Evaluating the Effectiveness of an Education Group Intervention on the Psychological Wellbeing of Breast Cancer Patients

A thesis

submitted in fulfilment

of the requirements for the degree

of

Master of Applied Psychology (Behaviour Analysis)

at

The University of Waikato

by

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2020

Abstract

Breast cancer (BC) is a significant health problem for New Zealand (NZ) women, with approximately 3,300 women diagnosed every year. Psychosocial distress is commonly associated with a BC diagnosis; 20-50% of women with BC will suffer from psychological distress within the first year after diagnosis. Distress is associated with less adherence to treatment; exacerbated preexisting psychological and psychiatric conditions; slower recovery from surgery and other treatment; and poor Quality of Life (QOL) and well-being. To treat distress, the Cancer Society of New Zealand, a local organisation that helps cancer patients, delivers a psychoeducational intervention called the Living Well (LW) programme. This programme deals with emotions, relaxation, perceptions, coping, self-care, and informs patients about their cancer, treatment and what to expect. Very little research has been done in NZ to assess the effectiveness of such programmes. To evaluate the effectiveness of the LW programme for individual BC patients, a repeated measures design was used to investigate the effect of the programme as measured by the Hospital Anxiety and Depression Scale (HADS), a screening tool commonly used to identify anxiety and depression in BC patients.

Stage I-II BC patients referred to the Cancer Society and enrolled in the LW programme were recruited for the study. HADS scores were collected and analysed weekly using a repeated measures design prior to, during and after the intervention (LW programme).

Analysis shows that the participants reacted similarly to the LW programme, as demonstrated by their HADS scores. Across all phases of the study (baseline, intervention and post-intervention) mean depression scores were lower than anxiety scores. During baseline mean anxiety scores were slightly higher, on average, than the intervention and post-intervention phases.

While no consistent systematic effect on well-being from attending the LW programme was found, psychosocial distress in the breast cancer patients recruited for the study was evident. Therefore, there is value and benefit to provide interventions, to aid women by providing information so that they are better informed, can develop improved coping strategies, and develop new avenues for social support.

Acknowledgements

This thesis could not have been completed without the love and support of many people in my life. Firstly, I would like to gratefully acknowledge and express my gratitude to the six participants who willingly participated in my study. Without you, this study would not have been possible. Thank you for sharing your journey with me. I wish you all the best for the future. Additionally, special thanks to Kay Taylor, Supportive Care Nurse from the Cancer Society of New Zealand, your help and support was greatly appreciated.

To my supervisors Dr. Tim Edwards, Dr. Tania Blackmore and Dr. Lynne Chepulis, thank you for your time, encouragement, vast knowledge, patience, positivity, and guidance throughout this journey. I truly appreciate it.

Finally, special thanks to my family and friends near and far who never seemed to doubt that I could do this. Thank you for your support, kindness and encouragement continuously throughout my life, and in particular for cheering me on throughout this thesis. The coffees and chats have been immensely appreciated.

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Chapter One: Introduction

Cancer is a global disease, with an estimated one in six deaths attributed to it worldwide (World Health Organization, 2018). Cancer rates are only predicted to increase in the future as populations age (Thakkar, McCarthy, & Villano, 2014). Breast cancer is the most common cancer to affect women, and a leading cause of female cancer deaths (World Health Organization, 2018).

In New Zealand (NZ), nine women a day are diagnosed with breast cancer, which equates to approximately 3300 women diagnosed each year (Ferlay et al., 2015; Ministry of Health, 2018a). Although not as common, approximately 25 NZ men are diagnosed with breast cancer each year. In 2015, breast cancer accounted for 15% of female cancer deaths in NZ (Ministry of Health, 2018a) with approximately 600 deaths per year. According to the Ministry of Health (2018b), the risk of being diagnosed with breast cancer is less common in women under the age of 50 and increases with age; 70% of women diagnosed with breast cancer, and 80% who die from the disease are 50 years or older. The incidence rate of breast cancer in NZ is rising, increasing by 18% over the last decade (Ministry of Health, 2018a). However, over the last 20-30 years there have been significant improvements in breast cancer treatment, resulting in a steadily declining mortality rate (Ades, Tryfondidis, & Zardavas, 2017).

Breast cancer treatment and survival depends on the stage at diagnosis, the size and location of the tumour, and tumour characteristics. The individual’s age, general health, and menopausal status can additionally affect prognosis and treatment options (National Cancer Institute, 2019). Treatment typically consists of surgery, chemotherapy, radiotherapy, and/or endocrine therapy, with treatment modality or combinations of treatment dependent on stage of disease. Stage is based on the location, size and grade of the primary tumor, the spread of the cancer to lymph nodes or other parts of the body, and whether specific biomarkers are present (National Cancer Institute, 2019). Early stage breast cancer (stage I-II) is confined to the breast with or without regional lymph node involvement, while late stage breast cancer (stage IV) indicates that the cancer has grown and has spread beyond the breast and nearby lymph nodes to additional organs in the body (Shulman & Torode, 2014). For women diagnosed with early stage breast cancer, early detection and treatment improves prognosis and long-term survival (Shulman & Torode, 2014).

Non-invasive (stage 0) and early stage breast cancer have a better prognosis and higher overall survival rates than later stage cancers, with early stage breast cancer having a 5-year survival rate of between 90-100% (Weiss et al., 2018). Early stage breast cancer is highly treatable, however it does require immediate treatment which typically consists of surgery, frequently followed by radiation. When breast cancer metastasises in its later stages eliminating tumours becomes increasingly challenging and can have a significant effect on the survival rate (National Cancer Institute, 2019). Typically, the later the stage the more treatment that is likely to be needed (American Cancer Society, 2019).

Impact of Cancer

Despite relatively good outcomes, a significant number of NZ women still die from breast cancer or suffer from recurrent disease. The psychological impact of cancer is becoming increasingly important and is now recognised by the NZ Ministry of Health Breast Cancer Guidelines (Ministry of Health, 2009). A cancer diagnosis can significantly impact well-being, both for the patient and the immediate family. Well-being is a multi-dimensional concept, with general psychological well-being typically being a broad and complex term that is unlikely to ever be completely captured or measured (Kvalsvig, 2018). Psychological well-being incorporates a combination of functioning effectively and feeling good (Huppert, 2009). Psychological well-being also encompasses negative aspects of quality of life associated with psychological morbidity, such as anxiety, depression and emotional distress, and positive aspects that include morale, life satisfaction, self-esteem, a sense of rationality and happiness (Abu-Helalah, Al-Hanaqta, Alshraideh, Abdulbaqi, & Hijazeen, 2014; Bowling, 1991). Stable psychological well-being occurs when individuals have the psychological, physical and social tools that they require to adequately manage and deal with specific challenges (Dodge, Daly, Huyton, & Sanders, 2012). Therefore, when individuals face challenges for which they do not have adequate resources for, well-being is negatively impacted. When negative emotions are severe or long-lasting and interfere with an individual's ability to function in their daily life, stress results and psychological well-being becomes compromised (Huppert, 2009). Psychological distress and well-being, although clearly distinct, are negatively associated with one another (Massé et al., 1998; Veit & Ware, 1983).

The National Comprehensive Cancer Network (NCCN) defines distress as "a multifactorial unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment" (Holland et al., 2013, p. 192). The term distress is often utilised as it encapsulates psychological well-being and a wide range of psychological issues in addition to including cancer-specific concerns and more generalised symptoms of worry, fatigue, and fear (Holland et al., 2013; Park, Chun, Jung, & Hyoung Bae, 2017). Furthermore, the word 'distress' is commonly recognised as a less stigmatising term than other psychological or psychiatric terminology such as anxiety and depression, and is now becoming more acceptable to oncologists and cancer patients (Institute of Medicine and National Research Council, 2004; Larouche & Edgar, 2004).

Distress extends along a continuum, extending from common feelings of dejection, vulnerability, and worry to difficulties that can become disabling, such as depression and anxiety. For cancer patients, distress can occur at any point along the cancer continuum, from initial diagnosis to treatment and beyond, with the level of distress varying among individual patients. Specific to breast cancer, distress can occur irrespective of treatment type (Lim, Devi, & Ang, 2011). Many patients with newly diagnosed and recurrent cancer show particularly high levels of distress (Holland et al., 2013). A breast cancer diagnosis and treatment can have significant long-term impacts on an individual's life, including their physical, functional, spiritual, emotional, and social well-being, in addition to impacting their psychological adjustment and distress (Park et al., 2017). Furthermore, it is important to recognise that although many patients' psychological distress tends to improve over time, many patients still suffer from negative emotions and physical side effects even after treatment has ended (Cook et al., 2015). Around 20 to 50% of women with breast cancer suffer from psychological distress at some stage in their cancer journey, especially in the first year after diagnosis (Bidstrup et al., 2015; Park et al., 2017). Previous studies have reported that one in seven women with breast cancer experience chronic distress from their diagnosis alone (Helgeson, Snyder, & Seltman, 2004; Henselmans et al., 2010; Lam et al., 2010). The identification of distress in breast cancer patients has become more challenging as cancer care has become hurried and pressurised (Lang-Rollin & Berberich, 2018).

Certain risk factors can increase the likelihood of experiencing distress and poor well-being. These include being female, being of young age, having poor social support, marital status, financial situation, employment status, whether or not there is a history of psychological distress or other serious comorbid (additional) disorders, and physical factors (Agarwal et al., 2013; Enns et al., 2013; Ganz et al., 1993; Jemal, Thomas, Murray, & Thun, 2002; Holland et al., 2013; Leedham & Ganz, 1999; Maunsell, Brisson, & Deschenes, 1992, 1995; Park et al., 2017; Schag et al., 1993; Schimozuma, Ganz, Petersen, & Hirji, 1999; Schover, 1994; Wenzel et al., 1999). Further risk factors also include treatment (Pehlivan, Ovayolu, Ovayolu, Sevinc, & Camci, 2012; Tan & Karabulutlu, 2005; Yavuzsen, Karadibak, Cehreli, & Dirioz, 2012), the stage of cancer, and the dose and length of treatment (Bultz & Johansen, 2011; Enns et al., 2013; Lam et al., 2010; Park et al., 2017; Runowicz et al., 2016). Women with chronic distress often hold a pessimistic view which may influence the adoption of ineffective coping strategies when dealing with their cancer diagnosis and adherence to treatment (Lam, Shing, Bonanno, Mancini, & Fielding, 2012; Carver et al., 1993); indeed, distress is one risk factor for nonadherence to treatment in women with primary breast cancer (Partridge, Wang, Winer & Avorn, 2003).

Age is an important factor concerning distress and breast cancer. Premature menopause, amenorrhea (the abnormal absence of menstruation), and hormonal changes related with breast cancer treatment can be associated with cognitive impairment and mood disorders, and can be devastating for young women if they are faced with fertility decisions as a result of treatment (Warga, 2000). For some younger breast cancer patients, their diagnosis may also be their first encounter with the health-care system other than minor health conditions or childbirth, which can cause heightened anxiety (Institute of Medicine and National Research Council, 2004). Vickberg (2003) found that younger women had greater fears regarding the possibility of disease recurrence, as well as being possibly more susceptible to negative effects of their diagnosis and treatment, such as potential infertility, higher expectations about physical appearance, fatigue, poor sexual functioning, and acute toxicities of radiation and chemotherapy treatments (Akel et al., 2017; Al- Sulaiman et al., 2018). Additionally, increased anxiety in younger patients can be a result of more aggressive disease and the expectation to return to premorbid functioning, which is defined as an individual’s cognitive functioning prior to a trauma or disease (Hamer et al., 2017; Sariego, 2010). Younger women who do not have a partner or spouse may have more anxiety around attractiveness, reproduction, and future intimate relationships following a breast cancer diagnosis and treatment such as mastectomy (Schover et al., 1995). Issues such as sexual dysfunction are often not acknowledged by the cancer care team, with the majority of breast cancer patients receiving minimal or no aid in dealing with the adverse effects that breast cancer and its treatment have on sexual intimacy (McKee & Schover, 2001) or biological changes (fatigue and hormonal changes). Physical factors contribute not only to poor well-being, but to increased psychological distress in younger women and greater distress for their husbands and family (Bloom & Kessler, 1994; Northouse, 1994).

Social support is another important factor that can either mitigate or exacerbate distress. Social support includes emotional or practical support, such as preparation of meals, assistance with daily functioning, and aid in transportation (Adler & Page, 2008) and marital status and can predict psychological co-morbidity amongst breast cancer patients (Abu-Helalah et al., 2014). For example, Karakoyun-Celik et al., (2010) found that breast cancer patients who were unaccompanied in their medical appointments had higher levels of anxiety and depression. The association between marital status and distress in breast cancer patients is unclear. Marital status, particularly not being married or in a relationship, can be a risk factor for psychosocial distress (Al-Sulaiman et al., 2018), while being married can provide a level of social and emotional support and thereby mitigate distress (Peled, Carmil, Siboni-Samocha, & Shoham-Vardi, 2008; Srivastava et al., 2016). Studies have found that married women felt more supported and protected by their husbands, and therefore were less psychologically distressed in comparison to single women (Peled et al., 2008; Srivastava et al., 2016). However, this may be subjective and dependent on the quality of the marriage or relationship. Finance has been identified as another predictor of psychological well-being (Ell et al., 2005; Hopwood, Haviland, Mills, Sumo, & Bliss, 2007; Jassim & Whitford, 2013;

Montazeri, Vahdaninia, Ebrahimi, & Jarvandi, 2003), with patients of low income typically being at an increased risk for having psychological distress secondary to breast cancer (Dastan & Buzlu, 2011). Villar et al. (2017) found that after treatment, breast cancer patient's anxiety was most common in those who were not in active work, which includes being a homemaker, having time off, or being unemployed.

Further psychological stressors that can exacerbate distress include fear and apprehension about death and disease recurrence, sexuality and attractiveness concerns related to altered body image, adjustments to femininity, and treatment-related anxiety (Baucom, Porter, Kirby, Gremore, & Francis, 2006; Henselmans et al., 2010; Paterson, Lengacher, Donovan, Kip, & Tofthagen, 2016; Reich, Lesur, & Perdrizet-Chevallier, 2008; Spiegel, 1997; Vahdaninia, Omidvari, & Montazeri, 2010). Additionally, breast cancer patients who are anxious may have a pessimistic and negative view regarding their health conditions and cancer prognosis, therefore, may be more inclined to be highly distressed (Park et al., 2017). Furthermore, distress related to a new breast cancer diagnosis and its treatment can also exacerbate preexisting psychological and psychiatric conditions such as depression, anxiety, severe stress disorder, and adjustment disorders. Breast cancer patients may experience behavioural and emotional changes during diagnosis and treatment (Conley, Bishop, & Andersen, 2016). If untreated, the psychological impact of breast cancer can have a detrimental impact on therapy and treatment adherence; influence the biological progression of the cancer; adversely affect well-being, quality of life and functioning; and can result in increased mortality and morbidity (Adler & Page, 2008; Al-Sulaiman et al., 2018; Conley et al., 2016; Martinez & Pasha, 2017; Nakatani et al., 2013). More severe psychological distress can also occur in the form of anxiety and depression, with breast cancer patients having the highest rates of anxiety and depression compared to patients with other types of cancer (Mehnert et al., 2014). Research suggests that nearly 50% of patients had at least one episode of depression, anxiety, or both following their breast cancer diagnosis (Burgess et al., 2005), with anxiety generally more common than depression in breast cancer patients (Abu-Helalah et al., 2014; Payne, Hoffman, Theodoulou, Doisk, & Massie, 1999; Yi & Syrjala, 2017). Depression, although often misdiagnosed and undertreated among breast cancer patients, can affect between 20% to 30% of early stage breast cancer patients, which rises to more than 50% for those with advanced and palliative disease (Fallowfield, Hall, Maguire, & Baum, 1990; Fulton, 1997; Zabora, BrintzanhofeSzoc, Curbow, Hooker, & Piantadosi, 2001).

In addition to psychological and social support factors, physical factors, such as fatigue, pain, and disrupted sleep can also influence breast cancer patient's distress and well-being (Institute of Medicine and National Research Council, 2004). Fatigue is one of the most common adverse effects of breast cancer treatment and causes substantial impairment in social, emotional, and occupational functioning (Wagner & Cella, 2004). Studies investigating the prevalence of fatigue among breast cancer patients found that up to 99% of patients experienced some degree of fatigue during radiotherapy and/or chemotherapy, with more than 60% suffering moderate to severe fatigue (Bower et al., 2000, 2006). Breast cancer patients with two or more comorbid conditions, including pulmonary and cardiac conditions, may have increased levels of distress post-diagnosis compared to those without comorbid conditions (Ganz et al., 1993; Lo-Fo-Wong et al., 2016). Additionally, physical recovery following breast cancer surgery may be impaired in individuals with psychological comorbidities and this may be partly responsible for an increase in psychological distress (Institute of Medicine and National Research Council, 2004).

Depressive symptoms can occur on a spectrum from mild to severe and are challenging to evaluate for clinicians. Moreover, medical professionals, particularly oncologists, may be unfamiliar with screening for depression, which may lead to breast cancer patients who are suffering from depression being overlooked (Greenberg, 2004). The incidence of depression seems to be contingent on factors including level of patient disability and physical impairment, pain, disease severity, and past history of depression (Aapro & Cull, 1999; Hopwood et al., 2007; Lansky et al., 1985; Massie & Holland, 1990; Reich et al., 2008). During breast cancer consultations between medical professionals and family, discussion about life expectancy and survival, treatment outcomes on quality of life, and using the word ‘cancer’, which for many patients is a term synonymous with death, are factors which may increase depression and anxiety (Dowsett et al., 2000; Reich et al., 2008).

Depression also impacts on treatments such as surgery and outcomes following treatment. Studies have compared psychological disorders, including depression, in women with breast cancer who undergo different surgical procedures, including mastectomy and lumpectomy. Goldberg, Scott, and Davidson (1992) found a significantly greater prevalence of depression in women who were scheduled for breast surgery compared to women who were found to have benign disease at the time of breast biopsy. Furthermore, women treated with a mastectomy may suffer depression more than women who are treated by conservative surgery such as a lumpectomy. Hjerl et al. (2003), who analysed early and late stage breast cancer patients, found that depression was a negative prognostic factor after breast cancer and identified a link between depression and a moderate but significantly increased risk of mortality, dependent on stage of cancer and time of depression. Cancer induced or long-term depression had no significant effect for early or late stage breast cancer patients and there was no statistically significant difference identified between early- and late-stage patients. However, postoperative depression was found to increase mortality in early stage breast cancer, although the effect was nonsignificant for late-stage patients. Watson, Haviland, Greer, Davidson, and Bliss (1999) linked depressive symptoms to a significantly reduced chance of survival at five years follow up for early stage breast cancer patients. Furthermore, breast cancer survivors report a higher prevalence of mild to moderate depression with a reduced quality of life in all domains of life except for family functioning (Weitzner, Meyers, Stuebing, & Saleeba, 1997). Thus, treatment of depression in women with breast cancer is likely to increase longevity and improve coping strategies and quality of life. Diagnosis, surgery and recurrence of breast cancer are crucial factors to consider when assessing depression in order to prevent the development of psychiatric disorders (Okamura, Yamawaki, Akechi, Taniquchi, & Uchitomi, 2005). It is crucial to include interventions that aid the psychological well-being of breast cancer patients alongside their treatment.

Psychological Interventions

With the prevalence of cancer-related psychological distress, identifying the psychological status of breast cancer patients is a crucial consideration. However, the psychological needs of breast cancer patients are largely overlooked. Traditionally, in routine clinical practice, stigma related to psychological and psychiatric needs, time constraints, poor understanding of psychological needs by the oncology team, and a shortage of community resources often negatively influence the discussion of psychological issues (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Holland et al., 2013). However, in NZ the needs of cancer patients are being addressed through the implementation of relatively new services such as the Cancer Psychological and Social Support Service (CPSSS) which has been funded by the Ministry of Health since 2016 and operates in six District Health Boards that manage cancer centres (Esplin, Smith, Cherrington, Boyle, & Niemi, 2018; Ministry of Health, 2017). The first step to treat psychological distress is to identify it. Screening tools are a useful and effective way to consistently identify distress and the psychosocial needs of breast cancer patients. Instruments that measure psychological well-being focus almost exclusively on straightforward psychological constructs including depression and anxiety, such as those measured by the Hospital Anxiety and Depression Scale (HADS).

Screening Instruments

The HADS was established by Zigmond and Snaith (1983) and is a widely used, reliable, self-administered questionnaire that can identify minor psychiatric impairment and provide clinically meaningful results (Alawadi and Ohaeri, 2009; Hopwood et al., 2007; Mehnert and Koch, 2008). This 14-item scale, which takes between 2 to 5 minutes to complete, can screen for depression and anxiety and was designed for use in a medical setting for patients with diverse medical and chronic illnesses, including breast cancer (Abu-Helalah et al., 2014; Alawadi & Ohaeri, 2009; Mehnert & Koch, 2008; Osborne, Elsworth, Sprangers, Oort, & Hopper, 2004; Payne et al., 1999). The HADS has been used to monitor outcomes of breast cancer patients in various psychosocial interventions (Montazeri et al., 2001; Spiegel et al., 1999), and can estimate the prevalence of psychosocial distress in breast cancer patients (Institute of Medicine and National Research Council, 2004). Furthermore, the HADS is sensitive to time changes along the cancer continuum and to the assessment of responses to psychotherapeutic and psycho-pharmacological intervention (Petersen & Quinlivan, 2002).

An advantage of the HADS over other scales that measure emotional functioning and well-being is that it provides an estimate of the clinical level of distress by implementing separate threshold scores for normal, borderline abnormal or abnormal levels of depression and anxiety (Hopwood et al., 2007). Furthermore, the HADS has the advantage of being concise and succinct, and avoids contamination by physical symptoms due to items not coinciding with somatic conditions that may be produced by cancer (Lam et al., 2012). Validation of the HADS has been derived from patients with cancer (Herrmann, 1997; Burton et al., 1995). Thus, due to the HADS good psychometric properties (Thomas, Glynne, Chait, & Marks, 1997) and adequate use in the breast cancer population (Abu-Helalah et al., 2014; Akel et al., 2017; Bellver-Perez, Peris-Juan, & Santaballa-Beltran, 2019; Watson et al., 1991), the HADS was selected as the tool in this current study. Screening instruments such as the HADS provide a method of efficiently evaluating a large number of individuals and consequently identifying those suffering from psychological distress, which may result in better utilisation of health care resources (Payne et al., 1999). Breast cancer patients who are increasingly anxious and depressed have higher HADS scores and are likely to be less functional and more symptomatic (Abu-Helalah et al., 2014; Alawadi and Ohaeri, 2009). While the HADS and other psychometric assessment tools can measure the presence of distress, the next step is to treat the distress. One method to do this is to use an intervention to mitigate the impact of distress and thereby improve well-being.

Education

Numerous breast cancer patients rely on family, friends, and their community for support, or find information and support on the internet. However, some women do not have social support built into their lives and may lack access to psychosocial services (Institute of Medicine and National Research Council, 2004). Therefore, one type of intervention-based therapy that has been developed for breast cancer patients is education. Educational interventions can differ in terms of their format (individual, group, and family therapy) and content (psychodynamic (Spiegel et al., 1999), cognitive-behavioural (Antoni et al., 2001; Edelman & Kidman, 2000), psychoeducational (Okamura, Fukui, Nagasaka, Koike, & Uchitomi, 2003), peer discussion (Helgeson, Cohen, Schulz, & Yasko, 1999, 2001), and support groups (Samarel, Fawcett, & Tulman, 1997). The choice of intervention is often associated with various factors including the type and stage of cancer, where the individual is on the cancer continuum (e.g. diagnosis, treatment, or post-treatment), their psychological and emotional state, the stigma associated with seeking psychological support, and the availability and financial costs of professionals. According to the Institute of Medicine and National Research Council (2004), while breast cancer patients may benefit from a variety of psychosocial and educational interventions, such as psychoeducation, not all interventions are equally effective for all patients due to individual patient characteristics such as personality.

Psychoeducational interventions, in addition to other interventions such as psychological and social support, counselling, and psychotherapy, address distress that can arise following a cancer diagnosis and treatment (Grassi, Spiegel, & Riba, 2017; Zimmermann, Heinrichs, & Baucom, 2007). Psychoeducational interventions provide information to individuals and groups regarding illness in a social and supportive interaction (Institute of Medicine and National Research Council, 2004), and aims to give the patient a sense of control whilst additionally providing the opportunity for patients to restore lost and perceived control (Helgeson & Cohen, 1996). Furthermore, in breast cancer patients psychosocial and educational interventions have been specifically established to enhance psychological and social adjustment to cancer; social support, coping, and quality of life; improve physical functioning and well-being; and decrease psychological distress (Andersen et al., 2004; Boesen et al., 2011; Geiger, Mullen, Sioman, Edgerton, & Petitti, 2000; Grassi et al., 2017; Helgeson et al., 1999, 2001; Kissane et al., 2007; Mehnert et al., 2011; Meneses et al., 2007; Neises, 2008; Park, Bae, Jung, & Kim, 2012; Scheier et al., 2005; Stanton et al., 2005; Yavuzsen et al., 2012; Zimmermann et al., 2007). Intervention methods can be direct, such as written materials, lectures, videos, and additional media sources, as well as indirect, such as modelling of effective coping behaviours by group members and peer discussions.

Typically, psychoeducational interventions will include four major themes including psychotherapy, education, coping, and emotional support (Okamura et al., 2003). These interventions often incorporate techniques such as those used in behavioural analysis, which has been defined as a discipline that uses scientific methods to explain relations between environmental inputs and behavioural outputs, then uses these relations to explain, and if feasible, improve the behaviour of humans and animals (Poling, 2015). These interventions aim to modify behaviour to a meaningful degree and to demonstrate that the interventions implemented are responsible for the improvement in behaviour (Broardstock, 2011). Interventions may address emotions, relaxation, perceptions, coping and managing the illness and its side effects, self-care, and they can also inform patients about their cancer, their treatment and what to expect, particularly patients with inadequate information.

One aim of psychoeducational interventions is to improve health knowledge and literacy, which is tailored to meet patient's levels of literacy or education and has a critical impact on health outcomes (Costas et al., 2013). The knowledge of cancer patients influences their capability to contribute in the decision-making processes for treatment choices, adherence, and their ability to cope with their cancer to improve medical outcomes. Increased knowledge about cancer diagnosis and treatment has been identified as a key factor in the variation in survival (Goodwin, Samet, & Hunt, 1996). By modifying behaviour and providing breast cancer patients with information that is culturally appropriate and tailored to the patients' needs and literacy levels, improvements can be seen in the management of breast cancer, compliance with treatments, and prevention of progression or relapse (Cummings & Cummings, 2008).

Medical staff can be highly effective at implementing psychoeducational interventions for breast cancer patients, in individual or group environments, preferably directly after diagnosis or surgery (Zimmermann et al., 2007). Group therapy for cancer patients is equally, and perhaps substantially more in the instance of group psychoeducational interventions, effective when compared to individual therapy (Sheard & Maguire, 1999). Group psychoeducational interventions are generally cheaper and more cost effective than other therapies, and easy to implement, deliver and reproduce (Sheard & Maguire, 1999; Tong et al., 2019). A group format can provide patients with the opportunity to learn in a setting with other patients who are in similar situations, consequently alleviating the sense of isolation and delivering additional social support (Adamsen & Rasmussen, 2001; Jones et al., 2013). Group interventions can offer several benefits for patients such as improved information regarding disease, improved self-esteem and emotional well-being, increased sense of control and empowerment, social support from others in similar situations, and facilitation of positive relationships (Balabanovic, Ayers, & Hunter, 2012; Edelman, Bell, & Kidman, 1999; Ussher, Kirsten, Butow, & Sandoval, 2006). Additionally, decreases can be seen in cancer worry and perceived risk of disease recurrence (Cameron, Booth, Schlatter, Ziginskas, & Harman, 2007).

In breast cancer patients, psychoeducation has been shown to improve quality of life (Chujo et al., 2005; Faller et al., 2013; Wang et al., 2017; Zimmermann et al., 2007), provide confidence and comfort, enhance a sense of control (Campbell, Phaneuf, & Deane, 2004; Helgeson et al., 2001), decrease the distress caused by the illness (Fawzy & Fawzy, 1998), alleviate the sense of isolation, and deliver additional social support (Adamsen & Rasmussen, 2001; Jones et al., 2013). Additionally, patients can learn how to confront stressors with a positive attitude and use active behavioural strategies (Andersen, 1992). Research suggests that psychoeducational interventions that provide patients with adequate resources and information to better understand, adjust and cope with their symptoms can reduce duration, frequency, and intensity of breast cancer disease and treatment-related symptoms (Jones et al., 2013) and can assist in normalising a cancer patient’s circumstances and decrease uncertainties for the future by facilitating communication with others in a similar situation (Fawzy, Fawzy, Arndt, & Pasnau, 1995; Tong et al., 2019).

A review by Helgeson and Cohen (1996) found clear and consistent benefits of psychoeducational group interventions for people with cancer. However, there was less evidence whether these benefits were short term or had a lasting impact, particularly in breast cancer patients. In a later study Helgeson et al. (1999) compared psychoeducation and peer discussion group interventions in early stage breast cancer patients. The psychoeducational intervention focused on delivering information to patients about breast cancer and how to cope with the diagnosis and negative effects of treatment, with the idea to enhance the patient’s control over their illness. The peer discussion group, which involved facilitators encouraging patients to assist each other, aimed to provide emotional support through the expression of feelings. The study found consistent positive benefits for the psychoeducational intervention group immediately after and six months following the intervention. These benefits included enhanced body image, increased self-esteem and perceived control, improved discussions with peers and family, and decreased aversive thoughts and uncertainty regarding breast cancer. The decrease in aversive cognitions and improvements in self-esteem contributed the greatest to the increase in quality of life. However, no benefits were found for the peer discussion group. Instead greater intrusive and avoidant thoughts were found compared with patients who were not in the peer discussion group. The authors additionally proposed that information-based psychoeducational groups demonstrated greater improvements in regard to their physical functioning whilst emotion-focused peer discussion groups were effective for women who lacked support from their medical team or family (Helgeson, Cohen, Schulz, & Yasko, 2000). Helgeson et al. (2001) then looked at longer-term effects of a brief 8-week intervention compared to a peer discussion group in early stage breast cancer patients. They found that some of the benefits such as higher levels of energy, decreased physical pain and improved physical functioning and quality of life remained over a three-year timeframe. It was suggested that these results may be a consequence of the patients in the psychoeducational intervention obtaining information, such as information associated to well-being, nutrition and exercise, that they were able to use immediately and in the long-term to ease daily functioning. Therefore, it was concluded that there are well-defined and consistent benefits of a brief psychoeducational intervention for early stage breast cancer patients, with some effects remaining long-term. Long term benefits were additionally found by Jones et al. (2013). Jones et al., (2013) compared breast cancer patients who received standard print material (usual care) to breast cancer patients who received standard print material (usual care) in addition to attending a two-hour single session group psychoeducational intervention designed for breast cancer patients. Six months after the intervention patients who had attended the intervention demonstrated persistent increased knowledge concerning their illness and its after-effects and enhanced preparedness to transition into the recovery phase. Moreover, Edelman, Craig and Kidman (2000) reviewed the evidence for the efficacy of “supportive” compared to “psychoeducational” approaches in cancer patients. Supportive groups focus on the expression of emotions and the development of social support and emphasise discussion and expression of feelings and emotions. Psychoeducational groups encourage various coping skills such as goal setting, problem-solving and relaxation. The authors found that the majority of evidence suggests that cancer patients, including those with breast cancer, experience greater benefits from attending psychoeducational groups rather than supportive groups.

Studies have also specifically demonstrated the benefits of psychoeducational interventions on the well-being of breast cancer patients. Ram, Narayanasamy, and Barua (2013) focused on the impact of group psychoeducation that was completed over 4-weeks. The intervention emphasised the delivery of medical information and the causes of cancer, prognosis and treatment strategies. The authors concluded that the intervention played a crucial role in improving well-being and decreasing depression. Al-Sulaiman et al. (2018) used six 60- to 90- minute psychoeducational-based interventions over 12-weeks, for women with early stage breast cancer. Participants were randomised into either a psychoeducational intervention, a crisis counselling group, or a control group. The intervention consisted of four core components: coping and problem-solving guidance, stress management and behavioural training, health education, and psychological support. It was found that the intervention was effective in improving psychological well-being and quality of life at 18-months follow-up. It was also found that 95% of patients in the study were compliant with treatment. This study also demonstrated that psychoeducation had a larger advantage over counselling, particularly in improving patient’s well-being. The significant improvements found in the psychological well-being of patients in both intervention groups (counselling and psychoeducation) were suggested to be a result of patients having the opportunity to express their concerns and emotions in addition to learning various coping mechanisms to deal with their illness. Doulbeaut et al. (2009) evaluated the effectiveness of an 8-week psychoeducational intervention after early-stage breast cancer treatment. The intervention consisted of 2-hour sessions involving thematic conversations and education in stress management strategies. The intervention was found to be effective, and reduced negative moods/emotions, such as anxiety, depression and fatigue, and improved interpersonal relationships, health status, and role and emotional functioning.

Maeda, Kurihara, Morishima, and Munakata (2008) investigated the effectiveness of a psychoeducational intervention on adaptive coping and psychological well-being in early stage breast cancer patients over six-months. The intervention involved three sessions consisting of three components: providing psychological information, delivering treatment information, and counselling. Five measures were utilised, which included the HADS (Japanese version), and took place after surgery (pre intervention), 1 month (post-intervention) and 3 months after discharge (follow-up). HADS scores for anxiety and depression did not significantly differ between baseline, intervention and post-intervention phases and the authors found no consistent systematic effect on well-being over 6 months. Andreis et al. (2018) evaluated the impact of 13 psychoeducational groups in women with breast cancer where the intervention involved helping patients deal with the emotional, physical, and lifestyle adjustments associated with cancer. Using the HADS and Body Image Scale (BIS), no effect on anxiety was found, but a statistical difference, thus improvement, in depression score at baseline and post-intervention was found. Cipolletta, Simonato, and Faccio, (2019) investigated the effectiveness of psychoeducational-based groups and found that in addition to improving well-being, a psychoeducational intervention can create emotional support, novel social relationships that alleviate the sense of loneliness and isolation, and opportunities to increase personal resources for breast cancer patients. After the intervention, support was also found to be a good predictor of both physical and psychological well-being.

Applied Behaviour Analysis

Another type of intervention is Applied Behaviour Analysis (ABA). ABA is a psychological based method which has promise for treating cancer-related psychological issues, however, as far as the researcher is aware, ABA has not been implemented for this purpose in the cancer field. ABA interventions use principles of learning theory whereby the theoretical foundation lies in the behavioural conditioning studies of Thorndike (1898), Pavlov (1927), and Skinner (1938;1953). ABA can be applied in a systematic and measurable approach to improve, reduce, maintain and/or generalise target behaviours (Broadstock, 2011). Behavioural interventions can be applied to all aspects of life (Redd, Montgomery, & DuHamel, 2001) as human behaviour is shaped by its consequences (Baum, 2005). ABA work is wide-ranging, with early behavioural interventions in humans being practical, aiming to adjust environmental and social conditions and coping skill deficits that adversely influence daily performance. ABA has produced effective and influential interventions in fields such as education, clinical psychology, people with developmental disabilities and autism spectrum disorder (ASD), and behavioural medicine and medical conditions, such as cancer (Mundy, DuHamel, & Montgomery, 2003; Redd et al., 2001; Slocum et al., 2014). In individuals with ASD or with intellectual disabilities, ABA has proven a highly effective intervention (Rosenwasser & Axelrod, 2001; Weiss, DelPizzo-Cheng, LaRue, & Sloman, 2010) and can decrease inappropriate behaviour, increase communication and teach appropriate social behaviour and learning. Although not as common, various interventions have been applied to cancer patients including behavioural interventions (Mundy et al., 2003), psychological interventions (Andersen, 1992), psychosocial interventions (Baum & Andersen, 2001), and exercise training interventions (Loughney, West, Kemp, Grocott, & Jack, 2018). Although not widely applied, there has also been significant progress made concerning the application of ABA to a broader range of socially significant behaviours including improving academic skills (Campbell & Anderson, 2011; Eckert, Ardoin, Daly, & Martens, 2002), health-related behaviours (Alessi, Petry, & Urso, 2008; Washington, Banna, & Gibson, 2014), and sport performance (Brobst & Ward, 2002; Harrison & Pyles, 2013). Moreover, there is potential to utilise ABA to improve health literacy and consequently decrease hospital mortality and morbidity rates (Lynch & Franklin, 2019). However, despite the existence of ABA research showing it's potential to improve various socially significant problems in a variety of populations, it is not currently widely utilised used in a medical/health setting. Given the psychological impact of breast cancer on patients and their families, there is potential for these techniques to be applied to breast cancer patients through psychoeducation.

Design

One type design often used in ABA is repeated measures, which is commonly used because of its emphasis on the behaviour of individuals (Baer, Wolf, & Risley, 1968). The repeated measures design requires fewer participants and less time to conduct an experiment compared to that of independent measures, or group designs (Verma, 2015). All subjects take part in the experiment and all participants serve as their own control. Repeated measures design typically use three to five subjects to investigate whether the implementation of an intervention leads to observable changes in a dependent variable over time (Janosky, Al-Shboul, & Pellitieri, 1995). Each participant comprises a comprehensive basis for reasonable conclusions, though without evidence of generality to other individuals (Johnston & Pennypacker, 2009). Information concerning generality comes from looking at the results of individuals together and by replication with individuals from other populations. The common purpose of repeated measures designs, such as reversal designs and multiple-baseline designs, is to demonstrate experimentally the extent to which the effects of manipulating aspects of the environment reliably result in behavioural change. Thus, this design controls factors that cause variability between participants, advises how participants respond to treatment, and allows for repeated measures at baseline and post-intervention. The success of the intervention could be determined through individual characteristics, therefore there is no need for group percentages (Butler, Sargisson, & Elliffe, 2011). It is beneficial for researchers to be aware of a repeated measures design as few participants are required to be recruited and the design can be a cost-effective and time adequate option, especially with small samples. Limited research has used a repeated measures design to investigate the effects of an intervention on well-being in breast cancer patients, however, in small numbers of breast cancer patients repeated measures designs have been shown to effectively demonstrate the effects of other health interventions, such as a Pilates intervention (Keays, Harris, Lucyshyn, & Maclntyre, 2008), an upper extremity resistance exercise programme (Sander, 2008), and cognitive-behavioural therapy (CBT) (Quesnel, Savard, Simard, Ivers, & Morin, 2003).

There is a small amount of studies which have used repeated measures designs in participants with other cancer types. A repeated measures AB design (two part design composed of “A” baseline and a “B” intervention phase) was used to evaluate an acceptance-based intervention for children and adolescents with cancer who were experiencing pain despite having received pharmacological intervention (Cederberg, Dahl, von Essen, & Ljungman, 2017). The acceptance-based intervention, which was delivered in addition to the standard pain management, involved a 15-minute pain exposure exercise comprising instructions on how to practice attentive focus, such as awareness of their cognitions, feelings, and bodily sensations, whilst simultaneously acknowledging the pain stimuli. The intervention was found to help all five of the participants to cope with the pain in the moment and to decrease discomfort of pain at follow-up. Three participants also reported decreased pain intensity. Gershon, Zimand, Lemos, Rothbaum, and Hodges (2003) investigated the use of virtual reality as a distractor to alleviate pain and anxiety in a pediatric cancer patient using an A-B-C-A repeated measures design. The design involved four consecutive appointments comparing no distraction (A), non-virtual reality distraction on a computer screen (B), and virtual reality distraction with a headset (C). The study found value for using virtual reality as a distractor during painful medical processes which was demonstrated by the decrease in pain and anxiety ratings, fewer identified behavioural indicators of distress, and reduced physiological arousal. The authors also proposed that following the virtual reality condition, benefits of decreased anxiety, pain and pulse rate were sustained even when the virtual reality was not in use. A further study used a repeated measures design (A_1BA_2), involving a baseline phase, an intervention phase and a back to baseline phase, to investigate the effectiveness of an internet intervention on nine patients with a diagnosis of prostate cancer (Kazer, Bailey Jr, Sanda, & Kelly, 2011). The study aimed to teach men how to reassess their perspectives on prostate cancer and provided tools for self-care management. They found trends that indicated a positive impact of the intervention on quality of life. These studies demonstrate the usefulness and potential of repeated measures design to assess the effectiveness of interventions in the cancer population.

The NZ Ministry of Health recognises that psychosocial support is an essential component of quality supportive cancer care and to aid in alleviating distress associated with cancer (Ministry of Health, 2010, 2017). As a result, the Ministry of Health funded the CPSSS (Esplin et al., 2018; Ministry of Health, 2017) which focuses on delivering emotional, social and psychological support to people and their families whose cancer has had a large impact on their life from early diagnosis through to the end of treatment. The service aims to improve consistency in regard to access and service delivery, with particular focus on patients with complex psychological and social needs related to their diagnosis, Māori and Pacific communities, remote and rural populations, and people with socio-economic disadvantage (Esplin et al., 2018). Although psychosocial support needs and services in NZ have not been greatly evaluated and assessed, a preliminary evaluation of the CPSSS service has found it to be vastly beneficial and valuable to patients and their families in regard to overall health and well-being and adherence to treatment (Esplin et al., 2018). Additionally, patients and their families have acknowledged the benefits of various psychological strategies which were provided to them by the service, such as the management of panic attacks, managing life during treatment, transport assistance, and income support.

The Cancer Society of New Zealand and New Zealand Guidelines Group suggest that cancer patients can experience enhanced quality of life and decreased distress when receiving adequate psychological, social and cultural support (Ministry of Health, 2017). In NZ, specific support and education groups, such as the Living Well (LW) programme and the Look Good Feel Better workshop, delivered by the Cancer Society, aid women affected by a breast cancer diagnosis. The Look Good Feel Better workshop has been shown to benefit women with low self-esteem and poor body image by increasing social interaction and self-image and diminishing anxiety (Taggart, Ozolins, Hardie, & Nyhof-Young, 2009). The LW programme is a psychoeducational-based group intervention also run by the Cancer Society in NZ. The LW programme is a design similar to the Cancer to Health Program which is a psychoeducational intervention designed in the early 2000s at Ohio State University for cancer patients. The Cancer to Health Program aimed to change patient behaviour; teach patients to become physically active, methods to reduce their distress and how to seek social support; strategies to improve well-being, quality of life, and mood; and ways to communicate with their treatment team (Ohio State University, 2018). Andersen et al. (2010)., who designed the programme, found that breast cancer patients who participated in the program had notably improved health, mood and immune responses, and a decreased risk of breast cancer recurrence. The LW programme is one of several established programmes offered by the Cancer Society approximately three to four times a year. The programme is administered at the Cancer Society Lodge in Hamilton, NZ, by specially trained liaison nurses with the addition of expert speakers from a variety of backgrounds and professions. The LW programme consists of two 4-5 hour sessions over a 2-week period (i.e. two sessions), and typically involves 15-35 participants. The aim of the LW programme is to assist women to cope with cancer-related treatment side-effects to improve their quality of life, well-being, body image, and self-esteem by providing them with adequate information regarding what to expect and how to manage their cancer journey. The sessions offer participants of any stage and type of cancer practical ways of living well, building knowledge, and provides tools to increase self-confidence and self-help skills.

Summary, Aim and Hypotheses for the Present Study

The present study aimed to assess the effects of the Living Well (LW) programme on the psychological well-being of breast cancer patients in the Waikato region. The study used a repeated measures design which involved baseline, intervention, and post-intervention phases (A_1BA_2).

Data was obtained via completion of the HADS questionnaire each week for four weeks before the intervention (the LW programme) began, two weeks during the intervention phase (which involved participants attending the LW programme), and four weeks post-intervention. Results were analysed by comparing the HADS scores collected during baseline, intervention and post-intervention phases. The HADS was administered to each participant at least nine times so that an overall understanding of the participant's psychological distress could be confidently obtained, and researchers could determine whether participation in the LW programme mitigated these feelings in any way.

It was hypothesised that the psychoeducational intervention (the LW programme) would improve well-being in breast cancer patients, as measured by a decrease in HADS scores post-intervention.

Chapter Two: Method

Subjects

Breast cancer patients referred to the Cancer Society between the 15th of May and the 20th of August 2019 were invited to participate in this study. Ethical approval for this study was obtained from the Human Research Ethics Committee (Health) of the University of Waikato under HREC(Health) 2019#43. Approval to recruit participants from the Cancer Society was also obtained from the Chief Executive from the Waikato Bay of Plenty Division of the Cancer Society.

The participants included six females, all with a diagnosis of breast cancer (mean age: 56 years; age range: 41-73 years) and all residing in the Waikato region. Participant characteristics are shown in Table 1.

Table 1

Demographic Profile of Participants

ID	Ethnicity	Locality	Stage	Referral	Marital status	Employment	Age
1	Other	Urban	Diagnosis	Self-referred	Married	Self-employed	58
2	NZE	Urban	Treatment	CNS	Married	Retired	73
3	Other	Rural	Treatment	CNS	Married	Unemployed	41
4	NZE	Urban	Post-treatment	BCC	Married	Full-time	56
5	NZE	Urban	Diagnosis	CNS	Married	Other	61
6	NZE	Urban	Treatment	CNS	Separated	Benefit	47

Note. NZE = New Zealand European; CNS = Cancer Nurse Specialist; BCC = Breast Care Centre

The Hospital Anxiety and Depression Scale (HADS) was administered each week by the researcher to each participant at an agreed upon location. However, the participants who were unable to meet the researcher directly during the baseline phase (weeks 1-4) completed the HADS form via a phone call each week. Whichever method was used during baseline was consistently used throughout the rest of the study for each participant. For example, if a participant initially completed the HADS in person, subsequent HADS scores were also collected in person (and likewise if via telephone).

In accordance with the Cancer Society protocol, the Living Well (LW) programme is presented in a format that meets the specific needs of the group of patients enrolled at one particular time. Table 2 shows the topics that were covered in the first session of the Hamilton LW programme and Table 3 shows the second session of the Hamilton LW programme.

Table 2

Hamilton Living Well Programme 2019- Session 1

Presenter	Topics
Cancer Society Nurse	Meet and Greet
Oncologist	A new normal; Understanding the cancer experience; What is cancer
Dietician	Eating healthy through your cancer journey
Physiotherapist	Lymphoedema and PINCnSteel
Supportive care nurse	Debunking myths
Cancer Society Nurse	Wrap up and evaluation

Note. PINCnSteel = PINC and Steel Cancer Rehabilitation Program

Table 3

Hamilton Living Well Programme 2019- Session 2

Presenter	Topics
Cancer Society Nurse	Meet and Greet
Employee from HQSC NZ	Advanced Care Plan
Counsellor	Cancer and uncertainty
Sport Waikato	Healthy movement and exercise
Clinical psychologist	Managing cancer related fatigue
Cancer Society Nurse	Wrap up and evaluation

Note. HQSC = Health Quality & Safety Commission

Materials

Demographic Questionnaire. Demographic information was obtained via a self-report form prior to the commencement of the study (see Appendix A). The information collected included age; gender; contact details of the participant; ethnicity; the area in which the participant resided in; date of cancer diagnosis; any previous cancer diagnosis; stage on the cancer continuum; date of referral to the Cancer Society and by whom; any previous psychological, psychiatric or counselling services since diagnosis; participation in any previous Cancer Society programmes; family support; marital status; employment status; accessed resources regarding cancer since diagnosis; and day and time that was suitable to be contacted by the researcher.

Participant information sheet. A Participant Information Sheet (see Appendix B) was provided to participants which explained: the purpose of the study, what participation in the study would involve, the possible benefits and risks of the study, each participant's rights and instructions on what to do if participants changed their mind and no longer wanted to participate in the study, and the contact information of the researcher, the researcher's supervisor and the cancer liaison nurse (from the Cancer Society).

Consent form. Participants were given two consent forms for the study. The consent form stated that the participant had been given the Participant Information Sheet, that they had been given the opportunity to ask any questions, and had been informed that they could withdraw at any time from the study. All participants signed one copy of the consent form, which was retained by the researcher (see Appendix C).

Confidentiality was ensured by assigning a study ID (1-6) to all participants. In addition, all data was stored electronically in password protected files on the University of Waikato servers. Data will be stored for 5 years, which is the standard University of Waikato data storage period. No information that could personally identify participants was used.

HADS. In addition to the demographic questionnaire completed at the start of the study, participants completed the HADS at several time points throughout the study. The HADS require each participant to evaluate and report on the severity of any anxious or depressive symptoms felt in the previous week. Responses to each item are quantified on a four-point Likert scale, ranging from 0 to 3. The scoring of each subscale can range from 0 to 21, with higher scores indicating higher levels of anxiety and depression (Zigmond & Snaith, 1983).The subscales for anxiety and depression are interpreted separately using the following ranges: normal (0-7), mild (8-10), moderate (11-14), and severe (15-21). For both the anxiety and depression subscale a score of 0 to 7 is classified as normal, a score of 8 to 10 suggests borderline depressive or anxiety disorder, and a score of 11 or higher is indicative of possible clinically significant levels of anxiety and depression according to recommended thresholds (Hopwood, Howell, & Maguire, 1991; Zigmond & Snaith, 1983).

The reliability and validity of the HADS has been established for cancer patients (Bidstrup et al., 2015; Moorey et al., 1991). It has good internal consistency (Cronbach's alpha 0.76-0.93 and 0.81-0.90 for the anxiety and depression subscales respectively, and 0.87 for the general scale) (Montazeri et al., 2003; Petersen & Quinlivan, 2002; Villoria & Lara, 2018), and test-retest reliability shows a high correlation, r>0.80, after up to 2 weeks, emphasising the stability of the HADS to withstand situational influences (Herrmann, 1997).

Possible confounding factors independent of participation in the intervention (LW programme) could impact upon participant's well-being and psychological distress and therefore influence results. Thus, for the purposes of this study, an additional question was provided at the end of the HADS for participants to complete to record these possible confounding variables. This additional question read as 'Have you had changes to your personal circumstances, such as changes to your financial situation, marital status, working conditions and/or social support (you do not need to answer this question if you do not feel comfortable doing so)? Y / N. If yes, please specify?' Yes/No responses were coded as 0=No, 1=Yes. This question was designed to record any additional changes, that may, or may not have been cancer-related, that the participant may have experienced that week which may subsequently have influenced or impacted on their HADS scores (e.g. confounding variables).

Scores on the HADS were considered the dependent variable and attendance at the LW programme was considered the independent variable. The effectiveness of the LW programme on participant's well-being was measured through administering the HADS to participants before the LW programme began (i.e., baseline), during the LW programme (i.e., during the intervention) and after the LW programme (i.e., post-intervention) had been completed and then analysing these scores across all phases (baseline, intervention and post-intervention).

Experimental design. A repeated measures design was used to assess the impact of the intervention (the LW programme) on specific individuals, rather than groups of individuals. Continuous assessment was utilised, where the behaviour of each participant was observed repeatedly over the duration of each phase of the study (baseline, intervention, post-intervention) so that the degree of variability in HADS scores could be determined in each phase and compared with any variability that was observed as the phases changed. The intervention was implemented after a fixed time period of three to four weeks (depending on when the participant began the study).

The repeated measures design involved a reversal design (A_1BA_2), which involved alternation of the baseline (A) and intervention (B) phase: three to four weeks of observation (baseline phase A_1) followed by two LW sessions (intervention phase B) and then another four weeks of observation (reversal phase A_2).

Procedure

In accordance with the Cancer Society protocol, when participants are referred to the Cancer Society via self-referrals, general practitioner (GP), cancer nurse specialist (CNS), and other medical professionals, they receive a home visit from a cancer liaison nurse. During the home visit, the cancer liaison nurse establishes rapport with each patient and advises their family/whanau of the services that the Cancer Society offers. For the purposes of this study, this initial visit was used as the point of patient recruitment, where the cancer liaison nurse identified and approached potential patients for participation in the study and likewise identified any extremely vulnerable patients who were consequently not approached for participation. Participants who were referred through the above pathways between the 15th of May and the 16th of August 2019, in addition to indicating interest in the LW programme and meeting the inclusion criteria (below) for participation in the study, were consequently assessed by the Cancer Society liaison nurse. The inclusion criteria for this study included: being over the age of 18 years old; being newly referred to the Cancer Society; having a stage 1 or 2 breast cancer diagnosis; not currently participating in other Cancer Society support groups or having previously attended the LW programme run by the Cancer Society.

Participants deemed suitable for the study based on the inclusion criteria (above) were informed that a study was being conducted by a masters' student from the School of Psychology at the University of Waikato. The Cancer Society liaison nurse asked each participant for consent to have their contact details passed on to the researcher (master's student) for further information regarding participation in the study. If those individuals who were approached were interested in participating in the study and gave consent for their details to be passed on to the researcher, they were given a Participant Information Sheet, consent form and demographic questionnaire form (which was completed at a later date with the researcher). The researcher then contacted each participant and arranged to meet them at an agreed upon location (except for one participant who requested to complete the Participant Information Sheet, consent form and demographic questionnaire form via a phone conversation due to their location). Meeting with each participant allowed the researcher the opportunity to establish rapport, explain the Participant Information Sheet, and ask the participant to complete the consent and demographic questionnaire forms. The researcher clearly outlined to participants that the decision to participate, or not participate, did not affect the level of care that they were due to receive from the Cancer Society or any other health professionals. The researcher arranged a weekly meeting with the participant at an agreed upon location and time in order to begin collection of baseline data each week using the HADS scale. However, if participants indicated that they were unable to meet directly with the researcher each week, the alternative process of the researcher calling the participant each week via the telephone and administering the HADS scale was suggested.

After consent had been received and prior to the commencement of the LW programme, baseline data was collected (in person or via a phone call) for at least three weeks. The intervention phase began once the collection of the baseline data was completed i.e., (3-4 baseline data points) and in accordance with the LW programme dates set by the Cancer Society (2nd of September and 9th of September). Each participant was asked to attend both sessions of the LW programme. The HADS form was administered each week after the LW session had finished in the same manner in which it was completed during the baseline phase (i.e., in person or via a phone call). As the LW programme consisted of two sessions, the HADS form was completed twice during this phase (after the first session and again after the second session).

After completion of the two-week LW programme, further HADS scores were collected at multiple timepoints, as per the baseline phase. To achieve this, participants were asked to complete the HADS form once a week for four weeks after the LW programme was completed. For consistency of data collection, the completion of the HADS forms occurred in the same manner as the baseline and intervention phases of the study. At least nine HADS forms were completed by each participant.

Data from baseline, intervention, and post-intervention were graphed for all participants and visually assessed for changes in HADS scores during baseline, intervention and post-intervention. Mean anxiety and depression scores from the HADS were also calculated for baseline, intervention and post-intervention and graphed. Visual analysis was used to determine the effectiveness of the LW programme and whether attendance had altered the participants pre-intervention HADS scores.

Chapter Three: Results

Results for each participant were collected during baseline (week 1 to week 4), intervention (week 5 and week 6) and post-intervention (week 7 to week 10) phases (see Figures 1-6). The solid vertical line in the graph indicates condition changes between the baseline and intervention phases and the intervention and post-intervention phases. The dotted line with circles represents the depression scores and the solid line with squares represents the anxiety scores.

For participant 1 (see Figure 1) depression scores remained low and stable in the range of 1 to 2 during both baseline and post-intervention. During the intervention phase, there was an increase in week 6 to a score of 4. However, all of these scores fell within the "normal" range for depression. Across all phases, anxiety scores were higher than depression scores. Apart from week 1, scores during baseline were fairly stable and largely within the "normal" range for anxiety. Anxiety scores in the intervention phase increased from the "borderline abnormal" range to the "abnormal" range. During the post-intervention phase, anxiety scores were variable ranging between 7 and 14 ("normal- "abnormal").

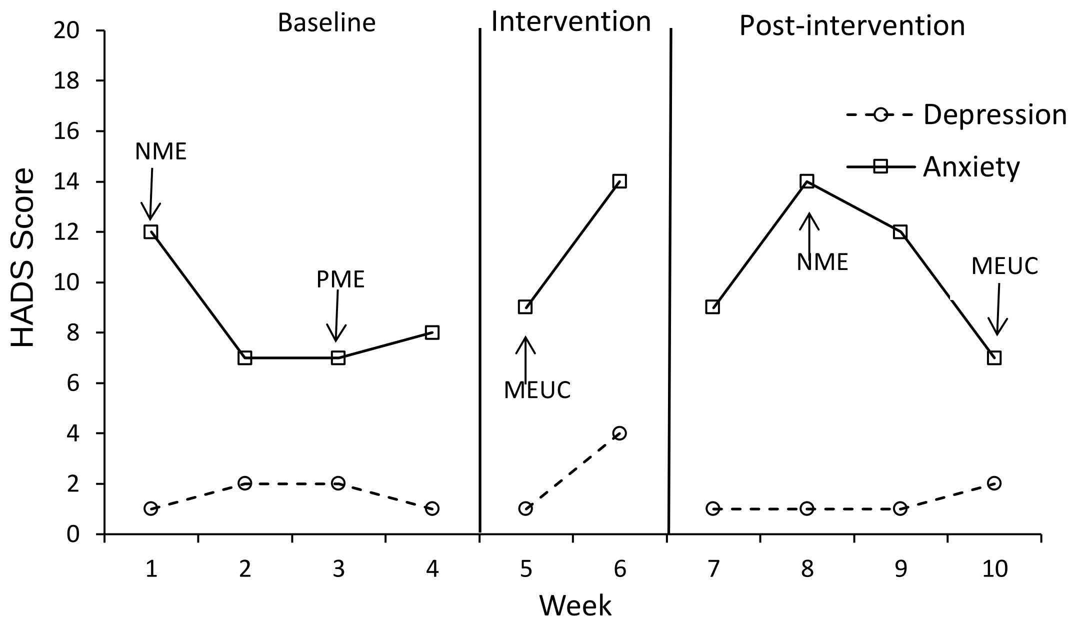

Figure 1. HADS scores for participant 1 during each phase

PME=positive cancer-related medical events; NME= negative cancer-related medical events; MEUC= medical events unrelated to cancer

The depression scores for participant 2 (see Figure 2) remained low during baseline ranging between 1 to 7 (“normal”) except during week 2 where there was increase to 9 (“borderline abnormal”). During the intervention and post-intervention phase, depression scores remained low and within the “normal” range. Anxiety scores were higher than depression scores and ranged between 8 to 11 (“borderline abnormal” – “abnormal”) during baseline, intervention and post-intervention phases except during week 2 of the baseline phase where the anxiety score increased to 17 (“abnormal”).

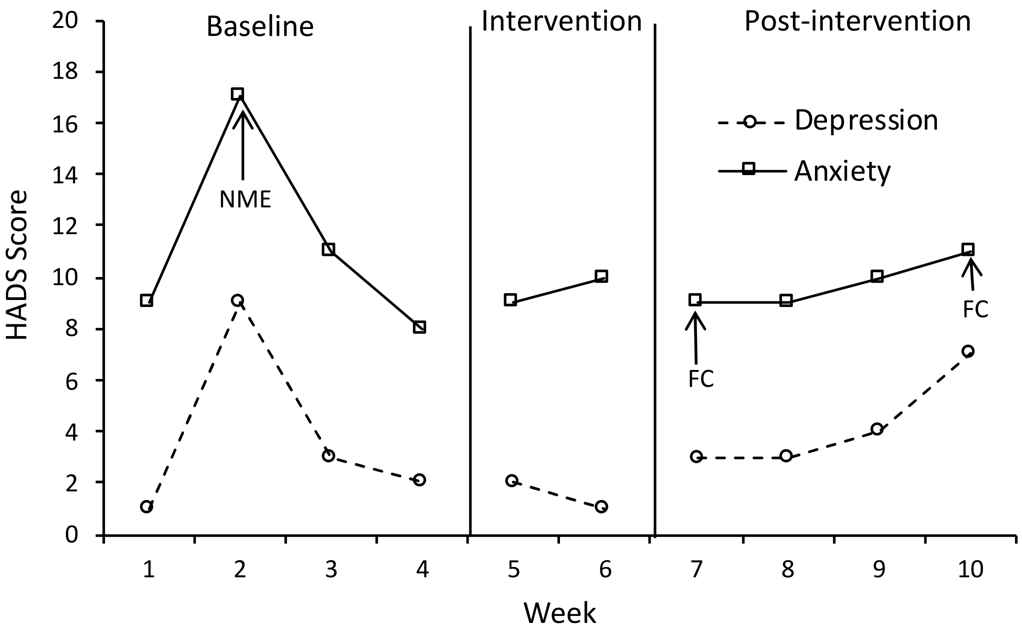

Figure 2. HADS scores for participant 2 during each phase

NME= negative cancer-related medical events; FC= family related changes

Participant 3 (see Figure 3) did not complete the HADS during week 2. Depression scores remained low and stable ranging between 0 to 3 ("normal") across all phases. Anxiety scores also remained stable and low ranging between 0 to 5 ("normal") across baseline, intervention, and post-intervention.

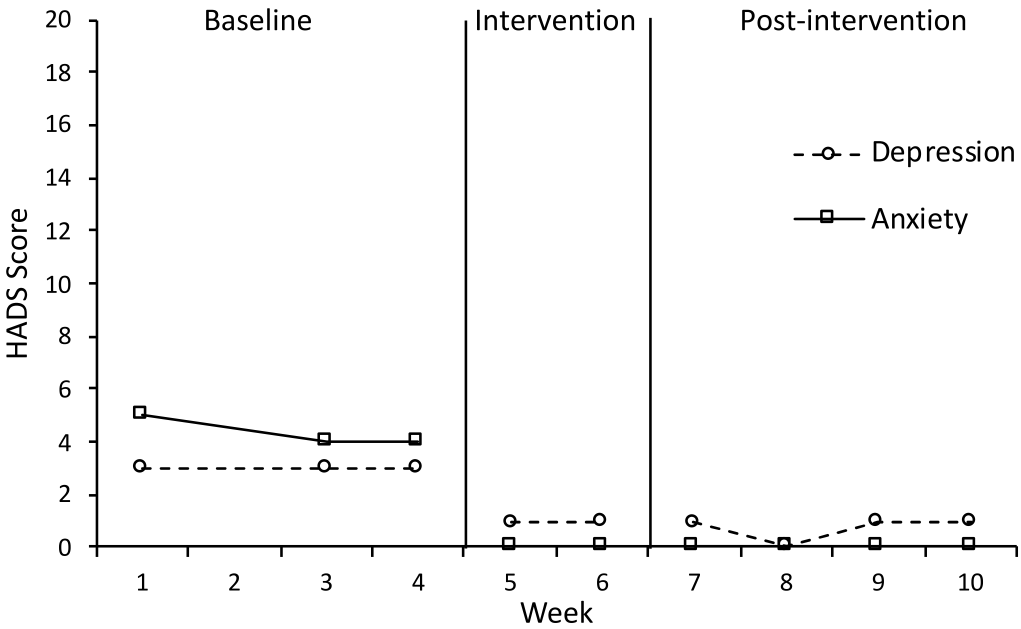

Figure 3. HADS scores for participant 3 during each phase

For participant 4 (see Figure 4) depression scores were relatively low with a slight decreasing trend to week 4 during baseline (“normal”). Scores remained low and in the “normal” range during intervention and post-intervention, except for week 8 where the score increased to 8 (“borderline abnormal”). Anxiety scores were initially higher than depression scores during baseline, ranging between 13 to 5 (“abnormal”- “normal”). Anxiety scores decreased to the “normal” range during intervention and post-intervention, however there was a slight increase in scores during the last weeks of post-intervention.

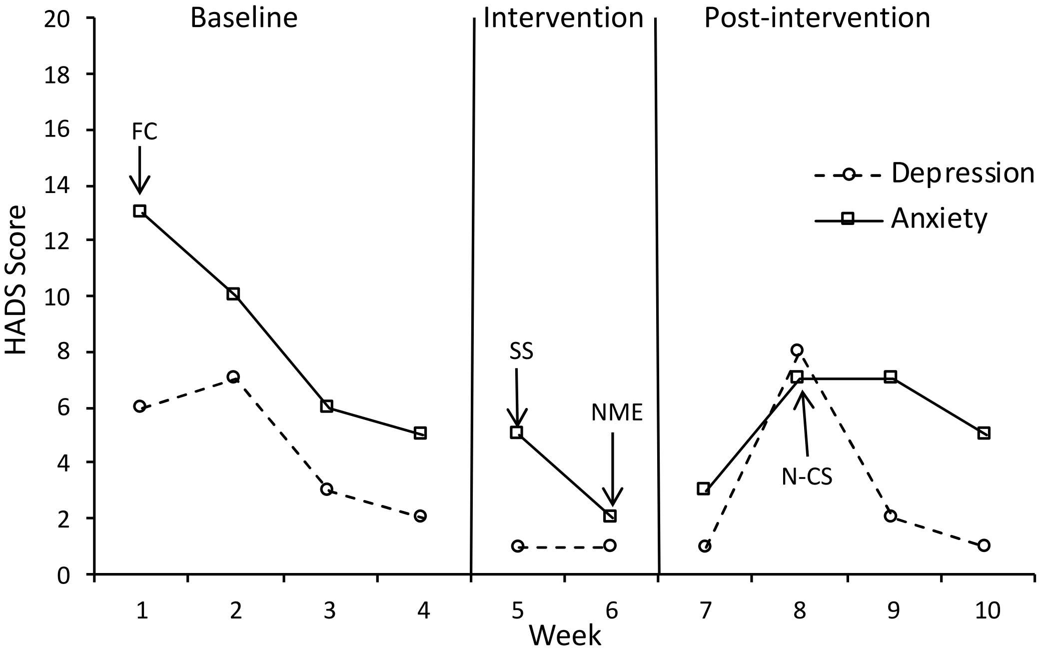

Figure 4. HADS scores for participant 4 during each phase

NME= negative cancer-related medical events; FC= family related changes; N-CS= non-cancer related stress; SS= changes to social support

Participant 5 (see Figure 5) did not complete the HADS in week 1. Depression scores were slightly variable and low in baseline remaining in the "normal" range (0-7) then increased to 13 ("abnormal") before decreasing back to 5 ("normal") in the intervention phase. Post-intervention depression scores were stable, ranging from "normal" to "borderline abnormal". Anxiety scores were higher than depression scores ranging between 10 to 19 ("borderline abnormal" – "abnormal") across all phases. There was a decreasing trend during baseline, then in intervention and post-intervention anxiety scores were slightly variable and higher ("abnormal") than scores in baseline.

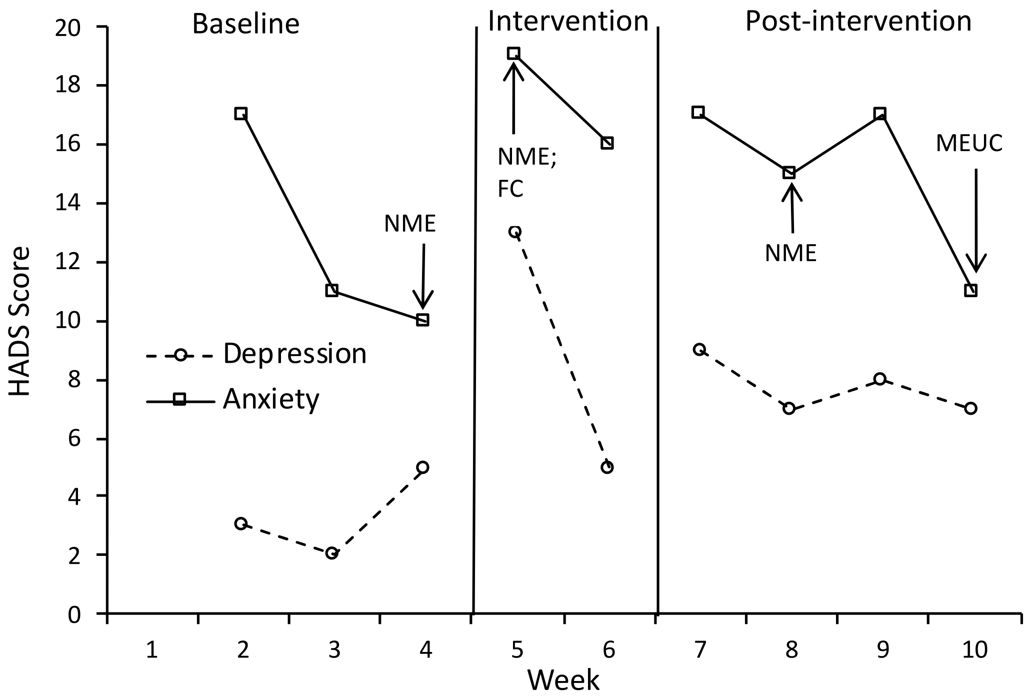

Figure 5. HADS scores for participant 5 during each phase

NME= negative cancer-related medical events; FC= family related changes; MEUC= medical events unrelated to cancer

Depression scores for participant 6 (see Figure 6) started high (12) in week 1 but then remained relatively stable and ranged between 5 to 9 (“normal”- “borderline abnormal”) for all remaining phases. Scores for anxiety were again higher than depression scores across baseline, intervention and post-intervention phases. Anxiety scores decreased during baseline in week 4 (“abnormal”), and after a slight increase in week 5 a further decrease occurred in week 6 of the intervention phase to the “borderline abnormal” range. Scores for anxiety increased then decreased again during post-intervention, but were still generally lower than baseline levels.

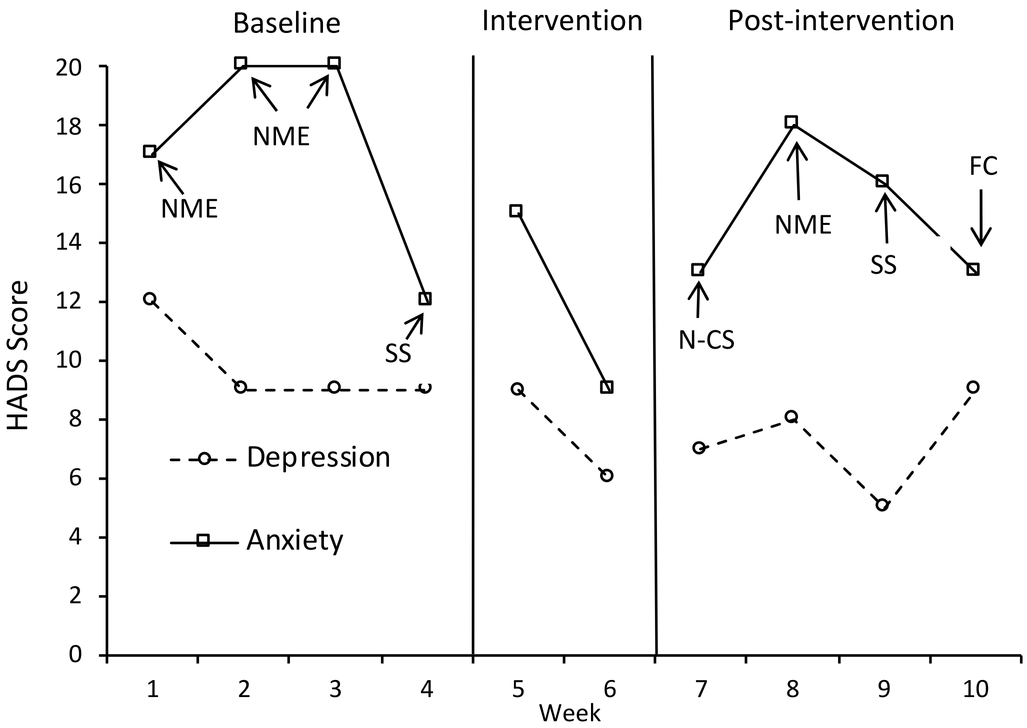

Figure 6. HADS scores for participant 6 during each phase

NME= negative cancer-related medical events; FC= family related changes; N-CS= non-cancer related stress; SS=changes to social support

Figure 7 shows the mean HADS scores for depression and anxiety across all study phases (baseline, intervention, and post-intervention) for the six participants. Across all phases, mean depression scores were lower than anxiety scores and were within the “normal” range. During baseline mean anxiety scores were higher than the intervention and post-intervention phases and within the “borderline abnormal” range. During the intervention and post-intervention phases the mean anxiety scores were similar and also remained within the “borderline abnormal” range. Due to the small sample size (n= 6) and the minimal differences in anxiety and depressions scores among phases therefore no statistical tests were run.

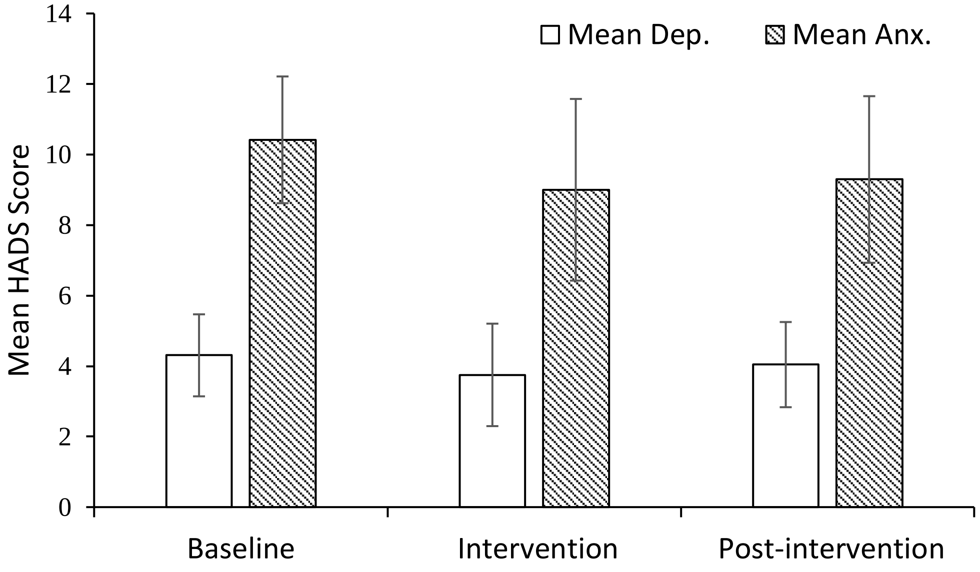

Figure 7. Mean HADS scores for depression and anxiety across all study phases for the six participants. The error bars represent standard error of the mean.

An additional question was included at the bottom of the HADS form. This question asked ‘have you had changes to your personal circumstances, such as changes to your financial situation, marital status, working conditions and/or social support?’ Participants could respond by indicating Yes or No, and then expand if they selected Yes. This data was analysed and several main themes were identified. The most common theme was negative cancer-related medical events, with 83% of participants reporting events that negatively impacted on them that week, such as treatment decisions and side effects. Negative cancer-related medical events were followed by family-related changes (67%) such as additional family members being diagnosed with cancer, death of an immediate family member or marital issues. Other reasons for changes in participant’s circumstances included non-cancer related stress (33%) which comprised financial issues and stress at work; medical events unrelated to the participant’s breast cancer (33%); and changes to social support (33%) which included joining various social groups such as walking and yoga, cancer support groups, partaking in hobbies, and receiving psychological support. Seventeen percent of participants reported positive cancer-related medical events such as negative biopsy results. One participant responded that they were impacted by personal changes, however, this participant did not elaborate what these changes were.

Chapter Four: Discussion

The current study evaluated the effectiveness of a psychoeducational-based group intervention (the LW programme) on the psychological well-being of women diagnosed with early stage breast cancer patients in the Waikato region. It was expected that attending the LW programme would help inform participants about their cancer, diagnosis and treatment and would therefore reduce anxiety and depression scores as measured by the HADS.

The intervention in this study did not have a consistent systematic influence on the HADS scores for all participants as indicated by the lack of a systematic and clinically significant decrease in the scores corresponding with the treatment. Mean depression scores across all phases (baseline, intervention, and post-intervention) were lower than anxiety scores for all participants and remained within the normal range (0-7), whilst mean anxiety scores, which were higher in baseline than intervention and post-intervention, remained in the borderline abnormal range (8-10) across all phases. Individual depression and anxiety scores were variable across all phases, thus there was no clear evidence that the LW programme was effective in improving well-being in the breast cancer patients who attended.

The current study found no consistent systematic effect on well-being from attending the LW programme. Psychoeducational-based interventions tend to be most beneficial to cancer patients who have relatively few psychosocial coping resources, such as lack of support, lack of informational support from a medical team, or few personal resources (i.e., low perceived control, low self-esteem) (Helgeson et al., 2000). The level of support from family and friends can moderate the effectiveness of a psychoeducational-based intervention (Cipolletta et al., 2019; Helgeson et al., 2000). All participants in the current study reported a high level of social support, such as family and friends, which may explain why no changes were seen as a result of attending the LW programme. However, three participants did report a benefit of the programme in that it provided additional avenues for social support, such as yoga and walking groups. Cipolletta et al. (2019) also reported that their psychoeducational intervention was associated with improvements in interpersonal relationships and introduced various opportunities for increasing social support.

HADS scores did not differ significantly between phases in the current study, suggesting that there was no effect of the intervention on the well-being of the six participants who participated in the programme. Maeda et al. (2008) also found over a three-session psychoeducational intervention, that their intervention was not effective for all fourteen participants, as indicated by HADS scores not differing between baseline, intervention, and post-intervention phases. Additionally, no consistent systematic effect on well-being over 6 months was identified. Andreis et al. (2018) also found no significant effect of a psychoeducational intervention on anxiety, however, there was a statistical difference and therefore improvement in depression scores between baseline and post-intervention. Chujo et al. (2005) studied the effects of a psychoeducational group intervention in women with recurrent breast cancer and found that although there were lower mean anxiety and depression scores after the intervention these were insignificant. The authors do suggest that these insignificant results may be due to the small sample (n=39).

In contrast, Ram et al. (2013) and Al-Sulaiman et al. (2018) found that psychoeducational-based interventions improved well-being in breast cancer patients. These studies differed from the current study as they used different measures (WHO-5 Wellbeing Index and Depression, Anxiety and Stress Scale 21 item version (DASS-21) respectively) and the intervention phase of their studies was conducted over a much longer time period (4 weeks and 12 weeks respectively). Furthermore, Doulbeaut et al. (2009) found a significant reduction in anxiety and a reduction in depression in breast cancer patients after an 8-week psychoeducational intervention consisting of two-hour sessions. All participants in the current study only participated in a 2-week intervention (over 2 days) with a follow-up duration of 4-weeks, which may explain the differences seen. Additional differences between the study by Doulbeaut et al. (2009) and the current study were the different measures used and the intervention in the study by Doulbeaut et al. (2009) being based on cognitive behavioural therapy principles.

Participants in the current study had consistently higher mean anxiety scores compared to depression before, during and post intervention. Consistent with the current findings, Maeda et al. (2008) and Andreis et al. (2018) also found anxiety scores measured by the HADS were higher than those of depression in early stage breast cancer patients. Anxiety typically affects between 20% to 50% of women diagnosed with breast cancer, and is more common than depression (Abu-Helalah et al., 2014; Bottomley, 1997; Dastan & Buzlu, 2011; Lim et al., 2011; Payne et al., 1999; Yi & Syrjala, 2017). Young age, having low social support and having a low income are risk factors of increased anxiety. In the current study, two participants were under the age of 50 years. Participant 6 (47 years) had higher levels of anxiety than depression and their anxiety levels were relatively higher (in the abnormal range) compared to all of the other participants. This finding is consistent with other research which has found that younger women with breast cancer commonly experience more psychological distress (Al-Sulaiman et al., 2018; Peled et al., 2008), are at increased risk of reporting high anxiety (Doulbeaut et al., 2009), depression (Davis et al., 2018), and are more likely to have a decreased quality of life and increased symptom burden than older women (Hamer et al., 2017).

All participants in the current study reported having good levels of social support, so the high anxiety scores seen cannot be attributed to a deficit in this area. Maeda et al. (2008) also reported that participants who reported high levels of support demonstrated less distress, noting that social support may have resulted in better adaptive coping and psychological state. Al-Sulaiman et al. (2018) also found that significant improvements in patient’s anxiety, depression and stress scores and their well-being could be attributed to social support levels. A systematic review and meta-analysis on the effectiveness of psychoeducational interventions, with breast cancer patients found that increased support from family can improve well-being (Matthews, Grunfeld, & Turner, 2017). In the current study one participant (participant 6), who had the highest anxiety scores, was separated and going through a divorce at the time of the study, which likely contributed to her anxiety level, as divorce is a significant life stressor (Sbarra, Hasselmo, & Nojopranoto, 2012). Additionally, three participants reported financial issues (participant 6, who had the highest levels of anxiety compared to the other participants, and participants 2 and 3). These participants were not currently in paid employment and typically had higher anxiety scores compared to their depression scores. Al-Sulaiman et al. (2018) also found that patients who reported financial difficulties tended to have high depression, anxiety and stress scores.

In the current study participant 6 reported having physical symptoms (such as difficulty breathing and heart palpitations) during baseline, which led them to worry about cancer progression. Participant 4 reported feeling fatigue which consequently led them to worry about cancer recurrence. Experiencing fatigue and psychological stressors, such as fear concerning spread of disease, treatment-related anxiety and misinterpretation of neutral physical symptoms as progression or recurrence of disease is common and can exacerbate anxiety and anxious preoccupation (Baucom et al., 2006; Henselmans et al., 2010; Institute of Medicine and National Research Council, 2004; Lasry & Margolese, 1992; Lee-Jones, Humphris, Dixon, & Hatcher, 1997; Reich et al., 2008; Spiegel, 1997; Villar et al., 2017). Women diagnosed with breast cancer are also faced with a number of treatment decisions which can be associated with anxiety levels. Participant 6 reported having concerns regarding having a mastectomy without reconstruction. She felt that this decision was out of her hands and was worried about the cosmetic outcome of surgery, which resulted in her seeking psychological support. The week that participant 6 was informed that she required a mastectomy was the same week where her highest anxiety score on the HADS was recorded. Mastectomy is an invasive procedure which is related to body image concerns and decisions on whether to have reconstruction and can cause worry and anxiety (Dicks et al., 2019). Certain breast cancer treatment can be traumatic and significantly affect body image (Vahdaninia et al., 2010; Villar et al., 2017), sexuality, attractiveness and femininity (Reich et al., 2008), which consequently exacerbates anxiety. For some societies, the female breast is regarded as a symbol of intrinsic femininity, maternal pleasure and sexual desire, and are fundamental to the image of what many people consider “being a woman”. Thus, given the significance society places on female breasts, any alterations or surgery may make woman feel less attractive, adversely affecting their self-esteem, confidence and sexuality. Participant 1 reported feeling anxious leading up to her surgery, largely due to it being her first ever surgery (week 1 on Figure 1). This was reflected by her high anxiety score during the week of her surgery. Participant 5 was more anxious after learning that she required additional surgery due to cancer progression, which was also reflected in her high anxiety score at that time (week 5 on Figure 5). During this week, the participant’s anxiety and depression scores were the highest scores that the participant reported throughout the study. Villar et al. (2017) found that women are relieved, tend to be less anxious and appear to have a more positive outlook on the future once adjuvant treatments have been completed.

Although there is only limited research on psychoeducational interventions, they have been found to be helpful for breast cancer patients (Neises, 2008; Yavuzsen et al., 2012). In the current study, participant 6 reported that the group format provided them with “more avenues for social support and consequently joined a walking group and yoga”, and the programme had been beneficial and had allowed them the opportunity to meet others on “similar cancer journeys”. Cipolletta et al. (2019) also found that participants reported that the group format of the intervention provided them the opportunity to develop new social relationships which alleviated the sense of loneliness and isolation. Group formatted interventions can provide opportunities for effective support concerning the impact of cancer; increase of personal resources; provide a safe space for the expression of emotion; and the sharing and exchange of experiences, emotions and information regarding the illness and everyday life (Cameron et al., 2007; Ussher, Kirsten, Butow, and Sandoval, 2008). Cipolletta et al. (2019) found that the group structure of the psychoeducational intervention was useful for breast cancer patients by providing a network which allowed participants the opportunity to exchange knowledge regarding cancer, accept changes, develop new social ties, and be less dependent on medical staff.

In the current study however, participant’s 1 and 6 decided not to attend two workshops (Advance Care Plan and Cancer and Uncertainty), which were in the second session of the LW programme. Both participants reported that they did not want to be surrounded with others who had cancer or who were medically worse than they were, nor did they want the LW programme to be detrimental to their current positive outlook. Furthermore, after the completion of the LW programme participant 1 reported that they felt “down and depressed” due to too much confrontation of seeing others who were in similar situations or more unwell than they were. In contrast, Cipolletta et al. (2019) reported that a group situation is not intended to be depressive but rather a space where the expression of anxiety and worries is encouraged and by listening to other participant’s experiences patients can improve and develop their coping strategies and discover prospects for improvement. Furthermore, the authors note that the group psychoeducational intervention endorsed altruism, which is a critical experience as it allows members to identify with each other and possibly feel useful to other members who are suffering in a similar manner.

Other research suggests that there can be difficulties with the group aspect of psychoeducational interventions, and that they are often recognised by patients as only necessary for those who are in substantial need or distress (Ussher et al., 2008). In a qualitative analysis investigating reasons for attending or not attending group interventions and support groups, it was found that group formats were commonly identified by cancer patients as negative places surrounded by sick people where negative stories were exchanged, other people's issues would become a burden, and death would be discussed, thus having a detrimental effect on patient's well-being and influencing them to avoid the group (Ussher et al., 2008). Helgeson et al. (2000) state that members participating in group interventions may not always behave in supportive ways and group situations can make participants feel uncomfortable. Breast cancer patients have reported being distressed by making social comparisons in group situations, such as feeling anxious about one's own illness when faced with someone worse-off (Helgeson et al., 2001). However, this did not appear to be a factor for Al-Sulaiman et al. (2018), Cipolletta et al. (2019), Doulbeaut et al. (2009), or Maeda et al. (2008). Thus, the variable results in the current study suggest that group interventions, including psychoeducational interventions, may not always be advantageous or the most suitable means of support and education for every individual due to individual differences. Therefore, it is critical that cancer patients and their support systems are made aware of alternative avenues of support and education, such as CPSSS and individual counselling, and attention should be given to exposing the positive experiences that can occur within group interventions in order to challenge common misunderstandings.

Strengths and Limitations

The current study used a repeated measures design which involved multiple measurements. Participants were exposed to all treatment conditions (the LW programme).

With participants being effectively compared against themselves, there is no risk of individual differences impacting the results.

A major limitation of the current study was that repeated measurement in a baseline will not control for history effects that appear between the last baseline measurement and the first intervention measurement (Engel & Schutt, 2008). The longer the duration between the two measurement points, the more likely it is that an event may influence the participant's scores threatening validity. Thus, a multiple baseline design would have been ideal to control for history effects. In a multiple baseline design the time that the intervention starts is staggered across participants, each change from baseline to treatments is a chance to observe the effects of the intervention, thus making this change at various times allows the researcher to disregard alternative explanations for any behaviour change that occurs during treatment (Morgan & Morgan, 2009). Therefore, if a participant's behaviour is stable during baseline and changes only when the intervention occurs, it can be confidently concluded that the change occurred from the treatment and not from some uncontrolled variable. As the LW programme is a group intervention and due to time and practical constraints the programme could not realistically be offered multiple times in close succession by the Cancer Society, thus all participants were exposed to the LW programme at the same time.

The short time frame of the LW programme as well as additional confounding variables (significant personal events participants were experiencing) were unable to be controlled for and so may have influenced the results of the study. The fact that some participants completed the HADS via telephone and other participants completed the HADS face-to-face with the researcher may have impacted the results in that some participants who answered face-to-face may have provided answers that they deemed socially desirable or may have been less open. Moreover, the sole measure (the HADS) utilised in this study relied on a self-report format which may have been subject to socially desirable responses leading to lower scores. Other limitations include the homogenous characteristics of participants. Participants were a similar ethnicity, predominantly NZ European, thus, unfortunately there was no representation of participants who identified as Māori or Pacific Peoples. However, ethnicity was not intended as the chosen focus for the current study. The needs of minority populations have rarely been investigated, particularly in NZ, thus, it would be of interest to extend this study to investigate the impact of psychosocial cancer-related distress on different ethnic groups, other populations such as men, and participants under the age of 40. Studying other cancer types and later stage cancers is also important to gain a broader understanding of the LW programme and the support in NZ of diverse groups affected by cancer. Given the limitations imposed by the small sample size, it would be beneficial to develop a larger quantitative study which could potentially add to the literature by creating a multi-location study capable of obtaining larger numbers of participants.

Psychoeducational interventions which are brief in session and duration can still have a substantial impact on a variety of patient variables such as quality of life and well-being. Although what constitutes ‘brief psychoeducation’ can differ, a systematic review found that the median length of psychoeducation is typically 12 weeks (Xia, Merinder, & Belgamwar, 2011). A study by Scheier et al. (2005) was successful in enhancing physical and psychological functioning among breast cancer patients in only four psychoeducation sessions for a duration of two hours each. There is evidence to suggest that moderately short, but intensive, interventions, delivered by experienced and trained professionals are more effective than more prolonged and drawn out interventions or interventions offered by staff that are not adequately trained (Sheard & Maguire, 1999). However, more sessions of the LW programme would allow for more data, allow for a greater number of participant concerns to be addressed, and may produce greater changes in anxiety and depression scores. The current study only followed participants over a short period of 4-weeks after the intervention, thus little is known about participant’s well-being over the longer term. Although short-lived effects of psychoeducational interventions are critical, specifically if they occur during times of marked distress, it would be of interest to administer a 6-month and 3-year follow-up post the LW programme to further investigate participant’s well-being. Additionally, the one-week interval between the first session of the LW programme and the second session of the LW programme may have been too short for participants to take in the information delivered at the first LW session, feel more informed and comfortable, and for anxiety and depression to reduce. Thus, future research could obtain data over a longer course of time post-intervention and the second session of the LW programme could be delivered after a longer interval. It should also be noted that not all participants attended the full two day LW programme. Two participants did not attend two of the workshops on the second session of the LW programme which may have consequently impacted results as there was less data (HADS scores) collected. Furthermore, the LW programme was not designed for a specific cancer type, therefore participants in the current study may have been better suited to a programme specifically designed for breast cancer patients and their concerns. It is unknown whether the breast cancer intervention (Look Good Feel Better) was advertised to the participants in the current study.

Not all psychoeducation content is the same, therefore, developing an effective psychoeducation programme can be challenging. Furthermore, the differences in outcomes between studies could be due to differences in specific components of the psychoeducational programmes that are utilised. A component analysis, which is a systematic analysis of independent variables that comprise a treatment/intervention (Baer et al., 1968; Cooper, Heron, & Heward, 2007), can enhance the effectiveness of behavioural interventions and allow for the identification of active and necessary components in an intervention and the relative contributions of various variables in an intervention which are responsible for behaviour change (Ward-Horner & Sturmey, 2010). The component analysis involves repeated measures design with the components being systematically introduced and/or withdrawn, in addition to the replication of effects within and/or between subjects (Dallery, Riley, & Nahum-Shani, 2015). A component analysis was not conducted with the LW programme but would have likely been beneficial and helped to improve the overall effectiveness of the LW programme.

Implications

The findings in this study have practical applications for organisations such as the Cancer Society and can be used to inform such organisations of the effectiveness of intervention based programmes. While no clear effect of attending the LW programme was demonstrated, there is still a clear need to address psychosocial distress concerning a breast cancer diagnosis. Interventions may be more effective if they involve more sessions and patients need to be informed regarding other avenues for psychosocial cancer-related support such as the free service provided by the CPSSS which caters to a more individual rather than group format.

Conclusion

The aim of the current study was to assess the effects of the LW programme on the psychological well-being of early stage breast cancer patients in the Waikato region. No effect of attending the LW programme was found for this group of participants, as demonstrated by no consistent decrease in HADS scores during and post attending the programme. Across all phases of the study, mean depression scores were lower than mean anxiety scores. Mean anxiety scores were only slightly higher in baseline compared with mean anxiety scores during the intervention and post-intervention. The results of this study suggest that the LW programme had no consistent effect on well-being for this group of participants, however, psychosocial distress in the breast cancer patients recruited for the study was evident, and reflected in the HADS scores obtained. There is a need for psychosocial interventions to address the psychosocial needs of cancer patients, and to provide information to better inform, help develop improved coping strategies, and develop new avenues of social support. While limitations impacted the findings of this study, the results contribute to future research regarding the psychological support of breast cancer patients and their families in NZ. Continuing research is needed to support the psychological health of patients struggling with a breast cancer diagnosis.

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Appendix A

Participant Questionnaire:

Name:

Address:

Contact phone number:

Email address:

Gender (circle one):

Female Male

Date of birth:

What area do you live in (circle one):

Urban Rural

Ethnicity (circle one):

New Zealand European Maori Samoan Cook Island Maori

Tongan Chinese Indian Other (please specify):

Date of cancer diagnosis:

Have you had a previous cancer diagnosis? (circle one):

Yes No

If yes, are you able to provide details of the type and stage:

Stage on cancer continuum (circle one):

Diagnosis Treatment Post-Treatment Recurrence

Date of referral to the Cancer Society:

Who referred you to the Cancer Society (circle one):

General Practitioner (GP) Cancer Nurse Specialist (CNS)

Self-Referred Other (please specify):

Have you ever received psychological, psychiatric or counselling services since your diagnosis? (circle one):

Yes No

Have you participated in any previous Cancer Society groups/programs? (circle one):

Yes No

If Yes, please specify the below:

Name of Programme(s):

Dates of Programme:

Location (city):

Do you have family/social support? (circle one):

Yes No

Marital status (circle one):

Single	Married, in a Civil Union, or in a De Facto Relationship	
Divorced	Separated	Other:

Employment status (circle one):

Full-time employed	Part-time employed	On leave but still employed
Unemployed	Unemployed and looking for work	Studying
Retired	Other:	

What, if any, resources have you accessed in regard to your cancer since diagnosis (circle one):

Internet	Social Media (i.e. Facebook)
Pamphlets	Other (please specify):

Are you able to meet the researcher once a week for 4-6 weeks BEFORE and AFTER the Living Well Programme to complete a questionnaire (circle one)?

Yes No

If yes, please circle what day and time, and specify what location (e.g., café, your house) would be suitable?

Monday Tuesday Wednesday Thursday Friday Saturday Sunday

Morning (between 9-12) Afternoon (1-4) Night (6-8)

Location:

If no, what day and time would be suitable for the researcher to contact you each week via phone to complete the questionnaire? (circle one):

Monday Tuesday Wednesday Thursday Friday Saturday Sunday

Morning (between 9-12) Afternoon (1-4) Night (6-8)

Any additional information that you think may be useful to the researchers:

Appendix B

Participant Information Sheet

Study title: Evaluating the effectiveness of an Education Group Intervention on the psychological wellbeing of breast cancer patients

Lead investigator: Brittany Ryan, University of Waikato

You are invited to take part in a study where we are planning to evaluate the effectiveness of an education-based intervention on your psychological wellbeing. This project will be conducted by a master's student from the School of Psychology at the University of Waikato. Whether or not you take part is voluntary. If you do not wish to take part, you do not have to give a reason. If you do want to take part now, but change your mind later, you can withdraw from the study at any time. Please read this information sheet carefully before deciding whether you wish to participate.

This **Participant Information Sheet** will help you decide if you would like to take part. It explains why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends.
If you consent to participating we will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Please feel free to do this.

If you agree to take part in this study, you will be asked to sign the **Consent Form** on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is nine pages long, including the Consent Form and a Patient Questionnaire sheet. Please make sure you have read and understood all the pages.

What is the purpose of the study?

Providing education and social supports to people affected by cancer can improve mood and psychological wellbeing. Little is known about the impact of education approaches on the psychological wellbeing of cancer patients, particularly in New Zealand Therefore, the primary aim of this study is to evaluate the effectiveness of an education-based intervention on the psychological wellbeing of breast cancer patients. We are aiming to recruit between 4-12 people for the study, and the outcomes of this study will help us to better understand the effects of an education-based intervention on the psychological wellbeing of people diagnosed with breast cancer in New Zealand.

What will my participation in the study involve?

To participate in this study, you must be over the age of 18 years, have been recently referred/self-referred to the Cancer Society of New Zealand, diagnosed with stage 1 or 2 breast cancer, and not have previously attended the Living Well Programme run by the Cancer Society. You should also not currently be involved in any other Cancer Society support group.

You will have been referred to the Cancer Society and as per their protocol will have received a home visit by a Cancer Society nurse. During this visit, if you consented to your contact details being passed on to the master's student, you would have received this patient information sheet and consent form. As you have consented to your contact details being passed on to the researcher you will consequently receive a phone call from the researcher to arrange a face-to-face meeting where you will receive additional information regarding the study, have time to ask any questions you may have and the researcher will go over this patient information sheet and the consent form more thoroughly with you. You are welcome to have support people at this meeting with the researcher if you choose. It is important for you to note that whether you to decide to participate in this study or not, the level of care that you receive from the Cancer Society or any other health professional will not be affected.

If you agree to participate, the researcher will arrange with you a weekly meeting at an agreed upon location and time where you will be asked to complete one questionnaire each week. This will occur for 4-6 weeks BEFORE the Living Well Programme begins. This questionnaire will take 5-10 minutes to complete.

After the 4-6 weeks of completing the questionnaires, you will be invited to participate in the Living Well Programme. This consists of **two** 4-5 hour education sessions occurring over a two 2 week period (i.e. 5 hour session one week and another 5 hour session the following week. The two-day programme offers practical ways of living well, building knowledge, self-confidence, and self-help skills to cancer patients of any stage and type. The programme will be run by specially trained liaison nurses with expert speakers from a variety of backgrounds and professions. Topics included in the programme will cover understanding cancer, managing the side-effects of cancer treatment, nutrition, self-care, relaxation and stress management, and communication. The Living Well Programme will take place at the Cancer Society Lodge, situated in central Hamilton with plenty of parking available. After both sessions, you will be asked to please complete the same questionnaire (which you completed for 4-6 weeks previously).

After the Living Well Programme has finished, we would appreciate if you would meet the researcher each week at the same location (that you meet the researcher before the programme) for another 4-6 weeks where you will complete the same questionnaire (taking 5-10 minutes to complete). Thus, you will be asked to complete the questionnaire a total of 10-12 times throughout the study.

However, if you are unable to meet with the researcher each week alternatively the researcher can contact you via the phone each week, where the researcher will administer the questionnaire over the phone. This phone call will occur for 4-6 weeks BEFORE the Living Well Programme, after BOTH of the Living Well Sessions, and 4-6 weeks AFTER the Living Well Programme has ended. Each phone call should take 5-10 minutes.

Data will be stored electronically in password protected files at the university.

Total time of the study is expected to be approximately 10-12 weeks (from the initial questionnaires until the final questionnaires).

What are the possible benefits and risks of this study?

We hope that this study will allow researchers to gain a better understanding of effective forms of social support for breast cancer patients in New Zealand, and that this data can then be used to evaluate the effect of an education intervention on psychological wellbeing in breast cancer patients and inform later studies.

What are my rights?

Participation is entirely voluntary and whether you choose to participate or not will not affect the medical treatment you receive. If you do sign the consent form, then later change your mind, please let the researcher(s) know and we will remove you from the study. You may withdraw from the study at any time (please contact the researcher, the study's supervisor or the Cancer Society Nurse, whose details are all listed at the end of this information sheet).

You have the right to see and, if necessary, correct the **information** held about you. Information will be held either in your clinical / medical records or in a locked, password protected file on the researcher's computer.

Confidentiality is ensured, as all data from the study will be kept strictly confidential in a locked file/computer at the University of Waikato. No one other than those involved in the study will have access to this information without your permission. No information that could personally identify you will be used in any reports on the study.

What happens after the study or if I change my mind?

Participants will be provided with their individual surveys and on completion of the study a summary of the research findings.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints after reading this information sheet or about the study at any stage, you can contact:

Brittany Ryan, Master's student, Chief Investigator in the study

School of Psychology, University of Waikato

Phone: 0277574365

Email: brittryan_94@hotmail.com

Tim Edwards, Study's Supervisor

School of Psychology, University of Waikato

Phone: 07 837 9409

Email: tim.edwards@waikato.ac.nz

Kay Taylor, Cancer Society Nurse

Cancer Society of New Zealand

Phone: 07 9035809

Email: kaytaylor@cancersociety.org.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@advocacy.org.nz

This research project has been approved by the Human Research Ethics Committee (Health) of the University of Waikato under HREC(Health)2019#43. Any questions about the ethical conduct of this research may be addressed to the Secretary of the Committee, email humanethics@waikato.ac.nz, postal address, University of Waikato Te Whare Wananga o Waikato, Private Bag 3105, Hamilton, 3240.

Appendix C

CONSENT FORM: Evaluating the effectiveness of an Education Group Intervention on the psychological wellbeing of breast cancer patients

Please tick to indicate you consent to the following:

I have read, or have had read to me in a language of my choice, and I understand the Participant Information Sheet.	Yes ☐	No ☐
I have been given sufficient time to consider whether or not to participate in this study.	Yes ☐	No ☐
I have had the opportunity to use a legal representative, whānau / family support, or a friend to help me ask questions and understand the study.	Yes ☐	No ☐
I am satisfied with the answers I have been given regarding the study. I have a copy of this consent form and information sheet.	Yes ☐	No ☐
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes ☐	No ☐
I consent to the research staff collecting and processing my information	Yes ☐	No ☐
I understand that my participation in this study is confidential and that no material which could identify me personally will be used in any reports on this study.	Yes ☐	No ☐
I understand the compensation provisions, in case of injury, during the study.	Yes ☐	No ☐
I know who to contact if I have any questions about the study in general.	Yes ☐	No ☐

Declaration by participant:

I hereby consent to take part in this study.

Name:

Signature: Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Date:

Signature:
