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UNIVERSITY OF CALGARY

"The Challenge Led to Healing": Survivors' Experiences of Emotional Distress in a Breast Cancer Recovery Group

by

Michelle Elizabeth McCowan

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE

DEGREE OF MASTER OF SCIENCE

GRADUATE PROGRAM IN EDUCATIONAL PSYCHOLOGY

CALGARY, ALBERTA

APRIL, 2018

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Abstract

As the number of women living beyond breast cancer continues to grow, the issue of emotional distress during survivorship has become increasingly salient. Many breast cancer survivors, distressed or not, choose to seek post-treatment support through group programs. Nonetheless, there has been a startling lack of research into participants' experiences within these survivorship groups. In this study, I conducted semi-structured interviews with five breast cancer survivors who felt distressed during their participation in a cancer recovery group program. Interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009) of participants' experiences resulted in three overarching themes: (a) Contextual Challenges and Distress, (b) Group-Related Challenges and Distress, and (c) Coping and Healing. I discuss these findings within the context of relevant literature and present implications for group facilitators, care providers, and researchers in psychosocial oncology.

Acknowledgements

To the incredible women who participated in this study, your courage and vulnerability is at the core of this work. Your willingness to share your experiences is the reason this document exists. I will never be able to thank you enough.

To Dr. Sharon Robertson, you are the embodiment of exceptional supervision. Your mentorship and guidance has shaped and polished this work at every stage. Thank you for echoing my excitement about this topic and for modeling patience and presence in the research process. I am immensely grateful for your kindness, thoughtfulness, and unwavering commitment to my professional development.

To the Breast Cancer Supportive Care Foundation, your support of this research is reflective of the organization's tireless efforts to improve the programs, services, and supports available to individuals and families affected by cancer. Thank you for believing in the importance of this work.

To Dr. Nancy Moules and Dr. Kaori Wada, it was a gift to have you on my examining committee. Thank you for your ideas, comments, and generous encouragement.

Lastly, I would like to acknowledge the Social Sciences and Humanities Research Council of Canada, the Linda Barry Hollowell Graduate Scholarship, and the John D. Petrie QC Memorial Graduate Scholarship. I am honoured to have received the support of these families and institutions; Their gifts offered a critical contribution to this research.

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Chapter One: Introduction

"Provide cancer patients, survivors, their families and caregivers with the best possible psychosocial, physical, and supportive care throughout their cancer journey"

– Strategic priority, Alberta's Cancer Plan to 2030 (Alberta Health, 2013)

Despite progress in prevention and treatment, the burden of cancer in Canada is enormous and growing. Current estimates suggest that 1 in 2 Canadians will develop cancer in their lifetime and the number of new cancer cases is expected to increase by approximately 40% by the year 2030 (Canadian Cancer Society, 2017). The combination of greater incidence (related to an aging population) and improved survival rates means that the number of cancer survivors[1] continues to grow (Miller et al., 2016). As such, the Canadian health system is anticipating significant increases in the demand for cancer services across all points on the cancer pathway, from diagnostic services to long-term survivorship supports.

Over recent decades, the domain of cancer care has shifted and expanded (Bultz, 2016; Turner, 2015). No longer merely a question of physical treatments to extend life, documents such as Alberta's Cancer Plan to 2030 (Alberta Health, 2013) reflect an emphasis on the psychosocial aspects of cancer and cancer recovery. In the past 15 years especially, there has been increased recognition of the urgent need for supportive interventions to address the emotional pain and distress experienced by people with cancer and their families (Bultz, 2016). This recognition and awareness led to the development of the field of *psychosocial oncology*—"a specialty in cancer care concerned with understanding and treating the social, psychological,

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[1] For the purposes of this thesis, the term 'survivor' refers to persons who have completed primary treatment following a cancer diagnosis. Similarly, 'survivorship' refers to the period of time from post-treatment onwards. I use these terms (a) for readability and (b) in order to be consistent with the majority of literature in this area; however, I appreciate that not all people with a history of cancer identify with the term 'survivor' and that some prefer other terms to describe the post-treatment phase of their cancer experience.

emotional, spiritual, quality-of-life, and functional aspects of cancer, at all stages of the disease trajectory" (Canadian Association of Psychosocial Oncology, 2017). Although a relatively new field, psychosocial oncology is growing internationally (e.g., Hellbom et al., 2011; Reese, Weis, Schmucker, & Mittag, 2017; Turner, 2015), reflecting a shift towards an increasingly comprehensive biopsychosocial approach to cancer care.

Embedded in psychosocial oncology is an emphasis on identifying and mitigating the distress that people with cancer experience as a result of the disease and its treatment (Canadian Association of Psychosocial Oncology, 2017). In the cancer care context, distress is viewed as extending along a continuum from common reactions to the threats of cancer, such as sadness and fear, to problems that can become disabling, including depression, anxiety, or spiritual / existential crisis (National Comprehensive Cancer Network, 2017). Existing research indicates that emotional distress, often experienced in the form of depression or other adjustment difficulties, is a problem for approximately half of all people with cancer. Large-scale studies report that anywhere between 35% and 65% of patients and survivors experience clinical levels of distress (Carlson et al., 2004; Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013; Holland et al., 2010). For some, distress may be transient, whereas for others, it can persist for years (Carlson et al., 2013; Mitchell, Ferguson, Gill, Paul, & Symonds, 2013).

Accumulating evidence for the importance of exploring and addressing patients' and survivors' distress resulted in the recognition of distress as the *sixth vital sign* in cancer care (Health Canada, 2006). In this way, emotional distress was elevated to the level of the five key physiological indicators that have traditionally been used as a measure of a patient's state: temperature, respiration, heart rate, blood pressure, and pain (Bultz & Carlson, 2006). This addition was a formal acknowledgment of the importance of distress as a marker of wellbeing

across the cancer trajectory. Even more recently, major provincial and national cancer policy documents including Alberta's Cancer Plan to 2030 (Alberta Health, 2013) and the Canadian Strategy for Cancer Control: 2017-2022 (Canadian Partnership Against Cancer, 2016) have identified cancer-related distress as a national health issue and have highlighted the work that remains to be done to monitor and respond effectively to patients' experiences of distress at all stages of disease and survivorship. For example, one of Alberta Health's commitments towards the enhancement of cancer care in the province is to "monitor and manage all distressing symptoms before, during and after treatment in an integrated fashion" (Alberta Health, 2013, p. 32). There is a clear consensus, in these documents and among experts in the field, that research on the experiences and needs of patients will be critical to this envisioned future of cancer care (Canadian Partnership Against Cancer, 2016; Carlson et al., 2013).

Despite these stated commitments to exploring and addressing distress across the entire cancer continuum, research in the field to date has primarily focused on screening for distress at diagnosis, during active treatment, and/or in cases of recurrent disease; these efforts have been slower to develop in the realm of survivorship care. One of the reasons for this unequal distribution of existing literature could be that many survivorship services and supports are now offered through community-based agencies and primary care providers, rather than in the hospitals and treatment centres (Alberta Health, 2013). Regardless, the need to explore the specific concerns of individuals in the survivorship phase is becoming increasingly salient as the number of survivors in Canada continues to expand. This is especially true for cancers with high survival rates, such as breast cancer (Miller et al., 2016).

Indeed, women with breast cancer represent one of the largest survivorship groups, both in Canada and globally (Canadian Cancer Society, 2017; Institute for Health Metrics and

Evaluation, 2013; Stanton, Rowland, & Ganz, 2015). This growing cohort means that investigations into the survivorship experiences of women with breast cancer are urgently warranted[2]. Notably, a common method by which women with breast cancer seek support in the survivorship phase is through group programs. Breast cancer support groups are one of the most highly accessed group types within psychosocial oncology (Davison, Pennebaker, & Dickerson, 2000) and thanks to the efforts of clinicians and researchers in the field, a variety of breast cancer group types have been made available to survivors. Their effectiveness in improving emotional and psychosocial outcomes among participants has been well-documented (e.g., Andersen, Shelby, & Golden-Kreutz, 2007; Butler et al., 2009; Giese-Davis et al., 2011; Kissane et al., 2007; Montazeri et al., 2001; Schellekens et al., 2017; Tabrizi, Radfar, & Taei, 2016; Winzelberg et al., 2003). That said, previous research indicates that the issue of distress is relevant to the group context, in that at the time of their group participation, many breast cancer survivors are likely to be experiencing residual challenges of diagnosis and treatment, including anxiety and depressive symptoms (D'Souza, Daudt, & Kazanjian, 2017; McFarland, Shaffer, Tiersten, & Holland, 2018; Palmer et al., 2017; Syrowatka et al., 2017). Further, some aspects of breast cancer group involvement have the potential to be upsetting for participants (Manne, Ostroff, Winkel, Grana, & Fox, 2005; Williams & Jeanetta, 2016), and within-group issues (such as conflict) have implications for the wellbeing of group members (Manne, Kashy, Siegel, & Heckman, 2017). Surprisingly, following an extensive search of the relevant literature, I was unable to find any research on the concerns of breast cancer survivors who experienced

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[2] This is not to say that explorations into the experiences of men and non-binary-gendered people with breast cancer are not warranted. Initial work has explored the specific concerns of men with breast cancer, on the basis that this small population has unique needs (Williams et al., 2003).

difficulties or distress during their group participation. In fact, there appeared to be a noticeable lack of available information about participants' experiences in cancer survivorship group programs in general. As such, learning from the participants of breast cancer survivorship groups represents a valuable opportunity to expand distress-exploration efforts to the survivorship phase of cancer care.

Coming to the Topic: Personal and Professional Influences

"Because we are researchers and humans, our professional and personal selves are likely to intertwine…" – Hays and Singh (2012), p. 197

Although difficult to articulate, I appreciate the value in trying to convey how my selection of this research topic was shaped by my own priorities, interests, and past experiences. In short, several of the women in my family have been deeply affected by both mental health concerns and physical health challenges, including breast cancer. My interest in women's health issues and the intersections of physical and mental wellness are undeniably rooted in my own family history. Since my initial entry into the field of psychology (during my undergraduate studies), I have dedicated my time and energy to clinical work opportunities and community involvements that reflected these interests. I became involved in a variety of psychosocial support initiatives for people dealing with physical illness and/or mental heath concerns. In recent years (prior to and during my Master's studies in counselling psychology), I have had the chance to assist with weekend retreats for young adults with cancer, community-based groups for women living in poverty or facing homelessness, and a clinic-based psychoeducational group for adults with health concerns and a history of early life trauma. My involvement in these groups allowed me to observe first-hand the transformative power of group programs for people facing illness and other life challenges, as well as the incredible complexity of the processes that occur

in group support settings, regardless of the particular group type or focus. As I engaged in additional clinical training experiences and program evaluation projects, I was struck by the way that pre- and post-group questionnaires, and even general feedback forms, failed to capture the depth and nuances of participants' group experiences. I witnessed clear evidence that not every group was right for every person, and that for some, their group experience included very real challenges and tribulations, few of which seemed to be captured or recorded in any way. At this point, I had also become increasingly interested in the field of psychosocial oncology (and had had the opportunity to work in a counselling capacity with several breast cancer survivors). Admittedly, I found myself feeling as though the lack of research into participants' experiences of challenges in cancer support groups somehow reflected a collective failure to fully realize psychosocial oncology's commitment to explore patients' concerns across *all* stages of the cancer trajectory. From my personal and professional perspective, this struck me as a critical opportunity to honour and learn from the stories of women in a seemingly overlooked stage of the cancer recovery journey and to open new avenues for investigation into the challenges of group recovery supports.

Purpose of the Study

In light of the above-described research and personal imperatives, my primary aim in the current study was to explore the experiences of breast cancer survivors who felt distressed within a professionally facilitated cancer recovery group program. Given the striking lack of previous research on this topic, and my desire to understand the depth and complexity of the survivors' group experiences, I felt the need to explore this question using a qualitative methodology that prioritizes lived experiences (i.e., Interpretative Phenomenological Analysis [IPA]). More specifically, I chose this methodology for its ability to support a rich and detailed exploration of

(a) participants' unique individual experiences and (b) the ways in which their collective experiences converge (explained further in Chapter Three). Thus, the central research question guiding this study was as follows: How do breast cancer survivors experience and manage group-related emotional distress? The inclusion of this aspect of 'managing' reflects that I invited participants to share, to whatever extent they wanted, their understanding of how they had managed or coped with the emotional challenges they faced in the group context.

Significance

In many ways, a national and international shift is occurring in the way that the psychosocial concerns of people with cancer are prioritized and attended to. As the number of people who are surviving beyond cancer treatment continues to expand, the need to understand the issues that these survivors face in the years following diagnosis and treatment has been widely recognized. A myriad of group-based intervention, education, and support programs are being offered for breast cancer survivors in Canada and elsewhere and an impressive research base has developed to evaluate and compare the outcomes of these group programs. While undeniably useful, these quantitative investigations are limited in their ability to (a) capture the richness of group participants' experiences and (b) shed light on the challenges and difficulties that participants face in these groups (particularly if these challenges fall outside the pre-determined variables of interest). Thus, the current study—with its emphasis on voicing the lived experience of group participants who felt distressed in a breast cancer group program—offers an important complement to the existing quantitative outcome studies of group supports for women with breast cancer. The exploration of key themes in survivors' experiences of managing group-related emotional distress not only serves to draw attention to the emotional

challenges associated with group participation, but can also help to elucidate new opportunities for group facilitators and clinicians to learn from survivors' ability to navigate these challenges.

Organization of the Thesis

In the chapter that follows (Chapter Two), I provide a more detailed description of the existing theoretical and empirical literature that provided the foundation for the current study. In Chapter Three, I introduce my chosen qualitative approach to inquiry and outline the study's methodological details, from design through to analysis. Next, I present the study findings, written as a combined narrative of participants' accounts (Chapter Four). In the final chapter (Chapter Five), I discuss the findings in the context of relevant literature and offer implications for both practice and research.

Chapter Two: Literature Review

In this chapter, I present an integrated review of the published literature that provided the research context for the current study. I begin by offering an overview of the complex challenges embedded in cancer diagnosis, treatment, and recovery, with particular attention to the post-treatment experiences of women with breast cancer and to cancer-related distress. Next, I introduce several theoretical models of stress and coping and highlight their relevance to the issue of coping with life-threatening illness. I then review pertinent literature on (a) the role of group supports in cancer survivorship care and (b) participants' experiences within these group programs. To conclude the chapter, I summarize the influences of these existing works on the scope and methodology of the current study.

The Impacts of Cancer: Looking Across Diagnosis, Treatment, and Recovery

Regardless of the particulars of one's diagnosis, the cancer experience involves numerous transitions, stressors, and adjustments (Ellis & Isenberg-Grzeda, 2018). The acute physical and emotional consequences of cancer have long been recognized, but the expanding reach of the field of psychosocial oncology has enabled further exploration into the enormity of the psychosocial burden of cancer (Bultz, 2016; Turner, 2015). As part of nation-wide initiatives to develop clinical practice guidelines for the psychosocial care of adults with cancer, comprehensive reviews have been conducted to summarize the most critical cancer-related challenges that patients face. For example, Turner et al. (2005) reviewed the issues that people with cancer experience across the physical, emotional, social, and practical (e.g., financial) realms. Although I intentionally focus here on the challenges of cancer *recovery*, the challenges of cancer are not delimited by any particular stage or phase; rather, they should be viewed as

"parallel threads" that span the entire cancer care continuum—from diagnosis through to survivorship (Ellis & Isenberg-Grzeda, 2018, p. 38).

Physical Challenges in Cancer Recovery

Following treatment, most cancer survivors have to deal with changes to their appearance or physical functioning. Survivors often experience significant treatment-related consequences, including fatigue, nausea, pain, and sleep disturbance (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010; Monti et al., 2013; Stanton et al., 2015). These symptoms can persist for many years, even up to 10 years after the end of primary treatments (Bower, 2014; Harrington et al., 2010). One longitudinal study demonstrated that patients' reported levels of pain and fatigue did not decrease significantly in the year after diagnosis: At the one year mark, 40% of the patient sample still reported clinically significant levels of fatigue (Carlson et al., 2013). Patients from marginalized and underserved populations are even more likely to experience negative health consequences long into cancer survivorship (Lee Smith & Hall, 2015; Surbone & Halpern, 2016).

The physical symptom burden among women with breast cancer has been particularly well documented. Even with advancements in treatment technologies and symptom management efforts, breast cancer survivors report a multitude of treatment-related symptoms that impede their day-to-day activities, social involvements, and quality of life (Bloom, Stewart, Oakley-Girvan, Banks, & Shema, 2012; McFarland et al., 2018). The most commonly reported symptoms include pain, fatigue, sleep disturbances, skin discomfort, and lymphedema; however, the symptoms that patients rate as most distressing relate to problems with nausea, memory, and concentration (D'Souza et al., 2017; McFarland et al., 2018). Body image difficulties are also common following treatment and are associated with depression and reduced quality of life

(Esplen, Wong, Warner, & Toner, 2018; Fingeret, Teo, & Epner, 2014). For some women, the visible effects of surgery, chemotherapy, and radiation (e.g., scarring, hair loss, and changes to / loss of their breast) are perceived as disfiguring (Fang, Shu, & Chang, 2013), and treatment-induced menopause can contribute to concerns about sexual functioning (Collie et al., 2014; D'Souza et al., 2017; Knobf, 2011). A recent qualitative study of women's concerns following cancer treatment revealed that physical treatment-related symptoms interfered with participants' daily functioning and contributed to their psychological distress (Liao, Liao, Sun, Ko, & Yu, 2018).

Taken together, the physical consequences of cancer treatment can bring about numerous losses including losses of functioning, self-image, sexual function, social roles, and confidence in one's health and future (Gökler-Danışman, Yalçınay-İnan, & Yiğit, 2017; Pillai-Friedman & Ashline, 2014). Recognizing these changes and losses serves to contextualize the emotional reactions of people facing cancer, which often extend far beyond primary cancer treatment.

Social and Emotional Challenges in Cancer Recovery

A cancer diagnosis is inevitably an immense psychosocial stressor, as is reflected in the literature across disciplines (Collie et al., 2014; D'Souza et al., 2017; Howell et al., 2015; Monti et al., 2013). For instance, women with breast cancer can experience consequences such as anxiety, apprehension, sadness, social isolation, and disruptions to their relationships with family and friends (Bloom et al., 2012; D'Souza et al., 2017; Power & Hegarty, 2010). For some, these experiences are transient. For others, they persist and are costly to the survivors' quality of life over the long term (Carlson et al., 2013; D'Souza et al., 2017; Harrington et al., 2010). The emotional consequences of cancer can also manifest in interpersonal problems and problems with re-integration, such as return to work issues (Costanzo et al., 2007; Hodgkinson et al., 2007;

Knobf, 2011). In recent years, research contributions from nursing, psychiatry, and psychosocial oncology have helped to emphasize the complexity of these issues as they relate to people living beyond cancer treatment.

Cancer-Related Psychosocial Distress

As introduced in the previous chapter, the recognition of distress as the sixth vital sign in cancer care has brought patients' emotional experiences to the forefront of cancer research. The National Comprehensive Cancer Network (NCCN) defines distress as "an unpleasant experience of a mental, physical, social, or spiritual nature" (2017, p. 8). The NCCN highlights that distress ranges from common feelings of sadness and fear to more severe symptoms that can interfere with a person's ability to care for his/her emotional needs, relationships, etc. The term *distress* was carefully chosen as a non-stigmatizing umbrella term to capture the range of complex, unpleasant emotional responses that cancer patients might experience (Holland & Bultz, 2007).

Since the Canadian Strategy for Cancer Control (Health Canada, 2006) officially recognized emotional distress as the sixth vital sign, Canadian researchers, policy makers, and clinicians have been at the leading edge of initiatives aimed at recognizing, assessing, and addressing cancer-related distress. As part of such initiatives, routine screening for distress has been internationally endorsed and incorporated into standard clinical care in many countries, including Canada (Donovan, Grassi, McGinty, & Jacobsen, 2014; Howell et al., 2015; Turner, 2015). As a result, much of the cancer-related distress research to date has been dedicated to establishing brief distress assessments that can detect clinically significant issues of emotional wellbeing among cancer patients. One of the most widely-used measures has been the single item Distress Thermometer (Roth et al., 1998). A systematic review of international translations and validations of the Distress Thermometer indicated that 18 non-English translations had been

validated and tested clinically among people with cancer, reflecting international attention to the issue of cancer-related distress (Donovan et al., 2014).

Beyond the development and validation of distress measurement tools, research on cancer-related distress has focused on quantifying the benefits of distress screening (Lomauro, Dawson, Magda, Tobias, & Kelly, 2017) and exploring the associations between distress and other cancer-related outcomes (e.g., decreased quality of life, reduced satisfaction with medical care, and poorer physical health outcomes; Bidstrup, Johansen, & Mitchell, 2011). Tracking the distress trajectories of cancer survivors has been another area of focus. A meta-analysis of research in this area indicated that cancer-related distress, particularly anxiety, can persist for 10 years or longer among long-term survivors (Mitchell et al., 2013). In response to findings of persistent distress among patients, prominent Canadian researchers (e.g., Carlson et al., 2013) explicitly encouraged future explorations into the specific concerns associated with patients' distress across the cancer trajectory.

In short, nearly all of the research on cancer-related distress has been directed towards improving the detection and tracking of cancer-related distress rather than investigating the different facets of patients' and survivors' distress experiences. A recent exception is Vehling and Philipp's (2018) review of distress in cancer survivorship, which highlighted existential distress as a distinct dimension of cancer-related distress, one that requires attention and intervention as patients transition to long-term survivorship. However, the large majority of the articles included in Vehling and Phillip's review used only quantitative methodologies, even when exploring highly complex and charged topics such as faith, meaning, spirituality, and the effects of stressful life events (e.g., Davis et al., 2018).

Stress and Coping in the Context of Cancer

The combination of the above-described challenges of the cancer experience leads us to the question of how people with cancer cope with the physical and psychosocial stressors of diagnosis, treatment, and recovery. Lazarus and Folkman's (1984) *Transactional Model of Stress and Coping* provided a foundation for more recent models of coping with illness, several of which I describe in this section.

Transactional Model of Stress and Coping

Within the Transactional Model, stressful experiences are understood as person-environment transactions (i.e., interactions). In the face of an external stressor, a person evaluates the threat of the event and makes judgements as to whether it is positive, stressful, controllable, challenging, etc. This process is called *primary appraisal* (Lazarus & Folkman, 1984). In the *secondary appraisal* process that follows, the person assesses the degree of control he/she has over the stressor and evaluates available coping resources and options. Depending on the perceived controllability of the stressor, the individual will either attempt to alter the problem (i.e., *problem-focused coping*) or regulate his/her emotional reaction to the problem (i.e., *emotion-focused coping*).

Problem-focused coping is most likely to be applied when the person perceives that the situation is amenable to change; that is, that something can be done (Folkman & Lazarus, 1980). Notably, problem-focused coping can involve internal adjustments (e.g., motivational change), external change (e.g., adjusting situational factors), or both. Emotion-focused coping is more likely to be employed when the person perceives that nothing can be done to actively alter the threat of the environmental stressor. Instead, coping efforts are directed towards reducing felt distress, for example, by avoiding reminders of the stressor or comparing one's situation to less

fortunate others (Lazarus & Folkman, 1984). From the earliest origins of this work, Folkman and Lazarus (1980) noted that health-related stressors tend to favour an emotion-focused approach to coping, but that individuals' coping patterns often include both emotion- and problem-oriented approaches.

Coping with Illness

As an extension of Lazarus and Folkman's (1984) Transactional Model, Folkman and Greer (2000) developed a coping model specific to the issue of adjusting to serious illness and disease. This model highlights the role that emotion-focused coping efforts play in reducing the distress that people experience when facing illness diagnosis and management. According to this model, the emotional distress of illness incites a process of searching for meaning, which can include a newfound focus on relationships, a reordering of priorities, or some other means of reappraisal (Owen et al., 2006). Success in reappraisal and the search for meaning allow for a reduction in distress (Folkman & Greer, 2000). Although critical in emphasizing the role of meaning in coping with illness, the Folkman and Greer model did not include a framework of the specific coping strategies used by people facing health crises. Moos and Holahan (2007) offered this framework through their description of eight major categories of coping skills commonly employed by people dealing with illness or sudden disability. The eight categories in the Moos and Holahan (2007) model included: (a) logical analysis and the search for meaning, (b) positive reappraisal, (c) seeking guidance and support, (d) taking problem-solving action, (e) cognitive avoidance or denial, (f) acceptance and resignation, (g) seeking alternative rewards, and (h) emotional discharge.

The common thread in recent models of coping with illness has been the emphasis on meaning. This shift reflects a broader movement away from the problem- vs. emotion-focused

dichotomy to an expanded view of the importance of meaning in psychological adjustment to stress.

Meaning-Making Coping

In general, meaning-making refers to "the restoration of meaning in the context of highly stressful situations" (Park, 2010, p. 257). *Meaning-making coping* is recognized as another extension of the Transactional Model of Stress and Coping (Folkman & Moskowitz, 2000; Park & Folkman, 1997), and interest in meaning-making processes following stressful life events continues to grow. Theoretical perspectives on meaning-making differ in their specifics, but there seems to be a consensus across theories on several key concepts. These commonalities are reflected in Park's *Integrated Meaning-Making Model*, which posits that distress occurs when there is a discrepancy between an individual's appraisal of a particular situation (i.e., *situational meaning*) and their basic goals and fundamental beliefs about the world (i.e., *global meaning*). The resulting distress then drives a *meaning-making process* to reduce this discrepancy. The processes of meaning-making can be automatic or deliberate and can involve both cognitive and emotional processing (e.g., trying to identify benefits in the challenging situation and exploring one's emotional reactions). Notably, meaning-making does not always result in *meanings made*, which refers to the feeling of having successfully "made sense" of a situation (Park, 2010, p. 258). This distinction between process (e.g., searching for significance) and outcomes (e.g., acceptance, perceptions of personal growth) is a unique strength of Park's model: a refreshing contrast to other models that confound these two by referring generally to meaning-making.

Park's concept of 'meanings made' has particular relevance for the field of psychosocial oncology, where topics such as posttraumatic growth, identity reconstruction, and benefit-finding are frequently examined. As White (2004) summarized, cancer challenges people's global

beliefs in a meaningful, just, and coherent world. In facing life-threatening illness, one can lose the comfortable illusion of having life under control or having unlimited time left to live. As such, exploring the topic of meaning-making and meanings made at the individual level is essential to understanding the mechanisms involved in cancer-related distress.

Indeed, the literature on stress and coping among women with breast cancer heavily emphasizes the role of meaning-making coping during breast cancer treatment and survivorship. In a study of breast cancer survivors' wellbeing at five years post-diagnosis, Tomich and Helgeson (2002) reported that survivors who were still searching for meaning in their experience had less positive affect and more negative affect than healthy controls. The strongest correlate of quality of life (for both survivors and healthy controls) was having found a strong sense of purpose in life. In another longitudinal study of women with breast cancer (Sears, Stanton, & Danoff-Burg, 2003), 83% of the women reported at least one benefit of their cancer experience, and the use of meaning-making coping following treatment predicted positive health outcomes and positive mood one year later. A more recent study of coping strategies among breast cancer survivors in Norway found that the survivors' coping efforts centered around finding meaning: At one year after surgery, most of the women reported an increased appreciation for life, a greater focus on their life priorities and family relationships, and greater compassion towards others (Drageset, Lindstrøm, & Underlid, 2016). A small number of other qualitative studies have addressed the issue of meaning-making in the context of cancer (e.g., Baker et al., 2016; van der Spek et al., 2013) but have lacked a focus on the cancer type (i.e., breast cancer) or cancer stage (i.e., survivorship) of greatest relevance to the current study.

Apart from these few, most of the literature on meaning-making in the context of cancer survivorship focuses on the results of randomized controlled trials of meaning-focused clinical

interventions (see Vehling & Philipp, 2018 for a review). As an example from the breast cancer survivorship context, Lee, Cohen, Edgar, Laizner, and Gagnon (2006) found that a meaning-making coping intervention for breast cancer survivors significantly improved participants' self-esteem, optimism, and self-efficacy.

Overall, although the seminal stress and coping models are still highly referenced across health disciplines, the current state of the field of psychosocial oncology seems to reflect a heightened emphasis on meaning-making. This emphasis is mirrored in the focus of many newly developed group interventions for cancer patients and survivors (Vehling & Philipp, 2018). Trends related to group interventions are particularly important to consider given the popularity of group programs as a means of seeking support across the cancer trajectory.

Group Recovery Support in Psychosocial Oncology

Professionally led support groups provide an effective means for cancer patients and survivors to access information, strengthen coping skills, and reduce social isolation (Flynn et al., 2013; Power & Hegarty, 2010). Support group attendance has been associated with improved psychological wellbeing among survivors of various cancers (Gottlieb & Wachala, 2007), with evidence of reductions in anxiety (Arch & Mitchell, 2016; Montazeri et al., 2001), depression (van der Spek et al., 2017), fatigue (Arch & Mitchell, 2016), and cancer-related trauma (Winzelberg et al., 2003). The continued growth in both interest and participation in cancer support groups suggests that patients and survivors find that certain support needs are met in these groups that are not met elsewhere (Price, Butow, & Kirsten, 2006).

Support Groups in Breast Cancer Survivorship Care

Breast cancer support groups have long been one of the most highly accessed group types within psychosocial oncology (Davison et al., 2000), likely related to the high survivorship rates

among women with breast cancer (Stanton et al., 2015). Approximately 89% of breast cancer patients in North America survive for at least five years after diagnosis, making survivorship support a critical aspect of breast cancer care (Miller et al., 2016). Even outside of North America, improvements in the prognosis for women with breast cancer have led to international initiatives to support breast cancer patients as they transition to survivorship (Breast Cancer Care, 2018; Loh, Packer, Chinna, & Quek, 2013; Matthews, Grunfeld, & Turner, 2017). Breast cancer survivors' need for ongoing support around a multitude of post-treatment concerns—physical, social, and psychological—are often addressed within group programs that offer a combination of informational and social support. As explained by Gottlieb and Wachala (2007), breast cancer support groups often reflect some combination of three major intervention models: supportive-expressive, psychoeducational, and cognitive behavioural models. Mindfulness-based groups also have a significant presence within breast cancer survivorship care (Carlson, 2017).

The *supportive-expressive group therapy* model (Spiegel, Bloom, & Yalom, 1981; Spiegel & Classen, 2000) focuses on mutual support and the provision of opportunities for emotional expression and discussion of existential issues, such as fear of death. This group approach is based on the idea that increasing participants' felt sense of social support and encouraging them to face and adjust to their existential concerns can help to reduce symptoms of cancer-related distress. The evidence for the psychosocial benefits of supportive-expressive group therapy for women with metastatic breast cancer is well-established (Butler et al., 2009; Classen et al., 2001; Giese-Davis et al., 2002, 2011, Kissane et al., 2004, 2007), but the benefit of supportive-expressive groups for non-metastatic samples remains relatively untested and "appears to be questionable" (Ho et al., 2016, p. 4930). One notable exception is a randomized

controlled trial of a supportive-expressive discussion group for Iranian breast cancer survivors, which evidenced improvements in loneliness, hope, and quality of life for participants (Tabrizi et al., 2016). Other breast cancer support groups may still include existential themes even if they are not specifically labelled as supportive-expressive therapy groups. These existentially-focused groups tend to support meaning-making coping (introduced above) with the inclusion of topics such as coping with loss and grief, living with uncertainty, accepting missed opportunities, and finding new possibilities and priorities (Vehling & Philipp, 2018).

Psychoeducational groups are those that emphasize the provision of information. Many psychosocial oncology groups include psychoeducational components (e.g., teaching coping strategies); however, in some settings the term is reserved for groups that are entirely focused on offering informational guidance (e.g., medical information, treatment recommendations, nutrition) rather than expression or group discussion (Gottlieb & Wachala, 2007). In the context of breast cancer group supports, past trials of group programs described as 'psychoeducational' have indicated feasibility and effectiveness, with demonstrated reductions in participants' self-reported anxiety, depression, and fatigue (Dolbeault et al., 2009; Matsuda, Yamaoka, Tango, Matsuda, & Nishimoto, 2014; Scheier et al., 2005; Stanton et al., 2005).

Cognitive-behavioural support groups are generally distinguished by their emphasis on offering specific coping skills aimed at helping participants make adjustments to their thought patterns and behaviours (e.g., relaxation exercises, thought challenging, activity planning). According to a large meta-analysis of psychosocial interventions for women with breast cancer (Matthews et al., 2017), cognitive-behavioural interventions appeared to be the most effective in reducing anxiety and depression during breast cancer recovery. However, Matthews et al.'s review only included quantitative outcome studies, and the number of cognitive-behavioural

interventions included in the analysis was greater than any other intervention type. In another recent meta-analysis, Kalter et al. (2018) reported that the impact of coping skills training on the quality of life of cancer patients was higher among patients with distress than among non-distressed patients. Unfortunately, neither of these reviews was specific to group interventions; they also included individual support interventions.

Mindfulness-based intervention (MBI) is another form of group intervention that has gained a notable presence in the psychosocial oncology literature, particularly around the use of MBIs to address cancer-related distress. Overall, research evidence indicates that MBIs (e.g., imagery, meditation, yoga) can help to reduce a broad range of physical and psychological symptoms experienced by cancer survivors (Carlson, 2017). For breast cancer survivors specifically, a meta-analysis of three randomized controlled trials of mindfulness-based stress reduction interventions reported that participation in the mindfulness-based groups led to small reductions in survivors' depression and anxiety symptoms (Cramer, Lauche, Paul, & Dobos, 2012). Notably, a mediation analysis of a Mindfulness-Based Cancer Recovery group intervention (Carlson & Speca, 2010) revealed that within-group social support (as opposed to improved mindfulness) may largely explain the positive outcomes for breast cancer survivors who participated in the recovery group (Schellekens et al., 2017).

While these many outcome studies and meta-analyses offer convincing evidence for the usefulness of group intervention programs of various types in reducing symptoms and improving outcomes among breast cancer survivors, their quantitative and comparative nature means that these findings contribute little to an understanding of (a) the therapeutic processes occurring within these groups or (b) the lived experiences of group participants.

Participants' Experiences in Cancer Recovery Group Programs

With the continued expansion in the availability and diversity of group support programs for cancer survivors, understanding the therapeutic processes and challenges that occur within these groups ought to be a primary research priority (Manne et al., 2017). Unfortunately, limited empirical attention has been directed to group process issues in the context of cancer care and survivorship. As such, in reviewing this topic, I had to draw from general group process literature (not specific to cancer recovery groups) in order to contextualize the relatively small number of published findings that exist on the topic of therapeutic process considerations in cancer groups.

Therapeutic Processes in Illness Support Groups

According to Yalom and Leszcz (2005), any successful support group will reflect a complex interplay of several *primary therapeutic factors*. These factors influence the success of the group (the whole) as well as the experiences of individual group members. Yalom, an expert in the area of group psychotherapy and group process, highlighted that groups for the 'medically ill' generally differ from other types of support groups in that illness groups do not tend to emphasize interpersonal here-and-now processes (e.g., it would be rare for a stroke recovery group to include exercises designed to recapitulate and correct relational patterns that stem from one's early life experiences). Instead, certain other therapeutic factors become particularly important in illness support groups: *universality, cohesiveness*, *modeling*, the *instillation of hope, existential factors, imparting information*, and *altruism* (Yalom & Leszcz, 2005).

In the context of illness support groups, *universality* is often powerful, as group members come to realize that they are not alone even in their most unacceptable feelings, fears, and reactions. Through the recognition of their similarities and shared concerns, group members

can feel seen and accepted by other members in a way that reduces the isolation of illness. Notably, this factor is strongest in highly homogenous groups: Yalom and Leszcz note that cultural heterogeneity can leave minority members feeling excluded, particularly if their attitudes around disclosure and expression differ from the majority. Closely related to universality is *cohesiveness*. This multi-faceted factor includes three related but distinct relationships; that is, the individual's relationship to (a) the group facilitator, (b) the other group members, and (c) the group as a whole. It also subsumes the concept of group climate, which refers to the degree of engagement, avoidance, and conflict in the group as a whole. Members of highly cohesive groups feel warmth, comfort, and a sense of belonging in the group; they feel valued and supported by others members and are thus more likely to explore deeply. This exploration can occur outwardly, through expression and disclosure, or inwardly, through self-reflection (Yalom & Leszcz, 2005). Group cohesiveness is often cited as a precondition or prerequisite factor, in that issues of group cohesiveness interfere with the proper functioning of other therapeutic factors (e.g., modeling).

Within reasonably cohesive illness support groups, members often learn effective coping skills through the *modeling* of other group members. This process can help individual members challenge or shift their normal patterns, even if just briefly, to test out new behaviours, perspectives, or strategies. Watching other members cope effectively with a shared illness can *instill hope* for improvements in circumstance, comfort, or connection. As Yalom and Leszcz point out, some minimum level of hope is required just to keep the client coming back to the group for each session. Related to hope are the *existential factors* that are often at play in illness support groups. These groups can play an important role in supporting members as they grapple with fundamental questions and fears that are often otherwise disregarded or concealed.

Imparting information is another important process in illness support groups, especially as it relates to illness-specific information and other health-related considerations. Although the most structured information will likely come from the group facilitator(s), the exchange of information and suggestions between members often plays an important role—even though the advice itself is not necessarily helpful, the process of giving it conveys interest and care. More specifically, the therapeutic factor of *altruism* refers to the felt benefits of offering support, suggestions, and/or reassurance to other members. This act of giving has intrinsic benefits for the 'givers', allowing them to feel useful to the group and to practice shifting flexibly from help recipient to help provider. Which of the above factors are experienced as most therapeutic depends on the individual group member; Each member will benefit from a different cluster of therapeutic factors (Yalom & Leszcz, 2005).

Not mentioned within Yalom and Leszcz's group factors, but highly cited in group process literature, is Festinger's (1954) *social comparison theory*. Festinger argued that many of the processes that occur in social groups can be explained by the human drive to compare one's own abilities and opinions with that of others. In times of uncertainty, people naturally seek the company of other people as a way of evaluating the appropriateness of their own thoughts, feelings, and behaviours. In the context of a support group, the process of social comparison can offer therapeutic benefit by normalizing members' experiences: Each has the opportunity to see that others, facing the same illness or circumstances, experience similar feelings and thoughts (Gottlieb & Wachala, 2007).

Although these therapeutic factors and social theories offer important information about the processes that occur in support groups, the authors themselves recognize the inherent inability of any explanatory system to fully capture the complexity of the group environment;

that is, they emphasize that "… there is no end to the number of pathways through the experience" (Yalom & Leszcz, 2005, p. 2).

Therapeutic Processes in Cancer Support Groups

Existing evidence for the way that the common therapeutic factors and processes described above occur specifically in cancer-related support groups is limited (Manne et al., 2017). In a guiding overview of group therapy for cancer patients, Spiegel and Classen (2000) acknowledged that cancer groups share many key therapeutic benefits with other types of support groups (e.g., reduced isolation, sharing in a safe environment) but argued that the relevance of mortality issues and the primacy of existential concerns is a distinguishing feature of cancer support groups. A few more recent studies have tried to elucidate the specific aspects of support group involvement that cancer patients and survivors found most helpful. For example, participants' feedback about a professionally-led cancer survivorship support group (Living Life After Cancer Treatment) indicated that participants felt they had benefitted from the ways that the group met some of their "unmet social support needs" and "unmet informational needs" (Flynn et al., 2013, p. 2). Some cancer support group participants expressed the importance of being able to talk freely about their illness and fears without further burdening their family members. They were also happy to be listeners so that others could do the same (Flynn et al., 2013; Yaskowich & Stam, 2003). Although these identified factors do not map directly onto Yalom and Leszcz's therapeutic factors, they likely reflect processes related to *group cohesion, universality*, *imparting information*, and *altruism.* Carmack Taylor et al. (2007) addressed the role of *modeling* in cancer support groups, highlighting the ways that distressed members can benefit from observing and modeling the coping skills of non-distressed members.

In the context of breast cancer support groups specifically, women in a professionally facilitated breast cancer group highlighted that helpful group processes included mutual trust and sharing, shared acknowledgment of the impact of hair loss, countering post-treatment isolation, and consolidation of information (Power & Hegarty, 2010). Another study, supposedly the first to study *cohesion* in a cancer support group, asked participants in a breast cancer group therapy program to rate (a) how involved they were in the group experience and (b) how supported they felt by the group. Greater involvement and felt support were strongly associated with positive post-group outcomes (Andersen et al., 2007). A recent study by Manne et al. (2017) demonstrated a similar relationship in two different breast cancer groups: Engagement in the group process was associated with greater post-treatment wellbeing, whereas within-group conflict was associated with more post-treatment anxiety and lower wellbeing scores. In other words, group process issues had important consequences for participants. The findings of this study exemplify the importance of exploring not only those aspects of cancer support groups that participants find helpful, but also those that pose issues for them. Unfortunately, Manne et al. used only quantitative Likert-scale measures of group process (Group Climate Questionnaire-short form) and treatment outcomes (Mental Health Inventory-38). The use of brief rating scales offers useful correlational information, but sacrifices the ability to capture the nuances and depth of participants' felt experiences of engagement, cohesion, conflict, anxiety, etc. related to their group involvement.

Challenges and Unintended Consequences of Group Participation

The lack of research attention to the lived experiences of cancer support group participants appears to have occurred as a side effect of the recent emphases on improving methods of screening for cancer-related distress and quantifying the outcomes of various

individual and group interventions (primarily through randomized controlled trials). Given the major role of group supports in cancer survivorship care—and the expectation that this role will continue to expand with increasing survival rates—the impetus for exploring the experiences of group participants and the challenges they face is particularly great. As Gottlieb and Wachala (2007) highlighted, research on the support offered to women with breast cancer by their natural social networks shows that some supporters become emotionally over-involved in others' concerns, offer false reassurance, or provide unsolicited advice. These support attempts, although well-intentioned, can exacerbate patients' distress and leave them feeling misunderstood and unsupported (Manne et al., 2005). Although it is highly plausible that similar processes would occur in the context of breast cancer support groups, there is a glaring lack of research into the interpersonal dynamics that affect the experiences of group participants.

One of the potential reasons that such little information exists as to cancer survivors' experiences of within-group challenges is that at the conclusion of most group intervention programs, the information collected from participants is typically aimed at evaluating quantitative pre- to post-group changes. Even if participants are asked to give qualitative feedback about their satisfaction with the group intervention, they are rarely asked to comment on any aspect of the group (e.g., composition, format, discussions) that they may have found disappointing, challenging, or upsetting (Gottlieb & Wachala, 2007). In a rare study of the lived experiences of breast cancer survivors, Williams and Jeanetta (2016) reported that the majority of the 15 women they interviewed had found that group supports were not a good match for them. In contrast to extensive findings about the benefits of cancer support group participation, these women reported that they found several aspects of group involvement to be upsetting, including "depressing" group meetings and/or feeling guilty about having a better prognosis than

other members of their groups (Williams & Jeanetta, 2016, p. 636). Several limitations of this study are relevant here. First, the researchers' aim was to capture participants' experiences of breast cancer survivorship in general: It was not specific to their group experiences. Thus, the women's comments about their group participation represented only a small segment of a broader interview and were not explored in detail. Second, study participants were recruited through a group program that teaches 'beauty techniques' to women actively undergoing chemotherapy and radiation, to help them combat treatment-related appearance side effects. Thus, it is unclear to what extent the participants were referring to this Look Good Feel Better group (as opposed to other cancer-related support groups) when describing the group-related challenges they faced. Third, the broad scope of the interview topic was not conducive to any discussion of the strategies or coping skills that the participants used to manage these challenges. Despite these limitations, Williams and Jeanetta's findings offer clear evidence that some cancer support group participants, even if a minority, experience challenges in the group setting and that these challenges have implications for them in their recovery. The fact that feedback about these breast cancer survivors' group experiences arose organically in a broader interview also lends support to Gottlieb and Wachala's (2007) suggestion that qualitative feedback opportunities ought to be offered following cancer support group programs, as quantitative rating scales tend to offer a positively-skewed representation of group members' experiences.

Overall, the lack of available information about participants' experiences in cancer survivorship group programs, let alone the experience of breast cancer survivors specifically, has left open a vast arena of opportunity for the exploration of cancer survivors' lived experiences of participating in recovery support groups. Further, the paucity of group process research in the psychosocial oncology field means that an exploration of the challenges faced by cancer

recovery group participants could offer foundational information about the ways that participants' methods of coping with group-related challenges coincide with existing models of how patients and survivors cope with the stressors of illness and recovery.

Summary and Application to the Current Study

Within this chapter, I have presented a review of the cross-disciplinary literature that informed the current study. In doing so, I integrated existing literature on the following topics: cancer-related losses and challenges, cancer-related distress, stress and coping in the context of illness, the role of group supports in breast cancer survivorship, and the therapeutic processes and challenges that can occur in the group context. Within these areas of research, there is convincing evidence that breast cancer survivors, like others living with the post-treatment consequences of cancer, often experience significant cancer-related losses and persistent psychosocial symptoms. The recognition of distress as the sixth vital sign in cancer care has brought increased attention to the issue of emotional distress across the cancer continuum (from diagnosis to survivorship), although the large majority of research on cancer-related distress has been directed towards quantifying and tracking survivors' distress rather than investigating the nuances of their distress experiences. Notably, in response to findings that cancer-related distress can occur long into survivorship, experts in the field of psychosocial oncology have commented on the current need for research into individuals' distress experiences across the cancer trajectory.

The existing literature base offers clear demonstrations of the major role that group support interventions play in breast cancer survivorship care and the successes of various group programs in improving outcomes among breast cancer survivors. However, the fact that past research has been largely quantitative means that there remains a very limited, almost non-

existent, representation of the lived experiences of breast cancer survivorship group participants. Given the evidence that many women with breast cancer experience significant levels of distress in survivorship, and that certain aspects of group involvement can be upsetting for some participants, there is a clear need for a focused inquiry into the challenges faced by breast cancer survivorship group participants.

In short, although the existing psychosocial oncology literature provides limited insight into the experiences of breast cancer survivors who participate in group support programs, the combination of extant literature across numerous fields provides both a strong foundation and a clear motivation for an exploratory investigation into the lived experiences of group participants whose group involvement included emotional challenges or distress. Given the paucity of existing literature on the topic, my sense was that an in-depth qualitative exploration of these participants' experiences also represented a unique opportunity to learn from individual survivors' attempts and abilities to cope with the challenges of their group involvement. In the following chapter, I present the details of my decision to use a particular idiographic qualitative research methodology to meet this research aim; I then describe the methodological and analytic procedures that characterized the current study.

Chapter Three: Methodology

In this chapter, I explain the methodological and procedural elements of my exploration into breast cancer survivors' experiences of group-related emotional distress. I first address my choice of a qualitative approach, Interpretative Phenomenological Analysis (IPA; Smith, 1996), and describe the theoretical foundations of this approach. Next, I present the details of the study design, including participant recruitment, data collection, and analysis. I address my preconceptions about the study topic and discuss how I embedded the practice of reflexivity into my research process. I conclude the chapter with a description of ethical considerations in the study design and methods of evaluating quality in qualitative research.

Choice of Qualitative Methodology

My choice of a qualitative approach for the current study was made with careful thought and consideration of (a) my guiding research question, (b) my desire to honour the story of each study participant, and (c) my personal beliefs about the qualitative research process. IPA addresses each of these considerations, positioning it as most able to meet my need for an in-depth, systematic, and theoretically supported qualitative methodology that prioritizes the lived experiences of participants.

The overarching research question driving this study relates to the *experiences* of breast cancer survivors (i.e., How do breast cancer survivors experience and manage group-related emotional distress?). The appropriate methodology had to emphasize personal experience to the same extent. By definition, IPA is a qualitative methodology committed to the detailed exploration of how participants make sense of their lived experiences (Pietkiewicz & Smith, 2014). This alignment of study aim and methodology is critical to the coherence of qualitative research (Harper & Thompson, 2012).

Although the primary factor in my choice of qualitative methodology was IPA's alignment with my research question, it was also important to me that my chosen method honour participants' stories as inherently meaningful. Any qualitative approach that reduces participants' individual experiences to measures of frequency seemed inappropriate for the current study, especially given that the research topic invites personal and nuanced stories of emotion, illness, and coping. IPA has been deemed particularly appropriate for the exploration of topics that are complex and emotionally-laden (Smith & Osborn, 2015). It prioritizes individual cases and values each participant's unique perspectives on the phenomenon of interest (Smith, Flowers, & Larkin, 2009). Thus, participants' distinct voices are honoured in the research process.

Lastly, IPA, more so than any other qualitative method that I encountered during my graduate studies, is congruent with my personal understandings of the qualitative research process. IPA's central aim fits with my beliefs about the meaningfulness and complexity of human experience. IPA also reconciles the hesitancy I feel towards qualitative approaches that claim to produce findings that are free from any influence of the researcher's interpretations. Specifically, I believe that it is impossible for researchers to separate themselves entirely from their impressions, ideas, and past experiences. In contrast to more descriptive methods, IPA welcomes the researcher's role by recognizing that analysis involves actively engaging with, and thus interpreting, the raw data (Smith et al., 2009). This stance is reflective of IPA's core theoretical foundations.

Theoretical Foundations of IPA

As a methodology, IPA has a relatively short history, having only formally been established with Jonathan Smith's (1996) seminal publication in *Psychology and Health*.

However, IPA is grounded in a long and involved intellectual history, dating back to key philosophical traditions from the early 1900s. In this section, I introduce each of IPA's three central theoretical influences—*phenomenology, hermeneutics*, and *idiography*—and address how the IPA epistemological framework draws from each of these theoretical traditions.

Phenomenological Tradition of IPA

In its most basic sense, phenomenology refers to the study of human experience (van Manen, 1997). The founding principle of phenomenological inquiry is that experience should be examined in its own terms, as it naturally occurs, rather than dissected into predetermined categories or theoretical concepts (Husserl, 1999/1907; Smith, 1996). Edmund Husserl, often called the father of phenomenology, wrote extensively on the need to return to the question of everyday human experience as it is lived: to access and understand experience in a rigorous way (Laverty, 2008). Notably, Husserl believed that the world of everyday experiences—which he referred to as '*lebenswelt*' (meaning 'lifeworld')—should be accessed with careful objectivity, such that the true meaning of an experience could be discovered. Husserl's phenomenology, then, was about examining experiences with the aim of getting at its true '*eidos'* or 'essence' (Moules, McCaffrey, Field, & Laing, 2015). In order to get at the essence of an experience, Husserl promoted the process of 'bracketing', which involves putting aside one's preconceptions and assumptions about a phenomenon to instead try to see it 'as it is' (Husserl, 1999/1907; Laverty, 2008). According to Smith et al. (2009), Husserl's approach is reflected in the IPA framework through its emphasis on describing lived experience.

Martin Heidegger, Maurice Merleau-Ponty, and Jean-Paul Sartre each made significant contributions to phenomenology in building on, and diverging from, Husserl's work. Heidegger, who was an apprentice of Husserl, introduced the concept of '*dasein'* or 'being in the world'

(Moules et al., 2015). Dasein refers to the fact that humans exist in the context of language, culture, history, and relationship; a person's position in the world inevitably influences their understanding (Heidegger, 2010/1927; Laverty, 2008). Similarly, Merleau-Ponty and Sartre emphasized the role of context in how people make sense of their experience: Merleau-Ponty focused on the *embodied* nature of experience (i.e., the unique position of every body in the world means that experience is never entirely shared), and Sartre wrote about the importance of biographical and social influences on human meaning-making (Smith et al., 2009). Taken together, these three philosophers moved phenomenology towards a more interpretive stance, one that recognizes that studying experience involves "the interpretation of people's meaning-making activities" (Smith et al., 2009, p. 18). IPA is phenomenological in this latter sense. It aims to explore lived experience through first-person accounts, but does not claim to produce objective statements about the phenomenon of interest (Smith & Osborn, 2003).

Hermeneutic Tradition of IPA

IPA's second theoretical axis, hermeneutics, refers to the theory and practice of interpretation (Moules, 2002). As described above (and as is indicated in its name), IPA adheres to an interpretive phenomenology, which means that it treats experience as interpreted and contextual, rather than fixed (Moules, 2002). The hermeneutic tradition goes beyond phenomenology in addressing the philosophical issues of interpretation that are relevant to IPA.

Friedrich Schleiermacher, often cited as the father of contemporary hermeneutics, offered lasting ideas related to interpretation as an artistic and creative process (Grondin, 1997; Moules, 2002). He argued for the inextricable role of language in understanding, stating that "language is the manner in which thought is real…. no one can think without words" (Schleiermacher, 1998, p. 8). He believed that a holistic and detailed analysis of a text can allow the analyst to find

meaning in the writer's words beyond what the writer himself may recognize (Schleiermacher, 1998; Smith et al., 2009). This idea is reflected in the concept that hermeneutic inquiry involves "exploring what lies behind the surface of phenomena, while recognizing that any one source of insight does not stand alone" (Moules et al., 2015, p. 12).

Martin Heidegger's contributions to hermeneutics occurred largely through his work in the realm of hermeneutic phenomenology. His philosophical concepts, such as dasein ('being in the world'), helped to bridge phenomenology and hermeneutics. He maintained a phenomenological emphasis (on articulating experience) but moved away from Husserl's focus on discovering essential features of the world. Instead, Heidegger advocated for careful attention to the rich and relational nature of "life as it is lived" (Moules et al., 2015, p. 24). He highlighted that phenomenology is necessarily hermeneutic, in that looking at how a phenomenon appears requires the analyst to interpret and make sense of that appearance (Heidegger, 2010/1927). This sense-making occurs in the context of the analyst's preconceptions and experience (see below).

Hans-Georg Gadamer's philosophical hermeneutics, which incorporated and built on the legacies of Schleiermacher and Heidegger, emphasized the importance of the researcher's role and the relevance of historical contexts in interpretation (Moules, 2002). In *Truth and Method* (1989/1960), Gadamer wrote extensively on the concept of truth. According to Gadamer, uncovering truth in understanding simply means that one has found a meaningful account that corresponds to experience (Gadamer, 1989/1960; Moules, 2002). Accordingly, truth is not a measure of objectivity or frequency. Gadamer (1989/1960) also emphasized the importance of recognizing one's preconceptions and maintaining openness during interpretation, such that "the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings" (p. 269).

The hermeneutic tradition, as it relates to these and other philosophers, is what informs the interpretive element of the IPA approach. In particular, several key hermeneutic concepts are explicitly taken up in IPA: fore-conception, the hermeneutic circle, and the double-hermeneutic.

Fore-conception. Fore-conception (Heidegger, 2010/1927) is one aspect of the hermeneutic idea that every learner, listener, or reader has prior experiences, assumptions, and preconceptions that influence their understanding. Thus, all understanding is interpretive. IPA embraces this concept in many ways, especially in describing the 'researcher as interpreter' and the need for reflexive and transparent awareness of the researcher's preconceptions (Pietkiewicz & Smith, 2014). Notably, as Smith (2009) points out, the researcher can and should attempt to become aware of his or her biases and preconceptions before starting the interpretation. That said, we are often unaware of the prejudices we posses. Some of these previously unrecognized preconceptions and assumptions might become evident through the process of engaging with the text and trying to make sense of it (Moules, 2002). In other words, fore-conception influences how one engages with a text, and engaging with that text can reveal one's fore-conception. This cyclical and dynamic nature of interpretation is referred to as the hermeneutic circle.

Hermeneutic circle. The hermeneutic circle is one of the most prominent concepts in hermeneutic theory and is an essential component of IPA (Shinebourne, 2011). It describes the "dynamic relationship between the part and the whole" (Smith et al., 2009, p. 28). The hermeneutic circle manifests in several ways in IPA analysis. For example, the researcher should consider each section of a participant's transcript (i.e., the part) in the context of the entire transcript (i.e., the whole). But, the meaning of the transcript (i.e., the whole) is made up of the segments contained within it (i.e., the parts). The hermeneutic circle is also reflected in the non-linear nature of IPA analysis (Smith et al., 2009). Throughout the analysis, the researcher

attends to the data at various levels of partialness (e.g., individual words) and wholeness (e.g., the entire dataset) and moves back and forth between them (Laverty, 2008).

Double-hermeneutic. The related concept of the double-hermeneutic addresses the issue that IPA naturally involves two levels of interpretation. The researcher is trying to get as close as possible to the participant's inner world, but access to experience is always dependent on what the participants says about their experience (Smith & Osborn, 2003). To add to the complexity, the researcher has their own preconceptions that influence how they make sense of what the participant says. In short, the double-hermeneutic in IPA refers to the fact that the participant conveys their interpretation of their experience to the researcher, who then conveys their interpretation of the participant's account in a written summary (Smith & Osborn, 2015).

IPA's Idiographic Perspective

The third major theoretical influence on IPA is idiography, which is characterized by an in-depth focus on the particular (Shinebourne, 2011). IPA reflects this idiographic stance in several ways: (a) it is committed to exploring how a *particular* group of people experience a *particular* phenomenon in a *particular* context, and (b) it prioritizes detailed in-depth analysis. This commitment to gathering meaning from individual cases is in stark contrast to large-scale data collection aimed at making population-level claims. Notably, IPA's focus on the particular determines the type of participant sample that is appropriate for an IPA study (see below). In an idiographic approach, the emphasis is not on numbers or group data, but on the new understandings offered through participants' unique perspectives and relationships to the phenomenon of interest. Idiography relates to a particular approach of moving from specific cases to more general understandings (i.e., theoretical transferability; Smith et al., 2009).

In sum, rather than being tied to one particular theory or theorist, IPA reflects a combination of emphases from several theoretical traditions. As will become evident in subsequent sections of this chapter, all research procedures for the current study (e.g., participant recruitment, data collection, and data analysis) were established with careful consideration of IPA's phenomenological, hermeneutic, and idiographic underpinnings.

Participant Characteristics and Recruitment

The intention of IPA research (i.e., illuminating the meaning of a very particular experience for a group of individuals that have shared that experience) naturally requires a relatively homogenous sample. Furthermore, because IPA aims to investigate individual participants' lived experiences in detail (idiographic approach), having a small number of cases is standard practice. A sample size in the range of three to six participants has been deemed appropriate for Master's-level research, although the exact number should depend on the quality and depth of the data from participant interviews (Smith et al., 2009; Smith & Osborn, 2003). The sample for the current study consisted of five adult female breast cancer survivors who identified as having experienced distress during their participation in a clinic-based recovery group program.

Collaboration with the Breast Cancer Supportive Care Foundation

The explanation of how I came to have the opportunity to learn from these five women is important to note. Specifically, the participants in this study were recruited through the Breast Cancer Supportive Care Foundation (BCSCF) in Calgary, AB. BCSCF is a non-profit organization that provides care to breast cancer patients through individual and group support programs. Services at the BCSCF clinic include medical consultation, screening services for people with a family history of breast cancer, and specialized counselling support for breast

cancer patients and their families—all services are provided free of charge (Breast Cancer Supportive Care Foundation, 2014).

The breast cancer recovery group program at BCSCF is a 12-week program for women who have finished primary breast cancer treatment, designed to support their transition from illness to wellness. Each weekly group meeting is three hours long and is guided by two facilitators (psychologists and/or physicians). The recovery group program emphasizes learning and discussion as part of an overarching intention to equip participants "with the information, tools, strategies, and support they require to reconcile their cancer experience and to successfully manage other life challenges as they arise" (Breast Cancer Supportive Care Foundation, 2014). The program reflects a holistic approach to wellness and addresses physical, emotional, relational, and spiritual aspects of wellbeing. Topics addressed within group sessions include managing the effects of treatment, body image and sexuality, loss and grief, fear of recurrence, nutrition and exercise, and enhancing relationships. The recovery groups are closed groups, meaning that the same women (a maximum of 10 participants) meet weekly for 12 weeks.

BCSCF's support of this project is what ultimately allowed me to engage in this work. For many reasons, the barriers to conducting research within the realm of cancer care and psychosocial oncology are significant. The regulations and restrictions around accessing patient populations in Alberta (as regulated by our provincial health body; Alberta Health Services) generally preclude independent Masters-level research involving folks in the cancer care system. This seems to be especially true for students outside of medicine and oncology-specific programs. The barriers to conducting research in this area made it all the more important that BCSCF agreed to enable this project: a project designed to explore a clinical concern with relevance to the broader psychosocial oncology community.

Eligibility Criteria

Participants were deemed to be eligible to participate if they (a) had attended two or more sessions of a breast cancer recovery group at BCSCF within the past five years; (b) experienced emotional difficulty or distress at one or more points during their group participation; (c) were over the age of 18 years; (d) spoke English fluently; (e) were not currently experiencing significant emotional distress.

Only adult, female, English-speaking breast cancer survivors are eligible to participate in BCSCF's recovery group program; thus, most of the above-listed inclusion criteria described all members of the recovery group population. From that population, I recruited participants who had experienced emotional difficulty or distress related to their involvement in the group program. Potential participants who reported that they were experiencing significant emotional distress (at the time of eligibility screening and/or during the informed consent process) were excluded from the study to avoid the potential for any increased distress and/or risk. These participants were immediately provided written referral information for appropriate services and community counselling supports (see Appendix A).

Recruitment Procedures

The recruitment of participants for this study involved a purposive (criterion-based) sampling method (Ritchie, Lewis, Elam, Tennant, & Rahim, 2014). An administrative assistant at BCSCF emailed a recruitment letter to all past participants of their recovery group program (distributed through their email listserv). This recruitment letter (see Appendix B) outlined the aims and general description of the study and invited recipients to contact me directly if they were interested in participating. Letters were emailed to past participants of the recovery group program on a rolling basis. That is, letters were first sent out to those individuals who

participated in the group in 2017, followed by those who participated in 2016, then 2015, etc. The intention of sending recruitment letters gradually was to avoid over-recruiting (i.e., having more participants respond with their desire to participate than could be interviewed in the timeframe of this study). Recruitment ended four months after the initial recruitment emails were sent, when a sample size of five participants had been reached.

A total of 11 women contacted me, either via email or phone, to express interest in participating in the study. In each instance, I introduced myself, reminded the potential participant about the purpose of the study, and described what participation would entail. I then screened the interested participant for eligibility according to the study's inclusion and exclusion criteria (see Appendix A). Of the 11 women who contacted me, eight met the study inclusion criteria. Two women felt that the emotional challenges they had experienced in the group were minimal and/or insufficient for the study purposes, and one potential participant had to be excluded on the basis of ongoing emotional distress (related to cancer recurrence). Of the eight eligible participants, two booked interview appointments but had to withdraw their involvement due to personal emergencies and changed life circumstances (e.g., moving to a new city). Lastly, one eligible participant chose not to participate as she felt that her recollection of her group experience had been severely impacted by treatment-related memory impairments. For the five participants who were eligible and wanting to participate, arrangements were made for a meeting time at a private and secure location on the University of Calgary main campus.

Data Collection: Eliciting Participants' Stories

I conducted an in-person, semi-structured, audio-recorded interview with each participant. At the beginning of each interview, I verbally reviewed the study consent form with the participant (see Appendix C) and highlighted key considerations related to their involvement

(e.g., the aim of the study, participants' rights, relevant contact information, and available counselling supports). As part of signing the informed consent form, participants were invited to indicate whether they wanted to receive a copy of the preliminary study analyses so as to provide feedback. All participants indicated their interest in doing so. As the final step before starting the audio-recorded portion of the interview, participants selected a pseudonym to be used during their interview and in the report of study findings.

As per recommendations from the authors of the IPA methodology (Smith et al., 2009; Smith & Osborn, 2003), the interviews I conducted with participants were semi-structured. Conducting interviews in this way gives participants the freedom to direct the interview towards the most meaningful aspect of their experience and to tell their stories in their own words (Harper & Thompson, 2012). It also allows the researcher to engage participants in a dialogue rather than a strict questioning. Smith and Osborn (2003) recommend the use of an interview guide to facilitate conversation related to the researcher's area of interest (i.e., the research question) and to provide prompts for the participant as necessary. As such, I developed an interview guide (see Appendix D) that included three short demographic questions and seven open-ended questions. These questions and associated prompts were carefully chosen to help elicit the details of participants' experiences of living with and managing difficult emotions as part of their group participation. In accordance with a *funnelling* technique (Smith & Osborn, 2003, p. 62), I designed my interview guide to proceed from the general to the specific. As indicated in the guide (Appendix D), I invited participants to share their experiences with me very generally before inquiring about the details of their emotionally distressing experiences. The hope was that this funneled design would give participants an opportunity to gradually build comfort with me and with the interview process, and that the more general aspects of our

conversation would help to provide context for later, more detailed, descriptions (Pietkiewicz & Smith, 2014). Preparing this interview guide in advance of the first interview also helped me to be intentional about the wording of my questions and to prepare to sensitively handle difficult and potentially charged topics.

At the conclusion of the interview, I gave the participant a handwritten thank you card and a small token gift to express my gratitude for their involvement. I also provided reimbursement (up to $10) for any parking or public transit costs associated with the interview. The duration of the participant interviews ranged from 70 to 105 minutes.

Data Analysis

IPA's in-depth, inductive, and interpretive approach to analysis is aimed at exploring participants' understandings of their own experiences (Smith et al., 2009). The analysis is designed to illuminate the key elements of the phenomenon of interest, while being firmly grounded in the individual participant accounts (Smith & Osborn, 2015). As described by Smith et al. (2009), IPA analysis is "an iterative process of fluid description and engagement with the transcript" (p. 81). Throughout the analytic process, the researcher is interpreting participants' interpretations of their own experience (the double hermeneutic). As such, the final product of the analysis reflects the joint interpretive efforts of the researcher and participants. Although naturally subjective, this final narrative is produced through a systematic, rigorous, and reflective process (Smith et al., 2009).

Reflexive Practice: Addressing My Preconceptions

An essential component of rigorous analysis in any qualitative method is the researcher's ability to critically evaluate the role of the self in the research process (Darawsheh & Stanley, 2014). This concept of *reflexivity* relates to an ongoing process of self-appraisal: It involves the

explicit acknowledgment of how the researcher's position (including preconceptions, beliefs, and personal experiences) influences the research process and outcomes (Berger, 2015). Indeed, various forms of reflexive practice are embedded in the IPA approach (Pietkiewicz & Smith, 2014). The IPA researcher is encouraged to reflect on their position in approaching their research topic, particularly in terms of what they expect to find (Smith et al., 2009).

As introduced in Chapter One, I arrived at the current research question having already amassed some familiarity and experience with the topic. My familiarity came from secondhand exposure (i.e., through my review of the relevant literature) as well as some firsthand experiences (i.e., conversations with breast cancer survivors and care providers). Most notably, I had conducted a pilot study to explore psychosocial oncology professionals' understanding of women's experiences in breast cancer group programs. From the time that I was first approaching the current study, I was keenly aware that the same experiences that brought me to this topic also influenced the lens through which I approached my research question, conducted interviews, and drew conclusions from the analysis. With that in mind, I engaged in several reflexive practices as a way to stay attuned to my own reactions and biases throughout the research process: I maintained an electronic research journal from study inception onwards. This journal included notes about (a) my various exposures to the topic, (b) my early predictions about my study findings, (c) my impressions of my interactions with each participant, and (d) my initial reactions and thoughts as I engaged with each participant's transcript.

Sample of a reflexive process. One of the more consistent aspects of my reflexive practice was my note-taking before and after each participant interview. By tracking my expectations for what I might hear in participants' stories—and how these expectations changed with each subsequent interview—I made my preconceptions explicit. The following list is an

attempt to summarize my preconceptions, as they were recorded in my research journal, prior to meeting with any participants:

- The percentage of breast cancer survivors who experience group-related distress[3] will be small (compared to those who don't).
- For distressed group participants, the group experience will have been memorable and impactful.
- The stories of distressed group participants will reflect known elements of group process (e.g., group cohesion).
- Distressed group participants will have varying degrees of recollection of their group experience (e.g., due to chemotherapy-related memory impairments).
- Distressed group participants' group experiences will be intertwined with their personal challenges in the cancer recovery process.
- Previous trauma is likely to be associated with group-related distress.
- Distressed group participants will have tried to hide their distress to some extent.
- Distressed group participants will be more likely to have dropped out of their group and/or abstained from participating in group-related research.
- Distressed group participants will not have had extensive opportunity to discuss their group experiences.
- The most distressed group participants may choose not to participate in this study (to avoid the potentially upsetting consequences of describing the experience).

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[3] I have used the language of 'distress' and 'distressed group participants' for the purpose of brevity, as all participants endorsed the word 'distress' at the time of eligibility screening.

- Distressed group participants who choose to participate in this study will feel encouraged and validated through the process of sharing their story.

After my first participant interview, I made note of the following impressions and interpretations (which in essence became preconceptions for subsequent interviews):

- Distressed group participants will have had both positive and negative experiences within their group. Thus, they may have intense (and simultaneous) positive and negative feelings about their past group experience.
- Cultural factors can play an important role in participants' group experience.
- Language barriers are a potential source of group-related distress.
- Distressed group participants might be hesitant to speak about the negative aspects of their group experience, for fear that it would have consequences for the group program (e.g., reduced funding).

Overall, by engaging constantly with my own biases and shifting understandings, I aimed to enhance the credibility and transparency of my analytic process. This reflexive practice helped me to ensure that I stayed attuned to the nuances of each participant's story and embraced the aspects of their experience that challenged my preconceptions.

Analysis Procedure

The procedure for data analysis put forth by Smith et al. (2009) offers a helpful and instructive guide to proceeding through the analytic task of an IPA study. That said, the interpretive nature of IPA is such that the analysis should involve "a healthy flexibility", with space for adaptation, intuition, and innovation (Smith et al., 2009, p. 79). Although the guiding texts on IPA analysis (Smith et al., 2009; Smith & Osborn, 2003) make it very clear that the proposed steps to analysis are not intended to be prescriptive, my own analytic process for the

current study did align closely with Smith et al.'s steps and strategies. As such, I present a personalized overview of these steps here, while encouraging the reader to refer to Smith et al. for a more detailed description of the involved procedures. I also provide some abbreviated samples of my analysis for one participant ('Wendy') for added clarity.

Step 0: Preparing for analysis. Prior to analysis, I transcribed my interview recordings verbatim at the semantic level (i.e., all spoken words, pauses, laughter, interruptions, etc.). At this stage, I removed any information that could identify the participants or the people they spoke about (e.g., group members, family members' names, names of workplaces). When a participant referred to another person by name, I replaced the name with a pseudonym. Although a time-consuming task, I committed to transcribing all five interviews myself to help me begin the process of immersing myself in each participant's story.

Step 1: Building familiarity with the individual stories. Analysis officially began as I familiarized myself with the first participant's story. Having transcribed the interview myself, I was able to imagine the participant's voice when I read and re-read her interview transcript. This sort of sensory engagement in subsequent readings enables a more complete analysis (Smith et al., 2009; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). To help me maintain my focus on the participant's experience, rather than being distracted by my own reactions and ideas, I made use of my research journal as a place to record my initial impressions. The emphasis in this initial stage of analysis was on "entering the participant's world" (Smith et al., 2009, p. 82).

Step 2: Examining the individual stories. Having become intimately familiar with the interview transcript, I began to make notes of elements of interest within it. This stage involved producing detailed notes and comments at several levels (Smith et al., 2009):

- *Descriptive comments*, which focus on the content of what the participant said. These comments are intended to summarize and bring attention to what seem to be the most important aspects of the participant's experience.
- *Linguistic comments* examine the participant's use of language (e.g., laughter, repetition, use of metaphors), which can deepen the researcher's understanding of the participant's emotional state and/or sense-making process.
- *Conceptual comments*, which extend the annotation to a more reflective and interpretive level. These comments start to shift the focus from the participant's exact words and specific experiences to a more overarching look at the broader meaning that these experiences seem to hold for the participant.

Through a process of annotating the participant's entire transcript at these three levels (see Table 1), the analysis moves from descriptive summaries of the participant's experience to preliminary questions and interpretations. Here, the researcher is adding depth to the analysis: engaging with the text in a more reflective way and maintaining an openness to a broad range of possible meanings and interpretations (Smith et al., 2009).

Table 1

Sample of Initial Notation Process

Original Transcript	Initial Notations
Interviewer: And then once you were in the group, what was your general experience of being in the group?	
Participant: So, <u>initially I had really high hopes</u>. Like <u>I laid my cards on the table</u> and I was really open and talked about my fears, and that kind of stuff. <u>But as the group went along, I started to shut down</u>. And the only reason I finished the group was because I'm a person that's committed and because I felt like it would help…the	- Optimism about group involvement - Metaphor: cards on the table; *image of openness, trust, transparency* - Felt "shut down" over the course of the group - Felt obligated to continue; *sense of*

research and whatever. I knew they spent a lot of money. But I actually started feeling kind of rejected. Because I was in the grieving process, to be honest, and laying my cards on the table. And then there was one participant that would say to me, "well if you would just think positive, everything will be better. I just think positive and everything is good". And she'd come in and hug everybody… and I really felt shut down to go to the spot of trauma. So I started feeling like I didn't have permission in the group to do that. So I just kind of sat there and I felt… I felt almost more lonely. Because I thought, why I am in this group where I thought people would relate, but we're not allowed…we can't really get into any of the … like, it's, "well if you just think positive". And I felt like I was defending myself. Because I'd go, "well I am a positive person". And if you know me now […], I'm an *extremely* positive person. But I felt put down, to be honest.	*responsibility and/or indebtedness?* - Shifted away from openness, honesty, vulnerability; *quiet rejection* - Alone in the grieving process - Contrast between her coping and another member's coping - *Shut down by the superficiality of group member interactions?* - Worsened loneliness; *unexpected isolation?* - Expectation of shared experience / perspectives among group members - Other group members unwilling *(or unable?)* to meet her in the depths of grieving - Felt the need to defend herself; *felt that her way of coping was being disregarded / misunderstood by other group members*

Step 3: Developing themes within the individual stories. Having annotated the participant's transcript, my attention shifted to developing *emergent themes*. These emergent themes are concise phrases intended to capture the depth and complexity of the participant's experience while reducing the quantity of data. Smith et al. (2009) note that at this stage of analysis, the researcher works primarily with the initial notations, rather than the transcript itself. Although slightly more abstract than my initial notations, I was careful to ensure that the emergent themes I developed were firmly grounded in the particulars of the participant's lived experience. This balance reflects the nature of IPA as a descriptive and interpretive endeavor.

As recommended by Smith and Osborn (2003), I noted the emergent themes in the opposing margin of the transcript from my initial notations (see Table 2). I developed an average of 150 emergent themes per participant and worked closely with my research supervisor to confirm that the emergent themes were both conceptually appropriate and reflective of the participant's descriptions.

Table 2

Sample of the Development of Emergent Themes

Emergent Themes	Original Transcript	Initial Notations
	Interviewer: And then once you were in the group, what was your general experience of being in the group?	
Unmet expectations Shutting down Felt sense of obligation to the group Rejection Loss of confidence in sharing Loneliness in the group Unmet hope for shared understanding Lack of group permission to explore trauma of cancer	**Participant**: So, initially I had really high hopes. Like I laid my cards on the table and I was really open and talked about my fears, and that kind of stuff. But as the group went along, I started to shut down. And the only reason I finished the group was because I'm a person that's committed and because I felt like it would help…the research and whatever. I knew they spent a lot of money. But I actually started feeling kind of rejected. Because I was in the grieving process, to be honest, and laying my cards on the table. And then there was one participant that would say to me, "well if you would just think positive, everything will be better. I just think positive and everything is good". And she'd come in and hug everybody… and I really felt shut down to go to the spot of trauma. So I started feeling like I didn't have permission in the group to do that. So I just kind of sat there and I felt… I felt almost more lonely. Because I thought, why I am in this group where I thought people would relate, but we're not allowed…we can't really get into any of the … like, it's, "well if you just think positive". And I felt like I was defending myself. Because I'd go, "well I am a positive person". And if you know me now […] I'm an *extremely* positive person. But I felt put down, to be honest.	- Optimism about group involvement; *unmet hopes?* - Metaphor: cards on the table; *image of openness, trust, transparency* - Felt "shut down" over the course of the group - Felt obligated to continue; *sense of responsibility and/or indebtedness?* - Shifted away from openness, honesty, vulnerability; *quiet rejection* - Alone in the grieving process - Contrast between her coping and another member's coping - *Shut down by the superficiality of group discussions?* - Worsened loneliness; *unexpected isolation?* - Expectation of shared experience / perspectives among group members - Other group members unwilling *(or unable?)* to meet her in the depths of grieving - Felt the need to defend herself; *felt that her way of coping was being disregarded / misunderstood by other group members*

Step 4: Connecting themes within the individual stories. This stage captures the researcher's process of organizing (or 'mapping') the emergent themes within the transcript into a more meaningful structure that reflects how the various themes relate to one another. Given that I worked with my data electronically, my first task involved listing all of the emergent themes in chronological order (i.e., the order they appear in the transcript) in a Word document. I then began to group them into clusters of related concepts. In doing so, I relied most on two of six strategies that Smith et al. (2009) offer as potential ways to organize emergent themes:

- *Abstraction*, in which related emergent themes are grouped together under a new 'superordinate' theme.
- *Subsumption*, in which one emergent theme becomes superordinate and other closely related themes are then classified under it.

As Smith et al. (2009) point out, this stage of analysis demands that the researcher be explorative and innovative in deciding how best to organize themes to highlight the most important aspects of the participant's account. In deciding which emergent themes to discard and which to keep, I was careful to maintain an awareness of my original research question. The dynamic nature of IPA analysis also meant that these decisions could be temporary, as I had the freedom to return to this task and make adjustments after analyzing subsequent transcripts.

Following the recommendation of Smith et al. (2009), once I felt comfortable with the patterns I had identified among emergent and superordinate themes, I created a graphic representation of these thematic relationships (see Appendix E). At the same time, I started to compile relevant transcript excerpts for each theme to (a) confirm that the thematic organizational structure made sense when considering the participant's own words and (b) facilitate the later task of writing the final narrative.

This entire process of reading and re-reading, making initial notations, and developing and organizing emergent and superordinate themes (i.e., Steps 1 to 4) is intended to be completed for each transcript before any attempt is made to compare participant cases (i.e., Step 5). I was fortunate in that the significant time between my participant interviews (from several weeks to a month) helped me to distance myself temporarily from the previous participant's story so that I could really honour the uniqueness of each subsequent participant. The practice of tracking my impressions and new assumptions after each interview (as described above) also helped me to be transparent and reflective about the ways I was inevitably influenced by each participant encounter. Doing justice to the individual stories, rather than jumping right away into a compare and contrast mindset, is essential to IPA's idiographic commitment (Smith et al., 2009).

Step 5: Looking across the individual stories. In this fifth stage of analysis, the researcher engages in the creative process of looking at patterns across all of the emergent and superordinate themes from all participant cases. This process involves integrating, combining, reordering and/or relabeling of existing themes to create a master summary of themes for the entire participant sample. Once again, I followed Smith et al.'s (2009) recommendation to represent the outcome of this step in table form (Table 3, p. 60). This master table offers a visual depiction of the superordinate and lower-level themes for all participants.

It was at this stage of analysis that I emailed the findings to participants for their comments and feedback. Only one participant responded with additional comments about her group experience: She echoed a suggestion she had made during her interview, which was that it would be helpful for individual counselling support to be offered to distressed group participants after their group involvement. She also commented that the study findings (as they were summarized) were highly reflective of her own experience.

Step 6: Writing the narrative account. Although Smith et al. (2009) describe the writing stage separately from the rest of the analytic procedure, I conceptualized it as the final step of my analysis, in that the narrative account represents the culmination of the researcher's efforts to make sense of what the participants have said. The focus here is on presenting the findings intelligibly to the reader, through a very intentional combination of analytic commentary and direct excerpts from participants. Indeed, the final narrative should read as a natural weaving of the voices of participants and researcher (Smith et al., 2009). In this way, the narrative account for the current study reflects a collaborative effort (between myself and the study participants) to help the reader get a sense of the participants' experiences.

Overall, the analytic procedures for the current study reflected the core IPA process of moving from the particular to the shared while remaining grounded in the individual stories. Although I abided by a sequence of published steps for IPA analysis (Smith et al., 2009; Smith & Osborn, 2003), I am cognizant of the important role I played as the researcher in making the ultimate decisions and interpretations in the data analysis process. I have attempted to reflect this awareness consistently and visibly throughout this report.

Ethical Considerations

At every stage of this study, I was highly attuned to issues related to participants' wellbeing and privacy. Although I address these considerations throughout this thesis, I have chosen to highlight several examples of steps that I took to protect participants from the minimal risks associated with participation in this study.

First, the process of recalling personal experiences, especially distressing experiences, has the potential to be tiring and/or upsetting for participants. As such, I advised all participants of these potential risks prior to their participation. I also provided them with a general

description of interview topics in advance of the interview so that they were aware of the topics to be discussed. In addition to providing contact information for accessible counselling supports in the study consent form (Appendix C), I highlighted this information in each informed consent discussion and reminded participants prior to the interview that they could take breaks, stop the interview, and/or end their study participation at any time without consequence.

To enhance participant privacy, I employed intensive security measures to protect all study data (e.g., contact information and de-identified data were stored in physically separate secure locations to further ensure that data could not be linked to individual participants). I also designed all recruitment and data collection procedures such that BCSCF physicians and staff would not know which past group participants contributed to the study. This was made explicit in the study recruitment letter (Appendix B). Particular care was also given to exclude any information from the final report that would make it likely for anyone, including BCSCF staff, to identify participants.

All aspects of this study were reviewed and approved by the Health Research Ethics Board of Alberta – Cancer Committee (HREBA-CC) and the Breast Cancer Supportive Care Foundation's Ethics Review Board.

Evaluating Quality of IPA Research

Beyond ethical considerations, the question of quality in qualitative research is complex and debated, as exemplified by the many terms used to refer to quality in qualitative research (Hays & Singh, 2012). As stated by Rolfe (2006), "… the real issue is not whether a universal standard for judging the validity of qualitative research has or has not been argued, but rather, why so many different positions should remain not only viable but also fiercely contested" (p.

306). Arguably, individual studies should be evaluated based on criteria that align with the methodological approach being used (Harper & Thompson, 2012).

In the guiding text on IPA methodology, Smith et al. (2009) recommend the use of Yardley's (2000) criteria for enhancing and assessing the quality of IPA studies. Yardley's four criteria—referred to as guiding principles—include (a) sensitivity to context, (b) commitment and rigour, (c) transparency and coherence, and (d) impact and importance. Readers can thus consider the quality of the current study according to these four criteria.

Yardley's (2000) first criterion, *sensitivity to context*, refers to the researcher's sensitivity to existing literature on the study topic, to the sociocultural context of the study, and/or to the experiences of the participants themselves. This sensitivity can be demonstrated at various stages of the research, from selecting IPA as the study's methodology (which honours individual participants' unique challenges) to engaging sensitively with participants in the interview process. Smith et al. (2009) highlight that the inclusion of participant quotes in the final report of an IPA study demonstrates a sensitivity to the original materials obtained from participants.

The second criterion, *commitment and rigour*, refers to the thoroughness and completeness of data collection and analysis (Smith et al., 2009; Yardley, 2000). As Yardley describes, this practice often involves prolonged engagement with the topic and immersion in the study data. In IPA research specifically, the researcher's commitment manifests in the careful selection and recruitment of an appropriately homogenous study sample (often requiring significant time and dedication), and in the researcher's focused attunement to the participants' words, both during the interview and in the analysis afterwards (Smith et al., 2009).

The third criterion, *transparency and coherence*, relates to the clarity with which the researcher describes the details of the research process (Yardley, 2000). Providing reflexive

commentary (e.g., regarding preconceptions) and details of all data collection and analysis procedures (e.g., recruitment, interview procedures, analytic steps) indicates that the researcher is prioritizing honesty and transparency in their research conduct (Emden, Hancock, Schubert, & Darbyshire, 2001). Coherence in IPA research also relates to how well the described research procedures fit with the theoretical assumptions of IPA (Smith et al., 2009; Yardley, 2000).

Lastly, Yardley's (2000) criterion of *impact and importance* refers to whether the study offers interesting or useful contributions to theory, practice, and/or the community for whom the findings were intended to be relevant. Health-related research has an advantage in this domain, in that participants' experiences of problems and issues can easily produce creative ideas and solutions for clinical application (Yardley, 2000).

Summary

In this chapter, I provided an in-depth explanation of my choice of IPA as the methodological approach for the current study and offered a concise summary of IPA's theoretical underpinnings. I described the details of the study design (i.e., participant recruitment, data collection, and data analysis), including examples to demonstrate the analytic procedures. The methodological details and considerations (i.e., considerations related to ethics and research quality) described in this chapter serve to contextualize the findings presented in Chapter Four.

Chapter Four: Findings

This chapter is dedicated to the presentation of the results of my analysis of women's experiences of emotional distress related to their involvement in a breast cancer recovery group. As outlined in Chapter Three, the description that follows (i.e., the narrative account) reflects a weaving of participants' stories and words, summarized and integrated to reflect my own interpretation of the participants' experiences as they were described to me. To begin, I provide an overview of the demographic information of study participants. The rest of the chapter is dedicated to the narrative account that addresses the study research question: How do breast cancer survivors experience and manage group-related emotional distress?

Participant Demographics

The five women who participated in this study ranged in age from 51 to 70 years, with a mean age of 60 years. All five participants reported being married or in a long-term partnership. All participants also reported having children (children ranged from adolescents to adults). The women had all participated in a recovery group program at BCSCF within the past five years and had continued to attend their group until the end of the 12 weeks (i.e., none had left the program part way through).

In the following section, I provide a brief introduction to each participant, including a summary of how they came to be involved in a group program following breast cancer diagnosis and treatment. This information serves to contextualize the participants' respective contributions to the narrative account that follows.

Kim

Kim is a South-Asian woman in her 50s. With the exception of her husband, she has no family in Canada, as all of her family lives in China, her country of origin. English is not Kim's

first language, which led her to experience significant challenges in navigating the healthcare services she received in Canada following her breast cancer diagnosis. In the time following her surgery, she sought out numerous programs and classes through Calgary's cancer centre and cancer-focused support agencies. Through her involvement at these clinics and agencies, Kim became acquainted with several women who strongly recommended that she participate in BCSCF's recovery group program. Kim's participation in the group program occurred approximately one year following her diagnosis, within the first year after her treatments.

Carol

Carol is a Caucasian woman in her early 70s. As soon as she was diagnosed with breast cancer, a colleague recommended that she seek support from BCSCF. At BCSCF, she received what she felt was exceptional care from the physicians and medical staff. However, after two years had passed since her diagnosis, Carol's perception was that she was still "nowhere close to getting better". As she described, "I needed help! I needed help to recover and I wasn't getting very far". She decided to join the recovery group on this basis.

Wendy

Wendy is a Caucasian woman in her early 50s. Soon after her diagnosis, several of Wendy's closest friends, who had also had breast cancer, recommended the services at BCSCF and the recovery group program in particular. Wendy had had an extremely positive experience in a non-cancer related group support program prior to her diagnosis and was optimistic that the recovery group would provide her with a similar sense of "connectedness" and opportunity for "normalizing". Wendy participated in the recovery group program during the first year following her breast cancer treatment.

Annie

Annie is a Caucasian woman in her mid 50s. While receiving chemotherapy treatment following her breast cancer diagnosis, Annie was referred to BCSCF through her oncologist's office. Through her work with a physician at BCSCF, she then learned of the opportunity to participate in the recovery group program. Annie participated in the recovery group within the first several years after her active treatment (exact timing unspecified).

Margo

Margo is a Caucasian woman in her early 70s. During the early phases of her breast cancer recovery process, Margo was seeking support from a physician at BCSCF. The physician recommended the recovery group to her. Margo was immediately attracted to the idea of finding "some support", with the hope that the group might provide "an extra push and an extra crutch to lean on" as she continued in her recovery. Margo's participation in the recovery group program occurred within the first year following her diagnosis. At the time of starting her group participation, Margo was only two months past the end of her treatment.

Participants' Experiences of Group-Related Emotional Difficulty: The Findings

My analysis of the participants' accounts resulted in three overarching themes: (a) *Contextual Challenges and Distress*, (b) *Group-Related Challenges and Distress*, and (c) *Coping and Healing*. These broad overarching categories capture a total of 11 superordinate themes, as is depicted in Table 3 (p. 60). The 11 superordinate themes reflect the most salient aspects of participants' experiences as they described them to me. Not all of these superordinate themes would necessarily apply to any one participant. Rather, the superordinate themes capture both the intersections and idiosyncrasies of the participants' accounts. In establishing these final superordinate themes (which I developed from a total of 78 superordinate themes from

Table 3

Summary of Overarching, Superordinate, and Subthemes

Overarching Theme	Superordinate Theme	Subthemes
Contextual Challenges and Distress	Trauma and Loss	Trauma and Loss in Childhood Trauma and Loss in Adulthood Cancer-Related Trauma and Loss
	Physical Impacts of Diagnosis and Treatment	
	Social Impacts of Diagnosis and Treatment	
	Emotional Impacts of Diagnosis and Treatment	Shock Vulnerability Fear Worry Isolation
Group-Related Challenges and Distress	Disconnects from the Group	Disconnect from Other Group Members Disconnect from Group Content Disconnected by Cultural Contrasts
	Disruptive Group Member(s)	
	Taking On Others' Pain	
	Intensity of Disclosure and Self-Reflection	
	Confronting One's Mortality	
Coping and Healing	Healing through the Group Experience	Applying Strategies and Lessons from the Group Helpfulness of Group Sharing and Processing Importance of Group Member Connection
	Drawing on Individual Resources	Using Specific Skills and Strategies Seeking Other Supports Strength through Faith Engaging in a Sense-Making Process

individual participants' transcripts), I divided several of the superordinate themes into subthemes to capture more detailed and nuanced meanings from the individual accounts. For example, the superordinate theme 'Trauma and Loss' includes three subthemes: (1) Trauma and loss in childhood, (2) Trauma and loss in adulthood, and (3) Cancer-related trauma and loss. Table 3 reflects the complete list of overarching themes, superordinate themes, and their subthemes. The narrative account that follows is structured accordingly. The themes are not listed in order of importance; rather, I chose the order of presentation according to what I felt would be most meaningful and clear for the reader.

Theme 1: Contextual Challenges and Distress

As participants spoke of their experiences in the recovery group, they regularly wove in references to their life history and circumstances outside of the group environment. Their rich descriptions of the challenges, traumas, and losses they had faced—or were facing at the time of their group involvement—offered a clear demonstration that their group experiences ought to be considered as experiences-in-context. This overarching theme focuses on the relevance of participants' personal losses and challenges to their experiences of distress in the group context.

Trauma and loss. In describing the personal and emotional contexts that surrounded their group involvement, participants disclosed major losses and traumas[4] that they had faced in their lifetimes, from the time of early childhood to co-occurrence with their group participation. Although the timelines and the exact nature of their losses varied, these stories of grief, pain, and suffering served to provide important context—either implicitly or explicitly—for the ways that participants experienced the group process.

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[4] The word 'trauma' is not used in a clinical or diagnostic sense, but rather to mirror the words that the participants themselves used to describe their subjective experiences.

Trauma and loss in childhood. Several participants identified particular early life experiences, either single events or ongoing challenges, as having had important and lasting consequences for them. Carol, referring to her intensive childhood fear that she would be taken away from her family, explained, "I didn't want to lose them. So I was constantly protecting them, thus becoming a major caregiver. I was fearful of the […] world." Margo's words echoed the idea that several women in the group carried fears rooted in childhood traumas: "Some of us had traumatic childhood experiences. Myself and one other had separation anxiety […] the trauma of that stays with me to this day." Annie described her history as a "hell ride". As she summarized, "My house burnt down when I was a little kid, my parents divorced, all of my sisters and myself were sexually abused and my mom would not believe us. Yeah, just a life of loss."

Trauma and loss in adulthood. All five participants spoke of the challenges and losses they had experienced in adulthood (outside of their cancer experience). For some, they spoke of a particular "traumatizing experience" (Margo) such as the aftermath of an abusive partnership (Margo), the sudden death of a sibling (Annie), or an accident causing significant physical injury (Annie). For these women, the consequences of their past traumas were long lasting, including "horrible pain" (Annie) and carrying the weight of "psychological and post-traumatic issues" (Margo). For Carol, the experience of having been divorced suddenly by her partner left her highly attuned to issues of rejection in her life:

> I broke down. It was very difficult for me, my heart was broken. I was rejected. And I had never been rejected. […] Being 40 years old [*age changed*] and being told 'I don't love you any more and I'm leaving, I'm out of here'.

While Carol's loss had occurred many years prior to her group participation, others had lost loved ones more recently. Three participants (Wendy, Annie, and Margo) experienced the death of a parent in the time immediately leading up to / during their own diagnosis and treatment. These parental deaths left some participants feeling "overwhelmed with the feelings of the loss" (Wendy), as the loss of a parent was then compounded by the losses involved in cancer diagnosis and treatment.

Cancer-related trauma and loss. For all of the participants, the process of being diagnosed with and treated for breast cancer came with losses of incredible magnitude. Participants explicitly referred to their cancer experience as trauma, describing it as a "traumatic, life-altering event" (Margo) and explaining, "it's like PTSD" (Annie). Wendy even coined the term "post-traumatic chemo disorder" to capture that the treatment process involves "going through trauma" and "a lot of losses", with immense threats to one's physical body and emotional safety. She explained, "It was the grieving of my health, it was the uncertainty of life, and it was facing my mortality. So all of that was very overwhelming." For several participants, the cancer experience left them battling the pervasive ways in which cancer impacted them "emotionally and physically" (Kim). Carol described that for her, the far-reaching impacts of her cancer were confusing and overwhelming:

> I didn't like some of the words like you 'fight' cancer, but you know, you really do have to fight cancer. What the cancer did to your brain. What it did to your feelings. What it did to your skin. What it did to your body image. And yet, you know, of all of the things, having my breast cut off wasn't such a big deal. It was diseased, it was rotten. It needed to come off. That makes sense to me. But all of the other stuff didn't make sense.

For Kim, the problems she was facing surrounding her cancer and its impacts on her relationship with her family members left her so overwhelmed that she experienced suicidal ideation around the time of the group: "I even thought I should end my life at that time […] because I had no ability to face these problems, you know? [*tearful*]" These accounts highlighted participants' conceptualization of cancer as trauma and introduced some of the ways in which cancer had impacted every domain of their lives. Further, these impacts of cancer meant that some participants arrived to their groups in a state of fear and hypervigilance that led them to be triggered by one or more aspects of group involvement. For example, simply being in a room with a group of other people was triggering at first for one participant (Carol) who was dealing with fears of contamination after chemotherapy: "It was overwhelming. Just the change. I mean, I could hear people breathing in the room."

Overall, participants' experiences of trauma and loss (across the lifespan and within the context of cancer) seemed to contribute in important ways to their distress in the group context. Specifically, the past challenges and losses they had experienced left several participants feeling overwhelmed at the time of their group participation and/or caused them to experience distress in response to specific triggers in the group environment. Feeling rejected, feeling silenced, listening to other women's stories of abandonment—all are examples of triggers that participants described that were either subtly or explicitly connected to their personal histories. Even outside of the issue of trauma, the vast (a) physical, (b) social, and (c) emotional consequences of cancer diagnosis and treatment clearly had important implications for participants' within-group experiences, which I describe in the next three sections.

Physical impacts of diagnosis and treatment. At the time they participated in the recovery group program, all five women were still coping with physical changes related to their

cancer treatments. For several participants, their physical symptoms had made the group experience particularly difficult: pain, chronic fatigue, "chemo brain" (cognitive dysfunction associated with chemotherapy), nausea, and exhaustion all added to the difficulty of getting to the group and rising to the emotional challenge of the group work. As Kim summarized, "everywhere is painful, you know?" This sentiment was echoed by Margo: "I was having so much pain, residual effects of the chemo and possibly radiation […] and that probably contributed too to my, sort of, emotions." For Carol, it was chronic fatigue that had the greatest impact on her group involvement: "Like you just didn't even want to go. You're motivated, but your body won't listen." Lastly, some participants were arriving to the group with a reduced sense of confidence and self-esteem as a result of the physical changes they had experienced, as Wendy emphasized: "Cancer was very very difficult on my self-esteem […] because at that time, I had no breasts, no hair. So I was feeling like I was trying to centre myself again and feel like a woman."

Social impacts of diagnosis and treatment. In addition to the physical consequences of breast cancer, two of the participants were dealing with major social ramifications of suddenly becoming "sick". For Kim, her diagnosis was met with messages of blame from many of her close friends, specifically those from a Chinese cultural background: "They think that breast cancer is a very ugly thing, you know […] Maybe you didn't marry? Maybe you didn't have children? I don't know why they had the license to judge me." Wendy's diagnosis resulted in a painful loss of friendships too, in that many of her friends "didn't know how to cope with this": "It makes you feel like nobody likes you anymore. People are afraid of you when you have cancer." For Wendy, this meant that upon entering the recovery group, she was "feeling a lot of rejection and feeling alone in terms of friends".

Emotional impacts of diagnosis and treatment. Participants shared that in the months and years following their treatments, they were in uncharted waters emotionally. As one participant (Margo) summarized, chemotherapy and radiation caused "emotional pain" beyond the physical symptoms. In describing the emotional consequences of diagnosis and treatment, participants highlighted their experiences of shock, vulnerability, fear, worry, and isolation.

Shock. Most participants explicitly mentioned shock as one of the major reactions that occurred for them following their breast cancer diagnosis. Margo commented, "It was shock and awe probably in the beginning. Awe in the sense that it can't be happening to me, I don't believe this is happening to me." For some, the shock was relevant beyond the immediate news of diagnosis and continued into the time that they were involved in the group. Wendy explained that for her, the "state of vulnerability and shock" lasted "for a year".

Vulnerability. Three of the participants (Carol, Wendy, and Annie) emphasized that their state of "fragility" (Annie) and "vulnerability" (Wendy) had particular implications for their group experience. For Carol, her state of vulnerability left her feeling uncertain about the group process and led the group experience to feel "a little bit intimidating". She explained, "I was very vulnerable when I was sick. And I wasn't really sure how much I could disclose, or not disclose. I didn't know these people […]." Wendy commented that she felt breast cancer leaves women "in such a vulnerable spot", which Annie echoed in stating, "you're already mentally fragile".

Fear. Fear of cancer recurrence and fear of death were very powerful for several of the participants at the time of their group involvement and in many ways, it surrounded their group experience. Margo explained that going into the group, she felt like cancer was going to "drag

me down and carry me away". She said she was "looking over my shoulder all the time" and "filled with anxiety". As Wendy stated, "fear was huge for me".

Worry. Associated with participants' fear for their own lives was the experience of worrying for their family members, particularly their children. As Annie described, it was horrible to watch her loved ones be "destroyed and distraught" in response to her diagnosis and treatment; She worried about the impacts on them. "I was so worried about hanging in there for them that I wasn't hanging in there for me" (Annie). Kim too said she was "so worried" for her daughter. Wendy, who was dealing with cancer not long after losing her mother, said, "I was emotionally drained with my Mom dying. And it was 50 times worse when you're worried about your own children and your own family."

Isolation. Four of the participants referred to being isolated in their emotional experience in some way. For Kim, this was the result of both the physical distance from her family and friends and certain Chinese cultural norms around emotional expression. She explained that "the Chinese way" included the expectation that personal problems be kept to oneself: "Even family problems, in our culture, we never talk to outsiders […]. We don't want to speak outside. Because you know, back in our country, everybody would point at you, judge you" (Kim). Although Annie was not physically separated from her children, she intentionally hid her emotional reactions from them to protect them: "I would 'happy face, everything is fine', then the kids would walk out the door to school and I would start crying." Others expressed that they felt isolated as a result of their friends and family being unable to fully understand their cancer experience. Carol reflected, "Unless you've gone through that experience, I don't think people understand what it feels like." Thus, although for different reasons, many of the participants had felt isolated in their emotional experience: "You really feel alone in your emotions" (Wendy).

Theme 2: Group-Related Challenges and Distress

This second overarching theme encompasses the various group-related factors and processes that participants described as being sources of distress for them during their group participation. Overall, participants spoke about inter-member dynamics; less so about the facilitators of their groups. When the participants did speak about their group facilitators, their comments were generally very positive. For example, Annie said, "Our leaders were wonderful…" and Carol commented, "I trusted them". In describing the group-related distress they experienced, participants made explicit connections to their pasts, illuminating the ways in which contextual factors (described above) served to intensify their reactions to the challenges that arose for them during their group involvement. For example, Carol's experience of being waitlisted and excluded from an earlier round of the recovery group program brought up familiar and unwelcome feelings of rejection related to her divorce many years earlier: "It was traumatic. Very traumatic for me when I found out that I couldn't be in this class. I was rejected. […] I was not okay." Indeed, a particularly striking pattern in participants' accounts was that many of the aspects of the group that they found distressing were those that caused them to experience emotional reactions (e.g., feelings of vulnerability, fear, isolation) that seemed to have been sensitized by their cancer experience or past losses.

Disconnects from the group. For several participants, the experience of feeling closely connected to a group (i.e., the women in their recovery group) was powerful and therapeutic. Unfortunately, the reverse was also true: Participants who felt disconnected from the group in some way—disconnected from the other members and/or from the group content—had to navigate the emotional consequences of being unintentionally excluded.

Disconnect from other group members. The experience of feeling "on a different page" (Wendy) from other women in the group occurred for a few participants, but at different levels of intensity. Annie described that the women in her group "were completely different" from one another, had very "different outlooks", and took extremely different approaches to treating their cancer. Regardless, Annie felt that they "got close very fast". Kim too spoke about various ways in which she was different from the other members of her group, which she referred to as the "local people, Western people", in contrast to her Chinese heritage. More specifically, Kim felt that she was an exception in some ways; for example, in not having nearby social supports. Wendy's experience of feeling that "there was a mismatch" between herself and the other women in her group had more severe emotional consequences, leaving her feeling "more isolated", "more lonely", "rejected", and "put down". Wendy described the disappointment she felt in realizing that the other women in her group were in "a different spot" than she was in terms of their desire or readiness to discuss the difficult aspects of cancer recovery:

> I was in the grieving process, to be honest, and laying my cards on the table. I thought other people would feel that way too, be in the same place. But in this group, it was very much, 'let's just be friends, and hug each other' […] I felt like I would kind of scare them if I brought up anything deep.

She explained, "the magnitude of it [the cancer] was not the same for them as it was for me. We were in totally different places. And framing it differently." As a result, Wendy "felt shut down to go to the spot of trauma". She became tearful while sharing with me that reminders of the experience left her feeling "like the ugly duckling" and "an outsider" even after years had passed since her participation in the group program. Wendy concisely articulated that the rejection she felt within the group context had compounded the existing social consequences of

her cancer diagnosis: "…the cancer I felt a rejection from, and then the group I felt a rejection from." Adamant that the disconnect "wasn't anyone's fault", she clarified, "It's not that I feel like I don't like anybody in the group. It's not that. It just didn't meet my need, and it caused me extra pain." Wendy offered the suggestion that she, and likely others, "would have benefited from individual counselling to process those triggers from the group" and recommended that "scheduled individual counselling" be offered and encouraged following the group program.

Disconnect from group content. Some of the same hopes and expectations for the group that led Wendy to feel disconnected from other members also left her disappointed by the group's emphasis on what she felt were the more superficial aspects of recovery (e.g., nutrition and exercise). Her hope had been that they would more directly address "grief and loss, sort of, and self-care, and dealing with the trauma. So that was kind of the way I came into it." Paradoxically, the experience of feeling disconnected from the other group members meant that by the end of the group meetings, Wendy did not feel supported enough to engage in some of the group activities that did address some of the deeper topics: "I was like, nobody can relate to me, I'm not going to be honest. I was done. I just did not want to do this memory box. Because I didn't feel supported." Other participants struggled with the group materials in different ways, from finding that the quantity of at-home exercises was "a bit much" (Carol), to noticing that some of the informational content (e.g., nutritional recommendations) had limited cross-cultural applicability (Kim).

Disconnected by cultural contrasts. Although largely captured in the above subthemes, it seems important to note that for three of the participants (Kim, Carol, and Margo), cultural variables, including language barriers, added to the complexity of the challenges they experienced in the group. Kim explicitly stated that certain aspects of the group were difficult

for her "because of the language barriers". She explained that at some points, the group content became "very hard to follow". As described earlier, Kim was also dealing with the stark contrast between the group norms (of open sharing) and the messaging she received from her family and Chinese cultural community: "Being Chinese here is a very difficult situation. First, our English. Second, our culture. […] My husband, the Chinese way of thinking, thinks 'everything should be inside, don't complain too much'." Relatedly, Margo noted that her cultural background had added to the difficulty she experienced when disclosing about the darker aspects of her childhood: "I didn't grow up in a culture of hugs and bare your soul. I grew up in a culture of stiff upper lip and you know, keep it under wraps and just zip it, right? And move on."

Disruptive group member(s). Another source of distress for participants was the presence of "difficult women" (Annie) in a group. For Annie, this seemed to be the most distressing element of her group experience. She described that one person in her group was "a bully" with "no regard for what anybody else was going through" and who "just bulldozed over". Annie explained that her empathic tendencies made it "very distressing" to observe the effects of this person's insensitivity towards the circumstances of other women in her group. She described the impact of this one participant on the group as "disruptive" and "damaging". Although she acknowledged that her group facilitators made every reasonable attempt to mitigate the impact of this person's behaviour on the group process, she suggested that additional procedures need to be put in place:

> I think there should be some sort of recognition of people that are damaging the morale of the group, and I think that they should kick them out. I really do. Because this was devastating for this group.

Taking on others' pain. Even participants who did not feel closely connected to their fellow group members described that they felt sadness in response to other group members' pain and losses. Often this sadness related to health changes that had occurred for group members, such as metastasis of their cancer. For example, Kim described the horrible sadness that came from having multiple group members discover brain metastases, and Wendy described that she often "left [group meetings] feeling really sad" for the physical losses experienced by some of her group members. For participants who felt a strong "bond" (Margo) within their group, they were particularly attuned to the ways in which they had felt the pain of other members. Margo offered insight into this experience:

> I felt some of their…it was like we cried together almost. Somebody would tell their story and break down or… the rest of us would hear the emotion in their voice and feel their pain.

Annie, who described herself as "an empathy sponge", acknowledged that this experience of taking on others' pain is something she had dealt with in the past. She commented, "I'm kind of sponge-like […] and so I have to really watch myself or I take on everybody else's grief."

Intensity of disclosure and self-reflection. In addition to the pain of hearing about others' losses, for some, the group involved a difficult process of deep excavation, in which the women "dug deep into their psyches to bring out the things that had really been upsetting and distressing, not just with the cancer, but in their lives, on their journey" (Margo). Margo shared that she was nervous about this process, not knowing how she was going to "handle that": "It wasn't just your experience with cancer, you were going back into the issues you'd dealt with in your life, whether it be from childhood…some of us had traumatic childhood experiences." She highlighted that for her, there was "quite a bit of emotion involved in the openness". The

language she used to describe her disclosures, including “baring my soul” and “laying bare”, paints a powerful image of the emotional nakedness, or vulnerability, that she felt in sharing her never-before-shared personal experiences.

For Wendy, the felt expectation to disclose her private experiences felt “really intrusive” when it occurred in a partner-sharing situation. She commented that the partner work could be appropriate in other groups, but that within the context of cancer recovery, it was “too much”, particularly “when there’s trauma”: “You’re so vulnerable with your emotions that that was just too pointed”. In her mind, she explained, there needed to be “a more gentle way to bring out the feelings” where each person could “share on [their] own terms”. Less structured methods of sharing, she suggested, would “help people dealing with different stages” of grief.

For Carol, it was not the issue of revealing her past to others that was distressing, but rather a process of deep self-reflection and “stirring up” that led to revealing truths. In working through various “pieces” of recovery in the group, she explained that “some of those pieces were… they were revealing”. She expressed that there were significant emotional challenges that came along with perspective changes that occurred for her in the course of the group, which she referred to as “mindshifts”. She gave the following example: “I’m a major caregiver. So it was hard to say, ‘you know what, I can’t save the world. I’m just going to save myself.’”

Confronting one’s mortality. As described above, for most participants, the recovery group represented a time of deep exploration, deep reflection, and confronting new truths. But for some, that experience included the overwhelming process of admitting the realities of cancer, its far-reaching impacts, and its very real threat to their lives. For Annie, the process of being in the group and completing the assigned homework / self-reflection tasks caused her to move from a position of denial, in which she was happily ignoring some of the “dirty details” about her

cancer, to facing the realities of her diagnosis. As she described, at the beginning, "you think, 'this is fun, this is just a little bit of homework'", until the homework "makes you think about things you don't normally want to think about." Annie explained that one of the most difficult aspects of her group experience was "admitting I had breast cancer". She had developed strong methods of protecting herself from the heavy implications of her diagnosis (e.g., by focusing on supporting others, helping to "fix everybody else's life"), but the group caused her to turn her attention to her own experience:

> The course was all about focusing on *you*, like what are *you* going through? How is this affecting *you*? And that's, like I said, why I didn't want to do the questions. Because I'm like, oh, then I really have to say, 'yes, I've got this too'.

Annie powerfully captured the way that existential distress was woven into that experience: "When I was going through the questions actually doing the work—it made me feel like, oh I might not be alright. I might not live."

For other participants, they were distressed by another form of reminders about their own mortality: the death of a fellow group member. Wendy reflected, "It's hard to have a group where the end result could be that you're dead." She highlighted that being in a group where people's health can decline so suddenly and rapidly has the potential to be traumatizing for some: "She sat beside me saying 'yeah, I'm palliative'. And then [months later], she died. I found that very traumatizing." As Wendy described, the consequences of meeting a person who is dealing with a similar diagnosis and then learning of their death, is something that brings one's mortality to the forefront: "It makes it all resurface that, yeah, I could be next".

Theme 3: Coping and Healing

The third overarching theme, *Coping and Healing,* captures the diverse ways in which participants managed the challenges and distress they experienced related to their group involvement. Within this overarching theme, participants' personal (idiosyncratic) ways of coping are reflected, with an attunement to how their individual processes also overlapped with one another. Their accounts highlighted themes of managing, processing, healing, and making sense of their group experiences. Perhaps not surprisingly, participants' descriptions of how they managed group-related emotional distress were often inextricably linked to a broader conversation about how they were coping with and processing their cancer experiences in general (i.e., the contextual challenges and distress that surrounded their group experience). Overall, in navigating the distress they experienced at the time of their groups, participants tended to draw on (a) lessons and strength offered to them by their recovery group and (b) their own personal skills and resources.

Healing through the group experience. Although participants experienced distress in the group setting, nearly all participants indicated that their group had also been a source of healing or support for them in their journey of recovery. How the group was supportive to them differed across participants. Some benefited from the skills and lessons they learned in the group and/or from the opportunity to share and process in the group environment. For those participants who felt connected to the group, the experience of feeling closely bonded to fellow group members was a source of reassurance, affirmation, and strength as they faced significant challenges—within the group and contextually.

Applying strategies and lessons from the group. Participants found strength and healing in various aspects of the group content, from specific exercises and recommendations to broader

lessons of agency, assertiveness, and self-forgiveness. In terms of embracing strategies, Margo expressed that the healing that occurred for her in her group was related to the strengthening of her existing coping skills and health practices. As someone who felt she had a relatively strong repertoire of health practices going into the group, she described that the group enhanced her pre-existing skills: "Using the tools that the RG gave me, I just felt I went from strength to strength." She explained that she focused her attention on areas in the group content where she felt she had the greatest opportunity to improve: "I especially paid attention to the nutrition and the exercise and the meditation—these are the things that got me through."

For Kim and Carol, their groups offered meaningful lessons that were relevant to their coping. Kim, whose problem-solving skills led her to feel that she often carried the weight of others' problems, said that the group helped her to "separate the problem, like, 'this problem belongs to who?'" She expressed that the group helped her to find clarity in the chaos of the personal challenges she was facing ("Before, I had these thoughts, but I didn't know how to organize them") and that she felt empowered by lessons that imparted the idea that "you are the manager of yourself". Carol shared that the group offered her helpful lessons in assertiveness, for example, "learning to say, 'this doesn't taste good to me today', instead of just eating it." Furthermore, the group served to free her from a place of self-blame: "This group made me realize that there's a whole bunch of factors for cancer; it's not just your lifestyle or your anger. You can't say it's just one thing. So I was able to forgive myself."

Helpfulness of group sharing and processing. All of the participants but one (Wendy) found that the experience of sharing and processing within group discussions ultimately offered some sort of healing, even if the act of sharing had originally been a source of distress for them. Annie commented on the dual nature of emotional processing in the group: "It was hard. But

also so good, it was such a valuable thing." Margo echoed that although it was "difficult" and upsetting to share about her personal past and to "speak about what truly was deep down inside", the act of sharing left her with a sense of "freeing up a part of me that maybe was a prisoner" and that "the challenge led to healing". Similarly, although participants experienced pain in response to hearing other group members' stories of trauma, loss, and hurt, the sharing that occurred in the group enabled some participants to find gratitude for their own circumstances and to feel "fortunate, if you can feel fortunate with cancer" (Margo). As Carol explained:

> I found out that there were people in my group that were a whole lot worse off than I was […] I learned to appreciate my family, the support I got, when I heard about some people who weren't even getting that.

Carol noted that sharing within the group also helped her to reduce the feeling that she was burdening her family with the "same old" stories of her pain, and Kim expressed that the group was the "first time that I felt so free to talk to people". Kim expressed how powerful this was for her, to have the new experience of sharing openly with others and not being met with blame or criticism:

> And in there, at least, nobody judged me. Nobody ignored me […] They respect my culture. My person. My personality. My skills. Yeah, everybody respects. Respect. Safe. Patience and listening.

Overall, participants highlighted that a prerequisite for the helpfulness of emotional processing in the group was that the group feel like "a safe place" (Margo) where each participant felt they would be "listened to and respected" (Carol).

Importance of group member connection. This subtheme further demonstrates that a felt sense of connection among group members is what seemed to allow participants to draw on

the group as a source of strength and a means of coping. Carol explained that the fact that the members of her group "just clicked" and that she really "felt like I belonged to that group", meant that she found the group discussions to be "reassuring", "inspiring and so reaffirming". Similarly, Margo reflected that the fact that the members of her group "gelled so well" enabled them to "lift each other's spirits so much". Margo's connection to her fellow group members also offered her a source of encouragement in facing group-related challenges. Specifically, Margo said that the "value [she] placed" on creating a growth-promoting, encouraging, and supportive environment for other women in the group helped her to "overcome the challenges" associated with disclosing about her history and past traumas.

Similarly, Annie described that with the exception of the few disruptive members, the rest of her group felt like a "band of brothers" who "could always count on each other". This meant that they "shared strength" in times of difficulty and "borrowed strength from each other", both in coping with the consequences of an extremely disruptive group member and in facing the challenges of their broader recovery.

Drawing on individual resources. This superordinate theme highlights that participants drew upon the personal resources (i.e., skills, wellness practices, and strategies) that they were equipped with prior to their group involvement in order to cope with group-related challenges and distress. In addition to these strategies, some participants found overall strength in their faith and/or in the support of persons and professionals outside of the group context. For many participants, the process of successfully making sense of their group experience was also an important aspect of their longer-term coping.

Using specific skills and strategies. The strategies captured within this subtheme were generally introduced by participants as being particularly relevant to their immediate coping with

the difficulties of the group; that is, what helped them to get by and get through at the time of their group involvement. Examples of the strategies that participants used included focusing on solving manageable problems, distraction, gentle exercise, relaxation and rest, meditation, and finding humour and levity in difficult situations.

In describing her coping strategies, Kim referred to "finding resources", taking a "first step", and "next steps". She described a very logical step-wise approach to finding resources and focusing her attention on the pragmatic tasks of recovery, both before and during her group involvement. To address the distress that her physical post-treatment symptoms were causing her at the time of her group participation, Kim embraced a problem-solving approach and advocated for a referral to a specialty clinic that could address her concerns. Kim alluded to the fact that her analytical approach to problem solving and solution finding had been an important part of her professional work in China, and that these skills were reflected in her coping strategy.

For Carol, the process of coping with the emotional challenges of the group had more to do with cognitive re-framing (noticing and adjusting unhelpful thought patterns) in an effort to practice optimism. She described how this became an everyday wellness practice for her:

> I do affirmations every day, and I really work on changing my mindset. The more I tell myself that I love myself, that I'm important or I'm valuable, the better my day is. I just keep believing that I'm going to be better.

At the time of the group however, it was distraction that was particularly helpful to Carol in dealing with the emotional letdown she would often feel immediately after sessions. She described that she would tell herself, "Okay, well let's read this. Maybe it will keep your mind busy." She learned to do something fun or treat herself after group meetings to cope with the

transition out of the great intensiveness of the group meetings, although she admitted that this strategy "took a while to figure out".

In talking about her process of managing distress, Wendy introduced a thoughtful list of skills and strategies that she used, including going on "walks", taking "zen time" (laying down and resting), and "writing all of my anger". Describing herself as "a journaler", she found that journaling was particularly helpful in allowing her "to get out the feelings". She described that some of the strategies that she had used to cope with her cancer diagnosis and treatment, including more intensive exercise, were not useful to her at the time of the group because she was so "emotionally exhausted" from "fighting back what I wanted to say [in the group]". She found that she needed to recognize and allow for the fact that "the whole next day [after a meeting] was like a debrief-it day, a process day." Wendy also shared that finding humour and holding on to hope were important aspects of her coping. She commented, "a good laugh, with a good cry, is… oh my god […] it's so therapeutic." Within the group, she tried to remain "hopeful" that "maybe somebody could relate". From Wendy's perspective, finding hope is an important aspect of coping with all aspects of the cancer experience: "The hope of moving on. The hope of a future. The hope that you can cope with it."

Margo and Annie both highlighted humour in their descriptions of what enabled them to cope. Annie emphasized the role that "comedy" played in helping her, and her fellow group members, to cope with the damaging impacts of a disruptive group member: "That levity lowered the stress level of the room. And that helped a lot with the leaders and the one woman. That helped a lot." Margo connected her use of humour as a coping strategy within the group to her broader experience of using humour to counteract the threat of cancer: "You have to laugh at yourself and you have to laugh at the stuff that happens. It takes the power away from it."

Seeking other supports. When participants needed additional coping support or help with managing group-related distress**,** they turned to various support persons outside of the recovery group, including their children, friends, siblings, neighbours, and religious communities. Other participants sought the services of health professionals to help them address contextual sources of distress (e.g., physical pain, family relationship concerns) that were affecting them at the time of their group participation.

Debriefing with loved ones after a difficult group meeting was a practice that several participants found enormously helpful. Wendy said, "I debriefed it a lot with my sister, because I could talk to her on the way there, and on the way back". Similarly, Carol, who was "really close" with her daughter, said she "would debrief with" her and found the support to be very reassuring.

For Annie, helpful supports outside the group included the consistent and supportive presence of a neighbour, whom she saw every day, and the feelings of being cared for by her religious community. When she was facing the hardest part of her group involvement and coming to terms with the implications of her diagnosis, she described feeling "completely surrounded by prayer, the whole way through".

Wendy described herself as "very very fortunate" to have "two best friends that have both gone through breast cancer", because unlike her group experience, her conversations with these friends allowed her to "really go to that level and just be there for each other". In light of the fact that her group meetings left her feeling "even more isolated", Wendy said she was grateful that she "was able to seek out what I needed from other people". She credited "all of the extra supports" (including clinicians at the BCSCF clinic) with having supported her in coping with the challenges and distress that occurred for her in the group context.

In Margo's case, the additional professional health supports she sought were intended to help reduce the physical pain she was experiencing at the time of the group (side effects of the chemotherapy and radiation that she had finished only months prior). Margo's account indicated that the process of reducing some of her physical pain symptoms had important implications for her ability to manage painful emotions that came up for her during her group participation.

Strength through faith. In addition to the strategies and supports described above, some participants relied on faith to help them in coping with distress—both general distress and distress that arose in the group. Annie, for example, made explicit reference to the role of her religion and faith in helping her to manage the various challenges in her life, outlining her perspective that "you have to bless the difficult situations, and thank God for them, because they made you the person you are". The ability to view challenges as God's lessons and gifts helped her to find purpose in the emotional upheaval she experienced in being in the group and facing the reality of her cancer: "When I was going through, I had an ahhhhh [*leaning back, as if to escape*] from doing the questions and admitting that I had breast cancer, but… my faith… my faith carried me through this."

Although Carol did not refer to a God specifically, she did allude to her faith in a greater plan, describing certain events as being "meant to be" and her belief that things "happened for a reason". She also shared one of her favourite quotes, which she found to be helpful in coping with fear and uncertainty: "I flow easily with change, my path is divinely guided, and I'm always going in the right direction". This sense of divine guidance on one's path served as a source of comfort and peace during difficult times.

Engaging in a sense-making process. While the above three subthemes (i.e., 'using specific skills and strategies', 'seeking other supports' and 'strength through faith') primarily

capture the ways in which participants immediately managed the distress they experienced within their group involvement, this subtheme captures that participants continued to manage their distress by reflecting on their group experience, making sense of it, and finding hidden gifts in the challenges they experienced. This sense-making process tended to occur after the group meetings had ended.

At the time that I interviewed them, participants were a minimum of one year out from their group participation. For some, the time that had passed since their group involvement provided a safe distance from the experience that enabled them to talk about it: "That's why I can talk to you today. Because it's past. It's history for me" (Kim). Kim may not have been in a place to comment in the same way on the sources of her distress immediately after the group, particularly given that she had experienced suicidal ideation around the time of her group participation. Similarly, Wendy clarified that reflecting on her group experience from a place of being "more whole and healed" enabled her to "see what happened" in a different way:

> If you did this with me right after the group, you would have gotten a different story from me. This took me a long time to process. So if I did it right after, I probably would have had a lot more anger, and probably would have said that I didn't like the people. Because I would not have been able to step back and figure out why they were being kind of mean to me. But I don't see it that way now.

For Wendy, coping with the distress of her group experience included making sense of the differences between herself and the other members of her group, a process of "recognizing that because of different experiences and how we decide to face them, we all are in different places… the continuum is huge. You've got maturity, stage of life, and you've got trauma". Similarly,

Annie found that coping with her group experiences involved a process of making sense of the pain she and other group members had experienced as a result of having a "bully" in their group:

> I do think that maybe she was put there for a reason. […] Maybe we all have to be different in order to help each other through this, that, and the other, and to just help each other heal. Maybe we all need to be there, and we all need to be different, and there needs to be somebody whose horrible for the rest of us to realize that we can still be suffering, but we don't have to be that person.

Within participants' sense-making processes, there was a particular emphasis on the ways that they had tried to positively reframe the challenges they had experienced, in their cancer journeys and within the group specifically, in order to find gratitude and an appreciation for some aspect of their circumstances (i.e., benefit finding). In other words, several participants had looked for positive changes that had resulted from the adversities and difficulties they experienced. For instance, Kim focused on the ways that she was "lucky". In looking back on her cancer experience and the struggles she experienced at the time of the group, she said she had "absorbed some good things from this experience" and commented, "Even in a bad thing, I had good things supporting me." She noted that a silver lining of having been the only non-"Western person" in her group was that her English had become "much improved [*laughter*]". Similarly, Annie focused on the benefits that her diagnosis had brought about for her family's faith and their relationships to one another, describing that her cancer "brought my Dad to the Lord" and "brought my family nice and close". As detailed above, Annie had also arrived at a place where she could appreciate some indirect benefits of the presence of a disruptive group member for the opportunity it offered her (and the other members) to self-reflect, practice patience, and clarify their own sense of how they wanted to live and act in the face of cancer.

Taken together, participants' accounts illustrated that the process of coping with challenging group experiences often continued well beyond their active involvement in the group. In the ongoing process of making sense of distressing experiences, both within the group and in the broader context of cancer, participants practiced gratitude and found it within themselves to be attuned to "blessings in disguise" (Margo).

Summary

In this chapter, I presented an integrative account of my interpretative phenomenological analysis of five women's experiences of emotional distress in a breast cancer recovery group program. The final analysis resulted in three overarching themes: *Contextual Challenges and Distress*, *Group-Related Challenges and Distress*, and *Coping and Healing*. Together, these overarching themes reflect that participants' experiences of group-related distress occurred within the context of their personal histories, life challenges, and the far-reaching physical, social, and emotional costs of living through cancer diagnosis and treatment. Participants shared powerful stories of the difficulties and distress they experienced within the group context, including feeling disconnected from their group, dealing with a disruptive group member, taking on the pain of others' losses, and/or disclosing and facing painful realities. These challenges required—and in some cases even indirectly enabled—participants to engage in a process of managing, coping, healing, and making sense of their experiences. In the chapter that follows, I situate the study findings within the relevant literature before offering a discussion of the implications of this work.

Chapter Five: Discussion and Implications

In this final chapter, my aim is to summarize, discuss, and contextualize the findings of this study within the existing academic literature. To begin, I offer a schematic model that captures my overall interpretation of the relationships among the overarching themes presented in Chapter Four. Next, I situate the study findings within the relevant literature by highlighting the ways in which the current findings echo and extend concepts from other research contexts and also invite new understandings. Lastly, I present a critical reflection on this study's strengths and constraints before concluding with a discussion of implications for group facilitators, other health practitioners, and researchers.

Depicting the Findings

As detailed in Chapter Four, my analysis of the lived experiences of five breast cancer survivors who felt distressed during their participation in a recovery group program resulted in three overarching themes: *Contextual Challenges and Distress*, *Group-Related Challenges and Distress*, and *Coping and Healing*. To illustrate my understanding of the relationships between these overarching categories—and the 11 superordinate themes contained within them—I developed a summary in the form of a schematic model (see Figure 1, p. 87). As depicted in Figure 1, participants' experiences of difficulty in the group setting (i.e., *Group-Related Challenges and Distress*) occurred within the context of their historical experiences, personal challenges, and life circumstances at the time of the group (i.e., *Contextual Challenges and Distress*). Participants' experiences of managing and navigating the emotional challenges of group involvement (i.e., *Coping and Healing*) are reflected in a forward-pointing arrow to symbolize the dynamic nature of this process.

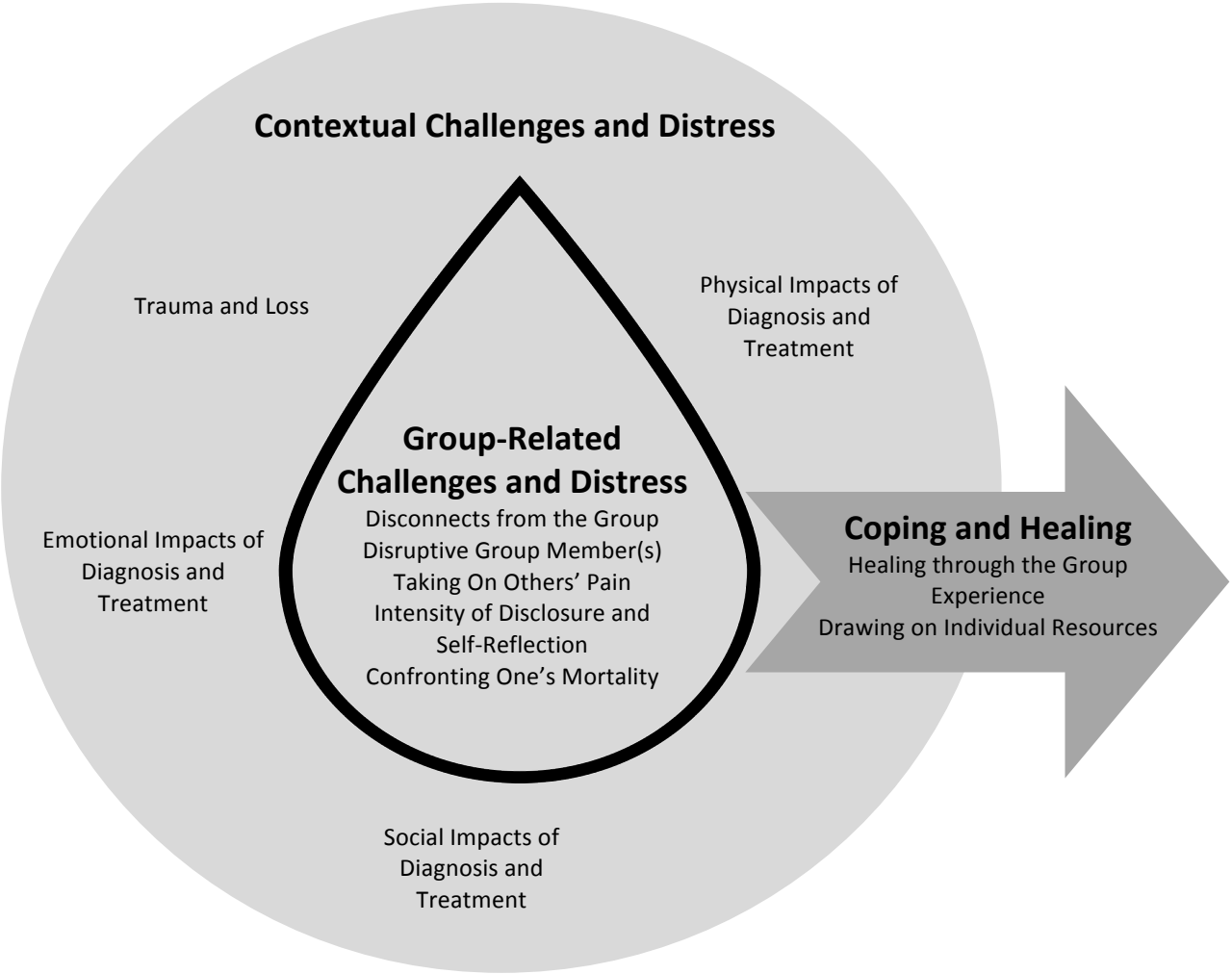

Figure 1. Schematic model of overarching and superordinate themes

Contextualizing the Findings

The process of honouring the relationships between 'the part' and 'the whole' is fundamental to IPA methodology (Smith et al., 2009). As such, an important task in this final chapter was for me to consider the part (i.e., the understandings offered by the current study) within the whole (i.e., the existing literature base). Given that the paucity of research exploring breast cancer survivors' lived experiences in a recovery group setting, I have drawn connections to studies from across disciplines that address closely related questions and concepts. The sections that follow are dedicated to the discussion of each of the study's three overarching themes.

Contextual Challenges and Distress

During my analysis of participants' accounts, it became exceedingly clear that trying to discuss participants' group-related distress without addressing the personal and emotional contexts that surrounded their group experience would be like starting a book in its middle: a preclusion of deeper understanding. Indeed, one of the most important aspects of the current study seems to be that, free from the limits of interview time constraints or pre-determined variables, I had the flexibility to welcome and explore participants' descriptions of how past traumas, losses, cancer-related threats, and residual impacts of treatment had influenced their group experiences. In this way, the findings of the current study reached beyond existing literature to offer additional insights into the factors and circumstances that may shape breast cancer survivors' experiences of group-related distress.

Trauma and loss. Participants in the current study shared powerful stories of major challenges and losses they had experienced from the time of childhood up to the time of their group involvement. These stories about participants' personal histories arose naturally within

the study interviews and were entwined with participants' descriptions of how and when they felt distressed in their recovery groups. For the purposes of this discussion, I have combined the subthemes of 'Trauma and loss in childhood' and 'Trauma and loss in adulthood' to enable a broader consideration of the effects of past trauma and losses on breast cancer survivors' group experiences. I then discuss the issue of cancer-specific trauma and loss.

Effects of past traumas and losses. As described, one type of contextual consideration that was especially salient in participants' accounts was the trauma and loss they had experienced in their lives outside of their cancer journey. These non-cancer-related challenges ranged from traumatic childhood experiences such as sexual abuse, to losses in adulthood such as family deaths, sudden accidents, abusive partnerships, and the loss of important relationships through death or divorce. Regardless of the details of their particular losses, all participants communicated that their past experiences had compounded the emotional burden of cancer and/or influenced the way that they experienced the group process.

The fact that all of the participants in the current study reported having experienced childhood trauma and/or major losses is saddening and striking, but not entirely surprising when considered in the context of existing findings: Past studies have reported high rates of trauma history and stressful life events among women with breast cancer. For example, Han et al. (2015) reported that almost half of a U.S. sample of women with breast cancer reported a history of childhood abuse or neglect (on a Childhood Trauma Questionnaire). Similarly, in a study of 94 women with metastatic breast cancer (Palesh et al., 2007), 42% of the women were deemed to have experienced one or more traumatic events that met the full traumatic event exposure criterion from the post-traumatic stress disorder (PTSD) module of the Structured Clinical Interview for DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders-Fourth

Edition; American Psychiatric Association, 2000). The traumatic events reported by the women with breast cancer in Palesh et al.'s study included childhood sexual assault, accidents involving close family members, and abuse during marriage; all of which closely aligned with those mentioned by participants in the current study. In Palesh et al.'s study, the authors referred to events that did not meet DSM-IV-TR criteria for a traumatic event as 'stressful life events'. This category included events such as the death of a parent or immigration to a new country. In the current study, all five participants described major losses and stressors that would have been conceptualized by Palesh et al. as 'stressful life events' (e.g., three participants had experienced the death of a parent soon before or during their breast cancer treatment). Importantly, the current study indicated that these past stressful life events had long-lasting consequences for participants, including consequences related to emotional distress within their groups.

Previous research on stressful life events and cancer-related distress helps to support the notion that a history of stressful events and losses may exacerbate the distress that participants experience during their recovery. In a recent large-scale study involving 957 people with cancer, Langford et al. (2017) discovered a significant relationship between the number of stressful life events experienced by patients (according to the Life Stressor Checklist-Revised) and the severity of their cancer-related distress. Similarly, for women with breast cancer, childhood trauma has been associated with depressive symptoms, intrusive thoughts, fatigue, and stress (Goldsmith et al., 2010; Han et al., 2015; Kuhlman et al., 2017). Numerous mechanisms for this relationship have been suggested, including sensitization of physiological stress response systems (e.g., hypothalamic-pituitary-adrenal system; Palesh et al., 2007), long-term psychosocial ramifications of childhood maltreatment (Gallo-Silver & Weiner, 2006), and the potential for cancer diagnosis and treatment to trigger cognitive and emotional responses that

relate to prior trauma experiences (Goldsmith et al., 2010). Based on the findings of the current study, it seems that the aftermath of past traumas and stressful life events may leave participants in an emotional state (e.g., "overwhelmed", "rejected") that heightens their susceptibility to distress in the group context, particularly when triggered or compounded by the threats of cancer diagnosis and treatment.

Cancer-related trauma and loss. For participants in the current study, breast cancer diagnosis and treatment was threatening in significant ways, leading several participants to explicitly conceptualize their cancer experience as a "trauma" and to describe cancer-related consequences as being "like PTSD". The concept of cancer-related trauma has been fairly extensively explored in the psychosocial oncology literature, especially since life-threatening illness was officially recognized (in the DSM-IV-TR) as one of the possible precipitating stressors for PTSD (Kangas, Henry, & Bryant, 2002). However, the issue of whether cancer qualifies as a traumatic stressor continues to be debated in the literature (Voigt et al., 2017), with some arguing that the application of PTSD criteria to the cancer context is complicated by cancer's chronic and sometimes terminal nature (Kangas et al., 2002) as well as by the challenge of trying to discriminate between psychiatric symptoms and natural reactions to cancer and its side effects (Knobf, 2011). Regardless, the concept of cancer-related PTSD is widely used to recognize a complex response to the threats of cancer diagnosis and treatment, with symptoms including intrusive thoughts about illness, re-experiencing aspects of illness or treatment, and hyperarousal or hypervigilance (Andrykowski & Kangas, 2010; Green et al., 2000). Among breast cancer survivors, reported rates of cancer-related PTSD have ranged from 3% to 20%, which is higher than in the general population (Andrykowski & Kangas, 2010). Some authors have indicated that while a full diagnosis of PTSD is rare, around 40% of breast cancer survivors

experience persistent 'subsyndromal' symptoms (O'Connor, Christensen, Jensen, Møller, & Zachariae, 2011; Shelby, Golden-Kreutz, & Andersen, 2008; Voigt et al., 2017).

Clearly, the pervasive psychological impacts of diagnosis and treatment described by the participants in the current study are well within the range of experiences reported by other women with breast cancer. Because this study did not involve any diagnostic components (or aims), I have no basis on which to say whether the five women in this study would have met criteria for cancer-related PTSD at any point during their cancer journey. Nonetheless, their references to "post-traumatic chemo disorder" and "PTSD" following cancer seemed indicative of the difficult emotional states that all five women experienced prior to or during their group involvement. Perhaps, then, participants' own understanding of having been traumatized by their cancer experience—independent of any formal diagnostic evaluation—could in itself be an important marker of risk for distress in the group setting. This suggestion aligns with a constructivist perspective, which de-emphasizes 'objective' diagnoses and emphasizes the importance of each individual's perceptions of their own circumstances and lived experiences, including distress (Neimeyer & Raskin, 2000).

Physical and psychosocial issues of survivorship. As described in other words above, breast cancer diagnosis and treatment had far-reaching consequences for the participants in the current study. Participants' accounts indicated that at the time of their group involvement (i.e., two months to several years following treatment), they were coping with various physical, emotional, and social sequelae of cancer. These findings align closely with existing literature on the physical and psychosocial challenges of cancer survivorship (Bower, 2014; Carlson et al., 2013; Harrington et al., 2010; Reese et al., 2017; Turner et al., 2005), and breast cancer survivorship in particular (Bloom et al., 2012; D'Souza et al., 2017; Knobf, 2011; McFarland et

al., 2018; Monti et al., 2013). Extending beyond this existing literature, the findings of the current study demonstrated that these physical, social, and emotional challenges had important implications for participants' group experiences.

Physical impacts. From a physical standpoint, participants experienced varying levels of residual pain, cancer-related cognitive difficulties, chronic fatigue, and nausea during the weeks that they participated in their groups. All of these symptoms have been reported previously in empirical studies and reviews of the physical concerns of breast cancer patients and survivors (Bloom et al., 2012; Bower, 2014; Durá-Ferrandis et al., 2017; McFarland et al., 2018). However, these past studies have used quantitative questionnaires and problem checklists to identify the women's physical concerns, and none have examined the role that these symptoms play in contributing to their felt challenges in group support settings. Thus, the current participants' accounts of how their physical symptoms, particularly pain and fatigue, led to challenges with (a) getting to group meetings and (b) managing the emotional tasks of group participation may be important for group facilitators to consider.

Notably, several of the participants who reported that physical pain influenced their emotional reactions in the group were those that had most recently completed their chemotherapy and/or radiation treatments (e.g., one was only two months from the end of her treatment). That said, none of the participants implied that they felt their group participation had occurred too early in their recovery, and participants who were further out from the end of their treatment still experienced physical symptoms that interfered with their group experience (e.g., chronic fatigue). Thus, it seems it would be an oversimplification to assume that increasing the time between end of treatment and group enrollment would benefit participants by reducing their physical symptoms at the time of group involvement. Further, excluding potential group

participants on the basis of pain symptoms would also eliminate a potentially valuable opportunity for survivors to learn skills related to managing post-treatment symptoms (indeed, this is one of the topics in BCSCF's recovery group program). Instead, assessing survivors' pain symptoms at the start of their group participation could provide an important foundation for acknowledging and validating their physical pain and referring them to appropriate physical treatment supports. In this way, group administrators / facilitators would be helping to address the intersection of physical and emotional pain that was evident in the current participants' accounts.

In addition to physical pain, several participants were highly attuned to the ways that the physical changes they were dealing with during the group (e.g., loss of hair and breasts) had impacted them psychologically, particularly in terms of confidence, self-esteem, and identity. These challenges meant that at the time of the group, participants were feeling de-centered, uncertain, and vulnerable, all of which had implications for the way they experienced challenges in the group. Tasks and interactions that likely would have felt manageable otherwise (e.g., attending early morning group meetings or receiving unhelpful comments from a fellow group member) felt distressing in the context of physical losses and lowered self-esteem. Although the relevance of these concerns to group-related distress is a novel contribution of the current study, the findings align with past research on the psychosocial consequences of cancer-related physical changes, including body image difficulties (Esplen et al., 2018; Fang et al., 2013; Fingeret et al., 2014; Williams & Jeanetta, 2016). Grief, reduced self-confidence, and distress about changed femininity have all been associated with body image concerns among women with breast cancer, and these concerns have been the target of body-image-focused interventions in breast cancer survivorship (Boquiren, Esplen, Wong, Toner, & Warner, 2013; Pillai-Friedman & Ashline,

2014; Rezaei, Elyasi, Janbabai, Moosazadeh, & Hamzehgardeshi, 2016). In William and Jeanetta's (2016) qualitative study of breast cancer survivors' general experiences, participants described that body changes had a major negative impact on their ability to cope with the challenges of survivorship. When considered together with the current study, this suggests that the physical consequences of breast cancer treatment can bring about losses and reductions in wellbeing and confidence that make it more difficult for survivors to cope with challenges and stressors, including those that occur in the group context. Thus, acknowledging and addressing these physical concerns early on in recovery group programs (e.g., at intake or in initial sessions) could offer one potential avenue towards the reduction of survivors' distress within group settings. Similar reasoning can be applied to the social and emotional difficulties that some women experience in breast cancer survivorship.

Social impacts. For several participants in the current study, concerns around social support and stigma seemed to exacerbate the consequences of breast cancer, which in turn influenced their distress in the group setting. Lack of social support from family and friends has previously been recognized as a source of emotional distress following breast cancer (e.g., Manning-Walsh, 2005), and this issue was clearly illustrated in several of the current participants' accounts of painful social isolation that left them feeling "rejected" and "alone". While one of my participants expressed that her isolation was a result of friends not "knowing how to cope" with her diagnosis, another participant explained that people in her social community (primarily Chinese) "think that breast cancer is a very ugly thing" and that she felt blamed and judged by friends. This distressing social dynamic has been conceptualized as a form of cancer stigma, in which people tend to want to assign the responsibility of "getting" a cancer diagnosis to the patient as a way to reduce the threat to themselves (Gökler-Danışman et

al., 2017, p. 779). This stigma can result in a lost sense of connectedness and belonging to previous sources of support and even threaten one's personal and social identity (Berjot & Gillet, 2011). The fact that the participant for whom lack of social support was the greatest contributor to distress was the only Asian (minority) woman in the current sample is also not surprising in the context of existing literature. In a large-scale study of breast cancer patients in the U.S., Tejeda et al. (2017) found that minority women reported greater psychological consequences of breast cancer and that the strongest mediator of the relationship between race/ethnicity and psychological distress was unmet social support.

Emotional impacts. Previous research has clearly demonstrated that women with breast cancer often experience shock, vulnerability, fear, worry, and feelings of isolation following their diagnosis and treatment (Bloom et al., 2012; Cappiello, Cunningham, Knobf, & Erdos, 2007; D'Souza et al., 2017; Knobf, 2011; Power & Hegarty, 2010). These emotional reactions align directly with the accounts of participants in the current study (as per the subthemes under 'Emotional impacts of diagnosis and treatment' in Chapter Four). Overall, participants highlighted that the emotional consequences of cancer left them in a place of "fragility" and "vulnerability" as they started their group participation. They described that their anxiety and vulnerability led to the group seeming to be "intimidating" at first and made certain aspects of their group involvement more difficult. In the past, some researchers and clinicians have suggested that group members' anxiety may increase during cancer support group involvement in cases where patients come in to the group particularly vulnerable and anxious (Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2012). Research on the topic of existential distress in cancer survivorship offers important considerations as to why participants in the current study might have been in a particularly heightened state of emotional vulnerability at the

start of their group involvement. In a review of existential distress among cancer survivors, Vehling and Philipp (2018) highlighted that survivors are likely to experience existential concerns to the extent that cancer caused them to question their central goals, identity, or life philosophy. This serves to explain the distress of one participant who described that her cancer experience left her grappling with the "uncertainty of life" and "facing [her] mortality". In fact, it struck me that the words of some of my participants aligned with those of women with untreatable lung cancer (Liao et al., 2018) and metastatic breast cancer (Svensson, Brandberg, Einbeigi, Hatschek, & Ahlberg, 2009), indicating that these participants' emotional reactions may reflect a heightened attention to the life-threatening nature of cancer.

In sum, participants in the current study indicated that their recovery group experiences were shaped and impacted by the challenges and losses they had faced in their personal lives, from childhood through to the time of their group involvement. In many ways, their descriptions fit neatly with existing literature on the consequences of childhood trauma, stressful life events, and the physical and psychosocial survivorship issues associated with breast cancer. However, participants' accounts of how these concerns contextualized their group experiences offers an extension of knowledge in the field. More specifically, these contextual factors not only influenced the emotional state that participants were in as they headed into their groups, but also how they reacted to circumstances that arose in the group setting. Essentially, participants' histories of personal challenges served as an important backdrop to their group experiences.

Group-Related Challenges and Distress

In describing their group experiences, participants had many positive things to say about ways in which their group involvement had been helpful to them, about the facilitators of their groups, and/or about the general importance of group supports during breast cancer survivorship.

I mention this as a reminder that the focus here on the challenges experienced by group participants is not intended to paint an image of participants' group experience as being wholly negative or difficult. Rather, the issues discussed in this section represent the results of an intentional exploration into distress experienced by group participants, designed to shed light on those aspects of cancer recovery group involvement that typically go unseen.

Participants' accounts indicated that the distress they experienced in the group context was, for the most part, temporary and linked quite closely to specific challenges, triggers, and/or group process issues. Notably, the distressing elements of their group involvement seemed to be those that brought up feelings of isolation, sadness, vulnerability, and fear—many of the same emotions that had surrounded the women's past traumas, losses, and cancer-related challenges.

Disconnects from the group. This first superordinate theme under 'Group-Related Challenges and Distress' captured the details of the ways in which participants felt disconnected from their recovery groups: that is, through feeling unlike the other women in their group, feeling disconnected from group discussions or homework, and/or experiencing cultural differences and disconnects. A consistent thread in participants' accounts of these closely related sources of disconnection was that they all had implications for participants' feelings of distress in the group context.

Disconnect from other groups members. Three participants in the current study referred to clear differences between themselves and the other women in their respective recovery groups; however, one participant (Wendy)'s experience of feeling different from other members was immensely more distressing to her than it was for the other two participants. A critical distinguishing feature of Wendy's experience seemed to relate to the issue of *closeness*. Other participants who perceived themselves to be different from their fellow group members in some

way still described that they "got close" as a group and that they felt supported and respected by other members. In contrast, Wendy's differences from her fellow group members left her feeling isolated and lonely in her experience. This distinction aligns with existing group process literature on the therapeutic issue of *group cohesiveness* and also provides initial evidence for the relevance of differing *illness perceptions* as a potential source of disconnection among members in illness support groups.

Group connection, or cohesiveness, is considered one of the essential therapeutic factors of group therapy and its importance in cancer support groups has been explicitly highlighted (Andersen et al., 2007; Manne et al., 2017; Yalom & Leszcz, 2005). Indeed, cohesiveness is often described as a precondition for other therapeutic factors: In cohesive groups, members feel accepted and understood, and this enables them to explore, express, and process (Yalom & Leszcz, 2005). As group members disclose their concerns, they come to recognize their similarities to one another and begin to feel less isolated in the experience of illness. Although few studies have specifically examined group process factors in cancer settings, Andersen et al. (2007), as part of a broader randomized controlled trial, found that higher perceived group cohesion was associated with lower distress and fewer symptoms among breast cancer patients who participated in a skills-enhancement group intervention. Highlighting the other end of this spectrum, Manne et al. (2017) reported that women with breast cancer who perceived higher group conflict (interpersonal distance or mistrust between members) reported adverse effects (higher anxiety) following their involvement in either an educationally-focused or a discussion-focused group program. In light of this literature, it is not surprising that the participant in the current study who felt most disconnected from her group experienced this as a major source of

group-related distress. Indeed, a perceived "mismatch" with other group members appeared to result in a worsening of this participant's existing feelings of loneliness, rejection, and isolation.

In terms of the source of this mismatch, Wendy's account indicated that she felt she was "on a different page" from the other women in her group, particularly in terms of how they perceived cancer and its magnitude. She explained that she had come into the group hoping to discuss the trauma of cancer diagnosis and treatment, including grief and loss, but that other group members were in "a different spot" in terms of wanting to discuss these painful topics. She expressed that she had felt she would "scare them" if she brought up anything too deep. In one qualitative study of breast cancer self-help groups (Gray, Fitch, Davis, & Phillips, 1997), several group members admitted that "they did not reveal some of their deeper feelings and conflicts in the group for fear that the group could or would not tolerate them" (p. 283). The words of one participant in Gray et al.'s study were nearly identical to the words that the participant in my study used in describing the vulnerability of "laying [her] cards on the table" and the subsequent disappointment she felt in the superficiality of her group's discussions:

> … It would be nice to put it on the table and say I'm really scared about this and maybe hear somebody else say the same thing'. I guess I would like to think that eventually you could reach that deeper level and talk about things like that. (p. 283)

An important distinction to make here is that Gray et al.'s study involved women at all stages of disease and highlighted that it was generally the women with advanced disease who felt that their concerns were too much for the group to bear. Instead, the current findings demonstrate that group participants may feel disconnected from their group on the basis of differing illness perceptions, regardless of their stage of disease. Illness perception—which refers to a patient's "subjective understanding of his/her condition" (Gökler-Danışman et al., 2017, p. 777)—has

been presented in other health contexts as one way to explain how individuals with the same diagnosis can react in very different ways to their condition (Benyamini, 2011). Those who feel a need to maintain a shallowness in their communication to avoid amplifying others' fear are likely to experience worsened feelings of isolation (Figueiredo, Fries, & Ingram, 2004; Yalom & Leszcz, 2005), as was clearly reflected in the participant's account of feeling "more lonely" in her group sessions.

Disconnect from group content. Although I conceptualized the issue of 'Disconnect from group content' as being distinct from 'Disconnect from other group members' based on the way that participants described their experiences, the above discussion of key issues in one participant's sense of being disconnected from her fellow group members demonstrates that these two forms of group disconnection may be tightly intertwined for some breast cancer recovery group participants. For instance, it seems that the differences between Wendy's desire to discuss grief, loss, and cancer-related trauma and her fellow group members' lack of desire/readiness to address these topics left her feeling disconnected from the other members (i.e., feeling like "the ugly duckling" of her group) and the group content (i.e., disappointed by the superficiality of group discussions). Although the BCSCF's recovery group program is not intended to be trauma therapy, 'grief and loss' is listed as one of the topics of the program (Breast Cancer Supportive Care Foundation, 2014). Interestingly, Wendy expressed that by the time these topics came up in the group, she had already determined that she was alone in wanting to explore the topics deeply, and as such, she "shut down" and maintained a level of superficiality that aligned with the other members. This issue clearly reflects a complex and dynamic interaction between group content and interpersonal process in determining the helpfulness of group participation for any given individual. Additional efforts to offer potential

group participants clear expectations of the scope of the topics that will be addressed in any particular group program may help to reduce the discrepancies in expectations among group participants; Future research could explore the helpfulness of providing this sort of 'pre-group preparation' (Yalom & Leszcz, 2005) for participants in breast cancer recovery group programs.

Lastly, the other two participants who reported any difficulty with group content described that the quantity of homework tasks felt somewhat overwhelming in the context of severe post-treatment fatigue or that specific aspects of the group's informational content had limited cross-cultural applicability. The first comment further emphasizes the importance of identifying participants' physical limitations at the time of their group involvement (addressed above) and the second serves to introduce the issue of cultural contrasts as a source of within-group difficulty.

Disconnected by cultural contrasts. From a group process perspective, Yalom and Leszcz (2005) identified that cultural heterogeneity among group members can significantly interfere with therapeutic group dynamics and that the consequences tend to be greatest for participants from minority cultures. In line with Yalom and Leszcz's work, the current study offers additional insight into cultural contrasts as a form of group heterogeneity that seemed to have consequences for participants' within-group distress.

Indeed, a cultural contrast that was relevant for several participants in the current study was that the norms around emotional expression, disclosure, and sharing in their recovery group differed from those of their community / culture of origin. Past research has demonstrated cross-cultural differences in emotional expression among female cancer survivors (Ho, Chan, & Ho, 2004; Tsai & Lu, 2017); however, much of this research has focused on international differences, particularly between women from Western-European and Asian countries. Notably, one of the

participants in the current study who found that the expectations of stoicism in her culture of origin had made it much more difficult for her to disclose in the group setting also highlighted generational changes in norms around emotional expression: As a woman in her 70s, she felt that the cultural climate (across national borders) has shifted in recent years towards favouring emotional expression to a greater extent. Her experience highlights that attending to cultural differences solely on the basis of country of origin would lead to missed opportunities to recognize individual-level cultural differences that impact group members' experiences.

Furthermore, several participants in the current study identified language barriers as another source of difficulty for them in the group environment, as well as cultural differences that made some of the group's informational content (e.g., nutritional recommendations) less relevant. These two issues have been highlighted in previous commentaries about cultural disparities in cancer care (Surbone & Halpern, 2016). As such, the current findings lend additional support to the previously identified need for clinicians and policy makers in medicine and psychosocial oncology to consider cultural barriers within cancer survivorship supports.

Disruptive group member(s). For one participant in the current study, the presence of a disruptive group member was the most upsetting aspect of her recovery group participation: She described being highly distressed by the way that a particular group member treated other women in the group, that is, with a seeming lack of regard for their opinions or circumstances. The way this individual was described aligns closely with Yalom and Leszcz's (2005) conceptualization of the "monopolist", one of several "problematic" roles that can occur in support groups (p. 391). Yalom and Leszcz offered suggestions for therapists facing this group dynamic; however, the recommendations were targeted to psychotherapeutic groups emphasizing here-and-now processes and interpersonal learning opportunities. To the best of my knowledge,

no published studies on such dynamics in a cancer support group currently exist. However, a suggestion has been made in general group therapy literature that group members, and facilitators, tend to overestimate the role of personal character and underestimate the role of intersubjectivity and whole-group dynamics in the development of the 'problem member' (Gans & Alonso, 1998; Wright, 1998). In other words, group members tend to think that the difficult, disruptive, or problematic behaviours of a particular member are due to that individual person's personality (i.e., he/she is a difficult person), rather than recognizing the complexity of the interpersonal processes that occur among all group members (and the group's facilitators) to create problems and conflicts within the group. According to the authors, this helps to explain why group participants will often express a keen desire to remove a disruptive member from their group, particularly early on in the group's development (Gans & Alonso, 1998; Wright, 1998). In the current study, the only participant who expressed a want to remove a group member indicated that this was a result of the distress she experienced in watching other members be hurt and "bulldozed over". As such, this participant's experiences may be further understood through a discussion of empathic pain in the group context.

Taking on others' pain. For nearly all of the participants in the current study, a great source of sadness for them in the group was hearing about the losses experienced by their fellow group members, particularly as they related to cancer. While an empathic stance among group members is an important contributor to therapeutic group process (Yalom & Leszcz, 2005), research on empathy / empathic distress has indicated that individuals experience different levels of distress depending on the perspective they take in hearing about another person's pain. Imagining oneself in the situation of a person who is hurting ('emotional empathy') has been found to lead to greater physiological stress than merely thinking about the other person's

feelings ('compassionate empathy') (Buffone et al., 2017). In the context of a breast cancer recovery group, it is logical that participants would be likely to experience the former to some degree. Given the extent of their shared experiences, it seems unlikely that a participant would be able to entirely avoid feeling the pain of a group member facing breast cancer-related health losses (e.g., cancer metastasis). Indeed, several participants described feeling great sadness and grief when group members experienced losses that they could relate to.

Intensity of disclosure and self-reflection. For other participants, the most emotionally difficult aspect of their group involvement related to disclosing and sharing within the group. As introduced above, part of this challenge seemed to relate to cultural differences in emotional expression. An additional consideration, however, relates to the issue of trauma. Indeed, each of the participants who found within-group discussions of their personal challenges to be distressing had experienced what they described as past trauma (either traumatic childhood experiences or cancer-related trauma). This finding suggests the importance of (a) being attuned to participants' trauma histories in cancer recovery groups and (b) providing "gentle" and unstructured sharing opportunities that do not feel intrusive to participants.

Beyond these specific suggestions, participants' accounts of feeling distressed in the process of disclosing personal issues brings up the question of how trauma ought to be managed in non-trauma-focused groups (e.g., illness recovery groups). Although the topic of disclosure has long been studied in the context of group therapy (see Vinogradov & Yalom, 1990 for a review of self-disclosure in group psychotherapy), this literature has focused on the adaptive functions of group members' willingness to share personal material in the support group context, rather than on the risks of trauma-related disclosures. To the best of my knowledge, there is a scarcity of research on the effects of trauma disclosures in non-trauma groups such as illness

support groups. It seems that future group process research specific to illness support groups will be essential to the development of best practice guidelines for the management of trauma disclosure within cancer recovery groups.

In the meantime, there may be particular opportunities to accommodate participants' varying degrees of comfort with disclosure in a way that minimizes their distress in cancer recovery group settings. As a result of growing awareness of cultural differences in verbal expression and disclosure in the context of cancer, several group interventions have been developed that intentionally include non-verbal methods of expression, including writing, drawing, singing, and movement (Ho et al., 2016). Although many of these interventions (e.g., body-mind-spirit therapy; Chan, Ying Ho, & Chow, 2002) were designed specifically for Chinese clients, the current findings indicate that there may be some potential for similar non-intrusive approaches to be helpful for breast cancer survivors with a history of trauma. Exploring the usefulness and acceptability of such methods in existing breast cancer recovery groups could help to provide alternatives for group participants who feel distressed by more "pointed" methods of expression (e.g., sharing in partners).

As presented in Chapter Four, closely related to the issue of participants' distress in revealing their pasts to others was the fact that other participants experienced distress in response to deep self-reflection; specifically, reflection that led to revealing truths about themselves and the world.

Confronting one's mortality. This concept of revealing truths came up in several ways in participants' accounts: first, through challenges to core beliefs and identities, and second, in response to reminders of one's mortality. The apparent connection between 'revealing truths' and within-group distress among participants in the current study aligns with existing literature

on the concept of *existential distress*, described within the field of psychosocial oncology as a "distinct dimension of cancer-related distress that can result from fundamental loss and change in the context of a life-threatening illness" (Vehling & Philipp, 2018, p. 47). Past reviews have underlined the relevance of existential concerns among cancer survivors, indicating that between 30% and 50% of cancer survivors experienced distress related to identity changes, lack of control, and uncertainty about the future (Ellis & Isenberg-Grzeda, 2018; Vehling & Philipp, 2018). Within the context of group supports, Yalom and Leszcz (2005) suggested that existential factors are often particularly relevant in illness support groups, as the group can be an opportunity for members to discuss fears, uncertainties, and changed beliefs. Indeed, the aim of encouraging individuals to face and address their existential concerns is central to the supportive-expressive group therapy model and has been incorporated into various meaning-focused interventions (Lee et al., 2006; Spiegel et al., 1981; Spiegel & Classen, 2000; Vehling & Philipp, 2018). That said, the current findings indicate ways in which breast cancer survivors may become distressed by existential issues that arise within the course of group participation.

In terms of existential distress related to identity, one participant in the current study spoke poignantly about the pain she experienced, as someone who had always identified strongly with her caregiver role, in being confronted with the importance of attending to her own needs first. Perhaps then, her emotional response to a topic (i.e., self-care) that others may view as innocuous can be understood in terms of its threat to her identity as a caregiver, contextualized by the identity threats imbedded in the cancer experience (Baker et al., 2016). For other participants, existential distress occurred as a result of facing the mortality risk of cancer for the first time, or being reminded of it through the death of a group member. One participant described that it was only in her group experience that she truly began to face the reality of her

diagnosis, moving from a place of denial to "admitting" she had breast cancer and starting to acknowledge cancer as a real life threat. The fact that this process of facing her diagnosis occurred after she had finished treatment aligns with existing literature indicating that during breast cancer treatment, many women put their emotional responses aside to focus on "doing what they have to do" to get through, leading their emotional reactions to surface in new ways after the end of treatment (Cowley, Heyman, Stanton, & Milner, 2000; Knobf, 2011, p. 3). Similarly, the death or worsening health of a group member led to a resurfacing of participants' fear of death, leaving them with the vague and distressing notion that "I could be next".

In short, participants' accounts of the distress they experienced in the breast cancer recovery group context pointed to particular challenges in the group environment (i.e., disconnects from the group, disruptive group members, taking on others' pain, difficulties with disclosure and sharing, and existential threats) that left participants with painful feelings of isolation, sadness, vulnerability, and fear. This served as a natural foundation for exploring participants' experiences of coping with these group-related challenges.

Coping and Healing

As presented in Chapter Four, there was great diversity in participants' accounts of how they managed and coped with the distress they experienced in the recovery group setting. In many ways, participants' individual approaches to coping with distress that came up for them in the group were closely related to how they were managing challenges outside of the group (e.g., the psychosocial consequences of treatment). This connection is not surprising given that personality traits and individual characteristics (e.g., beliefs about personal control) are known to influence stress appraisal and coping (Carver & Connor-Smith, 2010; Lazarus & Folkman, 1984). In describing the third overarching theme in participants' stories, *Coping and Healing*, I

situate the findings within existing group process and coping literature to demonstrate how participants drew on resources offered by the recovery group as well as their own personal resources to help them cope with the challenges they faced within their groups.

Healing through the Group Experience. I appreciate that it may seem a bit paradoxical to discuss the ways that participants' group participation helped them to cope with the distress of their group participation. However, this paradox is resolved in recognizing that, for most participants, the general therapeutic benefits of group involvement indirectly helped them to cope with the temporary distress they experienced in the group. More specifically, the group offered them skills, perspectives, and interpersonal support that helped them to feel strengthened and encouraged in their recovery—an important foundation for their efforts to cope with the distress that arose for them in the group setting. Given the close connections and interactions between the three subthemes under 'Healing through the group experience' (see p. 60), these topics are presented together in the following section.

In terms of skills and lessons offered by the group, participants spoke about the helpfulness of specific information and guidance (e.g., related to nutrition, exercise, and meditation), as well as the healing that resulted from lessons of agency, assertiveness, and self-forgiveness. Others spoke about the therapeutic benefit of sharing openly with other group members and feeling accepted and understood. In each of these cases, the group offered the participant an opportunity to heal in some way. These accounts align with existing theoretical and empirical evidence for the ways in which informational support, skills training, and perceived acceptance and social connection all offer important therapeutic benefits in illness support groups (Carmack Taylor et al., 2007; Flynn et al., 2013; Gottlieb & Wachala, 2007; Gray et al., 1997; Manne et al., 2017; Schellekens et al., 2017; Spiegel & Classen, 2000; Yalom &

Leszcz, 2005). Participants' descriptions of the importance of feeling connected to other group members, feeling that one belongs to the group, and experiencing the group as a "safe place" directly echoes the concepts of 'we-consciousness', 'group integration', 'mutual support', and 'trust and intimacy', all of which relate to group cohesiveness (Yalom & Leszcz, 2005).

It seems important to note here that past qualitative findings about breast cancer survivors' perceived benefits of participating in professionally-facilitated groups (Flynn et al., 2013; Power & Hegarty, 2010) appear to represent only the perspectives of participants who felt closely connected to their fellow group members; They do not describe the experiences of any participants who felt disconnected from their group for any reason. Both of these studies used focus groups to gather participants' experiences, so it is likely that the non-private nature of data collection discouraged the involvement of group members who felt disconnected from their groups. Thus, the insight offered by the current study into the experiences of a breast cancer survivor who felt particularly isolated by her differences from other group members provides an addition to this literature. That said, her experiences do coincide with evidence that support group members who feel less supported by other members are (a) less likely to express themselves in the group context and (b) less likely to experience positive post-group outcomes (Andersen et al., 2007; Yalom & Leszcz, 2005).

Overall, participants in the current study who felt closely connected to the other members in their group (i.e., groups with high levels of cohesiveness) benefited from a sense of renewed strength or reassurance related to their group involvement. In contrast, the participant who felt disconnected from her group found that she relied solely on her existing coping skills and personal resources in facing her felt distress.

Drawing on individual resources. Even for participants who found the group to be a source of general strength and healing, their experiences of coping with group-related challenges and distress included the use of coping skills, strategies, and resources that they were equipped with prior to their group involvement. Overall, participants noted that they used strategies such as distraction, focused problem-solving, exercise, meditation, journaling, finding humour, and positive thinking. Several sought additional support from loved ones or medical professionals, and others found strength in their faith and spirituality. Further, even after their groups had ended, participants continued to manage the distress they had experienced in the group context by making sense of their within-group challenges in new ways.

To highlight the ways that the coping strategies, skills, and processes described by the current participants fit within existing models of stress and coping, I present a combined discussion of the four subthemes of 'Drawing on individual resources' (i.e., 'Using specific skills and strategies', 'Seeking other supports', 'Strength through faith', and 'Engaging in a sense-making process'). Specifically, in this next section, I demonstrate how participants' approaches to dealing with group-related distress included problem-focused, emotion-focused, and meaning-making approaches, as described by Lazarus and Folkman's (1984) Transactional Model of Stress and Coping and Park's (2010) Integrated Meaning-Making Model.

Problem-focused coping. Problem-focused coping refers to an individual's attempts to directly modify a stressor or stressful event in some way, including attempts to find practical solutions (Lazarus & Folkman, 1984). For participants in the current study, their problem-focused coping efforts related to seeking out program referrals, services, and treatments that they felt would directly ameliorate the issues they were facing, both in the group and outside of it. For example, one participant who recognized that the physical pain she was dealing with was

exacerbating her emotional reactions to challenges in the group sought out specific treatments (e.g., massage and acupuncture) to reduce her physical pain. Another participant described that her natural inclination towards problem-solving led her to take a pragmatic approach to finding resources, including resources to address her physical pain. These examples align with previous findings that women with cancer often employ a problem-oriented approach to the extent that they feel they can make shifts and improvements in their situation (Drageset et al., 2016). For example, women with incurable lung cancer made efforts to establish treatment plans for pain management, even in the face of progressive disease (Liao et al., 2018).

Emotion-focused coping. Most of the strategies that participants used to cope with the distress of within-group challenges can be categorized as emotion-focused; that is, they were designed to help manage or tolerate emotional reactions associated with the stressor (Lazarus & Folkman, 1984). Examples of emotion-focused coping strategies include distancing oneself from reminders of the stressor, focusing on positive thoughts, and finding expressive outlets. In the current study, participants indicated that they used the following strategies to manage the emotional distress they felt in the group context: practicing optimism, focusing on positive thoughts, maintaining hope, distracting oneself after group meetings, exercising, resting, journaling, finding humour, and debriefing with friends and family members. These strategies overlap almost entirely with strategies reported by women with lung cancer (Liao et al., 2018) and women with breast cancer (Drageset et al., 2016; Williams & Jeanetta, 2016) who were asked how they were coping with diagnosis and treatment. Several of the few existing studies that have explored the support group experiences of breast cancer survivors have also referred to some of these same strategies (Gray et al., 1997; Høybye, Johansen, & Tjørnhøj-Thomsen, 2005). For example, in Høybye et al.'s study of breast cancer survivors' involvement in an

online support group, one participant described that laughter "can heal, maybe not our breast cancer but our souls." (p. 215). That said, even in these group-related studies, participants were describing the practices and strategies that were helpful in coping with the emotional distress of cancer, rather than distress specific to challenges in the group setting. The variety of emotion-focused coping strategies described by participants in the current study indicates that they were able to use personal skills, strategies, and social supports to cope with the emotional reactions they experienced in their group. This finding aligns with the Transactional Model of Stress and Coping, as several of the group-related challenges that participants faced likely would have seemed outside of their control (e.g., cultural contrasts) and thus more likely to favour emotion-focused coping (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984).

Meaning-making coping. Meaning-making coping is a popular concept within the psychosocial oncology literature. It has been presented as one explanation for the improvements in psychological functioning that some individuals experience following cancer (Folkman & Greer, 2000; Sears, Stanton, & Danoff-Burg, 2003; Stanton, Rowland, & Ganz, 2015; Taylor, 2000) and is thought to encompass the concepts of benefit-finding, religious coping, and post-traumatic growth (Park, 2010; Park & Folkman, 1997). Meaning-focused interventions have been adapted for psychosocial oncology settings, including group settings, with encouraging evidence of improved psychological adjustment of cancer survivors through enhanced personal meaning, optimism, and gratitude (Lee et al., 2006; van der Spek et al., 2017; Vehling & Philipp, 2018). The accounts of participants in the current study indicated that in addition to problem- and emotion-focused strategies that helped them to cope with distress at the time of their group involvement, some participants continued to manage their distress after the group had ended by reflecting on their group experience, making sense of it (i.e., finding reasons and explanations),

and noticing hidden gifts in the challenges they had experienced (e.g., opportunities for learning and gratitude). In her Integrated Meaning-Making Model, Park (2010) emphasizes the distinction between 'meaning-making' as process and 'meanings made' as successful outcome, highlighting that it is only the products of successful meaning-making that result in reduced distress. This suggests that what was most helpful in reducing participants' distress after their group experience was not simply the process of searching for meaning, but rather the fact that they were able to successfully find gratitude, acceptance, and new understandings.

Summary

Overall, participants' accounts of the distress they experienced in the recovery group context pointed to particular challenges in the group environment, many of which caused painful emotional reactions that were reminiscent of, or exacerbated, the emotional consequences of past traumas, losses, and cancer-related stressors. In many ways, participants' experiences of group-related distress align neatly with existing findings from a broad variety of literature bases (e.g., group process theory, social psychology, health psychology, and psychosocial oncology). However, when considered together, the current findings offer a uniquely integrated story of the challenges of breast cancer recovery group participation and the diverse ways in which group participants manage to cope with, and make sense of, these challenges.

Quality and Constraints of the Current Study

In Chapter Three, I introduced Yardley's (2000) principles of quality in qualitative research as an appropriate means of evaluating IPA research (Smith et al., 2009). In this section, I return to these criteria and reflect on the quality of the current study according to each of Yardley's four principles: (a) sensitivity to context, (b) commitment and rigour, (c) transparency and coherence, and (d) impact and importance.

In terms of sensitivity to context, my attention to contextual influences on participants' experiences is reflected in every stage of this research, beginning with my selection of IPA as the method of inquiry. As described in Chapter Three, I specifically chose IPA for its idiographic emphasis and attention to the unique contextual elements of participants' stories that would likely be lost in other research approaches. This sensitivity to context is demonstrated in my study findings; for example, in my description of the contextual challenges and losses that influenced participants' experiences in the group setting. In addition, I carefully located the current study in the context of existing research by conducting a thorough review of the extant literature and indicating how the current study was informed not only by past research but also by my own personal and professional experiences. Sensitivity to context also includes sensitivity to ethical issues in research (Yardley, 2000). As I noted in Chapter Three, I was carefully attuned to ethical questions in the study design, which led me to decide to exclude potential participants who reported distress at the time of eligibility screening. While I still believe this was a necessary precaution from an ethical standpoint, it does mean that the participants in my study are those who had a particular distress trajectory; as in, they felt distressed at the time of their recovery group involvement but now perceive themselves to be in a relatively distress-free emotional space that allowed them to participate safely.

The second criterion, commitment and rigour, relates to the thoroughness and completeness of my data collection and analysis. An important aspect of commitment and rigour is attentiveness to participants' narratives throughout data gathering and analysis (Smith et al., 2009; Yardley, 2000). I conducted and transcribed all participant interview recordings myself, which offered the benefit of an additional level of familiarity and thoroughness (Hays & Singh, 2012). I continued to engage actively and repeatedly with participants' words throughout the

entire analysis process: Even at the stage of the final written account, I integrated participants' words as quotes. Another key aspect of commitment and rigour within IPA methodology is the careful recruitment of a sufficiently homogenous participant sample (Smith et al., 2009). All participants in the current study were women between the ages of 50 and 70 who had participated in a breast cancer recovery group program at the BCSCF clinic within the past five years and who had felt distressed at some point during their group participation. Such homogeneity among participants is essential to the objective of an IPA study (i.e., to explore the lived experiences of a particular group of people in a particular context) and allowed for an in-depth exploration of both their unique individual experiences and those that they shared. However, the natural consequence of working with a highly homogenous sample is that other voices that deserve to be heard are not captured. For example, four of the five participants in this study were Caucasian, which means that the current study offers little in terms of discussing the particular experiences of women of visible minorities in this breast cancer group context. That said, the high representation of Caucasian women in the current study may be reflective of the general patterns in breast cancer group programs, as minority women tend to access formal breast cancer group supports at lower rates than Caucasian women (Taylor et al., 2003). A similar consideration is that the participants in the current study had all participated in a particular recovery group program (across different years). Although different breast cancer survivorship group support formats (e.g., weekend retreats, purely instructional groups, non-facilitated groups) likely pose some of their own unique challenges for participants, past reviews have indicated major overlap between purportedly different group 'types' (Gottlieb & Wachala, 2007). In other words, the current study can be seen as offering initial understandings as well as avenues for exploration in other group settings. Indeed, rather than having the aim of empirical

generalizability (a concept from the quantitative paradigm), IPA adheres to the concept of *theoretical transferability*, or the extent to which a study provides a "rich, transparent, and contextualized analysis of the accounts of the participants" that enables the reader to "make links between the analysis […], their own personal and professional experience, and the claims in the extant literature" (Smith et al., 2009, p. 51).

In relation to Yardley's third criterion, transparency and coherence, I intentionally described each aspect of my research process openly and in detail, including all procedures related to recruitment, data collection, and analysis, as well as my own biases and personal interests in the topic. This reflexive stance, which I aimed to demonstrate clearly and consistently throughout, helps to enhance the transparency of a study, and in turn, its value to readers (Hays & Singh, 2012; Yardley, 2000).

In terms of the fourth criterion, impact and importance, I have made a determined attempt to communicate—from the very first page of my introduction to the last page of this chapter—the importance of the current work in offering enriched understandings of the challenges of breast cancer recovery group participation and the ways in which participants cope with the emotional impacts of these challenges. Similarly, I have made references throughout as to the benefits of exploring this largely unexplored topic. In the section that follows, I comment on how the current findings point to specific opportunities for improvement and innovation in practice.

Implications for Group Facilitators and Care Providers

Through the generous gift of their stories, participants in this study offered a compelling case for the need to acknowledge the potential emotional challenges of cancer recovery group participation. Although participants alluded to some very specific stressors and supports that

were relevant to them personally (see Chapter Four), I have chosen to focus here on the implications that I believe reflect important convergences in participants' accounts, in terms of how group facilitators and other care providers can mitigate group member distress and support the wellbeing of breast cancer recovery group participants.

Embracing a Context-Sensitive Multidisciplinary Approach

This idea subsumes multiple recommendations: First, to be attuned to the contextual situations and needs of recovery group participants and second, to draw upon multidisciplinary supports to best meet those needs. Suggesting that health professionals be sensitive to participants' life circumstances and challenges may seem unnecessary, as sensitivity is a recognized hallmark of quality care. However, the current findings powerfully indicate the importance of being sensitive to specific aspects of group participants' life contexts, including their history of traumas or losses, their experiences of distressing physical symptoms, and their social and cultural contexts. Depending on the particular group program or environment, this sensitivity could be demonstrated in a variety of ways, from normalizing that cancer can trigger emotional reactions from long-ago losses, to providing recommendations and referrals to appropriate complementary treatments (e.g., for pain management). From a cultural standpoint, context-sensitivity could include respecting and adapting to different norms around emotional expression (e.g., offering opportunities for non-verbal expression) and/or addressing language barriers (e.g., providing translated resources). In short, I would encourage care providers across disciplines to practice this sensitivity to context by consistently reflecting on the following: *How could we make this group / service more accessible to participants in light of their emotional, physical, and cultural contexts?* Based on the insights I gained from the current study, it seems

that this sort of context-sensitive approach could serve to vastly decrease breast cancer survivors' susceptibility to distress in the group context.

Screening and Preparing Group Participants

The current study also led me to some ideas as to how specific practices in screening and preparing participants prior to group involvement could help to mitigate some potential sources of within-group distress. For instance, the majority of the participants in the current study made reference to "trauma", either in terms of past experiences (e.g., childhood trauma) or in reference to having been traumatized by cancer (e.g., "post-traumatic chemo disorder"), and the findings clearly demonstrated that these past experiences influenced participants' group-related distress. Screening potential group participants for trauma history (based on the individual's own definition) could help group facilitators to get a better sense of each survivor's needs and hopes for what the group will offer (e.g., addressing grief and loss vs. receiving health-promotion information). It could also help facilitators to adapt group exercises to be trauma-sensitive (e.g., emphasizing the option to 'pass' if a particular topic is overwhelming). Indeed, group facilitators could borrow from existing clinical guides for trauma-informed practice to support them in appropriately managing the issue of trauma in the recovery group setting (e.g., Knight, 2015; Poole & Greaves, 2012). Even if no particular clinical decisions are made on the basis of this screening, gently inquiring about perceived traumas (cancer-related or otherwise) could also normalize that group participation may trigger emotions associated with past life events. In other words, this screening would serve to prepare participants for the fact that group involvement can present unique challenges for folks who have experienced past traumas or recent losses. Ideally, this preparation would help participants to make sense of their reactions in the group context and

perhaps even facilitate the difficult process of coming to view within-group challenges as opportunities for reflection, learning, and healing.

Recognizing Existential Concerns

My findings also revealed that existential concerns became highly relevant for some participants in the course of their group involvement (e.g., through suddenly facing the realities of diagnosis or observing another group member's health worsen). Thus, even within breast cancer groups that are not specifically existentially-focused, there may be an important need to acknowledge that uncertainty and fear are likely to be a part of many members' group experience. Further, recognizing and honouring the diversity in the ways that survivors cope with existential concerns will be important for group facilitators, regardless of program type. Even in programs without the aim or capacity to address existential concerns explicitly, facilitators could support participants by acknowledging this aspect of the cancer experience and encouraging them to seek supportive environments in which they can discuss these concerns. For some participants, this may include seeking supports from within their religious or spiritual communities.

Evaluating Ongoing Support Needs

Relatedly, the current findings indicated that some participants may have benefitted from additional supports beyond the end of their group involvement. For several participants, their process of making sense of their group experiences, particularly the challenges, continued long after their last group session. One participant explicitly recommended that scheduled individual counselling sessions be offered for participants who had felt triggered in some way during group sessions. While incorporating post-group individual counselling sessions will not be feasible in every organization or clinic, engaging participants in a simple check-in / screening process at the

end of their group involvement would enable facilitators or other care providers to identify participants who are still in need of additional support and to guide or refer them accordingly.

Training and Supporting Group Facilitators

I recognize that each of my above recommendations is essentially a call to group facilitators to expand their focus slightly, be attuned to something extra, or to do something more. While I firmly believe these expanded perspectives and intentional actions will benefit cancer recovery group participants, I also appreciate that facilitators are already managing numerous therapeutic tasks and challenges, from working to nurture group cohesion to monitoring and managing group progress. Thus, I want to emphasize that my recommendations, although primarily directed at group facilitators, are founded on a broader endorsement for the types of professional supports (e.g., training, consultation, supervision) that will enable and encourage group facilitators to take up these additional elements of responsiveness to the needs of cancer recovery group participants.

Implications for Future Research

In addition to prompting explorations in clinical practice, my hope is that the current study will catalyze additional research into this relatively unexplored topic (i.e., participants' lived experiences in cancer recovery group programs). What follows is a compilation of several suggestions as to how future research could build upon and extend the current findings.

Expanding Methods of Group Evaluation

Although perhaps subtle, an important finding in the current study was that asking group participants about their experiences in terms of 'what was hard, and how did you manage?' (as opposed to simply 'what went well?') resulted in rich and nuanced accounts of group-related challenges, distress, and coping. It provided an opportunity for participants to share those

aspects of their experience that a typical post-group quantitative rating scale would fail to capture. In other words, asking about challenges proved to be a fruitful means of exploring participants' experiences and discovering creative solutions. Thus, expanding the standard methods of cancer survivorship group program evaluations (i.e., pre- and post- quantitative assessments) to include even some elements of the current approach (i.e., inviting participants to comment on their experiences of group involvement, including what was disappointing or upsetting) would likely contribute to an immensely improved understanding of group process considerations in cancer support groups, and in turn, facilitate practice improvements.

Exploring Time Effects

As noted earlier, all of the participants in the current study were at least one year out from the end of their group participation, and several participants alluded to the fact that their descriptions may have been even more intense or emotionally valenced had they not had the time to process their experiences at length before speaking with me. As such, a longitudinal investigation into the experiences of distressed group participants could offer important insight into how participants' understandings of their group experiences (and within-group challenges) tend to change over time. Such an investigation would expand on the current findings by further exploring the dynamic nature of the longer-term coping processes described by participants in the current study.

Investigating the Role of Trauma

From my perspective, one of the most striking findings in the current study was the extent to which participants' experiences of within-group distress were influenced by their contextual life experiences, particularly trauma and loss. Indeed, the current findings provide initial insights into the ways that past trauma can shape the within-group experiences of breast cancer survivors;

however, future research could examine this relationship in greater detail to enhance clinical applicability. For example, future research efforts could explore whether having had certain life experiences (e.g., childhood neglect or abuse, the recent loss of a parent, etc.) predisposes group participants to find particular group formats or specific group activities more distressing than others, and if so, how this information can be used to lessen the acute distress felt by group participants and to support their recovery in the most effective manner possible.

Considering Cultural Influences

Similarly, the current findings demonstrated that cultural factors influenced participants' experiences of distress in the group context, and as such, additional research into the intricacies of cultural differences in the needs and preferences of cancer recovery group participants are likely to be immensely valuable to the long-term development of effective group supports. As is the case with most research on breast cancer survivorship issues, the majority of the participants in the current study were Caucasian. Although women of other ethnicities may represent a smaller proportion of breast cancer recovery group participants, my sense is that efforts to intentionally recruit women from minority or underserved populations will provide clinically relevant information as to how cultural disconnects and barriers can lead to distress among group participants, and how these barriers can be addressed. That said, I would caution against reducing explorations of cultural influences to a singular aspect of cultural identity (e.g., ethnicity or language spoken). Instead, I would encourage explorations into participants' own perceptions of how various aspects of their cultural identity or cultural norms influenced their experiences in the group context.

Concluding Reflections

In conclusion, the current study represents a rare qualitative exploration into the experiences of distressed cancer recovery group participants. For countless reasons, I am incredibly grateful to the five breast cancer survivors who courageously offered their voices to this work. In being willing to describe their moments of pain and difficulty, participants helped to bring attention to emotional challenges of breast cancer recovery group participation and offer insight into the factors and processes that enabled them to manage, cope, and even find lessons in the group challenges they faced.

As a listener and learner, I was profoundly moved by the participants' descriptions of their post-treatment recovery as a time of fragility, vulnerability, and fear—emotions that were contextualized by their past losses and that had clear implications for their within-group experiences. My hope is that we, as friends, family members, or care providers to those living beyond breast cancer, might recognize this vulnerability and make room for it within our cultural narratives of survivorship: May we honour their strength, but also welcome their tears.

I will undoubtedly carry this perspective with me, not only in my future clinical work but also in my attempts to contribute to research that is guided by the voices of group participants themselves. In that vein, I will end with the words of one of my study's participants:

"When you listen to people, there's so much to be learned" – Annie

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Appendix A

Eligibility Screening Form

Name: _____ Date: _____

Please circle or highlight the appropriate response:

Have you been a part of a breast cancer recovery group at the Breast Cancer Supportive Care Foundation (BCSCF)? Please answer **yes** if you attended **two or more** sessions (weeks)	Yes / No
Did your group participation occur within the last **five years?**	Yes / No
Did you experience difficult emotions or distress at some point(s) during your group participation?	Yes / No
Are you a female over the age of 18?	Yes / No
Do you speak English fluently?	Yes / No
Are you currently experiencing significant emotional distress?	Yes / No

If you are currently experiencing significant emotional distress, please be advised that the following community agencies can offer you support and/or counselling services:

Distress Centre (24-hour Crisis Line)	Phone: (403) 266-4357	Fees: None
Eastside Family Centre (Walk-In)	Phone: (403) 299-9696	Fees: None
Calgary Counseling Centre	Phone: (403) 691-5991	Fees: Sliding-Scale
Catholic Family Services Counselling	Phone: (403) 233-2360	Fees: Sliding-Scale

If you are experiencing distress related to your cancer diagnosis, please contact the Tom Baker Cancer Centre's Department of Psychosocial Resources: (403) 355-3207.

Thank you for taking the time to complete this form!

Appendix B

Participant Recruitment Letter

As a past participant of the Recovery Group program at the Breast Cancer Supportive Care Foundation (BCSCF), you may be eligible to participate in a study that will help us to learn more about women's experiences within the group program. The time commitment is minimal, and your input will be extremely valuable in helping us understand how to more effectively care for breast cancer patients/survivors in group settings.

There is a growing awareness that although group interventions are helpful for many people, for others, the group experience can be distressing at times. We appreciate that groups are not easy. If you experienced emotional difficulty or distress at any point during your group participation, we would really like to interview you. Regardless of whether you stayed in the group or withdrew after several sessions, we want to learn from what you have to say about your experience. You can help us to better understand the difficult parts of being in a group setting.

If you are willing to participate, we will arrange a time that is convenient for you to complete a private, audio-recorded interview at Breast Cancer Supportive Care or at the University of Calgary (you can choose which location you prefer). The interview will take about 90 minutes (up to 2 hours), with breaks throughout as needed. We will reimburse you for your parking or transit costs.

We ask that you do not participate if you are currently experiencing distress that would make this interview too difficult for you. We want to make sure that you are in an emotionally safe place.

Although the Breast Cancer Supportive Care Foundation supports this research and encourages you to participate, they are not involved in the research process from this point on. This study is being conducted by Michelle McCowan (MSc. student in Counselling Psychology) and Dr. Sharon Robertson (R. Psych, Professor, University of Calgary). The BCSCF team (including your doctors and Recovery Group facilitators) will not know whether you do, or do not, decide to participate in this research. Participation will be confidential and anonymous.

If you think you might be willing to participate, or if you would like more information, please contact **Michelle** directly at **(xxx) xxx-xxxx** or **xxxx@ucalgary.ca**

Thank you kindly for your consideration!

Contact:
Michelle McCowan
xxxx@ucalgary.ca
(xxx) xxx-xxxx

Supervisor: Dr. Sharon Robertson, Educational Studies in Counselling Psychology,
xxxx@ucalgary.ca, (xxx) xxx-xxxxx

This study has been approved by the Health Research Ethics Board of Alberta – Cancer Committee

Appendix C

Informed Consent Form

UNIVERSITY OF CALGARY

Informed Consent Form for Participation in a Research Study

Study Title: Breast Cancer Survivors in a Community-Based Support Group: Experiences of Managing Group-Related Emotional Difficulty

Protocol ID: HREBA.CC-XX-XXXX

Graduate Student Researcher:
Michelle McCowan, BSc. Honours MSc. in Counselling Psychology student

Supervisor (Primary Investigator):
Dr. Sharon Robertson, R. Psych Werklund School of Education, University of Calgary
Professor Educational Studies in Counselling Psychology
(XXX) XXX-XXXX xxxxx@ucalgary.ca

Sponsor: Social Sciences and Humanities Research Council of Canada (SSHRC)

You are being invited to participate in a research study because you have participated in a breast cancer recovery group program and have identified that you felt emotionally overwhelmed or distressed at some point(s) during your participation. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason. Deciding not to take part or deciding to leave the study will not result in any penalty or any loss of medical or health-related benefits to which you are entitled.

If you do consent to participate in this study, you will need to sign and date this consent form. You will receive a copy of the form.

A Note About the Terms Used in This Form
To make this form more readable, we have used the term "survivor" to refer to any person who has received treatment following a cancer diagnosis. We appreciate that cancer survivorship can be defined in many ways, and we will do our best to use whatever language you prefer should you choose to participate in this study.

What Is the Background Information for This Study?
Professionally led support groups can help breast cancer survivors to access information, strengthen coping skills, and connect with others. However, facilitators of breast cancer support groups have indicated that it is common for group members to experience some difficulty (e.g., anxiety or distress) as part of the group process. Very little is currently known about how women experience the difficult aspects of participating in breast cancer group programs.

Why Is This Study Being Done?
The purpose of this study is to explore the following question: How do breast cancer survivors experience and manage emotional difficulty related to their participation in a community-based support group? We are hoping to find out more about your personal experiences of participating in the group and managing the emotionally difficult aspects of being in a group program.

What Will I Be Asked To Do?
You will be asked to participate in a one-on-one interview that will be about 90 minutes (up to 2 hours) in length. You can choose whether you want to complete the interview in a private room at the Breast Cancer Supportive Care Foundation (Suite #414, 301 14th Street NW) or at the University of Calgary (2500 University Drive NW). If you choose the Breast Cancer Supportive Care location, all attempts will be made to schedule your interview so that you will not see any of your past or current care professionals or group facilitators while you are arriving at / leaving from your interview. You will be sent the general interview topics before the interview so that you know what topics might be discussed.

During the interview, you will be asked to speak about your experiences in the recovery group program. Specifically, you will be asked about your personal experiences of managing the emotionally difficult aspects of being in the group. The interview will be audio-recorded for analysis purposes. Participation is completely voluntary, and you may decline to answer any or all of the interview questions or stop your participation at any time.

How Many People Will Take Part in This Study?
Up to 10 people will take part in this study.

Will There Be Any Follow-Up Involved in This Study?
If you are interested in providing feedback on the initial analysis of the data from your interview, the researchers will send you a summary of the preliminary analyses so that you have the opportunity to give your feedback. You will be asked to provide your input within two weeks of receiving the data. If no response is received within that timeframe, it will be assumed that you agree with the analysis.

> I am interested in providing feedback on the preliminary analysis of the data: Yes____ No____
> If yes, I can be reached by email at: _____

What Type of Personal Information Will Be Collected?
Your name, email and/or phone number will be collected only for the purpose of scheduling the interview and for study follow-up (if requested above). If you agree to participate, you would be asked to provide your age, gender, and the year in which you participated in the group program. No information that identifies you will be collected during the interview. To protect your anonymity, you will be invited to create a pseudonym for the interview. Any individual references in the final report or other presentations of the study data will be masked using this pseudonym.

What Are the Potential Risks of Participating in This Study?
There are no significant risks involved in participating in this study. Risks of participating in this study are similar to those encountered in everyday life. However, because some of the interviews questions will be of a sensitive nature, it is possible that you might become upset during the interview. If you are currently experiencing significant emotional distress, we ask that you do not participate in this study.

You will be given several scheduled breaks during the interview and you will have the option to take a break whenever you would like. You will also have the option to stop the interview and/or withdraw from the study at any time. The interviewer will be able to debrief will you if you are feeling upset. If this distress persists and you would like professional assistance, the following is a list of community agencies that can offer you support and/or counselling services:

Distress Centre (24-hour Crisis Line)	Phone: (403) 266-4357	Fees: None
Eastside Family Centre (Walk-In)	Phone: (403) 299-9696	Fees: None
Calgary Counseling Centre	Phone: (403) 691-5991	Fees: Sliding-Scale

If you are experiencing distress related to your cancer diagnosis, you can contact the Tom Baker Cancer Centre's Department of Psychosocial Resources: (403) 355-3207.

What Are the Potential Benefits of Participating in This Study?
Participation in this study may or may not be of personal benefit to you. However, based on the results of this study, it is hoped that in the long-term, patient/survivorship care can be improved.

How Will My Personal Information Be Kept Confidential?
Participation in this study is anonymous and confidential. Only the researchers (Michelle McCowan & Dr. Sharon Robertson) will have access to your interview recording and interview transcript. Your name will not be in the audio-recordings or the interview transcripts. The information collected during this study, including short quotes / excerpts from your interview, will be published and/or presented in a summary format, and your real name will not be used. The data from this study will be stored for no more than five years, at which time it will be destroyed (i.e., shredded / deleted in a manner consistent with the University of Calgary's policy). Should you choose to withdraw from the study (which you can do any time up to one week following your interview), you will be asked if the information that has already been collected can be used; if not, it will be destroyed as described above.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. Every effort will be made to keep your identifiable information confidential and to follow the ethical and legal rules about collecting, using, and disclosing this information.

Will My Healthcare Providers Be Informed of My Participation in This Study?
Your health care provider(s) and group facilitators will not be informed by the study team that you are taking part in the study.

Will I Be Compensated for Participating in This Study?
You will not be paid for taking part in this study, nor should you incur any significant costs. You will be offered compensation for your parking cost at the interview location (or your public transit cost).

What Are My Rights as a Participant in This Study?
You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of these results, please let the researcher know. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

Signatures (written consent)

Your signature on this form indicates that 1) you understand to your satisfaction the information provided to you about your participation in this research project, and 2) you agree to participate in the research project.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: (please print) _____

Participant's Signature: _____ Date: _____

Researcher's Name: (please print) _____

Researcher's Signature: _____ Date: _____

Questions/Concerns

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

Michelle McCowan / Dr. Sharon Robertson
Educational Studies in Counselling Psychology, Werklund School of Education
University of Calgary
(###) ###-#### / (###) ###-####

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta – Cancer Committee at:
Telephone: 780-423-5727 Toll Free: 1-877-423-5727

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept the original consent form.

Appendix D

Interview Guide

Interview date: _____ Participant Pseudonym: _____
Participant ID#: _____

Interview start time: _____

Introductory comments: Before we begin, I want to remind you about a few things related to the interview process. I want to acknowledge that the questions I am going ask you are very personal and they have the potential to be distressing or upsetting to you. I ask that you please let me know if you are uncomfortable at any point during the interview. We'll make sure to take breaks, but please let me know if you want to stop or take a few moments to rest at any time. As a reminder, I've also given you a list of resources in your consent form in case you want to seek any follow-up support.

Finally, I want to assure you again that, although I am recording the interview, everything you say will be totally anonymous, which is why we've had you pick a pseudonym.

Demographics: Before we get into the main content of the interview, I'd like to ask you a few quick demographic questions. If you don't mind, would you please begin by telling me…

1) Age: _____

2) The year in which you participated in the recovery group support program: _____

3) Whether or not you stayed in the group until it ended (i.e., at 12 weeks): Yes / No

Questions for discussion:

Now that we've covered that basic information, I'm wondering if you could start by telling me about **how you came to be in the recovery group support program**.

- How did you find out about it?
- What were your expectations of the group?

What was your general experience of being in the group?

- What was it like for you to be a group member?
- Did the group meet your expectations? How so?
- In what ways, if any, was the group helpful to you?
- In what ways, if any, was the group experience challenging?

Reminder: As we move into these next questions, I know we may get to some things that you don't feel ready or prepared to talk about, and that is totally okay. Only tell me the things that you feel ready to say.

You mentioned that you felt emotionally distressed or challenged at one or more points during or after your group sessions. **Can you tell me about that?**

What was that like for you?

- What impact did these difficult things have on you?
- How did you react? How did others react?
- Did the influence of that extend beyond the group session(s)?

How did you manage or deal with the distress / difficult emotions you felt?

- What was helpful or not helpful to you? (within the group)
- Did you seek out support of any type?
- If so, what was / has been your experience with these sources of support?
- If not, would you be willing to share what prevented you from seeking support?

What might have been helpful to you had it been available at the time?

In what ways would you say you were successful in working through the difficult parts of being in the group?

- What meaning did you make from the process of working through that?

Is there any other aspect of your experience that you would like to share?

- Anything I should have asked you, but didn't?
- If I could take one thing away from this interview, what would you hope that it would be?

Interview end time: _____

Appendix E

Sample of IPA Step 4: Connecting Themes Within an Individual Story

Step 4a. Chronological List of Emergent Themes

Contrast to past group experience
Unmet hope for shared understanding
Unmet expectations
Rejection
Loneliness in the group
Unmet goal of addressing the trauma
Shutting down
Loss of confidence in sharing
Lack of group permission to explore trauma of cancer
Superficiality of within-group interactions
Lack of group member readiness to explore difficult issues
Group member ignorance of cancer risks
Differences in understanding
Modified approach to sharing
Censoring expression of thoughts and emotions
Lack of fit with group
Unmet goal for meaningful social connection

Step 4b. Grouped Emergent Themes

Unmet expectations
Contrast to past group experience
Unmet goal for meaningful social connection
Unmet hope for shared understanding
Unmet goal of addressing the trauma

Rejection
Loneliness in the group
Lack of fit with group
Differences in understanding

Superficiality of within-group interactions
Lack of group permission to explore trauma of cancer
Lack of group member readiness to explore difficult issues
Group member ignorance of cancer risks

Shutting down
Loss of confidence in sharing
Censoring expression of thoughts and emotions
Modified approach to sharing

Step 4c. Development of Superordinate Themes

Unmet Hopes and Expectations
- Unmet expectations
- Contrast to past group experience
- Unmet goal for meaningful social connection
- Unmet hope for shared understanding
- Unmet goal of addressing the trauma

Superficiality of Group
- Superficiality of within-group interactions
- Lack of group permission to explore trauma of cancer
- Lack of group member readiness to explore difficult issues
- Group member ignorance of cancer risks

Disconnect from Other Group Members
- Rejection
- Loneliness in the group
- Lack of fit with group
- Differences in understanding

Shutting Down in the Group Setting
- Shutting down
- Loss of confidence in sharing
- Censoring expression of thoughts and emotions
- Modified approach to sharing