

**Acceptability and Effectiveness of an Adapted Internet-Delivered Cognitive
Behavioural Therapy Programme for Depression and/or Anxiety
in Breast Cancer Survivors**

Selin Akkol Solakoglu

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in partial fulfilment of the requirements for the degree of

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Supervised by: Prof. David Hevey

Declaration

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Summary

Depression and anxiety are the most common psychological problems experienced by breast cancer survivors. However, survivors' need for psychosocial care is usually under-recognised; even when recognised, the lack of available mental health clinicians prevents them from accessing psychological services. Internet-delivered cognitive behavioural therapy (iCBT) is an easily accessible and evidence-based alternative that has been proven effective in reducing depression and anxiety symptoms in the general population. Studies for health conditions, especially for cancer survivors, are becoming more frequent, with studies showing promising improvements. However, no study to date has investigated the effectiveness of iCBT for depression and/or anxiety, specifically with breast cancer survivors in Europe. Although the inclusion of the social environment in the iCBT programmes designed for people with chronic illnesses is suggested as best practices in digital health interventions, no study has evaluated if including carers in an iCBT programme is acceptable. This thesis investigated an adapted 7-week iCBT programme's acceptability and effectiveness in reducing breast cancer survivors' depression and/or anxiety.

A mixed-method approach combining qualitative and quantitative methods was used. Study I qualitatively evaluated the acceptability of iCBT programme and carer access to the iCBT programme with five breast cancer survivors and three carers. The findings of Study I and evidence from the literature informed Study II, in which an iCBT intervention was adapted considering the specific needs of breast cancer survivors and the carer access aspect. Study III evaluated the effectiveness of the adapted 7-week iCBT programme by comparing the iCBT and treatment-as-usual control (TAU) groups. Seventy-two breast cancer survivors living in Ireland and the UK who completed their medical treatment and were cancer-free, and four of their carers participated in the study. The iCBT group received the intervention online with weekly post-session feedback from a trained supporter. The Sociodemographic and Clinical History Questionnaire was used to assess demographic and clinical information of the participants. The Hospital Anxiety and Depression Scale (HADS) was used as the

primary outcome measure. The secondary measures included the European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC-QLQ-C30), Breast Cancer Worry Scale (CWC), Brief Coping Orientation to Problems Encountered (Brief COPE), Medical Outcomes Study Social Support Survey (MOS-SSS), which were completed at baseline, post-intervention, and 2-month follow-up. Both survivors and carers completed Survivor-Carer Cancer Communication and Relationship Quality measures. Other measures included Helpful Aspects of Therapy Form (HAT) and Satisfaction with Online Treatment (SAT). Programme effectiveness was evaluated on an intention-to-treat and per-protocol basis using Linear-Mixed-Models. Study IV qualitatively investigated the experienced acceptability of the adapted iCBT programme as well as user experiences with it and provider experiences with their role.

Study I revealed a need for easily accessible, evidence-based psychological treatments for breast cancer survivors both shortly after diagnosis and medical treatment completion. Survivors and carers found the iCBT programme and carer access acceptable. Study III indicated that the guided iCBT group had lower distress than the TAU control group at post-intervention, $t(55) = -1.81, p = .075$. This difference was statistically significant at 2-month follow-up, $t(45) = -3.16, p = .003$. Survivors found the availability of the supporter very helpful and were highly satisfied with the programme. Study IV findings revealed that survivors found the adapted programme acceptable. User experiences findings revealed similar results with suggestions to improve the programme further. The findings also identified the reasons for low preference for carer access. Survivors and providers reported a lack of understanding of the tools such as the TFB Cycle. Following the discussion of the results based on the findings in the literature, strengths, limitations, and suggestions for future research are provided. It was concluded that the adapted guided iCBT programme can ease the adaptation to life after treatment and reduce breast cancer survivors' psychological distress.

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Publications and Conference Presentations Arising from this Thesis

Publications

Akkol-Solakoglu, S., Hevey, D., & Richards, D. (2021). A randomised controlled trial comparing internet-delivered cognitive behavioural therapy (iCBT) with and without main carer access versus treatment-as-usual for depression and anxiety among breast cancer survivors: Study protocol. *Internet Interventions*, 24, 100367. <https://doi.org/10.1016/j.invent.2021.100367>

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Conference Presentations

Akkol-Solakoglu, S., & Hevey, D. (August, 2021). Breast cancer survivors' and main carers' perspectives on the acceptability of internet-delivered cognitive behavioural therapy. Presented as a give me 5 minutes oral presentation at the 35th Annual Conference of the European Health Psychology Society.

Akkol-Solakoglu, S., & Hevey D. (September, 2019). Internet-delivered cognitive behavioural therapy intervention protocol for psychological distress in women with breast cancer. Presented at the 6th Scientific Meeting of the European Society for Research on Internet Interventions (ESRII). Copenhagen, Denmark.

List of Abbreviations

Brief COPE	Brief Coping Orientation to Problems Encountered
C	Carers
CBT	Cognitive Behavioural Therapy
CWC	Cancer Worry Scale
EORTC-QLQ	The European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire
HADS	Hospital Anxiety and Depression Scale
HADS-T	Hospital Anxiety and Depression Scale Total
HAT	Helpful Aspects of Therapy
ITT	Intention-to-Treat
iCBT	Internet-delivered Cognitive Behavioural Therapy
M	Mean
MCAR	Missing Completely at Random
MOS-SSS	Medical Outcomes Study Social Support Survey
SAT	Satisfaction with Online Treatment
SD	Standard Deviation
P	Participant
PP	Per-Protocol
RCT	Randomised Controlled Trial
S	Survivor
TAU	Treatment-as-Usual

CHAPTER 1

General Introduction and Literature Review

1.1. Introduction

Breast cancer is a chronic and life-threatening disease that makes individuals vulnerable to psychological distress during the diagnosis and treatment and the period following the treatment completion (McKiernan, Steggles, Guerin, & Carr, 2010). Following the medical treatment individuals often experience fear of cancer recurrence and lose social support, which contribute to increases in depression (Burgess et al., 2005; Fann et al., 2008; Hegel et al., 2006; Reich, Lesur, & Perdrizet-Chevallier, 2008) and anxiety symptoms (Hopwood, Sumo, Mills, Haviland, & Bliss, 2010; Linden, Vodermaier, MacKenzie, & Greig, 2012; Osborne, Elsworth, & Hopper, 2003), and decreases in their quality of life (Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012). Providing easily accessible evidence-based treatments to help breast cancer survivors deal with depression and anxiety symptoms is crucial. Since survivors who are left untreated experience poorer physical health, more pain, and fatigue, has more substance use, poorer quality of life, less acceptance and compliance with adjuvant treatments, higher prevalence of metastasis, higher risk of relapse and mortality, and lower survival time (Chida, Hamer, Wardle, & Steptoe, 2008; Colleoni et al., 2000; Hopko et al., 2008; Hopko, Lejuez, Ryba, Shorter, & Bell, 2016; Hopko, McIndoo, Gawrysiak, & Grasseti, 2014; Reich et al., 2008; Reuter et al., 2006; Reyes-Gibby et al., 2012; Spiegel & Riba, 2015; H. Yang et al., 2017).

Internet-delivered cognitive behavioural therapy (iCBT) is an evidence-based alternative that can support cancer survivors by normalising their feelings and helping them learn how to manage unhelpful thinking, behaviours, moods, which may decrease their distress (Igelström et al., 2020). There is well-established evidence on the effectiveness of iCBT for the treatment of depression (Gerhard Andersson & Cuijpers, 2009; Hedman, Lindefors, & Ljótsson, 2012; Wright et al., 2019),

anxiety (Richards & Richardson, 2012; Titov et al., 2009), and comorbid depression and anxiety (Newby et al., 2013; Spek et al., 2007) in the general population. However, iCBT trials aiming to reduce depression and anxiety among cancer survivors are scarce. No RCT in Europe evaluated the effectiveness of an iCBT programme for depression and anxiety among breast cancer survivors in a randomised controlled trial.

This narrative literature review aims to describe breast cancer (its definition, prevalence, risk factors, symptoms, and treatment), psychological distress experienced by breast cancer survivors, and evaluate factors influencing psychological distress such as coping, the role of carer support and cancer-related communication, and provide the empirical evidence on the effectiveness of cognitive behavioural therapy (CBT) and internet-delivered cognitive behavioural therapy (iCBT) for depression and anxiety. The review ends by discussing the gaps in the literature that informed the aims of the present study.

For the literature review, the following databases were searched: PsycArticles, PsychInfo, MEDLINE, Cochrane, and ScienceDirect, using the search terms pertaining to breast cancer, coping, perceived social support, communication, carer, cognitive behavioural therapy, internet-delivered cognitive behavioural therapy, and effectiveness. Where appropriate, reference lists of the studies were checked for additional publications. The review includes studies conducted with people with breast cancer receiving medical treatment during the study or who had completed medical treatment. Studies from the general cancer literature were included for particular topics where there was no research with breast cancer survivors.

1.2. Definition of Cancer Survivorship

According to the National Cancer Institute, cancer survivorship begins at diagnosis and continues until the end of life. Family members, friends, and caregivers are also included in this definition as they are also affected (Denlinger et al., 2014). Throughout this thesis, “breast cancer

survivor” refers to a person who has a history of breast cancer, and this definition does not contain affected members of family, friends, or caregivers. An individual who has provided emotional support to a survivor at some point (during the diagnosis, treatment, or after treatment completion) will be referred to as “carer”.

1.3. Definition of Breast Cancer

Breast cancer can be defined as the name given to a group of cells in the breast that begin to grow out of control (American Cancer Society, 2017). This group of cells usually form a tumour that can be often felt as a lump and can be seen on an x-ray. If the cells can invade or spread (metastasize) into surrounding tissues or distant areas of the body, then the tumour is malignant, called cancer. Breast cancer can start from different breast parts, such as in the ducts that carry milk to the nipples or in the glands that make breast milk.

There are two major types of breast cancer, carcinoma in situ and invasive breast cancer (Maughan, Lutterbie, & Ham, 2010). Carcinoma in situ is a non-invasive carcinoma, stage 0. It occurs when cancer cells are contained within the breast milk duct (ductal carcinoma in situ) or lobule (lobular carcinoma in situ). They are named in situ because these cancer cells are confined in the region where they were originally formed. In lobular carcinoma in situ, an incidental microscopic finding of abnormal tissue grows in the breast's lobules. Although it does not progress to invasive breast cancer, it raises subsequent invasive breast cancer risk. On the other hand, ductal carcinoma in situ can progress to invasive breast cancer. Invasive breast cancer, also known as infiltrating breast cancer, includes stages I, II, III, and IV and occurs when cancer cells spread beyond the basement membrane of duct or lobule to neighbour breast parenchyma. Invasive breast cancer is also classified as early breast cancer (for stages I, IIa, IIb), locally advanced breast cancer (for the stages IIIa, IIIb, IIIc), and advanced breast cancer (distant metastases).

1.4. Prevalence of Breast Cancer

Breast cancer is the most common cancer among women in the world (Abrahams et al., 2015) and the second most common cancer overall (Breast Cancer Statistics, <https://www.wcrf.org/dietandcancer/cancer-trends/breast-cancer-statistics>).

According to the cancer statistics of the Irish Cancer Society (2018), in Ireland, breast cancer is the second most common cancer in women. Incidence rates in 2021 revealed that one in every nine women in Ireland has a lifetime risk of being diagnosed with breast cancer. The number of estimated cases per year for female invasive breast cancer was 3141 between 2015 and 2017, as reported by the National Cancer Registry of Ireland (2018). While the five-year survival rate was 86.3% between 2010 and 2014, the ten-year survival rate was 79.5% for female breast cancer patients between the ages of 15 and 99 (National Cancer Registry Ireland, 2018).

In the UK, breast cancer is the most common cancer in women (Facts and Statistics, 2021, <https://breastcancer.org/about-us/media/facts-statistics>). One in every seven women in the UK has a lifetime risk of developing breast cancer. Approximately 55,000 women are diagnosed with breast cancer each year in the UK. The five-year survival rate for women in the UK is 85%, meaning that almost nine in ten women survive breast cancer for at least five years.

1.5. Risk Factors for Breast Cancer

Risk factors for breast cancer are age (the risk increases until 65 years and decreases after 65 years), family history of breast cancer, especially first-degree relatives, late age at first full-term pregnancy (increased risk after 30 years), never having a full-term pregnancy, early menarche and/or late menopause, certain genetic mutations for breast cancer (e.g. in the BRCA1, BRCA2, ATM, and CHEK2 genes), certain breast disorders such as atypical hyperplasia or lobular carcinoma in situ, postmenopausal high bone density, and high-dose radiation to the chest (Rim & Chellman-Jeffers, 2008). Geographical location is another risk factor for breast cancer. Women living in

Western/developed countries have a five times higher risk than those living in Far Eastern countries (McPherson, Steel, & Dixon, 2000). There are also more modifiable risk factors such as obesity, recent and long-term hormone replacement therapy, recent use of oral contraceptives, alcohol use, tobacco use, diet, and a low level of physical activity (Rim & Chellman-Jeffers, 2008). However, the findings in the literature about some of these risk factors are inconsistent. For example, although the evidence supports that obesity increases the risk of breast cancer two times in postmenopausal women, the correlations between the incidence of breast cancer and diet/fat intake, alcohol, and tobacco use are inconsistent (McPherson et al., 2000). All in all, risk factors contributing to the development of breast cancer and medical treatment options should be considered as a whole in coping with breast cancer since all of these contribute to the psychological adjustment of the illness.

1.6. Symptoms of Breast Cancer

Although the most common symptom is breast lump before seeking help, about 1 in 6 women with breast cancer experience a broad spectrum of symptoms (Koo et al., 2017). Non-lump breast symptoms of breast cancer consist of nipple abnormalities such as retraction, change in appearance, and discharge, breast pain, skin abnormalities, contour abnormalities, ulceration, infection or inflammation, swelling, and rash. Non-lump presenting symptoms of the breast are associated with pro-longed diagnostic intervals. Signs indicating a regional/distant breast disease are an axillary lump, axillary pain, oedema of the upper limb, neck lump, or other lymph node involvement; distant symptoms might represent late-stage breast cancer. There are also general non-specific symptoms associated with breast cancer, including musculoskeletal pain, fatigue, weakness, or weight loss.

1.7. Treatment of Breast Cancer

Medical treatment options for breast cancer differ based on cancer stage and type (Maughan et al., 2010). Treatments include rigorous breast cancer surveillance, annual mammography and clinical breast examination every six months (for lobular carcinoma in situ); breast-conserving surgery, in which only the part with tumour is removed from the breast tissue, followed by radiation therapy (for ductal carcinoma in situ, Stage 0); breast-conserving surgery followed by radiation therapy to decrease both five-year recurrence rate and risk of 15-year breast cancer mortality (for Stages I and II), chemotherapy followed by local therapy such as radiation therapy, surgery, or both (for Stage III). At Stage IV, addressing and understanding the breast cancer survivor's treatment goals are very important to decide on the treatment options consisting of radiotherapy, chemotherapy, and endocrine therapy. Patients' hormone receptor status, rate of disease progression, and willingness to tolerate adverse effects of treatment determine the systemic treatment in the last stages.

1.8. Psychological Distress in Breast Cancer Survivors

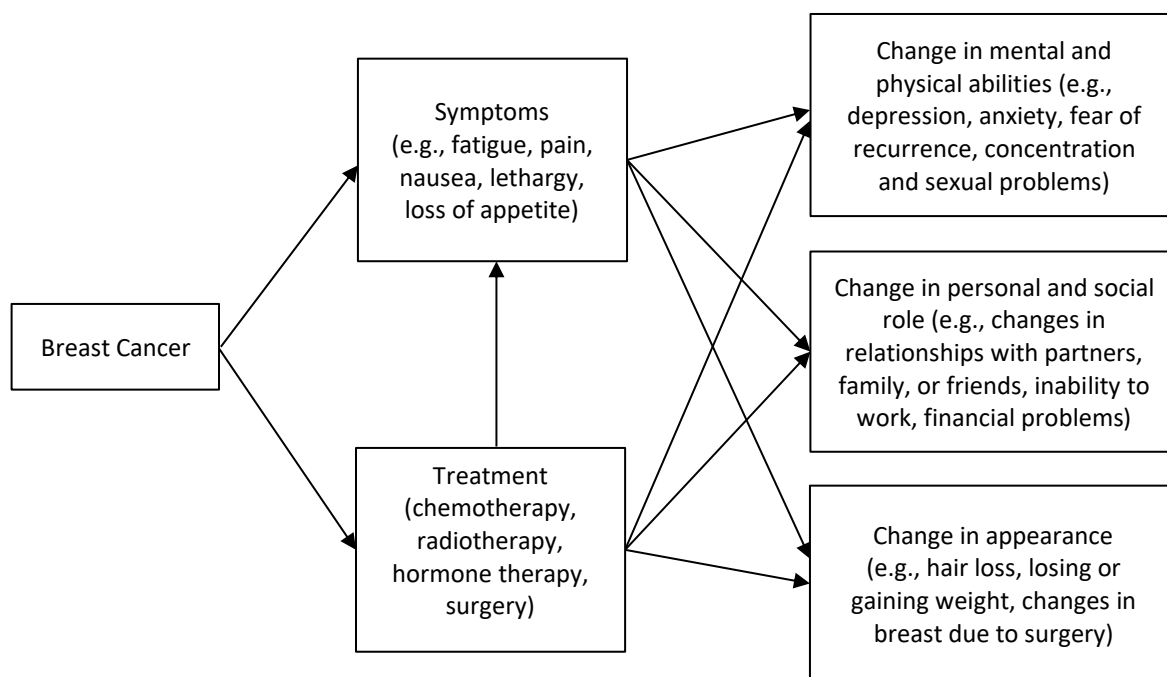
Most people who receive the cancer diagnosis react initially with numbness, shock, and disbelief, followed by anger, anxiety, and depression (Moorey & Greer, 2012). Negative consequences of cancer diagnosis and treatment on individuals' lives are demonstrated in Figure 1. People who cope well with the initial diagnosis may feel psychologically overwhelmed after completing their treatment if their cancer recurred or spread. Even though the experience of distress is an understandable reaction to cancer and many adjust well after a certain time, a subset of breast cancer patients continue to experience clinically significant levels of distress (Fann et al., 2008) even 20 years after their initial treatment, if left untreated (Kornblith et al., 2003).

A study with 222 women with breast cancer reported that 33% had depression and anxiety at diagnosis, 15% at one year when most of them completed their treatment and were cancer-free, and 45% when cancer recurred (Burgess et al., 2005). Another study revealed that more than one-third of

129 breast cancer survivors experienced distress about 5,5 years after the diagnosis (Ploos Van Amstel et al., 2013). A recent systematic review of 20 studies in long-term cancer survivors, who received their diagnosis five or more years ago, showed that a pooled prevalence of depression and anxiety symptoms was 21% (Brandenburg et al., 2019). The studies included frequently used the HADS and Center for Epidemiologic Studies Depression Scale (CES-D).

Figure 1

Consequences of Breast Cancer Diagnosis and Treatment



Note. Adapted from Mooney and Greer (2012) Oxford Guide to CBT for People with Cancer, Oxford University Press, New York.

In a study examining psychological and physical adjustment patterns of 287 women with breast cancer who remained disease-free through 4 years of follow-up, four distinct trajectories for psychological adjustment and physical adjustment were identified (Helgeson, Snyder, & Seltman, 2004). They found that 43% of the women started with very high mental functioning/lowest level of distress and maintained with only a modest change throughout the year 4. Whereas, other three groups revealed ups and downs over the 4-year course in their mental and physical functioning. For example, one group representing 18% of the women (group 3) demonstrated a small but consistent improvement in mental functioning over time. However, two other groups followed extremely different adjustment trajectories, although both started at equally low levels of mental functioning. While a larger group of women (27%, group 2) showed rapid mental improvement by 13 months and then remained steady, the smaller group (12%, group 1) showed immediate and substantial decline until 31 months, then a modest improvement toward the end of the study. A smaller group of women who deteriorated in mental health functioning had fewer personal resources (e.g. personal control) than groups 3 and 4, which showed improvement over time. They also had fewer social resources (different kinds of support received from family and friends) than group 4, which had very high physical functioning initially and remained the same over time. These suggest that the course of adjustment to breast cancer is not the same for all women and, lack of personal and social resources are important predictors of deterioration in their psychological and physical functioning. Considering the long-term psychological impact of breast cancer and distinct trajectories of psychological adjustment, the emotional and psychological needs of breast cancer survivors require close attention and are of critical importance.

1.8.1. Depression and Anxiety in Breast Cancer Survivors

Major depression is one of the most common psychological disorders in cancer patients (Croyle & Rowland, 2003). Research has shown different depression rates among breast cancer

patients depending on the differences in the study population, design, treatment phase, method of assessing depression. For example, one study found that approximately 50% of women with breast cancer have a risk of being diagnosed with depression, anxiety, or both in the year following the diagnosis, followed by 25% risk in the years two, three, and four, and 15% risk in year five (Burgess et al., 2005). The research on the epidemiology of major depression after breast cancer revealed lower depression rates varying between 10% and 25% among breast cancer patients (Fann et al., 2008). A systematic review of 32 observational studies reported a broader prevalence rate of depression, ranging from 1% to 56% in breast cancer survivors (Zainal, Nik-Jaafar, Baharudin, Sabki, & Ng, 2013).

Clinical depression is associated with significant impairment in the physical and psychological functioning of individuals with breast cancer. Compared to non-depressed women with breast cancer, women with breast cancer and comorbid depression reported a higher prevalence of metastasis and experienced more intense pain (Ciaramella & Poli, 2001; Hopko et al., 2008) and fatigue (Reuter et al., 2006). Depression is associated with decreased quality of life (Reich, Lesur, & Perdrizet-Chevallier, 2008; Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012), and a higher risk of relapse or mortality among people with breast cancer (Chida, Hamer, Wardle, & Steptoe, 2008; Hjerl et al., 2003; Somerset, Stout, Miller, & Musselman, 2004).

The risk for major depression is higher during the first year after the breast cancer diagnosis, particularly after receiving radiation therapy and adjuvant chemotherapy (Fann et al., 2008). Although surgery is seen by many as 'necessary evil' and better tolerated as it will root breast cancer out, they find the subsequent chemotherapy and radiotherapy more difficult to cope with (Moorey & Greer, 2012). Similarly, another study found that breast cancer survivors experienced significantly more distress in the first 2 years than the 2-5 years following the surgery. Breast cancer survivors who underwent surgery, radiotherapy, and chemotherapy experience more distress than those who had surgery only. Indeed, a study with breast, lung, and prostate cancer patients revealed that people who currently or recently engaged in chemotherapy or radiotherapy acknowledge distress as a

problem requiring a solution and welcome emotional support and help (Baker et al., 2013). Patients who had not yet been engaged in chemotherapy or radiotherapy, on the contrary, viewed emotional distress as a temporary and understandable reaction that does not require professional intervention. These patients also did not want to talk about their emotional needs and rejected emotional support and information. These findings suggest that psychological interventions in the early cancer trajectory may not be appropriate and may contradict survivors' natural coping methods. In the light of these findings, it can be suggested that psychological interventions targeting depression and anxiety symptoms may be more suitable for those who completed their active cancer treatment, and those who had chemotherapy, radiotherapy, and surgery may benefit more.

Anxiety is another commonly reported psychological morbidity among women with breast cancer (Hopko, Lejuez, Ryba, Shorter, & Bell, 2016; Puigpinós-Riera et al., 2018; Spiegel & Riba, 2015). Like the depression rates, anxiety among breast cancer patients ranges between 10% to 50%, depending on the differences in the sample and diagnostic criteria used (Segrin, Badger, Dorros, Meek, & Lopez, 2007). The risk factors for anxiety were not differentiated from those for depression in the literature in the studies mentioned above. Indeed, most studies examined the risk factors either only for depression or both depression and anxiety. The risk of depression and anxiety is higher if a breast cancer survivor has metastatic progression, previous episodes of depression and anxiety, negative illness perception, and low levels of social support (Jacob, Bleicher, Kostev, & Kalder, 2016; Kus et al., 2017).

Danger and vulnerability are two key elements of anxiety (Moorey & Greer, 2012). If the person thinks that their cancer may come back in the period after their treatment ended, the danger is present and threatening to the person's physical and social well-being. The person's perception of whether they have sufficient resources to cope with the threat is described as their vulnerability. These two elements determine the level of anxiety the person experiences. For example, if the person does not trust that their cancer is cured and does not have faith in their coping abilities in case

of possible recurrence, their fear will increase. Uncertainty of the future, potential metastases, and fear of physical suffering lead to emotional concerns that cause considerable anxiety among survivors (Voogt et al., 2005).

1.8.2. Fear of Recurrence in Breast Cancer Survivors

Fear of recurrence is one of the most commonly reported problems that persist long after the treatment completion among breast cancer survivors (Custers et al., 2014; Mehnert, Berg, Henrich, & Herschbach, 2009; Otto, Szczesny, Soriano, Laurenceau, & Siegel, 2016) and other cancer survivors (Niedzwiedz, Knifton, Robb, Katikireddi, & Smith, 2019; Simard & Savard, 2009; Yang et al., 2019).

Fear of recurrence is a general concern for some survivors regardless of the cancer type, as everyone with cancer lives with the constant possibility that cancer will return (Moorey & Greer, 2012). Studies in the literature reported different prevalence rates regarding the fear of recurrence among breast cancer survivors, depending on the patient and treatment characteristics. For example, one study reported that approximately 56% of women who had curative treatment for breast cancer had moderate to high levels of fear of recurrence (van den Beuken-van Everdingen et al., 2008). On the other hand, Koch et al. (2014) showed that most breast cancer survivors (82%) reported low levels of fear of recurrence and only 11% had moderate and 6% had high fear of recurrence. Younger age (under the age of 55) and considering oneself as a tumour patient were the strongest predictors of moderate to high fear of recurrence.

Lee-Jones, Humphris, Dixon, and Hatcher (1997) proposed a model explaining the antecedents of fear of recurrence, cognitions and emotions associated with recurrence, and its consequences. The model suggests that both internal stimuli (e.g., somatic stimuli interpreted as symptoms) and external stimuli (e.g., contact with health professionals such as hospital appointments, exposure to media or magazine articles related to cancer, family concerns about the reappearance of the disease, person's predisposition and past coping style) play a role in activating

cognitive and emotional responses associated with fear of recurrence. In line with this, Gil and colleagues (2004) showed that the most frequent triggers of uncertainty about recurrence were hearing about someone else's cancer.

Cognitions include worrying thoughts about the recurrence of cancer, doubts about the eradication of cancer, and concerns that the doctor is not checking carefully enough. Knowledge of the cure and survival rates and experience with cancer will also influence individuals' degree of concern about the chances of cancer returning (Leventhal, Diefenbach, & Leventhal, 1992). The behavioural responses to the perceived risk of recurrence include body checking, seeking advice from professionals, friends, and relatives, and limited planning for the future. Psychological consequences of fear of recurrence are a misinterpretation of symptoms, increased somatic anxiety, and panic attacks (Lee-Jones et al., 1997). High levels of fear of recurrence were associated with higher depression and lower quality of life (van den Beuken-van Everdingen et al., 2008). Gil and colleagues (2004) suggested that healthcare professionals can help survivors effectively deal with uncertainty through education and counselling, reducing psychological distress.

1.9. Coping with Breast Cancer

1.9.1. *An Extended Stress-Coping Model for Chronic Illnesses*

One prominent theoretical approach conceptualising stress and coping as a unique phenomenon is Lazarus and Folkman's stress-coping model (1984). It suggests that people who are facing a stressor evaluate the stressor, and this evaluation/appraisal of the stressor, in turn, determines their emotional and behavioural responses. They suggest two types of evaluation processes: primary appraisal and secondary appraisal. *Primary appraisal* refers to the evaluation of the significance of and personal meaning of an event for the person in terms of whether it has positive, neutral, or negative meaning. If the person evaluates breast cancer as a challenge and interprets it as positive, the resulting emotions will be positive. If breast cancer threatens an

individual's physical or psychological self, which is common in the case of chronic illness, then it will result in negative emotions. There are four types of primary appraisals. *Benign appraisals* are made when individuals perceive the situation as no threat to their well-being. *Harm/loss appraisals* are made when individuals believe that the stressor has already caused damage. *Threat appraisals* are made on the presence of beliefs focusing on the possibility of future damage. *Challenge appraisals*, however, are made when individuals perceive the stressful event as an opportunity for self-growth or development. Two types of negative emotions can be distinguished based on how the stressor is perceived. When the stressor is perceived as a threat, the individual feels anxiety; the individual feels anger or grief if the stressor implies personal damage and loss (Lazarus & Folkman, 1984).

Emotional changes during the chronic illness can also be associated with *secondary appraisal*, which refers to one's evaluation of personal resources in terms of their capacity to meet the situation's demands (to reduce the threat, damage, or loss caused by the event) (Lazarus & Folkman, 1984). Appraisals are important because they are significantly associated with depression (Gallagher, Parle, & Cairns, 2002). Gallagher and colleagues (2002) revealed that 40% of the variance in depression scores of breast cancer patients at 6 months following the diagnosis was predicted by their primary appraisal of threat, and their secondary appraisals including their ability to cope with breast cancer and confidence in the support available from the family at 2 months following the diagnosis, after controlling for psychological functioning. Lower primary appraisal of threat and greater secondary appraisal of self-efficacy and confidence in their ability to cope with the disease were associated with more improved psychological functioning.

Lazarus and Folkman (1984) defined *coping* as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Two different forms of cognitive and behavioural efforts were differentiated: problem-focused and emotional-focused coping. Problem-focused coping refers to the efforts directed at the problem or stressful situation (external event) to change its demands on a

person, such as planning what to do or seeking information. Emotion-focused coping refers to the efforts to change one's emotional reactions or internal state (internal event), including avoidance, seeking emotional support, and positive reappraisal. Both strategies have adaptive potential for the individual. Lazarus and Folkman (1984) highlighted that it is necessary to consider the context in which the strategies are used to evaluate outcomes of problem-focused and emotion-focused coping.

Although Lazarus and Folkman's stress-coping model is the most widely used for stress and coping in chronic illnesses, it has some conceptual and methodological limitations. Maes et al. (1996) evaluated the model's limitations and concluded that it could be more usefully considered as a frame of reference than a theory because of three main reasons. First of all, the model lacks concepts respecting the common and specific features of chronic illness, and the situational dimension is poorly represented in the model. The situational dimension could be distinguished by its valence (stressfulness of the situation), controllability (opportunities for control within the situation), changeability (the probability that situation will change by itself), ambiguity (the degree to the situation lacks sufficient information or unpredictable), and recurrence (the likelihood that the stressful situation will happen again). Secondly, the model does not consider interactions with the context or other life events that might affect coping processes. For instance, the importance of social support and other environmental factors on coping and adjustment were given insufficient attention in the psychological focus of the coping model. Finally, the model neglects the effects of the individual's life goals and social relationships on the meaning of the disease and coping behaviours.

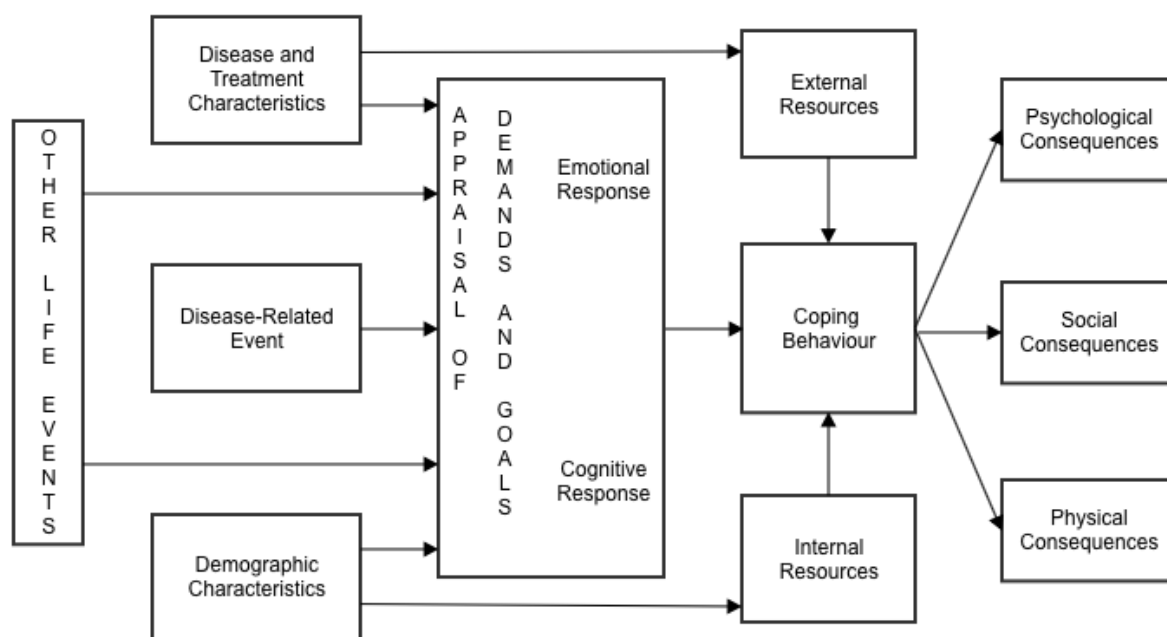
Based on the limitations of Lazarus and Folkman's stress-coping model, Maes and colleagues (1996) suggested an extended model for coping with chronic diseases (see Figure 2), which is used as a reference in the conceptualisation of the present study and its hypotheses.

This model suggests that other *important life events* such as the death of a partner or loss of a job can contribute to the appraisal of disease-related events, and thus, coping with the stressor. For instance, a patient will probably evaluate the diagnosis of cancer differently if she receives the

diagnosis after the death of her partner or the loss of her job compared to a patient without these psychologically stressful life events. In line with this, it was found that the number of adverse events in a person's life predicts depressive symptoms (Cohen & Hoberman, 1983). However, no research directly investigated the effects of stressful life events on the appraisal of the illness demands and goals.

Figure 2

Maes, Leventhal, and de Ridder's Extended Model for Coping with Chronic Disease



The model also suggests that *disease and treatment characteristics* can have a major effect on the appraisal of chronic disease and thus influence coping strategies (Maes et al., 1996). Several studies evaluated the relationships between characteristics of cancer and its treatment, coping strategies, and psychological distress among cancer patients and survivors. For example, Deimling and colleagues (2006) examined the association between cancer and treatment characteristics, such as

cancer type, cancer stage at diagnosis, years since diagnosis, the total number of treatments, treatment type (chemotherapy, radiation therapy), and the number of symptoms during cancer treatment, current symptoms attributed to cancer, and coping strategies among long-term older adult survivors of breast, prostate, and colorectal cancer. Among cancer and treatment characteristics, they found that only a higher number of symptoms during the treatment was a significant predictor of cancer survivors' use of planning and venting behaviours, with small effect sizes. None of the other cancer and treatment characteristics was significantly related to coping dimensions, which consisted of planning, acceptance, venting, denial, and social support.

In addition, *demographic characteristics* such as age, gender, race, and social class can contribute to the interpretation of chronic illness and coping with the chronic illness (Maes et al., 1996). Deimling et al. (2006) found that age significantly predicted the coping strategy used by long-term cancer survivors. Increased age was associated with less use of coping such as planning, venting, denial, and seeking social support. In addition, being African American was associated with having less depression, anxiety, and cancer-related worries than being Caucasian; this may imply cultural differences in the appraisal of cancer. Thus, the use of different coping styles can differ between African Americans and Caucasians and between younger and older adults. In addition, there is a finding suggesting that females, lower educated, and older patients with chronic illness are likely to use more avoidant and/or emotion-focused coping (Maes et al., 1996).

The goals or values of the individual can also have a significant impact on the appraisal of the chronic illness based on the expectancy-value theory (Maes et al., 1996). Expectancies can be defined as one's degree of confidence in attaining goals. Carver, Scheier, and Pozo (1992) have pointed out that expectancies affect people's behaviours in a way that when expectancies are favourable, people will invest more effort in attaining their goals. If expectancies are not favourable, people may invest less effort or even cease their effort in managing their condition. Adjusting one's effort according to expectancies is an adaptive form of behaviour; however, problems arise when people want to pursue

their goals or disengage, but situational demand does not allow them. Facing a chronic illness such as breast cancer can be an example of a situational demand, which may imply that the person cannot pursue her current goals in her life, resulting in the negative appraisal of the stressor. The more important these goals are and the more they are threatened by the stressor, the more stress the person experiences.

Actual coping behaviour is not only determined by a person's demand and goal appraisals, but also by the appraisals on *demand-resources* and *goal-resources* (Maes et al., 1996). The resource can be defined as objects, conditions, personal characteristics, or energies that have value for the individual or serve as a means to attain valued resources. There are two types of resources, external and internal, that can be used to cope with demand and goal conflicts and influence the coping behaviours of survivors.

External resources include money, time, distance from professional help, and social support (Maes et al., 1996). It is known that cancer patients' psychological adaptation depends mainly on their ability to cope and live with cancer and an important determinant of this is their social environment (Helgeson & Cohen, 1996). In the process of adaptation to breast cancer, the relationship with a partner becomes crucial for patients who are married or in an intimate relationship (Belcher et al., 2011; Fergus & Gray, 2009; Manne et al., 2006; Manne et al., 2016) because one way for women with breast cancer to cope with this stressful life experience is to turn to their partners for emotional and practical support (Manne et al., 2016; Pistrang & Barker, 1995).

Internal resources, on the other hand, consist of energy or physical strength, personality characteristics such as intelligence, depression, trait anxiety, optimism, autonomy, locus of control, or self-efficacy. Research has demonstrated several personality characteristics associated with appraisal, coping, and adaptation (Deimling et al., 2006; Schou & Ruland, 2005; Sharif, 2017; Steiner, Wagner, Bigatti, & Storniolo, 2014). For example, Deimling et al. (2006) found that optimism, as a stable dispositional characteristic, was related to greater planning and seeking social support among older

adult long-term breast, colorectal, and prostate cancer survivors. They also found that optimistic individuals reported lower levels of depression and anxiety, and they were less likely to have worries about cancer. Schou and Ruland (2005) found that optimistic women tended to respond with the fighting spirit, which improved their health-related quality of life and functioning. On the other hand, pessimistic women tended to use hopeless/helpless (e.g., I feel like giving up) as a coping strategy, which had a negative effect on their global quality of life and functioning. Their use of coping strategies did not differ 12 months after surgery, suggesting that fighting spirit and hopelessness/helplessness are relatively stable coping strategies and are strongly associated with women's personality traits of optimism and pessimism. Another study found a significant relationship between locus of control and depression and quality of life through a mediating role of uncertainty among breast cancer patients (Sharif, 2017). Patients with an external locus of control believed that they had less control over their health outcomes and thus were less likely to seek information about their illness and treatment effects, which increased uncertainty. This uncertainty, in turn, was associated with decreased quality of life and increased depression.

1.9.2. Active and Avoidant Coping Strategies

Although some studies describe many categories of coping strategies, they can sometimes be categorised as active or avoidant coping (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004). Active, adaptive, problem-focused, favourable, and approach coping all refer to strategies where individuals dealing with a stressful situation accept and actively attempt to deal with the situation. Active coping consist of different strategies including active problem-solving, seeking emotional support, and planning. On the other hand, avoidant and maladaptive coping refer to strategies where people tend to avoid dealing with problems by cognitively, emotionally, and physically distancing themselves from the stressful situation. Avoidant coping strategies include denial, behavioural disengagement, and alcohol/drug use.

1.9.3. Coping Strategies and Psychological Distress

The extended stress-coping model suggests that many different factors influence and determine the coping behaviour of the person dealing with a chronic illness and are related to three outcomes: *psychological, social, and physical consequences*. Maes et al. (1996) emphasized that literature findings are consistent in relation to the different consequences of *avoidant emotion-focused coping* and *active problem-focused coping strategies* have on individuals' psychosocial and physical adjustment. Patients using avoidant emotion-focused strategies have more adjustment problems compared to those using the active problem-focused strategies. For example, Bigatti, Steiner, and Miller (2012) examined the extent to which the transactional theory of stress explains the relationship between cognitive appraisals, coping strategies, and depressive symptoms in women with mostly (71.9%) advanced-stage breast cancer. They revealed that higher appraisals of harm/loss and greater use of escape-avoidance coping predicted higher depressive symptoms. The overall model accounted for 51% of the variance in depressive scores and suggested the presence of direct adverse effects of harm/loss appraisal and escape-avoidance coping in advanced breast cancer patients' depression. However, no significant mediation effect of coping in the relationship between appraisals and depressive symptoms was found.

A more recent study among cancer patients evaluated the mediator role of coping in the relationship between perceived social support and post-traumatic growth (Cao, Qi, Cai, & Han, 2018). They found that higher levels of social support predicted greater use of adaptive coping strategies such as acceptance, active coping, positive reframing, and planning, which were positively associated with post-traumatic growth. The findings suggest that finding ways to encourage survivors to use adaptive coping strategies can help them to adjust better and experience post-traumatic growth.

In line with these findings, Perez-Tejada et al. (2019) found that passive (or avoidant) coping strategies were associated with higher psychological distress among breast cancer survivors. Deimling

et al. (2006) also found that survivors who used denial as a coping strategy were more anxious to a greater extent. Similarly, survivors who used venting and denial together reported the highest level of depression. Individuals who had the most symptoms during treatment worried the most about cancer. Although active coping strategies have been viewed as positive and more adaptive than avoidant coping strategies in most studies, Lazarus (2000) suggests that the outcomes depend on the situation where the strategies are used (as cited in Kershaw et al., 2004).

In summary, several factors comprising other important life events, disease-related events, disease and treatment characteristics, demographic characteristics affect individuals' demand and goal appraisals, which in turn, determines their coping behaviour (active problem-focused vs. avoidant emotion-focused coping) and their internal and external resources. Coping behaviour, in turn, results in psychological, social, and physical consequences.

1.10. Perceived Social Support

In the extended stress-coping model (Maes et al., 1996), perceived social support is viewed as an important factor contributing to the coping behaviour of individuals dealing with a chronic illness. Social support has been conceptualised in several different ways in the literature. Cohen and Wills (1985) suggested a distinction between two types of social support: structural social support, referring to the presence of social relations (e.g., marital status, number of personal contacts, and social interactions) and functional social support (e.g., role of one's social network, the kind of resources the network can offer, one's perceived availability of these resources). While perceived support means one's potential access to social support, received support refers to the reported receipt of support sources during a specific time frame. Studies that compared the two constructs demonstrated that the concept of social support as a personal perception is more strongly associated with adjustment to stressful life events (Cohen & Hoberman, 1983; Cohen & Wills, 1985; Wethington & Kessler, 1986). Sherbourne and Stewart (1991) suggested four dimensions of functional

support/perceived social support: emotional/informational, tangible, positive social interaction, and affectionate support (Sherbourne & Stewart, 1991). *Emotional support/ Informational support* includes the expression of positive affect, empathetic understanding, the encouragement of expressing feelings, and the offering of advice information, guidance, or feedback. *Tangible support* includes the provision of material aid or behavioural assistance. *Positive social interaction* includes the availability of others to do fun things with you. *Affectionate support* involves expressions of love and affection.

There are two well-known hypotheses on the effects of social support on health. The buffering hypothesis suggests that social support affects health by protecting the person against the harmful effects of high stress. The protective function of social support only occurs in the presence of a strong stressor, and little or no buffering occurs under low-stress conditions (Sarafino & Smith, 2011). Buffering may work in two ways: high social support might positively affect people's appraisals about the stressful situation and their response to the stressor after the initial appraisal. For instance, when people with high social support are in a high-stress situation, they may be less likely to appraise the situation as stressful than those with low social support.

On the other hand, according to the direct effect hypothesis, people's health and well-being benefit from social support regardless of how stressful is their life (Sarafino & Smith, 2011). For example, the beneficial effects of social support are similar under high and low stressors. Having high social support may provide people with strong feelings of belongingness and self-esteem. It is possible that people with social support may feel encouraged to pursue a healthy lifestyle because others care about them and need them. However, the beneficial effects of social support exist only when people perceive them as supportive. Social support might not be beneficial when the help is insufficient, or the wrong kind or the person may not want help. The compatibility between the type of support needed and the type received is also critical (Horowitz et al., 2001). For example, people who received emotional support found the support unhelpful and ineffective when they needed

instrumental support. Likewise, when people need emotional support but are offered instrumental support, they also think it is unhelpful. Thus, the benefits of received social support depend on the perceptions of recipients. In line with these findings, Uchino (2009) found that perceived support is a better predictor of good health compared to actual support received.

A study examined the relationship between perceived social support and coping strategies (behavioural avoidance, distancing, focusing on the positive, seeking social support) among advanced cancer patients (Zabalegui, Cabrera, Navarro, & Cebria, 2013). They found that most of the patients (97%) used all coping mechanisms jointly; however, patients who had greater perceived social support focused more on the positive, sought and used more social support than those with lower perceived social support. Perceived social support was unrelated to emotion-based coping mechanisms such as cognitive and behavioural avoidance and distancing. However, these findings may not be generalisable to cancer patients who completed their treatment or patients with early-stage cancer.

1.10.1. Perceived Social Support and Psychological Distress

A considerable body of research provided evidence for the positive effects of perceived social support on breast cancer survivors' quality of life (Huang & Hsu, 2013; Kroenke et al., 2013), depression (Hughes et al., 2014), and anxiety through the use of functional coping strategies (Zabalegui et al., 2013; Zamanian et al., 2020). Most of these studies focused on the mediating or moderating effect of perceived social support on the relationships between depression and anxiety, coping, and quality of life.

For example, Huang and Hsu (2013) evaluated the moderating/buffering role of perceived social support between depressive symptoms and the quality of life of breast cancer survivors in Taiwan. When breast cancer survivors suffered from depression, perceived social support positively affected their quality of life. They suggested that high perceived social support protects against

depression by helping people counteract frustration and isolation and rebuild their sense of well-being.

A study examined how social networks, social support mechanisms affect the quality of life in breast cancer survivors (Kroenke et al., 2013). Their findings indicated that each type of perceived social support, including emotional/informational support, tangible support, positive social interaction, and affectionate support, was associated with a higher overall quality of life. However, emotional/informational support was associated with better emotional and social well-being, but not physical well-being.

Hughes and colleagues (2014) examined the relationships between perceptions of social support, pain, inflammation, and depressive symptoms among 164 breast cancer survivors with stages 0-IIIa. They found that breast cancer survivors who had lower perceived social support before treatment experienced greater levels of depressive symptoms, pain, and inflammatory levels over time than their counterparts with more social support. Thus, early interventions should target improving patients' social networks to improve their life quality during survivorship.

In a recent study, Zamanian et al. (2020) examined the relationship between perceived social support, coping strategies (including active coping, planning, positive reframing, acceptance, humour, religion, emotional support, instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement, self-blame), and depression-anxiety symptoms in women with breast cancer. They found that the protective effect of perceived social support on depression was mediated through three coping strategies: active coping, acceptance, and positive reframing. The protective effect of perceived social support on anxiety was mediated through only one coping strategy: positive social interactions.

Overall, these findings suggest that greater perceived social support reduces breast cancer survivors' vulnerability to psychological distress and improves their quality of life; those with high support tend to use more functional coping strategies.

1.11. Role of Carers in Breast Cancer

A large and growing body of literature has investigated the ways patients and their carers cope together with cancer-related distress (Berg & Upchurch, 2007; Bodenmann, 1995; Bodenmann, Randall, & Falconier, 2017; Kayser, Watson, & Andrade, 2007; Manne, 2009). Cancer and its consequences affect individuals with cancer and their intimate partners, spouses, family, children, and friends. Moreover, each of their responses to illness may determine each other's adjustment and levels of psychological distress.

1.11.1. Carer Support

Women with breast cancer identify their partners, next of kin, and friends as main carers and primary support persons (Emanuela, Letizia, & Chiara, 2015). For example, 94% of breast cancer survivors identify their partner or spouse as the most important supporter, for 12%, it was their close relative, and for 5.4%, it was friends (Salakari et al., 2017). For the majority of women who are in a romantic relationship, their primary carers are often their intimate partners, and they provide the primary source of social and emotional support (Manne et al., 2016; Ockerby, Livingston, O'Connell, & Gaskin, 2013; Pistrang & Barker, 1995).

While many breast cancer survivors particularly see their partners as the primary source of emotional and practical support (Manne, Siegel, Heckman, & Kashy, 2016), partners may not always be able to provide the support women need due to their own psychological distress, problems in the couple relationship, or complicated motivations about their caregiving role such as acting to avoid feeling guilty and trying to fit in social expectations about their role (Brandão, Schulz, & Matos, 2014). However, they are in a very critical position since they can positively or negatively impact survivors' psychological well-being (Segrin et al., 2007; Sormanti & Kayser, 2000).

1.11.2. Carer Support and Psychological Distress

Given that many women living with breast cancer view their partners or spouses as main carers, the majority of the studies in the literature have focused mainly on the role of partner support on women's psychological adjustment, distress levels, and quality of life. These studies revealed that perceived carer support significantly contributes to or protects women living with breast cancer against psychological distress.

Borstelmann et al. (2015) examined the role of perceived partner support on anxiety among 675 young women with breast cancer stages I to III. Among women in a romantic relationship or married, 20% of them were not receiving support from their partner. Such women who have a partner but were not receiving support had higher odds of anxiety symptoms than women who received support from their partner. Considering the potential of partner support to protect against the impact of stress among breast cancer patients, they suggested that interventions aiming to enhance partner support and reduce anxiety might be beneficial. However, due to the cross-sectional nature of the study, it might be the case that women with higher anxiety levels perceive social support as less available or not meeting their expectations and needs, rather than low social support increasing women's anxiety.

In Manne and colleagues' study (2005), the relationships between partner unsupportive responses, avoidant coping, and distress were examined among 219 women with early-stage breast cancer and their partners. Patients' perceptions of their partners' unsupportive behaviour were associated with higher patient distress, through greater use of avoidant coping, pushing their aversive thoughts and feelings away. The distress experienced by patients was present for a year and a half, suggesting long-term detrimental effects of perceived unsupportive partner behaviour. It is important to underline that partner unsupportive behaviour did not have a negative impact unless the patient perceived them as unsupportive, emphasizing again, the importance of patients' interpretations and cognitions. Waters, Schootman, and Jeffe (2013) showed that women with early-stage breast cancer

who had lowest levels of perceived social support tend to have lower quality of life, including aspects of general health, emotional-well-being, and had role limitations due to emotional problems, and social functioning, six months after the completion of definitive surgery.

A qualitative study investigated the role of partner support and changes in relationships during cancer from the perspective of women with cancer (Sormanti & Kayser, 2000). Just over half (57%) of the women perceived the support received from their partners as adequate; the remainder reported that their partners could have been more supportive. The large majority of women reported that the support received from their partners helped them cope with cancer's psychological demands. Furthermore, it is important to note that additional emotional support was the most desired for a considerable number of women compared to the other three types of support: instrumental support, medical support, and medical presence. This is an interesting finding because emotional support was also the type of support received from partners mostly. The finding reveals women's substantial need for emotional support for coping with cancer, which has also been demonstrated by other studies with breast cancer patients and their partners (Helgeson & Cohen, 1996).

As many studies have investigated the role of partner support in women's psychological adjustment, little is known about the social support systems of breast cancer patients without partners (Ginter & Braun, 2019). A qualitative study investigated how women without partners navigate social support challenges following their breast cancer diagnoses among 20 women. They found that caregivers may vary for women who do not have intimate partners. Women without partners reported their siblings, children, and occasionally parents as their caregivers, but had a less built-in support system than a spouse or intimate partner supporting them. Within family systems, patients' siblings provided the most support, including emotional and instrumental support. While siblings could step in and provide emotional support, many parents, particularly mothers, were unable to cope with the knowledge that their daughters had breast cancer, and as a result, turned

away from them. Mothers' reactions, in turn, hurt participants regardless of understanding the reasons behind their mothers' avoidance (Ginter & Braun, 2019).

Given the critical impact of perceived support on women's psychological adjustment (Manne, 1999; Manne et al., 2014; Holmberg, Scott, Alexy, & Fife, 2001; Segrin et al., 2007; Sormanti & Kayser, 2000; Templeton, 2008), psychological interventions should target improving perceptions of social support to help breast cancer survivors deal with psychological distress more effectively.

1.11.3. Cancer-Related Communication Between Survivors and Their Carers

Open communication includes disclosure of thoughts, information, and feelings, whereas avoiding communication is deciding not to discuss particular issues and topics, withholding some details (Goldsmith, Miller, & Caughlin, 2007). Cancer-related communication includes the meaning of breast cancer, feelings, changes in daily life, relationship issues, plans for the future, treatment, side-effects of treatment, concerns about recurrence or spread, sex, sexuality, body image, household burdens, and death.

To date, several studies in the literature have conceptualised communication as part of relational coping and evaluated whether and how mutual communication about cancer influences psychological distress (Li & Loke, 2014; Manne et al., 2006; Tiete et al., 2020) and relationship satisfaction (Manne et al., 2006) and intimacy (Manne, Siegel, Kashy, & Heckman, 2014). These studies suggest that open and mutual cancer-related communication between survivors and their carers is critical for their psychological adaptation and well-being. However, cancer-related communication may not be easy for survivors and their carers; studies reported that 14 to 43% of people experience cancer-related communication problems (Tiete et al., 2020). In Keller et al.'s (1996) study, talking about the illness was a difficulty reported by 21% of partners and 11% of patients (as cited in Kornblith et al., 2006). Similarly, 20% of informal carers reported that they could

only talk to the patient about the illness 'a little'; it was even more difficult, especially when cancer had recurred, or the patient was in palliative care in only phase (Thomas, Morris, & Harman, 2002).

Research shows that couples find it difficult to communicate openly and sensitively about their breast cancer-related concerns due to multiple reasons such as to protect oneself or one's partner from the discomfort of discussing difficult cancer-related topics, prevent unproductive discussions, and to maintain normality and optimism (Goldsmith & Miller, 2014; Goldsmith et al., 2007; Kornblith et al., 2006). Some women with breast cancer avoid cancer-related communication also because of unsupportive responses from their partners (Manne, Winkel, et al., 2005). For example, spouses criticising how a woman is coping with breast cancer, undermining the severity of illness, or changing the topic when a woman starts talking about a cancer-related concern may discourage women from communicating about their concerns and feelings (Yu & Sherman, 2015). For other women, emotional isolation is viewed as the norm because of multiple fear of burdening loved ones and not wanting to give an impression that they were giving up (Kornblith et al., 2006; Northouse et al., 2002).

1.11.4. Cancer-Related Communication and Psychological Distress

Although the literature in this area is scarce, emerging literature has evaluated the effects of cancer related-communication on breast cancer patients and their carers' psychological distress (Donovan-Kicken & Caughlin, 2011; Goldsmith et al., 2007; Li & Loke, 2014; Manne & Badr, 2008; Manne et al., 2006; Yu & Sherman, 2015). For example, in a recent review of the literature on the mutual impact of communication, reciprocal influence, and congruence between caregiver-cancer patients dyads, it was found that the quality of the communication and the nature of the relationship between patients and caregivers is important (Li & Loke, 2014). Patients' and caregivers' satisfaction with the communication with each other was associated with lower distress and better marital adjustment.

Manne et al. (2006) examined the relationship between psychological distress, relationship satisfaction, and three types of communication strategies (mutual constructive communication, mutual avoidance, and demand-withdraw communication) used by 147 women and 127 partners during and after breast cancer treatment. They found that mutually constructive communication (e.g., open discussion of cancer-related topics, expressing feelings and concerns related to cancer, and attempting to find a solution) was associated with less psychological distress and higher relationship satisfaction for both. In contrast, demand-withdraw communication (e.g. one partner pressures the other partner to talk about a cancer-related issue, while the other partner withdraws) was associated with more psychological distress and less relationship satisfaction for both. Mutual avoidance was also associated with higher psychological distress for both patient and partner, but it was not associated with relationship satisfaction. These suggest that improving mutually constructive communication and preventing demand-withdraw communication and mutual avoidance between women living with breast cancer and carers may help reduce survivors' distress.

Another study investigated whether breast cancer patients' avoidance of talking about cancer affects their psychological distress through certain coping behaviours among 140 women undergoing treatment or who had recently completed treatment for breast cancer (Donovan-Kicken & Caughlin, 2011). The more patients avoided cancer-related communication, the less they received emotional support from others, which was in turn associated with higher depression and anxiety. Moreover, patients who avoided cancer-related communication tended to blame themselves more for having cancer, and self-blame, in turn, was associated with higher depression and anxiety. In addition, the more patients avoided cancer-related communication, the harder it was for them to accept the illness, and lower levels of acceptance were associated with greater depression and anxiety. Therefore, avoiding communication about breast cancer can be associated with increased psychological distress by decreasing women's use of emotional support and acceptance and increasing their self-blame.

Yu and Sherman (2015) examined the relationship between communication avoidance of cancer-related topics and psychological distress and the mediating role of coping in this relationship among 338 women diagnosed with breast cancer. The results showed that higher self- and perceived-partner communication avoidance predicted greater psychological distress through passive coping strategies, including greater disengagement and lower engagement coping. The most avoided topics were emotionally valenced ones, such as disease progression and sexuality, whereas practical ones were the least avoided topics. They suggested enhancing cancer-related communication and women's adaptive coping skills by discouraging the use of disengagement coping strategies and encouraging engagement coping strategies for psychosocial interventions to alleviate psychological distress.

A recent randomised pilot trial evaluated the efficacy of a 4-week intervention to improve communication between patients with cancer and their caregivers and its effects on psychological distress levels among 64 patient-caregiver dyads (Tiete et al., 2020). The brief dyadic communication intervention was feasible and acceptable for couples coping with cancer. However, they did not find a significant reduction in psychological distress in couples who received the intervention. They concluded that dyadic interventions focusing on problem-solving and communication skills improvement might not be enough to reduce emotional distress.

Taken together, the studies mentioned above suggest that open and mutual cancer-related communication between survivors and carers may reduce breast cancer survivors' depression and anxiety symptoms; however, interventions focusing only on improving the communication between survivors and carers may not be enough to decrease their emotional distress. Therefore, interventions providing skills to manage depression and anxiety and having additional components to enhance open communication may be more beneficial. Carer involvement in psychological interventions may promote open communication about cancer-related issues and help to reduce the psychological distress of breast cancer survivors.

Overall, multiple factors such as coping strategies, perceived social support, cancer-related communication between survivors and their carers contribute to the levels of psychological distress in breast cancer survivors. Therefore, interventions should target breaking the pathways between stressors and intervene to remove or decrease their effect on survivor's psychological distress. Based on the literature review, breast cancer survivors' psychological distress may be alleviated through enhancing survivors' perceived social support, encouraging the use of active coping strategies, and open communication about cancer-related concerns between survivors and carers.

1.12. Treatment of Depression and Anxiety in Breast Cancer Survivors

1.12.1. Cognitive Behavioural Therapy (CBT)

Different psychotherapy approaches have been used in order to help individuals with cancer cope with psychological problems. Of these, cognitive behavioural therapy (CBT) has proven its well-established effectiveness in the treatment of depression and anxiety among individuals with cancer (Brothers, Yang, Strunk, & Andersen, 2011; Groarke, Curtis, & Kerin, 2013; Hopko et al., 2008; Horne & Watson, 2011; Osborn, Demoncada, & Feuerstein, 2006; Tatrow & Montgomery, 2006; Xiao et al., 2017; Ye et al., 2018). Horne and Watson (2011) reported that there had been concerted attempts in recent years to include CBT as part of the enhancement of cancer patients' psychological care. The fundamental aim of CBT in the treatment of psychological distress is to make people aware of how their cognitive distortions and irrational thinking patterns negatively influence their ability to cope with stress and then to help them identify their own distorted beliefs and negative automatic thoughts, and to challenge and modify them in the light of the current or previous behaviours of themselves and others; often resulting in improvement in mood and depressive symptoms (Horne & Watson, 2011).

The cognitive theory underlying CBT proposes that dysfunctional thinking is common in all psychological disturbances affecting the patients' mood and behaviour. According to the cognitive

model, when individuals learn to evaluate their thinking and start thinking more realistically and adaptively, their emotional state and behaviours will improve. For instance, if a cancer survivor is feeling quite depressed while watching a TV programme about cancer recurrence, she might have an automatic thought, an idea that just seemed to pop in her mind: "Although they say I am currently free from cancer, I'm sure that I'll die from this cancer". This thought may result in a particular reaction: she may feel sad (emotion) and go to bed to escape and be unable to sleep (behaviour). If she then examines the validity of this idea in a more realistic way, she may conclude that she had catastrophised and that, in fact, she is doing well since her treatments have ended and the likelihood of such a negative consequence is very minimal. Looking at herself from this new, realistic perspective would probably make her feel better and bring about more functional and adaptive behaviour.

CBT is often adapted for cancer patients to focus on problem-solving, where issues are targeted and resolved by using techniques that impact thinking and the intensity of negative ruminations. CBT has some main techniques used throughout each session, such as Socratic questioning, summary, and homework (Horne & Watson, 2011). A significant part of CBT consists of self-monitoring of thoughts and conducting behavioural experiments to test what actually works in a real-life environment. Content-related techniques of CBT can be divided into cognitive and behavioural, which are interlinked and influence each other.

Cognitive techniques include identifying automatic thoughts, associated feelings and behaviours using a thought diary and the practice of responding to automatic thoughts in more constructive and helpful ways. The therapist helps the client understand his/her own situation by providing some education about the disorder, which includes explaining how thoughts affect mood and behaviour by giving examples from the client's own thinking patterns. In this way, the skills model of coping is introduced to the patient. Psychoeducation also includes descriptions of identifying negative automatic thoughts and thinking errors.

The primary behavioural technique used in CBT is behavioural activation (Horne & Watson, 2011). As depressed patients often withdraw from daily activities that had previously given them pleasure, sense of achievement and lifted their mood, one of the most important initial goals for patients with depression is scheduling activities (Beck, 2011). For this purpose, a diary sheet is mostly used where the patients list the things they are doing and their associated mood for a one or two-week period (Horne & Watson, 2011). It helps therapists see if the patient is under-occupied and helps patients notice how mood differs depending on what they are doing. For instance, for breast cancer survivors who completed their treatments, activity schedules can be planned by negotiating which regular routines can be put back into their lives. Another behavioural technique is distraction, a useful mood limiting technique that introduces the idea of “thought stopping”, which helps patients limit difficult and uncomfortable thoughts. This technique can be introduced to use in difficult situations when negative thoughts have a realistic basis. For example, some negative thoughts that advanced breast cancer survivors may have a realistic basis, such as the possibility of treatment failure.

Acceptance and Commitment Therapy (ACT) is a third wave of cognitive and behavioural therapies that focuses on increasing psychological flexibility and enabling a person to act effectively with their distressing symptoms (Hayes, 2004). Although the ACT approach was not used in the present thesis, it is also commonly used in the psychological treatment of individuals with cancer. ACT is different from CBT in that it aims to change a person’s relationship with their thoughts rather than changing the content of the thoughts, choose actions that are consistent with their values, rather than choosing actions to reduce symptoms. ACT uses acceptance, mindfulness, and behavioural techniques. According to the acceptance and commitment theory, acceptance is the active and non-judgemental embracement of the here and now experience. Acceptance means actively experiencing events as they are, not as what others say they are. There is an emphasis on values in the ACT approach, which distinguishes it from other treatment approaches. ACT suggests that only within the

context of values action, acceptance and defusion can create a sensible whole. Therefore treatment involves listing values in different life domains; for example, family, relationships, spirituality, and health, and motivating actions in meaningful life directions. Another important aspect of the ACT is commitment. It aims to help individuals build flexible and effective responses by reducing or eliminating experiential avoidance and encouraging patterns of action that is in line with one's values in life. ACT was consistently shown to be effective among individuals with cancer. A recent systematic review and meta-analysis of thirteen trials with patients with breast cancer showed that ACT has moderate to large effects in reducing anxiety, depression, and stress and improving hope. However, they suggested that the evidence on the effectiveness of ACT on physiological symptoms, fear of cancer recurrence, and psychological flexibility needs to be treated with caution.

1.12.2. Effectiveness of CBT in Breast Cancer

The effectiveness of CBT among women with breast cancer has been evaluated in three different meta-analyses and was found effective for depression, anxiety, and other important outcomes. In their meta-analysis of 20 studies, Tatrow and Montgomery (2006) included only the studies that used CBT techniques targeting distress and pain among breast cancer patients. For distress, the meta-analysis yielded an effect size of 0.31, indicating that 62% of breast cancer patients in CBT treatment groups had a significant reduction in distress levels. For pain, an effect size of 0.49 was found, indicating that 69% of breast cancer patients had less pain after receiving CBT treatment. The analyses also revealed that individually delivered treatment approaches are significantly more effective for improving distress among breast cancer patients compared to group treatments.

In a more recent meta-analysis of 13 randomized controlled trials with major depression as the main outcome variable, Xiao and colleagues (2017) examined the effectiveness of CBT among women who underwent breast cancer surgery. The meta-analysis based on three outcome measures of Self-Rating Depression Scale (Zung, 1965), Hospital Anxiety and Depression Scale (HADS; Zigmond

& Snaith, 1983), and Hamilton Depression Rating Scale (HAM-D; Hamilton, 1960) yielded a large effect size of -0.87 (out of 8 studies), a moderate effect size of -0.50 (out of 3 studies), and a very large effect size of -2.61 (out of 2 studies), respectively and a large overall effect size for individually delivered CBT in decreasing depression among breast cancer patients. Individually delivered CBT was effective in reducing depression among breast cancer patients in the post-operative period.

Another meta-analysis of 10 randomized controlled trials of CBT, in which depression, anxiety, quality of life, stress, and hyperarousal cluster of symptoms were the main outcome variables, provided additional support for the effectiveness of CBT in breast cancer patients (Ye et al., 2018). Outcomes revealed statistically significant effect sizes for depression (-1.11), anxiety (-1.10), quality of life (0.57), and stress (-0.40). The effect of CBT on depression and anxiety was considered as large and on quality of life as medium.

Besides the demonstrated short-term effectiveness of CBT, CBT techniques were also effective in the long-term on depression and quality of life outcomes of breast cancer patients. Stagl and colleagues (2015) conducted a randomized controlled trial with an 11-year follow-up to examine the long-term psychological benefits of a 10-week, group-based cognitive-behavioural stress management programme among women with stage 0 to IIIb breast cancer who underwent surgery. Their results revealed that women who received the stress management programme after surgery had lower depressive symptoms ($d = 0.63$) and higher quality of life ($d = 0.58$) than the control group at 8 to 15 years follow-up. Nonetheless, results should be interpreted with caution since women in the follow-up were older and had fewer depressive symptoms at the time of diagnosis than those who did not participate in the follow-up. Based on the results, they suggested that early implementation of CBT interventions can have long-term benefits on the psychosocial functioning of breast cancer survivors.

Despite the effectiveness of CBT in treating depression and anxiety symptoms among breast cancer survivors, there is a constant challenge for the adequate provision of evidence-based

treatments (Etzelmueller, Radkovsky, Hannig, Berking, & Ebert, 2018). The challenge stems from the costs, distance to service locations, perceived personal stigma of mental disorders and treatments, lack of trained therapists, inadequate treatment, delayed treatment provision (Kessler et al., 2001; Mohr et al., 2010; Wang et al., 2007; Wittchen et al., 2011). For example, in Ireland, people with depression reported facing additional challenges due to a shortage of trained professionals in addition to relatively underdeveloped health services (Department of Health and Children, 2006). Niedzwiedz et al. (2019) reported that a key barrier is the lack of physician time to assess depression and anxiety symptoms. The normalisation of distress and attribution of the somatic distress symptoms to cancer could also be barriers.

1.12.3. Internet-Delivered Cognitive Behavioural Therapy (iCBT)

To overcome the limitations of traditional face-to-face treatments and to have greater access to psychological treatments, new ways to deliver CBT have been developed during the last 15 years (Andersson, 2009). Of these, the use of the internet in providing psychological interventions has been the most common approach in studies. The most researched and supported form of digital treatments are based on the CBT approach (Arnberg, Linton, Hultcrantz, Heintz, & Jonsson, 2014; Fairburn & Patel, 2017). There are many different variations of CBT programmes using the internet. Various terms have been used such as online CBT, web-based CBT, computer-based CBT, computerised CBT, internet-based CBT, and internet-delivered CBT.

In iCBT programmes, the same content and principles of CBT (psychoeducation, cognitive and behavioural strategies) used in traditional face-to-face therapy are delivered using structured modules written in text and presented with pictures, animations, audio files, and videos (Salamanca-Sanabria et al., 2018). These interventions are highly structured and involve psychoeducation, explanation of CBT model, encourage tasks between sessions, use thought challenging and monitoring of thinking patterns, feelings and behaviours, and adjuvant resources such as

asynchronous messaging option with a supporter (National Institute for Health and Care, 2009). The techniques used in traditional CBT are also used in iCBT interventions without face-to-face contact with a psychotherapist. The key emphasis of CBT in the low-intensity interventions is on the value of between-session homework and assessment, monitoring, and evaluation of the progress (Christen, 2010).

iCBT programmes can be entirely self-guided without any supporter contact, or users may receive therapist or supporter contact via asynchronous e-mails, synchronous online chat, or phone calls (Synnot, Hill, Summers, & Taylor, 2014). Synchronous interaction involves real-time contact between the users and therapists, such as contact via phone, video, or messenger services. In contrast, asynchronous interaction involves delayed interaction, such as secure email communications during treatment (Andersson & Titov, 2014), in which therapist and user do not have to be online simultaneously.

iCBT interventions have distinct advantages over traditional services for patients with mental health problems including increased access or speed of access to evidence-based treatment, increased number of people who can access these treatments, service flexibility, responsiveness, and capacity, patient choice, and cost-effectiveness of services (Bennett-Levy, Richards, & Farrand, 2010). For example, McCrone et al. (2004) examined the cost-effectiveness of iCBT for anxiety and depression in primary care by comparing iCBT ($n = 146$) with treatment-as-usual ($n = 128$) among people with depression or anxiety. They found that the costs were £ 40 higher (90% CI = £ 28 to £ 148) for people who received iCBT over 8 months. However, lost employment costs were £ 407 less (90% CI = £ 196 to £ 586) for these people. iCBT was clinically superior to treatment-as-usual with negligible additional cost with a modest decrease in depression scores. A systematic review of 16 studies by Donker et al. (2015) conducted an economic evaluation of internet-delivered interventions for psychological disorders, including depression and anxiety, among other disorders. Most of the included studies used CBT as the treatment model and were guided (had support from a coach or

therapist). Results demonstrated that guided internet interventions for depression and anxiety were more cost-effective than wait-list, treatment-as-usual, group cognitive behaviour therapy, attention control, telephone counselling, or unguided iCBT (Donker, Blankers, Hedman, Ljótsson, et al., 2015).

Besides the advantages, it is also important to acknowledge the potential disadvantages of internet-based delivery, including the potential for individuals not to seek face-to-face help because of the belief that the internet alone will be enough, the lack of legislation around privacy, confidentiality and consent, problems of engagement, high rate of attrition, and lack of continuity of care (Christen, 2010). Low adherence and high dropouts are the most important challenges of digital health interventions (Karekla et al., 2019). Compared to traditional interventions, nearly twice as many users with chronic illnesses drop out from self-guided interventions, which does not provide any human or computer support (Macea, Gajos, Daglia Calil, & Fregni, 2010). On the other hand, guided iCBT interventions providing support through an actual therapist e-mail or an animated digital character to guide the user through content have been found to have similar adherence rates (83.9% of the treatment was completed) with face-to-face CBT interventions (80.8% of the treatment was completed) (van Ballegooijen et al., 2014).

Overall, iCBT is a cost-effective treatment option and has distinct advantages over traditional face-to-face CBT modalities. These include the convenience of time and space, anonymity, self-management solutions, and less dependency on others for transportation, as well as disadvantages, such as low adherence and high drop-out rates. Although there is a lack of awareness regarding the ways to comprehensively address these drawbacks, minimization of poor adherence and high drop-out rates might be possible when working with populations with chronic illness by following the recommendations for best practices (Karekla et al., 2019).

1.12.4. Effectiveness of iCBT on Depression and Anxiety

As with the growing body of literature in the field of internet interventions, an increasing number of studies investigated the effects of the iCBT for depression and/or anxiety, and indicated positive results (Andersson, 2018). The clinical guideline published by the National Institute for Health and Clinical Excellence (2009) recommends iCBT as a treatment option for mild to moderate depression.

The first systematic review and meta-analysis that evaluated the effectiveness of iCBT on depression, was conducted by Richards and Richardson (2012). Their systematic review of RCTs of computer-based interventions for depression included 40 studies, and 19 RCTs were included in the meta-analysis. The inclusion criteria were extensive: studies using different variations of computer-based technologies for depression, with different types of communication employed (synchronous, asynchronous, and face-to-face), as well as with various methods and frequency of support (self-administered or therapist-led, or blended delivery using both formats) were included. Participants had depression (diagnosis or self-report), with or without comorbidities such as anxiety or physical health problems. The results across 19 studies indicated a moderate effect, Cohen's $d = 0.56$. Therapist-supported interventions ($d = 0.78$) and administrative-supported interventions ($d = 0.58$) were more effective in terms of improvement of depression symptoms and had greater retention compared to studies without support ($d = 0.36$), in which the effect size was also lower. However, the overall effect size across 14 studies at follow-up ($d = 0.20$) was considerably smaller than those at post-treatment, suggesting that computer-based treatments may have relatively short-term benefits. It may also be due to varying follow-up periods in the studies included.

Among internet-based interventions, iCBT with guidance/therapist support has been consistently found as more effective and beneficial for patients compared to self-guided or unguided internet interventions (Andersson & Cuijpers, 2009; Baumeister, Reichler, Munzinger, & Lin, 2014; Richards & Richardson, 2012; Spek et al., 2007). In their meta-analysis, Spek et al. (2007) found that

internet-based interventions with therapist support had a large effect; whereas, treatments without support had a small effect. Their results were confirmed by another meta-analysis, in which computerized interventions with support had an effect size of $d = 0.61$; whereas, unsupported interventions had a much smaller effect of $d = 0.25$ (Andersson & Cuijpers, 2009). Similarly, Baumeister et al. (2014) found that guided interventions ($d = -0.27$) revealed better results compared to unguided ones ($d = -0.15$) in individuals with depression, yet with a smaller difference than suggested before (Richards & Richardson, 2012).

Another important finding from Richards and Richardson's study (2012) is that the type of support given did not differentiate the effect on the outcome. Even though the support was not given by a mental health professional and did not have the aim of being therapeutic, it had similar benefits as therapist-supported interventions. Likewise, Titov et al. (2013) found no difference between clinician- and technician-supported internet-delivered treatment for depression. Both resulted in large effect sizes and had high levels of acceptability.

A recent Cochrane meta-analysis, including 20 studies with a total of 1418 participants, compared the effectiveness of guided iCBT interventions to face-to-face CBT interventions for psychiatric and somatic disorders (Carlbring, Andersson, Cuijpers, Riper, & Hedman-Lagerlöf, 2018). All included studies compared the effects of iCBT with some form of CBT (10 individual and 10 group format) on different conditions such as depressive symptoms, social anxiety disorder, and panic disorder. Results indicated that iCBT and face-to-face treatment have equivalent overall effects. No significant difference was found between the two treatment formats in terms of drop-out rates. However, out of 20 studies, only three were judged as having a low risk of bias according to quality assessment in terms of random sequence generation, allocation concealment, blinding of outcome assessment, data completion, and reporting bias.

As regards the iCBT effectiveness studies on anxiety problems, a systematic review was conducted on therapist-supported iCBT for anxiety disorders in adults in 38 RCTs for a variety of

anxiety disorder diagnoses such as social phobia, panic disorder, generalized anxiety disorder, post-traumatic stress disorder, obsessive-compulsive disorder and specific phobia (Olthuis, Watt, Bailey, & Hayden, 2016). Three main comparisons between groups were conducted: therapist-supported iCBT versus waiting-list control, therapist-supported versus unguided iCBT, and therapist-supported iCBT versus face-to-face CBT. The therapist-supported iCBT had more clinical improvement in anxiety, disorder-specific anxiety, and general anxiety at post-treatment than waiting list. However, the quality of evidence was low. In the second comparison, no difference was found between therapist-supported iCBT and unguided iCBT for anxiety, disorder-specific anxiety, and general anxiety symptoms; again, with low-quality evidence. In the third comparison, compared to face-to-face intervention, therapist-supported iCBT was not different in terms of improvement in anxiety, disorder-specific anxiety symptoms, and general anxiety symptoms at post-treatment.

A systematic review and meta-analysis conducted by Richards, Richardson, Timulak, and McElvaney (2015) evaluated the efficacy of internet-delivered treatment for generalised anxiety disorder with 20 studies in the systematic review and 11 RCTs in the meta-analysis. Among these, 9 studies used CBT-based treatment protocols, 7 used transdiagnostic protocol, and 4 used disorder-specific treatment protocol. The results revealed that a significant positive post-treatment effect for generalised anxiety disorder symptoms and pathological worry compared to the waiting-list control group. The findings supported the efficacy of CBT-based treatment protocols as well as transdiagnostic and disorder-specific protocols.

In a study investigating the trajectories of change on psychological distress in patients with depression and generalised anxiety disorder, it was found that distress symptoms decreased throughout each module in people who completed the 6-week iCBT programme (Sunderland, Wong, Hilvert-Bruce, & Andrews, 2012). The decrease in psychological distress was curvilinear during the progression of the programme, meaning that the greatest reduction in psychological distress was observed between the first few modules and a slight decrease followed it in the following modules.

Among the participants, two different trajectories of change were identified. While a large group responded well to the treatment modules, a smaller group had a lower response. The significant differences between these two groups were their level of psychological distress and symptom severity at baseline. Low responders tend to have higher symptom severity and psychological distress at baseline compared to those who responded well. The study indicates that most participants (ranging between 75 to 80%) benefit from iCBT programmes for depression and anxiety, prescribed by general practitioners and mental health specialists. iCBT can be used as an initial step within a stepped care model treatment and patients who did not respond well to iCBT can be further provided high-intensity treatments like face-to-face therapy or medication.

To sum up, evidence in the literature suggests that iCBT is a clinically effective treatment for reducing mild-to-moderate depression and anxiety symptoms as long as individuals are guided in the programme with the help of a therapist or supporter. As argued in a recent study, the evidence for the effectiveness of iCBT for severe symptoms is less established in the literature (Richards, Duffy, Burke, et al., 2018).

1.12.5. Effectiveness of iCBT for Depression and Anxiety in Cancer Survivors

Although there is well-established evidence favouring guided iCBT for depression and anxiety in the general population, no RCT to date evaluated the effectiveness of an iCBT programme for depression and anxiety specifically in breast cancer survivors. Internet interventions designed specifically for breast cancer survivors have so far focused on insomnia (Dozeman, Verdonck-de Leeuw, Savard, & van Straten, 2017a; Zachariae et al., 2018), sexual dysfunction (Hummel et al., 2018), body image (Hummel et al., 2018), treatment-induced menopausal symptoms (Atema, Leeuwen, Kieffer, & Oldenburg, 2019; Atema, Leeuwen, et al., 2016), and fatigue (Harriët J.G. Abrahams et al., 2017). Internet interventions aiming to reduce depression and anxiety symptoms among cancer survivors are also scarce with only a few RCTs (Alberts, Hadjistavropoulos, Dear, &

Titov, 2017; Murphy et al., 2019; Willems, Mesters, Lechner, Kanera, & Bolman, 2017). These studies included survivors with all cancer types, and were not specific to breast cancer survivors.

One RCT in Australia investigated the effectiveness of an iCBT intervention for depression and anxiety in cancer survivors (Murphy et al., 2019). The study investigated the effects of iCBT for clinical depression and/or anxiety in 114 survivors with early-stage cancer in Australia (*iCanADAPT Early*) by comparing clinician-supervised iCBT and treatment-as-usual. The majority of the participants were breast cancer survivors (67%); the rest had prostate (5%), gynaecological (6%), lymphoma (5%), bowel (4%), melanoma (4%), and other (11%) cancer types. The intervention included an 8-lesson programme completed over 16 weeks. It consisted of general and cancer-specific CBT skills. The findings showed that survivors in the iCBT group had a greater decrease in their depression and anxiety symptoms over time than the TAU group. Furthermore, the iCBT group reported lower general distress, fear of recurrence, and better quality of life at post-treatment compared to the treatment-as-usual. These findings suggest the effectiveness of clinician-supervised iCBT for clinical depression and anxiety in cancer survivors.

An RCT in Netherlands compared the short-term effectiveness of an adapted iCBT and waiting list control group on 339 cancer survivors' depression, anxiety, quality of life, and fatigue (Willems et al., 2017). The content of the intervention modules was based on principles of problem-solving therapy and CBT approaches. On average, participants in the intervention used 2.22 modules. The iCBT programme was found effective in reducing depression and fatigue, and improving emotional and social functioning of survivors 6 months after the baseline assessments, however, with small effect sizes. No significant effect of the intervention was found for anxiety and quality of life. As the participants in the study had a relatively good overall quality of life at the baseline, it was suggested that lower functioning of survivors at baseline would result in greater effects.

A feasibility trial was conducted with 15 recent cancer survivors in Canada to investigate the effects of an iCBT programme on depression and anxiety (*The Wellbeing Course*) (Alberts et al., 2017).

Participants had breast (38.9%), colon (11.1%), non-hodgkin lymphoma (11.1%), and other (39.2%) cancer types. The programme consisted of 5 online lessons completed over the course of 8 weeks. Participants who received the intervention had statistically significant improvements from pre-treatment to post-treatment on depression symptoms. Results also revealed that 64% of the participants met the criteria for reliable improvement and 55% had reliable recovery on depressive symptoms at post-treatment. Similarly, 64% met the criteria for reliable recovery and improvement on anxiety symptoms. Participants were also highly satisfied with the treatment, with 77% (14/18) reporting either satisfied or very satisfied. All participants thought that it was worth their time and they would recommend the intervention to others.

There are also some iCBT studies that did not target depression and anxiety together, but focused on depression (Duffececay et al., 2013) or distress (Beatty, Koczwara, & Wade, 2016). For example, Beatty et al. (2016) evaluated the efficacy of a 6-week self-guided iCBT intervention (*Cancer Coping Online*) as compared to the attention control group among 60 people recently diagnosed with cancer. The attention control group had the information-only version of the intervention, included the information about the same six topics, but without worksheets, activities, relaxation/meditation exercises, or journal. They found that the iCBT group had lower levels of cancer stress, anxious preoccupation at post-intervention, and better global quality of life at 6-month follow-up, with small to moderate between-effect sizes. They concluded that their iCBT intervention is promising in decreasing cancer-specific distress, and improving coping and aspects of health-related quality of life. Nevertheless, caution was advised in the interpretation of their findings, as the study lacked the power to detect statistically significant interactions, and participants reported low levels of distress at baseline. They also suggested that the use of interventions tailored specifically for cancer types may increase the levels of treatment adherence.

In Duffececay et al.'s (2013) study, the feasibility and acceptability of an 8-week iCBT integrated into an internet support group were compared to unguided iCBT alone in 31 post-treatment cancer

survivors. The intervention aimed to increase efficacy and adherence by adding a support group consisting of other cancer survivors. It consisted of CBT techniques and interactive tools to support the implementation of CBT skills such as mood, activity, and thought diaries. The findings revealed that among patients meeting the depression criteria, both iCBT combined with an internet support group and iCBT only group had a large decrease in their depressive symptoms. A similar pattern was observed in the full sample including non-depressive individuals, although the change was smaller than the depressed sample. However; there was no significant time and treatment interaction. The overall feedback was positive specifically on the usefulness of the CBT framework. Participants in the combined iCBT and internet support group found it useful to share their thoughts with other cancer survivors. Indeed, most of them emphasized that giving and receiving support was the main reason for them to participate in this programme. Nevertheless, it may be premature to make any decision about the efficacy of intervention considering the low power due to the small sample size, no control group, and ambiguity about cancer types, cancer stages, and its distribution among the intervention groups.

Taken together, evidence on the effectiveness of iCBT in cancer survivors seems promising; however, is still insufficient. More RCTs are needed to draw conclusions on the effectiveness of iCBT for depression and anxiety for breast cancer survivors (or cancer survivors). Considering the gap in the literature on the effectiveness studies and the qualitative studies on the acceptability of iCBT for depression and anxiety in breast cancer survivors, it is critical to first explore and evaluate the acceptability of iCBT intervention format and how an iCBT programme would fit the needs of breast cancer survivors, before evaluating its effectiveness.

In conclusion, according to the literature review mentioned in this chapter, many breast cancer survivors experience psychological distress. The use of coping strategies (active vs. avoidant) and perceived social support contributes to the development and maintenance of their depression and anxiety symptoms. Informal carers play a critical role as the support they provide and their

communication patterns (open communication or avoidance) determine women's psychological distress. Therefore, an iCBT intervention focusing mainly on reducing survivors' depression and anxiety symptoms and encouraging open cancer-related communication with the inclusion of carer in the iCBT treatment may be beneficial. Findings support the clinical and cost-effectiveness of guided iCBT for depression and anxiety in individuals with cancer; however, its effectiveness and acceptability on breast cancer survivors' depression and anxiety and inclusion of carers in the iCBT interventions have not been investigated in the literature yet.

1.13. The Need for the Present Study

There are some important gaps in the literature that the present study aims to fill. First of all, to date and the researcher's knowledge, no study has qualitatively examined the perspectives of women with breast cancer and their carers about the acceptability of iCBT and carer inclusion in the treatment. Work is needed to examine the acceptability of iCBT and carer inclusion before the development or adaptation of any interventions. Secondly, even though the findings on the effectiveness of iCBT intervention programmes among cancer patients seem promising, the evidence is limited to the studies in Australia (Murphy et al., 2019) and Canada (Alberts et al., 2017). Further work is needed to provide robust support specifically for cancer survivors in Europe for differences in healthcare systems. Thirdly, although the critical importance of carer support for women's distress was shown, and studies suggested active participation of carers in the intervention, there is no well-established evidence on the added benefits of including carers to iCBT, using an individual-focused approach. No study to date has examined if there are added benefits of including carers for the cancer-related communication between women and carers and psychological distress of women with breast cancer. Lastly, studies on internet-interventions conducted in breast cancer patients have focused on insomnia (Dozeman, Verdonck-de Leeuw, Savard, & van Straten, 2017; Zachariae et al., 2018), sexual dysfunction (Hummel et al., 2015), body image (Hummel et al., 2018), treatment-

induced menopausal symptoms (Atema, van Leeuwen, et al., 2016), and fatigue (Abrahams et al., 2017); however, no research has examined the outcomes of depression and anxiety symptoms.

Understanding the mechanisms of change in iCBT that accounts for the changes in breast cancer patients' depression and anxiety symptoms is key when developing or adapting the interventions. The evidence for what makes psychotherapy work reveals that mechanisms of change include both general and specific factors (Wampold & Imel, 2015). General factors comprise therapeutic alliance, credibility of treatment, and belief about the potential of intervention. Specific factors consist of cognitive and meta-cognitive mechanisms: change in dysfunctional attitudes, repetitive negative thinking patterns, improvement in emotion regulation abilities, cognitive and behavioural treatment skills usage, and therapist behaviours (Wampold & Imel, 2015). In the light of the literature review above, it can be said that positive change in survivors' coping can contribute to improvement in depression and anxiety symptoms of survivors. Therefore, iCBT focusing on replacing unhelpful coping behaviours with more functional ones, may be acceptable and effective.

1.14. Aims of the Present Study

In light of the findings and gaps in the literature, the main aims of the present study are to evaluate the acceptability and effectiveness of an iCBT programme for depression and anxiety in breast cancer survivors and of giving main carers access to the same intervention programme. This project consists of four studies. Study I focuses on the qualitative evaluation of the perceived acceptability of an iCBT programme and carer access to treatment for breast cancer survivors and their main carers. Study II adapted an already established intervention, *Space from Depression and Anxiety*, for breast cancer survivors with and without main carers. Study III is an RCT comparing the effectiveness of the adapted iCBT programme with and without carer access, and treatment-as-usual for depression and anxiety in breast cancer survivors. Study IV qualitatively evaluated experienced

acceptability of the adapted iCBT programme, survivors' experiences of using it, and supporters' experiences with their role. Each study is described in detail in the following chapters, respectively.

CHAPTER 2

Study I: Breast cancer survivors' and their carers' perceptions of an Internet-delivered cognitive behavioural therapy and carer access to the treatment

2.1. Introduction

As mentioned earlier in Chapter 1, studies have revealed that about 1 of every 2 people with breast cancer are at risk of being diagnosed with major depressive disorder (Zainal et al., 2013) and anxiety (Segrin et al., 2007). However, many people with depression and anxiety cannot access treatment and remain untreated due to multiple barriers, including shortage of trained mental health professionals, time constraints, poor mobility, rural and remote location, and concerns about mental health stigma (Collins, Westra, Dozois, & Burns, 2004). Therefore, with the advancements in modern information technology, many psychologists and researchers have started to use the internet to improve access to psychological services (Andersson, 2018). Therapist-assisted, internet-delivered cognitive behavioural therapy (iCBT) is a promising approach to make evidence-based treatments more accessible (G. Andersson, 2010) ; Baumeister et al., 2014; Richards & Richardson, 2012).

Regarding best practices in digital interventions for chronic illnesses, Karekla et al. (2019) suggested a thorough assessment of the survivors' motivations to engage in the digital intervention before developing an intervention, especially when the target population has a severe chronic health condition and when psychological problems are present. In line with this, the UK Medical Research Council guidance for developing and evaluating complex interventions underlined the importance of assessing acceptability and feasibility before conducting a large scale study (Craig et al., 2008).

Acceptability has become an important domain to consider in designing, implementing, and evaluating internet-delivered interventions (Sanchez et al., 2019). It was described by Sekhon, Cartwright, and Francis (2017) as "a multi-faceted construct that reflects the extent to which people

delivering or receiving a healthcare intervention consider it to be appropriate based on anticipated or experienced cognitive and emotional responses to the intervention". The framework notes the distinction between perceived vs. experienced acceptability. It suggests that acceptability can be evaluated prospectively (pre-intervention) or retrospectively (post-intervention). Based on this framework, acceptability in the present study refers to survivors' and their carers' anticipated (prospective) responses to the intervention. Sekhon et al. (2017) suggested that the acceptability assessment prior to participation in the intervention can provide information regarding the aspects that need to be modified to increase acceptability and uptake.

Studies using a qualitative approach allow for deeper exploration of users' experiences and provide rich data on perspectives regarding acceptability of a programme that cannot be measured through quantitative methods. Therefore, qualitative studies are essential for developing effective iCBT programmes (Alberts, Hadjistavropoulos, Titov, & Dear, 2018). Indeed, developing or adapting an intervention before assessing its acceptability for a certain population or setting may result in the failure of the trial. Some trials on internet-delivered interventions (e.g., with women with menopausal problems (Lindh-Åstrand et al., 2015) and people with hearing loss (Manchaiah, Rönnerberg, Andersson, & Lunner, 2014)), failed because of problems with recruitment and retention of participants. Lindh-Åstrand and colleagues (2015) suggested that a pilot study with telephone interviews to check user-friendliness and the actual level of need for support before study commencement would have been helpful. In their publication on the lessons learned, Manchaiah et al. (2014) suggested investigating user preferences about the mode of treatment (face-to-face vs internet-delivered), understanding population characteristics, and help-seeking behaviour of the population before the intervention. They also suggested for future studies that it would be worthwhile to conduct a pilot or feasibility study before conducting an RCT.

Andersson (2018) recommended that programme developers involve the targeted users more in the development and updating of interventions, for example by asking them to give feedback

when designing interventions or by including them as active collaborators in the research. Despite the presence of failed trials on internet interventions (Lindh-Åstrand et al., 2015; Manchaiah et al., 2014), to the best of my knowledge, only two qualitative studies examined cancer survivors' perceptions of an iCBT programme for depression and anxiety; one prior to the intervention to assist the development of the intervention (Karageorge et al., 2017) and one at post-intervention to learn about user experiences with iCBT (Alberts et al., 2018).

Karageorge et al. (2017) conducted focus groups and individual interviews with people with early-stage cancer and cancer survivors to evaluate the acceptability of the preliminary version of a new 8-lesson, clinician-guided, iCBT programme (*iCanADAPT Early*) for the treatment of clinical depression and anxiety. Participants found the programme highly acceptable in terms of the internet delivery format, good engagement, and user-friendly material. They supported the idea of combining depression and anxiety iCBT resources for early-stage cancer survivors. In addition, they highlighted the need for a separate course to address the needs of people with advanced-stage cancer.

Alberts et al. (2018) assessed both survivors' and providers' perspectives about the transdiagnostic iCBT programme for depression and anxiety. They found that the majority of cancer survivors liked the flexibility, convenience and privacy of the programme. Many thought that programme helped them feel less alone following cancer treatment. However, finding time to complete the programme due to particular commitments and experiencing difficulties with concentration, fatigue, and pain kept a minority of survivors from working through the lessons. Survivors suggested addition of information on common physical side effects following cancer treatment such as fatigue and sexual dysfunction. Providers, who work within the field of social work in cancer centres, particularly liked the accessibility of the programme and its ability to provide support following cancer treatment. Their concerns included the programme's fit for particular survivors such as for individuals who are less comfortable with the internet and who have less motivation and energy. However, the findings of this study may not be generalisable to breast cancer

survivors. Alberts et al.'s study (2018) included people with different types of cancers (e.g., breast, colon, Non-Hodgkin lymphoma, multiple myeloma, CNS lymphoma, sarcoma, ovarian, endometrial), and people with different types of cancer may respond differently to therapy (Tatrow & Montgomery, 2006).

Many studies examining the factors influencing psychological adjustment of breast cancer survivors have reported that perceived support from carers, who are usually partners, is important (Borstelmann et al., 2015; Gremore et al., 2011; Manne, Ostroff, et al., 2005; Manne et al., 2014; Ockerby et al., 2013). Interestingly, support from the social environment (particularly with significant others) not only influences psychological adjustment of survivors, but it may also influence their adherence and engagement in internet-delivered interventions (Melville, Casey, & Kavanagh, 2010). For example, while carers who are supportive can motivate individuals to continue using the programme, carers who are unsupportive can actually be a potential source of stress and unconsciously sabotage survivors' attempts for change and engagement with the programme, which may result in high drop-out rates affecting the effectiveness of the treatment (Karekla et al., 2019).

Based on the evidence suggesting that caregiver attitudes towards iCBT are important for survivors to benefit from such programmes, Karekla et al. (2019) highlighted the importance of including caregivers to implement best practices in digital interventions designed for people with chronic illnesses. For example, significant others' attitudes toward the intervention can be assessed before the commencement of the intervention. These findings and recommendations suggest that carers' perceptions of the iCBT programmes and their willingness to be included in such programmes are equally important for implementing effective iCBT programmes for women with breast cancer. However, to the best of my knowledge, no study has examined the acceptability of including caregivers in digital health interventions.

Investigating the perspectives of breast cancer survivors and informal carers using a qualitative study design is important since the effectiveness of iCBT interventions depends on the

extent to which target populations are willing to use them (Alberts et al., 2018). The present study explores the perspectives of women with breast cancer and their informal carers on the prospective acceptability of an iCBT programme and the inclusion of carers in such programmes. As suggested by Bowen et al. (2009), the semi-structured interview questions in this study will not only address views on the acceptability of iCBT programmes and inclusion of carers but will also assess the demand for such a programme, and will seek guidance on the adaptation of an iCBT intervention.

2.2. Method

2.2.1. Participants

Women who currently have or have had any stage (0-IV) breast cancer and their informal carers (e.g., partners, family members, friends who have supported them following the diagnosis) were recruited for the present study. The study was advertised through the Irish Cancer Society's research newsletter, posters hanged on noticeboards at hospitals, college, public libraries, support groups for breast cancer survivors on Facebook and Twitter between March 2019 and April 2019. Six women contacted the primary researcher (SA), 5 agreed to take part in semi-structured interviews. One woman was unable to travel, thus was excluded from the study. All participants were asked if they have any primary carers who may be interested in participating the study. Two of the five women did not have a primary carer who supported them during the diagnosis or treatment. One of them had a carer living outside of Ireland, therefore, was unable to participate. One carer contacted the researcher and agreed to participate, but the survivor could not participate in the interview due to transportation issues. As a result, interviews were conducted with 8 participants, consisting of five survivors and three carers, which lasted between 28.25 and 71.15 minutes ($M= 49.75, SD= 14.14$). The shortest interview was conducted with a carer (the daughter of a breast cancer survivor), and the longest interview was conducted with a survivor in a home setting. The demographic and health-related characteristics of the participants are demonstrated in Table 1 and Table 2 below.

Table 1*Demographic Characteristics of Survivors and Carers*

Code	Status	Gender	Age	Carer	Education	Employment	Relationship status	Children
S1	Survivor	Female	27	Partner	Bachelor's degree	Full-time	In a relationship	0
S2	Survivor	Female	53	None	Bachelor's degree	Part-time	Not in a relationship	1
S3	Survivor	Female	55	Friend	Master's degree	Part-time	Married	2
S4	Survivor	Female	58	Husband	Bachelor's degree	Unemployed	Married	2
S5	Survivor	Female	44	Friend & sister	Diploma	Unemployed	Not in a relationship	1
C1	Daughter	Female	26	-	Bachelor's degree	Full-time	In a relationship	-
C2	Partner	Male	30	-	Master's degree	Full-time	In a relationship	-
C3	Friend	Male	61	-	Primary school	Retired	Not in a relationship	-

Note. The term "S" is used to refer to survivors and "C" will refer to carers.

Table 2*Health-related Demographic Characteristics of Survivors*

Code	Breast Cancer Stage	Recurrence	Time since last diagnosis (months)	Mastectomy	Chemotherapy	Radiotherapy	Hormonal therapy	Family history of breast cancer
S1	2	No	5	No	Completed	No	Completed	No
S2	2 & 4	Yes	84	Yes	Started	Completed	No	No
S3	2	No	144	Yes	Completed	Completed	Started	No
S4	3 & 4	No	15	Yes	Completed	Completed	No	No
S5	4	No	18	No	Started	No	Started	Yes

Note. The term "S" is used to refer to survivors.

As seen in the Table 2, although all survivors were educated, they had diverse characteristics that varied in age, the nature of the relationship with a carer, employment status, and relationship status. Participants were from different age groups. Survivors' age ranged from 27 to 58 ($M = 47.40$, $SD = 12.54$). They had carers who were partners, friends, husbands, and sisters, and one

participant did not have a carer. Carers' age also ranged from 26 to 61 ($M = 39$, $SD = 19.17$). Two of the survivors were working part-time, the other two were unemployed, and only one worked full-time. One survivor was in a relationship, two were single, and two were married. The health-related characteristics of the survivors were also diverse. Three participants completed their active breast cancer treatment. They had breast cancer diagnoses with stages 2, 3, and 4 and the time since receiving the diagnosis varied from 5 to 144 months ($M = 53.20$, $SD = 59.61$). However, the majority did not have a recurrence.

2.2.2. Materials

Two forms were prepared to collect information about survivors' and carers' demographics and health status. The survivor demographic information form included questions about age, education level, nature of their relationship with primary carer, relationship status, length of the relationship, number of children, employment status, stage of breast cancer, time of initial diagnosis, presence or absence of breast cancer recurrence and mastectomy, treatments that they have started or completed, and presence or absence of family member diagnosed with breast cancer. The carer demographic information form was relatively short and included questions on age, education level, the nature of the relationship with survivor, relationship status, and employment status. The primary researcher conducted all the interviews and audio-recorded using a Sony ICD-PX440 voice recorder.

Based on the acceptability of the healthcare interventions framework, which comprises seven components (Sekhon et al., 2017), two separate interview scripts and questions were prepared for survivors and carers, focusing primarily on the affective attitude, burden, and perceived effectiveness. The first section of both interview scripts deliberately involved broad questions designed to prompt participants to tell their own stories about breast cancer. For example, their concerns, coping mechanisms, effects of breast cancer on survivor-carer relationship, and how they deal with the cancer-related problems together. The second part of the interview included questions

that allowed them to share their opinions on the acceptability and suitability of internet-delivered interventions for their needs.

The survivors' questions comprised of three main parts: (1) psychological experiences of breast cancer (e.g., *Do you have any concerns related to breast cancer? If so, what are they? How do you deal with them?*), (2) acceptability of internet-delivered programmes for women with breast cancer (e.g., *What would you think about an internet-delivered psychological support programme like this in which you can log in with your phone, computer or tablet?*), and (3) acceptability of giving main carers access to the internet-delivered programmes prepared for breast cancer survivors (e.g., *If your main carer would have access to your internet-delivered psychological support programme, what would you think about that?*).

The carers' questions comprised of two main parts: (1) psychological experiences of main carers about breast cancer (e.g., *Do you have any concerns related to survivor's breast cancer? If so; what are they? How do you deal with them?*) and (2) acceptability of giving main carers access to the internet-delivered programmes prepared for breast cancer survivors (e.g., *If you could access to the survivors' programme, do you think a programme like this might be useful for you to understand survivors' needs?*).

The Space from Depression and Anxiety, an iCBT programme, developed for a general population to decrease depression and anxiety symptoms, was used in the study. The module content is presented in Table 3. It has been evaluated in numerous studies, and its effectiveness was demonstrated in the general population and university students (Richards, Timulak, et al., 2015; Richards, Timulak, et al., 2016; Richards, Murphy, et al., 2016; Sharry, Davidson, McLoughlin, & Doherty, 2013). The programme consists of 8 online modules completed ideally over 8 weeks. Each module includes quizzes, personal stories, exercises and a summary. The programme assigns a trained supporter to each user, who provides weekly feedback on their progress. Additional resources and tools are also available in the programme, such as a journal, mindfulness and relaxation audio

exercises, activity scheduling, activities list, and mood monitor. The programme was used to first evaluate its acceptability in terms of its content, structure, and suitability for carer access before potentially adapting it for the breast cancer survivor population.

Table 3

Space from Depression and Anxiety: Description of Module Content

Module	Brief Description
1. Welcome to SilverCloud	This module introduces the platform and explains all the functions, privacy, icons, and buttons on the platform.
2. Getting Started	This module outlines the basics of CBT and provides information on depression and anxiety and introduces some of the key ideas of Space from Depression and Anxiety.
3. Understanding Feelings	This module focuses on mood monitoring and emotional literacy. It helps users explore different aspects of emotions, physical reactions, action, inaction, and how they are all connected using the Thoughts-Feelings-Behaviour (TFB) cycle.
4. Boosting Behaviour	Focus of this module is on behavioural activation to improve mood. Users are encouraged to plan and record activities and chart how their activities influences their mood
5. Spotting Thoughts	This module aims to help users to identify and note unhelpful and negative thinking patterns and record the connection between their thoughts, feelings, and behaviours using thought records
6. Challenging Thoughts	This module encourages users to identify and challenge their hot thoughts and find a more balanced and realistic thought using thought records
7. Managing Worry	This module explains the role of worry in anxiety and worry cycle. It also introduces some techniques such as worry time, problem solving, and living in the present.
8. Bringing It All Together	This module encourages users to reflect on what information and skills they have learned and helps them to make a plan to stay well by watching out for personal warning signs and maintaining social support.

2.2.3. Procedure

The study was approved by the School of Psychology Research Ethics Committee, Trinity College Dublin (Approval ID: SPREC102018-23). The interviews took place in a distraction-free room in college; however, due to the medical condition of one survivor, one interview took place in the survivor's home. At the beginning of the semi-structured interviews, participants were given an information sheet, consent form, and demographic and demographic and health information form to complete. The information sheet outlined the aim of the study, the nature of the participation, how participant data will be used, circumstances in which confidentiality may be broken, right to withdraw from the study. Participants were informed that interview would last approximately an hour.

After the instructions were given and the consent form was signed by the participants, the interview began with questions about their experiences with breast cancer. When the questions in the first part was complete, the *Space from Depression and Anxiety programme* was introduced and shown to the participants on the researcher's personal laptop (Macbook Pro 16"). Then, participants were allowed to ask their questions about the programme. Next, participants were asked questions about the acceptability of an internet-delivered programme for their needs and the acceptability of giving carers access to the survivors' programme content. On completion of the interviews, participants were thanked and given a debriefing form, which provided information on rights to access data, rights to withdraw from the study and details of counselling services for participants who may feel psychological distress by participating in the study.

2.2.4. Data Analysis

All the interviews were transcribed verbatim by the primary researcher. After the transcription is completed, the names of the participants and others mentioned during the interviews were anonymised to ensure confidentiality. The codes and themes were identified, and thematic maps were drawn using the qualitative software MAXQDA Analytics Pro 2020. Descriptive statistics

on the demographic and health data were performed using IBM SPSS Statistics Version 21. Data were analysed using an inductive and data-driven thematic analysis approach suggested by Braun and Clarke (2006), with a focus on explicit and broader meanings and implications of the data.

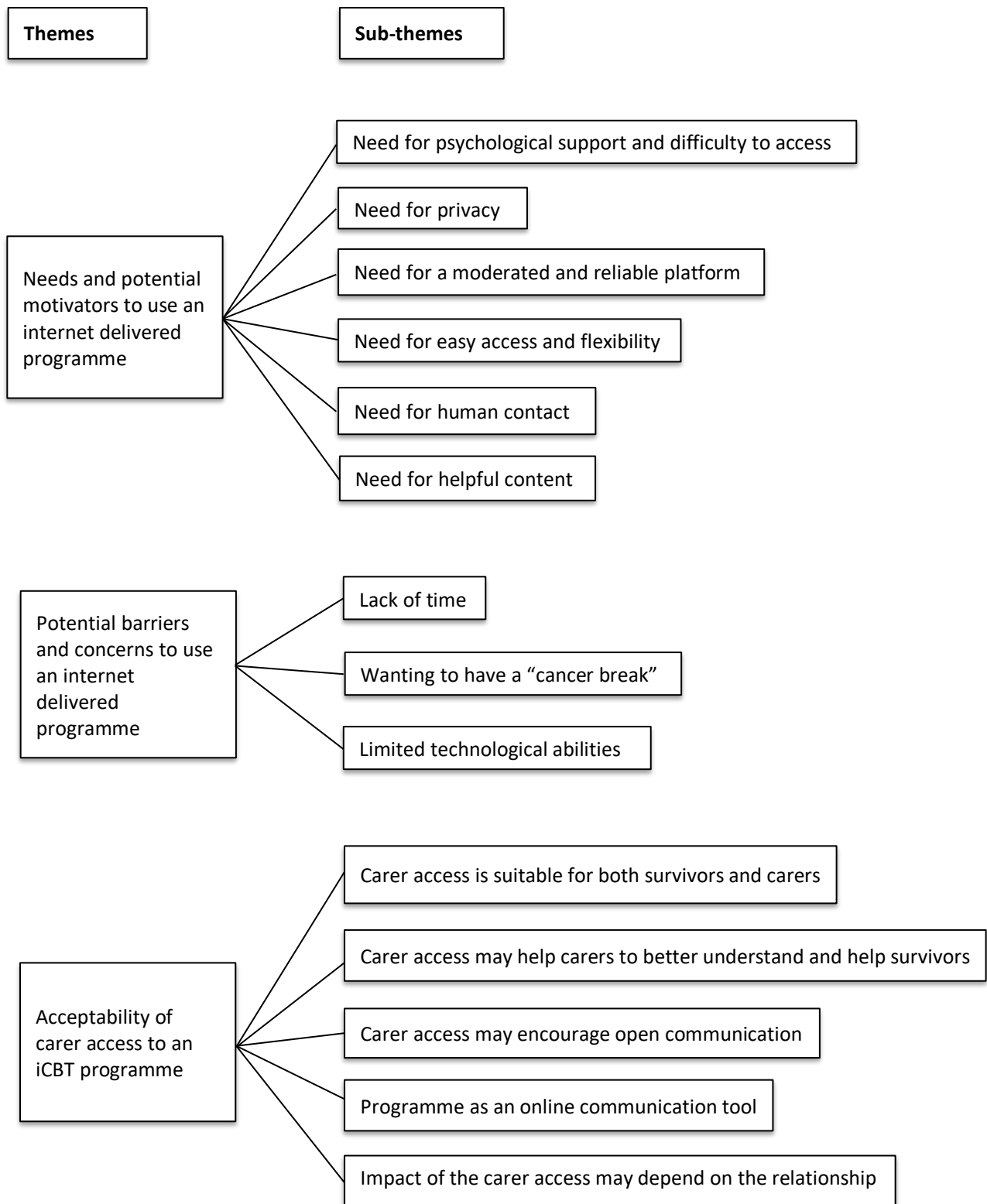
After the data were transcribed, the transcripts were checked back against the original audio recordings for accuracy. The data were re-read carefully for familiarisation and searching for meanings and patterns. Initial codes were generated at this stage. A decision was made to code the content of the entire dataset to fully understand the patterns of relationship between the concerns and needs concerning psychological support. In this phase, as many potential themes and patterns as possible were coded. Second, different codes that showed a common, recurring pattern were organised and coded into potential themes. Themes were then reviewed and data within the themes were checked to see if they create a meaningful and coherent pattern together and if themes were distinct. Finally, the validity of themes and subthemes in relation to the data set was checked, mapped, revised and refined. In this phase, themes were identified that either (1) answered the main research question of the study (acceptability of internet-delivered interventions) or (2) provided novel data to add to the literature (fills the gap); the rest were discarded.

2.3. Results

Survivors and carers expressed positive attitudes in regards to the internet-delivered intervention programmes. Three key themes and various subthemes were identified around the three areas: (1) Needs and potential motivators to use an internet-delivered treatment, (2) Potential barriers and concerns to use an internet-delivered treatment, (3) Views on the acceptability of carer access. The thematic map is shown in Figure 3.

Figure 3

Thematic Map Illustrating Three Main Themes and Their Sub-themes



2.3.1. Theme 1: Needs and Potential Motivators to Use an Internet-Delivered Treatment

There was a consensus among survivors and carers in regards to their positive attitudes towards internet-delivered treatments, and on their accounts they expressed a great need for psychological support. For example, survivors mentioned that: *“I’m at home on my own a lot of the time this is huge for me because it’s a help”* [S2], *“If I had that now, might have helped me a lot”* [S4]. Of note, one participant who was receiving CBT stated that: *“This is brilliant because it captures loads of things in here that I’m doing now, that might have been useful while ago”* [S3]. Similarly, there was a consensus among carers in terms of its acceptability and potential benefits: *“I think anything, anything, as far as a bit more engagement and more information can be helpful.”* [C2]. All mentioned that knowing about the programme in the first place would be a motivator for them to use it. They viewed internet-delivered therapy as an acceptable alternative to face-to-face therapy due to the following reasons.

Subtheme 1. The need for psychological support and difficulty to access

Several accounts identified the lack of psychological support from hospitals as a significant problem; many survivors outlined how they have been *“trying so hard”* [S5] to get psychological help. They liked the idea of internet-delivered treatment particularly because access to psychological support services was very challenging.

Several accounts of survivors identified the lack of psychological support from hospitals as a significant problem; many survivors outlined how they have been *“trying so hard”* [S5] to get psychological help. Many liked the idea of internet-delivered treatment particularly because access to psychological support services was very difficult.

“I think it’s a really good idea because it’s such a struggle to find support outside now.” [P5]

Survivors addressed two critical periods where they needed psychological support the most: shortly after the diagnosis and after the treatment has ended. On a few occasions, survivors mentioned struggling with serious psychological problems and their frustration about the difficult to access psychological support services. One survivor described her difficulty to get psychological help even when she was feeling suicidal at the time after the diagnosis:

“Sometimes I do I have... like last year was a very bad year because I was diagnosed (.)...I was like oh, I was overwhelmed with anger and stress because we were living in a hostel myself and my daughter just after being diagnosed. And I was like oh, I just felt like suicidal I have to say.” [S5]

In terms of the timing of the intervention, most survivors and carers suggested the idea of giving some time (ranging from a few days to a month) to let survivors process the feelings associated with the diagnosis as they will be given so much information at the time of the diagnosis:

“I would say not long after the diagnosis you need the most support, really. Because it's then you need the help with everything that's been thrown at you.” [S4]

“I do think that the earliest possible intervention is the best. So, from like a couple of days after that, say the day you are diagnosed, a couple of days after. Give yourself a chance to let it sink in, but then don't let it sink in too much that you think all hope is lost, you better off kind of have 2 or 3 days to process it, and then go and this is how we help.” [C1]

Although many survivors and carers explicitly valued and suggested the idea of “*early but not too early*” [S3] approach after the diagnosis, some survivors also described the time after treatment as the time they started to struggle with psychological difficulties such as “*depression*” [S5], “*post-traumatic stress disorder and anxiety*”:

“It was only after the treatment finished that I struggled badly with anxiety and things like that ... It took almost another year before I could see somebody about my mental health. And at that stage, I was in a very bad position mentally. ...I was never offered mental support and there was no counselling from the hospital. There was nothing that the hospital could provide. My own GP just wasn't interested in mental health. He just kept saying but you're better, your treatment is over, you know, stop being silly, off you go. ..., I was very bad with post-traumatic stress and anxiety (...) I feel mine got so bad because it was left for so long.” [S2]

Subtheme 2. Need for privacy

Privacy and anonymity were positioned as appealing aspects of internet-delivered treatments. One of the carers explained this, who highlighted that there is *“so much stigma attached to mental health issues”* [C2]. Survivors and carers both addressed the privacy of internet-delivered treatments as advantageous for survivors, especially those who are more reserved.

“I think it's kind of probably hard to go and see someone in person, but if you can just be like privately on your own and at your home, where you're comfortable, it would make it easier to start with anyway.” [S1]

“I actually do think that it would be very beneficial to have a programme like that available. Given what I know about my mom, my mom is very private. She wouldn't talk to somebody about how she feels, whereas something like that she would use because it's her own self-directed kind of help and it's private, there is no one talking to her...” [C1]

Subtheme 3. Need for a moderated and reliable platform

Many survivors liked the internet-delivered support because they viewed it as a reliable and trustworthy resource compared to the other platforms such as online forums, where the information

people share is not controlled. They particularly mentioned their desire *to be among people who felt the same* [S3] and to *read the stories of others* [S1] who have gone through the same experience and with whom they can relate. This led many survivors to be active online and visit unmoderated online support groups and forums while resting at home. Three survivors described instances where they went to unmoderated online support groups and forums with the motivation of reading stories of people who had similar experiences. One survivor described these unmoderated online forums as the *“main kind of support”* [S1] she had used initially. While being attracted to online forums, some survivors also perceived the online forums as unsafe.

“I think the programme would be a safer way for people to look for information online about illness because it's moderated, it's controlled... Whereas, on unmoderated forums online, all sorts of stuff goes on and nobody is minding the people in it.” [S3]

They also highlighted that visiting online support groups and forums sometimes resulted in frustration and increased anxiety:

“... when I was going through it, every time I seem to go on Facebook, I seem to be reading about the horrors of chemo and so forth. For me, I found that I had to actually stop reading them because I was like dead and buried (...) You realize, like you can't believe everything you read but, I just seemed to only see negative things...” [S4].

Subtheme 4. Need for easy access and flexibility

Being able to access the programme 24/7 was seen as an important and valuable feature of the programme by many survivors as this meant that they do not need to travel for an appointment. A survivor, who was receiving face-to-face CBT, emphasised the value of the *“longer duration of human contact in face-to-face therapies”*; however, she saw the easy access in online programmes as important and valuable:

"I wouldn't say that you totally kind of discard a need for face-to-face human contact sometimes but I think that it's a 24 hour 7 availability of that is very good." [S5]

On the other hand, another survivor explained her preference for online therapy over face-to-face therapy because of easy access:

"Probably just because it's easier to access. So you have access to it on your laptop or whatever rather than ... Sometimes it's not always easy to find if you want to go to a counsellor or therapy sessions, trying to find someone right that you gel with [smiles] as well".

Survivors liked the idea of an internet-delivered programme also because of its flexibility and allowing them to work through the content at their own time and pace: *"the advantage is that you can do it on your own time"* [S5] and another survivor emphasized the importance of not having a strict schedule for her:

"If I can use it at my own pace rather than somebody saying to me you haven't done anything on this in a week. I would have to do it at my pace, so that would be the main thing." [S2].

These accounts suggest that easier access and flexibility are the important features of the iCBT interventions over traditional treatment delivery methods and makes iCBT programmes more acceptable for breast cancer survivors and their carers.

Subtheme 5. Need for human contact

Many survivors, who liked the idea of receiving online therapy, also expressed the value of having a sense of human contact by addressing the importance of having a supporter in the programme who provides non-simultaneous weekly feedback. A survivor, who is a single mother,

explained that an internet-delivered programme would help her if she felt down as she knew that there would be a support person available to help her:

“I’m at home 80% of the week on my own... This is huge for me because it’s a help, it’s a support. I feel if I’m sitting at home and I’m just feeling rotten, I can tap into this and there’s somebody there that they may not be there for a couple of days, but I know that they will be there.” [S2]

Subtheme 6. Need for helpful content

Many survivors and carers mentioned that if they find the content in the programme helpful, that will encourage them to use it. Survivors and carers emphasized the importance of having information on understanding and expressing feelings, mindfulness exercises, learning how to manage anxiety and mood, and mood monitor tools.

All survivors and carers mentioned that if they could get information about *“understanding feelings and how to express those feelings to other people”*[S1] that would be beneficial for them. Survivors and carers both mentioned that they are struggling to understand and express their feelings. How an online programme addressing emotions and feelings can improve survivors’ mood was described by S3, who highlighted that expressing the feelings even to a computer can be helpful:

“When you have breast cancer, you have a lot of free time. You’re just feeling kind of crap. So something like this, you can go back to it and forward to it when you’re feeling worried or even just to pass a bad time...you are saying kind of I’m not feeling okay and I think even admitting to the computer that you’re not feeling okay would be good.” [S3]

Mindfulness, meditation, and relaxation exercises were also noted as beneficial content by many survivors [S1, S2, S4, S5] and carers [C2, C3]. For example, S5, an advanced stage breast cancer

survivor, mentioned that *“I find breathing exercises very helpful to relax”*. C2, who is a partner of a breast cancer survivor, stressed the importance of mindfulness in dealing with uncertainty:

“The hardest bit about coping is not knowing what’s going on; so it’s not necessarily information needs around your plan but, just to even to calm a person down, to the extent that they breathe. So mindfulness stuff would have a huge impact...”[C2]

Learning how to manage anxiety and mood was another content topic that was seen as significant and potentially beneficial by survivors [S1, S4, S5] and carers [C2, C3].

“I would say if I had to have that programme I would have been always going in for the anxiety issues and maybe trying to control the mood.”[S4]

Some survivors liked the mood monitor, which is a tool that allows one to see which events influence their mood. For example, S2 mentioned that:

“I think the mood monitor is brilliant because I think you can see then what may be. Okay, I have chemo every Wednesday, so I can see on Tuesdays I'm very bad. So it's obvious that's the cause - you know, you can see a pattern emerge and you can understand your own mood rather than just feeling bad and not knowing why.” [S2]

2.3.2. Theme 2: Potential Barriers and Concerns to Use an Internet-Delivered Treatment

Subtheme 1. Lack of time

Lack of time was identified by both survivors and carers as one of the potential barriers to using an internet-delivered treatment programme. This was a concern especially evident for carers. A survivor mentioned that:

“Probably if it was too busy. Carers are not sick, so they don't have time to sit around on something like this all the time. So they're not going to want hundreds of messages or loads of things to have to do. So, the less they have to do I think the better.” [S2]

Some noted that young breast cancer survivors might not have time to engage with the programme during the treatment due to childcare responsibilities. Survivors highlighted the importance of practicality and clarity of the content in the programme. Some survivors mentioned that the complexity or difficulty to understand the programme may be another discouraging thing for themselves and carers:

“... I guess if it was like taking a long time to see their sessions or modules taking a long time to get through... if the text, the videos are very kind of detailed or too kind of complex.” [S1]

Subtheme 2. Wanting to have a “cancer break”

Some survivors mentioned that they could get “cancer fatigue” because of going to treatments and hospitals, and they may prefer “cancer break” and may not want to engage in any cancer-related things. Similarly, a carer mentioned that feeling overwhelmed with cancer may be a barrier to use it:

“... if someone is, you know, into probably if someone feels like they can't cope and it's overwhelming then they'd probably be less likely to go and use the platform like this, you know. In a way, you know, they're kind of in hold to a certain extent.” [C2]

Instead of using active problem-solving strategies, some breast cancer survivors may choose to deal with their concerns by avoiding cancer overall:

“I try not to think about anything like it's ... I pretend I never had cancer and I just live my life now to the best I can.” [S4]

One survivor explained that mood changes during treatment may be a barrier to engage with the programme: *“if you're anxious about a scan coming up you don't want to have to sit and do something like this.”* [S2]. This may suggest that introducing an online programme during cancer treatment can lead to a low or inconsistent engagement with the programme. Survivors' mood can change very frequently during treatment such as chemotherapy, when they have a scan, or see the doctor.

Subtheme 3. Limited technological abilities

Some survivors and carers raised concerns regarding whether older people may have limited technological abilities. A carer, who is 61 years old, mentioned that most of his generation do not use the internet, *“but it's getting better as everybody needs to know how to use them”* [C3]. He also explained that *“...it's slower but I'm still doing what I need to do.”*, but others at his age may *“not be great”* at using it.

2.3.3. Theme 3: Views on the Acceptability of Carer Access

Subtheme 1. Carer access is suitable for both survivors and carers

Survivors mentioned turning to their partner [P1], husband [P4], friends [P3, P2, P5], and sister [P5] for emotional support. They emphasized that people around them are *“trying to support”* [P4] them and *“doing the best they can do to understand how they are feeling”* [P4]; however, carers *“don't understand”* [P4, P5] them fully. Thus, such access was seen as making a *“huge”* [P2] difference for the relationship between survivors and carers, especially by survivors. Many survivors and carers saw carer access to the survivors' programme as an appealing alternative over a couple-based approach since the latter requires couples to find a time that suits both. For example, one survivor mentioned that:

"I think having his own separate login and separate access that, you know, he doesn't need me to use it or we don't need to like, do it together... would be better. He can do it himself privately." [S1]

When carers' need for psychological support for themselves was explored, they preferred having access to survivors' programme rather than having a separate programme designed for themselves. There was a consensus among all carers regarding their preference for having access to survivor's programme rather than having a separate programme designed explicitly for themselves. However, all expressed their willingness to learn more so that they could help survivors better.

"I don't feel like I need any support unless it's to free me up to give support to her."[C2]

Subtheme 2. Carer access may help carers to better understand and help survivors

Most survivors expressed their need for normalisation and validation of their cancer-related concerns. They talked about their negative experiences with people around them, who failed to show empathy towards them due to a lack of knowledge about what is normal and acceptable and what is not. S2 provides an excellent example of survivors' need to hear that what they feel and experience is "normal" by healthy others: *"I thought I was gone mad, I really thought that the chemotherapy had affected my brain and I was gone mad because everybody was telling me, you're better. It's gone. You're fine. What is wrong with you? And nobody was saying this is normal, you know, this is normal after a diagnosis."*

This suggests that some carers may fail to meet the survivor's need to communicate and normalise their cancer-related concerns due to their lack of knowledge about the psychological effects of the illness and treatment. Carers experience difficulty understanding what survivors are going through was also highlighted in S1's explanation: *"it is hard for carers to know what to do or what to say."*

Many survivors and carers observed that even the educational content in the programme could help carers to gain knowledge and better understand what survivors are going through. The partner of a young breast cancer survivor [C2] mentioned that he did not feel that he was educated on the best ways of helping survivors, but he noted his willingness to improve himself to help his partner better:

“Being educated on, you know signs, or ... how to act better to mitigate the chances of sort of being emotionally overwhelmed. Cause...you know whatever is going on today we will deal with it, you know. There is no science behind our approach..., but maybe that could be improved. If I knew how to.”

A similar sense of improved understanding of survivors’ feelings and needs through carer access to an online programme was expressed by S2, an advanced stage breast cancer survivor who does not have someone providing consistent support for her, but gets support from different friends:

“... it's very hard to sit and explain to someone why you're not happy, you know, because like that everyone is saying “but cancer is gone, you should be so happy” or why you don't want to go to something as they organized a night out... So this would help them to understand.”

Subtheme 3. Carer access may encourage open communication

Survivors and carers expressed their difficulties in communicating their feelings or concerns regarding cancer. S1 explained that physical symptoms or disturbances are easier to express and talk about than negative feelings and emotions such as frustration. Most importantly, many survivors explained it as a mutual difficulty between the survivor and carer rather than being a one-sided problem:

“It can be quite mentally exhausting trying to think of everything. And it's hard to express that sometimes, like it's easier with the physical stuff. If I have stomach pain or whatever, it's easy

you can just go get tablets. But, if I am feeling bad and I don't know how to express it then it's kind of harder for him as well because he doesn't know how to help or what to say..." [S1]

Survivors' difficulties expressing feelings and needs were explained by fear of not feeling understood by healthy others. This was also accompanied by fear of upsetting the carer: *"My sister understands sometimes that I'm still sick with cancer that she feels I'm able to do things I am not able to do. I suppose just when you are talking about something that they don't understand you just feel angry that they don't understand. I express it to a certain amount but not too much. I kind of want to keep it just to myself [smiles]. I don't want to upset them as well."* [S5]. On the other hand, carers' difficulties in expressing their feelings were explained by lack of knowledge and poor communication skills in terms of not knowing how to react or what to say: *"I think carers are very good people and carers care. And carers want to make you feel better. They just don't know how. They don't know what to say. That's a huge thing I get from people all the time. It's... "I don't know what to say", "I didn't call you because I didn't know what to say", "I didn't want to upset you"."* [S2].

Two carers claimed that if they were given access to the content in the survivors' programme it would provide a reference point and encourage them to discuss what they learned with survivors and they would be able to make a plan together. For instance, C1 mentioned that:

"I mean, if you're going through something and you feel like no one understands it's a lot harder than you think someone came to you and I know what you are going through, I'm able to help. And then, you can discuss what you both learned, and then you can make a plan."

Similarly, survivors emphasized that knowing that their carer is also reading what they are reading would make it easier to open up a conversation about their feelings while preserving their privacy. Carer access through a separate account would, at the same time, give survivors an option to reveal what they would like to express and what they would like to keep to themselves:

“I like that idea because then that can open up a conversation about what did you put? What did you think about that? Did you feel that in and maybe you might get more open communication...It certainly opens more channels for communication.” [S3]

Subtheme 4. Programme as an online communication tool

On a few occasions, some survivors and carers also discussed the idea of sharing the login and using the programme as an online communication tool between them. They explained that if carers have access to what they write in the exercises, to their journal, or their mood monitor, they can understand how the survivor feels on that day or week without verbally telling them. Of note, these survivors were the ones who mentioned having difficulty with expressing their feelings. This can be understood by the account of a survivor:

“You can't sit with someone and say: ‘ Look I have a scan on Friday. And I'm going to be a nightmare all week. Just avoid me’. But if they can see it, you don't have to say it... I think for them to see that mood monitor, to me, is a big thing. And for them to be able to see and understand that ‘Oh God, she really did feel bad on Thursday, she must be really scared about the scan. So maybe next time she's having a scan I can be a little bit more support’...” [S2]

Similarly, a male carer, indicated the programme may be used as an extra tool providing information about how the survivor is doing and may alert carers to the problems before they happen:

“Well, it could be (...) a potentially, sort of more early warning sign, or you know you could, kind of, an extra tool to check out how she is getting on.” [C2]

Subtheme 5. Impact of carer access may depend on the relationship

Although the positive impact of carer access on the communication between survivor and carer was a salient theme, some survivors and carers also treated it with caution. They emphasized that it *“depends on the people around them”* [S5] and their relationship, or *“depends on what the person has written down ... I don’t really know, hmm, what kind of an impact would happen to me, until I saw what it was.”* [C1] if the programme login was shared.

The possible influence of relationship quality before the intervention was best expressed by S3’s account, who emphasized that if the person who supports them does not agree to do it then it may create a conflict between the survivor and carer:

“If you’ve got a partner who is able to deal with the fact that we might have to talk about emotions, fine. But, sometimes men find it difficult, so they might kind of feel scared I suppose, and want to run away and say, ‘Oh I’m not doing that’ you know. So...it could be a source of argument or perhaps even conflict kind of depending on the relationship, depending on their attitude to emotional issues.” [S3]

Others stressed the importance of considering the relationship dynamics between survivors and carers when evaluating the suitability of including carers as active participants in online therapy programmes. C2 and S4, who described their relationships with their partners as good, emphasized that the programme would not impact their relationship as *“it’s a good relationship from the get-go”*.

2.4. Discussion

This study explored breast cancer survivors’ and their informal carers’ perspectives regarding the acceptability of iCBT programmes and giving carers access to the programme. Survivors and carers viewed internet-delivered therapy positively and thought it could help survivors deal with cancer-related distress. This finding is not surprising considering that access to evidence-based treatments is not easy for survivors with chronic illness (Karekla et al., 2019) and they do not have an

alternative option to deal with the concerns such as uncertainty about their illness persisting long after cancer diagnosis and treatment (Gil et al., 2004).

Concerning the timing of support, all survivors and carers thought that introducing the intervention shortly after the diagnosis would be better as some survivors may lose their hope over time. However, most survivors also reported having psychological difficulties following the end of treatment and needing psychological help. Survivors' need for psychological support at the end of treatment is consistent with Baker et al.'s (2013) findings. They found that survivors who received chemotherapy or radiotherapy acknowledged distress as a problem requiring a solution, welcomed emotional support and saw value in information about the processes underlying distress and about locally available services for survivors with emotional needs. Considering the impact of chemotherapy and radiotherapy, scans, appointments with doctors on survivors' mood as mentioned by a survivor as a potential barrier to engage with the programme, providing the internet-delivered treatments after the treatment completion may be more suitable.

Survivors also mentioned various other factors that would motivate them to use an internet-delivered intervention, including their need for privacy, need for a moderated and reliable platform, easy access and flexibility, human contact, and helpful content. It was evident in survivors' and carers' comments that privacy makes internet-delivered programmes more appealing for women who are more reserved, private, and concerned about stigma than other treatment options such as face-to-face counselling. This was also mentioned in Alberts et al.'s (2018) study as one of the aspects that cancer survivors liked about the iCBT programme. These findings were also in line with Karageorge et al.'s study (2017), which revealed that participants liked the internet-delivery mode because it was more continuously available, flexible, and private than the appointments with psychologists.

Survivors reported that reading others' stories would help them normalise their experience and make them feel less alone. In line with this finding, cancer patients and survivors in an iCBT intervention (Karageorge et al., 2017) reported that inclusion of a survivor character provided hope

and education about survivorship for active treatment participants and normalised the experience for survivor participants. The inclusion of a character in active treatment served as a reminder of how far they had come for survivor participants, and it normalised the experience of active treatment participants. Lieberman and Goldstein (2006) suggested four basic activities in internet-based bulletin boards that support breast cancer survivors' psychosocial improvement: (a) reading about others' experiences; (b) receiving support, information and advice; (c) giving support, information and advice; and (d) writing emotionally about one's own experiences. Future iCBT interventions should include personal stories of survivor characters, whom the participants can relate.

Another interesting finding was that survivors and carers emphasized the importance of having an online moderated programme providing reliable and trustworthy information, as online forums and groups (e.g., on Facebook) are unmoderated, and the information there may not be trustworthy. It is known that for many people, the internet serves as a resource to access health information (Bennett & Glasgow, 2009). Women with breast cancer generally seek support in online support groups to cope with breast cancer (Han et al., 2008). However, nearly three-quarters of online health information seekers reported that they largely trust the health information on the internet and do not check the source of information (Fox & Livingson, 2006, as cited in Bennett & Glasgow, 2009). Therefore, it is important to provide a sense of trustworthiness in the internet-delivered programmes to encourage participants to engage with the programme. Karekla and colleagues (2019) suggested that a sense of trustworthiness, expertise and credibility can be achieved by using content from theory-driven evidence-based psychological approaches, provided in written formats, citations, and with empirical references supporting the approach.

Survivors also liked 24/7 availability and flexibility of the programme as it allows them to access psychological support at their convenience and pace. Two other studies reported similar results (e.g., Alberts et al., 2018; Bennett & Glasgow, 2009). Survivors reported that they liked working through the programme at their available times and the comfort of their own home without

requiring an appointment with a mental health professional. Some survivors found the flexible nature of the internet-delivered therapy helpful as it meant that when they are experiencing nausea or fatigue, they will not have to attend an appointment with a psychologist or psychotherapist (Alberts et al., 2018).

Another aspect that survivors liked was the availability of human contact, which can provide social reinforcement (Andersson et al., 2012) and may help users build an alliance with the programme. The importance of having a supporter in the programme is consistent with a meta-analysis, which showed that guided self-help programmes and face-to-face therapy for depression and anxiety had no statistically significant differences at post-treatment and at follow-up period up to 1 year (Cuijpers, Donker, Van Straten, Li, & Andersson, 2010). Although the empirical findings on the relationship between the therapeutic alliance in guided iCBT and outcome measures of depression and/or generalised anxiety are mixed (Hadjistavropoulos, Pugh, Hesser, & Andersson, 2017; Hedman, Andersson, Lekander, & Ljótsson, 2015; Nordgren, Carlbring, Linna, & Andersson, 2013), a recent study revealed that higher therapeutic alliance at mid-treatment and post-treatment was moderately correlated with overall satisfaction with the iCBT programme in survivors treated for depression and anxiety (Hadjistavropoulos et al., 2017).

Contrary to the survivors who explicitly reported their need for psychological support, carers, the majority of whom are males, expressed that they do not need such support for themselves as they were not affected as much as survivors. However, all carers expressed willingness to be part of the treatment if it helps them help survivors in a better way. Male carers' reluctance to receive support for themselves but willingness to get help to help survivors can be explained by the evidence that men, regardless of whether they are a survivor or partner, generally have lower levels of distress compared to women (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Moreover, most survivors and carers viewed the lack of time or difficulty to find time as a barrier for carers' willingness to use the programme. Considering that carers of women with breast cancer are mostly

their partners or spouses (Emanuela et al., 2015; Manne et al., 2016; Pistrang & Barker, 1995), iCBT programmes focusing mainly on survivors' psychological distress in which carers play the role of motivating survivors rather than having the full responsibility to complete the programme together may be more achievable for the couples dealing with breast cancer.

One of the most significant and unexpected findings about survivors' and carers' concerns was participants' consensus on struggling with expressing their feelings towards each other. This was interesting as many survivors also described their social environment and their relationship with significant others (partners, family members, friends) as key in their adjustment to life following the diagnosis, in line with the previous literature (Helgeson, Snyder, & Seltman, 2004; Hughes et al., 2014; Ng et al., 2015; Thornton et al., 2014). Survivors had difficulty in emotional expression due to fear of not being understood by carers, fear of upsetting them or being an additional burden. Whereas, carers' difficulty resulted from not knowing how to react or express their feelings, even in the context of a good relationship. This confirms the previous findings that cancer survivors feel constrained in communicating about their concerns with their significant others. Although they provide support for survivors' physical impairment, carers often react with withdrawal or distancing themselves from survivors' emotional distress (Bolger, Foster, Vinokur, & Ng, 1996; Porter et al., 2009).

In line with these findings, survivors and carers noted that content on understanding and expressing feelings would be the most beneficial content for them, along with mindfulness and relaxation exercises and content on managing anxiety and mood. Therefore, internet interventions developed for breast cancer survivors should consider this need during the process of content development. Supporting this suggestion, a systematic review of the effectiveness of survivor-family carer (couple) interventions showed that when interventions included support for the survivor-family carer relationship they improved the emotional health of cancer survivors (Hopkinson et al., 2012). However, it is also important to emphasize that it is necessary to hold a delicate balance between over- and under-expression of negative emotions. Lieberman and Goldstein's (2006) found that the

expression of specific negative emotions such as anger and sadness was associated with lower depression and greater quality of life among breast cancer survivors, while the expression of anxiety resulted in the reverse effects, i.e., it was associated with higher depression and lower quality of life. In line with this, another study revealed that combined use of negative and positive emotion words could be beneficial for women with breast cancer (Han et al., 2008). This suggests that not all emotional expression is certainly beneficial. It may be more helpful for women with breast cancer if iCBT programmes encourage them to use not only negative emotion words but also the positive emotion ones, either through writing or talking to significant others.

Another important finding was that both survivors and carers liked the idea of giving carers access to the survivors' programme content. Both viewed carer access as sufficient and acceptable. In recent years, there has been a growing awareness of the interdependence of adjustment among couples coping with breast cancer (Dorros, Card, Segrin, & Badger, 2010; Rottmann et al., 2015). However, couple-based interventions for cancer have lower uptake rates than individual-based interventions, especially when both the survivor and the partner are required to participate in the intervention simultaneously (Regan et al., 2013). Similarly, a systematic review of the effectiveness of survivor-family carer (couple) intervention revealed that recruitment and attrition was a problem in these interventions (Hopkinson et al., 2012). Therefore, giving survivors an option to provide their carers access to the iCBT content without requiring simultaneous log-in by survivors and carers could be more appealing for this population.

Survivors and carers thought that carers having access to the educational content could better understand what survivors are going through and provide better empathy towards survivors, who expressed a need to feel understood, to have their experience normalised, and to receive validation from significant others (Regan, Levesque, Lambert, & Kelly, 2015). Both highlighted that carer access to the educational content would provide a reference to each of them, and this may make it easier to open up a conversation about breast-cancer related topics or concerns. Knowing

that both are equally aware of what is going on for survivors emotionally may alleviate survivors' fear of not being understood by carers and help both of them to embrace the "we" approach (Rottmann et al., 2015) towards the illness. Although many survivors and carers liked the idea of carer access, some survivors also expressed hesitancy in requesting carers to use an online programme as it may burden the carer, create additional issues in the survivor-carer relationship, if the relationship was not good or if carers have negative attitude towards emotional issues (Hopkinson et al., 2012). The role of relationship quality may be an important factor in the effectiveness of iCBT programmes for breast cancer survivors. It should be addressed and explored in the future design of iCBT.

Survivors and carers also mentioned that having access to the same information can help survivors and carers to openly communicate about cancer-related concerns and their feelings more easily. Open and mutual communication can decrease distress (Li & Loke, 2014; Manne et al., 2016), increase relationship satisfaction (Manne et al., 2016), coping, and quality of life (Li & Loke, 2014) for survivors and their carers. Some survivors also suggested using the iCBT programme as an online communication tool, in which survivors and carers share the exact log-in details, which would give carers access to survivor's journals, exercises, and mood monitor. Survivors thought that this would take away the necessity to verbally share their concerns with carers as they would be able to see what is going on by looking at their input in the programme. Carers had viewed this as an extra opportunity to check how the survivor is doing emotionally. Some survivors' preference for indirect communication of feelings through an online programme rather than an open expression was interesting. It may be explained by the survivors' difficulty or lack of knowledge on how to express their feelings. However, these findings may also be explained by individual differences among survivors in coping strategies. For example, cancer survivors high on neuroticism have a natural tendency to use more passive or avoidant types of behaviour to cope and have negative attitudes towards emotional expression (Laghai & Joseph, 2000; Zakowski, Herzer, Barrett, Milligan, & Beckman, 2011).

Some survivors also emphasized that the effects of carer access depend on the relationship. If the relationship is already good, then carers may be more willing to do it. However, if the relationship quality is poor and the carer does not engage with the programme, it may worsen the relationship. Therefore, it is important to be cautious about giving carers access to the treatment programme. As relationships vary in quality, it could be more feasible to ask survivors who have carers whether they would like to give their carers access or not. Another option could be assessing perceived social support, the relationship quality of the person with the user, and carers' attitudes toward the intervention prior to the intervention commencement, as Karekla et al. (2019) recommended.

2.4.1. Study Strengths

To the best of our knowledge, this is the very first study that qualitatively examined the acceptability of iCBT for breast cancer and carer access to the treatment from the perspectives of breast cancer survivors and their informal carers before using the iCBT treatment. Although Karageorge et al. (2017) also investigated the acceptability of an iCBT programme for early-stage cancer patients with depression and/or anxiety, the current study is different as it was conducted with breast cancer survivors with different stages of cancer. The current study is distinct as it also investigated the perspectives of the carers and the acceptability of carer access. The results of this study also provide evidence for the demand for internet-delivered interventions and their acceptability for breast cancer survivors and their informal carers. Besides, the findings suggest that giving carers access to survivors' programme content may help carers better understand and help survivors by improving carers' understanding of the survivors, open communication, and shared knowledge. Based on these findings, a pilot RCT will evaluate whether the inclusion of carers in iCBT programmes is preferred by breast cancer survivors and, if so, whether carer inclusion results in improvements in survivor-carer communication and relationship quality and reductions in survivors' psychological distress (Akkol-Solakoglu et al., 2021).

2.4.2. Study Limitations and Future Research

There are some limitations in this study that should be considered when interpreting the findings. One potential limitation is that carers in this study were recruited through survivors, who were asked if their carers would be interested in participating in this study. Future studies may benefit from recruiting survivors and carers separately. Second, the sample size was small in this study. Five women with breast cancer and three informal carers participated in the interviews. Although the number of informal carers was very limited, the individuals had a breadth of different roles (e.g., partner, daughter and friend). Future qualitative studies should explore the acceptability of iCBT programmes and of giving carers access to the online programme content with a larger number of survivors and carers. The perspectives of experts in the field of psycho-oncology could also provide valuable insight. During the interviews, participants were asked if giving carers access to the programme content would be acceptable, which may have biased participants' responses. Future qualitative research would benefit from exploring it with more broad questions such as how carers can be included in iCBT interventions. This may bring about different ways and provide a broader range of options that may inform the design of future studies with carer involvement.

2.4.3. Conclusions

In conclusion, the findings of this study provide a novel and rich understanding of the acceptability of iCBT programmes for breast cancer survivors and carer access from two different perspectives. The findings also provide important insights regarding the programme features, content, and the timing for the delivery of the programme, which informed the design and implementation of a pilot RCT aiming to reduce psychological distress in breast cancer survivors (Akkol-Solakoglu, Hevey, & Richards, 2021).

CHAPTER 3

Study II: Adaptation of an internet-delivered cognitive behavioural therapy for breast cancer survivors and their informal carers

3.1. Introduction

iCBT has been found to be effective for depression and anxiety symptoms. However, low adherence to treatment (e.g. low engagement, failure to complete a sufficient dose of treatment) can result in poor treatment outcomes for individuals (Richards & Richardson, 2012). Therefore, rather than applying a “one-size-fits-all” approach, adapting an intervention tailored to the needs of the users is necessary to improve the benefits of the psychoeducational and therapeutic interventions.

Adaptation can be defined as a systematically planned and proactive process of modifying key characteristics of an intervention, recommended activities, and delivery methods while preserving the core theoretical elements and internal logic of the programme (Escoffery et al., 2019; McKleroy et al., 2006). Adaptation of an effective evidence-based intervention has often been preferred rather than designing and evaluating a brand new intervention for each new context or population since the former requires fewer human and financial resources (Movsisyan et al., 2019). Evidence-based interventions refer to empirically-tested prevention and treatment interventions designed for various health conditions (Alvidrez et al., 2019).

In a recent systematic review, many studies viewed the overall aim of adaptation to ensure intervention salience and its fit with the new context/population and to address the specific needs of the new target audience (Movsisyan et al., 2019). Other specific aims included enhancing acceptability, local commitment, support and collaboration, fostering ownership of the intervention, facilitating enrolment, engagement, retention, and satisfaction with the intervention, supporting successful implementation, use, and sustainability of the intervention. Interestingly, maintaining the

effectiveness of the intervention was noted by only a few studies as the direct adaptation aim. Similarly, in a systematic review of adapted evidence-based public health interventions frequently reported reasons for adaptation consisted of the need for cultural appropriateness (64.3%), focusing on the new target population (59.5%), and implementing the intervention in a new setting (57.1%) (Escoffery et al., 2018).

While acknowledging the essentiality of adapting interventions in the implementation process, some researchers raised their concerns that any modification to the original evidence-based intervention could threaten its efficacy or effectiveness (Escoffery et al., 2019; Rabin, Brownson, Haire-Joshu, Kreuter, & Weaver, 2008). In a systematic review of adaptations of evidence-based public health interventions, only half of the studies reported a pre-existing adaptation framework as a guide for the adaptation process (Escoffery et al., 2018). Therefore, there is a tension between maintaining adherence and fidelity, the degree to which an intervention is implemented as it is in the original protocol while being sensitive to the needs, culture, and context of the new target population (Card et al., 2011; Escoffery et al., 2019). This tension resulted in emerging adaptation frameworks that suggest some steps to be followed to make the evidence-based interventions fit the new population or context better while minimizing the modifications that could reduce the effectiveness of the intervention. Many studies suggested that using theories and frameworks in the adaptation of programmes improves its acceptability, fit, and effectiveness; however, to the best of my knowledge, no study has explored whether applying the frameworks and following specific steps influences intervention outcomes (Escoffery et al., 2019).

3.2. Adaptation Frameworks

The majority of the frameworks in the literature have provided general guidance for steps in the adaptation of evidence-based psychological interventions for new populations and contexts (Card

et al., 2011; Escoffery et al., 2019; McKleroy et al., 2006; Smith & Caldwell, 2007). The present review will explain the steps of the three different adaptation frameworks and the overlap between them.

Recently, a systematic review of adaptations of evidence-based public health interventions (Escoffery et al., 2019) identified 11 common adaptation steps (among 13 frameworks): (a) assessing community or population of interest, (b) understanding the evidence-based interventions, (c) selecting the evidence-based intervention, (d) consulting with experts, (e) consulting with stakeholders, (f) deciding on adaptations, (g) adapting the original evidence-based intervention, (h) training staff, (i) testing the adapted materials, (j) implementing the adapted evidence-based intervention, and (k) evaluating the intervention. Importantly, more than five of the included studies suggested to use the following steps when adapting evidence-based interventions: (a) assess community or population of interest, (b) understand the original evidence-based intervention, (c) select an evidence-based intervention, (d) decide what needs to be adapted, (e) adapt the original programme, (5) test the adapted materials, (f) implement the intervention, and (g) evaluate.

A systematic review by Movsisyan and colleagues (2019) similarly identified 11 unique steps based on the commonalities and differences in the approaches of the reviewed studies. These steps were categorised into four broad phases (Exploration, Preparation, Implementation, and Sustainment), forming the EPIS implementation framework. Many studies in the review highlighted the significance of having an exploration phase before implementing an adaptation. *The exploration phase* includes an initial assessment (step 1), in which the needs of the target population, the system, the organisational capacity, and thereby the need for a new intervention are explored. Then, appropriate intervention is selected for adaptation (step 2). During this step, relevant evidence-informed interventions are identified, their fit with the new context is evaluated, which leads to the selection of the best match. After this, components and the underlying theory of the selected intervention are examined (step 3) to determine its adaptability to the new context. *In the preparation phase*, it is important to identify potential mismatches of the intervention with the next

context (step 4), which in most cases was done by the assessment of the resources and distinctive characteristics of the new population, to develop an intervention model (step 5), and to establish important networks and capacity to run the intervention (step 6). *The implementation phase* is focused on the actual adaptation and it marks the value of developing an adaptation plan (step 7), including identification of the core components of the programme that should be kept and not modified, pilot testing the adapted version of the intervention (step 8), and revision and implementation of the adapted intervention (step 9). Finally, in the *sustainment phase*, the adapted intervention is evaluated (step 10) in terms of important study outcomes as well as the establishment of routine and ongoing supervision and monitoring. During the final step (step 11), activities are planned to disseminate the adapted intervention and sustain it through training and ongoing re-assessments. Movsisyan et al. (2019) highlighted that this step-by-step approach does not necessarily follow a linear process; four phases often took place in parallel or a different order in line with the best practices in intervention development.

The 7-step framework suggested by Card et al. (2011) was developed to adapt an existing effective programme for the new population. Card et al.'s framework (2011) was developed based on a review of literature on the adaptation of prevention programmes for teen pregnancy sexually transmitted infection, and HIV. The proposed steps are: (1) select a suitable effective programme; (2) gather the original programme materials; (3) develop a programme model; (4) identify the programme's core components and best-practice characteristics; (5) identify and categorise mismatches between the original programme model or materials and the new context; (6) adapt the original programme model if warranted; and (7) adapt the original programme materials. They recommended researchers carefully review five important areas during the adaptation: the language of the materials (appropriateness of the language for the developmental level, cultural norms and values, language background and literacy level of the target population), updating and checking the relevance of research-based information for the population, ensuring examples and images are up-to-

date and culturally relevant to the characteristics of the population, updating staff training based on the adapted version of the programme, and adapting the evaluation materials based on the adaptation.

Card et al.'s (2011) framework encourage practitioners and researchers to adhere to the original programme's theory of change and core components as well as the best practices in the literature during the adaptation process and to make appropriate changes, when necessary, to better suit the programme to the target population's needs and characteristics. Although they suggested keeping the modifications during the adaptation process as minimal considering the resource-limited settings, they highlighted that the process of adaptation should ideally involve a variety of key stakeholders such as local community leaders, programme staff, and members of the target population. Likewise, Andersson (2018) recently proposed that further development in internet interventions will involve clients more in the development and updating of the interventions as active collaborators or feedback providers in the design of interventions.

The three frameworks had many steps that overlap. First of all, three frameworks (Card et al., 2011; Escoffery et al., 2019; Movsisyan et al., 2019) had three steps that were common: a selection of a suitable evidence-based programme, deciding on the adaptations by identifying potential mismatches with the new context, and the adaptation of the programme content and materials. Escoffery et al. (2019) and Movsisyan et al. (2019) had other common steps that were not outlined by Card et al. (2011). Both had steps of assessing the needs of the population of interest and organisational capacity to implement the programme, pilot testing the adapted version of the programme in the new target population, revising the adapted intervention if necessary, developing an implementation plan, and evaluating the effectiveness of the adapted intervention. As outlined, the frameworks of Escoffery et al. (2019) and Movsisyan et al. (2019) are more comprehensive as they also included evaluation and implementation of the adapted programme in their framework. In contrast, Card et al. (2011) did not include those steps.

3.3. Adaptation of the iCBT Intervention

The present study aims to adapt an evidence-based intervention programme to reduce depression and anxiety among the general population for breast cancer survivors and their carers. Using an integrative approach, combining the steps suggested by Escoffery et al. (2019), Movsisyan et al. (2019), and Card et al. (2011), an iCBT programme was adapted. The use of only Card et al.'s (2011) framework was considered during the adaptation process; however, considering that the iCBT interventions for cancer survivors are only recently emerging, initial assessment of the selected acceptability of iCBT programme and pilot testing before the implementation of the programme were necessary. Given limited resources, the 11-step framework was created by integrating the most important steps (See Table 4).

Table 4

Overview of the Steps Used in the Adaptation

Step 1	Literature review of the psychological needs of breast cancer survivors and the need for an iCBT intervention
Step 2	Understanding and selecting an effective evidence-based iCBT programme that will fit the breast cancer survivors
Step 3	Evaluation of the perspectives of breast cancer survivors and their carers on the acceptability of the selected iCBT programme
Step 4	Identification of potential mismatches between the selected programme and the needs of survivors and their carers
Step 5	Adaptation of the programme content guided by the existing literature and the findings from the interviews with potential users
Step 6	Evaluation of the personal stories by a breast cancer survivor and revision of the stories based on the feedback
Step 7	Evaluation of the adapted material by two experts (one in CBT and one in CBT & psycho-oncology)
Step 8	Selection of the outcome measures for the new population

Step 9	Planning the dissemination of the adapted programme, participant recruitment, and training of the supporters
Step 10	Pilot testing the acceptability and effectiveness of the newly adapted programme
Step 11	Evaluation of the user and provider experiences

Steps 1 and 2 went in parallel due to the time restrictions in the project. Initially, a literature review was conducted (see Chapter 1) to assess the psychological needs of breast cancer survivors. The literature review indicated that depression and anxiety are two very common psychological problems among breast cancer survivors (Croyle & Rowland, 2003; Fann et al., 2008; Hopko et al., 2016; Puigpinós-Riera et al., 2018; Spiegel & Riba, 2015) and that the CBT approach and techniques have been found highly effective in the treatment of depression and anxiety among them (Tatrow & Montgomery, 2006; Xiao et al., 2017; Ye et al., 2018). However, many cancer survivors cannot access psychological interventions and remain untreated due to the under-recognition of their need for psychosocial care and lack of available mental health clinicians (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). Notably, many studies have revealed that iCBT is an easily accessible and evidence-based alternative that has been found effective in the treatment of depression and anxiety in the general population (Carlbring et al., 2018; Richards & Richardson, 2012; Spek et al., 2007) as well as in cancer survivors (Murphy et al., 2019).

It was also well established that perceived carer support (Borstelmann et al., 2015; Manne, Winkel, et al., 2005; Waters et al., 2013) and open cancer-related communication between survivors and their carers (Li & Loke, 2014; Manne et al., 2006; Tiete et al., 2020) were important predictors of breast cancer survivors' psychological distress. Therefore, carer inclusion in the iCBT intervention by giving them access to the iCBT programme was considered rather than a couple-focused intervention given the limited timeline as interventions requiring simultaneous participation of both the survivors

and the carer have lower uptake rates (Hopkinson, Brown, Okamoto, & Addington-Hall, 2012; Regan, Lambert, & Kelly, 2013).

Based on the literature review, inclusion of an online supporter, evidence-based techniques, self-control over treatment, anonymity, engaging and user-friendly content are the key features for improving engagement and overall satisfaction with iCBT programmes (Richards & Timulak, 2013; Richards, Murphy, et al., 2016; Titov et al., 2013). An evidence-based programme, the Space from Depression and Anxiety, which integrated these key features in its development (Richards, Murphy, et al., 2016) and was found effective and acceptable for the treatment of depression and anxiety among adults and university students (Richards, Timulak, et al., 2015; Richards, Timulak, et al., 2016; Richards, Murphy, et al., 2016; Sharry et al., 2013) was selected. The selected programme is based on the CBT approach and consists of 7 modules delivered on an online platform. The core components of the programme are psychoeducation, cognitive restructuring, and behavioural activation. Each module consists of psychoeducation, quiz, summary, and personal stories, including experiences of people who present their problem and explain their own journeys of using the programme. Additional resources, including mindfulness and relaxation exercises, journal, activity scheduling, mood monitor, and helpful thoughts list, are also available in the programme. Considering its effectiveness, structure, well-prepared content, its targeted development for those with mild-to-moderate depression and/or anxiety, and the underlying programme theory on which it is based, the Space from Depression and Anxiety programme was regarded as potentially being a good fit for adaptation; however, it was necessary to evaluate whether it is acceptable for breast cancer survivors and whether it is acceptable to give carers access to the iCBT intervention.

Acceptance is one of the key aspects that has been considered in the design, evaluation, and implementation of healthcare interventions. To successfully implement an intervention, not only it should be acceptable to intervention deliverers (e.g., researchers or healthcare professionals), but also to its recipients (e.g., survivors) (Sekhon et al., 2017). To the best of my knowledge, no study to

date has examined the effectiveness and acceptability of an iCBT programme for depression and anxiety in the breast cancer context. Therefore, a decision was made to evaluate the perspectives of breast cancer survivors and their carers regarding the acceptability of the iCBT programme before starting the adaptation.

Step 3 involved conducting semi-structured interviews with breast cancer survivors and informal carers. These interviews provided an opportunity to use a live demonstration of the Space from Depression and Anxiety programme to explore their perspectives (see Chapter 2 for details). The findings of the interviews significantly informed the adaptation process with the identified themes regarding the specific needs and attitudes of this population towards the iCBT programmes. First, survivors viewed the iCBT as a good alternative to provide the support and information they needed with an easily accessible, flexible, private, and reliable guided programme. On the other hand, the lack of time, feeling too overwhelmed with cancer, and limited technological abilities were the potential barriers to their engagement with the programme. Carers viewed the access option as more suitable for their needs rather than having a separate programme. They reported that carer access might help carers understand and help survivors better, and encourage both to discuss what they learned. Moreover, both survivors and carers noted their lack of skills and knowledge on expressing feelings, and they highlighted that the iCBT programmes should address this need.

Based on the interview findings, we decided to adapt the Space from Depression and Anxiety programme for breast cancer survivors and give them an option to provide their carers access to the same treatment programme. As carers reported that they do not need support for themselves but need evidence-based information on how to provide support to survivors, a decision was made to develop an intervention to decrease survivors' depression and anxiety symptoms while giving them an option to provide their carers access. Therefore, the adapted programme does not aim to improve depression and/or anxiety of informal carers but provide them knowledge on breast cancer, its impact on their psychological well-being, ways of expressing their feelings, and active listening

techniques, and encouraging them to listen to breast cancer-related concerns of survivors and have open communication with them. Based on the interviews and the literature findings, there were two critical periods for breast survivors when they needed professional support the most: shortly after the diagnosis and after the completion of the treatment.

Following the interviews, two psycho-oncologists were consulted to learn about their opinions for the recruitment and the timing of the intervention delivery. They suggested that providing a face-to-face treatment alternative will be essential if the iCBT intervention is delivered shortly after the diagnosis. However, a face-to-face treatment alternative provided by the psycho-oncologists in the hospital was not an option due to the limited number of mental health professionals. Considering Baker et al.'s (2013) findings and lack of resources in this project to provide a face-to-face treatment alternative, a decision was made to provide the intervention for survivors who completed their active breast cancer treatments (e.g., chemotherapy, radiotherapy, and surgery).

Step 4 and Step 5 went in parallel. They included identifying the mismatches between the intervention programme and the new target audience and the adaptation of the programme content was largely guided by the interviews and the literature review. Firstly, the programme name was modified as Space in Breast Cancer from Depression and Anxiety to increase users' sense of belonging to the programme and thus increase their motivation to use it. During the adaptation, the core programme content (i.e., psychoeducation, cognitive restructuring, and behavioural activation) was retained to not threaten the programme's effectiveness. Keeping the evidence-based core components was integral (Escoffery et al., 2019; Rabin, Brownson, Haire-Joshu, Kreuter, & Weaver, 2008).

The core components of the CBT were kept; however, the psychoeducation material lacked information about the prevalence of depression and anxiety among breast cancer survivors, the definition of breast cancer, the impact of breast cancer on well-being, negative thinking regarding the

diagnosis and treatment, normalisation of feelings such as fear, worry and tension in response to the diagnosis and treatment, the effectiveness of CBT on breast cancer survivors' depression and anxiety, and quality of life. Therefore, information about these was added to the text.

Although the programme had a module on understanding feelings there was no information on how to express them, which was highlighted by both survivors and carers as the biggest difficulty they have and need information about. Therefore, information and techniques to express feelings (e.g., using "I feel" statements) were added to the module. Avoidance of communicating about cancer and the difficulty in talking about feelings were commonly reported by many other studies (Donovan-Kicken & Caughlin, 2011; Goldsmith et al., 2007; Kornblith et al., 2006; Zhang & Siminoff, 2003).

Fear of recurrence is widely documented in the breast cancer literature (Koch et al., 2014; Lee-Jones et al., 1997; Mehnert et al., 2009; van den Beuken-van Everdingen et al., 2008). The anxiety module was revised to include text on the normalisation of worry in response to cancer and the possibility of cancer recurrence, which was frequently mentioned by many survivors during the interviews.

Fatigue was another difficulty mentioned by some survivors during the interviews and is one of the most commonly reported difficulties by breast cancer survivors (Reuter et al., 2006; Stagl et al., 2015; Vargas et al., 2014). Cancer survivors who used a different iCBT programme also expressed a desire for additional information on fatigue (Alberts et al., 2018). Therefore, information on managing cancer-related fatigue and tiredness was added during the adaptation as it lacked in the original programme.

Distraction techniques were also added for survivors to use when they are dealing with difficult situations. It was emphasized that some of their negative automatic thoughts could have a realistic basis, but they may still be unhelpful. Based on Moorey and Greer (2012)'s suggestions, distraction techniques such as focusing on the surroundings when feeling sad or anxious, and

describing them in detail and aloud if possible, having a conversation with someone, and performing a mental exercise (e.g., playing a distracting game on the phone or do a crossword or puzzle) were included.

Some sections in the programme had to change completely. For instance, the personal stories in the original programme reflected the general population, and the majority of them did not apply to the breast cancer survivors and their carers. For example, the characters in the personal stories reported experiencing depression and/or anxiety because of college coursework, workplace problems, and marital problems. However, during the interviews, survivors were mostly concerned with the fear of recurrence, difficulty to express their feelings and concerns regarding breast cancer, changes in daily life and functioning following the treatment (See Chapter 1). Therefore, the personal stories were rewritten to help them relate to personal stories. For example, fear of recurrence were addressed in the examples and personal stories. New stories and examples were mostly inspired by the experiences of the interview participants and the clinical knowledge of the researcher (SA). The names and personal details of the participants were changed in the personal stories to maintain confidentiality. In total, 6 personal stories were prepared: 2 representing single breast cancer survivors, 2 for informal carers, and 2 for couples. Careful attention was paid to ensure that the stories accurately portrayed different experiences and backgrounds.

Photos in the personal stories section of each module were also replaced with young, middle-aged, and old women images and an image of a man representing a carer, that best suited the new characters created. As the programme is delivered to a wide range of individuals, we wanted to capture as many different characteristics as possible regarding age, gender, and race. The photos were selected from the website <http://www.istockphoto.com>.

The examples of thoughts, feelings, and behaviours cycle (TFB cycle) did not address the common negative thoughts experienced by breast cancer survivors and carers; thus, the examples were changed completely with the ones such as *"I can't cope with breast cancer"* or *"My cancer will*

come back". Furthermore, there were other examples in the programme that did not fit the new context. An example of catastrophising in the thinking traps section was "*Stumbling over a few words when giving a presentation and then thinking the whole thing was a mess*", which did not match the new context. Therefore, it was modified with "*Although your doctor says your prognosis is good, you still believe that you can't recover from cancer*" to reflect common negative and unbalanced thinking patterns among breast cancer survivors who completed their treatments.

Some information needed to be adapted, but not changed completely. For instance, in the boosting behaviour module, pleasure experiences (e.g., going to a movie, spending an evening with good friends), and master/achievement experiences (e.g. taking up a new hobby, cooking a meal) were added to give survivors some examples of activities they could perform to increase their activity level and improve mood. Moreover, the physical activity section was changed. Information was added that suggested gentle exercises, such as walking out in fresh air, gentle stretching, and yoga as recommended by health professionals for breast cancer survivors (Culos-Reed, Carlson, Daroux, & Hatley-Aldous, 2006; Moadel et al., 2007). Exercise guidelines for cancer survivors suggest that every survivor should avoid inactivity and recommend moderate-intensity aerobic exercises at least three times per week, at least 30 minutes (Campbell et al., 2019; Irwin et al., 2008). Furthermore, questions on quizzes in the original programme focused on the general population. For example, one question was about whether anxiety and depression are two of the most common psychological difficulties, and the answer provided the prevalence of depression and anxiety in the general population. However, as the new programme mainly targets breast cancer survivors, we added information on the prevalence of depression and anxiety among breast cancer survivors to help them understand that what they are experiencing is normal and that many other people are going through the same issues. Besides, emergency phone numbers for UK participants were added to the Help page.

Step 6 included evaluating the content by a breast cancer survivor, a middle-aged woman who recovered from breast cancer and was cancer-free. She specifically evaluated the personal

stories and character backgrounds created by the researcher to evaluate if they are coherent, relatable, and distinct enough from each other. Based on the feedback given, over-similarities, over-expectation on survivors, and excessive side effects were noted, and stories were modified accordingly. For example, there were strong overlaps of similar relationship issues in two of the characters who were married. Similarly, both single survivors fear cancer recurrence. The stories were changed to have more balance and to not give the impression that only single survivors have fear of recurrence. Over-expectation on survivors was another concern as one of the characters talked about starting to Zumba classes with another woman; this was changed with walking out in fresh air. Excessive side effects such as complete hair loss were another concern. Considering that the participants were survivors who completed their treatments, complete hair loss and its influences on the survivor were removed from the story.

Step 7 consisted of evaluating the programme by two experts, who were selected based on the criteria: a) native speaker of English; b) PhD in clinical psychology; and c) experience in CBT and/or psycho-oncology. One of them was an expert in CBT and psycho-oncology (D.Clin.Psych Cert CBT), and the other was an expert in CBT (D.Clin.Psych). The evaluation of the programme content by two experts was done separately. First, the clinical psychologist, an expert in CBT and psycho-oncology, reviewed the first three modules of the adapted programme and gave feedback. Then, the primary researcher reviewed the changed and edited the whole programme content based on the received feedback. Afterwards, the other clinical psychologist who is an expert in CBT reviewed the adapted content including all eight modules. The programme content was changed accordingly, and the final version was created.

Step 8 included modification of the outcome measures that were not appropriate to use with breast cancer survivors and adding validated measures to evaluate the satisfaction and effectiveness of the adapted programme. For example, a Sociodemographic and Clinical History Questionnaire (Richards, Timulak, & Hevey, 2013), used in the original programme to collect data on

sociodemographic information, was expanded to include health-related questions such as the stage of breast cancer, the length of time since the diagnosis and whether they have someone who supports them.

The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) was used instead of the Patient Health Questionnaire- 9 Item Scale (PHQ-9, Kroenke, Spitzer, & Williams, 2001) and the Generalised Anxiety Disorder Questionnaire- 7 Item Scale (GAD-7, Löwe et al., 2008) in the original programme. As it was validated and extensively used in measuring psychological distress among cancer survivors (Mitchell, Meader, & Symonds, 2010). The HADS was optimal as it was developed to use in medical practice and used more frequently to assess distress among people with a medical condition such as cancer (e.g., Duffececay et al., 2013; Fann et al., 2008; Murphy et al., 2019; Tatrow & Montgomery, 2006) as compared to PHQ-9.

Moreover, secondary outcome measures including the European Organisation for Research and Treatment of Cancer Quality of Life (EORTC QLQ-C30; Aaronson et al., 1993), Breast Cancer Worry Scale (CWS; Custers, Kwakkenbos, van de Wal, Prins, & Thewes, 2018), Brief Coping Orientation to Problems Encountered Inventory (Brief COPE; Carver, 1997), Modified Medical Outcomes Study Social Support Survey (mMOS-SS; Moser, Stuck, Silliman, Ganz, & Clough-Gorr, 2012), all of which have been used among cancer survivors, were used to measure if the programme use leads to changes in survivors' quality of life, fear of cancer recurrence, use of coping strategies, and social support perceptions. The Survivor-Carer Cancer Communication scale (Francis, Worthington, Kypriotakis, & Rose, 2010; Siminoff, Rose, Zhang, & Zyzanski, 2006) and Survivor-Carer Relationship Quality were used to measure survivors' and their carers' communication and relationship quality after using the adapted intervention programme, which includes the personal stories of both survivors and carers as well as strategies to express their feelings towards each other and active listening strategies. Other measures such as Helpful Aspects of Therapy Form (HAT; Burke,

Richards, & Timulak, 2019; Llewelyn, 1988), Satisfaction with Online Treatment (SAT; Richards & Timulak, 2013) were kept as they were suitable for the new population.

Step 9 included planning the dissemination of the adapted iCBT intervention, recruitment, and training of the supporters. After the SilverCloud Health team had prepared the adapted material, a recruitment email was sent by the School of Psychology at Trinity College Dublin to students and graduates of the applied psychology master's course, to find people interested in providing feedback to breast cancer survivors. 10 master's students applied, and they were provided training to introduce the programme and supporter role by an experienced assistant psychologist. After that, another training by SA was given to provide psychoeducation about breast cancer, its psychological impact on survivors, and a CBT framework in the context of cancer care. The supervision process started before the recruitment had started, and the meetings included practice on case examples prepared by the researcher, and potential issues were covered.

A decision was made to recruit breast cancer survivors through social media platforms such as Facebook, Twitter, and LinkedIn by the researcher's social media accounts. Moreover, the charities in Ireland and the UK, such as Irish Cancer Society, ARC Cancer Support, Breast Cancer Now, Pink Ribbon Foundation UK, Against Breast Cancer UK, England, & Wales, were also contacted via email with a link to study to request them to share the study with their members. The recruitment poster for the study, the text to share the study on social media platforms, and the Qualtrics link, including the information leaflet, screening questions, and outcome measures, were also prepared in this stage. Separate links for survivors and carers were prepared as carer access was going to be given based on survivors' preferences.

Step 10 included the pilot testing of the newly adapted programme, which will be described in detail in the next chapter. The pilot RCT will focus primarily on the evaluation of (1) the programme effectiveness on the survivors' outcomes of depression, anxiety, quality of life, fear of recurrence, coping strategies, and perceived social support, (2) the effects of giving main carers access to the

same programme, (3) the helpful and hindering events for both survivors and carers when using the internet-delivered programme, and (4) satisfaction of both survivors and carers with the overall internet-delivered programme.

Finally, Step 11 focused on the evaluation of the programme from the users' perspectives. Specifically, the subjective experiences of breast cancer survivors and their carers using the internet-delivered programme will be qualitatively evaluated through semi-structured online interviews. The evaluation process and the user experiences with the adapted iCBT intervention will be explained in detail in Chapter 5.

3.4. Strengths and Limitations of the Adaptation

The adaptation process of the new programme has some strengths and limitations. Strengths include the exploration of the perspectives of survivors and their carers on the needs and acceptability of such programme before the commencement of the adaptation, adapting the programme content based on the user perspectives and the literature, and the evaluation of the adapted content by a breast cancer survivor and experts in the CBT and psycho-oncology field. Some important steps, such as establishment of networks, capacity, and infrastructure, suggested by Movsisyan et al. (2019) couldn't be followed, and some steps were partially followed due to the limited time and financial resources in the current research project. The primary researcher attempted establishing networks within the psycho-oncology context, but it was difficult as the study was not conducted in a medical setting (e.g., hospital). However, it could significantly improve the reach of the programme and thus the number of participants who take part in the pilot testing. This may have some implications during the pilot testing and use of the new programme. Furthermore, evaluation of the programme by a survivor did not include all the module content but only the personal stories in the programme. Further studies could benefit from including the target population, and asking them to evaluate and give feedback on the adapted programme content. As

this may increase its acceptability. Also, intervention revision and implementation of the adapted intervention after the pilot-testing would improve its effectiveness and acceptability; however, it was not possible given the three-year timeline in this project.

3.5. Conclusions

This chapter provided a review of the adaptation frameworks of health interventions and documentation of the decision-making process of the adapted *Space in Breast Cancer from Depression and Anxiety* programme. Although there are existing frameworks for the adaptation of effective health interventions, it is still unknown if applying these steps have any positive effect on health outcomes and if they are acceptable for the population of interest.

Likewise, Movsisyan et al. (2019) recently noted that there is no guidance on addressing how important decisions should be made, such as when, to what extent, and how to adapt intervention programmes, when adapting complex population health interventions. Digital interventions were also criticised for being often adapted in an unsystematic manner without relying on a theoretical framework, which decreases the capabilities of the intervention to be more appealing for users and lower user engagement (Karekla et al., 2019). For example, a study on guided web-based interventions for insomnia targeting breast cancer patients first conducted in-depth interviews with the patients to explore whether or not it is feasible to implement an online insomnia intervention for breast cancer patients in routine care and then adapted the intervention based on the interviews and the literature (Dozeman et al., 2017b). However, to the best of my knowledge, details regarding the decision-making process of the adaptation were not reported; it was not stated which, if any, steps and theoretical framework were followed during the adaptation process.

In conclusion, *Space in Breast Cancer from Depression and Anxiety* was carefully adapted following 11 steps, which included the participation of the target user population and experts in the

adaptation process. The newly adapted iCBT programme aims to effectively decrease depression and anxiety symptoms of breast cancer survivors.

CHAPTER 4

Study III: A pilot randomised controlled trial comparing internet-delivered cognitive-behavioural therapy (iCBT) for depression and anxiety among breast cancer survivors

4.1. Introduction

As mentioned in the earlier chapters, the literature review (in Chapter 1) and findings of the interviews with breast cancer survivors and their carers (in Chapter 2) informed and assisted the adaptation process of the intervention programme for breast cancer survivors and their carers. This chapter describes the third study by explaining the therapeutic aims of the new iCBT intervention for breast cancer survivors and their carers, the methods used to evaluate its effectiveness, presents the results of the pilot RCT, and then discusses the findings in the light of the literature review and the findings from the interviews with breast cancer survivors and their carers.

4.1.1. Therapeutic Rationale of the Intervention Components

There are three core components in the intervention aiming to reduce the low mood and anxiety symptoms of breast cancer survivors. These core components are provided through the modules and a variety of tools in the programme.

4.1.1.1. Psychoeducation

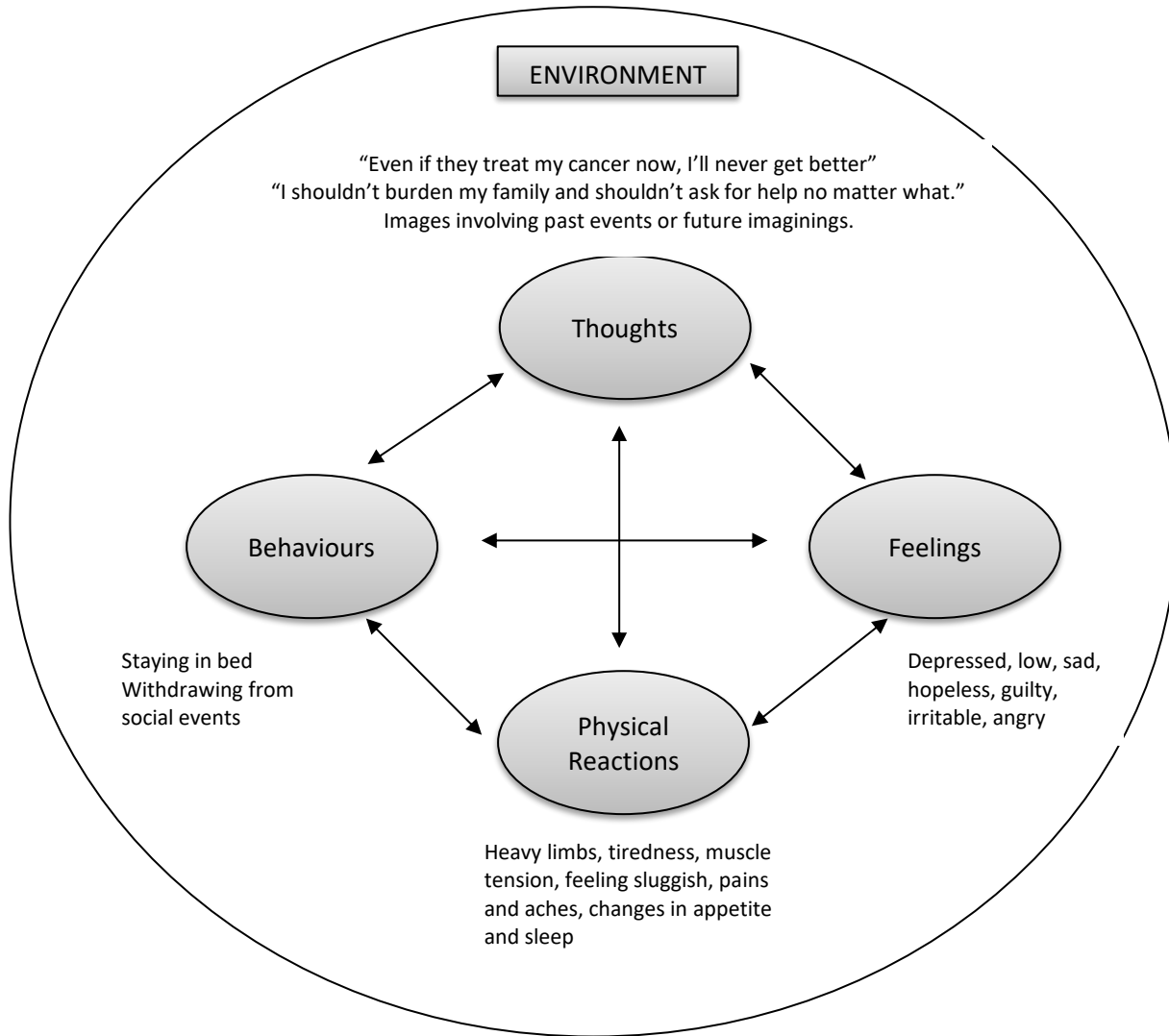
The *Space in Breast Cancer from Depression and Anxiety* programme has a strong emphasis on psychoeducation, and as mentioned in the previous chapter, it includes information on a variety of topics such as breast cancer, demonstrating how depression and anxiety operate in breast cancer, explanation of the CBT approach, the relationship between thoughts, feelings, and behaviours,

importance of behavioural activation, understanding and expressing emotions, how lifestyle choices such as sleep, alcohol and caffeine consumption, diet, physical activity, and medication influences well-being, learning about negative thinking and thinking styles, challenging unhelpful thinking patterns and coming up with an alternative and balanced way of thinking, and understanding the differences between practical vs. hypothetical worries.

CBT suggests that the meaning of cancer or cancer-related other stressful events for the person directly influences their emotional and behavioural reactions, particularly their coping, and that there is a complex relationship between thoughts, feelings, behaviours, and physical reactions (Moorey & Greer, 2012). To explain this relationship to breast cancer survivors, the cycle of the Thoughts-Feelings-Behaviours (or TFB Cycle) was presented in the first module (see Figure 4). This model emphasizes that thoughts, feelings, physical reactions, and behaviours influence each other and one can break the cycle by changing the way they think and the way they behave. The TFB cycle was introduced to help survivors understand the difficulties they experience and how to overcome them by changing their thinking and behaviours.

Figure 4

The Cycle of Thoughts, Feelings, Behaviours, and Physical Reactions



Note. Adapted from Padesky and Greenberger (2020) *The Clinician’s Guide to CBT Using Mind Over Mood*, Guilford Press, New York. The model reflects the constant interaction between thoughts, feelings, physical reactions, and behaviours, which are also influenced by the environment. Examples under each part indicate how a problem may represent itself in the breast cancer context.

Psychoeducation has been identified as one of the key components determining the success of the internet-delivered interventions (Brown & Lewinsohn, 1984; Richards, Dowling, O'Brien, Viganò, & Timulak, 2018). Among participants who used a guided internet-delivered treatment for depression, provision of psychoeducational information (e.g., information explaining CBT, the TFB cycle, the importance of behavioural activation, learning about emotions, learning about core beliefs, thinking styles, and negative thoughts, and the relationship between behaviours, thoughts, and emotions) was the most frequently reported helpful event (Richards, Dowling et al., 2018). Participants found it helpful and thought that it increased their awareness and insight and helped them better understand depression and its contributing factors.

In a meta-analysis, passive psychoeducation has also been found effective in reducing depression and anxiety symptoms and psychological distress among individuals with no medical condition with a small but significant effect ($d= 0.20$) (Donker, Griffiths, Cuijpers, & Christensen, 2009). The passive psychoeducational intervention provides information, educational materials, or feedback/advice. For example, leaflets, posters, audio-visual aids, lectures, internet material, or software aiming to educate the person about the nature and treatment of depressive and/or anxiety disorders. Similarly, Meneses et al. (2007) found that psychoeducational intervention, delivered in three face-to-face sessions and five monthly follow-up sessions (three by telephone and two in-person) improved the quality of life of breast cancer survivors who are in the first year of survivorship and gains were maintained at 6-month follow-up.

Although, to the best of the researcher's knowledge, no iCBT study evaluated the effects of passive psychoeducation among cancer survivors, Ebert et al. (2017) compared the effectiveness of a guided iCBT for depression and treatment as usual plus online psychoeducation about depression in adults with Type 1 and Type 2 diabetes mellitus. Although the reduction in depression severity was greater in the iCBT treatment group ($d= 1.48$), individuals in the control condition who received online education about depression also showed improvements in depression severity ($d= 0.55$). These

findings suggest that psychoeducation, informing people about the nature of the problem and the evidence-based treatment, is an important component of the internet-delivered interventions of comorbid psychological distress and chronic health problem.

4.1.1.2. Behavioural Techniques

As cancer is a demoralising experience for many, it may result in a progressive reduction in activities (Moorey & Greer, 2012). This reduction may also begin due to the symptoms of the treatment such as fatigue and nausea. Although most survivors get back to normal life after the completion of their radiotherapy and chemotherapy, some remain inactive. Depression and anxiety symptoms may also maintain this state of inactivity since depression causes social withdrawal and loss of motivation and interest in pleasant activities and anxiety symptoms can lead to avoidance of social situations and encounters (Moorey & Greer, 2012). Behavioural techniques in the programme aim to help survivors regain a sense of control with the use of self-help techniques.

The behavioural techniques in the current intervention mainly focus on behavioural activation and include activity scheduling, relaxation and breathing exercises, distraction, and planning for the future. The goal of behavioural activation is to increase individuals' overt behaviours that are likely to generate reinforcing environmental contingencies, which will improve their thoughts, mood, and life quality (Hopko, Lejues, Ruggiero, & Eifert, 2003, as cited in Hopko et al., 2011). The *Boosting Behaviour* module in the current intervention encourages individuals to increase their activity levels by planning both achievement and pleasure activities and underlines the idea that action is the first step, not the motivation. It also makes them aware of the challenges such as cancer-related fatigue or tiredness that may lead to avoidance and help them to tackle these challenges for example by planning activities to reduce the fatigue. Scheduling activities can provide survivors a structure for the day or the week and these events can give them something to look forward to (Moorey & Greer, 2012) and may lead to improvements in their thoughts and mood.

The effectiveness of behavioural activation has been empirically validated for the treatment of depression by different meta-analyses (Cuijpers, van Straten, & Warmerdam, 2007; Mazzucchelli, Kane, & Rees, 2009). A recent meta-analysis demonstrated that internet-delivered behavioural activation is effective at reducing depression and anxiety symptoms at post-treatment and short-term follow-up (Huguet et al., 2018). Besides, behavioural activation has also been found effective in reducing distress the breast cancer context. For example, an RCT conducted by Hopko et al. (2011) compared the effects of 8 sessions of brief behavioural activation and problem-solving therapy among 80 depressed breast cancer patients. They found that both behavioural activation and problem-solving therapy effectively decreased depression and anxiety symptoms and improved quality of life, social support, and medical outcomes, and these gains were maintained at 12-month follow-up. Another study evaluated the efficacy of behavioural activation in treating anxiety among breast cancer patients and they found that 41% reported a clinically significant decrease in their anxiety (Hopko, Clark, Cannity, & Bell, 2016). These individuals tended to have more severe anxiety and depression at baseline.

Relaxation and mindfulness exercises are also added as additional techniques for survivors to use. As they are simple and effective tools for having rapid control over anxiety (Moorey & Greer, 2012). Relaxation techniques are based on the idea that a state of muscle relaxation is incompatible with tension and anxiety and when one practices them regularly, rapid relaxation will be achieved more easily in anxiety-provoking situations (Öst, 1987; Padesky & Greenberger, 2020). Progressive muscle relaxation aims to help people recognise physical tension and practice relaxation, within a cycle of tension and relaxation by initially tightening the muscles and then relaxing them. A recent meta-analysis revealed that relaxation therapy which involves progressive muscle relaxation is as effective as CBT in the treatment of generalised anxiety disorder, specific phobias, social anxiety disorder, and panic disorder (Montero-Marin, Garcia-Campayo, López-Montoyo, Zabaleta-Del-Olmo, & Cuijpers, 2018).

Staying in the present or mindfulness exercises in the intervention aim to help survivors become aware of what they are experiencing when they are anxious and help them live fully in the present moment by practicing to focus on their breath. Mindfulness predicts increased self-regulated behaviour and a positive emotional state (Brown & Ryan, 2003). Indeed, Brown and Ryan (2003) demonstrated that an increase in mindful awareness over time predicted a reduction in mood disturbance and stress in individuals with early-stage breast and prostate cancer, suggesting that these exercises can help breast cancer survivors to manage mood disturbances by being more mindful.

4.1.1.3. Cognitive Techniques

Cognitive techniques are one of the most important treatment components in the iCBT intervention aiming to give survivors relief from emotional distress. As mentioned earlier in Chapter 1, cognitive models of adjustment and coping assume that our interpretations of the stressful events determine our responses and reactions to these events (Lazarus & Folkman, 1984). Therefore, a variety of cognitive coping techniques are introduced in the programme such as thought monitoring, identifying cognitive distortions, and searching for alternatives.

Cognitive theory and CBT recognizes three levels of thought: “automatic thoughts”, “underlying assumptions”, and “core beliefs”(or “schemas”) (Padesky & Greenberger, 2020). Automatic thoughts are unplanned, moment-to-moment thoughts (words, images, memories) that run through people’s minds throughout the day. For example, a survivor who felt a twinge in her chest may think that “Something must be terribly wrong”. These thoughts are the most immediately accessible cognitions and are easiest to change especially if they are tested within specific situations. In the programme, the TFB cycle was used as a thought record tool, in which survivors were asked to identify their thoughts connected to a strong emotion and to look within that specific situation for evidence that supports their thought and evidence that does not support the thought. And then, they

are asked to generate an alternative/balanced thought considering all the evidence and see if this new perspective leads to any changes in their feelings. The underlying assumption is conditional “If...then...” beliefs (e.g., If I complain about my pain, my family will think that I am too weak) or rules that include “should” statements (e.g. I shouldn’t burden my family and shouldn’t ask for help) and guides people’s lives and relationships with others. Core beliefs or schemas are people’s beliefs about the self, others, and the world and guide their interpretations of the situations. Going through a life-threatening illness such as cancer might confirm their fears and activate core beliefs that they had at the back of their mind (e.g. I’m weak and vulnerable, The world is dangerous and unpredictable) (Moorey & Greer, 2012). Although core beliefs are important to address, as the iCBT programme is a brief and low-intensity programme, it mainly focuses on cognitions on the levels of automatic thoughts and underlying assumptions, as suggested by Padesky and Greenberger (2020). This is because automatic thoughts and underlying assumptions are easier to test as compared to core beliefs and work on automatic thoughts and underlying assumptions usually results in fairly rapid improvement in mood and likely to bring more adaptive core beliefs.

These techniques are important skills for survivors to manage their mood after the treatment completion through noticing negative automatic thoughts and cognitive distortions at the times of strong moods, looking at the evidence to see whether their thoughts are realistic and reflecting the situation, whether they are ignoring any strengths and positives, generating alternative explanations that are more realistic and balanced, and looking at the alternative outcomes (Moorey & Greer, 2012).

According to Moorey and Greer (2012), survivors who can cope selectively attend to aspects of their life that they have control over, whereas survivors with negative adjustment are occupied with negative automatic thoughts and selectively attend to negative aspects in their life. Distraction techniques in the current programme were also introduced under the *Coping with Difficult Situations* section, where it was underlined that some negative thoughts may have a realistic basis (e.g.

possibility of treatment failure or death) but may still be unhelpful. Distraction techniques were only encouraged to use in such cases as it may become a safety-seeking behaviour for survivors (Moorey & Greer, 2012) and prevent them from developing active coping skills.

Overall, all three components have been demonstrated to reduce psychological distress and they encourage survivors to use active, problem-focused modes of coping rather than to use avoidance to promote better adjustment (Heim, Valach, & Schaffner, 1997). The current iCBT programme provides survivors and carers a variety of skills and tools to help them deal with difficulties in more efficient ways.

4.1.2. Therapeutic Aims of the Intervention

The newly adapted 7-week guided iCBT programme for breast cancer survivors has the following therapeutic aims:

- (a) educate survivors and carers about breast cancer, its psychological influence, and how to improve low mood and worries using the CBT approach,
- (b) help them develop and use effective coping skills to deal with low mood and worries,
- (c) promote a sense of personal control over life after active treatment completion,
- (d) improve their mental adjustment to life after active medical treatment completion,
- (e) improve open communication about cancer-related feelings and concerns between survivors and their carers.

4.1.3. Study Aims and Hypotheses

This pilot RCT had six main aims:

- a. To evaluate the effectiveness of an adapted iCBT on reducing breast cancer survivors' depression and anxiety symptoms

- b. To determine changes in breast cancer survivors' quality of life, coping, fear of cancer recurrence in response to the intervention
- c. To evaluate changes in breast cancer survivors' perceived social support, cancer communication, and relationship quality in response to the carer access to survivors' intervention content
- d. To evaluate changes in carers' cancer communication and relationship quality in response to their access to survivors' treatment content
- e. To compare the effects of an adapted iCBT with and without main carer access on breast cancer survivors' depression and anxiety symptoms
- f. To evaluate the helpful aspects of the iCBT intervention and satisfaction with the programme among breast cancer survivors

Hypothesis about the primary outcomes are as follows:

- H1. Survivors in the iCBT group are expected to show a greater reduction in depression and anxiety symptoms than survivors in the TAU control group at post-intervention and 2-month follow-up.

Hypotheses about the secondary outcomes are as follows:

- H2. Survivors in the iCBT group are expected to have greater improvements in cancer-related quality of life, active and avoidant coping, and fear of recurrence compared to survivors in the TAU control at post-intervention and 2-month follow-up.
- H3. Survivors in the iCBT group are expected to use more active coping than survivors in the TAU control at post-intervention and 2-month follow-up.
- H4. A reduction in depression and anxiety symptoms of survivors in the iCBT group is expected to be mediated by the change in active and avoidant coping strategies after controlling for depression and anxiety levels at baseline

- H5. An improvement in cancer-related quality of life in the iCBT group will be mediated by the change in active and avoidant coping strategies after controlling for cancer-related quality of life at baseline.

The effects of carer access were planned to be explored using the following research questions:

- RQ1. Is there a difference in depression and anxiety scores between iCBT alone (Group 1) and iCBT with the carer access (Group 2) at post-intervention after controlling for baseline depression and anxiety scores?
- RQ2. Is there a difference in perceived social support between iCBT alone (Group 1) and iCBT with the carer access (Group 2) at post-intervention after controlling for baseline perceived social support?
- RQ3. Is there a difference in survivor-carer relationship outcomes (cancer-related communication quality and relationship quality) of survivors in iCBT with carer access between baseline and post-intervention?
- RQ4. Is there a difference in survivor-carer relationship outcomes (cancer-related communication quality and relationship quality) of carers in iCBT with carer access between baseline(pre-) and post-intervention?

4.2. Methods

4.2.1. Study Design

This pilot trial aimed to analyse the effectiveness and acceptability of an adapted 7-week iCBT intervention in reducing depression and anxiety among breast cancer survivors. The study was originally designed to compare three groups: iCBT alone (Group 1), iCBT with carer access to intervention (Group 2), and TAU control (Group 3), as described in the protocol paper (Akkol-Solakoglu et al., 2021). This study was not designed as a full randomised controlled trial, but a pragmatic pilot trial as survivors' allocation to the iCBT alone or iCBT with the carer access group was based on their preference rather than random assignment. Two intervention groups, iCBT alone (Group 1) and iCBT with carer access (Group 2) used the same iCBT programme. The only difference was that carers of the survivors in the iCBT with carer access group had access to the iCBT programme

with their own separate accounts. Treatment-as-usual control (Group 3), on the other hand, continued the usual care recommended by their hospital and did not receive any iCBT programme during or after the completion of this study. All groups were tested at baseline, post-intervention, and 2-month follow-up. Participants in the TAU control group were not provided the intervention due to the limited timeline and resources in the project.

Out of 53 women randomised to the iCBT intervention group, only 8 women preferred the iCBT with carer access condition, and only 4 of those carers signed up for the programme. As the iCBT with carer access arm (n= 4) did not have sufficient power to make group comparisons, the main analyses were conducted with two randomised group arms: iCBT alone (n= 48) and TAU control (n= 24). The effects of using the iCBT with a carer accessing the same programme were examined in an exploratory manner using research questions rather than confirmatory hypothesis testing.

4.2.2. Study Setting and Participants

Breast cancer survivors who completed their active medical treatment and were cancer-free participated in this study. Participants were recruited through online cancer support groups, cancer research email listings, and internet social media advertising (Facebook, Twitter, LinkedIn), forums, bulletins, and social media accounts of cancer charities. A Qualtrics link and a text explaining the study details were provided on the advertisement poster, which was shared on social media. All survivors who showed an interest in this trial read the information leaflet and signed the digital informed consent through the provided Qualtrics survey link. Participants were recruited between October 2020 and May 2021. The recruitment has initially started in Ireland and extended to UK to enhance the data collection process. Eligibility criteria for the recruitment of survivors and carers are described in Table 5. As this is a pilot RCT, no limit was set for the time since the treatment completion or breast cancer stage as an exclusion criterion for survivors.

Table 5

Eligibility Criteria for Survivors and Carers

Inclusion criteria for survivors

- (1) being female
- (2) having completed the active breast cancer treatments such as chemotherapy, radiotherapy, and surgery and being cancer-free
- (3) being at least mildly confident with using the internet
- (4) being at least mildly confident in reading and writing in English

Inclusion criteria for carers

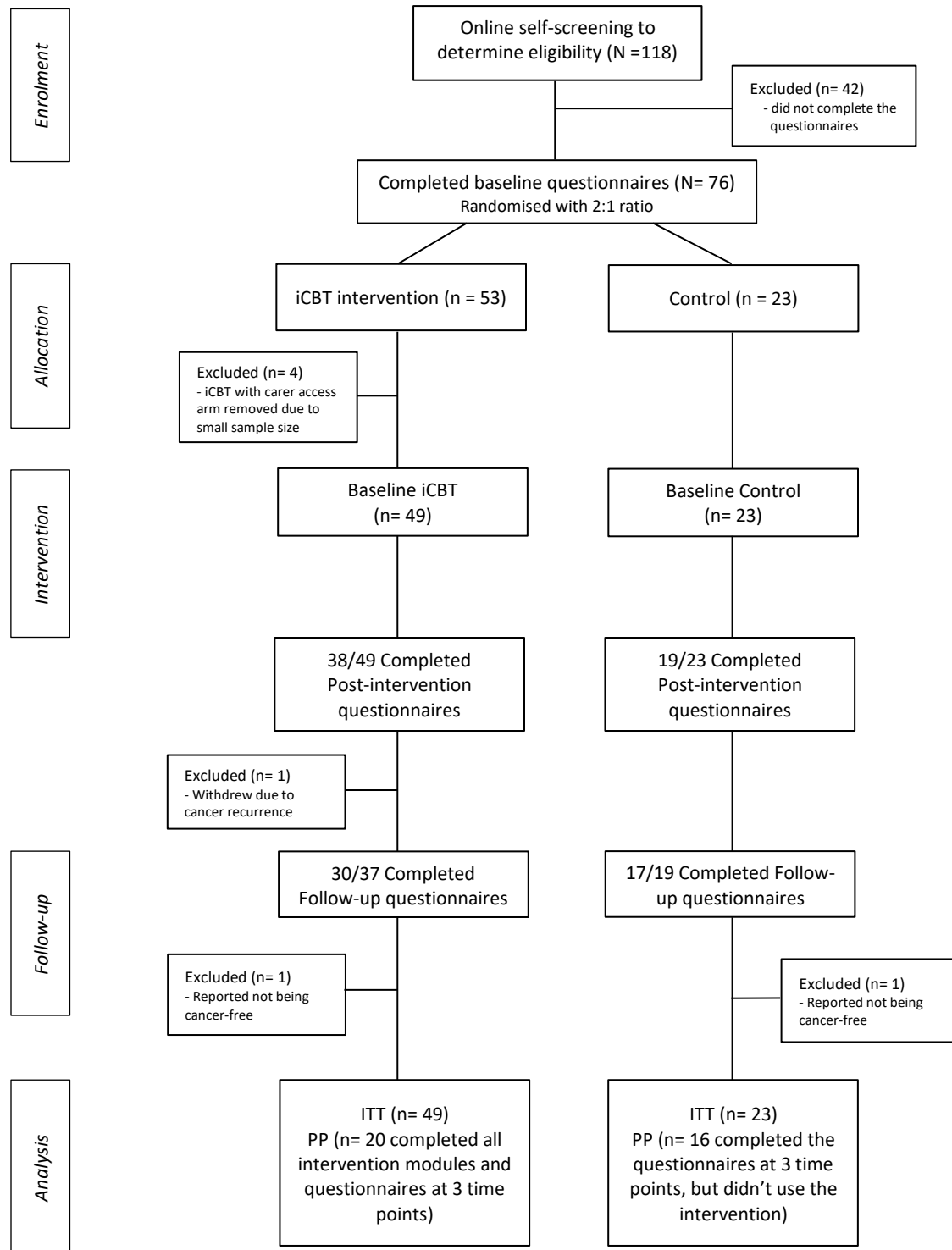
- (1) currently caring or have cared for a woman living with breast cancer (such as a partner, spouse, friend, or relative)
- (2) being at least mildly confident with using the internet
- (3) being at least mildly confident in reading and writing in English

Exclusion criteria for survivors and carers

- (1) current suicidal ideation or intent
 - (2) current alcohol or drug misuse
 - (3) enduring mental health disorders such as schizophrenia, psychosis, and bipolar disorder
 - (4) currently being in psychological treatment for depression or anxiety
-

Figure 5

CONSORT Flow Diagram



4.2.3. Sample Size

The G-Power software programme was used to carry out power analysis. Based on the initial study design, the required sample size was calculated for three-group, pre-test, post-test, and follow-up, as described in the study protocol (Akkol-Solakoglu, Hevey, & Richards, 2021). The data from a randomised controlled trial of an iCBT programme for depression and anxiety among cancer survivors revealed a large within-between interaction effect size for the HADS-Total after comparing the pre-treatment and post-treatment scores of the iCBT and the TAU (Murphy et al., 2019). To calculate the sample size, we powered for the changes in the primary outcome (measured by the HADS-Total) when comparing the two treatment groups with the TAU. Assuming a medium effect size ($f = 0.30$) for the pre, post, follow-up comparisons between three groups with a power of 0.80 and a 0.05 alpha, the sample size was calculated as 27 breast cancer survivors in each group and 81 in total. Taking the 25% attrition rate into account (Richards, Duffy et al., 2018), we initially aimed to recruit 108 breast cancer survivors in total ($n = 72$ for iCBT, and $n = 36$ for TAU using 2:1 allocation ratio).

Although we intended to have a 3-arm study and compare two iCBT groups with the control group, only 4 participants ended up in the iCBT with the carer access group, which reduced the statistical power to detect the effects of carer access between the two iCBT groups. Therefore, the proposed study design had to be adjusted, and sample size requirement had changed to two-arm pilot RCT (iCBT vs. TAU control). Assuming a medium effect size ($f = 0.30$) for the two-arm study with a power of 0.80 and a 0.05 alpha, the required sample size was recalculated as 20 participants per group, and a total of 60 participants for two groups (with 2:1 allocation ratio). Assuming an attrition rate of 25%, it was concluded that recruiting a total of 75 breast cancer survivors was required at baseline ($n = 50$ for iCBT and $n = 25$ TAU control).

4.2.4. Randomisation

Randomisation of the participants was handled by Qualtrics. Participants who meet the eligibility criteria and completed the baseline questionnaire (n= 76) were randomly assigned to iCBT treatment (n= 53) or treatment-as-usual control (n= 23) using 2:1 ratio. In the questionnaire, survivors randomised to the iCBT group were asked about their preference of giving their carers access to the programme through a separate log-in details. As the iCBT with carer access group had a very small sample size (n= 4), it was removed from the main analyses. A decision was made to run the analyses based on the two fully randomised groups: iCBT intervention group and control group.

4.2.5. The iCBT Intervention

The intervention, Space in Breast Cancer from Depression and Anxiety programme, consists of 7 modules and its module content is based on the principles of CBT (see Table 6). As mentioned earlier, different therapeutic components such as psychoeducation, behavioural activation, self-monitoring, and cognitive restructuring exist in the programme. It also has a variety of tools and features such as goal setting, reminders, quizzes, videos, journal, activity scheduling, thought diary, worry tree, CBT cycle, uncovering core beliefs, and support network map, staying well planner, and staying in the present exercises.

Moreover, acknowledging that survivors might have needed to take some break during the holiday period (Christmas and New Year time), supporter reviews were paused between the 23th of December 2020 and 4th of January 2021. Survivors were send a message to encourage them working through the suggested tools and modules during this period whenever they could.

Table 6*Description of the Module Content in the Adapted iCBT Programme (Akkol-Solakoglu et al., 2021)*

Module	Description
1. Getting Started	This module provides information about breast cancer, depression, and anxiety, and why they occur in breast cancer patients. It also introduces the basics of CBT.
2. Understanding Feelings	This module introduces emotions, outlines their function, and how they are related to our physical body reactions. It also encourages users to express their feelings and includes examples about how to do it tactfully.
3. Boosting Behaviour	Boosting behaviour is a module focusing on behavioural activation as a way to improve users' moods. It helps them identify and plan pleasurable activities that will give them a sense of achievement and help them feel better.
4. Spotting Thoughts	This module aims to help users identify their unhelpful, negative thinking patterns, distorted thinking errors and build their own TFB cycles.
5. Challenging Thoughts	Challenging Thoughts module helps users identify and challenge their unhelpful hot thoughts and find an alternative thought that is more balanced and realistic.
6. Managing Worry	This module explains the role of worry in anxiety and introduces the worry cycle. It also introduces techniques to manage both real and hypothetical worries.
7. Bringing It All Together	This module encourages users to reflect on what information and skills they have learned and helps them plan to stay well by watching out for personal warning signs and maintaining social support.

4.2.6. Supporters

Each participant in the iCBT intervention group was assigned one of 10 supporters, who were applied psychology master's students, and all had an undergraduate degree in psychology. Before starting their roles, the supporters received a 1.5-hour training on the online health supporter role by an experienced psychologist with a clinical psychology degree. The training aimed to familiarise them with the role of a supporter and the platform used, provide information on how to communicate

effectively with the users, write reviews based on the best practices, and what to look for when writing the reviews. In addition, the supporters received additional psychoeducation training on breast cancer, its psychological impact on individuals, how the CBT approach is used in the psycho-oncological context. This training followed several case scenarios for supporters to role play and practice the skills they have learned before starting the supporter role.

Supporters provided asynchronous post-session feedback per participant per session and in a written text through the SilverCloud platform. The mean number of participants per supporter was ($M= 5.5$, $SD= 1.26$); supporters provided feedback to a minimum 3 clients and maximum 7 clients in total. Supporters scheduled the time of their feedback on the same day over the 7 weeks and participants were informed about which day they will receive the feedback. If the timing of the feedback had to change, supporters left a message to the survivors to inform them about the change of the review date. The supporters were provided 1-hour weekly supervision by the principal researcher (SA).

The supporters' feedback included: (a) corrective psychoeducational information if the survivor's answers indicated that they had not fully grasped the core concepts or the tools, (b) general support to maintain or increase survivor's engagement with the programme, (c) encouragement for survivors to apply and practice the skills they have been learning in their daily life, and (d) provision of empathy and understanding towards the challenges the survivor is experiencing.

4.2.7. Measures

Screening Measure

Sociodemographic and Clinical History Questionnaire: This instrument was developed as a screening measure for an online CBT intervention (Richards, Timulak, & Hevey, 2013) and was adapted for the current study. The original measure consists of questions regarding alcohol or drug misuse, suicidal thoughts, confidence in using the internet, diagnosis of an organic mental health

condition (i.e., schizophrenia, psychosis, and bipolar disorder), previous and current engagement with psychotherapy or counseling for depression or anxiety. Health-related questions including the time of the breast cancer diagnosis, the length of time since the diagnosis, the length of time since medical treatment completion, medical treatments received (chemotherapy, radiotherapy, surgery, or hormonal therapy), presence of other medical conditions, history of recurrence, presence of a carer, and the nature of the relationship with the carer.

Primary Outcome Measure

Hospital Anxiety and Depression Scale (HADS): The HADS is a 14-item self-report measure was developed to assess anxiety and depression symptoms in medical settings (Zigmond & Snaith, 1983). It consists of two subscales: depression (HADS-D) and anxiety (HADS-A), each consisting of seven items. Response scale range from 0 “not at all” to 3 “most of the time”. HADS-D and HADS-A subscale totals can be summed, after reverse scoring of eight items. The HADS-T is the total score of depression and anxiety subscales, ranging from 0 to 42, and it will be used in the present study. A higher score on the HADS-T represents higher psychological distress. The HADS was chosen over other questionnaires due to its focus on depression and anxiety symptoms without relying on somatic symptoms such as fatigue or insomnia, which are experienced by cancer survivors as a result of their illness and/or medical treatment. The HADS has been extensively used and validated for measuring distress among cancer survivors (Mitchell et al., 2010; Vodermaier, Linden, & Siu, 2009) and has been shown to effectively discriminate between oncology patients with and without distress (López et al., 2012). Internal reliability of the HADS scale in the present study was good; Cronbach’s alpha was .87 for Time 1.

Secondary Outcome Measures

Quality of Life (EORTC-QLQ-C30): The European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC; Aaronson et al., 1993) was used to evaluate the overall health-related life quality of survivors. The scale consists of a 30-item scale that assesses various facets of health-related quality of life. In the present study, only the final item (“How would you rate your overall quality of life during the past week?”) was used to measure survivors’ quality of life, and the item is rated on a 7-point scale ranging from 1 “very poor” to 7 “excellent”.

Breast Cancer Worry Scale (CWC): The scale was originally developed to assess the fear of developing breast cancer among women who are at risk of hereditary breast cancer (Lerman, Trock, Rimer, Jepson, & et al, 1991). The six-item version of the Cancer Worry Scale (Custers et al., 2018) was used to assess survivors’ concerns about breast cancer recurrence and its impact on their daily functioning. Example items consist of: “How often have you thought about your chances of getting cancer again?”, “Have these thoughts affected your mood?” Responses are rated on a 4-point scale ranging from 1 “never” to 4 “almost always”. The total CWS score range from 6 to 24; higher scores indicate more frequent worries about breast cancer coming back. The 6-item version of the CWS has a good construct, convergent and divergent validity, and high internal consistency to detect fear of cancer recurrence among breast cancer survivors, and demonstrated a Cronbach alpha coefficient of .90 (Custers et al., 2018). Internal reliability in the present sample was excellent with a Cronbach’s alpha of .91 for Time 1.

Brief Coping Orientation to Problems Encountered (Brief COPE): The Brief COPE is a measure developed to assess strategies used to cope with a stressful life event (Carver, 1997). It consists of 28 items, and it is the abbreviated version of the full 60-item COPE Inventory (Carver, Scheier, & Weintraub, 1989). The Brief COPE (Carver, 1997) assesses 14 coping strategies: self-distraction, active

coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. Responses are rated on a 4-point scale ranging from 1 "I haven't been doing this at all" to 4 "I have been doing this a lot". The instruction was modified in the current study to ask how participants had been coping with breast cancer-related stress in their life. Example items are: "I've been turning to work or other activities to take my mind off things", "I've been concentrating my efforts on doing something about the situation I'm in". The Brief COPE has demonstrated reasonably reliable Cronbach alpha levels between .50 and .90 for each subscale (Carver, 1997; Rand et al., 2019). In the present study, instead of 14-factor structure, two coping dimensions assessing efforts to move toward goals (active coping) and disengage from goal pursuits (avoidant coping) were used (similar to other studies Kershaw et al., 2004; Rand et al., 2019) to assess potential changes in survivors' ways of coping with breast cancer-related stress. Active coping consisted of 12 items from the subscales of active coping, emotional and instrumental support, positive reframing, planning and acceptance. Avoidance coping consisted of 10 items from the subscales of behavioural disengagement, self-distraction, denial, venting, and self-blame. Each dimension was obtained by summing all the items, and their mean were calculated. Humour, religion, and substance abuse subscales were not included to maintain consistency with other studies that used two-dimension approach (Kershaw et al., 2004; Lambert, Girgis, Lecathelinais, & Stacey, 2013). Internal reliability of the active coping in the present study was acceptable; Cronbach's alpha was .79 for Time 1. The internal reliability of the avoidant coping at Time 1 was poor with a Cronbach's alpha of .58.

Medical Outcomes Study Social Support Survey (MOS-SSS): MOS-SSS was originally developed to assess the perceived availability of functional social support to people with chronic illnesses (Sherbourne & Stewart, 1991). The scale assesses four dimensions of social support: (1) emotional/ informational support (the expression of positive affect, empathetic understanding, and

the encouragement of expressions of feelings, and the offering of advice, information, guidance, or feedback), (2) tangible support (the provision of material aid or behavioural assistance), (3) positive social interaction (the availability of other persons to do fun things with you), and (4) affectionate support (involving expressions of love and affection). In the present study, only the emotional/informational support subscale (8 items) will be used to measure whether carer access has influenced the emotional/informational social support perceptions of survivors. Example items include: “if you need it, how often is someone available you can count on to listen to you when you need to talk?”, “if you need it, how often is someone available to give you good advice about a crisis?”. The responses range from 1 “none of the time” to 5 “all of the time”; higher scores indicating better perceived social support. The scale demonstrated excellent reliability for the overall scale with a Cronbach’s alpha of .97 and subscales with alpha levels of .96, .94, .91, and .92, respectively. Many studies conducted with breast cancer patients have also used this scale (Ganz et al., 2003; Kornblith et al., 2003; Kroenke et al., 2013; Liao et al., 2013; Sousa Rodrigues Guedes et al., 2020). Internal reliability in the present sample was excellent with a Cronbach’s alpha of .93 for Time 1.

Survivor-Carer Cancer Communication: Cancer-related communication difficulties between the survivors and carers will be measured by 6-items drawn (Family communication subscale) from the 30-item measure of Patient-Family Discord (Francis et al., 2010; Siminoff et al., 2006). This subscale was chosen since the items are specific to cancer communication and expression of feelings about cancer, which were addressed during the adaptation of the iCBT intervention and may be influenced by the carer access. The word ‘family’ was changed with the ‘carer’ in the breast cancer survivors’ version as this study is focusing only on the carer and survivor relationship. Some items examples include: “My carer does not really listen when I talk about my cancer”, “I avoid talking about cancer to my carer because I don’t want to upset them”. In the carer version of the scale, items were changed as “She does not really listen when I talk about her cancer”, “I avoid talking about

cancer to her because I don't want to upset her". Responses are rated on a 5-point ranging from 1 "strongly agree" to 5 "strongly disagree". The total scores range from 6 to 30, higher scores indicating greater cancer-related communication. The scale demonstrated a reliability coefficient of .63 (Francis et al., 2010). Internal reliability in the present sample was similar with a Cronbach's alpha of .61 for Time 1.

Survivor-Carer Relationship Quality: The relationship quality between survivors and carers was measured using a single item, where they were asked to rate the quality of their relationship with each other on a scale ranging from 0 to 10. A score of 0 represents a very poor quality of the relationship, and 10 represents an excellent quality of the relationship between survivor and carer. This single item scale assessing the relationship quality was used to allow survivors and carers to base their judgments on the aspects of their relationship that are most important for them (based on Cantril, 1965; Kuijer et al., 2004; Rottmann et al., 2015).

Other Measures

Helpful Aspects of Therapy Form (HAT): The HAT scale was used to assesses the most helpful and hindering effects during each module of the iCBT intervention (Burke et al., 2019; Llewelyn, 1988). It asks participants to describe, in their own words, what was most helpful and what was least helpful in each module for them. The responses can include anything that participants, the module, or supporters said or did. To clarify their associated impacts, participants are also asked to describe what made the event helpful or hindering for them. The HAT was administered at modules 2 to 7 on the online platform.

Satisfaction with Online Treatment (SAT): The SAT scale was developed to measure satisfaction with online treatment (Richards & Timulak, 2013). The first part of the scale includes

questions about the use of the computer to access treatment, how easy it was for them to use online treatment, whether the treatment they received would have a lasting effect on them, and whether they would specifically recommend online treatment to others. Responses are rated on a scale ranging from “agree very strongly” to “disagree very strongly”. The second part of the scale consists of two qualitative questions asking participants to describe what they most liked and least liked about the treatment. The SAT was given to participants at post-treatment when participants completed the iCBT programme. Internal reliability in the present sample was excellent with a Cronbach’s alpha of .91.

4.2.8. Procedure

The study was approved by the School of Psychology Research Ethics Committee, Trinity College Dublin (Approval ID: SPREC022020-09). The trial was registered with clinical trial registry ISRCTN (Trial registry number: ISRCTN96180849). A Qualtrics link was shared along with the study poster, which directed interested individuals to read the information leaflet, sign the digital informed consent, and complete the screening questionnaire assessing inclusion criteria, demographic information, and health status. They were able to complete the baseline questionnaires only if they were eligible. As participants’ eligibility was determined based on their responses to the screening questions set up in the Qualtrics link, all participants were responsible for self-screening. The Qualtrics link was designed to automatically exclude respondents who select “yes” to the questions asking current suicidal ideation or intent, current alcohol or drug misuse, and organic mental health conditions (e.g., schizophrenia, psychosis, and bipolar disorder) current psychotherapy for depression or anxiety. Potential participants who responded yes to the questions regarding current suicidal ideation and intent received an error message on the screening page, which provided contact details for recommended support services in Ireland and the UK. Eligible survivors proceeded with the baseline questionnaires, including the HADS-T, EORTC QLQ, CWS, Brief COPE, MOS-SSS, survivor-carer

cancer communication, and survivor-carer relationship quality.

After filling out the questionnaires (Time 1), participants were automatically randomised to two groups by Qualtrics. Those randomised to the iCBT group and reported having a carer were asked about their preference for giving their carer access to the intervention programme. Survivors preferred to participate with their carer were allocated to the iCBT with carer access group and were asked to provide their carers' names and email addresses. Carers were contacted via email and asked to complete the informed consent, screening questionnaire, survivor-carer cancer communication, and relationship quality measures through a separate Qualtrics link. Survivors, who did not have a carer and did not want carer access were not asked about their preference. Survivors who signed up for the iCBT programme were assigned a supporter by the primary researcher (SA).

All survivors were reassessed online at post-intervention (Time 2), and at 2-month follow-up (Time 3). Carers did not provide Time 2 and Time 3 data. After completing the intervention, survivors were asked about their satisfaction with the programme on the Time 2 questionnaire. Debriefing forms were provided at the end of the Qualtrics questionnaires.

4.2.9. Data Analysis

4.2.9.1. Initial Data Screening and Descriptive Statistics

After data collection ended, data was organised and prepared in the Statistical Package for the Social Sciences (SPSS) Version 21. Initially, the data was examined for normality of the data, potential outliers, and missing data. The data of participants who followed the link but failed to provide consent to participate and did not complete the baseline questionnaire ($n = 42$) was deleted. The normality of data distribution was determined by evaluating the Skewness and Kurtosis levels (acceptable values are between -3 and +3 to prove normal univariate distribution) and performing the Shapiro-Wilk's test of normality ($p > .05$ if the data is normal). The data was also examined using Normal Q-Q Plots (the data points are closer to the diagonal line if data is normally distributed),

boxplots (to identify any outliers in the data), and histograms (frequency distribution of data is approximately bell-shaped curve if data is normally distributed). Levene's test for homogeneity of variances was also conducted for the baseline outcome measures; $p > .05$ indicated the homogeneity of variances between the groups.

Descriptive statistics were conducted to identify demographic and health-related participant characteristics and evaluate any differences between the two groups (iCBT and control group) at baseline. Considering that iCBT with carer access group had a very small sample size, it was not included in the between-group comparisons, except for cancer-related communication and relationship quality with carer. To ensure there is no unintended difference between the iCBT and the control group at baseline, one-way analysis of variance (ANOVA) (for continuous variables), and Chi-square test (for categorical variables) were performed. A p value $< .05$ would indicate there is a statistically significant difference between the means of two groups.

4.2.9.2. Adjusted Data Analyses

As outlined in the published protocol paper (Akkol-Solakoglu et al., 2021), the initial analysis plan included comparing three groups (iCBT alone, iCBT with carer access, and TAU control) on the primary outcome measure of HADS, and the secondary outcome measures such as fear of cancer recurrence, active and avoidant coping, and quality of life. However, the planned analyses had to be adjusted as the sample size of the iCBT with carer access group was too small for results to be meaningful for the three group comparisons. The decision was made to exclude the iCBT with carer access group data ($n = 4$) from the primary analyses, and run the main statistical tests with the iCBT (alone) and TAU control groups. Using the LMM, two groups were compared on the repeated outcome measures (HADS, CWS, QOL, Active and Avoidant Coping, MOS-SSS) over time.

LMM was used to test group, time, and interaction effects for all continuous dependent variables. As planned and outlined in the protocol paper (Akkol-Solakoglu et al., 2021), the intention-

to-treat (ITT) was used as the primary approach to assess the effectiveness of the intervention. Based on the ITT principles, participants' data are included regardless of their compliance with the treatment protocol, and analysed according to their original group assignment. In other words, participants who left the intervention early or who did not comply with the intervention protocol are still considered in the intervention group. On the other hand, the Per-protocol (PP) approach only examines the data of participants who were compliant with the study protocol (e.g., did not switch the allocation arm throughout the study, adhere to the assigned condition) and who actually received and completed the intervention. As the ITT analysis approach reflects the daily clinical practice where noncompliance and deviations from the therapeutic plans happens, preserves the balancing of risk factors by randomisation, and maintains the study power (Tripepi, Chesnaye, Dekker, Zoccali, & Jager, 2020), it was used as the primary approach. The PP approach was used as a secondary and supportive analysis method to understand the effects of actually having received the assigned intervention. ITT and PP protocols are described in detail in Table 7.

Table 7

Description of the Data Treatment Approach for ITT and PP Analyses

Group	ITT Analysis	PP Analysis
iCBT intervention	Includes all participants who were randomly assigned to the iCBT intervention group and provided baseline data (Time 1).	Includes all participants who were randomly assigned to the iCBT intervention group, completed all 7 modules of the iCBT intervention (without carer access), and provided complete responses to baseline (Time 1), post-intervention (Time 2), and 2-month follow-up questionnaire (Time 3).

TAU control	Includes all participants who were randomly assigned to the TAU control group, did not receive the intervention, and provided complete responses to baseline questionnaire	Includes all participants who were randomly assigned to the TAU control group, did not receive the intervention and provided complete responses at Time 1, Time 2, Time 3.
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Mixed Models using Restricted Maximum Likelihood (REML) estimation was performed to account for missing data due to participant drop-out at post-intervention and follow-up. Mixed models for ITT and PP were estimated separately for each outcome variable with time, group, and interaction of time and group as fixed effects. A p value < .05 would indicate statistically significant group-by-time interaction, meaning that there are significant differences between groups over time. In other words, change in participants' scores from pre-to-post intervention or pre-intervention to follow-up, is different depending on the treatment received (iCBT vs. TAU control).

The LMM analysis assumes that the data is missing at random, which was investigated in the current study using Binary Logistic Regression to compare non-completers (drop-out = 0) and completers (no drop-out = 1). ANOVA tests was performed to investigate whether there is a significant difference between completers and non-completers on continuous demographic and health-related variables, and baseline measures. Chi-square tests were conducted to evaluate the differences between completers and non-completers on categorical demographic and health-related variables. A p value < .05 would indicate statistically significant differences between those who completed the study and those who dropped out.

To investigate the differences in mean scores from baseline to post-intervention and baseline to follow-up between two groups (iCBT versus control), independent samples t-tests were conducted for each outcome measure. Within-group effects for each group were conducted using paired samples t-tests. A p value < .05 would indicate statistically significant differences within a group (iCBT or TAU control) at different times (for within-group comparisons) and between groups (iCBT vs. TAU

control) at a specific point in time (for between-group comparisons). Considering the limitations caused by the small sample size on significance testing, within-group and between-group effect sizes were calculated to indicate intervention effects. Effect sizes were also calculated for non-significant effects ($p > .05$) to understand potential significance. Hedge's g was calculated using the difference in means between two groups (iCBT vs. Control) and dividing it by the pooled standard deviation and adjusting it for sample size. For Hedges' g an effect size 0.20 is considered small, 0.50 moderate, and 0.80 large.

To understand the mechanisms of change underlying the iCBT intervention, potential mediating effects of active coping and passive coping were tested using the PROCESS macro for SPSS by Hayes (2013). Four mediation analyses were performed to separately test the mediating effects of active coping and avoidant coping on two dependent variables. The first model tested whether active coping mediates the effect of the treatment received (Treatment-as-Usual vs. iCBT) on distress. The second model tested whether active coping mediates the effect of the treatment received (Treatment-as-Usual vs. iCBT) on quality of life. The third model tested whether avoidant coping mediates the effect of the treatment received (Treatment-as-Usual vs. iCBT) on distress. The fourth model tested whether avoidant coping mediates the effect of the treatment received (Treatment-as-Usual vs. iCBT) on quality of life. The mediation models were constructed following the suggestions for mediation analysis in clinical research by Hayes and Rockwood (2017). The difference scores were constructed separately for each mediator (active coping and avoidant coping) by subtracting the Time 2 scores from Time 1 scores. The difference scores for dependent variables (depression and anxiety, and quality of life) were also constructed separately for each variable in a similar way. The treatment group (TAU = 0, iCBT = 1) was added as the independent variable in each mediation model. As the difference scores were used as measures of change, Time 1 measures of the each dependent variable (baseline HADS-T and baseline QOL) were added as a covariate. A bootstrapping method ($n = 5000$ bootstrap re-samples) with a 95% confidence interval (Preacher & Hayes, 2008) and significance

testing at $p < .05$ was used to test the indirect effects. The bootstrapping method was preferred over the Sobel test since it does not impose the assumption of normality of the sampling distribution and the sampling distribution of the indirect effect is frequently non-normal. If the 95% confidence interval does not include the value of zero, this supports a claim of mediation, i.e., the effect of the independent variable on the outcome variable is contingent upon the effect of the proposed mediator.

We planned to explore any differences between two intervention groups (iCBT alone and iCBT with carer access) on HADS-T and MOS-SSS at post-intervention. In addition, we wanted to explore any differences in both survivors' (in the iCBT with carer access group) and carers' communication quality and relationship quality at post-intervention. However, these analyses also had to be adjusted due to the insufficient power in the iCBT with carer access arm and no post-intervention data provided by carers. Considering these limitations on the current sample, we decided not to proceed with the exploratory analyses.

Several studies suggest a cut-off score of ≥ 15 on HADS-Total as optimal for cancer survivors to identify an increased need for psycho-oncological care (Linden et al., 2012; Mitchell, Meader, & Symonds, 2010; Vaganian et al., 2020). The ITT sample was used to determine clinically significant and reliable change between pre-intervention and post-intervention and between pre-intervention and follow-up. First, using the HADS-T cut-off score in the ITT sample, participants were categorised as non-distressed (HADS-T score ≤ 14) and distressed (HADS-T score ≥ 15). Then, pre-post-intervention and pre-intervention-follow-up comparisons were made to determine the proportion of participants who were clinically distressed and recovered at post-intervention and 2-month follow-up. A reliable change index (RCI) based on Jacobson and Truax's (1991) approach was also used to assess whether and how many participants achieved clinically significant and meaningful changes post-intervention and follow-up on depression and anxiety symptoms (HADS-Total). The RCI is recommended to assess changes in mental distress after psycho-oncological interventions (Vaganian et al., 2020). The RCI was

calculated by subtracting a participant's post-test score from pre-test score and dividing it by standard error of the difference between the two test scores. According to Jacobson and Truax (1991), an RCI value greater than 1.96 is unlikely to occur ($p < .05$) without actual clinical change and it is more than the fluctuations of an imprecise measurement. Based on the RCI, a person is considered "recovered" if the difference between pre-test and post-test value is greater than the RCI and if the post-test score is lower than the pre-determined cut-off point of 15 on HADS-T. A person is considered "improved" if there is a statistical change, but the values did not pass the pre-determined cut-off point. A person is "unimproved" if there is no statistical change, regardless of whether the cut-off point is crossed. A person is considered "deteriorated" if there is a statistically significant worsening of the symptoms (Vaganian et al., 2020).

Responses of survivors and carers to the open-ended questions in the HAT and SAT questionnaires were initially planned to be analysed using the thematic analysis method (Braun & Clarke, 2006) as described in the protocol paper (Akkol-Solakoglu et al., 2021). However, due to the nature of the answers provided by the participants, an in-depth theme analysis was not possible. Therefore, a decision was made to analyse the data using the descriptive content analysis. Common themes, and patterns concerning helpful and unhelpful aspects of the iCBT programme, and their impact on survivors were identified to provide insight into participants' experiences. Following the initial raw data interpretation, codes were separated into helpful aspects, unhelpful aspects, and their impacts. The data of survivors in iCBT with carer access group ($n = 4$) was also included in both HAT and SAT analyses.

4.3. Results

4.3.1. Initial Data Screening, Descriptive Statistics, and Baseline Comparisons

No extreme outliers were identified in any of the outcome measures in the data. Closer inspection of non-extreme outliers showed nothing problematic, therefore, they were retained to

reflect variability. Normality testing for dependent variables across two groups indicated that the data was mostly normally distributed. Only baseline QoL ($p = .009$) and relationship quality with carer ($p = .001$) of the iCBT group were not normally distributed. The central limit theorem suggests that if the sample size is larger than 40, it is still appropriate to use parametric tests despite some minor deviations from normality. Independent samples t-tests ($N_{\text{iCBT}} = 38$, $N_{\text{Control}} = 19$) were performed for each outcome variable to ensure no unintended difference between the iCBT and the control group at baseline. The results revealed no significant differences between the two groups on any variables (see Table 8). Levene's test of homogeneity of variances revealed no significant differences in the iCBT group and the control group variances.

Descriptive statistics revealed that survivors' age ranged from 28 to 74 ($M = 47.82$, $SD = 8.56$), indicating various age groups (see Table 8). The majority of the survivors were from Ireland, and had Stage 2 (35.5%), Stage 3 (34.2%), and Stage 0 & I (23.7%) breast cancer, and only one had advanced (stage 4) breast cancer (1.3%). Time passed since survivors' medical treatment completion varied greatly between 0 months to 220 months ($M = 30.88$, $SD = 32.09$). More than half of the survivors did not have any other medical conditions; the ones that had reported having asthma ($n = 5$), rheumatoid arthritis ($n = 4$), thyroid disease ($n = 4$), hypertension ($n = 3$), diabetes ($n = 2$), and other conditions. Sixty-one percent (61%) of the participants did not have any previous experience with psychotherapy for depression or anxiety. The majority (87.5%) reported feeling confident using computers and the internet. Only a small minority (2.8%) reported feeling not very confident. No significant differences between iCBT and control group on any characteristics was found, except for the hormonal therapy. A greater percentage of participants in the control group (95.2%) received hormonal therapy than the iCBT group (68.2%).

Participants who had carer access to the iCBT programme were married, all had an early-stage breast cancer diagnosis, none of them had any other medical condition, and all reported being confident with computers and the internet (See Table 9). Interestingly, survivors who preferred carer

access to iCBT programme reported higher relationship quality with their carer and had higher scores on cancer-related communication with carer than the other two groups, although the trend was not statistically significant. All carers were spouses with age ranging from 40 to 66 ($M = 50$, $SD = 11.63$), and all were confident using computers and the internet.

Survivors' baseline mean HADS-T score was 16.09 for the control group, and 17.12 for the iCBT group, suggesting moderate levels of depression and anxiety in the sample at baseline. Participants also had moderate levels of fear of recurrence and moderately good quality of life at baseline. Survivors were using more active coping strategies compared to avoidant coping strategies when dealing with breast cancer-related problems. Survivors in both groups reported moderate levels of perceived social support. Survivors had high levels of relationship quality with their carers at baseline. Survivor-carer cancer related communication at baseline was also moderately good. As can be seen on Table 9, similar to survivors, carers also reported high relationship quality and moderately good cancer-related communication at baseline.

Table 8*Demographic, Health-related Characteristics, and Baseline measures by Groups*

		Control	iCBT	iCBT with carer*		
		N= 23	N= 49	N= 4	F/ χ^2	p value
Demographics						
Age (years)	Mean Age (SD)	49.30(9.66)	47.12 (7.92)	47.25 (4.79)	$F(1,70) = 1.02$.317
	Min-Max	28-69	34-74	43-54		
Location	Ireland	14 (60.9%)	30 (61.2%)	3 (75%)	$\chi^2(1) = 0.001$.977
	UK	9 (39.1%)	19 (38.8%)	1 (25%)		
Education	High school	0	4 (8.2%)	0	$\chi^2(4) = 5.58$.233
	Third-level non-degree	8 (34.8%)	11 (22.4%)	2 (50%)		
	Bachelor's degree	6 (26.1%)	17 (34.7%)	1 (25%)		
	Master's degree	5 (21.7%)	13 (26.5%)	0		
	Ph.D. or higher	4 (17.4%)	4 (8.2%)	1 (25%)		
Relationship status	Not in a relationship	4 (17.4%)	9 (18.4%)	0	$\chi^2(2) = 0.014$.993
	In a relationship	2 (8.7%)	4 (8.2%)	0		
	Married	17 (73.9%)	36 (73.5%)	4 (100%)		
Presence of a carer	Yes	17 (73.9%)	38 (77.6%)	4 (100%)	$\chi^2(1) = 0.115$.735
	No	6 (26.1%)	11 (22.4%)	0		

Relationship with carer						
	Spouse	12 (70.6%)	27 (71.1%)	4 (100%)	$\chi^2(5)= 4.29$.509
	Partner	2 (11.8%)	6 (15.8%)	0		
	Daughter	0	2 (5.3%)	0		
	Sister	1 (5.9%)	2 (5.3%)	0		
	Mother	1 (5.9%)	1 (2.6%)	0		
	Father	1 (5.9%)	0	0		
Health Characteristics						
Breast cancer stage	Stage 0&1	5 (21.7%)	12 (24.5%)	1 (25%)	$\chi^2(4)= 3.47$.482
	Stage 2	6 (26.1%)	18 (36.7%)	3 (75%)		
	Stage 3	10 (43.5%)	16 (32.7%)	0		
	Stage 4	1 (4.3%)	0	0		
	Doesn't know	1 (4.3%)	3 (6.1%)	0		
Time since diagnosis (months)	Mean Time	45.61 (46.80)	42.20 (23.98)	26.75 (23.13)	$F(1,70)= 3.14$.081
	Min-Max	8 - 230	7 - 120	11 - 60		
Time since treatment completion (months)	Mean Time	34.13 (46.43)	29.35 (22.96)	20.25 (27.44)	$F(1,70)= 2.38$.127
	Range (Min-Max)	0 - 220	0 - 108	1 - 60		
Treatments received	Chemotherapy	15 (71.4%)	34 (77.3%)	4 (100%)	$\chi^2(1)= 0.262$.609
	Radiotherapy	17 (81%)	38 (86.4%)	4 (100%)	$\chi^2(1)= 0.311$.577
	Hormonal therapy	20 (95.2%)	30 (68.2%)	4 (100%)	$\chi^2(1)= 7.14$.008
	Surgery	20 (95.2%)	43 (97.7%)	4 (100%)	$\chi^2(1)= 0.277$.599
Other medical condition(s)	Yes	8 (34.8%)	21 (42.9%)	0	$\chi^2(1)= 0.424$.515
	No	15 (65.2%)	28 (57.1%)	4(100%)		

Mental Health Factors						
Previous experience with psychotherapy for depression or anxiety	Yes	9 (39.1%)	19 (38.8%)	1 (25%)	$\chi^2(1) = 0.001$.977
	No	14 (60.9%)	30 (61.2%)	3 (75%)		

Computer Literacy						
Confidence in using computers and Internet	Mildly confident	1 (4.3%)	1 (2.0%)	0	$\chi^2(3) = 4.95$.176
	Average	2 (8.7%)	5 (10.2%)	0		
	Confident	9 (39.1%)	8 (16.3%)	1 (25%)		
	Very confident	11 (47.8%)	35 (71.4%)	3 (75%)		

Baseline Measures	Control		iCBT		t (df)	p
	M	SD	M	SD		
HADS-Total	16.09	5.60	17.12	7.12	0.61 (70)	.542
QOL	4.83	1.30	4.69	1.39	-0.38 (70)	.702
CWC	15.91	3.63	16.82	4.50	0.84 (70)	.403
Brief COPE, Active	2.72	0.49	2.60	0.52	-0.96 (70)	.343
BRIEF COPE, Avoidant	1.97	0.34	1.99	0.44	0.17 (70)	.864
MOS-SSS	2.97	0.97	3.35	0.88	1.65 (70)	.103
Relationship quality	8.29	1.40	8.58	1.24	0.75 (53)	.454
Cancer communication	17.59	4.76	18.68	4.29	0.85 (53)	.401

Note 1. *Characteristics of the iCBT with carer access group was included for the descriptive purposes only and not included in the group comparisons on the demonstrated variables.

Note 2. M refers to mean, SD refers to Standard Deviation. $N_{\text{control}} = 23$, $N_{\text{iCBT}} = 49$ for all measures, except for relationship quality and cancer communication which had $N_{\text{control}} = 17$, $N_{\text{iCBT}} = 38$.

Note 3. HADS-Total: Hospital Anxiety and Depression Scale; QOL: Quality of Life scale; CWC: Cancer Worry Scale; Brief COPE: Brief Coping Orientation to Problems Encountered; MOS-SSS: Medical Outcomes Study Social Support Survey.

Table 9*Demographic Characteristics of Carers at Baseline*

Demographics		n
Age	Mean Age (SD)	50 (11.63)
	Min-Max	40-66
Education	High school	2(50%)
	Bachelor's degree	1 (25%)
	Ph.D. or higher	1 (25%)
Relationship with carer	Spouse	4 (100%)
Computer Literacy		
Confidence in using computers and Internet	Confident	1 (25%)
	Very confident	3 (75%)
Baseline Measures		SD
Relationship quality	8.50	1.00
Cancer communication	19.75	4.43

Note 1. N_{carers} = 4.

Note 2. M refers to Mean, SD refers to Standard Deviation

4.3.2. Completers versus Non-completers

Binary Logistic Regression analysis showed no relationship between drop-out and group allocation, $\chi^2(2) = 1.31, p = .520$. The Hosmer and Lemeshow test was also not statistically significant ($p = 1.00$), indicating that the data was completely missing at random (MCAR). These findings indicate that there was no significant effect of group on participant drop-out.

There was no significant difference between completers and non-completers on their baseline depression and anxiety symptoms [$F(1, 74) = 2.48, p = .120$], fear of recurrence [$F(1, 74) = 0.78, p = .380$], quality of life [$F(1, 74) = 0.00, p = .977$], use of active coping strategies [$F(1, 74) = 4.46, p = .038$], use of avoidant coping strategies [$F(1, 74) = 0.66, p = .419$], perceived social support [$F(1, 74) = 1.70, p = .196$], relationship quality with carer [$F(1, 57) = 0.10, p = .749$], cancer-related communication with carer [$F(1, 57) = 0.10, p = .750$]. However, a statistically significant difference was found on use of active coping at baseline between completers and non-completers [$F(1, 74) = 4.46, p < .05$]. Completers reported greater active coping at baseline ($M = 2.73, SD = 0.47, 95\% CI [2.59, 2.86]$) than non-completers ($M = 2.47, SD = 0.55, 95\% CI [2.24, 2.69]$).

There were no statistically significant differences in completers and non-completers across age [$F(1, 74) = 0.31, p = .577$], time since cancer diagnosis [$F(1, 74) = 0.14, p = .706$], and time since treatment completion [$F(1, 74) = 0.00, p = .959$]. Chi-square tests revealed no significant association between completers and non-completers in terms of their level of confidence in using computers and the internet [$\chi^2(3) = 4.37, p = .224$], previous experience with psychotherapy for depression and anxiety [$\chi^2(1) = 0.29, p = 0.592$], breast cancer stage [$\chi^2(4) = 2.71, p = .607$], presence of a carer [$\chi^2(1) = 0.11, p = .915$], relationship status [$\chi^2(2) = 0.97, p = .616$], and location (Ireland vs. UK) [$\chi^2(1) = 1.07, p = .303$]. However, being diagnosed with other medical conditions was significantly associated with survivors' study non-completion [$\chi^2(1) = 6.39, p < .05$] with a medium effect size (Cramer's $V = 0.29$). Also, high level of education was significantly associated with survivors' study completion [$\chi^2(4)$

= 12.99, $p < .05$], and had a large effect size (Cramer's $V = 0.40$). A higher proportion of completers had bachelor's, master's, or a PhD degree.

4.3.3. Treatment Adherence and Engagement

The intervention included seven modules to complete. The intervention was flexible, meaning that the programme usage, pace, frequency, and duration were entirely up to participants.

Participants were informed that the programme is a 7-week programme and they are expected to spend approximately 1 hour and complete one module each week. However, for survivors who had engaged with the programme every week but still could not finish all the modules at the end of the 7 weeks, we decided to provide supporter feedback until they complete the programme. Therefore, not all survivors who completed all the modules in the programme completed them within 7 weeks.

Survivors' adherence to the programme was high. Out of 53 participants who signed up for the intervention programme, 45 (84.9%) began the first module, and 28 participants (52.8%) completed all 7 modules. Table 10 demonstrates the number of participants who started and completed each module. Among intervention completers, 24 (49%) were in iCBT alone and 4 (100%) in iCBT with carer access group. Treatment completion was defined as the completion of all 7 modules in the programme.

Survivors' engagement with the programme was also high. Participants approximately logged in 16 ($SD = 17.81$) times to the programme ($Min = 1$, $Max = 96$), and the average duration of each log-in was 16 minutes. Each user spent approximately 4 hours 20 minutes in the programme. On the contrary, carers' engagement with the programme was low. Carer client data showed that 3 carers logged in only once to the programme, and 1 carer logged in 5 times in total.

Table 10*Module Start and Completion Rates*

	Participants who started the module n (%)	Participants who completed the module n (%)
Modules		
1. Getting Started	45 (84.9%)	40 (75.5%)
2. Understanding Feelings	36 (67.9%)	32 (60.4%)
3. Boosting Behaviour	32 (60.4%)	30 (56.6%)
4. Spotting Thoughts	30 (56.6%)	29 (54.7%)
5. Challenging Thoughts	29 (54.7%)	29 (54.7%)
6. Managing Worry	28 (54.7%)	28 (54.7%)
7. Bringing It All Together	29 (52.8%)	28 (52.8%)

4.3.4. Research Data Attrition

Participant flow and attrition throughout the trial is captured in Figure 5. In the treatment group, the research response at post-test was 77.55% (38 participants) and at 2-month follow-up was 61.22% (30 participants). In the control group the response was slightly higher; the research response at post-test was 82.60% and 73.9% at 2-month follow-up. Overall data attrition at post-test was 20.8% and at 2-month follow-up was 34.7%. In other words, in the present study, approximately 79% of the participants completed the post-intervention assessments and 65% completed 2-month follow-up assessments.

4.3.5. Intention-to-Treat (ITT) Analysis

Observed means and tests of within-group comparisons on all outcome measures with effect sizes (Hedge's *g*) are shown in Table 11 and between-group comparisons are shown in Table 12.

4.3.5.1. Primary Outcome

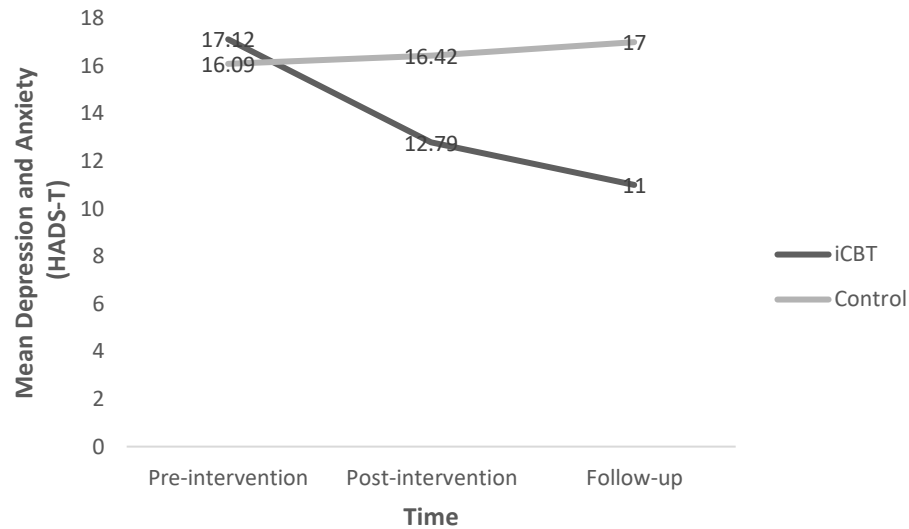
Hospital Anxiety and Depression Scale (HADS)

LMM for fixed effects revealed a statistically significant group-by-time interaction for the HADS-Total, $F(2,170) = 3.81, p < .05$. The results revealed that the iCBT group showed a statistically significant decrease in distress from baseline ($M = 17.12, SD = 7.12$) to post-intervention ($M = 12.79, SD = 7.42$), $t(37) = 2.74, p = .009$), and a statistically significant reduction from baseline to follow-up ($M = 11.00, SD = 5.87$), $t(29) = 3.96, p < .001$; however, the reduction between post-intervention and follow-up was not statistically significant ($t(29) = 0.92, p = .367$). While the reduction in distress symptoms of survivors in the iCBT group observed between baseline and post-intervention had a moderate effect size ($g = 0.59$), the reduction between baseline and follow-up had a large effect size ($g = 0.91$). On the other hand, the control group showed no statistically significant differences from baseline to post-intervention and follow-up. Although statistically non-significant, there was an increasing trend in control group survivors' HADS-T scores over time; they reported slightly higher depression and anxiety scores at post-intervention ($M = 16.42, SD = 6.48$) and follow-up ($M = 17.00, SD = 6.90$) compared to their baseline scores ($M = 16.09, SD = 5.60$).

Between-group comparisons (iCBT vs. control) revealed that iCBT group had lower distress scores at post-intervention ($M = 12.79, SD = 7.42$) as compared to the control group ($M = 16.42, SD = 6.48$), $t(55) = -1.81, p = .075$, with a moderate effect size ($g = -0.50$). This difference was significant at follow-up with iCBT group having significantly lower distress scores ($M = 11.00, SD = 5.87$) as compared to control group ($M = 17.00, SD = 6.90$), $t(45) = -3.16, p = .003$, with a large between-group effect size ($g = -0.94$). These results suggest that the iCBT intervention effectively reduced distress scores in breast cancer survivors. Figure 6 demonstrates the changes in mean distress scores between two groups, from baseline (pre-intervention) to post-intervention and from post-intervention to follow-up.

Figure 6

Changes in Distress Symptoms from Pre- to Post-intervention and Follow-up



4.3.5.2. Secondary Outcomes

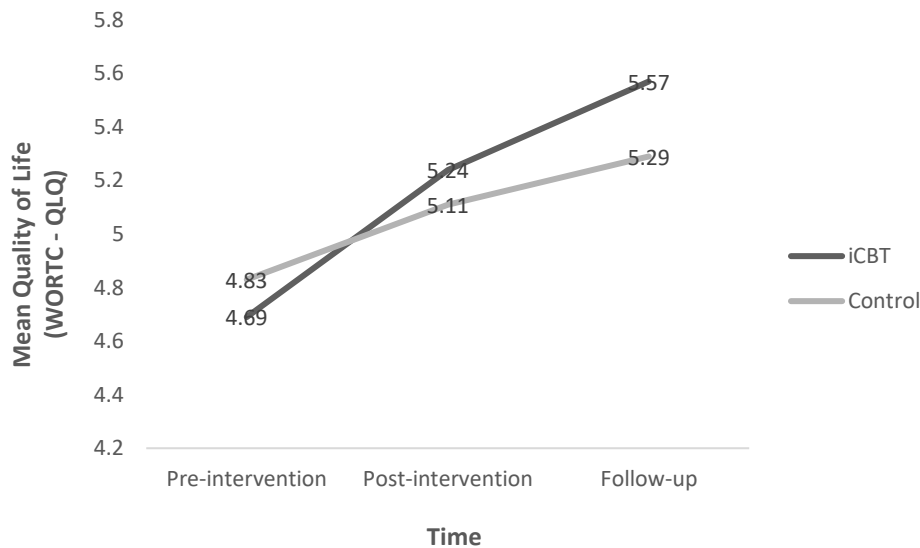
Quality of Life (EORTC-QLQ-C30)

LMM results for fixed effects showed no statistically significant group-by-time interaction for quality of life. A significant main effect of time was found for quality of life, $F(2,170) = 4.09$, $p < .05$.

Although fixed effects revealed that group-by-time interaction was non-significant, within-group comparisons revealed that the iCBT group appeared to experience marginally significant increase in their quality of life at post-intervention $t(37) = -1.89$, $p = .066$, and statistically significant increase from baseline to follow-up, $t(29) = -4.63$, $p < .001$. The increasing trend from baseline to post-intervention and follow-up can be seen in Figure 7.

Figure 7

Changes in Quality of Life from Pre- to Post-intervention and Follow-up



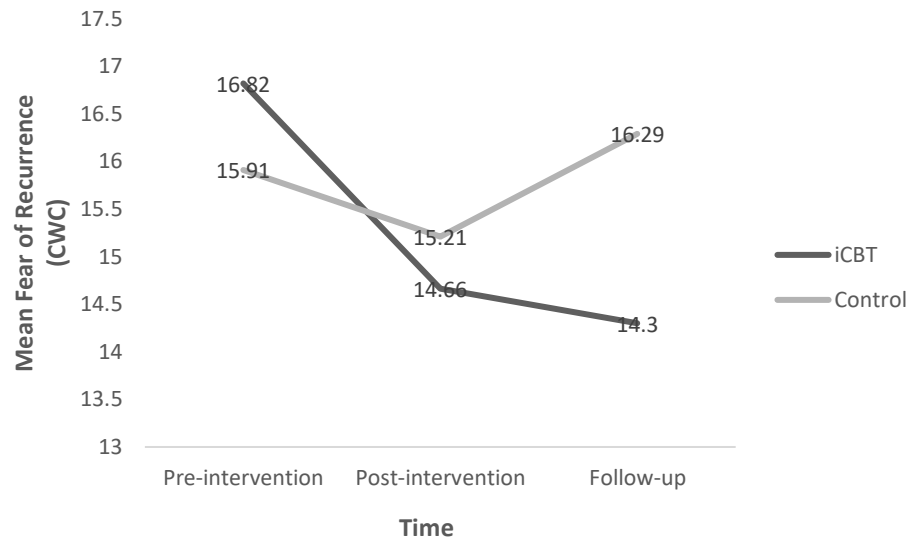
Breast Cancer Worry Scale (CWC)

LMM for fixed effects revealed no statistically significant effect of time, group, or group-by-time interaction for fear of cancer recurrence.

Within-group comparisons showed that there was a statistically significant decrease in fear of cancer recurrence of iCBT group from baseline to post-intervention ($t(37) = 2.57, p = .015$) with a moderate within-group effect size $g = 0.49$. As can be seen in Figure 8, this was maintained at follow-up. iCBT group's fear of recurrence showed a statistically significant decrease from pre-intervention ($M = 16.82, SD = 4.50$) to follow-up ($M = 14.30, SD = 3.68$), $t(29) = 3.17, p < .001$. This reduction had a moderate effect size ($g = 0.59$).

Figure 8

Changes in Fear of Recurrence from Pre- to Post-intervention and Follow-up



Brief Coping Orientation to Problems Encountered (Brief COPE)

No significant effect of time, group, or group-by-time interaction was found for active coping when fixed effects were considered. However, a trend approaching significance was obtained for a group-by-time interaction for active coping ($F(2,170) = 2.66, p = .073$), with between-group comparisons demonstrating that iCBT group using greater active coping compared to the control group at follow-up ($t(45) = 1.90, p = .063$). The changes in active coping can be seen in Figure 9.

Similarly, no significant effect of time, group, or group-by-time interaction was found for avoidant coping when fixed effects were considered. As shown in Figure 10, within-group comparisons revealed a significant decrease in avoidant coping strategies in iCBT participants at follow-up compared to pre-intervention, $t(29) = 2.12, p = .043$.

Figure 9

Changes in Active Coping from Pre- to Post-intervention and Follow-up

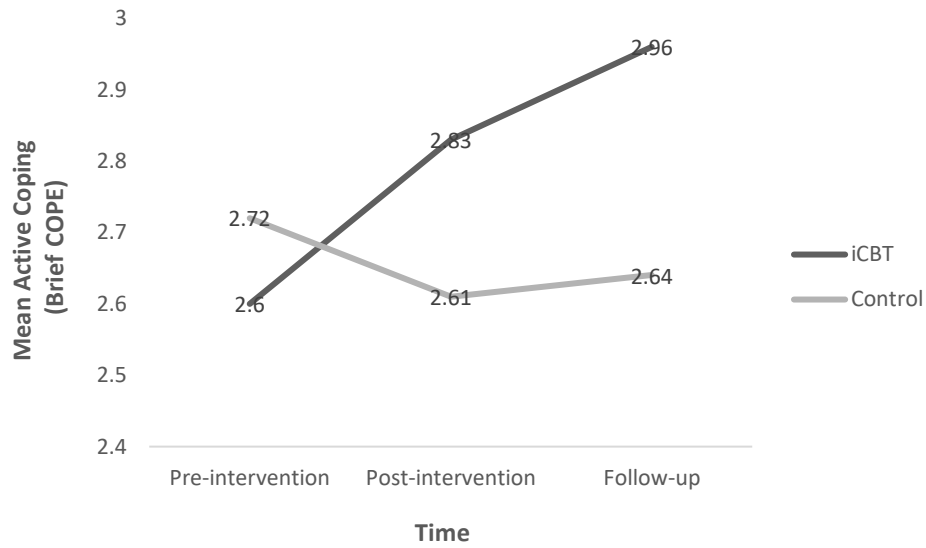
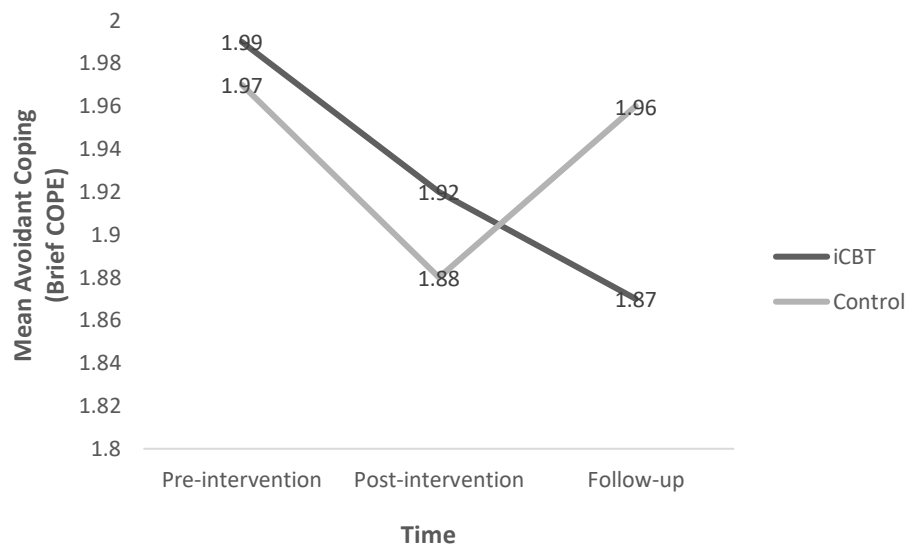


Figure 10

Changes in Avoidant Coping from Pre- to Post-intervention and Follow-up



Medical Outcomes Study Social Support Survey (MOS-SSS)

The fixed effect results showed no significant group-by-time interaction for perceived social support. The main effect of group was significant, $F(1, 170) = 7.76, p < .01$. Between-group comparisons, however, revealed that iCBT group had significantly higher perceived social support at follow-up compared to the control group, $t(45) = 2.08, p = .042$. The changes in MOS-SSS scores of two groups over time can be seen in Figure 11.

Figure 11

Changes in Perceived Social Support from Pre- to Post-intervention and Follow-up

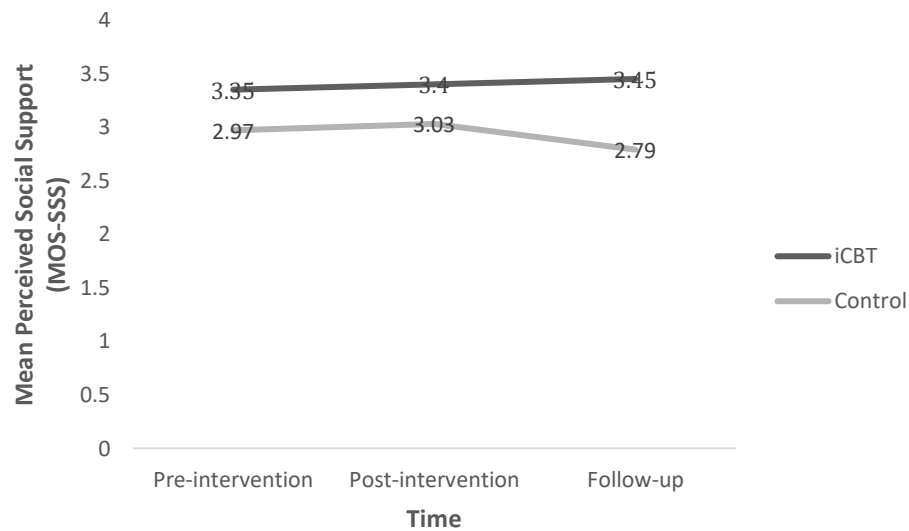


Table 11*ITT Model: Observed Means Groups Over Time and Within-group Comparisons*

	Pre-intervention	Post-intervention	Follow-up	Baseline - Post-test Within-groups	Effect sizes [95% CI] Hedge's g	Baseline -Follow-up Within-groups	Effect sizes [95% CI] Hedge's g
	Mean (SD)	Mean (SD)	Mean (SD)	t(df)= , p		t(df)= , p	
HADS-Total							
iCBT	17.12 (7.12)	12.79 (7.42)	11.00 (5.87)	t(37)= 2.74, p= .009**	0.59 [0.16, 1.02]	t(29)= 3.96, p= .000**	0.91 [0.43, 1.38]
Control	16.09 (5.60)	16.42 (6.48)	17.00 (6.90)	t(18)= -0.72, p= .483	-0.05 [-0.66, 0.55]	t(16)= -0.57, p= .574	-0.08 [-0.74, 0.57]
QOL							
iCBT	4.69 (1.39)	5.24 (1.00)	5.57 (0.94)	t(37)= -1.89, p= .066	-0.44 [-0.87, -0.01]	t(29)= -4.63, p= .000**	-0.33 [-0.82, 0.15]
Control	4.83 (1.30)	5.11 (1.29)	5.29 (1.26)	t(18)= -0.72, p= .480	-0.21 [-0.82, 0.40]	t(16)= -1.49, p= .155	-0.14 [-0.79, 0.52]
CWC							
iCBT	16.82 (4.50)	14.66 (4.15)	14.30 (3.68)	t(37)= 2.57, p= .015*	0.49 [0.06, 0.92]	t(29)= 3.17, p= .004**	0.59 [0.13, 1.06]
Control	15.91 (3.63)	15.21 (4.05)	16.29 (4.96)	t(18)= 0.77, p= .453	0.18 [-0.43, 0.79]	t(16)= 0.63, p= .951	-0.23 [-0.89, 0.42]
Active							
iCBT	2.60 (0.52)	2.83 (0.49)	2.96 (0.59)	t(37)= -1.33, p= .192	-0.45 [-0.88, -0.02]	t(29)= -1.63, p= .113	-0.24 [-0.72, 0.24]
Control	2.72 (0.49)	2.61 (0.56)	2.64 (0.45)	t(18)= 1.27, p= .219	0.21 [-0.40, 0.82]	t(16)= 0.561, p= .583	-0.06 [-0.71, 0.60]
Avoidant							
iCBT	1.99 (0.44)	1.92 (0.44)	1.87 (3.34)	t(37)= 0.92, p= .366	0.16 [-0.27, 0.58]	t(29)= 2.12, p= .043*	0.06 [-0.40, 0.51]
Control	1.97 (3.34)	1.88 (0.42)	1.96 (0.47)	t(18)= 0.76, p= .459	0.04 [-0.57, 0.64]	t(16)= 0.25, p= .807	-0.18 [-0.83, 0.48]
MOS-SSS							
iCBT	3.35 (0.88)	3.40 (1.07)	3.45 (0.92)	t(37)= -0.14, p= .889	-0.05 [-0.47, 0.37]	t(29)= -1.55, p= .133	-0.05 [-0.53, 0.43]
Control	2.97 (0.97)	3.03 (0.94)	2.79 (1.22)	t(18)= -0.67, p= .512	-0.06 [-0.67, 0.55]	t(16)= 0.57, p= .579	0.22 [-0.44, 0.87]

Note 1. $p < .05^*$, $p < .01^{**}$. Paired-samples t-tests were performed for within group comparisons.

Note 2. Baseline $N = 72$ ($N_{iCBT} = 49$ and $N_{control} = 23$), Post-test $N = 57$ ($N_{iCBT} = 38$ and $N_{control} = 19$), Follow-up $N = 47$ ($N_{iCBT} = 30$ and $N_{control} = 17$)

Table 12

ITT Model: Observed Means of Groups Over Time and Between-group Comparisons

	Pre-intervention	Post-intervention	Follow-up	Effects of Intervention Post-test Between-groups	Effect sizes [95% CI]	Effects of Intervention Follow-up Between-groups	Effect sizes [95% CI]
	Mean (SD)	Mean (SD)	Mean (SD)	t(df)= , p	Hedge's g	t(df)= , p	Hedge's g
HADS-Total							
iCBT	17.12 (7.12)	12.79 (7.42)	11.00 (5.87)	t(55)= -1.81, p= .075	-0.50	t(45)= -3.16, p= .003**	-0.94
Control	16.09 (5.60)	16.42 (6.48)	17.00 (6.90)		[-1.06, 0.06]		[-1.57, -0.32]
QOL							
iCBT	4.69 (1.39)	5.24 (1.00)	5.57 (0.94)	t(55)= -0.48, p= .635	0.12	t(45)= 0.84, p= .403	0.26
Control	4.83 (1.30)	5.11 (1.29)	5.29 (1.26)		[-0.43, 0.67]		[-0.34, 0.86]
CWC							
iCBT	16.82 (4.50)	14.66 (4.15)	14.30 (3.68)	t(55)= 0.43 p= .672	-0.13	t(45)= -1.57, p= .123	-0.47
Control	15.91 (3.63)	15.21 (4.05)	16.29 (4.96)		[-0.68, 0.42]		[-1.07, 0.13]
Active							
iCBT	2.60 (0.52)	2.83 (0.49)	2.96 (0.59)	t(55)= 1.49, p= .141	0.42	t(45)= 1.90, p= .063	0.58
Control	2.72 (0.49)	2.61 (0.56)	2.64 (0.45)		[-0.13, 0.98]		[-0.03, 1.18]
Avoidant							
iCBT	1.99 (0.44)	1.92 (0.44)	1.87 (3.34)	t(55)= 0.30, p= .762	0.09	t(45)= -0.79, p= .434	-0.03
Control	1.97 (3.34)	1.88 (0.42)	1.96 (0.47)		[-0.46, 0.64]		[-0.63, 0.56]
MOS-SSS							
iCBT	3.35 (0.88)	3.40 (1.07)	3.45 (0.92)	t(55)= 1.26, p= .213	0.35	t(45)= 2.08, p= .042*	0.63
Control	2.97 (0.97)	3.03 (0.94)	2.79 (1.22)		[-0.20, 0.91]		[0.02, 1.23]

Note 1. $p < .05^*$, $p < .01^{**}$ Independent-samples t-tests were performed for between group comparisons.

Note 2. Baseline $N= 72$ ($N_{iCBT} = 49$ and $N_{control} = 23$), Post-test $N= 57$ ($N_{iCBT} = 38$ and $N_{control} = 19$), Follow-up $N= 47$ ($N_{iCBT} = 30$ and $N_{control} = 17$)

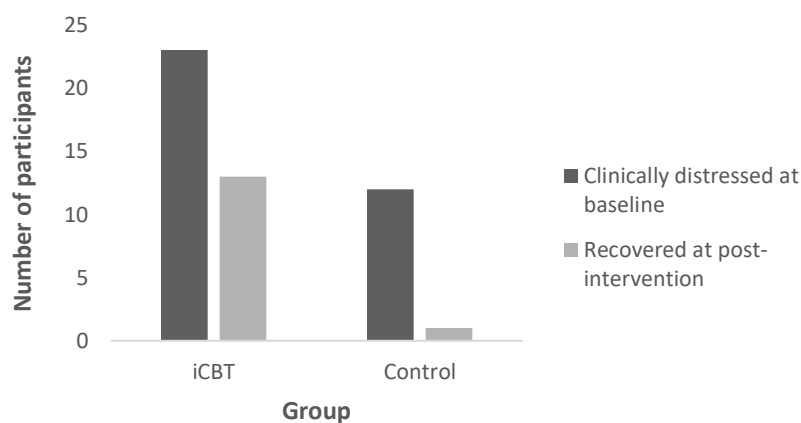
4.3.5.3. Clinically Significant and Reliable Change

A cut-off score of ≥ 15 on HADS-Total was used to determine the number of participants who were distressed at baseline and recovered at post-intervention and 2-month follow-up. RCI was used to determine the proportion of participants experienced clinically significant and reliable recovery, improvements, no change, and deterioration post-intervention and at 2-month follow-up.

A Chi-square test revealed that the differences between the iCBT and TAU-control groups on the number of cases recovered from pre- to post-intervention based on the HADS-T cut-off criteria were statistically significant, $\chi^2(1, N= 57) = 5.73, p = .017$. In the iCBT group, out of 38 participants who completed both pre- and post-intervention assessments, 23 (60.5%) met the criteria for being clinically distressed at baseline. Of those who were distressed, more than half (56.5%), 13 participants, recovered at post-intervention (had scores lower than 15 on HADS-T). In the TAU control group out of 19 participants who completed both pre- and post-assessments, 12 (63.2%) met the criteria for clinical distress at baseline. Of those who were distressed, only 1 (8.3%) of those recovered at post-intervention. Figure 12 shows the number of participants recovered (on the basis of HADS-T cut-off) from baseline to post-intervention based on treatment group.

Figure 12

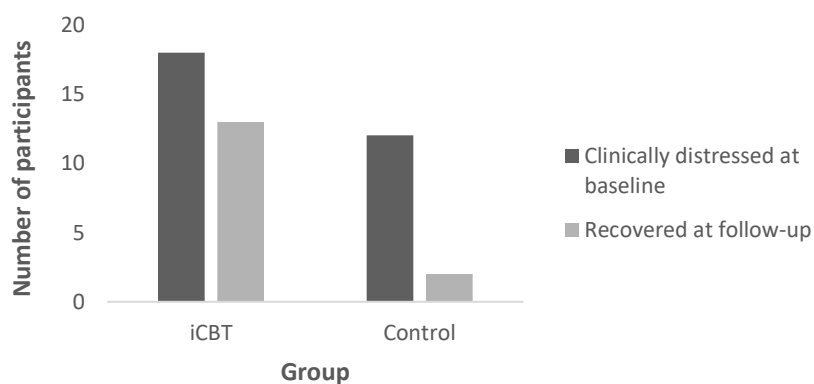
Number of Participants Recovered from Pre- to Post-intervention Based on the Cut-off



Chi-square test revealed that the differences between the iCBT and TAU-control groups on the number of cases recovered from pre-intervention to 2-month follow-up were also statistically significant, $\chi^2(1, N= 47) = 4.98, p = .026$. Out of 30 iCBT participants who completed both pre-intervention and follow-up assessments, 18 (60%) met the criteria for being clinically distressed at baseline. Of those who were distressed, the majority, 13 (72.2%) recovered at 2-month follow-up, revealing a higher proportion of recovery from pre-intervention to follow-up compared to pre-intervention to post-intervention. Out of 17 TAU control group participants, who completed both pre-intervention and follow-up assessments, 12 (70.6%) were clinically distressed at baseline. Of those who were distressed in the control group, only 2 (16.7%) recovered at 2-month follow-up. Figure 13 shows the number of participants recovered (on the basis of HADS-T cut-off) from baseline to 2-month follow-up based on treatment group.

Figure 13

Number of Participants Recovered from Pre-intervention to Follow-up Based on the Cut-off



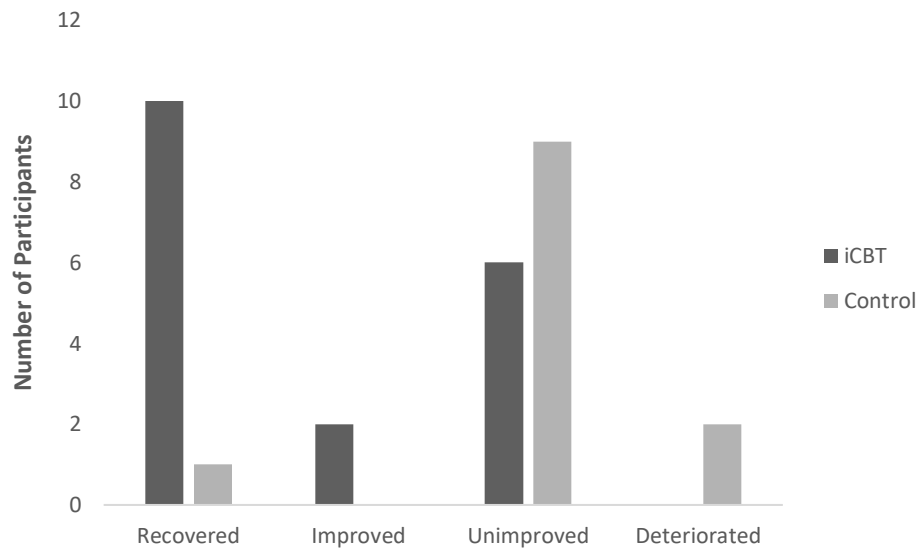
Second, RCI based on Jacobson and Truax (1991) approach was used to determine how many participants in each group had achieved a clinically reliable change at post-intervention and 2-month follow-up when compared to baseline. Coefficient alpha for the HADS-T was excellent with a value of

0.89. A difference on the HADS-T that exceeds 5.77 was considered as reliable change in the present study.

In the iCBT group 55.6% (n = 10) compared to 8.3% (n = 1) in the control group had achieved reliable recovery on distress symptoms from baseline to post-intervention based on the RCI criteria. Moreover, 11.1% (n = 2) in the iCBT group had clinically meaningful improvements compared to zero participants in the control group. While 33.3% (n = 6) had no change in the iCBT group, 75% (n = 9) in the control group showed no reliable change at post-intervention assessment. Importantly, while none of the participants in the iCBT group had deterioration, 2 control group participants deteriorated at post-intervention (See Figure 14). These differences between the iCBT and control groups were statistically significant, $\chi^2(3, N= 30) = 11.21, p = .011$.

Figure 14

Participant Classification based on the Reliable Change Index at Post-intervention

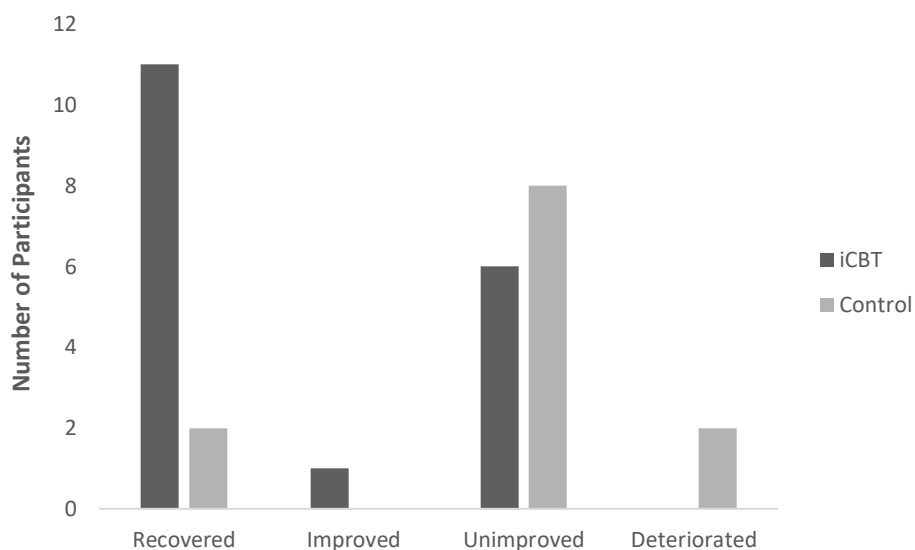


Note. $N_{iCBT} = 18, N_{Control} = 12$

In the iCBT group 61.1% (n = 11) compared to 16.7% (n = 2) in the control group had achieved reliable recovery on distress symptoms from baseline to 2-month follow-up. In the iCBT group 5.6% (n = 1) had clinically meaningful improvements compared to zero participants in the control group. While 33.3% (n = 6) in the iCBT group had no change, 66.7% (n = 8) in the control group had no reliable change at post-intervention assessment. Similar to the post-intervention analyses, while none of the participants in the iCBT group had deterioration, 2 control group participants deteriorated at 2-month follow-up (See Figure 15). These differences between the iCBT and control groups were statistically significant, $\chi^2(3, N= 30) = 8.66, p = .034$.

Figure 15

Participant Classification based on the Reliable Change Index at Follow-up



Note. $N_{iCBT} = 18, N_{Control} = 12$.

4.3.5.4. Dose and Response Relationship

The dose and response relationship between the recovery, improvement, and no change at post-intervention and the number of modules completed was investigated among clinically distressed

iCBT participants using the Chi-square test. The results revealed no statistically significant association between the number of modules completed and the distress outcomes at post-intervention, $\chi^2(8, N=20) = 6.50, p = .591$. Despite being non-significant, those who completed all seven modules had the highest rate of recovery (See Table 13). Out of 14 participants who completed all the modules and completed the post-intervention questionnaires, 8 achieved clinically reliable recovery and 1 had improvement in distress symptoms at post-intervention.

Likewise, the dose and response relationship between the recovery, improvement, and no change at 2-month follow-up and the number of modules completed was not statistically significant, $\chi^2(2, N=17) = 2.55, p = .279$. Despite being non-significant, the greatest rate of recovery at follow-up was also achieved by the participants who completed all seven modules (See Table 14). Out of 14 participants who completed all the modules, 10 achieved clinically reliable recovery in distress symptoms at 2-month follow-up.

Table 13

The Number of Modules Completed by the Participants and Distress Outcomes at Post-Intervention

The number of modules completed	Recovered	Improved	Unimproved	Deteriorated
1	1	0	1	0
2	0	0	1	0
3	0	0	1	0
4	2	0	0	0
7	8	1	5	0

Table 14*The Number of Modules Completed by the Participants and Distress Outcomes at Follow-Up*

The number of modules completed	Recovered	Improved	Unimproved	Deteriorated
1	0	0	1	0
2	0	0	0	0
3	0	0	0	0
4	1	0	1	0
7	10	0	4	0

4.3.8. Per Protocol (PP) Analysis

Based on the Per Protocol analysis approach, out of 72 participants, a total of 36 (50%) participants ($n = 20$ in the iCBT group and $n = 16$ participants in the control group) who complied with the protocol (e.g., completed the intervention) and also provided complete answers to all the questionnaires at Time 1, Time 2, and Time 3 were included in the analyses. The Shapiro-Wilk value indicated that the data are normally distributed. PP analyses were run using the HADS-T as the dependent variable since it was the only primary outcome measure.

Hospital Anxiety and Depression Scale (HADS)

PP results are presented in Table 15. There was a significant group-by-time interaction for the HADS-Total, $F(2, 102) = 3.35, p < .05$. Pairwise comparisons revealed that participants in the iCBT group reported significantly lower distress symptoms at post-intervention ($M = 10.42, SD = 4.33$) compared to control group ($M = 17.88, SD = 5.67$), $t(33) = -4.41, p < .001$, yielding a large effect of the intervention at post-intervention ($g = -1.47, 95\% CI [-2.21, -0.73]$). The effects of the intervention remained at follow-up; the iCBT group had significantly lower distress symptoms at follow-up ($M = 9.16, SD = 3.99$) compared to the control group ($M = 17.69, SD = 6.50$), $t(35) = -4.76, p < .001, (g = -1.59, 95\% CI [-2.34, -0.84])$.

Within-group comparisons showed that compared to pre-intervention ($M = 14.58, SD = 4.65$), the iCBT group had significant reduction in distress symptoms at post-intervention ($M = 10.42, SD = 4.33$), $t(18) = 3.20, p = .005$, with a large effect size at post-intervention ($g = 0.91, 95\% CI [0.26, 1.56]$). This reduction was maintained and improved at follow-up for the iCBT group ($M = 9.16, SD = 3.99$), $t(18) = 4.23, p = .001$, yielding a larger effect size ($g = 1.23, 95\% CI [0.55, 1.90]$). On the other hand, for control group participants no statistically significant changes in distress symptoms was obtained between pre-intervention ($M = 17.00, SD = 4.78$) and post-intervention ($M = 17.88, SD = 5.67$) and pre-intervention and follow-up ($M = 17.69, SD = 6.50$).

4.3.9. Mediation Analyses

Mediation analyses ($n = 57$) were run to explore underlying mechanisms of change in depression and anxiety symptoms following the iCBT intervention. The results revealed no significant indirect effect of the change in the active coping on the relationship between the treatment group (iCBT vs TAU) and the reductions on the distress from pre-intervention to post-intervention, after controlling for the baseline distress ($b = -.470, SE = .515, 95\% CI [-2.17, .060]$). Likewise, there was no significant indirect effect of the change in the avoidant coping, after controlling for the baseline distress ($b = -.006, SE = .658, 95\% CI [-1.33, 1.35]$).

No significant indirect effect of the change in the active coping was found on the relationship between the group and the change in the health-related quality of life from pre-intervention to post-intervention, after controlling for the baseline quality of life ($b = -.046, SE = .080, 95\% CI [-.054, .300]$). Similarly, no significant indirect effect of the avoidant coping was found on the relationship between the group, after controlling for the baseline quality of life ($b = -.001, SE = .080, 95\% CI [-.153, .186]$).

Table 15*PP Model: Observed Means of Groups Over Time and Between-group Comparisons*

	Pre-intervention	Post-intervention	Follow-up	Effects of Intervention Post-test Between-groups	Effect sizes [95% CI]	Effects of Intervention Follow-up Between- groups	Effect sizes [95% CI]
	Mean (SD)	Mean (SD)	Mean (SD)	t(df)= p	Hedge's g	t(df)= p	Hedge's g
HADS-Total							
iCBT	14.58 (4.65)	10.42 (4.33)	9.16 (3.99)	t(33)= -4.41, p= 0.000**	-1.47	t(35)= -4.76, p= 0.000**	-1.59
Control	17.00 (4.78)	17.88 (5.67)	17.69 (6.50)		[-2.21, -0.73]		[-2.34, -0.84]

Note 1. $p < .01^{**}$. Paired-samples t-tests were performed for between-group comparisons.

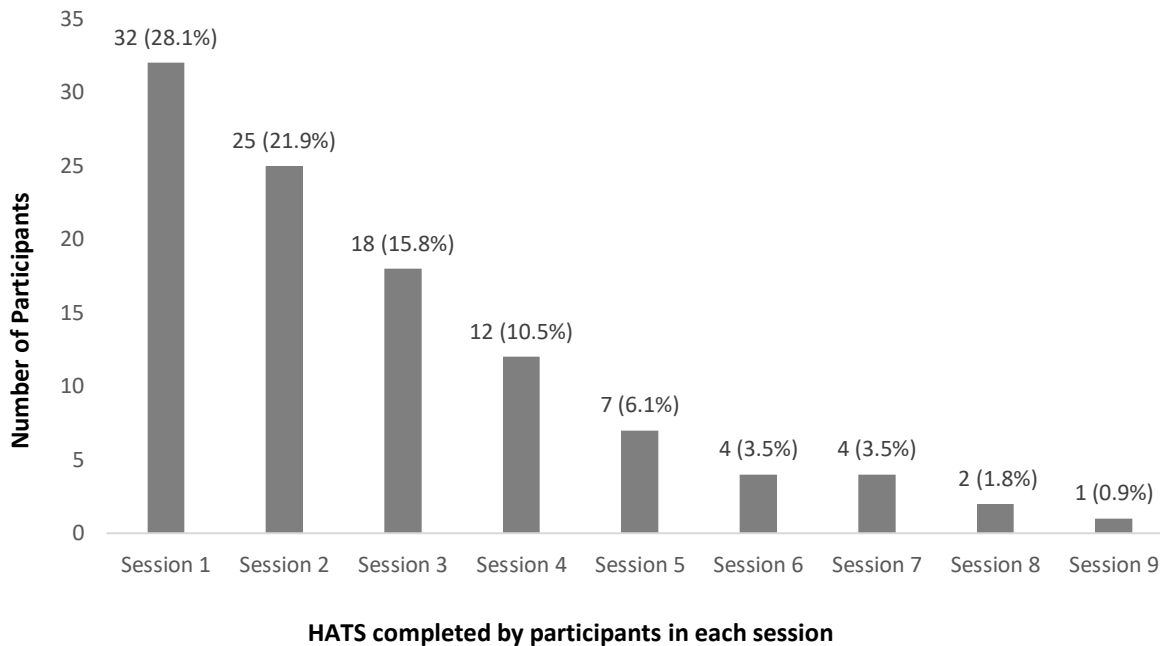
Note 2. Baseline, Post-intervention, and 2-month Follow-up $N = 36$ ($N_{iCBT} = 20$ and $N_{control} = 16$)

4.3.10. Helpful Aspects of Therapy Form (HAT)

A total of 32 survivors completed the HAT questionnaire, with ages ranging from 34 to 61 ($M = 46.09, SD = 6.49$). A total of 105 HAT questionnaires were completed by participants during their participation in the intervention. The response rate to HAT questionnaire was low, as 12 participants (37.5%) completed 1 to 4 sessions, 7 participants (21.9%) completed 5 to 7 sessions, and 2 (6.25%) participants completed 8 or 9 sessions. Although the programme had seven sessions, survivors who were consistently engaging with the programme were given extra time to complete the modules; therefore, there were participants who had more than 7 sessions. The number and percentages of completed questionnaires in each session is demonstrated in Figure 16.

Figure 16

Distribution of Completed HATs in Each Session



4.3.10.1. Helpful Events

Five main helpful events (supporter, core CBT content and tools, mindfulness, and long-term access) were identified by the clients who used the iCBT programme. Table 16 describes each helpful event, their description, and the number of participants identified each event.

Table 16

Descriptions of the Helpful Events and the Number of Participants Identified Each Event

Helpful Event	Description	Number of participants identified each item (N = 32)
Supporter	Clients' comments about the availability, encouragement, feedback, and suggestions of a supporter	21/32
Core CBT content and tools	Clients' reports about psychoeducational CBT content and tools in the programme	17/32
Mindfulness	Clients' reference to mindfulness, relaxation, and breathing exercises in the programme	8/32
Long-term access	Clients' comments related to having longer access to the programme including the need to reread the material, use of tools and materials even when the intervention ended	4/32
Personal stories	Clients' reference to personal stories of survivors and carers in the programme	2/32

The majority of the survivors ($n = 21/32$) thought that the most helpful event was the encouragement and feedback given by the supporter. They found it helpful to receive encouraging and constructive feedback on their progress, even when they could not engage with the programme. They also found supporter's explanations and clarifications of tools such as TFB cycle and mood monitor very helpful. For example,

"The lengthy response from my supporter is very encouraging. I feel I'm really being listened to which is very comforting." [P21, session 2]

"The helpful advice from my supporter is the best thing as I find it very encouraging. She advised me to track my mood and it made me realise that sleep has a major contribution to how I feel." [P18, session 2]

Core CBT content was another most frequently mentioned helpful event for many participants ($n = 17/32$). Survivors mentioned variety of core CBT activities in the programme including TFB cycle, recognising feelings, differentiating hypothetical vs. real worries, recognising warning signs and triggers, challenging thoughts, mood monitoring/tracking, behavioural activation/activity scheduling, worry tree, thinking traps, and goal setting.

"Practising the TFB cycles is helping me link everything together." [P14, session 2]

"Consciously categorising each worry as practical or hypothetical allows me sort through those I want to focus on. From there taking practical steps becomes easier." [P17, session 2]

Mindfulness was another helpful event for many ($n = 8/32$) as it helped them to slow their thinking down, focus on the present moment, and reduce stress.

"I am finding the breath work fantastic is helping slow me down, slow thoughts down." [P6, session 3]

Accessibility of the programme content for 1-year from the date survivors signed up for the programme was another helpful event identified by some survivors ($n = 4/32$).

“I feel that I have only scratched the surface and having longer access to the program will help me to further develop my ability to cope using the tools from the course.” [P13, session 4]

Some survivors ($n = 2/32$) also commented on the helpfulness of the personal stories of survivors and carers in the programme.

“I like reading about other people’s experiences and seeing some other perspectives, such as the partner.” [P14, session 3]

4.3.10.2. Impact of Helpful Events

Four associated impacts of helpful events were identified by the breast cancer survivors. These events included feeling understood/supported/validated, self-awareness/insight/reflection, improvement in mood and well-being/making a progress, feeling in control. Table 17 includes the description of each helpful impact and the number of participants identified them.

Table 17

Descriptions of the Impact of Helpful Events and the Number of Participants Identified Each Impact

Impact of helpful events	Description	Number of participants identified each item (N = 32)
Feeling understood, supported and validated	Clients’ reports of feeling understood, supported, validated, and cared for. It also includes normalisation of feelings and concerns. Outcomes of the encouragement, empathy,	18/32

	feedback, and suggestions provided by the supporter.	
Self-awareness/ insight/ reflection	<p>Understanding and noticing something previously not known or recognised by the client.</p> <p>Outcome of core CBT content such as our thoughts are not facts, understanding how mood is linked with thoughts and behaviours, and ways to improve it.</p>	17/32
Improvement in mood and well-being /making a progress	<p>Clients noticing the progress they made compared to the start of the programme. They feel more confident, happy, positive, content, and less anxious, think less about cancer, and prioritise themselves. It may also include supporter’s comments on clients’ improvement. This may encourage clients to practice the skills learned and re-reading the programme content.</p>	13/32
Feeling in control	<p>Clients acknowledgement that they are capable of managing their mood and attain desired goals by using the tools provided by the programme and being aware of their triggers and warning signs.</p>	4/32

For many survivors ($n = 18/32$), one of the most frequently mentioned helpful impact was feeling understood, supported, and validated by the supporter feedback. Survivors repeatedly mentioned that the programme content was helpful but what made it even more helpful was the weekly feedback from the supporter. Having someone keeping track of their progress meant that there is somebody out there caring for them, which helped them build confidence over their use of the programme and the tools. Survivors found it helpful when their supporter clarified misunderstood concepts such as hot thoughts and TFB cycles on their feedback, and thought that receiving feedback on their progress was the key event that encouraged them to continue using the programme.

"Felt understood and cared for." [P29, session 1]

"It makes me feel listened to & supported." [P32, session 4]

"It was a great help to feel that someone at the other end could understand my feelings and encourage me to work towards more positive ways of thinking and feeling." [P12, session 3]

Many survivors ($n = 17/32$) also thought that the programme helped them gain awareness, insight, and reflection regarding their moods, thinking and behaviours. It encouraged them to look from different perspectives and information and exercises on the relationship between thoughts-feelings-and behaviours provided them insight regarding the ways to break the unhealthy vicious cycle and improve their mood and reduce their anxiety.

"I think that I got a greater awareness of thought traps and automatic thoughts and hopefully will be able to recognise them in future and this will hopefully take away some of their hold on me." [P13, session 1]

“Really focusing on what it is that is impacting my mood at the moment... probably for the first time.” [P17, session 1]

“It feels like the programme is really coming together for me, either with new ways to think about things I was a little aware of, or nudges to manage things more proactively.” [P16, session 5]

Survivors ($n = 13/32$) reported that as a result of using the core CBT tools and receiving supportive feedback, they recognised making progress and improvements in their mood and well-being and decreasing in distress. Having done something for themselves each week has also provided them a sense of achievement and confidence. Supporters’ positive feedback on their achievements has helped them see the improvements.

“Finding it very helpful overall and have not been as anxious in the past couple of weeks and its showing in my everyday life.” [P18, session 5]

“It made me feel happy & content that I was doing something recognisably constructive for myself, without being aware that I was doing so.” [P32, session 5]

Another helpful impact of the programme for some ($n = 4/32$) was feeling in control as a result of learning core CBT skills and having access to tools to manage their mood and concerns. Acknowledging how their mood is affected by thoughts and behaviours, and learning new ways to help themselves provided survivors a sense of efficacy, and sense of control over their problems.

“Helped me feel more positive and supported and that I'm taking a bit more control gradually in managing how I feel and finding ways to help myself.” [P7, session 4]

“When I start to lose control or become nervous, I can instantly remember the coping strategies and bring myself back to the present moment.” [P22, session 6]

4.3.10.3. Hindering Events

Survivors identified four hindering events during their participation in the intervention. These events include the questionnaire, busy schedule and impact of Covid, psychological and physical factors, and examples/stories of other survivors. Table 18 demonstrates the description of each event and the number of participants identified them.

Table 18

Descriptions of the Hindering Events and the Number of Participants Identified Each Event

Hindering event	Description	Number of participants identified each item (N = 32)
The questionnaire	The HAT questionnaire in the platform hindered them to read supporter’s feedback and interrupted participants’ engagement with the programme content, also difficulty to answer questions due to memory problems	9/32
Busy schedule and impact of Covid	It was difficult for participants to find time to engage with the programme due to being busy at work, not having free time, and feeling low as a result of lockdown or ill due to Covid-19	6/32

Psychological and physical factors	When participants felt negative or low, experienced fatigue and sleep problems	3/32
Examples/stories of other survivors	Relates to any comment made about examples and personal stories triggered negative thoughts and/or memories	1/32

Surprisingly, the most frequently mentioned hindering event for many survivors ($n = 9/32$) was the HAT questionnaire itself. They reported that the questionnaire was asking about the previous session including the supporter’s feedback however it did not allow them to read their supporter’s feedback before filling it out. This was particularly a problem, when they wanted to log in to the programme during the week just to do some mindfulness exercises. Survivors also reported their difficulty to remember what happened during the last session.

“When I log on I can't move past this questionnaire but I find it hard to answer without being able to look back over the last modules and feedback from my coach. It's a small thing but it gets in the way of reflecting when I have to rely on my memory of the past week.” [P16, session 4]

“I don't like this questionnaire. It pops up when I log in and I can't seem to look at anything else before doing it. This is a nuisance especially if there's been a few days gap and I want to do something specific like relaxation or remind myself about the last session.” [P13, session 2]

Another hindering event identified by some survivors ($n = 6/32$) was having a busy schedule (e.g., work, life), and the impact of Covid-19. During the lockdown, they had to adjust to a new life

which they found difficult. The side effects of Covid-19 vaccine had also impact on survivors' physical well-being and created an obstacle for their engagement with the programme.

"Very busy week at work - dedicating time to the programme more difficult." [P17, session 2]

"I didn't have a lot of free time to read course information since the last review. I'm finding it difficult to disentangle the effects of lockdown / shielding from the effects of my cancer treatment." [P16, session 2]

Having my Covid vaccine made me ill, cranky and tired for about 4 days so I wasn't able to give the programme as much time as usual - however, I am feeling better now." [P22, session 6]

Psychological and physical factors were also hindering for some survivors ($n = 3/32$). These included feeling negative, experiencing fatigue and sleep problems. Feeling negative might especially have influenced participants' thinking about the helpfulness of the programme, and decreased their motivation to engage.

"The main hinderance I have found is always me! I tend to panic too quickly and the negative thoughts start to race. If I don't get enough sleep it also makes it worse. So I am the hindrance!" [P22, session 3]

One survivor (out of 32) also explained that the negative thoughts she experienced after reading the examples was an hindering event for her during the intervention. She explained that reading the examples triggered new negative thoughts.

"Some new negative thoughts that hadn't occurred to me until I read them in the examples..."
[P17, session 4]

4.3.10.4. Impact of Hindering Events

There were only three impacts of hindering events (confusion and frustration, pressure and guilt, and mood deterioration) identified in the data. Table 19 includes the description of the impact of each hindering event and the number of participants referred to each.

Table 19

Descriptions of the Impact of Hindering Events and the Number of Participants Identified Each Event

Impact of hindering events	Description	Number of participants identified each item (N = 32)
Confusion and frustration	The programme or some aspect of it creating difficulties, confusion, and frustration	1/32
Pressure and guilt	Feeling under pressure to engage with the programme each week	1/32
Mood deterioration	Experiencing mood deterioration (e.g., low mood) after engaging with the programme material	1/32

The impact could be minimal from the HAT questionnaire as the majority did not explicitly mentioned any impact. However, one of the identified underlying impact was confusion as one participant indicated not understanding the questions in the HAT. Another impact could be frustration caused by the questionnaire popping up every time they logged into the programme before letting them read their supporter's review. Participants also found it difficult to remember what happened in the previous session if they had not been logging in frequently.

"This questionnaire system needs to be revamped - because it pops up the minute you sign in - so you are answering questions based on a session you haven't had yet." [P22, session 7]

"If there is a gap between a session & this questionnaire coming up I have forgotten what struck me in that session so I don't know if I am giving an accurate picture" [P5, session 3]

One participant explained feeling pressure to engage with the programme each week and they found it difficult due to their other commitments. Although participants were informed that the programme is flexible and they can use it at their own pace, one participant mentioned feeling guilty when she could not engage with the programme.

"I'd started to answer the questions and needed to take time to think about some of them, so I was feeling a little guilty about not having come back to look at them yet." [P16, session 1]

"I feel there is pressure to partake every week. I do not always feel in a place to do this every week. And as things go on, it feels harder and I start thinking that I haven't logged on last week, so I have to log on this week." [P8, session 1]

One survivor explained that after reading examples of thoughts and feelings of other survivors, her mood deteriorated. Of note, this participant decided to stop using the programme

after completing the Challenging Thoughts module due to experiencing more low mood than before she started the programme.

“After experiencing an increase in low mood, and finding my partner and best friend had spotted this, I made the decision not to continue with the programme... a difficult decision as I hate letting people down and not seeing through my commitments.” [P17, session 5]

4.3.11. Satisfaction with Online Treatment (SAT)

Thirty-seven female survivors in the iCBT group completed the SAT questionnaire, with ages ranging from 34 to 74 years ($M = 47.16$, $SD = 8.34$). A Likert type scale with 5-response options was used in the SAT questionnaire. Agree very strongly and agree strongly responses were summed and classified as “Agree” on the table. Disagree very strongly and disagree strongly responses were summed and classified as “Disagree”. Similarly, very helpful and quite helpful responses were summed for the final item.

As seen from Table 20, the majority of the survivors who used the programme thought that the treatment will have a long-lasting effect (72.9%), and would recommend it to other people (72.9%). found the online programme helpful (78.4%). Although many survivors (% 67.5) were also happy to use the computer/phone to access treatment and many (62.1%) thought that they found the online treatment easy to use, there were substantial minority who disagreed or choose neither as a response on these two items.

Table 20*Survivors' Satisfaction with the Online Treatment*

	Agree n (%)	Disagree n (%)	Neither n (%)
I was happy to use the computer/phone to access treatment	25 (67.5%)	4 (10.8%)	8 (21.6%)
I found the online treatment easy to use	23 (62.1%)	5 (13.5%)	9 (24.3%)
I feel the treatment received will have a long lasting effect	27 (72.9%)	5 (13.5%)	5 (13.5%)
I would recommend the online treatment to other users	27 (72.9%)	4 (10.8%)	6 (16.2%)
	Very helpful and Quite helpful	Not really helpful	Not at all helpful
How helpful you found the online treatment programme	29 (78.4%)	4 (10.8%)	4 (10.8%)

The two qualitative questions in the SAT questionnaire asked participants what they most liked, and least liked about the treatment. The majority of the survivors most liked ($n = 12$) the weekly feedback from their supporters. Some examples of the survivors' responses include: *"I liked the support and suggestions from my coach. I really looked forward to my supporter's contributions"*, *"The feedback was very helpful and the programme was excellent"*, *"Regular, meaningful support, encouragement and positive feedback from coach"*, *"I enjoyed the coaching aspect as it made me motivated to 'keep up'..."*, *"The combination of tools, information and coaching based on my actions and writing"*.

The second most liked aspect of the programme for survivors was easy access ($n = 11$). For example, survivors explained that: *"Have resources there whenever you want to access them"*; *"That I could access it when convenient..."*; *"Easy access"*; *"Accessible and easy to use"*; *Ease of use, convenience when I am out of the country"*; *"Able to access it at times that suit me"*; *"The ability to access it online"*.

Other aspects many survivors most liked were meditations ($n = 5$) (E.g., *"I really enjoyed the mindfulness exercises"*), programme flexibility ($n = 5$) (E.g., *"I like the idea of structured modules to work through in my own time"*), easy to understand the content ($n = 4$) (E.g., *"Easy to understand well explained"*), anonymity ($n = 2$) (E.g., *"...can be private and shared"*; *"anonymous"*).

Less mentioned aspects liked by some survivors included TFB cycle ($n = 1$) (E.g., *"I had previously had counselling for 3 years lost my cancer treatment. This program helped me put my feelings, thoughts and behaviours into perspective. I loved the TFB cycle."*), personal stories ($n = 1$), and other useful tools ($n = 2$) (E.g., *"...the graphs to do to break down problems and realise sometimes the problem is so small"*), normalisation of feelings ($n = 1$), and programme reminding helpful coping strategies ($n = 1$).

When survivors were asked the least liked aspects of the programme, many responded that they disliked nothing and were pleased with the treatment ($n = 5$). On the other hand, one of the most frequently mentioned aspects least liked by many survivors was the programme being impersonal/general/not relevant ($n = 5$). Some examples of survivor responses: *"It felt impersonal and overly general"*; *"Some of the people's stories weren't relevant to me."*; *"It felt a little impersonal and isolating when I felt sad feelings as a result of what I was reading in the modules. It made me feel a little lonely."*

Another least-liked aspect was difficulty navigating in the programme ($n = 5$): *"I found the website unwieldy and hard to understand. I seemed to go round in circles. I needed more guidance on how to navigate and to know what was expected of me each week..."*; *"I found the format of the modules a little confusing to use"*; *"The interface was sometimes confusing and it was hard to tell how long things would take or when each bit was 'done'"; "I found the programme a bit clunky to use at times"; "Difficult to navigate"*

Some survivors ($n = 4$) explained that the programme would have been more helpful if they had it during the time near treatment completion (E.g., *"I am two years post-treatment. It would have*

been more helpful to me maybe if I had access 18 months ago as I needed it more than"). Others (n= 4). mentioned not having time to do it (E.g., "...it was the time to do as I have been constantly busy").

Some (n = 3) mentioned technical difficulties (E.g., "any technical difficulties just frustrated me and made me feel more under pressure and useless"). Others (n = 3) disliked the questionnaires, as explained by two survivors: "There is a glitch with the questionnaire that comes up after your coach has left a review - you can't access anything in the programme until you have filled in this questionnaire - but it pops up before you are able to read your coach's review - so basically you are answering questions on a session that hasn't occurred yet. Other than that, I thought everything was very good."; "Sometimes I found the questionnaires difficult to fill out because I had forgotten some of the material."

Two survivors expressed their desire to receive face-to-face support: "Face to face would have been nice"; "message didn't sink in online". Two others found the format of the modules confusing. As one survivor explained: "I found the format of the modules a little confusing to use, and it felt a little impersonal and isolating when I felt sad feelings as a result of what I was reading in the modules. It made me feel a little lonely."

Of note, one survivor reported feeling distressed due to some examples given in the programme: "Some of the examples given actually created new negative thoughts and feelings not previously experienced that I then had to deal with. Found giving negative thoughts sufficient consideration to articulate them in writing very challenging - often leaving me feeling low after the session".

4.4. Discussion

To date, this is the first RCT that evaluated the effectiveness of an iCBT programme for depression and anxiety symptoms in breast cancer survivors in Europe. The results supported the hypothesis for the primary outcome: participants who received the intervention had statistically

significant and large reductions in their distress at post-intervention compared to the control group, and these reductions were maintained at 2-month follow-up. These findings suggest that the newly adapted programme effectively reduces distress symptoms of breast cancer survivors who completed their active medical treatment and were cancer-free. It is important to note that these effects were achieved with weekly, asynchronous, non-clinician supporter contact.

Moreover, many survivors receiving the iCBT achieved clinically meaningful recovery and improvements on their distress, which was maintained and experienced by even more survivors at 2-month follow-up. The increase in the number of people who recovered at follow-up could be due to survivors continuing to practice the CBT skills they have learned in the programme. Supporting this explanation, survivors identified 1-year access to the iCBT programme as a helpful event. This is an important finding and may suggest that practicing the CBT skills after the completion of the iCBT programme could decrease depression and anxiety symptoms further.

Survivors had moderate levels of psychological distress and fear of recurrence at baseline. They reported moderately good life quality, moderate levels of perceived social support. They were exhibiting more active coping behaviour than avoidant coping. Survivors who had carers reported high relationship quality with their carers and moderately good cancer-related communication with them. Likewise, carers also reported high relationship quality and moderately good cancer-related communication at baseline.

The findings in the present study are in line with the previous iCBT trials conducted with cancer survivors in Australia (Murphy et al., 2019) and in Canada (Alberts, Hadjistavropoulos, Dear, & Titov, 2017). Murphy et al. (2019) showed that survivors in the iCBT group had significant improvements in depression and anxiety symptoms, distress, fear of recurrence, and quality of life. The effects were maintained at a 3-month follow-up. Similarly, Alberts et al. (2017) revealed that cancer survivors who received a self-guided iCBT programme had significant reductions in depression and anxiety symptoms post-intervention, with effects maintained at 3-month follow-up.

Based on the Stress-Coping model for chronic illnesses, an increase in active coping and a decrease in avoidant coping were expected in between-group comparisons. However, no significant between-group differences were found on active and avoidant coping. A possible explanation could be the finding that study completers reported significantly greater use of active coping at baseline than non-completers. The findings could also be affected by the low reliability of the avoidant coping measure.

Although no significant group-by-time effect was found on the secondary outcome measures, participants who received the iCBT intervention had improvements in their quality of life and decreases in avoidant coping strategies from pre-intervention to 2-month follow-up. Improvements in the quality of life of iCBT participants could be explained by the alleviation of depression and anxiety symptoms. The decrease in avoidant coping strategies may have occurred due to the CBT strategies learned in the programme, such as planning and engaging in pleasure and achievement activities, challenging their negative and unhelpful thinking, scheduling a worry time, and creating an action plan. Moreover, fear of cancer recurrence significantly decreased in the iCBT group from pre-intervention to post-intervention, and the effects were maintained at a 2-month follow-up. The decrease in fear of recurrence may have occurred in response to CBT skills that specifically addressed how to deal with cancer-related worries, and fear of recurrence. For example, learning to differentiate between practical and hypothetical worries and letting them go if they are hypothetical may have contributed to their decreased worries related to cancer recurrence. However, the reduction could also be associated with the overall CBT skills learned during the intervention process. A systematic review and meta-analysis (Tauber et al., 2019) showed that contemporary CBTs focusing on processes of cognition such as worry, rumination, and attentional bias and aiming to change the way in which individuals relate to their inner experiences had larger effects on reducing fear of cancer recurrence compared to traditional CBTs focusing on the content of cognition. Significant within-group reductions in the iCBT group on secondary outcome measures despite no group-by-time-

interaction effects may be due to the small sample size leading to the low power, which reduces the ability to detect effects.

This study also showed that despite carer access being an acceptable option for both when given an option, survivors still preferred to use the programme by themselves and not involve their carers in the iCBT programme. It is important to note that most of the carers, who were given access, also did not engage with the programme. However, it is not known whether this was due to the recruitment method in the present study (carers recruited through survivors) or because it was not feasible for the carers. As only a small number of survivors had carers with access to the iCBT programme, this study failed to compare the effects of using an iCBT programme with and without carer access on survivors' psychological well-being. Exploratory analyses also couldn't be conducted as carers did not engage with the programme provided; three out of four carers logged in to the programme only once. Several questions still remain to be answered regarding the carer involvement in iCBT programmes. The reasons behind survivors not preferring carer access, carers' disengagement with programme, and acceptable ways of involving carers in iCBT programmes should be explored further.

The engagement with the iCBT programme was high; survivors spent an average of 4 hours and 20 minutes in the programme. The average time spent per log-in was 16 minutes. A recent study that used the *Space from Depression and Anxiety* programme with general population reported a lower engagement with 3 hours 58 minutes as the average time spent on the programme (Richards et al., 2020). These time differences may reflect the lack of psychological support services for breast cancer survivors after the completion of cancer treatment despite the substantial need. High engagement could also be due to prolonging the treatment period for those highly engaging with the programme, but could not finish all the modules on time. The majority of the participants in the present study met the criteria for clinical levels of depression and anxiety at baseline. However, many did not have any experience with psychotherapy for depression or anxiety, supporting the findings

regarding the under-recognition of psychosocial care needs of cancer survivors in the literature (Fallowfield et al., 2001).

Survivors' satisfaction with the newly adapted iCBT programme was also high. Consistent with the previous iCBT studies with cancer survivors for depression and anxiety (Alberts et al., 2018; Karageorge et al., 2017), the majority of the survivors were highly satisfied with the iCBT programme. Survivors found the programme helpful, thought that it will have a long-lasting effect on them, and would recommend it to others. Similarly, many were happy to use the computer/phone to access treatment and found the programme easy to use. Of note, the percentage of people who reported being happy to use the computer/phone to access treatment and thought that the programme was easy to use were lower than the other items. This might be due to some participants' need or preference for face-to-face treatment. The HAT questionnaire and its impact on survivors' engagement with the programme could have also contributed and may be one of the reasons why some people did not find the programme easy to use.

In the present study, 78% of the cancer survivors completed post-test assessments, and 61% completed 2-month follow-up assessments. Another study that also used the SilverCloud platform for reducing depression in general adult population revealed lower research response rates than the present study, with 63% completion at post-test and 52% at 3-month follow-up (Richards, Timulak, et al., 2015). However, the present study's completion rates are lower than other iCBT studies with cancer survivors. In Murphy et al.'s study (2019), in which an iCBT was used in the treatment of depression and anxiety in cancer survivors, 92% completed post-test and 79% completed the 3-month follow-up assessments. These differences may be due to the characteristics of the sample or procedural differences such as recruitment methods. For example, a telephone interview assessment used at the beginning of Murphy et al.'s study (2019) could have contributed to higher study completion rates. Another iCBT study for managing treatment-induced menopausal symptoms in breast cancer survivors also reported higher completion rates than the present study, with 95.3% at

10-week follow-up and 92.9% at 24-week follow-up (Atema et al., 2019). Identifying potential participants through hospital registries and telephone screening to confirm participants' willingness to invest time in the iCBT could have possibly contributed to higher completion rates in Atema et al.'s study (2019). Telephone screening and assessing participants' motivation for change should be considered in future trials to increase completion and engagement.

This study identified various helpful and hindering events and their potential impacts on the participants. Significant events research aims to receive in-session feedback from clients on their thoughts about the helpfulness of the psychotherapy process (Elliott, 2008; Timulak, 2010). Helpful events identified by survivors included supporter feedback, core CBT tools, mindfulness, long-term access to the iCBT programme, and personal stories of survivors and their carers, all except one, were also identified by clients in previous iCBT studies (Burke et al., 2019; Richards, Dowling, et al., 2018). Although platform accessibility was identified in these previous studies, one unanticipated helpful event in the present study was having 1-year access to the programme from the date they signed up. Some clients found that the programme was beneficial; however, they believed that having 1-year access will allow them re-read the material and further improve their ability to cope with their problems.

Personalised and non-judgemental feedback provided by supporters made clients feel supported, understood, validated, and cared for, which is in line with the previous iCBT research for depression in the general population (Richards, Dowling, et al., 2018). Survivors' responses varied when defining the helpfulness aspect of the feedback. For example, they found the feedback as detailed and pertinent, constructive and personal. They also thought that the feedback provided encouragement, guidance, suggestions, reassurance, validation, assistance, advice, and explanation of constructs. They also liked to hear their supporter's positive feedback on their progress. Survivors believed that they would be less likely to engage with the programme without supporter feedback, and they would not have as many benefits as they had now. The supporters in the present study were

applied psychology master's students; clients' reports suggest that supporters established rapport with the clients through empathy. This is in line with the evidence from a systematic review, which indicated that the qualification of those providing guidance might be of minor importance for the post-intervention symptom severity in internet-based mental health interventions (Baumeister et al., 2014). In line with this, in an iCBT trial (*Wellbeing After Cancer*) cancer survivors in the technician-guided group were more satisfied with the level of the support compared to the self-guided group (Dirkse et al., 2020).

Enhanced self-awareness, insight, and reflection was another client-identified helpful impact of the programme, consistent with the previous iCBT studies that used the HAT questionnaire (Burke et al., 2019; Richards, Dowling, O'Brien, et al., 2018; Richards & Timulak, 2012). Survivors made better sense of their experiences and difficulties. With the psychoeducation provided in the programme, survivors explained noticing their negative thinking patterns, gaining insight into how their mood is related to their behaviours, and reflecting on what factors they can control in their lives by being more proactive. Likewise, the new insights were identified by clients receiving face-to-face psychotherapy sessions (Swift, Tompkins, & Parkin, 2017).

Improvement in mood and well-being was also identified as helpful impact of the iCBT programme by the survivors, which is in accordance with the significant events identified in previous studies (Richards, Dowling, et al., 2018). As mentioned earlier, improving the mood and well-being of the breast cancer survivors was one of the main goals of this intervention. This finding further supports the quantitative findings of the RCT. Survivors felt happier, calmer, less critical of themselves, could focus better, recognised that they think less about cancer, and prioritized self-care. This finding suggests that the programme not only decreased survivors' depression and anxiety symptoms, but it also had an overall positive impact on their general well-being.

Increased sense of control/self-efficacy was another helpful impact identified by the survivors in the present study, and is in line with the findings of an iCBT study for generalised anxiety disorder

(Burke et al., 2019). Survivors felt more in control of their mood by understanding how their thinking and behaviour influence their feelings. They also acknowledged the ways to help themselves with the tools provided in the programme. Survivors referred to factors that increased their sense of control: supportive and positive feedback, coping strategies learned, tools (using worry tree), and learning that they have power over how they feel about their situation.

Compared to the helpful events and their impact, fewer survivors reported hindering events, and only a few reported their impact on them. This could mean that the hindering events had only minimal influence on survivors. However, hindering events are essential to be identified, as, for some clients, they may result in deterioration, which increases the drop-out and feelings of hopelessness (Rozenal, Boettcher, Andersson, Schmidt, & Carlbring, 2015). While identifying the hindering events, it is also important to differentiate what results from the iCBT programme and the client characteristics. In the present study, it was unexpected that the HAT questionnaire was the most frequently hindering event. Survivors did not understand the questions or did not like the timing of the questionnaire as they found it difficult to remember what happened in the previous session. They also did not like that the questionnaire prevented them from reading the supporter's review. This could have been frustrating for some survivors and confused those who did not understand the questions. Hindering events resulting from the intervention such as this should be considered in future studies to increase the helpfulness of the iCBT intervention and improve user experience.

Another hindering event identified was a busy schedule; for some, this was also associated with the changes brought by the Covid situation. Survivors thought that being busy at work or life in general and not having free time to dedicate to the programme acted as a hindering event. Survivor-related psychological and physical events such as being negative, fatigued, and having sleep problems prevented survivors from engaging with the programme. As a result, some felt pressure or guilty as they wanted to complete the treatment on time. Due to the tight schedule of the intervention (7-week) and limited time in the supported mode, this finding was expected. Time pressure was also

previously identified as the treatment-related negative effect of internet interventions (Rozenal et al., 2015).

It is important to note that one survivor experienced deterioration in mood after working with the programme material, namely the examples and stories of other survivors. She felt that reading them triggered some negative emotions and bring back memories. Research shows that negative events in internet interventions are not more common than those in face-to-face psychotherapy for mild to moderate depression (Oehler, Görge, Hegerl, & Rummel-Kluge, 2021). However, it could be that those negative events could be more easily addressed in face-to-face psychotherapy. As pointed out by Rozenal et al. (2015), many symptoms, indeed, could be a natural reaction to being exposed to situations or emotions that have been previously avoided, and deterioration does not necessarily have long-term effects. For clients who reported deterioration, alternative treatment options such as face-to-face therapy could be offered to address the reasons and triggers more extensively.

4.4.1. Study Strengths

To date, and to the best of my knowledge, this is the first iCBT trial aiming to reduce depression and anxiety symptoms specifically in breast cancer survivors in Europe. This study is also the first pilot trial that evaluated the acceptability and feasibility of carer inclusion in an iCBT programme for cancer survivors and provided novel insights regarding the inclusion of the social environment in digital interventions. A notable strength of this study is the inclusion of survivors from various age groups and survivors who completed their treatments at different times and who had different levels of education, which increases the generalisability of the findings. Another strength of this study is using a mixed-method approach combining quantitative methods with qualitative measures, which broadened the understanding of the acceptability and effectiveness of the newly adapted programme.

4.4.2. Study Limitations and Future Research

There are limitations that should be considered when interpreting the results. First, the present study only included female breast cancer survivors, who completed their active treatment and were cancer-free. Also, only one participant had Stage 4 breast cancer. Caution is needed for generalisability of the findings for male breast cancer survivors, survivors who had other cancer types, and survivors with metastatic breast cancer. Second, due to the recruitment strategy used in the study (recruiting all survivors and making carer access based on preference), we could not randomise sufficient people into each arm, which prevented us from making three group comparisons. Solely recruiting survivors with carers who were willing to take part would allow us to have sufficient people in each group. However, we did not only recruit survivors who were willing to participate with their carers as this would hinder the access of survivors who do not have a carer. Third, the reliability of the avoidant coping measure was low, which might have attenuated the observed effects. However, the rest of the measures demonstrated good reliability, indicating that the participant responses to the measures had acceptable quality. Fourth, the follow-up of the groups had to be ceased at 2-months for practical reasons. Future research is needed to establish the long-term effects of the iCBT programme on depression and anxiety symptoms of breast cancer survivors. Fifth, the HADS questionnaire has some problems with its structure, wording, expressions used, and varying response keys, and lacks items measuring sleep and appetite disturbance (Coyne & van Sonderen, 2012). Although HADS was validated and extensively used in cancer settings, case finding utility of the HADS-T in cancer settings was found poor in a meta-analysis (Mitchell et al., 2010). Thus, the HADS could have also limited us to find clinically depressed and anxious survivors in the present study. The last, small sample size might have reduced the statistical power to detect potential mediating effects of the active and passive coping on depression and anxiety symptoms and quality of life. Other potential mediators of change such as change on automatic thoughts may require further attention in future iCBT programmes to understand better underlying mechanisms of change in iCBT interventions.

4.4.3. Conclusions

In conclusion, the present study showed that the adapted iCBT intervention programme effectively reduces depression and anxiety symptoms and could be offered to breast cancer survivors who completed their active medical treatment and are free from breast cancer. The intervention effects were also maintained at 2-month follow-up. Overall, survivors were highly satisfied and engaged well with the programme. More research is required in this area with larger sample and longer follow-up period in order to validate and expand on the findings of this study.

The HAT and SAT questionnaires also provided some insight into the clients' experiences with the newly adapted iCBT programmes. Although they helped us identify the areas that require improvements, such as the HAT questionnaire itself and the easiness of the programme use, more qualitative research is required on user and provider experiences and acceptable ways of involving carers in iCBT programmes.

CHAPTER 5

Study IV: Qualitative evaluation of the adapted internet-delivered cognitive behavioural therapy for breast cancer survivors

5.1. Introduction

This chapter describes Study IV, which combines two qualitative studies aiming to understand (1) experienced acceptability of the adapted iCBT programme based on an acceptability framework, user experiences with the programme (including facilitators and barriers to engagement, helpful and unhelpful aspects of the programme), and (2) provider experiences with their supporter role. Research conducted with survivors and providers will be presented in two separate parts with their own introduction, methods, results, and discussion. Part I will explain the study conducted with survivors and Part II will focus on supporter (provider) experiences.

The chapter starts with the Part I outlining the need for studying experienced acceptability with an adapted iCBT programme and user experiences with it, and study's objectives; then, it describes the methodologies used to analyse the survivor data. Next, it presents the identified themes resulted from the data. It then discusses the findings based on the existing literature on the experienced acceptability and user experiences. In the Part II, the need for studying provider experiences is outlined with the study objectives. Then, the methodologies used to analyse the provider data is described. Next, it presents the identified themes resulted from the provider data. It then discusses the findings based on the existing literature on the provider experiences. Finally, the chapter describes the strengths and limitations of the overall study with suggestions for future research and provides conclusions.

5.2. Part I: A Qualitative Study with Survivors

5.2.1. Experienced Acceptability

According to Sekhon et al. (2017), acceptability of an intervention reflects the extent to which people are delivering or receiving a healthcare intervention consider it to be appropriate in the following stages of the intervention: (a) before participating in the intervention (prospective acceptability), (b) while participating in the intervention (concurrent acceptability), or (c) after participating in the intervention (retrospective acceptability). However, some researchers argue that perceptions of the acceptability of psychological interventions may change for individuals after using the intervention (Sanchez et al., 2019; Sanjida et al., 2018). Users' perceptions can be influenced by various factors such as the process of participating in an intervention, its content, the perceived or actual effectiveness of the intervention. Study I evaluated survivors' and their carers' perspectives on the prospective acceptability of the iCBT programme without using it; it is essential to evaluate the adapted programme's acceptability after its use by the survivors. Sekhon et al.'s (2017) Theoretical Framework of Acceptability (TFA) was used to assess prospective acceptability of the programme.

5.2.2. User Experiences

As mentioned in the general literature review, digital health interventions for improving the psychological well-being of individuals with chronic conditions still face low adherence and high dropout rates, which impact on treatment outcomes and effectiveness (Karekla et al., 2019). It was also the case in the current pilot clinical trial: 20.8 % overall attrition rate was observed at post-intervention and 34.7% of attrition at 2-month follow-up, which is slightly lower than the expected 25% drop-out rate for the iCBT interventions for depression and anxiety (Richards, Duffy, Blackburn, et al., 2018). While it is crucial to evaluate intervention effects on treatment outcomes, effectiveness studies may not provide detailed insight into users' interactions and experiences with the intervention. Therefore, exploring user experiences can provide an in-depth understanding of the

factors influencing acceptability, engagement, and treatment completion. It could help improve the treatment, ultimately leading to higher retention and programme effectiveness and utility (Karekla et al., 2019).

Consideration of a broader systems perspective by including clients and their significant others providing care was suggested for low-intensity CBT interventions providing support to clients with health-related conditions (Proudfoot et al., 2010). Researchers indicated that significant others could be included in the internet-delivered treatment either by separate log in and passwords to take carers to a separate intervention content or by having carers access the site together with the client and work through the material. Following the recommendations of Proudfoot et al. (2010), breast cancer survivors' and their carers' attitudes toward incorporating carers into an iCBT programme were evaluated in Study I. Survivors and carers both liked the idea of carer access to the breast cancer survivors' programme through separate log in and passwords and expected potential benefits such as carers' better understanding of survivors and open communication about cancer-related concerns. However, in the pilot trial evaluating the feasibility and acceptability of the carer access (Akkol-Solakoglu et al., 2021), out of 60 women with carers, only 8 women preferred to give their carer access to their programme, and only 4 of those carers signed up for it. Therefore, it was essential to understand the reasons behind the low preference for carer access and explore alternative ways to incorporate carers of breast cancer survivors in the internet-delivered treatment programmes.

Qualitative interviews were used to explore experienced acceptability of the iCBT programme and user experiences with it. They provide rich data from a purposive sample of individuals who have experienced the phenomenon of interest and helps one understand the phenomenon concerning what it is and how it is perceived, explained, and experienced (Connelly & Peltzer, 2016). Semi-structured interviews were needed to understand the subjective experiences of survivors who completed the intervention with or without carer access. In addition, the interviews can add insights and aid understanding towards the decision-making process of survivors about their no carer access

preference, which could be lacking if a quantitative method was used only. Exploring the user experiences can also provide information on ways to improve the programme for survivors before conducting a full RCT.

This qualitative study has three main objectives:

1. Evaluate the experienced acceptability of an iCBT programme for breast cancer survivors who completed all the modules
2. Gain an in-depth understanding of survivors' experiences with the iCBT programme, its impacts, helpful and unhelpful aspects, facilitators and barriers to programme engagement, and suggestions to improve it
3. Explore the reasons behind higher preference for no carer access and acceptable ways of incorporating carers in iCBT programmes

5.2.3. Method

5.2.3.1. Participants

Interviews were completed with 15 female breast cancer survivors, aged between 40 and 74 ($M = 49, SD = 9.20$). Participants who (1) provided consent at the beginning of the intervention to participate in the interviews after completing the adapted programme and (2) completed all seven modules in the iCBT programme, were contacted via email or phone. The interviews were conducted between March and May 2021 and lasted between 31.14 and 69.52 minutes ($M=54.23, SD= 9.35$).

5.2.3.2. Materials

The primary researcher (SA) conducted the interviews using a Zoom video communication app. Interviews were audio-recorded using a Sony ICD-PX440 voice recorder. The semi-structured interview protocol was prepared to investigate (1) breast cancer survivors' perspectives on the

experienced acceptability of the iCBT programme that they completed, and (2) experiences of using the adapted iCBT programme. The data in relation to user experiences is explained in detail in Chapter 6.

Considering the two aforementioned aims of the interviews with survivors, two sets of questions were prepared. First, questions assessing the theoretical framework of acceptability (TFA; Sekhon et al., 2017), including seven components (affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness, and self-efficacy) were prepared. These questions aimed to evaluate each TFA construct to evaluate experienced acceptability of the adapted iCBT programme with breast cancer survivors and identify aspects of the intervention to modify and possibly increase its acceptability.

Second, questions regarding the participants' experiences of using the programme were based on Alberts et al.'s (2018) assessment of perceptions of an iCBT programme for cancer survivors. The questions about user experiences assessed what they found helpful, unhelpful, aspects they liked and disliked about the programme, facilitators of and barriers to programme completion, how the programme can be improved. Additional questions were asked regarding the carer access aspect of the programme to explore the reasons behind giving or not giving the carer access and other ways of including and supporting carers in internet-delivered programmes.

5.2.3.3. Procedure

The study was approved by the School of Psychology Research Ethics Committee, Trinity College Dublin (Approval ID: SPREC022020-09). Written consent to participate in the interviews was obtained at the beginning of the RCT. Participants who provided written consent were contacted again through email or phone call after completing the intervention. Participants who provided verbal consent were sent an email that included the date and time of the interview with a Zoom meeting link. At the beginning of the interviews, participants were reminded about the aim of the interview,

research procedures, participant rights, and data use and protection procedures. Participants were encouraged to share their views openly, and it was noted that there are no right or wrong answers to the questions raised. Participants were notified of their right to withdraw from the interview and measures taken to protect confidentiality. Participants were allowed to ask if they have any questions before the interview began. The interviews were transcribed verbatim and all the audio recordings were deleted after the transcription.

5.2.3.4. Data Analysis

Descriptive statistics on the demographic characteristics of all participants were performed using IBM SPSS Statistics Version 21. The interview data were analysed using the qualitative software MAXQDA Analytics Pro 2020. A deductive approach using a theoretical framework and a semantic approach was chosen to analyse interview data.

Deductive (theory-driven) thematic analysis approach was used to capture the explicit meaning (Clarke & Braun, 2017) of the experiences acceptability of the novel iCBT programme based on the TFA framework developed by Sekhon and colleagues (2017) for healthcare interventions. Interview transcripts were deductively coded into seven pre-defined overarching themes based on the interview guide. Table 15 has a complete list of all themes adopted from Sekhon's framework with the definitions of each construct and the code examples. This theoretical framework has the advantage of allowing researchers to assess the acceptability of healthcare interventions prospectively (before its use) and retrospectively (after using it).

Interview data exploring the user experiences were coded and analysed also using a semantic approach, which focuses on characterisation of explicit and surface meaning of content. This approach was found the most appropriate form of data analysis to describe user experiences pertinent to the aims of the present research. The same steps described in Chapter 2 were followed when conducting the analyses. It involved repeated reading of the data to understand it, identifying

key concepts and patterns by coding, sorting the codes into themes, and then grouping and organizing emergent themes into meaningful categories, then defining and giving names to the themes. Next, the codes and themes were revised and finalised. Although the data analysis method was presented with a step-by-step procedure, it was iterative and did not necessarily follow the described order.

5.2.4. Results

Characteristics of the survivors and their preference for carer access is demonstrated in Table 19. Survivors who took part in the interviews were aged between 40-74 ($M = 49$, $SD = 9.2$). Most of the participants were from Ireland ($n = 11$), and the rest were from the UK ($n = 4$). None of the participants had Stage 4 breast cancer, and the time the treatment completion varied largely between 0 and 108 months. Participant characteristics and their preference for carer access are described in Table 21. Survivor's reasons for not preferring carer access included the carer's lack of time, not wanting to burden or upset the carer, the carer would not be interested. Survivors who preferred carer access provided various reasons such as wanting them to benefit from the programme, helping them to better understand themselves, and talking about it together.

Table 21*Demographic Characteristics of the Survivors and Their Preference for Carer Access*

Code	Age	Breast cancer stage	Time since treatment completion (in months)	Presence of a carer	Carer access preference	Reason for carer access preference
P1	43	2	60	spouse	yes	"I think he doesn't understand my worries and also he probably has worries about cancer which he has nobody to discuss with"
P2	48	2	13	no	-	-
P3	41	2	56	no	-	-
P4	40	-	20	partner	no	"Carer can't commit"
P5	42	2	0	no	-	-
P6	54	2	3	spouse	no	"I would like to do this for me. I suspect he would not have time and would be rather upset at having to confront things and would not feel comfortable giving his responses"
P7	74	3	108	spouse	no	"My husband would not be interested in doing this"
P8	53	3	4	daughter	no	"I think they have enough to deal with and I haven't asked them to do this"
P9	47	2	3	partner	yes	"I'd like her to benefit too"
P10	54	2	51	daughter	no	"I chose my daughter who was a great support to me. However, my daughter is currently in the midst of A-Levels"
P11	45	2	1	spouse	yes	"I would like my spouse to gain insight into how I might be feeling and to be able to talk about this together"
P12	61	2	53	spouse	no	"I prefer to try to deal with my feelings about my breast cancer worries by myself most of the time"
P13	40	3	36	spouse	no	"My husband wouldn't have time at the moment"
P14	45	1	2	spouse	no	"Feel this is something I need to go through alone - not sure he'd see the reason for it"
P15	48	2	42	spouse	no	"Because I don't want my carer to think more about cancer than he already does"

Note. P4 did not know breast cancer stage. Time since treatment completion was asked when participants signed up for the programme.

As a result of the thematic analyses, three overarching themes were identified which includes: (1) experienced acceptability of the programme for survivors, (2) survivors' experiences of using the programme, (3) perspectives on carer access and involvement. The results will be presented in three different sections.

5.2.4.1. Experienced Acceptability of the Adapted iCBT Programme

Evaluation of the experienced acceptability of the programme based on the TFA framework resulted in seven themes. The list of the seven component constructs with corresponding definitions and theory-driven codes from the interviews is presented in alphabetical order in Table 22.

Table 22

Experienced Acceptability of the iCBT Programme for Breast Cancer Survivors

Component constructs	Description of the component Example quotes from survivors
Affective attitude	<p>How an individual felt about the intervention</p> <p>“I didn’t feel that it was a chore to do it and I <i>looked forward</i> to doing it and I found it really really beneficial. It’s very <i>positive</i>, you know.” [P12]</p> <p>“I thought it was going to really dissect my mind in a way ... but it didn’t and it’s a gentle CBT. I mean you can go as deep as you want really. You can go to whatever level you want with it.” [P2]</p>
Burden	<p>The amount of effort that was required to participate in the intervention</p> <p>“But I definitely don’t think there’s a lot of time needed, you know, half an hour, an hour a week I think. Yeah, it’s definitely do-able.” [P1]</p> <p>“Like there was times there was a lot of reading but I used to just come back to it because if I felt overwhelmed with too much reading, I would just say ‘right, I’ll read this and then I’ll read the rest tomorrow.’ So like that, I was breaking it down.” [P4]</p>
Ethicality	<p>The extent to which the intervention had good fit with an individual’s value system</p> <p>“...I’m a fairly analytical person so because it was based on scientific ideas or at least psychological ideas, it made sense to me and I could sort of relate that theoretically to something that was, you know, in my mind, equivalent to medicine, if that makes sense... Because it has a basis in psychology, to me, it wasn’t mumbo-jumbo.” [P6]</p> <p>“I didn’t notice anything that might have gone against and values or belief...I <i>really</i> think anyone who is diagnosed with cancer needs mental health therapy because it’s going to affect them in some way or another. So I’m <i>really</i> into all this, anything that helps my mind.” [P3]</p>

Intervention coherence	The extent to which the participant understood the intervention and how it worked
	<p>“There was a lot of overview in each of the modules which, you know, gives you the opportunity. It acts as a springboard so that if you do want to-to sort of find out more and get more involved, you can do that. But you have that introduction to each of those sort of areas, which I thought was very good.” [P10]</p> <p>“what I think would have helped me was if you had maybe a fifteen or twenty minute clip from whoever, from yourself or whoever is sponsoring the programme to say ‘this is what we’re’- ‘This is what we’re doing. This is what we’re about. This is what you can expect’.” [P15]</p>
Opportunity costs	The extent to which benefits, profits or values must be given up to engage in the intervention
	<p>“Values that I had to give up? Nothing. I just had to be honest with myself...It was time that I was probably going to waste somewhere else so it was a little bit of an investment in myself.” [P2]</p> <p>“I wouldn’t have decided to do it if I wasn’t comfortable with the idea that I’d get more out of it than I might lose in doing it. But it’s hard to overcome the sense that here I am sharing personal information, like <i>really</i> personal information online.” [P9]</p>
Perceived effectiveness	The extent to which the intervention is perceived to achieve its purpose
	<p>“...it helped me move forward and actually begin a phase of recovery that I think I would have found that I was kind of stuck on”. [P9]</p> <p>“I find now that I <i>question</i> the negative thoughts now rather than just kind of let it sit in my head and kind of be truth to me. <i>Now</i>, I kind of question it and try to think of, you know, the realities and the positives and not just...” [P11]</p>
Self-efficacy	The participant’s confidence that they could perform the behaviour(s) required to participate in the intervention
	<p>“...there was a time that I was going to be in a really bad mood. And then actually when I did something like one of the little tools. It just- five minutes and I was like ‘oh my God, what was I crying over?’ you know. It just helped me to rationalise everything.” [P3]</p> <p>“It’s not complicated, as I said, apart from the CBT cycle. It’s <i>easy</i>. I think you can do <i>as much</i> or <i>as little</i> as you want and you put <i>as much</i> or <i>as little</i> as you want into doing it and that’s down to circumstances and individual people and things, I think...The <i>more</i> that you go through it and the <i>more</i> you can see the benefits of it, the <i>more time</i> you give to it anyway because you can see how much it’s benefiting you so...” [P12]</p>

Note. The seven component constructs were adopted from Sekhon and colleagues’ (2017) theoretical framework of acceptability for healthcare interventions. The quotes represent a small sample of the transcript data.

Affective Attitude

Many survivors enjoyed participating in the intervention and felt that the programme was warm and positive. They found the overall experience very supportive and gentle. Many of them explained that they looked forward to the supporter feedback each week, and they were happy to recommend the programme to other survivors. Interestingly, survivors found it easier to build a relationship with a supporter online compared to a professional face-to-face. One client indicated that she liked the programme better than a counsellor session she had before:

“It was very positive. I found it kind of a warm and a positive programme as opposed to- I did one counselling session in hospital and I didn’t like it. I just found her a bit confrontational about some of the things that I was saying and I was just kind of like okay, that’s not for me. Whereas, I did like this.” [P14]

However, some survivors mentioned having low expectations at the start of the programme, and others did not know what to expect from the programme when they signed up for it. Some noted that they did not expect much as it was an online programme and they highlighted that it was much nicer than what they expected.

“...for me it was a much nicer experience than what I thought it was going to be.” [P2]

“I wasn’t sure what to expect, to be honest, and I really- No offence, I wasn’t expecting that much, you know [laughs]...I kind of wasn’t sure if I was going to get anything from something that was online. But, actually, I really was surprised in how helpful I found it.” [P14]

Burden

Survivors largely agreed that the amount of effort required to engage with the intervention

was manageable. Many survivors explained that there was *just the right amount of content* and the pace was good. Regarding the degree of effort, there were different opinions. While some thought that “it wasn’t an effort at all”, others thought that “it was a bit of effort”, as described by two survivors:

“I didn’t think of it as effort at all. I mean, it’s online.” [P6]

“I suppose there was a bit of effort, you know, in digging deep inside myself yes but not too much, not too much.” [P1]

On the other hand, survivors who had full-time jobs and children thought that their participation required considerable effort. However, knowing that if they did not make an effort, they would not get the benefit of the programme, helped them encourage themselves.

“I mean it definitely was an effort. I have three children. I have a job. You know, I have things to do. Yes, there were evenings when I was like ugh, I don’t have time for this...” [P14]

It is important to note that a few survivors reported feeling overwhelmed at times with too much reading on some modules, and the HAT questionnaire interrupting their engagement with the programme. Moreover, some found it hard as they had limited time to complete the programme within the 7-week period. For example, one survivor explained that:

“I find it hard to get a good amount of time to do it. I just felt, for me, that it wasn’t possible to finish everything within that time so...” [P11]

Ethicality

All survivors explained that the intervention has a good fit with their values, as the

programme was based on a scientific framework of CBT. Survivors reported that there was nothing against their values and beliefs in the content of the programme. As one survivor described:

“...I wasn't offended by anything. I was more intrigued about things like I hadn't thought about. And how, in a way, maybe it helps you think about you recovering.” [P8]

Some survivors also felt that their supporters respected their values and beliefs, which they found very positive. As one client described:

“I didn't find any of it went against my beliefs in anything. And actually, it was quite nice because ...praying really helps me to cope in life and I believe it really makes a difference, and I mentioned (...) doing it and my supporter was very supportive of that, which was really nice, you know. Kind of saying that's great, to keep doing that.” [P11]

Intervention Coherence

Many survivors thought that they understood the intervention rationale and how it worked well, and it was easy for them to follow the logic of the modules because of how the programme was structured. As one survivor described:

“I think they were quite logical the way they followed one on from the other... and I think actually the way they were- that each module was set up was good in the way that logically, in your head, to try and work through the session, it made sense.” [P5]

However, some survivors mentioned that themselves and their carers felt lost, and it was not easy to understand how the intervention works at the beginning of the intervention. As one client described:

“Certainly at the start, it wasn't obvious to me what way it was going.... Because at the start, I wasn't even sure where- where anything- And then how do I ask questions? Is it just a

technical question or what's it all about?" [P15]

Opportunity Costs

None of the survivors thought they had to give up any benefits, profits, or values to engage in the intervention. They viewed the programme as a great opportunity, considering the lack of psychological support for breast cancer survivors.

"Values that I had to give up? Nothing. I just had to be honest with myself...It was time that I was probably going to waste somewhere else so it was a little bit of an investment in myself."

[P2]

Only one survivor noted not feeling comfortable with sharing personal information online; however, she thought that the benefits of signing up for the programme would outweigh the risks:

"...I suppose it was weird like putting really personal information out on the internet, which I wouldn't really do except in really much more- I mean, it did feel like a private exchange but it was a leap of faith to do that online. I think I was so used to the idea that Facebook and whatever- Data leaks are possible and that your information is spread all online. Like, I wouldn't have decided to do it if I wasn't comfortable with the idea that I'd get more out of it than I might lose in doing it. But it's hard to overcome the sense that here I am sharing personal information, like really personal information [yeah, of course] online." [P9]

Perceived Effectiveness

Many survivors found that the intervention helped them gain insight into themselves and provided the tools to deal with their low mood and worries, making them feel more in control of their problems and feel calmer and more relaxed. Some survivors also mentioned seeing a noticeable

difference in themselves, as described by one survivor:

“...I was actually suffering from depression. ...And then real fear about the future. And I was stuck. I couldn’t kind of move forward. I think the thing about the programme is that it helps you to do that.... I’m not saying I don’t have bad days. I still have difficult days and worry about, you know, recurrence. I mean, there’s nobody who doesn’t but... I’ve got the tools now... I’ve got tools that I can use and I still do use and I will use to help me deal with my feelings. I mean the difference between when I started the programme and when I finished it is just like, massive [laughs].” [P12]

The lack of psychological supports for breast cancer survivors was one of the most common codes that appeared on survivors’ evaluations of the programme. Many of them reported a shortage of psychological support once the medical treatment was completed. However, survivors did not necessarily want to lean further on their carers for emotional support post-treatment. Survivors found it helpful to have a structured programme they can work through to support themselves, and they thought that this programme provided aftercare for them.

“...The hospitals are amazing and I’ve never knock the hospitals but there’s no aftercare when you’re treated...So I just feel the aftercare- There was none. And I just feel this [the programme] helped me in for aftercare.” [P4]

Although most of the survivors found the programme effective in decreasing their distress and helping them start recovering, some noted that improvement in their mood could not be only attributed to the programme. They thought it results from a combination of different factors such as improved weather, the restrictions lifted, and the tools they learned in the programme to manage their distress.

“Now, I’m not saying the intervention made my mood better. I think it was a combination of things like work and that sort of thing and personal life. It kind of- It improved...And then this was an added, you know, tool to help.” [P3]

Self-efficacy

Survivors felt confident about performing the behaviours required to participate in the intervention. Having an online programme where they could work through the programme at their own time and pace made them feel confident and have less pressure, even for those who have been feeling tired:

“I thought it was very good and a lot less pressure. Because it’s nice to be able to just do it in my home and not have to go anywhere or meet anyone, in a way. When you’re (...) recovering from breast cancer, I’m quite tired still so it was nice to be able to do it when I could...” [P11]

Survivors emphasized that they need to practice the programme's techniques and tools for two main reasons. First, they thought that there is ‘no quick fix’ and they need to keep working to see the benefits. Second, despite feeling confident about engaging with the programme, many needed to reread the modules because of experiencing ‘chemo brain’ and difficulty remembering the things learned in the programme. As mentioned by two clients:

“So, while the programme is great for the amount of- Any of these things are great for the time that you’re doing them. That’s only really the start. And you have to work, to keep at it after that. That’s the really hard bit, in some ways.” [P15]

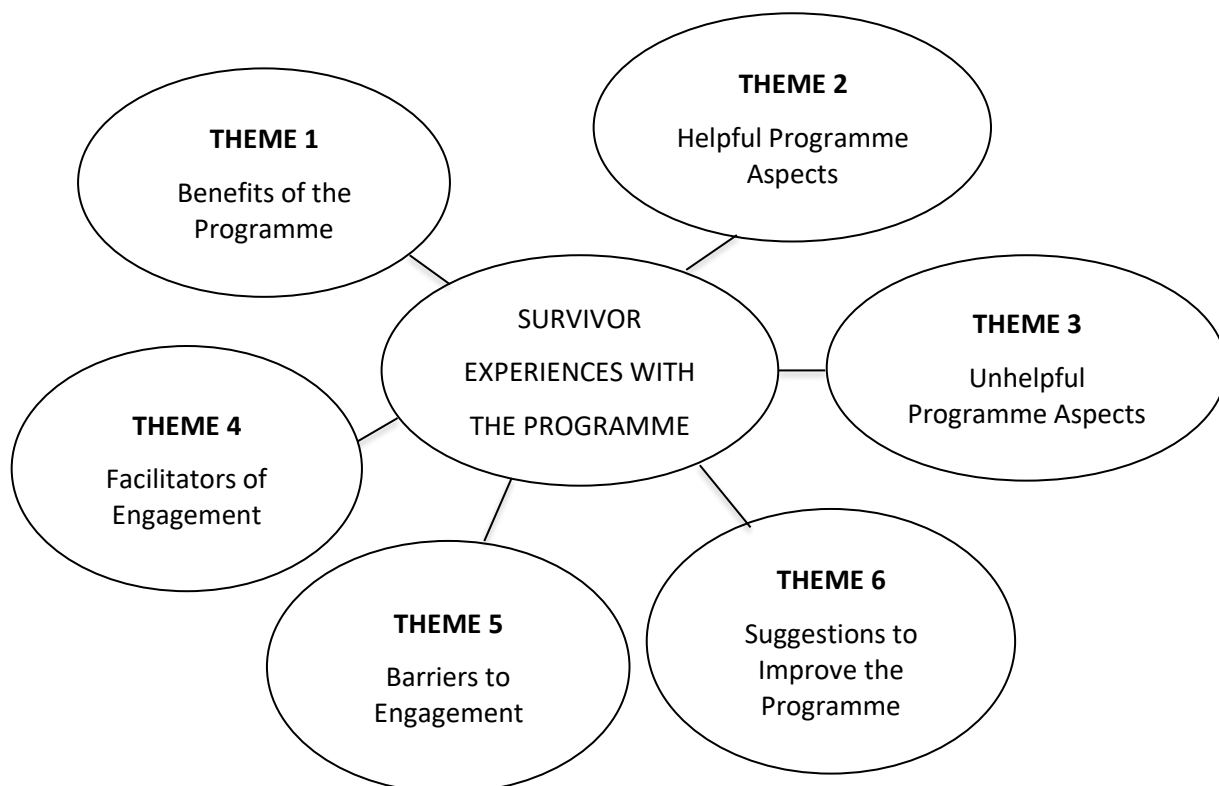
“I’ve already looked at a couple of the early modules again because I’d forgotten. I mean chemo brain is a thing. ...You know, to refresh on what the earlier modules had said. I mean I feel very confident using it and you know, I’ll probably re-read it two or three times.” [P6]

5.2.4.2. Survivors’ Experiences with the iCBT Programme

Inductive thematic analyses assessing survivors’ experiences with the iCBT programme resulted in 6 main themes, described in Figure 17.

Figure 17

Thematic Map Illustrating Survivor Experiences of Using the Programme



Theme 1: Impact/ Benefit of the Programme

1.1. Learned new techniques and skills to manage distress

One of the most common themes that appeared on survivors' evaluations of the programme was learning different techniques and new skills to manage their distress, which they found very helpful. These skills included noticing negative thinking, questioning and challenging distorted and unhelpful thinking, being more active, and doing things they enjoy. As one survivor described:

"I think I have become a little bit more sort of 'Okay, I'm feeling this but why am I feeling this? Is this actually true or is this just me and my interpretation. How real is that really?'"

[P12]

Survivors noted that they may still feel down or get anxious and did not get rid of all the problems. Still, it has become easier for them to recognise when they think negatively; they now know how to get into a better place using the techniques they learned in the programme. As one survivor described:

"So, if I get caught in that real bad place in my head, that while I still get caught in it, what is becoming easier is recognising that I'm there and then okay, how do I- not necessarily how do I fix it but how do I get myself back out of it? What are the tools then that I need to start working on now to get myself to work my way out of this?" [P15]

1.2. Self-awareness and insight

Many survivors commented that the programme helped them better understand their thoughts, feelings, and behaviours, and have awareness and insight about the difficulties they are experiencing.

“With the self-criticism, I used to think that’s just the way I am and I’m always going to be like that. That’s not actually true. I realize that now. It doesn’t have to be like that forever.”

[P1]

“So that really helped me to realize quickly that staying in bed too long affected my mood. I needed to get up and I needed ...to walk and to do things for myself.” [P11]

1.3. Increased sense of control over problems and recovery

Acquiring knowledge and new skills helped many survivors understand that they can manage their distress by working actively towards them, which made them feel more in control over problems such as self-criticism, worries about recurrence, the future, and their recovery.

“That’s the main thing I’d say about the programme...It puts you more in control, I think. It gives you the tools to feel that you’re more in control of your of your thoughts.” [P12]

“Planning for wellness...That kind of makes you see that recovery isn’t just something that’s happening to you. You can assist your own recovery and I found that useful... You might still get a recurrence but at least you’ll have done everything that you can to help yourself...”

[P14]

1.4. Helped processing suppressed feelings/ Acceptance of nonlinear recovery

About half of the survivors mentioned that they could not properly process what has happened to them as they were expected to go back to “normal” life after their medical treatment ended. *But internally, it was not over* for them. They found this challenging as so many things have

changed in their lives, including their beliefs, relationships, activity levels, and new problems arose such as fatigue, night sweats, changes in sleep, concerns about returning to work, recurrence, and their future arose. They repeatedly explained that the programme helped them process feelings that they had not dealt with before, which brought up suppressed emotions to the surface and made them more emotional during the intervention. But many of the survivors viewed it as something positive.

“It brought up some emotions that I probably hadn’t dealt with and it probably made me kind of cry and take stock at times and that was good because maybe there was elements there that I had buried and hadn’t dealt with...” [P2]

Survivors also explained how the programme helped them realise that recovery takes time and is normal not to bounce back straight away. As one survivor described:

“... The recovery is frustrating and you wonder why you’re not bouncing back straight away. And I think this kind of reminded me that okay, this- It’s not just me. You know, I shouldn’t be able to snap out of it. You know, that this is a process that’s going to take a long time.” [P14]

1.5. Self-prioritisation

Many survivors mentioned that they have not been prioritising themselves, especially those who have children and family. They liked that the programme encouraged them to prioritise themselves and focus on their own needs. Taking time for themselves by being more active, engaging in pleasurable activities, or listening to staying in the present exercises led to improved mood.

“It made me realize you know, I need to make more time for myself. So say I went, I joined

back in the gym... and I was doing something for myself like even if it was just five minutes of meditation or trying just to do something on my own and I think that definitely has helped me, you know, with my mood.” [P1]

“I think one of the other big things about it is that you’re giving yourself time to do something which you just don’t. And I think, you know, when you’re a Mum in a family and you’ve got everything else going on and dealing with everybody else’s problems...” [P12]

1.6. Feeling calmer and relaxed

Many survivors reported improvements on their mood. They said that they were feeling calmer and more relaxed than how they felt before the programme start. Many thought this was due to the information provided in the programme and actively working to improve their mood.

“...the nights I couldn’t sleep because I was worrying about something- It allowed me to put those worries in a compartment where you could say ‘right, well I’m going to deal with them tomorrow’. And it helped me relax then...I definitely became more relaxed and happier.” [P5]

It is important to note that some survivors underlined that the improvement in their mood could not be explained only by the programme. It resulted from a combination of different factors such as improved weather, the restrictions being lifted, as well as the tools they learned in the programme.

“I’m not saying the intervention made my mood better. I think it was a combination of things like work and that sort of thing and personal life. It improved...And then this was an added, you know, tool to help. It helped me stop and kind of think and rationalise things better. [P3]

1.7. Improvements on communication with others

About half of the survivors also mentioned that improvements on their mood also benefitted their relationship with others such as their partners, children, and colleagues. Some survivors explained that they started to communicate better with their loved ones.

“I definitely see a change with my interactions with my family; with my son. I went through a time where I just felt I didn’t have the energy for him and then I felt guilty but I’m starting to be easier on myself and that actually makes it better... So, I think it’s really improved that for me...and my patience with my husband as well [laughs]. I feel like I’m much more aware of my moods and when I feel low. Then I can express it to him in a good way, in a real way, rather than just being, irritated [laughs] or short with him. Because I was a bit like that.”

[P11]

Theme 2: Helpful Aspects of the Programme

2.1. Content

Challenging Thoughts module

Regarding the programme content, survivors found some of the modules, tools, and exercises more helpful than others. Throughout the data, there was an agreement between survivors that Challenging Thoughts was one of the most beneficial modules. Survivors found this module interesting and noted that this module resonated with them more as they learned how to re-evaluate their negative thinking and look at the situation from a different perspective. As one client described:

“Is this really going to happen? I found that section really interesting ...you say something to yourself and you sort of think ‘Is this going to happen?’. You think ‘Well, is it?’ or ‘what

evidence have you got for that?’ or ‘is that really like that?’ So, I think writing down situations and how you’re feeling each day...that does help so I have continued doing that...”

[P12]

Managing Worry module

Managing Worry was another module that was commonly seen as one the most helpful aspects of the programme. They explained that the module and the tools helped them deal with overthinking and rumination, and take a step back. They particularly found the content about differentiating practical and hypothetical worries, letting the worry go, worry tree, and scheduling a worry time beneficial. One survivor with previous experience with CBT described:

“...I was trying to solve problems that couldn’t be solved...So, I think, remembering that yes, problem-solving skills are good for problems that can actually be solved but for problems that can’t be solved, you need to recognize that there is uncertainty in the future and kind of living with that. So, I think that’s been helpful to remember that again.” [P13]

Boosting Behaviour module

Survivors also found Boosting Behaviour module and Activity Scheduling tool one of the most helpful aspects of the programme. They explained that they have become more active, and planning and doing things they enjoy helped improve their mood.

“...the idea of doing things that you enjoy to kind of cope with difficult times in life or difficult thoughts - that was another thing that stood out to me. And I did that. And it really helped me to kind of focus on the things that make me happy...” [P11]

Staying in the Present exercises

Survivors found the Staying in the Present listening exercises very helpful, especially the ones such as Safe Space, Compassionate Companion, and Body Scan. Survivors liked these exercises because they were *short and easy to do* and *did not require them to make a big commitment*, but were also helpful to manage their worries and focus on the present moment. As one survivor explained:

“...I was surprised, for a start, that they did help. The relaxation ones especially. They were so very relaxing... So you spend your whole life planning and working and I suppose this is the first time when it’s been okay for me to not have to plan and not to have to sort of get stressed about the next step. Because, I’m alive, you know! And just relaxing and being and not thinking about anything other than this moment.” [P6]

Spotting Thoughts module

Spotting Thoughts was also mentioned as another helpful content in the programme. For many survivors, remembering their “thoughts are not facts” and noting down their thoughts, feelings, and behaviours provided an insight into their problems. They found that noticing negative thinking has become easier for them. As two survivors described:

“And I did one of those things- you know. What is it? The feeling, behaviour- that cycle. I was doing that and then like within five minutes I was like ‘oh I’m fine now’. You know, it just puts stuff in perspective and made me realise that those thoughts that were going around in my head (...) just weren’t- You know they weren’t real. They were just thoughts.” [P3]

“... there’s another thing on negative thinking and mood. You know, automatic thoughts. Just

remember that just because you think them doesn't make it true. I found that was very good..." [P14]

Personal Stories

Personal stories were noted as one of the most helpful aspects of the programme. Many survivors found the stories relatable and real and helped them normalise their own experiences. Reading other people's stories made survivors feel that they are not alone, their problems are common, and they can cope with them with the tools and techniques provided.

"So I thought the stories, the fears, the anxieties, everything else was very- Everything was very real. I could resonate with everybody's story." [P2]

Some survivors also mentioned that personal stories provided them guidance on how to use a tool in a particular situation:

"I thought they were very good in explaining how to maybe use a tool in a situation, to really think about it. So, I found them very helpful." [P11]

2.2. Delivery

Supporter feedback

All survivors agreed that supporter feedback was one of the most significant sources of motivation for them and reported that they felt supported by the feedback. They explained that "not having a face of the supporter made it easier for them to open up to the supporter, and they looked forward to getting feedback from their supporter each week. Many survivors also reported that supporters' feedback made the programme more personalised.

"I found the most helpful part of the whole thing was the counsellor...I found her excellent. Absolutely excellent ...It certainly helped me a lot with- She would suggest directions to go...For when you're feeling this way or that way. She would say well 'try this or try that'. Then 'read this or read that' you know, in the programme...Which was very helpful." [P7]

"It made it feel like it wasn't just a programme. That there was actually someone there who was, you know, paying attention to what you were doing, which I think was really good. That sort of personalized bit." [P10]

It is important to note that there was an emphasis on the beneficial role of the supporter in the programme such that some survivors thought that the programme would not have the impact it had if there was no supporter:

"I think it wouldn't work if you didn't have somebody. You know, it wouldn't work as well. ...You'd just read it as an article and you might take on one or two things but it wouldn't have the impact that this does because you know, it drifts in for one thing and there's a human being at the end of the week saying you did well...Or maybe you need to work on this." [P14]

Easy access

Another favourable aspect of the programme for survivors was easy access to the programme. Many survivors found the programme easy to integrate into their daily life as it was easily accessible, as described by (P6, female) *"It just became part of my routine in the morning or, sort of after lunch..."*. Another survivor also explained:

"I think with everyone with a smartphone, the technology is there. The fact that it's an app. If

I wanted it in the car and watched seagulls or do whatever, I can just put it on through the speaker in the car and just get a hot chocolate or a cup of coffee and just take some time out and revisit it. The fact that it's so accessible is fantastic.” [P2]

Some explained that they live far from main cities and having support they can access online was a great opportunity for them:

“Well I live right up the top of the country. So, there's no way I would've been able to access anything like this with everything that's going on and the fact is like this is actually such a great course.” [P8]

1-year access

Many survivors also thought that having 1-year access after the programme completion is very helpful as remembering all the things they learned in the programme can be difficult for them. Some survivors mentioned that they would reread the information in the programme to refresh their memories.

“I mean, it's really helpful having it still an option for the next year because I think you- When you finish something, it's hard because to remember everything and I think if you can go back over it for a while, you're, again, you're more likely to continue that going forward.”
[P12]

For survivors, this also meant that if they need some support along the way, the programme is there to lean on for further support. As one participant explained:

“I love that I can keep using it and I can go back to it when I feel, you know, I need a bit more

support. I can go back and read and put some tools to use so...” [P11]

Timing

Survivors who completed all the modules also thought that the timing of the programme was right for them as it was after they completed their medical treatment. They reported that they would not be able to concentrate on the programme if it was offered during their medical treatment.

“I can look back now and reflect on it better. And that’s just me. I just couldn’t do it while I was having treatment. I wouldn’t have got what I got out of it now.” [P8]

Survivors also thought that the intervention was very timely also because of the COVID-19 pandemic and lockdown. Since they had a lot of time to think and ruminate and had less social support because of the restrictions, all of which triggered their worries and low mood.

“...The pandemic has led people to be more introverted because we’re spending a lot of time by ourselves and I think it gives you an awful lot of time to dwell. I think it gives you a lot of time to think. I think it was the perfect opportunity and perfect time for (...) direction in a more positive sense.” [P2]

Privacy, anonymity, non-judgement

The privacy of the programme, anonymous and non-judgemental feedback were other appealing and helpful aspects of the programme for some survivors. Many survivors mentioned that they would not be as open if they had a person in front of them; having a programme delivered

online made them feel more comfortable about opening up about their private concerns:

“...you were taking to a faceless interface which means you can really say what you want [laughs]. If that makes some sense.” [P2]

“It kind of felt intimate actually because you find yourself talking about things that you may not talk about face to face. Like I started talking about vaginal dryness, you know [laughs], which I may not have if I’d been sitting beside somebody.” [P14]

2.3. Structure

Flexibility

Another helpful aspect of the programme for survivors was its flexibility. Many survivors found it helpful to work on the programme at their own pace during their own time. Since some of them were still feeling tired and did not have time and energy due to other responsibilities; being able to *do as much or as little as they want and put as much or as little as they want into doing it* was helpful for them. As one client described:

“Personally, was the fact I could go back and look at modules at my own speed, that I could go ahead also and look at things and then slow down and think ‘No, you’re not taking in what’s in front of you. Stop and slow down.’ ” [P8]

“I thought it was very good yeah and a lot less pressure. Because it’s, you know, it’s nice to be able to just do it in my home and not have to go anywhere or meet anyone, in a way.” [P11]

Programme flow/ Layout

Survivors also mentioned how they liked the simplicity of the programme: the way it was laid out and flowed made it easier to follow the modules and understand the logic of concepts.

“I think the ease. How easy it was to use. I think if it had have been too complicated or you know, not as inviting visually. It was a lovely simplified version, very inviting without being over complicated... To me, it just flowed just in the right way...” [P2]

“I think they were quite logical the way they followed one on from the other. I think actually the way they were- that each module was set up was good in the way that logically, in your head, to try and work through the session, it made sense.” [P5]

Mix of different material

Some survivors liked the variety of the material in the programme, such as the inclusion of text, audio, and other visual tools. The visual elements in the programme made it easier to remember the concepts for some survivors. As two survivors described:

“I liked the mix of things. I thought it was a really good mix. You know, there’d be something written and there might be a little video. Then there might be a relaxation exercise and a little activity to do. Then there might be something to write. But a nice little mixture...” [P6]

“The visual way you go through the module and the visual tools and the visual aids. They were really useful for me because I can kind of picture them now and remember them since then. I think, you know, the way it was quite graphic was good.” [P13]

Theme 3: Unhelpful Aspects of the Programme

3.1. Did not find anything unhelpful

About half of the survivors viewed the experience as very positive overall and explained that they did not find anything unhelpful or disliked in the programme. Survivors noted that there might have been things not relatable to them, but nothing in the programme was unhelpful.

“I didn’t really find anything that was unhelpful. You know like I found something new about yourself...There might have been a couple of things that I thought ‘oh I can’t really relate to that’ but I wouldn’t have said it was unhelpful.” [P1]

“There wasn’t really anything that I particularly disliked, you know. I found it easy to use and, it was helpful.” [P13]

3.2. Unrelatable/ triggering content

Personal stories

Even though some survivors found personal stories very helpful and relatable, others did not like them or found them less helpful due to two main reasons. First, for some survivors, personal stories brought up negative emotions, and they found it upsetting to revisit cancer experiences. A few survivors mentioned that they avoided reading them as they did not want to remember the times they were going through treatment. As two survivors described:

“...I kind of didn’t want to read them. I tend to avoid that now because I just feel I don’t want to go back there... I don’t know I shouldn’t say it triggers something in me but I kind of feel I don’t want to be reminded of that.” [P3]

“So every time I saw a girl- a lady with a turban, I went ‘oh no’, you know? [laughs]. It’s that’s sort of- I can’t do it. I remember the turban. I remember all that. No, I don’t want to go back there, thank you...” [P7]

Second, some survivors found it difficult to identify with personal stories as they did not found them real and authentic. As one survivor described:

“...They were nearly like models [laughs]. It looked too good. I understand totally why things were as they were but to me, that felt a little bit unreal to me.” [P15].

Moreover, one survivor found that two carers’ stories were two extreme examples:

“...the two carer examples... there were two extremes if that makes sense... I can’t think of any days I sat on the sofa crying...” [P6].

Staying in the Present exercises

Although the many survivors liked and enjoyed the Staying in the Present exercises, a few survivors found that mindfulness exercises were triggering more negative thoughts. Therefore, they did not do the mindfulness exercises.

“I don’t know, mindfulness sometimes works but sometimes I find that I can’t really focus on it enough, that my mind wanders or that it actually makes me feel worse because the bad thoughts creep in [laughs]”. [P13]

Similar to the personal stories, a few survivors did not find these exercises authentic or real; they found them artificial, as described by one client:

"I should say I did not find them helpful. That's what I should say...I just found them very, very forced. Very artificial." [P7]

Theme 4: Facilitators of Programme Engagement

4.1. Programme-related factors

Supporter feedback

Besides seeing it as a helpful aspect of the programme, all survivors viewed supporter feedback as a key motivator for their engagement and programme completion. They liked the tone of the supporter feedback, found it very supportive and encouraging. Many survivors mentioned they were looking forward to receiving the feedback. Knowing someone is there and will provide feedback on their progress made them engage with the programme even when they are having a bad day.

"Because it...encourages you to keep on track- If you were doing it without the coach, I think if you had a particularly bad day or something, you'd sort of go 'ugh', you know, and leave it. Whereas if you know that there's somebody there sort of checking in on you as such and is probably going to go at the end of the week 'oh well, you didn't do much'...It encourages you in a positive way to keep going." [P6]

"I think the thing that kept me going was the supporter... she was empathetic but (...) she just got the tone absolutely right. It wasn't condescending or patronising or- She treated you like an adult but made really good suggestions and gave you good feedback." [P7]

Evidence-based and CBT approach

Many survivors explained that knowing that the programme was based on the science of psychology and evidence-based CBT approach motivated them to engage with the programme. Some of the survivors already had experience with CBT, and others never tried but heard about the CBT and were interested in trying it. As three survivors described it:

“I’m a fairly analytical person so because it was based on scientific ideas or at least psychological ideas. It made sense to me and I could sort of relate that theoretically to something that was, in my mind, equivalent to medicine...Obviously Cognitive Behavioural Therapy is one of the mainstays for treatment for a lot of situations. So that also furthered my interest...” [P6]

“I’ve been looking for some sort of- I’d done CBT before and it had been very helpful so I was looking for something to kind of help me through this stage of recovery from cancer.” [P11]

“I’d never done CBT before. I’ve heard of all the benefits. We’ve had it in my family and my two children have been counselled for different things so I’m a full believer in that but I never reached out during treatment, like I said.” [P8]

Reminders

Some survivors thought that setting reminders was a significant factor for their engagement with the programme and facilitated their programme completion. Some thought that if they had not set the reminders, they could have forgotten to engage with the programme.

“...because with work, I was forgetting and then I was saying ‘there’s something I have to do’

and I wouldn't remember but once I set the reminders it was easier to do it...That was a great help on the settings.” [P4]

4.2. Personal factors

Being ready for change

For many survivors, experiencing worry and/or feeling low was the main motivation to take part in the present study. They explained that they wanted to feel better and were ready to make the necessary changes to achieve that. Survivors viewed being open and ready for change as critical factors playing a key role in their engagement with the programme and its completion.

“I mean, obviously wanting to, feel better, improve my mood. Wanting to be proactive about what and how I was feeling, what I was thinking and how I was behaving.” [P11]

“...You do have to engage with it or you wouldn't get anything from it. So, I suppose you have to be in a situation where you want to change, where you want something to happen.” [P12]

Some survivors also noted their higher motivation to use the programme, especially when they were feeling bad. As one survivor explained:

“You see with me, I suppose I work better when I'm feeling low like right now I'm absolutely fine and I wouldn't really go near the app because I feel I don't need to, you know.” [P3]

Seeing the benefits of the programme

Many survivors explained that the more they saw the benefits of using the programme, the more motivated they were to engage with it and continue using it. Seeing the benefits of using the

tools and applying the skills they learned encouraged them to prioritise the programme and integrate it into their lives, and as a result, helped them to complete it. As two survivors explained:

“... feeling calmer. I mean, the impact of doing it definitely motivated me.”[P10]

“...being able to change your behaviour or whatever on a daily basis, that helped. That motivates you in itself because you’re doing something for yourself. You’re using something from the programme. You’re using it in your daily life and that is making a difference. And so, that in itself will motivate you...The more you see that it’s helping you, the more that you prioritise it.” [P12]

Wanting to contribute to cancer research

About half of the survivors mentioned that their motivation to participate and complete the programme came from their willingness to contribute to cancer research. Survivors liked that the research is being done for breast cancer survivors’ mental health and wanted to become part of it. Some also empathised with the researcher who needed volunteers to conduct the study.

“I think it can be very hit and miss in terms of patients accessing them. So I think anything that might help, you know, in terms of putting a framework in place for cancer survivors can only be a positive... So anything that might help us move forward...I really want to be a part of.” [P15]

“I kind of felt ...I’m signing up to something that- I know that it’s research and I know that it’s going to be beneficial hopefully. I wanted to complete it so I made myself complete it, you know. I wasn’t going to just sign up and not do it.” [P3]

Feeling sense of achievement/ Empowerment

Many survivors also mentioned that having done something for themselves to improve their situation provided a sense of achievement and empowerment, and that encouraged them to keep using the tools and techniques in the programme.

“having those tools to be able to do that yourself...You feel a sense of achievement, that you have actually sort of done something for yourself to improve your situation and I think, doing that, you’re more likely to stick with it.” [P12]

“you kind of got a bit of a dopamine hit, I suppose, from having done something, you know [laughs].” [P14]

Theme 5: Barriers to Programme Engagement

5.1. Programme-related factors

The HAT questionnaire

The HAT questionnaire, which was presented at the beginning of sessions 2 to 7, was a commonly reported barrier for survivors’ engagement with the programme and was off-putting for many. Survivors provided different reasons why it was unhelpful. Some found the questionnaire confusing and reported that it was not clear that it was asking about the previous session.

“...what I really found very off-putting was- ‘How did you find this session?’ But I didn’t have the session. What do you mean? Are you meaning last week’s?” [P15]

Others found it challenging as it was hard for them to remember what happened in the

previous session as they had memory issues, and thought that it was not suitable to ask such questions for breast cancer survivors:

"...after the coach had left feedback, you just get this screen like 'tell us what you thought of the programme' and I'm like hang on, I can't remember what she said. I only glanced at it and then you couldn't do anything else until you'd given that feedback. And it was like, this is a site designed for people with breast cancer. We've got memory issues. So [laughs], that was not very suitable..." [P9]

Layout/ Difficulty navigating

Many survivors identified the layout and difficulty in navigating through the programme as significant barriers to their engagement with it. They felt that it was not clear how to navigate through the programme, navigation through pages was not smooth, and they were not sure whether they completed a module or if there were more pages to read. Some also reported that the programme did not work well on their iPads.

"It was the layout, maybe... I didn't understand at the start what I was after doing." [P4]

"I found the software itself quite tricky. So, I think the first time I did it I felt like I was in a funnel and it just- Read this scenario, this scenario and I was like hang on, how long is this going to take? Can I stop and come back to it. It felt like this massive process with no clear end point. Just in a session. And that scared me off a bit so I probably didn't come back to it for a week or two." [P9]

"It was kind of tricky to navigate. I wasn't sure if I was seeing the whole thing or where the next tab was." [P13]

5.4. Difficulty understanding some tools/ Lack of clarity

Some survivors found some of the tools such as the TFB Cycle, Setting Goals, Managing Worry particularly difficult to understand, which may have influenced their motivation to engage with the programme. For some, the association between their actions and their mood was not clear on Mood Monitor. The TFB Cycle was especially challenging for many survivors as they found it hard to know what to write under each section (thoughts, feelings, physical reactions, and behaviours); therefore, some survivors did not use it. In addition to finding it challenging, one survivor found it painful to think deeply about her thinking, feelings, and behaviours:

"...what I found hard was the TFB cycles... I wasn't really sure what to say. Like, I also found them painful to do at times...Because I knew what I was doing to myself and I- And I found it painful to call myself out on it." [P14]

"That's the one [TFB Cycle] I found really hard to get to grips with. I mean, I did do it but I found the actual bit online really complicated to understand how to do it and it took me a long time to get to grips with it." [P12]

Another survivor explained that setting goals at the start of the programme was challenging for her as she did not know what the programme was about and what is possible to achieve by using it. Therefore, she was unsure what she could achieve by using the programme:

"I didn't feel any way capable of articulating what my goals were because I didn't know what

the programme was... I just felt intimidated [laughs] and it was a bit of pressure right at the start to be like 'Why are you here? What do you want?'" [P9]

5.2. Personal and situational factors

Reluctance to think

Many survivors noticed that they sometimes felt reluctant to think about breast cancer and themselves; they wanted to avoid thinking about it at times as they found it painful, which was a barrier for their engagement with the programme:

"...reluctance to think about myself...So I had to sort of think about myself and how I was doing. So that would be the only hard." [P7]

"If you're just having a normal day at home, the idea of having to go back into the breast cancer zone is painful and difficult at times. You know, because sometimes you just want to forget about it." [P14]

Fatigue/ Difficulty concentrating

Many survivors also reported that fatigue, difficulty concentrating, and lack of energy hindered them from engaging with the programme at times. Mental and physical fatigue resulted from different factors for individuals, including treatment side effects, a busy work schedule, and having a new baby.

"I really struggle with fatigue still, mental fatigue from the treatment. I had chemotherapy and radiotherapy kind of in a short space of time last year...So, it's about having a clear space of time that I can actually concentrate and that I'm not tired... Fatigue maybe hindered

me a bit to do more..." [P11]

"sometimes I just felt too tired [laughs]. And we had a few weeks where the baby was having either sleep problems or other issues so I just didn't have the energy to give to it." [P13]

Difficulty to find time/ Impact of COVID-19

Many survivors explained that finding and making time to do it was difficult due to other caring responsibilities they had for children and parents, and the impact of the COVID-19 on their daily life, which had hindered them from engaging more with the programme.

"I don't think it was a decrease in motivation, I think it was the impact of other things going on in my life that I was doing or family, you know. I've got two daughters who need, you know, my support and various other people who need my support... it was almost trying to fight to have some time [laughs] to myself." [P12]

"I kind of felt that I should have given more time but I had the time but it was kind of allocating the time and I suppose in the middle of a pandemic my life was a bit crazy. And then my husband actually got coronavirus halfway through." [P1]

Being unsure about the potential benefits

Two survivors felt that the programme or some of the tools in the programme would not help them, which had an influence on their motivation to engage with the programme.

"... I had a fear that it wouldn't help me so kind of like, why would I do it if it's not going to help me. I really had to press through that every time. Well, not every time. Definitely at the

beginning but once I got, you know, through that, You know, it was helpful and it got less and less over because I knew it was helping me.” [P11]

“...some of the tools..., I suppose, I didn’t give it the time. I felt I wasn’t going to get anything out of it but maybe I would’ve. I don’t know. The mood monitor, for example. I did that a few times and felt well actually, I’m not sure that that’s relevant to me right now, even though I can see how it’s a good tool.” [P13]

Theme 6: Suggestions to Improve the Programme

Based on their personal experiences with the iCBT programme, survivors provided important suggestions to improve its content, delivery, and structure for future studies.

6.1. Suggestions for the Content

Revision of Personal Stories

Survivors who found personal stories triggering, not relatable or authentic, suggested some changes in the stories. Their suggestions inclusion of stories where a survivor is trying to put on a brave face and keep it going rather than crying and being upset. Other suggestions included survivors having concerns about returning to work or giving up work, or finances. Problems with kids, fertility, lack of support, and effects of menopause on mood were other themes that were suggested to include in personal stories. They also suggested the inclusion of more general life problems independent of breast cancer for survivors who are further along in their journey. One survivor felt that personal stories were heavily anonymised, which made the stories stiff and suggested researchers *get people to come forward with their actual story [P14]* to provide more

convincing and relatable stories.

“...to me it would ring more true if the story was changed slightly so that these people came home and their- the mother or the wife made an effort to keep going and put on a brave face but then they found evidence that they had been sitting there crying or something because they found a box of tissues in the bin or something.” [P6]

The lack of a story with work-related issues was noted by many survivors. As one survivor described:

“...the biggest challenge I had with my illness was, and with anxiety, was going back to work. And I had a lot of like chemo fatigue and chemo brain and just worry that I wasn't going to be able to do my job the first time...” [P13]

Not having stories where a survivor has a problem not specific to breast cancer made it difficult to relate for breast cancer survivors who were far out of their treatment. Therefore adding stories with more general problems that are not specifically related to breast cancer (e.g., work or family problems) would cover the expectations of survivors.

“So I'm five years out... Maybe wasn't an appropriate candidate because my anxieties, my worries, my feelings aren't really related to breast cancer anymore. It's more just life- Whatever's happening in life. ...I feel like I've gotten over it and I've come through it. I was using it for just personal issues, you know, not cancer issues as such.” [P3]

More examples, guidance, and clarity for the tools

Survivors discussed their need for more guidance and examples for some tools such as TFB

Cycle, Staying Well, and Mood Monitor.

“(TFB Cycle)...was quite difficult. I sort of got it all wrong the first time. I was putting things in, some of them in the wrong section, but after a while and with some help from my supporter, I sort of got to grips with it. I think a lot of people would find that quite hard to... It might need a little bit more explanation as to- Maybe an example of what you could put into each section.” [P12]

“Staying well. I didn’t do this properly. I think mine were very negative. Oh, yeah, that was it. It was kind of like the TFB cycle but you know, you had to fill out stuff about how to stay well. Mine, I don’t think I knew how to do it properly.” [P14]

One survivor explained that she was not able to link the influence of what she was doing on her mood, while she was using the Mood Monitor. Therefore, more guidance on the Mood Monitor would provide more clarity and make it easier for survivors to understand the relationship:

“Maybe I wasn’t using it [Mood Monitor] properly at that point. I wasn’t linking. Just putting in there the smiley face or whatever or whatever. I wasn’t linking that for quite a while to other things that were happening on a day-to-day basis, I think.” [P12]

Providing further resources

Two survivors suggested that providing further reading resources such as books and websites for survivors who are interested in reading more can improve the programme. They highlighted that it should be added at the end or after the programme completion so that survivors do not feel that they have to read them.

“it might be a good idea to say ‘ if you would like to find out more about CBT’, which I knew nothing about before we started, you might read this or there’s this handy website or something.” [P7]

“I did wonder at one point whether it would be beneficial to have links to helpful websites. ...it would be best to include them at the end so that people could refer to them if they wanted to and not feel that that was something they had to do as part of the programme itself.” [P10]

6.2. Suggestions for the Delivery

Making the treatment widely available in oncology clinics

There was a consensus between survivors’ accounts that they benefitted greatly from the programme and mentioned that the treatment should be made widely available as psychological support services are very limited for cancer survivors post-treatment. They thought that if the programme was made widely available by the hospitals and oncology clinics, then many people would benefit from it.

“It could be rolled out to every oncology unit in the country which would be an improvement for everybody.” [P2]

Some survivors also discussed that the programme should not only be made widely available for all cancer survivors but also for other people with chronic illnesses:

“I really think these things should be adapted for everyone or for all cancers, not just breast.”
[P3]

"I actually do hope that a lot more people can benefit from it because although I went to a cancer- The Marie Keating Foundation, I do think that what you're offering is more than just for cancer patients. You know, there's other people that have got other illnesses that would benefit from sort of the same modules." [P8]

Providing the programme nearer treatment completion time

Although many survivors found the timing of the programme very helpful, including those who are far out of their treatment (P10, P13, P15), some survivors noted that introducing the programme nearer treatment completion time would have been even more helpful as the first year following the treatment completion is very stressful and worrying starts during that time:

"I think like say if we were doing it you know when I was nearer the treatment time like a year after, the managing worry section would be really beneficial... I think definitely after you've completed your treatment because I think that's a scary time. After you have your operation and have done all your chemo and radiation. And then there's a real worrying time after that between kind of then and maybe your next check-up and mammogram. It would be good at that point." [P1]

However, survivors emphasized that it was good that the programme was offered for those who completed their treatment as they would have found it challenging to read and pay attention to the programme during the treatment: *"When you're in treatment, you're too- I have support; family, friends and oncology. But I don't think I would have had just the attention span to read and it was too much. I can look back now and reflect on it better. And that's just me. I just couldn't do it while I was having treatment." [P8]*

Providing more time to complete the programme in the supported mode

Some survivors thought that if they were given more time to complete the programme in the supported mode (with post-session feedback from their supporter), that would have been very helpful as some found it challenging to do one module each week. As one survivor explained:

“So, I’m slower at it. ...I know it was only six or seven weeks, and I knew that from the beginning but it would- That’s the one thing I would say about it. It would be nice to have the support of the supporter for a little bit longer, you know? Maybe a couple more weeks. I found it hard to finish the whole thing within that time.” [P11]

Adding face-to-face human contact half-way through

Some survivors explained that they found the interview beneficial as it helped them to reflect on what they learned in the programme. They suggested that adding face-to-face human contact halfway through the intervention would have been very helpful them to reflect on how they are finding it and make the programme more personal:

“I think like the Zoom thing you’re doing- I think that you could do that half-way through. I know every week it would be difficult to do everybody because there’s probably loads. But if you could do it half-way through just to see how people are getting on. ...I know that you touch base with people through the email which is great but I just think this makes it real or something.” [P4]

“If you had- Even something like a focus group maybe half way through, that you might have a call or a Zoom call that people could participate in. You know, how are you finding it? What do you think of this? Even at that stage, that you could say ‘oh, I missed that bit. I must go

back and have a look at that. That sounds really interesting.’ Or ‘Oh, I got a different take on it or I really liked... Not every week necessarily because maybe that wouldn’t work but maybe half way through... You know, just something a little bit personal.” [P15]

Interaction with other survivors/ forum

One survivor, who could not relate to the personal stories, mentioned her need to interact with other survivors. She explained that reading personal stories of others did not feel very interactive as they did not feel real. Not being able to interact with others made her alone. She suggested adding a forum where people can share their own experiences with each other to facilitate more interaction among users.

“I don’t know if it would be possible to have a more interactive thing where, you know, I can speak or I can listen to you and say yeah, that really resonates for me because X,Y,Z. I think that forum that we had mentioned and it does take, you know, two or three people to get it going.” [P15]

6.3. Suggestions for the Structure

Clear explanation of expectations from the users

Many survivors expressed that what is expected from them or how to work through the programme was not clear when they started using the programme. Some survivors felt confused, overwhelmed, and lost due to programme’s layout and being unclear about what to do.

“I found it confusing. Was I supposed to do module one for week one, module two for week two, module three for week three? It wasn’t clear to me what I was supposed to be doing.” [P7]

Survivors suggested adding more explanation either in text or video at the beginning of the programme to clarify its structure, content and what is expected from users. As two survivors described:

“But what I think would have helped me was if you had maybe a fifteen or twenty minute clip from whoever, from yourself or whoever is sponsoring the programme to say “This is what we’re doing. This is what we’re about. This is what you can expect’.” [P15]

“...Or if at the start. Like, each week there would be several pages of information about specific topics to read and there’ll be tools that you can try that are associated with them. And then the coach will look at what you’ve said about the tools and give you feedback...And it’s okay to start something and come back to it later.” [P9]

Clarifying or Removing the HAT questionnaire

For many survivors, the HAT questionnaire at the beginning of each session interrupted the flow of the programme and their engagement. Survivors found the questionnaire frustrating and overwhelming as the programme did not allow them to look at the modules before they fill it out. Survivors suggested to clarify the questionnaire by giving it at the end of the session not at the beginning of the next session, or providing it a couple of times but not after each session.

“Maybe make it clearer when that thing comes up about the questionnaire...” [P6]

“I would have preferred to be in the module, finish the module and then have the questionnaire, not have it the next day you came to it so it’s just fresh in your mind.” [P10]

Smoother navigation on the website

Survivors suggested improving the navigation of the programme on the website and the app to provide a clarity and better experience for the users. As mentioned by two survivors:

“The thing that I did not like was when you finished a module and you went back to do the next module, it didn’t automatically take you onto the next module ...I’m not particularly intuitive with computers. Sometimes I wouldn’t be able to find what I’m supposed to. It certainly took me a couple of weeks to get used to the programme.” [P10]

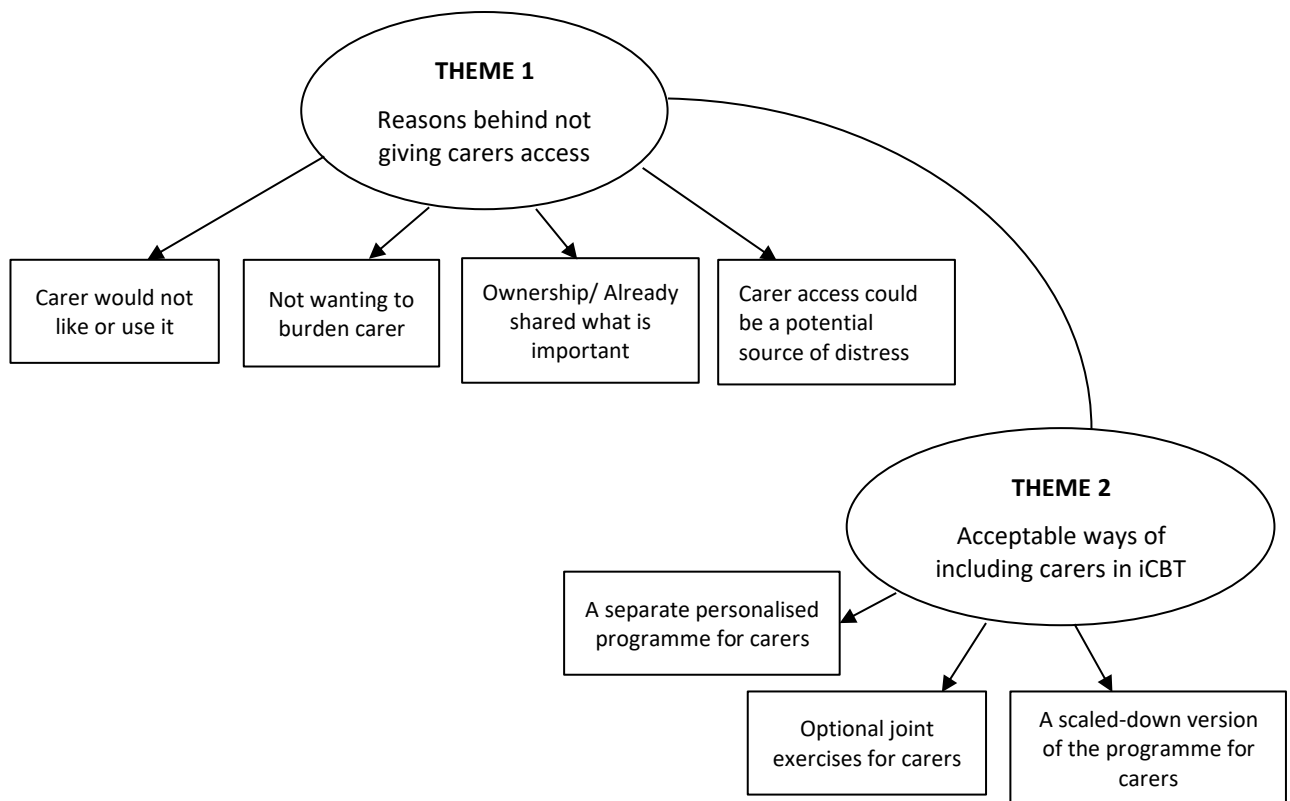
“Well clearer navigation on the website...I expected to be taken into (supporter’s name) reply from that week and then a really clear lead to what I have to do this week. And I wasn’t getting that. I don’t know if I did something wrong or what. Eventually, I learned to navigate. I mean, I did the whole website but I went round in so many circles... I did the same thing about three times and then I found a bit I hadn’t done so I went off and did that.” [P7]

5.2.4.3. Survivors’ Perspectives on Carer Access and Involvement

Survivors’ views on carer access to the programme and acceptable ways of carer involvement was another overarching theme identified in the interviews. Main themes and subthemes are presented in a thematic map in Figure 18.

Figure 18

Thematic Map Illustrating Survivor Perspectives on Carer Access and Involvement



Note. Themes are presented in circles and subthemes are presented in rectangles. Arrows indicate the relationship between themes and subthemes.

Theme 1. Reasons behind not giving carers access

Survivors who had carers provided variety of reasons regarding their decision on not giving their carers access to the programme.

1.1. Carer would not like it or use it

Many survivors thought that their carers would not like the programme or would have used it due to three main reasons:

Desire to move on

Survivors had a common experience in that their carers wanted to forget the breast cancer experience and move on. Many reported that their partners and family members have been unwilling to speak about breast cancer after the completion of their medical treatment. Survivors were frustrated about their carers unwillingness to talk about it and their desire to forget. Therefore, survivors felt reluctant to ask them to take part or told them about the programme. As one survivor described:

“I very rarely talk to my husband about the experience. I think if people don’t talk about it and don’t have anything to do with it after it’s done, they think that it’s gone away [laughs]... I think if you’re out of it for a long time, I’m not sure that the carers would want to be involved [laughs]. It’s just bringing them back to something that they’d rather not think about, rather forget.” [P10]

Unwillingness to talk about feelings

Survivors also noted that their carers, especially husbands or male partners, are solution-driven and not open to talk about their feelings and concerns. Therefore, they thought that their carers would not like the programme or engage with it. Many noted that their carers tend to shut down their emotions and focus more on the practical side of things.

“He probably just didn’t want to face having to do it and- Not in a bad way but I think he’s just not great at talking about things like feelings and stuff like that.” [P1]

“One, he’s a man. Two, he doesn’t do feelings(...) he would not be somebody who would spend time delving into feelings or anything like that.” [P7]

Lack of time

Many survivors who viewed their carers as not open to talk about feelings also thought that their carers did not have time to engage with the programme. Therefore they preferred no carer access:

“I just don’t think he had time. I mean I did tell him about it and he did say well ‘if you want me to interact with it’ he would, but I presumed...he probably would’ve logged in two or three times and that would’ve been about it.” [P6]

“My husband’s been working from home anyway so he hasn’t got much time.” [P12]

1.2. Not wanting to burden the carer

Many survivors prioritised how their loved ones feel about their diagnosis and mentioned that they acted put together and talked very carefully as they did not want to upset or frustrate them. They felt that asking for them to use the programme may mean that something is wrong and would burden the carer, and therefore they did not want to involve them. As two clients described:

“...But you can’t keep talking like that to your family. They want you back. The new version is what they’re getting. They’re not getting the version they had before and I think it just makes them sad, I mean. So, in a way, you have to be very careful talking- In my experience, I’m careful about how I talk about it.” [P8]

“I know my two girls end up, you know, end up working about me all the time as well. So, I haven’t told them anything about the programme....” [P12]

Many survivors also felt that they were unable to support their loved ones while trying to deal with emotional and physical effects of diagnosis. Furthermore, if their carers would have signed up for the programme and could not engage with it, they would have felt guilty. As one survivor described:

“I think it probably got added to her list of things to feel guilty about, not having done more of that.” [P9]

1.3. Ownership/ Already shared what is important

Many carers said that they preferred no carer access also because they wanted to have an ‘ownership’ in the programme. They wanted to decide what to share and what to keep it to themselves.

“I suppose, I sort of thought that I’d just prefer to do this first on my own and then if there’s anything I thought that he needed to know, I could tell him. And for me, that worked better because at least I’m having ownership of that particular situation because I haven’t had ownership really of anything over the last couple of years.” [P6]

“You know, he’s a great, supportive husband but I feel that this is something I have to do on my own.” [P14]

Regardless of whether they selected carer access, many survivors indeed shared some of the content they found helpful with their carer:

“Now saying that, he does like some of the videos; the short ones. If it goes too long, he just loses interest where the short ones he likes. So, I send him a few but I don’t tell him where they’re from. I just say ‘I’m doing this. Listen to this. This is good.’ So he did benefit but he didn’t realize.” [P4]

“I told him some of the things that I’ve picked up on it and he was very supportive and thought they were, you know, great. But I just couldn’t see him doing it.” [P6]

“... because (spouse’s name) wasn’t able to go through it all [mmhmm] but there’s definitely like – I’ve shared with her some of the tools and some of the thinking and I think- But actually, at the same time, it was good to have something that was just for me...” [P9]

1.4. Carer access could be a potential source of stress

Some survivors thought that if they asked their carers to use the programme and they did not use it, it could be a potential source of stress for the survivor as it may have led to arguments and created hassle in the relationship. As three survivors described:

“He’s dealt with my breast cancer in different ways than I have so I think for him, having to read all of that stuff, he would’ve just said ‘well I’ve thought of this anyway,’ you know. So I just thought we- It’s just one less argument or hassle that we’d have to have or him going ‘well I told you that, you know, ten months ago’ or something like that...” [P6]

“No because I said I wanted to enjoy it and it wouldn’t have been enjoyable if he had have just been like ‘ugh do I have to do this?’ So that’s why I just said no [laughs].” [P4]

“It’s much easier for me just to do it than nag him about it so I’m not sure that saying to him ‘oh I need to do part of a course for you’- I think that could maybe end up being really stressful and end in an argument because I’d be like ‘Can we do the course? Can we do the course? Can we do the course?’ [laughs].” [P13]

Theme 2. Acceptable ways of including carers in iCBT programmes

When survivors were asked about other ways of including carers in iCBT programmes for breast cancer survivors, they provided variety of answers, which can be mainly categorised into three subthemes.

2.1. A separate personalised programme for carers

Survivors thought that any sort of emotional support for carers would be great as they get so little and *it is not recognised widely [P15]*. However, they mentioned that rather than giving carers access to survivors’ programme, a personalised and separate programme is needed for carers. As carers have different issues and concerns than survivors and there is not support for them to address these accordingly, as described by two clients:

“...with the carers, worries are going to be different to the patients so I’m not sure if the same programme will work for both.” [P5]

“There’s definitely things lacking because there isn’t anything out there to give them support

because I've never seen anything that I could recommend to my girls to say this might be of use to you. Any place I've seen, it's all about the person that's recovering. It's not really about the families..." [P8]

Many felt that the programme was more tailored for the patient rather than the carer and the focus should be on a carer rather than the person recovering. They thought that survivors' programme may "reflect upon how they felt about hearing about a diagnosis, how it changed their lives." [P8]. Some of them thought that they do not need to dwell on survivors' stories:

"I think they might need their own. I don't know if they need to be dwelling on our story. Maybe they need to be dwelling on their own story. 'Yes, I feel annoyed that they're sick. Yes, I'm annoyed that they can't get out of bed.' No, I don't think they need to be in our programme. Maybe they need their own programme." [P14]

Some survivors thought that if the study was advertised to carers separately, not through survivors, that would have made survivors more comfortable. They thought that carers using the programme as part of survivors' involvement in the study do not give carers an opportunity to have their own identity outside of their caregiver role. As described by three survivors:

"Even having it as part of this, it's not giving, to me at least, a carer their own identity. You're still the identity of 'the carer of (participant name)' or, you know, whoever it is. But the carer has their own identity." [P15]

"And it's aimed for them, you know. That it's not 'oh we're just doing this because our partners had cancer like and we're just doing this because'. So it's something for them

separate to it maybe...” [P4]

“It could be like, you know, are you suffering from breast cancer or are you taking care of somebody who is? Here’s a way to make the most of it or positively deal with the emotions and stuff like that...Yeah I actually would’ve felt more comfortable, you know, had the programme been offered to my husband separately and then he wouldn’t have had to tag in on to mine. If that makes sense?” [P6]

2.2. Optional joint exercises with carers

Many survivors also thought that adding optional exercises in survivors’ programme that carers and survivors can do together may be another way of including carers rather than asking a carer to do something completely separate. Survivors emphasized that these exercises can be optional so that it does not affect the flow of the programme for people without carers.

“Is there any way that you could include some sort of joined exercise that people could do together if they wanted to?” [P7]

“I don’t know whether you could have a section on it...Have a section that you could work through together maybe.” [P12]

One survivor explained that it’s not easy to have conversations with each other, therefore the joint exercises can be a way of encouraging communication between survivors and carers:

“Maybe just something to kind of talk through because it was talking about how it could be helpful for a carer to do the programme and then you can start conversations or you can talk about things that have come up. But sometimes that’s not always easy so to maybe have something to focus on, to kind of motivate those conversations.... maybe exercises to do, to

think through, whatever anxiety or negative thought together.” [P11]

“I mean, if you could even say go for a walk together or hang out together or have this conversation.” [P14]

2.3. A scaled-down version of the programme for carers

Many survivors also suggested that having a scaled-down version of the programme for carers. They thought that a 7-week programme can be intense, and the parts that are less relevant to carer can be removed. They thought that if it is shorter, then carers would be more likely to do it, considering that many carers may still have caring responsibilities or not have much time to engage with the programme.

“...I don’t know if it has to be as detailed maybe for carers. Maybe a scaled-down version? He probably would’ve done it if it was just one or two, you know, a couple of pages of reading and not to the same extent to what I done.” [P1]

“I’m just thinking a carer might not have time to commit as much as (...) if they’re still caring. I’m just thinking if it was (spouse’s name), he’d want it shorter and briefer.” [P4]

“Because I suspect in most cases, they just need or want, you know, a little bit of help whereas it’s quite intense, I would’ve thought, for someone who is a carer to do the whole programme.” [P10]

However, some survivors did not like the idea of shortening the programme, and thought that having access to the same information and tools would make it easier for them to communicate about the programme with each other:

"...I can't imagine having a shorter version for them... It's good for my husband to do the exact thing that I'm doing so he knows what I'm talking about, if I want to talk to him about it or he knows oh, he can support me and say, you know, that tool might help." [P11]

5.2.5. Discussion

The present study sought to understand the experienced acceptability of a novel 7-week iCBT programme with fifteen breast cancer survivors, as well as their experiences with using the programme. Thematic analysis resulted in three overarching themes: (1) experienced acceptability of the iCBT programme, (2) survivor experiences of using the iCBT , and (3) survivor perspectives on carer access and involvement in iCBT. Each theme will be discussed in separate sections; the first two will be discussed in the same section due to the congruence in the findings, and the third will be discussed in a separate section.

5.2.5.1. Findings on Experienced Acceptability of the iCBT Programme and User

Experiences with it

Many survivors commented positively about the programme. They found it acceptable and felt that it was a very positive, warm, and gentle programme, in consistent with the findings of a previous iCBT study for depression and/or anxiety in cancer survivors (Alberts et al., 2018; Karageorge et al., 2017). Many survivors highlighted the need for improving access to iCBT programmes. They thought that the iCBT programme should be made available to all women. Survivors felt that if the programme is offered in oncology clinics around the country, many people could benefit from it. Such positive expression may suggest that the *Space in Breast Cancer from Depression and Anxiety* has significant potential to facilitate an easier transition for breast cancer survivors to life post-treatment and fill the deficiencies in psychological services in oncology.

One interesting theme under the affective attitude as well as personal and situational barriers to engagement was that some survivors did not have any expectations or had low expectations when they signed up for the programme. These survivors reported being unsure about the potential benefits of the programme; however, they were surprised at how beneficial it was for them. A possible explanation for this might be that the actual experience of using an intervention may have changed users' perceptions of the programme, as stressed by Sekhon et al. (2017). Another explanation could be due to the pilot nature of the clinical trial. Regardless of its reasons, this finding highlights the need for helping potential participants to have realistic expectations at the early phases of the study, as having no expectations or low expectations from the programme could have possibly contributed to a lack of motivation to engage with the programme and resulted in drop-out (Karageorge et al., 2017). One possible solution could be to set the expectations during the recruitment stage in future recruitment efforts by providing information regarding the effectiveness of iCBT programmes through information leaflets or social media posts. Another possible solution could be providing quotes from previous users of the programme. Participants' expectations could be understood at the recruitment stage through semi-structured interviews, which would allow the correction of any misinformation/misunderstanding as early as possible.

Although many survivors found the intervention beneficial and supportive even if they had completed their medical treatment years ago, some thought that it could have been even more helpful if they used the programme nearer their treatment completion time. This finding is consistent with the interview results of Study I, in which survivors reported that the programme would be more helpful if it is offered some time after the diagnosis or treatment completion. It is also consistent with the results of open-ended questions in the SAT questionnaire in Chapter 4, in which survivors reported that the programme would have been more helpful nearer treatment completion. Also in line with Study I findings, survivors in the present study believed that the

transition from medical treatment to 'normal' life was very stressful as the net of safety from the hospital was gone after treatment completion, and worries about recurrence and success of medical treatment started during that time. Participants' concerns regarding existing services focusing mainly on the medical treatment of cancer and lack of services addressing the psychosocial needs of survivors and carers are consistent with the existing literature (Fallowfield et al., 2001; Jacobsen & Jim, 2008). In line with this, a previous study indicated that the transition from the period of diagnosis and medical treatment to survivorship, also known as the re-entry phase (Mullan, 1984), comes with distinct challenges and can be psychologically disruptive for some cancer survivors (Stanton et al., 2005). These challenges include the expectations of others that the end of treatment should be celebrated, individual should recover soon after the treatment completion, should return quickly to their sense of self pre-diagnosis, and should no longer need support after treatment is over (Stanton et al., 2005), Unrealistic expectations of the others (e.g., family members and significant others) from breast cancer survivors following the treatment completion are consistent with the reports of the survivors in the present study.

In line with the quantitative and qualitative findings in Chapter 4, survivors perceived that the programme has achieved its purpose and was effective in helping them manage their distress. A previous study investigated the processes of change and the psychological experiences of users of the Space from Depression programme found similar findings (Richards, Dowling et al., 2018). They found that the programme provided awareness and insight, new coping skills/behavioural change, feeling supported/validated, self-efficacy/empowerment/sense of achievement, relief, improved well-being, and connection to users. Also, in line with the findings, another study (Bendelin et al., 2011) found that people who take responsibility for treatment and attribute success to themselves benefitted more from an iCBT programme for depression. However, improved communication with significant others was a novel finding in this study, which was not reported in the HAT or SAT

questionnaires in Chapter 4, and also considering the findings of previous iCBT studies with cancer survivors (Alberts et al., 2018; Karageorge et al., 2017). This difference could be explained by the carer access aspect of the programme or information on expressing feelings effectively, which was added during the adaptation process. This finding could also be an indirect effect of survivors' improved well-being as a result of the reduction in their distress.

A variety of beneficial aspects of the programme were identified by the survivors. Notably, all thought that supporter feedback was the key aspect and facilitator for their engagement and programme completion. Knowing they will receive feedback from a person who follows their progress motivated many survivors to engage consistently with the material and provided a better understanding and guidance throughout the intervention. Indeed, it encouraged them to engage with the programme even when they had significant life events such as diagnosis of partner with COVID-19. This finding is consistent with SAT and HAT findings in Chapter 4, and also with that of Alberts et al.'s qualitative study (2018), in which supporter feedback was reported as a critical motivating factor for cancer survivors who used an iCBT programme for depression and anxiety. It is important to note that many of our participants also stressed that the supporter feedback is vital, and in fact, they would have left the programme if they did not have a supporter.

Survivors also appreciated the private nature of the programme and non-judgemental feedback, which made them feel connected with their supporter. This finding is also in line with the results of an iCBT trial (Alberts et al., 2018), in which cancer survivors, who considered themselves as private, believed that the programme was a better fit than other treatment options such as cancer support groups. Unique to this study was the comparison of the programme with a face-to-face session with a psychotherapist or counsellor. Interestingly, survivors with a previous counselling or psychotherapy experience explained that they felt more comfortable opening up about their concerns to a 'faceless interface' than a person in face-to-face consultations. Bargh, McKenna, and

Fitzsimons (2002) suggested that some people can more easily express their true selves on the internet than face-to-face communication venues. Since it can be relatively anonymous, and the costs of disclosing negative or taboo aspects of self are reduced. This finding is critical as stigma about psychological care prevents many cancer survivors from seeking and accessing psychotherapy or counselling (Dilworth, Higgins, Parker, Kelly, & Turner, 2014) and expressing their concerns and problems openly to mental health professionals. As this was seen as a strength of the programme by many, privacy and non-judgemental feedback in the programme can be emphasized in future recruitment efforts. However, it is worth mentioning that, in line with the SAT results, a small number of survivors still desired some face-to-face interaction, as they found the interview with the researcher very helpful to reflect on what they have learned in the programme. Adding a real-time interaction with a supporter (e.g., Zoom or phone call) halfway through the programme and at the end could be incorporated in future studies as requested by the survivors. Enhancing the communication with the users during the intervention could also prevent the implementation problems (Rozenal et al., 2015). For instance, a call mid-treatment could provide an opportunity for participants to ask their questions regarding the use of some tools, for example, TFB Cycle and Mood Monitor, or discuss the possible negative effects of the intervention, if there are any. However, this would possibly require additional training for the supporters with no or little experience with the iCBT programmes.

The accessibility and flexibility of the programme were other helpful aspects of the programme for many survivors, which is in line with the SAT results in Chapter 4. The importance of easy access to the intervention was especially highlighted by those living in rural areas. Supporting this, research shows that individuals living in rural areas experiences distinct challenges as they have limited access to oncology and mental health services (Loughery & Woodgate, 2015). The programme's flexibility allowed survivors to work on the programme at their own pace and intensity

and also at a time and place suitable for them. Also, they felt less pressure than face-to-face therapy or counseling. Some also liked that the programme did not require them to get an appointment with a mental health professional since many of them have still felt tired, lacked energy, and found it hard to find a professional to get along well. These findings are in accordance with a previous study that indicated that patients liked the programme's flexibility as it allowed them to work at times working for them without requiring an appointment with a mental health professional (Alberts et al., 2018).

There were different contrasting opinions between survivors on some aspects of the programme. Specifically, while some survivors found personal stories, staying in the present exercises, and programme layout helpful, others found them less useful. To begin with, some of the survivors thought that personal stories were relatable and liked that they covered the stories of people from various backgrounds. In contrast, others did not find personal stories authentic and could not relate to them. These results are consistent with the HAT results in Chapter 4, in which personal stories were identified as both helpful and hindering events. This finding is consistent with findings in a previous study that used the SilverCloud platform for generalised anxiety disorder (Walsh & Richards, 2017). However, what is surprising is that some survivors in the present study also found personal stories upsetting as they acted as reminders of their own difficult times. A few survivors were triggered by the photo of a survivor with a turban and did not read the rest of the stories. Similarly, while most survivors reported enjoying listening to the mindfulness exercises as also reported in the HAT questionnaire, a small minority of the participants in the present study found them artificial and unhelpful and experienced more negative thoughts. This was somewhat surprising; however, supporting this, qualitative research found that mindfulness exercises may increase the awareness of difficult feelings and result in exacerbation of psychological problems (Farias & Wikholm, 2016). This was also the case for TFB Cycle; one of the participants found it painful to think deeply about her thoughts, feelings, and behaviours, and to become aware of them.

Negative experiences due to insight (memories, understanding, self-awareness, and knowledge) have also been reported in a large qualitative study examining negative experiences of 558 individuals who participated in four different iCBT trials (Rozental et al., 2015).

Regarding the intervention coherence, experiences of survivors varied from person to person. While some survivors commented favourably about the programme layout and found it easy to understand how the intervention worked, some others found the layout confusing and felt lost. For example, some participants were not sure how many pages were left to read in each module or whether they have completed the module or not. It could be possible that the navigation difficulties in the programme may also have contributed to this confusion. For some survivors, what is expected from them and how they can proceed with the modules and get the most benefit from it were not clear. Even though the information about the treatment rationale, duration, amount of time that should be spent on each module each week, and supporter feedback were explained in the information leaflet, many could not remember it. Survivors suggested that the inclusion of an introduction video summarizing the process and providing a more clear structure could clarify the treatment rationale and expectations from users, which could improve intervention coherence. Considering high rates of up to 67% of memory or concentration problems among breast cancer survivors (Jaremka et al., 2014), adding a video at the beginning of the programme could improve the intervention coherence and may enhance treatment completion rates. Moreover, adding a progress bar in the programme could also be considered to clarify the number of pages left to read in each module for participants in future studies.

Survivors identified important facilitators for their engagement with the programme that helped them complete it. Programme-related facilitators included supporter feedback, an evidence-based CBT approach, and an option to set reminders in the programme. While some survivors had previous experience with the CBT, others did not, but they heard about its benefits. Survivors

thought that the intervention had good fit with their value system; knowing that the programme is based on the CBT approach, scientific theories, and evidence motivated many to engage with the programme. This finding matches those observed in Chapter 4, in which survivors identified core CBT content and tools as helpful events. This finding is also consistent with what Karekla et al. (2019) previously recommended for best practices for digital interventions to improve engagement and adherence in people with chronic illnesses. They suggested that digital interventions should consist of theory-driven evidence-based psychological intervention content and convey a sense of trustworthiness, expertise, and credibility to the user. Research suggests that perceived credibility significantly predicts users' intention of revisiting a website (Hong, 2006). Providing further resources at the end of the programme could improve the perceived acceptability of the programme as requested by the participants in the present study. As Karekla et al. (2019) suggested previously, providing empirical references supporting the programme approach can give a sense of trustworthiness and credibility for its users.

The most important personal factors that provided an intrinsic motivation and facilitated engagement were survivors' readiness for change, seeing the benefits of the programme, desire to contribute to cancer research, and sense of achievement/ empowerment following the completion of exercises and modules in the programme. During the interviews, survivors emphasized that the timing was right for them to use the programme, as they needed something to improve their psychological well-being and were open to do the inner work. This finding implies that survivors' motivation for the change was an important internal factor influencing their motivation to engage with the programme material. As previously identified in the literature (Bendelin et al., 2011), users' motivation is the most important aspect of the guided iCBT interventions. In an iCBT study for generalised anxiety disorder in the general population (Walsh & Richards, 2017), seeing visible improvement was also reported as one of the facilitators for participant engagement.

Survivors also observed significant barriers for their engagement with the programme that must be addressed in the future delivery of the iCBT programmes for cancer survivors. Namely, filling out the HAT questionnaire at the beginning of each session was the most common barrier for many. The HAT questionnaire was also identified as a hindering event in Chapter 4. The questionnaire interrupted the access to supporters' weekly feedback and module content if they did not complete it and diminished survivors' enjoyment of the programme. Survivors thought that it required too much effort for them to remember what happened in the previous session. They found it unsuitable considering that many cancer survivors have memory problems and experience "chemo brain". Difficulties with concentration and "chemo brain" were previously reported by recent cancer survivors as mental barriers in Alberts et al.'s study (2018), although the HAT questionnaire was not used there. This finding is important, as the questionnaire increases the participants' cognitive burden and possibly decreases survivors' confidence that they could perform the behaviours required to participate in the intervention. It could be possible that the questionnaire impacted programme completion and drop-out rates; therefore, it should be removed or made optional in future studies.

In accordance with the SAT results in Chapter 4, difficulty navigating in the programme was another commonly reported barrier for survivors' engagement. Some survivors were not good with computers and found it hard to navigate through some pages and modules. However, this could not be only attributed to the limited computer literacy of the participants, as survivors who felt confident about using computers also thought that the navigation on the programme was not as smooth as they expected. In another study conducted using the SilverCloud platform, navigation problems were also reported as a barrier to engage with the programme material (Walsh & Richards, 2017). This finding suggests that future studies should investigate the factors making the navigation difficult in the programme and focus on improving it to provide a better experience for the users.

One unanticipated and critical finding is that survivors found it difficult to understand using some tools. For example, many survivors noted their difficulty in filling out the TFB Cycle and their frustration regarding it. It took many of them some time to get to grips with it, and some of them gave up. This was also in line with the intervention data, in which out of 25 participants who completed all the modules in the programme, 21 of them filled out the TFB cycle and shared with their supporter, 3 used the TFB but not shared it, and 1 never used it. Interestingly, out of those 21, only 9 attempted to identify and challenge their hot thought by examining the evidence supporting and against it, and only 7 were able to come up with an alternative/balanced thought. This finding supports survivors' difficulty to understand the TFB as a tool. This finding is critical as understanding the relationship between thoughts, feelings, behaviours, and physical reactions occupies a central place in the CBT and challenging unhelpful and negative thoughts is one of the core techniques in CBT (Beck, 2011; Padesky & Greenberger, 2020). Future studies must improve the understanding and implementation of the TFB cycle and coming up with more alternative/balanced thinking. Similarly, one survivor reported having difficulty setting goals at the start of the programme as she was not aware of what goals she can achieve by using the programme. Another survivor explained that she did not understand the rationale of the Mood Monitor until after she completed all the modules. Implementation problems associated with difficulties performing certain assignments that lead to sadness and greater distress have been observed in other clinical trials of guided and unguided iCBT (Rozental et al., 2015). One possible solution could be providing more guidance on how to use the TFB Cycle and Goal Setting, and clarifying the purpose of the Mood in future studies.

Survivors also identified some personal barriers such as reluctance to think, physical and mental fatigue, and lack of time for their engagement with the programme. The lack of time and busy schedule were also reported in the SAT and HAT results. Difficulties with finding time, concentration, and fatigue were also identified as barriers by recent cancer survivors in a previous

iCBT study (Alberts et al., 2018). The finding that the survivors identified 1-year access as helpful in the present study and in Chapter 4 could be explained by the lack of time, mental fatigue, and concentration problems. Although reluctance to think was not identified previously as a barrier for user engagement in the literature, avoidance behaviour was reported by service users of the digital mental health platform (Bucci, Schwannauer, & Berry, 2019). According to the cognitive perspective (Moorey & Greer, 2012), three processes may operate, namely cognitive avoidance, cognitive distortion, and affective avoidance, to prevent individuals from strong emotions when significantly distressing events happen. Survivors' reluctance to think about breast cancer and avoidance of reading personal stories, for example, could be interpreted as a form of cognitive avoidance. Although avoidance can be an adaptive strategy in the adjustment phase when feelings become too overpowering, in the long term reluctance to remain in contact with experiences may be unhelpful. Since survivors' attempts to control their thoughts and feelings may prevent emotional processing of the diagnosis, treatment, and its influence on their life, and possibly increase the intrusiveness of the experiences they are trying to avoid (Moorey & Greer, 2012). Providing this information in the programme content may be helpful for survivors who tend to use cognitive and affective avoidance as a coping strategy.

Finally, other life events and the impact of the COVID-19 pandemic were also seen as barriers by some survivors for their engagement and compliance. The effect of COVID-19 was also identified as a hindering event in Chapter 4. Some survivors in the current study reported their significant others became ill, and others found the required changes in their lifestyle difficult (e.g., family members working from home), which interrupted their engagement with the programme. A study conducted with the general population in Australia observed an initial increase in anxiety and concern about COVID-19 (Staples et al., 2020). It may be the case that the COVID-19 may have increased survivors' distress levels in Ireland and the UK, and motivated them to take part to learn

ways to cope with the distress. The pandemic could also have interrupted the engagement of users with the programme due to forced lifestyle changes that came with the COVID-19. On the other hand, there were also some positive aspects noted about the effects of the COVID-19 pandemic. Some survivors who finished their treatment many years ago found that the timing of the programme was good, as their fear of recurrence and concerns about the future started to increase during the pandemic.

5.2.5.2. Findings on Carer Access and Carer Involvement in iCBT Programmes

Although carer access was found acceptable for both survivors and carers in Study I, when an option was given, the majority of survivors preferred to participate alone without carer access. Many survivors thought that their carers would not like the programme and use it. This finding is interesting considering the positive attitude towards carer access in Chapter 2. When this preference was explored further, survivors provided various reasons, including carers' desire to move on and unwillingness to talk about feelings, and their lack of time. Survivors shared a common and frustrating experience that their carers want to forget about the breast cancer and move on after the medical treatment is completed. This is in accordance with the findings of a previous study (Thomas et al., 2002), which found that carers often felt that they had to be and often wanted to be strong and positive, tried to maximise the sense of 'life carrying as normal' to manage their own and other person's emotions. This pattern is in line with the findings of another study (Harrow, Wells, Barbour, & Cable, 2008), in which male partners of women diagnosed with cancer reported their desire to move on from cancer and focus on re-establishing normality after completion of medical treatment, despite struggling with the daily reminders of cancer and ongoing challenges they continue to experience in their lives. These findings could suggest that using a programme focusing on breast cancer-specific problems and concerns may not be suitable for carers, especially the ones

who have provided care a long time ago.

Fear of burdening loved ones was another reason for survivors not to ask their carers to get involved in this study. Previous studies in the literature also showed that fear of being a burden on the family is a common concern among breast cancer survivors (Ho, So, Leung, Lai, & Chan, 2013; Kornblith et al., 2006; McKiernan et al., 2010). Similarly, breast cancer survivors reported their desire to maintain normality and limit the impact of breast cancer on their significant others in another study (Fergus & Gray, 2009). Although survivors reported their need to be understood better by their carers and talk about their ongoing concerns with their partners and children in the present study and Study I described in Chapter 2, they were afraid of frustrating them and reminding them “the experience”. This is an important finding, as cancer survivors’ fear of being a burden can inhibit receipt of social support (Kornblith et al., 2006; McKiernan et al., 2010) and lead to emotional isolation (Kornblith et al., 2006).

Another interesting finding was that survivors wanted to have ownership in the programme as they needed to feel more in control of their situation and independent of their partners. In fact, many survivors explained that they had already shared some content they found helpful with their partners and daughters even though they did not give them access to the programme. This finding can be explained by survivors’ need to achieve self-efficacy and improve their confidence in their ability to manage cancer-related concerns by themselves (Gallagher et al., 2002). As previously highlighted in the study of Berg and Upchurch (2007), while maintaining autonomy and independence becomes more important in late adulthood, dealing with a chronic illness such as breast cancer may lead to increased dependency on the spouse for many individuals. For people with chronic illness, independence becomes more prominent in their “hoped-for selves: selves one wants to become”, as opposed to being dependent, which is part of their “feared-selves: selves one wishes to avoid becoming.” (Berg & Upchurch, 2007). It can be, therefore, possible that carer access

was seen as intimidating for survivors who wanted to retain their independence while using the programme.

Some survivors thought that carer access could be a potential source of distress. This is in line with the findings of Study I, where survivors reported that the impact of carer access depends on the relationship quality. Survivors thought that if their carers had been given access and they had not use or like it, it may lead to frustration and create conflict in their relationships. As highlighted previously by Karekla et al. (2019), while partners can be a source of social support and motivation to adhere to a digital intervention, partners can also be a potential source of distress, for example, if their involvement lead to communication problems. It is therefore possible that survivors did not want to be negatively influenced by their carers' potential disengagement with the programme and wanted to prevent potential distress during the intervention.

Survivors provided significant suggestions regarding the involvement of their social environment, including family members, partners, siblings, that must be considered in the future design of digital interventions. One important suggestion was that most survivors thought that carers should get a separate and personalised programme targeting their unique needs and concerns rather than using a programme focusing on survivors' concerns. This finding is somewhat unexpected as Study I showed that survivors and carers liked the idea of carer access to survivors' programme; carers also indicated their preference for access to survivors' programme as opposed to having a separate programme for themselves. This rather contradictory result may be due to the small sample size in Study I and direct questioning of participants' opinions on carer access rather than directing a more open-ended question exploring their opinions on involving carers in the design of digital interventions. Another possible explanation might be that carers are less likely to disclose their concerns than survivors; indeed, only 50% of carers with psychological difficulties seek help, as reported by Pitceathly and Maguire (2003). Therefore, even if they needed psychological support, it

is possible that they withhold this information during the interviews.

Another important finding was that survivors thought that a separate recruitment process for carers would be more suitable. Some survivors did not like that carers were recruited through them rather than by individual means. They thought that carers have a separate identity and should be viewed as separate agents from being a carer of someone. Survivors' suggestion to keep the recruitment of carers separate from themselves may be explained by the fear of identifying their significant others as "carers" which seems to conflict with carers' desire to move on and survivors' desire to regain or maintain independence and autonomy during their recovery. These findings suggest that a separate iCBT programme focusing on improving carers' psychological wellbeing could be more acceptable. Supporting this, a recent study revealed that informal caregivers were satisfied with a therapist-supported iCBT programme aiming to reduce caregiver burden and improve wellbeing (Biliunaite, Dumarkaite, Kazlauskas, Sanderman, & Andersson, 2021).

Some survivors thought that carers could also be involved by the addition of optional exercises for survivors and carers to complete together in the present version of the programme. Many survivors thought that it would be easier for them to ask their partners or spouses to do these exercises together compared to asking them to complete a 7-week programme. In line with the previous findings in Study I, in which survivors and carers emphasized the difficulty to start conversations with each other, survivors thought that exercises encouraging conversations or activities could be helpful. This is consistent with previous research, which suggested that partners can be involved in digital interventions via positively reinforcing successful interactions (Karekla et al., 2019). Doing some exercises together with their carers may encourage survivors and increase their engagement with the programme. Examples they provided include going for a walk together, have a conversation on a topic, or discussing what tools are effective. This finding may suggest that the current iCBT programme can possibly be improved by adding optional joint exercises for

survivors who have carers. Designing exercises positively reinforcing successful interactions between survivors and carers is an important aspect to consider in future studies aiming to involve the social environment of the survivors in the intervention.

Creating a scaled-down version of the programme was another option suggested by some survivors. Survivors thought that a 7-week programme might be quite intense and a brief version of the programme is more likely to work for carers who would like to get involved but have busy work schedules or ongoing caregiving responsibilities. However, some survivors thought that a brief version might miss important information included in the main programme. Informal caregivers found the 8-week iCBT programme suitable for their needs (Biliunaite et al., 2021). Future studies could evaluate whether a brief version of the programme would meet the needs of carers; this could be done by requesting carers to evaluate and compare full-version and a brief version of the same programme. Alternatively, carers could be asked how can the existing programme be shortened.

5.3. Part II: A Qualitative Study with iCBT Providers

5.3.1. Provider Experiences

Sekhon et al. (2017) stated that “acceptability is a necessary but not a sufficient condition for effectiveness of an intervention.” Since the successful implementation of an intervention depends not only on the acceptability to recipients (e.g., survivors) but also intervention deliverers (e.g., supporters, providers, researchers, healthcare professionals). For recipients, content, context, quality of feedback may influence an intervention’s acceptability. Recipients are more likely to adhere to treatment recommendations and have improved clinical outcomes if they consider it an acceptable intervention. On the other hand, providers may not deliver the treatment as intended if the intervention has low acceptability for its recipients, which could influence the overall intervention effectiveness. To fully understand the iCBT programme’s acceptability, it is also

essential to understand the experiences of supporters who provided weekly feedback to breast cancer survivors in the programme.

Qualitative surveys can provide adequate richness and depth and can be used to make sense of participants' subjective experiences, practices, and narratives (Virginia Braun, Clarke, Boulton, Davey, & McEvoy, 2020). A qualitative survey was preferred instead of semi-structured interviews to minimise the potential impact of the primary researcher's role as a supervisor on the supporters' responses.

5.3.2. Method

5.3.2.1. Participants

Participants were 10 female supporters, aged between 25 and 41 ($M= 26.40$, $SD= 5.36$), who provided weekly feedback to breast cancer survivors. All supporters received training and were master's level postgraduate students during their involvement in the study. Seven of them have been working as an assistant psychologist, one have been working as a rehabilitation assistant, one as a helpline practitioner, and one as a social care worker.

5.3.2.2. Materials

The supporter questionnaire included short open-ended questions evaluating what they liked most and least about being a supporter for breast cancer survivors, main challenges on the supporter role, what helped dealing with the challenges, what would have been more helpful to improve their experience as a supporter.

5.3.2.3. Procedure

After the completion of the interviews, a qualitative questionnaire evaluating supporters'

experiences with their role was prepared on Qualtrics. The questionnaire link was sent via email to all supporters after they completed the reviews with all of their clients.

5.3.2.4. Data Analysis

Online qualitative survey data were analysed using thematic analysis to describe supporter experiences. The same steps described in Chapter 2 was followed when conducting the analyses. It involved repeated reading of the data to understand it, identifying key concepts and patterns by coding, sorting the codes into themes, and then grouping and organizing emergent themes into meaningful categories, then defining and giving names to the themes.

5.3.3. Results

Six main themes and various sub-themes were identified.

Theme 1: Rewarding and Educational Experience

Providers, who are called a 'supporter' in the programme, found the supporter role as both rewarding and educational experience. Some found it challenging at the beginning as they did not have a similar online supporting experience before. However, all mentioned that they enjoyed being a supporter and learned much about the role, CBT and what it is like for someone who had experienced breast cancer to deal with anxiety and depression. As two supporters described:

"I really enjoyed being a supporter. I learnt so much more about CBT and breast cancer and I am very grateful for the experience." [P1]

"It was daunting at first but as I got more used to it, it was both rewarding and educational."

[P5]

Theme 2: Aspects of the Role Supporters Most Liked

2.1. Visible improvement/ Positive feedback from participants

Supporters found it very rewarding to hear the achievements and progress of the participants while using the programme. Receiving positive feedback and seeing that the participants benefiting from the programme provided a sense of achievement for many:

“I found it very rewarding when my clients would share achievements with me that they had experienced (related to what they had learnt doing the programme) when partaking in the programme.” [P1]

“The one thing I liked the most was the overall sense of reward. It was clear that a lot of women were helped from this program and that I was a little part of that.” [P3]

“I loved hearing client feedback, when they were happy with their supporter. It made it very rewarding and actually felt like I was helping someone for the first time in my career.” [P5]

2.2. Learning more about CBT and breast cancer

Supporters had different levels of knowledge and skills regarding the CBT and the psychological difficulties breast cancer survivors experience. However, all supporters thought that they deepened the knowledge of CBT and learned about breast cancer.

“Though I had some previous knowledges of CBT and the skills used within the programme, there was still a lot to learn in the beginning such as information around Breast Cancer and what challenges this can bring up for people. Also, the way in which the CBT skills are presented and utilised within the programme.” [P2]

2.3. Providing safe space/ Building rapport

Supporters felt privileged to hear stories of breast cancer survivors and being able to provide them support to open up about their difficulties and concerns. As one supporter explained:

“What I enjoyed most about being a supporter for a breast cancer survivor was providing a safe space for the survivors to open up about their difficult experiences. It was a privilege to hear their stories and struggles throughout the programme and to be able to offer some guidance on how to manage these challenges.” [P2]

Theme 3: Aspects of the Role Supporters Least Liked

3.1. Having to call clients

The least favourite aspect of the role for many supporters was having to call the clients. They found it stressful to call clients when the clients disengaged with the programme or when they did not fill out the post-assessment questionnaire. While many participants appreciated the calls from their supporters and got back to the programme or filled out the questionnaire, those who wanted to leave the programme might get frustrated with the follow-up calls. Not knowing how the person would react made it stressful to make the call for some supporters, as explained by two supporters:

“I found having to call clients a little stressful a times; not knowing how they would react to your call was a little nerve-wracking.” [P1]

“Calling Clients repeatedly. Some Clients do not appreciate the follow-up calls especially when they wish to disengage from the programme.” [P4]

Theme 4: Challenges of the Supporter Role

4.1. Time commitment

As supporters were also working full-time while working in the project, they experienced difficulties to find time to write their reviews and attend 1-hour weekly supervision meetings, as described by a supporter:

“Sometimes it was difficult to commit to supervision each week, and fit it in around a busy schedule including working full time.” [P7]

4.2. In-depth learning of the tools and content

Many supporters found it difficult to learn the programme content and tools in-depth, especially at the beginning. Although the content and the tools were explained in the training, some realised that they did not fully understand the tools in detail.

“I felt in the beginning that I didn't fully understand the tools/ modules and what was being asked of me as a supporter. This made the reviews difficult to write and sometimes took a long time.” [P2]

4.3. Working with disengaging clients/ drop-outs

Some supporters found it challenging to have clients dropping out from the programme or not engaging consistently with the programme material. For example, two supporters had only 1 client who completed the programme modules, and the rest of the clients engaged with only 1 or 2 modules. As one supporter described:

“Clients dropping out and not engaging was challenging for me personally” [P3]

4.4. Working with highly engaging clients

Supporters who had clients engaging with a lot of the material during the week and using a variety of tools found it difficult to keep their reviews concise and short. At the beginning of the role, they were tempted to respond to everything with a fear of leaving something important for the client behind and therefore the tendency was to write long reviews, which were time consuming. Similarly, some supporters found it challenging to respond to a personal information that a client shared. As three supporters explained:

“The part that I found most challenging and I suppose liked the least was having a week in which a survivor had a lot of different aspects that they brought up. It was difficult to form a review that both acknowledge all of their struggles but didn't over burden them in skills to try. Looking for the main 'theme' (if any) was challenging as I was conscious that I didn't want to leave any aspect out or undermine any aspect for the survivor.” [P2]

“The length of reviews - I always wrote them so long!!” [P9]

“The main challenge for me was knowing what to respond with when someone shared something very personal ...when someone said something that was affecting them out of the blue I felt like I was glancing over it at the start.” [P5]

4.4. Anonymity/Building relationship online:

Supporters also found it challenging to build a strong relationship online with a person they have not met face-to-face and without making a full assessment.

“Making that human connection strong even though you never met the person.” [P7]

"I suppose the anonymity of it. In my main job I see the clients in front of me and can get a wider view of how I can help. Here, I don't get to see the client as a whole or make an assessment of them as a person, but I guess that is limited since the role was to refer to the programme than give my own advice." [P9]

Theme 5: What Helped to Deal with the Challenges

5.1. Weekly supervision/ Feeling supported by supervisor

Supporters valued the weekly supervisions and felt supported throughout the process. They found it helpful to have a space to ask their questions and hearing other supporters' perspectives on the challenges of each other.

"The weekly supervision was brilliant! I found it a really supportive space to bring any issues I had experienced that week. Being able to talk about a specific challenge and gain other people's perspectives on how to respond to a particular point really beneficial. The peer-support in this way was also great. I felt we had a really supportive group and never felt judgement of my reviews." [P2]

Supporters also found it very helpful to focus on each tool in the programme, and discuss the possible scenarios and clarify how to help clients to benefit from each tool on their reviews.

"Supervision was very helpful especially when the tools were broken down and explained individually I found this to be extremely helpful and made me feel more confident in explaining the tools." [P6]

5.2. Setting time to finish reviews

Supporters found it helpful to set a time slot to write down all the reviews and reading once and making the necessary corrections before sending it. This helped them to deal with the overthinking and keep changing the review that they wrote.

“Setting out time slots where I had to finish reviews. Ensuring not to overthink the reviews too much; send them once I had read over them once.” [P1]

5.3. Having one or two clients at a time/ Spreading reviews over a few days

One supporter also found it helpful to have one or two clients at a time or spreading the reviews over a few days, rather than having them all on the same day; at the beginning they were spending more time on each review, which was putting more time pressure on them.

“I do think however having one or two clients at a time is a lot less stressful than having more at the one time. Perhaps spreading clients out over a longer period of time so that supporters have no more than one/two clients at a time could be helpful.” [P1]

Theme 6: Suggestions to Improve the Supporter Experience

6.1. In-depth work on tools before starting the role

Supporters found it very helpful to go through one tool each week. They thought that this prepared them well in terms of how to respond to a client who used the tool, and made them feel more confident in the role of a supporter. They suggested that it would have been more helpful if each tool was explained in more detail before they started the supporter roles. As two supporters described:

“I think going through each of the tools in detail before we had started may have been beneficial for the reviews. As there was a lot of information to take in at the beginning, it was

difficult to both pick out the main aspects of what survivors had presented and then to be able to give more in-depth support through the tools.” [P2]

“To spend time learning more about the tools at the beginning.” [P6]

6.2. Early access to client engagement before the review date

Another supporter thought that it may be helpful to have access to clients’ feedback and engagement with the programme one day before the review due date to give them more time to think about their feedback.

“Access to clients feedback/work a day before review is due. Reduces the pressure on supporters.” [P4]

6.3. Supervision every two weeks

While many supporters found weekly supervisions very helpful to deal with the challenges faced, one supporter suggested to have biweekly supervisions to reduce the time commitment pressure on the supporters:

“Cut supervision down to once every two weeks” [P8]

5.3.4. Discussion

5.3.4.1. Findings on Supporter Experiences

Six main themes and various subthemes were identified in relation to supporter experiences with the role. There were a number of important similarities between the responses of clients and supporters. Although supporters found the experience of providing support to breast cancer

survivors rewarding and educational, they found it difficult to understand some of the tools in the programme, such as TFB Cycle and Worry Tree. It is important to highlight that survivors also had difficulties with these tools. Therefore, it is possible that they could not provide helpful assistance on the use of tools to clients who could not understand how to fill out the TFB Cycle. Interestingly, even when supporters did not understand the tools in-depth, clients felt supported by their feedback and identified it as the most beneficial aspect and a key motivator for their engagement with the programme. This finding could suggest that receiving support from someone with little experience with CBT and its tools is still better than no support. Consistently, evidence in the literature suggests no significant difference between clinician-assisted and technician-assisted (non-clinician supervised by a clinician) internet-delivered programme for depression in the general population (Titov et al., 2013). Low-intensity CBT interventions use practitioners who do not necessarily have high-intensity CBT qualifications; however, they still require some core CBT skills to provide adequate assistance to clients (Bennett-Levy, Richards, & Farrand, 2010). Going through each tool during the supervision meetings helped supporters better understand the tools themselves and respond to clients who did not understand how to use them. As supporters suggested, future interventions would benefit from more intense training, where supporters could better understand each tool before starting their role. Considering most supporters lacked experience with CBT and working with mental health digital platforms, additional training focusing only on the use of tools could solve this problem and help supporters build confidence.

Similar to breast cancer survivors, supporters found it challenging to work full-time and commit to the supporter role at the same time. When they started their roles, many of them tended to spend about 1-hour to write each review. To reduce time spent writing the reviews, they found it helpful to set a time to write their reviews and read them only once before sending them. Moreover, some supporters found it difficult to write their reviews for clients who were not engaging well and

did not have much material to give feedback. Some also found it hard to write a review for clients engaging highly with the programme material, as they were inclined to address everything, which made it difficult to keep their reviews concise. Supporters thought that weekly supervision meetings, where they receive regular feedback and discuss their challenges with other supporters, helped deal with these difficulties. They felt being supported by the supervisor during the process. Contrary to survivors who found it surprisingly easy to build a rapport with their supporters, some supporters found it challenging to build a relationship online and with a person they never met.

Supporters liked receiving positive feedback from clients, hearing visible improvements noticed by the clients, and finding it very meaningful to provide a safe space for participants to share their concerns and difficulties. However, most supporters did not like making phone calls when their client did not engage with the programme for two consecutive weeks or did not complete the questionnaire. Some found it stressful, as they were uncertain about how the client would respond to their call. Even though following the call script alleviated the stress, additional training on making phone calls could be another solution to improve the supporters' confidence.

5.4. Study Strengths

The study has several strengths. First and foremost, the findings described and interpreted a rich collection of data and provided an understanding of the potential factors influencing the programme's acceptability, barriers, and facilitators to engagement, suggestions to further improve the programme. While survivors were grateful to take part in the intervention as they benefitted from it, they provided important suggestions to improve the programme that should be considered in the programme's update before evaluating its effectiveness with a larger sample. Some of the survivors could benefit from the removal of the HAT questionnaire or making it optional, the photo of a breast cancer survivor with a turban, the inclusion of work-related problems in personal stories,

additional information on how to use the main tools, an introductory video clarifying the research aims, and the process of using the programme, and smoother navigation in the programme.

Second, qualitative data and analyses not only provided insight into programme-related factors but also personal and situational factors that influenced participants' engagement. For example, being ready and motivated to change provided an intrinsic motivation for many survivors and made them more open to reflect on their experiences, even when it was painful to do so. This knowledge could be applied in future trials by evaluating participants' motivations for change and providing additional material to motivate those who are not yet ready before the programme start. In addition, our findings revealed that seeing the benefits of the programme and their progress encouraged many to complete the programme. This finding could be used to improve the users' motivation by helping them to see their progress more quickly. This could be done by supporters in their reviews or by adding tools for them to keep track of their progress, how close they are getting to the initial goals they set at the beginning of the programme.

Third, the qualitative survey provided important information on supporter experiences and challenges with their role. Coupled with the findings from survivor interviews, the information provided by supporters gave information on how to improve experiences of both. To clarify, while supporters found it difficult to comment on the use of some tools such as TFB Cycle, Mood Monitor, Worry Tree on their reviews, survivors also found it difficult to comprehend and use these tools. This could suggest that supporter training that includes more in-depth work on the tools may enhance supporters' confidence in giving feedback on particular tools, which is also likely to improve users' experiences with the programme.

Fourth, carer access to the same iCBT programme through survivors did not seem to be an attractive option for everyone, which was evident in Study III. However, the findings of the present study contributed to the understanding of reasons why carer access was not preferred by many. The

findings showed that there were both process and content issues in relation to carers' involvement. About process-related issues, survivors did not like that carers were recruited through survivors as they did not want to burden carers with additional responsibilities and remind them of the 'breast cancer experience.' Content issues included the unsuitability of the programme content for carers' unique needs. In the light of the lessons learned about carer involvement in this study, future studies could benefit from recruiting carers separately and providing a programme addressing their unique needs rather than focusing mainly on survivors' problems and concerns.

5.5. Study Limitations and Future Research

The findings must be interpreted with caution due to their limitations. First of all, the interviews were conducted with survivors who completed all seven modules in the programme. Therefore, survivors participated in the interviews might be more positive about the programme, and the findings may not reflect the perspectives of non-completers. Future research could benefit from evaluating perspectives of participants who did not complete all programme modules, and dropped out at the different stages of the iCBT programme. Secondly, this study, unfortunately, could not involve carers' perspectives as carers who were given access either did not sign up for the programme or did not use it to the extent to provide feedback. Given that alternative ways of involving carers were suggested by survivors, caution must be applied, as the findings do not reflect carers' perspectives. As Karekla et al. (2019) suggested, tailoring and matching the needs of two people can be tricky for digital interventions. Future research exploring carers' perspectives on the programme's acceptability and alternative ways of their involvement is therefore essential to inform digital health interventions exploring ways to incorporate individuals' social environment in the oncology context. Thirdly, survivors were interviewed by the principal researcher of the project, who adapted the programme content and designed the study, which may have influenced responses of

participants. However, the interviews were conducted by the principal researcher considering her extensive understanding of the iCBT programme and its various aspects. This could be considered as a strength of the data collection process, as skilful interviewing is necessary to facilitate a richer discussion and elicitation of the data necessary for the in-depth data analysis process (Connelly & Peltzer, 2016). Finally, supporters in the present study did not have previous experience with CBT. Therefore, providers with previous experience in CBT might have different experiences with the supporter role.

5.6. Conclusions

This study provided important insight into the factors influencing an iCBT programme's acceptability, provided suggestions to improve the programme, and provided alternatives to incorporate carers in the iCBT programmes. Gaining an in-depth understanding of these factors could improve users' experience in future digital health interventions in the oncology context. Moreover, supporters' experiences of using an iCBT programme provided an important deficiency in their training, which could have impacted survivors' use of certain tools and engagement with the programme. The findings suggest that further practices with the tools are required in the training process of supporters with little or no previous experience with the iCBT programmes. One of the future aims could be to further improve the iCBT programme for breast cancer survivors by following the suggestions mentioned above. Further research, however, is required with a large sample of carers to gain an in-depth understanding of their needs and perspectives on the alternative ways recommended for their involvement. Taken together, the findings suggest that the 7-week novel iCBT programme can be an acceptable option for breast cancer survivors to facilitate the transition from medical treatment to life after treatment and help them recover.

CHAPTER 6

General Discussion and Conclusion

6.1. Introduction

This chapter aims to provide general discussion of the thesis' main findings and conclusion. It starts by summarising the key findings then, it discusses theoretical implications, key clinical and practical implications, and highlights the distinct contributions of the studies conducted. Finally, it describes the key strengths and limitations of the thesis and provides an overall conclusion.

6.2. Key Findings from Thesis

This thesis consisted of four studies, one of which was the adaptation, and has identified various key findings. The interviews findings (in Study I) supported the lack of psychological services addressing the psychosocial needs of breast cancer survivors after completing medical treatment. Survivors were positive about using an iCBT programme and identified various motivators to use it, including their need for psychological support shortly after the diagnosis and completion of medical treatments. Other motivators included need to have access to a moderated and reliable platform characterised by helpful content, privacy, easy access and flexibility, and with human support provided during the programme. Survivors and carers thought that the lack of time, need for a "cancer break", and limited technological abilities for those over 60 could be the potential barriers to using an iCBT programme. They thought that carer access could suit the needs of survivors and carers; it may help carers understand survivors better and encourage open communication between them. However, there were also concerns regarding the impact of carer access since it could create further conflict between survivor and carer in problematic relationships. In line with this, many of the survivors who participated in the RCT (in Study III) preferred participating without carer access to

avoid potential distress resulting from carers' disengagement with the programme and not to burden their carer. Survivors also provided reasons such as thinking that their carer would not like or use the programme due to their desire to move on, carers' unwillingness to talk about their feelings, and lack of time. In addition, regardless of their preference, some survivors shared important things they learned from the programme with their carers. Survivors suggested other ways to include carers in iCBT programmes, such as a separate personalised programme designed for carers addressing their unique needs, having optional joint exercises in the survivors' programme that could be done with carers, and offering a less intense, scaled-down version of the programme for carers. These suggestions contrasted with Study I findings, in which carers expressed a preference for access to survivors' programme rather than having a separate programme. Considering the small sample size in Study I, it was concluded that this needs to be further investigated with a larger sample of carers.

The findings of the pilot RCT supported the effectiveness of the newly adapted programme for reducing distress symptoms, with significant effects maintained up to 2-month follow-up. More than half, 55.6%, of the clinically distressed survivors in the iCBT group had achieved a reliable recovery from distress at post-intervention compared to 8% recovered in the control group, suggesting that the adapted programme leads to clinically meaningful decreases in survivors' distress. Of note, none of the survivors in the iCBT group had clinically reliable deterioration at post-intervention and 2-month follow-up. However, 2 control group participants had deterioration at post-intervention and follow-up.

Survivors who used the iCBT programme were highly satisfied with the programme and thought that it would have a long-lasting effect. They identified various helpful events, such as supporter feedback, core CBT content and tools, mindfulness, long-term access, and personal stories, some of which was also reported during the post-iCBT interviews outlined in Chapter 5. The

results of the HAT on the helpful impacts and interview findings had some overlaps. Both found that survivors felt understood, supported, and validated, gained self-awareness, insight, and reflection, and recognised improvement in their mood and well-being, and felt more in control of their mood. Other findings consistent across the HAT questionnaire and interviews were regarding the hindering events. The HAT questionnaire itself was reported by many survivors as an unhelpful aspect for the users. Similarly, navigation problems, having a busy schedule and impact of COVID-19, psychological factors (feeling negative) and physical factors (fatigue and sleep problems) were other events that were identified as hindering and being barriers to participants' engagement.

The findings of the interviews post iCBT provided distinct and more in-depth information regarding the user experiences and ways to improve the programme further. In line with the therapeutic aims of the programme, survivors reported learning new coping skills to manage their distress, gaining self-awareness and insight, increased sense of control over their problems and recovery, processing suppressed feelings, feeling calmer and relaxed, prioritising themselves over others, and improved communication with significant others. Most importantly, survivors stressed their need for examples and guidance for the tools such as TFB Cycle, Mood Monitor, and Worry Tree. They found the TFB cycle particularly difficult to fill out. This was critical as it occupies a central piece in CBT and is one of its core techniques. Interestingly, the supporters also reported the need for in-depth learning of the same tools. Survivors also suggested including further resources (e.g., websites, books) at the end of the programme. They expressed a desire for the programme for being widely available in oncology clinics, and thought that it would have been more helpful if it was offered near treatment completion. They also wished that they had more time to complete the programme in the supported mode, and face-to-face contact half-way through the intervention. Survivors also suggested to fix the navigation problems and inclusion of a video at the beginning of the programme providing information about the research and expectations from users.

6.3. Theoretical Implications

The findings of the studies in this thesis make several contributions to the expanding field of internet interventions for breast cancer survivors and cancer survivors in general. There are certain theoretical implications and contributions to the digital health interventions and chronic illnesses literature.

The extended stress-coping model for chronic illnesses (Maes et al., 1996) was considered when developing the hypotheses of the RCT. The model suggested that different factors such as external and internal resources, and emotional and cognitive responses that determine the coping behaviour of the person dealing with a chronic illness, which is associated with psychological, social, and physical outcomes. Based on the model, we expected that the iCBT programme can encourage the use of more active and problem-focused coping and less avoidant and maladaptive coping, with the CBT skills introduced, such as behavioural activation and cognitive restructuring techniques. Thus, we hypothesised that the iCBT group would use more active and problem-focused coping and less avoidant and maladaptive coping than the control group at post-intervention. In addition, based on the stress-coping model we expected that the increase in the use of active coping behaviours and decrease in avoidant coping behaviours may explain the improvements in psychological distress, if any. Therefore, we hypothesised that a reduction in distress symptoms of the iCBT group would be mediated by the change in active and avoidant coping behaviours. However, contrary to the expectations informed by the stress-coping model, no group-by-time interaction or mediating effects were found for active coping or avoidant coping behaviours. Therefore, the hypotheses were rejected. These findings suggest that the reduction in survivors' distress post-intervention cannot be explained by the changes in their coping behaviours, rejecting the applicability of the stress-coping model in the present sample. As discussed in Chapter 4, the non-significant interaction and mediation effects for avoidant coping could be explained by the low reliability of the measure. The

non-significant interaction and mediation effects for active coping could be explained by survivors' greater use of active coping behaviours at baseline. As discussed earlier, these non-significant effects may also be because of the small sample size reducing the statistical power to detect potential significant effects.

Despite the non-significant between-group effects on active and avoidant coping, the qualitative findings indicated that survivors gained new skills and techniques to manage their distress and had improved communication with significant others. This might suggest that the iCBT intervention improved particular coping techniques that the Brief COPE scale did not measure. The non-significant effects on coping behaviour may also suggest that there may be other variables that were not included in the present thesis that explains the underlying mechanisms of change in psychological distress. Considering the extended stress-coping model and cognitive-behavioural theory, future studies should go beyond looking at the behavioural processes and investigate the effects on the cognitive processes, such as secondary cognitive appraisals. For example, receiving the iCBT intervention can lead to greater secondary appraisal of self-efficacy and confidence in survivors' ability to cope with their distress. This is also supported by the findings of the interviews outlined in Chapter 5, in which users reported increased sense of control over their problems and recovery. A meta-analysis of clinically controlled studies evaluating the emotional outcomes and mechanisms of change in online CBT interventions indicated that cognitive factors are important mechanisms of change in online CBT interventions (Mureşan, Montgomery, & David, 2012). Another study reported that of the 37 studies reported, only two conducted mediation analyses and found significant effects (Mogoş, Cobeanu, David, Giosan, & Szentagotai, 2017). One of them found that the positive beliefs about rumination (Newby, Williams, & Andrews, 2014), and the other found the dysfunctional attitudes, worrying, a negative problem orientation, and perceived control mediated the effect of iCBT on depressive symptoms (Warmerdam, van Straten, Jongasma, Twisk, & Cuijpers,

2010). Future research studying the underlying mechanisms of change in the iCBT programme could investigate the mediating effects of these variables.

Based on the extended stress-coping model (Maes et al., 1996), external resources, such as perceived social support, improve the psychological well-being of people with chronic illness. We expected that providing carers access to the same intervention could improve survivors' perceptions of support and increase the impact of the iCBT programme further by resulting in lower psychological distress. Therefore, the study design was planned such a way to explore whether carer access to the iCBT intervention results in further improvements in survivors' perceived social support and psychological distress than the iCBT alone group. However, due to the small sample size in the iCBT with carer access group we could not explore the possible differences. Future digital interventions for people with chronic illness that investigates the effect of the inclusion of social environment on psychosocial outcomes of users can test the utility of the stress-coping framework.

6.4. Key Clinical and Practical Implications

The findings of the thesis have meaningful clinical and practical implications. The results showed the acceptability and preliminary effectiveness of the novel iCBT programme in reducing the distress symptoms of breast cancer survivors, with beneficial effects maintained up to 2-months. Survivors were also highly satisfied and engaged with the programme, with an average of 4 hours and 20 minutes spent in total. These findings suggest the value of conducting a larger trial in Europe with a waiting-list control group. If proven effective, the programme could be offered as an easily accessible and effective alternative for breast cancer survivors who completed their medical treatment but do not have access to psychosocial services or are on the waiting list for face-to-face treatment.

The iCBT intervention resulted in statistically significant reductions in distress at 2-month

follow-up; however, the reductions were non-significant at post-intervention. The non-significant reductions turning to significant reductions at 2 months post-intervention may be explained by the skills developed and built over time with the practice of the modules and tools. Supporting this explanation, survivors mentioned re-reading the programme material and practicing the tools during the interviews conducted post-intervention. Padesky and Greenberger (2020) underlined that positive outcomes in CBT could only be achieved by clients' active participation in practising the skills, and change is unlikely to occur without this type of engagement. The findings may suggest that skills practice is also necessary for positive outcomes in the iCBT interventions and similar to face-to-face CBT.

The qualitative findings revealed that survivors need recognition of their psychosocial needs post-treatment and normalisation that the recovery takes time. Survivors felt pressure to feel 'okay' after treatment completion despite feeling negative emotions, which was one of the reasons that prevented them from processing their feelings and starting their psychological recovery. Given under-recognition of distress by oncologists (Fallowfield et al., 2001; Söllner et al., 2001) and male partners' desire to move on from cancer after medical treatment completion (Harrow et al., 2008), it is imperative to inform carers about the long-term psychological impact of breast cancer diagnosis and treatment on cancer survivors. Although the aim of the carer access was to inform and educate carers on the distress experienced by survivors, the low preference for carer access did not allow it. Another way of doing this could be to provide a brief training to oncologists to inform carers on the psychological impact and help them acknowledge the recovery as a non-linear process. This could help survivors accept their negative emotions, and also encourage more open communication between survivors and carers.

This thesis included the first study investigating the acceptability of carer access and inclusion in digital health interventions for people living with chronic illness. However exploratory, it

may offer some practical insight into whether and how carers can be included in digital interventions targeting a population with chronic health conditions. As discussed in Chapter I, the beneficial impact of greater carer support (Manne, 1999; Manne et al., 2014; Holmberg, Scott, Alexy, & Fife, 2001; Segrin et al., 2007; Sormanti & Kayser, 2000; Templeton, 2008) and open cancer-related communication with carers (Li & Loke, 2014; Manne et al., 2006; Tiete et al., 2020; Yu & Sherman, 2015) on cancer survivors' psychological distress is well known. Therefore, we aimed to improve perceived social support and cancer-related communication by providing carers access to survivors' programme through a separate login. However, carer access was not preferred by the majority of the women. Survivors three main suggestions: a separate programme designed for carers, optional joint exercises to be included in the adapted programme, and a brief version of the adapted programme. Based on these, it is important that future studies focus on differentiating carers who need a separate iCBT programme addressing their own psychosocial needs and those who need to understand survivors better and view carer access as sufficient.

The interview findings also contributed to the existing knowledge of women's difficulty to communicate openly about their breast cancer-related concerns. The majority of the survivors in the present study did not tell their carers about the study. Even if they did, many did not tell about the carer access aspect of the programme. Survivors provided reasons, which were in line with the literature, such as (1) carers' desire to move on, unwillingness to talk about their feelings, lack of time, (2) not to burden their carer, (3) to have ownership, and (4) carer access being a potential source of distress.

Furthermore, the qualitative findings demonstrated that breast cancer survivors had a positive experience with programme, they found it warm and gentle, which adds to the recently developing body of qualitative research with cancer survivors, investigating the acceptability of iCBT programmes (e.g., Alberts et al., 2018; Karageorge et al., 2017). Survivors' experience with the

programme was largely positive in line with the previous study (Alberts et al., 2018). However, they shed new light on the ways to improve the programme further. For example, the finding that some survivors reported not having any expectations at the start of the programme and being unsure about the potential benefits provides important practical implications. This indicates the need for providing clear information about the study, and its potential benefits at the early stages. Likewise, the HAT questionnaire being a barrier for survivors was unexpected as the previous studies that used the HAT in a population without chronic illness did not report such an issue (e.g., Richards, Dowling, et al., 2018; Richards & Timulak, 2012). This highlights the importance of carefully selecting the questionnaires during the adaptation of healthcare interventions considering the distinctive characteristics of the new target population (Movsisyan et al., 2019).

Finally, exploring both survivors' and supporters' experiences documented a common difficulty on the programme tools. When updating the programme, we need to revise the explanations provided for the use of programme tools, and the training should be expanded with more focus on how to provide feedback to users interacting with the particular tools. Such revision in the content and the training process would improve user and provider experiences, programme acceptability, and increase the chances of successful implementation, as proposed by Sekhon et al. (2017).

6.5. Strengths of Thesis

There are several strengths of the thesis. Qualitative interviews conducted at the beginning of the project provided insight into the need for and acceptability of iCBT programmes for breast cancer survivors from two different perspectives. It is the first study that explored survivors' and carers' perspectives on the acceptability of carer access to an iCBT programme. The interview findings were used to inform the adaptation of the intervention. It informed the timing of the

intervention delivery (after the treatment completion), content (information on how to express feelings was added), and structure of the intervention (carer access was made optional).

The novel iCBT programme was systematically adapted using an integrative approach that combined the most important steps suggested by three adaptation frameworks for the evidence-based psychological interventions (Card et al., 2011; Escoffery et al., 2019; Movsisyan et al., 2019), with the findings from the interviews with survivors and carers, and using breast cancer and digital health intervention literatures. The new content was evaluated by two experts in CBT, and a breast cancer survivor was involved in the evaluation of new personal stories in the programme. The iCBT intervention was specifically tailored for breast cancer survivors. Beatty et al. (2016) argued that more personalised interventions are more desirable and may lead to greater levels of adherence, which may also explain high engagement and adherence in the current study.

The programme was guided with feedback provided by supporters, who were applied masters level psychology students and received two trainings, one of which focused on the use of SilverCloud Health platform and the role of a supporter, and another focused on psychological impact of breast cancer and use of CBT for people with cancer. Supporters received weekly supervision provided by the researcher and supervisor. The supervision aimed to encourage supporters provide an effective post-session feedback that build trust with the user, create a sense of expertise, effectively manage user expectations, and facilitate the individual in defining and reaching their own goals.

The sample of the RCT consisted of individuals with diverse demographic characteristics (e.g., age ranging from 28 to 74) and health-related characteristics (e.g., with stages of breast cancer, treatment completion time varied between 0 and 220 months), increasing the generalisability of the findings across breast cancer survivors with different characteristics.

The acceptability and effectiveness of the intervention were investigated using a mixed

method approach that consisted of quantitative methods comparing pre-, post-, and 2-month follow-up as well as semi-structured interviews conducted with users and providers. The mixed method approach enabled findings to be verified and corroborated, providing a detailed and comprehensive understanding of the programme effects. The quantitative study showed the preliminary effectiveness and satisfaction with the programme. The interview findings contributed to our understanding of user and provider experiences, and provided suggestions that will prove useful in improving the iCBT programme further in future research.

6.6. Limitations of Thesis and Suggestions for Future Research

In interpreting the findings of this thesis, it is important to acknowledge the limitations. The major limitation of Study I was the small sample size, although the data reached saturation. A total of eight participants, five female survivors and three carers, participated in the interviews. Despite the limited number of informal carers, it was fairly representative, given the variety of individuals with different roles (e.g., partner, daughter, and friend). Mason (2010) suggests that factors other than the sample size, such as the interviewer's skill, affect the quality of data collected and determine the data saturation. Future qualitative studies aiming for larger samples could consider collaborating with hospitals and oncology clinics for the recruitment. The time limitations in the present study did not allow it. Another limitation is that during the interviews in Study I, participants were asked if giving carers access to an iCBT programme would be acceptable and how it would affect them. Not using broad questions may have biased the responses of the participants. Future qualitative research using broader questions such as "Should carers be included in iCBT interventions? If so, how carers can be included in iCBT interventions?" could decrease the possibility of biased responses.

The major limitation of the adaptation described in Study II is that one crucial step in the

preparation phase suggested by Movsisyan et al. (2019) could not be followed due to the project's limitations on time and financial resources. The establishment of networks, capacity, and infrastructure could not be done, which could have improved the programme's reach and the sample size of the RCT (Study III). Although the primary researcher attempted to build networks by reaching out to psycho-oncologists, oncologists, and charities, it was not easy since hospitals and charities wanted to prioritise advertising their own research. Future research could benefit from collaborating with hospitals and charities at the earlier stages. Another major limitation was not exploring any carers' perspectives for evaluating the adapted material and the acceptability of including carers through survivors.

There are a few limitations in the pilot RCT (Study III) to be considered when interpreting the findings. One is the relatively small sample size, limiting the generalisability of the findings. The small sample may also have limited the ability to obtain statistically significant intervention effects on the secondary outcome measures and mediation models. Another is the low reliability of the avoidant measure, which may have attenuated the observed effects on the LMM and mediation models. Moreover, the small sample size in the iCBT with carer access condition did not allow for three group comparisons (iCBT alone, iCBT with carer access, and TAU control) as planned in the protocol paper (Akkol-Solakoglu et al., 2021). However, this resulted from the pragmatic nature of the trial, evaluating the effects of the iCBT with carer access in an exploratory manner rather than confirmatory hypothesis testing.

Furthermore, the effectiveness findings cannot be generalised to all breast cancer survivors as the survivors in the RCT had moderate levels of distress symptoms at baseline. In addition, the majority of the sample had a high level of education and no other medical problems. Only one participant had Stage 4 breast cancer. These sample characteristics limit the generalisability of the findings. The long-term effects of the intervention are still unknown as the study had to be ceased at

a 2-month follow-up due to time restrictions. Therefore, questions remain regarding the maintenance of the observed improvements of the iCBT group in the long run. Further research is needed to explore the programme's long-term effectiveness with at least 1-year follow-up period to indicate whether the effects are lasting.

Finally, the major limitation of Study IV is the lack of interviews with carers. Although carers were invited, none of the carers contacted responded to the researcher. The interview findings regarding the alternative ways of including carers in iCBT interventions must be interpreted with caution as they reflect only survivors' perspectives, and carers may not agree. Future qualitative research with carers is required to investigate whether alternative carer inclusion options recommended by survivors are acceptable for them.

6.7. Conclusion

In conclusion, the newly adapted, 7-week guided iCBT programme demonstrated acceptability and preliminary effectiveness in reducing psychological distress in breast cancer survivors who completed their active medical treatment and were cancer-free. Given the under-recognition of psychological services and lack of mental health clinicians to support breast cancer survivors who completed their medical treatment, the iCBT has the potential to ease the adaptation to life after treatment and alleviate the psychological burden on many breast cancer survivors. This research showed that acceptability and effectiveness of Inclusion of carers in digital health interventions require further research. One future aim could be to update the programme content based on the users' suggestions and extend the supporter training to further improve the programme's acceptability before evaluating its effectiveness with a broader sample. Another aim could be to conduct interviews or focus-groups with a large sample of carers to explore the acceptability of the survivors' suggestions regarding their inclusion.

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Appendices

Appendix A. Ethical Approval Letters

Chapter 2

F.A.O. Selin Akkol-Solakoglu
Approval ID: SPREC102018-23

School of Psychology Research Ethics Committee

20th December 2018

Dear Selin,

The School of Psychology Research Ethics Committee has reviewed your application entitled "Perceptions of Online Support- Women with Breast Cancer and Their Partners" and I am pleased to inform you that it was approved.

Adverse events associated with the conduct of this research must be reported immediately to the Chair of the Ethics Committee.

Yours sincerely,



Richard Carson
Chair,
School of Psychology Research Ethics Committee

Chapter 4 and 5



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin

Ollscoil Átha Cliath | The University of Dublin

F.A.O. Selin Akkol-Solakoglu

Approval ID: SPREC022020-09

School of Psychology Research Ethics Committee

15th July 2020

Dear Selin,

The School of Psychology Research Ethics Committee has reviewed your application entitled “Acceptability and Effectiveness of an Adapted Internet-Delivered Cognitive Behavioural Therapy Intervention for Mild to Moderate Depression and/or Anxiety in Women with Breast Cancer and their Main Carers”, and I am pleased to inform you that it was approved.

Please note that you will be required to submit a completed **Project Annual Report Form** on each anniversary of this approval. Copies of the form are available for download from the Ethics section of the School website.

Please note that you must be familiar with and adhere to the attached ‘Safety Protocol for Adults’.

Adverse events associated with the conduct of this research must be reported immediately to the Chair of the Ethics Committee.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Richard Carson'.

Richard Carson
Chair,
School of Psychology Research Ethics Committee

Appendix B. Information Leaflets

Chapter 2

Survivor Information Sheet

The Suitability of Internet-Based Psychological Support Programmes for Breast Cancer Patients and Main Carers

Dear participant,

This study is conducted by Selin Akkol-Solakoglu, who is a Ph.D. Research student in the School of Psychology at Trinity College Dublin. The study is supervised by Prof. David Hevey. The aims of the study are to gain a deeper understanding of the breast-cancer related experiences of women, suitability of internet-based psychological support programmes for women with breast cancer themselves, and also women's opinions on whether giving main carers access to patients' internet-based programme would be beneficial for main carers to understand patients' needs. The data collected from this study will be used in the development of a psychological support programme specifically tailored for the needs of women with breast cancer and their main carers.

The study involves a short questionnaire about your background and an interview It will take about 1 to 1,5 hours. Interview will be audio recorded for the purposes of research. However, all personal information provided throughout the study will be kept confidential in line with GDPR 2018. The study may be written up for publication or presented at conference, but your names will not be used and you will not be identified as an individual in our reports. Confidentiality may be broken in circumstances in which;

Confidentiality may be broken in circumstances in which;

- The research team has a strong belief or evidence exists that there is a serious risk of harm or danger to either the participant or another individual. This may relate to issues surrounding physical, emotional and/or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity.
- Disclosure is required as part of a legal process or Garda investigation. In such instances, information may be disclosed to significant others or appropriate third parties without permission being sought. Where possible, a full explanation will be given to the participant regarding the necessary procedures and also the intended actions that may need to be taken.

Participation in this study is completely voluntary. You can withdraw for any reason, without penalty or consequence up until the interview has been transcribed. No identifying information will be

recorded as part of the interview. After the interview has been transcribed, the audio recording will be destroyed and your data will be anonymous. Consequently, as the data will be anonymous, you will not be able to access your own personal data under the Freedom of Information legislation. As the interview recording will be transcribed the day after interview, then you must contact the researcher within 24 hours after the interview if you want to withdraw from the study. Your data will be kept in accordance with GDPR 2018 regulations.

If you would like to obtain further information about the study, please email Selin Akkol-Solakoglu at akkolsos@tcd.ie

Selin Akkol-Solakoglu, Ph.D. Student

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: akkolsos@tcd.ie
Phone number: (01) 896 3913

Prof. David Hevey

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: heveydt@tcd.ie
Phone number: (01) 896 3914

Carer Information Sheet
*The Suitability of Internet-Based Psychological Support Programmes
for Breast Cancer Patients and Main Carers*

Dear participant,

This study is conducted by Selin Akkol-Solakoglu, who is a Ph.D. Research student in the School of Psychology at Trinity College Dublin. The study is supervised by Prof. David Hevey. The aim of the study are to gain a deeper understanding of the main carers' experiences about breast cancer diagnosis and to understand their opinions on whether giving main carers access to patients' internet-based programme would be beneficial for them to understand patients' needs. The data collected from this study will be used in the development of a psychological support programme specifically tailored for the needs of women with breast cancer and their main carers.

The study involves a short questionnaire about your background and an interview It will take about 1 to 1,5 hours. Interview will be audio recorded for the purposes of research. However, all personal information provided throughout the study will be kept confidential in line with GDPR 2018. The study may be written up for publication or presented at conference, but your names will not be used and you will not be identified as an individual in our reports. Confidentiality may be broken in circumstances in which;

- The research team has a strong belief or evidence exists that there is a serious risk of harm or danger to either the participant or another individual. This may relate to issues surrounding physical, emotional and/or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity.
- Disclosure is required as part of a legal process or Garda investigation. In such instances, information may be disclosed to significant others or appropriate third parties without permission being sought. Where possible, a full explanation will be given to the participant regarding the necessary procedures and also the intended actions that may need to be taken.

Participation in this study is completely voluntary. You can withdraw for any reason, without penalty or consequence up until the interview has been transcribed. No identifying information will be recorded as part of the interview. After the interview has been transcribed, the audio recording will be destroyed and your data will be anonymous. Consequently, as the data will be anonymous, you will not be able to access your own personal data under the Freedom of Information legislation. As the interview recording will be transcribed the day after interview, then you must contact the researcher within 24 hours after the interview if you want to withdraw from the study. Your data will be kept in accordance with GDPR 2018 regulations.

If you would like to obtain further information about the study, please email Selin Akkol-Solakoglu at akkolsos@tcd.ie

Selin Akkol-Solakoglu, Ph.D. Student

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: akkolsos@tcd.ie
Phone number: (01) 896 3913

Prof. David Hevey

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: heveydt@tcd.ie
Phone number: (01) 896 3914

Chapter 4 and 5

Participant Information Leaflet

Name of Study: Acceptability and Effectiveness of an Adapted Internet-Delivered Cognitive Behavioural Therapy Programme for Mild to Moderate Depression and/or Anxiety in Women with Breast Cancer and Their Main Carers

Female breast cancer survivors in Ireland and the UK are being invited to take part in a research study that is being done in Trinity College Dublin. Their main carers (such as a spouse, family member, or friend who provides support) will also be invited to take part based on the survivor's preference. This study is conducted by Selin Akkol-Solakoglu, who is a Ph.D. candidate in the School of Psychology, for the purposes of obtaining a Ph.D. degree in Psychology funded by the Trinity College Dublin Postgraduate Research Award. This study has been approved by Trinity College Dublin Research Ethics Committee on 15 July 2020.

Before you decide whether or not you wish to take part, please read this information sheet carefully. Please feel free to ask Selin Akkol-Solakoglu if you have any questions about the study. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your carer, family, friends or GP.

This leaflet has five main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Future Research

Part 5 – Further Information

Site	Online through SilverCloud Platform
Principal Investigator(s) and Co-Investigator(s) (insert names, titles and contact details)	<p>Principal Researcher: Selin Akkol-Solakoglu, MSc., PhD student in Psychology Research Contact Details: School of Psychology, Áras an Phiarsaigh, Trinity College Dublin, Dublin 2 Email: akkolsos@tcd.ie Phone Number: (01) 896 3913</p> <p>Project Supervisor: Dr. David Hevey, Head of School of Psychology Contact Details: School of Psychology, Áras an Phiarsaigh, Trinity College Dublin, Dublin 2 Email: heveydt@tcd.ie Phone Number: (01) 896 3914</p>
Study Organiser/ Sponsor (if applicable)	Trinity College Dublin & SilverCloud Health
Data Controllers	Trinity College Dublin
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 Email: dataprotection@tcd.ie

Part 1 – The Study

Why is this study being done?

We are doing this study to help breast cancer patients to learn how to cope with low mood and worries about breast cancer with an easily accessible, evidence-based, online programme. The programme was developed based on cognitive-behavioural therapy and adapted specifically for breast cancer patients who completed their medical treatments and their main carers (partners, family members, friends who are the main person supporting the patient). The programme consists of 8 modules and includes psychoeducation, information and exercises on how to motivate yourself, how to question your thoughts and provide alternatives, mindfulness practices and reflective exercises about your thoughts, feelings, physical reactions and behaviours.

Why have I been invited to take part?

Women who have completed their active breast cancer treatment (can still be on hormonal therapy) and their main carers in Ireland and the UK have been asked to take part in this study. Breast cancer survivors do not have to have carers or participate with their carers to take part, they will be asked about their preference whether to include their carers or not.

Do I have to take part? Can I withdraw?

Participation in this study is entirely voluntary. You are free to withdraw from the study at any time from the time of providing consent up to the point of completion of the analyses of data, August 2021, without explanation. Withdrawal from the study will not in any way affect your usual medical care or psychological support in any way.

If you wish to opt out, please contact Selin Akkol-Solakoglu (principal researcher), on (01) 896 3913 or email akkolsos@tcd.ie, who will be able to organise this for you.

What happens if I change my mind?

You can change your mind at any time about your participation in the study. If you change your mind and choose not to take part any more you can contact primary researcher Selin Akkol-Solakoglu (email: akkolsos@tcd.ie), who will arrange this for you. If you wish, you can ask for your data stored to be destroyed until August 2021, since the analyses are expected to be completed at this date. If you request this before August 2021, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards. However, it will not be possible to destroy data already used in research analyses after this time.

How will the study be carried out?

The recruitment for this study will take place online between 30 October 2020 and 31 May 2021 through the SilverCloud Health platform. 108 women who completed their breast cancer treatment and main carers of some will be taking part in the study. Women will be randomly assigned to one of two groups: iCBT treatment (72 women) or treatment-as-usual control group (36 women). Survivors who are assigned to the iCBT group will be given an option to choose from iCBT alone or iCBT with main carer access.

Group 1 (iCBT alone): Participants in the iCBT alone group will complete the 7-week programme.

Group 2 (iCBT with main carer access): Participants in the iCBT with the main carer access group will also complete the same programme by themselves, but their main carers will also have access to the same programme content using a separate account. Thus, carers will not have access to survivors' responses to exercises. This will give carers and survivors shared knowledge and encourage them to discuss what they have learned. Carers will not be assigned a supporter. They will be asked to complete some measures at the beginning, at the end of the study, and 2 months after the study ended.

Group 3 (treatment-as-usual): Participants in the treatment-as-usual group will continue their usual care recommended by their hospital and will not receive iCBT during this study. They will be completing the same measures at the beginning, at the end of the study, and 2 months after the study ended.

The online programme consists of 7 modules and participants in iCBT groups will be required to work on the programme throughout the 7 consecutive weeks. The modules include evidence-based information on psychological effects of breast cancer and personal stories of breast cancer survivors and their carers. It also includes exercises on how to motivate yourself, how to question your thoughts and provide alternatives, mindfulness practices, and reflective exercises about your thoughts, feelings, physical reactions, and behaviours. You are expected to go through the modules and do the exercises at your own pace. Each module approximately takes 1 hour to complete. At the end of each week, you will get feedback on your progress on the programme from a supporter, who is a trained applied psychology student or graduate. You will also be able to ask questions to your supporter through the platform.

Your progress on the programme and the effectiveness of the programme will be evaluated using valid and reliable questionnaires measuring depression and anxiety symptoms, quality of life, breast cancer-

related worries, coping, perceived social support, relationship quality, and communication quality. You will be asked to complete these measures **immediately before starting the programme, immediately after the programme, and 2 months after the completion of the programme**. Acceptability of the programme and giving access to carers will be assessed with the questions regarding satisfaction with the online programme, helpful aspects of programme as well as with the interviews that will be conducted with voluntary participants at the end of the programme.

What will happen to me if I decide to take part?

After signing the informed consent form, you will be randomly assigned to one of two groups (iCBT or treatment-as-usual). If you are assigned to the treatment group, then you will be asked your preference to either participate in the intervention alone or with your carer. At the end of the questionnaire, you will be immediately informed about your group assignment. If you are in the iCBT group, you will be provided a link at the end of this survey to access Space in Breast Cancer from Depression and Anxiety programme. You will be able to log in to the programme by creating a username and password. You will have access to the whole programme including 7 modules. You are expected to spend approximately 1 hour (at least) on the programme and **complete one module every week**. You will have access to the programme 7/24 and will be able to use it no matter where you are as long as you have internet access.

If you are in the (treatment-as-usual) control group, you will be asked to complete the same measures at the same time points as the other two groups, without doing the iCBT intervention. This will allow us to see if using this programme alone or together with the main carer is helpful compared to the usual treatment.

During this study, regardless of your group assignment, you will be asked to complete some measures, consisting of questions about your mood, quality of life, coping style, cancer-related worry, social support, relationship and communication quality with your carer if you have one. You will be asked to complete these measures immediately before starting the programme, immediately after the programme, and 2 months after the completion of the programme.

At the end of the programme, we will conduct interviews with women and their main carers, who are interested in sharing their experiences of using this programme. Interviews are optional, you can opt yourself in or out of the interviews in the consent form.

What will happen to my carer if I decide to take part in with my carer?

If you choose to participate with someone who has supported you (a partner, spouse, family member, or friend), then your carer will be given access to the same intervention programme. They will be able to go through the same modules and information but will have their own account. This will give carers an opportunity to reach evidence-based information and help them understand what you have been going through and give you an opportunity to discuss and practice what you have learned in the programme. If you choose to participate with your carer, we will ask you to provide their email address in the questionnaires so that we can send them a link to access the programme.

What will happen to my Data?

- Personal and sensitive data (name, contact details, age, education level, relationship with carer, depression, anxiety symptoms) will be collected in order to identify whom the intervention works best for based on these factors.
- Only necessary personal data will be collected, and it will be used for the purpose of this research objective alone. Personal data will be kept confidential and anonymous, and that personal data will not be processed in a way that is likely to cause you damage or distress.
- Completed questionnaires on the SilverCloud platform will be downloaded by the primary researcher and will be stored in an encrypted files in a password-protected computers to ensure high standards of security.
- Your personal data will be kept strictly confidential and will not be disclosed unless there is a risk of harm to yourself or other individuals or disclosure is required by law or that explicit consent for disclosure has been provided by yourself. In such cases you will be informed in advance and we will have to breach confidentiality.
- All data collected as part of this study will be pseudo-anonymised once downloaded from the platform, which means that any identifiable characteristic of your data will be replaced with a pseudonym, a value which does not allow your data to be directly identified.
- In accordance with the General Data Protection Regulation (GDPR), the screening questionnaires will not be kept for longer than is necessary for the purpose for which they were collected. All the electronic documents will be deleted and destroyed after a period of twelve months in accordance with the standard university procedures. Collected data will not be subject to any further processing that is incompatible with the aim of the present study.
- Findings of this study are expected to published in scientific journals and/or conferences. However, all data will be presented as a group, will be kept completely anonymous and you will not be able to identified as an individual.
- Participation in this study is voluntary; therefore, you can withdraw from the study at will, without explanation, and without penalty. You can withdraw at any point in time, from the time you sign up for the experiment until the completion of data analyses in December 2020. If you prefer to withdraw after data has been collected until the December 2020, the data you provided will be removed from analyses and destroyed.
- Under the GDPR regulations you have the following rights in relation to your data:
 - The right to access to your data and receive a copy of it
 - The right to restrict or object to processing of your data
 - The right to object to any further processing of the information we hold about you (except where it is de-identified)
 - The right to have inaccurate information about you corrected or deleted

- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise these rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting your study researcher or contact Data Protection Officer (contact details are provided below). The primary researcher and the project supervisors are the data controllers of your personal data. If you have any questions in relation to this research please do not hesitate to contact a member of the research team.

Are there any benefits to taking part in this research?

Taking part in this study may help you to know more about psychological impact of breast cancer, how to manage your mood and cancer-related worries, how to change your thinking patterns, how to be more active, and how to express your feelings as well as learn and practice new coping strategies. You will have access to the programme even after the study has ended, which means you will be able to go back to the modules and practice the skills that you have learned.

Taking part in this research may not directly benefit you if you are randomly assigned to treatment-as-usual group. However, research performed with your data will help us to better understand whether internet-delivered interventions can be beneficial for women with breast cancer in managing their mood and also whether including main carers to patients' intervention programme can help patients to manage their mood and worries in a better way. By participating, you are helping to increase breast cancer patients' access to easily accessible and evidence-based treatments in Ireland. You are also helping to advance science and psychological support treatments for cancer patients for future generations.

Are there any risks to me or others if I take part?

There is a risk that a connection to your identity could be made. Great care will be taken by the research team to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low. Only if the research team has a strong belief or evidence exists that there is a serious risk of harm or danger to either the yourself or another individual data confidentiality may be broken. This may relate the issues surrounding physical, emotional and/or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity.

Cognitive Behavioural Therapy is an evidence-based treatment approach that helps you to learn and practice some coping skills to better deal with mood problems. Managing your mood and coping requires facing your fears and your unhelpful thinking patterns and this may cause short-term discomfort during the study. However, you can talk to your supporter about the discomfort or any unpleasant feelings on the platform and you have right to stop taking part at any point of time during the study if you would like to.

What happens if something goes wrong when I'm taking part in the study?

In the event that you feel psychologically distressed by participation in this study, we encourage you to contact your GP or

Counselling Service of Irish Cancer Society (for residents in Ireland)

South Circular Road phone: **01 707 8880**

Eccles Street phone: **01 830 7333**

MacMillan Cancer Support Line (for residents in the UK)

phone: **0808 808 00 00** (available 7 days a week 8am-8pm)

Alternatively, you can call **NHS 111** if you need urgent medical help or advice

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

The outcome of this research will not be reported to the participants directly. However if you would like a summary of the findings, then please contact the researchers. The results of the study will be reported in medical/scientific journals and disclosed at medical/scientific conferences. No information which reveals your identity will be disclosed.

Part 2 – Data Protection

The following information should also be included as standard in Participant Information Leaflets, in order to ensure compliance with the 2018 Health Research Regulations.

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Personal data including:

- your name,
- contact details,
- age,
- education level,
- current and past attendance to counseling-psychotherapy for depression and/or anxiety,
- confidence in reading and writing in English,
- confidence in using the internet,
- alcohol or drug misuse
- diagnosis with a severe and enduring mental health condition
- suicidal thoughts,
- stage of the breast cancer diagnosis,
- time of the diagnosis
- medical treatments completed,
- presence of other medical conditions
- relationship status,
- nature of the relationship with the carer,
- participant consent,
- responses to questionnaires:
 - Hospital Anxiety and Depression Scale, Quality of Life (EORTC QLQ), Breast Cancer Worry Scale, Brief COPE, MOS Social Support Survey (for survivors only)

- Survivor-Carer Cancer Communication, Survivor-Carer Relationship Quality, Helpful Aspects of Therapy Form, Satisfaction with Online Treatment, and interview questions about experiences of using the programme (for both survivors and their carers) will be collected.

Your personal data is needed to:

- identify factors that may have an effect on your mood during the intervention
- assess your eligibility to be involved in the intervention programme
- to determine if the intervention programme is acceptable and effective on psychological outcomes measured in this population.

Identifiable data rather than anonymised data is required as data should be collected pre-intervention, post-intervention, and 2-months after the completion of the intervention to allow us to compare how you were feeling before and after using this programme and 2 months later (to see the long-term effects of the programme). Use of personal data for this activity are not expected to result in harm to the individual. All personal information provided throughout the study will be kept confidential in line with GDPR 2018.

What will happen to my personal data?

Your personal data will be processed only as is necessary to achieve the objective of the health research and will not be processed in a way that damage or distress will be caused to you as the research participant. All data will be saved on an encrypted file in a password protected computer.

The screening questionnaires will not be kept for longer than is necessary for the purpose for which they were collected in accordance with the General Data Protection Regulation (GDPR). Individual participant identifying information will be deleted after we have all required data from the you; at that point all data will be irreversibly anonymised and the anonymised data will be retained indefinitely by the research team to facilitate data access and future publications.

The TCD research team will be the data controller, which means we will decide how and why our data is processed, and SilverCloud will be the data processor, which means they will follow the principal researcher's and the project supervisor's instructions. According to SilverCloud's data storage and sharing policy all the data collected in the EU stays in the EU.

Who will access and use my personal data as part of this study?

The research project team, primary researcher Selin Akkol-Solakoglu and the project supervisor Dr. David Hevey, will access to your personal data as part of this study.

SilverCloud's online iCBT platform will be used to provide the iCBT programme and collect measures from participants. The TCD research team will be the data controller, which means we will decide how and why your data is processed, and SilverCloud will be the data processor, which means they will follow the principal researcher's and the project supervisor's instructions.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. Here are some examples of how we do this:

- As the intervention will be run online, there will not be any physical documents to store. After data is downloaded from the platform, each participant in this study will be assigned a code number (to match patients and their main carers and to ensure anonymity) and all electronic data files will be named according to this code so that the identity of the participants will not be apparent to observers other than the research team.
- Trinity College desktop Apple Mac and the laptop of the primary researcher will be used for the encryption and to storage of data in addition to the backed-up data on the OneDrive cloud storage. Both devices and the software programme are password protected and the password will be known only by the primary researcher and the supervisor.
- Any presentation or publication in relation to the study will not include any participant names and you will not be identified as an individual in our reports.
- A Data Protection Impact Assessment was carried out and an indication of the level of risk identified.
- The research team are bound by a professional code of ethics regarding sensitive data, and your data will be kept confidential. Confidentiality may only be breached in circumstances in which the research team has a strong belief or evidence exists that there is a serious risk of harm or danger to either the participant or another person. Disclosure may also be required as part of a legal process or Garda investigation. In such instances, information may be disclosed to significant others or appropriate third parties without permission being sought from the participant.
- The project supervisor has received the GDPR training. The primary researcher has received the online training for postgraduate students “Research Integrity and Impact in an Open Scholarship Era”.
- In order to prevent unauthorised access or disclosure, SilverCloud have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information that is collected online. All SilverCloud employees are contractually and ethically bound to respect the confidentiality of any personal data held by SilverCloud.
- SilverCloud has a documented Information Security Management System (ISMS) covering the areas of technical and organisational security described in this document and holds ISO 27001:2013 and Cyber Essentials certifications. SilverCloud maintains ISO 27001:2013 certification. Audits are conducted by a third party twice per year as part of their on-going compliance programme.

However, if something did go wrong a full explanation will be given to the participant regarding the necessary procedures and also the intended actions that may need to be taken.

What is the lawful basis to use my personal data?

Ordinary personal data will be processed lawfully, fairly and in a transparent manner in relation to the data subject under the lawful basis content.

By law,¹ we can use your personal information for scientific research² (in the public interest³). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Principal Investigator of your study: Selin Akkol-Solakoglu, School of Psychology, Áras an Phiarsaigh, Trinity College Dublin, Dublin 2, Ireland. Email: akkolsos@tcd.ie or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

¹ The European General Data Protection Regulation (GDPR)

² Article 9(2) (j)

³ (Article 6(1)(e))

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, this study has been approved by Trinity College Dublin Research Ethics Committee. Approval was granted on 15 July 2020. Any of the research project team members do not have a link to the committee, they are working under the School of Psychology behind the Research Ethics Committee.

Who is organising and funding this study? Will the results be used for commercial purposes?

This study is conducted by Selin Akkol-Solakoglu under the supervision of Dr. David Hevey for the purposes of obtaining an academic qualification PhD in Psychology. This research and PhD fees are funded by Trinity Postgraduate Studentship. We are not being paid to recruit patients to this study. The results of the effects of the intervention will be disclosed to SilverCloud Health who are research collaborators.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying patients to take part in the study. It will not cost you anything if you agree to take part, the use of the programme is free of charge.

Part 4 – Future Research

Will my personal data be used in future studies?

No, your data will not be subject to further processing that is incompatible with the purpose of the present study. Further processing, if any, will be specified to the general area or a health-related area of the original research. You will be informed as much as possible when obtaining consent for future use of your personal data. The data processing measures and safeguards in existence for the original study are in place for any future processing of your data.

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- Principal Investigator: Selin Akkol-Solakoglu, School of Psychology, Áras an Phiarsaigh, Trinity College Dublin, Dublin 2, Ireland. Email: akkolsos@tcd.ie.
- Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

If you would like to take part in this study, you will be asked to sign the Consent Form on the next page. You can download this information leaflet and the signed Consent Form to keep.

If you give permission to be contacted for future research on the Consent Form, we would like to contact you to learn about your experiences of using the programme after the programme completion.

Thank you for taking your time to read this information leaflet.

Appendix C. Consent Forms

Chapter 2

Consent form

The Suitability of Internet-Based Psychological Support Programmes for Breast Cancer Patients and Main Carers

I confirm that I have:

- 1) read the information sheet
- 2) have had the opportunity to ask questions about the research and all such questions have been answered
- 3) I am aware of my rights in relation to data access
- 4) agreed to participate in this research study

Signature of participant

Date

Please tick if you are happy to be contacted to take part for future research.

I agree to be contacted for future research by the research team.

Chapter 4 and 5

CONSENT FORM

<p>STUDY NAME: Space in Breast Cancer from Depression and Anxiety: Acceptability and Effectiveness of an Adapted Internet-Delivered Cognitive Behavioural Therapy Programme for Depression and/or Anxiety in Women with Breast Cancer and Their Main Carers</p> <p>Centre ID:</p> <p>Identification Number for study:</p>
--

Consent Form

<p>There are 2 sections in this form. Each section has a statement and asks you to initial if you agree. The end of this form is for the researchers to complete.</p> <p>Please ask <u>any</u> questions you may have when reading each of the statements.</p> <p>Thank you for participating.</p> <p>Please Initial the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.</p>	
General	Initial if you agree
I confirm I have read and understood the Information Leaflet for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study is entirely voluntary , and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason. I understand that deciding not to take part will not affect my future medical care.	
I understand that I will not be paid for taking part in this study .	
I understand that I will not pay to take part in this study .	
I know how to contact the research team if I need to.	
I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researchers by email or phone as part of this research study.	

Data processing	
I understand that personal information about me, including the transfer of this personal information about me outside of the EU, will be protected in accordance with the General Data Protection Regulation.	
I understand that depending on the condition I am assigned there may be no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me.	
I understand that I can stop taking part in this study at any time without giving a reason and this will not affect my future medical care.	

Your opinions are very important to us. At the end of this 7-week intervention, we would like to conduct interviews with voluntary participants to hear about your experiences of using the Space in Breast Cancer from Depression and Anxiety programme.

Interviews will be conducted **online** through the GDPR compliant Zoom application and will take about 45 minutes.

- Yes, I want to take part in the interview
- No, I do not want to take part in the interview

Participant Name (Block Capitals)

Participant Signature

Date

To be completed by the Principal Investigator or nominee.

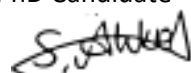
I, the undersigned, have provided full explanation to the above patient the nature and purpose of this study in a way that they could understand on the SilverCloud platform. I have explained the risks and possible benefits involved. I have provided my contact details and encouraged them to ask questions on any aspect of the study that concerned them.

Participants will be able to download a copy of the information leaflet and consent form with contacts of the study team on the SilverCloud platform.

Researcher name Selin Akkol-Solakoglu

Title and qualifications M.Sc., PhD Candidate

Signature



Date

03.02.2020

Appendix D. Debriefing Forms

Chapter 2

Study Information/Debriefing – Survivor Version

Acceptability of Internet-Based Psychological Support Programmes for Breast Cancer Patients and Their Carers

Thank you for agreeing to participate in this study. We greatly appreciate your cooperation. The aims of this study are to gain a deeper understanding about the opinions of women with breast cancer about the acceptability of internet-based psychological support programmes for themselves, and also about acceptability of having a separate internet-based programme specifically for their male partners.

Women with breast cancer participated in this study. You were asked about your cancer-related experiences, your personal opinions about the acceptability of internet-based programmes and acceptability of having a separate internet-based programme for your carers. The information gathered from this study will provide a description for us from the breast cancer survivors' point of view about having an internet-delivered psychological support programme for themselves and also what they think about if their carers have a separate internet-based programme for themselves and also what they think would be most beneficial for themselves in these programmes. Based on the data collected from this study, it is expected to develop or adapt a psychological support programme specifically tailored for the needs of women with breast cancer and their carers.

In the event that you feel psychologically distressed by participation in this study, we encourage you to contact your GP or Counselling Service of Irish Cancer Society (phone: 01 707 8880 (South Circular Road) / 01 830 7333 (Eccles Street); email: info@arccancersupport.ie)

Thank you again for your participation in this study. If you have further questions about the study, please email to Selin Akkol-Solakoglu at akkolsos@tcd.ie

Selin Akkol-Solakoglu, Ph.D. Student

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: akkolsos@tcd.ie
Phone number: +353 1 896 3913

Prof. David Hevey

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: heveydt@tcd.ie
Phone number: +353 1 896 3914

Signature of participant

Date

Study Information/Debriefing – Carer Version

Acceptability of Internet-Based Psychological Support Programmes for Breast Cancer Patients and Their Carers

Thank you for agreeing to participate in this study. We greatly appreciate your cooperation. The aims of this study are to gain a deeper understanding about the opinions of partners of women with breast cancer about the acceptability of having a separate internet-based psychological support programme specifically for themselves.

Carers of women with breast cancer participated in this study. You were asked about your personal experiences regarding breast cancer, your personal opinions about the acceptability of having a separate internet-based psychological support programme for yourself. The information gathered from this study will provide a description of what carers think about having a separate internet-delivered psychological support programme for themselves and also what they think would be most beneficial for themselves in these programmes. Based on the data collected from this study, it is expected to develop or adapt a psychological support programme specifically tailored for the needs of women with breast cancer and their carers.

In the event that you feel psychologically distressed by participation in this study, we encourage you to contact your GP or Counselling Service of Irish Cancer Society (phone: 01 707 8880 (South Circular Road) / 01 830 7333 (Eccles Street); email: info@arccancersupport.ie)

Thank you again for your participation in this study. If you have further questions about the study, please email to Selin Akkol-Solakoglu at akkolsos@tcd.ie

Selin Akkol-Solakoglu, Ph.D. Student

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: akkolsos@tcd.ie
Phone number: +353 1 896 3913

Prof. David Hevey

School of Psychology
Áras an Phiarsaigh
Trinity College Dublin
Dublin 2
Email: heveydt@tcd.ie
Phone number: +353 1 896 3914

Signature of participant

Date

Chapter 5

Internet-delivered Cognitive Behavioural Therapy Intervention with and without Main Carer Access for Depression and Anxiety in Breast Cancer Survivors

Thank you for your participation in this study. We greatly appreciate your cooperation. In the event that you feel psychologically distressed by participation in this study, we encourage you to contact your GP.

If you are resident in the Republic of Ireland:

You can also contact Counselling Service of Irish Cancer Society (phone: 01707 8880 (South Circular Road) / 01830 7333 (Eccles Street; email: info@arccancersupport.ie)

If you are resident in the UK:

You can also call NHS 111 if you need medical help or advice that is not life-threatening. If you would like to speak to an impartial person in confidence, you can contact Samaritans on 116123 for round-the-clock support. You can also contact them by email (jo@samaritans.ie).

If you have further questions, please send an email to the principal investigator of this study Selin Akkol-Solakoglu at akkolsos@tcd.ie

Selin Akkol-Solakoglu, Ph.D. Student

School of Psychology

Áras an Phiarsaigh

Trinity College Dublin

Dublin 2

Email: akkolsos@tcd.ie

Phone number: (01) 896 3913

Prof. David Hevey

School of Psychology

Áras an Phiarsaigh

Trinity College Dublin

Dublin 2

Email: heveydt@tcd.ie

Phone number: (01) 896 3914

Chapter 2



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



SilverCloud
Digital Mental Health Platform



Interested in an Online Intervention for Managing Breast Cancer-Related Distress?

Trinity College Dublin Centre for Psychological Health is looking for **breast cancer survivors** who are interested in the new **“Space in Breast Cancer from Depression and Anxiety”** programme.

This is an internet-delivered programme that aims to help breast cancer survivors cope with psychological distress and manage their mood. The programme was adapted by the expert psychologists with the involvement of breast cancer survivors and their carers.

This is a valuable opportunity to help manage your mood and improve your well-being with **complete confidentiality** and **free of charge**. As the programme is delivered online, it is completely flexible. You can access the programme 24/7, whenever it suits you and whenever you need it. All you need is internet access.

Survivors will also be given an option to give their main carers (e.g. partners, family members, or friends) access to the same programme content using a different account, allowing them to discuss what they learned in the programme.

To learn more about the intervention and sign up, go to the link below:

https://tcdecon.qualtrics.com/jfe/form/SV_eX0KrBkdL3YCY1

If you have any questions, please feel free to email primary researcher Selin Akkol-Solakoglu (PhD candidate) at akkolsos@tcd.ie

Chapter 4 and 5



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



SilverCloud
Digital Mental Health Platform

Have you completed your breast cancer treatment and interested in an online programme for managing your distress?

Researchers at the School of Psychology, Trinity College Dublin are looking for **breast cancer survivors** in Ireland and the UK interested in the new "Space in Breast Cancer from Depression and Anxiety" programme.

- If you
- (1) are older than 18
 - (2) have completed your active breast cancer treatment (can still be on hormonal treatment) and are currently cancer-free
 - (3) are confident in reading and writing in English
 - (4) are confident in using computers and have access to the internet
 - (5) are not currently receiving counselling or psychotherapy
 - (6) are not having problems with alcohol or drug use
 - (7) do not have a diagnosis of severe and enduring mental health condition (e.g. psychosis, bipolar disorder)
 - (8) do not have suicidal ideation, this programme may be for you.

The programme is a 7-week online Cognitive Behavioural Therapy intervention to empowering you to think and feel better. If you need help to manage your low mood and cancer-related worries during these challenging times you may benefit from this programme.

The programme was developed by expert psychologists with the involvement of breast cancer survivors and their carers. It is completely confidential, flexible, free of charge. You will also be given an option to give your main carer (e.g. partners, family members, or friends) access to the same programme.

To take part or find out more click the above link or email primary researcher Selin Akkol-Solakoglu at akkolsos@tcd.ie

Appendix F. Screening Questionnaire

Chapter 4

The questions below evaluate your suitability for the study:

Have you completed your active breast cancer treatment (e.g. radiotherapy, chemotherapy, surgery)?

- Yes
- No

How confident are you in reading and writing in English?

- Not confident
- Mildly confident
- Average
- Confident
- Very Confident

How confident are you with using computers and the internet?

- Not confident
- Mildly confident
- Average
- Confident
- Very confident

In the past, have you received counseling-psychotherapy for depression or anxiety?

- Yes
- No

Are you currently attending counselling-psychotherapy for depression or anxiety?

- Yes
- No

Has your use of alcohol or other drugs meant that you could not fulfill obligations such as work or study?

- Yes
- No

Have you ever been diagnosed with a severe and enduring mental health condition (e.g., schizophrenia, psychosis, bipolar disorder)?

- Yes
- No

Do you ever experience thoughts that you would be better off dead or of hurting yourself in some way?

- Not at all
- Several days
- More than half the days
- Nearly every day

Do you have any current plans to end your life?

- Yes
- No

Appendix G. Sociodemographic and Clinical History Questionnaires

Chapter 2

Background Information – Survivor Version

DIRECTIONS: Please answer each question as accurately as possible by marking the correct answer and/or filling the space provided.

1. What county do you live in? _____
2. What is your age? _____
3. What is the highest degree or level of school you have completed?
 - Primary school

 - Lower secondary (e.g. Inter/Junior Cert)
 - Upper secondary (e.g. Leaving Cert)
 - Third-level non degree (e.g. Diploma)
 - Bachelor degree / Professional qualification
 - Postgraduate Master's Degree
 - Doctorate
4. What is your marital status?
 - Not in a relationship
 - In a relationship
 - Married
5. How long have you been in a relationship with your partner? _____ years
6. Do you have children? Yes No
If yes, please indicate how many children do you have _____
7. What is your employment status?
 - Full-time
 - Part-time
 - Working at home
 - Unemployed
 - Retired
 - Student
8. What stage breast cancer do you have?
 - Stage 0 & 1

Stage 2

Stage 3

Stage 4

9. How long ago did you receive your initial diagnosis? _____ years

10. Have you had breast cancer recurrence? Yes No

11. Have you had a mastectomy? Yes No

12. Please circle whether you have started or completed the treatments below

Chemotherapy: Started Completed

Radiotherapy: Started Completed

Hormones: Started Completed

Active surveillance only: Started Completed

13. Has someone in your family been diagnosed with breast cancer before? (i.e. mother, grandmother, sister, aunt) Yes No

Background Information – Carer Version

DIRECTIONS: Please answer each question as accurately as possible by marking the correct answer and/or filling the space provided.

1. What county do you live in? _____
2. What is your age? _____
3. What is the highest degree or level of school you have completed?
 - Primary school

 - Lower secondary (e.g. Inter/Junior Cert)
 - Upper secondary (e.g. Leaving Cert)
 - Third-level non degree (e.g. Diploma)
 - Bachelor degree / Professional qualification
 - Postgraduate Master’s Degree
 - Doctorate
4. What is your marital status?
 - Not in a relationship
 - In a relationship
 - Married
5. How long have you been in a relationship with your partner? _____ years
6. Do you have children? Yes No
If yes, please indicate how many children do you have _____
7. What is your employment status?
 - Full-time
 - Part-time
 - Working at home
 - Unemployed
 - Retired
 - Student
8. What stage breast cancer does your partner have?
 - Stage 0 & 1
 - Stage 2
 - Stage 3
 - Stage 4

Chapter 4

Sociodemographic and Clinical History Questionnaire

Full name:

Email:

Gender:

- Male
- Female
- Prefer not to say
- Prefer to self describe as

Age:

Your location:

- Ireland
- UK

Phone/ Mobile:

What time of the day do you prefer to be called?

- Morning (please provide a specific time)
- Afternoon (please provide a specific time)
- Evening (please provide a specific time)

Highest degree or level of education you have completed:

- Some high school
- High school
- Third-level non degree (e.g. Diploma)
- Bachelor's degree / Professional qualification
- Master's degree
- Ph.D. or higher

What is your relationship status?

- Not in a relationship
- In a relationship
- Married

What stage breast cancer did you have at the time of the diagnosis?

- Stage 0 & 1
- Stage 2
- Stage 3
- Stage 4
- I don't know

How long ago did you receive a breast cancer diagnosis? (please indicate in **months**)

How long ago did you complete your breast cancer treatment? (please indicate in **months**)

Please indicate which treatments you have received (select all that apply)

- Chemotherapy
- Radiotherapy
- Hormonal therapy
- Surgery
- Other

Do you have any other medical condition(s)?

- Yes (please specify)
- No

Is there somebody who has been providing the main support to you throughout your cancer diagnosis, treatment, or after the completion of your treatment?

- Yes
- No

Your main carer can also access their own version of the same programme as you: this will give them information to help them better understand what you have been going through. They will not be able to see your responses on your programme. They only see the same information content that you see.

Would you like your carer to have access to their own version?

- I would like to participate by myself
- I would like to participate with my main carer

Your carer's name:

Please provide your carer's email address:

Can you tell us why you prefer to do it either by yourself or with your carer having access?

Appendix H. Hospital Anxiety and Depression Scale (HADS)

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over your replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much	0		Not at all
1		Not quite so much	1		Occasionally
2		Only a little	2		Quite Often
3		Hardly at all	3		Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
3		Very definitely and quite badly	3		Definitely
2		Yes, but not too badly	2		I don't take as much care as I should
1		A little, but it doesn't worry me	1		I may not take quite as much care
0		Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could	3		Very much indeed
1		Not quite so much now	2		Quite a lot
2		Definitely not so much now	1		Not very much
3		Not at all	0		Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
3		A great deal of the time	0		As much as I ever did
2		A lot of the time	1		Rather less than I used to
1		From time to time, but not too often	2		Definitely less than I used to
0		Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all	3		Very often indeed
2		Not often	2		Quite often
1		Sometimes	1		Not very often
0		Most of the time	0		Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
0		Definitely	0		Often
1		Usually	1		Sometimes
2		Not Often	2		Not often
3		Not at all	3		Very seldom

Please check you have answered all the questions

Appendix I. European Organization for Research and Treatment of Cancer Quality of Life Core

Questionnaire (EORTC-QLQ-C30)

For the following question please select the number between 1 and 7 that best applies to you.

How would you rate your overall quality of life during the past week?

1 (Very poor) 2 3 4 5 6 7 (Excellent)

Appendix J. Breast Cancer Worry Scale (CWC)

Cancer recurrence is a common concern among many breast cancer survivors. These questions are not meant to make you concerned but we would just like to know if these are worrying you at all and if they impact your daily functioning. Please answer the questions based on your experiences during **the past week**.

How often have you thought about your chances of getting breast cancer (again)?

- Never
- Sometimes
- Often
- Almost Always

Have these thoughts affected your mood?

- Never
- Sometimes
- Often
- Almost Always

Have these thoughts interfered with your ability to do daily activities?

- Never
- Sometimes
- Often
- Almost Always

How concerned are you about the possibility of getting breast cancer one day?

- Never
- Sometimes
- Often
- Almost Always

How often do you worry about developing breast cancer?

- Never
- Sometimes
- Often
- Almost Always

How much of a problem is this worry?

- Never
- Sometimes
- Often
- Almost Always

Appendix K. Brief Coping Orientation to Problems Encountered (Brief COPE)

These items deal with ways you've been coping with the stress in your life since you found out you were going to have to have this operation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently.

Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true for you as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Appendix L. Medical Outcomes Study Social Support Survey (MOS-SSS)

People sometimes look to others for companionship, assistance, or other types of support. Please answer the questions based on the support available to you during the **past week**.

If you need it, how often is someone available...

to listen to you when you need to talk?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

to give you good advise about a crisis?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

to give you information to help you understand a situation?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

to confide in or talk to about yourself or problems?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

whose advice you really want?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

to share your most private worries and fears with?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

to turn to suggestions about how to deal with a personal problem?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

who understands your problems?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

Appendix M. Survivor-Carer Cancer Communication Scale

Survivor Version

Please answer the questions based on your relationship with your carer:

My carer does not really listen when I talk about my cancer

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I avoid talking about cancer to my carer because I don't want to upset her

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I prefer not to talk about my cancer with my carer

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I don't tell my carer about my problems because there is nothing they can do to help

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

The cancer has provided my carer and me the opportunity to talk about some things that we never would have talked about

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I am frustrated when my carer is overprotective of me because of her cancer

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Carer Version

Please answer the questions based on your relationship with the breast cancer survivor you are supporting:

She does not really listen when I talk about her cancer

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I avoid talking about cancer to her because I don't want to upset her

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I prefer not to talk about her cancer with her

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I don't tell her about my problems because there is nothing she can do to help

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

The cancer has provided her and me the opportunity to talk about some things that we never would have talked about

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

I am frustrated when she is overprotective of me because of her cancer

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

Appendix N. Survivor-Carer Relationship Quality

Survivor Version

Please rate the quality of your relationship with your main carer (the person who is your main supporter):

Very Poor Excellent

0 1 2 3 4 5 6 7 8 9 10

Carer Version

Please rate the quality of your relationship with the person you are supporting:

Very Poor Excellent

0 1 2 3 4 5 6 7 8 9 10

Appendix O. Helpful Aspects of Therapy Form (HAT)

1. Of the events, which occurred in this session, which one do you feel was the most **helpful** or **important** for you personally? (By "event" we mean something that happened in the session. It might be something you said or did, or something your therapist said or did.)

2. Please describe what made this event helpful/important and what you got out of it.

3. did anything else particularly **helpful** happen during this session?

YES NO

(b. Please describe the event briefly:

4. did anything happen during the session, which might have been **hindering**?

YES NO

(b. Please describe this event briefly:

Appendix P. Satisfaction with Online Treatment (SAT)

I was happy to use the computer to access treatment

- Agree very strongly
- Agree strongly
- Neither agree nor disagree
- Disagree strongly
- Disagree very strongly

I found the online treatment easy to use

- Agree very strongly
- Agree strongly
- Neither agree nor disagree
- Disagree strongly
- Disagree very strongly

I feel the treatment received will have a long-lasting effect

- Agree very strongly
- Agree strongly
- Neither agree nor disagree
- Disagree strongly
- Disagree very strongly

I would recommend the online treatment to other users

- Agree very strongly
- Agree strongly
- Neither agree nor disagree
- Disagree strongly
- Disagree very strongly

Please rate how helpful you found the online programme

- Very helpful
- Quite helpful
- Not really helpful
- Not at all helpful

What did you most like about the online treatment?

What did you least like about the online treatment?

Appendix R. Interview Protocols

Chapter 2

Interview Script and Questions – Survivors

The purpose of this interview is to understand your personal experiences about breast cancer, your personal opinions about acceptability of internet-based psychological intervention programmes for yourself and whether giving your main carers/supporters access to the programme would be beneficial. I will be asking you some questions about your experiences with breast cancer and your opinions about the suitability of online psychological support programs for your needs and suitability of giving access to your main carers. Your personal opinions are very valuable for us to be able to develop a psychological support program tailored specifically for your needs. Throughout the interview please keep in mind that there are no right or wrong answers. Please feel free to express yourself comfortably.

The interview will be audio recorded because we don't want to miss any of your comments that will be helpful for our research. However, everything you say during the interview will be kept confidential. The study may be written up for publication or presented at conference, but your name will not be used and you will not be identified as an individual in our reports. I would like to remind you that participation in this study is voluntary and you have the right to withdraw from the study at any time. There are no risks associated with participation in this study. However, if you feel uncomfortable about any question, you have right to refrain from answering.

The interview will last about 1 hour. But if you need a break throughout the study, feel free to take them. Before we begin, please read the Information Sheet carefully and sign the Consent Form if you are happy to participate. If you have any questions please do not hesitate to ask.

Psychological Experiences about Breast Cancer

1. Do you have any concerns related to breast cancer? If so;
 - a. What are they?
 - b. How do you deal with them?
2. Has your relationship with your main carer been affected by breast cancer? If so, how?
3. How do you deal with the cancer-related problems with main carer?

Acceptability of Internet-based Psychological Intervention Programmes for Women with Breast Cancer

At times it can be challenging and you may feel anxious, down, stressed, or overwhelmed. During these times you may need support to cope and manage your mood. There are different professional psychological support options such as face-to-face therapy or group therapies. However, access to these services might be difficult in terms of getting a referral, or waiting times can be long. To overcome these barriers, internet-delivered support programmes have been developed based on the evidence from face-to-face psychological intervention programmes. In internet-based support programs there are modules that help you to cope with cancer-related distress and manage your mood, you can work on each module at your own pace, and you can communicate with and receive feedback from your supporter via messages in the programme.

Before we start, I would like to briefly show you how an internet-based psychological support programme might look like. (PowerPoint slides from *Space from Depression and Anxiety* programme will be shown).

4. What would you think about an internet-based psychological support programme like this in which you can log in with your phone, computer or tablet?
5. Do you think an internet-based psychological support programme like this might help you to cope with your breast cancer-related distress?
6. What might help you the most in that programme?/ What the program might include?
7. What would help or encourage you to use the programme?
8. What would stop you or decrease your motivation to use the programme?
9. When would it be most helpful for you to get the intervention programme like this? (e.g. shortly after diagnosis, weeks or months after diagnosis, before the radiotherapy/chemotherapy, at the end of treatment)

Acceptability of Giving Main Carers Access to Internet-based Psychological Intervention Programme for Women with Breast Cancer

Having access to your psychological support programme might help your main carers to understand what you are going through better.

1. If your main carers would have access to your internet-based psychological support programme, what would you think about that?

2. What do you think your main carers would find most useful in that programme?
3. What would help or encourage your main carers to use the programme?
4. What would decrease their motivation to use the programme?
5. When would it be most helpful for your main carers to get access to the intervention programme like this? (e.g. shortly after diagnosis, weeks or months after diagnosis, before the radiotherapy/chemotherapy, at the end of treatment)
6. If your main carers have access to your programme, how would that have an impact on you?
7. If your main carers have access to your programme, how would that have an impact on them?
8. Do you think having main carers who can access to your support programme would have an impact on your relationship?

Closing Questions

Is there anything you would like to add? Are there any other issues in relation to the suitability of online support programmes for women with breast cancer and their main carers or that you feel need to be discussed?

Closing Remarks

If there are no further comments, we will end the session. Thank you very much for sharing your thoughts and opinions with me. I encourage you to read the debriefing sheet which provides more information about the aims of the research. If you have any further questions, please feel free to get in touch. My contact details are provided on the debriefing form.

Interview Script and Questions – Main Carers

The purpose of this interview is to understand your personal experiences about breast cancer and your personal opinions about whether internet-based psychological support programmes developed for patients can be useful for carers to understand patients' needs better. I will be asking you some questions about your experiences with the patients' breast cancer and your opinions about the suitability of accessing their online psychological support programme. Your personal opinions are very valuable for us to be able to understand how main carers/supporters of patients can be helped using online programmes. Throughout the interview please keep in mind that there are no right or wrong answers. Please feel free to express yourself comfortably.

The interview will be audio recorded because we don't want to miss any of your comments that will be helpful for our research. However, everything you say during the interview will be kept confidential. The study may be written up for publication or presented at conference, but your name will not be used and you will not be identified as an individual in our reports. I would like to remind you that participation in this study is voluntary and you have the right to withdraw from the study at any time. There are no risks associated with participation in this study. However, if you feel uncomfortable about any question, you have right to refrain from answering.

The interview will last about 1 hour. But if you need a break throughout the study, feel free to take them. Before we begin, please read the Information Sheet carefully and sign the Consent Form if you are happy to participate. If you have any questions please do not hesitate to ask. If you are ready, we can begin.

Psychological Experiences of Main Carers about Breast Cancer Diagnosis

1. Do you have any concerns related to patients' breast cancer? If so;
 - a. What are they?
 - b. How do you deal with them?
2. Has your relationship with the patient been affected by breast cancer diagnosis? If so, how?
3. How do you deal with the cancer-related problems with the patient?

Acceptability of Giving Main Carers Access to Internet-based Psychological Support Programme

At times it can be challenging for main carers as much as patients and you may feel anxious, down, stressed, or overwhelmed because of not knowing how to help them. During these times you may need to understand patients' needs and what they are going through.

There are different professional psychological support options such as face-to-face therapy or group therapies. However, access to these services might be difficult in terms of getting a referral, or waiting times can be long. To overcome these barriers, internet-delivered support programmes have been developed based on the evidence from face-to-face psychological intervention programmes. In internet-based support programmes, there are modules that help patients to cope with cancer-related distress and manage their mood. They can work on each module at their own pace, and they can communicate with and receive feedback from their supporter via messages in the programme. In internet-based psychological support programmes, patients can log in with their phone, computer or tablet wherever they want.

Before we start, I would like to briefly show you how an internet-based psychological support programme for breast cancer patients might look like.

5. If you could access to the same programme, do you think a programme like this might be useful for you to understand patients' needs?
6. What might help you the most in that programme?
7. What would help or encourage you to use the programme?
8. What would decrease your motivation to use the programme?
9. When would it be most helpful for you to get access to the intervention programme like this? (e.g. shortly after diagnosis, weeks or months after diagnosis, before the radiotherapy/chemotherapy, at the end of treatment)
10. How would having access to patients' support programme have an impact on you?
11. How would having access to patients' support programme have an impact on the patient?
12. Do you think having access to patients' support programme would have an impact on your relationship?

Closing Questions

Is there anything you would like to add? Are there any other issues in relation to the suitability of online support programmes for main carers of breast cancer patients or that you feel need to be discussed?

Closing Remarks

If there are no further comments, we will end the session. Thank you very much for sharing your thoughts and opinions with me. I encourage you to read the debriefing sheet which provides more information about the aims of the research. If you have any further questions, please feel free to get in touch. My contact details are provided on the debriefing form.

Chapter 5

Survivor Interview Protocol

The purpose of this interview is to understand your personal experiences of using the internet-delivered intervention programme. Therefore, I will be asking you some questions about your experiences of using the programme, what you liked and disliked about the programme, how was the impact of them accessing to the programme on your relationship), how you would improve it, barriers to and facilitators of programme completion. Your personal opinions are very important for us to understand the effects of using this programme and how the programme can be improved for future studies. Throughout the interview please keep in mind that there are no right or wrong answers. Please feel free to express yourself comfortably.

The interview will be audio recorded because we don't want to miss any of your comments that will be helpful for our research. However, everything you say during the interview will be kept confidential. Recordings will be transcribed and then we will delete the recordings. The study may be written up for publication or presented at conference, but your name will not be used and you will not be identified as an individual in our reports. I would like to remind you that participation in this study is voluntary and you have the right to withdraw from the study at any time. There are no risks associated with participation in this study. However, if you feel uncomfortable about any question, you have right to refrain from answering.

The interview will last about 1-1,5 hour. But if you need a break throughout the study, feel free to take them. Before we begin, please read the Information Sheet carefully and sign the Consent Form if you are happy to participate. If you have any questions please do not hesitate to ask.

Survivor Interview Questions

1. How did you feel about taking part in this Breast Cancer intervention? (affective attitude)
2. How did you find the required amount of effort to take part in the intervention? Did your participation require too much time or cognitive effort? (burden)
3. Did the intervention fit well with your values and beliefs? (ethicality)
4. Did the intervention components help you to manage your mood? (intervention coherence)
5. Did the overall intervention help you to manage your mood? (perceived effectiveness) / What role did using the Breast Cancer programme play in managing your mood?
6. How confident did you feel to participate in the intervention? (self-efficacy)
7. What benefits or values that you had to give up to engage in this intervention? (opportunity costs)
8. What factors had influenced your motivation to use/ disuse this programme? (user experience)
9. What were the most helpful aspects of the programme for you? (user experience)
10. What were the most unhelpful aspects of the programme for you? (user experience)
11. What were the aspects that you liked the most about the programme? (user satisfaction)
12. What were the aspects that you disliked the most in the programme? (user satisfaction)
13. How would the programme be improved? (user perceptions)

Questions for survivors whose carers also used the programme:

1. How did you feel about your carer having access to the Breast Cancer programme? (affective attitude)
2. How did you find the required amount of effort for his/her to take part in the intervention? Did his/her participation require too much time or cognitive effort? (burden)
3. Did the intervention fit well with his/her values and beliefs? (ethicality)
4. Did the intervention components help him/her to help you? (intervention coherence)
5. Did the overall intervention help him/her to help you? (perceived effectiveness) / What role did your carer having access to the Breast Cancer programme play in managing your mood?
6. How confident did s/he feel to participate in the intervention? (self-efficacy)
7. What benefits or values that s/he had to give up to engage in this intervention? (opportunity costs)

8. How was him/her using the programme helpful for you? (user experience)
9. How was him/her using the programme unhelpful for you? (user experience)
10. How did him/her having access to your programme impact your relationship? (user experience)
11. What were the aspects that s/he liked in the programme? (user satisfaction)
12. What were the aspects that s/he disliked in the programme? (user satisfaction)
13. What would be the other ways of including carers in these types of programmes? (user perceptions)