiding relationship and severe stressful non-cancer life events, along with being younger in age (hazard ratio = .96, p <.01) and any previous episodes of depression or anxiety during the period of the study (hazard ratio = 1.55, p <.01). Another possible estimate of prevalence and predictors of distress by Bleiker et al. (2000) involved 317 Dutch patients with early stage breast cancer. The study used the Impact of Events Scale (Horowitz et al., 1979) as a general measure of psychological distress as well as for intrusive and avoidance symptoms, and items from the Symptom Checklist 90 (Derogatis et al., 1973) to measure sleep problems and health complaints, at two months post-surgery. The Impact of Events Scale was administered again at 21 months post-surgery. They found that intrusive thoughts (β = .60, t = 5.3, p <.01), health complaints (β = .28, t = 2.2 p = .03), and sleep problems (β = .25, t = 2.1 p = .04) at the first measure predicted psychological distress at the second measure and explained 48% of the variance. Regarding prevalence, 16% of the women reported high levels of psychological distress at the second measure, almost two years after diagnosis. The prevalence of psychological distress in breast cancer survivors seemed dependent on the length of time since diagnosis and influenced by several factors such as stressful life events, social support, intrusive thoughts, and health factors including cancer recurrence. The timing of intervention from the first few months following medical intervention, up to about the fourth year, was most likely to be of assistance to the treatment of psychological distress in survivors.

These studies demonstrate that the characteristics of survivor groups matter, and while Boyes et al. (2009) provided a snapshot of quality of life in a state of

Australia, the remoteness demographic of participants was not reported in any of the above studies. An overview of regional breast cancer survivor needs in Chapter 1 suggested unmet psychological needs in this population (Girgis et al., 2000), who likely experience poorer quality of life (DiSipio et al., 2008), and reduced access to psychological services (Youl et al., 2016) compared to urban survivors. At best, psychological distress in survivors of early breast cancer are comparable or lower than the population who have not experienced cancer, however, at worst, a quarter of survivors may be experiencing distress years following treatment.

Measure of Psychological Distress

Psychological distress in breast cancer survivorship likely includes symptoms of depression, anxiety, and stress. Many measures of psychological distress are used in the literature, including multiple measures per study, which impacts the reporting of results. Of the measures used in the abovementioned articles, the Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983) was frequently used for a conceptualization of psychological distress that included anxiety and depression, whereas the Impact of Events Scale (Horowitz et al., 1979) was used for a more stress-related focus of psychological distress. Neither measure seems to capture the combination of all three common facets.

The Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 2002)

The Depression, Anxiety and Stress Scale (DASS) is one instrument that may capture common aspects of psychological distress reported in breast cancer survivorship. This scale is widely used in applied and research psychology due to its accessibility and validation in Australia, however, it is not a measure reviewed or commonly used in cancer research. While the introduction of yet another scale for use in cancer research may reduce the comparability to conceptual and prevalence studies, it aligns with applied interventions for mental health in Australia. For example, this scale is used by General Practitioners in the assessment of anxiety and depression (The Royal Australian College of General Practitioners, 2019).

The Depression, Anxiety, and Stress Scales (DASS), developed by Lovibond and Lovibond (1995), includes 42 items that measure self-reported negative emotional states, separated into the three scales of Depression, Anxiety and Stress. According to the DASS manual (Lovibond & Lovibond, 2002), the full-scale DASS has a .81 correlation with the Beck Anxiety Inventory, a .74 correlation with the Beck Depression Inventory, and provides discrimination between anxiety and

depression by eliminating some shared symptomology. Standardisation was initially with patients from a university psychology clinic (n = 125) and university students (n = 504), followed by student and white and blue collar workers (N not reported) who completed the scale as part of a general health screening program (Lovibond & Lovibond, 2002). Validity checks used 678 outpatients diagnosed with anxiety and depressive disorders and other populations (Brown et al., 1997). A shortened version, the DASS-21 (Antony et al., 1998), with 21 self-rated statements, has shown reliability and validity comparable to the DASS-42 using clinical and non-clinical samples (N = 307) with Cronbach's alphas of .94, .87, and .91 for Depression, Anxiety, and Stress, respectively.

In regards to the use of the measure in cancer care, performance of the DASS-21 has shown to be comparable to the Beck Depression Inventory (BDI-II; Beck, 1993) and the Hospital Anxiety and Depression Scale (HADS; Zigmond, 1983) in a study by Bener et al. (2016). Participants for this study were 1042 women from Qatar with breast cancer contacted via a disease registry between January 2010 to December 2014. They were screened for depression using the DSM-IV (American Psychiatric Association, 1994), and also completed the three abovementioned measures. Responses on the DASS-21 were scored as per the DASS-42 instructions, and converted into a dichotomous variable of 'normal' and 'depressed or anxious' using the cut-offs prescribed by the DASS manual scoring system. Kappa coefficients calculated between the scales indicated good agreement between DASS-21 and HADS (κ = 0.8, p <.01), and between DASS-21 and BDI-II (κ = 0.75, p <.01). The DASS-21 was comparable to the other measures in sensitivity (r = .82), specificity (r = .85), positive predictive value (r = .70) and negative predictive value (r = .93) for depression when correlated with cut-off scores from a sample of women with postpartum depression in Qatar, which the authors describe as a commonly used cut-off points.

Another study by Fox et al. (2018) looked at how the DASS-21 performed in cancer patients (n = 376) compared to non-cancer participants (n = 207). In addition to comparing the DASS-21 between populations, a number of validity measures were administered, including an independent measure of quality of life including depressed mood from the McGill Quality of Life Inventory (Cohen et al., 1995), health as measured by the first item of the SF-36 health questionnaire (Ware Jr & Sherbourne, 1992), and suicide ideation using the ninth item of the PHQ-9 (Kroenke

et al., 2001). The authors first considered the structural validity of the DASS-21 with cancer patients and found that a two-factor model with Depression and Anxiety scales was significant (S-Bχ^2 = 158.99, p <0.1, CFI = .94, RMSEA = .05). Internal consistency for the DASS-21 for cancer patients was α = .90 for the Depression scale, α = .70 for the Anxiety Scale. Both samples demonstrated good construct validity through correlations with validity measures. The responses of the cancer patients on Depression and Anxiety scales were significantly (p <0.1) correlated with quality of life (Depression r = -.73, Anxiety r = -.36), single-item depression measure (Depression r = .69, Anxiety r = .39) and self-rated health (Depression r = -.25, Anxiety r = -.31).

These studies provide evidence for validity of the DASS for use with cancer populations, however, the measure may not function as originally constructed with non-cancer samples. For example, Fox et al.'s (2018) study found that the DASS is best captured by a two-factor model that does not include a distinct scale for stress, however, the article did not report how the stress items loaded into their model. There also does not seem to be an agreement regarding the treatment of the DASS score results, with the scoring in these two studies being dichotomous or based on a two-factor model, both differing from the DASS manual's guidelines for scoring. While the DASS-21 is not widely used in breast cancer survivor quality of life research, it is a widely used measure in Australia by health professionals and the validation was based on an Australian population. The use of this measure in breast cancer survivor research may increase the translation of research to applied settings in regional Australia

Fear of Cancer Recurrence

Fear of cancer recurrence is a construct of interest that has emerged from cancer and breast cancer research on survivors, and seems particularly relevant to the quality of life of regional breast cancer survivors (DiSipio et al., 2010). A broad conceptualization of fear of cancer recurrence as applied in breast cancer literature is the fear that cancer will return or progress at a future point, and may involve fear of the consequences of cancer and cancer treatment for the cancer survivor and significant others (Ozakinci et al., 2014). A commonly-cited and ongoing difficulty in studying and operationalizing the construct for the purposes of intervention is the lack of unified definition or consensus on what constitutes as targets for intervention (Lebel et al., 2016). There is ongoing work to conceptualize fear of cancer

recurrence as a clinical construct in order to improve the targeting of interventions to address survivor's concerns (Mutsaers et al., 2016). A model of fear of cancer recurrence may assist in the understanding and targeting of this construct to improve quality of life for survivors (Fardell et al., 2016).

A Model of Fear of Cancer Recurrence

Fardell et al. (2016) provided an overview of theoretical perspectives relevant to fear of cancer recurrence, and a synthesized theoretical approach. They drew on the strengths of the Common-Sense Model of Self-Regulation particularly for illness cognition (Leventhal et al., 1992), the Self-Regularity Executive Function model of anxiety disorders (Wells & Matthews, 1996), along with Relational Frame Theory (Hayes et al., 2006) and Acceptance and Commitment Therapy (Hayes et al., 2011), to provide a model for how fear of cancer recurrence can be understood. Their model of fear of cancer recurrence is a multidimensional construct incorporating circumstances, beliefs, and emotions related to the chronicity and severity of cancer, and the processing of these beliefs and emotions. Fardell et al. (2016) also considered that worries focused on controlling, avoiding, and suppressing thoughts about cancer recurrence led to an increase of fear of cancer recurrence and maintained high levels of fear. They proposed that clinically-relevant levels of fear may develop and persist if someone is unable to shift their focus from symptoms due to a belief that monitoring or worrying assists with preparation for cancer management.

The components of the formulation proposed by Fardell et al. (2016) were:

1. Vulnerability factors. These were historic and current variables that made someone more likely to experience a heightened fear of cancer recurrence. It may include previous losses or traumatic life events and other current stressors. Vulnerability factors impacted the cancer experience and a heightened fear of cancer recurrence.
2. Lack of information. This was the limited knowledge of facts related to the risk and checking for the actual recurrence of cancer. A lack of information impacted the heightened fear of cancer recurrence.
3. The cancer experience. This was how a person experienced the illness and treatment. A person's cancer experience was associated with heightened fear of cancer recurrence and life impacts of cancer including existential challenges.

4. Heightened fear of cancer recurrence. This was a heightened perceived vulnerability to cancer recurrence. There was a bi-directional relationship between heightened fear of cancer recurrence and responses to cancer, as well as a bi-directional relationship with the life impacts of cancer and existential challenges.
5. Life impact of cancer and existential challenges. These were changes that happened due to the cancer experience and the person's response, such as changes to self-concept and difficulty in planning for the future. Life impact affected response to cancer.
6. Problematic style of information processing. This included all maladaptive styles of processing information, including rumination, threat monitoring, and attempts to control uncontrollable thoughts. This affected a heightened fear of cancer recurrence.
7. Response to cancer. This was a person's emotional, behavioural, and cognitive responses to cancer and associated issues. The authors listed distress, anxiety, and depression under emotional responses. Behavioural responses included avoidance or excessive checking. Cognitive responses included intrusive thoughts and images of cancer recurrence. Although these categorizations of affect, cognition, and behaviour showed a departure from classifications in other literature, the overall categories could be understood; response to cancer impacted unhelpful beliefs about the importance, impact, and control of worries, and reduction of distress and intrusion over time.
8. Unhelpful beliefs about the importance, impact, and control of worries (metacognitions). This was the perception of usefulness and control over certain mental processes. For example, a person may perceive that they cannot stop thinking about recurrence. Metacognitions impacted problematic styles of information processing.
9. Reduction of distress and intrusions over time. This referred to a return to normal functioning.

Fardell et al. (2016) proposed that clinically-relevant fear of cancer recurrence, which did not reduce naturally over time, may develop and maintain due to unhelpful beliefs about the importance, impact, and control of worry; problematic styles of information processing; a heightened fear of cancer recurrence; and how this again shapes life impact of cancer and existential challenges. Although a model

like this is preliminary, and the actual relationships between the components are untested, it provided some direction for the application of theoretical orientation to focus treatment targets. For example, treatment for fear of cancer recurrence may incorporate techniques that change the problematic style of information processing, or it may incorporate techniques that change the amount of attention given to these problematic styles.

Towards a Distinct Construct of Fear of Cancer Recurrence

There is a body of literature that has begun to formulate the fear of cancer recurrence construct, across different cancer types, synthesizing patient experiences, clinical features, theories, and treatment. Initially, there was some interest in the stress or trauma-like symptom comparisons with fear of cancer recurrence, and consideration that it may fit under existing diagnostic criteria for mental illness. An example of this is a study by Mehnert et al. (2009), which considered the nature of intrusive thinking in fear of cancer progression. They surveyed 1083 female breast cancer survivors in Hamburg, Germany. Most (76.4%) had low fear of cancer progression. Of the sample, about a third (37%) of the respondents met the criteria for intrusive thoughts and hyperarousal as associated with post-traumatic stress disorder. Twenty-one percent met the criteria for avoidance. However, post-traumatic stress disorder itself was not significantly associated with moderate and high levels of fear of progression. In their discussion, the authors noted that their estimate of prevalence of high fear using a short German form of the Fear of Progression Questionnaire (Mehnert et al., 2006) was lower (9%) in contrast to a comparable population study with a Dutch adaption of the Concerns about Recurrence Scale (van den Beuken-van Everdingen et al., 2008) which reported prevalance at 56%. This suggests that what is classified as a high level of fear of recurrence or progression is highly dependent on the measure.

Due to poor descriptive fit between fear of cancer recurrence and other existing mental illness conditions, researchers in the area of fear of cancer recurrence have moved away from description of symptoms in relation to clinical cut-offs for existing disorders and now consider fear of cancer recurrence to be distinct from other currently recognized anxiety and stress-related disorders. For example, Mutsaers et al. (2016) conducted semi-structured interviews with a convenience sample of 40 cancer survivors drawn from the aforementioned study by Lebel et al. (2016) to consider distinct clinical features of fear of cancer recurrence. They used

the Semi-Structured Interview on Fear of Cancer Recurrence developed by Simard and Savard (2015), with a score of five or higher indicating high fear of cancer recurrence. Comparing the ten participants who scored five or more with the 30 participants who scored four or less, ten features mostly seen in high scorers emerged. These were death-related thoughts, feeling alone, and cancer or fear associated imagery, preoccupation for 30 minutes or more a day, recurrent thoughts that are difficult to control, more thoughts as time goes on, certainty that the cancer will return, distress, impairment to functioning, and intolerance of uncertainty. Of the ten participants with a high fear of cancer recurrence, eight had breast cancer. Of the remaining 30, seven had breast cancer. Mutsaers et al. (2016) considered elements present in fear of cancer recurrence and their relationship to mental illness, such as generalised anxiety disorder, somatic symptoms disorder, and illness anxiety disorder, and concluded that, while fear of cancer recurrence shares some features, it does not fit into an existing diagnostic category. Fear of cancer recurrence seemed to be a separate construct.

A theoretical review was conducted by Simonelli et al. (2017) in an attempt to establish fear of cancer recurrence as a clinical presentation, including triggers, prevalence and trajectory, risk factors, and associated constructs. However, while their review established fear of cancer recurrence within models of illness requiring clinical management, they referred to the concept as an unmet psychosocial need rather than a mental illness. They indicate that when fear becomes maladaptive, it manifested or worsened psychological conditions such as anxiety disorder, trauma or stress disorder, and somatic symptom disorder. Regarding triggers, Simonelli et al. (2017) considered elements identified by Simard and Savard (2015) for use in their semi-structured interview, including references and reminders of cancer, such as attending a funeral, and physical symptoms such as fatigue. Their review indicated that there was, at that time, no consensus on the frequency, duration, and severity of symptoms considered clinically significant, therefore prevalence and trajectory was difficult to estimate. However, within this scope, their review of the literature indicated that fear of cancer recurrence was non-associated with actual threat of disease and tended to reduce over time, but that it could also be enduring for years. Some associated risks of developing fear included pre-existing mental illness, the personality characteristic of higher neuroticism, being younger, being of a racial and ethnic background (for example low acculturated Latinas in the United States),

fewer social supports, unemployment, and financial difficulties. Simonelli et al. (2017) considered a number of theoretical frameworks to assist with formulation and treatment. Their proposed conceptual model of the key components of fear of cancer recurrence theory shares many of the same elements as the Fardell et al. (2016) model, with appraisal/response and processing at the centre for clinical intervention. They propose the following ways of managing fear of recurrence: Education, cognitive behavioural therapies, cognitive-existential therapies, supportive therapies that involve a social component, and mindfulness and acceptance and commitment therapies. They concluded that the limitations of current studies is sampling of mostly white, female, breast cancer survivors with a cross-sectional in design. However, for the purposes of this thesis, the overrepresentation of breast cancer survivors suggests that the information presented in this review likely matches women's experiences of breast cancer survivorship.

A definition of fear of recurrence by expert consensus was published by Lebel et al. (2016) on behalf of the University of Ottawa Fear of Cancer Recurrence Colloquium attendees. This event involved a two-day colloquium during which 12 experts attended, along with 10 trainees and two patient advocates. The group used a series of rounds to elicit consensus opinion from experts. Each opinion was voted on anonymously by the group, and the top three valued definitions proceeded to the next round, over three rounds. From this process, a definition of fear of cancer recurrence was achieved. This group reported that fear of cancer recurrence could be defined as the "…fear, worry or concern relating to the possibility that cancer will come back or progress" (p.3267). Another process was used to determine clinical features. This involved collating preliminary statements from attendees about diagnostic characteristics of clinical fear of cancer recurrence. Later, these were analyzed using content analysis with Nvivo 10, however, did not go through consensus rounds. Clinical features as defined were, "(1) high levels of preoccupation, worry, rumination, or intrusive thoughts; (2) maladaptive coping; (3) functional impairments; (4) excessive distress; and (5) difficulties making plans for the future."(pp. 3266-3267). This research is relatively new in fear of cancer recurrence research and may assist to inform future studies.

However, conceptualising fear of cancer recurrence with a medical and illness lens may have been reactionary to the poor fit of this construct within psychopathology, rather than of benefit to the patient, clinician, or researcher. For

comparison, a systematic review and meta-synthesis by Vrinten et al. (2016) frames fear of cancer as a population characteristic rather than an illness. In this meta-synthesis, fear is conceptualised relationally and functionally with a variety of outcomes for the individual that may be protective or harmful. For example, fear may be related to how cancer is conceptualised, and the response of ignoring, trusting, reassuring, or accepting in response to the conceptualisation impacts people's adaptiveness to cancer in the face of fear. These subtleties can be useful in clinical practice without medicalising the term.

A review by Maheu et al. (2021) further highlighted the confusion of measures with constructs, sometimes with the same measure applied to similar but distinct issues such as health anxiety, worry, and uncertainty in illness. This demonstrates that the distinction of fear of cancer recurrence is not just from medical constructs such as anxiety disorder and stress disorder, but also other psychosocial contexts. Maheu et al. (2021) used qualitative and content analysis procedures to consider structure features and relationships across constructs. In this review, fear of cancer recurrence differed from health anxiety as anxiety could exist in individuals with no health concerns, whereas fear of cancer recurrence only existed in individuals with personal experience of the illness. Fear of cancer recurrence may be more related to uncertainty in illness, as both were more likely associated with cancer-specific factors. This again suggests that fear of cancer recurrence may be more akin to a survivorship concern rather than mental illness.

Measuring Fear of Cancer Recurrence

One difficulty in measuring fear of cancer recurrence is that its conceptualization, including expert consensus, is still in progress and has yet to be fed back into measuring this construct, and in capturing the non-medicalised aspects of the construct. Fear of cancer recurrence can include specific symptoms related to type of cancer, and general concerns, for example, concerns about mortality. It can also be referred to using different terms such as 'concerns about recurrence' for example in Vickberg (2003) and 'fears of progression' for example in Berg et al. (2010). A review of self-report measures for fear of cancer recurrence was conducted by Thewes et al. (2012). They found six measures of fear of cancer recurrence which were included as subscales in quality of life or other psychosocial measures. There were ten brief measures of fear of cancer recurrence consisting of between two and ten questions, and four longer questionnaires for fear of cancer recurrence, consisting

of more than ten questions. The main limitations of many of these questionnaires for the purpose of use with breast cancer survivors is that their creation was not yet guided by a unified definition and conceptional model; there was limited evidence of internal and external validity for some of the measures; and questionnaires lacked specificity for different types of cancer. Additionally, this review did not consider single-item measures of fear of cancer recurrence. Thewes et al. (2012) applied the Medical Outcomes Trust criteria (Scientific Advisory Committee of the Medical Outcomes Trust, 2002) to evaluate patient-reported outcome questionnaires. Of the measures reviewed, the Concerns About Recurrence Scale (Vickberg, 2003) and the Fear of Progression Questionnaire (Berg et al., 2010) were the highest rated, both scoring 4.5 out of seven points. Vickberg's scale is a breast cancer specific scale. Since the review, new brief measures of fear of cancer recurrence such as the Fear of Cancer Recurrence 4 and Fear of Cancer Recurrence 7 (Humphris et al., 2018), and breast cancer specific measures such as The Cancer Worry Scale (Custers et al., 2014) have been developed, but not compared.

The Concerns about Recurrence Scale (CARS; Vickberg, 2003)

Vickberg (2003) reported that existing measures of fear of cancer recurrence treated women's fears as one-dimensional, whereas an examination of types of fear may have better clinical utility. The Concerns about Recurrence Scale (CARS) was constructed following a systematic examination of women's experiences, followed by clinician feedback and factor analysis. Questions were derived from a literature review of women's experiences and piloted on a group of 16 breast cancer survivors interviewed about fear of cancer recurrence, as well as discussed with five professionals who worked with breast cancer patients. Following this, a modified version of the survey was sent to 373 patients by their physicians, of which 189 were completed and returned. The Impact of Events Scale (Horowitz et al., 1979) and Mental Health Inventory (Veit & Ware, 1983) were used to test the convergent validity of items of the CARS. A factor analysis of the responses indicated a four-factor solution accounting for 70% of the variance. These factors included Health Worries (11 items, $\alpha = .94$), Womanhood Worries (seven items, $\alpha = .91$), Role Worries (six items, $\alpha = .90$), and Death Worries (two items, $\alpha = .94$). The questionnaire also provides an Overall Fears score, which had an internal consistency of $\alpha = .87$. Regarding Overall Fears, a high level of overall fear was defined by a response in the higher third of the six-point Likert scale. Moderate

levels were defined by a rating in the middle third, and little to no fear was defined by a rating in the bottom third. Approximately 46% of participants in Vickberg's study indicated little to no fear, about 45% indicated moderate levels, and approximately 10% indicated high levels of fear of recurrence. Fears had significant positive correlations with Intrusive Thoughts (r = .64) and Avoidance (r = .50) subscales of the Impact of Events Scale, and the Distress (r = .54) subscale of the Mental Health Inventory. Overall Fears had a significant negative correlation with the Well-Being (r = -.44) subscale of the Mental Health Inventory. This demonstrates good convergent validity with psychological distress.

The main strength of the CARS is that it has maintained good psychometric properties when used in several studies with breast cancer survivors (for example, Akechi et al., 2014; Lebel et al., 2013) which improves comparability of studies. A limitation of CARS for generalizability is that the standardization sample was mainly ethnically white women with post-college education. Most had breast-conserving surgery and had undergone radiation and/or chemotherapy. Furthermore, the descriptive characteristics of respondents were that 63% had a local disease and 37% had regional disease. As fear of cancer progression is associated with disease progression (Mehnert et al., 2009), participants with early-stage breast cancer may have less fear compared to those with late-stage or metastasized breast cancer. There was also no information on whether participants had experienced actual cancer recurrence, which is a potential confound for fear of cancer recurrence.

CHAPTER 3 – INTERVENTION CONSIDERATIONS FOR EARLY BREAST CANCER SURVIVORS

Psychological interventions that address the needs of women survivors of early breast cancer would need to include more than one outcome variable due to the interplay between commonly raised difficulties. For example, fear of cancer recurrence has been associated with poorer quality of life (Koch et al., 2014), as has psychological distress (Paraskevi, 2012; Reich et al., 2008). The review of quality of life, psychological distress, and fear of cancer recurrence in Chapter 2 provided targets to consider in intervention for breast cancer survivors that are broadly relevant to wellbeing. In theory, psychosocial interventions for quality of life should focus on the way interventions target perceptions of health to improve subjective wellbeing, happiness, and satisfaction with life (Wilson & Cleary, 1995). Interventions may focus on increasing wellbeing, rather than just symptom reduction for unwanted experiences (Cella, 1994). Adaption in cancer survivorship may require survivors to form new goals and assumptions that improve quality of life based on their personal context, including a sense of self that can encompass the experience of cancer-related issues in survivorship (Naus et al., 2009). Psychological interventions would ideally target goal directed behaviour within the context of women's personal experiences. Strategies for dealing with stressful life events, intrusive thoughts, health factors, and fear of cancer recurrence are particularly relevant for survivors from the first few months, up to about the fourth year or survivorship (Bleiker et al., 2000). As a survivor's current situation is most predictive of wellbeing or distress in survivors, interventions for psychological distress may benefit from an approach that addresses current cancer and non-cancer related issues (Deimling et al., 2002).

Fear of cancer recurrence is particularly problematic when survivors cannot shift their focus from perceived cancer-related symptoms (Fardell et al., 2016). Problematic experiences may include ongoing death-related thoughts, loneliness, cancer or fear associated imagery, preoccupation, recurrent thoughts that are difficult to control, an increase in thoughts with time, intolerance of uncertainty, and certainty that the cancer will return (Mutsaers et al., 2016). When this fear is maladaptive, it is associated with distress and impairment in function, as well as worsening psychological conditions such as anxiety disorders, trauma or stress disorders, and

somatic symptoms, but not associated with the actual threat of disease (Simonelli et al., 2017). Psychological interventions would ideally consider both targeting an ability to shift focus, as well as addressing the distress or intolerance for some thoughts and feelings if these impair functioning. Ultimately, psychological interventions may be of benefit to survivors if they can help survivors find strategies towards an increase in quality of life and decrease in fear and distress.

Coping and Survivorship

The contributions of Wilson and Cleary (1995) and Cella (1994) to cancer survivor wellbeing, with a focus on subjective experiences over symptoms reduction, sit withing a broader framework of understanding and achieving pleasure, happiness, and vitality. Ryan and Deci (2000) developed Self Determination Theory to guide research into self-determination, focused on the social-contextual conditions that promote or limit human processes of self-motivation towards healthy development. This theory highlighted the role of intrinsic motivation in wellbeing, which is of value when considering wellbeing in situations where pain may be unavoidable or earthly pleasures unattainable. It echoed the observations of previous works, such as in psychiatrist Victor Frankl's book, Man's Search for Meaning (1985), where Frankl proposes that meaning and purpose can be discovered through creating a work or deed; experiencing something or encountering someone; and the attitude we take towards unavoidable suffering. Frankl's work focused on psychological wellbeing with observations born from exceptional circumstances. This perspective of wellbeing in the face of unavoidable pain is particularly relevant for women following breast cancer, where medical intervention may necessitate changes to the body that remove avenues of identity and pleasure, and the introduction of permanent change and pain. Known issues in long-term survivorship include cardiotoxicity, which is damage to heart muscle, after adjuvant therapy; premature ovarian failure; body image issues; low self-esteem; low sexual satisfaction; osteoporosis, which is where bones become fragile; and metabolism changes, which are changes to the way the cells of the body change food into energy (Nardin et al., 2020). These are some of the concerns that breast cancer survivors may face. An understanding that intrinsic wellbeing and development is still possible under these conditions forms a basis for intervention to address breast cancer survivor wellbeing.

Elliot et al. (2011) proposed a tested model of coping that incorporated the expression of goals, coping, and wellbeing that further clarifies the types of coping

that may be beneficial to wellbeing survivorship. Their model focuses on the role of stress and coping, highlighting the role of avoidance or engagement coping in the examination of short term coping behaviours and long term coping styles that impact subjective wellbeing. In the short term, personal goals can be expressed as avoidant of distress (e.g., I don't want to think about breast cancer recurrence) or approaching aspects of subjective wellbeing (e.g., I want to focus on things that enrich my life). Avoidance goals are related but distinct to avoidance coping, which evades direct engagement with a problem. Elliot et al. (2011) proposed that avoidance was a stress management strategy that had the unintended effect of increasing distress and undermining subjective wellbeing.

To test this model, Elliot et al. (2011) conducted two studies with cohorts of undergraduate students. The first study (n = 260) included a measure of avoidance personal goals, subjective wellbeing, negative affect, and life stressors. It also included additional control variables for social desirability, and neuroticism and extroversion. Measures were compiled from previously validated measures, with internal consistencies of between α = .76 to .82 when used in this study. The measures were administered during the first week of an academic semester and repeated after 15 weeks. Avoidance personal goals was significantly and negatively correlated with subjective wellbeing cross sectionally (r = -.20, p <.01) and 15 weeks after (r = -.27, p <.01). It was significantly positively correlated cross sectionally with life stressors (r = .18, p <.01). There was a negative correlation between life stressors at first measure and subjective wellbeing at second measure (r = -.40, p = .01). A greater number of avoidance goals decreased subsequent subjective wellbeing (β = -.20, p <.01), and participants who expressed more avoidance goals experienced more life stressors (β = .20, p <.01). Life stressors partially mediated the relationship between avoidance goals and wellbeing, (β = -.23, p <.01), with participants who experienced stressors more likely to report lower wellbeing.

Elliot et al.'s (2001) second study (n = 159) added two constructs: cognitive avoidance, which represented realistic thinking about a problem, and emotional discharge, which were attempts to reduce tension by expressive negativity, controlling for behavioural inhibition system sensitivity. The introduction of these additional constructs assisted in separating coping from a broad avoidance disposition. Measures had internal consistencies of between α = .67 to .89 when used in this study and were again administered during the first week of an academic

semester and repeated after 15 weeks. In addition to replicating the findings from the first study, it was found that participants who pursued avoidance goals used more cognitive avoidance ($\beta = -.21$, $p < .01$), and emotional discharge ($\beta = .25$, $p < .01$). Cognitive avoidance and emotional discharge predicted lower subjective wellbeing ($\beta = -.14$, $p < .05$, and $\beta = -.14$, $p < .01$ respectively), as well as more reported life stressors ($\beta = .32$, $p < .01$, and $\beta = .30$, $p < .01$ respectively). Elliot et al. (2011) proposed that in addition to direct and mediated effects of avoidance goals on subjective wellbeing, cognitive avoidance and emotional discharge also partially mediated the effect of avoidance goals on life stressors. The treatment implications of this model are that both initial avoidance goals and avoidance coping strategies must be targeted as they both impact wellbeing.

With regards to coping in breast cancer, Yang et al. (2008) looked at engagement (active coping, planning, seeking instrumental support, and positive reframing) and disengagement coping (denial, alcohol/drug use, and behavioural disengagement) in a study of 65 women who were diagnosed with the first recurrence of breast cancer. The importance of this study was that the effect of coping strategies was examined in a group where the feared outcome of cancer recurrence was actually present. This study measured women's traumatic stress (Impact of Events Scale; Horowitz et al., 1979), symptom stress (combined measures with internal consistency of $\alpha = .70$ to .95 in this study), and engagement/disengagement coping (a brief COPE measure; Carver et al. 1989), on quality of life (Medical Outcomes Study – Short Form; Ware Jr & Sherbourne, 1992). Overall, participants used more engagement coping ($M = 1.84$) than disengagement coping ($M = .24$). In a model testing coping as a moderator of traumatic stress and quality of life, only the disengagement aspects of coping were a significant moderator of quality of life ($\beta = -.37$, $p < .01$). In a model testing coping as a moderator of symptom stress and quality of life, engagement coping was a significant moderator of quality of life ($\beta = .25$, $p < .05$), however, symptom stress was not predictive of quality of life. In a mediator model with disengagement coping as a mediator for subsequent quality of life, disengagement coping explained 36% of the variance, χ^2 (2) = 1.22, $p = .54$; RMSEA = .00; CFI = 1.00. In this model, traumatic stress impacted disengagement coping ($\beta = .41$, $p < .01$), however, direct effect of traumatic or symptom stress on quality of life was not significant when mediated by disengagement coping. In a model where disengagement coping was a

mediator of symptom stress, the model explained 40% of variance in quality of life and better fitted the data of participants, χ^2 (2) = 1.33, p = .52; RMSEA = .00; CFI = 1.00. The effect of stress on disengagement coping (β = .35, p <.01) and disengagement coping to quality of life were both significant (β = .35, p <.01 and β = -.25, p <.05 respectively). This study by Yang et al. (2008) again highlighted the detrimental impact of avoidance directly and indirectly on quality of life, and adds that engagement coping may be helpful when stressors are generalised rather than traumatic.

Studies of coping on fear of cancer recurrence are preliminary. Qualitative accounts of coping, fear of cancer recurrence, and quality of life provide additional insight into women's experiences. Thewes et al. (2016) sampled a combination of 38 Australian and Canadian women aged 45 years or less, with non-recurring early breast cancer, for a qualitative account of their survivor experience. In their sample, women with low fear of cancer recurrence reported a greater repertoire of coping. These women perceived coping as a personality trait. Women with moderate or high fear of cancer recurrence described coping strategies as effortful, ineffective, or time consuming. Distraction and cognitive avoidance were used to a greater degree by these women. The authors also described an obsessional, avoidant quality to women with high fear of cancer recurrence; these women experienced anxiety if coping strategies and healthy lifestyle behaviours were not completed. Women with higher fear of cancer recurrence feared the suffering and reductions in quality of life related to treatment and illness. The authors noted that, despite the literature on avoidance-based coping strategies and reassurance seeking, these strategies were sometimes perceived by their participants as helpful. Thewes et al. (2016) stated that there was some support for the use of interventions that addressed obsessive or ruminative thinking style rather than just the verbal content of the fears.

Another qualitative study on breast cancer survivors by De Vries et al. (2014) examined the use of problem-focused coping strategies and emotion-focused coping strategies with 27 women. Problem-focused coping strategies included confrontative coping such as letting feelings out, accepting responsibility such as taking responsibility for survival, planful problem solving such as writing down questions for doctors if nervous, and positive appraisal such as considering the positive aspects of surviving breast cancer. Emotion-focused coping strategies included distraction, self-controlling such as self-isolation when distressed, and escape-avoidance such as

keeping busy to avoid thinking. De Vries et al. (2014) found that, in regard to fear, every woman in their focus group spoke about helpful emotion-focused coping styles. This style of coping included distancing, self-controlling, escape-avoidance, and seeking social support. It is of interest to note that the two qualitative studies with women survivors indicate that aspects of avoidance-based coping are seen as helpful to patients, even though models of coping indicate that it tends to lead to poorer quality of life.

Broad Overview of Psychological Interventions for Survivors

Psychological interventions from both cognitive and behavioural approaches as well as mindfulness-based approaches have shown broad utility in improving specific and general factors related to quality of life in cancer survivors, and there is increasingly a focus on unifying psychotherapies under an inclusive family of cognitive and behavioural therapies (Collard, 2019). There are several studies on Cognitive Behavioural Therapy (CBT) protocols, and Mindfulness Based Stress Reduction (MBSR; Kabat-Zinn, 2009) protocols. Both modalities tend to show small to medium effects on quality of life for cancer patients during their treatment. For example, a meta-analysis of randomised control trials of CBT and Patient Education on a heterogenous sample of cancer survivors by Osborn et al. (2006) examined the effects of both programs on a number of psychological variables and quality of life. Individual sessions of CBT for this population had a significant and large effect size (g = .91) for quality of life at follow-ups which ranged from one week to 12 months depending on the study. In comparison, Patient Education did not have a significant effect at follow-up. CBT also produced large and significant effect sizes for depression (g = 1.21) and anxiety (g = 1.99) separate from a quality of life measure, though these effects were driven by individual therapy and not group therapy. A meta-analysis of mindfulness-based approaches for patients and survivors of breast cancer consisting of MBSR and Mindfulness Based Cognitive Therapy by Haller et al. (2017) indicated that there was a small short-term overall effect (standard mean difference = .21) in comparison to usual care for women undergoing or within two years of active treatment for breast cancer, however, the clinical relevance of this is unclear. Fatigue, sleep, stress, anxiety, and depression were similarly improved, with small effects for depression up to six months (standard mean difference = -.26), and anxiety up to 12 months (standard mean difference = -.08). The authors argued that, while these effects were statistically significant, it was unclear whether the change

was clinically meaningful. While this study provided useful estimates of effect size for mindfulness-based therapies, it included women undergoing treatment, and women within two years post treatment.

However, less clear in the literature on wellbeing and cancer survivorship is whether approaches that work for patients have the same effects for survivors. A meta-analysis on studies with cancer patients and survivors by de la Torre-Luque et al. (2016) may assist to clarify differences between effects for patients compared to survivors. This analysis was conducted on studies with cancer patients and survivors from English and Spanish speaking backgrounds. For a population not distinguished by cancer type, improvements to quality of life were seen with psychological intervention. There was a significant small effect size for patients under medical treatment (g = .24), and a significant medium effect size for survivors (g = .46). The authors suggested that quality of life becomes more relevant over time and psychological treatment can be considered within the context of promoting adaptive coping, including coping with the side-effects of medical management. Matsuda et al. (2014) looked at studies on psychoeducational support on quality of life in early-stage breast cancer patients at six-month follow-ups, focusing on information from randomised control trials. They found that these interventions provided during active medical intervention did not provide significant benefit to global quality of life scores at follow up, however, they did, at times, improve breast cancer symptoms and emotional-related wellbeing. However, this study included a wide range of psychoeducational and other psychosocial support, mostly low intensity, such as a self-help workbook, online coping program, internet peer support, and writing intervention. There was no cohesive theory about why these programs should be analysed together, other than that they were classified as ‘psychoeducational’.

While a review of all therapies that apply to women breast cancer survivor’s wellbeing is outside of the scope of this chapter, the above studies provide a basis for the exploration of cognitive and behavioural approaches to wellbeing in survivors, with a caution against generalising the effects of patients to survivors. Psychological approaches to survivor wellbeing are further limited by a lack of clarification regarding actual therapy tasks, therapy intensity, and how these impact specific outcomes.

Limitations in Intervention for Breast Cancer Survivors

The lack of theoretical cohesion highlighted in studies like Matsuda et al. (2014) show a particular difficulty with translating theoretical research into applied intervention studies. While many psychotherapies that use mindfulness and/or cognitive and behavioural strategies to improve quality of life, and while meta-analyses of these groups of treatments may show effectiveness, the results may be diluted by treatment fidelity and a lack of theoretical cohesion in activities and targets of intervention. For example, while avoidant coping is associated with poorer quality of life, a core component of CBT relies on categorising certain internal processes as undesirable, and then actively trying to get rid of them, which can be viewed as an internal escape from distress (Hulbert-Williams et al., 2015). Furthermore, while meta-analyses may make a therapy seem uniform in the field of cancer care, the treatment techniques can vary greatly between studies (see, for example, Tatrow & Montgomery, 2006) from hypnosis to problem-solving, to distraction, to communication training. Even MBSR, despite having a more predictable structure and set of activities, can vary widely in descriptions of content and format delivered in practice (Smith et al., 2005). For example, the treatment delivered in a study by Tacón et al. (2004) was eight 1.5-hour sessions, whereas Reich et al. (2017) used a six two-hour sessions format. Furthermore, sessions may involve a number of diverse activities, including yoga, relaxation, and meditation, for example as described in Carlson et al. (2004), which do not target a single construct of mindfulness or a coherent theory of why these strategies should be grouped together (Chiesa & Malinowski, 2011). Sometimes, mindfulness strategies are also used as part of cognitive and behavioural approaches, such as in Mindfulness-Based Cognitive Therapy. The definitions and delineations of different approaches are not clear.

Another challenge for interventions for quality of life in breast cancer survivors is the specific factors that treatments focus on. As mentioned previously, quality of life following primary breast cancer intervention involves a wide variety of factors and the construct is not well defined. As such, a wide variety of quality of life measures are employed in studies (Gill & Feinstein, 1994) and may not be directly comparable. Traditionally, CBT interventions tend to focus on specific symptom reduction, such as insomnia (Fiorentino & Ancoli-Israel, 2006), pain (Tatrow & Montgomery, 2006), or menopausal symptoms (Mann et al., 2012), with

the assumption that a reduction in these symptoms will increase an overall sense of wellbeing or functioning. Each study has such a narrow focus that the main conclusion that can be drawn is that specific CBT works for specific symptoms, but the generalisability to women who experience multiple symptoms is unclear. Mindfulness based strategies fairs a bit better by targeting a process, mindfulness, rather than specific symptoms reduction. By targeting a process that is associated with a number of cognitive functions, such as emotion regulation, non-attachment, and reduced rumination (Coffey et al., 2010), mindfulness-based therapies such as MBSR can be applied across symptomology. However, there is some concern about a therapy that only increases mindfulness, as there is some evidence that this technique can increase stress and depression in some cases as well as potentially amplifying certain mental disorders such as psychotic disorders, anxiety and depression (Dobkin et al., 2012; Farias & Wikholm, 2016). While the targets of CBT may be too narrow to capture the needs of breast cancer survivors, MBSR, while process-oriented, may not be targeted enough to the processes relevant in adaption in breast cancer wellbeing, such the framing of goals related to wellbeing as outlined in the Naus et al. (2009) model.

This mismatch of approaches to breast cancer survivor wellbeing can also be seen in the literature on fear of cancer recurrence. Thewes et al. (2014) conducted a descriptive survey of 141 Australian health professionals working in cancer care to examine commonly used approaches. They recruited participants through professional organizations, and participant characteristics indicated that the respondents were mostly well established in their profession, for example, with many respondents indicating 10 years or more since the completion of their professional training. Amongst clinical health professionals, defined as oncologists, surgeons, nurses, and palliative care staff, provision of information and referral to psychosocial support were the most commonly indicated strategies used to manage fear of cancer recurrence. Other methods of management included stress management techniques and medical investigations. Psychotropic medications were the least used method. Amongst psychosocial professionals, defined as psychologists, social workers, psychiatrists, and other professionals, the most used modalities were Acceptance and Commitment Therapy (ACT; Hayes et al., 2011), mindfulness and other ACT subcomponents; and cognitive approaches, including CBT and subcomponents. Other approaches indicated with some frequency included

validation/normalizing, and psychoeducation. The authors interpreted the spread of approaches to managing fear of cancer recurrence in the context of a limited consensus on how it is managed. They point to the concurrent use of strategies from different psychological traditions as evidence that clinicians rely on individual experience rather than considering the models of mechanisms of fear of cancer recurrence. ACT and CBT may be commonly used because these are common therapy modalities in Australia, rather than because they are the best fit for a presentation where fear of cancer recurrence is a feature.

Acceptance and Commitment Therapy and the role of Experiential Avoidance

While Thewes et al. (2014) mentioned that clinician familiarity with acceptance and commitment therapy (ACT) is the main driver behind its use to address fear of cancer recurrence in breast cancer survivors, this in addition to a review of the approach may present it as uniquely placed to be an impactful approach in the quality of life of early breast cancer survivors in regional Australia. ACT (Hayes et al., 2011) is a psychotherapy that is compatible with engagement approaches to wellbeing. This therapy is grounded in behavioural principles and incorporates the use of mindfulness techniques to engender psychological flexibility. The evidence base for ACT is wide, spanning from efficacy in treatment of mental illness (Powers et al., 2009), to chronic pain (Veehof et al., 2011), to sports performance (Bernier et al., 2009), and workplace engagement (Moran, 2015), with good outcomes in function improvement. Overall, ACT purports to target experiential avoidance (Hayes & Wilson, 1994), a transdiagnostic factor in disorders such as anxiety and depression (Spinhoven et al., 2014). In addition to its most researched effect in the treatment of psychopathology, and preliminary studies on its application in addressing the quality of life in cancer patients and survivors, ACT involves specified processes that may map onto conceptual models informing intervention to improve quality of life and address psychological distress and fear of cancer recurrence. These factors, in addition to the familiarity of the therapy in Australian oncology health professionals working with fear of cancer recurrence, make it a feasible option for regional areas where training a clinician to deliver a new therapy modality may be impractical.

ACT purportedly works by reducing emotional avoidance and increasing the capacity for behaviour change by undermining the impact of evaluation, acceptance of verbal explanations for behaviour, and the discourse that cognitive and emotional

control are achievable and desirable (Hayes & Wilson, 1994). This framework is consistent with aspects of adaption to cancer, for example, if ACT can assist a person navigate new experiences simultaneously without avoidance-based coping, and while remaining adaptive and engaged in goal-directed behaviours, this both reduces the impact on quality of life posed by coping styles proposed by Elliot et al. (2011) and Yang et al. (2008), and increases success in the adaption process relevant to quality of life outcomes proposed by Naus et al. (2009). Where ACT differs from traditional CBT is in the focus of the therapy and a person's relationship to their experiences. Whereas traditional CBT processes focuses on symptom reduction and are employed for reduction in specific cancer-related complaints, ACT processes focus on valued action. The focus on valued action fits with the definition and purpose of quality of life in cancer and its intervention by Cella (1994), that wellbeing in cancer treatment and survivorship must consider quality of life rather than just symptom reduction. Paradoxically, ACT does not focus on symptom reduction, rather, it proposes that symptom reduction is a product in the pursuit of a meaningful existence (Hayes et al., 2006). Whereas CBT focuses on challenging thoughts to create doubt in biased or irrational cognitions, ACT focuses on function-oriented interpretations, even if there is no basis for these thoughts (Hayes et al., 2011). This again is important in breast cancer survivorship, given that cancer recurrence is a possible scenario. The model of cognitive processing for fear of cancer recurrence by Fardell et al. (2016) addresses this perpetual uncertainty by proposing a shift of focus from symptoms rather than disputing the likelihood of the feared outcome. The focus of valued action over symptom reduction, as well as a disengagement from maladaptive coping strategies are examples of how ACT may be a good fit compared to other psychological interventions in addressing the wellbeing needs of women survivors of early breast cancer.

ACT Processes

ACT targets the underlying behavioural and verbal processes that cause an individual to disengage from functional behaviours (De Houwer, 2013), and may be a good fit for breast cancer survivors adapting to changes over time. There are six core ACT processes that create a reduction of avoidant style coping through the development of psychological flexibility. The processes are: acceptance, defusion, contact with the present moment, self-as-context, values, and committed action, which are described in Hayes et al. (2006):

Acceptance is a present-moment processing of private events as a method of empowering greater flexibility in response to those events. This involves noticing internal and external states, allowing for examination of experiences that can be aversive, such as pain or fear, before choosing how to respond. Acceptance reduces the reactivity to adverse events on an individual's behaviour. In breast cancer survivors, a reduction in reactivity may assist with adaption as outlined by Naus et al. (2009); being able to accept a sense of self that includes difficult cancer experiences, and remain adaptive to the current situation, may assist quality of life.

Defusion is a process that targets the development of non-reactivity or functional change to thoughts, allowing new learning or responses to thoughts and feelings to occur. Rather than changing the thought itself, defusion aims to change how an individual interacts with the thought. Again, by changing the reactivity, defusion aims to reduce the influence of unworkable thoughts on behaviours. In breast cancer survivors, this process may assist in the addressing the obsessive or ruminative thinking style rather than focus on the verbal content of fears as proposed by Thewes et al. (2016).

Contact with the present moment involves an attentional shift to ongoing internal and external events in the present. This allows for an increased responsiveness to present-moment events rather than automatically falling back into past patterns of thinking and behaving. Contacting the present decreases the focus and need to defend past, future, and conceptualised selves. This frees up an individual to respond to events of the present. Given that Deimling et al.'s (2002) study on long term survivors emphasised the role of temporal factors on psychological distress, with recent life events predictive of distress, responsiveness to present-moment events may assist breast cancer survivors to remain adaptive in long term survivorship.

Self-as-context serves to highlight the sense that there is a thinker who is separate yet encompassing of all her thoughts and feelings. It is a perspective standpoint from which someone can be aware and encompassing of many thoughts, feelings, and experiences without attachment to them. This process inserts a non-reactive perspective or sense of self. In breast cancer survivors, a concept of self is relevant to the model of quality of life proposed by Naus et al. (2009) that emphasised the personal context where someone's appraisal of perceived threats, and coping, lead to life decisions that impact on health wellbeing; the process of self-as-

context creates awareness without attachment, which may help to broaden a survivor's appraisal. Similarly, a self-as-context targets the existential challenges in Fardell et al.'s (2016) fear of cancer recurrence model by changing a survivor's self-concept.

Together, Hayes et al. (2006) refer to these processes as a behavioural definition of mindfulness. These processes work together to reduce experiential avoidance by disentangling experiences from pre-existing perceptions of experiences. For example, a survivor may think that she will be a burden if she discusses her breast cancer experience with others. This may cause feelings of shame and withdrawal from social situations. ACT processes can assist her in many ways, such as through noticing the reactions she has to her thoughts, changing her perspective of self to be broader than one of shame, or focusing on the terms of her current existence, rather than comparing her current needs to the needs of her past or future.

Values are sets of internalised rules that orient a person to behaviours that are meaningful to them. Values provide guidance regarding the workability of a behaviour; a behaviour is workable if it aligns the outcome with a value. Targeting values-based behaviours aligns with the work of Wilson and Cleary (1995) and Cella (1994) as well as the intrinsic motivation outlined by Ryan and Deci (2000), as a process that assists survivors achieve healthy development regardless of circumstance.

Committed action is the behaviour towards value-consistent goals. These two processes help individuals to create and enact on a direction for their attention and behaviour. In breast cancer survivors, this process may represent the opposite of avoidance-based coping. As Elliot et al. (2011) discovered, both avoidance-framed goals and avoidance-based coping strategies increased stress, and reduced subjective wellbeing. Additionally, in the face of a feared outcome, Yang et al. (2008) clarified that disengagement coping mediated stress and quality of life. Committed action in ACT is an alternative to avoidant and disengaged coping, possibly reducing the ill-effects of these styles of coping for survivors by offering a different strategy for stressors.

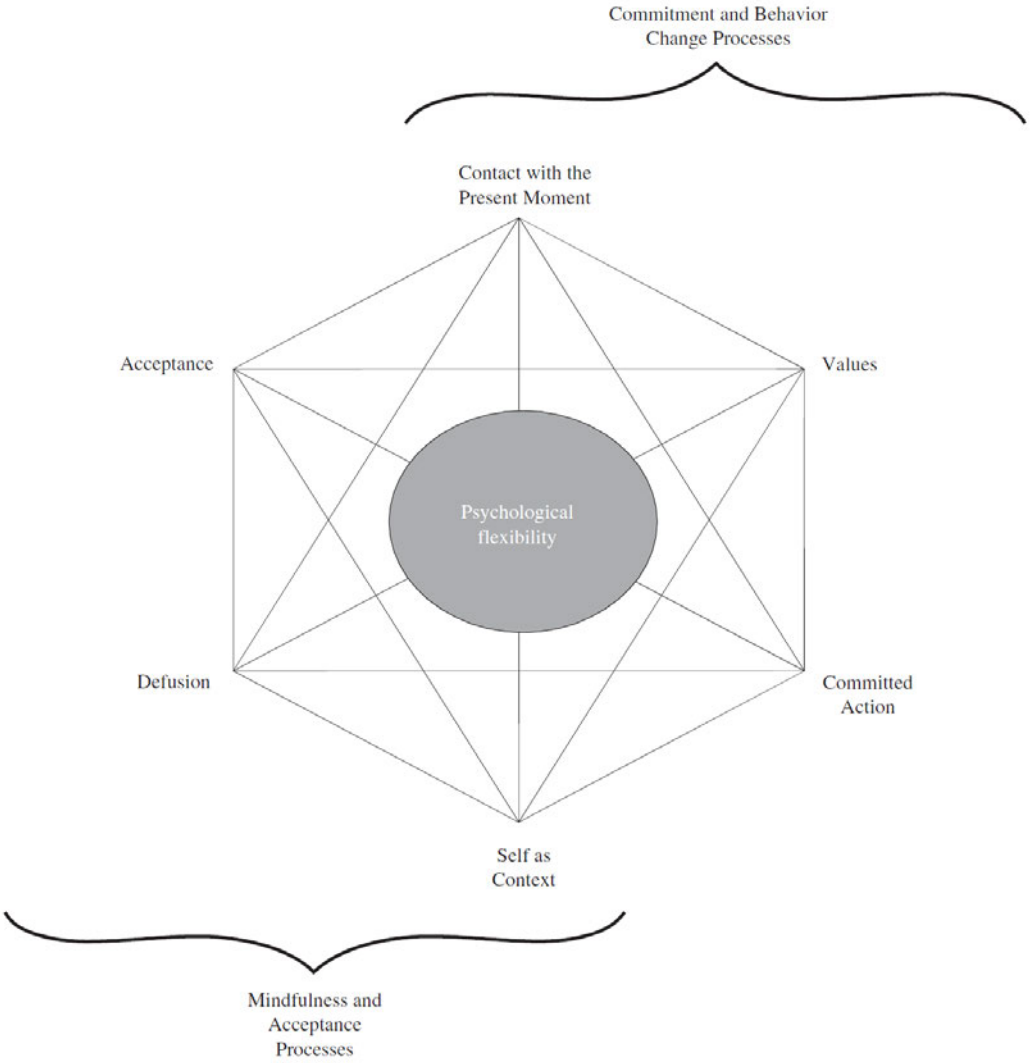
Values and committed action, along with contact with the present moment and self as context are grouped by Hayes et al. (2006) to be processes related to the behavioural change component of ACT. For example, if a woman chooses social

engagement as a value to her, she may choose to focus her attention on how to improve her social contact despite feelings of shame. Each step she takes towards this value, rather than towards an avoidance of shame, is a committed action in line with her values.

By applying the six core processes, wherever relevant, an individual responds adaptively to her internal and external environment to move towards a meaningful or valuable direction (Hayes et al., 2011). The inclusion of values and committed action makes ACT a directive therapy. Rather than training mindful awareness as a therapy in itself like MBSR, ACT helps to channel mindfulness skills to assist an individual's chosen direction. Figure 3.1 is a visual representation of the ACT hexaflex, which is a model of ACT processes.

Figure 3.1:

The ACT hexaflex



The ACT hexaflex, Copyright Steven C. Hayes. Used by permission.

ACT and Cancer So Far

Evidence for ACT in cancer care has been demonstrated on an individual treatment basis in a preliminary study on an Australian population. Feros et al. (2013) investigated the use of an ACT protocol in individual therapy sessions to treat 45 cancer patients from a major city in New South Wales, Australia, with varying cancers and treatment stages. About half of these participants had breast cancer (48.9%). The protocol specified four modules across nine one-on-one sessions that focused on increasing effective action orientation, mindfulness, self as context, and formal value clarification and commitment. Feros et al. (2013) found that participants who engaged in the intervention had improved distress, mood, and

quality of life, with a large effect size for distress (d = 1.11) and mood (d = .99), and medium effect size for quality of life (d = .56) at follow up. These outcomes were maintained at a 3-month follow-up (d = .87, 1.12, and .47 respectively). This study employed the DASS-21 (Lovibond & Lovibond, 2002) and FACT-G (Cella et al., 1993) for outcomes measurement, with the use of the DASS important in comparing outcomes to clinical psychology practice outcomes in Australia. However, availability of resources such as clinicians is important to consider in regional settings, and individual therapy may occupy a clinician's time more than group therapy.

A group-based ACT intervention for cancer patients in the United States by Arch and Mitchell (2016) found similar results to Feros et al. (2013), suggesting that group-administration of ACT is possible for cancer patients. This study involved 42 participants who experienced anxiety during transition from active treatment to post treatment. The groups consisted of 8 – 12 participants, with facilitation guided by a group manual and participant workbook. Activities in the manual aimed to cultivate awareness and acceptance of thoughts and emotions about cancer, defusion from thoughts and beliefs about cancer and unhelpful self beliefs, and clarifying personal values and commitment to activities in line with personal values. Groups ran for approximately 2 hours over seven weekly sessions. There were moderate to large reductions in anxiety (d = .75 to 1.00), fear of recurrence (d = .34 to .66), and trauma symptoms (d = .58 to .84), as well as small increases in participant-reported vitality (d = .52 to .77), with results maintained at a 12-week follow-up.

A strength of the Arch and Mitchell (2016) study was the use of multiple baseline measures prior to the intervention, which showed no significant change in the abovementioned areas prior to intervention. It also assessed whether change in psychological flexibility, as measured by the Cancer Acceptance and Action Cancer Questionnaire created for the study, during the intervention predicted change in outcomes. A change in cancer-related psychological flexibility predicted changes in depression, physical pain, traumatic impact of cancer, vitality, life meaning, and life manageability in a hierarchical linear model (all p <.05). However, as with Feros et al. (2013), there was no comparison group in this study and the studies combined different cancer types. Like Feros et al. (2013), this study also reported results as standardised against their first baseline measurement. Additionally, this study did not comment on change across categories of symptoms, such as from a severe to a

normal levels of symptoms, which reduces its clinical utility. For example, it was unclear whether the reduction in symptoms amounted to a clinical reduction in anxiety (i.e., participants would no longer meet screening criteria post intervention).

One study on ACT in cancer care that did have a comparison condition was a pilot randomised trial conducted by Mosher et al. (2018) in the United States using telephone-based ACT with 47 metastatic breast cancer participants to improve fatigue and sleep. This study compared ACT to an education/support condition. The ACT condition consisted of a discussion of coping strategies, practice of mindfulness, practice of cognitive defusion, cultivating a transcendent sense of self, identifying core values, and identifying and practicing values-based actions. The education/support condition consisted of orientation to the cancer centre and treatment team, with an overview of quality of life issues and physical quality of life, discussion of social quality of life, referral to resources, discussion of other aspects of quality of life, resources for managing financial challenges, tips for evaluating health information, and review of prior sessions with a referral to websites with cancer-related information. Those in the ACT condition experienced a small decrease in symptom interference and moderate decreases in fatigue and sleep disturbance maintained 12 weeks post baseline measurement ($d = -.019$ to $-.31$). Those in the education/support condition also showed decreases in these outcomes, however, they were smaller than those seen in the ACT condition. Small reductions in depressive symptoms were seen in both groups within the same measurement timeframe (e.g., $d = -.30$ for ACT compared to $d = -.22$ for Education/support). While the study was not group-based, it was more specific in the targeting of breast cancer patients and provides a clearer picture of an ACT-based intervention for this population. Administration of health services through telephone is an innovation aimed to increase service provision in regional areas (Platt et al., 2015) and this study by Mosher et al. (2018) provides support for telephone delivery of ACT to the cancer patients. However, again the clinical utility of changes seen in the study is questionable. However, given that this was an exploratory study into the benefits of brief telephone intervention, the limited effects could be due to a departure from treatment conditions that were previously evaluated to be effective, for example, as mentioned previously, interventions in a group setting. The trade-off between interventions with a longer duration and group setting, versus a shorter duration and

individual setting is uptake and adherence, with patients more likely to engage in low intensity interventions (Beatty et al., 2018).

Montesino & Luciano (2016) recruited 12 participants for a study specifically on the effects of ACT and fear of cancer recurrence in women diagnosed with breast cancer. It unclear whether the women had completed primary intervention for breast cancer, with time since diagnosis varying between one to 66 months. Women were first identified to have anxiety using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 198) and asked to rate from one to ten their fear intensity and interference with an area of value for the women. Eight participants were assigned to active treatment, and four to the wait-list control condition. A significant reduction in fear interference was detected in the treatment group immediately post (p = .04), at 1-month (p = .02), and at 3-months (p = .01) following intervention, but not significant for the control group (p = .18). Reduction in fear intensity was not significant post and 1-month following for the treatment group, however, was significant at the 3-months measurement for the treatment group (p = .02) and not the control group (p = .66). There was a larger effect size of intervention for interference (d = 2.43) compared to intensity (d = 1.74), and in both cases outperformed the control group (d = -.39 and .31 respectively). Montesino & Luciano's (2016) results are similar to that of Feros et. al (2013) that demonstrate continued and possibly increased gains compared to baseline following ACT intervention, and to capture the effect of ACT, longer term follow-up is needed. Taking advantage of the comparatively smaller sample size, this study may have benefited from the addition of individual analyses to determine whether some individuals were driving the group effect disproportionately.

These studies and others, along with the theoretical underpinnings of ACT, provide some grounds for using ACT with a cancer population in a group intervention context. However, the needs of patients and survivors as well as the impact of psychological interventions for the two groups are different (de la Torre-Luque et al., 2016), and the abovementioned studies are with cancer patients, not survivors. It is possible that ACT can also assist in addressing wellbeing in breast cancer survivors. However, given that the evidence base for ACT is still building, it is noted that, outside of the cancer care setting, ACT has not been shown to outperform other therapy modalities, such as CBT, in metanalyses of randomised control trials (Öst, 2014). The advantage compared to CBT thus far is that there is

some evidence that ACT works through its purported processes (Jiménez, 2012), and these processes align with quality of life and fear of cancer recurrence as conceptualised in cancer survivorship. Overall, ACT may be considered a comparable therapy which matches conceptual aspects of breast cancer survivor wellbeing.

Experiential Avoidance

As experiential avoidance is a target of ACT, a review and inclusion of this construct is relevant when considering this therapy modality in improving quality of life and managing psychological distress and fear of cancer recurrence. Experiential avoidance is someone's unwillingness to maintain contact with a private experience, such as a sensation, emotion, or thought, and thus their engagement in strategies to avoid these experiences (Hayes et al., 1996). While experiential avoidance is well defined, there is some confusion over the overlap with other terms used in ACT. Experiential avoidance is a process embedded in several other relevant psychological processes associated with ACT, such as psychological flexibility, psychological inflexibility, and acceptance (Hayes et al., 2011). There is ongoing effort related to the clarification of these related concepts. For example, while experiential avoidance is often described at the opposite of psychological flexibility (Hayes et al., 2006), this has not been directly tested. Experiential avoidance and psychological inflexibility are often referred to interchangeably, with avoidance describing a process of maintenance for psychopathology and flexibility describing a process of increasing vitality. Often, the constructs or processes of psychological flexibility and experiential avoidance are measured using the same measure, for example, in Silberstein et al. (2012), Levin et al. (2014), and Whiting et al. (2015), which all refer to their construct of interest as psychological flexibility despite using versions of the Acceptance and Action Questionnaire (AAQ; Hayes et al., 2004), which is a measure associated with experiential avoidance. Whether psychological flexibility and experiential avoidance are two ends of the same construct has not been comprehensively tested because the primary measure for experiential avoidance in the literature, the AAQ-I (Hayes et al., 2004) and its variants, is also used as the measure for psychological flexibility, with higher scores indicating higher experiential avoidance and lower psychological flexibility. This review of experiential avoidance will include literature on psychological flexibility where the measure for both are the same.

Interventions targeting experiential avoidance have some broad utility, as the process underlies many mood and behavioural disorders. Kashdan et al. (2006) conceptualised it as a generalised psychological vulnerability. In their paper, they add that experiential avoidance is not a problem if it does not impair someone's ability to live coherently with their self and pursue meaningful goals. It is problematic in situations where it is applied rigidly and inflexibly, because it consumes significant time, effort, and energy, and struggling with private events impairs overall functioning. Kashdan et al. (2006) proposed that taking action towards valued goals requires contact with a range of emotions, sometimes painful, and that experiential avoidance is problematic because it reduces an individual's ability to contact emotions, thereby impairing their ability to pursue goals and experience pleasure. To support this, Kashdan et al. (2006) conducted a series of studies included in the same paper to clarify how experiential avoidance may maintain distress and reduce engagement.

In the first study, Kashdan et al. (2006) set out to observe whether forms of coping predicted anxiety-related distress, and if this was mediated by experiential avoidance. Participants were 382 university undergraduate student volunteers, mostly Caucasian (64.9%). Participants completed a randomly ordered battery of questionnaires to measure experiential avoidance, adaptive and maladaptive coping with emotions, tendency to inhibit emotional responses, uncontrollability over anxiety-related events, and measures known to covary with anxiety-related symptoms. These measures were: the Acceptance and Action Questionnaire (AAQ-I; Hayes et al., 2004) to measure experiential avoidance; the Coping Style Questionnaire (Roger et al., 1993) to measure coping strategies for emotional events; the Emotion Control Questionnaire (Roger & Najarian, 1989) to measure tendency to inhibit the expression of emotional responses; the Anxiety Control Questionnaire (Rapee et al., 1996) to measure perception of control over anxiety; the Anxiety Sensitivity Index (Peterson & Reiss, 1993) to measure fear of anxiety related symptoms; the Body Sensations Questionnaire (Chambless et al., 1984) to measures physiological symptoms associated with anxiety; Spielberger Trait Anxiety Inventory Form – Y (Spielberger et al., 1983) to measure trait anxiety; and the Suffocation Fear Scale which is an unpublished questionnaire the authors accredit to Rachman and Taylor (1994) which measures fear of suffocation. Kashdan et al. used zero-order correlations to consider how experiential avoidance may be related to

anxiety and coping variables. Experiential avoidance was significantly related to many facets of less adaptive coping (r = -.24 to -.33), more maladaptive emotional responding (r = .22 to .34), and less perceived control over anxiety-related events (r = -.50). Kashdan et al. then used linear regression analyses to consider mediation of above-mentioned variables by experiential avoidance. Experiential avoidance significantly predicted the impact of emotional coping, emotional responding and anxiety controllability (i.e., for anxiety sensitivity on emotional coping, responding and controllability, β = .21 to .37; body sensations, β = .12 to .18; trait anxiety, β = .57 to .63; fear of suffocation, β = .21 to .33).

In the second study Kashdan et al. (2006) examined causal relationships between experiential avoidance and daily affect, meaning, and hedonic functioning, to establish that experiential avoidance may serve to disrupt engagement and pleasure in daily activities. Kasdan et al. recruited 97 undergraduate students, mostly female (n = 64) and Caucasian (76%). Participants were asked to complete a battery of questionnaires at the end of each day for 21 days. Measures included the AAQ-I (Hayes et al., 2004), and Emotion Regulation Questionnaire (Gross & John, 2003) as dispositional self-report measures. Daily affect, event, and hedonic functioning were measured by: a daily positive and negative affect scales with nine items for positive affect and five items for negative affect; a question on intensity of gratitude emotions experienced; social anxiety questions modified from the Fear of Negative Evaluations Scale (Rodebaugh et al., 2004) and International Consensus Group on Depression and Anxiety (Ballenger et al., 1998); perceived meaning in life measured by two items; perceived life satisfaction measured by one item; daily curiosity using items modified from the Curiosity and Exploration Inventory (Kashdan et al., 2004); and daily positive and negative events using items from the Daily Events Survey (Butler et al., 1994). To assess the reliability of these measures, Kashdan et al. used a multilevel random coefficient modelling software to provide reliability estimates, and found that the measures had good reliability. Experiential avoidance was again significantly related to many facets of experiencing. For example, it had significant negative relationships with positive affect, gratitude, meaning in life, life satisfaction, and curiosity (β = -.04 to -.20, effect size r = .38 to .55), and positive relationships with negative affect (β = .19, effect size r = .52), and social anxiety (β = .28, effect size r = .47). It also significantly predicted positive events (β = -.11, effect size r = .36) and negative events(β = -.03, effect size r = .23). This study

supports the idea that experiential avoidance limits someone's ability to derive pleasure and engagement in life. From these studies, Kashdan et al. (2006) assert that experiential avoidance is an etiologic and maintenance factor for anxiety disorder as well as reduces capacity to engage in meaningful living.

There is some evidence that experiential avoidance is a lasting trait unless it is addressed. In response to the proposal that experiential avoidance may be a product of emotional disorders (i.e., when someone is depressed, they are more likely to perceive feelings or situations as aversive, and then more likely to disengage), Spinhoven et al. (2014) conducted a longitudinal correlation study, looking at the stability of trait experiential avoidance at times two (T2), four (T4), and six (T6) years. A total of 2316 participants, mostly Dutch, completed a Dutch translation of the AAQ-I. Of these participants, 64.2% had no six-month recent depressive or anxious disorder. The others had dysthymia, major depression, generalised anxiety disorder, social anxiety disorder, panic disorder, and agoraphobia, with about half (50.8%) having one or more comorbidities. They divided participants into four groups: a) the unaffected group with no disorder, b) the occurrence group with no disorder at first measure but disorder at second measure, c) the recovery group with disorder at first measure but no disorder at second measure, and d) the affected group with disorder at both measures. There was significant change in experiential avoidance across all groups, except for the affected group, however, this may be more an artifact of sample size as the effect size of change in the unaffected group was between micro and small (d = .11). There was a small effect for the occurrence (d = .22) and recovery groups (d = .34). Spinhoven et al. (2014) then considered cross sectional differences in experiential avoidance between the different groups. Using ANOVAS, they found a significant effect of measures taken at T2 on measures at T4. Those with experiential avoidance at T2 were more likely to be experiencing a disorder, and more likely to develop a disorder at T4. Spinhoven et al. (2014) examined the mediation effect of experiential avoidance at T2 on T4, along with fear and distress disorders at T2, predicting a distress disorder T6. They found that experiential avoidance at T2 significantly predicted experiential avoidance at T4 (β = .70), and that experiential avoidance at T4 significantly predicted a distress disorder at T6 (β = .42). This pathway had more predictive value on a distress disorder at T6 than a fear or distress disorder at T2 (β = .07 and .26 respectively). These results suggest that experiential avoidance tends to be a stable

trait over time and has more predictive value of current and subsequent anxiety or distress disorder than the presence or absence of an anxiety or distress disorder at earlier points.

A measure of experiential avoidance: The Acceptance and Action Questionnaire (Bond et al., 2011)

A widely used measure of experiential avoidance is the AAQ (Hayes et al., 2004) , and its derivatives, such as the AAQ-II (Bond et al., 2011). The authors indicate that the AAQ measures a construct referred to as acceptance, experiential avoidance, and psychological inflexibility (Bond et al., 2011), however, it is often used as a measure of psychological flexibility including in breast cancer research, for example, in González-Fernández et al. (2017).

A preliminary assessment of the first version of this measure was published by Hayes et al. (2004), with some authors of the paper also involved in the advance of Relational Frame Theory (Hayes et al., 2001) and ACT (Hayes et al., 2011), which are the theory and therapy, respectively, related to experiential avoidance and psychological flexibility. Hayes et al. (2004) developed a nine-item questionnaire initially for use in population studies or other non-specific applications. They proposed that, if the conceptual understanding of experiential avoidance and ACT are correct, then the measure should correlate with a broad range of measures related to dimensions of health, pathology, and behaviour. A 32-item pool was generated by the authors, with some reverse-scored, and included statements, such as ‘You can’t really control what you think’, ‘I avoid putting myself in situations where I am uncomfortable’, and ‘I try hard to avoid feeling depressed or anxious’. Data was drawn from a number of studies investigating the relationship of such items with other constructs. Exploratory and confirmatory factor analyses were conducted with two separate clinical samples. The first sample consisted of 460 clients, mainly Caucasian, from a university counselling centre. The second sample consisted of 491 clients receiving psychotherapy through a health cooperative. In the exploratory analysis, the authors pursued a one-factor model, with a lack of consensus on best fit, initially with 16 items, but shortened to nine due to the desire for the questionnaire to be feasible for population studies. These nine items were then modelled with a second sample. The authors tested whether their measure correlated with, but did not measure the same, constructs as existing measures. They found that the nine-item AAQ-I correlated with several health and pathology measures, such as versions of

the BDI (Beck & Steer, 1993) , and the General Health Questionnaire (Goldberg, 1978). The means differed by gender and ethnicity, with females in clinical populations (F = 21.3, p <.01) and non-Caucasians in non-clinical populations (F = 9.3, p <.01) scoring significantly higher. As a limitation, Hayes et al. (2004) stated that the AAQ may not be sensitive enough to assess the impact of acceptance-based treatment, such as ACT, as therapy should target individual and specific thoughts and feelings that are difficult for the person, whereas the AAQ is a general measure.

Bond et al. (2011) developed a 7-item version of the AAQ, called the Acceptance and Action Questionnaire II (AAQ-II). Bond et al. (2011) noted that the alpha coefficient for internal consistency in the original AAQ-I was α=.70 and the test-retest reliability was α=.64 over four months. They suggested that this may partially be due to test-taker's understanding and comprehension of the items. Bond et al. (2011) used a panel of 12 experts to generate items, followed by a subpanel of five experts who rated items for clarity. The expert panel created 49 items, which were then read by adults familiar (n = 26) and unfamiliar (n = 18) with the measure to provide feedback about clarity and readability. They then removed several items whose factor loadings were below .30 and used the remaining 27 items to analyse factor structure of a two factor and one factor solution. Bond et al. (2011) retained a one factor model that consisted of seven items with a coefficient of α = .88 which explained 50.68% of the variance. In three separate samples used for confirmatory factor analysis, the items maintained good fit and comparable coefficients. They then compared the new measure to a truncated list of other psychometric measures that the original AAQ considered and found that there was convergent validity between the measures, including the Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995). They also examined its test-retest reliabilities at three and 12 months, which were .81 and .79, respectively. Overall, the process that Bond et al. (2011) undertook improved the psychometric properties of the AAQ.

Criticisms of the AAQ and AAQ II

There are many criticisms of the AAQ and AAQ II, some by its own creators. Firstly, there is concern that the measure is too simple to capture the construct of experiential avoidance in a meaningful way within individual responding (Hayes et al., 2004). In a paper that considered experiential avoidance as a functional and dimensional approach to diagnosis and treatment, Hayes et al. (1996) described experiential avoidance as a process that includes both unwillingness and action to

avoid unwanted experiences, with the type of unwillingness and avoidance behaviours as distinct with each person and environment. However, both the AAQ and AAQ-II focus on broad unwillingness only, which makes it insensitive to context.

Wolgast (2014) highlighted a few construct validity shortcomings of the AAQ and AAQ-II including that they do not distinguish between process and outcome, that there is insufficient discriminant validity of negative affectivity and neuroticism, and that it is unclear whether these measures distinguish between experiential avoidance and psychological inflexibility as traits that impact psychological wellbeing and functioning. To clarify what the AAQ-II measures, Wolgast (2014) created two additional scales, Distress and Acceptance, using expert consensus of 30 participants, which had $\alpha = .85$ and .75, respectively. These scales modelled the wording of the AAQ-II and were used in a factor analysis with the items of the AAQ-II to consider whether control/avoidance and behavioural flexibility were captured in the same measure. (Wolgast, 2014) found that the AAQ-II items measured general distress rather than acceptance/nonacceptance. He also highlighted discriminant validity issues by showing that the AAQ-II was not distinct from the Positive and Negative Affect Scale (Watson et al., 1988), with bi-variate correlations between the measures as -.61 and .67 respectively.

In the construction of a multi-dimensional measure of experiential avoidance, the Multidimensional Experiential Avoidance Questionnaire, Gámez et al. (2011) noted that the AAQ may only measure nonacceptance of distress and the interference with values, rather than the broader scope of experiential avoidance. They also indicated a lack of research into the overlap between the AAQ and neuroticism and negative affectivity, despite conceptual distinction of these with experiential avoidance. In the first phase of their study, they considered the definition of experiential avoidance to encompass the following facets: Nonacceptance of negative experiences, interference with values and/or goals, avoidance without awareness, and attitudes or beliefs about negative experiences. They grouped six experiential domains: behaviours, emotions, thoughts, memories, autonomic sensations, and pain. They recruited university students ($n = 312$) to conduct an exploratory factor analysis. Eight factors were retained with 79 items. These items were further refined in a second phase of the study, and several other psychometric measures were obtained for convergent and discriminatory validity on another

sample of university students (n = 314) and patients (n = 201) from mental health clinics. The comparison measures did not include the BDI (Beck & Steer, 1993), however, they did include the Neuroticism Scale of the Big Five Inventory (John et al., 1991). They also used this to further refine items and establish scores for mental health patients. They found that their items had explanatory power in both populations beyond neuroticism and also both versions of the AAQ. The third phase of the study examined replicability in student, psychiatric, and community dwelling populations. They found that the six subscales all loaded significantly onto a single factor of experiential avoidance, however, Distress Endurance had a weak loading for patient and student samples. The final questionnaire contained 63 items.

Multi-dimensional measures are continuing to be developed to measure experiential avoidance and other related constructs. Another example is the Comprehensive Assessment of Acceptance and Commitment Therapy Processes (Francis et al., 2016), which was developed to better measure the effects of ACT processes that purportedly increase psychological flexibility. However, while these measures show promise, the AAQ-II's main defence is its current utility in facilitating comparisons of treatments in a wide range of existing studies. A seven-item measure with good psychometric properties is useful across clinic and research settings as a brief way of measuring and comparing the effects of treatments that target experiential avoidance across a number of studies, including clinical trials. Additionally, while the new measures show promise, they have not yet been used with breast cancer patients, and their psychometric properties as an outcome measure have not been established.

Experiential Avoidance in Cancer

Hulbert-Williams et al. (2015) proposed avenues through which targeting psychological flexibility may be a viable psychological intervention approach for cancer patients. They argued that current psychological interventions for cancer patients have poor descriptions and the justification for intervention components limits comment, understanding, and application of the therapeutic framework to the process of change. For example, if ACT reduces experiential avoidance or increases psychological flexibility as the avenue through which it affects other variables of interest such as anxiety, depression, and quality of life, then research into ACT interventions should include a measure of experiential avoidance. If anxiety and depression changes with ACT intervention, but experiential avoidance remains the

same, then the purported mechanisms of action for change in ACT intervention would be incorrect. Studies that incorporate measures that check the mechanisms of action for therapy can assist with improved understanding of therapy processes that create change. Hulbert-Williams et al. (2015) proposed that an understanding of potential mediators such as experiential avoidance in ACT intervention models can improve a generalised effect that may be both personalized and broadly suit the way adaption to cancer and treatment occurs in patients. ACT, underpinned by a focus on psychological flexibility rather than pathology, may better assist and describe the course of adjustment in treatment and survivorship.

Romano (2013) considered the role of experiential avoidance in health outcomes for cancer survivors. Her thesis proposed a mechanism of action for the effect of mindfulness on the health and mental health of cancer survivors in which experiential avoidance mediates the relationship between mindfulness and anxiety, mindfulness and depression, and mindfulness and physical health. She recruited 76 cancer survivors to complete several questionnaires. Of her participants, 50 had breast cancer as the primary diagnosis. Romano used the Medical Outcomes Study Short Form (McHorney & Ware, 1995) to measure health-related quality of life, the HADS (Zigmond & Snaith, 1983) to measure anxiety and depression, the Mindfulness Attention Awareness Scale (Brown & Ryan, 2003) to measure dispositional mindfulness, and the AAQ-II (Bond et al., 2011) to measure experiential avoidance. Her model showed that mindfulness had a direct effect on experiential avoidance (d = -.61), and that experiential avoidance impacted anxiety (d = .60) and depression (d = .50), more so than the direct effect of mindfulness on depression (d = -.24) and anxiety (d = -.27).

There is some evidence for the usefulness of targeting experiential avoidance in breast cancer patients and survivors. A survey of psychological flexibility and breast cancer was conducted by González-Fernández et al. (2017) with responses from 122 women survivors. They used a number of measures for mood and quality of life, such as the European Organisation for Research and Treatment of Cancer QLQ-C30 (Aaronson et al., 1993), a short form of the BDI (Beck & Steer, 1993) , and the HADS (Zigmond & Snaith, 1983). Experiential avoidance was measured by a Spanish translation of the AAQ-II (Bond et al., 2011) with good internal consistancy (α = .88). Greater emotional distress and poorer quality of life were associated with higher experiential avoidance (r = .50 and .70 respectively).

Aguirre-Camacho et al. (2017) looked experiential avoidance in early breast cancer patients who had recently received a diagnosis of breast cancer and were without other complications such as metastatic breast cancer, mental illness, or cancer recurrence. This group of 54 participants completed group-based CBT without the targeting of experiential avoidance. Participants completed the FACT-B (Brady et al., 1997), HADS (Zigmond & Snaith, 1983), and the AAQ-I (Hayes et al., 2004), as outcome measures for the group. While anxiety (t = 3.62, p <.01) and depression (t = 2.30, p = .02), showed improvement with intervention, experiential avoidance (t = -1.51, p = .13) and quality of life (t=-1.81, p = .07) did not change significantly. This adds support the findings of Spinhoven et al. (2014) that experiential avoidance may not change without direct intervention.

Together, these studies provide some direction for how experiential avoidance may apply to breast cancer survivor wellbeing. Experiential avoidance may be an underlying process that increases and perpetuates general distress, affecting wellbeing through different pathways. Contemporary models and interventions for fear of cancer recurrence, such as the Fardell et al. (2016) model, are starting to incorporate processing and response to unwanted Ies, which experiential avoidance can assist to explain.

Research Question and Aims for Study One

A wellbeing project was sought by a rural breast cancer foundation in Toowoomba, Queensland, due to the concerns raised by health professionals and patients who had completed their primary breast cancer intervention in the region. Anecdotal reports indicated that there was not enough structured group support for survivors following primary care, and more was needed to support women's quality of life and wellbeing post-treatment. While patients received cancer education and some exercise practice as part of their usual course of treatment, a breast cancer nurse working in a private hospital setting, G.F., reported the need for post-treatment psychological intervention to maintain wellbeing. An additional concern was the effectiveness of social groups, such as peer support groups. G.F. reported noticing that some women would not attend social support groups because they perceived a lack of focus on recovery, thereby limiting therapeutic benefit.

Study 1 aimed to investigate the contribution of ACT to the outcome of women's quality of life during cancer recovery. This project was a pilot study conducted in conjunction with a biological research project on the effects of quality

of life and health biomarkers, with the intention to inform a larger trial. This project was conducted in conjunction with a biological research project on the effects of quality of life and health biomarkers. The psychological component focused on exploring the following questions:

1. Does a group-based ACT intervention improve the reported quality of life of women post primary breast cancer treatment?
2. Does a group-based ACT intervention produce clinically relevant outcomes in anxiety, depression, and stress?
3. Does a group-based ACT intervention reduce fear of cancer recurrence?
4. Does a group-based ACT intervention produce results due to an improved psychological flexibility as the literature suggests?
5. Are certain women more likely than others to benefit from ACT intervention?

It was proposed that a greater understanding of the mechanisms of change and wellbeing would contribute to more targeted and effective programs in this area.

CHAPTER 4 - STUDY ONE

Method

Design

The design of this study was an unblinded, three-arm crossover, pilot randomised control trial. A computer-generated block randomization technique was used by one of the investigators with no clinical involvement in the trial, GB, to allocate participants into three equal groups of eight participants in each group. Participants were randomly assigned to three conditions:

1. Group A: received six weeks of ACT followed by six weeks of a breast cancer education program (BCE).
2. Group B: received six weeks of BCE followed by six weeks of ACT.
3. Group W: is the waitlist condition that waited for six weeks, then received 6 weeks of ACT.

Eligible participants were women aged 18 years and older who had completed primary treatment (survey, chemotherapy, and/or radiation) for early breast cancer (Stage 1 – 3) in the previous two years. Participants were excluded if they were currently undergoing mental health treatment, had a history of current severe psychiatric disorders (e.g., active psychosis, substance use disorder, post-traumatic stress disorder), and/or were unable to read or understand spoken English.

There were several practical concessions due to the community nature of the project. Firstly, following consultation with the research team, which included researchers and clinicians who were passionate about working with this population group, it was decided that the experiment would be designed to allow all participants to access the main active treatment, which is acceptance and commitment therapy. This was a deliberate concession to the research design with consideration for the immediate needs of the local community and the study participants. Secondly, as some of the participants may have been in an age group where they had school-aged children, the timing of the trial prioritized school holidays and public holidays over a wash-out period. Also, although comparable psychotherapy interventions from similar fields typically had eight sessions (e.g., mindfulness-based stress reduction), this adapted ACT protocol was shortened to six sessions to make it more feasible for participants to attend all sessions. Thirdly, this study was conducted as part of a larger research project including biomedical science to consider the biomarkers of

stress. The biological component of this study is not reported in this chapter, except where it impacted treatment design. Consent forms and information forms contained a combination of information required for the psychological and biological components of the study. One of the limitations cited for the biological component of the study was the lack of washout period between interventions, however, a washout period is not standard for psychotherapies as the effect of the therapy is anticipated to continue following the cessation of therapy sessions. For example, in the Feros et al. (2013) study, experiential avoidance continued to decrease three months post active intervention.

The group sessions were conducted in a regional Queensland private hospital on a Saturday morning commencing at 8am or 9:30am. Participants were asked to fast at Week 1, Week 6 and Week 12, and saliva and blood was taken for a biological study that occurred as part of an overarching project. Catering was provided at each session. Where sessions ran concurrently, two to three rooms were provided. Surveys were collected digitally, either emailed to participants to be completed prior to attending sessions or completed via tablet on the day of a group. Two participants were not fluent with technology use. In these cases, the survey was 1) printed out for them to complete, then entered into the survey by an experimenter, or 2) completed with the help of a participant's family member or, 3) delivered orally over the phone by an experimenter, who entered the responses into the computer.

Funding and in-kind support for the trial consisted of grants and scholarships from The University of Southern Queensland; funding from the partnering hospital, St Andrews Hospital; and funding from a local charity supporting breast cancer patients and their families, Blush Cancer Care Inc. Ethics approval was obtained from the Darling Downs Hospital and Health Services Human Research Ethics Committee (HREC/17/QTDD/51) and the University of Southern Queensland Human Research Ethics Committee (H17REA184). The trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12617001322325).

Recruitment Process

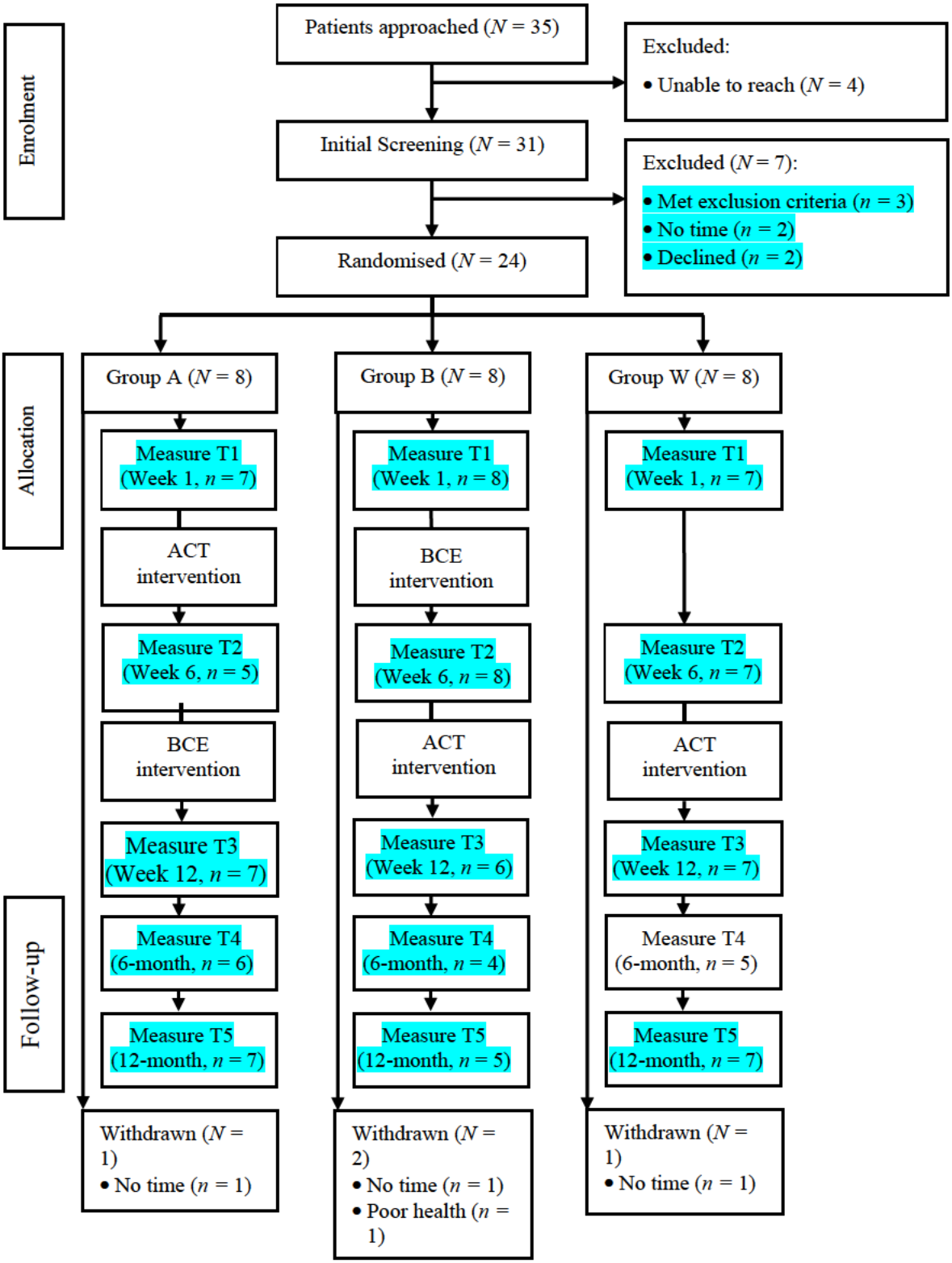
A rolling recruitment was conducted over two months, and the number of participants recruited informed the allocation of participants to conditions. Participants were provided a consent form (Appendix A) when contacted by one of the experimenters, GF. For the purpose of allocation using block randomization,

each group must have contained an equal number of participants. The participants were survivors, as defined as women who had completed their primary treatment for breast cancer, such as surgery and chemotherapy within the past two years. Women who were current or prior oncology patients at a regional Queensland hospital were invited by the hospital's breast care nurse using a rolling recruitment method. Most participants were provided the consent information at the time of the invitation (Appendix B), however, some participants recruited over the phone did not receive this information until the intake interview.

Twenty-four women survivors of breast cancer were required to fill three equal groups of eight. A total of 35 women were contacted by the nurse, of which 31 responded and gave consent for a psychologist to contact them and provide preliminary information about the study. Eighteen of these women had already received preliminary information from the nurse. Following the provision of this information, 29 of the women continued to a face-to-face or phone interview with the psychologist to assess inclusion and exclusion criteria, availability to commit to the activities of the study, and for participants to ask any questions about the study or the treatment. Regarding the exclusion criteria of psychiatric disorders, relevant sections of the Structured Clinical Interview for DSM-5 Disorders—Clinician Version (First et al., 2016) were used if participants reported any symptoms of relevant disorders. Of these women, three met exclusion criteria, two declined to participate, and one was unable to participate due to time commitments. Those that met exclusion criteria related to mental health were also already under management for these conditions by a health professional. Over the course of the study, an additional four participants chose to withdraw from the study. Figure 4.1 is a representation of the design of the study, including the participants that were excluded or withdrawn.

Figure 4.1:

Flow Chart of Recruitment, Measurement, and Conditions of Intervention



Interventions

Acceptance and Commitment Therapy. The acceptance and commitment therapy intervention consisted of six consecutive weeks of group-based, manualized intervention delivered by psychologists, with a psychologist or provisional psychologist observer in case participants required individual care. All facilitators had self-identified as having encountered ACT in their studies and were using ACT techniques in their practice or personal lives. The manual was adapted from ACT Now: Adjusting To Cancer, Committing To Your Values, Taking Action Now, which was used on an Australian study by Feros et al. (2013). The manual consisted of a facilitator manual and a patient workbook created by Bilich, Blackledge, Ciarrochi, Feros, and Lane for Feros et al. (2013). The facilitator's manual contained 'hints for running therapy sessions' that outlined the manner in which the intervention was to be delivered as well as therapy tasks. The patient workbook consisted of summaries and activities relevant to the information covered in the sessions. The delivery of the content was adapted for group delivery by M.C., one of the experimenters who is a registered psychologist with experience in ACT interventions. Facilitators were given extra notes with a guide to audio resources, and time and activity allocations so that the content may be delivered within six sessions, 90 minutes each. These adaptions are provided in Appendix B. Group A and B had the same facilitator, S. Group W was facilitated by another facilitator, N.

For the purpose of treatment fidelity, the facilitators for the ACT intervention discussed the manual with one of the experimenters, M.C., prior to and during the sessions if they had questions. Another experimenter, N.H., sat in on some of the sessions. Both experimenters had at least an intermediate knowledge of ACT and contextual behavioural sciences as gained through research, conference participation or attendance, and/or practice, with at least five years of practice and experience.

Breast Cancer Education. The breast cancer education consisted of six consecutive weeks of group-based activities that increased participant's exposure to different methods of managing aspects of breast cancer recovery. Topics included an introduction to yoga, sexuality and breast cancer, exercise and breast cancer, osteoporosis and physiotherapy, diet and breast cancer, and mindfulness and breast cancer. Each session was delivered by a suitable facilitator from the relevant field (e.g., yoga instructor, nurse, dietician, exercise physiologist). This program sequence

was specifically organized for this experiment by one of the experimenters, G.F. The facilitators drew from their existing knowledge, some presentations that they had delivered previously, and did not follow a standard protocol.

This program was constructed by the breast cancer care nurse to be a condensed version of treatment that the women may have expected to receive as part of their routine participation in hospital or community programs following primary intervention. This program was an approximation of what could be considered treatment as usual and a comparative approach to survivor wellbeing.

Measures

Self-report measures for quality of life, fear of cancer recurrence, psychological distress, and experiential avoidance were obtained at Week 1, Week 6, Week 12, Week 36 (6 months after all intervention), and Week 60 (12 months after all intervention). A sample of the online survey is provided in Appendix C.

The Depression, Anxiety, and Stress Scale (DASS), developed by Lovibond and Lovibond (1995), measures self-reported negative emotional states, separated into the three scales of Depression, Anxiety and Stress. It is widely used in applied and research psychology due to its accessibility and validation in Australia, as well as the ability to classify symptom severity. In regard to the scoring of the Depression, Anxiety and Stress Scale (DASS), Lovibond and Lovibond (2002) provided descriptions based on score ranges, which were adapted from a 42 item scale to a 21 item scale. Scoring of the DASS-21 for the purpose of comparison with the original standardized sample was multiplied by two, which is a common treatment in clinical settings. An additional benefit of this calculation is that information to inform reliable and clinically significant change could be based on a larger, more representative sample of women, rather than a sample of 49 participants of which only 61% were female. Higher scores reflect more symptom severity. The highest possible score for each subscale is 42 and lowest possible is 0.

The Acceptance and Action Questionnaire II (AAQ-II; Bond et al., 2011) was intended for use with population-based studies of experiential avoidance. A reduction in AAQ-II score indicated a reduction in experiential avoidance, which is an increase is psychological flexibility. Although a cancer specific AAQ has been adapted from the AAQ-II with $\alpha = .91$ (Arch & Mitchell, 2016), the AAQ-II remains the more widely used measure of experiential avoidance in cancer research. The lowest possible score on this measure is 7 and the highest possible is 49. Higher

scores indicate more experiential avoidance, with a suggested clinical range above 24 – 28.

The Functional Assessment of Cancer Therapy Scale – Breast (FACT-B; Brady et al., 1997) covers physical, functional, social, and emotional wellbeing, satisfaction with treatment, and satisfaction with relationships with a Breast Cancer Subscale related to quality-of-life issues specific to patients with breast cancer. These can be combined to create one score. The lowest possible score is 0 and highest possible is 148. Higher scores indicate better wellbeing.

The Concerns About Recurrence Scale (CARS) developed by Vickberg (2003) to assess women's fears about possible breast cancer recurrence. The lowest possible score is .13 and highest possible score is 4.27 for the full scale. Part of the measure produces an Overall Fear score of mean ratings. The lowest possible score for the Overall Fear subscale is 1 and highest possible is 6. Higher scores indicate more fear.

The Mindfulness Attention Awareness Scale (Brown & Ryan, 2003) was also included as a fidelity measure as mindfulness is incorporated into acceptance and commitment approaches, however, this was removed from analysis as it was not administered correctly, and four items were not presented to participants. Additionally, as the breast cancer education intervention also contained mindfulness training, the change in score cannot be attributed just to ACT.

Attendance and survey completion were used as a feasibility measure. Participant attendance at all sessions of the interventions and completion of the survey were recorded. If the survey was not completed one week after it was available between Week 1 and Week 12, it was marked as received late. If the survey was not completed within one month after it was available between Week 36 and Week 60 it was marked as received late.

Feedback from facilitators provided some indication of fidelity to the program. The main facilitators of the ACT intervention provided feedback to an experimenter post first group facilitation. The feedback was elicited in the following categories following observations throughout the active treatment: therapy protocol, participation, therapy process, group process, and administration issues. The feedback was typed verbatim (Appendix D).

Given the regional focus of this study, a remoteness classification was used to capture this demographic in this sample, represented in Table 4.1. The Modified

Monash Model 2019 (MMM) is a classification system for city, rural, remote, or very remote areas that is used nationally for the purpose of workforce distribution (Australian Government Department of Health, 2021). The MMM is a classification of geographic area with good clinical utility because it is used by the Australian Government to define eligibility requirements that encourage doctors to train and work in rural communities.

Table 4.1

Modified Monash Model classifications

MMM Classification	Description	Percentage of the Australian Population	Examples from Queensland, Australia
1	Metropolitan areas	71.33	Brisbane, Sunshine Coast
2	Regional centres	8.99	Toowoomba, Mackay
3	Large rural towns	6.50	Gympie, Yeppoon
4	Medium rural towns	3.97	Charters Towers, Emerald
5	Small rural towns	7.27	Sarina, Mundubbera
6	Remote communities	1.17	Mt Isa, Camp Island
7	Very remote communities	.77	Longreach, Birdsville

Note. Percentage of the Australian population obtained from (Versace et al., 2021), with a total population of 23 220 413 people.

Data Treatment

There was no treatment of missing data, except for the purpose of comparison to the Feros (2013) study. An a priori **power analysis was not conducted as the statistical method would be informed by the number of participants that could be practically recruited, and that completed the pilot trial and measures. Once this information was known, levels of analyses were explored based on the data available. Of 24 participants recruited, 20 completed the program, however, there were points of missing data. There were two points of data missing for Week 6, five at 6-months post intervention and one at 12-months post intervention (**see Figure 4.1**).** At the time of collecting data at Time 5, 12 months following the end of all interventions in the study, Participant 9 noted that she had biliary cancer, which may have affected her responses.

Descriptive statistics and correlations were obtained for the measures. The characteristics of the data included ceiling and floor effects with large within group variation for all measures and time points (Appendix E). This, as well as the small number of participants in each group, made group-level analysis inappropriate regarding the intervention outcomes of this study. All results from this analysis are, therefore, descriptive and considered preliminary results from a pilot study which may inform hypothesis generation for future studies. Time 1 data and overall data are presented in the Results section.

The direction and strength of correlation of the mindfulness measures, MAAS, with the other constructs do not fit with the literature on mindfulness-based interventions and quality of life (Haller et al., 2017). The MAAS was expected to correlate positively with FACT-B (e.g., the more mindfulness, the better quality of life) and negatively with CARS (e.g., the more mindfulness, the less fear about cancer recurrence). Upon examination of the survey format and responses, this result may be an artefact of how the measure was read by participants. On the MAAS, a 1 indicates “Almost Always” and 6 indicates “Almost Never” to questions such as “I could be experiencing some emotion and not be conscious of it until sometime later”. A higher score should indicate more mindfulness, but the way the scale is presented is the opposite of how the other measures present their scoring. For example, a 1 on CARS can indicate “Not at all afraid”, and a 0 or 1 on the FACT-B is “not at all” or “a little bit”. The difference in the way that the questionnaires were presented may have confused some respondents. However, we cannot be sure that every participant

read it this way at every time point, therefore, the validity of the MAAS in this experiment is further called in question. The MAAS will be removed from further analysis. Other than the MAAS, the direction of the correlations between the constructs fit with the relationships proposed in the review of the literature.

For individual analyses, reliable and clinically significant change were calculated for the FACT-B, AAQ-II and DASS-21, and reliable change calculated for the CARS and FACT-B. The Leeds Reliable Change Indicator calculator (Morley & Dowzer, 2014) was used to calculate reliable change indices for all measures and clinically significant change for the AAQ-II and DASS-21. This calculator was created to compute reliable change based on the statistical method of Jacobson and Truax (1991). The Excel spreadsheet calculator for single cases can be obtained from https://dclinpsych.leeds.ac.uk/research/. A reliable change is defined as a change where the difference between someone's pre-test score and post-test score is larger than the standard error of difference between the two test scores (Jacobson & Truax, 1991). Where the mean and standard deviation of a non-clinical comparison group is not known, then the level of functioning after therapy should fall more than 1.96 standard deviations outside the range of the clinical population (Morley & Dowzer, 2014). Where the means and standard deviations for both clinical and non-clinical comparison groups are known, and the groups overlap, the level of functioning should place a patient reliably closer to the mean of the comparison group (Criterion C; Morley & Dowzer, 2014). Where there is little overlap in these groups, the level of functioning should fall within the range of the comparison non-clinical group, within 1.96 standard deviations of the mean of the comparison group (Criterion B; Morley & Dowzer, 2014). Morley and Dowzer (2014) state that as it is possible to score below the cut-off score at pre-treatment, these scores should be excluded from analysis because patients who make a reliable improvement can make a clinically significant change, however those that score below the cut score at pre-treatment are unlikely to make further improvements. Neither Morley and Dowzer (2014) nor Jacobson and Truax (1991) discuss the treatment of possible deteriorations in treatment using this model. In Jacobson and Truax (1991), participants are either noted as 'improved but not recovered' as denoting reliable change, and 'recovered' as denoting clinically significant change.

To calculate clinical significance for the FACT-B, Yost and Eaton (2005) proposed distribution and anchor-based approaches to determine minimally

important differences for the FACT-B to be 7 to 8 for the overall measure, and 2 to 3 for the subscales. As this classification of clinically significant change is different to that of the calculator, they are reported independently of whether there was a reliable change.

Change scores were computed for each participant from their pre and post scores per intervention, by subtracting post-intervention score from pre-intervention score in measures where higher scores indicated higher distress, such as for the DASS, CARS, and AAQ. Change score for the FACT-B, where higher scores indicated improved wellbeing, was created by subtracting the pre-intervention score from the post-intervention score. These calculations meant that positive change scores for all measures indicated improvement, and negative change scores indicated deterioration.

Correlation tables were generated for all measures, including sub-scores for the FACT-B, CARS, and DASS to consider whether the measures were functioning as expected for this population. Visual inspection of scatterplots, group bar graphs, and individual bar graphs, as well as for the change scores, were conducted for the purpose of assisting with decisions for a larger trial, such as consideration for individual differences compared to group-level change.

Descriptive information about the attendance and completion of surveys, as well as feedback from facilitators, was gathered for the purpose of informing the researchers on whether a larger trial may be tolerated, and issues that may be encountered by facilitators using the adapted manual in a group setting. Group attendance was collected each session by an investigator, MC. This was used to calculate percentage of attendance and demonstrate actual number of participants present per session. Descriptive information was also gathered on the number of surveys completed and whether they were completed late, to calculate a percentage. Facilitator feedback was gathered through semi-structured interviews exploring the use of the protocol, participation, facilitator engagement with ACT processes, group structure, and practical administration issues.

Analyses

The first research question in this study was, ‘Does a group-based ACT intervention improve the reported quality of life of women post primary breast cancer treatment?’. The methods employed to consider this were 1) individual analysis for reliable and clinically significant change and 2) individual change scores

pre and post ACT intervention with visual inspection to inform possible improvements and deteriorations. For reliable and clinically significant change, The Leeds Reliable Change Indicator by Morley and Dowzer (2014) was used with the following information: For the reliable change index (RCI), the reliability of the FACT-B was reported as .79, in line with this sample. Clinically significant change was not calculated as the FACT-B does not distinguish between 'clinical' and 'nonclinical' scores, rather, it shows what women with or without disease are likely to score.

Additionally, descriptive statistics for group-level mean and standard deviation for pre, post, and follow-up were reported for comparison to Feros (2013), which is another Australian study that used the same ACT protocol. In the Feros et al. (2013) study, the Functional Assessment of Cancer Therapy – General (FACT-G) was used. This measure is similar to the FACT-B, except without the specific Breast Cancer Subscale. For the purpose of comparison, the FACT-G score was computed. Missing data was imputed from available information at the most recently obtained measure. Several differences between the studies were important to note. Firstly, the sample characteristics and size of the Feros et al. (2013) study was 45 cancer patients with different cancers, cancer stages, and treatment stages. Secondly, there was no 3-month follow up score collected in this study, therefore the 6-month follow up was used. For this study, it is not possible to separate ACT effects from BCE effects at the 6-month mark.

The second research question for this study was, 'Does a group-based ACT intervention produce clinically relevant outcomes in anxiety, depression, and stress?'. The methods employed to consider this were 1) individual analysis for reliable and clinically significant change and 2) individual change scores pre and post ACT intervention with visual inspection to inform possible improvements and deteriorations.

The Depression, Anxiety and Stress Scale (DASS-21) was used to consider psychological distress in quality of life. The measure distinguishes between Normal, Mild, Moderate, Severe, and Extremely Severe levels of Depression, Anxiety and Stress related symptoms. These categories were created by examining the percentiles of scores in a normative sample (Lovibond & Lovibond, 2002). Only the individual scores which fell above the Normal range of the DASS were considered for further

analysis. The descriptors, percentile range, and scores range are presented in Table 4.2.

Table 4.2

Depression, Anxiety and Stress Scale Descriptors

Category	Percentiles	Depression	Anxiety	Stress
Normal	0 – 78	0 – 9	0 – 7	0 – 14
Mild	78 – 87	10 – 13	8 – 9	15 – 18
Moderate	87 – 95	14 – 20	10 – 14	19 – 25
Severe	95 – 98	21 – 27	15 – 19	26 – 33
Extremely Severe	98 – 100	28+	20+	34+

The Leeds Reliable Change Indicator by Morley and Dowzer (2014) was used with the following information: To calculate reliable change, the reliability of the DASS was reported as .87 for Depression, .89 for Anxiety and .91 for Stress in line with this sample. To calculate clinical significance, Criterion C was used, which is recommended for when there is no significant overlap indicated between clinical and comparison groups. Comparison norms were taken from a sample of females from the measure's original standardization (Lovibond & Lovibond, 2002; N = 1870, Depression, M = 6.14, SD = 6.92; Anxiety, M = 4.80, SD = 5.03; Stress, M = 10.29, SD = 8.16). Clinical sample mean and standard deviation were taken from Ronk et al. (2013), an American outpatient sample of patients experiencing depression, anxiety, stress and adjustment disorders (N = 1000, Depression, M = 13.32, SD = 11.10; Anxiety, M = 9.09, SD = 8.82; Stress, M = 15.01, SD = 10.00).

Again, results were compared to Feros et al. (2013). In their study, the DASS scores were analysed in two ways. First, the DASS scores were analysed by collapsing the Normal and Mild categories into one 'Normal' category and seeing what percentage of participants fell into this category for Depression, Anxiety and Stress symptoms pre and post therapy. Their study reported the percentage of participants in the 'Normal' category pre intervention and at 3-month follow-up. For the purpose of replication and comparison, the scores in this study were additionally analysed in the same way. In this study, there were two points of missing data for this analysis. In these cases, the pre-therapy scores were used. At the 6-month follow-up, there were five points of missing data, and post-therapy scores were used.

The second analysis of the DASS scores conducted by Feros et al. (2013) was to compute an overall 'mood disturbance' mean and standard deviation from combining the score of the 21 DASS items. They obtained scores for participants at pre therapy, mid therapy, post therapy and 3-month follow-up. For comparison, in this current study, missing data was imputed from available information with the most recent prior value used.

The third research question in this study was, 'Does a group-based ACT intervention reduce fear of cancer recurrence?'. The methods employed to consider this were 1) individual analysis for reliable and clinically significant change and 2) individual change scores pre and post ACT intervention with visual inspection to inform possible improvements and deteriorations.

The Concerns about Recurrence Scale does not provide a clinical value of fear of cancer recurrence, and the literature on a clinical construct is still building. As such, clinically significant change was not computed for this measure. Vickberg (2003) indicated a score of 5 – 6 on the Overall Fear subscale to be a 'high fear' of cancer recurrence, 4 – 3 as 'moderate fear', and a score of 1 – 2 to be 'low fear'. Of 20 participants, 3 were found to have high fear immediately prior to commencing the ACT. These participants were identified as possible candidates to demonstrate whether ACT reduced fear of cancer recurrence. However, one of these cases, Participant 4, did not return a survey immediately post intervention. Therefore, it was decided that more cases would be added from the moderate fear category to increase the numbers for analysis. The Leeds Reliable Change Indicator by Morley and Dowzer (2014) was used with the following information: To calculate reliable change, the reliability of the Overall Fear subscale of the CARS was reported as .92 in line with this sample.

The fourth research question in this study was, 'Does a group-based ACT intervention produce results due to an improved psychological flexibility as the literature suggests?'. Prior to reliable and clinically significant change calculations, Pearson's correlations were computed for the AAQ-II and FACT-B including subscales, and the AAQ-II and CARS Overall Fear subscale to explore the relationship of the variables. Scatterplots were generated for a visual examination of the data, which provided reason to conduct further correlations to explore the effect of a clinical cut-off score. A clinical cut off score of 20 was adapted for use in this study, with scores of less than 20 indicating a relatively lower level of experiential

avoidance (low avoidance) and score of 20 or higher indicating a higher level, or a clinically relevant level, of experiential avoidance (high avoidance). Of 20 participants, five were found to have experiential avoidance scores that are associated with high avoidance immediately prior to commencing ACT. These were identified as possible candidates to demonstrate whether ACT reduced experiential avoidance. To calculate reliable change, the reliability of the AAQ-II was reported as .93 in line with this sample. To calculate clinical significance, clinical and normal sample norms were taken from Bond et al. (2011), with the mean score and standard deviation of a clinical sample as M = 28.34, SD = 9.92, and non-clinical sample as M = 18.51, SD = 7.05. Criterion for clinically significant change was set to Criterion C, which is recommended for when norms are available for a comparison group, and the norms may overlap. Individual analysis for reliable and clinically significant change, and individual change scores pre and post ACT intervention with visual inspection to inform possible improvements and deteriorations were also conducted.

The fifth research question for this study was, "Are certain women more likely than others to benefit from ACT intervention?". Bar graphs that compared ACT and BCE interventions were generated to consider possible effects of participation in each condition. This then directed a closer inspection of individual pre and post intervention scores to consider the individual changes that drove these group effects. Reliable change indices were calculated using the Leeds Reliable Change Indicator (Morley & Dowzer, 2014) using the information described above for each scale, for individuals who had the largest changes in pre and post score to consider significant improvements and deteriorations.

This study also included an education condition, BCE, and analysis of changes related to education and the timing of interventions may also assist in providing comparison to the outcomes based on ACT. Five participants were selected for further analysis given the configuration of their scores across time points. Participants were selected if some points of their distress that were higher than normal, or they experienced reliable deteriorations following treatment. The aim is to consider possible treatment and treatment order effects to gain a greater understanding of the driving forces behind change and wellbeing that may contribute to development of more targeted and effective programs in this area. For these participants, a line graph plotting scores pre and post conditions, as well as at 6-month and 12-month follow-ups was generated, with an emphasis on information

may indicate the degree of usefulness of ACT. Participant 24 was chosen for scores that indicated distress across several areas, including fear, depression, anxiety, stress, with some deterioration and lack of improvement across intervention. Participant 4 was chosen due to a high level of experiential avoidance and a pattern of deteriorations following BCE, yet improvements following ACT intervention. Participant 1 was chosen due to distress that seemed to either deteriorate or remain unchanged with ACT intervention. Participant 9 was selected due to points of deterioration experienced during both BCE and ACT interventions, and also the confound of actual cancer recurrence reported at the 12th month follow up, which is the only case of cancer recurrence from the data available. Participant 14 was chosen due to the unusual low rating of experiential avoidance across all time points (rated as 7, which is the lowest possible score on the AAQ-II), yet experienced fluctuations in distress across treatment conditions.

Results

Participant Characteristics

Participants were between 42 and 71 years old, with an average age of 56.30 years, mostly residing in a regional centre. The average age of first diagnosis of breast cancer was 54.53 years old, with a range from 41 to 69 years. Most participants (*n* = 15) were engaged in paid employment as their primary occupation. Four participants out of 20 indicated both breasts affected by breast cancer. All participants had breast surgery, and most (*n* = 15) also had radiotherapy and chemotherapy. The most common complimentary therapies accessed by these women were cardio exercise (*n* = 13) and massage (*n* = 14). No participants indicated that their sleep was ‘very good’ in the past month. All participants indicated that English was their primary language. A summary of demographic details is presented in Table 4.3.

Table 4.3

Study 2 Demographic Tables

Characteristics	*n*	*M*	Range	*SD*
Age	20	–6.30	42 - 71	7.71

Characteristics	*n*
Relationship status	(20)
Partnered	16
Not partnered	4
Highest level of education	(20)
Secondary school	6
Certificate I - IV	2
Diploma	6
Bachelor’s degree	2
Post graduate degree	4
Occupation	(20)
Paid work	15
Household duties	3
Retired	2
Regionality	(20)
MMM 2	17
MMM 4	1
MMM 5	2

Treatment Characteristics	*n*	*M*	Range	*SD*
Age at first diagnosis	19	–4.53	41 - 69	7.71

Treatment Characteristics	*n*
Breast affected by breast cancer	(20)
Left	8
Right	8
Both	4
Hormone Receptors	

Treatment Characteristics	*n*
Hormone Receptors	
Oestrogen positive	12
Progesterone positive	1
Hormone receptor negative	4
Don't know	3
Breast surgery	20
Surgery to the armpit	17
Medical Treatments	
Breast prostheses	9
Breast reconstruction	2
Radiotherapy	15
Chemotherapy	15
Hormonal therapies	14
Ovarian treatments	4
Hysterectomy	9
Removal of ovaries	5
Other treatments	3

Health Related Behaviours	*n*	*M*	Range	*SD*
Hours of weekly activity	20	33.30	5 - 60	19.83

Health Related Behaviours	*n*
Complimentary Therapies	
Cognitive and Behaviour Therapy	2
Acceptance and Commitment Therapy	1
Mindfulness Based Stress Reduction	2
Counselling for adjustment difficulties	8
Occupational Therapy	1
Relaxation	8
Meditation	3
Moving meditation (e.g., tai chi, yoga)	8
Cardio exercise	13

Health Related Behaviours	*n*
Diet change	8
Complimentary Therapies	
Massage	14
Prayer/ spiritual practices	4
Sleep quality in the past month	(19)
Very bad	1
Fairly bad	9
Fairly good	9
Very good	0

Feasibility and Fidelity Analysis

Attendance and Survey Completion

Of the 24 participants randomised among groups A, B and W, there were four dropouts. Two participants did not attend any of the intervention or complete surveys. The reasons cited by the participants was time pressure from prior work commitments, and prior commitments. One participant attended four BCE sessions and one ACT session but withdrew citing work as the reason. One participant attended three BCE sessions and three ACT sessions but withdrew citing time pressures and family commitments impacting health. Of the 20 participants who completed the study, the attendance rate is presented in the Table 4.4. Actual numbers of participants per session is presented in Table 4.5. The sessions ran weekly for 12 consecutive weeks from September to December 2017. Some attendance reportedly dropped in late November to December due to family and other obligations in the lead up to the Christmas period. This affected attendance of BCE intervention for Group A, and attendance of ACT intervention for Group B and W. Overall attendance during the program was 83%.

Table 4.4

Percentage Attendance per Group and Intervention

Category	Group A	Group B	Group W	Total
All attendance	88.14	87.50	75.71	83.78
ACT attendance	90.42	83.33	75.71	83.15
BCE attendance	85.71	91.67	-	88.69

Note. ACT = Acceptance and commitment therapy. BCE = Breast Cancer Education

Table 4.5

Actual Number of Participants Present per Session

Session	Group A Week 1 – 6, ACT Week 7 – 12, BCE	Group B Week 1 – 6, BCE Week 7 – 12, ACT	Group W Week 1 – 6 Wait Week 7 – 12, ACT	% attendance
1	6	5	-	84
2	7	5	-	92
3	6	6	-	92
4	6	5	-	85
5	6	6	-	92
6	7	6	-	100
7	6	5	6	85
8	6	4	6	80
9	6	6	5	85
10	5	5	5	75
11	7	5	5	85
12	6	5	5	80

Note. ACT = Acceptance and commitment therapy. BCE = Breast Cancer Education

The distribution of surveys returned is displayed in Table 4.6. 73% of surveys were completed on time, 19% of surveys were completed late, and 8% of surveys were not completed.

Table 4.6

Percentage of Surveys Completed, Completed Late, and Not Completed (N = 20)

Category	Week 1	Week 6	Week 12	6-month	12-month	Total
Completed on time	80	85	65	65	70	73
Completed late	20	5	35	10	25	19
Not completed	0	10	0	25	5	8

Note. Survey marked late if not completed within 1 week for Week 1 – 12, and within 1 month for 6 – 12 months.

Facilitator Feedback

The full interview with S and N can be found in Appendix D. Overall, the ACT protocol seemed well received. Both facilitators reported that the content for coursework and homework seemed excessive. S reported some difficulty with the abstract nature of some of the metaphors and familiarity with the materials. Both facilitators reported good participation and support from the participants. Both facilitators reported that the participants engaged with the content. Both facilitators indicated value from running the groups. S reported that one participant monopolized the conversation. N reported that the conversation was 'derailed' to personal conversations. Both facilitators attempted to relate the information from the manuals to the participants' experiences. S reported that she was unfamiliar, felt 'clunky', and wanted to be more experiential in future administration. N reported an alignment with the 'spirit of the ACT model'. Both facilitators had favourable comments on the structure and size of the groups. Both facilitators commented on participant absences and how this was managed. N indicated that a six-session structure was 'squashed' and suggested an eight-session structure. S spoke about resources that she would like to set up for the next round, including finger traps and a CD player. N reported satisfaction with the group arrangements but was confused about the billing.

Descriptive statistics for outcome measures

Descriptive and correlation information for primary measures

There was no missing data for Time 1, with a total of 20 participants completing information for all measures. Women in this study had a pre-intervention average FACT-B score of 104.2 (*SD* = 18.30), CARS score of 1.63 (*SD* = .91), and MAAS score of 2.76 (*SD* = .72). The average AAQ-II score was 13.85 (*SD* = 7.33), which is below the clinical cut off of 24 – 28 (Bond et al., 2011). The average Depression (*M* = 6.80 , *SD* = 7.47) and Stress (*M* = 13.10, SD = 9.57) were within the Normal range. Anxiety (*M* = 7.30 , SD = 9.21) in this cohort was within the Mild range. Internal reliability of measures ranges from .69 for the FACT-B to .97 for the CARS. Descriptive statistics for scales gathered prior to any intervention is presented in Table 4.7.

Scores for the AAQ-II remained under the clinical cut off at each measurement point (*M* = 12.93 to 14.65), lowest at Time 4 (*N* = 15), as did the Depression (*M* = 1.47 to 6.80) and Stress (*M* = 3.07 to 13.10) scores. Anxiety fell

from a Mild range at Time 1 (M = 7.39) to Normal for all other time points (*M* = 6.56 to 1.87), lowest at Time 4 (*N* = 15). Women in this study had post intervention average FACT-B score of 105.65 (*SD* = 18.80), CARS of 1.51 (*SD* = .85), and MAAS of 2.60 (*SD* = .98). Scores with clinical cut offs such as the AAQ-II (*M* = 14.25, *SD* = 7.69), DASS Depression (*M* = 6.50, *SD* = 7.03), Anxiety (*M* = 5.70, *SD* = 8.16), and Stress (*M* = 12.00, *SD* = 9.18), were all within the non-clinical range post interventions. This information is summarised in Table 4.8. A table of the subscales and scales across separate time points, from Time 1 to Time 5 is provided in Appendix F. All measures retained an acceptable level of internal reliability (α = > .60) across time points and within subscales, except for the Emotional Wellbeing Subscale of the FACT-B at Time 4, α = .49.

Group Allocation

An analysis of variance was conducted to consider whether the effects of ACT on experiential avoidance differed across treatment groups. There was no significant effect of ACT on experiential avoidance across treatment groups, $F(2,15)=0.232$, p=0.80. An analysis of variance was conducted to consider whether the effects of ACT on quality of life differed across treatment groups. There was no significant effect of ACT on quality of life across treatment groups, $F(2,15)=0.745$, p=0.49.

Table 4.7

Descriptive Statistics for Scales Across Time 1 (Pre Intervention)

Measurement	FACT-B	CARS	DASS	DASS-D	DASS-A	DASS-S	AAQ-II	MAAS
N_p	20	20	20	20	20	20	20	20
M	104.2	1.63	27.20	6.80	7.30	13.10	13.85	2.76
SD	18.30	.91	24.28	7.47	9.21	9.57	7.33	.72
α	.69	.97	.95	.89	.91	.89	.93	.83
Possible range	0-148	.13-4.27	0 – 126	0-42	0-42	0-42	7-49	1-6
Actual range	53-139	.13-3.5	0 – 76	0-20	0-32	0-30	7-33	1.64-4.09
Skew	-.74	.60	1.088	.81	1.44	.51	1.23	-.04
Kurtosis	2.31	-.09	.31	-1.05	1.25	-1.18	1.08	-.39

Note. N_p = Number of participants responded. FACT-B = Functional Assessment of Cancer Therapy – Breast; CARS = Concerns about Recurrence Scale; DASS = Depression, Anxiety and Stress Scale; DASS-D = DASS Depression Subscale; DASS-A = DASS Anxiety Subscale; DASS-S = DASS Stress Subscale; AAQ-II = Acceptance and Action Questionnaire II; MAAS = Mindfulness Attention Awareness Scale.

Table 4.8

Descriptive Statistics for Scales Across Timepoints of Measurement

Measurement	Time 1 *N* = 20		Time 2 *N* = 18		Time 3 *N* = 20		Time 4 *N* = 15		Time 5 *N* = 19	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
FACT-B	104.20	18.29	103.50	18.80	105.65	22.33	109.80	19.63	106.58	22.69
CARS	1.61	.91	1.34	.82	1.51	.85	1.34	.68	1.22	.80
DASS	27.20	24.28	26.44	21.98	24.20	22.48	6.40	11.94	16.32	16.35
DASS-D	6.80	7.47	6.56	7.06	6.50	7.03	1.47	3.74	3.79	4.32
DASS-A	7.39	9.21	6.56	8.11	5.70	8.16	1.87	5.26	3.79	5.49
DASS-S	13.10	9.57	13.33	8.57	12.00	9.18	3.07	3.69	8.74	8.36
AAQ-II	13.85	7.34	14.17	7.25	14.25	7.69	12.93	6.63	14.63	8.81
MAAS [a]	2.76	.72	2.66	.83	2.60	.98	2.43	.77	-	-

Note: FACT-B = Functional Assessment of Cancer Therapy – Breast; CARS = Concerns about Recurrence Scale; DASS = Depression, Anxiety and Stress Scale; DASS-D = DASS Depression Subscale; DASS-A = DASS Anxiety Subscale; DASS-S = DASS Stress Subscale; AAQ-II = Acceptance and Action Questionnaire II; MAAS = Mindfulness Attention Awareness Scale.

[a] The 11-item MAAS was not administered at Time 5.

Pearson's correlations for all data gathered across 5 time points is summarised in Table 4.9. FACT-B was significantly ($p \leq .01$) negatively correlated with the CARS (r = -.62), DASS Depression (r = -.30), DASS Anxiety (r = -.30), and DASS Stress (r = -.44), and AAQ-II (r = -.69). CARS was significantly ($p \leq .01$) and positively correlated with DASS Depression (r = .28), DASS Stress (r = .31), and AAQ-II (r = .69). The AAQ-II was significantly and positive correlated with Depression (r = .37), DASS Anxiety (r = .48), and DASS Stress (r = .48). The MASS ad significant and positive correlations with the CARS (r = .31), DASS Depression (r = -..45), DASS Anxiety (r = -.43), and DASS Stress (r = -.54), and), and AAQ-II (r = .38). "

Table 4.9

Correlations for Scales Across All Timepoints of Measurement

Variable	FACT-B	CARS	DASS-D	DASS-A	DASS-S	AAQ-II	MAAS
FACT-B	-	-.62*	-.30*	-.30*	-.44*	-.69*	-.29
CARS		-	.28*	.20	.31*	.69*	.31*
DASS-D			-	.84*	.78*	.37*	.45*
DASS-A				-	.73*	.48*	.43*
DASS-S					-	.48*	.54*
AAQ-II						-	.38*
MAAS							-

Note. FACT-B = Functional Assessment of Cancer Therapy – Breast; CARS = Concerns about Recurrence Scale; DASS = Depression, Anxiety and Stress Scale; DASS-D = DASS Depression Subscale; DASS-A = DASS Anxiety Subscale; DASS-S = DASS Stress Subscale; AAQ-II = Acceptance and Action Questionnaire II; MAAS = Mindfulness Attention Awareness Scale.

* $p \leq .01$, two tailed.

Research Question 1:

Does a group-based ACT intervention improve the reported quality of life of women post primary breast cancer treatment?

No participant scores showed a reliable improvement or deterioration immediately after the ACT intervention. Table 4.10 presents the scores and change

immediately pre and post acceptance and commitment therapy, as well as at 6 and 12 months. Three reliable changes were observed in later measures (6 and 12 months). There was one reliable improvement, Participant 7's score rose from 105 to 139 at the 6-months measure and maintained at 134 at the 12-months measure. Both 6 and 12-months scores were reliable improvements compared to pre-treatment. Participant 22 recorded a drop in score from 90 to 59 at the 6-months measure, which was a reliable change. However, it rose again to 85 at the 12th month measure, which was not a reliable change compared to pre-treatment. Participant 9 recorded a drop from 97 to 64 at the 12-month mark. At the time of the survey, Participant 9 emailed the experimenter and noted that she had since been diagnosed with biliary cancer, which was noted as a potential confound.

Nine participants had minimally important difference that exceeded 7 points following ACT intervention. Of these, four were deteriorations, and five were improvements. Participant 11 who had a pre-ACT score of 126, showed deterioration following ACT with a score of 111. She did not complete the measure at 6-months, however, at 12-months continued to have a lower score than pre-ACT of 112. Participant 1 had a pre-ACT score of 112 and post-ACT score of 104 which was a clinically significant deterioration. At 6-months her score rose to 114, which is not significant compared to her pre-ACT score, and to 123 at 12-months, which is a significant improvement. Participant 12 showed the same pattern of deterioration from 42 to 32 pre to post-ACT, did not complete measures at 6-months, and showed improvement to a score of 50 at 12-months. Participant 13's score deteriorated from 111 to 101, and returned to 110 and 109 at 6-month and 12-month post. Participant 23 improved from 124 to 131, however, did not complete any follow up measures at 6-months and 12-months. Participant 4 improved from 86 to 94 and maintained this minimally important difference at 6 and 12-months with scores of 105 and 102 respectively. Similarly, participant 14 improved from 119 to 142, maintaining at 136 and 131 respectively. Participant 15 improved from 113 to 125, maintaining at 122 and 128 respectively. Participant 6 improved from 93 to 108 post act, did not have a significant improvement with a score of 99 at 6-months, but did have a significant improvement from baseline with a score of 101 at 12-months.

At 6-months post intervention, there were eight participants with minimally important differences compared to pre-intervention baseline, two participants had deteriorations. Of the six improvements, three were new improvements not seen

immediately post intervention. Both deteriorations (Participant 24 with a score of 107 to 97, and Participant 22 with a score of 90 to 59) did not carry to the 12-months mark. At 12-months Participant 24's score was 102, and Participant 22's score was 85. Of the improvements, Participant 9 improved from a score of 97 to 107 at 6-months, but deteriorated to a score of 64 at 12-months. Participant 5 showed an improvement from 95 pre-intervention to 113 at 6-months, but the improvement was not maintained at 12-months with a score of 94. Participant 7 improved from 105 to 139 at 6-months, maintaining at 134 at 12-months.

At 12-months post intervention there were ten participants with differences, two were deteriorations and eight were improvements. Of these, only Participant 16 was not previously mentioned. She improved from a pre-intervention score of 107 to 126 at 12-months.

Table 4.10

Reliable and Clinically Significant Changes in Quality of Life, Pre and Post Acceptance and Commitment Therapy Intervention

ID	Group	Pre ACT	Post ACT	RCI	CSC	At 6 months	RCI	CSC	At 12 months	RCI	CSC
17	A	109	104	no	no	115	no	no	114	no	no
9	A	97	99	no	no	107	no	yes	64	yes	yes
18	A	99	103	no	no	110	no	no	105	no	no
3	A	92	-	-	-	91	no	no	93	no	no
5	A	95	-	-	-	113	no	yes	94	no	no
11	A	126	111	no	yes	-	-	-	112	no	yes
7	A	105	101	no	no	139	yes	yes	134	yes	yes
24	B	107	102	no	no	97	no	yes	102	no	no
23	B	124	131	no	yes	-	-	-	-	-	-
1	B	112	104	no	yes	114	no	no	123	no	yes
4	B	86	94	no	yes	105	no	yes	102	no	yes
19	B	115	112	no	no	-	-	-	120	no	no
14	B	119	142	no	yes	136	no	yes	131	no	yes
12	B	42	32	no	yes	-	-	-	50	no	yes
22	W	90	88	no	no	59	yes	yes	85	no	no

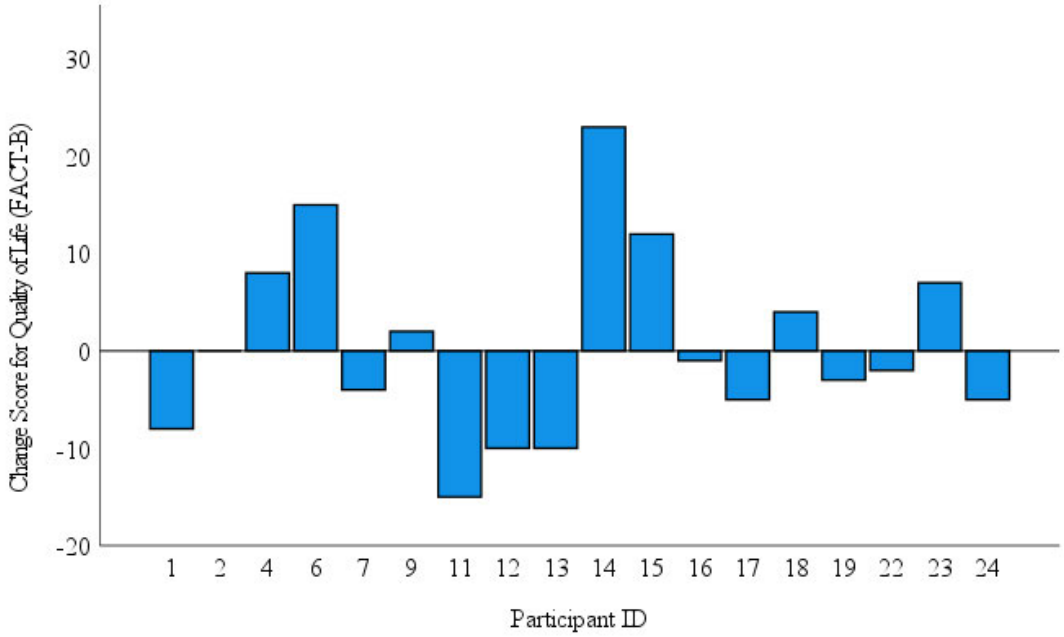
ID	Group	Pre ACT	Post ACT	RCI	CSC	At 6 months	RCI	CSC	At 12 months	RCI	CSC
6	W	93	108	no	yes	99	no	no	101	no	yes
15	W	113	125	no	yes	122	no	yes	128	no	yes
13	W	111	101	no	yes	110	no	no	109	no	no
2	W	126	126	no	no	130	no	no	132	no	no
16	W	107	106	no	no	-	-	-	126	no	yes

Note. ACT = Acceptance and commitment therapy. RCI = Reliable change index. CSC = Clinically significant change based on minimally important differences defined by Yost and Eaton (2005) for FACT-B.

Figure 4.2 displays the change scores that show the improvements versus deteriorations in quality of life for the 18 participants where pre to post ACT scores were available, irrespective of reliability or significance.

Figure 4.2:

Individual Participant Change Scores for Quality Of Life Pre and Post ACT Intervention



Note. No change bar indicates no change. Positive scores indicate improvement. Negative scores indicate deterioration.

Comparison to Feros et al. (2013)

Participants in this study had a higher mean score than those in the Feros et al. (2013) study at pre, post, and follow-up measure points. This suggests that the participants in this study had better quality of life, starting at the pre-treatment point, compared to Feros et al. (2013). Results are presented in Table 4.11.

Table 4.11

Comparison of Mean and Standard Deviation of Mood Disturbance in Feros Et Al. (2013) and Current Study (N = 20).

Measurement	Feros et al. (2013)			Current Study		
	Pre	Post	3-month	Pre	Post	6-month
M	62.68	72.23	71.57	78.65	79.60	80.95
SD	18.33	15.44	19.78	14.14	15.56	17.89

Research Question 2:

Does a group-based ACT intervention produce clinically relevant outcomes in anxiety, depression, and stress, which are psychological components of quality of life?

There were 20 instances where a score of Depression, Anxiety, and/or Stress was elevated above a Normal range. Elevated scores in one of more of these areas was present in a total of ten participants. At Time 1, pre-intervention, the mean scores for depression (M = 6.8, SD = 7.47), anxiety (M = 7.30, SD = 9.21), and stress (M = 13.10, SD = 9.60) in the women of this study were all within a 'Normal to Mild' range, with the overall summary of scores across the experiment being slightly lower than this.

Table 4.12

Reliable and Clinically Significant Changes in Level of Depression, Anxiety and Stress Symptoms Pre and Post Acceptance and Commitment Therapy Intervention for Participants Whose Scores Were Elevated Above a Normal Level

ID	Group	Pre ACT	Post ACT	RCI	CSC	At 6 months	RCI	CSC	At 12 months	RCI	CSC
						Depression					
5	A	20	-	-	-	0	yes	yes	12	yes	no
1	B	20	20	no	-	0	yes	yes	0	yes	yes
24	B	18	26	yes	-	14	yes	no	8	yes	yes
2	W	16	14	no	-	4	yes	yes	0	yes	yes
12	W	14	8	yes	yes	-	-	-	12	no	no
15	W	16	0	yes	yes	0	yes	yes	0	yes	yes
						Anxiety					
1	B	18	18	no	-	0	yes	yes	0	yes	yes
14	B	14	0	yes	yes	0	yes	yes	0	yes	yes
24	B	28	26	no	-	20	yes	no	22	yes	no
2	W	16	16	no	-	0	yes	yes	2	yes	yes
12	W	12	16	no	-	-	-	-	8	no	-
						Stress					
5	A	30	-	-	-	4	yes	yes	20	yes	no

ID	Group	Pre ACT	Post ACT	RCI	CSC	At 6 months	RCI	CSC	At 12 months	RCI	CSC
						Stress					
18	A	24	18	yes	no	6	yes	yes	22	no	-
1	B	16	22	yes	-	2	yes	yes	2	yes	yes
4	B	18	6	yes	yes	0	yes	yes	10	yes	no
14	B	20	0	yes	yes	0	yes	yes	2	yes	yes
24	B	28	28	no	-	12	yes	no	20	yes	no
2	W	26	14	yes	no	8	yes	yes	2	yes	yes
12	W	20	22	no	-	-	-	-	22	no	-
22	W	18	14	yes	no	4	yes	yes	16	no	-

Note. ACT = Acceptance and commitment therapy. RCI = Reliable change index. CSC = Clinically significant change.

Overall, several improvements were seen across Depression, Anxiety and Stress symptoms immediately and at 6th and 12th month follow ups compared to pre-intervention scores. Of 20 possible improvements, eight symptoms improved immediately following ACT intervention and four of these scores improved to a Normal range. At the 6th month mark, 17 symptoms showed improvement compared to baseline with 14 of these returned improved a Normal range. At the 12th month mark, there were 15 symptom improvements compared to baseline with 10 of these in a Normal range. The majority of participants who experienced psychological distress prior to ACT intervention had recovered to within a Normal range by 12 months. Scores for the 6th and 12th months post intervention cannot be attributed solely to the ACT intervention and are only presented to consider wellbeing in survivors.

Depression

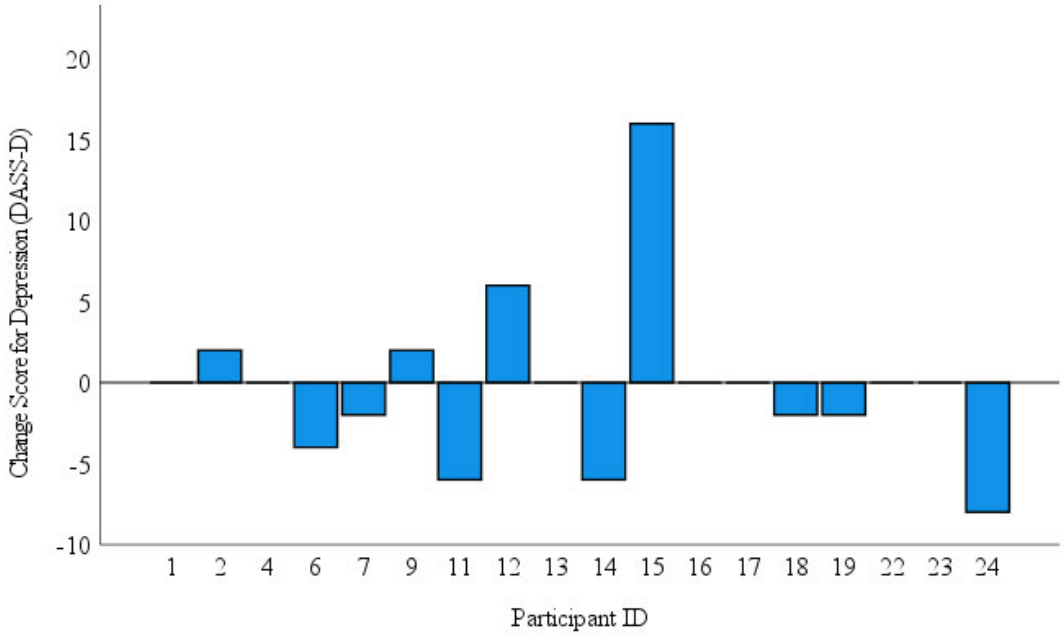
Of the six participants who had a level of symptoms of Depression above the Normal range, two participants (Participants 12 and 15) experienced reliable and clinically significant improvements, with scores reducing to a Normal range. One participant (Participant 24) experienced a reliable deterioration from 18 (Moderate) to 26 (Severe) when measured immediately post ACT intervention. Figure 4.3 illustrates all change scores to show improvement and deteriorations in Depression from pre to post ACT irrespective of reliability, significance, or level of initial psychological symptoms. For the following figures 4.3 to 4.5, positive scores indicate improvement.

Figure 4.3 shows the individual change scores for the 18 participants where data was available for depression scores pre and post ACT intervention. Visual inspection of the figure indicated Participant 15 made the largest gain, with a score of 16 (Moderate) pre-intervention dropping to a score of zero immediately post ACT intervention. This was a reliable and clinically significant change. Gains experienced by Participant 12 immediately post ACT intervention were also significant, from a score of 14 (Moderate) to a score of eight (Normal). Participant 24 had the largest deterioration, from 18 (Moderate) to 26 (Severe). Visual inspection also revealed that Participant 11 and 14 showed some deterioration. Participant 14's score changed from two (Normal) to eight (Normal) immediately following ACT intervention. Participant 11's score change from 0 (Normal) to six (Normal) immediately

following ACT intervention. Both Participant 14 and 11 still had scores within the Normal range pre and post ACT intervention, and these changes were not considered for further analysis.

Figure 4.3:

Individual Participant Change Scores for Depression Pre and Post ACT Intervention



Note. No change bar indicates no change. Positive scores indicate improvement. Negative scores indicate deterioration.

Anxiety

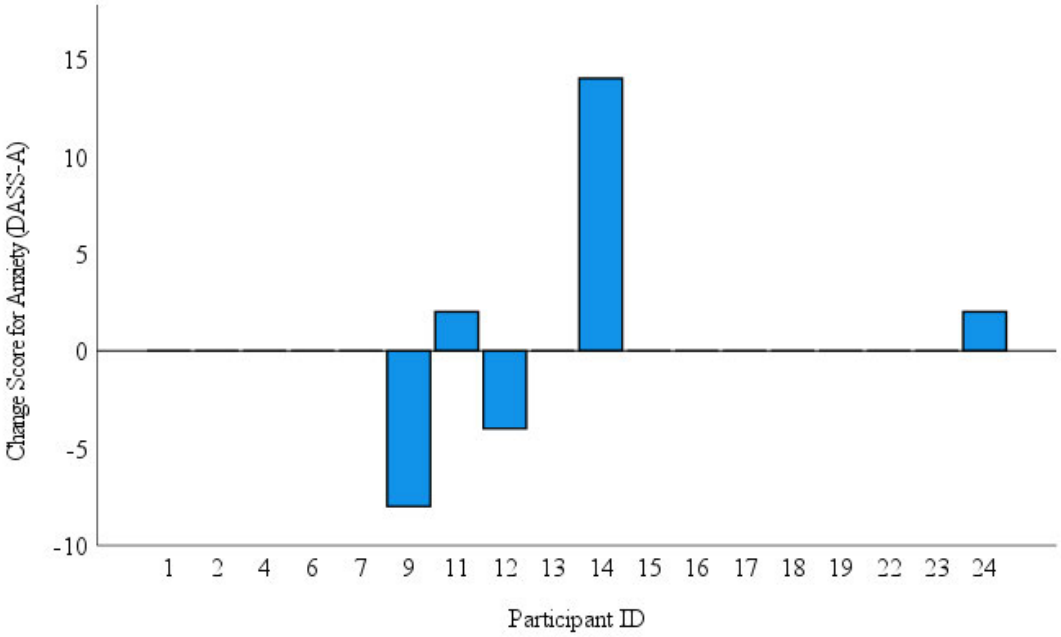
Of five participants with levels of symptoms above the Normal range for Anxiety, one showed a reliable and clinically significant improvement immediately following ACT intervention. This was Participant 14, whose score improved from 14 (Moderate) to 0 (Normal). There were no significant deteriorations in Anxiety immediately following ACT intervention. Figure 4.4 illustrates the change scores of 18 participants where pre and post ACT intervention data were available to show improvement and deteriorations in Anxiety irrespective of reliability, significance, or level of initial psychological symptoms.

A visual inspection notes that most Anxiety symptoms scores did not change immediately after ACT intervention. Participant 14's improvement is captured by the figure. Additionally, Participant 9 and 12 had Anxiety scores that appeared to deteriorate. In this case, Participant 12's deterioration from a score of 12 (Mild) to 16

(Moderate) was not a reliable change. However, Participant 9's score deterioration from two (Normal) to 10 (Moderate) was a reliable change

Figure 4.4:

Individual Participant Change Scores for Anxiety Pre and Post ACT Intervention



Note. No change bar indicates no change. Positive scores indicate improvement. Negative scores indicate deterioration.

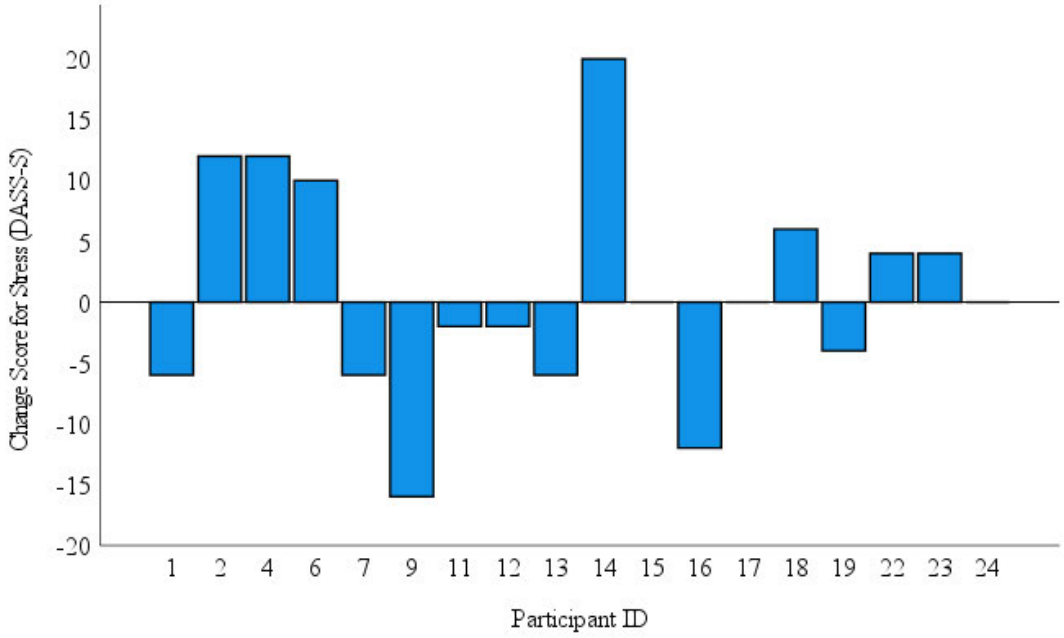
Stress

Several reliable improvements were seen in Stress immediately post ACT intervention. These were for Participants 18, 4, 14, 22 and 2. Participants 4 and 14's scores returned to a Normal range following intervention. Participant 18's Stress score improved from 24 (Moderate) to 18 (Mild). Though Participant 2's score improved from 26 (Severe) to 14 (Normal) and Participant 22 improved from 18 (Mild) to 14 (Normal), these were not considered clinically significant changes as the cut-offs for a Normal level of symptoms for Stress were based on the female norms and standard deviations of the DASS manual (Lovibond & Lovibond, 2002) rather than the overall population sample. As such, for a Stress score to be considered in the Normal range for the calculator that was used to compute reliable and clinically significant change, it had to be eight or less, whereas a Stress score is usually considered Normal when it is 14 or less. There was one significant deterioration of Stress score immediately following ACT intervention. This was for Participant 1 whose score rose from 16 (Mild) to 22 (Moderate).

Figure 4.5 illustrates all change scores to show improvement and deteriorations in Stress from pre to post ACT of the 18 participants where this data was available, irrespective of reliability, significance, or level of initial psychological symptoms. A visual inspection of the figure indicates that the abovementioned improvements and deterioration are captured by the figure. Additionally, Participants 16, 7 and 13 seemed to have levels of deterioration that warranted further investigation. Participant 16's score deteriorated from eight (Normal) to 20 (Moderate), which was a reliable change. Participant 7's score changed from two (Normal) to eight (Normal), and Participant 13's score changes from four (Normal) to 10 (Normal). As these scores remained within the Normal range pre and post ACT intervention, the changes were not considered for further analyss.

Figure 4.5:

Individual Participant Change Scores for Stress Pre and Post ACT Intervention



Note. No change bar indicates no change. Positive scores indicate improvement. Negative scores indicate deterioration.

Comparison to Feros et al. (2013)

Participants in the current study started (Pre-therapy) with a higher percentage of participants with normal symptoms for Depression, Anxiety and Stress compared to Feros et al. (2013). Results are presented in Table 4.13.

Table 4.13

Comparison of Percentage of Normal Mood Pre, Post and Follow-Up in Feros et Al. (2013) and Current Study (N = 20).

Category	Percentage of participants with normal symptoms				
	Feros et al. (2013)		Current study		
	Pre-therapy	3 month post	Pre therapy	Post therapy	6-month post
Depression	41.0	90.0	84.2	84.2	95.0
Anxiety	38.5	68.2	78.9	84.2	95.0
Stress	46.2	86.4	73.7	73.7	95.0

Participants in the current study also started with and had a lower mean of mood disturbance compared to Feros et al. (2013). Results are presented in Table 4.14.

Table 4.14

Comparison of Mean and Standard Deviation of Mood Disturbance in Feros Et Al. (2013) and Current Study.

	Feros et al. (2013)			Current Study		
	Pre	Post	3 month	Pre	Post	6 month
M	24.26	19.44	13.75	12.85	12.40	4.95
SD	11.66	10.75	9.39	11.30	11.21	7.30

Research Question 3:

Does a group-based ACT intervention reduce fear of cancer recurrence?

Reliable change indices for participants with moderate or high levels of fear of cancer recurrence pre ACT are presented in Table 4.15 ($N = 7$). Of the seven participants who indicated either moderate or high overall fear of cancer recurrence pre intervention, three experienced reliable reduction immediately post ACT intervention. Two did not change post intervention, and one point of data (Participant 12) was missing. There were three points of reliable reduction in fear at the 6-months mark, and five points of reliable reduction in fear at the 12-months mark, compared to the baseline. Again, improvements at the 6 and 12-months mark cannot be wholly

attributed to the ACT intervention, however, they are presented to consider the wellbeing of survivors in the longer term.

Table 4.15

Reliable Changes in Level of Overall Fear of Cancer Recurrence Pre and Post Acceptance and Commitment Therapy Intervention for Participants With Moderate to High Fear

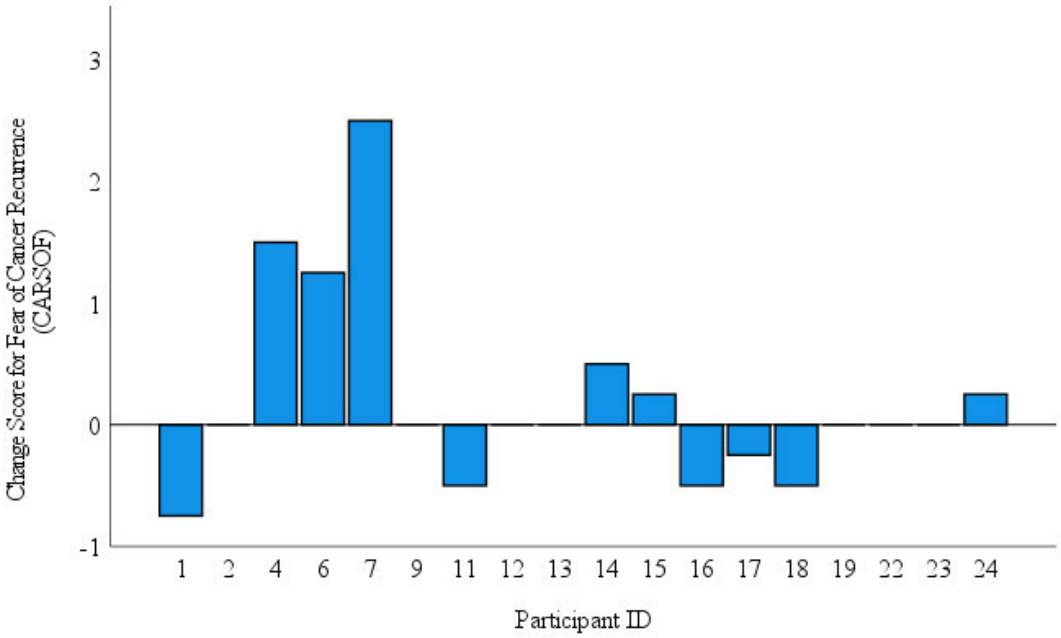
ID	Group	Pre ACT	Post ACT	RCI	At 6 months	RCI	At 12 months	RCI
7	A	4.50	2.00	yes	2.00	yes	1.00	yes
24	B	5.50	5.25	no	3.00	yes	2.75	yes
4	B	4.50	3.00	yes	4.00	no	3.25	yes
12	W	6.00	-	-	-	-	6.00	no
6	W	3.75	2.50	yes	2.50	yes	2.75	yes
15	W	3.75	3.50	no	4.25	no	2.50	yes
13	W	3.00	3.00	no	2.25	no	2.50	no

Note. ACT = Acceptance and commitment therapy. RCI = Reliable change index.

Figure 4.6 shows the change scores for overall fear improvements versus deteriorations for the 18 participants where data was available pre to post ACT, irrespective of reliable change or level of initial fear. For this figure, positive scores indicate improvement. Participant 7 had the greatest improvement, from a score of 4.50 (moderate to high fear) to 2 (low fear). Participant 4 improved from 4.50 (moderate to high fear) to 3.00 (Moderate fear), and Participant 6 improved from 3.75 (moderate) to 2.50 (low to moderate fear). A visual inspection of the figure showed that Participant 1 had the greatest level of deterioration immediately following ACT intervention. Participant 1's score rose from 2.00 (low fear) to 2.75 (low to moderate fear), however, this was not a reliable change. Changes less than 1 point are not an indication of reliable change.

Figure 4.6:

Individual Participant Change Scores for Overall Fear of Cancer Recurrence Pre and Post ACT Intervention



Note. No change bar indicates no change. Positive scores indicate improvement. Negative scores indicate deterioration.

Research Question 4: Does a group-based ACT intervention produce results due to an improved psychological flexibility as the literature suggests?

A correlation table containing an analysis at the subscale level is provided in Appendix G. Experiential avoidance was highly and significantly negatively correlated (p <.01) with overall quality of life (r = -.69), emotional wellbeing subscale (r = -.68), breast cancer subscale (r = -.68), total concerns about cancer recurrence (r = -.69), and overall fear subscale (r = -.63). Experiential avoidance was significantly positively correlated (p <.01) with health worries (r = .63), womanhood worries (r = .72), and role worries (r = .57). This suggests that experiential avoidance is related to overall quality of life and fear of cancer recurrence, as well as specific aspects of both constructs.

Correlations for AAQ total score, and AAQ >20

During the exploration of the data, visual inspection of scatterplots of experiential avoidance and other constructs showed what appeared to be stronger correlations for AAQ scores of 20 or more. For example, Figure 4.7 suggests a stronger negative correlation between experiential avoidance and Quality of Life for

values of experiential avoidance >=20. Figure 4.8 suggests a stronger positive correlation between experiential avoidance (values >=20) and Concerns About Cancer Recurrence.

Figure 4.7

Scatterplot of Quality of Life (FACT-B) by Experiential Avoidance (AAQ-II) Combined Across All Time Points, N = 92

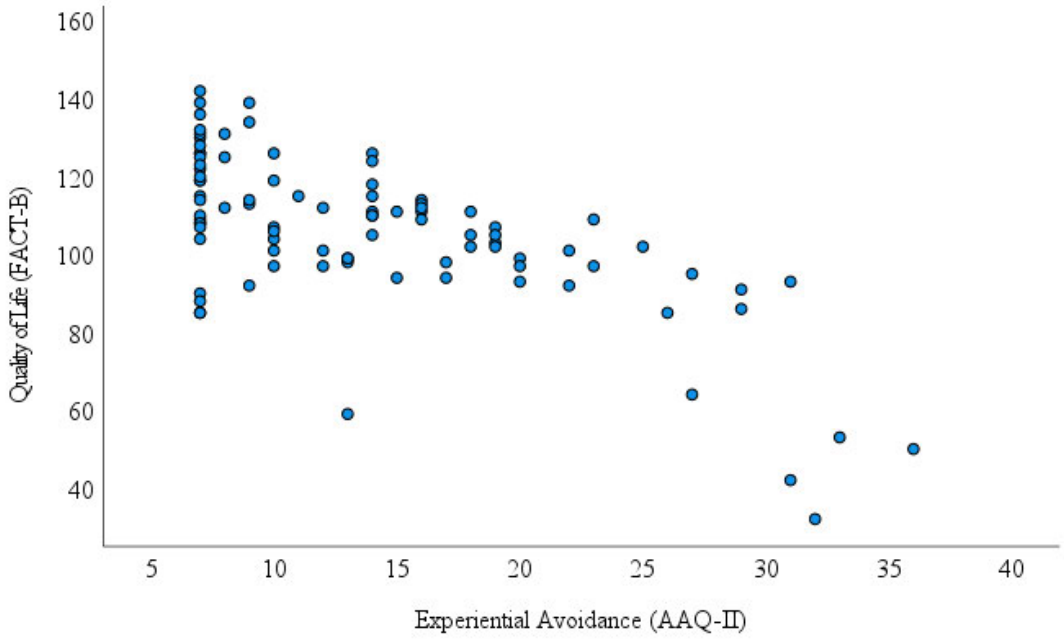
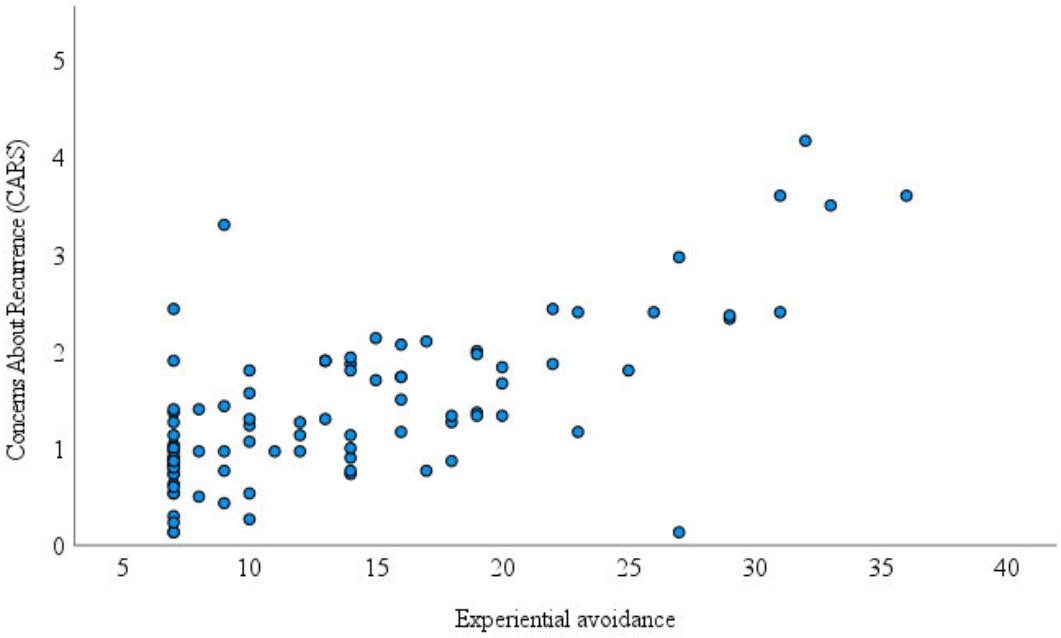


Figure 4.8

Scatterplot of Concerns About Cancer Recurrence (CARS) by Experiential Avoidance (AAQ-II) Combined Across All Time Points, N = 92



Although the AAQ validation papers indicate a cut-off score of 24 – 28 or more as indicative of experiential avoidance contributing to possible clinical concerns (Bond et al., 2011; Hayes et al., 2004), the lower cut-off of 20 was explored in this study due to 1) the ceiling and floor effects that meant that not many participants scored over 24, and 2) the association with the AAQ and variables of interest in this study seems to be evident at a score of 20. Table 4.16 highlights the difference in correlation coefficients using Spearman's r with this cut-off.

Table 4.16

Correlation Co-Efficients for AAQ-II With FACT-B and Subscales, CARS and Subscales, and DASS-21.

	AAQ-II 19 or less		AAQ-II 20 or more	
N_{pxt}	74		18	
Variable	*r*	*p*	*r*	*p*
FACT-B	-.32*	<.01	-.75*	<.01
Physical wellbeing	-.35*	<.01	-.07	.77
Social wellbeing	-.04	.76	-.71*	<.01
Emotional wellbeing	-.30*	<.01	-.69*	<.01
Functional wellbeing	-.06	.61	-.68*	<.01
Breast cancer related wellbeing	-.39*	<.01	-.65*	<.01
CARS	.42*	<.01	.67*	<.01
Overall fear	.26*	.03	.50*	.03
Health worries	.38*	<.01	.58*	.01
Womanhood worries	.46*	<.01	.76*	<.01
Role worries	.36*	<.01	.50*	.03
Death worries	.23	.05	.55*	.02
Depression	.10	.42	.50	.85
Anxiety	.10	.39	.44	.86
Stress	.27*	.02	.21	.40

Note. FACT-B = Functional Assessment of Cancer Therapy – Breast; CARS = Concerns about Recurrence Scale; *$p < .05$, two tailed; Death worries for AAQ < 19 was not significant at p = .053.

A clinical cut off score of 20 seemed to make a difference to some variables, but not others. For example, an experiential avoidance score of less than 20 had a weaker correlation with overall quality of life with a medium effect, $r(74) = -.32$, $p < .01$, compared to AAQ-II score of 20 or more, which had a stronger correlation with overall quality of life with a large effect, $r(18) = -.75$, $p < .01$. A similar distinction appears for fear of cancer recurrence where lower levels of experiential avoidance have a weaker correlation, with moderate effect $r(74) = .42$, $p < .01$, and higher levels of experiential avoidance have a stronger correlation, with large effect

$r(18) = -.67$, $p < .01$. This result is not seen for psychological distress; when depression, anxiety and stress scores are separated by higher or lower experiential avoidance, the correlations are mostly not significant.

Only three participants had an AAQ-II score of 24 or higher prior to the ACT condition. Therefore, the lower cut-off for experiential avoidance of 20 was used, given the stronger correlation with variables of interest. Five participants had AAQ-II scores of 20 or higher pre ACT intervention. Reliable change indices for these participants are presented in Table 4.17. Of five participants, two showed reliable and clinically significant reductions in experiential avoidance immediately following ACT. Participants 4's score improved from 29 to 15, and Participant 6 improved from 20 to 7. At the 6-month follow-up, four participants showed clinically significant change. At the 12-month follow-up, three maintained reliable and clinically significant change. Figure 4.9 shows the change scores for experiential avoidance improvements versus deteriorations for all participants from pre to post ACT irrespective of reliability, significance, or level of initial avoidance. For these figures, positive scores indicate improvement.

Table 4.17

Reliable and Clinically Significant Changes in Experiential Avoidance Pre and Post Acceptance and Commitment Therapy Intervention, for Participants who Scored < 20 on the Acceptance and Action Questionnaire – II.

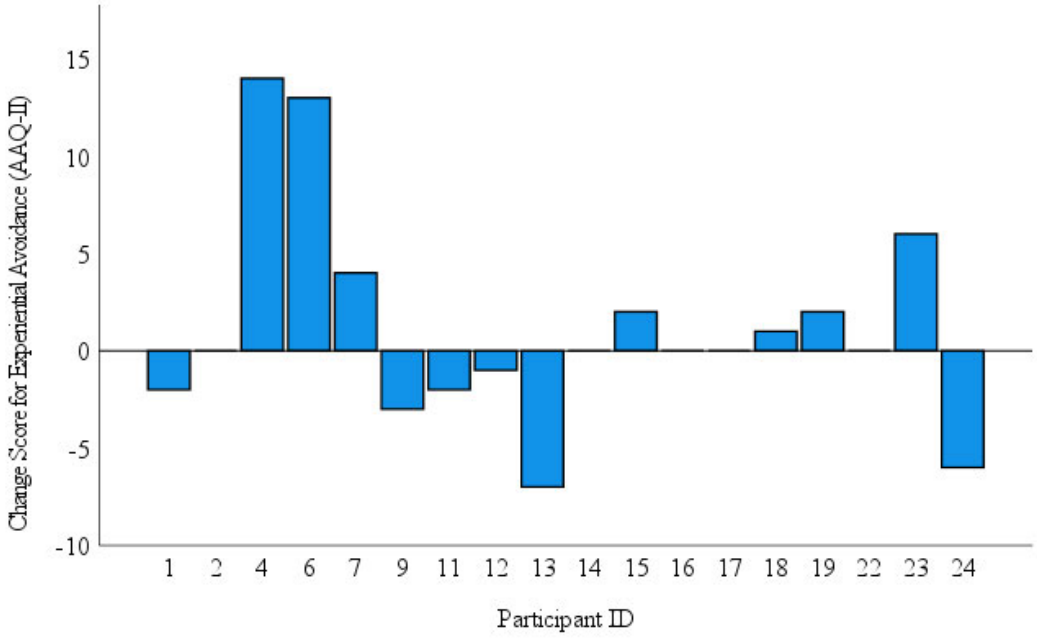
ID	Group	Pre ACT	Post ACT	RCI	CSC	At 6 months	RCI	CSC	At 12 months	RCI	CSC
18	A	20	19	no	-	14	yes	yes	18	no	-
5	A	27	-	-	-	16	yes	yes	17	yes	yes
4	B	29	15	yes	yes	19	yes	yes	18	yes	yes
12	W	31	32	no	-	-	-	-	36	yes	-
6	W	20	7	yes	yes	13	yes	yes	12	yes	yes

Note. ACT = Acceptance and commitment therapy. RCI = Reliable change index. CSC = Clinically significant change. RCI and CSC compared to pre-ACT score

A visual examination of change scores for all 18 participants where data was available pre and post ACT intervention is presented in Figure 4.9. Visual examination indicates that Participant 23 showed the third highest rate of improvement. Participant 23's experiential avoidance reduced from 14 to 8, however, as her level of experiential avoidance was below the level of concern, no further analysis was warranted. Participant 13 and 24 appeared to experience some deterioration immediately following ACT treatment. Participant 13's score deteriorated from 15 to 22, and Participant 24's score deteriorated from 19 to 25. Both of these were reliable changes.

Figure 4.9:

Individual Participant Change Scores for Experiential Avoidance Pre and Post ACT Intervention



Note. No change bar indicates no change. Positive scores indicate improvement. Negative scores indicate deterioration.

Research Question 5:

Are certain women more likely than others to benefit from ACT intervention?

Comparison with Breast Cancer Education

A visual examination group data suggested no difference in experiential avoidance in Group A or B following education intervention (Appendix E, Figure

E.3). However, that of individual data showed that Participant 4 experienced high and increasing in experiential avoidance following BCE (Appendix E, Figure E.4). Participant 4's score rose from 22 to 29 immediately following BCE, which is a reliable change. Otherwise, results indicate that although ACT reduced experiential avoidance for this participant, BCE did not significantly increase or reduce it.

A visual examination of group score bar graphs indicated that overall fear of cancer recurrence for all three groups decreased following ACT intervention (Appendix E, Figure E.5), whereas it increased for relevant groups following BCE (Appendix E, Figure E.7). The BCE changes seemed driven by Participants 4, 19 and 24 (Appendix E, Figure E.8). Reliable change calculations were performed for these participants. Participant 4 and 19's changes were not reliable. Participant 24's deterioration from 4.5 (moderate to high fear) to 5.5 (high fear) was reliable.

A visual examination of group data indicated that quality of life reduced in Group A following ACT (Appendix E, Figure E.9), but increased for Group B, who had BCE followed by ACT (Appendix E, Figure E.9 and C11). Additionally, both Group A and B showed increase in quality of life following BCE (Appendix E, Figure E.11). A visual examination of individual data indicated this reduction in Group A was largely driven by Participant 11 (Appendix E, Figure E.10), whose score fell from 126 to 111, which was not a reliable change. However, the increase in Group B was driven by Participant 23, whose score rose from 98 to 124, was a reliable improvement (Appendix E, Figure E.12). There were no reliable deteriorations in quality of life immediately following the education treatment.

Visual examination of group score bar graphs indicated a possible increase in depression following ACT for Group A and B (Appendix E, Figure E.13), and reduction in Group W. This increase seen for Group B seemed reversed for BCE, where group-level depressive symptoms seemed to reduce (Appendix E, Figure E.15). For ACT, the individuals driving this effect are known; Participant 24 with a reliable deterioration and Participant 14 whose change was not reliable for Group B, and Participant 11 for Group A whose change was not reliable (Appendix E, Figure E.14). For Group W, the biggest differences were found for Participant 12 and 15, again reliable changes. The reduction in depression following BCE for Group B seemed driven by Participant 14 and 4 (Appendix E, Figure E.16), which were not reliable changes. Conversely, visual examination of individual scores following education intervention (Appendix E, Figure E.16) showed a possible increase in

depression score for Participant 9, whose score changed from two (Normal) to 12 (Mild). This was a reliable deterioration. Increases and reductions to group-level depression scores were not related to the same participants.

Visual examination of group score bar graphs indicated possible increase in anxiety following BCE (Appendix E, Figure E.19). In Group A, this was driven by Participant 9, however, this change was not reliable. In Group B, this was driven by Participant 14, whose score changed from two (Normal) to 14 (Moderate) immediately after BCE, which is a reliable deterioration (Appendix E, Figure E.20).

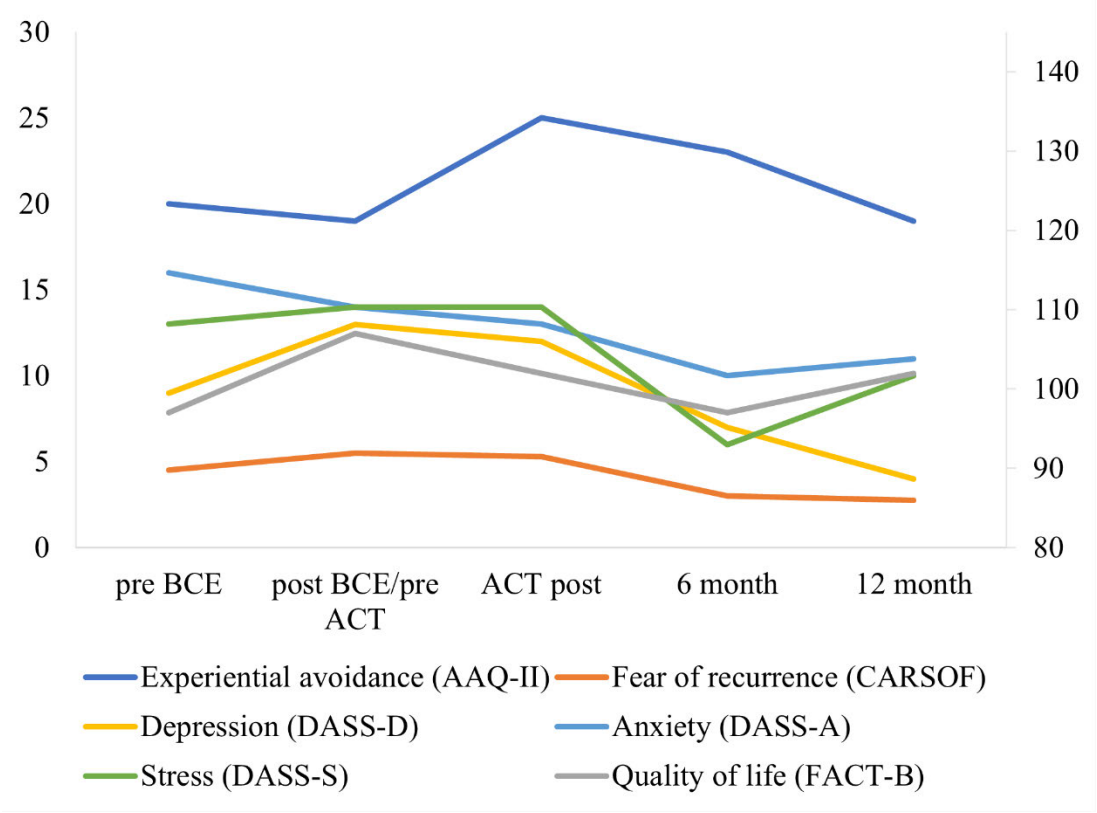
Visual examination of group score bar graphs suggested possible increase in stress following BCE for Group B (Appendix E, Figure E.23). This was driven by Participant 4 and 14, whose scores changed from 10 (Normal) to 18 (Mild), and six (Normal) to 20 (Moderate) respectively. These were reliable deteriorations (Appendix E, Figure E.24). Additionally, visual examination of individual bar graphs (Appendix E, Figure E.24) showed that Participant 1 in Group B, who received BCE before ACT, experienced the biggest reduction in stress following BCE, with scores reliably improving from 24 (Moderate) to 16 (Mild). Participant 1 also experienced a significant deterioration in stress from 16 (Mild) to 22 (Moderate) following ACT intervention (Appendix E, Figure E.22).

Further Individual Analyses

Figure 4.10 represents Participant 24's scores across time points. In this case, the increases or decreases in experiential avoidance were not associated with changes in other scores. Participant 24 did not benefit from participating in ACT or BCE.

Figure 4.10

Participant 24 (Group B) Scores Over Time Points

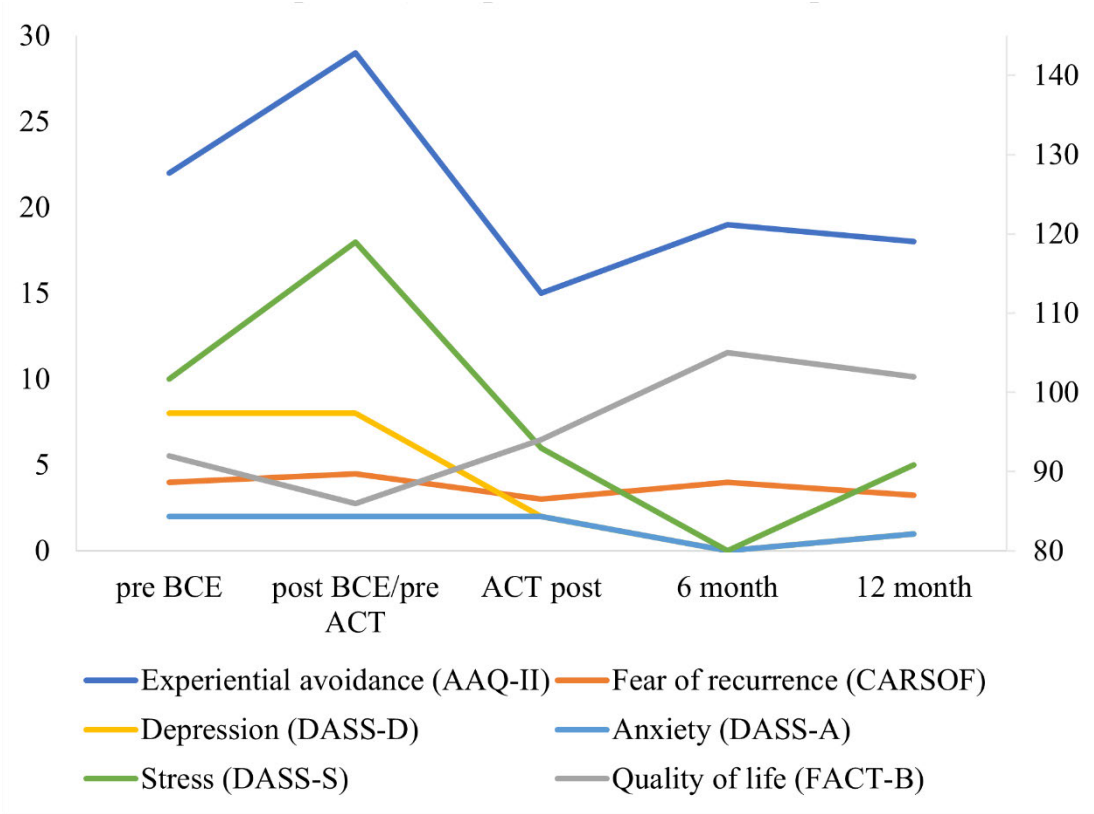


Note. BCE = Breast cancer education; ACT = Acceptance and commitment therapy; AAQ-II = Acceptance and Action Questionnaire II; CARSOF = Concerns About Cancer Recurrence Overall Fear Subscale; DASS = Depression, Anxiety, and Stress Scale; FACT-B = Functional Assessment of Cancer Therapy Scale – Breast. Left hand scale for AAQ-II, DASS, and CARSOF. Right hand scale for FACT-B.

Figure 4.11 represents Participant 4's scores across time points. Experiential avoidance and stress scores both increased following BCE and decreased following ACT intervention. Depression did not increase with BCE but did decrease with ACT intervention. Quality of life had an inverse relationship with experiential avoidance and stress. Participant 4's gains in treatment for experiential avoidance and stress following ACT intervention were maintained at 6 and 12 month follow-up.

Figure 4.11

Participant 4 (Group B) Scores Over Time Points

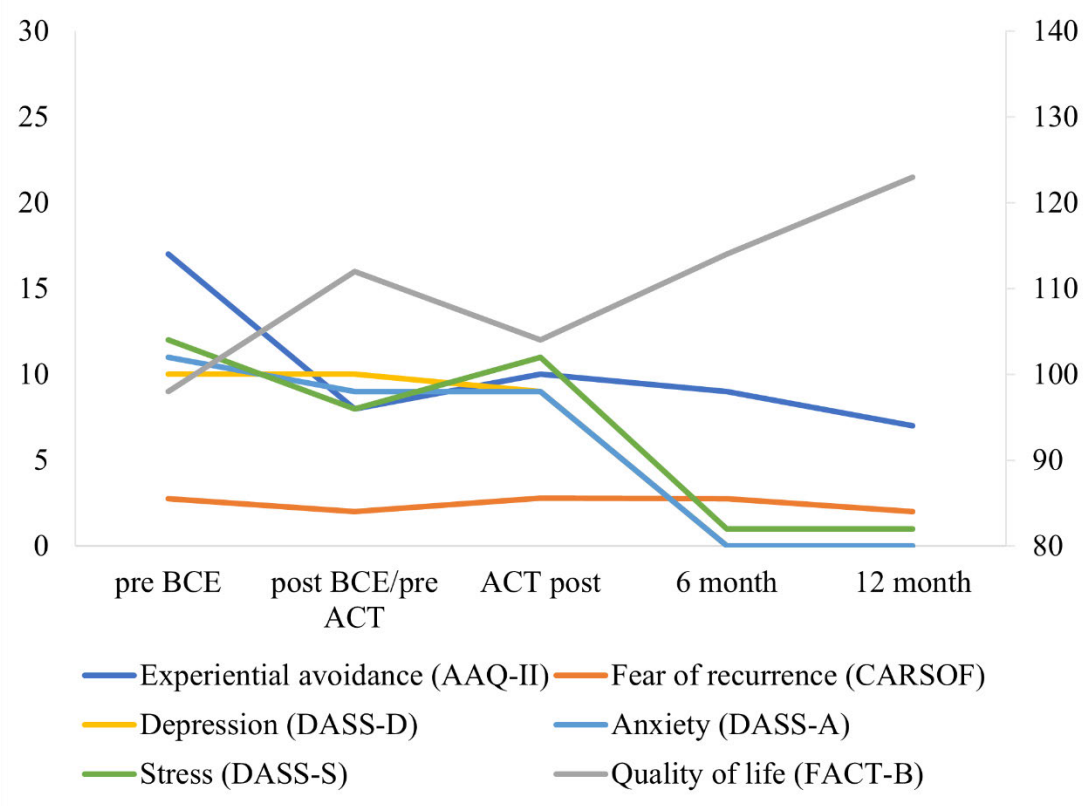


Note. BCE = Breast cancer education; ACT = Acceptance and commitment therapy; AAQ-II = Acceptance and Action Questionnaire II; CARSOF = Concerns About Cancer Recurrence Overall Fear Subscale; DASS = Depression, Anxiety, and Stress Scale; FACT-B = Functional Assessment of Cancer Therapy Scale – Breast. Left hand scale for AAQ-II, DASS, and CARSOF. Right hand scale for FACT-B.

Figure 4.12 represents Participant 1's scores across time points. In this case, experiential avoidance was already low prior to any intervention. Quality of life increased following BCE and decreased following ACT. In the longer term, Participant 1 experienced an improved quality of life with low experiential avoidance, fear, and psychological distress.

Figure 4.12

Participant 1 (Group B) Scores Over Time Points

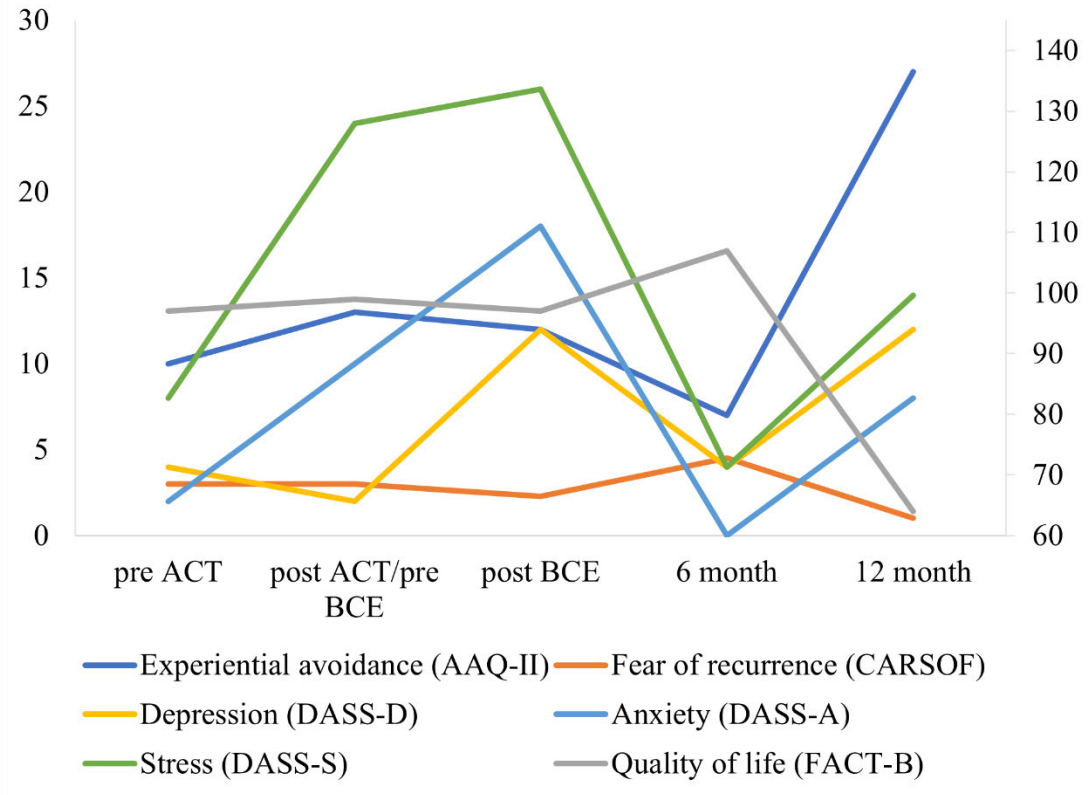


Note. BCE = Breast cancer education; ACT = Acceptance and commitment therapy; AAQ-II = Acceptance and Action Questionnaire II; CARSOF = Concerns About Cancer Recurrence Overall Fear Subscale; DASS = Depression, Anxiety, and Stress Scale; FACT-B = Functional Assessment of Cancer Therapy Scale – Breast. Left hand scale for AAQ-II, DASS, and CARSOF. Right hand scale for FACT-B.

Figure 4.13 represents Participant 9's scores across time points. Participant 9's scores seem to suggest that participation in any intervention increased psychological distress, without significant impact to her quality of life. Participant 9 had low experiential avoidance throughout all time points, except for 12 months. Her quality of life was unaffected by interventions or level of psychological distress. Engaging in ACT increased levels of stress, further increased through BCE alongside increased levels of anxiety and depression.

Figure 4.13

Participant 9 (Group A) Scores Over Time Points

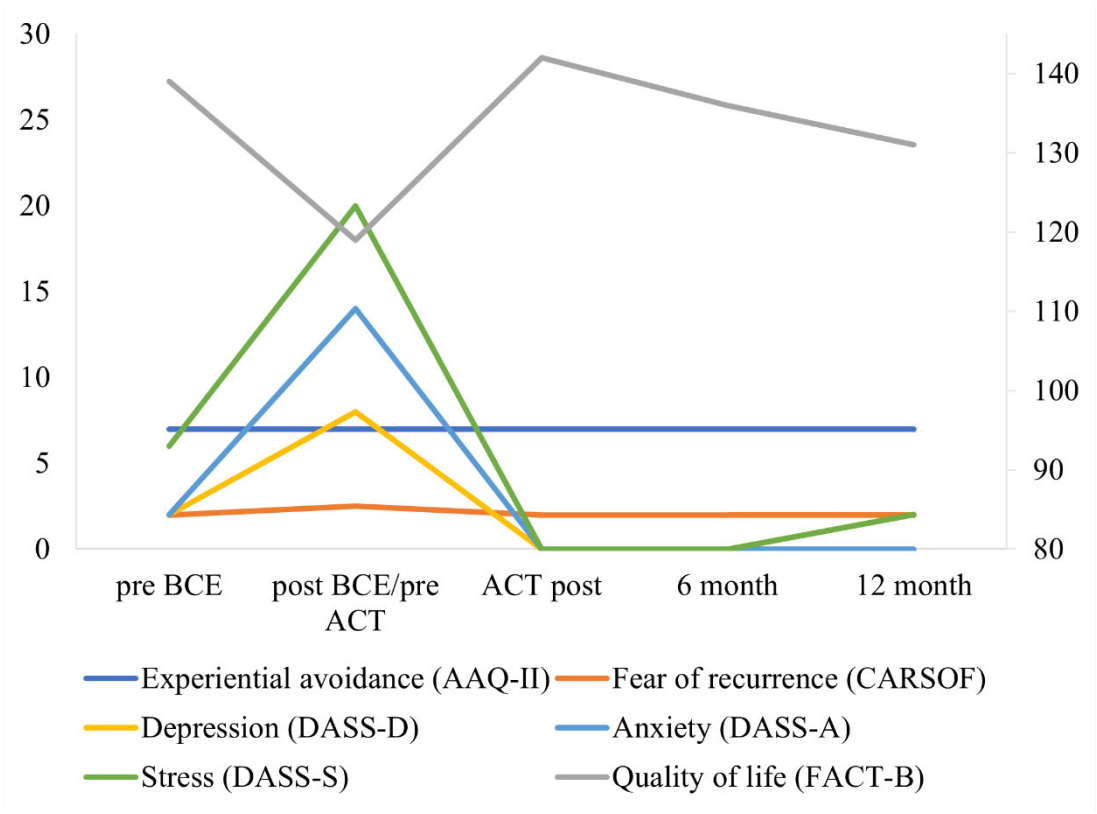


Note. BCE = Breast cancer education; ACT = Acceptance and commitment therapy; AAQ-II = Acceptance and Action Questionnaire II; CARSOF = Concerns About Cancer Recurrence Overall Fear Subscale; DASS = Depression, Anxiety, and Stress Scale; FACT-B = Functional Assessment of Cancer Therapy Scale – Breast. Left hand scale for AAQ-II, DASS, and CARSOF. Right hand scale for FACT-B.

Figure 4.14 represents Participant 14's scores across time points. In this case, there was a clear inverse relationship between quality of life and psychological distress, with poorer wellbeing and higher distress during the breast education intervention, which improved and maintained following ACT.

Figure 4.14

Participant 14 (Group B) Scores Over Time Points



Note. BCE = Breast Cancer Education; ACT = Acceptance and commitment therapy; AAQ-II = Acceptance and Action Questionnaire II; CARSOF = Concerns About Cancer Recurrence Overall Fear Subscale; DASS = Depression, Anxiety, and Stress Scale; FACT-B = Functional Assessment of Cancer Therapy Scale – Breast. Left hand scale for AAQ-II, DASS, and CARSOF. Right hand scale for FACT-B.

Summary of results

Research Question 1 considered the impact of group-based ACT on quality of life for women survivors of breast cancer. Two types of change analyses were employed for individual participants (n = 18) pre and post ACT intervention: reliable change indices, and minimally important differences. No individuals showed reliable change based on the first type of analysis. Using the criteria of minimally important differences, there were five improvements and four deteriorations noted immediately following ACT intervention compared to pre-intervention scores. At 12-months post intervention, there were nine improvements and one deterioration in participants compared to pre-intervention scores. The participant who had deteriorated, Participant 9, reported that she had biliary cancer. Scores of the quality of life measure, FACT-B, were used to calculate a FACT-G score for a descriptive

comparison with Feros et al. (2013). Women in this study had higher quality of life at pre, post, and follow-up measures.

Research Question 2 considered whether group-based ACT produced clinically relevant outcomes for psychological distress. The mean pre-intervention score for Depression (M = 6.8, SD = 7.47) and Stress (M = 13.10, SD = 9.60) were in the Normal range, and Anxiety (M = 7.30, SD = 9.21) in the Mild range. Individual scores above a Normal level of symptoms (n = 20) were chosen for analysis of reliable and clinically significant change, some of these scores belonging to the same participants, for example, Participant 1 who scored 20 on Depression, 18 on Anxiety, and 16 on Stress. There were nine reliable improvements across symptoms of psychological distress post ACT intervention, five of these clinically significant and four returning to a Normal range. At 12-months post intervention, there were 10 scores with reliable and clinically significant improvement. In comparison with Feros et al. (2013), women in this study had descriptively more percentage of participants with normal symptoms for psychological distress pre, post, and at follow-up.

Research Question 3 considered the impact of group-based ACT on fear of cancer recurrence. Reliable change indices were calculated for participants with moderate or high levels of fear of cancer recurrence (n = 7). Three showed reliable improvements post-ACT, and 5 had reliable improvements by 12-months.

Research Question 4 focused on the process of ACT to affect change, considering whether ACT produces an increase in psychological flexibility. Data across all five time points of measurement were combined (n = 92) to compute correlations between experiential avoidance and quality of life, and experiential avoidance and fear of cancer recurrence. Experiential avoidance was highly and significantly negatively correlated (p <.01) with overall quality of life (r = -.69), emotional wellbeing subscale (r = -.68), breast cancer subscale (r = -.68), total concerns about cancer recurrence (r = -.69), and overall fear subscale (r = -.63). Experiential avoidance was significantly positively correlated (p <.01) with health worries (r = .63), womanhood worries (r = .72), and role worries (r = .57). Correlation coefficients between experiential avoidance scores 19 or less (n = 74) compared to 20 or more (n = 18) had descriptively different strengths, generally stronger correlations when participants scored 20 or more. For example, quality of life had a weak correlation at lower experiential avoidance scores (r = -.32) and

strong at higher experiential avoidance scores (r =-.75), and both relationships were significant. A cut off score of 20 was used to include additional scores for analysis of the research question as not enough participants (n = 3) scores above the clinical threshold of 24 indicated by the measure's validation paper (Bond et al., 2011). Of five participants who had a pre-ACT score of ≥ 20, four returned the follow-up measure post-ACT, of which two had reliable and clinically significant improvements. At 12-months, four had reliable improvements compared to baseline, three of which were clinically significant.

Research Question 5 explored whether certain women were more likely than others to benefit from ACT intervention. Analyses consisted of preliminary visual comparison using group and individual bar graphs with the control condition of Breast Cancer Education (BCE), and the selection of participants who had distress higher than Normal or experienced reliable deteriorations following treatment. Overall, there seemed to be no difference in experiential avoidance following BCE, some increase in fear of cancer recurrence after BCE that reduced following ACT, some increase in anxiety following BCE, mixed effects for quality of life and depression where it decreased following BCE for some groups but increased for others. Examining individual participant's reliable change indices showed that these differences were driven by 11 reliable changes. The selection of participants highlighted a number of possible effects of interventions at an individual level. For Participant 24, experiential avoidance was not associated with changes in other measures. In Participant 4, experiential avoidance increased with BCE and decreased with ACT, and seemed associated with stress. Participant 1 also showed an increase of experiential avoidance after BCE and reduction after ACT, with improved quality of life, fear, and distress at follow-ups. Participant 9's scores showed an increase in avoidance, distress and fear during participation in any intervention, and decrease at the 6-months follow-up, increased again at the 12-months follow-up with the confound of biliary cancer. Participant 14's experiential avoidance remained consistent through intervention and follow-up, but like Participant 4 and 1, her distress rose and quality of life fell during BCE, and improved following ACT.

Discussion

This pilot study provided valuable insight into community-based research, balancing design needs and community needs in a regional setting to deliver an intervention with the intention of benefiting the local community of regional breast cancer survivors. Support for the feasibility of ACT to improve the wellbeing of women post primary treatment of early breast cancer was shown though the engagement of the women in the program and preliminary outcomes of the intervention. Some participants who experienced elevated psychological distress or fear of cancer recurrence prior to the study seemed to benefit from participation in the study, with many showing reliable improvement following the intervention, and some showing recovery to Normal levels, especially for anxiety and stress symptoms. Those that experienced moderate or high fear of cancer recurrence prior to the intervention tended to experience moderate to low fear following the intervention. Overall, women's wellbeing improved at six and 12 month follow-ups.

The pilot study demonstrated that a six-week group ACT intervention for this population is feasible. Engagement as measured by attendance, return of surveys, and facilitator feedback indicated an acceptable level of engagement, with 83% attendance in the overall program and 92% survey completion. Additionally, feedback from facilitators suggested that the participants were engaged in the intervention. Facilitators also seemed to make an effort to adapt the content of the sessions to the circumstances of the participants. Although the familiarity of the facilitators with ACT, the use of clinicians in training such as provisional psychologists, or the contents of the manual may be a potential limitation, pilot studies since such as Arch (2021) have used novice facilitators, and still had comparable results with cancer patients and survivors.

Preliminary results of the intervention generally matched the known literature. While a direct comparison is not achievable given different population characteristics, including cancer stage and type, the participants in this study commenced with better quality of life and lower levels of distress compared to Feros et al. (2013). These participants also tended to show a good quality of life and lower distress and fear at 6 and 12 month follow-ups. This finding of improvement in long-term survivorship supports the general trend of good quality of life found by Ganz et al. (2003) and others, even though there is also some evidence in the literature that women in regional Australia face unique challenges to their wellbeing (DiSipio et

al., 2010; Youl et al., 2016). It was assumed based on past research that the quality of life of women in regional Australia may be lower due to the unique challenges of regional and rural living. However, this was not the case for this sample of women who were enrolled in a private hospital for cancer care. Future research may need to show replication of this in a regional public health system as Spilsbury et al.'s (2005) review of breast cancer treatment in urban and regional Australia indicated the largest differences in healthcare outcome for patients to be between urban and regional pubic hospitals.

In addition to expected population characteristics for quality of life, the preliminary findings of this pilot study also supported the relationship between the variables of interest. Fear of cancer recurrence and psychological distress had a negative association with quality of life. Additionally, experiential avoidance showed similar associations, with a significant negative correlation with quality of life, $r(92) = -.69$, $p < .01$, and also significant but differing strengths of correlation depending on if experiential avoidance was high (a score of 20 or more), $r(18) = -.75$, $p < .01$, or low (a score less than 20), $r(74) = .42$, $p < .01$. High or low experiential avoidance was also relevant to the strength of the relationship between experiential avoidance and fear of cancer recurrence, with high scores demonstrating a stronger significant correlation $r(18) = .67$, $p < .01$, than lower scores, $r(92) = .42$, $p < .01$. An overall positive association between experiential avoidance and psychological distress, as found in the literature, was also supported, with significant correlations; r(92) = .37 for depression, .48 for anxiety, and .48 for stress, all $p < .01$. However, this association between experiential avoidance and psychological distress did not seem to matter if experiential avoidance was high or low.

The correlation between these variables did not always translate into practice, and additional research into these relationships may help clarify some of the strengths and shortcomings of ACT for women survivors of breast cancer. The proposed benefit of ACT for women survivors of early breast cancer was to improve wellbeing and reduce distress through the targeting of experiential avoidance. If experiential avoidance is associated with components of fear, psychological distress and quality of life as the literature suggests, then a decrease in experiential avoidance should produce improved wellbeing in these women. Of the four participants where experiential avoidance was high pre-treatment, and immediate follow up could be obtained, two participants showed clinically significant reductions in experiential

avoidance immediately following ACT, and these scores maintained at 6 and 12 month follow-ups. No participants with high experiential avoidance showed deterioration in experiential avoidance scores following ACT. However, two participants who had low experiential avoidance pre-treatment had high experiential avoidance immediately following ACT. These participants belonged to the groups that received ACT towards the latter part of the program, in November-December. At the time, there was some reported concern about rising distress levels due to the Christmas period. However, even if this was not the case, it is worth considering how well ACT works through its purported mechanism of reducing experiential avoidance.

The impact of ACT on psychological distress also requires clarity but is likely beneficial. Of 18 possible points of improvement for psychological distress symptoms above a Normal range, eight showed reliable improvement, of which five recovered to a Normal level of symptoms. Those experiencing a level of stress above a Normal range were most likely to see a reliable improvement or recovery from these symptoms immediately following ACT, with gains maintained at a 6-month follow-up. However, there was also one point of deterioration found in depressive symptoms and one point of deterioration in stress symptoms following ACT intervention. Additionally, there were two points of psychological distress that were in a Normal range prior to ACT, that rose above a Normal range following ACT. These findings suggest that while ACT can reduce psychological distress, undertaking intervention when not experiencing psychological distress may very occasionally increase anxiety or stress. Future recruitment of participants should screen out participants who in a Normal range of psychological distress, as they are unlikely to benefit from the intervention. To put the possibility of deterioration of psychological distress from Normal following ACT intervention in context, it is two data points out of a possible 87 data points, in a sample where 73% (for stress) to 84% (for depression and anxiety) of participants had a Normal range of symptoms post therapy, and 95% were in the Normal range at a 6-months follow-up. Therefore, it is still safe for participants to engage in ACT if they do not experience psychological distress, however, adequate screening will assist in targeting effective intervention.

The use of two different calculations for change in the FACT-B showed different outcomes. This is likely due to the reliability of the measure. Although the

measure had acceptable reliability (α=.69), the margin of measurement error and ceiling effect meant that it was difficult to record a reliable and significant change. Participants had to improve by about 31 points, which made it unrealistic for some women to achieve a reliable improvement, especially given that women who report no disease score an average of 118 on this scale and the maximum score achievable was 148. However, of the few participants whose scores were lower (e.g., Participant 12 started with a score of 42), their scores did not improve significantly after intervention. Using Yost and Eton's (2005) guidelines on minimally important differences detected minimally important differences, which included improvements and deteriorations, at 27 points across 15 participants. Their approach combined a distribution approach which looked at normal distributions with standard error not unlike the approach of Jacobson and Truax (1991) on which the Leeds Reliable Change Indicator bases its assumptions, with participant reports including retroactive reports of noticeable change to compute a range of fixed change scores that are likely noticeable to patients and meaningful to clinicians. Yost and Eton's (2005) method may be more practical in detecting clinically significant change, however, the reliability of the changes calls for tentative interpretation.

The impact of ACT on quality of life also remains unclear, and there are limited studies on experiential avoidance and quality of life for women breast cancer survivors to assist in understanding the outcomes. While there was correlation between experiential avoidance and quality of life, there was no reliable change for quality of life following ACT.

Participants who experienced some distress or deterioration following interventions were selected in an attempt to understand the driving forces behind change and wellbeing. Where experiential avoidance was high, it tended to have an inverse relationship with quality of life; the more avoidance, the less quality, irrespective of psychological distress. In cases where experiential avoidance was low, quality of life had an inverse relationship with psychological distress. With evidence that patient education improved the outcome of management of chronic disease (Adams, 2010), breast cancer education treatment likely plays a key role in survivor wellbeing. However, if learning about aspects of breast cancer care increases stress, this may impact a survivor's ability to implement the information due to avoidance-based coping strategies. On two occasions, aspects of psychological distress were observed to significantly increase following breast

cancer education, and decrease following ACT, suggesting that ACT may assist with wellbeing through reduction of psychological distress, even when experiential avoidance is low or unchanged with ACT intervention. This highlights the need to further understand the relationship between experiential avoidance, quality of life, and psychological distress. If ACT can reduce stress or increase acceptance-based strategies for distress, this may be a pathway through which ACT has some effect on wellbe125rea125sThe effect of ACT was clearest in reducing fear of cancer recurrence. ACT was effective at reducing fear of cancer recurrence for participants who had a moderate or high fear pre-treatment. Of six participants who indicated moderate or high fear, four demonstrated reliably improvement immediately following ACT, with three of these maintained at 6 and 12 month follow-ups. Additionally, there were no deteriorations in fear following ACT intervention. This provides preliminary support of the link between experiential avoidance and fear of cancer recurrence, however, while this link has been explored as part of an untested theoretical model (Fardell et al., 2016), there are limited studies on this in the cancer population.

Several limitations of this study are due to a compromise between community needs and recruitment, sample size, and controlling for treatment effects. The main limitation of this study was the participant characteristics; floor effects for distress, fear, and avoidance, along with ceiling effects for quality of life, meant that the sample had a higher chance of deteriorating than improving over time, especially due to the extra load of attending weekly sessions and the impending arrival of a busy Christmas period for women, some with young families. Although this may be considered a recruitment flaw as participants recruited were not experiencing significant difficulties, recruitment was conducted by a breast cancer care nurse who knew the population well. This, along with the feedback from facilitators, suggests that the participants selected were expected to benefit from the intervention.

Furthermore, while the intervention was based on an adapted version of the manual used in Feros et al, (2013) intended to improve comparability to similar studies, the comparison in practice is limited by the group format, the change to the length of sessions, and change to the number of sessions. Due to the group administration, an additional health practitioner was recruited to observe and provide additional support if required, however, the effect of this was not analysed or accounted for. There was no consideration given to whether a protocol for an

individual therapy can be adapted to account for group dynamics, and the possible impact to therapeutic processes and outcomes resulting from these adaptions.

Since the completion of this study in 2017, and completion of follow-up measures in 2018, there have been a number of larger ACT trials for cancer patients and cancer survivors with the aim of reducing psychological distress and increasing wellbeing. A key study by Arch et al. (2021) involved a large scale randomised control trial of group based ACT delivered in community oncology clinics. Cancer survivors (N = 135) were randomly allocated into a 7-week, 2-hour ACT condition or an enhanced usual care condition where participants were encouraged to access local resources. The main target of the program was on anxious symptoms, though the study also examined moderating factors such as age and avoidance. Outcome measures included the Overall Fear subscale of the Concerns About Recurrence Scale (Vickberg, 2003) for fear of cancer recurrence, anxiety symptoms through the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), with the Cancer Acceptance and Action Questionnaire (Arch & Mitchell, 2016) to measure possible moderating effect of experiential avoidance on outcomes. They found that participants improved from both types of interventions, more from ACT. Specifically, participants with a higher baseline of anxiety or avoidance that was more than one standard deviation from the mean of the sample improved more from the ACT intervention. Arch et al. (2021) suggested that screeners for severity in anxiety, fear of cancer recurrence, and avoidance at baseline for potential participants of ACT intervention will assist in the targeting of supportive care needs.

What remains unclarified is the link between key variables that are relevant in these interventions, namely, how fear of cancer recurrence, psychological distress, and experiential avoidance affect quality of life in survivors. Prior to another study on the effects of ACT on cancer survivor wellbeing, further study into the mechanism through which ACT may improve quality of life will need to be considered. An empirical link between experiential avoidance, fear of cancer recurrence, and psychological distress must be established with women survivors of breast cancer before results of interventions can be explained or improved. This is especially important for women living in regional areas who have limited access to treatment, including psychological intervention, and resources must be spent on effective targets. Of the unique challenges that survivors face in regional Australia is the access to health care (Hunter et al., 2019) and unmet need of survivors in terms

of addressing anxiety, depression, and fear of cancer recurrence (Girgis et al., 2000). Research into the mechanisms of action for interventions such as ACT and clarifying factors associated with quality of life will assist in improved targeting of intervention to outcomes.

Change in Research Direction

Between 2019 – 2020, there were discussions with oncology staff from a regional public hospital for the purpose of collaborating on a randomised two-arm crossover study of acceptance and commitment therapy and treatment as usual control for breast cancer survivors. However, due to an administration error made by the author discovered in February 2020, where the study did not gain higher level managerial support, the study was dismantled, and a new application would have to be completed. In March 2020, following discussion with supervisors, it was decided that a survey would be a suitable follow-up study to clarify some of the findings in Study 1. This was a timely decision as the COVID-19 pandemic related restrictions in March 2020 made a follow-up trial with women possibly immunocompromised by cancer therapy treatment untenable.

CHAPTER 5 - A PREMISE FOR STUDY TWO

Several findings from the first study warranted a survey to further investigate how ACT and the inclusion of experiential avoidance can assist in addressing the wellbeing of women following early breast cancer treatment in regional Australia. The first is to clarify the current quality of life for women survivors of early breast cancer across regional Australia, including areas that are more remote than regional centres to determine if there is a difference between survivors' quality of life, psychological distress, fear of cancer recurrence, and experiential avoidance based on remoteness. Studies reviewed in previous chapters differentiate between urban and regional environments, however, do not separate remoteness levels. The second is to consider the importance of constructs such as experiential avoidance in predicting quality of life in a model containing other known variables. Given that health resources in regional areas are scarce compared to urban areas, understanding the targets of intervention within a wider context can help with the prioritisation of resources. The third is to consider experiential avoidance as a construct of interest in women breast cancer survivor's quality of life, particularly given the higher rates of unmet need regarding fear of cancer recurrence in regional women, and the possible association between experiential avoidance and fear of cancer recurrence.

Limitations in Current Quality of Life Research for Regional Survivors

Chapter 1 provided an overview of the issues women survivors of early breast cancer face that are specific to regional Australia, starting from the access to healthcare and treatment considerations as patients, to the concerns and unmet needs reported by survivors. There are a few limitations to these studies. Firstly, most tend to be state-based, and may not be sensitive to issues that are present in some states but not others. For example, the most populated state of New South Wales has population of 8,186,800 (Australian Bureau of Statistics, 2021) and a geographic footprint of 801,150 km^2 (Geosciences Australia, 2021). In comparison, the largest geographic location of Western Australia with 2,527,013km^2 has a population of 2,685,200. The spread of population and geography may create different challenges in terms of the impact of travel on intervention choices as highlighted by Collins et al. (2018), availability of access to allied health professionals to address psychological needs as highlighted by Girgis et al. (2000), and the ability to provide regionally tailored services as highlighted by Murphy et al. (2015). While these three

studies all considered regional survivors, they were conducted in the most populated states with comparatively less geographic variation. This limitation of state-based studies was noted by Dasgupta et al. (2018) in their systematic literature review of variations in outcomes of breast cancer care for Australian women by residential location. The review included 74 quantitative studies published between 1990 to 2017. Dasgupta et al. (2018) identified the need for standardised geographic classifications and found a general pattern of poorer survival and variations in clinical management for women patients, though many unknowns in survivorship. An updated survey of women's quality of life with a national focus would assist in clarifying the current experiences of women survivors of early breast cancer living in regional areas.

Another limitation of the reviewed studies is the lack of separation of remoteness levels. While still state-based, there are some examples of studies that focus on the experiences of women survivors of early breast cancer living in regional areas that provide more specification regarding remoteness levels. These studies provide some comment on the quality of life for women in regional and rural Australia. In her thesis, DiSipio (2009) analysed original and secondary data about the wellbeing of regional and rural women in Queensland diagnosed with unilateral breast cancer. Geographic remoteness was classified using the Accessibility/ Remoteness Index of Australia (ARIA) which combines accessibility of places to service centres or remoteness of places. Remoteness areas as described by the Queensland Government Statistician's Office (2019) include Major Cities which are relatively unrestricted to a wide range of goods, services, and opportunities for social interaction; Inner Regional areas with some restrictions; Outer Regional areas which are significantly restricted; Remote Areas that are very restricted; and Very Remote areas which have very little accessibility. In DiSipio (2009), Major city suburbs such as Annerley or the Gold Coast were classified as Urban. Inner Regional areas such as Toowoomba and Bundaberg were classified as Regional. Outer Regional and Remote/Very remote areas such as Cairns, Townsville, Longreach, and Mt Isa were classified as Rural. This study found differences between urban and regional/rural survivor quality of life as measured by the FACT-G, $F(1, 577) = 7.30$, $p < .01$, which was driven by women under 50 years old, $F(1, 201) = 7.60$, $p < .01$. There was no difference between regional and rural cancer survivor quality of life as measured by the FACT-G, $F(1, 314) = .10$, $p = .74$. DiSipio (2009) used several age-adjusted

analyses, differentiating between women under 50 years old from those 50 years and older because of the possible effect of age on quality of life, which she attributes to the different life demands and treatment of disease depending on life stage. There was difficulty in recruiting women from remote and very remote regions of Queensland. To capture the experiences of regional survivors, prioritising remote regions, Gunn et al. (2021) conducted a qualitative survey with 22 long term cancer survivors in the state of South Australia that included four participants from Inner Regional areas, 11 from Outer Regional areas, and seven participants from Remote or Very Remote areas using the ARIA classification. Participants interviewed ranged from less than 12 months to over five years post treatment, with breast cancer survivors being the most numerous of cancer categories (n = 8). Concerns related to quality of life identified in the interviews included the lack of continuity of care, the lack of availability of relevant local services to improve quality of life, the lack of information about how these services may be accessed and how they may help, and the travel or financial cost of accessing services. The quality of life concerns for more remote survivors captured in Gunn et al.'s (2021) study were focused on practical issues limiting continuation of care. While one participant reported generalised worries, overall, the qualitative study did not focus on the psychological components of quality of life.

Additional constructs of interest in a survey of quality of life

While the above-mentioned issues apply to research in regional and rural Australia, the disparity between breast cancer survivorship and quality of life in regional versus urban settings is not unique to this continent. A systematic review of 14 studies on breast cancer survivorship in rural settings from the United State of America by Anbari et al. (2020) found similar results regarding gaps and needs. This paper noted that reporting of rurality using specific criteria related to population density and urbanisation was only used in two of the studies reviewed, resulting in a varying or undefined use of the term 'rural'. In this review, quantitative studies emphasised the impact of cancer treatment on long term survivorship and health behaviours in survivorship as factors impacting the wellbeing of regional breast cancer survivors. Six qualitative studies included in the review focused on the impact of travel, health behaviours and knowledge, and psychosocial variables such as social support. The review recommended an increased focus on ongoing education, stronger support systems, co-ordinated care, awareness of financial burdens, and a

focus on wellness rather than disease monitoring. The review acknowledges that studies so far on rural breast cancer survivor quality of life is limited, with little knowledge directing interventions for this population.

The inclusion of psychological variables alongside other known components of regional breast cancer survivor quality of life can assist in informing targets of intervention, which assists the resource allocation in regional health settings where access to follow-up care and health services are limited. Mols et al. (2005) conducted a systematic review of predictions of quality of life for long-term breast cancer survivors who had lived for at least five years post diagnosis. Ten articles published after 1996 met their criteria for reporting, and then predictors were rated for level of evidence from strong to weak, inconclusive, or no evidence, by a predetermined rating scale devised by the authors, Mols and Vingerhoets. Strong evidence was consistent findings in at least two high quality studies, whereas weak evidence was findings of one high quality study or consistent findings in at least three or more low quality studies. Chemotherapy, medical condition, social support, and income had strong evidence for predicting quality of life. Employment status, underage children in the home, ethnicity, trait and state anxiety, health perceptions, life stress, locus of control, and purpose had weak evidence for predicting quality of life. Age at diagnosis, current marital status, time since diagnosis, and stage of disease had inconclusive evidence for predicting quality of life. Mols et al. (2005) provides an overview of the issues that are relevant in long term survivor's quality of life, but not issues specific to regional survivors.

The main constructs of interest from Study 1 were quality of life, fear of cancer recurrence, and experiential avoidance. In terms of other factors that may also impact quality of life, a number of known and considered factors to quality of life based on Mols et al. (2005) and pertaining to rurality based on DiSipio (2009), and how they will be measured, provides direction on what variables may be included alongside psychological variables of interest in survivors' quality of life. As the additional variables chosen for inclusion in this survey have been identified in a published paper reviewing the literature, they will not be reviewed in detail in this chapter. Including variables that are known to be associated with of quality of life will assist research questions pertaining to the impact of the variables of interest, such as experiential avoidance, on quality of life within a model.

Social Support

Mols et al. (2005) considers there to be strong evidence in the literature of social support as a predictive factor of quality of life. A more recent study by Fong et al. (2017) using a sample of 157 female breast cancer survivors in a longitudinal design with a 1-year follow-up showed that social support quality was a significant predictor of psychological distress and emotional-wellbeing. Social support quality was predictive of distress and wellbeing in a model that included demographic factors such as age, race, education, and marital status; and health factors such as cancer stage.

A measure of social support is The Medical Outcomes Study Social Support Survey (MOS Social Support Survey), a social support survey developed for patients in the Medical Outcomes Study with chronic conditions (Sherbourne & Stewart, 1991). Recruitment of patients for the validation of this measure occurred through random sampling of private clinics with doctors, psychologists, and other mental health providers who agreed to participate in the study. Inclusion criteria was English speaking patients over 18 years old who had one or more chronic health condition such as hypertension, diabetes, heart disease and depression. A 50-item pool of questions was generated based on support dimensions recommended by Sheldon Cohen, a researcher with books and peer reviewed works on social support, stress, and health. Decisions related to inclusion or exclusion of questions included multidimensionality of the survey, response burden, and distinctness from other measures of loneliness, mental health, family functioning, and social activity limitations. It focused on perceived availability of types of support. A final battery of 19 social functional support items were grouped into the following dimensions: emotional support, informational support, tangible support, positive social interaction, and affectionate support. These subscales had internal consistency ranges between a Cronbach's α of .69 to .82. Principal components factor analysis of the items indicated factor loadings between .67 – .88 to one factor.

Lifestyle Behaviours (Exercise And Smoking)

Lifestyle behaviours are everyday activities that are shaped by an individual's values, knowledge and norms, and cultural and socioeconomic conditions (Jarosz, 2018). In cancer survivorship, these can include behaviours like exercise and smoking (Blanchard et al., 2004). Exercise is a well-documented contributor to quality of life and health in general. McNeely et al. (2006) conducted a systematic

review and meta-analysis where three studies combined to yield 194 breast cancer patients and survivors showed that exercise led to significant improvements in quality of life compared to usual care (Weighted Mean Difference = 4.58 for FACT-G, 6.62 for FACT-B). These studies used FACT-G and FACT-B as measures of quality of life. The guideline regarding exercise for breast cancer survivors is moderate intensity activity, three to five days per week, 20 to 60 minutes per session, and resistance training (Courneya et al., 2003). The Breast Cancer Network of Australia summarises exercise guidelines as 2.50 – 5.00 hours of moderate intensity, or 1.25 – 2.50 hours of vigorous activity each week (Breast Cancer Network Australia, 2021). An updated systematic review of exercise in breast cancer survivors again found strong evidence for exercise and quality of life outcomes for women, however, specificity regarding the exercise guidelines and adherence to exercise training principles was lacking in many studies (Neil-Sztramko et al., 2017).

While lifestyle behaviours often focus on exercise, smoking is also a behaviour of interest due to the established effects of smoking on the occurrence of cancer (Reynolds, 2013). The association between quality of life and smoking is difficult to assess due to the low prevalence of the behaviour; of a sample of 316 participants in a study by Blanchard et al. (2004), 94.30% met smoking recommendation. A literature review of predictors of distress in women breast cancer survivors by Syrowatka et al. (2017) of studies conducted between 2000 and 2016 found six studies that contained cigarette smoking as a variable for quality of life. Of these studies, two indicated that smoking was associated with lower quality of life and higher distress.

Financial Strain

Income was listed as highly predictive of quality of life for breast cancer survivors by Mols et al. (2005). The impact of financial strain on women's quality of life is well documented, for example, Perry et al. (2019), where financial strain was significantly associated (all $p < .05$) with more symptoms of depression ($d = .53$ to .85), anxiety ($d = .32$ to .59), physical symptoms ($d = .50$ to .80), and physical health ($d = .50$ to .74) for three samples of breast cancer survivors. Additionally, the review by Dasgupta et al. (2018) highlighted this as a factor in rural survivorship, suggesting that rural Australian breast cancer survivors may feel financial burden as an additional difficulty compared to urban counterparts.

Chemotherapy

The long term side effects of chemotherapy on breast cancer survivors is well known, with four out of 18 of the studies reviewed by Syrowatka et al. (2017) indicating that chemotherapy predicted distress in breast cancer survivors.

There is evidence that women who had chemotherapy in cancer treatment continue to experience fatigue (Byar et al., 2006) and other mental differences (Broeckel et al., 2000) following the completion of treatment. Long term side effects that impact quality of life include cardiomyopathy, neuropathy, neurocognitive dysfunction, early menopause and associated bone, cardiovascular, and fertility concerns (Tao et al., 2015). Mols et al. (2005) considers there to be strong evidence for chemotherapy as a predictor of quality of life, with patients who had chemotherapy generally reporting a lower quality of life against comparison groups. The impacts of other cancer treatments were not included in the Mols et al. (2005) review due to the lack of studies on this that met their inclusion criteria.

Age At Diagnosis and Time Since Diagnosis

In the Mols et al. (2005) study there was inconclusive evidence regarding age at diagnosis and time since diagnosis as predictors of quality of life. However, there is the distinction in the literature for 'young' survivors of breast cancer, generally a group of women diagnosed on or before 50 years of age. Young survivors may experiencing more fear of cancer recurrence (Lebel et al., 2013), perceived intrusiveness into intimacy and motherhood or fertility issues (Arès et al., 2014), and changes to mental functioning (Champion et al., 2014). These studies suggest that there may be differences related to age or stage of life and perceived quality of life, as impacted by breast cancer and breast cancer treatment. Mols et al. (2005) also found inconclusive evidence regarding the effect of time since diagnosis on quality of life. Specifically, two studies they reviewed on time since diagnosis did not influence quality of life, but a third study, Bloom et al. (2004), indicated that survival years was a predictor of better psychological and social wellbeing. Bloom et al. (2004) was a population-based study where 185 women under 50 years old at diagnosis and who were cancer-free five years on were surveyed on several quality-of-life factors. Most women surveyed indicated improved quality of life in physical (r = -.62) and mental (r = -.60) health. About 10% of those surveyed indicated worsening health. As age at diagnosis and time since diagnosis are often reported in

studies of quality of life, inclusion of these variables in surveys assists with the comparability of studies.

Remoteness

In addition to articles reviewed in Chapter 2, DiSipio (2009) also found differences in quality of life based on remoteness. While it is difficult to recruit rural and very rural participants, this is nonetheless an important finding to clarify where possible. Clarifying the differences in quality of life based on remoteness may assist with planning of services to address these differences. As with Study 1, the following study will continue with the use of the Modified Monash Model 2019 to classify remoteness. The classification is based on the Australian Statistical Geography Standard – Remoteness Areas (ASGS-RA) which is updated following the census conducted by the Australian Bureau of Statistics, and similar to the classification model used by DiSipio (2009).

Study 1's participants mostly resided in regional centres as defined by the Modified Monash Model. As mentioned in Chapter 4, the Modified Monash Model 2019 (MMM) specifies the characteristics of city, rural, remote, or very remote areas that is used nationally for the purpose of workforce distribution. Information about the classification of remoteness areas is provided by the Australian Government Department of Health (2021), It incorporates the ARIA classification and provides good clinical utility as it is used by the Australian Government to consider the distribution of health services and in the incentivising of health practitioners. Metropolitan areas are defined as the Major Cities accounting for 70% of Australia's population. Regional centres are Inner and Outer Regional areas that are within 20km drive of a town with over 50,000 residents. Large rural towns are in or within 15km drive of a town between 15,000 to 50,000 residents. Medium rural towns are in or within a 10km drive of a town between 5,000 to 15,000 residents. Small rural towns are the remaining areas of inner and outer regional areas that do not fall within the classification of a regional centre, large or medium rural town. Remote communities are remote mainland areas. They are also remote islands less than 5km offshore, without a bridge, and with a population of less than 1000. Very remote communities are very remote areas and islands more than 5km offshore. A table summarising MMM classifications can be found in Chapter 4, Table 4.1.

The Role of Experiential Avoidance in Quality of Life for Regional Survivors

Experiential avoidance may be a construct of interest, particularly for those in regional areas for whom fear of cancer recurrence is a reported concern (Youl et al., 2016). While experiential avoidance did not always decrease following ACT intervention in Study 1, it was positively correlated with fear of cancer recurrence (r = .69), and negatively correlated with overall quality of life (r = -.69). Experiential avoidance may be a psychological factor related to early breast cancer survivor quality of life, however, it has not been included in models that include other known factors that impact women's quality of life. Chapter 3 introduced some possible ways in which experiential avoidance may apply to breast cancer survivor wellbeing. Since the review, a new study was found that related experiential avoidance to breast cancer quality of life and psychological distress. Novakov (2021) conducted a cross sectional survey of breast cancer patients, considering the moderating effect of psychological inflexibility on emotional state, fatigue, and functional status in women undergoing radiotherapy for breast cancer. In this study, the measure for psychological inflexibility was the same as experiential avoidance, the AAQ-II (Bond et al., 2011). Novakov (2021) recruited 64 women undergoing treatment and used Serbian adaptions of the AAQ-II (Bond et al., 2011), DASS-21 (Lovibond & Lovibond, 2002), the Fatigue Assessment Scale Serbian (Michielsen et al., 2003), the Upper Extremity Functional Index (Stratford et al., 2001), and Quality of Life Instrument – Breast Cancer Patient Version (Ferrell et al., 1995). Significant correlations were found between all the variables of interest. Significant correlations between psychological inflexibility (experiential avoidance) and other variables were between r = -.48 with functional status, to r = .59 for fatigue. This was followed by five moderation analyses on whether psychological inflexibility moderated the relationship between affect state, fatigue, and functional status on overall quality of life. Psychological inflexibility had a significant direct and moderation effect, with a significant interaction for depression, R^2 = .13, $F(1,60) = 15.56$, β = .42, t = 3.94, p <.01; anxiety, R^2 = .10, $F(1,60) = 12.10$, β = .47, t = 3.48, p < .01; fatigue, R^2 =.07, $F(1,60) = 7.34$, β = .17, t = 2.71, p = .01; and functional status, R^2 =.04, $F(1,60)$ = 4.32, β = -.06, t = -2.08, p = .04; on quality of life. The moderation effect of psychological inflexibility on the stress to quality of life relationship was not significant. These small models did not seem to account for much of the variance in the relationships and it is unclear whether co-variates were included. Novakov

(2021) concluded that psychological flexibility may have a moderating effect on adverse experiences, lending a protective factor for quality of life in breast cancer. However, moderation studies based on a smaller sample may require further clarification or replication in future studies, and fear of cancer recurrence was not measured in this study.

Actual Cancer Recurrence

Accounting for actual cancer recurrence may be important for both quality of life and fear of cancer recurrence studies. An Australian study by Kemp-Casey et al. (2016) estimates annual incidents of breast cancer recurrence at 3.3% per year between 18 months and 6 years post diagnosis. This study was based on a New South Wales cohort of 2416 women recruited between 2003 – 2008 who were followed up from 18 months post diagnosis until recurrence, death, or end of data in 2010. It suggests there is a small portion of women who will have actual cancer recurrence; that there is a chance that a feared outcome may be true. A study reviewed in Chapter 3 by Yang et al. (2008) looked at the impact of breast cancer recurrence and coping style on quality of life. These women reported significant traumatic and general stress symptoms, suggesting that actual cancer recurrence is a variable in survivor's quality of life. This was supported by a study conducted by Lebel et al. (2008), which found that second cancer experience and three-month intrusion and avoidance experience significantly predicted six-year intrusion and avoidance symptoms (R^2 = .38, p <.01). Participants were 86 women from Quebec in Canada who were followed-up at three, seven, 11, and 15-months post diagnosis. Lebel et al.'s (2008) study is an example of combining practical and treatment aspects of quality of life along with psychological variables to predict a psychological component of quality of life. In this case, the focus was stress in breast cancer survivorship and involved mostly psychological factors such as fear of the future, poor perceived health, and avoidance coping. The study also included factors that were not related to psychology or perception such as the occurrence of stress-related problems and cancer recurrence. Currently, there is no information on the impact of experiential avoidance on fear of cancer recurrence for women who have experienced breast cancer recurrence. Accounting for actual recurrence may provide more insight into the effect of experiential avoidance when the feared outcome is true.

Measuring Psychological Distress

In Study 1, psychological distress was measured by the DASS-21, however, to design a survey that included more measures, including a measure for social support, a shorter measure of psychological distress was considered to reduce the burden on respondents. While the DASS-21 is a broadly used measure with good clinical and research utility, a new measure was chosen to maintain clinical utility and increase brevity. The Kessler 10 (K10) was considered as a comparable and brief measure of psychological distress. General Practitioners in Australia use the Kessler 10 (K10) as their routine outcome measure for treatment (see for example, Lyons (2017). The K10 (Kessler et al., 2002) was created as a brief measure of non-specific psychological distress in the general population. Two pilot surveys with pools of 45 questions, then 28 questions were administered in mail (n = 1401) and phone (n = 1574) pilot studies with 54.80% and 52.90% engagement respectively. This data was considered using a test information curve with high test information values indicating lower standard errors. Items that fell within the 90th to 99th percentile of this curve were retained. Following this, a 10-question scale and a 6-question scale was tested in clinical interviews with convenient samples (N = 1000). The clinical survey assessed the K10 against diagnostic criteria including global assessment of functioning of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) and showed good discrimination for both clinical and community samples. Andrews and Slade (2001) presented normative data using the K10 on an Australian national sample of 10,641 people. They found a mean score of 14.20, median of 12.00, and range of 10 – 50, with most people reporting little or no distress. All participants in these studies were adults.

Research Questions And Aims For Study Two

To clarify the possible association between experiential avoidance, fear of cancer recurrence, and quality of life, and additionally to consider the contemporary wellbeing of women survivors of breast cancer in regional Australia, the following research questions are proposed:

1. What is the current quality of life, rate of fear of cancer recurrence, and distress for women who have completed breast cancer intervention, living in regional and rural and remote Australia? This question aims to clarify the characteristics of this population and update the data that is available.

2. What are the factors that account for the quality of life in women following primary breast cancer care? This question aims to include previous research to inform the factors that potentially impact regional women. It is predicted that variance in women's quality of life will be accounted for by the following variables: Fear of cancer recurrence, experiential avoidance, social support, remoteness, financial strain, exercise, smoking, chemotherapy, age at diagnosis, cancer recurrence, and time since treatment.
3. Does experiential avoidance influence engagement in behaviours that improve women's quality of life? This question aims to clarify another possible pathway through which experiential avoidance may contribute to women's quality of life by affecting women's behaviours regarding engaging in positive action to improve their wellbeing. It is predicted that women with high experiential avoidance will have reduced rates of exercise and increased rates of smoking.
4. Does experiential avoidance influence the relationship between factors associated with quality of life? In Study 1, experiential avoidance seemed to have a different association with quality of life depending on whether it was high or low. A moderation effect was seen in the study by Novakov (2021). It is predicted that experiential avoidance has a moderating effect on quality of life factors, especially when experiential avoidance is high. As experiential avoidance increases, the helpful effects of quality of life factors decrease, and unhelpful effects of quality of life factors increase.
5. What is the relationship of fear of cancer recurrence on quality of life? It is expected that women who have a higher fear of cancer recurrence have a lower level of quality of life, which is an observation widely reported in the literature and a founding assumption of interventions for fear of recurrence. This question aims to replicate this finding in Australian regional women and consider the role of experiential avoidance.
6. Does experiential avoidance enhance fear of cancer recurrence for women who have had a recurrence of cancer? The aim of this question is to account for the effect of experiential avoidance on fear of cancer recurrence where a possible feared outcome is true. It is predicted that women who have had a recurrence of cancer will have a higher fear of cancer recurrence if they have

a high experiential avoidance, compared to women who have recurrence but low experiential avoidance.

The analyses and results addressing these questions are presented in Chapter 5.

CHAPTER 6 - STUDY TWO

Methods

Design

The design of this study was a cross sectional survey delivered online. A priori power analyses was conducted using G*Power (Faul et al., 2007) for sample size estimation. Input was based on data from Study 1, with consideration to possible analyses that would assist in answering the research questions of Study 2, focusing on the key variables of quality of life, fear of cancer recurrence, psychological distress, and experiential avoidance. Tests would include t-tests, analyses of variance, multiple regression, and chi-square. The effect size between the variables based on correlations was considered small ($d \approx 0.2$ to 0.3) between quality of life and depression ($r = -.30$) to moderate ($d \approx 0.5$) between quality of life and fear of cancer recurrence ($r = -.62$) and experiential avoidance ($r = -.69$). With a small effect size ($f^2 = .02$), significance criterion of $\alpha = .05$, and power = .80, the minimum sample size needed for one of the more involved analyses, moderated multiple regression with experiential avoidance as a covariate, is N = 395. For independent sample t-tests, the minimum sample size for a moderate effect is N =102 and small effect is N = 620. Following discussion with supervisors, it was decided that recruitment would aim for 500 participants for the purpose of detecting most effects.

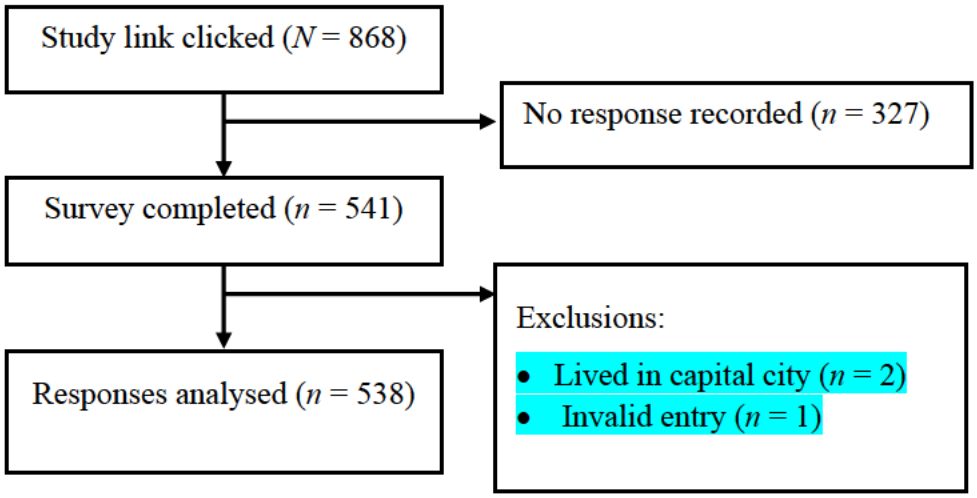
Original data was collected through an online survey between March 2021 and July 2021. A printable copy of the survey is attached in Appendix H. Ethics approval was obtained from the University of Southern Queensland Human Research Ethics Committee (H21REA005). Support to conduct the survey was through the University of Southern Queensland. Funding for the cost of social media advertisement and a donation to the Breast Cancer Network Australia was provided by the author.

The design of this survey prioritised classifications of rurality such as the Modified Monash Model (MMM) (Australian Government Department of Health, 2021), and distress measures such as the Kessler 10 that are used in applied clinical settings. MMM is used by the Australian Government to define eligibility and encourage rural training pathways for doctors. The Kessler 10 (Kessler et al., 2002) is used by General Practitioners as a quick measure of psychological distress or

symptoms of mental illness when preparing treatment for patients. Figure 6.1 illustrates the survey recruitment process.

Figure 6.1

Flow Chart of Survey Recruitment



Participants

Eligible participants were women aged 18 years and older who had completed primary treatment (surgery, chemotherapy, and/or radiation) for early breast cancer (Stage 1 – 3) and lived within Australia but outside of a capital city. Participants were excluded if they lived in a capital city as the research in Australia shows a different population and health demographic in these groups (Australian Institute of Health and Welfare, 2020).

Measures

Acceptance and Action Questionnaire II (Bond et al., 2011) was intended for use with population-based studies of experiential avoidance. The lowest possible score on this measure is 7 and the highest possible is 49. Higher scores indicate more experiential avoidance, with a suggested clinical range above 24 – 28. For the psychometric properties of this scale, refer to Chapter 3 where the scale is reviewed.

The Functional Assessment of Cancer Therapy Scale – Breast (FACT-B; Brady et al., 1997) covers physical, functional, social, and emotional wellbeing, satisfaction with treatment, and satisfaction with relationships, with a Breast Cancer Subscale related to quality-of-life issues specific to patients with breast cancer. These can be combined to create one score measuring quality of life. The lowest possible score for the FACT-B is 0 and highest possible is 148. Higher scores indicate better wellbeing. Range for the subscales are 0 – 28 for Physical, Social and Functional Wellbeing Subscales, and 0 – 24 for Emotional Wellbeing Subscale. The Breast Cancer Subscale scores range from 0 to 40.

The FACT-B contains the Functional Assessment of Cancer Therapy Scale – General (FACT-G; Cella et al., 1993), using the same subscales of the FACT-B minus the Breast Cancer Subscale. The lowest possible score is 0 and highest possible score is 108. For the psychometric properties of this scale, refer to Chapter 3 where the scale is reviewed.

The Concerns About Recurrence Scale (CARS) was developed by Vickberg (2003) to assess women's fears about possible breast cancer recurrence. Part of the measure produces an 'Overall Fear' score of mean ratings. The lowest possible score is 1 and highest possible is 6. Higher scores indicate more fear. Little to no fear about the possibility of cancer recurrence is calculated as the 'lower third' of the Likert scale (1 – 2), moderate fear as 'middle third' of the Likert scale (3 – 4) and

high level of fear as the 'higher third' of the Likert scale (5 – 6). For the psychometric properties of this scale, refer to Chapter 3 where the scale is reviewed.

The Medical Outcomes Study Social Support Survey (MOS-SSS; (Sherbourne & Stewart, 1991) was created to measure perceived availability of social support for use with patients with chronic health conditions. The subscales of emotional/information support, tangible support, affectionate support, and positive social interaction that are produced with this survey can be combined into a single overall support index score, with higher scores indicating more perceived support, with a range of 0 – 100. This is recomputed to a range of 1 – 5 in line with scoring guidelines for comparison studies. For the psychometric properties of this scale, refer to Chapter 5 where the scale is reviewed.

The Kessler 10 (Kessler et al., 2002) is a brief measure of non-specific psychological distress. The score range is from 10 to 50, with higher scores indicating more psychological distress. For the psychometric properties of this scale, refer to Chapter 5 where the scale is reviewed.

A measure of remoteness was computed from participant postcodes. Participants were required to enter their postcode, which was then matched to the most populous possibility of MMM. For example, a postcode of 4655 may correspond to a MMM of 2 or 5, and therefore 2 would be recorded. Data from the 2019 update of the MMM was utilised to determine classifications (Australian Government Department of Health, 2021).

Health behaviours regarding exercise and smoking were gathered with the following binary (Yes/No) questions: "Do you get at least 2.5 hours of moderate physical activity a week?" and "Do you currently smoke tobacco/cigarettes?". The number 2.5 hours was based on Courneya et al. (2003) and guidelines on the Breast Cancer Network Australia's webpage (2021) on exercise for breast cancer related health.

Information on whether a participant had chemotherapy was part of a question matrix with the stem: "What treatment(s) did you have for breast cancer?" The possibly responses, which participants could select multiple, included chemotherapy. This question matrix was duplicated from Study 1, which was used for comparison to biological studies that were important to another researcher.

Information on age at diagnosis was obtained from the question "When you were first diagnosed with breast cancer?". Time since treatment was calculated from

subtracting the participant's response to "What year did you last have primary treatment for breast cancer? (e.g., last had chemotherapy, surgery, and/or radiation)" from the current year, 2021.

There were two questions about participant finances, with the second being used to calculate financial strain. This question included the stem: "How easy is it for you to live on this amount of money per fortnight?" The responses were Likert scale from one to six possible options ranging from Extremely Easy (1) to Extremely Difficult (6).

Information on cancer recurrence was obtained from the binary (Yes/No) question "Have you had a recurrence of cancer?"

Samples, Recruitment, and Data Decisions

Participants were recruited from a convenience sample, using the snowballing method, with most of the recruitment occurring through group posts and advertising on the social media platform Facebook. Permission was sought from social media group moderators before posting. Advertisement targeting terms were as follows:

Location: Australia

Exclude Location: Australia: Canberra (+40 km) Australian Capital Territory; Sydney (+40 km) New South Wales; Darwin (+40 km) Northern Territory; Brisbane City (+40 km) Queensland; Adelaide (+40 km) South Australia; Hobart (+40 km) Tasmania; Melbourne (+40 km) Victoria; Perth (+40 km) Western Australia.

Age: 18-65+

Gender: Female

People who match: Breast Cancer Care, Breast Cancer awareness, Cancer awareness, Breast Cancer Network Australia, Living Beyond Breast Cancer or Breast Cancer Campaign.

Detailed targeting expansion: On. This option lets Facebook expand detailed targeting to reach more people when it's likely to improve performance. Expansion is not available for all objectives.

An incentive was provided for participation, and this was communicated on the advertisement and Facebook page set up for the purposes of snowballing. For every completed survey, $1 would be donated to the Breast Cancer Network

Australia, an organisation that provides free information and support to Australians affected by breast cancer. Examples of information posted on social media is attached in Appendix I. Participant consent and recruitment information is attached in Appendix H along with the survey. Potential participants could access the survey through a weblink.

Data was collected electronically through an online survey designed using the USQ Survey Maker tool, based on Lime Survey. To manage missing values, the survey contained a setting where responses must be provided to proceed. Completed surveys were exported into spreadsheets and IBM SPSS Statistics for analysis. Statistical significance level was set to $p = .05$, and where variances were not equal, Levene's variance test was used, and non-equal variances with associated degrees of freedom were reported.

The survey was made available from 30 March 2021. Rolling recruitment continued until a total of 541 completed responses were obtained. The survey was closed on 12 July 2021.

The following treatment was completed of the data prior to analysis:

- Responses that included non-numerals for numerical responses were re-entered as numerals. Examples: an entry of "March 2020" was recoded as "2020". An entry of "29 months" was recoded as 2.5 (years).
- Responses that were entered in shortened or abbreviated form, or incorrectly entered but still comprehensible, were recoded. For example: a response of "97" for year was recoded as "1997"; a response of "2915" for year was recorded as "2015"; a response of "465530" for postcode was recoded as "4655" as 5530 is not an Australian postcode, however, 4655 corresponds to a postcode in Regional Australia.
- Responses that were not standard but could be calculated based on other details were calculated. Examples: For time spent living in the regions, one respondent reported "born in country, lived in city for 10 years, moved back". Her time spent in the region was calculated using the formula: (2021 – date of birth) – 10. A response for age at diagnosis was "2016". Her age at diagnosis was approximated by using the formula: year of last–treatment - date of birth.

- Where two time-related responses were given, the most recent response was retained. Example: A respondent indicated that they had breast cancer at 44 and 57, so 57 was retained.
- Responses that could not be quantified were removed, but the rest of the responses for that respondent retained. For example, for fortnightly income, one response was "farmers, hard to say". This information was removed and income left as a missing data point.
- Data was excluded if the participant indicated a post code that was of a capital city.
- Responses were deleted if participant indicated that they were still undergoing treatment. This occurred in 2 cases.
- One set of data was deleted because the responses said "test".

A total of 538 responses were retained for analysis.

Data analysis was completed using IBM SPSS Statistics 27, with the PROCESS macro (Hayes, 2017) for moderation analysis in Research Question 4.

There were 17.7% of responses that fell within what is classified as 'Metropolitan', which is an MMM designation of 1. However, these areas contained postcodes that fell outside of capital cities, for example, the Sunshine Coast in Queensland, Australia. These responses were retained for analysis for two reasons:

1) Most respondents indicated living in a regional location for 10+ years. While regions may change their remoteness classifications over time due to population growth and migration, to these women, their identification with regional Australia may have been formed when their regions were less populated.
2) This provided an opportunity to consider any differences in characteristics of a more metropolitan population compared to rural population.

A separate experiential avoidance variable was computed using the responses of the Acceptance and Action Questionnaire. A "high" experiential avoidance was a score of 20 or more, as informed by Study 1. A "low" experiential avoidance was 19 or less. This variable was created for the purpose of clarifying some results from Study 1. Each of the main scales were examined for reliability. Upon analysis of the Cronbach's alphas of subscales, FACT Emotional Wellbeing Subscale had an alpha of .56 due to responses on the Item 2, "I am satisfied I am coping with my illness". Respondents on this survey responded differently to this question than expected

given their responses on other questions of the scale. With the item deleted, the subscale's alpha value increases to .82, which is in line with the internal consistency reported in Cella et al. (1993) and Brady et al. (1997). This provided a contextual rationale for item deletion in cases where the Emotional Wellbeing Subscale was used in analysis. The Breast Cancer Subscale also had a low internal consistency, with a Cronbach's alpha of .45. However, with item deletion, the highest internal consistency is at .59, which is still low. At the overall scale level, the FACT-B's internal consistency is at .83, which is acceptable. Deletion of any subscale would reduce the overall internal consistency, therefore it was decided that the subscale could not be used for analysis. A decision was made to retain all items and subscales for overall analysis due to acceptable internal consistency in the overall scale, however, analysis required on the subscale level would not include the Breast Cancer Subscale as it does not have acceptable internal consistency, and would include a modified version of the Emotional Wellbeing Subscale with Item 2 removed to increase consistency. Each of the remaining variables of interest were examined regarding fitness for certain analyses.

A correlation matrix was created with all variables of interest to consider whether the direction of known relationships is supported by this sample. The main variables had correlations in the direction that is expected from the literature and thus retained for analysis.

Analyses

Analyses to address the first research question regarding current wellbeing for women survivors of breast cancer included a descriptive account, comparison with previous studies, and comparison across remoteness levels and participant age. The data from this survey was first compared to the results of Study 1. In the case of comparison to Study 1, due to the small sample size and heterogeneity of the results, a non-parametric independent samples test (Mann-Whitney U test) was used to compare means for quality of life and fear of cancer recurrence. Quality of life was further compared to the normative sample for FACT-B from Bradey et al. (2017) and converted to FACT-G for comparison with DiSipio's (2009) sample of regional and rural women. As the data treatment differed and standard deviations were not provided in DiSipio's thesis, intendent-sample t-tests could not be computed in this

case. Bar graphs for quality of life, fear of cancer recurrence, and psychological distress across remoteness levels were created, with 95% confidence intervals.

For further comparison with DiSipio (2009), analysis of variance were completed between FACT subscales in regional and rural residence groups as this was the type of analyses performed in the DiSipio (2009) study. While the populations recruited are different regarding stage of survivorship, it is possible to form categories of urban, regional, and rural that resemble those used in previous research by DiSipio. This would not be a direct replication; however, it may assist in a comparison of survivorship information. DiSipio's remoteness classifications, based on the Accessibility/Remoteness Index of Australia, were translated in the current study into MMM1 for Urban, MMM2-3 for Rural, and MMM4-7 for Regional as these categories matched those of the index. DiSipio presented two tables on women's wellbeing, comparing regional to rural women, and comparing urban to regional and rural women. These comparisons were further stratified by age; under 50 years old, and 50 years or older. DiSipio used estimates of clinical significance from the Yost and Eton (2005) guidelines. These guidelines specified minimally important difference of clinical significance for the FACT-B at 7 – 8 points. Subscales of the FACT-B are clinically relevant at 2 – 3 points of difference. In this study, the Emotional Wellbeing Scale and Breast Cancer Subscale was omitted due to low internal reliability and deleting items to increase reliability would make it less comparable to the scales that DiSipio used.

Another analysis to address this research question was to compare two distinct remoteness groups, for example, MMM1 which is made up of metropolitan areas and MMM5 which is medium rural towns best described as areas of between 5000 – 15,000 people. These two samples have the same sample size (n = 95) and are distinct enough regarding living environments that it would make a useful comparison. These two samples have the same sample size (n = 95) and are distinct enough regarding living environments that it would make a useful comparison. T-tests for these two groups were computed for quality of life, fear of cancer recurrence, psychological distress, and experiential avoidance. Results were presented in table and graph form.

Fear of cancer recurrence is an often-cited issue for young cancer survivors. T-tests were completed to examine the responses of women under 50 years of age (young survivors), compared to those 50 years and older, on fear of cancer

recurrence, quality of life, psychological distress, and experiential avoidance. Results were again presented in table and graph form.

For the second research question regarding the factors that account for quality of life in women survivors of breast cancer, variables from the literature review were included in a general linear model. These were: Fear of cancer recurrence, experiential avoidance, social support, remoteness, financial strain, exercise, smoking, chemotherapy, age at diagnosis, cancer recurrence, and time since treatment. Some consideration was given to categorical variables that contained numerous categories. Remoteness categories MMM6 and MMM7 contained a combined total of 25 responses, which is much less than the other categories. As such, Remoteness was recoded from seven categories to three categories: Urban (MMM1), Rural (MMM2-3), and Remote (MMM4-7), guided by similar classifications from DiSipio (2009). Following the initial general linear model analysis, financial strain was found to be significantly associated with quality of life when the respondent indicated Difficult, Very Difficult or Extremely Difficult, but not so when they indicated Extremely Easy, Very Easy, or Fairly Easy. As there was a clear distinction between Easy and Difficult, this variable was then reduced from six categories to two categories; Easy and Difficult.

While chemotherapy is the main treatment with an established link to quality of life in the literature (Mols et al., 2005), there is little information on the impact of other treatments, and number of treatments, on women's quality of life. These other treatments were not included in the general linear model as they were not indicated in the literature, however, are worth exploratory analysis. A correlation matrix was created for quality of life and subscales with number of breast cancer treatments and type of treatment (lumpectomy, mastectomy, mastectomy with reconstruction, radiotherapy, hormonal therapies, and other treatment). For this analysis, the Breast Cancer Scale was not included due to low internal consistency ($\alpha = .45$). A one-way ANOVA was conducted to determine whether stage of cancer was related to the number of treatments accessed.

The third research question focuses on the role of experiential avoidance on health behaviours. The majority of this sample was already engaged in healthy behaviours. Of 538 respondents, 30.3% indicated that they did not achieve the requisite amount of weekly physical activity ($n = 163$). Only 6% were current smokers ($n = 33$). Given the small number of smokers, and the non-significant

contribution to the model, this population was not analysed. A dichotomous variable was produced from the AAQ-II scale, with scores less than 20 classified as “low experiential avoidance” and scores 20 or higher classified as “high experiential avoidance”. This lower cut-off was informed by the scores of Study 1 (see Table 4.16). A chi-square test of independence was performed to examine the relation between experiential avoidance and exercise. A follow-up consideration is whether experiential avoidance may impact the effect of exercise on quality of life; whether there is an interaction between experiential avoidance and exercise on quality of life. This was tested using a factorial analysis of variance.

For the fourth research question, a series of multiple regressions were computed between the independent variables determined by the literature and general linear model (financial strain, exercise, chemotherapy, psychological distress, social support, fear of cancer recurrence, and time since treatment) on quality of life. The dichotomous variable of experiential avoidance from Study 1 (high/ low) was first explored using moderator analyses with no co-variates. A moderated multiple regression model was then computed to further consider the impact of psychological distress on quality of life as moderated by experiential avoidance within a model containing co-variates. This model used the other variables (financial strain, exercise, chemotherapy, social support, fear of cancer recurrence, and time since treatment) as co-variates.

The fifth research question regarding the relationship between experiential avoidance and quality of life was a follow up on Study 1 data suggested that there would be a relationship between experiential avoidance and fear of cancer recurrence, and experiential avoidance and quality of life. In Study 1, this was observed using the combined data across time points; 92 data points when combining 20 participants responses over 5 time points. However, as the relationship may have been due to the repeated measure of the same cohort, Study 1 considered the relationship between experiential avoidance and fear of cancer recurrence and quality of life. As acceptance and commitment therapy (ACT) is purported to work primarily through decreasing experiential avoidance, establishing a relationship between experiential avoidance and fear of cancer recurrence and quality of life would provide some support for the therapy. In this current study, the question was first considered using simple linear regression for quality of life by fear or cancer recurrence, experiential avoidance by quality of life, and fear of cancer recurrence by

experiential avoidance. Independent samples t-tests were performed using the dichotomous AAQ-II variable to consider whether participants who have high experiential avoidance are significantly different from those that have low experiential avoidance in different facets of quality of life and fear of cancer recurrence. High and low experiential avoidance was informed by the results of Study 1 These results were displayed as bar graphs with 95% confidence intervals.

The final research question considering the role of experiential avoidance in fear of cancer recurrence for women with actual recurrence used a factorial analysis of variance.

As this survey was run in 2021 during the pandemic stage of COVID-19 in Australia, the survey contained an open question regarding the impact of COVID, which is "Do you think that your experience through COVID-19 affects your current wellbeing? If so, in what way?". Independent sample t-tests were performed to determine whether there was a difference in the two groups of respondents on the main scales used in this study, followed by a factorial analysis of variance due to the finding of lower quality of life for women in metropolitan areas.

Results

Participant Details

A summary of the demographic and clinical details of participants is presented in Table 6.1. The largest group of respondents reside in regional centres (23.8%), are between 51 – 60 years old (40.7%) and completed their treatment in the last 2 years or less (56.1%). The distribution of Stage 1 (39.8%), Stage 2 (35.7%), and Stage 3 (24.5%) breast cancer in respondents indicated over-representation of Stage 3 cases, which the Australian Government Cancer Centre estimates to be about 12.1% of women breast cancer cases (National Cancer Control Indicators (2018, April 6).

Table 6.1

Study 2 Demographic and Clinical Details

Characteristics	*N*	*M*	Range	*SD*
Age	537	57.22	27 – 81	9.42
Age at diagnosis	538	52.00	26 – 77	9.40
Years since last treatment	537	3.82	0 – 50	5.11
Number of different types of breast cancer treatment	538	3.23	1 – 7	1.07
Years living outside of a capital city	537	36.94	1 – 78	19.59

Characteristics	*N*	%
Age by category	(537)	
30 years old or less	2	.4
31 – 40 years old	21	3.9
41 – 50 years old	99	18.4
51 – 60 years old	219	40.8
61 – 70 years old	149	27.7
71 – 80 years old	46	8.6
81 years or more	1	.2
Cultural or ethnic identity	(538)	
Australian	486	90.3
Australian Aboriginal	4	.7
Australian South Sea Islander	1	.2
Oceanian	1	.2
North-West European	30	5.6
Southern and Eastern European	4	.7
North African and Middle Eastern	1	.2
South-East Asian	2	.4
People of the Americas	1	.2
Sub-Saharan African	1	.2
Other	7	1.3

Characteristics	*N*	%
Relationship status	(538)	
Married/ committed	450	83.6
Divorced/ separated	49	9.1
Widowed	15	2.8
Single	24	4.5
Highest level of education	(538)	
Primary school	1	.2
High school	155	28.8
Undergraduate or trade qualification	189	35.1
Post graduate qualification	193	35.9
Financial strain (how easy is it to live on fortnightly income)	(538)	
Extremely easy	69	12.8
Very easy	98	18.2
Fairly easy	204	37.9
Difficult	112	20.8
Very difficult	23	4.3
Extremely difficult	32	6.0
Stages of early cancer	(538)	
Stage 1	214	39.8
Stage 2	192	35.7
Stage 3	132	24.5
Age at diagnosis	(538)	
30 years old or less	2	.4
31 – 40 years old	67	12.5
41 – 50 years old	177	32.9
51 – 60 years old	183	34.0
61 – 70 years old	97	18.0
71 – 80 years old	12	2.2
Type of treatment (multiple categories can be selected)	(538)	
Lumpectomy	259	48.1

Characteristics	*N*	%
Type of treatment (multiple categories can be selected)	(538)	
Mastectomy	178	33.1
Mastectomy with reconstruction	80	14.9
Radiotherapy	392	72.9
Chemotherapy	310	57.6
Hormonal therapies	352	65.4
Other	68	12.6
Number of different treatment types	(538)	
1	37	6.9
2	80	14.9
3	198	36.8
4	175	32.5
5	42	7.8
6	4	.7
7	2	.4
Currently on tamoxifen	(538)	
Yes	154	28.6
No	384	71.4
Recurrence of cancer	(538)	
Yes	44	8.2
No	494	91.8
Years since last treatment	(537)	
2 years or less	302	56.2
3 – 5 years	116	21.6
6+ years	119	22.2
Current smoker	(538)	
Yes	33	6.1
No	505	93.9
Moderate physical activity of 2.5 hour per week	(538)	
Yes	375	69.7
No	163	30.3

Characteristics	*N*	%
Impact of COVID on wellbeing	(538)	
Yes with adverse impact	244	45.4
No response, no impact, or no adverse impact	294	54.6
Geographic remoteness	(538)	
Metropolitan areas (MMM 1)	95	17.7
Regional centres (MMM 2)	128	23.8
Large rural towns (MMM 3)	119	22.1
Medium rural towns (MMM 4)	76	14.1
Small rural towns (MMM 5)	95	17.7
Remote communities (MMM 6)	17	3.2
Very remote communities (MMM 7)	8	1.5
Years living in a regional location	(535)	
0 – 2 years	5	.9
3 – 9 years	44	8.2
10+ years	486	90.8

Note. Stage 1 to 3 are stages of early breast cancer, with ascending numbers denoting the severity of the condition.

Descriptive and correlation information for primary measures

Descriptive statistics for the main scales of quality of life, fear of cancer recurrence, experiential avoidance, psychological distress, and social support are summarised in Table 6.2. This information for subscales is presented in Appendix J, with histograms in Appendix K, and overall scales in Table 6.2 below. All scales had an acceptable level of internal consistency for this sample, with Cronbach's alpha ranging from .83 (FACT-B) to .94 (AAQ-II). Women scored an average of 92.80 on the FACT-B. They had an average of 'moderate fear' of cancer recurrence (*M* = 3.59) as measured by the CARS Overall Fear subscale. Experiential avoidance was on average below the clinical cut off (*M* = 19.64). Psychological distress had an average score of 19.72. Social support had an average score of 3.56.

Table 6.2

Descriptive Statistics for Overall Main Scales

Measurement	FACT-B	CARS-Overall Fear	AAQ-II	K10	MOS-SSS
N	538	538	538	538	538
M	92.80	3.59	19.64	19.72	3.56
SD	21.22	1.34	9.10	7.48	.91
α	.83	.92	.94	.92	.87
Possible range	0 – 148	1 – 6	7 – 49	10 – 50	1 – 5
Actual range	22 – 140	1 – 6	7 – 49	10 – 49	1 – 5
Skew	-.38	-.08	.64	1.08	-.05
Kurtosis	-.21	-.92	-.10	1.10	.21

Descriptive information for all other variables are presented in Table 6.3 and 6.4. The mean age of diagnosis for respondents was 52 years (*SD* = 9.40) and were on average 3.82 years following primary treatment (*SD* = 5.11). Age at diagnosis, time since treatment, smoking, and cancer recurrence all had a skewness that was greater than +3 to -3. Time since treatment also does not follow a normal distribution, with most respondents completing treatment within the past two years or less. Cancer recurrence and smoking for this population also occurred infrequently, with most participants reporting no recurrence of cancer (*n* = 494) and were not smoking (*n* = 505). Most participants indicated that they engaged in 2.5 hours of exercise or more a week (*n* = 375).

Table 6.3

Descriptive Statistics for Other Variables of Interest

Measurement	MMM	Age At Diagnosis	Time Since Treatment	Financial Strain
N	538	538	537	538
M	3.06	52	3.82	3.03
SD	1.52	9.40	5.11	1.27
Range	1 – 7	26 – 77	0 – 50	1 – 6
Skew	.37	-.01	3.22	.39
Kurtosis	-.74	-.50	16.98	.04

Table 6.4

Descriptive Statistics for Other Variables of Interest, Binary Variables

Measurement	Chemotherapy	Smoking	Exercise	Cancer Recurrence
N	538	538	538	538
Yes	310	33	375	44
No	228	505	163	494

Table 6.5 is a summary of the correlations among all variables. Quality of life was significantly positive correlated with social support (r = .53), age (r = .19) and exercise (r = .14). It was significantly negatively correlated with psychological distress (r = -.76), experiential avoidance (r = -.73), fear of cancer recurrence (r = -.55), women who had chemotherapy treatment (r = -.13), financial strain (r = -.44), and smoking (r = -.14). No significant relationship was detected between quality of life and remoteness (r = .08), stage of breast cancer (r = -.08), or cancer recurrence (r = .03). Additionally, fear of cancer recurrence was significantly positively correlated with psychological distress (r = .79), experiential avoidance, (r = .55), financial strain (r = .18), and cancer recurrence (r = .11). It was significantly negatively correlated with social support (r = -.14), age (r = -.27), and age at cancer diagnosis (r = -.24). No significant relationship was detected between fear of cancer recurrence and remoteness (r = -.06), years since treatment (r = -.08), stage of breast cancer (r = .05), chemotherapy (r = .07), exercise (r = -.05), or smoking (r = .06). Psychological

distress was significantly positively correlated with experiential avoidance (r = .80), financial strain (r = .41), and smoking (r = .11), and negatively correlated with remoteness (r = -.11), age (r = -.13), age of diagnosis (r = -.09), and years since treatment (r = -.09). No significant relationship was detected between psychological distress and stage of breast cancer (r = .02), chemotherapy (r = .03), exercise (r = -.08), or cancer recurrence (r = .02). Additionally, experiential avoidance was significantly positively associated with financial strain (r = .37), smoking (r = .13), and significantly negatively associated with age (r = -.21) and age at diagnosis (r = -.16).

Increased age was associated with better quality of life, lower fear of cancer recurrence, lower psychological distress, and lower experiential avoidance. Increased financial strain was associated with lower quality of life, and lower social support, with higher psychological distress, higher experiential avoidance, and higher fear of cancer recurrence. Increased remoteness was associated with decreased psychological distress, and no other relationships between remoteness and other variables was detected.

Table 6.5

Pearson Correlation Matrix of Variables of Interest

Variable	Quality of Life (FACT-B)	Social Support (MOS-SSS)	Psychological distress (K10)	Experiential Avoidance (AAQ-II)	Fear of recurrence (CARS-OF)	Remoteness (MMM)	Age	Age at diagnosis	Time since treatment	Stage of Breast Cancer	Chemotherapy	Financial Strain	Exercise	Smoking
Social Support (MOS-SSS)	.53**	-												
Psychological distress (K10)	-.76**	-.40**	-											
Experiential Avoidance (AAQ-II)	-.73**	-.43**	.80**	-										
Fear of recurrence (CARS-OF)	-.55**	-.14**	.48**	.55**	-									

Variable	Quality of Life (FACT-B)	Social Support (MOS-SSS)	Psychological distress (K10)	Experiential Avoidance (AAQ-II)	Fear of recurrence (CARS-OF)	Remoteness (MMM)	Age	Age at diagnosis	Time since treatment	Stage of Breast Cancer	Chemotherapy	Financial Strain	Exercise	Smoking
Remoteness (MMM)	.08	-.02	-.11**	-.06	-.04	-								
Age	.19**	-.03	-.13**	-.21**	-.27**	.03	-							
Age at diagnosis	.10*	-.01	-.09*	-.16**	-.24**	-.01	.83*	-						
Time since treatment	.16**	-.03	-.09*	-.08	-.08	.02	.30**	-.17**	-					
Stage of Breast Cancer	-.08	-.05	.02	.01	.05	-.05	.12**	-.11*	-.01	-				
Chemotherapy	-.13**	.01	.03	.04	.07	-.01	-.27**	-.26**	-.10*	.44**	-			
Financial Strain	-.44**	-.31**	.41**	.37**	.18**	-.04	-.19	-.01	-.04	-.004	.04	-		
Exercise	.14**	.01	-.08	-.08	-.05	-.03	.16**	.12**	.10*	.21	-.03	-.02	-	

Variable	Quality of Life (FACT-B)	Social Support (MOS-SSS)	Psychological distress (K10)	Experiential Avoidance (AAQ-II)	Fear of recurrence (CARS-OF)	Remoteness (MMM)	Age	Age at diagnosis	Time since treatment	Stage of Breast Cancer	Chemotherapy	Financial Strain	Exercise	Smoking
Smoking	-.14**	-.15**	.11*	.13**	.06	.00	-.04	-.03	-.04	.05	.06	.13**	-.03	-
Cancer Recurrence	.03	.06	.02	-.02	.11**	-.01	.12**	-.06	.09*	-.05	-.07	.02	.02	.05

Note. N = 538, except Age and Time since treatment, *N* = 537; Pearson's correlations; * $p = \leq$ to .05; ** $p = \leq$ to .01.

Research Question 1:

What is the current quality of life, rate of fear of cancer recurrence, and distress for women who have completed breast cancer intervention, living in regional and rural and remote Australia? This question aims to clarify the characteristics of this population and update the data that is available.

Quality of life

The average quality of life, as measured by the FACT-B scale, for this sample (M = 92.8, SD = 21.2) is significantly lower than the normative sample of women from Brady et al. (1997) with local disease (M = 105.4, SD = 23.9), $t(602) = 4.31$, $p < .001$; or regional disease (M = 109.9, SD = 23.7), $t(576) = 4.67$, $p < .001$. It is also lower than the pre-intervention scores for the women in the sample from Study 1 (M = 104.2, SD = 18.3). A Mann-Whitney U test indicated that quality of life reported by the participants of Study 1 (Mdn = 102, N = 20) was significantly higher compared to the participants of Study 2 (Mdn = 95, N = *538*), $U = 3671.00$, $z = -2.41$, $p = .02$.

DiSipio's (2009) sample of regional and rural women 12-months post diagnosis scored an average of 86.3 on the FACT-G, and the score was not clinically significantly different from urban populations with a mean of 89.7. In the current sample, the mean FACT-G score is 69.78 (SD = 15.95).

Overall quality of life, and specific aspects of quality of life, were generally not correlated with remoteness. The only exception is for emotional wellbeing, $r(536) = .12$. $p < .01$, meaning that women living in more regional areas may have slightly better emotional wellbeing than their urban counterparts. Figures 6.2 and 6.3 show quality of life by remoteness, and for emotional wellbeing, which was the only significant correlation.

Figure 6.2

Mean Overall Quality of Life by Remoteness, Bars Represent 95% Confidence Interval (*N = 538*)

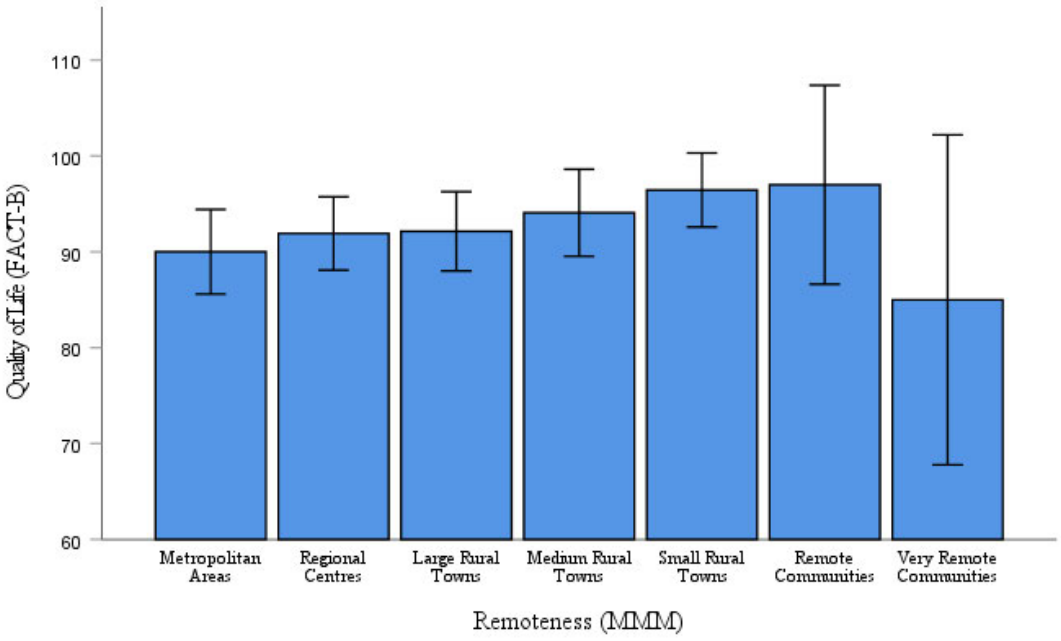
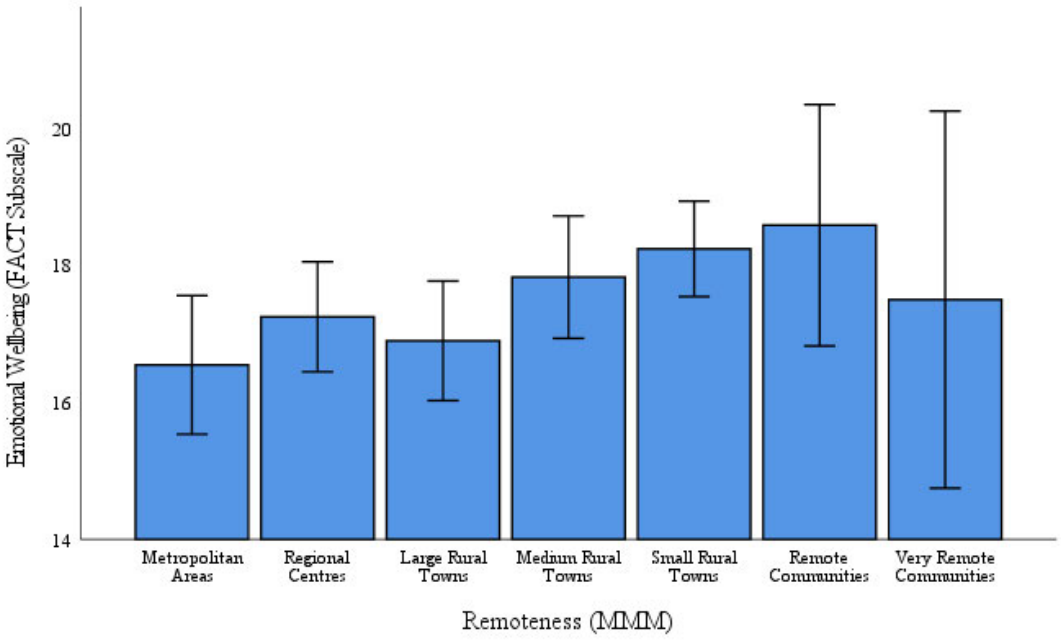


Figure 6.3:

Mean Emotional Wellbeing by Remoteness, Bars Represent 95% Confidence Interval (N = 538)



With remote and very remote communities removed from analysis, there is again a small correlation between quality of life and remoteness, $r(511) = .10$, $p = .03$, and with emotional wellbeing, $r(511) = .12$, $p < .01$, but again these relationships do not hold for the other subscales.

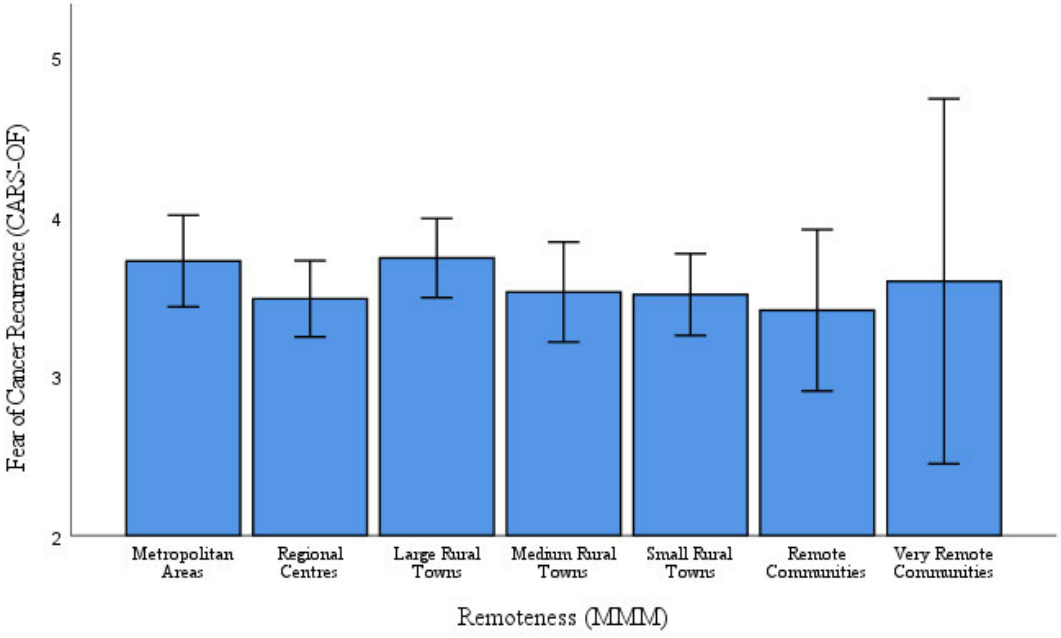
Fear of Cancer Recurrence

Fear of cancer recurrence for this group was in the moderate range (*Md* = 3.75, *N = 538*), which is higher than the pre-intervention scores of the women from Study 1 (*Md* = 2.38, *N* = 20), *U* = 3729.00, *z* = -2.34, *p* = .02.

There were no significant correlations between fear of cancer recurrence and remoteness. Figure 6.4 shows fear of cancer recurrence by remoteness, again with wider confidence intervals for very remote communities due to a low sample size.

Figure 6.4

Mean Fear of Cancer Recurrence by Remoteness, Bars Represent 95% Confidence Interval (*N* = 538)



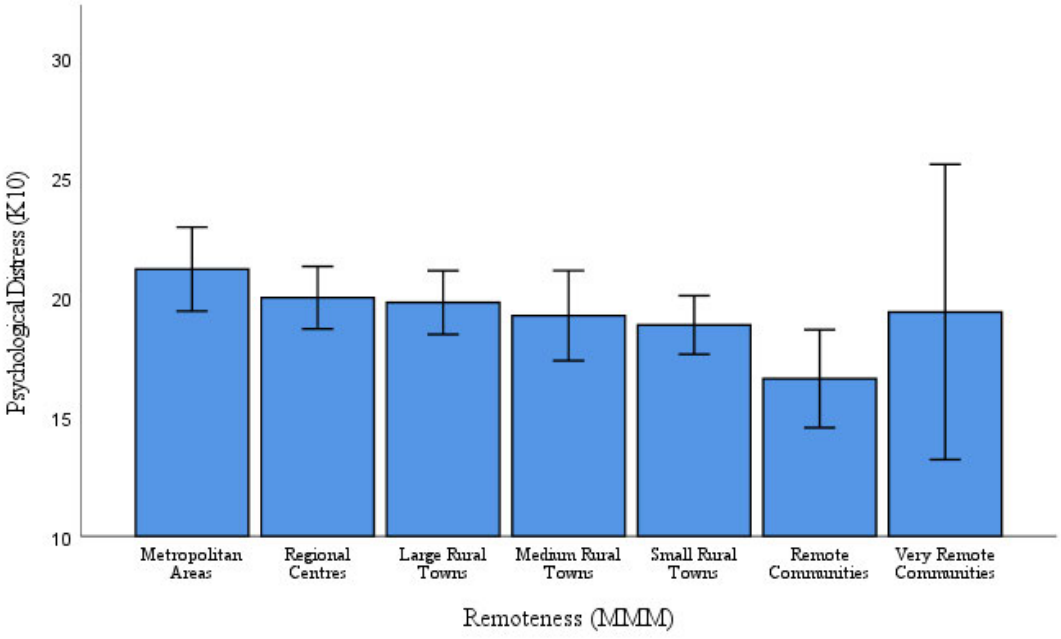
Psychological Distress

The average psychological distress for this sample (*M* = 19.72, *SD* = 7.48) was higher than the mean of the population based sample from Andrews and Slade (2001), which had a mean of 14.2.

There was a small significant correlation between remoteness and psychological distress, *r*(536) = -.11, *p* <.01. Figure 6.5 shows psychological distress by remoteness.

Figure 6.5

Mean Psychological Distress by Remoteness, Bars Represent 95% Confidence Interval (*N = 538*)



Comparison with DiSipio (2009)

Appendix L contains the data from this study laid out in the same tables, and using her analysis method, which were ANOVAs.

In this study, no statistical or clinically significant differences were found between regional and rural women or between older and younger women in each category. This finding was repeated when comparing urban women with regional/rural women.

DiSipio found that younger urban women scored higher for physical wellbeing (M = 24.8), than their regional/rural counterparts (M = 21.4). In this current study, the mean score for younger urban women in this category was 17.09, and 16.38 for regional/remote women.

Metropolitan Versus Rural Area

Overall difference in quality of life between metropolitan areas and small rural towns was significant, with women in small rural towns experiencing better quality of life, $t(188) = -2.18$, $p = .03$, with a small effect size, $d = -.32$. Emotional wellbeing was also significantly higher for women in small rural towns, $t(188) = 2.74$, $p < .01$, with medium effect size, $d = -.40$. Table 6.6 shows the differences between the two locations. Psychological distress was significantly better in small rural towns, $t(188) = 2.17$, $p = .03$, with a small effect size, $d = .31$. Psychological distress and experiential avoidance results are presented in Figure 6.6.

Table 6.6

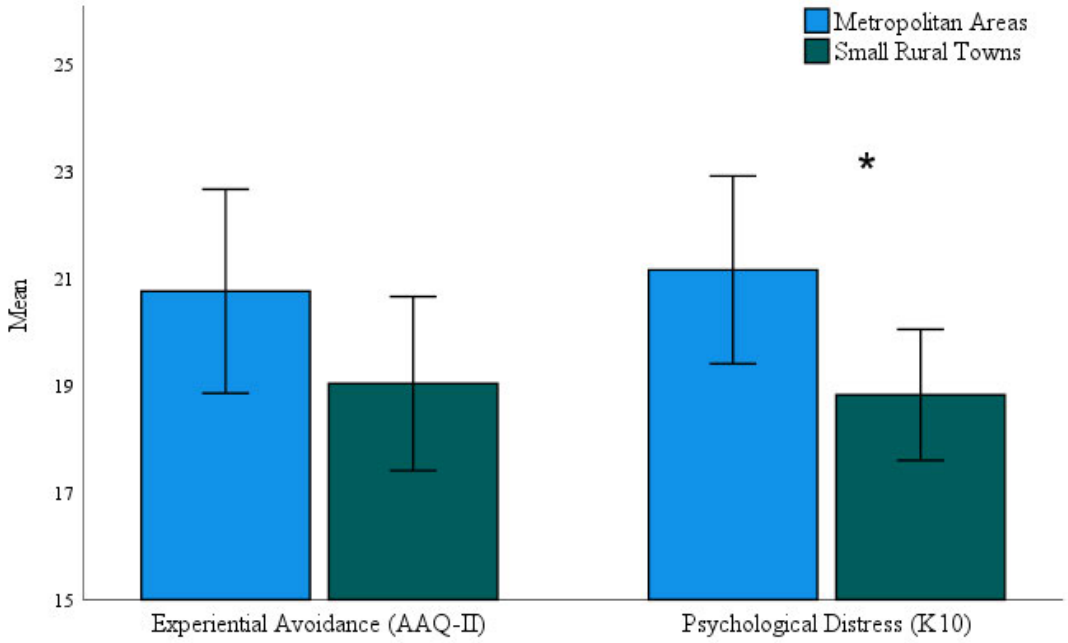
Wellbeing and Subscale Scores, Fear of Recurrence, and Psychological Distress for Metropolitan Areas and Small Rural Towns

Characteristic	Metropolitan areas (MMM1)			Small rural towns (MMM5)			Independent samples t-test			
	n	*M*	*SD*	*n*	*M*	*SD*	*df*	*t*	*p*	*d*
Quality of Life	95	90.01	21.66	95	96.45	18.95	188	-2.18	.03	-.32
Physical wellbeing	95	17.61	4.56	95	18.05	4.11	188	-.70	.48	-.10
Social Wellbeing	95	16.21	5.24	95	16.74	5.14	188	-.70	.49	-.10
Emotional Wellbeing[a]	95	16.5	4.97	95	18.24	3.42	166	-2.7	.01	-.40
Functional Wellbeing	95	18.29	6.27	95	19.43	5.37	188	-1.3	.18	-.19
Fear of Cancer Recurrence	95	3.72	1.41	95	3.51	1.26	188	1.07	.28	.16
Psychological Distress	95	21.17	8.62	95	18.83	6.02	188	2.17	.03	.31
Experiential avoidance	95	20.77	9.36	95	19.04	7.99	188	1.37	.24	.20

Note. p = p-value. d = Cohen's d, effect size. [a] For this analysis, Item 2 was deleted from the Emotional Wellbeing scale in order to increase the internal consistency to a Cronbach's alpha of .82.

Figure 6.6

Bar Graph of Mean Experiential Avoidance and Psychological Distress in Metropolitan Areas (n = 95) and Small Rural Towns (n = 95), Bars Represent 95% Confidence Interval

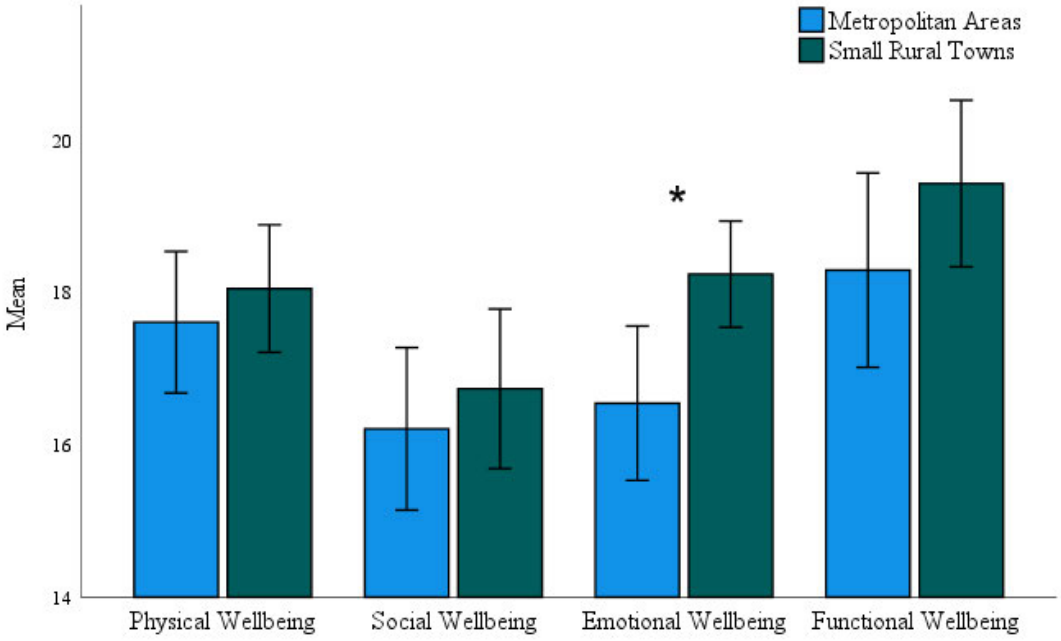


Note. * = significant at $p = \leq .05$

<Quality of life subscale results are presented in Figure 6.7.

Figure 6.7

Bar Graph of Mean Physical, Social, Emotional and Functional Wellbeing in Metropolitan Areas (n = 95) and Small Rural Towns (n = 95), Bars Represent 95% Confidence Interval



Note. * = significant at $p = \leq .05$

Young Cancer Survivors

In this sample, younger survivors had significantly more fear, $t(535) = 6.10$, $p < .01$; distress, $t(142) = 2.95$, $p < .01$; and experiential avoidance, $t(535) = 4.62$, $p < .01$, compared to older survivors. They also had a lower quality of life, $t(535) = -3.81$, $p < .01$, a difference that is clinically significant. Table 6.7, Figure 6.8 to 6.10 represents these result.

Table 6.7

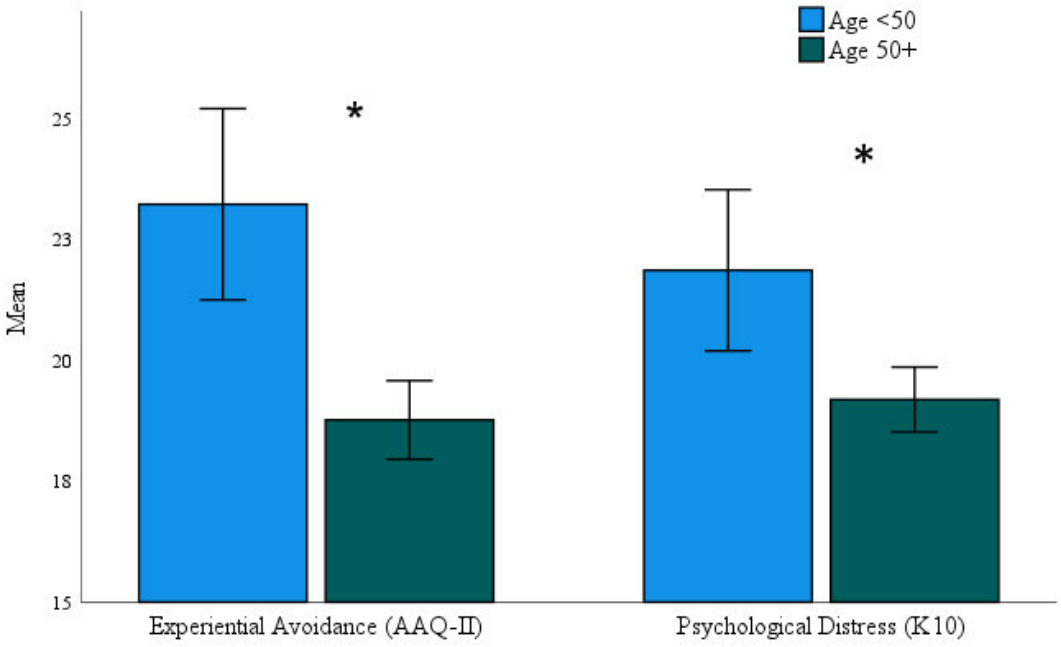
Fear, Quality of Life, Psychological Distress, and Experiential Avoidance for Younger and Older Breast Cancer Survivors

Characteristic	< 50 years old			≥ 50 years old			Independent samples t-test			
	n	*M*	*SD*	*n*	*M*	*SD*	*df*	*t*	*p*	*d*
Fear of cancer recurrence (CARS-OF)	107	4.28	1.21	430	3.42	1.32	535	6.10	<.01	.66
Quality of life (FACT-B)	107	85.87	21.79	430	94.51	20.77	535	-3.81	<.01	-.41
Psychological Distress (K-10)	107	21.86	8.69	430	19.19	7.07	142.83	2.95	<.01	.36
Experiential Avoidance (AAQ-II)	107	23.22	10.32	430	18.77	5.56	535	4.62	<.01	.50

Note. p = p-value. *d* = Cohen's d as a measure of effect size.

<<<<**Figure 6.8**

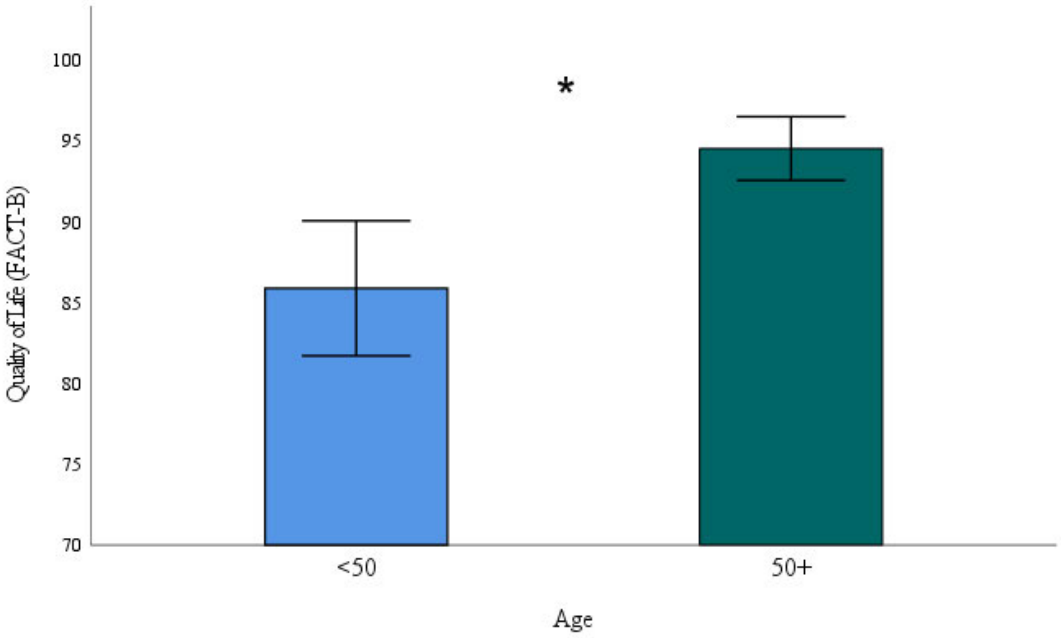
Bar Graph of Experiential Avoidance and Psychological Distress for Women Under 50 Years Old (n = 107) and 50 Years and Older (n = 430), Bars Represent 95% Confidence Interval



Note. * = significant at $p \leq .05$

Figure 6.9

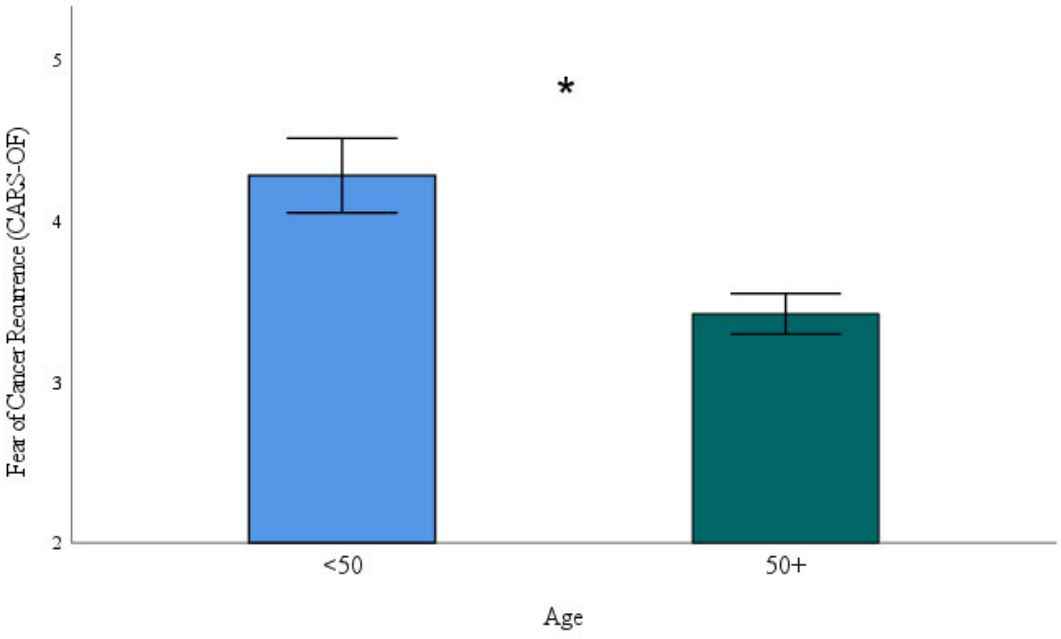
Bar Graph of Quality of Life for Women Under 50 Years Old (n = 107) and 50 Years and Older (n = 430), Bars Represent 95% Confidence Interval



Note. * = significant at $p < .05$

Figure 6.10

Bar Graph of Fear of Cancer Recurrence for Women Under 50 Years Old (n = 107) and 50 Years and Older (n = 430), Bars Represent 95% Confidence Interval



Note. * = significant at $p \leq .05$

Research Question 2:

What are the factors that account for the quality of life in women following primary breast cancer care? This question aims to include previous research to inform the factors that potentially impact regional women. It is predicted that variance in women's quality of life will be accounted for by the following variables: Fear of cancer recurrence, experiential avoidance, social support, remoteness, financial strain, exercise, smoking, chemotherapy, age at diagnosis, cancer recurrence, and time since treatment.

Table 6.8 outlines the levels for the categorical variables in the general linear model, with the reference level for each variable italicised.

Table 6.8

Levels for the Categorical Variables of the General Linear Model for Research Question 2

Variable	Label	Number of participants
Financial strain	*Easy*	*370*
	Difficult	167
Smoking	*No*	*504*
	Yes	33
Exercise	*No*	*163*
	Yes	374
Chemotherapy	*Not selected*	*228*
	Yes	309
Remoteness	*Urban*	*95*
	Regional	246
	Rural	196
Cancer Recurrence	*No*	*493*
	Yes	44

Note. Italicized = reference level for the general linear model

Table 6.9 shows the final general linear model. In this model, financial strain, exercise, chemotherapy, psychological distress, experiential avoidance, social support, fear of cancer recurrence, and time since treatment accounted for a significant amount of variance in quality of life. Smoking, remoteness, cancer recurrence, and age at diagnosis were not significant in this model.

Table 6.9

General Linear Model of Variables of Interest on Quality of Life

Variable	B	SE	p	CI (95%)
Financial Strain	4.94	1.13	<.01	2.71 – 7.16
Smoking	1.05	2.03	.61	-2.94 – 5.04
Exercise	-3.59	1.06	<.01	-5.67 – -1.51
Chemotherapy	3.63	1.02	<.01	1.63 – 5.64
Regional	-1.40	1.40	.32	-1.15 – 1.35
Rural	-.902	1.07	.40	-3.00 – 1.20
Cancer recurrence	-1.03	1.79	.57	-4.53 – 2.48
Psychological Distress (K10)	-1.12	.11	<.01	-1.34 – -.91
Experiential Avoidance (AAQ-II)	-.29	.10	<.01	-.47 – -.10
Social Support (MOS-SSS)	5.91	.60	<.01	4.73 – 7.09
Fear of Cancer Recurrence (CARS-OF)	-3.61	.44	<.01	-4.49 – -2.74
Time since treatment	.35	.10	<.01	.15 – .54
Age at diagnosis	-.04	.06	.46	-.15 – .07

Note. Adjusted R Squared = .73

Other Treatments and Quality of Life

Table 6.10 provides a summary of exploratory correlations between treatment and quality of life. Chemotherapy is significantly correlated with quality of life $r(536) = -.13$, $p < .01$, specifically with physical wellbeing $r(536) = -.16$, $p < .01$ and functional wellbeing, $r(536) = -.10$, $p = .02$. This finding is in line with existing literature. Relationships were also found for number of treatments for breast cancer and overall quality of life, $r(536) = -.10$, $p = .02$, specifically physical wellbeing, $r(536) = -.17$, $p < .01$; mastectomy for overall quality of life $r(536) = -.09$, $p < .05$, specifically functional wellbeing, $r(536) = -.09$, $p = .04$; and hormonal therapies with quality of life, $r(536) = -.13$, $p < .03$, specifically physical wellbeing, $r(536) = -.11$, $p = .01$, and emotional wellbeing, $r(536) = -.10$, $p = .02$. Although significant, all of these correlations were small. Lumpectomy, mastectomy with reconstruction, and radiotherapy did not correlate with any aspects of quality of life. It is expected that women with higher stages of cancer may go through more therapies.

Table 6.10

Correlations between Quality of Life with Type and Number of Treatments

Variable	Number of breast cancer treatments	Lumpectomy	Mastectomy	Mastectomy with reconstruction	Radiotherapy	Chemotherapy	Hormonal Therapies	Other treatments
Quality of Life	-.10*	.05	-.09*	.01	.03	-.13*	-.10	-.01
Physical wellbeing	-.17*	.01	-.08	.04	-.04	-.16*	-.11*	-.06
Social Wellbeing	-.02	-.03	.05	-.01	.01	.03	-.05	-.06
Emotional Wellbeing [a]	-.07	.01	-.04	-.02	.02	-.06	-.10*	.06
Functional Wellbeing	-.05	.05	-.09*	.05	.06	-10*	-.05	-.02

Note. * = Significant at least $p < .05$ [a] For this analysis, Item 2 was deleted from Emotional Wellbeing scale in order to increase the internal consistency to an Cronbach's alpha of .82.

<<<<<Table 6.11 summarises the descriptive statistics for number of treatments accessed by stage of breast cancer.

Table 6.11

Descriptive Statistics for Number of Treatments Accessed by Stage of Breast Cancer

Stage	*n*	*M*	*SD*	Minimum treatments	Maximum treatments
1	214	2.76	.97	1	5
2	192	3.45	.96	1	7
3	132	3.67	1.08	1	7

Note. M = mean number of treatments

Most women had more than one type of breast cancer treatment. A significant difference was found among groups, $F(2,535) = 41.86$, $p < .01$. Post hoc analysis using the Tukey t-test indicated that the average number of treatments was significantly lower for Stage 1 cancer ($M = 2.76$, $SD = .97$) compared to Stage 2 ($M = 3.45$, $SD = .96$) and 3 ($M = 3.67$, $SD = 1.08$), $p < .01$. There was no significant difference in number of treatments between Stage 2 and Stage 3 cancer.

Research Question 3:

Does experiential avoidance influence engagement in behaviours that improve women's quality of life? This question aims to clarify another possible pathway through which experiential avoidance may contribute to women's quality of life by affecting women's behaviours regarding engaging in positive action to improve their wellbeing. It is predicted that women with high experiential avoidance will have reduced rates of exercise and increased rates of smoking.

The majority of this sample was already engaged in healthy behaviours. Of 538 respondents, 30.3% indicated that they did not achieve the requisite amount of weekly physical activity ($n = 163$). Only 6% were current smokers ($n = 33$). The relation between experiential avoidance and exercise was not significant, $X^2 (2, N = 538) = 2.19$, $p = .14$.

Table 6.12 presents the descriptive statistics for a factorial analysis of variance for experiential avoidance on exercise, and outcome to quality of life.

Table 6.12

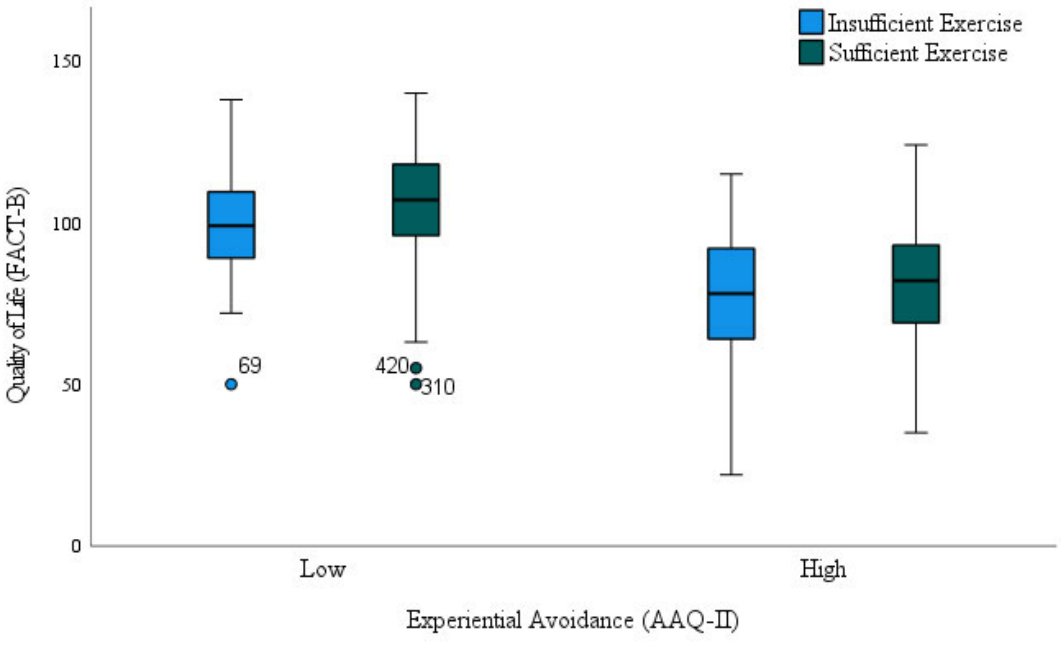
Descriptive Statistics of High and Low Experiential and Actual Cancer Recurrence

Categories	Experiential avoidance	N	M	SD
Sufficient exercise (2.5+ hrs)	Low	210	105.90	16.16
	High	165	80.70	17.74
Insufficient exercise (<2.5hrs)	Low	80	98.98	15.28
	High	83	77.72	20.67

While there were significant effects of experiential avoidance on quality of life, $F(1,534) = 201.02$, p <.01, and exercise on quality of life, $F(1,534) = 9.28$, p <.01, there was no significant interaction between experiential avoidance and exercise on quality of life, $F(1, 534) = 1.47$, $p = .23$. Results are represented in Figure 6.11.

Figure 6.11

Box Plot of Quality of Life by Experiential Avoidance and Exercise



Research Question 4:

Does experiential avoidance influence the relationship between factors associated with quality of life? In Study 1, experiential avoidance seemed to have a different association with quality of life depending on whether it was high or low. This effect

was also seen in a recent study (Novakov, 2021). It is predicted that experiential avoidance has a moderating effect on quality of life factors, especially when experiential avoidance is high. As experiential avoidance increases, the helpful effects of quality of life factors decrease, and unhelpful effects of quality of life factors increase.

Table 6.13 summarises the interactions of experiential avoidance in moderated regressions. Reference levels for categorical variables are the same as the general linear model indicated in Table 6.9. Experiential avoidance was not found to be a significant moderator of the effect of fear of cancer recurrence on quality of life. In these single regressions, experiential avoidance was a significant moderator of the effect of psychological distress on quality of life, $R^2 = .60$, $F(3, 534) = 258.53$, β =.58, $t = 2.23$, p = .“3.

Table 6.13

Moderated Regression With Interaction of Experiential Avoidance

Independent Variables	β	SE	*t*	*p*	R squared
Financial strain	-3.10	3.35	-.93	.36	.40
Exercise	-3.94	3.37	1.17	.24	.34
Chemotherapy	.48	3.07	.16	.88	.34
Psychological distress	.58	.26	2.23	.03	.60
Social support	.05	1.57	.03	.97	.45
Fear of cancer recurrence	-1.60	1.24	-1.28	.20	.43
Time since treatment	.39	.37	1.05	.29	.35

Note. β = coefficient, SE = standard error. For reference levels to categorical variables, see Table 6.9.

In a moderated multiple regression model including the other variables (financial strain, exercise, chemotherapy, social support, fear of cancer recurrence, and time since treatment) as co-variates, experiential avoidance was not a significant moderator of the effect of psychological distress on quality of life, $R^2 = .73$, F(9,

527) = 156.13, β =.07, *t* = .18, *p* = .86, and variance is better accounted for by other factors.

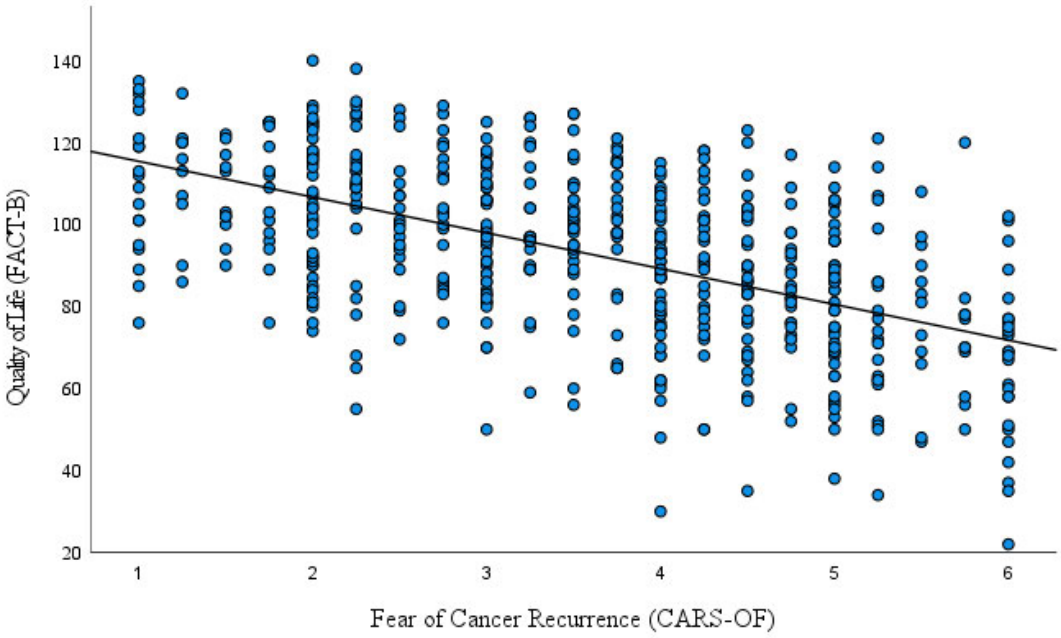
Research Question 5:

What is the relationship between fear of cancer recurrence and quality of life? It is expected that women who have a higher fear of cancer recurrence have a lower level of quality of life, which is an observation widely reported in the literature and a founding assumption of interventions for fear of recurrence. This question aims to replicate this finding in Australian regional women.

A scatter plot with a linear line of best fit illustrates the relationship between fear of cancer recurrence and quality of life captured in this data set, as seen in Figure 6.12

Figure 6.12

Scatter Plot of Quality of Life by Fear of Cancer Recurrence (N = 538)



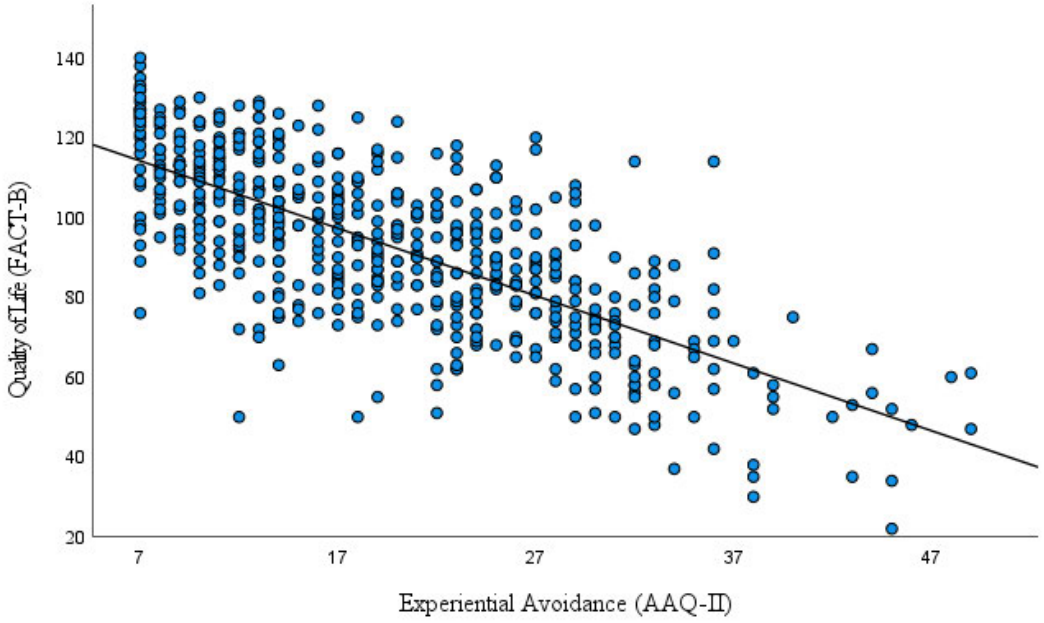
A simple linear regression was calculated to predict quality of life based on fear of cancer recurrence. A significant regression equation was found, R^2=.31, $F(1,536)$=236.15, p <.001. Higher fear of cancer recurrence was associated with lower quality of life.

Follow up from Study 1

The relationship between experiential avoidance and quality of life for this current data set is illustrated in Figure 6.13.

Figure 6.13

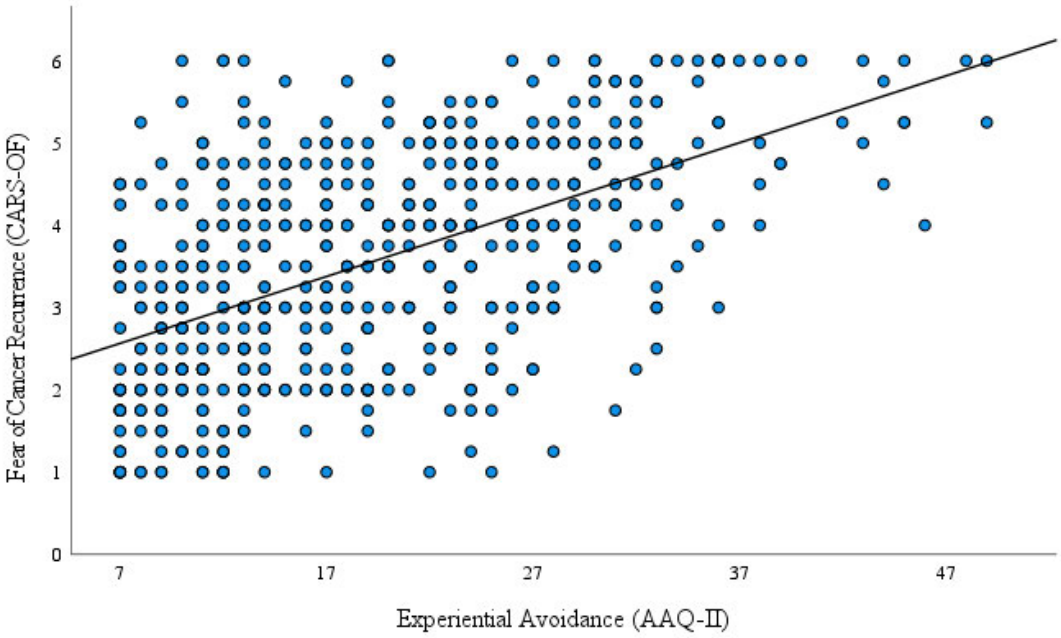
Scatterplot of Quality of Life by Experiential Avoidance (N = 538)



A simple linear regression was calculated to predict quality of life based on experiential avoidance. A significant regression equation was found, $R^2 = .53$, $F(1,536) = 594.11$, $p < .01$. Higher experiential avoidance was associated with lower quality of life. The relationship between experiential avoidance and fear of cancer recurrence for this current data set is illustrated in Figure 6.14.

Figure 6.14

Scatterplot of Fear of Recurrence by Experiential Avoidance (N = 538)



A simple linear regression was calculated to predict fear of cancer recurrence based on experiential avoidance. A significant regression equation was found, R^2=.30, $F(1,536) = 232.23$, p <.01. Higher experiential avoidance was associated with higher fear of cancer recurrence.

High and Low Experiential Avoidance

182reaA summary of independent sample t-tests for high and low experiential avoidance on quality of life, fear of cancer recurrence and psychological distress is presented in Table6.14.

Table 6.14

Independent Sample T-Tests of High and Low Experiential Avoidance on Quality of Life, Fear of Cancer Recurrence, and Psychological Distress

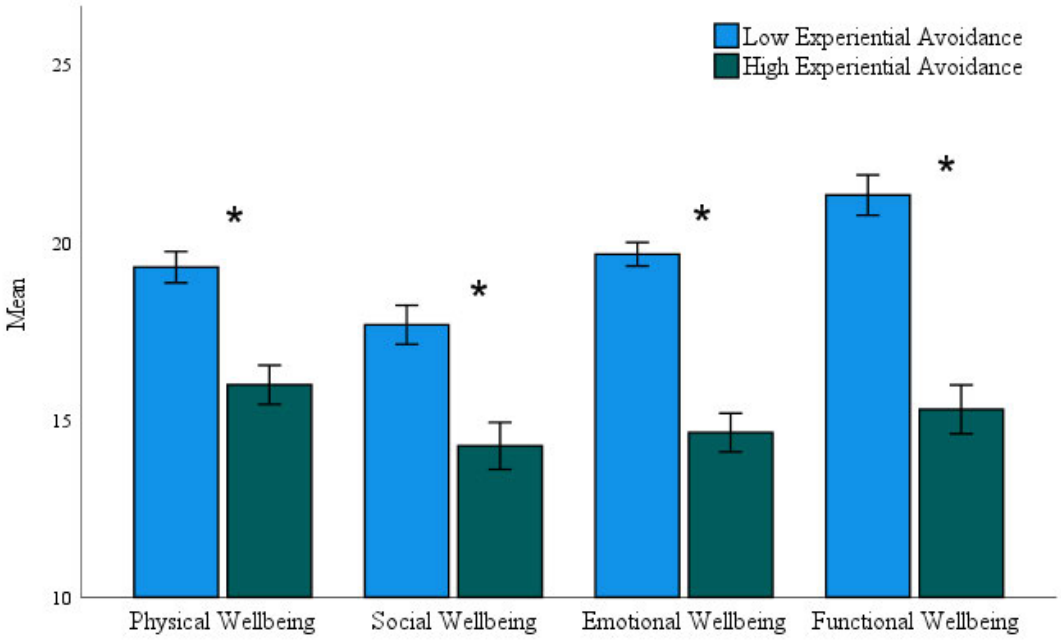
Categories	Low experiential avoidance			High experiential avoidance			Independent samples t-test			
	n	*M*	*SD*	*n*	*M*	*SD*	*df*	*t*	*p*	*d*
Quality of Life	290	103.99	16.20	248	79.71	18.78	491.30	15.92	<.01	1.39
Physical wellbeing	290	19.30	3.81	248	15.99	4.40	492.13	9.26	<.01	.81
Social Wellbeing	290	17.68	4.75	248	14.27	5.30	536	7.87	<.01	.68
Emotional Wellbeing	290	19.67	2.87	248	14.64	4.36	415.81	15.51	<.01	1.38
Functional Wellbeing	290	21.33	4.91	248	15.29	5.50	536	13.46	<.01	1.16
Fear of Cancer Recurrence	290	3.01	1.21	248	4.27	1.16	536	-12.28	<.01	-1.06
Psychological Distress	290	15.31	4.03	248	24.87	7.30	371.34	-18.38	<.01	-1.66

Note. d = Cohen's d, effect size. Breast cancer subscale was not included for analysis due to low internal reliability. There was no specific guidance for the calculation of clinical significance for Fear of Cancer Recurrence and Psychological Distress measures.

Women who had low experiential avoidance experienced significantly higher quality of life overall and in all testable sub domains compared to women who had high experiential avoidance. This is presented in Figure 6.15 and Figure 6.16. Large effect sizes were seen in overall quality of life (d = 1.39), physical wellbeing (d = .81), emotional wellbeing (d = 1.38), functional wellbeing (d = 1.16). There was a medium effect of experiential avoidance on social wellbeing (d = .68). Statistically significant and large effect sizes were also found for experiential avoidance and fear of cancer recurrence (d = -1.06) and psychological distress (d = -1.66) where those that reported high experiential avoidance had worse symptoms of fear and distress than those who low experiential avoidance. This is presented in Figure 6.17 and Figure 6.18.

Figure 6.15

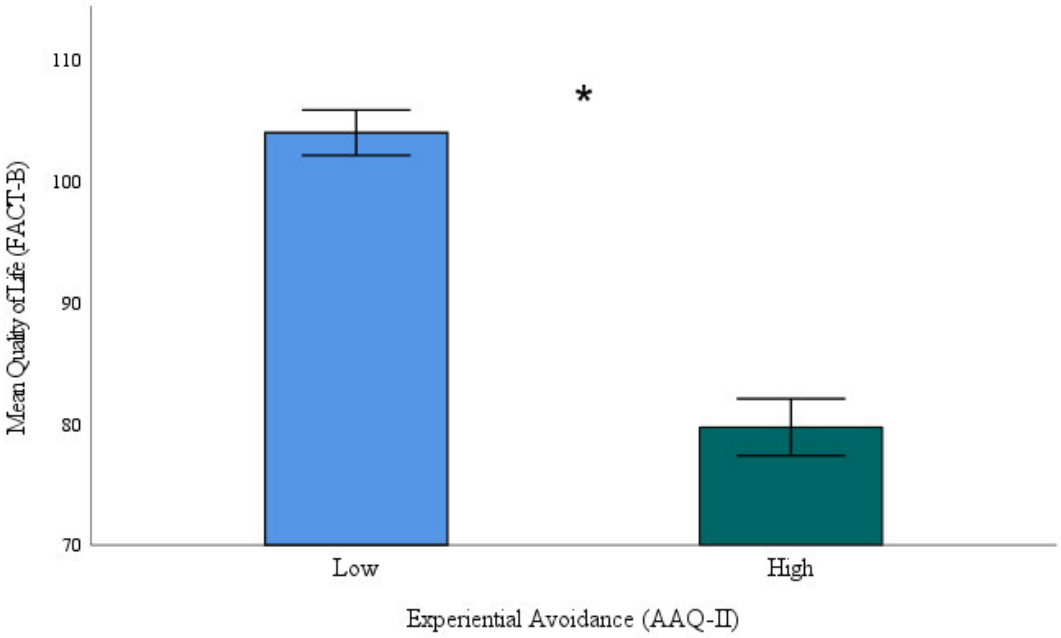
Bar Graph of Mean Physical, Social, Emotional, and Functional Wellbeing for Low (n = 290) and High (n = 248) Experiential Avoidance, Bars Represent 95% Confidence Interval



Note. * = significant at $p \leq .05$

Figure 616

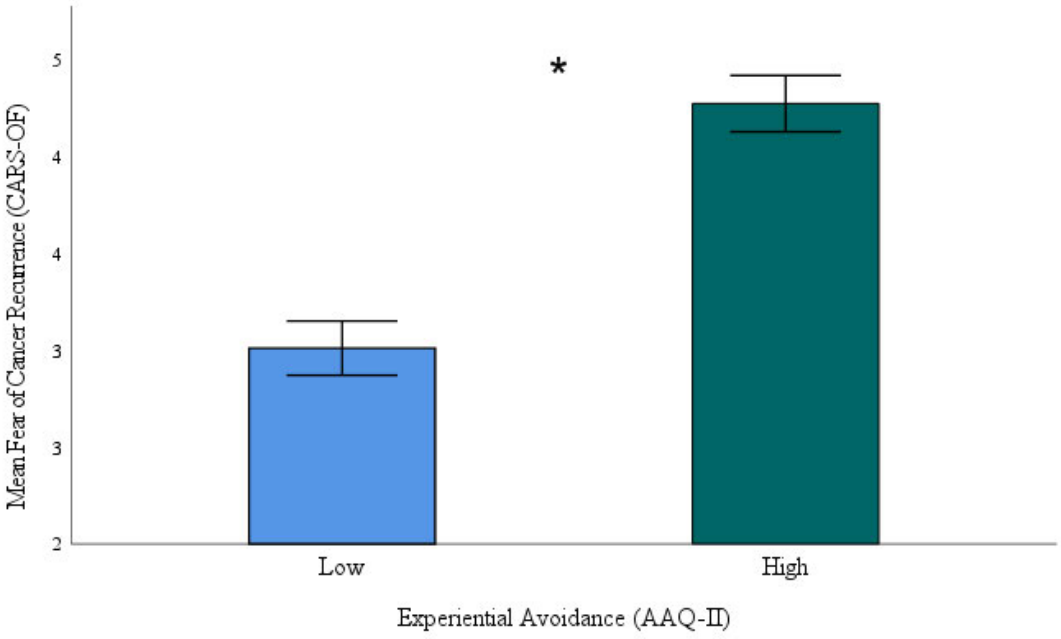
Bar Graph of Mean Quality of Life for Low (n = 290) and High (n = 248) Experiential Avoidance, Bars Represent 95% Confidence Interval



Note. * = significant at p <.05

Figure 6.17

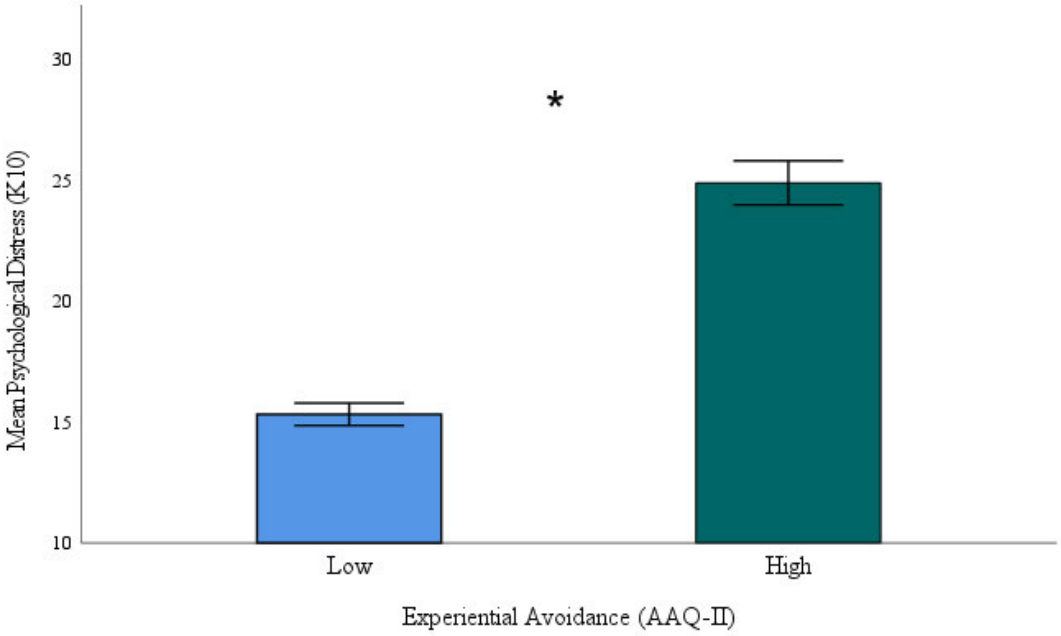
Bar Graph of Mean Fear of Cancer Recurrence for Low (n = 290) and High (n = 248) Experiential Avoidance, Bars Represent 95% Confidence Interval



Note. * = significant at p <.05

Figure 56.18

Bar Graph of Mean Psychological Distress for Low (n = 290) and High (n = 248) Experiential Avoidance, Bars Represent 95% Confidence Interval



Note. * = significant at $p = \leq .05$

Research Question 6:

Does experiential avoidance enhance fear of cancer recurrence for women who have had a recurrence of cancer? The aim of this question is to account for the effect of experiential avoidance on fear of cancer recurrence where a possible feared outcome is true. It is predicted that women who have had a recurrence of cancer will have a higher fear of cancer recurrence if they have a high experiential avoidance, compared to women who have recurrence but low experiential avoidance.

Table 6.15 presents the descriptive statistics for participant groups of interest in the factorial analysis of variance for experiential avoidance on the effect of fear of cancer recurrence in women with actual cancer recurrence.

Table 6.15

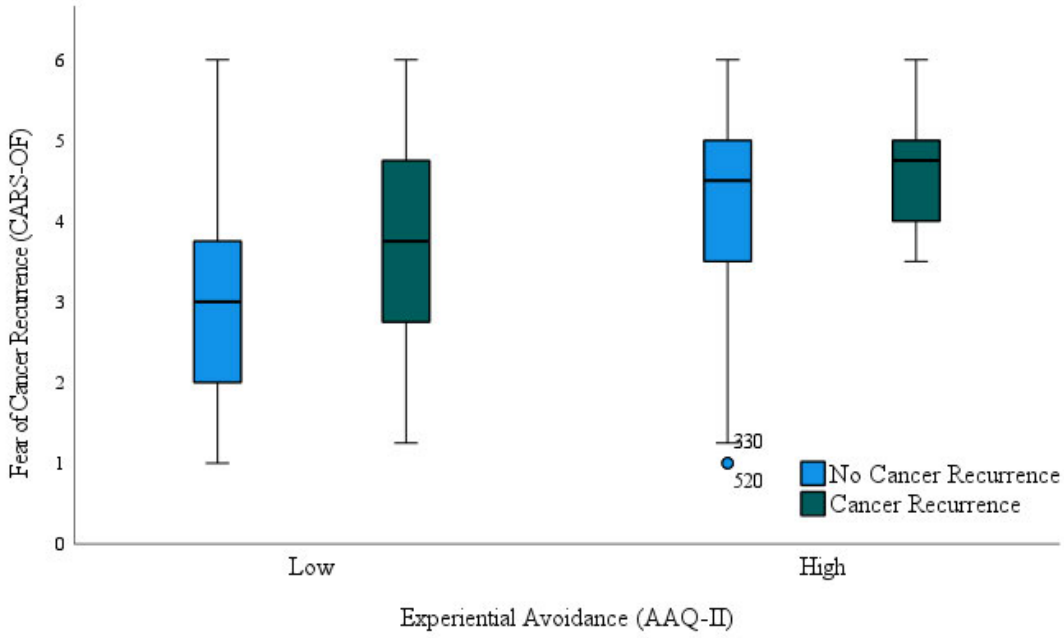
Descriptive Statistics of High and Low Experiential and Actual Cancer Recurrence

Category	Experiential avoidance	*n*	*M*	*SD*
No cancer recurrence	Low	263	2.93	1.18
	High	231	4.25	1.19
Cancer recurrence	Low	27	3.81	1.35
	High	17	4.57	1.30

There was no significant interaction between experiential avoidance and actual cancer recurrence on fear of cancer recurrence, $F(1, 534) = 2.14$, $p = .14$. There was a significant effect of actual cancer recurrence on fear of cancer recurrence, $F(1, 534) = 10.01$, $p < .01$, with an effect size of $\eta^2_{partial} = .02$. Women who had experienced breast cancer recurrence were more likely to fear it, however, this effect is small. There was a significant effect of experiential avoidance on fear of cancer recurrence, $F(1, 534) = 30.42$, $p < .01$, with an effect size of $\eta^2_{partial} = .05$. Women who had higher experiential avoidance were more likely to have more fear of cancer recurrence, with a small to medium effect. These results are presented in Figure 6.19.

Figure 6.19

Boxplot of Fear of Cancer Recurrence by High and Low Experiential Avoidance, and Actual Cancer Recurrence



Additional Question: Consideration of COVID-19

Forty-five percent of participants (n = 244) provided a response that indicated that their wellbeing was adversely impacted by COVID. The rest of the respondents either did not answer the question, answered in the negative (i.e. no impact), or indicated a positive impact (i.e. "I actually feel that having breast cancer and treatment during COVID-19 was probably not a bad time health wise as everyone was being very conscious of following good hygiene"). Written responses to this question are provided in a list in Appendix M.

Table 6.16 summarises the results of independent sample t-tests for those who were not affected or gave no response, to those who indicated a negative impact of COVID.

Table 6.16

Independent Sample T-Test for Quality of Life, Fear of Cancer Recurrence, Experiential Avoidance, Psychological Distress, and Social Support for COVID-19 Impact

Categories	No response, no impact, or positive impact			Negative impact			Independent samples t-test			
	n	*M*	*SD*	*n*	*M*	*SD*	*df*	*t*	*p*	*d*
Quality of life (FACT-B)	294	97.24	19.58	244	87.44	21.91	536	5.47	<.01	.47
Experiential Avoidance (AAQ-II)	294	17.59	8.30	244	22.12	9.43	488.49	-5.85	<.01	-.51
Fear of cancer recurrence (CARS-OF)	294	3.41	1.33	244	3.81	1.33	536	-3.51	<.01	-.30
Psychological Distress (K-10)	294	18.07	6.76	244	21.70	7.84	482.98	-5.70	<.01	-.50
Social support (MOS-SSS)	294	3.65	.91	244	3.46	.92	536	2.40	.02	.21

The group which indicated a negative impact of COVID-19 also responded significantly differently to the main scales compared to the group that had no response, no impact, or a positive impact. The effect sizes ranged from small to medium.

A factorial analysis of variance was conducted to examine whether living in metropolitan area was associated with increased reporting of COVID-19 impact compared to small towns, and the effect of this on quality of life. Table 6.17 presents the descriptive statistics for participants groups of interest.

Table 6.17

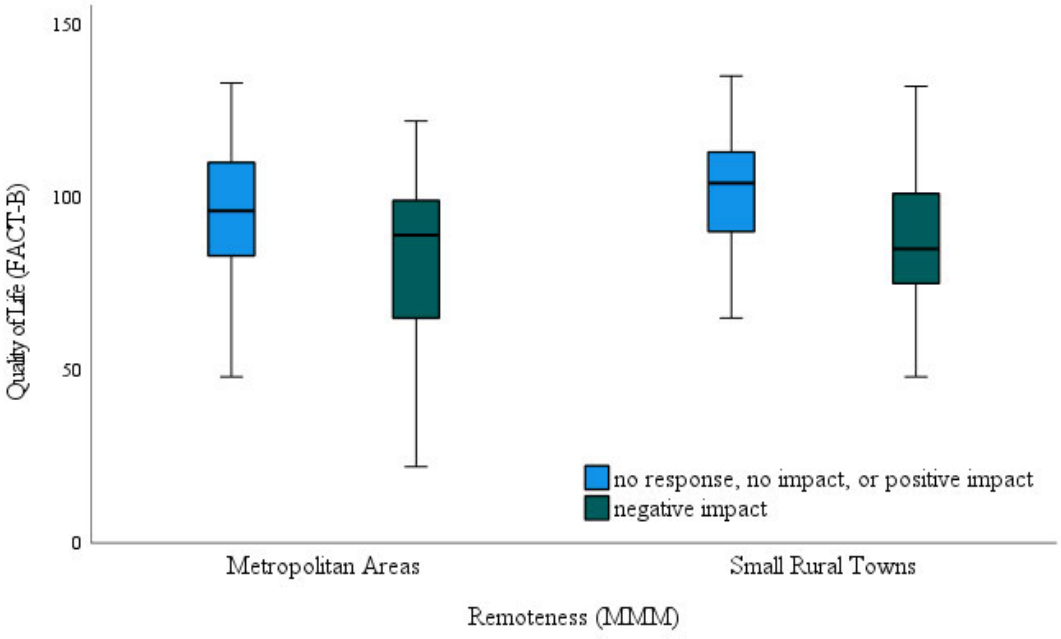
Descriptive Statistics of COVID-19 Impact and Remoteness

Categories	Remoteness	*n*	*M*	*SD*
No response, no impact, or positive impact	Metropolitan area	50	96.50	18.90
	Small rural town	54	102.52	16.28
Impact	Metropolitan area	45	82.80	22.45
	Small rural town	41	88.46	19.45

There were significant effects of remoteness on quality of life, $F(1,186) = 4.33$, $p = .04$ and COVID-19 impact on quality of life, $F(1,186) = 24.45$, $p < .01$, in line with previous findings. However, there was no significant interaction between remoteness and reported impact of COVID-19, $F(1, 186) = .004$, $p = .95$. The results are presented in Figure 6.20.

Figure 6.20

Boxplot of Quality o Life by Remoteness and Impact Of COVID-19



Summary of Results

Research Question 1 explored the current wellbeing of women survivors of early breast cancer in regional Australia. The current quality of life, fear of cancer recurrence, and distress for the women in this population are poorer compared to a similar Queensland sample, however, statistical significance cannot be computed in this case due to the difference in data treatment and analysis between the studies. Compared to the sample used to provide normative data for the validation of the FACT-B scale (Brady et al., 1997), the wellbeing of this sample is significantly lower compared with women with local disease (M = 105.4, SD = 23.9), $t(602)$ = 4.31, p <.01; or regional disease (M = 109.9, SD = 23.7), $t(576)$ = 4.67, p <.01.

There was a small and significant correlation between remoteness and emotional wellbeing, $r(511)$ = - .12, p <.01; and remoteness and psychological distress, $r(536)$ = -.11, p <.01; with women living in more regional areas faring better in these aspects. There was no significant correlation between remoteness and general quality of life, or remoteness and fear of cancer recurrence. This result was demonstrated again when comparing metropolitan areas from small rural towns (Table 6.6). The effect of age on quality of life, fear of cancer recurrence, psychological distress, and experiential avoidance were much more pronounced than

those of remoteness, with younger women significantly worse off in this regard (Table 6.7).

Research Question 2 considered the factors that account for quality of life in this population of women. In a general linear model with variables of interest on quality of life identified in the literature, financial strain, exercise, chemotherapy, psychological distress, social support, fear of cancer recurrence, experiential avoidance, and time since treatment were all predictive of quality of life (Table 6.9). Smoking, remoteness, actual cancer recurrence, and age of diagnosis were not significant predictors of quality of life in this model (Table 6.9). In addition to chemotherapy, the following features of cancer treatment were significantly correlated to facets of quality of life; number of breast cancer treatments, mastectomy, and hormonal therapies (Table 6.10). There was a significant difference between number of treatments and breast cancer severity $F(2,535) = 41.86$, $p < .001$; women who had Stage I cancer ($M = 2.76$, $SD = .97$) had less number of treatments than women with Stage II ($M = 3.45$, $SD = .96$) or III cancer ($M = 3.67$, $SD = 1.08$).

Research Question 3 and 4 explored possible pathways of influence of experiential avoidance. Question 3 examined whether experiential avoidance influenced behaviours that improved women's quality of life. There were no significant interactions between experiential avoidance and exercise on quality of life, $F(1,534) = 1.47$, $p = .23$. Question 4 considered experiential avoidance as a moderating factor with and without covariates on quality of life. Without covariates, experiential avoidance was a significant moderator of the effects of psychological distress on quality of life, $R^2 = .60$, $F(3, 534) = 258.53$, $\beta = .58$, $t = 2.23$, $p = .03$. However, with covariates proposed in the literature such as financial strain, exercise, chemotherapy, social support, fear of cancer recurrence, and time since treatment, experiential avoidance was not a significant moderator, $R^2 = .73$, $F(9, 527) = 156.13$, $\beta = .07$, $t = .18$, $p = .86$.

The core aim of Research Question 5 was to replicate previous findings that fear of cancer recurrence reduced quality of life. Regression analysis showed that higher fear of cancer recurrence predicted lower quality of life, $R^2 = .31$, $F(1,536) = 236.15$, $p < .01$. Additional regression analyses to follow up on observations from Study 1 found that high experiential avoidance predicted both lower quality of life, $R^2 = .53$, $F(1,536) = 594.11$, $p < .01$, and higher fear of cancer recurrence, $R^2 = .30$, $F(1,536) = 232.23$, $p < .01$. This result was also seen in independent samples t-tests

when experiential avoidance was considered as a dichotomous variable (high/low); there were significant differences between high and low experiential avoidance for quality of life including all the subscales, fear of cancer recurrence, and psychological distress (Table 6.14).

Research Question 6 considered whether experiential avoidance enhanced the fear of cancer recurrence for women who had experienced actual cancer recurrence. There was no significant interaction between experiential avoidance and actual cancer recurrence on fear of cancer recurrence, $F(1,534) = 2.14$, $p = .14$.

Additional analyses were performed to examine the impact of the COVID-19 pandemic on the responses of women to the survey. Independent sample t-tests showed a significant difference between respondents who indicated they were not impacted by COVID-19, compared to those who were impacted, on all of the main scales used in this survey (Table 6.16). There was no significant interaction between remoteness and reported impact of COVID-19 on quality of life, $F(1, 186) = .004$, $p = .95$.

Discussion

This study provided a current cross section of regional Australian women breast cancer survivors' quality of life. An important finding is that these women, mostly at the early stages of survivorship, are currently experiencing a poorer quality of life compared to similar cohorts. Women living in urban, regional, and remote areas are all affected. Women living in regional areas may now be experiencing slightly better quality of life, especially emotional wellbeing, compared to their urban counterparts. When comparing psychological distress between metropolitan areas and small rural towns, women living in towns experienced less psychological distress. However, no groups are experiencing better quality of life than women surveyed in DiSipio (2009). These results suggest that support for breast cancer survivors to increase quality of life is currently needed.

An unusual reversal in this population is of women living in urban areas experiencing poorer quality of life and increased psychological distress compared to their regional and rural counterparts. A speculation is that this is due to restrictions to metropolitan areas during COVID-19, for example, see news articles such as Pollard (2021, May 5) where regional migration is increasing, however, women in this study

were no more likely to report negative impact of COVID-19 if they lived in metropolitan areas than if they lived in small rural towns.

Other than this finding, results generally supported existing literature on quality of life such as reviewed by Mols et al. (2005). A correlation matrix of the variables of interests indicated that social support, psychological distress, experiential avoidance, fear of cancer recurrence, age, time since diagnosis, chemotherapy, smoking, and exercising were all associated in the predicted directions with quality of life. The only correlation that was not significant was between quality of life and age at diagnosis, however, it is still in the direction expected from the literature. This study also supported previous findings that survivors under 50 years of age do experience worse symptoms compared to survivors 50 years and older, such as seen in Disipio (2009). These young cancer survivors have a higher fear of cancer recurrence, psychological distress, and experiential avoidance, with a lower quality of life.

Of the variables from the literature, financial strain, exercise, chemotherapy, psychological distress, social support, fear of cancer recurrence, and time since treatment accounted for significant amounts of variance in quality of life. This study also included experiential avoidance as a variable, which has not been included in previous studies of models of quality of life in breast cancer survivors. Experiential avoidance also accounted for significant variance in quality of life. Smoking, remoteness, cancer recurrence, and age at diagnosis were not significant in this model.

Experiential avoidance was a significant predictor of fear of cancer recurrence, quality of life, and psychological distress, and these effects are large. A high level of experiential avoidance had clinically significant implications for lower physical, social, emotional, and functional wellbeing, as well as overall quality of life. Women with high experiential avoidance also experienced significantly worse psychological distress and fear of cancer recurrence. By comparison, the effect size of experiential avoidance is larger than those of reported COVID-19 pandemic impact on the same variables. These findings support the inclusion of measurement and treatment of experiential avoidance in breast cancer survivors who are struggling with quality of life, fear of cancer recurrence, and psychological distress.

While single moderated regressions found experiential avoidance to moderate the effect of psychological distress on quality of life, which provides tentative

support for Novakov (2021)'s proposal, the variance accounted for in the current study's single analyses was very limited. In a larger model that accounted for more variance and included co-variates such as financial strain, exercise, chemotherapy, social support, fear of cancer recurrence, and time since treatment, the moderating effect of experiential avoidance was not significant. This study suggests that while experiential avoidance is associated with variables of interest in breast cancer survivor wellbeing, we don't yet have a good model that captures the way that it impacts quality of life. Alternatively, as there are no longitudinal studies on experiential avoidance in cancer survivorship, it is still difficult to ascertain the causal directions of the variables; it may be that experiential avoidance is a product of some wellbeing variables.

Experiential avoidance is unlikely to impact engagement in healthy behaviours for breast cancer survivours. This population of women were generally engaged in healthy behaviours such as the recommended amount of exercise and were mostly non-smokers. While there were insufficient numbers to explore the impact of experiential avoidance on smoking, this study found in multiple ways that experiential avoidance does not significantly affect engagement in exercise. However, the idea that experiential avoidance may reduce the benefit of behaviours on wellbeing is worth further investigation. In this study, the interaction was not significant, which may be in part due to the wide variance of exercise behaviours and quality of life. The process rather than the topographical nature of experiential avoidance makes it at times a difficult variable to capture. As measurements of experiential avoidance improve to capture its momentary and contingent nature, such as in the work of Shima et al. (2021), it may be possible to reconsider the impact of experiential avoidance on the benefit of topographically healthy behaviours (i.e. doing the right thing for the wrong reason).

Another unique feature of this study is that it looked at fear of cancer recurrence in women who had actual cancer recurrence. However, the number of respondents who had experienced recurrence was 44, and conclusions to be drawn from this are limited. Women who had cancer recurrence in this study reported higher levels of fear of cancer recurrence. Of interest, the effect size of actual cancer recurrence on fear of cancer recurrence was smaller than the effect of experiential avoidance on fear of cancer recurrence. This suggests that fear of cancer recurrence

may be driven more by psychological constructs rather than direct experience with the illness.

The results of this survey indicate that support is needed for the quality of life of all Australian women breast cancer survivors, regardless of remoteness. Specifically, these women may benefit from financial support, social support, psychological support, and exercise programs to assist with improving their quality of life. Additionally, psychological support that can target psychological distress, fear of cancer recurrence, and experiential avoidance may be effective in improving quality of life, however, the mechanisms or models of action for the improvement are unclear.

The impact of cancer treatment on survivor quality of life could also expand to look at the impact of number of treatments and type of treatments. For example, another possible contributor to survivor quality of life is mastectomy compared to a lumpectomy or mastectomy with reconstruction. While reconstruction and lumpectomy were not associated with quality-of-life variables, a mastectomy was associated with poorer functional wellbeing and overall quality of life. Hormonal therapies are associated with poorer physical and emotional wellbeing.
Given that women in regional areas are less likely to receive lumpectomy with radiotherapy, and more likely to have mastectomies than urban counterparts (Collins et al., 2018), this may result in a disparity in quality of life outcomes for regional breast cancer survivors. Education on how certain therapies may have an impact to quality of life in survivorship may help regional patients make informed decisions about their future wellbeing. It may be worth tackling the short term inconvenience and life upheaval to obtain better quality of life in survivorship. On a societal level, increasing the availability of radiotherapy and breast reconstruction in regional Australia would be of benefit to the increasing number of survivors who live in these regions.

A main limitation of this study is the recruitment method. Previous comparable studies have recruited through cancer registries and doctors with design considerations for sampling bias and authentication of respondents. This study recruited through convenience and social media and a biased sample is possible due to who Facebook designates as a marketable audience. For example, those that Facebook may have marketed the survey to are women who matched cancer and breast cancer interests. Women experiencing lower cancer health related quality of

life, or for whom cancer is a pressing matter, may be more likely to engage in supportive cancer content on social media over other social media content. However there are no studies thus far to clarify whether there are biases in social media recruitment. There is also no way to verify that everyone who completed the survey actually was a breast cancer survivor. However, respondents were likely responding purposefully as the measures had good internal reliably, and the type of incentive offered for participation appeals mostly to survivors and their communities.

Furthermore, there were relatively few respondents from remote and very remote communities (n = 17 and 8 respectively). A national analysis of population distribution across MMM by Versace et al. (2021) found that 1.17% of the Australian population lived in MMM6, and .77% lives in MMM7 areas. Of the 538 participants recruited for this study, 3.2% were from MMM6, and 1.5% were from MMM7, which suggests that while there were comparatively few respondents from these communities compared to those from other areas, there was proportionate representation. While the representation of remote and very remote communities in this survey is proportionate with the Australian population, the small numbers in the survey resulted in larger variance of responses. While there is some indication that women in remote and very remote communities may experience lower quality of life, the significance of this difference is impacted by the wide confidence intervals associated with low respondent numbers. The wellbeing of women in these communities may be better assessed using other methods, such as qualitative analysis.

There were also limitations related to measurement of constructs. For example, the measurement of smoking and exercise were informed by recommendations for health in cancer survivorship, however, did not use a standardised questionnaire, and there was no investigation into whether these questions adequately measured the construct. This, and unequal sample sizes, may explain why this study did not find a relationship between smoking and quality of life, and exercise and quality of life, when these relationships are established in existing literature Another consideration due to participants' responses on the quality-of-life scale is that certain questions may not be uniformly relevant to survivors. For example, the statement "I am satisfied I am coping with my illness" created such division in responses that it affected the internal reliability of the Emotional Wellbeing Subscale. Survivors may no longer perceive cancer as an ever-

present illness in their lives, and terminology may need to be updated to reflect current survivor's perceptions of breast cancer. Long term survivors may not perceive themselves to be currently suffering an illness.

Finally, a cross-sectional survey of psychosocial outcomes limits conclusions on the possible causal factors related to psychosocial outcomes in health-related quality of life for regional and remote Australia. Longitudinal studies may assist in answering these questions, and there is some evidence from this survey that some women live in their regions long term. However, the population characteristics that underpin the remoteness classification where they reside have changed, which is a difficult confound to control in longitudinal studies focused on the effects of geographic remoteness on the variables of interest.

CHAPTER 7 - DISCUSSION AND CONCLUSION

As more women survive early breast cancer and the number of long term survivors in regional Australia continues to grow, approaches that assist with understanding and improving these women's quality of life become increasingly important. Often, these resilient women have gone through significant and diverse changes due to the illness and medical treatment. The impact of this on their quality of life is multi-faceted, requiring a specific understanding of the ways in which quality of life can be impacted and a theoretical cohesive approach driving interventions for quality of life. Many studies on quality of life intervention in breast cancer survivors focus on the efficacy of interventions (i.e. if they work) without considering how the specific assumptions and targets of the therapy may align with factors relevant to quality of life in cancer survivorship (i.e. why they work). Also, many of these studies occur in urban population samples, even though there is evidence that women living in regional and rural areas may face different challenges. This project focused on the wellbeing of women breast cancer survivors in regional Australia. The focus increases data available for regional Australia, and hopefully decreases the reliance on extrapolating data from urban samples in decision making for our vibrant and unique regional and rural communities. The pair of studies looked at the feasibility of an intervention that demonstrates some promise in both efficacy and theoretical cohesiveness in improving the quality of life of breast cancer survivors, and further explored the proposed mechanisms for these changes. The unique focus of this project was to consider how experiential avoidance may be a target of therapy to improve wellbeing and address fear of cancer recurrence, as well as looking at the role of experiential avoidance in the lives of women survivors.

Main Findings

Experiential avoidance was shown to be a significant predictor of quality of life in breast cancer survivors within a model that contained other strong and established predictors. Mols et al. (2005) summarised predictors of quality of life into four categories; demographic, social, psychological, and disease characteristics. Study 2 in this project considered variables from each category in a predictive model for quality of life. This approach differed from existing studies on predictors of quality of life in breast cancer survivors as it considers variables across domains,

rather than just within domains. For example, Engel et al. (2003) considered demographic, social, and disease characteristics, but not psychological characteristics for breast cancer patients, and Parker et al. (2003) included psychosocial and demographic variables but not social and disease characteristics in predictors for general cancer patient quality of life. In this project, a general linear model with both psychological and non-psychological contributors to survivor quality of life showed that significant predictors included a mix of both, suggesting that studies modelling predictors of quality of life in survivorship should include both. A model that includes well evidenced predictors from different facets of women's lives provides representation of living as a whole.

Of the demographic, social, and disease characteristics, it was financial strain, exercise, chemotherapy, social support, and time since treatment that accounted for significant variance. Wellbeing programs must target these aspects of survivorship, possibly through a combination of education and skills training. Financial strain emerged as an important consideration 'o survivor's wellbeing, which may be particularly relevant in regional areas where travel is a limiting factor in receiving interventions (Youl et al., 2016). Initiatives addressing breast cancer quality of life must include a financial component, with financial support as a priority, and financial counselling to assist in decision making. The research and application of exercise on wellbeing in survivorship is established, for example, see Zeng et al. (2014), and should be recommended for survivors. However, the premise for Study 1 included the input of a regional breast cancer care nurse whose observation was that while patients were educated in the benefits of exercise, psychological intervention post cancer treatment was lacking, which impacted women's wellbeing. Education on the long term impacts of chemotherapy and other treatments on quality of life, and how to mitigate or adapt to these effects, may assist patients with their coping in survivorship. This is embodied by the term 'new normal' where patients learn about the effects of their cancer treatment and how to remain adaptive (Ha & Ryu, 2021). While social support is an important area, again it was identified by the breast cancer care nurse initially due to a lack of focus on recovery in some of these groups. If social support is recommended, targets of intervention informed by models of quality of life, such as Naus et al. (2009), should be considered. In this case, education for family and friends of breast cancer survivors on understanding personal context and adaption may be beneficial. Time

since treatment is not a manipulatable variable, however, survivors may benefit from knowing that their quality of life is generally expected to improve with time. Intervention for non-psychological variables requires a combination of systems change that increases practical support to survivors, and education.

Of the psychological variables, psychological distress, experiential avoidance, and fear of cancer recurrence were significant in a general linear model of quality of life, suggesting that these are candidates for psychological intervention. Of these psychological constructs, experiential avoidance has yet to be firmly established in interventions for wellbeing in breast cancer survivors, even though it is strongly associated with fear of cancer recurrence and has predictive value in quality of life. Experiential avoidance significantly correlated with most other variables of interest in both Study 1 and Study 2: quality of life, fear of cancer recurrence, psychological distress as measured by two different measures, age, age at diagnosis, financial strain, and smoking. In this project, quality of life was not associated with actual cancer recurrence, remoteness, or stage of breast cancer. While the numbers of respondents with cancer recurrence was low (n = 44), this supports the idea that quality of life may be related to a survivor's subjective experience (Cella, 1994). As Wilson and Cleary (1995) proposed, psychological supports may assist in improving quality of life through interventions that impact perceptions of symptoms status and general health perceptions that feed into subjective wellbeing. Modelling and intervention for quality of life in breast cancer survivors would be incomplete without psychological variables such as experiential avoidance.

Where health resources are scarce, the inclusion of psychological and educational intervention may be a cost effective method of improving the wellbeing of survivors. This is not to say that this approach will reduce the real financial burdens and limited health services of these regions, however, may increase the ability of survivors to cope with these disparities. ACT is an approach that many Australian oncology health professionals are familiar with in the management of fear of cancer recurrence (Thewes et al., 2014). This is useful when considering the costs of training health professionals, and the targeting of constructs that are particularly relevant to the quality of life of regional breast cancer survivors. While Study 2 did not find a difference in fear of cancer recurrence reported based on remoteness, this is likely because general distress across all regions of Australia increased at the time

of the survey due to COVID-19. Women surveyed during this time had generally poorer quality of life compared to similar studies conducted previously. It may be of interest to note that while both effects were significant, the effect of experiential avoidance on these aspects of wellbeing had a larger effect than the impact of COVID-19 on quality of life (experiential avoidance, d = 1.39; COVID-19, d = .47), fear of cancer recurrence (experiential avoidance, d = -1.06; COVID-19, d = -.30), and psychological distress (experiential avoidance, d = -1.66; COVID-19, d = -.50).

The literature thus far has shown experiential avoidance to be an enduring characteristic predictive of both enhancing the negative aspects of wellbeing and reducing the ability to engage in wellbeing enhancing behaviours (Kashdan et al., 2006). There are also large trials now that demonstrate the utility of ACT in improving cancer survivor's wellbeing, for example, Arch and Mitchell (2016). However, it is still unclear how this intervention creates change in outcomes. Individual analysis of participant scores in Study 1 did not reliably show that decreases in experiential avoidance where applicable co-occurred with decreases in fear and psychological distress or increases in quality of life. It is still not known if ACT reliably improves wellbeing outcomes by decreasing experiential avoidance. This supports the notion of possibly moving away from named therapies in clinical intervention and increasing emphasis on common factors or pathways of change in intervention that are clinically useful. In moving towards an understanding of mediators and moderators of intervention, regardless of therapy modality, clinicians can hone in on relevant processes rather than rely on treatment protocols (Hofmann & Hayes, 2019).

When considering treatment targeting experiential avoidance and quality of life in survivors, characteristics such as age, actual cancer recurrence, and financial strain are factors to consider. Breast cancer survivors under 50 years old report significantly higher fear, distress, and avoidance, as well as lower quality of life, compared to survivors 50 years and older. Younger cancer survivors may be screened for high experiential avoidance using the AAQ-II or a similar measure prior to psychological intervention being suggested. While there was no interaction between experiential avoidance and actual cancer recurrence on fear of cancer recurrence, both experiential avoidance and actual recurrence were significantly associated with higher fear of cancer recurrence, with experiential avoidance having

a larger effect (experiential avoidance, $\eta^2_{partial}$= .05; actual cancer recurrence, $\eta^2_{partial}$= .02). Financial strain and experiential avoidance were significantly positively correlated. While this relationship was not explored further in this study, it may be that the provision of free and easily accessible help to address experiential avoidance in financial strain may assist in quality of life outcomes. Targeting experiential avoidance will not reduce the very real difficulties, including socioeconomic difficulties (Collins et al., 2018), that regional survivors of breast cancer face, rather, it may increase women's capacity to approach difficult decisions based on their values and with an outcome focus.

Participants with high or low experiential avoidance did show statistically and clinically significant differences in all aspects of quality of life, and statistically significant differences in fear of cancer recurrence and distress. This finding is clear in Study 1 and Study 2. High experiential avoidance was associated with lower overall and subdomains of quality of life. It impacted participant's subjective experiences of physical, social, emotional, and functional wellbeing. Experiential avoidance was not a significant moderator of fear of cancer recurrence or psychological distress on quality of life in a model containing psychological, practical, and health factors, however, it is a predictor of quality of life. This suggests that experiential avoidance may have a direct effect on quality of life.

However, while it was promising to see experiential avoidance having different correlation coefficients with quality of life and fear of cancer recurrence at high and low levels defined by observations in the Study 1, these observations failed to translate to additional usefulness in Study 2. Treating experiential avoidance as a categorical variable (high and low) did not add additional value when compared to treating experiential avoidance as a continuous variable. For example, the categorical variable did not detect interactions of experiential avoidance on actual cancer recurrence and fear of cancer recurrence, or on quality of life and exercise. In a model with other predictors, the dichotomous experiential avoidance variable did not moderate the relationship between fear of cancer recurrence and quality of life. Any effect detected by the dichotomous variable was already detected with the use of the continuous variable. This suggests that the dichotomous experiential avoidance variable is comparable to the continuous variable; there is no increasing differential effect of experiential avoidance on other variables of interest at high or low levels.

In Study 2, emotional wellbeing was shown to be higher in more regional areas compared to urban areas. However, due to the small sample size for remote and very remote communities, it is difficult to support the idea that this difference carries past small rural towns. In fact, very remote communities as a whole tended to report lower quality of life. In these areas, psychological intervention may be difficult to access, and due to the low population numbers, groups with breast cancer survivors difficult to organise. Increasing acceptability of telehealth options has been proposed as a way of engaging women in remote and very remote communities, however, the availability of technology such as the internet is a real challenge (Parliament of Australia, 2002). There is no quick or easy solution to servicing this population. Intervention is undoubtably costly, but a necessary focus of health initiatives. As a starting point for psychological intervention in these areas, the Boyes et al. (2009) study found that low levels of support were associated with anxiety, and low levels of positive social interaction were associated with depression. Increasing follow-up contact with health services and building local support networks for cancer survivors may be a starting point of investment in breast cancer survivor wellbeing.

While it is difficult to determine due to the confounding effect of COVID-19, this study tentatively supports the idea that the participants in Study 1 may have experienced better quality of life with lower fear of cancer recurrence compared to others regional early breast cancer survivors. There is some evidence in the literature to explain this, mainly that participating in clinical trials (Murphy et al., 2015) and treatment in a regional private hospital setting (Spilsbury et al., 2005) improve survivorship outcomes.

Strengths

Clinical Utility

A strength of this project is the focus on clinical utility. Both Study 1 and Study 2 provided some analyses on clinical significance in addition to statistical significance. The addition of clinical significance in studies may further assist with decisions regarding the allocation of support to areas with a high and noticeable need. The scales used to measure psychological distress in these studies, the DASS-21 and K10, are both widely used by Australian clinicians in the management of

psychological symptoms. Using these measures creates a shared language between researchers and clinicians, increasing the utility of research in clinical practice.

Understanding individual profiles of change and mechanisms of change has good clinical utility when considering the treatment of women in private practice settings. Reliance on group based studies or manualised protocols alone may not inform best practice in clinical settings as there is limited generalizability of large aggregated studies on accounting for individual variance (Fisher et al., 2018). This research project provided insight into the individual differences of ACT on women's wellbeing. While psychological distress was shown to improve for numerous points of symptoms of depression, anxiety, and stress, how these changes came about may be different for different women. For example, while Participant 4's results showed decreases in both experiential avoidance and psychological distress following ACT intervention as expected, Participant 18 also experienced reductions in distress following the treatment, but without a reliable change in experiential avoidance. These results taken together with results from Study 2 indicates that we still do not know the way ACT produces outcomes in patients, nor a model where experiential avoidance can adequately account for changes in fear of cancer recurrence and quality of life. We know that ACT is effective, and experiential avoidance is important, but we can't yet account for the individual differences in treatment effects or the process through which the treatment creates change. The incorporation of individual data and attempts to clarify experiential avoidance within models of quality of life can inform the better targeting of therapeutic approaches.

A focus on exploring and testing the proposed mechanisms of change within a therapy both assists with testing the theoretic assumptions of an approach, and increases the targeting of processes that may drive an effect. Increasingly, there is a call in the field of psychotherapy to move towards a common factors approach, considering the common processes that are primarily responsible for driving therapeutic change (Hofmann & Barlow, 2014). In the future, clinical interventions may rely less on protocols of named therapies such as Acceptance and Commitment Therapy, Cognitive Behaviour Therapy, or Mindfulness Based Stress Reduction, and instead focus on these specific processes (Hofmann & Hayes, 2019). For example, exploration of the impact of experiential avoidance on fear of cancer recurrence, underpinned by an understanding of control and avoidance within the fear of cancer recurrence model proposed by Fardell et al. (2016), provides an avenue for clinicians

to work with this particular area without necessarily using a named approach. Research would consider which approaches may target experiential avoidance, and whether this reduces the control and avoidance that serves to maintain a high fear of cancer recurrence. This type of research is not within the scope of this current study, but a contribution of Study 2 is a step away from a packaged approach to intervention to further explore a possible mechanism of action.

Comparability with Other Studies

Another strength of this research project is that it included measurement instruments and analyses that improved comparability to similar studies. In Study 1, the inclusion of specific measures, and the additional analysis of some of the results helped improve comparability to Feros et al. (2013), another Australian ACT preliminary study. In Study 2, the analysis of urban, regional, and rural cohorts separated by age provided a comparison to results from DiSipio (2009), demonstrating poorer quality of life compared to the previous cohort, and the current lack of significant or clinical differences between urban and regional/rural populations.

When Study 1 was being conducted, the use of the Depression, Anxiety and Stress Scale to measure psychological distress in breast cancer patients and survivors was uncommon. The measure was chosen for Study 1 to provide comparability to Feros et al. (2013) and for clinical utility. However, the use of the measure in more recent studies, such as Novakov (2021) provides some comparability of studies with each other, and also with data gathered in clinical settings where variants of the DASS are widely used.

Limitations

There are a number of limitations across both studies. Some limitations were due to deliberate design choices that prioritised the needs of the community, and clinical utility over design rigour. These considerations have been discussed in Chapter 4 (Study 1) and Chapter 6 (Study 2). Additional limitations are noted below.

Representativeness

A significant limitation of this research project was the failure to recruit an ethnically diverse cohort. Even in the larger Study 2, of 538 participants, only five participants identified as Australian Aboriginal or South Sea Islander. Indigenous

women breast cancer survivors' voices are not adequately represented in this sample. Indigenous Australians make up 3.3% of the total population (Australian Institute of Health and Welfare, 2021). Using this as a rough estimate of equivalence of the participants, a representative sample would have included at least 17 Indigenous respondents. The same is likely true for other Australian ethnic minorities who participated in the survey. This is very concerning given the difficulties that indigenous women with breast cancer in Australia are known to have. A review by Dasgupta et al. (2018) of 16 studies conducted between 1990 and 2015 on outcomes for this population found that indigenous women were more likely diagnosed younger, had advanced disease or comorbidities, reside in disadvantaged or remote areas, and less likely to undergo screening and surgery. Overall, there was a pattern of poorer survival, and no information on quality of life or treatment factors such as treatment choices, completion of treatment, or attendance at follow-up.

There was also likely a recruitment bias related to socio-economic status in Study 1, which was through a private hospital. Treatment through regional public hospitals (Spilsbury et al., 2005) and lower socio-economic status does have health disadvantages in Australia (Turrell & Mathers, 2000), and people with lower incomes in Australia are less likely to afford or be incentivised towards private health care. This has implications for the interpretation of Study 1 to cohorts outside of the private health sector. As mentioned in the discussion of Study 1, replication within the regional public health system is needed.

While not a focus of the study or psychological intervention, neither is it a design flaw, it is worth noting that financial strain significantly impacts quality of life for women breast cancer survivors and yet is ignored in psychosocial research and interventions. Financial counselling may be an overlooked component of addressing quality of life following primary breast cancer care. A report on the financial impact of breast cancer by Breast Cancer Network Australia (2016) indicated that out-of-pockets costs of treatment and care, time off work with no or inadequate leave entitlements and resulting income drop, and travel from rural and regional areas all increase the financial burden of the disease. The research component of the report did not explicitly link financial burden to quality of life, however, it is implied that out-of-pocket expenses between $7000 - $21000 in the first five years after cancer diagnosis, as well as loss of income, places significant stress to women's lives.

Effect Of Distress Reporting When Distress is High

There is a possible confound in how participants report psychological distress when experiential avoidance is high. If participants are intolerant and avoidant of aversive internal experiences, they may not be able to accurately report their level of psychological distress. While there is evidence in the literature that experiential avoidance and psychological distress are related, it is possible that the effect is actually stronger than that which is detected due to a portion of participants who are experientially avoidant inaccurately reporting their psychological distress. This may explain why it was difficult to match a reduction in experiential avoidance to a reduction in psychological distress in the participants of Study 1, and why the correlation co-efficients for experiential avoidance on depression, anxiety and stress were not significant when experiential avoidance was classified as high and low. In Study 2, moderation analysis initially indicated that experiential avoidance moderated the impact of psychological distress on quality of life. While this was not found to be significant in a larger model, again this could be diluted by possibly paradoxical reporting of distress when avoidance is high. Further clarification is required, however, clinicians may expect to see initial increases in distress while they work on experiential avoidance, followed by a decrease in distress when experiential avoidance falls below clinical levels.

An anticipated outcome of ACT is that patients will be more willing and able to experience states that they may find aversive, remain non-reactive in these experiences, and strive to engage in values-oriented behaviours. This therapy may provide a more focused targeting of fear of cancer recurrence in women survivors compared to cognitive behaviour therapy as it helps women accurately report their experiences. However, measurement of outcomes using self-reported scales of distress may be problematic.

Reason For Health Behaviours

As ACT promotes values-consistent behaviour at least in part by reducing experiential avoidance (for example, exercising because it's related to a value rather than not exercising because it's tiring and painful), it was expected that women who were less experientially avoidant may be engaging in more healthy behaviours. Most of the variables that experiential avoidance did not correlate with make sense; experiential avoidance would not be expected to impact demographic and disease

characteristics. However, that is it not correlated with exercise, and upon further analysis didn't seem to significantly affect the rate of sufficient exercise, is interesting and may benefit from clarification in the future. Kashdan and Rottenberg (2010) differentiate between motivations for behaviour based on acceptance or avoidance. For example, exercising due to the benefits to health may be motivated by acceptance, whereas exercising to not get sick may be motivated by avoidance. To the outside observer, the outcome of exercise time may be the same regardless of motivation, however, the impact to quality of life may be different due to the negative effect of avoidant coping on quality of life (Hack & Degner, 2004). Study 2 did not consider the reason why women were exercising, whether the behaviour fulfilled a freely chosen value, or whether it was fear or avoidance driven. The assumption was that engagement in adequate exercise was an expression of a health related value in breast cancer survivors, however, this was not measured. Measures that differentiate behaviour intention may assist in clarifying the role of experiential avoidance in driving behaviours such as exercise. For example, the Six Ways to Wellbeing measure (Basarkod, 2019) captures the reason people may engage in a healthy behaviour; pressure or values expression.

Study Design

Limitations specific to each study were discussed in the discussion section of each chapter, namely Chapter 4 and Chapter 6. However, study design choices are worth highlighting again as the practicalities of conducting research in regional areas can limit interpretation of results. Firstly, the rolling recruitment method of Study 1 was the most practical way of moving forward with a pilot study in a regional centre. However, as type of analyses depended on recruitment, the choice of individual or group analyses was driven partially by practicality. While there is considerable value in individual analyses in clinical work, and also in generating hypotheses for a larger trial, a larger sample size for Study 1 would have allowed for some group-level analyses that may have increased the generalisability of the results. Study 2 had adequate sample size for group-level analyses and answered some of the construct related questions generated following Study 1. However, the cross-sectional nature of the study limited the discussion on causality and how variables of interest may change over time. Given that there is evidence in the literature of treatment choices affecting long term quality of life, and limited follow-up in local primary care

settings following discharge from cancer services, longitudinal studies are needed to clarify the variables of interest in quality of life for long term breast cancer survivors, especially in regional areas.

Future Research

Remote and Very Remote Communities

Quantitative accounts of quality of life in remote and very remote Australian communities continue to be difficult to capture. The information available on remote and very remote community health from the Australian Institute of Health and Welfare (2020) indicates lower rates of breast cancer screening, a shortage of the health workforce, and health outcomes that are lower partially due to the higher proportion of Indigenous Australians who reside in these communities. Studies on regional and rural health often do not report specific numbers of participants from remote and very remote communities, even if the study purports to focus on geographically isolated regions, for example, White et al. (2011). Study 2 only had a combined number of 25 participants from remote and very remote communities nationally. Transparent reporting of remoteness in future Australian studies will help those conducting research on regional and rural communities to know how little we know about these communities so far. Reporting of remoteness may assist with future literature review and meta-analysis of remote and very remote community participants. Due to the small population, small and qualitative studies are needed to determine the unique impacts of living in these communities. The need for specific reporting regarding remoteness is not just an issue for Australian studies, given that this was raised in the Anbari et al. (2020) review of breast cancer survivorship in rural settings. Due to the comparatively small population of remote and very remote communities, an international effort may be required to understand the unique experiences of this population and to recruit adequate numbers to power statistical analyses.

Testing Models Of Fear Of Cancer Recurrence

Fear of cancer recurrence is a known associate of quality of life in breast cancer survivors. The work of Fardell et al. (2016) to understand the components of fear of cancer recurrence may provide a link between psychological flexibility/inflexibility more broadly, and fear of cancer recurrence. This is one

possible avenue through which targeting experiential avoidance can improve quality of life. In their model, Fardell et al. (2016) propose that past traumatic experiences may make certain individuals more vulnerable to fear of cancer recurrence, and may take actions to deliberately avoid feelings, thoughts, memories, or bodily sensations that they perceive as unwanted or aversive. Coping strategies focused on controlling, avoiding, or suppressing unwanted experiences related to fear of cancer recurrence can maintain the fear. Acceptance based approaches can help us understand and work with the role of cognition and beliefs as well as the behavioural consequence components of fear of cancer recurrence. While Study 1 and Study 2 have focused on ACT and experiential avoidance, it is possible that the impact of ACT on fear of cancer recurrence targets more than just the reduction of experiential avoidance. There is evidence that experiential avoidance, defined strictly, is only one core process targeted by ACT and there are other processes that are not captured by the AAQs (Francis et al., 2016).

However, before these processes can be clarified, models of fear of cancer recurrence need to be tested, and measurements may need updating as conceptualisations of fear of cancer recurrence change. For example, the widely used Concerns About Recurrence Scale (Vickberg, 2003) was created before the push to conceptualise fear of cancer recurrence as a clinical feature. As such, the purpose of the measure could not be to consider clinical cut-offs for symptoms. Future research on fear of cancer recurrence may focus on a testable model of fear of cancer recurrence, and how this relates to clinical or sub-clinical levels of fear. This may allow for increased utility regarding fear of cancer recurrence and experiential avoidance, as well as an exploration of the other processes of ACT.

Beyond Experiential Avoidance: A Focus On Psychological Flexibility

While ACT is an accepted therapy in psycho-oncology for the management of fear of cancer recurrence (Thewes et al., 2014), measuring the processes purportedly driving therapeutic outcomes poses a challenge. A difficulty previously highlighted is that the constructs experiential avoidance, psychological flexibility, psychological inflexibility, and acceptance have historically had the same outcome measure – versions of the Acceptance and Action Questionnaires. As such, it is hard to tease apart research on each construct. This interchangeability in use of terms is a methodological flaw that future studies may further clarify.

Psychological flexibility was not a focus of this thesis, however, is worth mentioning and pursuing in future studies on breast cancer survivor wellbeing and intervention for the wellbeing of this population, as there is some evidence that mental wellbeing and illness are different dimensions (Keyes, 2005), and that the absence of illness is not a guarantee of health in adults and older adults (Westerhof & Keyes, 2010). Kashdan and Rottenberg (2010) propose that it is dynamic flexibility and openness to emotions, thoughts, and behaviours in approach to situations (psychological flexibility) that is associated with wellbeing because it increases a person's chance of a good outcome, whereas experiential avoidance may be more associated with the ridged, context-insensitive responses seen in psychopathology. This distinction may assist in understanding differences in treatment outcome for women breast cancer survivors. Is ACT helpful because it reduces experiential avoidance, or because it increases psychological flexibility, or both? Perhaps women breast cancer survivors who have a high fear of cancer recurrence benefit from ACT because it reduces their experiential avoidance. However, for women who are not experientially avoidant, ACT may improve wellbeing by increasing psychological flexibility. This distinction is particularly relevant when considering treatment for younger and older survivors of breast cancer. For younger survivors who experience significantly more psychological distress and fear of cancer recurrence, targeting experiential avoidance may be most effective. For older survivors who have lower fear and distress, maintaining and increasing psychological flexibility when considering treatment decisions may be most effective. For example, older cancer survivors may prefer to trade length of life for quality of life (Shrestha et al., 2019).

Before intervention could be recommended in cases of high or low fear of cancer recurrence and quality of life, measures of experiential avoidance and psychological flexibility that are distinct with good psychometric properties must be developed. There has been advancement in measures over the past decade, with a number of candidates. For the purpose of clarifying the possible therapeutic process related to psychological flexibility, it may be beneficial to employ a measure that distinguishes aspects of psychological flexibility.

At the time of Study 1, The Comprehensive Assessment of Acceptance and Commitment Therapy Processes (Francis et al., 2016), a 22 item questionnaire, was mentioned as a candidate for measuring psychological flexibility as an ACT

therapeutic outcome. This measure allows for the calculation of subscales: openness to experience, behavioural awareness, and valued action. However, at the time of Study 1, the scale was dismissed for its length and limited validation outside of its original study. Since then, the measure has been used, usually alongside the AAQ-II, to measure treatment effectiveness of ACT interventions, for example, in Levin et al. (2019), Barrett-Naylor et al. (2018), and Petersen et al. (2021). In these studies however, the inclusion of the scale as a process measure uses it for an overall score rather than analysis on a subscale level, thus it has not yet shown the measure's possible research or clinical utility in differentiating psychological flexibility from experiential avoidance.

The Multidimensional Psychological Flexibility Inventory (Rolffs et al., 2018) is also a measure that breaks psychological flexibility down to its theoretical components. This questionnaire contains 59 questions grouped into flexibility and inflexibility subscales. The subscales for flexibility include acceptance, present moment awareness, self as context, defusion, values, and committed action. Inflexibility subscales include experiential avoidance, lack of contact with the present moment, self as content, fusion, lack of contact with values, and inaction. The authors have focused on clinical utility and are developing a profile to be accessible to clinicians online (Rogge, 2018). However, compared to other clinical outcome measures, the questionnaire is cumbersome to administer.

Recently, Gloster et al. (2021) developed a six question, one factor solution for measuring psychological flexibility that has good initial internal validity, test-retest reliability, and convergent validity, and may measure psychological flexibility rather than experiential avoidance. Each question corresponds to an aspect of psychological flexibility; being present, being open to experiences, leaving thoughts to be, a steady self, an awareness of one's own values, and being engaged. This questionnaire includes a prompt to consider the statements in the context of the past seven days, which is comparable to other measures of clinical utility such as the DASS (Lovibond & Lovibond, 2002), which also specifies to consider the statements in the context of the past week. Scale development consisted of a literature review and input from experts on ACT to generate six items, however, number of experts consulted, literature reviewed, and how consensus was reached in terms of items to retain were not provided. The items of the scale were tested on four independent clinical and non-clinical samples for a combined number of 744

participants. A Raykov's coefficient of .91 was found across the samples. The measure also showed good convergent validity with measure such as the AAQ-II (*r* = -.71). Measures like this are attractive to clinicians in terms of their brevity.

Future research may be able to use one or more of the abovementioned scales, depending on the focus on clinical utility or clarification of mechanisms of action, to further understand the impact of ACT and psychological flexibility on quality of life in breast cancer survivorship.

Conclusion

This project has contributed to the understanding of how ACT may impact the quality of life for women survivors of early breast cancer. Experiential avoidance is an important construct to consider when looking to reduce fear of cancer recurrence and increase quality of life. A feature of the first study of this project was the collaboration of researchers and hospital staff to address patient needs, prioritizing immediate benefit to the community. Following this, a renewed focus on clarifying how treatment targets were related to each other provided understanding of how approaches like ACT may affect quality of life. This project also provided an updated, national survey of quality of life for women early breast cancer survivors in regional Australia. To the best of the author's knowledge, a regional Australia-wide survey of this kind has not been conducted before. While there are sampling biases, this project provides an overview of these women's quality of life during the COVID-19 pandemic, where isolation and service interruptions occurred. A finding of this more recent research shows a clear deterioration in quality of life compared to previous samples, with women in urban areas experiencing poorer quality of life than their regional and remote counterparts. This suggests that interventions that help women improve their quality of life are more relevant now than before.

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APPENDIX A – Study 1 Consent and Information Form

University of Southern Queensland

Participant Information Sheet for USQ/SAH Research Project

Project Details

Title of Project:	Mind Over Matter - Effectiveness of Acceptance and Commitment Therapy (ACT) on quality of life following primary treatment for early breast cancer
Human Research Ethics Approval Number:	H17REA184 and HREC/17/QTDD/51

Research Team Contact Details

Research Study Coordinator: Dr Eliza Whiteside, eliza.whiteside@usq.edu.au, [redacted]

Breast Care Nurse: Gaye Foot, [redacted]

Description

This project is being undertaken as part of a collaboration between researchers in psychology and biomedical science at USQ and breast care nurses and psychologists at St Andrew's Hospital. The purpose of this project is to determine whether an eight week face to face program of Acceptance and Commitment Therapy affects the quality of life and health of women who have recently completed primary treatment for early breast cancer. These effects will be measured using online questionnaires and completion of a workbook with set questions as well as measuring blood pressure, resting heart rate and stress markers in blood and saliva. The program will run over 16 weeks during which you will receive an eight (8) week group based Acceptance and Commitment Therapy program and either an eight (8) week breast cancer education program or an eight (8) week period of no face to face activities but will be required to complete the questionnaire and provide a blood and saliva specimen tested. The order in which you receive programs these will depend upon which group to which you are randomly assigned.

The research team requests your assistance because you have recently been treated for early breast cancer.

Participation

Your participation will involve:

- Completing the *Preliminary Information and Consent Form* and returning to Gaye or Eliza.
- Undertaking a 60 – 90 minute clinical interview with a registered psychologist at USQ.
- Attending a face to face Acceptance and Commitment Therapy group program, or breast cancer education program with seven other women at St Andrews Hospital for either eight (8) or 16 Saturdays from 10 – 11.30 am. Morning tea will be provided.
- Learning Acceptance and Commitment Therapy strategies from an Acceptance and Commitment Therapy trained clinical psychologist as well as practicing the Acceptance and Commitment Therapy strategies and noting your reflections in a workbook.
- Responding to a brief daily phone text message regarding your behaviors (e.g. *Have you practiced your mindfulness today?).*
- If placed in the group that undertakes breast cancer education, you will learn about ways to better cope with breast cancer-specific issues such as the side effects of treatment, and known benefits from certain diets and physical activity. These sessions will be delivered by experts in their fields.
- Completing a questionnaire that will take approximately 30 minutes of your time at the beginning and end of each eight week program and at 6 months and 12 months after the

University of Southern Queensland

Participant Information Sheet for USQ/SAH Research Project

Project Details

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The research team requests your assistance because you have recently been treated for early breast cancer.

Participation

Your participation will involve:

Completing the Preliminary Information and Consent Form and returning to Gaye or Eliza.

Undertaking a 60 – 90 minute clinical interview with a registered psychologist at USQ.

Attending a face to face Acceptance and Commitment Therapy group program, or breast cancer education program with seven other women at St Andrews Hospital for either eight (8) or 16 Saturdays from 10 – 11.30 am. Morning tea will be provided.

Learning Acceptance and Commitment Therapy strategies from an Acceptance and Commitment Therapy trained clinical psychologist as well as practicing the Acceptance and Commitment Therapy strategies and noting your reflections in a workbook.

Responding to a brief daily phone text message regarding your behaviors (e.g. Have you practiced your mindfulness today?).

If placed in the group that undertakes breast cancer education, you will learn about ways to better cope with breast cancer-specific issues such as the side effects of treatment, and known benefits from certain diets and physical activity. These sessions will be delivered by experts in their fields.

Completing a questionnaire that will take approximately 30 minutes of your time at the beginning and end of each eight week program and at 6 months and 12 months after the final face to face session. Examples of the types of questions in the questionnaire are: I am satisfied with how I am coping with my illness and I am sleeping well with your answers ranked as Not at all, A little bit, Somewhat, Quite a bit or Very much.

Allowing your blood pressure and resting heart rate to be measured at the beginning and end of each program.

Allowing blood samples to be collected by a scientist trained in blood collection at the beginning and end of each program and at 6 and 12 months follow-up. These will be used to measure stress and inflammation biomarkers.

Providing saliva samples at the beginning of each Acceptance and Commitment Therapy and breast cancer education program session as well as at 6 and 12 months

follow-up. These will be used to measure salivary cortisol and amylase which are also stress biomarkers.

Your participation in this project is entirely voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Please note, that if you wish to withdraw from the project after you have submitted your responses, the Research Team are unable to remove your data from the project. If you do wish to withdraw from this project, please contact Gaye or Eliza. Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with USQ or St Andrew's Hospital.

Expected Benefits

It is expected that this project may directly benefit you by teaching you the skills embodied by Acceptance and Commitment Therapy. The study may also benefit other women and men affected by breast cancer and other cancers.

Risks

Sometimes thinking about the sorts of issues raised in the questionnaire can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact Lifeline on 13 11 14. You may also wish to consider consulting your General Practitioner (GP) for additional support.

There can also be pain and risks with providing a blood sample and you should advise the Research Coordinator if you have any clotting issues or other blood disorders that may affect the blood test procedure.

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses. Any data collected as a part of this project will be stored securely as per USQ's Research Data Management policy.

Consent to Participate

The return (by email or post) of a signed and dated Consent Form as well as the Preliminary Information Form indicates consent to participate in the study.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the USQ Ethics Coordinator on (07) 4631 2690, ethics@usq.edu.au or DDHHS HREC Coordinator on (07) 4616 6696, DDHHS-RESEARCH@health.qld.edu.au. The Ethics Coordinators are not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please keep this sheet for your information.

Consent Form for USQ/SAH Research Project

Project Details

Title of Project: Mind Over Matter - Effectiveness of Acceptance and Commitment Therapy (ACT) on quality of life following primary treatment for early breast cancer

Human Research Ethics Approval Number: H17REA184 and HREC/17/QTDD/51

Research Team Contact Details

Research Study Coordinator: Dr Eliza Whiteside, [redacted]

Breast Care Nurse: Gaye Foot, [redacted]

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the Participant Information Sheet regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au or DDHHS HREC Coordinator on (07) 4616 6696, DDHHS-RESEARCH@health.qld.edu.au if you do have any concern or complaint about the ethical conduct of this project.
- Are over 18 years of age.
- Agree to participate in the project.

Participant Name: _____

Participant Signature: _____

Date: _____

Please return this sheet to a Research Team member prior to undertaking the interview.

Preliminary Information Form (only complete and return if you consent to participating in the research study after reading and understanding the Participant Information and Consent form)

Mind Over Matter - Effectiveness of Acceptance and Commitment Therapy (ACT) on quality of life following primary treatment for early breast cancer

Please return completed form to the Research Project Coordinator, email eliza.whiteside@usq.edu.au or by post to ACTBC Study, Level 5, W Block, University of Southern Queensland, Darling Heights, 4350. You can also bring along to your interview.

First Name: _____

Surname: _____

Address : _____

Email: _____

Mobile: _____

Date of Birth (DD/MM/YY): _____

Education

Please indicate your highest level of completed education:

- ☐ Secondary
- ☐ Certificate I, II, III, IV
- ☐ Diploma
- ☐ Bachelor's Degree
- ☐ Postgraduate Degree

Household

Please indicate your relationship status:

- ☐ Single
- ☐ Coupled
- ☐ De facto relationship
- ☐ Married
- ☐ Divorced

Please indicate the number of people you live with:

_____

Please indicate the number of dependents you have:

_____

Please indicate the type of work you predominately engage in:

☐ House duties

☐ Caring for others

☐ Volunteering

☐ Paid work

☐ Retired

Please indicate the number of hours you engage in work-related activates (including house duties): _____

Medical

Please indicate whether you are receiving, or have received the following treatments for cancer (do not worry if you don't know the answers):

	Current	**Past**	**Not sure**
Breast surgery			
Breast conserving surgery			
Mastectomy			
Surgery to the armpit (axilla)			
Axillary dissection			
Sentinel node biopsy			
Breast prostheses			
Temporary			
Permanent			
Light weight breast form			
Partial prosthesis			
Breast reconstruction			

Implants			
Back muscle transfer			
Abdominal muscle transfer (TRAM flap)			
Other			
Radiotherapy			
Chemotherapy (if known)			
Intravenous			
Tablet			
Anthracyclines			
Mitotic inhibitors			
Antimetabolites			
Alkylating agents			
Hormonal therapies			
Anti-oestrogens (e.g. Tamoxifen)			
Aromatase inhibitors (e.g. anastrozole, letrozole, exemetane)			
Ovarian treatments (e.g. goserelin, or removing ovaries)			
Targeted therapies			
Trastuzumab (Herceptin)			
Lapatinib (Tykerb)			

Please indicate whether you are engaging or have engaged in the following complimentary treatments/activities:

	Current	**Past**
Psychotherapy		
Cognitive and Behaviour Therapy		
Acceptance and Commitment Therapy		
Mindfulness Based Stress Reduction		
Counselling for adjustment difficulties		
Occupational therapy		
Relaxation		
Meditation		
Moving meditation (e.g. yoga, tai chi)		
Exercise		
Diet change		
Massage		
Prayer/Spiritual practices		
Other (please specify): _____		
Other (please specify): _____		

Please indicate whether you are currently experiencing the following due to cancer/cancer treatment. Rate the intensity of associated distress from 1 (not distressing) to 10 (very distressing). Indicate any treatment you are receiving:

	Current	Intensity of Distress (1-10)	Treatment
Anxiety			
Bruising or swelling			
Changes in vision			
Depression			
Diarrhoea or constipation			
Dry or red skin			
Feeling 'vague' or 'foggy'			
Fluid around scars			
Hair loss			
Increased tiredness/easily fatigued			
Infection			
Lymphedema			
Menopausal symptoms (hot flushes, vaginal dryness, reduced sex drive			
Mouth ulcers			
Nausea and vomiting			
Skin reactions			
Pain in bones or joints			
Pain/discomfort/numbness in armpit			
Pain/discomfort/numbness in breast			
Permanent menopause			
Red or purple blood vessels			
Sexual difficulties			
Sore muscles			
Sore throat			
Stiffness in arm or shoulder			
Stroke			
Swelling in arms and legs			
Tenderness/aches in breast or chest			
Tingling in arm or shoulder			
Weight gain			
Weight loss			
Other (please specify): _____			
Other (please specify): _____			

Are you currently undergoing medical intervention for any conditions (other than cancer related)? YES/NO

If YES, please specify:

_____
_____
_____

Thank you for your time.

APPENDIX B - Act Now Group Adaptations

Note: Auditory recordings may not be available, but facilitators can find relevant ACT metaphors from a number of sources including:

Harris, R. (2009). ACT made simple: An easy-to-read primer on acceptance and commitment therapy. New Harbinger Publications.

Stoddard, J. A., & Afari, N. (2014). The Big Book of ACT Metaphors: a practitioner's guide to experiential exercises and metaphors in Acceptance and Commitment Therapy. New Harbinger Publications.

General Session structure **pg 5**

1. Experimental/centring exercise
2. Review experience since last session
3. Inquire about any completed life enhancement exercises and reactions to these
4. Inquire about ways in which in-session material is impacting life functioning
5. Present new material and encourage clients to follow their own experience rather than rules

Note: Not all activities in the manual/handbook must be completed if they do not relate to the participants' experiences. Highlight exercises they can do in their handbook that they can do as part of their practice. See pg 3 - 4 of the Therapist Manual for guiding principles. This adaptation provides page numbers as suggestions on where to find relevant material. Page numbers in brackets are from the participant handbook.

Session 1

1. Informed consent pg 7
   (10 minutes)

   - Briefly explain therapy (ability to deal with emotional distress and get more of what they really want out of life) including willingness to focus on intensely aversive experiences (use metaphor) with experiential focus.
   - Address ‘sharing’ in session - that is has to be relevant to ACT perspective.

2. Discuss how participants can get the most out of the sessions pg 8-9
   (20 minutes)
   - Stay open to experience
   - Participate
   - Stay present
   - Be patient with confusion
   - Provide schedule of sessions

3. Experiential activity: Mindfulness
   (10 minutes)
   - Examples: breath/sounds/sensations, thoughts and feelings, values/intent (reason they are here, what they want to work on)
   - Discuss experiences of mindfulness (e.g. what showed up?)

4. Short Break
   (10 minutes)

5. Values assessment
   (25 minutes)
   - Explain values pg 11-12
   - Sweet spot exercise or other values assessment pg 12
   - Before endorsing value, make sure that it is the client's pg 13
   - Personal Values Questionnaire

6. Assign home activities (5 minutes)
   - Complete activities in Act Now Booklet (pg 1 - 19)

7. Questions and/ or concerns and summary. (5 minutes)

Session 2

1. Experiential Activity
   (10 minutes)
   - Revisit mindfulness activities from previous week

2. Review experience of last session, what impacted most, and any exercises completed

   (10 minutes)

3. Creative helplessness, Part 1
   (20 minutes)
   - Discuss unproductive attempts to avoid or control pain pg 14
   - Review long term effects of avoidance and control (costs) pg 15

4. Short Break
   (10 minutes)

5. Creative helplessness, Part 2
   (20 minutes)
   - Use a metaphor (e.g. tug of war, quicksand) pg 17
   - Complete 1 - 2 of the activities in the booklet pg 18
   - Present remaining exercises and metaphors
   - Review understanding and acknowledge discomfort

6. Willingness
   (10 minutes)
   - Introduce willingness as an alternative response pg 19

7. Assign home activities (5 minutes)
   - Complete activities from Week 1, have a look at Page 19-29, some which will be covered in next session.

8. Questions and/or concerns and summary (5 minutes)

Note: The goal of creative helplessness in this session is to highlight unworkable ways of controlling internal states. It is not to offer a quick solution, but just to bring

participants' awareness and develop understanding in regards to the unworkability of some of actions.

Session 3

1. Experiential Activity
   (10 minutes)
   - Diffusion activity (e.g. leaves on a stream)

2. Review experience of last session, what impacted most, and any exercises completed
   (15 minutes)

3. Willingness Part 1
   (20 minutes)
   - Complete activities in Act Now Booklet (pg 19-29)

4. Short break
   (10 minutes)

5. Willingness Part 2
   (15 minutes)
   - Review cost of unwillingness pg 20
   - Review valued actions/values assessment

6. Values review
   (20 minutes)
   - Review Personal Values Questionnaire

7. Assign home activities (5 minutes)
   - Complete activities in Act Now Booklet (pg 29-39)

8. Questions and/ or concerns. Reminder of next session. (5 minutes)

Session 4

1. Experiential Activity
   (10 minutes)
   - Diffusion activity (e.g. Clouds in the sky)

2. Review experience of last session, what impacted most, and any exercises completed (20 minutes)
   - Highlight use of control strategies if used
   - Acknowledge willingness moves

3. Defusion, Part 1
   (20 minutes)
   - Recap struggle vs willingness
   - Introduce defusion pg 23
   - Present diffusion activities (eg ACT Now Booklet pg 41-49) pg 25

4. Short Break
   (10 minutes)

5. Defusion, Defusion Part 2
   (20 minutes)
   - Psychoeducation regarding the 'don't get eaten machine' (ACT Now Booklet pg 49)
   - Begin discussing mindfulness as a defusion strategy pg 26

6. Assign home activities (5 minutes)
   - Complete activities in the Act Now Booklet (pg 50 - 62)

7. Questions and/ or concerns. Reminder of next session. (5 minutes)

Session 5

- Experiential Activity
   (15 minutes)
   - Defusion activity

- Review experience of last session, what impacted most, and any exercises completed (20 minutes)
    - Highlight use of control strategies if used
    - Acknowledge willingness moves

- Defusion, Part 3 (25 minutes)
    - Discuss mindfulness as a defusion strategy
    - Present mindful eating
    - Present mindfulness of breath
    - Present ‘having’ thoughts rather than being’ thoughts
    - For more activities to present and discuss (eg ACT Now Booklet pg 62 - 70)

Short break (10 minutes)

- Observing Self, Part 1 (20 minutes)
    - Explain concept of observing self using the sky-clouds metaphor and or chess board metaphor (eg ACT Now Booklet pg 72 - 77) pg 28

- Assign home activities (5 minutes)

- Complete activities in the Act Now Booklet (pg 71 - 85)

- Questions and/ or concerns. Reminder of next session and discuss thoughts and feelings related to wrap up of groups

  (10 minutes)

Session 6

1. Experiential Activity

   (10 minutes)

   - Mindfulness Activity pg 28

2. Observing Self, Part 2

   (15 minutes)

   - Complete observing self exercises (eg ACT Now Booklet pg 78 - 85)

3. Values

   (30 minutes)

   - Recap values and vitality/meaning in life (eg Act Now Booklet pg 87 - 96)
   - Complete values exercise (eg Act Now Booklet pg 97 - 125)
   - Group discussion of valued action and experiences

4. Short Break

   (10 minutes)

5. Allow time to discuss overall experience of the program; what was helpful, what was confusing, and strategies that were implemented by participants throughout.

(15 minutes)

6. Experiential activity

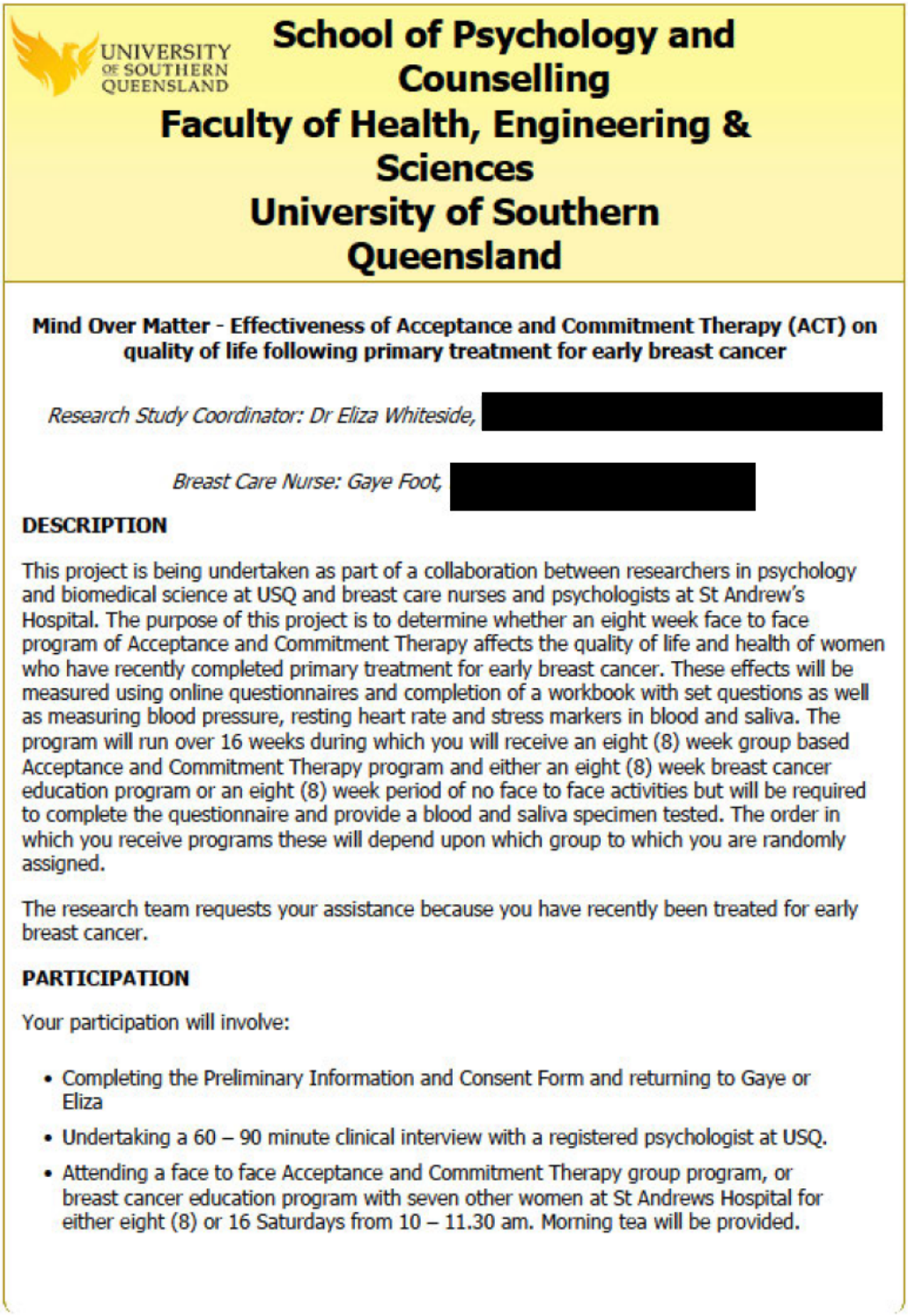
   (15 minutes)

   - An activity that cover and/or summarises the processes of ACT covered during the sessions.

7. Final questions and/ or concerns. Recap the purpose of the research and when/where results will be available.

   (5 minutes)

APPENDIX C - Study 1 Online Survey



UNIVERSITY OF SOUTHERN QUEENSLAND

School of Psychology and Counselling
Faculty of Health, Engineering & Sciences
University of Southern Queensland

Mind Over Matter - Effectiveness of Acceptance and Commitment Therapy (ACT) on quality of life following primary treatment for early breast cancer

Research Study Coordinator: Dr Eliza Whiteside, [redacted]

Breast Care Nurse: Gaye Foot, [redacted]

DESCRIPTION

This project is being undertaken as part of a collaboration between researchers in psychology and biomedical science at USQ and breast care nurses and psychologists at St Andrew's Hospital. The purpose of this project is to determine whether an eight week face to face program of Acceptance and Commitment Therapy affects the quality of life and health of women who have recently completed primary treatment for early breast cancer. These effects will be measured using online questionnaires and completion of a workbook with set questions as well as measuring blood pressure, resting heart rate and stress markers in blood and saliva. The program will run over 16 weeks during which you will receive an eight (8) week group based Acceptance and Commitment Therapy program and either an eight (8) week breast cancer education program or an eight (8) week period of no face to face activities but will be required to complete the questionnaire and provide a blood and saliva specimen tested. The order in which you receive programs these will depend upon which group to which you are randomly assigned.

The research team requests your assistance because you have recently been treated for early breast cancer.

PARTICIPATION

Your participation will involve:

- Completing the Preliminary Information and Consent Form and returning to Gaye or Eliza
- Undertaking a 60 – 90 minute clinical interview with a registered psychologist at USQ.
- Attending a face to face Acceptance and Commitment Therapy group program, or breast cancer education program with seven other women at St Andrews Hospital for either eight (8) or 16 Saturdays from 10 – 11.30 am. Morning tea will be provided.

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• Undertaking a 60 – 90 minute clinical interview with a registered psychologist at USQ.
• Attending a face to face Acceptance and Commitment Therapy group program, or breast cancer education program with seven other women at St Andrews Hospital for either eight (8) or 16 Saturdays from 10 – 11.30 am. Morning tea will be provided.
• Learning Acceptance and Commitment Therapy strategies from an Acceptance and Commitment Therapy trained clinical psychologist as well as practicing the Acceptance and Commitment Therapy strategies and noting your reflections in a workbook.
• Responding to a brief daily phone text message regarding your behaviours (e.g. Have you practiced your mindfulness today?).
• If placed in the group that undertakes breast cancer education, you will learn about ways to better cope with breast cancer-specific issues such as the side effects of treatment, and known benefits from certain diets and physical activity. These sessions will be delivered by experts in their fields.
• Completing a questionnaire that will take approximately 30 minutes of your time at the beginning and end of each eight week program and at 6 months and 12 months after the final face to face session. Examples of the types of questions in the questionnaire are: I am satisfied with how I am coping with my illness and I am sleeping well with your answers ranked as Not at all, A little bit, Somewhat, Quite a bit or Very much.
• Allowing your blood pressure and resting heart rate to be measured at the beginning and end of each program.
• Allowing blood samples to be collected by a scientist trained in blood collection at the beginning and end of each program and at 6 and 12 months follow-up. These will be used to measure stress and inflammation biomarkers.
• Providing saliva samples at the beginning of each Acceptance and Commitment Therapy and breast cancer education program session as well as at 6 and 12 months follow-up.These will be used to measure salivary cortisol and amylase which are also stress biomarkers.

Your participation in this project is entirely voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Please note, that if you wish to withdraw from the project after you have submitted your responses, the Research Team are unable to remove your data from the project. If you do wish to withdraw from this project, please contact Gaye or Eliza. Your decision whether you take

part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with USQ or St Andrew's Hospital.

EXPECTED BENEFITS

It is expected that this project may directly benefit you by teaching you the skills embodied by Acceptance and Commitment Therapy. The study may also benefit other women and men affected by breast cancer and other cancers.

RISKS
Sometimes thinking about the sorts of issues raised in the questionnaire can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately please contact Lifeline on 13 11 14. You may also wish to consider consulting your General Practitioner (GP) for additional support. There can also be pain and risks with providing a blood sample and you should advise the Research Coordinator if you have any clotting issues or other blood disorders that may affect the blood test procedure.

PRIVACY AND CONFIDENTIALITY

All comments and responses will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses. Any data collected as a part of this project will be stored securely as per USQ's Research Data Management policy.

CONSENT TO PARTICIPATE

The return (by email or post) of a signed and dated **Consent Form** as well as the Preliminary Information Form indicates consent to participate in the study.

QUESTIONS OR FURTHER INFORMATION ABOUT THE PROJECT

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

CONCERNS OR COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

If you have any concerns or complaints about the ethical conduct of the project you may contact the USQ Ethics Coordinator on (07) 4631 2690, ethics@usq.edu.au or DDHHS HREC Coordinator on (07) 4616 6696, DDHHS-RESEARCH@health.qld.edu.au. The Ethics Coordinators are not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please make a record of this page for your information.

I declare that I am:

• 18 years or over
• I consent to participate in this program

Click here to agree

THANK YOU FOR YOUR PARTICIPATION

To start the survey please click on the 'Next' button below

Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995)
These questions ask about your general psychological wellbeing. Please indicate how much each of the statements below 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

1 = Applied to me to some degree, or some of the time

2 = Applied to me a considerable degree, or a good part of the time

3 = Applied to me very much, or most of the time

	0	1	2	3
I found it hard to wind down	()	()	()	()
I was aware of dryness of my mouth	()	()	()	()
I couldn't seem to experience any positive feeling at all	()	()	()	()
I found it difficult to work up the initiative to do things	()	()	()	()
I tended to over-react to situations	()	()	()	()
I experienced trembling (eg, in the hands)	()	()	()	()
I felt that I was using a lot of nervous energy	()	()	()	()
I was worried about situations in which I might panic and make a fool of myself	()	()	()	()
I felt that I had nothing to look forward to	()	()	()	()
I found myself getting agitated	()	()	()	()
I found it difficult to relax	()	()	()	()
I felt down-hearted and blue	()	()	()	()
I was intolerant of anything that kept me from getting on with what I was doing	()	()	()	()
I felt I was close to panic	()	()	()	()
I was unable to become enthusiastic about anything	()	()	()	()
I felt I wasn't worth much as a person	()	()	()	()
I felt that I was rather touchy	()	()	()	()
I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	()	()	()	()
I felt scared without any good reason	()	()	()	()
I felt that life was meaningless	()	()	()	()

Mindfulness Attention Awareness Scale (Brown & Ryan, 2003)
Below is a collection of statements about your everyday experiences. Using the rating scale, please indicate how frequently or infrequently you currently have each experience. Please answer according to what *really reflects* your experience rather than what you think your experience should be. Please treat each item separately from every other item.

	Almost never	Very infrequently	Somewhat infrequently	Somewhat frequently	Very frequently	Almost always
I could be experiencing some emotion and not be conscious of it until some time later.	()	()	()	()	()	()
I break or spill things because of carelessness, not paying attention, or thinking of something else.	()	()	()	()	()	()

I find it difficult to stay focused on what's happening in the present.	()	()	()	()	()	()
I tend to walk quickly to get to where I'm going without paying attention to what I experience along the way.	()	()	()	()	()	()
I tend not to notice feelings of physical tension or discomfort until they really grab my attention.	()	()	()	()	()	()
I forget a person's name almost as soon as I've been told it for the first time.	()	()	()	()	()	()
It seems I am "running on automatic", without much awareness of what I'm doing.	()	()	()	()	()	()
I rush through activities without being really attentive to them.	()	()	()	()	()	()
I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there.	()	()	()	()	()	()
I do jobs or tasks automatically, without being aware of what I'm doing.	()	()	()	()	()	()
I find myself listening to someone with one ear, doing something else at the same time.	()	()	()	()	()	()

Functional Assessment of Cancer Therapy - Breast (Cella et al., 1993)

Below is a list of statements that other people with your illness have said are important. **Please indicate your response to each item as it applies to the past 7 days.**

Physical Wellbeing	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	()	()	()	()	()
I have nausea	()	()	()	()	()
Because of my physical condition, I have trouble meeting the needs of my family	()	()	()	()	()
I have pain	()	()	()	()	()
I am bothered by side effects of treatment	()	()	()	()	()

I feel ill	()	()	()	()	()
I am forced to spend time in bed	()	()	()	()	()
Social/family wellbeing	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends	()	()	()	()	()
I get emotional support from my family	()	()	()	()	()
I get support from my friends	()	()	()	()	()
My family has accepted my illness	()	()	()	()	()
I am satisfied with family communication about my illness	()	()	()	()	()
I feel close to my partner (or the person who is my main support)	()	()	()	()	()
I am satisfied with my sex life (regardless of your current level of sexual activity, please answer the question. If you prefer not to answer, please go to the next question)	()	()	()	()	()
Emotional Wellbeing	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	()	()	()	()	()
I am satisfied with how I am coping with my illness	()	()	()	()	()
I am losing hope in the fight against my illness	()	()	()	()	()
I feel nervous	()	()	()	()	()
I worry about dying	()	()	()	()	()

I worry that my condition will get worse	0	0	0	0	0
Functional Wellbeing	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (including work at home)	0	0	0	0	0
My work (including work at home) is fulfilling	0	0	0	0	0
I am able to enjoy life	0	0	0	0	0
I have accepted my illness	0	0	0	0	0
I am sleeping well	0	0	0	0	0
I am enjoying the things I usually do for fun	0	0	0	0	0
I am content with the quality of my life right now	0	0	0	0	0
Additional Concerns	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have shortness of breath	0	0	0	0	0
I am self-conscious about the way I dress	0	0	0	0	0
One or both of my arms are swollen or tender	0	0	0	0	0
I feel sexually attractive	0	0	0	0	0
I am bothered by hair loss	0	0	0	0	0
I worry that other members of my family might someday get the same illness I have	0	0	0	0	0

I worry about the effects of stress on my illness	()	()	()	()	()
I am bothered by a change in weight	()	()	()	()	()
I am able to feel like a woman	()	()	()	()	()
I have certain parts of my body where I experience pain	()	()	()	()	()

Concerns about Recurrence Scale (Vickberg, 2003)

The following questions ask you to tell us about any worries you may have about the possibility of breast cancer recurrence. By recurrence, we mean the breast cancer coming back in the same breast or another area or the body, or a new breast cancer in either breast. Althought most women who have been diagnosed with early stage breast cancer will never have another problem with breast cancer, we are aware that many women do worry about this possibility. Other women may not worry about recurrence at all. Either way, your answers to these questions are very important to us. We understand that it may be upsetting to think about or answer questions about hte possibility of recurrence. However, we need your help to understand how women think about this possibility.

How much time do you spend thinking about the possibility that your breast cancer could recur?					
I do not think about it at all 1	2	3	4	5	I think about it all the time 6
How much does the possibility that your breast cancer could recur upset you?					
It does not upset me at all 1	2	3	4	5	It makes me extremely upset 6
How often do you worry about the possibility that your breast cancer could recur?					
I never worry about it 1	2	3	4	5	I worry about it all the time 6
How afraid are you that your breast cancer may recur?					
Not at all afraid 1	2	3	4	5	Very afraid 6

Now we are interested in what your concerns are regarding a possible recurrence of breast cancer. When thinking about the possibility of a recurrence, what is it about that possibility that you worry about? Although each of the following items may be a possible consequence of recurrence, we are really interested in whether you actually worry about any of these things occurring. For example, you may believe that a recurrence of breast cancer could require further surgery. We would like to know whether you ever actually worry about this possibility. For the following questions, please rate how much you worry about each of the following items. If you do not worry about an item or if you think it does not apply to you, please select “Not at All”.

The following questions continue to ask you about any worries you may have about the possibility of breast cancer recurrence.	Not at all	A little	Moderately	A lot	Extremely
I worry that a recurrence of breast cancer would upset me emotionally	()	()	()	()	()
I worry that a recurrence of breast cancer would keep me from doing the things I had planned to do	()	()	()	()	()
I worry that a recurrence of breast cancer would threaten my physical health	()	()	()	()	()
I worry that a recurrence of breast cancer would make me feel	()	()	()	()	()
I am less of a woman	()	()	()	()	()
I worry that a recurrence of breast cancer would require chemotherapy	()	()	()	()	()
I worry that a recurrence of breast cancer would hurt my relationships with friends and family	()	()	()	()	()
I worry that a recurrence of breast cancer would make me feel that I don't have control over my life	()	()	()	()	()
I worry that a recurrence of breast cancer would threaten my identity (how I see myself)	()	()	()	()	()
I worry that a recurrence of breast cancer would interfere with my physical ability to carry out daily activities	()	()	()	()	()
I worry that a recurrence of breast cancer would threaten my life	()	()	()	()	()
I worry that a recurrence of breast cancer would harm my self-confidence	()	()	()	()	()
I worry that a recurrence of breast cancer would be more serious than the first diagnosis	()	()	()	()	()
I worry that a recurrence of breast cancer would cause financial problems for me	()	()	()	()	()
I worry that a recurrence of breast cancer would interfere with my sense of sexuality	()	()	()	()	()
I worry that a recurrence of breast cancer would require radiation treatment	()	()	()	()	()

I worry that a recurrence of breast cancer would cause me pain and suffering	()	()	()	()	()
I worry that a recurrence of breast cancer would mean losing my breast(s)	()	()	()	()	()
I worry that a recurrence of breast cancer would interfere with my ability to plan for the future	()	()	()	()	()
I worry that a recurrence of breast cancer would threaten my spirituality or faith	()	()	()	()	()
I worry that a recurrence of breast cancer would keep me from fulfilling important roles (in my job or at home)	()	()	()	()	()
I worry that a recurrence of breast cancer would lead me to feel less feminine	()	()	()	()	()
I worry that a recurrence of breast cancer would require further surgery	()	()	()	()	()
I worry that a recurrence of breast cancer would cause me to die	()	()	()	()	()
I worry that a recurrence of breast cancer would damage my romantic relationship(s)	()	()	()	()	()
I worry that a recurrence of breast cancer would keep me from fulfilling my responsibilities (in my job or at home)	()	()	()	()	()
I worry that a recurrence of breast cancer would make me feel badly about how my body looks or feels	()	()	()	()	()

Acceptance and Action Questionnaire II (Bond et al., 2004)
Below you will find a list of statements. Please use the scale to rate how true each statement is for you.

	Never true	Very seldom true	Seldom true	Sometimes true	Frequently true	Almost always true	Always true
My painful experiences and memories make it difficult for me to live a life that I would value.	()	()	()	()	()	()	()
I am afraid of my feelings.	()	()	()	()	()	()	()
I worry about not being able to control my worries and feelings.	()	()	()	()	()	()	()
My painful memories prevent me from having a fulfilling life.	()	()	()	()	()	()	()

Emotions cause problems in my life.	()	()	()	()	()	()	()
It seems like most people are handling their lives better than I am.	()	()	()	()	()	()	()
Worries get in the way of my success.	()	()	()	()	()	()	()

Treatment

Please indicate whether you are currently receiving, or have received the following treatments for cancer.	Current	Past	Not applicable
Breast surgery	()	()	()
Surgery to the armpit	()	()	()
Breast prostheses	()	()	()
Breast reconstruction	()	()	()
Radiotherapy	()	()	()
Chemotherapy	()	()	()
Hormonal therapies	()	()	()
Ovarian treatments	()	()	()
Other therapy	()	()	()

Complimentary Treatments

Please indicate whether you are current engaging or have engaged in the past, in the following complementary treatments/activities:	Current	Past	Not applicable

Cognitive and Behaviour Therapy	()	()	()
Acceptance and Commitment Therapy	()	()	()
Mindfulness Based Stress Reduction	()	()	()
Counselling for adjustment difficulties	()	()	()
Occupational therapy	()	()	()
Relaxation	()	()	()
Meditation	()	()	()
Moving meditation (e.g. yoga, tai chi)	()	()	()
Cardio exercise	()	()	()
Diet change	()	()	()
Massage	()	()	()
Prayer/Spiritual practices	()	()	()
Other	()	()	()

Symptoms

Are you currently experiencing any of the following symptoms due to your cancer/cancer treatment? If so, please rate the intensity of the distress on a scale from 1 (Not distressing) to 10 (Very distressing) and briefly describe what treatment (e.g., medication, physiotherapy, psychological therapy) you are receiving for any of the symptoms.

	Yes	No	1 (not distressing)	2	3	4	5	6	7	8	9	10 (very distressing)	

Anxiety	()	()	()	()	()	()	()	()	()	()	()	()	
Bruising or swelling	()	()	()	()	()	()	()	()	()	()	()	()	
Changes in vision	()	()	()	()	()	()	()	()	()	()	()	()	
Depression	()	()	()	()	()	()	()	()	()	()	()	()	
Diarrhoea or constipation	()	()	()	()	()	()	()	()	()	()	()	()	
Dry or red skin	()	()	()	()	()	()	()	()	()	()	()	()	
Feeling ‘vague’ or ‘foggy’	()	()	()	()	()	()	()	()	()	()	()	()	
Fluid around scars	()	()	()	()	()	()	()	()	()	()	()	()	
Hair loss	()	()	()	()	()	()	()	()	()	()	()	()	
Increased tiredness/easily fatigued	()	()	()	()	()	()	()	()	()	()	()	()	
Infection	()	()	()	()	()	()	()	()	()	()	()	()	
Lymphedema	()	()	()	()	()	()	()	()	()	()	()	()	
Menopausal symptoms (hot flushes, vaginal dryness, reduced sex drive	()	()	()	()	()	()	()	()	()	()	()	()	
Mouth ulcers	()	()	()	()	()	()	()	()	()	()	()	()	
Nausea and vomiting	()	()	()	()	()	()	()	()	()	()	()	()	
Skin reactions	()	()	()	()	()	()	()	()	()	()	()	()	
Pain in bones or joints	()	()	()	()	()	()	()	()	()	()	()	()	
Pain/discomfort/numbness in armpit	()	()	()	()	()	()	()	()	()	()	()	()	

Pain/discomfort/numbness in breast	()	()	()	()	()	()	()	()	()	()	()	()	
Permanent menopause	()	()	()	()	()	()	()	()	()	()	()	()	
Poor Sleep	()	()	()	()	()	()	()	()	()	()	()	()	
Red or purple blood vessels	()	()	()	()	()	()	()	()	()	()	()	()	
Sexual difficulties	()	()	()	()	()	()	()	()	()	()	()	()	
Sore muscles	()	()	()	()	()	()	()	()	()	()	()	()	
Sore throat	()	()	()	()	()	()	()	()	()	()	()	()	
Stiffness in arm or shoulder	()	()	()	()	()	()	()	()	()	()	()	()	
Stroke	()	()	()	()	()	()	()	()	()	()	()	()	
Swelling in arms and legs	()	()	()	()	()	()	()	()	()	()	()	()	
Tenderness/aches in breast or chest	()	()	()	()	()	()	()	()	()	()	()	()	
Tingling in arm or shoulder	()	()	()	()	()	()	()	()	()	()	()	()	
Weight gain	()	()	()	()	()	()	()	()	()	()	()	()	
Weight loss	()	()	()	()	()	()	()	()	()	()	()	()	

Demographics

The following are questions about your basic demographic details.

First Name: _____
Surname: _____
Date of birth: _____
Postcode: _____
Weight (kg): _____
Height (cm): _____
Gender: () Male () Female () Prefer not to answer
Is English your primary language: () Yes () No
Do you require support for reading and/or comprehension: () Yes () No
Please indicate your highest level of completed education:

() Primary school
() Secondary school
() Certificate I, II, III, or IV
() Diploma
() Bachelor's Degree
() Postgraduate Degree
Please indicate your relationship status: () Partnered () Not Partnered
Please indicate the number of people you live with: _____
Please indicate the number of dependents you have: _____
() Household duties
() Caring for others
() Volunteering
() Paid work
() Retired
Please indicate the type of work you predominantly engage in: _____
Please indicate the number of hours you engage in paid or unpaid work-related activities (including house duties): _____

Demographics (cont.)

Now there will be a few pages to fill out about your treatment and treatment history.

When were you diagnosed with breast cancer? (Month/Year): _____
Which breast(s) was affected? () Left () Right () Both
Was your breast cancer hormone receptor positive?
() Yes, oestrogen positive (ER)
() Yes, progesterone positive (PR)
() No, hormone receptor negative
() Don't know
Was your breast cancer HER2 receptor positive?
() Yes
() No
() Don't know

Demographics (cont.)
Please skip over the questions that do not apply.

Are you currently undergoing medical intervention for any conditions (other than cancer related)? () Yes () No
If you are currently undergoing medical intervention for other conditions, please Specify: _____
Have you had a hysterectomy? () Yes () No
Have you had both ovaries removed? () Yes () No
Have you had a menstrual period in the past 12 months? () Yes () No
Have you had a menstrual period in the past 3 months? () Yes () No
What age were you at menopause or when your ovaries were removed? : _____
Were you at menopause prior to breast cancer treatment? () Yes () No
What age were you at menarche (your first menstrual period)? : _____
Have you ever been pregnant? () Yes () No
How many pregnancies? : _____
What age were you at your first pregnancy? : _____
What age were you at your last pregnancy? : _____
Have you ever taken birth control pills? () Yes () No
If yes, for how many years did you take birth control pills? : _____
Have you ever taken any form of oestrogen or hormone replacement therapy (HRT) for menopause? () Yes () No
If yes, for how many years? : _____
During the past month, what was your usual bedtime? : _____
During the past month, how long (minutes) did it usually take you to fall asleep? : _____
During the past month, what time did you usually get up in the morning? : _____

During the past month, how many hours of actual sleep did you get? (May be different to number of hours spent in bed) : _____
During the past month, how would you rate your sleep quality overall?
() very good
() fairly good
() fairly bad
() very bad

During the past month, how often did you have a day nap?
() over 5 days/week
() 3-4 days/week
() 1-2 days/week

Thank you!
Thank you very much for completing the quesionnaire! You will be asked to complete similar online quesitonnaires periodically through the experiment. This one is the longest. The rest will not be as long.

If you expereinced any distress when completeing the questionnaires, please contact May Chi to discuss your experience: u1084563@umail.usq.edu.au, or via text on 0400533952.

Your responses are very valuable to the research, so thank you very much for your time and energy.

Sincerely,

The ACTBC Research Team.

PLEASE CLICK RIGHT THROUGH TO THE END OF THE SURVEY TO COMPLETE IT.

APPENDIX D - Feedback from Two Facilitators (S and N)

Protocol

S: Protocol (was) good. Talking to (the) ladies, (they) said (they) found it really useful (for) managing breast cancer and wholistic approach. Nice approach and very good.

Some of the instructions were abstract, for example, (the) observing self (exercises). (However, being) abstract is critique of ACT itself. (It was) more about the fact that the construct is a bit abstract. People were struggling with that in the last session; using those metaphors and trying to explain that helped.

I liked that each session builds on the last session, and the values were a common theme throughout. I like how it's building each session rather than disjointed.

With the manual, a lot of times I'm reading and people were flicking through and I'd have to explain I'm not. I found it a bit confusing about where to take the information from. I can see why the manual is so lengthy for them, but I guess there's also a lot of information, and they do reading in between, and it's helping them practice in between sessions. I guess sometimes I felt a bit lost in the information sometimes and I didn't know whether to condense it or to have some of the stuff in the therapist manual in their manual so that they can follow through with the information themselves.

I got a bit lost in the information because there's so much that sits with you because you can pick and choose. I didn't know what to pick out of the exercises. That's part of my delivery and I would direct them to the reading and I wasn't sure, and it seemed like a big chunk and I'm not sure of how structured it is.

They managed to keep on top of it from what they said. I wasn't sure about the page range but they seemed to be able to do it so it was anxiety on my part.

I'm going to be more sure of it the second time because I've got my head around it. Now I've done a run through I understand it more myself and I felt that it was disjointed sometimes because I wasn't sure in myself and whether that was coming across. The nature of act is that it's not as CBT structures, so I suppose it was my own confidence with the information that I wanted to cover.

Sometimes I have a clear idea of what I've been doing and other times I have to think 'what am I going to do in this time'. Rather than step oriented it's process oriented and I think it's a bit tricky.

N: I thought the protocol was good overall. If I could give a suggestion, it would be to have both the therapist manual and the participant workbook align. They were not aligned; one was written for a longer course than the other. If it was more aligned so that the therapist manual fitted with the client manual that would have been better.

I really liked the metaphors also contained diagrams. I think they really helped to bring the points to life for the participants. The participants gave that feedback as well; it really brought it to life.

I just love the ACT model generally; the use of metaphors is a really accessible way to explain what would otherwise be very difficult concepts to everyday people. The tug of war with the monster jumps to mind, the radio one, the passengers on the bus; they are three that really stood out for me and that we discussed more in the sessions.

I think I liked how it was chunked into pieces, so you weren't trying to teach every aspect of ACT in one go. The chunks flowed logically and overall, they seemed to flow.

I think there was one time or two times where it seemed like perhaps there were a lot of chunks in one session; maybe there was one in the beginning; there was willingness and values, and just a lot of different concepts in one session. It might have been better spread over a number of sessions.

The other thing is the amount of homework that was required; both reading and activities. In the end, a lot of our group just did the reading and we did as much of the activities that we could in the sessions. The reading and activities was too much for homework in each session. I do understand the value of doing it at home; I understand on a cognitive level, but on an every day level, you do get busy and life happens and it's not that easy to get it all done in a week.

I thought it was good. It was nice to have structure, to have a manual so that there was some sort of broad structure to follow in terms of teaching the core points of ACT. I didn't feel too restricted by that either; I think we were able to discuss the concepts in the group in our own way and using the real-life metaphors that came up in the group, real life examples I mean. So I didn't feel constrained by the manual; I thought it was good guidance.

I don't think there's anything negative I can say about the ACT approach and how it was presented in the manual. I didn't disagree with anything, or the way it was presented. I did feel able to include other bits that I've learned from ACT if it came up. I think that was probably been more because I'd talk to you about that.

Maybe the only thing I could say in terms of constructive feedback is that point about at least one week where I felt that too many concepts were trying to be squeezed into the one week and it felt like a bit too much that week. It was all useful stuff and worthwhile.

Participation

S: They seemed very engaged and supportive of each other and were willing to reflect on their experiences and experiences of the exercises which was good. The attendance rate was fantastic, I thought. I was quite surprised. I've run quite a lot of groups at the hospital and to commit to 6 weeks is a lot. I thought they were a lovely bunch of ladies. Nice, supportive, down to earth.

They definitely gave things a go. I guess some of them struggled with some of the exercises, which, of course is what we expect, and I guess I always try to encourage and validate that and encourage them to try and reflect on the difficulties which they seemed to be able to do.

I thought they really embraced it really well. They really wanted to. It's something that's very close to home for them. It's nice that they're keen to be involved in the research and getting the benefit out of learning the therapy approach.

Particularly with that group, there was one lady that would often, sometimes, she was quite monopolises which I think is a reflection of her passion and wanting to really share and being involved. I always struggle with that in groups when it's happening because I try to hear them and round off what they're saying and come back to other people. It's a tricky process. That was sometimes… I was conscious of trying to relate that to other people and invite other people to share but that sometimes didn't come across as well or I didn't manage that quite as well.

I feel though as well that even though it was something that was happening, she was still a very welcome and supportive member of the group and the intention was about support for other people. My point was trying to manage her without offending and keeping the balance.

Other than that, there were quieter members of the group and more talkative, which is the nature of people in the room. People seemed engaged but some struggled with the concepts more than others, but they were giving it a go, and I think they were a good bunch of ladies.

When doing exercises I imagine that some people struggled with some of those exercises and given the time of things I didn't really dedicate time to helping them. If it was a longer group I'd probably go around and help them with the exercises. I didn't check, but I imagine some of them struggled with the exercises and I didn't pay attention or help and support them through that, largely because of time.

I guess just helping those who may struggle with some of the concepts, or maybe upon reflection I might ask them to share and then I can explain it. For some people, perhaps, because it is an abstract approach, some people may take that on board more than other.

N: I don't think I was prepared for how moved and touched I would be by them. I think I went there expecting that I would be delivering this piece of training or therapy, I didn't realised that I would leave being inspired by them. In terms of the experienced they shared and what they'd been through, and how they were dealing with those difficult things with determination and strength and grace. I wasn't expecting; I was kind of blown away by them.

We had some group members that were more chatty than others and sometimes slightly derailed the conversation to personal topics that they wanted to talk about, which made it difficult to manage sometimes. I may have felt from the other participants that they were being derailed as well, that they were being taken off task by some of these conversations too. I found that difficult to manage, and I sometimes I find it difficult to take charge and manage the conversation when I need to.

I think they all really enjoyed the content. That was certainly their verbal feedback. They appreciated the lessons and messages. I think they were, in their different ways, able to connect with some part or other of the protocol. I know that one lady for example gave us the feedback that when we were doing the mindfulness exercises, we talked about mindfulness being a practice of paying attention to the present moment sometimes using an object or the breath, she gave the feedback that there was a fountain at her work and she would focus on the sound of the water, feel the sun on her face, and listened to the sound. She was able to make a mindfulness practice based on her own life from what we talked about in the session. She took the message and made it her own. I think each of them did that in their own way with different parts.

I think most of them were quite friendly and engaged with each other. As I mentioned before I think there were a couple of participants that tended to take the conversation and derail it a little. On the whole they seemed respectful of each other. If one was missing they would check in with how that person was and how that person would be going. They demonstrated some cohesion as a group.

Therapist/Facilitator Process

S: Something that I try to always do, which can be challenging, is, which upon reflection isn't always a good thing, when someone is talking and I'm trying to work out where they're going and how it's related to what we're talking about I always try about how to bring it back to the concept of what we've been talking about. I validate it and bring it back to the point, trying to explain the concept maybe even when they haven't quite got the concept. I try to reiterate the point without saying 'that's wrong'. I try to use people's experiences and shape that to bring it back to the content. I try to do that as much as I can.

If someone's going on a tangent, I'll try and round it up and bring it back to the point at hand.

I try to invite feedback from people and involve them in the process rather than just lecture, but that opens up tangents and then it takes us away from the book. I tried to engage them in conversation.

It was in the manual but to not… to try and normalize it and try not to be this expert and try to be this person who relates it back to 'and we all do this'. Try to normalize that process and relate it to every day experiences that all people struggle with rather than needing this expert who talks to them about that. Just trying to be normal and validating that.

I guess again, just me being very familiar with it. When I struggle with something, I'm not very structured person but with something kind of new, until I get my head around it, I felt a bit clunky. I struggled with knowing which bit to pick because it was a bit flexible. I felt a bit clunkily. I'm familiar with ACT but not with that group and not with concepts in that order, so being more familiar and prepared next time. Trying to manage that, and then I don't know, I'm hoping it didn't come

across too much, but that I lost it. But trying to slow thing through. Everything builds on everything else so even though I wasn't sure about where to go next, it all flows and links in. More structure is good to get your head around, but it goes against the act process.

Probably following the time guidelines better and cutting off a lot more of that chit chat.

Maybe do a few of the experiential exercises. I did do some of the experiential exercises, but trying to fit a bit more in. Rather than talking and reiterating points, but trying to highlight with exercises rather than talking.

No, it wasn't awkward to have you in there.

N: I 100% agree with and believe in the spirit of the ACT model, so I think it wasn't hard for me to engage with that stuff. What I find difficult is how to put that across to other people in a way that makes sense to them. I know that what I appreciate about it may be different from how it may make sense to you, which is what I liked about the metaphors, the make it easy to communicate and understand.

Over the course of the sessions, if anything changed, it's probably I developed more of an understanding and desire to make the ACT part, the elements of the ACT model, realistic for the participants; how they integrate it in their real lives. I'm thinking of the lady who brought her aromatherapy oils in another week and doing mindfulness with the oils because she uses the oils as part of her process other cancer. Some of the ladies loved that as well. The biggest change for me was trying to find ways to integrate ACT elements and protocol into daily life and each individual person. Not just the formulaic 'we're going to do this now' but 'how will this fit into your life and day to day activities'.

Group Structure

S: It seems to be running very well and you seem to be having a lot of contact with the ladies in between because they are more informed. You've already done the leg work and you're guiding them through that. It seems to be very well run in that regard.

They already know what's going to happen and what's happening next and I think that's really positive.

The way I've manage that (absence) is recapping. I've gotten the feedback from them in that they told me what was going on. It's been helpful in doing recap and having them guide that. I like that they're telling me and I'm on board with that and everyone's clear about what they're doing.

Now that you mentioned about it, someone said that they wanted results from the study and I said for the ladies to follow up with you. It's big research so it's probably going to be a while before the results come in.

N: The size was perfect. I think we had a few people missing at times but their absence besides the personal factors wasn't too… it didn't detract from the group. When all the participants were there it was also fine. It was a good number.

If anything, it could have been nice to stretch the group out to more than 6 weeks; with the kind of chunking of some of the elements, it seemed to be squashed into one group. It would have been nice to stretch it out, more like 8.

Administration

S: Bring fingertraps. Prepare materials. CD player has been moved. Bring CDs.

N: The blush ladies were fantastic. There was always food, water, everything was set up. Everything was perfect. I had no worries or concerns in that department. It felt comfortable to rock up and do the material. I didn't have to think about the other stuff.

The only thing now I think of it; I didn't know afterwards who to send the invoice to someone. I wasn't sure about GST and all that crap, so perhaps spelling that out a bit more. I'd never done my own invoices before so I got word out and I found my own template.

APPENDIX E - Group and Individual Bar Graphs of scores pre and post ACT and BCE interventions

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Figure E.1

Bar Graph of Mean Group Experiential Avoidance Pre and Post ACT Intervention (n = 18), Bars Represent 95% Confidence Interval

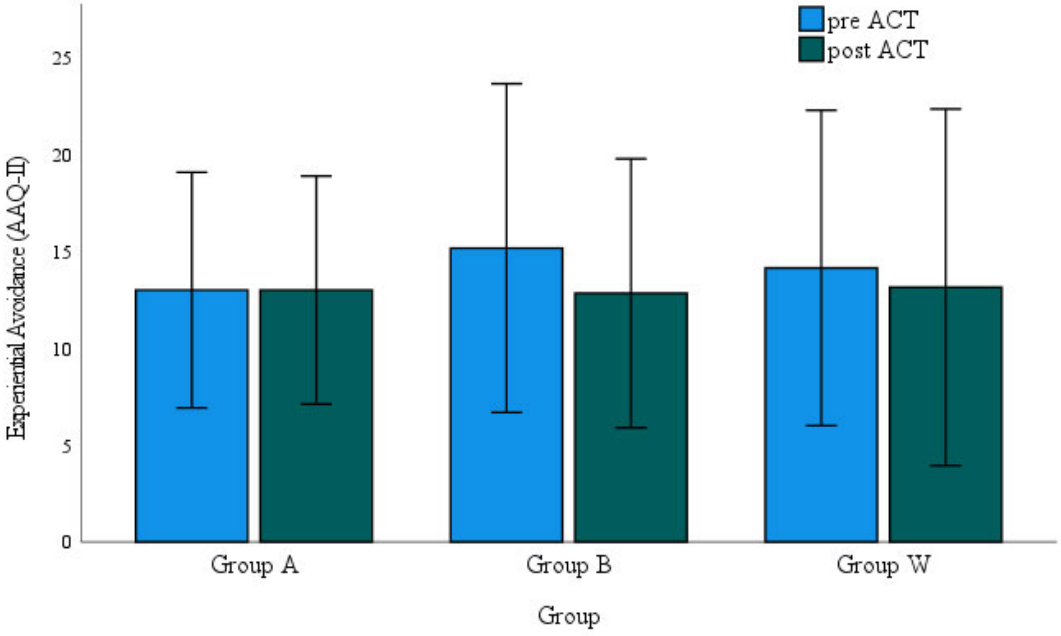


Figure E.2

Bar Graph of Individual Participant's Experiential Avoidance Pre and Post ACT Intervention (n = 18)

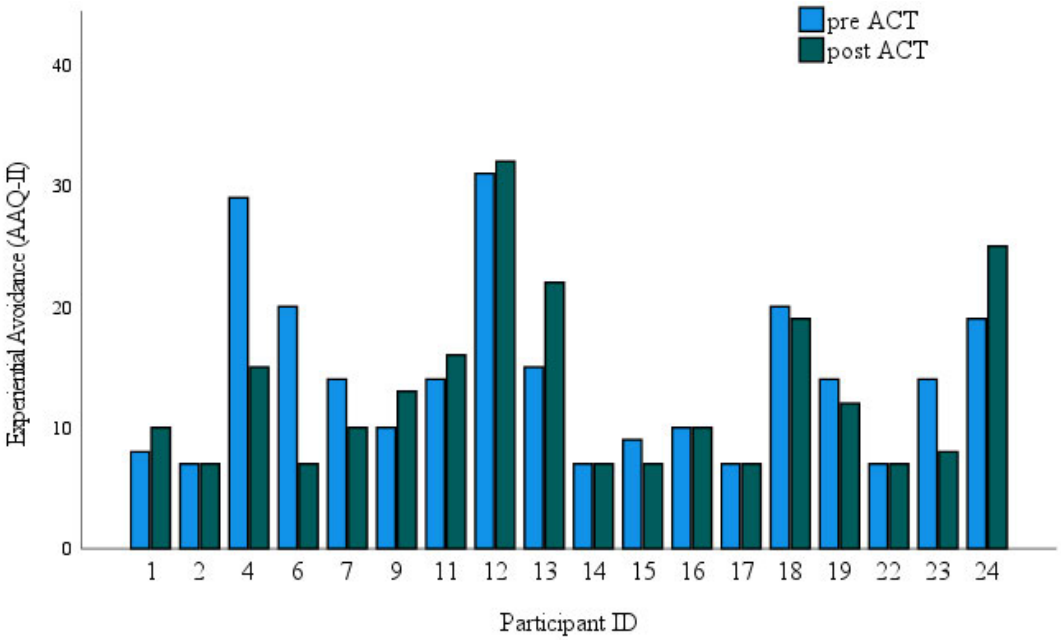


Figure E.3

Bar Graph of Mean Group Experiential Avoidance Pre and Post BCE Intervention (n = 11), Bars Represent 95% Confidence Interval

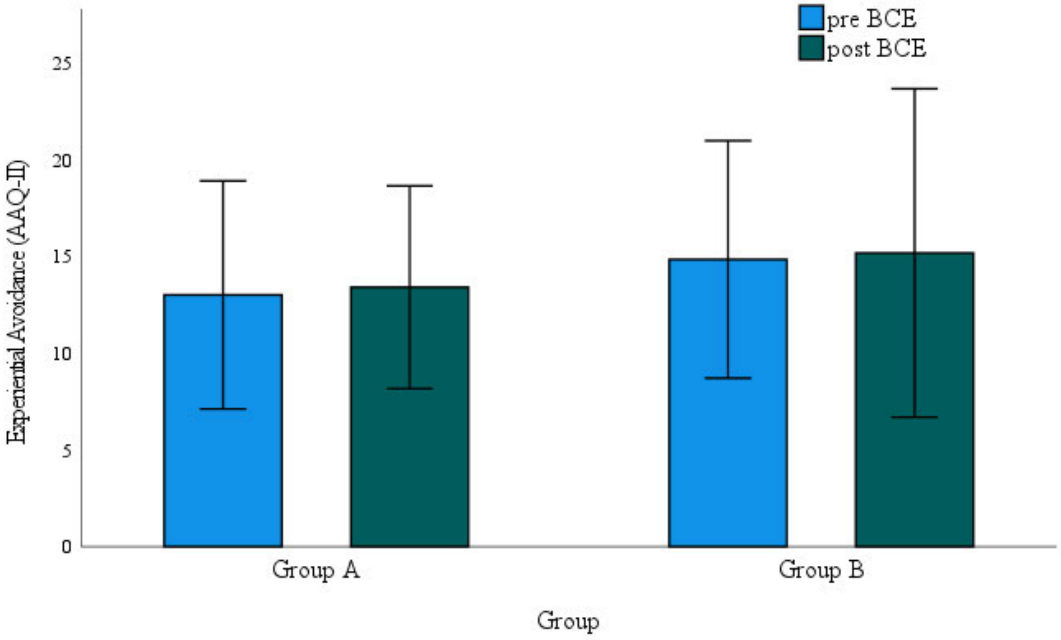


Figure E.4

Bar Graph of Individual Participant's Experiential Avoidance Pre and Post BCE Intervention (n = 11)

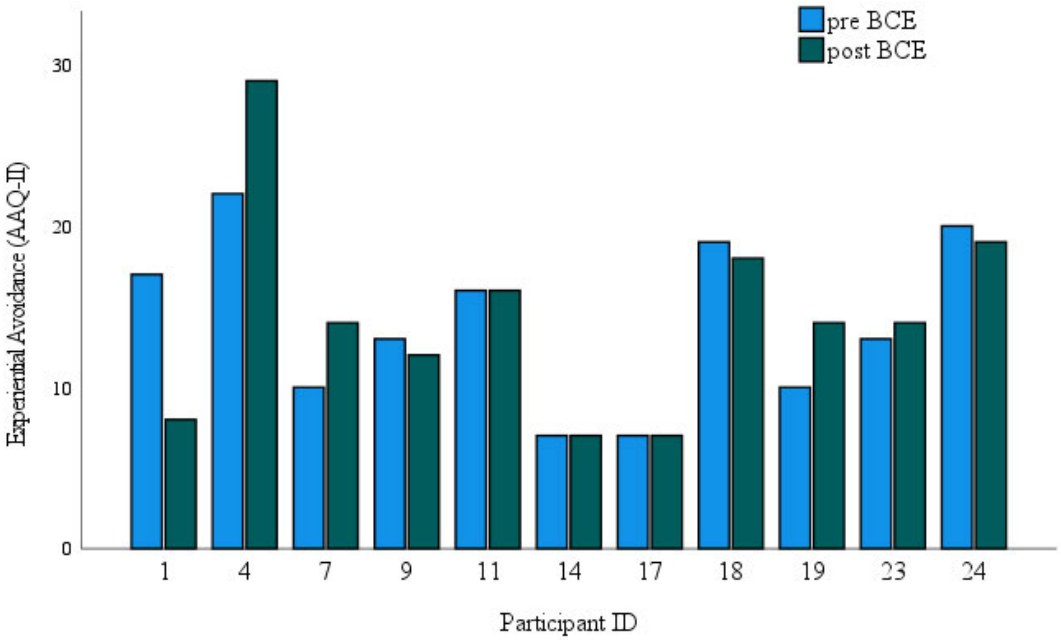


Figure E.5

Bar Graph of Mean Group Overall Fear of Cancer Recurrence Pre and Post ACT Intervention (n = 18), Bars Represent 95% Confidence Interval

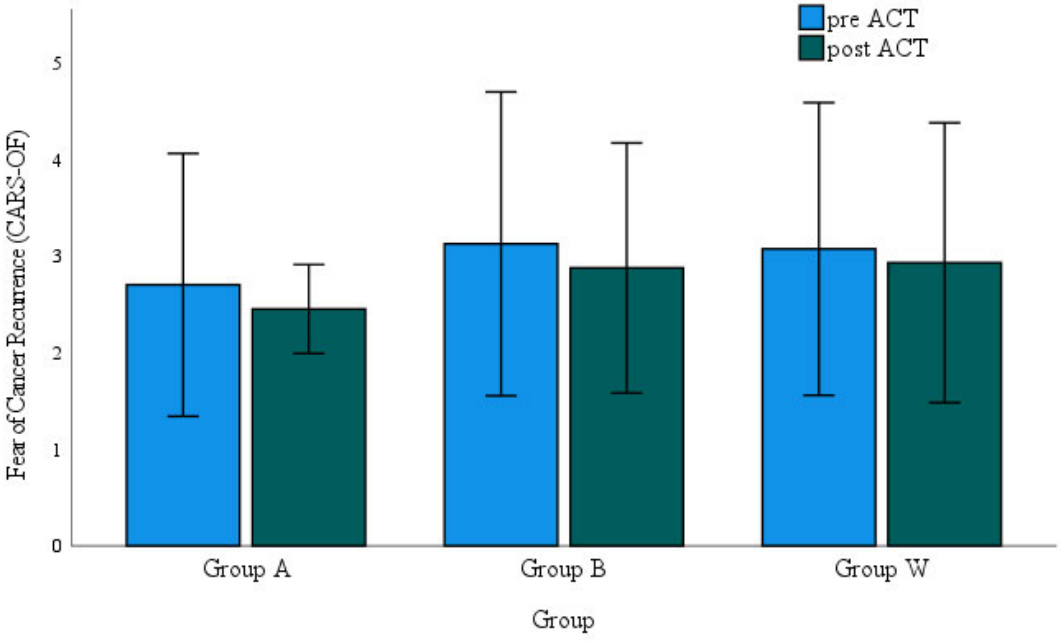


Figure E.6

Bar Graph of Individual Participant Overall Fear of Cancer Recurrence Pre and Post ACT Intervention (n = 18)

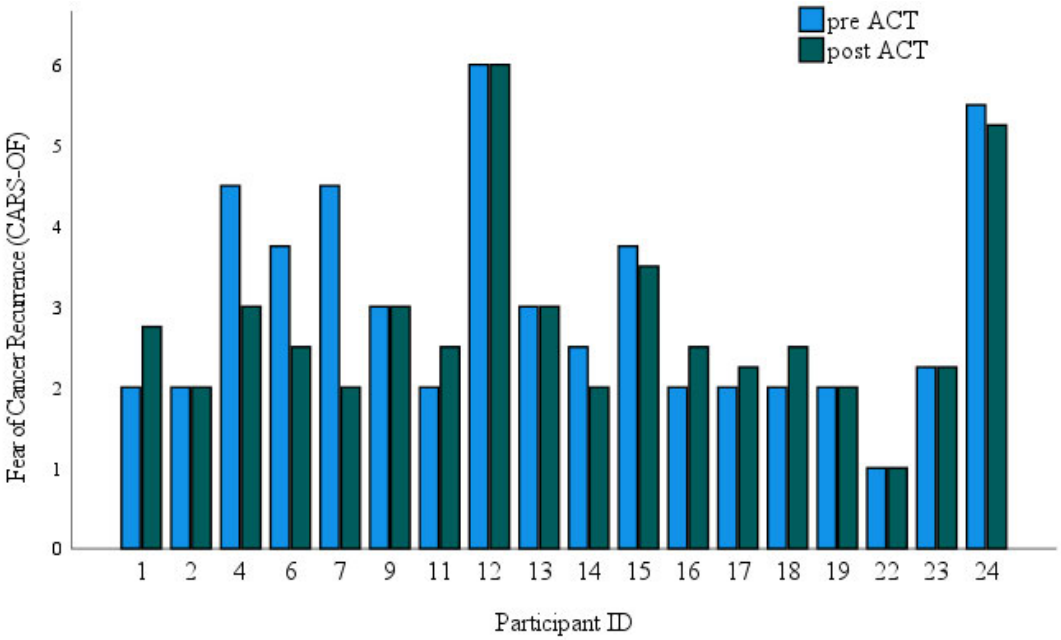


Figure E.7

Bar Graph of Mean Group Overall Fear of Cancer Recurrence Pre and Post EDU Intervention (n = 11), Bars Represent 95% Confidence Interval

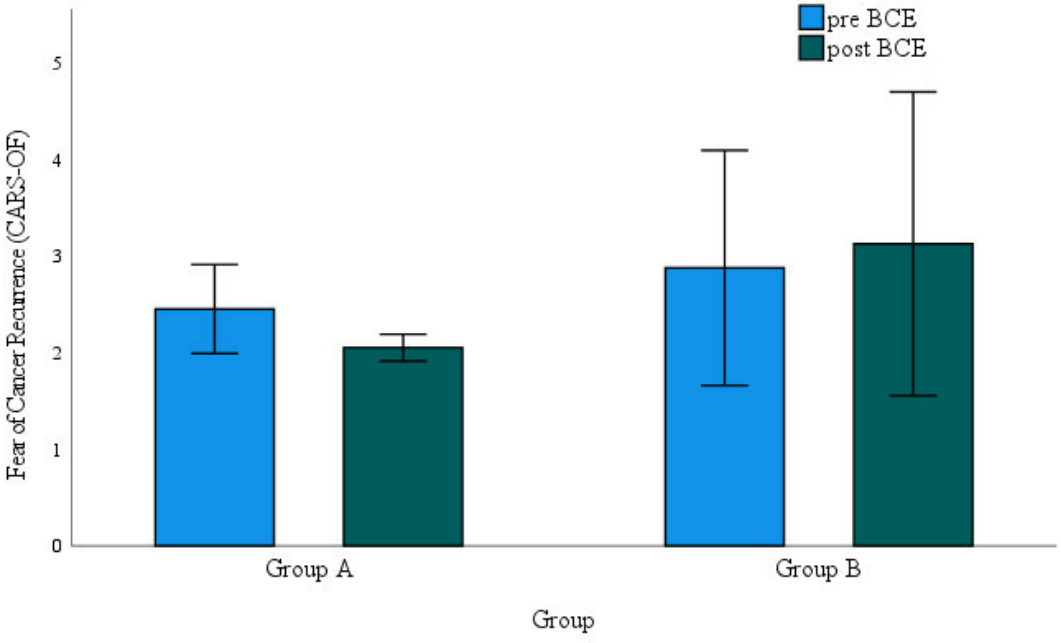


Figure E.8

Bar Graph of Individual Participant's Overall Fear of Cancer Recurrence Pre and Post BCE Intervention (n = 11)

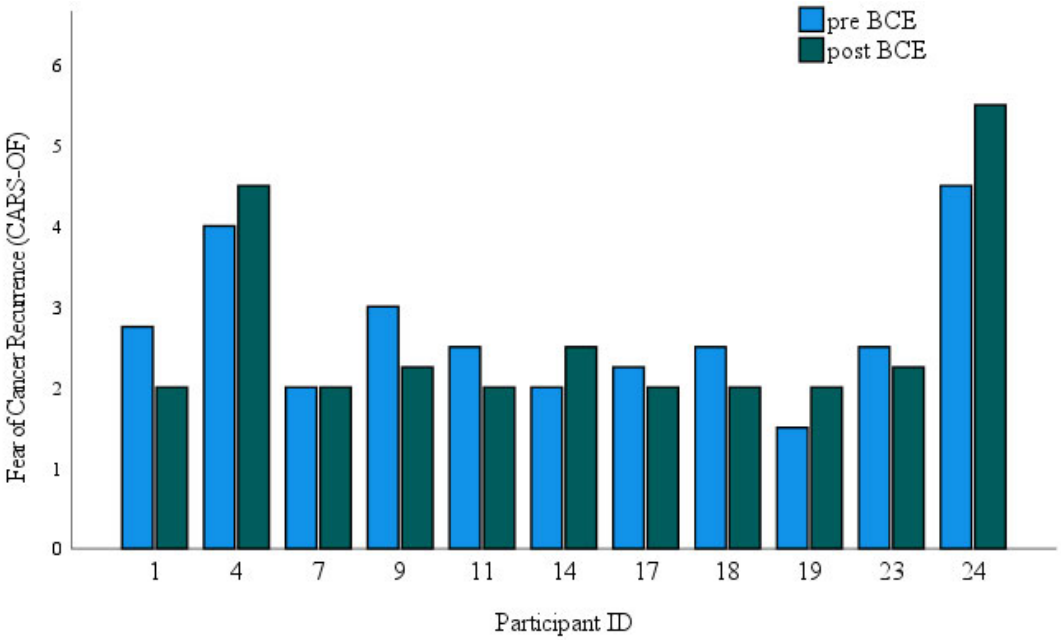


Figure E.9

Bar Graph of Group Quality of Life Pre and Post ACT Intervention (n = 18), Bars Represent 95% Confidence Interval

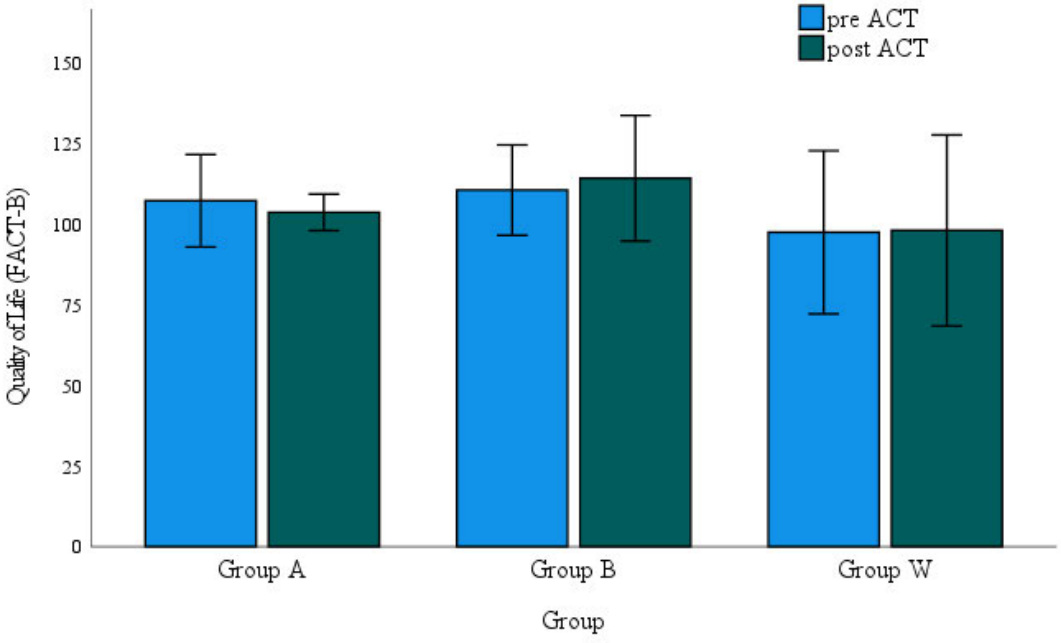


Figure E.10

Bar Graph of Individual Participant Quality of Life Pre and Post ACT Intervention (n = 18)

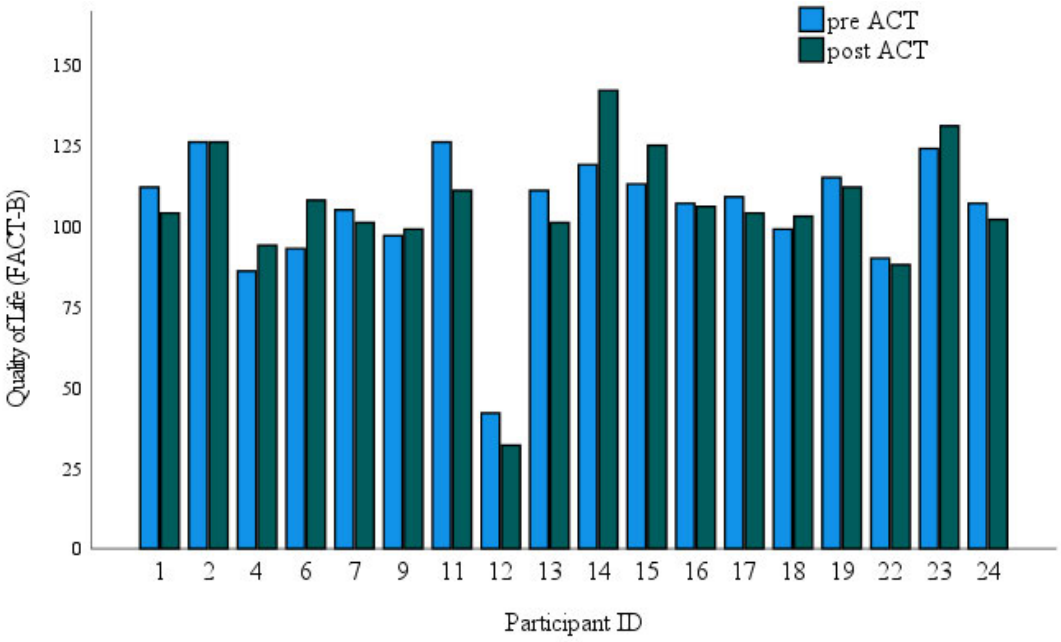


Figure E.11

Bar Group of Group Quality of Life Pre and Post BCE Intervention (n = 11), Bars Represent 95% Confidence Interval

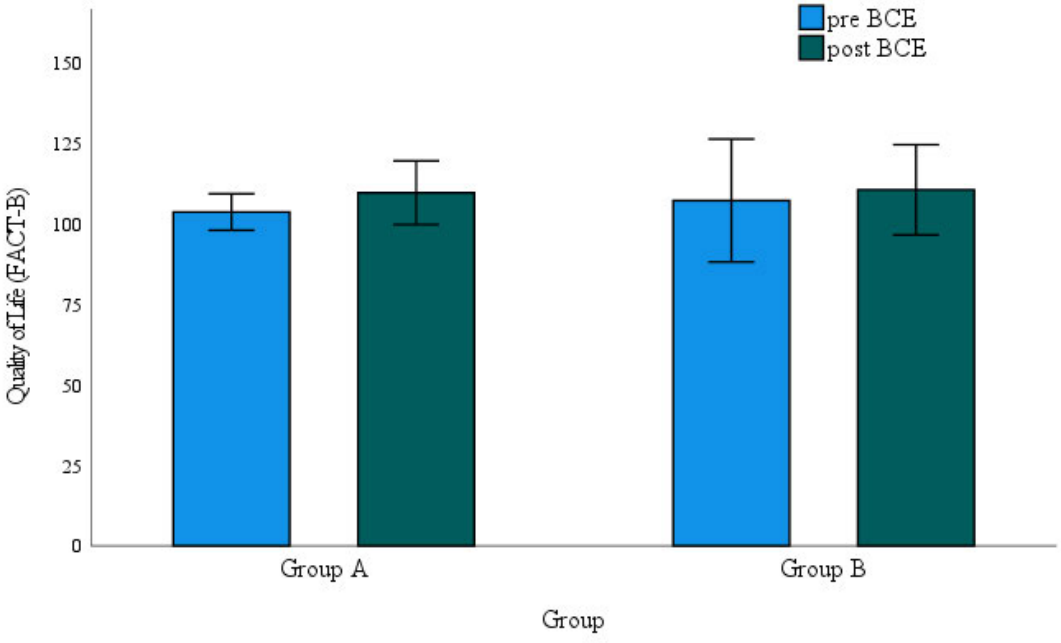


Figure E.12

Bar Group of Individual Participant Quality of Life Pre and Post BCE Intervention (n = 11)

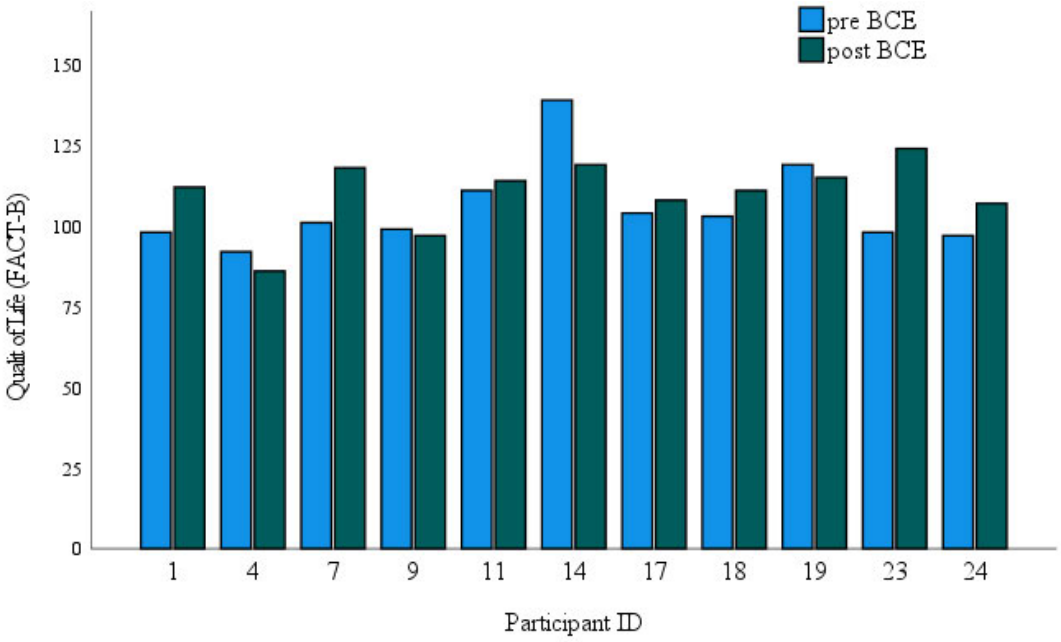


Figure E.13

Bar Graph of Group Depression Symptoms Pre and Post ACT Intervention (n = 18), Bars Represent 95% Confidence Interval

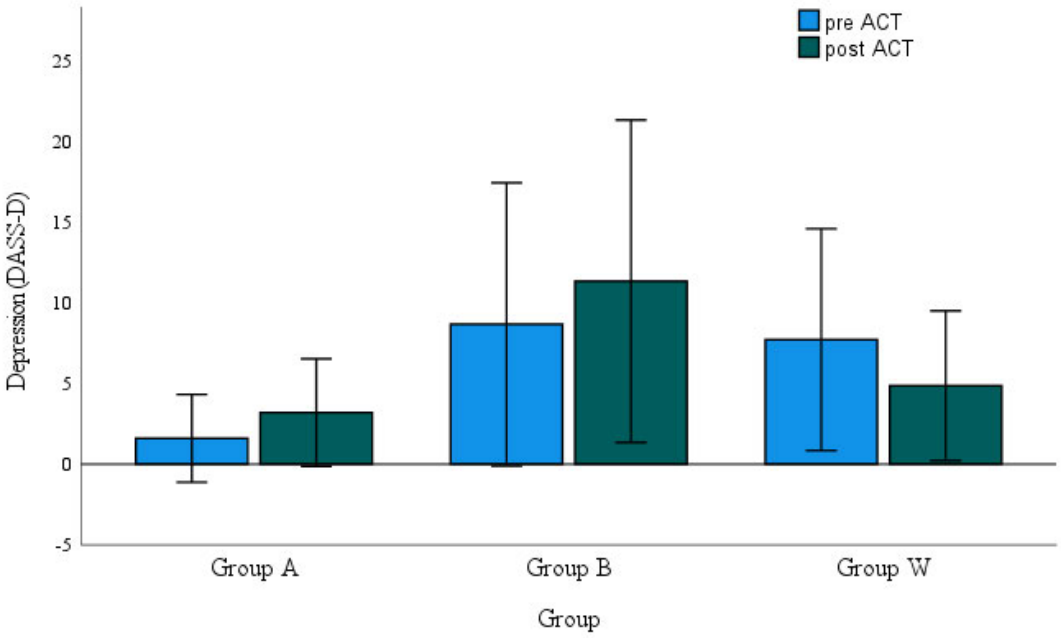


Figure E.14

Bar Graph of Individual Participant Depression Symptoms Pre and Post ACT Intervention (n = 18)

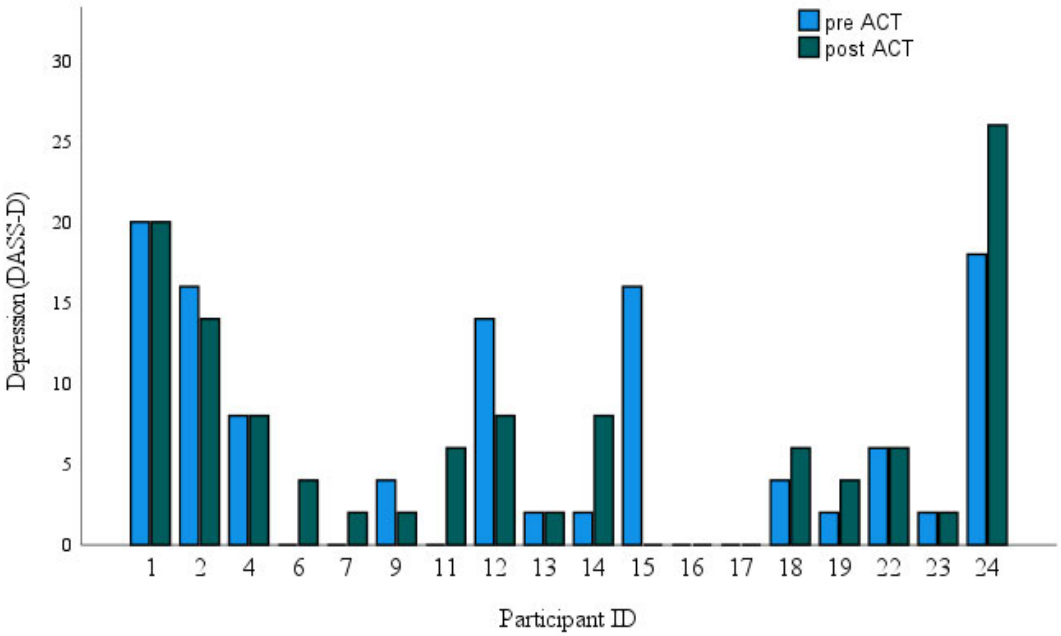


Figure E.15

Bar Graph of Group Depression Symptoms Pre and Post BCE Intervention (n = 11), Bars Represent 95% Confidence Interval

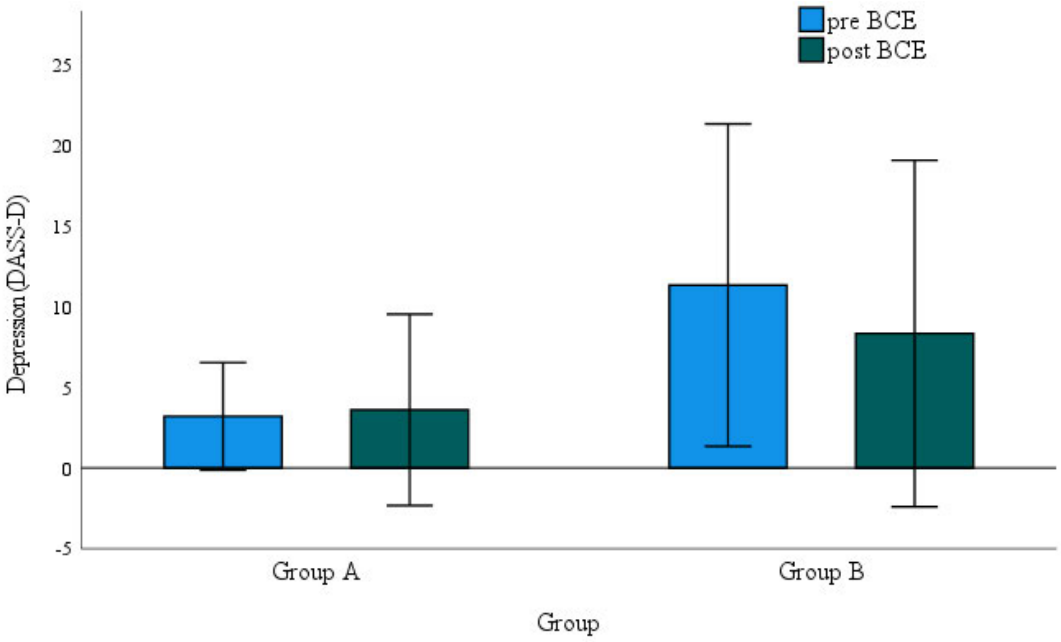


Figure E.16

Bar Group of Individual Participant Depression Symptoms Pre and Post BCE Intervention (n = 11)

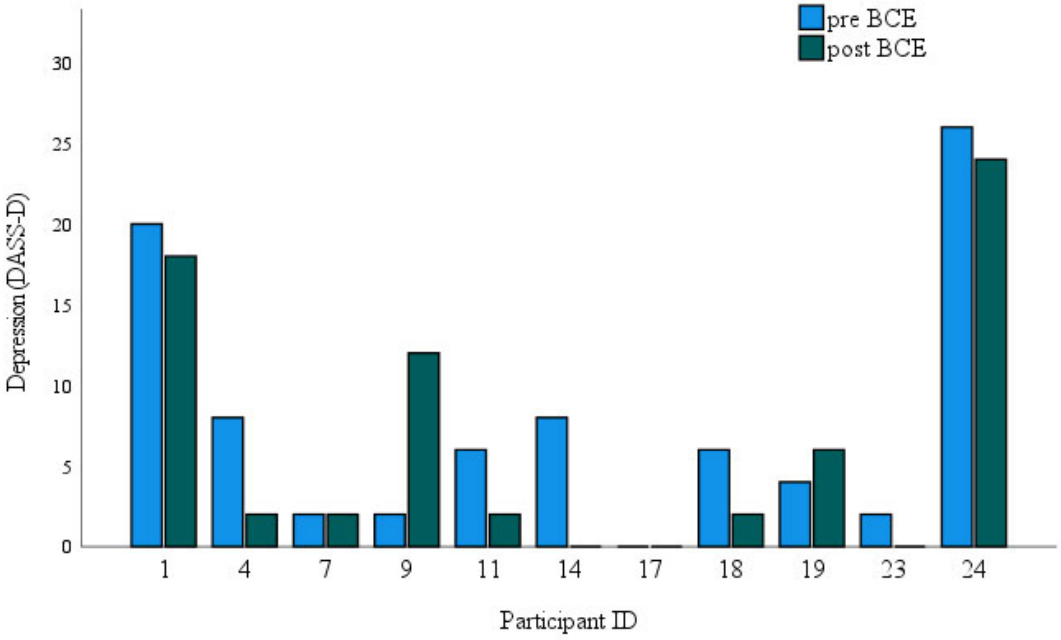


Figure E.17

Bar Graph of Group Anxiety Symptoms Pre and Post ACT Intervention (n = 18), Bars Represent 95% Confidence Interval

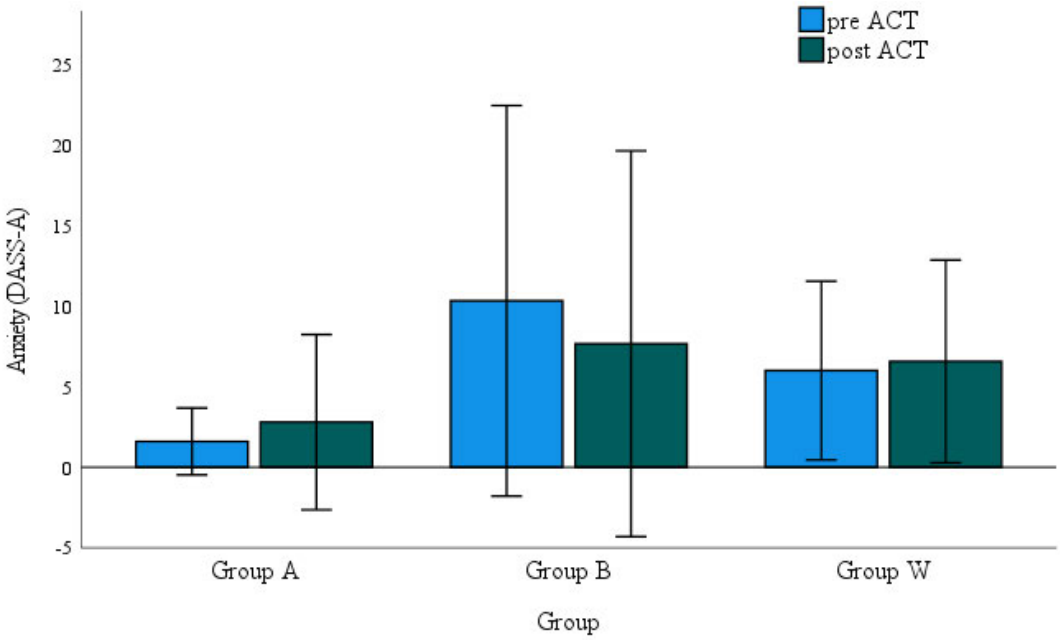


Figure E.18

Bar Graph of Individual Participant Anxiety Symptoms Pre and Post ACT Intervention (n = 18)

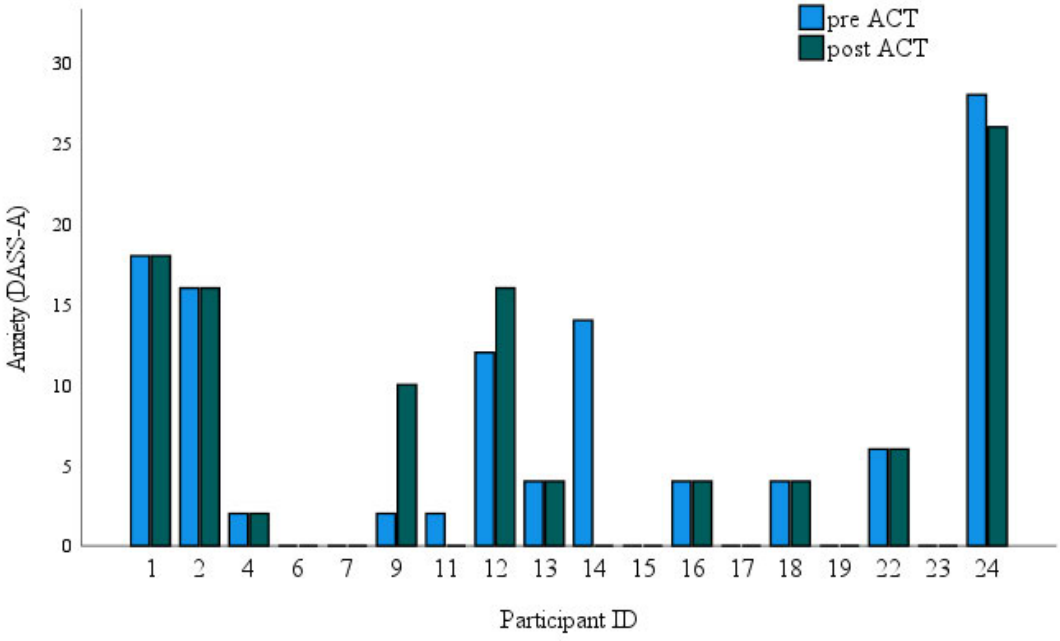


Figure E.19

Bar Graph of Group Anxiety Symptoms Pre and Post BCE Intervention (n = 11), Bars Represent 95% Confidence Interval

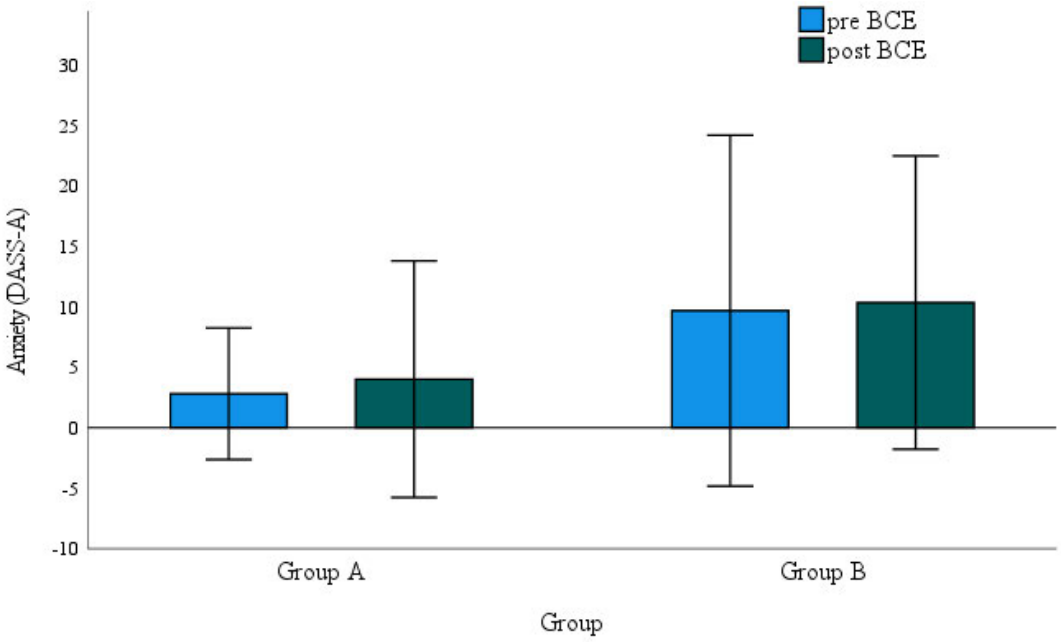


Figure E.20

Bar Graph of Individual Participant Anxiety Symptoms Pre and Post BCE Intervention (n = 11)

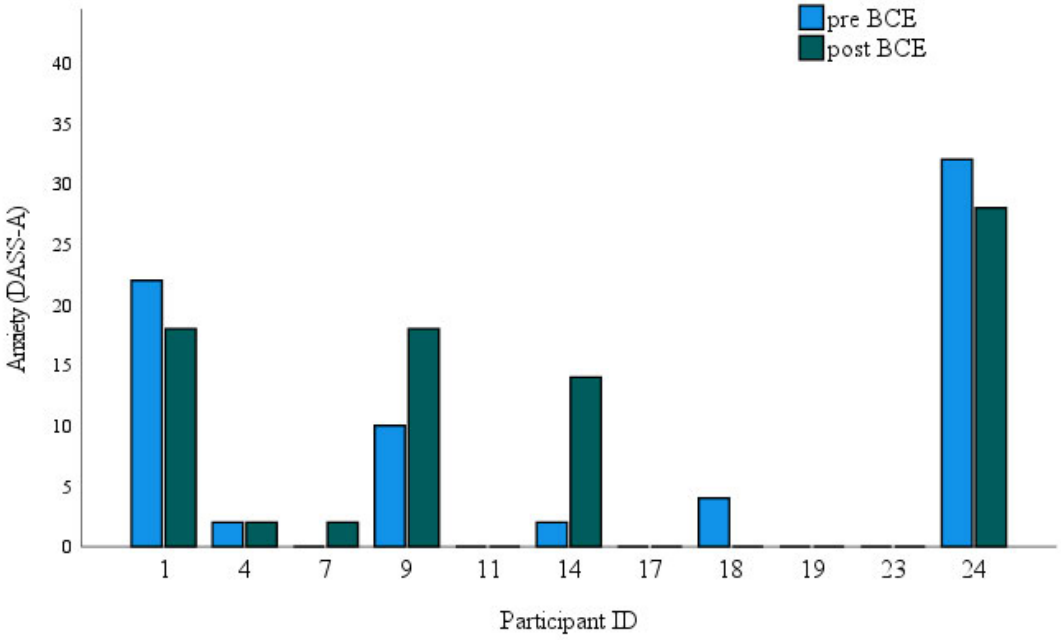


Figure E.21

Bar Graph of Group Stress Symptoms Pre and Post ACT Intervention (n = 18), Bars Represent 95% Confidence Interval

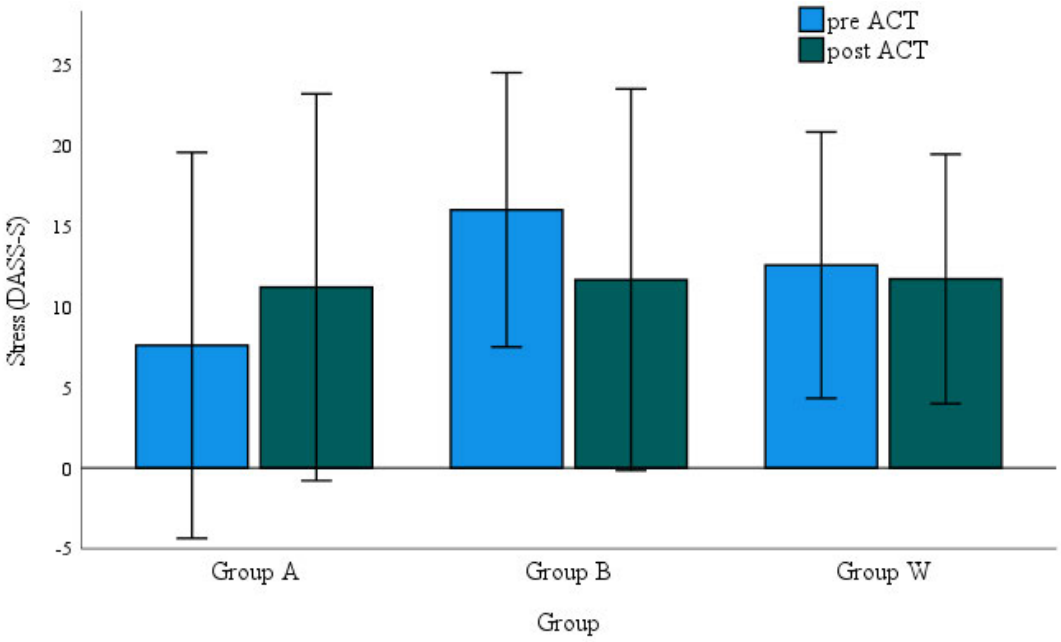


Figure E.22

Bar Graph of Individual Participant Stress Symptoms Pre and Post ACT Intervention (n = 18)

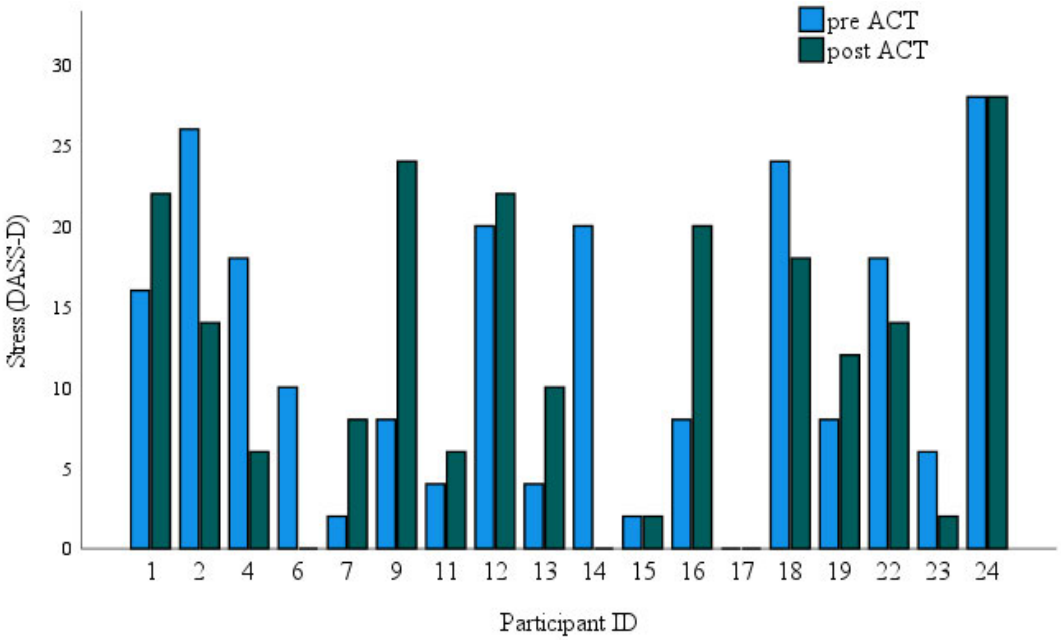


Figure E.23

Bar Graph of Group Stress Symptoms Pre and Post BCE Intervention (n = 11), Bars Represent 95% Confidence Interval

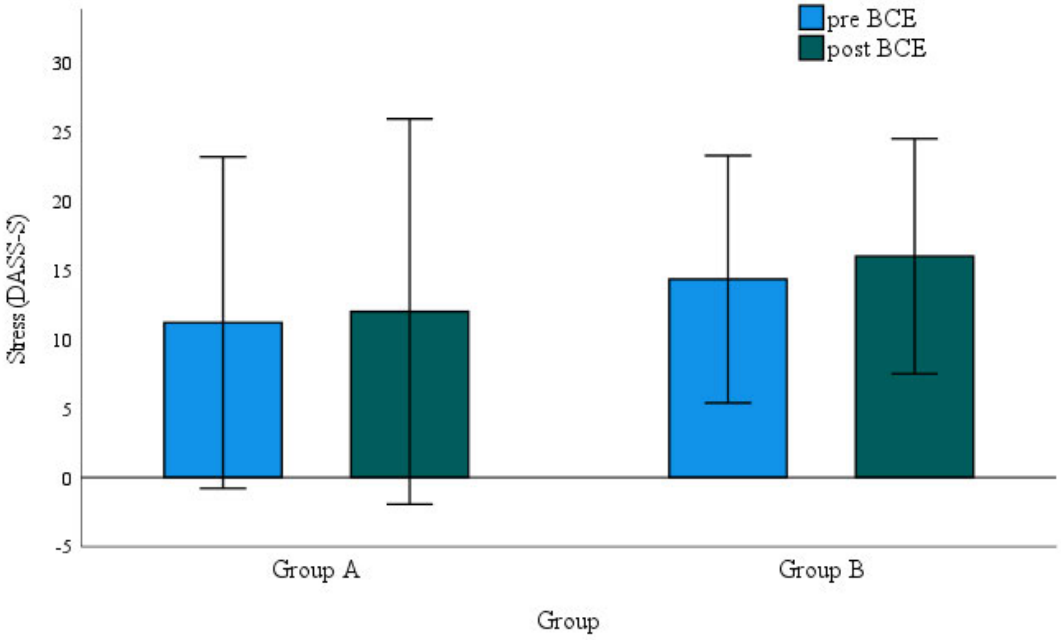
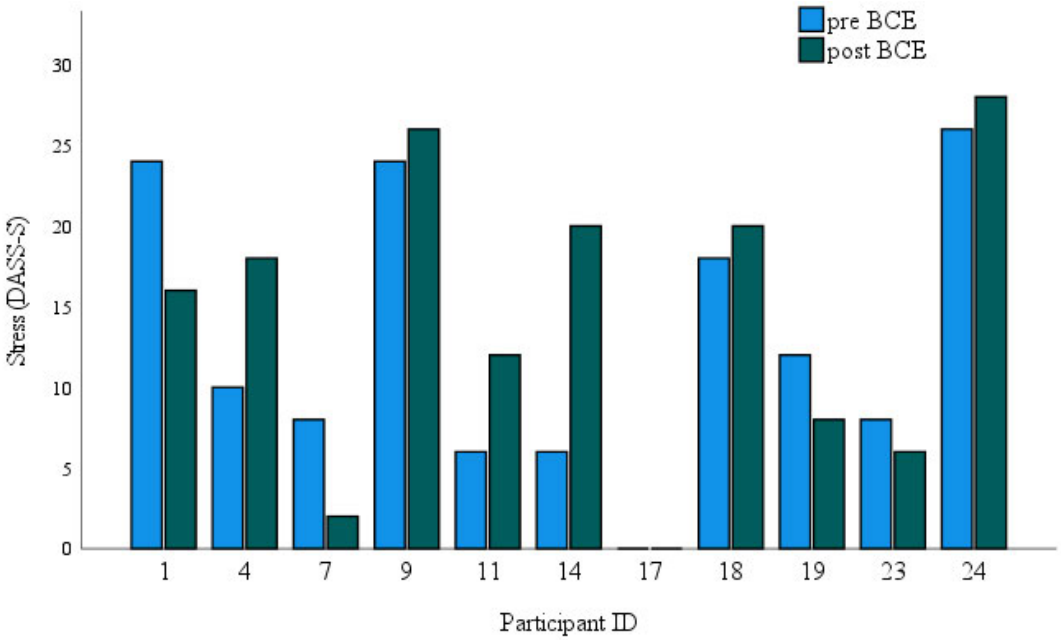


Figure E.24

Bar Graph of Individual Participant Stress Symptoms Pre and Post BCE Intervention (n = 11)



APPENDIX F - Study 1 Scale Descriptions

Depression Anxiety and Stress Scale

Table F.1

Depression Anxiety and Stress Scale Overall Score

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	20.76	27.20	26.44	24.20	6.40	16.32
SD	21.19	24.28	21.98	22.48	11.94	16.35
α	.95	.95	.95	.95	.93	.92
Possible range	0 – 126	0 – 126	0 – 126	0 – 126	0 – 126	0 – 126
Actual range	0 – 82	0 – 76	0 – 82	0 – 78	0 – 46	0 – 50
Skew	1.09	.78	1.04	.97	3.08	.64
Kurtosis	.31	-.89	.78	.13	10.53	-.97

Table F.2

Depression Anxiety and Stress Scale – Depression Score

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	5.20	6.80	6.56	6.50	1.47	3.79
SD	6.41	7.47	7.06	7.03	3.74	4.32
α	.87	.89	.90	.84	.83	.76
Possible range	0-42	0-42	0-42	0-42	0-42	0-42
Actual range	0-26	0-20	0-26	0-24	0-14	0-12
Skew	1.42	.81	1.69	1.21	3.10	1.08
Kurtosis	1.20	-1.05	2.68	.65	10.18	-.15

Table F.3

Depression Anxiety and Stress Scale – Anxiety Score

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	5.20	7.39	6.56	5.70	1.87	3.79
SD	7.60	9.21	8.11	8.16	5.26	5.49
α	.89	.91	.89	.91	.93	.77
Possible range	0-42	0-42	0-42	0-42	0-42	0-42
Actual range	0-32	0-32	0-28	0-26	0-20	0-22
Skew	1.65	1.44	1.33	1.34	3.37	2.24
Kurtosis	1.91	1.25	1.31	.50	11.78	6.13

Table F.4

Depression Anxiety and Stress Scale – Stress Score

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	10.37	13.10	13.33	12.00	3.07	8.74
SD	8.92	9.57	8.57	9.18	3.69	8.36
α	.91	.89	.88	.92	.71	.90
Possible range	0-42	0-42	0-42	0-42	0-42	0-42
Actual range	0-30	0-30	0-28	0-28	0-12	0-22
Skew	.53	.51	.15	.13	1.12	.44
Kurtosis	-.97	-1.18	-1.21	-1.23	.80	-1.50

Concerns About Recurrence Scale

Table F.5

Concerns About Recurrence Scale – Total Score

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	1.41	1.63	1.34	1.51	1.34	1.22
SD	.82	.91	.82	.85	.68	.80
α	.97	.97	.97	.97	.94	.97
Possible range	.13-4.27	.13-4.27	.13-4.27	.13-4.27	.13-4.27	.13-4.27
Actual range	.13-4.17	.13-3.5	.13-3.6	.3-4.17	.23-2.43	.13-3.6
Skew	1.04	.60	1.08	1.58	.20	1.60
Kurtosis	1.32	-.09	2.22	3.83	-1.09	3.41

Table F.6

Concerns About Recurrence Scale – Overall Fear Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	2.70	2.89	2.92	2.81	2.57	2.28
SD	1.21	1.26	1.31	1.24	1.04	1.16
α	.92	.86	.94	.96	.91	.96
Possible range	1-6	1-6	1-6	1-6	1-6	1-6
Actual range	1-6	1-5.5	1-6	1-6	1-4.5	1-6
Skew	1.04	.62	1.17	1.32	.50	1.80
Kurtosis	.72	-.74	.87	1.44	-.10	5.18

Table F.7

Concerns About Recurrence Scale –Health Worries Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	1.42	1.65	1.24	1.51	1.35	1.29
SD	.86	.97	.82	.86	.82	.82
α	.92	.93	.92	.94	.92	.91
Possible range	0-4	0-4	0-4	0-4	0-4	0-4
Actual range	0-4	0-3.55	0-3.27	.45-4	.18-3	0-3.64
Skew	.77	.36	.64	1.30	.34	1.31
Kurtosis	.52	-.30	.83	2.27	-.71	2.71

Table F.8

Concerns About Recurrence Scale –Womanhood Worries Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	.66	.7	.60	.81	.58	.56
SD	.82	.79	.78	.99	.76	.78
α	.91	.87	.91	.96	.88	.89
Possible range	0-4	0-4	0-4	0-4	0-4	0-4
Actual range	0-4	0-2.86	0-3	0-4	0-3	0-2.57
Skew	1.89	1.56	1.97	2.07	2.46	1.76
Kurtosis	3.64	2.02	4.56	4.88	7.68	2.13

Table F.9

Concerns About Recurrence Scale –Role Worries Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	1.33	1.67	1.23	1.43	1.24	1.05
SD	.91	1.08	.88	.86	.89	.77
α	.88	.93	.88	.88	.85	.77
Possible range	0-4	0-4	0-4	0-4	0-4	0-4
Actual range	0-4	0-4	0-3.17	0-3.5	.17-3.17	0-3
Skew	.75	.68	.56	.55	.81	.93
Kurtosis	.15	-.20	-.12	.39	-.15	.79

Table F.10

Concerns About Recurrence Scale –Death Worries Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	1.73	2.1	1.61	1.68	1.7	1.53
SD	1.05	1.20	1.04	.95	1.19	.90
α	.86	.87	.90	.87	.94	.69
Possible range	0-4	0-4	0-4	0-4	0-4	0-4
Actual range	0-4	0-4	0-4	0-4	0-4	0-4
Skew	.58	.20	.69	.82	.54	.73
Kurtosis	-.05	-.87	.76	1.09	-.40	2.21

Mindful Attention Awareness Scale

Table F.11

Mindful Attention Awareness Scale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	73	20	18	20	15	
M	2.63	2.76	2.66	2.60	2.43	
SD	.83	.72	.83	.98	.77	
α	.89	.83	.89	.929	.881	
Possible range	1-6	1-6	1-6	1-6	1-6	No Data
Actual range	1-4.82	1.64-4.09	1.27-4.09	1.09-4.82	1-3.73	
Skew	.22	-.04	.08	.57	-.06	
Kurtosis	-.49	-.39	-.95	-.31	-.41	

Functional Assessment of Cancer Therapy

Table F.12

Functional Assessment of Cancer Therapy – Breast Scale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	105.78	104.2	103.50	105.65	109.8	106.58
SD	20.14	18.29	18.80	22.33	19.63	22.69
α	.79	.69	.74	.85	.75	.86
Possible range	0-148	0-148	0-148	0-148	0-148	0-148
Actual range	32-142	53-139	42-126	32-142	59-139	50-134
Skew	-1.23	-.74	-2.13	-1.75	-.96	-1.06
Kurtosis	2.72	2.31	6.44	5.82	2.31	1.00

Table F.13

Functional Assessment of Cancer Therapy – General Scale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	80.29	79.95	78.11	80.75	83.13	80
SD	14.69	13.18	14.03	15.82	13.89	17.20
α						
Possible range	0-108	0-108	0-108	0-108	0-108	0-108
Actual range	27-104	48-101	34-92	27-103	43-104	42-102
Skew	-1.37	-.85	-2.02	-2.05	-1.63	-.94
Kurtosis	2.52	.78	5.06	6.75	4.71	.37

Table F.14

Functional Assessment of Cancer Therapy – Physical Wellbeing Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	21.64	21.4	21.28	21.60	22.8	21.37
SD	4.16	3.62	3.74	4.54	3.59	5.21
α	.76	.63	.65	.78	.73	.86
Possible range	0-28	0-28	0-28	0-28	0-28	0-28
Actual range	7-27	14-27	11-27	12-27	16-27	7-27
Skew	-.82	-.04	-1.01	-.74	-.72	-1.14
Kurtosis	.75	-.64	2.21	-.62	-.25	1.77

Table F.15

Functional Assessment of Cancer Therapy – Social Wellbeing Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	20.02	20.15	19.94	19.9	20.07	20.05
SD	5.98	6.06	6.23	5.77	6.83	5.83
α	.90	.90	.91	.89	.94	.90
Possible range	0-28	0-28	0-28	0-28	0-28	0-28
Actual range	1-28	3-28	5-28	4-28	1-28	5-28
Skew	-1.21	-1.47	-1.19	-1.15	-1.56	-1.03
Kurtosis	1.62	2.78	1.23	2.34	3.46	1.65

Table F.16

Functional Assessment of Cancer Therapy – Emotional Wellbeing Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	19.09	19.05	18.56	19.40	19.40	19.05
SD	4.09	3.63	4.74	3.98	2.75	5.14
α	.83	.79	.86	.86	.49	.90
Possible range	0-24	0-24	0-24	0-24	0-24	0-24
Actual range	2-24	7-24	2-23	4-24	12-23	3-24
Skew	-2.51	-2.01	-2.69	-3.27	-1.41	-2.35
Kurtosis	7.30	5.83	9.03	12.86	2.84	5.65

Table F.17

Functional Assessment of Cancer Therapy – Functional Wellbeing Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	19.54	19.35	18.33	19.85	20.87	19.53
SD	4.95	4.33	4.98	5.29	5.083	5.26
	.87	.79	.86	.89	.91	.88
Possible range	0-24	0-24	0-24	0-24	0-24	0-24
Actual range	7-28	10-26	8-25	7-28	9-27	11-27
Skew	-.59	-.50	-.67	-.98	-.86	-.30
Kurtosis	-.27	-.63	-.36	1.00	.58	-.91

Table F.18

Functional Assessment of Cancer Therapy – Breast Cancer Subscale

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	25.49	24.25	25.39	24.9	26.67	26.58
SD	7.40	8.25	6.73	7.85	7.81	6.70
α	.80	.82	.78	.83	.80	.75
Possible range	0-40	0-40	0-40	0-40	0-40	0-40
Actual range	5-39	5-38	8-36	5-39	14-38	8-35
Skew	-.70	-.91	-.80	-.62	.02	-1.26
Kurtosis	.50	.72	1.35	.90	-1.19	1.97

Acceptance and Action Questionnaire II

Table F.19

Acceptance and Action Questionnaire II

Characteristic	Total	Time 1	Time 2	Time 3	Time 4	Time 5
N	92	20	18	20	15	19
M	14.01	13.85	14.17	14.25	12.93	14.63
SD	7.47	7.34	7.25	7.69	6.63	8.81
α	.93	.93	.90	.94	.93	.96
Possible range	7-49	7-49	7-49	7-49	7-49	7-49
Actual range	7-36	7-33	7-31	7-32	7-29	7-36
Skew	1.08	1.23	1.12	.89	1.21	1.16
Kurtosis	.41	1.08	.76	-.23	1.07	.68

APPENDIX G - Student 1 Correlations

Table G.1

Pearson Correlation Matrix of Variables of Interest

Variable	Depression	Anxiety	Stress	Quality of life, breast cancer	Quality of life	Physical wellbeing	Social wellbeing	Emotional wellbeing	Functional wellbeing	Breast cancer related wellbeing	Total concerns about recurrence	Overall Fear	Health Worries	Womanhood Worries	Role Worries	Death Worries	Experiential avoidance
Depression	--																
Anxiety	.84**	--															
Stress	.78**	.73**	--														
Quality of life, breast cancer	-.30**	-.30**	-.44**	--													
Quality of life	-.22*	-0.19	-.39**	.96**	--												
Physical wellbeing	-.23*	-.25*	-.38**	.61**	.58**	--											

Variable	Depression	Anxiety	Stress	Quality of life, breast cancer	Quality of life	Physical wellbeing	Social wellbeing	Emotional wellbeing	Functional wellbeing	Breast cancer related wellbeing	Total concerns about recurrence	Overall Fear	Health Worries	Womanhood Worries	Role Worries	Death Worries	Experiential avoidance
Social wellbeing	-0.06	-0.03	-.25*	.75**	.85**	.22*	--										
Emotional wellbeing	-.37**	-.35**	-.41**	.77**	.73**	.41**	.43**	--									
Functional wellbeing	-0.09	-0.02	-0.20	.79**	.86**	.27**	.77**	.47**	--								
Breast cancer related wellbeing	-.38**	-.45**	-.41**	.82**	.62**	.52**	.36**	.66**	.44**	--							
Total concerns about recurrence	.28**	0.20	.31**	-.62**	-.48**	-.33**	-.28**	-.65**	-.26*	-.73**	--						
Overall Fear	.42**	.34**	.36**	-.45**	-.30**	-.24*	-0.03	-.63**	-0.12	-.63**	.79**	--					
Health Worries	.21*	0.13	.24*	-.59**	-.46**	-.28**	-.31**	-.61**	-.27*	-.68**	.97**	.67**	--				

Variable	Depression	Anxiety	Stress	Quality of life, breast cancer	Quality of life	Physical wellbeing	Social wellbeing	Emotional wellbeing	Functional wellbeing	Breast cancer related wellbeing	Total concerns about recurrence	Overall Fear	Health Worries	Womanhood Worries	Role Worries	Death Worries	Experiential avoidance
Womanhood Worries	.26*	.27*	.34**	-.65**	-.53**	-.34**	-.37**	-.62**	-.34**	-.71**	.85**	.60**	.76**	--			
Role Worries	.21*	0.1	.24*	-.50**	-.37**	-.34**	-.21*	-.48**	-0.18	-.62**	.93**	.64**	.89**	.72**	--		
Death Worries	0.05	-0.05	0.12	-.44**	-.36**	-0.19	-.25*	-.50**	-0.20	-.48**	.80**	.55**	.83**	.50**	.77**	--	
Experiential avoidance	.37**	.28**	.48**	-.69**	-.60**	-.49**	-.35**	-.68**	-.39**	-.68**	.69**	.63**	.63**	.72**	.57**	.38**	--

Note. $N = 92$; Pearson's correlations; * p = ≤ to .05; ** p = ≤ to .01

APPENDIX H - Study 2 Online Survey

Quality of Life Following Early Breast Cancer for Women in Regional Australia, and the Role of Experiential Avoidance

This survey is for women **living outside of capital cities** who have **completed their treatment** (chemotherapy, surgery, and/or radiation) for **early breast cancer** (Stage I – III).

Human Research Ethics Approval Number: H21REA005

Research Team Contact Details

Principal Investigator Details
May Chi
Email: [redacted]
Mobile: [redacted]

Supervisor Details
Associate Professor Gavin Beccaria
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Telephone: [redacted]

Description
This survey is for women living outside of capital cities who have completed their treatment (chemotherapy, surgery, and/or radiation) for early breast cancer (Stage I – III).

I am requesting your participation to help me learn more about your experience.

The purpose of this project is to understand the wellbeing of women who have had early breast cancer. I am looking at how different things may affect women's quality of life after their treatment. Past studies done by other researchers have suggested that there are many factors associated with women's wellbeing after treatment, including exercise, smoking, age at diagnosis, type of cancer treatment, socio- economic status, and many others. Past studies have also suggested that women sometimes have concerns about cancer recurrence.
Most of these studies are conducted with women living in major cities. I am looking to know more about how these sorts of things affect women living in regional and remote Australia.
I hope we can get snapshot of regional women's quality of life following breast cancer.

I understand that some treatments for breast cancer can last a long time, such as Hormone Replacement Therapy. It is ok if you are still on these therapies, as long as you have completed chemotherapy, surgery, and/or radiation.

This project is being undertaken as part of my Master of Psychology / PhD (Clinical Psychology) degree.

Participation
Your participation will involve filling out an online survey. This survey may take between 10 – 20 minutes.

Some questions may ask you about your thoughts about cancer, such as, "How often do you worry about the possibility that your breast cancer could recur?".

Your participation in this project is entirely voluntary. If you do not wish to take part, you are not obliged to. You will be unable to withdraw data collected about yourself after you have participated in this questionnaire because we will have no way of identifying you from your response.

Your decision whether you take part, do not take part, or to take part will in no way impact your current or future relationship with the University of Southern Queensland.

For every completed questionnaire, up to 2000 questionnaires, $1 will be donated to the Breast Cancer Network Australia (https://www.bcna.org.au/ (https://www.bcna.org.au/)), which is an organization that provides free information and support to Australians affected by breast cancer.

Expected Benefits
It is expected that this project may not directly benefit you. However, if we can understand what is going on for regional women after their treatment, then we may better target the support that may be required after primary medical intervention.

Risks
In participating in the questionnaire there are no anticipated risks beyond normal day-to-day living. However, if you experience a higher discomfort or inconvenience than you had expected to when answering the questions, please make use of free, confidential telephone counselling through Lifeline. Phone: 13 11 14.

You can also use a Breast Cancer specific help line through Breast Cancer Network Australia. Phone: 1800 500 258.

You can also contact me with your concerns, and I would be glad to assist with providing referral support. My direct phone number is [redacted]

Privacy and Confidentiality
All comments and responses will be treated confidentially unless required by law.

The names of individual persons are not required in any of the responses. No one will know if you personally completed the survey or not.

The data collected is stored in non-identifiable form and will be made available for future research purposes for projects about women, health, regional/ rural experience, and psychology. The results will be communicated to the community in a number of formats that may include written articles and oral presentations.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy (http://policy.usq.edu.au/documents/151987PL).

Consent to Participate
Clicking on the 'Submit' button at the conclusion of the questionnaire is accepted as an indication of your consent to participate in this project.

Questions or Further Information about the Project
Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Contact for Results
If you, or any interested parties, would like me to email you my thoughts and results after the preliminary data analysis, please contact me via phone [redacted] or email [redacted] I will get your email address, which I will not link to any data, and use only for the purpose of communicating the results to you.

Concerns or Complaints Regarding the Conduct of the Project
If you have any concerns or complaints about the ethical conduct of the project, you may contact the University of Southern Queensland Manager of Research Integrity and Ethics on +61 7 4631 1839 or email researchintegrity@usq.edu.au (mailto researchintegrity@usq.edu.au). The Manager of Research Integrity and Ethics is not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please keep this sheet for your information. To print a copy, press the keys CTRL+P and follow your computer's prompts.

Then click NEXT to start.

There are 32 questions in this survey.

Functional Assessment of Cancer Therapy - Breast (Cella et al., 1993)
Below is a list of statements that other people with your illness have said are important. Please indicate your response to each item as it applies to the past 7 days.

PHYSICAL WELLBEING
Please choose the appropriate response for each item:

	Not at all	A little bit	Some what	Quite a bit	Very much
I have a lack of energy	◯	◯	◯	◯	◯
I have nausea	◯	◯	◯	◯	◯
Because of my physical condition, I have trouble meeting the needs of my family	◯	◯	◯	◯	◯
I have pain	◯	◯	◯	◯	◯
I am bothered by sideeffects of treatment	◯	◯	◯	◯	◯
I feel ill	◯	◯	◯	◯	◯
I am forced to spendtime in bed	◯	◯	◯	◯	◯

SOCIAL/FAMILY WELLBEING
Please choose the appropriate response for each item:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to myfriends	◯	◯	◯	◯	◯
I get emotional support from myfamily	◯	◯	◯	◯	◯
I get support from my friends	◯	◯	◯	◯	◯
My family has accepted my illness	◯	◯	◯	◯	◯
I am satisfied with family communication about my illness	◯	◯	◯	◯	◯
I feel close to my partner (or the person who is my main support)	◯	◯	◯	◯	◯
I am satisfied with my sex life (regardless of your current level of sexual activity, please answer the question. If you prefer not to answer, please go to the next question)	◯	◯	◯	◯	◯

EMOTIONAL WELLBEING

Please choose the appropriate response for each item:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	◯	◯	◯	◯	◯

I am satisfied I am coping with my illness	◯	◯	◯	◯	◯
I am losing hope in the fight against my illness	◯	◯	◯	◯	◯
I feel nervous	◯	◯	◯	◯	◯
I worry about dying	◯	◯	◯	◯	◯
I worry that my condition will getworse	◯	◯	◯	◯	◯

FUNCTONAL WELLBEING

Please choose the appropriate response for each item:

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
I am able to work (including work at home)	◯	◯	◯	◯	◯
My work (including work at home) is fulfilling	◯	◯	◯	◯	◯
I am able to enjoy life	◯	◯	◯	◯	◯
I have accepted my illness	◯	◯	◯	◯	◯
I am sleeping well	◯	◯	◯	◯	◯
I am enjoying the things I usually do forfun	◯	◯	◯	◯	◯

I am content with the quality of my life right now	◯	◯	◯	◯	◯

ADDITIONAL CONCERNS

Please choose the appropriate response for each item:

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have shortness of breath	◯	◯	◯	◯	◯
I am self-conscious about the way I dress	◯	◯	◯	◯	◯
One or both of my arms are swollen or tender	◯	◯	◯	◯	◯
I feel sexually attractive	◯	◯	◯	◯	◯
I am bothered by hair loss	◯	◯	◯	◯	◯
I worry that other members of my family might someday get the same illness I have	◯	◯	◯	◯	◯
I worry about the effects of stress on myillness	◯	◯	◯	◯	◯
I am bothered by a change in weight	◯	◯	◯	◯	◯
I am able to feel like a woman	◯	◯	◯	◯	◯
I have certain parts of my body where I experience pain	◯	◯	◯	◯	◯

Social Support Survey Instrument (Sherbourne and Stewart, 1992)
People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Choose one number from each line.

Emotional/informational support
Please choose the appropriate response for each item:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone you can count on to listen to you when you need totalk	◯	◯	◯	◯	◯
Someone to give you information to help you understand a situation	◯	◯	◯	◯	◯
Someone to give you good advice about a crisis	◯	◯	◯	◯	◯
Someone you confidein or talk about yourself or your problems	◯	◯	◯	◯	◯
Someone whose advice you really want	◯	◯	◯	◯	◯
Someone to share your most private worries and fears with	◯	◯	◯	◯	◯
Someone to turn to for suggestions about how to deal with a personal problem	◯	◯	◯	◯	◯

Someone who understands your problems	◯	◯	◯	◯	◯

Tangible support

Please choose the appropriate response for each item:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to help you if you were confined tobed	◯	◯	◯	◯	◯
Someone to take youto the doctor of you needed it	◯	◯	◯	◯	◯
Someone to prepare your meals if you wereunable to do it yourself	◯	◯	◯	◯	◯
Someone to help with daily chores if you were sick	◯	◯	◯	◯	◯

Affectionate support

Please choose the appropriate response for each item:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone who shows you love and affection	◯	◯	◯	◯	◯
Someone to love and make you feel wanted	◯	◯	◯	◯	◯
Someone who hugs you	◯	◯	◯	◯	◯

Positive social interaction

Please choose the appropriate response for each item:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to have a good time with	◯	◯	◯	◯	◯
Someone to get together with for relaxation	◯	◯	◯	◯	◯
Someone to do something enjoyable with	◯	◯	◯	◯	◯

Additional Item

Please choose the appropriate response for each item:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to do things with to help you get your mind off things	◯	◯	◯	◯	◯

Concerns about Recurrence Scale (Vickberg, 2003)

The following questions ask you to tell us about any worries you may have about the possibility of breast cancer recurrence. By recurrence, we mean the breast cancer coming back in the same breast or another area or the body, or a new breast cancer in either breast.

Althought most women who have been diagnosed with early stage breast cancer will never have another problem with breast cancer, we are aware that many women do worry about this possibility. Other women may not worry about recurrence at all. Either way, your answers to these questions are very important to us. We understand that it may be upsetting to think about or answer questions about hte possibility of recurrence. However, we need your help to understand how women think about this possibility.

*For the following four questions please circle the number that comes closest to the way you feel. For example, for the first question you should circle "1" if you don't think about recurrence at all, circle "6" if you think about recurrence all the time, or circle "2", "3", "4" or "5" if the amount of time you spend thinking about recurrence is somewhere in between. **

Please choose the appropriate response for each item:

	1	2	3	4	5	6

How much time do you spend thinking about the possibility that your breast cancer could recur? (1 = I Don't Think About It At All, 6 = I Think About It All TheTime)	◯	◯	◯	◯	◯	◯
How much does the possibility that your breast cancer could recur upset you? (1 = It Does Not Upset Me At All, 6 = It Makes MeExtremely Upset)	◯	◯	◯	◯	◯	◯
How often do you worry about the possibility that your breast cancer could recur? (1 = I never Worry About It, 6 = I worry About It All TheTime)	◯	◯	◯	◯	◯	◯
How afraid are you that your breast cancer may recur? (1 = Not At All Afraid, 6 = Very Afraid)	◯	◯	◯	◯	◯	◯

Acceptance and Action Questionnaire II (Bond et al., 2004)

Below you will find a list of statements. Please use the scale to rate how true each statement is for you. *

Please choose the appropriate response for each item:

	Nevr true	**Very seldom true**	**Seldom true**	**Some times tru**	**Frequently True**	**Almost always true**	**Always true**

My painful experiences and memories make it difficult for me to livea life that I would value.	◯	◯	◯	◯	◯	◯	◯
I am afraid of my feelings.	◯	◯	◯	◯	◯	◯	◯
I worry about not being able to controlmy worries and feelings.	◯	◯	◯	◯	◯	◯	◯
My painful memories prevent me from having a fulfilling life.	◯	◯	◯	◯	◯	◯	◯
Emotions cause problems in my life.	◯	◯	◯	◯	◯	◯	◯
It seems like most people are handling their lives better than Iam.	◯	◯	◯	◯	◯	◯	◯
Worries get in the wayof my success.	◯	◯	◯	◯	◯	◯	◯

Kessler Psychological Distress Scale (Kessler et al., 2003)

During the last 30 days, about how often did... *
Please choose the appropriate response for each item:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
you feed tired out ofno good reason?	◯	◯	◯	◯	◯
you feel nervous?	◯	◯	◯	◯	◯

you feel so nervous that nothing could calm you down?	◯	◯	◯	◯	◯
you feel hopeless?	◯	◯	◯	◯	◯
you feel restless or fidgety?	◯	◯	◯	◯	◯
you feel so restless that you could not sitstill?	◯	◯	◯	◯	◯
you feel depressed?	◯	◯	◯	◯	◯
you feel that everything was an effort?	◯	◯	◯	◯	◯
you feel so sad that nothing could cheer you up?	◯	◯	◯	◯	◯
you feel worthless?	◯	◯	◯	◯	◯

Additional Information

The following are some questions related to diagnosis and treatment.

*What was your age when you were first diagnosed with breast cancer? **

Please write your answer here: _____

*What stage was the breast cancer at diagnosis? **

□ Choose one of the following answers Please choose only one of the following:

Stage I

Stage II

Stage III

*What year did you last have primary treatment for breast cancer? (e.g., last had chemotherapy, surgery, and/or radiation) **

Please write your answer here: _____

*What treatment(s) did you have for the breast cancer? **

□ Check all that apply Please choose all that apply:

Lumpectomy

Mastectomy

Mastectomy with reconstruction

Radiotherapy

Chemotherapy

Hormonal therapies

Other
*Are you currently receiving tamoxifen? **
 Choose one of the following answers Please choose only one of the following:
Yes
No
*Have you had a recurrence of cancer? **
 Choose one of the following answers Please choose only one of the following:
Yes
No
Demographic Information
*What year were you born? **
Please write your answer here: _____
*What is your post code? **
Please write your answer here: _____
*How many years have you lived outside of a capital city? **
Please write your answer here: _____
*How many years have you lived at your current postcode?**
Please write your answer here: _____
*Aproximately how much money do you receive per fortnight (after any deductions, such as tax) from all sources of income? (use whole dollars) **
Please write your answer here: _____
*How easy is it for you to live on this amount of money per fortnight? **
 Choose one of the following answers Please choose only one of the following:
Extremely easy
Very easy
Fairly easy
Difficult
Very difficult
Extremely difficult
*Do you get at least 2.5 hours of moderate physical activity a week? **
 Choose one of the following answers Please choose only one of the following:
Yes
No
*Do you engage in exercise: **
 Choose one of the following answers Please choose only one of the following:
Never
Rarely
Sometimes
Often
Always
*Do you currently smoke tobacco/ cigarettes? **
 Choose one of the following answers Please choose only one of the following:
Yes
No
*What is your cultural or ethnic identity? **
 Choose one of the following answers Please choose only one of the following:
Australian
Australian Aboriginal
Australian South Sea Islander Torres Strait islander
Oceanian
North-West European
Southern and Eastern European

North African and Middle Eastern
South-East Asian
North-East Asian
Southern and Central Asian
People of the Americas
Sub-Saharan African
Other

*What is your relationship status? **

 Choose one of the following answers Please choose only one of the following:

Married/ committed
Divorced/ separated
Widowed
Single

*What is your highest education level? **

 Choose one of the following answers Please choose only one of the following:

Primary school
High school
Undergraduate or trade qualification
Post graduate qualification

Final Question

Do you think that your experience through COVID-19 affects your current wellbeing? If so, in what way?

Please write your answer here: _____

Thank you for submitting your responses!

Remember, if you would like to know the preliminary results, email me at may.chi@usq.edu.au

Have a great day. May Chi

APPENDIX I - Example invitations

Invitation for Gatekeepers

I am looking for participation from women who live regionally and rurally, who have finished treated for breast cancer. I am interested in learning more about the wellbeing of women following their medical treatment. This survey is part of my PhD project.

I would be grateful if you could assist me in circulating the survey to interested participants.

Here is the link: LINK.

Invitation for Participants:

Are you interested in filling out a survey about breast cancer wellbeing?

I am looking for participation from women who live regionally and rurally, who have finished treated for breast cancer. I am interested in learning more about the wellbeing of women following their medical treatment. This survey is part of my PhD project.

If you are interested, please use the following link: LINK

APPENDIX J - Subscale Information for Study 2

Table J.1

Descriptive Statistics For Subscales

Measurement	FACT-G	Physical Wellbeing	Emotional Wellbeing	Social Wellbeing	Functional Wellbeing	Breast Cancer Scale	FACT-B	CARS Overall Fear	AAQ-II	K10
N	538	538	538	538	538	538	538	538	538	538
M	69.78	17.78	17.35	16.11	18.55	23.01	92.80	3.59	19.64	19.72
SD	15.96	4.41	4.41	5.29	6.00	7.00	21.22	1.34	9.01	7.48
α	.79	.85	.56	.86	.88	.45	.83	.92	.94	.93
Possible range	0-108	0-28	0-24	0-28	0-28	0-40	0-148	1-6	7-49	10-50
Actual range	16-100	3-24	0-24	0-24	0-28	4-40	22-140	1-6	7-49	10-49
Skew	-.48	-.77	-.96	-.59	-.48	-.26	-.38	-.08	.64	1.08
Kurtosis	-.22	.96	.91	-.24	-.28	-.32	-.21	-.92	-.10	1.10

Table J.2

Medical Outcome Scale – Social Support Survey Subscales

Measurement	Emotional/ Informational support	Tangible Support	Affectionate Support	Positive Social Support	Scaled Total Score
N	538	538	538	538	538
M	57.54	69.57	73.27	65.12	64.03
SD	26.10	27.85	29.31	25.96	22.92
α	.96	.94	.96	.96	.90
Possible range	0-100	0-100	0-100	0-100	0-100
Actual range	0-100	0-100	0-100	0-100	0-100
Skew	-.23	-.75	-.90	-.43	-.45
Kurtosis	-.75	-.39	-.35	-.43	-.45

APPENDIX K - Study 2, Histograms of main scaled variables, overlaid with a normative curve

Figure K.1

Histogram of Functional Assessment of Cancer Therapy – Breast (FACT-B), N = 538

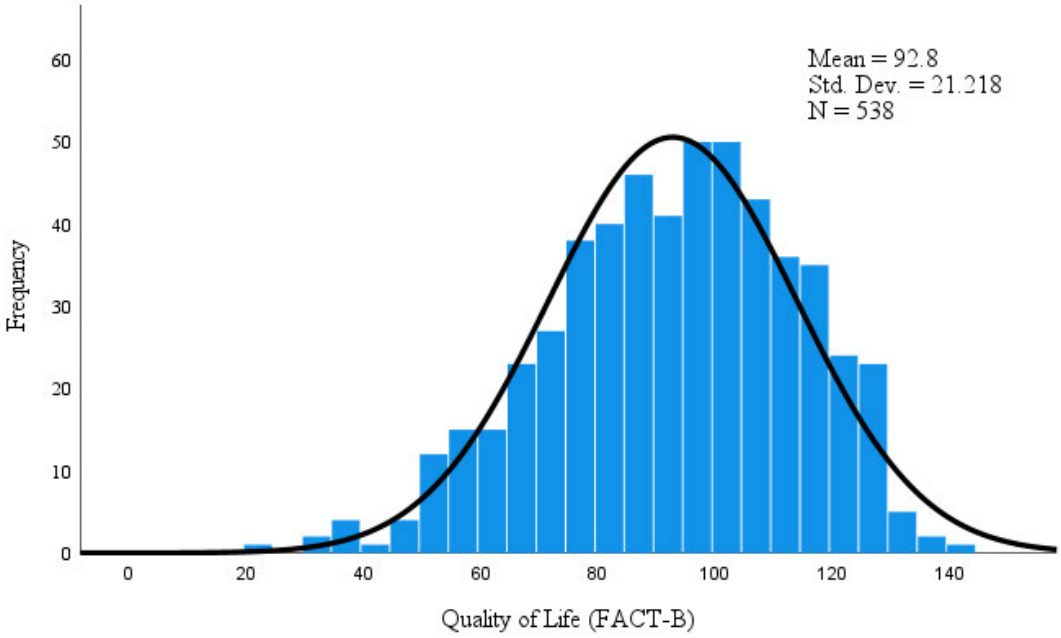


Figure K.2

Histogram of Concerns About Recurrence Scale, Overall Fear (CARS-OF), N = 538

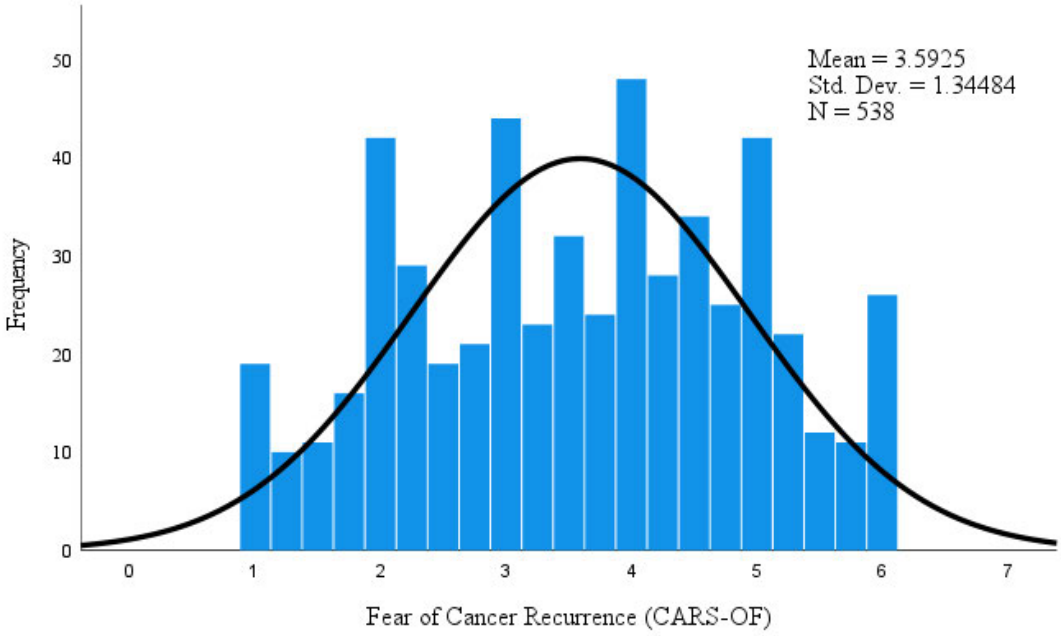


Figure K.3

Histogram of Acceptance and Action Questionnaire, Second Edition (AAQ-II), N = 538

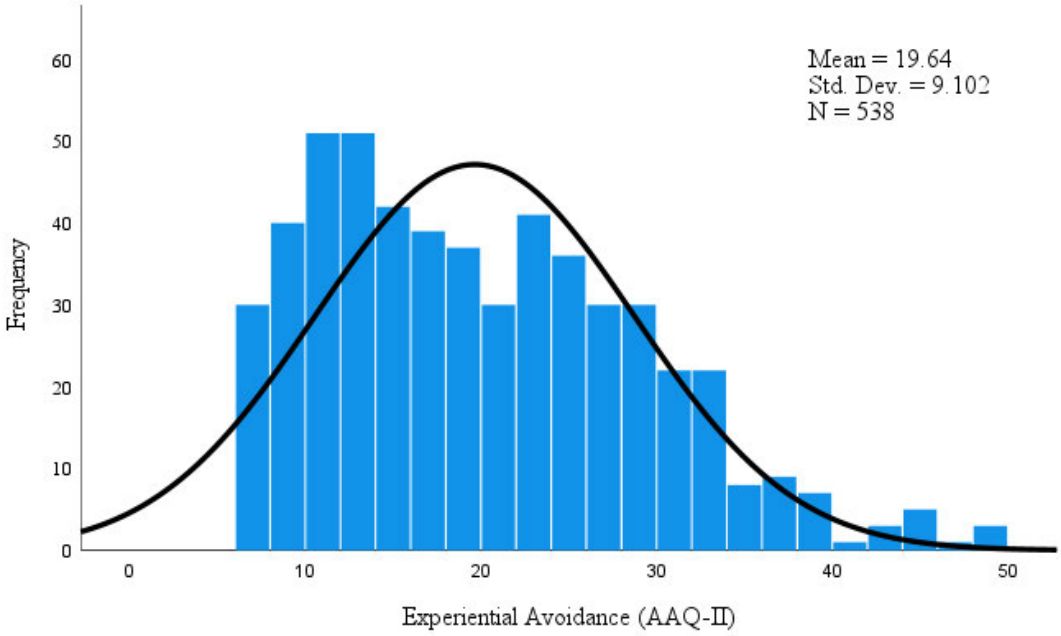


Figure K.4

Histogram of Kessler 10 (K10), N = 538

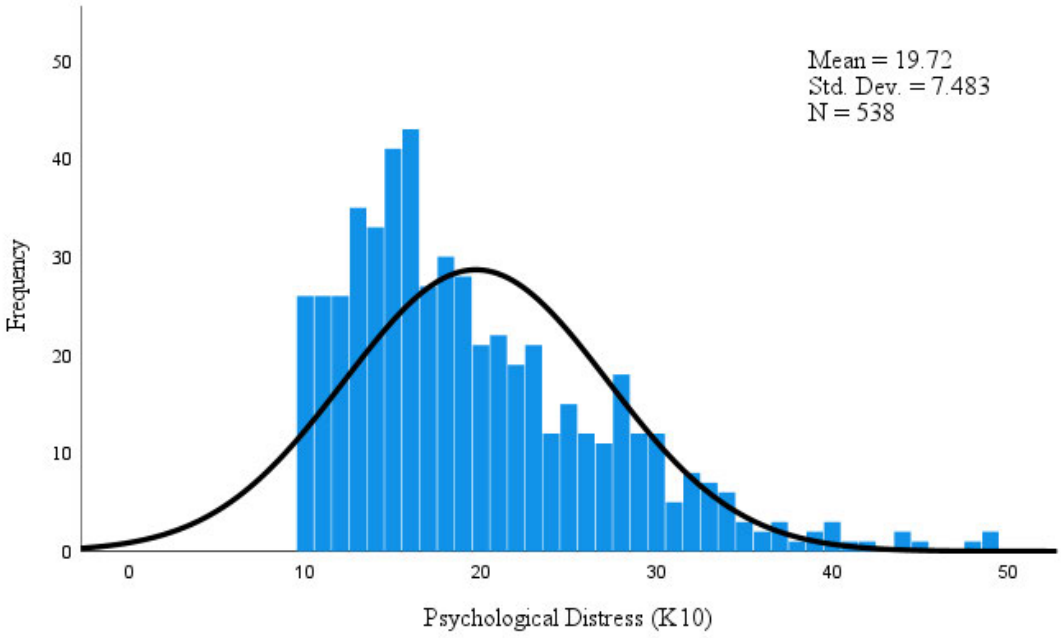
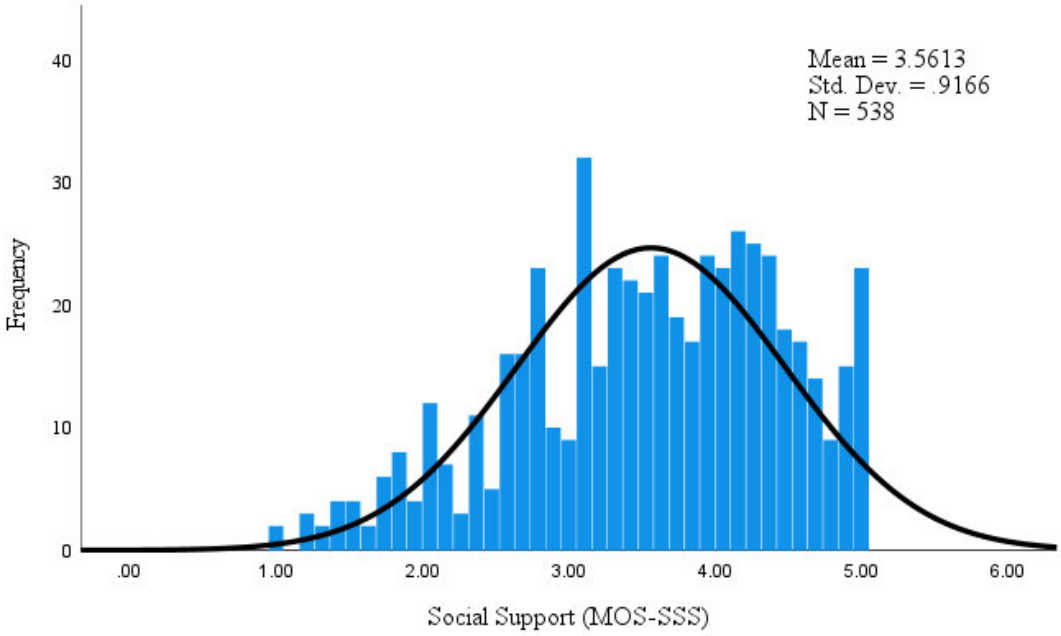


Figure K.5

Histogram of Medical Outcomes Study, Social Support Scale (MOS-SSS), N = 538



APPENDIX L - Comparisons to DiSipio (2009

Table L.1

FACT Scores for Regional and Rural Breast Cancer Survivors, Comparison to DiSipio (2009)

FACT Subscale	Age	Regional			Rural			Differences between residence groups			
		n	Mean	(95% CI)	*n*	Mean	(95% CI)	*F*	*df*	*p*-value	Clinical
PWB	All	247	17.57	(17-18.15)	196	18.11	(17.54-18.68)	1.61	1, 441	.21	No
	<50	49	15.88	(14.48-17.28)	35	17.09	(15.74-18.43)	1.47	1, 82	.23	No
	50+	198	17.99	(17.37-18.62)	161	18.33	(17.70-18.96)	.54	1, 357	.46	No
SWB	All	247	15.83	(15.15-16.51)	196	16.40	(15.68-17.12)	1.28	1, 441	.26	No
	<50	49	15.69	(14.30-17.09)	35	15.49	(13.75-17.22)	.04	1, 82	.85	No
	50+	198	15.86	(15.08-16.65)	161	16.60	(15.80-17.40)	1.67	1, 357	.20	No
FWB	All	247	18.32	(17.53-19.10)	196	18.97	(18.20-19.74)	1.32	1, 441	.25	No
	<50	49	17.37	(15.56-19.18)	35	17.31	(15.40-19.23)	.002	1, 82	.97	No
	50+	198	18.55	(17.67-19.43)	161	19.33	(18.49-20.17)	1.55	1, 357	.21	No
FACT-G	All	247	68.80	(66.69-70.91)	196	71.56	(69.54-73.59)	3.33	1, 441	.07	No
	<50	49	64.02	(59.08-68.96)	35	66.17	(61.10-71.24)	.36	1, 82	.55	No
	50+	198	69.98	(67.66-72.31)	161	72.73	(70.54-74.92)	2.79	1, 357	.10	No

Note. High scores indicate better wellbeing; PWB = physical wellbeing; SWB = Social wellbeing; FWB = Functional wellbeing; FACT-G = Functional Assessment of Cancer Therapy – General.

Table L.2

FACT Scores for Urban and Regional/Rural Breast Cancer Survivors, Comparison to DiSipio (2009)

FACT Subscale	Age	Urban			Regional/ Rural			Differences between residence groups			
		n	Mean	(95% CI)	*n*	Mean	(95% CI)	*F*	*df*	*p*-value	Clinical
PWB	All	95	17.61	(16.68 – 18.54)	443	17.81	(17.40-18.22)	.16	1, 536	.70	No
	<50	23	17.09	(15.26-18.92)	84	16.38	(15.40-17.36)	.45	1, 105	.50	No
	50+	71	17.82	(16.70-18.93)	359	18.14	(17.70-18.59)	.34	1, 428	.56	No
SWB	All	95	16.21	(15.14-17.28)	443	16.08	(15.59-16.58)	.05	1, 536	.83	No
	<50	23	16.96	(14.48-19.43)	84	15.61	(14.54-16.67)	1.27	1, 105	.26	No
	50+	71	15.90	(14.70-17.11)	359	16.19	(15.63-16.76)	.18	1, 428	.67	No
FWB	All	95	18.29	(17.02-19.57)	443	18.60	(18.05-19.16)	.21	1, 536	.65	No
	<50	23	18.00	(15-21)	84	17.35	(16.05-18.64)	.20	1, 105	.65	No
	50+	71	18.41	(16.96-19.86)	359	18.90	(18.29-19.51)	.41	1, 428	.53	No
FACT-G	All	95	68.66	(65-30-72.02)	443	70.02	(68.54-71.50)	.58	1, 536	.45	No
	<50	23	67.52	(59.17-75.87)	84	64.92	(61.41-68.43)	.43	1, 105	.51	No
	50+	71	68.97	(65.25-72.70)	359	71.22	(69.60-72.83)	1.23	1, 428	.27	No

High scores indicate better wellbeing; PWB = physical wellbeing; SWB = Social wellbeing; FWB = Functional wellbeing; FACT-G = Functional Assessment of Cancer Therapy – General.

APPENDIX M - COVID Descriptive Reponses

Written responses to "Do you think that your experience through COVID-19 affects your current wellbeing? If so, in what way?"

- No, it hasn't been a problem for me.
- Slightly. Less tests being conducted or offered.
- I've been on the public waiting list for some breast surgery to even me up and Covid has made the waiting much longer. The waiting is hard and I just want my boobs fixed.
- During treatment all support groups shut down due to covid.
- I feel like I was more isolated during treatment and didn't get the opportunity to connect with people going through what I am going through.
- No
- No
- No
- Yes. Not being able to have a support person at appointments,
- Yes I have recently started having panic attacks because I stress more about getting sick.
- No
- No
- More isolating. I loved t o travel and worry that the more time goes by, the more time i am loosing for the opportunities to do my traveling.
- Restrictions with travel plans as this was part of my retirement and Post Recovery Plans.Restricted time with Children and Grandchildren that live Interstate. I have found Video Link Drs Appointment's not as Beneficial or Reassuring.
- I was able to hide away for the year and do all of this alone. Even my husband stopped coming to appointments due to covid, so he could stay home with the kids while I had chemo. Now I am back in the world and it has changed and I missed it. Covid makes me anxious going to the hospital each time because they keep changing the protocols and I don't know what to expect.
- I actually feel that having breast cancer and treatment during COVID-19 was probably not a bad time health wise as everyone was being very conscious of following good hygiene
- No, I have been very fortunate to have been able to work from home and enjoy the company of my immediate family. I have also been able to keep in touch with other close family and friends.
- Made me more wary of social interactions. Stayed home a lot more
- No effect
- Want to travel and see the world-tick off bucket list.Frustrating when you want to live life to the fullest.
- Yes, I work in the health sector & there has been significant increased stress associated with the rate of change to how we work, increased use of ppe, social isolation at work as well as the expectation to meet targets/ throughput when we are required to clean & document much more than previously. Reduced efficiency at work has also led to lots of unpaid overtime being completed by many staff.
- No. Live in the desert. Closest Covid case over 1000 km away
- No.
- Yes, because I am unable to travel where I would like to go. It's important for me to be able to do this, as having survived my cancer, I realise that life is short.
- No
- No

- Very much affected. I am isolated and living alone so opportunities to socialise are very important but unavailable to me. I try to walk every day but it is becoming more difficult with arthritis, lymphoedema and other issues. I would prefer to go shopping but am steering clear of public transport and crowded shopping centres.
- We suffered a lot of disappointment throughout Covid with a World Championship in gymnastics cancelled. I coach 12 acrobats who made the team including a daughter & 2 nieces. I feel this overshadowed even my cancer diagnosis which happened at the end of Jan 2020 so basically at the start of covid. Chemo on your own in covid was hard as was the 3 hospital visits because of chemo, with limit on visitors but I feel this was second to my stress compared to my athletes missing their one shot at a World Championship. I still find it hard to accept & worry that I supressed the cancer stress & it will resurface at an unknown time.
- No
- No
- No, no more than I would expect the general population to b affected. Note, u asked about Tamoxifen but no other equally emotionally affecting medication. I am on Letrozol for the next 4.5 years which is like having menopause so not easy to deal with the side affects. I have experienced an increase in anxiety leading up to the 12 month mark to have a mamagram and it has taken some time to decrease the anxiety surrounding that (and work stress). I have sought treatment from a oncology pyschologist due to the anxiety.
- yes, having to go through appointments and treatments on my own. My family restricted from visiting a lot. My partner was not really supportive emotionally but he says he cared, he seemed annoyed.
- Worried about timing of covid jab and surgery.
- No
- No
- Testing for screening for recurrence or symptoms of pre existing conditions being rolled into corona virus symptoms and testing being delayed or being treated poorly as a result.
- Unable to attend specialist appointments in Melbourne. It’s hard to get your specialist to examine your breasts over the phone when an unexplained lump occurs or unexplained pain
- No
- Definitely. Ive not been able to have any support in hospital at all since diagnosis due to covid so have had to deal with it on my own
- My treatment was severely interrupted with my oncologist and surgeon closing and doing phone consultations. The treatment I received as radiation was very mixed and rushed never seeing anyone qualified only useless phone calls from a faceless person who did not care. Any empathy from medical professionals evaporated as patients such as myself became a faceless identity. My GP constantly saw me and volunteer groups provided support and did not get frightened by the thought of COVID 19.
- Added stress
- I am unable to yravel interstate to see some of my children and grandchildren. Even when borders are open, my husband is busy trying to hold our country hotel and motel business together in these difficult times. I dont want to leave him or to travel alone.
- No change
- Yes isolation virtual healthcare experience lack of capacity to have holidays away

- Alienation of face to face contact, physical touch eliminated, unable to travel to visit family and friends and visa versa, quarantine (whilst essential) is horrendous on mental health.
- No
- Not really. It would be nice to see my parents in the UK or for them to be able to visit given the past two years of treatment. But we’re all in the same situation.
- No

- Yes. Physical & mental health issues, changes of job & moving house all during this time have added to or resulted from higher levels of stress.
- No
- Yes. The initial fears when COVID began brought back strong memories of my fears that I had when I first found out about breast cancer. I had high anxiety about my breast cancer treatment increasing my risk of becoming seriously ill or dying from COVID19.
- Yes. Extremely challenging going through breast cancer during a pandemic. It's very isolating and lonely especially being unable to have a support person during appointments and surgeries. Even though I have finished treatment I still require check ups which I'm doing on my own.
- Lockdowns in Victoria have had a devastating affect on people's mental health. You are afraid you will loose your job or that you won't be able to meet commitments with home schooling etc. Having had to take off 6 months to have treatment the fear of not being not able to work again through no fault of your own plays on your mind and takes you to a dark place.
- Yes, missed once in a lifetime holiday that can't be rebooked which is sad. Even holidays aren't relaxing wondering about lockdowns, having to plan closer to home. Difficult to get cars etc makes things more stressful. Difficult accessing specialists etc due to lockdowns.
- Not really - worry a little about catching flu or similar so I avoid crowds
- A little more isolated, and concerned about health matters.
- Not at all. Being regional we were able to isolate easier but still able to visit shops etc. The biggest thing last year was not being able to hug the kids & grandkids. I had my partial mastectomy & radiation treatment in Sydney. Until last year I saw the same surgeon for checkups, he has retired but I still go to Sydney to see the new Dr for checkups. I am very lucky in that I have 3 sisters live in this same town, a great support.
- Yes. Less access to physical exercise program at the hospital.
- No
- Yes. No family support during radiotherapy treatnent appointments. Radiotherapy sessions felt like an uncaring priduction line. Have also moved states & as yet have no gp or oncologist in qld.
- I have been very careful with contacts during COVID-19 as I had lymph nodes removed. Don't want to get any infections.
- Not at all
- Not significantly
- Covid has increased my isolation and fear level. My usual supports have been affected.
- No not at all, having spent my whole life living on properties we are used to isolation to a certain degree & we are happy to not have to go to town or social outings.
- No
- A bit. Wanting to travel to other state to visit family. Sad we can't.
- No
- No.. not at all except worrying about whether my immune system is down.
- It was a good excuse for me to not have visitors when I didn't feel like it.! I wasn't able to have support during Drs visitors or chemotherapy days which didn't really worry me but I know of others who found this upsetting.
- During the Lockdown, I Definitely felt and still feel more isolated, with an elderly husband who has now been diagnosed with terminal cancer, so am also caring for him at home and dealing with all the necessary medical appointments, chemo etc on top of my own health concerns. This is a real challenge. The current lockdown in Vic and the stupid, inconsiderate people flouting the lockdown rules and putting others at risk when they should NEVER have left Melbourne (eg the couple driving from Melbourne to Qld who have both tested Positive) is of great concern to those living in rural towns, who they may have passed thru .... and the family who drove to Sydney and flew to NZ, bypassing the lockdown .... they should all be charged and sent to Howard Springs for quarantine! Hubby can't have the Covid injections and I am afraid that I may get ill from it (but will be having it next week). If I get ill from anything, he will have Into 'care' as we don't have family nearby to look after him at home and there is no way that he could care for me if I

was bed-ridden. He has mod-severe dementia as well as the Stage 4 cancer (first diagnosed with stomach cancer in 2010 - so I KNOW the very real chance of recurrence myself!) which really complicates everything too. Any major change of our current living conditions will be very challenging for him as he frets if I am not around. This is very much an ongoing fear, on my op of any recurrence fears that I already have myself. The enforced inactivity during the lockdown has increased my weight that I just can't shake .. Before I was diagnosed with breast cancer, I was a fit, pain free 65 year old woman enjoying life, getting out kayaking 34 times a week .... now, 3+ years post diagnosis and surgery, Rads and Tabs - the medications I am on makes me feel like an 80+ Year Old, with full body aches and pains and unable to enjoy my previous "life". This is NOT how I envisaged my 60s+ to be!

- no
- No
- No
- The inability to go out and meet a friend for coffee is a real issue 2. There is no emotional/physical relationship with my husband 3. He refuses to look at or touch my ugly body - he lacked any emotion at the time of diagnosis and when I was rushed into surgery 4. Being housebound in order to keep ourselves as safe as possible from the covid - we know where we have been but not where others have been 5. The lack of rural and regional treatments such as reconstruction
- No
- No
- no
- No, I felt/feel safer being away from people who may be ill
- No - it worked to my advantage
- I've put on weight because gyms are closed and I've spent months stuck in my lounge room. I like being able to work my own hours and nap when I need to instead of dragging my sorry arse through 8 continuous hours. Sometimes I log on at 4:30 am, rather then waiting untl 8:30 . I like that, takes the stress out of not sleeping well.
- Having to travel to a capital city for my operation during COVID -19 without family was difficult.
- Depression and anxiety has been much more severe
- It made me happier because it gave a reason for not seeing my family members - could not travel etc- it was an explanation for my feelings of abandonment. Once Covid restrictions end there will be no more reasons and I will have to accept that they just don't care and would be relieved if I died soon. Not my partner though, he cares or at least wants to do the right thing, and doesn't want me to depart any time soon.
- Living alone, Isolation was extremely hard, shortly after completing treatment. Occasionally have worries about ever being back in that situation.
- My experience of being part of a breast cancer medication trial has made it easier to accept the validity of the clinical trials for Covid-19 vaccines.
- Living in rural Victoria, there was no access to cancer care nurses or breast care nurses. Unable to visit Jane McGrath nurses. Surgery in Geelong (4 hours by road from home) with no visitors allowed. Unable to stay overnight for checkups and visits to oncologist. Feeling very much "left out" with no one to talk to and no friends able to visit. Now waiting for reconstruction surgery … on the list since September 2020 with NO likelihood of surgery for up to 2-3 YEARS… this plays EXTREMELY heavily on my well-being, and lists are just getting longer… FEELING FORGOTTEN!
- No
- Absolutely! I'm not saying my medical team did not try but it definitely was awful timing as the lockdown started as I finished chemotherapy. Right when I was feeling unwell, exhausted and emotionally depleted I wasn't able to get the help I needed.I know they were also frustrated. It

has definitely prolonged my recovery in general and meant that somethings like genetics were not really dealt with until 2021.

- Covid was great for keeping me healthy. People kept their distance, cleaned hands & wore barriers which limited my exposure to germs. Gave me confidence to leave home with minimal fear of any infection.
- Felt a sense of being isolated and scared
- No
- No
- No
- Not at all
- No,not at all
- Not really, living away from major cities has reduced the fears
- After my diagnosis and surgery in 2019 my whole family revalued many parts of our life so we were all very thankful. When COVID came along and locked us down we just went with it. As a family we could handle anything and were thankful that I was not in Melb hospital 200km away like I was just 12 mths before. Plus we live on a farm and that doesnt change because shops and cafes go into lockdown.
- No
- No
- No
- Drink too much alcohol and miss seeing family and friends so can be stressful
- Isolation from family They were unable to visit me for my 12 months of treatment Lots of video calls
- Yes. Unable to use gym & pool facilities. Self isolated because I had just finished treatment & had a compromised immune system
- Massively. While we live in regional Vic much of my family and friends are in Melbourne and the lockdowns and cases have been very stressful. I didn't go back to work as planned as I work in radiology at a hospital and I wasn't comfortable with going back and potentially being exposed to covid so soon after treatment. Exercise programs and appointments with lymphodema therapists and even m specialist being online or via phone have been difficult. Combine that with remote learning for my 2 sons (one of whom has ASD and ADHD). My anxiety and stress levels have been high at times to the point when I have occasionally taken medication prescribed by my oncologist to help. It has been a really crap time to try and recover from Cancer. I can only imagine that it has been horrendous for those people who he been having active treatment through out Covid.
- Less social activity due to concerns of compromised immune system from chemo - even pre-COVID. / near death reaction to second course of different chemo (Docetaxel) it took me nearly a year to recover. However, I have been recently able to have both a prophylactic mastectomy of the (non-cancerous) other breast plus a postponed-while-dealing-with-breast-cancer complete reverse shoulder replacement.
- No. I have still maintained treatments and relationships
- No
- Yes. Loved lockdown,- no work, just relaxing.
- Only in that lengthy travel plans and dreams had to be cancelled
- Yes it has affected my way of life in that I am more aware of hygiene and the need to register when going into shops etc and the fact I have to think twice about travelling from my current state
- Not at all
- I feel covid made surgery and chemotherapy more difficult with all the restrictions I had for support people and the extra stress of being put in such close proximity to covid patients when I was immunocompromised was the biggest factor. In the Sunshine Coast University hospital, some suspected covid patients were put on the same floor, just meters away from cancer patients.

- Most certainly. I had surgeries under covid rules. Very limited access to family and husband during a time when you are anxiously awaiting results. 2 I have two adult children. Both unable to visit etc. they live in New Zealand and Melbourne.
- I have found the lockdown hard with social isolation
- Yes, connecting with family was difficult. Being able to share experiences with family became non existent.
- It makes memories of the mascetomy hard as I had to go through it by myself with no emotional support at all at what was the hardest thing I have ever had to deal with.
- No
- Yes. I have low immunity and worried about getting it as well as this I can't see my kids due to lockdown. I was very unwell after having the 1st astra zeneca vacc. Worried about the 2nd dose.
- COVID-19 has not impacted my well-being. I live in NSW where restrictions have been minimal.
- Yes I'm scared and worried as I can't have the shot yet as I was having reactions to the Paclitaxle, affects my stress levels worrying I will get it
- No it does not and hasn't thus far
- Ring unable to travel overseas to spend time with close family.
- Missed seeing family n friends on a regular basis
- Maybe mentally it has been a little,harder, knowing cancer patients don't do well, if they catch COVID.
- No
- My treatment was lonely with visitor restrictions.
- No
- Yes, it affected my well being a lot. My first grandchild was born in November 2019, she lives in Qld and I live in northern NSW. Queensland border closures meant I missed seeing her for a lot of 2020 which made me very unhappy and depressed.
- Yes, due to having family living in UK
- No, not at all
- Yes I was living in a bio security area and was lucky to get home post COVID 19 security area as the area I live was closed off by the commonwealth. It caused great stress. My support person was my daughter who I had to send back to Victoria as it was unclear if she could return and could not come to ware I live as not a resident. I had phone review by radiation oncologist which was fine. It was a stressful time coming home as I would not have had support of stuck in regional town post radiotherapy.
- No
- Not really l think continued checks, and other issues caused by treatment sometimes wear me down. And life happens, better to live it than the alternate. M Need to be grateful for what you have
- YES potential lockdowns cause stress and disruption can't travel - reason i retired
- No
- No
- No
- Very little support groups were available because of covid, and any support was via phone which i feel didnt really give the emotional support thst i needed
- No
- No. It actually has helped by preventing being too busy and trying to do too much.
- Yes, lockdown reduced employment. Made it difficult to visit family in aged care.
- Frightened that I would get covid because I know I would die. The restrictions though helped me because I was too sick to travel anyway. I felt isolated from my sons though because they could not travel to see me
- Isolation/loneliness
- Yes as adds to overall depression, anxiety & lack of energy. Affects ability to be hopeful & optimistic.

- No
- No
- no
- No it was a good time for being at home.. Being with my husband...painting...gardeni g and catching up with house reno's.... It was good for my wellbeing. .
- Not being able to see specialist face to face wonder if something missed Not related to this question, you asked if I was on tamoxifen I said no but I'm on letrozole
- Yes Not being able to have support people during your care is incredibly difficult and makes a scary situation even harder.
- No. I think regional areas have been less affected by covid-19. Other than difficulty experienced in traveling long distances to appointments during lockdown.
- No not at all . I got diagnosed in November 2020
- Yes. I think it pushed me to my limits mentally as I became increasingly isolated as I became increasingly sick. As a social/outgoing person I found this difficult to cope with and I have struggled to reconcile and reintegrate to the level I would like. I also felt like I lacked additional support services that would usually be available after a cancer diagnosis.
- Yes, I was diagnosed April 2020, right at the peak of COVID lockdown. I had terrible treatment in hospital and wasn't allowed to have my husband with me. And I was told over the phone (while I was at work)that I had cancer without having any prior warning or preparation.
- No
- Having an immune deficiency it scares me.
- No
- Yea because I am unable to travel
- We have been lucky not to have Covid in our area so it has not effected us too much. It has, however prevented me from visiting Melbourne to see my specialists and have my scans.
- Not really - I don't have to go anywhere!
- I feel Covid-19 is responsible for my condition as 2020 was a very stressful year for members of my family and I feel sure that the stressful time worrying about family who lost a partner and attempting to relieve their stresses put increased pressures on myself to have caused my current health issues!!!
- Cv19 has had almost no impact on my life, advantage of living in a remote location.
- Yes I am very anxious. Husband and I both lost jobs during covid and breast cancer treatment. Very stressful and has caused us a lot of financial stress. Daughters anxiety was also effected during this time.
- If I wasn't living in a "border bubble " I would not have been diagnosed at an early stage nor have had surgery and treatment as quickly as I had. The only other option was to travel to a capital city that was in lockdown.
- No
- I don't think so
- No.
- No
- No. I am a positive person who tries to enjoy every day having had breast cancer twice in New Zealand
- No affect at all
- Scared my immunity will be compromised if I do too many activities in the community.
- Yes it made me quite anxious as I have my own business plus with breast cancer twice in my life then this COVID it seemed very overwhelming. But I'm very strong and family and fitness helped me a lot.
- No, I still had work and nothing much changed for me, other than the kids had home schooling.
- Having moved onto a rural property away from the city before the COVID outbreak I have felt reasonably 'protected' from the virus, although I've always been sure to take proper precautions when travelling into the local town or down to the central coast or Sydney. I haven't felt any

more isolated since the outbreak and in fact, living in a smaller community actually feels more cohesive and personal than living in the city.

- Not really
- No
- Not at all.
- No
- Much more wary of being in crowded spaces
- Want to travel to grandchildren while able to health wise and restricted. Minimal vaccinations available rural areas.
- Not with respect to breast cancer. Only in a way of wondering when I'll see all my family in Europe again
- Yes absolutely. I feel very isolated, not able to enjoy time with friends and family. I get. Angry that I have no control over what I am permitted to do (ie lockdowns,)
- Yes. During cancer I also had heart failure. My Doctors are located in Brisbane. We where cut off. Only Tele appointments. I stopped going. No support here for the young at Tweed Heads and no government assistance as my husband earns to much…but he lives and works in Sydney (Navy) I live in Tweed to support my 80yr old mother and to have friends/family to support me. $500 for medications, Doctors bills every 3 months, cut off from husband it was/is a nightmare…I am stuffed as I still have three kids at home. I am so worn out I feel like I will get cancer back from stress and heart problems. My organs are now breaking down. It never ends. 3yrs and still no end in sight. I am trying to keep my shit together. Hope this survey starts a change in people's day to day life. We need help. Just a health care card would make a difference. Cheers thanks for letting me whinge.
- Yes, the visitor restrictions stopped me having the contact with my son's and family from other areas of NSW and Qld that I longed for! Especially Christmas when I was wondering if it was my last!
- I have become more anxious and depressed and have changed hormone blockers as a result. I feel quite isolated which doesn't help my mental state. I have sought the help from my GP, Medical Oncologist and Psychologist. My relationship with my husband has significantly deteriorated throughout COVID to the point where we are now technically separated. Cancer, the death of my father and now COVID have all contributed to my current situation. I have a wonderful medical team who are presently investigating whether I have a recurrence or radiation recall. I had my first AZ 6 weeks ago and there is a suspicion that it may have caused/ contributed to my current issues although there's very little data available. All in all I am going through yet another anxious and distressing time. Good luck with your research ????
- Yes, as I am isolated from my sons and their families who live interstate and overseas and I am also a front line worker in Aged Care. This has contributed to my feelings of sadness and depression.
- No
- I do. I have sore joints, have gained weight and I get twinges of pain in the breast that had radiation. I often feel a bit 'fuzzy' in the head. I tend to exercise of a bike due to my arthritis in my feet. This has been exacerbated by the hormone treatment (anastrozole) which I have to take for another year.
- No.
- Returned into med
- No
- I don't think so. I hated having to work from home, but it didn't last long and very few teachers of young children felt eff3ctive. My family and income were unaffected.
- Yes. I May have had to have further investigation for cancer during Covid and it took 6 weeks to get a diagnosis. The wait for results and ongoing tests affected my mental health
- Perhaps. I was trapped in UK after being my dads carer whilst he was dying from prostate cancer. I missed my support group but it has now restarted

- No

- Yes, forced my family to stay at home and spend time together in a good way, family became more important as society was closed. It was nice to stop the running around and rushing and reconnect with self and family. In some ways it was nice to have a forced break from the world and live in safe home bubble. It was also scary that after beating cancer, if you get Covid19, reality for everybody is it could be fatal, makes me appreciate my life and choices more. Also found online community support, yoga and meditation.
- No. I'm in WA so COVID didn't affect us much.
- I think I was better equipped due to having to develop coping skills through over a decade of autoimmune disease and then my cancer diagnosis.
- No
- I've been able to take life slower and evaluate commitments.
- COVID meant that I had to work from home full time time for three months…lockdown occurred just as I was finishing my treatment and I was immune compromised. Whilst I could communicate remotely I was not able to see family or friends as often as I wanted. As we could not travel we did not take time away from work as often.
- No
- No
- No
- I can't go home to UK and my family can't come here.
- cautious to travel to melbourne for check up
- Yes. I feel Imhave no control because of lockdowns. I feel very lonely and isolated and angey
- No
- Yes. With lockdowns I am isolated from my friends and family. Being single and living with a flat mate this isolation affect my mental health.
- no
- I was feeling anxious about COVID 19 but after talking with my physiologist I have put strategies in place to help me deal with the anxiety.
- My experience of Covid-19 does not affect my own wellbeing. It has made it more difficult to travel to care for my elderly father.
- Yes scared me more because I was immunosuppressed
- Not being able to have my partner with me in hospital. Especially when I had my double mastectomy. No visitors at all
- In some ways it was good because I could hide and isolate which I had to do anyway because of extremely low white blood cell count. It meant we didn't have to deal with well meaning friends. We only told very few people for the first 4 or 5 months. In other ways extremely difficult because of border permits, lack of support in practical terms. The questionnaire seems largely irrelevant to me as it has been the aftermath of chemotherapy that I feel has wiped me out. It has yet to be determined whether I have a movement disorder. I feel unable to drive and live a way out of a country town, because of Covid, etc I haven't followed up on a breast form and bra, getting my hair cut, etc. I am so lucky to have my husband who does the shopping, etc but he is 81 so it has been very hard on him. Really a nightmare 15 months all up, with so many little mistakes along the way, which I attribute to the stress of Covid on the medical staff. Always the saviours were the nurses in chemotherapy and at our local hospital.
- No
- Yes, I felt very concerned if I contracted covid would my immune system cope with it. I worried about my future and getting back into the work force. Very conscious of cleanliness.
- I was able to continue working outside my home and I was to continue contributing to making other people stay fulfilled. I did feel sad that I missed a few important events however being able to FaceTime and call family it helped keep up morale. I am able to understand that lockdown and restrictions were necessary to stay safe and keep others safe

- Yes. Even more isolating.
- No
- No. But is was hard doing radiation during a lockdown period. I was scared I was going to Get COVID-19 when there was an outbreak at the local hospital.
- Only when shut downd happen
- No. COVID has not had much impact on me. It prevented me from going on holiday before I was diagnosed, but since diagnosis COVID has not prevented me from doing anything, rather it was the side effects of treatment that constrained me.
- Yes, there were no cancer support groups for me during my most difficult months as they were all canceled due to Covid
- No not at all.
- Tend to get Panic Attacks. Have left the workforce.
- No
- Yes living in Victoria our business has been closed for over 5 months during COVID lockdowns. We have no income when it's is shutdown so it is very disheartening and I have to work hard to keep positive and motivated
- Yes. My doctor is interstate and with the borders always closing, sometime it is difficult to know whether I can get to him.
- The only difficulty I found with being diagnosed and having surgery and radiation during COVID is that the hospital was in lockdown and I had no support person with me. My sister had to leave me at the front door. It would have been nice to have her with me till I went in for surgery. Cheers.
- I worry about my health and that of my children that are still in Melbourne. Having to do your first round of chemotherapy on your own as you cannot have your support person with you.
- Dealing with COVID 19 and the effect it had on my family was made more difficult as I was dealing with my cancer treatments at that time.
- Yes, not able to have a support person attend treatment was very hard. Allied services not available for months and group activities cancelled whilst having Radiation away from home. I feel let down and unsupported by the system. When I talk to other woman their experiences were so much more positive.
- Because my children live in capital cities, lockdowns and restrictions have sometimes limited when they can visit
- No
- A little not being able to see family and enjoy outings with friends was sometimes depressing
- It hasn't really affected me except when I couldn't travel to Brisbane to see my terminally ill sister or visit my 94 year old father. At that time I was very worried that I would not be able to see them if the worst happened.

- No not at all
- No
- No
- No not really
- Yes, I was in quarantine through treatment for 15 months during covid now have to get used to being around people again.
- I am fortunate to live in Far North Queensland, and the effects of covid up here have been minimal. I personally haven't been all that affected as I am quite a homebody.
- Worry about covid and if myself or my family will get it constantly.
- No
- Not really where we live
- Not really but initially when I started Chemo I was unable to have anyone with me. I found that hard. This is my second breast cancer and it was detected early so my treatment wasn't quite as tough. If it had have been my first experience I would have found it very difficult to go through

during Covid. Both mentally & physically. My first time I was never alone during my chemo which was a great comfort to me & my well being.

- Covid has made social interaction more difficult, leading to isolation and general sense of uncertainty.
- Covid limited ability to participate in a full range of usual exercise. Worked within covid restrictions to catch up with friends. Since there is nowhere else in the survey to put this, I am a little worried about your knowledge of current breast cancer treatment, given that you are doing this survey. You ask if tamoxifen is being taken, but do not ask about the aromatase inhibitors, such as anastrazole (Arimidex) is one brand name. This would be the current first choice, unless there are contraindications, then tamoxifen would be advised. The side effects of these medications can be significant for some women, but research shows that they give better long term results than tamoxifen.
- I'm fairly lucky living in remote regional Western Australia as life has pretty much remained unchanged.
- Yes. My children & grandchildren are the ones I get the most happiness from spending time with & not being able to see them whenever I want to has given me anxiety. The thought of the restrictions recurring also gives me anxiety.
- isolation leaves too much time to think. Miss time with interstate family
- Yes it took longer to see specialists & a small spot found after radiation on my lung turned into two different lung cancers next to each other stage 2 by the time I had surgery! Admittedly once I had a phone appt on the Monday with lung surgeon I was operated Friday! But I go private thanks to my husband making sure we have private health! 2 years prior to breast cancer I was diagnosed stage 4 nslc lung cancer met to adrenal gland. Survived that to get bc!
- Hardly at all. Being retired has meant that I haven't had to deal with many of the stresses that younger people have faced.
- No not really
- No
- Covid affected Breast screen and l had to wait longer for mammogram
- Currently struggling with allergic reactions to hormonal treatment which is to,continue for 10 years. Isolation from specialists (400 km) and costs of travel and accommodation to attend appointments. These are my two negative experiences. My cancer diagnosis occurred a month before my retirement so isolation and changed circumstances collided with exhaustion from procedures, radiation and travel to treatments,
- No. WA regional Not poorly affected
- No
- Feel like I have lost a year. We are trying to complete adventurous travel while we are physically fit and feel we have lost a year's chance to do so. I found it very hard to feel positive whilst being so restricted with activities and contact with others.
- No
- The continued uncertainty of the virus. Not knowing when and where it's going to strike. Not able to make plans or commitments because of the likelihood of needing to cancel
- Not applicable - have been very few effects / restrictions in my town.
- Afraid to present as sick i feel unable to shake off illness as easily, so people judge you as contagious well after your not, due to a lingering cough or chemo cough. Limits family movement around states cancelled trips and worry about lock downs
- I'm extremely mentally distressed and I see a psychologist over the phone that does nothing of benefit for me.
- No
- Not applicable
- Only because I haven't been able to travel between states to visit family. I missed a close sick elderly family member end of life visit and her funeral cause of Victoria'S lockdown. Missed visiting my daughter and grandchildren in Brisbane again cause of state border closures for 6

months These examples affected my well being at the time. I also had my stressed sister on phone from Melbourne fed up with lockdown and I was her sounding board. We were otherwise not affected in this area but I did feel all those small issues did affect my well being. Especially the fact that a funeral had to be held without anybody there. Felt so sad for my elderly relative who didn't deserve that lonely ending. I have bounced back now.

- No
- Difficulty in seeing family and friends during treatments and whilst in hospital due to adverse reactions to chemo
- No. If anything its made us slow down ad appreciate our lives more.
- Yes, I am much more anxious and can't stand crowds I'd people.
- It has been difficult to see my children who live in Sydney and my sister who lives in Queensland I miss regular visits
- Yes- anxiety of the unknown
- No
- It was restful, actually. I worked from home. Living rurally on property meant I could get outside in nature a lot, which felt healing. I rode my horse and hiked with the dogs. A slower pace was good.
- Absolutely. Having to go through surgery and treatment by myself was a horrible experience. My family didn't get to be my support when I needed them.
- Not at all.
- Not at all
- Yes, because I'm immuno-suppressed, I still stay home as much as possible, still wear a mask when I go out - we cannot trust/rely on others to do the right thing
- Covid has not affected my ability to attend appointments or be given treatment. I am Naturally a "loner" so isolating has not been a problem during this time
- Heightened anxiety over contracting COVID or blood clot from the vaccine.
- No
- No, however it has made me more aware of hygiene requirements
- Hard to see family. Everyone scared they might give each other an illness.
- Not at all.
- No.
- No
- No.
- N/
- No
- Isolated from family and friends in Canada. Heightened anxiety over the future.
- Not very much, being an introvert it didn't really affect me, in fact it was good not being around a lot if people, just the medical people that I had to see.
- No
- No we have pretty safe here.
- Between work (having own business with employees), kids and holidays being cancelled - yes - getting anxious Re things needing to change at the drop of a hat
- Very much so. Was weary hard to attend to my medical appointments . Been trough 4 lock downs not able to spend time with my family, not been Abel to attend to funerals of close loved ones was the worst. My anxzayety went up and up..... Trough all this very hard to keep interest in life ??????????????
- No. Was lucky that radiotherapy finished before covid 19 lockdown
- I think we all worry
- no, nothing haas changed
- No. Cancer drastically did and I wuit my executive role. Life is too short to dral with ongoing work stress/pressure
- No

- Very much so, as it prevents me from visiting my elderly mother and friends abroad. The uncertainty of whether or not I will see my mother alive one more time is a heavy weight for me to carry daily. Also, I miss spending a few close days with dear lifelong friends that could help me heal emotionally. Between cancer diagnosis and COVID-19 I haven't seen my mother for over 3 years now and my father passed away during my chemotherapy treatment, so I couldn't even travel to mourn with my family. I am afraid that the way things are going with COVID-19, the story will repeat again with my mother.
- No
- Not really, it's just a part of life now and we have to get used to it.
- No
- No it doesn't, we just need to be strong and do whatever is necessary for us to survive
- No
- No
- No. Enjoyed the break from work
- It was easier, as we were in lockdown when I was having my treatment - no one really knew that anything was wrong with me.
- No
- No
- No
- No ... was good as did not have visitors or people around so I could recover from the chemotherapy
- No, I found lockdown helpful as it reduced the commitments of my children and allowed me to just be at home with no outside expectations.
- no
- I was diagnosed as the world went into lockdown at the end of March 2020. Even getting in for an ultrasound was extremely difficult and surgeries were cancelled the night before my lumpectomy. With news reports and images of the crisis unfolding in New York with makeshift hospitals flooding the news and my local hospital reportedly being prepared for an influx of Covid cases I felt forced to self fund my surgery through a private hospital. It was incredibly traumatic as nothing was normal and you couldn't assume that you would receive treatment. I felt that if I didn't get my surgery in ASAP that it could be postponed indefinitely. Radiation therapy also experienced delays and I made sure that I was tested for Covid prior to my treatment so that I didn't potentially risk any other cancer patients' health. My siblings all live too far away from me to drive - minimum of 1800km and one sister in Seattle, so I haven't had a hug from my siblings since my diagnosis and have booked flights 4 times only to have each reunion cancelled due to Covid lockdowns. Even my workmates were not allowed to hug me upon diagnosis as we were in the midst of the pandemic and there was so much fear and confusion. Also I didn't get to meet my Breastcare nurse due to Covid restrictions so it's very difficult to have a connection with a voice on the end of the phone.
- Affects my mental wellbeing as my work is more stressful (I work in healthcare)
- Yes. It was isolating and I couldn't see my family.
- No.
- Not at all
- Surprisingly the only affect on me is the masks. I feel I can't breathe through them and have panic attacks.
- No not really
- No
- No I was able to accept the lockdown in 2020 as it was extension of how I lived through treatment
- Yes, didn't have a mammogram
- The main stress of dealing with COVID lockdowns is the worry that scheduled surgery & follow up treatments will be delayed for an undetermined amount of time.

- Negative affects such as: Increased health risks Societal worries & disfunction
- Makes me stress. Have enough stress
- No
- I found lockdown calming. We live on a farm, I didn't have to drive my kids to school. Medical appointments via skype/zoom. We could finally stay put and rest up after my treatment.
- Not being able to spend time with family affects my well-being
- No, I became more of a recluse after my cancer
- My recurrence was 2020 in the middle of covid so we stayed in the city about 3 months all up while i had a double mastectomy
- Yes Unable to see family in lock down
- No
- Lufe has nit alterred dramatically. Far North Qld has been relatively safe during covid with almost no lockdowns and very few diagnosed cases and very good control
- I have been reluctant to travel to my nearest city to have the follow up tests necessary ultrasound, mammogram, but intend to restart NOW!
- Like everything and everyone else . Breast Cancer has no impact on this Covid experience for me personally but it did others who had to do things alone or with less support .
- Loved lock down. I didnt have to deal with people
- Only some inconvenience when I can’t see my daughter who lives interstate
- I think my mental well being is affected by the amount of media attention. I was caught up in the emotion of it all for a while. I have improved by not looking at news on tv - I now read ABC on line for any news. I can choose the topics and only read as much as I need. I prefer being alone. In the last few months I have increased walking and meditation practice. I also read uplifting books. Mind you, I did need to consult a psychologist to be reminded of these positive health practices.
- Limits to social activities eg volunteering and seeing friends
- Yes, I feel very fortunate to have been able to access treatment during the peak of covid.
- Somewhat, my way of dealing with covid and the lack of support services offered even when I asked for them is to get animals that kept me seeing the joy. Without them and my daughter life would be quite bleak.
- Most definitely. These are such new and often confusing, scary times not only for myself but my children, grandchildren and extended family. Due to different health issues we/ I am at higher risk of COVID-19. Changes to how we live and work are ever changing and this has an impact on our mental health and at times physical health with not being able to see usual Drs and Specialist when needed.
- Not really,
- Treatment was very lonely, entered hospital on my own, all radiation was on my own , and when I returned home house was empty, just lonely.
- Going though breast cancer and treatment was hard especially with the side effects
- Yes and no! I missed some vital information at my first appointment before surgery and might have chosen a different treatment plan if things where better explained instead of being rushed threw.
- I am stressed I cannot see my overseas family I feel the world is in crisis and politicians are not to be trusted to deal with the pandemonium c. Maybe if I get cancer again I won’t be able to access treatment in a timely way
- Working in the medical industry you are constantly worried about what you might get from patients. Colds , covid etc. You try to do the right thing but patients still choose to come to clinics when there are directives to stay home if you have cold like symptoms.
- Inncreased sadness from not being able to plan travel to see family. Stress about what the future will be for everyone.
- Yes, I spend too much time in front of a computer and not enough time out and about, moving and being active. This has led to weight gain and physical problems.

- No
- Not at all ????
- Not really. I've become a hermit anyway. I am in pain 24/7 with Osteoarthritis and Rheumatoid arthritis. Suffer depression and lack of worth. For me to stay home is the norm. The treatment and medications have increased my weight to the degree my knees are wrecked but I'm too heavy for any operations. Several doctors blame my weight for everything but the agree that I have Lymphoma caused by the treatment. I can't win.
- Iam managing fairly well and gave great support from my wife
- Frustration with restrictions & uncertainty Frustration with others no cooperating with the Rule makers
- No
- No
- No
- I did not understand there was no remote/regional questions about how difficult it was to attend appointments or how much extra costs in travel for people that live more than an hour away with no public transport availability.
- No
- I was going through all my treatment through COVID 19 I think it was helpful in a way because I was able to be at home with my family it also made it difficult as I was worried I was going to get sick at the worst time possible.
- Yes Covid-19 has been difficult for every Australian. My international tourism business is none existent and does not look like changing until international borders re-open. My income has dropped significantly and I am living off savings since Jobkeeper finished in March 2021. So this does make you worry about finances. This is normal and would be the same if I was diagnosed with breast cancer or not. I do not think this financial worry (which is normal under the current circumstances) effects my health and concerns about breast cancer.
- No
- Lots of time frustrated.
- Not at all
- Increased worry about the disease, family interstate not easy to see them or be with them.
- During Covid I have been less active and feel my aches and pains more. Also being in lockdowns has been a very lonely experience and more importantly the worry I may get sick due to my compromised immune system. After my 2nd Covid Vaccination in 2 weeks time I feel this will improve my current fears and make me feel safer to be out and about again????.
- No.
- No
- Yes, I am scared to leave my home, as I can not trust everyone around me. I have been vaccinated with Pfizer. How ever, my anxiety does prevent me from leading a normal life due to covid.
- Increased anxiety
- No
- YES. I have to go to Perth soon for tests and consultation, and Perth its currently on lockdown with locally transmitted cases. Iam very anxious about going. Our region hasnt really been afected much by Covid, but I still worry about it reaching here, and procedures when I am inPerth
- No
- No
- I answered no to tamoxifen BUT I'm on femera a A1 hormone treatment Covid-19 has affected my ability to,catch up with friends interstate ,(they couldn't come in nor could I fly down to see them) and we have had several,lockdowns so have been unable to attend courses or events that may have helped with low mood/depression

- Yes I have isolated for the last 7 months to keep away from COVID and this seriously impacts your social connections. Although I have contact it is through a phone. I am looking forward to getting my vaccine and reestablishing my friendships face to face.
- No - life goes on!
- No not at all
- Yes! After initial double mastectomy and reconstruction, I developed infections. After 5 ops in 15 days, everything was removed and I was sent home to recover. Covid has been a huge issue in getting back in for reconstruction surgery. Surgery has been cancelled 3 times in the last 3 months. Surgery rescheduled for 12 July. Fingers crossed
- No
- No
- No
- No
- Minimily affected.
- Not really
- During COVID I lost my job in university sector just after I was diagnosed with cancer. Losing job was major stress during covid due to financial stress (mortgage) . Also as I was diagnosed during COVID there was reduced support from family and friends due to lock down and no visitors at hospital . Also all the volunteer services stopped including support groups. Now I feel like I missed out on the support I needed.
- No
- No
- No
- Yes. I had bucket list travel planned os that I can now not do. Fear of reoccurrence coinciding with delay in OS travel worries me. I want to do things. Now. I have no real fear of Covid after cancer. I just want to live and I'm grateful for every day.
- It was difficult to not be able to see my family at all, I was quite isolated for a time, and missed out on certain support groups and rehabilitation, but found exercises on YouTube which gave me more energy and enabled me to return to work. I was lucky to have a very supportive husband.
- It's made our financial situation worse & increased my anxiety
- no.
- Yes. Easier to feel down when isolated or can't look forward to holidays. Very frustrated/ angry over difficulty in accessing vacconation
- Yes - very isolated from my family who all live in other states - and especially my aunt and her BCS dragon boat team - they are a terrific support network for me and I haven't seen them for almost two years. I chose to have surgery as traveling for radiation was something I couldn't consider at the time. We had two kids in Uni- six hours away - and my husband couldn't take time off to take me to radiation as it would have been a two and a half hour round trip daily…
- Fear of lock downs. Fear of not seeing docs and specialists if I need to.
- Yes can't see family members
- No, I've had much counseling for depression so I have some coping skills.
- More work and stress than usual
- No
- My daughter is unable to visit for the School holidays with my granddaughter and I live alone.
- Yes. I had to go to all my appointments for this breast cancer and into hospital for surgery by myself. (4 weeks ago. Currently still deciding on chemo or not). My husband had to say goodbye to me in the carpark at 7:00 in the morning and pick me up 3 days later. It was horrible and made me stress about it even more.
- Yes, reduced amount of exercise
- It makes me very worried at times when there is an out break. Of my family and friends being safe. As most people do and my low immunity.

- Yes, it’s stressful when wanting/needing to cross state borders as the situation is ever changing. The fear of COVID restricts my activities and there are many things I choose not to do because of the risks. Lockdown was just over here in Victoria when I received my diagnosis and I felt like, what next? I am a glass half full person and live by, it is what it is and I just get on with what ever I need to do!
- Yes, frustrated that we are trapped / isolated on this island that is Australia and can’t travel to spend time with family & friends
- No
- No
- Just with concerns of immunity
- Has made having support during some of the treatments and appointments a bit more difficult but otherwise I haven't found its had any other adverse effects.
- A have a little anxiety. I have mild asthma and my partner is also a cancer survivor. I have 2 adult children living in Brisbane and 1 natural grandson. I cannot visit or have visitors when it suits us. I volunteer as I can't work anymore due to tiredness but find it only a little annoying to have to quarantine items for sale in the shop. I am anxious re Mum as she is frail and may have to move into a Nursing Home soon.
- Mental Health
- Not able to meet up for exercise and well being group
- It has not changed my sense of well-being. I am a home body and lock down suits me.
- No I don’t like to think like a victim. Make the most of a situation.
- Frustrated with the unnecessary limits put on us, particularly in view of travel restrictions. Travel is one of the things i enjoy most.
- Very difficult as all my children live in other states so I have not been able to see them
- No not really, as we live in rural NSW we are nearly always isolated on our property. Maybe it was a little unusual that we couldn’t meet up with our neighbours for a period of time, but rules relaxed and we were just about back to normal.
- Yes, it was very isolating going through treatment with Covid around.
- Yes because any I was very isolated
- No
- I am a temp/casual worker so there is the ‘no work-no pay’ issue. Not working during Covid, particularly if it is raining, gives me time to dwell on myself and my circumstances. During 2020 I was on hormone blockers and suffered terribly with bone & joint pain and fatigue. I came off those meds in Jan ‘21 and have been much better as a result. I wish we hadn’t had Lockdown 4.0 as that put me out of work again. The weather has been crap for 5 weeks so its been difficult to get out in the paddocks to do anything useful
- No - I learnt way too much about looking after myself - I had to because I had no Chemo or radiotherapy. All this meant my well-being wasn’t affected by COVID-19 despite living with metastatic cancer for the past 11 years. When are you researchers going to look at the well-being & survival of those that don’t do chemo/radiation/immunotherapy or do a combination? Of all the women I know that chose these paths, 100% are still alive & VERY well. Over the course of 15 years - that’s a substantial number...but of course we aren’t on any cancer records here in WA - you turn a blind eye to us so we end up falling off your radar! Of those that have done chemo/radiotherapy there are substantially less than 100% in that group alive today & those that are still alive are living with awful side effects. If you’re wanting to do something impactful with your research then look at studies that genuinely help women with breast cancer.
- Not at all
- No not living in rural NSW on a farm has very minimal mpact on me personally
- Not really, although my cancer treatment was undertaken without physical support of my husband during actual treatment. This was very difficult at the time and made the whole process a very lonely one and quite isolating. All fine now however.
- Yes, feelings of depression, isolation,

- Difficulty seeing doctors and specialists which makes me more anxious.
- During periods of hospitalisation, the covid settings added stress to treatments, in not being able to have visitors.
- Yes the stress of being a frontline worker although not recognised as such by the government is very taxing. Teachers who were compromised taught online and that involved an incredible amount of extra preparation often having slide shows ready for the next day's teaching at 11pm at night. When we returned to work it was like business as usual but the children were so different and the fatigue of dealing with everything really has not left. No doubt being an older teacher who's energy levels struggle at the best of times has not helped. Covid continues to be an issue and we were not given vaccinations when they first came out because we were not that essential after all, I am on a waiting list now to get my vaccination. Covid 19 is definitely the cloud in the room.
- No, not at all
- Not at all
- I felt going through treatment whilst COVID was on made me feel less isolated. I took the attention off me because we were all in something together. It's a strange thought but everyone's lives were changed because of COVID so I wasn't alone.
- I often feel down as COVID-19 has prevented me from seeing my family who either live overseas or interstate, for over two years, plus restrictions on social activities and being unable to get away for a decent holiday does not help the situation.
- No
- No, I worked right through it. However I NEED a holiday!!!
- Inability to see family members easily or as frequently as we did prior to Covid does impact mental well-being and fulfilment.
- No
- More time at home gives you more time to reflect. Mostly I feel more lucky than people in cities or overseas as I have countryside to view from my home.
- No
- No
- Not really- I've been very busy with work However my partner was diagnosed with COVID last year meaning I needed to self isolate for 2 weeks which caused a little anxiety
- Only somewhat. I wasn't able to go on my birthday holiday to Europe. It was to be the first time I have travelled in such a way and it was after that I was diagnosed so I guess it has made me feel I may never get the chance due to my health and if Covid hadn't happened I could've felt fulfilled before the diagnosis. I recently had a stint in emergency due to the possibility of a blood clot (all clear) and because the symptom was shortness of breath, I was treated as a possible Covid patient and that wasn't nice. At times through the journey I was in lockdown so that adds tot he feeling of loneliness and isolation that this diagnosis already brings.
- It's actually improved my life ! Because I'm a health care community worker I got to work at home in the Hospital in the Home program because I think my employees were concerned I might have been immunocompromised. This has led to another covid related job from home (contact tracing)
- Breast surgery (for Pagets) was delayed due to some lock-downs. I am to start chemo/immuno treatment next week for spinal/lung cancer found 3 months after breast surgery and am worried that I may have a bigger chance of catching Covid due to compromised immune system. Have only had 1 AZ jab... next not till end of September which is well into chemo. A lot of my appointments with oncologists - surgeon even GPs are via telephone - they make me feel rushed as opposed to face to face consultations.
- No
- No
- Covid-19 hasn't made much difference to my life apart from the early lockdown in 2020 which I rather enjoyed. It was nice to be at home with time to do things I enjoy, not just the chores. I

started walking every day and got fitter. So it's had quite a lot of positives for me. I would also like to add that I feel tired (as I answered earlier) because I have hypothyroidism caused by an attack on my immune system. This was diagnosed a few years after my cancer treatment. I've since read that low thyroid function can be a reason or risk factor for getting cancer.

- Yes. I've had to do surgery and treatment on my own as my husband was never allowed in to hospital with me
- With covid restrictions it has been harder to get appointments with a GP to arrange regular check-ups.
- Yes. It triggers health anxiety. Extra worry about contracting the virus and also concerns about the potential side effects of the vaccine. I missed some check ups as they were in sydney and I didn't want to travel during COVID. Also Having to got to hospital for treatment was stressful due to fear of getting COVID.
- No affect
- Yes, independent of my cancer diagnosis, Covid has made life harder.
- Wearing a mask 8 hrs day uncomfortable. Was unable to participate in group activities post treatment.
- Not really, we haven't been greatly affected in our area.
- Yes, as i am concerned that if i get covid i will have complications due to my illness. It has limited my abilities to socialize
- Border restrictions have been challenging. I live in NSW but travel into Queensland for treatment. When borders were closed you would never know how long it would take to cross giving you more anxiety. Other times you would cross the border easily therefore making you extremely early for your appointment resulting in a long wait at the doctors
- It was hard going through all of the operations and treatments by myself. My husband couldn't be with me at all.
- It increases anxiety, and there is a constant focus on physical and mental wellbeing. I worry that I have a lowered immune system post breast cancer which increases susceptibility to COVID. I have not been able to access my breast cancer doctor and services in Melbourne and have been using teleconference calls for check ups.(I live 3 hours away but on the NSW side of the border). Because of border restrictions I am sometimes cut off from my adult children, depending on COVID restrictions. This is distressing as time lost can never be repaid.
- No, living in a rural community has been a protective factor due to the preexisting isolation.
- No - really enjoying being at home… I am a person who enjoys occupying myself.
- Absolutely yes. My family live in Perth, WA and my best friend lives in Queensland. My partner and myself live in regional SA. We do not have a circle of friends here so it really is just my partner and myself. Not being able to have my family travel during my whole cancer experience because of covid border closures etc has been extremely difficult. It seems to become more difficult instead of easier. With each new covid outbreak here in Australia I feel more and more depressed with the belief that I will never have my family here to support me and share my experiences. And even worse that my best friend cannot be with me.
- Limited social contact...delayed access to oncologist face to face i have not seen my oncologist for 18 months only via phone
- No
- Maybe
- Yes. COVID 19 has helped to slow my life down and take note of what matters to ensure my energy is being used in the best way. Masks and checking in are annoying but they also provide a level of safety and health (from covid and other illnesses) that I appreciate. Telehealth appointments have been an efficient way of checking in, especially considering that I am 4 years out and not in the early stages past diagnoses/treatment.
- My husband of 54 years died on 11/4/2021, COVID made this time harder, as we were unable to farewell him in the way he deserved. I also lost my most valuable support with his loss.

- Isolation has increased and the “care factor” has dropped for individuals who are doing it by themselves.
- No
- No
- Lack of face to face discussion with friends & health professionals.
- Effects my well-being for the better. Quite like hermiting away and not having to deal with other peoples crap.
- Anxiety about other family members and some physical separation from friends
- No
- Positive. I feel life is calmer.
- I am a Registered Nurse therefore as an essential worker I ha e not thought about myself or my own needs. Because of Covid-19 I have missed a routine mammogram & ultrasound on my left breast which I have multiple cysts in
- A chance to relax exercise Meditate and reflect
- No
- No
- No
- No. We have been vert lucky in WA that COVID-19 has not really impeded on our well-being
- its taking a toll on my marriage
- Not at all. Living in the country makes it easier. But would like to see family who live overseas.
- Makes it hard to visit family and friends, makes you depressed, hard to cope with what you are going through, you feel isolated and alone
- COVID affected my ability to be with my adult children and socialising with friends. Luckily, my husband was with me 100% of the time (we voluntarily went into isolation with my diagnosis due to a very low immune system prior to COVID becoming official). Enforced lockdowns felt like a continual stream of being denied freedom to actively move within my social structure, gather support and be able to communicate physically with loved ones. It was extremely hard on my family who also needed reassurance and a pathway to express their feelings other than through facetime or social media (one of my children lives in Sydney- his mental wellbeing became a major worry for me). COVID has created a new way of life for us all and in some respects - without a strong foundation of love to support a family - it has caused divisions, that has taken a toll.