

**STORYING NEW MEANINGS OF HEALTH: A NARRATIVE ANALYSIS OF  
LIFESTYLE MODIFICATION AMONG BREAST CANCER SURVIVORS**

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## **Abstract**

Healthy lifestyle adoption among breast cancer (BC) survivors remains a poorly understood process. This study aims to qualitatively examine the unique change trajectories of BC survivors partaking in a pilot healthy lifestyle intervention. Four BC survivors were interviewed longitudinally at four time points (before, during, after, and three-months after the intervention). A multiple-case study, narrative analysis was applied to interview text consisting of ‘stand-alone’ narratives of each participant and ‘thematic intersections’ to elucidate cross-participant experiences. The results revealed that the participants offered a unique style of authorship, characterized by diverse struggles, victories, and motivational insights organized around broad themes related to patterns of resistance and caring for others. The rich, storied accounts suggest experiences of personal growth and that existential concerns can be both motivating and deterring in relation to health behaviour change. This research provides a nuanced and comprehensive grasp of healthy lifestyle modification in the BC survivorship stage.

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## Storying New Meanings of Health: A Narrative Analysis of Lifestyle

### Modification Among Breast Cancer Survivors

#### **Background on Breast Cancer**

Breast cancer (BC) is the most common type of cancer in women worldwide (World Cancer Research Fund Report, 2014). In 2017, it is estimated that 26,300 Canadian women will be diagnosed with BC (Canadian Cancer Society, 2017a), representing 25% of new cancer cases in women. BC is usually hormone-related and can be diagnosed in both pre-and post-menopausal women. Men can also be diagnosed with BC but it is rare; less than 1% of BCs occur in men (Canadian Cancer Society, 2017a).

The World Health Organization recognizes up to 20 sub-types of BC tumours (Viale, 2012). The classification system for diagnosis of BC is determined by stages; the classification depends on tumour size, metastases, and lymph node status. Primary BC refers to cancerous cells that have not spread beyond the breast or the lymph nodes. Types of BC can be classified into invasive or non-invasive categories. Non-invasive or 'insitu' refers to cancer cells that are restricted to the ducts or lobules whereas invasive BC entails cells that have spread beyond them into surrounding parts of the breast (Canadian Cancer Society, 2017b). In determining a treatment plan for an individual patient with BC, different factors are taken into consideration related to the type, size and spread of the tumour, as well as patient preference. Common treatments in North America include breast-conserving surgery (e.g., lumpectomy) or mastectomy, and adjuvant therapies such as chemotherapy, radiation, hormonal, or Herceptin therapy (World Cancer Research Fund Report, 2014).

The risk of BC is higher for women in developed countries and post-menopausal women between the ages of 50-69 compared to pre-menopausal women. The precise causes of BC still



largely remain unknown, but research suggests a combination of both genetic and environmental factors (Boyd, Martin & Minkin, 2010). The Canadian Cancer Society (2017c) lists a number of risk factors for developing BC, including family history of breast and other cancers, genetic mutations (BRCA1, BRCA2, TP53, PTEN), breast density, reproductive history, Ashkenazi Jewish ancestry, and hormonal replacement therapy. Importantly, obesity and overweight status have been studied extensively as a risk factor for BC. North America, western and northern Europe, Australia, and New Zealand have the highest incidence rates of BC due to the higher prevalence of the known risk factors of BC in those geographic locations, such as obesity (Ferlay, Héry, Autier, & Sankaranarayanan, 2010).

The current five-year relative survival ratio for Canadian women diagnosed with BC is 87 percent, meaning that 87 out of 100 women are expected to be alive within five years of a BC diagnosis (Canadian Breast Cancer Foundation, 2017). Epidemiological research consistently reports that early detection and effective treatments of BC have led to a relatively stable yet high number of BC survivors in North America. As of 2014, the estimated number of BC survivors was 3.1 million in the United States (World Cancer Research Fund International, 2014).

Although the BC mortality rate is declining, survivors continue to experience a host of challenges after treatment. Known BC treatment side effects include lymphedema, nausea, insomnia, fatigue, pain and weight gain (Mols, Vingerhoets, Coebergh, & Van de Poll-Franse, 2005; Shapiro & Recht, 2001). Psychosocial challenges for survivors are commonly reported as mild to moderate depression, anxiety, fatigue, poor body image, decline in cognitive functioning, sexual difficulties, poorer quality of life (QoL), and existential concerns (Gans et al., 2013; Mols, Vingerhoets, Coebergh, & Van de Poll-Franse, 2005). This review will focus on weight gain in BC patients and its relationship to BC survivorship.

## **Weight Gain in Breast Cancer Survivors**

Excess adiposity (fat cells) is a common issue following BC treatment, especially among those individuals receiving adjuvant chemotherapy and for women younger than the age of 60 (Uhley & Jen, 2007). “As many as 50–96% of women experience weight gain during treatment and many, including some women who remain weight stable during treatment, report progressive weight gain in the months and years after diagnosis” (Vance, Mourtzakis, McCargar, & Hanning, 2010, p. 292). This evidence is concerning given that weight gain is a negative prognostic factor for BC. Specifically, excess adipose tissue is associated with reduced quality of life (QoL), physical functional limitations, increased risk of cancer recurrence, and increased mortality (Rock et al., 2015; Young et al., 2014; Protani, Coory & Martin, 2010; Kirshbaum, 2007). In a study of BC survivors in rural areas, certain psychosocial factors were associated with weight gain after treatment including depression, anxiety about the future, diminished physical health, body image, and relationship issues (Befort et al., 2012).

Further compounding the adverse effects of weight gain in BC survivors is the number of women who are obese or overweight prior to a BC diagnosis and/or treatment. Rock et al., (2013) estimate that 70% of women are overweight or obese at the time of their diagnosis. Moreover, BC survivors with obesity have more than double the risk of cancer recurrence than their non-obese counterparts (Kamineni et al., 2013). A large scale pooled-analysis found a 17% increase in all-cause mortality for primary BC survivors with obesity when compared to non-obese survivors (World Cancer Research Fund International, 2014). Since studies have shown elevated mortality in BC survivors with higher body mass index ( $BMI = kg/m^2$ ), it is therefore recommended to maintain a BMI within the “healthy” weight range (Chan et al., 2015), which

would correspond to a BMI between 18.50 and 24.99 kg/m<sup>2</sup>, according to the World Health Organization's Global Database on Body Mass Index (2017).

The mechanisms underlying weight gain and increased cancer recurrence are still unknown, although the research suggests that a surplus of adiposity may influence BC progression through biological pathways associated with insulin and other hormonal mechanisms (Villarini et al., 2012a; Carmichael, 2006). The Diet and Androgens multi-site, randomized controlled trial (DIANA-5) looked at the effectiveness of adhering to a diet based on Mediterranean and macrobiotic recipes as well as moderate physical activity for BC survivors who have pre-established metabolic conditions associated with high levels of serum testosterone and serum insulin (i.e., more adiposity and greater risk for disease recurrence) (Villarini et al., 2012b). The results pointed to the potential mediating effects of hormonal mechanisms (testosterone and estrogen) in lowering overall body weight and improved prognosis.

The odds of developing cancer in general are increased by certain lifestyle behaviours, including tobacco use, excessive alcohol intake, physical inactivity, and low intake of fruits and vegetables (Spring, King, Pagoto, Van Horn, & Fisher, 2015). Interestingly, research conducted from 1975 to the present in women living in certain Asian countries showed that the risk of BC incidence increased by over 100% in countries like Japan, Korea and China alongside the adoption of Western lifestyle practices (Shin et al., 2010). It was postulated that consumption of a Western diet and reduced physical activity as well as an aging population, played a major role in the observed increase of BC.

### **Existential Difficulties and their Association with Lifestyle Modification**

An additional, post-treatment challenge of BC survivorship involves grappling with existential issues (Lagherdal, Moynihan, & Stollery, 2014; Kissane, Maj, & Sartorius, 2011;

Lethborg, Kissane, Burns, & Snyder, 2000). Loss of control, living with uncertainty, loneliness, and fear of cancer recurrence are often experienced after the individual's focus on treatment subsides (Rosedale, 2009; Yalom, 1980). When the individual's sense of predictability and control in his or her life is disrupted by illness, the stress can be overwhelming (Frank, 2013). These existential difficulties may be equally present in individuals at all stages of cancer, not solely advanced cancer as was commonly once thought (Lent, 2007). Physical concerns and somatic symptoms are positively associated with the stress that arises from fear of cancer recurrence (Hall, Lennes, Pirl, Friedman, & Park, 2017). Moreover, existential fears may fluctuate. For example, such fears may increase as soon as one month following a clear mammography result despite the immediate relief that a negative mammogram result might bring (McGinty, Small, Laronga, & Jacobsen, 2015). The anxiety associated with fear of cancer recurrence persists and is one of the greatest unaddressed issues for BC patients post-treatment (Armes et al., 2009).

There is a recent, emerging link between such existential issues and healthy lifestyle maintenance for BC patients (Pedersen, Groenkjaer, Falkmer, Mark & Delmar, 2016a; Pedersen, Groenkjaer, Falkmer, Mark, & Delmar, 2015b; Maley, Warren & Devine, 2013). Improved adherence to an exercise intervention for women undergoing BC treatment was related to feelings of control around one's life (Husebø, Karlsen, Allan, Søreide, & Bru, 2015). Recently, Pedersen, Groenkjaer, Falkmer, Marks and Delmar (2016) investigated the perceived meaning of weight and bodily changes after BC treatment. They found that weight gain not only contributes to body image disturbance and concerns with physical appearance, but also plays a role in increasing anxiety surrounding fear of cancer recurrence because of the known association between adiposity and recurrence. Another study showed that increasing physical activity

enhanced perceived control over one's health and the ability to cope with survivorship stress (Maley, Warren & Devine, 2013). Taken together, these findings indicate that BC survivors attempting to achieve weight loss may also be engaging, indirectly, in reducing fear of cancer recurrence by enhancing feelings of predictability and control over one's body and future. This body of research suggests that strategies used to achieve weight loss may promote enhanced QoL in other domains. For example, physical activity in BC survivors has been shown to enhance self-efficacy and improve general self-esteem when increased activity goals and other experiences of mastery are achieved (Awick, Phillips, Lloyd, & Mcauley, 2016).

### **Diet and Exercise Guidelines for BC Survivors**

Certain lifestyle factors have been implicated with respect to BC risk, incidence, recurrence, and mortality. Dietary intake (including foods such as fruits, vegetables and soy products), weight status, physical activity, and vitamin supplements are some of these variables under study. Government health departments worldwide have published guidelines for reducing risk of all types of cancers. While tobacco cessation is the number one lifestyle factor recommendation, a combination of healthy diet and weight, physical activity, and moderate alcohol consumption are second in importance and thus strongly suggested (Thomson et al., 2014). Specifically, engaging in moderate physical activity is associated with reduced risk of BC incidence and recurrence (Hamer & Warner, 2017). It is estimated that about one third of the most common cancers including BC can be prevented by maintaining a healthy weight through diet and physical activity (World Cancer Research Fund International, 2014). The 2015 Cancer Care Ontario (CCO) report on exercise and cancer recommends similar guidelines for individuals living with cancer and survivors (Segal et al., 2015). The expert panel who developed the guidelines proposes a total of 150 minutes of moderate-intensity, aerobic exercise three to five

times per week, and resistance training two days per week. Consistent with the CCO guidelines, walking for up to half-an-hour per day has also been suggested for BC survivors (Magné et al., 2011).

The research to date shows an increasingly strong and positive link between physical activity and better BC outcomes, whereas the research on dietary intake is not as impactful or conclusive (Chlebowski, 2013; Champ, Voleck, Siglin, Jin & Simone, 2012; Magné et al., 2011). For example, the research has not concluded that one particular diet over another reduces the risk of BC recurrence (Hamer & Warner, 2017). Still, food guidelines are recommended. Striving for a varied diet is generally endorsed, with servings of five portions of fruits and vegetables and less than two alcoholic beverages per day (e.g., a glass of wine), and limiting foods with saturated fats (Hamer & Warner, 2017; Magné et al., 2011). In general, plant-based diets are recommended and red meats are discouraged (Magné et al., 2011). Phyto-estrogens contained in soy products have been investigated and show no relationship to developing BC, debunking the commonly held association between soy and BC (Hamer & Warner, 2017). Guidelines from the metabolic disease literature have been used to guide cancer recommendations, which include low-fat diets, fruits, whole grains, and vegetable carbohydrates (Champ, Voleck, Siglin, Jin & Simone, 2012). Importantly, primary prevention of other chronic conditions, such as cardiac disease, may indirectly decrease risk of BC. Despite such recommendations, the link between food choices and BC risk remains equivocal (Magné et al., 2011).

### **Weight Loss and Lifestyle Interventions**

Healthy weight management following a BC diagnosis is often prescribed by healthcare providers to prevent adverse health outcomes such as secondary primary cancers, BC recurrence, and other chronic diseases (Rock et al., 2012). There are six major, more recent randomized

control trials in North America and Europe that evaluated lifestyle interventions for women after treatment for early stage BC: WINS, SUCCESS-C, DIANA-5, LISA, CHOICE & ENERGY (Reeves, Terranova, Eakin, & Demark-Wahnefried, 2014). The WINS and SUCCESS-C incorporated different methods including face-to-face visits with dietitians, or weekly phone calls with allied health professionals. The DIANA-5 used cooking classes and exercise sessions. In general, weight loss trials for BC survivors tend to incorporate both dietary and physical activity components, whereas behaviour modification strategies seem to be lacking. Combining all three components is considered best practice for overweight and obesity in general (Reeves, Terranova, Eakin, & Demark-Wahnefried, 2014).

Studies in the area of healthy lifestyle modification for BC survivors rarely entail qualitative approaches for data collection, resulting in a lack of understanding of the weight loss experience and its psychosocial impact. Qualitative studies have tended to focus on living with advanced stages of cancer or on the illness experiences of BC survivors and have been relied on for understanding broader survivorship issues. As such, there is a paucity of qualitative studies reporting on the impact of weight changes before and after BC treatment (Pedersen, Groenkjaer, Falkmer, Mark, & Delmar, 2016a). The Korean Breast Cancer Research Survivorship Group have called for enhanced personalized follow-up-care, which they suggest can be best mobilized by conducting more qualitative research in this population (Cho et al., 2014).

### **Effectiveness of Weight Loss and Lifestyle Interventions**

The documented negative psychosocial and physical effects of increased fat accumulation have led to a growing interest in the study of weight loss interventions for BC survivors, some of which have demonstrated a significant reduction in BMI (e.g., Reeves, Terranova, Eakin, & Demark-Wahnefried, 2014; Kirshbaum, 2007). The majority of such studies focus on weight loss

as the primary outcome (waist circumference & BMI), with fewer studies reporting on psychosocial-related outcomes (Reeves, Terranova, Eakin, & Demark-Wahnefried, 2014) – notwithstanding a small number of studies looking at the psychosocial effects of exercise. The studies that do focus on exercise alone have demonstrated improvements in depression, fatigue and exercise stamina for women with BC, in addition to loss of total body weight (Fong et al., 2012), and improvements in self-esteem, self- efficacy, and cancer-related cognitive impairment (Campbell, 2017; Awicks, Phillips, Lloyd, & McCauley, 2016). Despite the positive associations between exercise and post-treatment adjustment and weight loss, the research remains inconclusive. For example, the World Cancer Research Fund International BC Survivor Report (2014) states that conclusive evidence for being physically active after primary BC is also limited for certain outcomes such as predicting mortality.

Still, guidelines for cancer survivors, including those who are overweight or obese, recommend maintaining a healthy lifestyle and encourage moderate weight loss (defined as 5% to 10% of one's original, pre-diagnosis body weight) because there is a strong relationship between obesity and mortality. It is often suggested that the interventions are tailored to the individual to target cancer-related comorbidities such as cardiovascular disease and diabetes (Sedjo et al., 2016; Reeves, Terranova, Eakin, & Demark-Wahnefried, 2014; Rabin, 2008). A recent study of the Exercise and Nutrition to Enhance Recovery and Good health for You (ENEGRY) trial (Sedjo et al., 2016), the largest randomized controlled trial of a behavioural intervention for overweight and obese BC survivors, showed up to 6% weight loss in the intervention group, the moderate and recommended amount, but its positive influence on comorbid conditions was only short-term. The individuals in the intervention as well as control groups generally re-gained the weight one-year later, and there were no significant differences



between groups on non-cancer prescribed medications, doctor and emergency room visits, or in relation to being diagnosed with new medical conditions (Sedjo et al., 2016). However, with respect to psychosocial difficulties, Reeves, Terranova, Eakin, and Demark-Wahnefried, (2014) conducted a systematic review on weight loss interventions in women with BC and found safe and effective trials showing improvements in a number of challenging areas including QoL, fatigue, depression, and body image. Relatedly, Kang et al. (2017) found that BC survivors with higher physical functioning and fewer psychosocial difficulties, such as struggles with body image, were reporting positive QoL in the survivorship stage.

Despite reported improvements in psychosocial outcomes after participation in healthy lifestyle interventions, there remains a troubling trend in the literature in that weight loss achieved by BC survivors in such programs may not be sustained over the long-term, perpetuating a distressing cycle of weight loss and subsequent weight gain (Sedjo et al., 2016; Greenlee et al., 2012; Campbell et al., 2012). Young et al. (2014) have suggested that a sudden, disproportionate amount of weight loss i.e.,  $\geq 10\%$  of one's pre-diagnosis weight may actually contribute to poor health outcomes. Hence, a program which aims to support gradual, rather than drastic weight loss, may actually be an important factor in maintaining a healthy body weight over the long-term. Rock et al. (2015) recommend extended support interventions which incorporate self-monitoring strategies, meal planning, and cognitive restructuring for weight management programs. Another factor which seems increasingly important is individualized physical activity plans. The long-term results from a recent intervention controlled trial showed that BC patients who exercised during their treatments according to their physical activity preferences showed a significant and sustainable increase in their physical activity levels

compared to the control group (Baumann et al., 2017). This study is the first of its kind to show sustainable impact on physical activity levels two years post BC treatment.

A growing body of research seems to suggest that weight management interventions may have a place within holistic breast cancer rehabilitation programs—which simultaneously target the physical, cognitive, psychosocial, and existential challenges of survivors. Based on the aforementioned literature, healthy lifestyle interventions that also explicitly focus on working through psychosocial and existential difficulties of survivors, as an adjunct to weight loss, may be warranted. In order to address this need, the *Healthy Lifestyle Modification After Breast Cancer (HLM-ABC) program* was developed in the Psychosocial Oncology Lab based out of York University and the Sunnybrook Odette Cancer Centre. It is a professionally-facilitated, in-person and online intervention for women who have gained weight after BC treatment or who were obese prior to their BC treatment.

### **Healthy Lifestyle Modification after Breast Cancer (HLM-ABC) Intervention**

The HLM-ABC intervention addresses the need for a supportive, weight management group wherein BC survivors work individually and together to achieve moderate and sustainable healthy lifestyle goals. Other aims of the group are to improve overall sense of well-being, QoL, and body image. Attention was paid to tailoring the intervention to target the broader health issues of BC survivors such as addressing existential concerns after treatment (e.g., fears of cancer recurrence and living with uncertainty), fatigue, anxiety, and self-care (See Table 1 for a complete overview of the pilot study). The rationale for implementing a weight management program post-treatment is that it has the potential to offer a therapeutic environment at a time when BC survivors may be starting to notice and become distressed by weight gain. In the supportive group environment, participants may also work through existential concerns while

exercising agency over aspects of their lives that are, at least to some degree, more controllable—such as their health behaviours (e.g., healthy food preparation and consumption, increased physical activity, and other self-care practices such as meditation or mindfulness).

### **The Current Study**

Given that recent reviews on weight loss interventions for BC survivors have called for a more comprehensive assessment of patient-reported outcomes, including the assessment of psychosocial issues that are commonly overlooked, and the paucity of research using qualitative methods to examine these patient outcomes, the primary aim of this study was to develop an in-depth understanding of the experiences of BC survivors participating in the pilot HLM-ABC face-to-face intervention. To my knowledge, there are no studies that qualitatively examine healthy lifestyle modification in BC survivors. The rationale for the selected qualitative analysis—a narrative inquiry approach—will be presented in the methodology section. The study was based on a longitudinal design in order to capture the participants’ experiences at different time points – prior to beginning the program, while undertaking it, after completing it, and at follow-up three months later. A secondary aim was to understand the ways in which such changes or efforts to adopt a healthier lifestyle affect broader psychosocial adjustment (e.g., improved body image, self-nurturance, existential wellbeing) from the participants’ perspectives. Specifically, the current study addressed the following research objectives and questions:

- 1) What are the unique lifestyle change trajectories of each group member as they move through the program?
- 2) How do the survivors narrate their journeys throughout the pilot HLM-ABC intervention?
- 3) How do the participants understand their processes of change (or lack of change)?

- 4) What are the unique issues of BC survivors as they engage with a healthy lifestyle modification program during the survivorship stage?

### **Narrative Methodology**

Narrative inquiry is a group of research methods that employ the whole or parts of an individual's life story (Josselson, 2000). The study of *Erlebnis* (lived experience) was brought to life (pun intended!) by Wilhelm Dilthey, a 20<sup>th</sup> century German psychologist and hermeneutic philosopher. Narrative inquiry methods are commonly used in human science research such as sociology, anthropology, psychology, and education. In discussing narrative analysis, the words 'story' and 'narrative' are often used interchangeably (Kohler-Riessman, 2008). A 'story' is one type of narrative that has a specific form entailing a sequential and temporal order, and is often used as a general classification. However, many narrativists will use both terms as convention due to their intersecting definitions. Where the terms intersect within a research context is their shared temporal, sequential organization that often includes some type of rupture or disorder or 'complicating action' that the individual interprets in his or her distinct, idiosyncratic way (Kohler-Riessman, 2008). The construction of narratives by the author is seen as purposeful and functional in revealing what is most meaningful for the individual. Narrative analysts investigate the narrated experiences (usually in written form) through a hermeneutic approach, where meaning is derived from the text (Josselson, 2011a). Epistemologically, narrative analysis endeavours to capture multiplicity of *constructed* truths (Josselson, 2011b), a post-modern concept. The purpose of narrative inquiry is "the search for truths that are unique in their particularity, grounded in firsthand experience... narratives, then, are viewed as the building blocks of the construction of reality and meaning" (Wertz, Charmaz, McMullen, Josselson, Anderson & McSpadden, 2011, p.65). A set of analytical steps are used to reveal how people

understand their lives as a whole, or storied accounts of significant event(s) in their lives. Careful consideration is given to the context of the narrative. Throughout the analysis, the researcher takes into account why the narrator told their story in a certain way, to what end, to whom, and why.

There is no unified narrative theory or definition, but we know it is closely related to other types of qualitative methods such as case studies and phenomenological analysis (Josselson, 2000). Importantly, where narrative analysis differs from other forms of qualitative methods is that it preserves the totality of the textual account, as opposed to thematic analysis or grounded theory which deliberately fragments or categorizes the data across individual participants. The purpose of narrative analysis is to avoid dislocating the research participants from the context of their individual stories. A summary of important theoretical dimensions of narrative inquiry are discussed below following a sub-section on hermeneutics and its theoretical relationship to narrative research.

### **Hermeneutics**

As briefly mentioned above, hermeneutics applies to narrative inquiry, if not all qualitative methods (Rennie, 2012). Aligned with narrative aims, hermeneutics resides within the domain of text (Packer & Addison, 1989). Exegesis of biblical text was one of the first formal hermeneutic methods wherein obscure writings about the divine required the individual to find meaning within the text (Rennie, 2012). The interpretive stance is fundamental to hermeneutics; the researcher and text are in constant dialogue (Packer & Addison, 1989), which differs from empirical methods of knowing that aim to be as objective as possible. In hermeneutic modes like narrative, subjectivity and the interpreter's personal perspective are welcomed. Contemporary narrative researchers such as Polkinghorne (2005) and Josselson (2011) turn to the

epistemological foundations of hermeneutic philosophers such as Dilthey and Heidegger (Wertz, Charmaz, McMullen, Josselson, Anderson & McSpadden, 2011) to guide and inform their analyses. Dilthey (1996) is known for developing the ‘hermeneutic circle method’ where the parts and whole of a text inform one another. The circle method (Dilthey, 1996) relies on attention to the context, narrative linkages, inference and meaning-making, to which narrative research owes its historical roots (Rennie, 2012). Thus, the theoretical underpinnings of narrative research are fundamentally related to hermeneutics.

### **Narrative Dimensions**

**Narrative Coherence.** The storyteller/author is actively engaged in a process of “narrative composition and linkage” of the story he or she tells (Gubrium & Holstein, 1998, p.166). Regardless of the content, the author usually imposes a meaningful pattern on an experience by linking events and ideas in a sequential order (Kohler-Riessman, 2008). Gubrium and Holstein (1998) state that we can get an array of diverse narratives among individuals with similar life experiences (e.g., same career, disease, etc.) if we look closely into ‘how’ the story was crafted and ‘how’ the teller links a series of events. The story may or may not be linear or be evidently coherent (i.e., it may lack coherence) (Polkinghorne, 2005), but the importance of ‘howness’ is that “there is a relationship between the form of the story—its narrative structure—and the meaning-making process” (Kohler-Riessman, 1989, p.743). Close attention to ‘howness’, irrespective of ‘what’ is told, and the study of narrative linkages is a window into the person’s understanding of their experience and their reflexive perspectives.

**Temporality.** The contribution of a narrative approach is its ability to capture transformation over time (Gubrium & Holstein, 1998). The storyteller makes a series of choices in describing the past, present, and future. The individual relies on the passage of time as an

explicit or implicit guide to structuring the autobiographical narrative. Hinchman and Hinchman (1997) argue that “the formal quality of experience through time is inherently narrative” (1997, p.26). We can then understand how an individual constructs coherence through their orientation to time and sequencing of event(s) or chronology. The style and manner in which the narrative is composed, concerning its ‘narrative linkages’ and plotlines, determines its meaning and coherence as much as its content (Kohler-Riessman, 1989; Gubrium & Holstein, 1998). For the present study, we will attend to a story of change (or no change) over time in one’s attempt to implement health promoting lifestyle changes after treatment of BC.

**Meaning-Making.** Kleinman (1988) maintains that chronic illness can become pervasively imbedded in a person’s life, so much so that one’s biography becomes inseparable from it (Kleinman, 1988), while social constructionists emphasize the way in which experiences of self and identity are linguistically structured (Crossley, 2000). Narrative analysis relies on these assumptions concerning identity and language. Actively organizing and attempting to understand an illness, in this case—breast cancer, is a dynamic and ongoing narrative process, one that is rife with meaning. Becoming ill and transitioning into survivorship necessitates such storytelling pursuits because when the coherence, unity, and one’s expected life course is severely disrupted by illness, the act of storytelling becomes integral to the individual’s attempts to “reconfigure” a sense of order in her life (Crossley, 2000; Kohler-Riessman, 1990). Indeed, narrative analyses have been widely used in elucidating meaning-making stories of illness experience, in particular understanding cancer patient experiences (Pedersen, Groenkjaer, Falkmer, Mark & Delmar, 2016; Tighe, Molassiotis, Morris & Richardson, 2011; Collie, Bottorff & Long, 2000; Kohler- Riessman, 1990).

As the BC survivors narrate their journeys of personal transition while participating in a healthy lifestyle intervention, we gain their reflexive perspectives on the process of change. Each person tells a unique, evolving story about healthy lifestyle modification throughout their interviews. Attending to narrative elements of coherence, temporality and meaning-making, this analysis focused on how the individual constructed a story about healthy lifestyle change in time and space. As well, given that the intervention is partly focused on existential concerns of BC survivors, the depth and complexity of revealing these topics was well suited to narrative analysis which infers deeper meaning from a story's content and structure.

**Ethical Considerations.** When working with other people's narrations, the narrative analyst is tasked with honouring the truth of the story to their greatest capability while balancing responsible scholarship (Josselson, 2007). Besides the general ethical guidelines of any research project, in narrative there exists an interpersonal dynamic between the interviewer and the interviewee that usually ends with a co-constructed narrative. As Kohler-Riessman conveys (2015), "producer, process, and product are deeply interconnected" (p. 221). The joint subjectivities of researcher and participant ultimately come to be synthesized within the analysis. Importantly, ownership of the story must remain in the hands of the storyteller, so the researcher is morally obligated to be self-aware of her/his own biases. One of the primary tools of inquiry is the researcher's knowledgebase and personal lived and told stories. Thus, it is important to disclose (to oneself, to readers, and ideally to the research participants) one's significant stories and epistemological assumptions that inform the position of the researcher. In general, reflexivity in qualitative research calls for researchers to be aware of their intersubjective role as co-constructors of research data and knowledge (Finlay, 2002).



**Researcher Reflexivity.** I am the daughter of a BC survivor. It was impossible to ignore my own experiences as the participants spoke about their children. The difficulty of being reminded of my mother's story was present for me throughout the interviews. However, my role as the interviewer entailed following a scripted protocol, which helped to provide a distraction from my own story. As well, I am training to be a Clinical Psychologist, thus my current knowledge-base is primarily informed by psychology and theories of counselling. Disclosing these vulnerabilities and assumptions prior to the analysis phase is an obligation of the narrative analyst. As Clandinin and Connelly point out (2000), we cannot always be neutral, and objective researchers and so the interpersonal as well as intrapsychic dynamics must be considered in the pursuit of ethical narrative research.

**Therapeutic Implications.** During the process of constructing a narrative account of one's illness experience (influenced in part by the pre-determined, semi-structured interview guide and the types of questions asked), the research participant may be empowered. In the face of uncertainty, telling one's story can be healing by "rebuilding the individual's shattered sense of identity and meaning" (Crossley, 2000, p.527). The storyteller is in complete control of the impression of the self, one that is "sealed" in the narrative (Kohler-Riessman, 1990). Arthur Frank (2013), a medical sociologist who relates his personal illness experience to his research, sees illness narratives as the will of bodies who have been dislocated by disease. Thus for Frank, the telling of the illness story gives voice to the new, changed body of the individual. From this perspective, asking the women to partake in multiple interviews within the context of the current study may be conceptualized as part of the intervention itself. Because the act of storytelling is one of agency and control (Josselson & Lieblich, 1999), participants may experience the therapeutic benefits of constructing a story about their illness. A recent study showed that using

storytelling combined with artistic expression as an active rehabilitation intervention for cancer survivors and their relatives was effective for alleviating the difficult emotional sequelae associated with the illness (la Cour, Ledderer, & Hansen, 2016). It should be noted that perhaps the research method itself played a part in indirectly highlighting feelings of stability, control, and empowerment, although this was not a primary aim within the study.

## **Methods**

### **HLM-ABC Pilot**

To test and develop the HLM-ABC intervention, a 12-week, face-to-face group was piloted in Toronto, Ontario between November 2015 and March 2016. Participants met once a week at the Wellspring Cancer Support Centre located at the Sunnybrook Health Sciences Centre. The first 9 sessions were structured and followed an evolving protocol, whereas the booster sessions were open-ended and participant-directed (Table 1). All sessions were co-facilitated by a registered psychologist (KF) and a trained volunteer BC survivor. Each session was organized around a central topic, a group discussion, and a homework assignment to be reviewed at the next session. The homework was designed to encourage participants outside the sessions to form and practice healthy habits around eating and physical activity. During each group session, participants reflected on the homework assignment together, prompted by questions and discussion topics raised by the facilitators.

An online version of the HLM-ABC group is currently being trialed at the Sunnybrook Health Sciences Centre and follows a manualized structure informed by the pilot group feedback. Although the overall focus of the group is on achieving healthy lifestyle changes, common challenges associated with BC including struggles with body image and existential concerns were also addressed. The framework for the intervention is biopsychosocial in that the whole

individual is considered in relation to healthy lifestyle modification with an emphasis on thoughts, feelings, behaviours, bodily signals and sensations, and environmental and social contexts and triggers. A range of theories inform the HLM-ABC intervention, namely: self-determination theory (Ng et al., 2012; Patrick & Williams, 2012), the intuitive eating model as articulated by Tribole and Resch (2012), principles of mindful eating (Framson et al., 2009), behavioural activation (Leujez et al., 2011; Leujez, Hopko & Kopko, 2001), supportive-expressive group therapy (Tabrizi, Radfar, Taei, 2016; Kissane et al., 2007), Ryan's theory of health behaviour change (Ryan, Patrick, Deci Williams, 2008; Rabin, 2008), motivational interviewing (Clifford & Curtis, 2015; Miller & Rollnick, 2013), cognitive-behavioural therapy for weight management (Laliberte, McCabe, & Taylor, 2009), and dialectical behaviour therapy (specifically –balancing self-acceptance and change) (Linehan, 2014).

## **Procedures**

**Participant recruitment.** Healthcare providers at the Odette Cancer Centre (OCC) at the Sunnybrook Health Science Centre including dietitians, nurses, psychologists, and oncologists assisted with recruitment. They identified potential participants and obtained verbal consent to provide the individual's information to the study's research coordinator (SY). As well, flyers were posted in the OCC and the Louise Temerty Breast Centre waiting rooms.

The research coordinator contacted the prospective participants to explain the purpose and procedures of the study, answer questions, and to schedule a screening interview by telephone. The purpose of the screening interview was to confirm eligibility, but also to obtain demographic information, weight, medical/health history—specifically cancer diagnosis and treatment, assess for physical activity readiness, assess for past and current psychopathology or medical issues that could preclude the individual from benefitting from the intervention,

scheduling, and accessibility to and from the OCC. Participants were excluded from the study if they had an active eating disorder such as current, unmanaged symptoms of anorexia nervosa, bulimia nervosa or binge-eating disorder, an addiction, or a chronic medical condition other than cancer that was not being successfully managed. Otherwise, participants were screened based on the following eligibility criteria: (1) diagnosis of a primary BC (stages I-III), (2) completed primary BC treatment within the last five years (primary treatment includes surgery, chemotherapy and/or radiation). Participants may have still been receiving hormonal or Herceptin treatment which often continues after primary treatment; (3) ability to read and write in English); (4) self-reported weight increase of five or more pounds' post-treatment, and/or self-reported overweight status prior to BC diagnosis. Body mass indices ( $\text{kg}/\text{m}^2$ ) were calculated with objective height and weight to verify if participants met at least the overweight criterion ( $\geq 25 \text{ kg}/\text{m}^2$  BMI) (World Health Organization, 2017). Involvement in other types of individual or group interventions, such as cancer support groups, did not lead to exclusion. Information obtained from the screening interviews determined the final eligibility. When a participant's eligibility was unclear, the study team discussed and a decision was made based on the group consensus.

Active recruitment was open for one month beginning in October 2015. Six women expressed interest, five of whom were eligible. Initially all five participants attended the introductory session where they were taken through the consent form with the study coordinator (See appendix A for the consent form). A dietitian or the study coordinator weighed the participants and they completed pre-treatment questionnaires, however one participant withdrew from the study after attending the first session due to a work conflict. The final pilot sample consisted of four BC survivors.

This study's proposal was reviewed by the research ethics board of the Sunnybrook Health Sciences Centre and approval was obtained prior to recruitment. After the intervention took place, the research ethics board of York University reviewed and approved the data collection and analysis of this study for a master's thesis.

**Interview Structure.** This study used semi-structured interview guides and participants were interviewed using a longitudinal design at 4 time-points: (1) pre-treatment, (2) mid-way treatment, (3) post-treatment, and (4) three-months' post-treatment. All interviews were conducted by SY during a seven-month period between November 2015 and June 2016. The interview guides were developed by the study's core research team (SY, KF, DM) (See Appendix B for interview guides).

We hoped to acknowledge the totality of each woman's lived experience with BC survivorship. By the same token, participants were asked to attend to specific components of their cancer experience while relaying their personal story (Josselson & Lieblich, 1999), namely their experiences concerning eating and physical activity and the changes each was striving to make in these two domains. Participants were interviewed at the aforementioned time-points in order to capture a change trajectory as each individual progressed through the program, and three months thereafter. Topics that were addressed through the interview questions consisted of program goals, each woman's relationship to food and physical activity, barriers and facilitators to changing health-related behaviours, and coping with common BC survivorship difficulties (e.g., body image, social support). Following each round of interviews, the interview guide was revised by the core research team in an iterative fashion to reflect emerging themes and narrative storylines. Certain interview questions were repeated over time and across participants, whereas some questions were distinct to the individual and/or a specific interview or time point. For

example, only during the three-month post-treatment interview, participants were asked if they were able to maintain the lifestyle changes. The interviews were conducted by telephone and were audio recorded lasting between 45 minutes to an hour. Three of the four participants completed all of the interviews, except for one participant who declined the three-month follow-up interview due to a healthcare crisis. The final number of interviews was 15 in total.

### **Analysis**

All interviews were audio recorded and transcribed with ExpressScribe software by two research assistant volunteers. One volunteer was assigned to transcribing the pre-and mid-way treatment interviews, and another volunteer transcribed the post-treatment and three-month post-treatment interviews. Transcripts were managed with HyperRESEARCH software (Version 3.7.1; Computer Software, Researchware Inc., 2014). The present analysis was guided by the narrative inquiry frameworks of Reissman (1993, 2008), Josselson (2011), Clandinin & Connelly (2000), and the guidelines set out by the Centre of Interdisciplinary Research on Narrative (Randall, Baldwin, McKenzie-Mohr, McKim & Furlong, 2015) (See Table 2).

Initially, each set of transcripts belonging to a single participant was read in its entirety two to three times, beginning with the pre-interview, mid-way interview, post-interview, and the three-month post-interview. The primary researcher (SY) identified longer stretches of talk or “narrative segments” (Kohler-Riessman, 1990, p. 1195). Segments of narrative may take a clear form with a systematic plot development containing a beginning-middle-end structure, whereas some narrative segments may be purely descriptive and lack temporal organization (Polkinghorne, 2005; Feldman, Sköldberg, Brown & Horner, 2004). The original data do not have to be stated as a linear plot in order to use narrative methods, as long as the analysis “yields a storied account as a product” (Hoshmand, 2005, p.181). While our interview data are indeed

chronological, segments from different interview time points were pieced together to yield a coherent narrative.

The analysis was a two-phase process grounded in a hermeneutic approach. The researcher investigated the parts of the narrative as they relate to the whole, and vice versa, as if using both bottom-up and top-down analyses simultaneously (Josselson, 2011). The first phase consisted of a stand-alone analysis of each participant's story, not compared with the other participant narratives. In other words, each narrative was considered an individual unit unto its own, similar to a multiple-case study. By analyzing the implicit meaning embedded in each participant's account, we endeavoured to grasp a deeper meaning underlying the process of health behaviour changes after cancer. We then paid attention to broad concepts that emerged from the data which we could use to compare and contrast participants across their narratives. This second phase involved the identification of 'thematic interactions' that were similar notionally, yet uniquely experienced by each of the participants. The purpose of phase two was to show the complexity and nuances of health and attitude changes distinct to BC survivors as experienced by these four group members. At each phase, we looked closely at the content of participants' stories, 'how' the story was told and conveyed, its (in)coherence and its structure including language and organizational form (Clandinin et al., 2015; Hoshmand, 2005; Polkinghorne, 2005).

**Phase 1: Stand-alone Narratives.** Initially, the researcher identified broader place and time segments using Clandinin and Connelly's (2000) three-dimensional narrative inquiry framework, which considers the four dimensions of narrative accounts - Inward-Outward & Backward-Forward: (1) Inward dimension: refers to inner experiences such as feelings, reactions, desires; (2) Outward dimension: refers to environmental contexts and circumstantial

events; (3) and (4) Backward and forward dimensions: refer to time and sequences of events (e.g. beginning-middle-end structures of story).

Then, we used a structural, narrative analysis to uncover implicit meanings within the narrative form (Kohler-Riessman, 2008). To do so, the primary researcher (SY) used the framework adapted by Randall and colleagues to identify and tag narrative segments (Randall, Baldwin, McKenzie-Mohr, McKim & Furlong, 2015). This framework was selected because of its ability to capture the various dimensions that account for the ‘multilayeredness’ of narrative accounts. Narrative features commonly tagged and identified included constructs like narrative complexity: Is the story ‘thick’ or ‘thin’ with description? Are there subplots or layers to the story? As well, the researcher looked for examples of narrative arcs, for instance a sequential, ordered structure. Other narrative features that were tagged include narrative authorship or agency, tone, metaphors, and autobiographical reasoning (See Table 2 for a complete overview of narrative features and descriptions).

**Phase 2: Thematic Intersections.** After each narrative was individually analyzed, the primary researcher identified concepts that oriented the participants in a shared context i.e., the lifestyle modification intervention post-treatment for BC. These broad concepts were refined and articulated into central ‘thematic intersections’ that were cross-connected between participants. Originally, Josselson (2011) termed this compare and contrast framework “thematic interactions”; however, our purpose was to better understand common threads that are idiosyncratically experienced by each participant. Moreover, we felt the intersection metaphor was less mechanistic than ‘interaction’ and more in keeping with how the women’s respective lives traverse with one another in a finite yet genuinely meaningful way over the course of the group. In essence, the second phase of analysis allowed for a different perspective in which the



narratives were grouped together, to see if and how recurring themes emerged and informed one another across the women's narratives. The thematic intersections were similar in content and analyzed "both as individual units and in relation to one another" (Josselson, 1990, p.1195).

Randall's typology is still applicable here in order to compare narrative features across participants. For example, do participants tell their stories differently or similarly in terms of tone and agency? Lastly, it is important to note that all stages of the narrative analysis were collaborative. The research team discussed and debated narrative segments in an effort to integrate multiple perspectives in the analysis. Such discussion and interrogation of the emergent analysis is important for a strong foundation of interpretation and portraying the "narrative truth" for each participant (Hoshmand, 2005, p.179).

### **Participants**

All of the participants resided within the Greater Toronto Area and received their treatment from the OCC at the Sunnybrook Health Sciences Centre. The age range of the participants was between 37 to 56 years at the time of enrolling in the HLM-ABC program. Two of the participants were diagnosed with stage II BC and two of the other participants were diagnosed with stage III BC. All participants completed their active treatment within five years, between the end of 2013 and mid-2015. The participants received a range of treatments including bilateral mastectomy ( $n=2$ ), single mastectomy ( $n=1$ ), chemotherapy ( $n=4$ ), radiation ( $n=4$ ), hormonal therapy ( $n=3$ ), Herceptin ( $n=1$ ). One participant was scheduled to receive breast reconstruction surgery after the intervention. The participants' current menopausal status varied; postmenopausal ( $n=2$ ), postmenopausal as a result of ovarian suppression within treatment ( $n=1$ ), and premenopausal ( $n=1$ ).

Three participants identified themselves as White/Euro-American and one participant identified as Asian. All the participants had a university degree. One participant was currently working, two participants were employed on a current work leave, and one participant was recently retired. All of the participants have children. Participants were either married ( $n=2$ ) or single ( $n=2$ ). Two participants were living with their partners, one participant lived with her child only, and one participant lived with her child and parents (See Table 3 for an overview of participant demographics).

## Results

The narrative analysis was conducted in two phases. The first phase consisted of the individual stand-alone narrative case studies. Each of the four participants was assigned a pseudonym, *Sarah*, *Valerie*, *Eva*, and *Jessica*, respectively. Certain details were deliberately omitted and other potential identifying information was masked to ensure confidentiality of the participants. The second phase of the analysis consisted of the thematic intersections wherein the data were looked at across participants for a broader orientation to the stand-alone narratives. In the results section below, the phase 1 ‘stand-alone narratives’ will be presented followed by the phase 2 ‘thematic intersections’ analysis.

### **Sarah**

Sarah began her story focusing on her experience of defeat and hardship. She said that “life is tough” and she has learned that tragedy finds her in different ways. Sarah felt distinct from the other women in the group because she has a BRCA mutation—a genetic risk factor that increases the risk of developing breast cancer. To her, this risk factor represented her genetic destiny. This grim and hopeless future manifested in her self-portrayal as a permanently damaged woman. As such, her story had a ‘broken’ quality in both its structure and content.

During her pre-treatment interview, she did not foresee being able to make her desired lifestyle changes, which were to walk more and to find adaptive coping mechanisms for emotional eating. She said, “I’m just tired, exhausted, lazy, lacking motivation and also I found out too that I have low iron, so that’s my excuse. Sometimes... I just get so down and I can’t, and I don’t do anything you know.” The broken content of her story was, at times, mirrored in the non-linear structure of her narrative. In her mid-way interview, Sarah quickly interrupted herself after saying she did not gain any new insights about herself or adopt the HLM-ABC lessons, then rapidly shifted to saying that in fact she realized that she tends to eat when she is bored and doesn’t feel as “starving throughout the day.” Generally, she appeared to wrestle with the idea of believing she could make health behaviour changes that, in turn, may have impacted her fatalistic attitude towards long-term survival. This ambivalence translated into a series of small, disjointed narrative arcs throughout her interviews.

Sarah’s narrative lacked a coherent, beginning-middle-end structure. While she was willing to acknowledge some of the gains she felt she had made, she also made a point of detailing her circumstances that were unchanging. For instance, she referred to her medications that were, in her view, contributing to her weight gain. On several occasions, she also referenced the permanency of her ‘master narrative,’ specifically how her cultural heritage related to her health status: her family prepared large meals often, which posed an additional challenge for her in terms of overeating at family gatherings. This back and forth quality was common throughout her narrative, as Sarah often reverted back to her baseline attitudes, feelings, and, behaviours in describing her experience in the program.

Although Sarah narrated a broken story which on the surface seemed simple and lacked descriptiveness, there was an intentional and calculated configuration to the way she portrayed

herself. Visually, her transcripts were a series of short sentences with few stretches of elaborative talk. What ensued was a fast-paced conversation between the interviewer and participant. Below is an excerpt from Sarah's post-treatment interview illustrating this point:

I: What did you like most about the group?

P1: Um, the people.

I: Okay. And did you like, you know, being able to share your experiences, or hear their perspectives. What was it you liked about being around the other women?

P1: Mostly hearing their perspective.

I: Mhm. And how would hearing their perspective help you?

P1: I don't know. Um, I guess, too, um being able to share my perspective and reflecting. How did their perspective help me?

I: Yeah, how did the other women help you?

P1: There's the typical answer. That you're not alone, you know?

I: What's the other answer?

P1: I'm not sure. I guess that's, that's how you feel about it. Yeah. Um, I don't know.

Sarah then asked the researcher to probe her, representing an unwillingness to engage and to disclose information spontaneously in the interviews. On the surface, the content of her story was devoid of rich articulations. The start of her narrative was dominated by 'outward dimensions' (Clandinin & Connelly, 2000) where Sarah referred, on more of a superficial level, to her environmental stressors by positioning herself as a figurine on a static picture, as opposed to a three-dimensional character who interacts with the environment and displays an internal world. She responded to many of the researcher's questions with "I don't know," or that she did not remember or could not think of examples. Her 'thin' responses, coupled with numerous

references to her legitimate diagnoses and various medical conditions, nonetheless positioned her as a passive protagonist of her story—one who was completely overtaken by the state of her health. As well, Sarah directly communicated about her interview experience when she said, “it is hard to put it into words.” However, we came to learn that, in fact, there was a depth of intention underlying her deliberate lack of description.

Yet, all the while, Sarah’s narrative tone had a sarcastic overlay typified by her dark humour, which seemed to have served a deeper purpose. This dark tone added a layer of complexity to an otherwise sparse narrative. Sarah called herself “self-deprecating” and “blunt,” often cracking jokes and performing as a satirist of her own life. She described herself as “too heavy, too short, fat and ugly” in a jocular way, inviting her audience to laugh along with her. Her unique brand of humour showed itself, for example, when she asked if she could bring chips to the group and joked about snacking after we got off the phone. One of her favourite foods is “cancer-causing hot dogs.” Also noteworthy is how Sarah bookended her narrative with sarcastic remarks. After Sarah was reminded that the interviews would be recorded, her first line of the pre-treatment interview was “have fun listening to my voice”. During the last excerpt from her final interview, she ironically referred to herself as “Professor;” her way of poking fun at the lack of insight she felt she had offered the group. As we can see, the dearth of depth was intentional. The researcher was admittedly caught in the web of Sarah’s humour and responded by laughing along with her.

When attempting to understand her distinct, brash tone, we saw Sarah deliberately constructing a persona that had control over the interview process (the implications of which we will discuss in the meaning-making process of her narrative). For example, when the questions being asked forced her to abandon the sarcasm, she asked when the pre-treatment interview

would finish because she had reached her “mental limit.” Sarah posed, “are you going to give me therapy after this [interview]? (laughing). I’m joking.” Perhaps her use of dark humour was a means of coping with her disappointment and what seemed to be underlying sadness.

Sarah mentioned how scared she was of her cancer returning and it was possible that she looked to science to calm her existential fears. She said, “I know that diet and exercise are the number one scientifically proven ways to help prevent recurrences of cancer, yet knowing that is not enough for me to always stop eating and get off the couch.” She pressured herself to exercise, which had a paradoxical, paralyzing effect. Furthermore, Sarah seemed to convey that science and existential fears are two realms of thought and knowledge that might be incompatible with one another, given that she clung to scientific knowledge but it provided her no sense of relief or comfort. Thus, we can glean implicit meaning from the most striking part of her narrative—dark humour that might have served to protect her from confronting her reality of living with the knowledge of being at higher risk of cancer recurrence. Although it may well be a stable personality characteristic of Sarah’s to cope with humour, it is also possible that this trait was amplified in the context of her participation in a healthy lifestyle intervention.

Through both the interviews and the HLM-ABC program itself, Sarah navigated an internal conflict, between uncertainty (of disease recurrence) and certainty (of scientific evidence). Turning to the research evidence on maintaining a healthy weight after cancer was another coping strategy for her. Because this method was not effective, her form of rebellion seemed to be focusing on the ‘outward dimensions’ of her story, like referring to science, an external rather than internal response. Nevertheless, her sarcasm belied her deeper anxiety with respect to what the future holds; it captured the story of someone who was negotiating an intrapsychic space that was, at times, uncomfortable and unpredictable. Interestingly, when the

researcher joined with Sarah in her joking, Sarah intervened and switched the narrative tone. She usurped the interview procedure by speaking more seriously, getting to the heart of the matter or acknowledging her fear. For example, after a serious stretch of discourse during which Sarah was recalling her brother's insensitive comments about her weight, we saw her move quickly back and forth between a joking narrator to a serious narrator:

P1: I think I'm going to go and eat something after this! [hard laughing].

I: Oh boy, [laughing].

P1: I have kale juice, so you're okay.

I: Okay [laughing].

P1: No, I do eat for comfort, absolutely I do.

In these rare moments of earnestness, Sarah appeared to be more self-aware of her tendency to become disengaged with the interview process or the intervention when they became too emotionally intense. In general, she moved between two contrary stances with respect to making lifestyle changes which she never quite resolved in the narrative: wanting evidence and established guidelines, and desiring to carve her own unique path and exert agency over her life. In an evocative quote about the structure of the HLM-ABC program, we better understand her internal conflict:

Yeah I do like that it's not prescriptive, 'cause I resist all that stuff. So then it's harder for me to make a change at the same time because it's *not* prescriptive, or really there's no winning with me...Yeah I'll just say I'm not doing this, screw this, you can't tell me what to do.

By referring to 'no winning with her,' Sarah alluded to her polarizing needs for scientific evidence to direct her lifestyle, and to be free to do (i.e., eat and exercise) as she pleases. She

asked, “what is the final verdict on the ‘controversy of white pasta?’” She had heard contradictory evidence on whether or not the grains in white pasta are healthy and was consequently stuck on the issue.

Sarah’s involvement in the intervention was reminiscent of the character she portrayed during the interviews—a rebellious, truth-seeking participant. But, importantly, we saw a subtle change in her towards the end of the program. She channeled her rebelliousness into a more adaptive relationship with food. By the end of her interview series, Sarah declared, “food is not the boss of me.” This statement, evidence of her developing agency and self-efficacy, was vastly different than the “lazy” individual she perceived herself as being before starting the group. Sarah also began to soften as the interviews progressed. When initially asked about how she felt about her weight and body, she simply replied, “too fat.” By her last post-treatment interview, her response to the same question was, “well, I’m still too heavy, too fat, but I feel better about it now than before.” By this point in time, Sarah was gentler with herself, yet defended her “fatness” because it provided a sense of stability for her fluctuating and unpredictable circumstances. Her story of defeat evolved into a story of trying and doing her best, and perhaps even of resolution (to some degree) in terms of her increased insight into her habits of emotional eating. Sarah explained that she became more observant of her emotional eating triggers and knew the difference between treating herself and over-indulging. Still, Sarah kept her resistant style and humour close by, a reflection of its strength and purpose within her breast cancer survivor identity and the extent to which it has helped her to cope.

Sarah’s implicit exertion of power over the interview process, embedded within the threads of the narrative tone, may have evinced a perceived lack of control. Yet, by the end, Sarah was no longer a true victim. Throughout her participation, we witnessed her transition,



both narratively and behaviourally. She appeared more engaged during the intervention as well as in the later interview, and in brief spurts, was more willing to abandon her humour to reveal her underlying pain. Rigid, blunt, and comical, we saw Sarah develop throughout her narrative into a character who was “trying” and still progressing toward a position of greater self-understanding and health behaviour change.

### **Valerie**

Valerie’s narrative read like a prototypical ‘voyage and return’ story. She found herself experiencing a complete loss of control over her lifestyle choices post-treatment. Thus, she endeavoured to voyage back and reclaim her pre-treatment habits that were consistent with her self-concept as a healthy individual. Before her BC diagnosis, Valerie was satisfied with her scheduled fitness routine. After treatment, however, she found it difficult to reinstate it. In addition to logistical issues and competing time demands with work and family, Valerie’s lack of insight into her current lack of motivation seemed to present an additional barrier. Both of these factors interfered with a straightforward ‘return’ to her prior self, despite her wish to do so. Moreover, feeling apathetic toward fitness was not aligned with how Valerie saw herself, nor was it consistent with her prior experiences of successfully losing weight through exercise.

Valerie seemed to be struggling with two problems: prioritizing her health and coming to terms with her new body. With respect to prioritizing her health, she compared her current and former selves:

(When) you work out, you’re healthy but that wasn’t my focus, my focus was like do you feel good, do your clothes fit? And I felt good about myself and I could look in the mirror and feel great and then, then as secondary was . . . okay now I’m healthy. Whereas now,

through cancer and everything I understand the importance of being healthy that much more.

The shift in meaning of healthy lifestyle behaviours pre-to-post cancer from feeling “good” and looking “great” to “being healthy” posed a challenge for her. She went on to comment on her changed body and how it impacted her self-esteem.

You know, I’m sort of struggling with that too, the idea of body image, because my body’s changed. Um and probably struggled a bit more with that then the weight thing, because the weight thing I feel like if I just focus and get motivated in everything then I can just lose the weight, but where my mastectomy and my reconstruction are concerned you know, I will always have these scars.

Valerie conveyed a sense of permanent damage to parts of her body, but not its entirety. In this sense, she was ‘semi-altered.’ But with effort, she felt she could reach a desired weight as she has done in the past, and thereby regain control over aspects of her appearance like her weight. She differentiated between weight, her body, and her appearance. The biological number signifying her weight was not as important to her as the way she felt *in* her body. Moreover, if her clothing was not too tight, and was perceived as flattering for her body, then she was satisfied with her appearance. These distinctions and interrelationships added a complex quality to Valerie’s story.

In her final interview, Valerie achieved a resolution by being able to pinpoint reasons for her apathy, revealing an apparent reparative process throughout her narration. For example, she felt that the program’s ‘prescription’ of maintaining a healthy weight inspired an unconscious rebellion in her. Valerie engaged in active meaning-making, conveyed by her rich language, use of metaphors, and thick descriptions. She volunteered examples without prompting and told sub-

stories within the broad narrative. Overall, her narrative expression was linear and followed a beginning-middle-end structure, which translated into a clear, ‘problem-complicating action-resolution’ storyline.

Interestingly, over the sequence of her interviews, Valerie weaved back and forth saying she “just can’t do it,” yet also indicating that she thought she could. Her transparent way of dialoguing with herself during the pre-treatment interview showed a clear ‘window’ into her internal world:

“I know I can do it, I just somehow lack that motivation or I don’t know what it is and sometimes I question you know is it, you know, do I not want to do it? Like I want to do it, but do I not want to do it? Am I sabotaging myself [laughing] in my mind? I don’t know.”

This excerpt suggests that Valerie’s barriers were mental; but nevertheless, her tenacity and sense of personal agency also came through. She could accomplish her lifestyle goals with the “right” frame of mind - in her words, if “I’m in the right mindset, I can focus.” Valerie conveyed her desire to return to feeling efficacious, which for her depended on whether she gained understanding and awareness of her psychological barriers. Valerie rarely cited physical barriers that might have impeded her efforts to accomplish her lifestyle goals. Rather she attributed the main source of the problem to “everything is in the mind... it’s your mind that’s holding you back for whatever reason,” referring to her mental blocks. Overall, she seemed to have been experiencing a pervasive immobility—both in terms of discovering her psychological barriers and in carrying out her physical activity goals.

Historically, weight loss had entailed a simple course of action for Valerie. In her mind, she felt displaced from her identity as a “fit” individual because she could not reconcile her past

successful weight loss attempts and her current state of retaining the weight. Randall's (2015) concept of 'narrative openness' was evident in the narrative here in that Valerie considered her past sense of self to orient and inform her present self. She had two previous weight loss stories that she returned to in the narrative that seemed to be both a source of inspiration and a burden for her:

I just say forget it I'll never be that size again and I refuse to believe that because I know I have two examples - that being [during] university and I started exercising and lost the weight, and after my son, it took a lot longer for me to get there but as soon as I got a trainer I started exercising and lost the weight, so I know it can be done.

As Valerie narrated, we witnessed her struggling with these past, successful weight loss experiences that remained hanging over her. She was genuinely perplexed about her apathy and why she was not able to maintain her physical activity, which seemed to have contributed to her current frustration. Time and again, Valerie made yearning statements such as "I just want to get back to the way I was" yet this was not so simple for her.

Valerie drew liberally on metaphor in conveying her dilemma. For example, in detailing her cycle of surgeries and treatments that put a halt to her workout schedule, she said, "I'm at a ground zero type of thing," as a way of communicating her sense of enduring damage to her cardiovascular stamina. She added how she was impacted emotionally by feeling so far away from her desired self. In her words:

I know I'm not anywhere where I was before I had cancer that it's almost like, I don't know, it's like intimidating but overwhelming like to think, okay you know 'I'm so far away from getting back to where I was at' ... But then I also think well 'you have to start

from somewhere' and the more I get back to do it, you know the quicker I'll be back to where I was.

With a sense of nostalgia regarding her pre-cancer life, Valerie spoke of completing a "10-kilometer run." This mastery experience brought her pride and the run became a symbol of her success with fitness. It was not so much completing the 10-kilometer run that brought her satisfaction, but rather her commitment to training consistently. Related to this nostalgic tone was Valerie's repeated reference to returning to her past self. She often invoked the symbol of her "old jeans" to represent the person she was before her cancer. In her three-months-post interview, Valerie reminded us of how comfortable she used to feel in her skin and how she desperately hoped to salvage this lost part of herself:

I have a lot of nice clothes that, you know, I want to wear. And I just saw something on TV and this girl is just wearing like a plain black turtleneck with skinny jeans and I'm like, 'Wow, that was what I used to wear and I have that whole outfit upstairs but I can't fit into those jeans' so. You know and that kind of makes you feel sad, but it motivates me. It's like, that's what I want to do, I want to be able to just slip on a pair of jeans and t-shirt, because that's more of how I was.

The frequent allusion to the "old skinny jeans" hanging in Valerie's closet served as a concrete reminder of her idealized past self. The "old jeans" represented her personal standards for body image satisfaction and identity.

By her mid-way treatment interview, Valerie was on her way to achieving her health goals. She began this conversation by conveying her enthusiasm for a fitness class she had joined for cancer survivors. "I was actually able to sign up at [cancer support centre] and now I'm doing the twenty-week or thirty-week, or whatever it is um fitness program ... so that's great!" Joining

this fitness program proved to be a turning point in Valerie's narrative coinciding with a shift into a positivity bias. A narrative arc was evinced in how Valerie moved from being "impatient" with herself and her failure to achieve her former 10-kilometer run fitness level, to "tak[ing] things one day at a time" and aspiring to a more realistic short-term goal of running for five kilometers instead of ten. Establishing realistic goals was one of the HLM-ABC principles that Valerie succeeded in adopting in order to avoid setting herself up for disappointment: "You know it doesn't need to be 'run a ten K,' it's just, you know, doing something... you know it can be for just ten minutes but just try to do something every day, and that's been good too."

Then came one of the largest narrative arcs of Valerie's narrative—her realization of the main psychological barrier holding her back. That being an intense pressure she experienced to lose weight in order to be "healthy" post-BC treatment. She demonstrated a keen self-awareness as she openly revealed this 'aha!' moment she experienced:

I understand now what my problem was and that was really that inner rebel stopping me...It was no longer losing weight to, you know, to lose weight to fit into my clothes or whatever; it was to lose weight because of health. And then that's when you get, you know, the walls kind of go up [gestures barrier with her hands] - be like 'Whoa!' like there's someone telling me to do it. And then it's like, 'Well I don't want to do it,' cause someone's saying I *have* to do it, kind of thing... You know, now, because it's a health thing and everything else, I feel like it's an obligation to do it, not a choice.

Further amplifying this realization was Valerie's recognition that adopting a more healthful lifestyle would permit her to "be here" for her 5-year-old son. Her newfound patience with her progress thus far, combined with the drive to increase her fitness, seem to be linked through her experience of compassion for herself as well as for her son. Hence, Valerie became more

emotionally engaged with the intervention upon realizing that it was supporting her values of doing everything she could to preserve her health for her young child. With this awareness, Valerie felt like she was moving closer to her pre-cancer self even though, paradoxically, she was, in many respects, different.

Overall, Valerie's narrative was linear and plot-driven in how it began with a clear problem, progressed to an intermediary stage of problem-solving, and eventually came to a definitive resolution. Her self-reported health behaviour change and increased fitness spoke to a tangible change in characterization. She expressed herself in a rich, evocative way that suggested a depth of knowledge of self. Meaning-making occurred throughout her story, and we saw Valerie's self-concept evolve from being haunted by past accomplishments to reclaiming parts of her old self in a modified fashion. Finally, she discovered new aspects of herself and was welcoming of some of the changes to her body that came after her BC.

### **Eva**

Eva narrated a slow, albeit expressive story. Her main concern was her health and she hoped to lose weight to prevent cancer recurrence. A major barrier was feeling like the same unmotivated person she was before her diagnosis—someone who couldn't achieve the health goals she desired. Eva used phrases like "my default" or "historically I was a bad eater." She was able to lose weight in the past but once she saw results, she would give herself permission to "have an extra cookie," which ultimately resulted in no sustained progress. Eva's narrative was overlaid with a light-hearted and pleasant tone, but the sense of implicit hopelessness came through, likely as a result of her lifelong struggle with being overweight. Thus, beneath the levity lied a strong sense of 'narrative foreclosure' (Freeman, 2014) about her past. Consequently, Eva's past weight loss experiences loomed over her current attempt to lose weight in the HLM-

ABC program. Eva began her story with a focus on the more external dimensions of health behaviour change such as logistics and planning. Her narrative possessed few narrative arcs in the form of realizations, increased self-understanding, and behavioural change but we saw some evidence of the beginnings of transformation by the end.

An established ‘master narrative’ recurring throughout Eva’s story showed the development of her complex relationship with food. Food and the pleasure of eating were important within her family culture; her brother is a chef and her mother is an excellent cook. As she explained it: “My mom always jokes that our family runs on its stomach.” When planning a family trip, identifying tasty restaurants was an essential part of the trip organization. Eva also related how food was viewed as “a concrete way to take care of people because everyone needs to eat. So if, you know, you can make somebody food, you are able to take care of them in a ... very basic way.” In contrast to the social and nurturing function of food within Eva’s family dynamic, her relationship to physical activity and her appearance were complicated and burdensome.

Eva perceived the physical effects of her BC treatment and surgery as lasting and therefore felt powerless to affect change. She began and ended the intervention without any expectations for the group and how it might provide support. In the following excerpt, she spoke about how her surgery would impact her physical self long-term:

I think it’s um the surgery [that] was the biggest thing for me. While I was sad to lose my hair, it was, I knew it was temporary. But I am still struggling and I expect to struggle for a very long time with the physical changes brought on by the surgery. So I look different, and...I’m going to have limited, mobility in my left arm, [it] is never going to be the same and even if I work and work and work it just (won’t be the same) because of all the



stuff [laughing] they had to do.

Eva may have been intentionally vague about her “physical changes,” besides mentioning the functional losses in her left arm. Her non-specific style of narration was representative of a ‘thin’ story possibly reflecting that she had not yet come to terms with her altered appearance after treatment.

Eva referred to external barriers like “scheduling” and “logistics” to explain why she was de-motivated, but also felt there was more to explore given that when she *did* attempt to make lifestyle changes, she remained unproductive and stagnant. She chose to enrol in the group in order to “logically” understand why she was unable to maintain a satisfying weight. Eva’s narrative painted a picture of an individual who felt drained and despondent from the work she had to do in order to lose weight, and more broadly in relation to anything that changed about her body as a result of her cancer. In her post-treatment interview, Eva spoke more candidly about her experience and her lack of bodily acceptance. She said: “every night when I go to sleep – or lie down in bed I go ‘Oh right, I had a double mastectomy’ [laughing] and it is still kind of surprising.” It was as if there was a lag between the surgical procedure and loss of her breast, and Eva’s understanding of her new post-cancer self—which felt too scary to approach. The attachment to her old self was evident, and as a result she said she “self-sabotaged” by retaining her old eating habits. Eva’s identification with her pre-cancer self helped to explain the demoralized attitude towards lifestyle change that characterized the start of her narrative.

Eva’s sense of hopelessness came across as being deeply embedded in her identity and her self-concept. When asked in her mid-way interview if she had come to any new insights about herself, her body, food and/or physical activity, she replied with a telling quote that illustrated her self-perception as a passive, unadaptable person:

Um [long pause] I don't know how to put this, I think it's just when I have done group or you know individual therapy in the past, it's clear that you are always yourself no matter where you go, um and that, and that there is kind of no magic [laughs], no magic bullet to change some of the things you struggle with.

Eva's words revealed how firm her beliefs were rooted in her identity as an overweight person. Despite her despairing tone, she articulated herself in a rich, symbolic way – consistent with her manner of expression throughout the interviews. The word 'magic' in this case is a metaphor related to food preparation, in which Eva alluded to the Magic Bullet kitchen appliance to blend and chop food. Eva's light chuckling reinforced the casual tone that was likely intended with this metaphor and its double-entendre. But on a deeper level, the word "bullet" (and her cynical recognition of there being no magic wand with respect to weight loss) was also suggestive of the aggressively fixed way in which she defined herself. The experience of being penetrated by a bullet connoted finality and ending, where Eva could not overcome the damage caused by the bullet that was unexpectedly shot at her (i.e., by the cancer treatments and mastectomy). Her pervasive lack of agency when it came to affecting change was expressed through her use of evocative language—a stark contrast between her light chuckling tone and the 'deadly' serious content.

What stood out amidst her vivid use of imagery was Eva's light-hearted tone; she chuckled and laughed when detailing her psychological and physical difficulties. The researcher got the sense that Eva intended to tell a relaxed, shallow story that did not penetrate the vulnerability of her internal world. But what she intended to conceal was revealed by a still, faintly detectable underlying sadness and resignation that pervaded her story. Eva curated a passive person, but her self-characterization was more complex than she intended it to seem. For

one, she conveyed how her longstanding struggle with weight loss had to do in part with her own choices, based on the priorities she had established for herself:

Scheduling is a challenge . . . and I am the thing that causes me to have the plan and schedule and move stuff about and that's the thing that's going to be bumped [laughs]. So I'm just going to go home and hang out with my kid and my family.

Eva took full responsibility for not making the time for what she needed, for example time to exercise. By describing circumstances in which she felt she had no influence over her time management, she was in fact expressing a sense of agency. She was firmly grounded in her stance of prioritizing her daughter above all else. During the pre-treatment interview, the sound of Eva's daughter's chatter could be heard in the audio recording, as Eva literally juggled her in her arms while holding the phone. The interview was cut short and resumed later because she chose to attend to her daughter's needs. Not only was she dedicated to her family, she expressed this dedication with food as a "basic" nurturance as mentioned before. Eva's identity as a mother, evidenced by her desire to feed others, commanded her narrative and enlivened it with vigour and intensity. This sense of her 'sureness' was a new tone that began to surface over the course of her interviews and represented a narrative arc in an otherwise languid story.

Eva made sense of her participation in the group from a primarily cognitive standpoint, as her 'autobiographical reasoning' was primarily organized around her thoughts. Initially, she suggested her preference for a 'mind over matter' mentality when she sought out "mental tools" from the group, so that she could "trick" herself and "talk" herself into establishing healthy lifestyle habits. Also revealing in terms of Eva's narrative was what she did *not* say or not allow herself to think about. For instance, there was a dearth of emotional language throughout Eva's interviews, which suggested her preference for expressing herself in a rational, intellectualized

way. Up until and throughout her BC diagnosis, Eva coped with her weight challenges and body image difficulties by being a “champion avoider.” Thus, the avoidance appeared to support the split between Eva’s mind and body. This split was apparent in how she verbalized her aversion to body image topics during the pre-treatment interview:

“I would avoid things that made me deal with my body so I would you know, I didn’t like going shopping for clothes. I don’t... I got better at it as I got older but um [sighs] like yeah if I could ignore my body and concentrate on my brain then I would.”

Eva kept her responses to these hard questions about her body very short, politely yet directly conveying to the researcher that she was not willing to let go of her avoidance. Erecting a mental wall was effective in blocking what could have been suppressed pain. Eva may well have been attached to her cognitive strategies (including rationalizing, intellectualizing, and avoidance) for their effectiveness in helping her cope with the physical and psychological pain, anxiety, and body image issues associated with her surgery.

In line with her cognitively-oriented narrative style, Eva’s experience of self-efficacy was firmly grounded in her intellectual self. Throughout the group and during the interviews, she was invited, in subtle ways, to abandon her cognitive coping mechanisms and express her emotions. Thus, it is of note that Eva was willing to put herself through situations that challenged her avoidance that she otherwise would have tended to eschew. Nonetheless, Eva persisted in her inclination to privilege her thoughts and intellect over her emotions and feelings. She allowed difficult topics to surface just so long as her emotions were not brought to the forefront, and she could dance around her pain with rich language and therapeutic jargon like “inner critic” (gleaned from her previous counselling). This dance allowed her to never expose deeper vulnerabilities in the interview space.

During the post-treatment interview however, we saw a shift in Eva's narrative tone as she expressed more optimism and hope. She seemed to integrate and apply some of the group principles about self-care, including being more "gentle" with herself and "finding it easier to not beat [herself] up about making choices that are not so good, because it's not just, it's not just me." Eva's guilt relaxed when she witnessed that the other women in the group also struggled with maintaining their healthy lifestyle goals. However, her slight transformation remained mainly (and not surprisingly) in the cognitive realm and did not amount to significant behavioural changes. Instead, she said that the program helped her to keep certain healthy principles "top of mind." A more significant departure from Eva's initial characterization was noted, however, in her reference to 'internal' dimensions such as in her eventual recognition that some of her body image challenges came from an emotional, psychological place. In this moment of admission, it seemed like Eva was coming out not only to the researcher, but also to herself.

Nevertheless, Eva attributed the behavioural changes she reported making to her cognitive process. She said, "the more I'm talking about [it] has made me push um, push myself into like actually doing more physical activity" for instance, going for a walk outside during her lunch hour. Eva called herself a "structure monkey" who liked rules, guidelines, and knowing how things would work. She retained this hyper-rational persona over the course of her interviews, but with less intensity and more openness to let other aspects of her experience, like her feelings, guide her thinking. Eva said that the more she got outside, the more she was able to sustain "crazy running games" with her daughter. She felt both the physical and mental health benefits. This all made "logical" sense to her. Eva ended her three-month-post-treatment interview by saying that she was feeling more "capable" and "it gets easier to keep doing the

work,” whereas during her pre-treatment interview, she had seemed burned out by even the thought of pursuing a healthy lifestyle.

As a whole, Eva told a story that approached a redemption tale, but was never actualized or realized. It had two distinct parts: tragedy and hope. It followed a defined, linear structure, but only with a beginning and middle, lacking a definitive denouement. If the ‘end’ that Eva wanted for herself was to make tangible changes in her health behaviours, she was on her way to reaching this point but yet to achieve it. On the other hand, we saw a small yet distinct narrative arc in terms of her thought patterns. She was more willing to reveal parts of a vulnerable side, with her internal world beginning to break through the surface. Eva seemed to have reframed her thinking and ended her journey in the HLM-ABC program by just dipping her toes in change.

### **Jessica**

Jessica’s narrative was concentrated on preventing cancer recurrence through a healthy lifestyle, which for her entailed a balanced diet and calming physical activities (such as walking and yoga). Although Jessica had gained weight while in treatment and was hoping to reduce her waistline to a small degree, ample weight loss was not her primary focus because she considered herself to be “a normal weight person.” Interpersonal relationships and social support played a large role in Jessica’s lifestyle change narrative. Essentially, she functioned as a social system. If one part felt defective or conflicted, then the other parts suffered. For example, if Jessica’s mood (determined by the status of her interpersonal relationships) was low, it was difficult for her to remain focused on her lifestyle goals. Part of why she joined the group was to seek out alternative social supports because she felt abandoned by her friends during and after her cancer. Her friends used the word “not normal” to describe the person she had become, suggesting to Jessica that she was enduringly ‘branded’ as a diseased individual, a perception that she seemed

to have internalized. She was not confident she would return to a “normal state” and was therefore attempting to accept a new identity of being a lifelong cancer patient. Despite this pervasive forlornness, Jessica possessed a quiet confidence and wisdom. The other participants saw her as a peaceful, maternal figure. Ultimately, Jessica was committed to her efforts to stave off a cancer recurrence by adopting more healthful eating and activity practices.

Prior to the HLM-ABC program, Jessica was engaging in aerobic exercises and yoga stretches a few times a week, but her low mood would often usurp her energy, preventing her from staying committed. She also noted a relationship between her feelings and food choices – what she termed “the mood-food relationship.” As she explained, “I am easily affected by my mood. So if I can manage my stress, my anxiety, and my mood better, then I may actually master better eating habits.” Furthermore, feeling satisfied or unsatisfied with her lifestyle habits bore a close relationship to feeling ‘normal’ or ‘sick.’ For Jessica, feeling healthy was synonymous with feeling “normal.” As she explained:

I feel like a normal person attending the group. If not, I feel like a sick person. If I stay home for too long, only surrounded by my needy family members, I feel very bad. But then if I draw on some social activities like [the group and] then I feel like a normal person, too.

Importantly, Jessica held her cancer responsible for her social isolation, mood difficulties, and foggy “chemo brain” that, in turn, made her depressed, lethargic, and forgetful. The fact that she was diagnosed with cancer defined who she was, and although she believed these side-effects would gradually dissipate, she struggled through an “identity crisis.”

I feel kind of bad because... I have [had a] mastectomy and I feel like I’m only half a woman now. So my [body] image is not so good. So if I am at home I just dress in

cancer clothing. But if I am going out to see other people, then I need to put on special clothing to pretend that I am a normal woman... (*I: That must be very difficult.*)...I feel not so bad about it, I just accept it as it is because some people lost their legs, some people lost their arm and some people lost some part of important organs, but then I kind of say to myself ‘that’s no big deal.’ I just lost one side of the breast. I hope I can keep the other side healthy.

Firstly, Jessica felt embarrassed by her body perhaps as a result of feeling ‘othered’ and punished by her community in the form of social exclusion. She withdrew and hid herself as a result, further contributing to her isolation. Jessica’s isolation was thus complex, as it served as both a barrier to health behaviour change (keeping her ‘shut in’ and disengaged) *and* a source of motivation to enroll in structured, health-oriented groups and socialize.

So when I know this group is coming up I’m very happy to participate in it. Because I, I kind of now have an identity crisis. I think uh my normal friends, they desert me, they don’t call me, they don’t email me. They think I’m a cancer patient.

Yet, Jessica’s ability to maintain a sense of positivity after her mastectomy was inspiring for the other women. For instance, Valerie referred to Jessica in her own narrative, saying that Jessica’s calm appreciation for small achievements provided an optimistic presence in the group. In general, Jessica’s narrative was relationship-oriented. She was deeply affected by the actions of her friends, and when an interpersonal issue arose, she talked about how she would forgo her planned healthy lifestyle activities and become “grumpy” and de-motivated. During the interview process, Jessica maintained a sense of composure amidst describing her abandonment. She did have one positive social support experience to offer:



Actually, I only have this neighbour who cares for me . . . she's my friend, she is very nice. She knows I have cancer and then she got me a juicer and she gave the juicer to me to make juice. So I think it's very kind of her, yeah. And then I keep juicing every day. . . All, all my other friends they kind of keep a distance from me, I don't know. Maybe they don't know how to talk to a cancer patient, a cancer survivor. . .

Jessica's self-reference as both a "patient" and "survivor" suggested she had not fully transitioned to a state where the cancer was behind her. But her neighbour's act of "kindness" had inspired her to maintain a healthier diet, at least for a period of time after she received the juicer as a gift. Later, Jessica went on to describe the juice vividly, suggesting that the act of juicing was meaningful to her—engaging in healthy cooking was like a gift for her spirit and her body: "It always looks so pretty, the drinks they always have such vibrant colours, when you, when you make a smoothie with a juicer. Yeah and it tastes good." Overall, Jessica's narrative style was explicit, detailed, thoughtful, and serious. She treated herself and the HLM-ABC group with high priority but this was contingent, once again, on her personal relationships outside of the group going well.

The latter half of Jessica's interviews were narrated with positivity and hope for the future. She stated a myriad of benefits she derived from the group: self-awareness, self-motivation, "regaining balance" after setbacks or other sources of stress, feeling healthier emotionally, "a positive attitude towards life after cancer," and planning ahead. If, for example, her regular walking schedule was disrupted by the weather, she would plan to walk in the mall or around her home. Consistent with one of the primary aims of the HLM-ABC program, Jessica was able to maintain her new habits. In her three-month-post-treatment interview, she stated, "I am good at sustaining the exercise program and I now formed good habits of exercise, which I

begin to enjoy it and cannot do without it.” Jessica reached a position where her physical routines were firmly rooted in her lifestyle. Food, however, posed more of a challenge, as it remained interconnected to external events in her life:

But then for eating, because the past few months I felt a lot of stress at caring for my family members. And then I forgot all the healthy principles, I just eat whatever is available. And before I, if I have time, I will do more juicing, but then for the past few months I do not do any juicing at all, because I was so busy. And then I found my health deteriorate, like I’m not that healthy, because I eat a lot of junk food. So I think I need to work on more, on this goal. . . on maintaining healthy eating habits.

Despite her continued efforts around food, Jessica narrated a personal story of triumph because of her work ethic. She used phrases like “I want to try harder”, “self-discipline” and “self-initiate,” conveying an internal locus of control over her lifestyle. She compared the HLM-ABC intervention to “piano lessons” where students engage in incremental skill-building with each new lesson. The pilot group was even too unstructured for Jessica, and she requested more “concrete” educational principles and homework to keep her on track. The researcher got the impression that Jessica maintained her high level of motivation. Interestingly, at the three-month-post interview, Jessica felt “lighter” and was not deterred by her waistline retention:

I made a plan. My goal is to do sit-ups before I go to bed, some yoga in the morning too. And then I found it very good maintaining them and . . . it helps me [with] reducing my waistline, upon doing that. . . The measurement is the same [of her waist before starting], but I feel lighter. Maybe if I still work on them I can begin to reduce one inch. . . Once a year one inch, yeah. I hope I can reduce one centimeter quarterly.

Jessica maintained hope that the smaller changes she had initiated would eventually lead to bigger improvements. Furthermore, she added that she was now “more comfortable” with her body image. Although she spoke optimistically about her health goals, there was no resolution when it came to interpersonal satisfaction. As she put it at the end of the series of interviews, “Not many friends will give me any encouraging words. So I found this group is very warm and very supportive.” She was grateful for the temporary social outlet the group provided, yet Jessica remained disappointed with her friends’ lack of support, perpetuating her experience of isolation and further solidifying her narrow identity as a cancer survivor. The ‘narrative foreclosure’ of dwelling on her friends’ segregating attitudes towards her dampened the gratifying parts of her narrative.

Overall, the positive tone and specific examples Jessica provided in her narrative summed up to a stable and substantial difference in her previous lifestyle habits, which was a model for the other participants who were fairing worse than her. Her story had a smooth change trajectory when it came to forming and maintaining physical activity habits, where Jessica set clear goals that we saw evolve into concrete behavioural changes. Firmer habits around food consumption, on the other hand, still required work, which Jessica stated were on her radar for future improvement. Her lifestyle changes were told in conjunction with the challenge of her “identity crisis,” which had yet to resolve. Her story displayed an array of facets that were interdependent of one another, primarily informed by the quality of her social relationships.

### **Thematic Intersections**

The thematic intersections analysis involved the comparison of narrative content and aspects of storytelling between and across participants. Narrative themes emerged from the dataset of fifteen interviews. Themes centered on resistance, experiences of agency, motherhood

and family obligations, and how these factors buttressed or impeded the goal of lifestyle modification. Mothering as a BC survivor was related to the sub-theme of self-care and personal compassion, which for some participants felt threatening to their nurturing identities. Another major theme focused on the sense of kinship and belongingness that grew among the participants and contributed to a sense of therapeutic comfort amidst this group of survivors. Furthermore, the range of narrative complexity, personal agency, and narrative tone are discussed in view of the unique persona developments and character presentations within the four, distinct narratives.

**Patterns of Resistance.** The participant narratives revealed a spectrum in terms of the function and presentation of resistance. The complexity of resistance was organized around internal and/or external resistance – that is, resistance directed at behaviour change or directed at oneself. Sarah and Eva’s externally resistant stance was reflected in the overall tone of their narratives, with Sarah expressing explicit defiance in her biting humour and Eva passively surrendering in her light-hearted manner. Both contested the underlying principles of the intervention by avoiding the homework and contesting the self-care module. Yet these overtones revealed underlying pain, too challenging to face and accept. Both women therefore employed a type of resistance embedded within the narrative that functioned like a shield deflecting attention from their inner psychological processes. Interestingly, Sarah’s resistance seemed the most acutely impactful and served a clear protective function for the desolate future she hoped to avoid. Her tone, for example, was harsh when she reflected on her experience of being told how to function on a day-to-day basis (in reference to the health promotion campaigns directed toward cancer survivors): “Yeah I’ll just say I’m not doing this, screw this, you can’t tell me what to do.” Her rebellion gave the impression that Sarah was being mentally and physically

engulfed by her medical conditions. Her bitter and sharp narration was a strategy she used to fight back against her fears of cancer recurrence and ultimately what felt like her bleak future. In contrast, Eva's form of resistance was less obvious and related to her past stories of unsuccessful attempts to lose weight. Her mastery of avoidance when it came to her body image was a form of resistance that also served to protect her from further disappointment. In essence, Sarah's defiance was linked to controlling her future, whereas Eva's served the purpose of avoiding the repetition of her past.

While Sarah and Eva projected their resistance outward, Valerie and Jessica were more inwardly resistant, yet also more motivated. In particular, Valerie was focused on unpacking her psychological barriers:

I think I just learned a lot more about myself and why I do things I guess and why I, you know, choose, for example, not to work out, or choose to like make the decisions that I do. And so, it just helps me um, you know, understand better why I do and it makes it then easier to make the right choices.

Similar to Sarah, Valerie also had issues with others (e.g., healthcare providers) making proclamations about her lifestyle, but recognized how her own inner conflicts prevented her from overcoming lifestyle obstacles. Jessica did not show any active resistance towards the intervention, but had alternative motives for joining the group (i.e., relief from social isolation), which were not entirely aligned with the group's aims and ultimately led her to feeling somewhat disappointed with the group despite having successfully implemented healthy lifestyle changes. Notwithstanding the women's varied representations of resistance, it seemed that they all shared in their openness to cognitive adjustments and re-framing their attitudes of how they

conceptualized and thought about lifestyle modification after BC. As a group, they often preferred the ‘knowing and thinking’ to the ‘doing and acting.’

**Narrative Complexity and Character Agency.** All of the participants brought various degrees of complexity to their narrative tellings. In studying complexity, we consider various features of story such as level of descriptiveness, spontaneous speech, narrative tone, illustrative examples, process-oriented plots, metaphors, and overall richness. A story like Sarah’s lacked descriptiveness, but was nonetheless very textured in *how* it was recounted. The choppy, a-linear formatting was suggestive of an individual who was not particularly grounded in her lifestyle after BC. This type of story made sense with Sarah’s view of living in limbo, anticipating yet another cancer diagnosis because of her BCRA mutation. During her post-treatment interview, when asked “How are you currently feeling about your weight?” Sarah responded with a minimalist answer: “Well, I’m still too heavy, too fat, but I feel better about it now than before.” Valerie’s answer to this same question, on the other hand, began like this:

Um, I mean I think I’m pretty much the same where I was at. Um, the good thing was, you know, I did really in December start working out every day and... and one thing I noticed at that point is my muscles did come back. Like I felt better, I felt like I had more energy. So that was really good. And then...

In total, Valerie’s answer spanned half a page in length using different examples and sub-stories. Her depth gave weight and insight to her interview responses and her narrative in general. In comparison, Jessica and Eva’s narratives were of moderate complexity and moved between transparent to complicated plotlines. In terms of authorship agency, most of the participants held ownership of their curated personas save Eva who tended to portray herself as a non-efficacious,

passive character for the majority of her narrative. She did however convey a more agentic tone at the post-treatment mark.

**My Family Needs Me.** Balancing motherhood with healthy lifestyle was a layered theme that emerged during the interviews and group discussions. The problem of sacrificing communal family time for personal health reasons (i.e., for exercise and food preparation) resonated with three of the participants. For Jessica, tending to her family's needs affected her mood negatively; Eva prioritized spending time with her daughter; Valerie couldn't always find a babysitter for her son. Eva and Valerie eventually came to a resolution by incorporating their children into their physical activity, which proved to be a practical solution in terms of saving quality family time. In this regard, Jessica found the group's collective problem solving helpful:

The group members sharing um quite, quite helpful because like they're all young mums um surviving from cancer and they are trying their best to overcome obstacles and to lead a healthier lifestyle. Um their effort and their motivation is really inspiring.

Underlying the tension between family and health were feelings of guilt for taking time for self-care. Eva would relay anecdotes riddled with self-criticism related to her failures of not spending enough time with family, as well as in relation to weight. However, we saw a change in how she conceptualized lifestyle modification and setbacks, as reflected in her words below:

I might have some negative emotions coming up about not being able to just stick to uh, or to get you know a handle on the food piece of it. I think I can definitely feel better than I have in the past when I've tried stuff like this because um because there is sort of a more like forgiving... it feels like, like you can try stuff and if they don't work, well that's okay to figure out if you want to try something else.

In this passage, despite the potential to feel like a failure, Eva harnessed a more self-compassionate perspective toward adopting a healthy lifestyle. This attitudinal shift also translated into practice for her as she made more attempts at change, such as having her daughter engage in more physical movement with her.

**Forging New Meanings About Health Together.** Without prompting, a major theme that all four participants incorporated into their narratives was the instrumental role of group support. Each participant helped the other in normalizing their experiences, achieving their goals, and discovering new insights about their individual struggles. Below are quotes from each of the participants demonstrating their inter-psychic kinship and communal mentality that they established during the HLM-ABC group.

Eva: “I really liked, I really enjoyed the open group discussion... because there was a way to really um, hearing other women’s stories was very helpful in terms of, sort of, not feeling so alone, or just, or so like I’m unique in a bad way kind of thing. Like oh yeah, everybody has some of these same struggles.”

Jessica: “I am more prone to have my own lifestyle changes maybe by other peoples’ experience, um because they are real life experiences to make those choices and they, they can achieve those kinds of changes. I think they [hearing other women’s stories/experiences] are more effective for me rather than to learn about those theories and put it into my own practice. . . If I see new examples from real life experience, then I think I would want to try that too.”

Sarah: “The support and camaraderie. . . maybe gives me the confidence that I can do it.”

Valerie: “Even though we were very different and even though, you know, some people’s issues with food, some people’s exercise, but at the core I thought we were all the same.”



While each of the women found connection and support within the group, some engaged in more meaning-making than others. Arguably, Valerie gained the most striking insights about her psychological self and was able to articulate the process as it unfolded. It seemed that both Valerie and Jessica began the HLM-ABC program with more ‘narrative openness,’ therefore their stories followed more of a defined change trajectory with a clear beginning-middle-end structure. On the other hand, Eva and Sarah’s narrative felt less plot-driven and more character-driven. Their unique personalities emerged, providing the richness for the narrative in place of a defined trajectory and *denouement* of a healthy lifestyle intervention. Interestingly, these differing narrative styles and foci also seemed to parallel the extent to which the women were able to benefit from the intervention – with Eva and Sarah’s narratives and extent of lifestyle modification remaining at a more cognitive, rather than behavioural, level.

In summary, parts of the narrative content data coalesced to form broad themes related to the participants’ experiences of the HLM-ABC program. By comparing and contrasting their varying idiosyncrasies in relation to each theme in the first analysis, distinct patterns about the phenomenon of striving to make healthy lifestyle changes after BC were revealed. Research participants who share a common medical history and health goals apparently narrate vastly different stories, in different ways, around similar topics. With the secondary intersectional analysis, we can better understand how the participants’ narratives complement and inform one another’s experiences, permitting a broader orientation to the stand-alone narratives.

### **Discussion**

The current study aimed to reach an in-depth understanding of healthy lifestyle modification (or lack thereof) including psychosocial change among BC survivors enrolled in a pilot intervention to support health behaviour change. The dearth of qualitative studies relative to

the growing amount of quantitative and/or weight-loss outcome research has left a considerable gap in our knowledge about the *process* and *meaning* of healthy lifestyle change among BC survivors. To address this gap, four participants were interviewed longitudinally over a series of pre-determined time points: before, during, immediately after, and three months after their participation in the HLM-ABC intervention in order to understand their idiosyncratic lifestyle change trajectories, processes of change, and unique barriers to full participation in a holistic healthy lifestyle program. Equal attention was paid to the *content* of the interviews as to the storytelling *style* and ‘how’ each narrative was told, in order to glean deeper meanings of lifestyle modification. In so doing, the hope was to enrich our understanding of the experiences of BC survivors who are attempting to achieve a healthier lifestyle—a recommendation currently promoted by scientific bodies and cancer advocacy groups alike to support primary and secondary cancer prevention.

The content of the narratives spanned different psychosocial areas of interest such as group cohesion, existential challenges, personal agency, self-compassion, motivation, and body image. Previous research has shown that supportive-expressive group therapy programs for BC survivors can improve psychosocial difficulties, such as loneliness and quality of life in general (Tabrizi, Radfar, & Taei, 2016). All participants in this study experienced a sense of kinship and gratitude towards the other survivors for their candid involvement in the group. Established clinical practice guidelines for group psychotherapy considers ‘group cohesion’ a central therapeutic factor (Bernard et al., 2008). The mechanisms of cohesiveness include feelings of trust and togetherness forged by the group members. Yalom (1985) explains that group cohesiveness is a necessary precondition for mutual understanding and acceptance in a group support context. In the HLM-ABC, the participants reported feeling a sense of inter-psychoic

kinship. This tangible sense of comradery and support was identified as the ‘forging new meanings of health together’ thematic intersection. Not only was the communal environment a source of inspiration and validation, but it also helped the participants to gain insight into themselves and their own motivations and struggles by drawing on the experiences of others.

Results from the stand-alone narratives both echoed and added to the existing findings on the lived experiences of weight difficulties among BC survivors. For example, Pedersen, Groenkjaer, Falkmer, Mark and Delmar’s qualitative study (2015) described how BC survivors assign complex meanings to their bodies which can be quite psychologically burdensome. Their research revealed that survivors interpret their bodily changes in light of fears of cancer recurrence, seeing weight maintenance as vital to their survival. Knowledge of the association between excess adiposity and increased risk of cancer recurrence became an incentive to take control of one’s weight and to reduce existential fears. The current study corroborates Pedersen et al.’s (2015) research, as the majority of the participants enrolled in the HLM-ABC program had the intention of, at least indirectly, coping with fears of cancer recurrence.

A unique finding, however, was the incongruous paralyzing effect that enrolling in a structured intervention can have if the individual perceives their efforts to make lifestyle changes to be futile. Feelings of helplessness arose when participants considered the risk of other potentially unmodifiable factors, such as having a genetic mutation or previously unsuccessful experiences with weight loss. Eva’s story vividly illustrated this dilemma between claiming autonomous agency over one’s body and feeling overwhelmed and powerless to affect change. Doan and Gray (1992) touch on a socio-cultural phenomenon associated with autonomous agency within the cancer realm. They describe the concept of the ‘Heroic Cancer Patient’—a culturally-curated personality style in cancer patients and survivors which implicitly glorifies

overcoming adversity through a type of relentless resiliency. Those with the disease should adopt attitudes of extreme optimism in the service of their health, survival, and the prospect of “psychological self-transformation” (p.255). Yet, this cultural message essentially problematizes cancer incidence and prognosis, and communicates unrealistic expectations for a number of individuals. While this rhetoric has been helpful to some individuals with cancer, it can pose an existential dilemma for those who do not adopt this heroic stance. In her critique of ‘Pink Ribbon Culture,’ Ehrenreich (2001), who was at one time diagnosed with BC herself, argues that being a ‘survivor’ merits acclaim and honour, whereas weakened and scared women with BC are not given the same status and recognition. We saw this type of conflicted response with Eva, for example, when she attempted to maintain a kind of ‘heroism’ by exercising personal responsibility over her weight, which left her feeling overwhelmed, defenseless, and lacking in motivation.

Deci and Ryan’s self-determination theory implicates the importance of motivation in relation to health behaviour change (Patrick & Williams, 2012; Ryan, Patrick, Deci, & Williams, 2008). Their general theory of human motivation emphasizes the extent to which intrinsic versus extrinsic factors (i.e., intrapsychic vs. interpersonal pressure) and feelings of competence sustain motivation (Patrick & Williams, 2012). Intrinsically motivated individuals will carry out their health behaviours autonomously, whereas extrinsically motivated individuals generally respond to external forces. Our study saw clear intrinsic and extrinsic motivational styles at play, as well as evolving shifts in motivational style as the intervention proceeded. Eva, for example, felt pressured by what she “should” have been doing to stave off cancer whereas Jessica was more “inspired” by intrinsic feelings of well-being. For Jessica, a self-directed drive for health that was not attached to a certain weight-loss outcome proved to be a successful factor, as she reported

that the HLM-ABC program was mostly effective for her. Valerie's motivation, although influenced by a number of factors including her son and body image, was mainly conjured and sustained from an internal desire to return to her old self. On the other hand, Sarah's reliance on the dubious evidence for reduced risk of disease recurrence left her feeling angry. The scientific knowledge she possessed was an extrinsic factor that she ultimately came to perceive as a false promise, offering only an artificial sense of control in the face of her other more powerful and menacing cancer risk factors. As a result, Sarah expressed her discouragement and frustration toward the intervention by adopting an impish attitude towards it. In sum, self-determination theory provides a useful framework to help explain why some of these participants narrated stories of agency and others of impotence, in relation to the HLM-ABC program.

Pre-morbid weight status proved to be informative in the narrative accounts. For instance, Eva's attempt to re-write her perpetual story of weight loss defeat. She attributed much of her inability to execute lifestyle changes to her belief that "you are always yourself no matter where you go." She was seemingly referring to her pre-morbid weight that was unyielding to her weight loss efforts. Thus, she was dissatisfied with her weight at three-months post-treatment. Her immobility and lack of change trajectory within her narrative leads us to question the ways in which she was different from the other participants. In their review of weight loss interventions among BC survivors, Reeves, Terranova, Eakin, and Demark-Wahnefried (2012) call for the assessment of sub-groups of BC survivors (e.g., type of tumour at diagnosis) to investigate the contributing factors to poor versus successful weight loss in the diverse BC survivor population. Further to this point of more individualized care in helping women adopt a healthy lifestyle, the current study highlights the need for considering the difference between survivors with pre-morbid overweight status and those survivors who entered into the overweight range as a result

of their treatments. Previous failed attempts at calorie-restrictive diets often predict subsequent dieting failures (Amigo & Fernandez, 2007). A seminal paper on weight maintenance factors in overweight individuals concluded that weight loss and subsequent weight maintenance is associated with intrinsic motivation, self-efficacy, autonomy, and a number of other psychosocial factors (Elfhag & Rössner, 2004). Therefore, it seems important for future studies to investigate whether both engagement and outcome with a lifestyle intervention is potentially mediated by the survivor's pre-morbid struggles (and successes) in relation to weight. With this prospective knowledge, narratives of defeat, such as Eva's, might be proactively addressed with more individualized, supportive psychosocial strategies that account for factors like weight history and motivation.

The distinct *Patterns of Resistance* among these participants' narratives represented a strong thematic intersectional point that emerged from our cross-participant analysis. Resistance has been studied extensively in the context of various individual psychotherapy modalities, and has been operationalized in diverse ways (Messer, 2002, Moyers & Rollnick, 2002). Messer (2002), who comes from a psychodynamic background, reviews the concept of resistance broadly, explaining that resistance typically occurs within the therapeutic relationship between the therapist and the client. If the client perceives a loss of freedom or control on account of external forces or a poor therapeutic relationship, the client will often display resistance. It may manifest in different ways within or outside therapy, such as through avoidance, reactance, lack of motivation, disagreements between the therapist and client, etc. Fundamentally, resistance is considered to be a process by which clients assert their healthy human need for autonomy “and to protect their sense of self” (Messer, 2002, p.158). With the exception of Sarah, who displayed this type of relational resistance during the interview process to demonstrate self-efficacy and

exert control, this type of resistance was not observed among the other group members and the facilitators and/or between group members, as conveyed by their perceptions of group cohesion and reported satisfaction with the group facilitators. Instead, all participants displayed reluctance to changing their attitudes and behaviours outside the group. This explicit form of resistance was captured in some of their narrative accounts, namely the ‘howness’ of the participants’ storied experiences. Studying the ‘how’ of their narratives provided insight into the nature of their behavioural resistance. For example, Eva’s resistance was displayed in extreme avoidance of topics that made her uncomfortable. Vanessa and Jessica’s resistance was more internally focused, as they perceived their barriers to be mainly psychological and turned inward to find the reason and remedy their resistance—ultimately, to greater relative effect.

The transtheoretical model of health behavior change (Prochaska & Velicer, 1997) provides some explanation to the type of resistance that was encountered with the present sample of women. This model looks closely at behaviours as a process of change over time, according to six stages of change: pre- contemplation, contemplation, action, maintenance, and termination. According to this model, participants like Sarah and Eva seemed to be situated for the majority of the intervention in the pre-contemplation stage, not intending to take any foreseeable action in the near future despite their willingness to participate in the group. They were located at a cognitive processing stage, more inclined to *discussing* their ambivalence toward change rather than *acting* on change. However, the HLM-ABC program was designed according to an ‘action phase’. Eva and Sarah may have been misaligned in regard to their readiness for change, rendering them less amenable and responsive to the intervention at that given moment in their survivorship journeys.

The motivational interviewing (MI) literature focuses on remedying resistance by

enhancing intrinsic motivation and discussing ambivalence to change (Moyers & Rollnick, 2002). Clifford and Curtis (2016), experts in MI for nutrition and fitness, contend that although many practitioners will jump to a planning phase, it is important to provide empathic support to the individual who may have valid reasons for not wanting to change. Exploring these reasons for maintaining the “status quo” of their health behaviours helps to elucidate existing ambivalence and inspire “change talk” (statements from the client that favours commitment towards the client’s goal). Therefore, practitioners may find it beneficial to screen for potential readiness for change and/or incorporate MI and the transtheoretical model of health behaviour in their interventions in order to provide motivational support, if needed. The online version of the HLM-ABC program (which began in February 2017) incorporated a module specifically on barriers to change drawing on self-determination theory and MI theory, based on the difficulties observed in the pilot group participants. More studies focusing on motivation and resistance among BC survivors seeking weight management services are needed.

Murray contends that narrative research can capture an “ideological level” of analysis, revealing broader sociocultural assumptions and belief systems that may arise within an individual narrative (Murray, 2000, p.342). Interestingly, this group of participants had difficulty incorporating healthier habits into their lifestyles because of a conflict between their identities as cancer survivors who are culturally and medically sanctioned to stay healthy, and as mothers who must tend to their family’s needs before their own. The latter suggests a cultural-systemic phenomenon that feminist scholars have observed for some time. Functioning as a self-sacrificing mother in society has been termed the “good mother stereotype” (Etaugh & Bridges, 2013) and is associated with a code of behaviour where a mother should not act as if she is entitled to give to herself before she has taken care of others (Bepko & Krestan, 1990). This



theory helps to explain why asking the participants to make time to establish healthy habits may have elicited feelings of guilt and shame. For them, the time needed for healthy habits may have meant defying a “good mother” role.

Women’s hesitance to engage in self-care taps into a relatively new concept in Western culture—self-compassion—of which Buddhist philosophy has been a proponent for hundreds of years (Neff, 2003). Buddhist traditions explain self-compassion as *metta* or loving-kindness, whereby the love, kindness, and acceptance that one extends to others is also extended to the self (Gilbert, 2005). Aside from Jessica, who was the least self-critical, the other participants were not able to readily engage in healthier lifestyles as a self-compassionate endeavour at the outset of the intervention. The narrative lens adopted in this study was able to capture this sociocultural problem affecting the lives of women in general. Moss and Dyck (2002) claim that the female body has always been a socially constructed entity, whether or not it is healthy or sick. Thus, the female cancer survivor is burdened by both individual (or intrapsychic) and systemic (or socio-cultural) challenges. Seeing as how the overwhelming majority of BC survivors are women, healthy lifestyle interventions might aim to straddle the tension between biomedical and feminist discourses; that is, promote healthy lifestyle and self-compassion alongside psychoeducation around sociocultural notions that may be (more or less subtly) impeding their efforts. Wilkinson (2000) has suggested employing a multitude of research traditions such as positivist empiricism and experiential approaches to study women’s experiences of health and healthcare, particularly in breast cancer research. Outside the BC literature, narratives of women with HIV/AIDS and women utilizing reproductive technologies are similarly calling for attention to sociocultural norms hindering women’s health and healing processes (Clarke & Olesen, 1999).

## **Limitations**

This study eschewed a large sample size in order to capture the depth and complexity associated with the phenomenon of lifestyle modification after BC. Multiple-case study designs are typically very detailed and seek to capture the whole of an individual's experience (Yin, 2014), as is consistent with the goals of narrative research. That said, the results of this study are not generalizable to all BC survivors who choose to partake in healthy lifestyle or weight loss interventions.

Although all of the participants were BC survivors who received their treatment at the same facility and were within five years of their active treatment, they underwent a range of different treatments, were diagnosed at different stages of BC, and were situated in different BMI weight classifications. Therefore, future studies might choose to focus on uniformity of the participants in terms of BC history in order to customize healthy lifestyle plans as has been recommended (Sedjo et al., 2016; Reeves, Terranova, Eakin, & Demark-Wahnefried, 2014), and to better understand the mechanisms underlying healthy lifestyle maintenance.

The 'thematic intersections' analysis was derived from individual interviews. This section may have benefitted from analyzing transcripts from the audio-recorded HLM-ABC group sessions wherein group dynamics and thematic data may have arisen more naturally in the group support environment. Moreover, incorporation of discourse from the group sessions would have undoubtedly added more depth, colour, and nuance to the four stories reported here which were based on the interviews only.

Finally, narrative researchers often ask open-ended and intentionally non-leading questions to encourage free and genuine authorship by the participants. Although the participants in this investigation were asked general questions, this study also functioned as a pilot for the

online trial of the HLM-ABC program, which commenced shortly thereafter. For instance, a module on barriers to forming healthy habits was further expanded to include different types of resistance, as well as a self-compassion module in negotiating a new relationship to one's body. Thus, some of the questions were geared at program evaluation and specificities of the intervention. The authors did their best to focus this analysis on the aims of the present narrative study and separate out program evaluation data.

### **Implications**

As of late, particular consideration has been paid to researching the most effective ways of establishing and maintaining a healthy weight and BMI. Yet given the pervasive nature of fears of cancer recurrence, loneliness, body image challenges, and poor quality of life among BC survivors, healthy lifestyle interventions are potential avenues for alleviating psychosocial stress in addition to reducing adiposity. The research has been exclusively focused on measuring weight outcomes without bearing in mind questions of why or how BC survivors can maintain a healthy lifestyle. The HLM-ABC intervention demonstrated the potential for developing healthy lifestyle interventions that are psychosocially-oriented, and the current investigation contributed to a deeper understanding of weight change and subsequent lifestyle modifications among BC survivors. From the perspective of the BC survivors themselves, this study managed to capture their cognitive and emotional processes in their rich narrative accounts, offering additional knowledge regarding potential barriers to adoption and maintenance of healthy lifestyle during the survivorship stage. There is a potential tenuous relationship between weight loss (i.e., a modifiable risk factor) and cancer risk reduction if other, less-modifiable risk factors (i.e., genes, heredity) are evident. Knowledge of pre-morbid weight challenges may also need to be considered to minimize potential difficulties with intervention uptake and maximize success.

Future research studies may examine differences in weight loss outcomes between subgroups of survivors: those who were overweight pre-versus post-treatment.

The current findings show that BC survivor issues are also women's issues. Interventions cannot be displaced from broader cultural issues and values that affect women's daily lives. Survivors who are returning to their regular routines after treatment subsides will inevitably be negotiating among several day-to-day responsibilities amidst cancer-altered bodies and identities. Psychoeducation around the value of self-compassion might help to support the formation of healthy habits while also alleviating feelings of guilt. Admittedly, the line between change and acceptance is a fine one, but investigating the relationship between self-compassion and healthy lifestyle modification is a warranted avenue for future research.

Perhaps the strongest implication of these findings is that weight modification after cancer is exceedingly intermingled with existential challenges associated with survivorship. Some of our participants did not separate their fears of recurrence from healthy lifestyle attempts; rather, they saw the two as almost one in the same. For some survivors, building habits for a healthy lifestyle was their way of attempting to maintain a sense of control in their daily lives. Therefore, BC healthcare providers should be attuned to identifying fear of cancer recurrence and informing their patients of the potential value of engaging in a healthy lifestyle intervention beyond weight loss alone. However, it is also important to bear in mind that this 'added benefit' of such a program may be experienced as added pressure for a subset of women. Largely, these findings have the potential to inform oncology healthcare providers and program developers of the successful and less successful narratives of healthy lifestyle modification among BC survivors.

## **Conclusion**

This study sought to deepen existing knowledge of different courses of lifestyle change among BC survivors enrolled in a pilot intervention designed to support healthy lifestyle development and maintenance. The longitudinal study design permitted a processual window into the participants' experiences. They each narrated across time in the intervention, contributing to a full and rich narrative whole. By preserving the HLM-ABC context and each participant's individual experience explicated in detail, this research allowed the voices of BC survivors who were attempting to make difficult changes in service of their health to be heard and considered in all their complexities, with weight and importance.

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## Appendix A: Informed Consent Form

### INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Full Study Title:** Piloting a Face-to-Face Lifestyle Intervention for Healthy Weight Management and Improved Quality of Life in Breast Cancer Survivors

**Principal Investigator:** Karen Fergus, PhD, C. Psych, Patient and Family Support, Sunnybrook Odette Cancer Centre, 416-480-5000 x1243

**Co-Investigators:** Dana Male, MA, Department of Psychology, York University, Shira Yufe, MA Candidate, Department of Psychology, York University

**Sponsor:** This study is being funded by the Canadian Breast Cancer Foundation.

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### INFORMED CONSENT

You are being asked to consider participating in a pilot study. A pilot study is a small scale preliminary study conducted in order to evaluate feasibility of what would eventually be a research study. A research study is a way of gathering information on a treatment, procedure or medical device or to answer a question about something that is not well understood.

This form explains the purpose of this pilot study, provides information about the study, the tests and procedures involved, possible risks and benefits, and the rights of participants.

Please read this form carefully and ask any questions you may have. You may have this form and all information concerning the study explained to you. If you wish, someone may be available to verbally translate this form into your preferred language. You may take as much time as you wish to decide whether or not to participate. Feel free to discuss it with your friends and family, or your family doctor. Please ask the study staff or one of the investigator(s) to clarify anything you do not understand or would like to know more about. Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time.

### INTRODUCTION

You are being asked to consider participating in this pilot study because you have been diagnosed with primary breast cancer (Stages I-III), have completed active treatment within the past five years, and consider yourself to be overweight or have gained 10 or more pounds post-treatment. Because maintaining a healthy weight is important for breast cancer survivorship, there is a need to develop strategies and supports for women to help with the process of weight loss and healthy weight management post-treatment. This study will implement a 10-week in-

person group intervention designed to address diet and exercise, along with other psychosocial issues related to survivorship such as depression, fatigue, body image and social support. This research has the ability to improve the long-term health of breast cancer survivors by incorporating psychosocial interventions into standard medical care practices.

### **WHY IS THIS STUDY BEING DONE?**

The purpose of this study is to develop an effective group-based lifestyle intervention that helps breast cancer survivors sustain weight loss and improve their physical well-being. After this intervention is tested with a pilot group of participants, the researchers will conduct a randomized control trial where online delivery of the intervention will be compared to the face-to-face intervention. At that point, a secondary aim is to demonstrate that online delivery of this service is equally as effective as the more common face-to-face delivery. However, you are being asked to participate in the pilot study of this intervention before the randomized control trial commences in order to ensure the intervention is feasible.

### **WHAT WILL HAPPEN DURING THIS STUDY?**

Participants in this study will take part in a face-to-face group program. As part of your participation in the intervention, you will follow an individualized diet and exercise plan while participating in-person (in a private room at the Louise Temerty Breast Centre at Sunnybrook Health Sciences Centre) in 10 weekly 90-minute psychoeducational sessions of therapist-led group discussion about lifestyle modification and maintenance of health promoting behaviours. The group sessions will be video taped.

Your diet and exercise plans will be developed in consultation with a registered clinical psychologist and dietician, after having participated in a pre-treatment interview to obtain a history of your diet and exercise patterns. Thereafter, you will be asked to complete an online dietary and exercise recall measure on a weekly basis.

### **HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?**

It is anticipated that approximately 8 people will participate in this study, and recruitment will be through the Sunnybrook Louise Temerty Breast Center and announcements in the Greater Toronto Area. The length of this study for participants is about 27 months in total (2.5 months for the intervention, with the completion of additional questionnaires at 6, 12 and 24 months following completion of the program). The entire study is expected to take about 3 years to complete and the results should be known in 3.5 years.

### **WHAT ARE THE RESPONSIBILITIES OF STUDY PARTICIPANTS?**

If you decide to participate in this study you will be asked to do the following:

#### **Screening Interview**

The Screening Interview will take up to 45 minutes to complete. This information will enable us to determine if you are eligible to participate in the study.

During the Screening Interview, you will be asked to answer questions about your medical history, weight, accessibility to transportation to and from the study site, access to a computer and the Internet, as well as your readiness to engage in physical activity. Please note that you have the choice of not answering any questions should you not want to.

You may not take part in this study unless you have been diagnosed with non-metastatic breast cancer, have completed treatment within the previous 5 years, and consider yourself to be overweight/obese (BMI>25 or an increase in weight  $\geq$  10 pounds since completing treatment).

### **Baseline Measures**

Once enrolled in the study you will be asked to visit with your family doctor within two weeks of your baseline questionnaires, if possible. At this visit you will have your weight, height, and your waist circumference measured. This visit will take up to 30 minutes to complete.

Around the same time, you will be mailed a package including a set of questionnaires about your nutritional intake, physical activity, quality of life, mood, body image, and beliefs about your own abilities to reach your goals. The nutritional intake information is to be completed online, using an automated system that will prompt you to recall your recent food intake. It will take up to 40 minutes to complete these forms, which you will be asked to complete and return by mail with pre-paid postage.

### **Pre-treatment Interview**

You will be asked to take part in a pre-treatment interview that will last approximately 45 minutes and may be recorded. During this interview, you will be asked questions about your past and current health patterns, as well as personal promoters and barriers to maintaining a healthy lifestyle. This information will inform group discussion as well as the development of your individualized diet and exercise plan.

### **Intervention**

You will follow an individualized diet and exercise plan for the 10-week duration of the program, which will be designed in collaboration with a registered clinical psychologist and dietician. You will be asked to complete an online recall measure of your dietary and exercise behaviours on a weekly basis. Involvement in the group will include weekly attendance — in a private room at the Louise Temerty Breast Centre at Sunnybrook Health Sciences Centre— at 90-minute psycho-educational group discussions about lifestyle modification and maintenance of health promoting behaviours. Relevant issues specific to BC (e.g., self-esteem, depression, fatigue, changes in social support) will also be addressed. The group will be co-facilitated by a registered Clinical Psychologist and a doctoral trainee in clinical psychology and will be video recorded.

### **Midway-treatment Interview** (following approximately 5 group sessions)

You will be asked to take part in a mid-intervention interview that will last approximately 45 minutes and may be recorded. During this interview, you will be asked questions about the group sessions as well as personal promoters and barriers to maintaining a healthy lifestyle. This information will inform group discussion, the development of your individualized diet and

exercise plan, and the intervention for the randomized control trial.

### **Post-Treatment, 6-Month Follow-Up, 12-Month Follow-Up, and 24-Month Follow-Up Measurements**

After 10 weeks have passed or you have completed the program, you will be asked to visit your family doctor again to have your weight, height and waist circumference measured. You will have these measurements taken again 6 and 12 months and 24 months later (follow-up). These visits will take up to 30 minutes each.

At these same four time points, you will also be mailed and asked to complete the same set of questionnaires that you completed prior to beginning the program about your nutritional intake, physical activity, quality of life, mood, body image, and beliefs about your own abilities to reach your goals. These forms will take up to 40 minutes to complete.

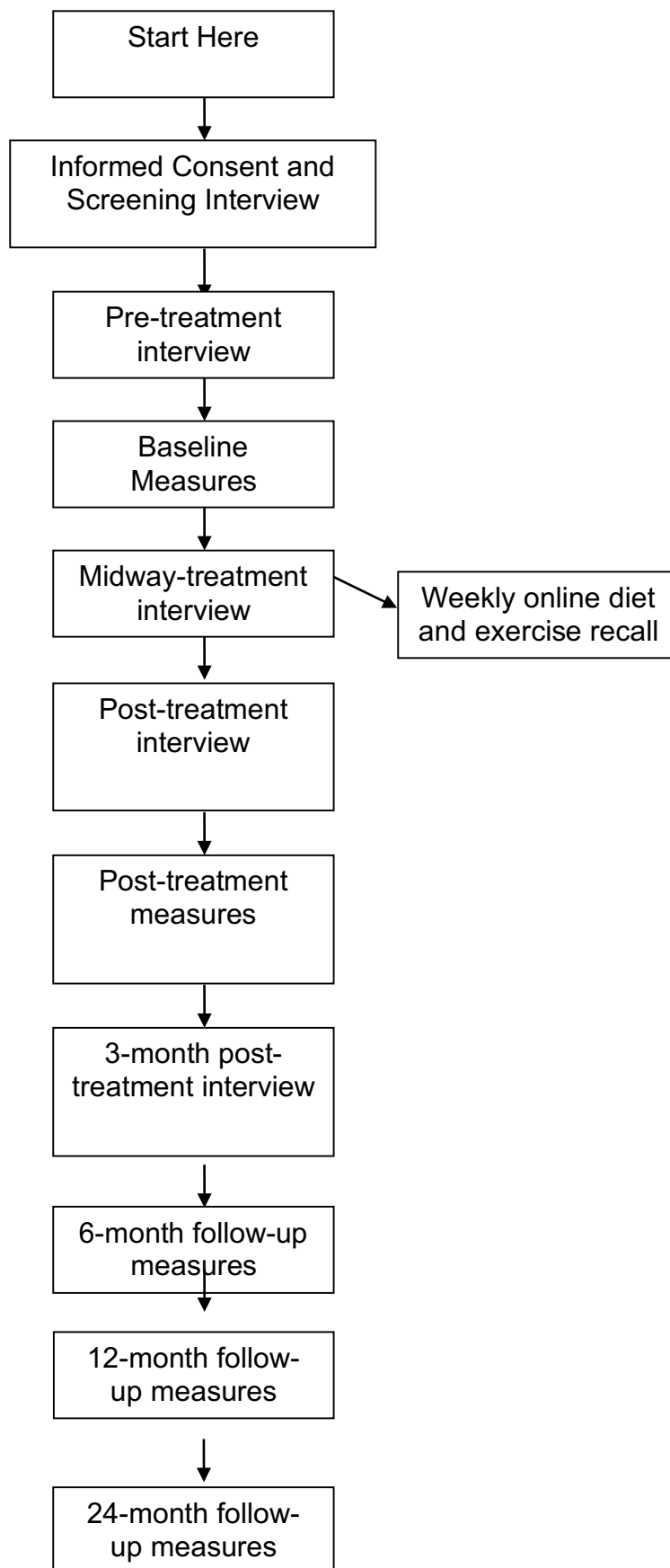
### **Post-treatment Interview**

You will be asked to take part in a post-treatment interview that will last approximately 45 minutes and may be recorded. You will be asked questions about your involvement in the study, particularly what you found to be most and least helpful. You will also be asked for feedback regarding how the intervention may be improved or refined in the future. This interview will take up to 45 minutes to complete.

### **3-Month Follow-Up Interview**

You will be asked to take part in another post-treatment interview after 3 months that will last approximately 45 minutes and may be recorded. During this interview, you will be asked questions about your involvement in the study, particularly your perceptions of the intervention and what you found to be most and least helpful a few months after ceasing the intervention. This information will inform the intervention of the randomized control trial.

Another way to find out what will happen during this study is to read the study plan below. Start reading at the top and read down the list, following the arrows.





## CALENDAR OF VISITS

Boxes marked with an X show what will happen at each time point.

Visit	Screening Interview	Pre-Treatment Interview	Baseline Measures	Midway Treatment Interview	Post-Treatment Measures
Time	45 mins	45 mins	70 mins	45 mins	70 mins
Informed consent	X				
Telephone Interview	X	X		X	
Questionnaire			X		X
Height, weight, waist circumference measurements			X		X

Visit	Post Treatment Interview	3-Month Post Treatment Interview	6-Month Follow-Up Measures	12-Month Follow-Up Measures	24-Month Follow-Up Measures
Time	45 mins	45 mins	70 mins	70 mins	70 mins
Informed consent					
Telephone Interview	X	X			
Questionnaire			X	X	X
Height, weight, waist circumference measurements			X	X	X

### WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

The potential risks associated with participating in this study are minimal and strategies have been put in place to mitigate these risks. You will have been screened over the telephone to assess your readiness/suitability to engage in physical activity prior to beginning the program and will have discussed any individual concerns regarding safe physical activity with your family doctor. Nevertheless, there is a minimal risk that you might experience physical pain or injury during exercise.

There is also the potential for you to become uncomfortable during the intervention group while discussing your experiences with breast cancer and its impact on your psychological, social and physical health. The facilitators for the group do their best to create a safe environment where such feelings can be explored in ways that are supportive. However, bear in mind that you will determine the extent of participation in the group and you always have the option to be less involved or remove yourself from the group if that seems to be the most appropriate action. Additionally, you may disclose information that may identify people or facilities. Out of respect for individuals' privacy, the facilitators will encourage participants to refrain from using names.

You will be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the study staff.

### **WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?**

You may or may not benefit directly from participating in this study. However, possible benefits include weight loss, increased quality of life, improved mood, more positive body-image, self-esteem, social support, and increased knowledge in healthy lifestyle management. Your participation may or may not help other people with breast cancer in the future.

### **WHAT OTHER CHOICES ARE THERE?**

If you decide not to participate in this study, other treatment choices may be available. These may include: independent diet and exercise, consultation with your family physician or other medical professionals (e.g. dietician), alternative structured weight loss programs, or not doing anything at all. This list is not exhaustive, and if you are interested, you can further discuss these treatment options with the investigator(s) before deciding whether to participate in this study.

### **CAN PARTICIPATION IN THIS STUDY END EARLY?**

The investigator(s) may decide to remove you from this study without your consent for any of the following reasons:

- The investigator(s) decide(s) that continuing in this study would be harmful to you
- You plan to undergo a medical procedure during the duration of the study
- You plan to participate in another structured weight loss program or take weight loss medication during the duration of the study
- You are unable or unwilling to follow the study procedures
- You develop a medical condition that is not successfully managed/treated
- You develop metastatic breast cancer or enter active cancer treatment

If you are removed from this study, the investigator(s) will discuss the reasons with you and plans will be made for your continued care outside of the study.

You can also choose to end your participation at any time without having to provide a reason. If you choose to withdraw, your choice will not have any effect on your current or future medical treatment or health care.

If you withdraw voluntarily from the study or at the request of your family doctor, you are encouraged to contact Dr. Karen Fergus immediately, at Department of Psychology, Sunnybrook Odette Cancer Centre, 2075 Bayview Avenue, Toronto, Ontario, M4N 3M5, karen.fergus@sunnybrook.ca.

If you withdraw your consent, the information about you that was collected before you left the study will still be used. No new information about you will be collected without your permission.

### **WHAT ARE THE COSTS OF PARTICIPATING IN THIS STUDY?**

Participating in this study may result in added costs to you for parking and transportation.

### **WHAT HAPPENS IF I HAVE A RESEARCH RELATED INJURY?**

If you become sick or injured as a direct result of your participation in this study, your medical care will be provided. Financial compensation for such things as lost wages, disability or discomfort due to this type of injury is not routinely available.

By signing this consent form, you do not give up any of your legal rights.

### **ARE STUDY PARTICIPANTS PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to participate in this study.

### **HOW WILL MY INFORMATION BE KEPT CONFIDENTIAL?**

You have the right to have any information about you and your health that is collected, used or disclosed for this study to be handled in a confidential manner.

If you decide to participate in this study, the investigator(s) and study staff will look at your personal health information and collect only the information they need for this study. "Personal health information" is health information about you that could identify you because it includes information such as your;

- name,
- address,
- telephone number,
- date of birth,
- new and existing medical records, or
- the types, dates and results of various tests and procedures.

You have the right to access, review and request changes to your personal health information. The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines:

- Representatives of the Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, the Sunnybrook Research Ethics Board, or the Ontario Cancer Research Ethics Board, because they oversee the ethical conduct of research studies at Sunnybrook

Access to your personal health information will take place under the supervision of the Principal Investigator.

“Study data” is health information about you that is collected for the study, but that does not directly identify you. This data will include video-recorded and transcribed discussions that take place in either the face-to-face, or online, group sessions. You will not be identified by name on any document and your identity will remain confidential.

Any study data about you that is sent outside of the hospital will have a code and will not contain your name or address, or any information that directly identifies you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The investigator(s), study staff and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

The Principal Investigator will keep any personal health information about you in a secure and confidential location for 10 years and then destroy it according to Sunnybrook policy.

When the results of this study are published, your identity will not be disclosed. The findings will be published in academic journals and presented to professional and general audiences. It is possible that word-for-word excerpts from your discussions and comments may be used in presentations and reports. Were this to occur, your identity would be concealed and protected. However, it is possible that you (or people who know you well) might recognize words-in-print or spoken in a presentation as belonging to you.

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 the results of this study, please contact Dr. Karen Fergus, at Department of Psychology, Sunnybrook Odette Cancer Centre, 2075 Bayview Avenue, Toronto, Ontario, M4N 3M5, karen.fergus@sunnybrook.ca.

A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. Law. This Web site will not include information that can identify you. At most, the Web site will include a summary of the results. You can search this Web site at any time.

### **DO THE INVESTIGATORS HAVE ANY CONFLICTS OF INTEREST?**

There are no conflicts of interest to declare related to this study.

## COMMUNICATION WITH YOUR FAMILY DOCTOR

Your family doctor may be informed that you are taking part in this study so that your study coordinators and family doctor can help you make informed decisions about your medical care.

## WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction, before you make any decision. You also have the right to ask questions and to receive answers throughout this study.

If you have any questions about this study you may contact the person in charge of this study, Dr. Karen Fergus, Department of Psychology, Sunnybrook Odette Cancer Centre, 2075 Bayview Avenue, Toronto, Ontario, M4N 3M5, karen.fergus@sunnybrook.ca.

The Sunnybrook Research Ethics Board has reviewed this study. If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call the **Chair of the Sunnybrook Research Ethics Board at (416) 480-6100 ext. 88144.**

## DOCUMENTATION OF INFORMED CONSENT

You will be given a copy of this informed consent form after it has been signed and dated by you and the study staff.

Full Study Title: Piloting a Face-to-Face Lifestyle Intervention for Healthy Weight Management and Improved Quality of Life in Breast Cancer Survivors

Name of Participant: \_\_\_\_\_

### Participant/Substitute decision-maker

By signing this form, I confirm that:

- This research study has been fully explained to me and all of my questions answered to my satisfaction
- I understand the requirements of participating in this research study
- I have been informed of the risks and benefits, if any, of participating in this research study
- I have been informed of any alternatives to participating in this research study
- I have been informed of the rights of research participants
- I have read each page of this form
- I authorize access to my personal health information, medical record and research study data as explained in this form

- I have agreed, or agree to allow the person I am responsible for, to participate in this research study
- I understand that my family doctor may be informed of my participation in this research study
- This informed consent document may be placed in my medical records

\_\_\_\_\_

\_\_\_\_\_  
 Name of participant/Substitute decision-maker (print)      Signature      Date

### **ASSISTANCE DECLARATION**

Was the participant assisted during the consent process?  Yes  No

The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant/substitute decision-maker.

The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that that participant/substitute decision-maker has understood the information translated.

\_\_\_\_\_

\_\_\_\_\_  
 Name of Person Assisting (Print)      Signature      Date

Person obtaining consent

By signing this form, I confirm that:

- This study and its purpose has been explained to the participant named above
- All questions asked by the participant have been answered
- I will give a copy of this signed and dated document to the participant

\_\_\_\_\_  
Name of Person obtaining  
consent (print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Statement of Investigator

I acknowledge my responsibility for the care and well being of the above participant, to respect the rights and wishes of the participant as described in this informed consent document, and to conduct this study according to all applicable laws, regulations and guidelines relating to the ethical and legal conduct of research.

\_\_\_\_\_  
Name of Investigator (print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## Appendix B: Interview Protocols

1. Pre-treatment Interview
2. Midway-Intervention Interview
3. Post-Treatment Interview
4. Three-Month Post-Treatment Interview

### **1. Pre-treatment Interview**

*Thank you for taking the time to speak with me today. The purpose of this call is to gain some personal information about your diet, exercise and weight history so that we have a sense of your history as you enter the group. By knowing more about your previous patterns of eating, exercising and feeling about your body, we will be in a better position to help you make use of the group to address your specific concerns and to help you develop realistic goals for yourself while participating in the group.*

*This lifestyle intervention is developed based on the assumption that how we behave and look on the outside is very much related to how we feel and think on the inside. For that reason, this program will involve group discussions surrounding not only diet and exercise, but also psychological and social issues faced by women in general and breast cancer survivors in particular that can interfere with healthy living. In order for us to help you make the most of each group session that you will attend, it would be helpful for us to know about some of your background and personal experiences related to eating, exercise, weight and body image and social support.*

*This process is entirely voluntary and you do not have to respond to any question if you do not wish to. In total, this interview should take no more than 45 minutes, and with your permission, I would like to audio-record it. [If participant agrees, start recording.]*

*Great, to begin, I am interested to know:*

What attracted you, personally, to participate in this study?

Do you consider yourself to be someone who leads a healthy lifestyle? Explain.

How would you describe your current lifestyle?

#### Diet:

We're interested in knowing about your eating patterns. For instance, how many meals do you typically eat in a day? Do you snack between meals? Any other times that you eat?

What are your favourite (both healthy and unhealthy) and least favourite foods?

How would you describe your relationship to food? [Positive? Negative? Complicated?]

How so?

#### Exercise:

What are your physical activity patterns. For instance, what types of activity do you do, like to do? How often?

Are there other types of physical activity or exercise that you would like to be doing, but can't seem to do? [If yes, please elaborate]



What would you say are your biggest challenges or barriers currently to maintaining a healthy weight or lifestyle in general? (Probe around barriers in relation to food and physical activity/fitness)

*As I mentioned, achieving a healthy weight or lifestyle extends beyond behaviour, and often involves deeper constructs, like body image, which can be especially important for women, and breast cancer survivors in particular. If you are comfortable, I would like to ask you about your feelings about your body and weight.*

How do you feel about your weight? Did this change at all after having undergone breast cancer treatment? What was this like before your diagnosis?

How do you feel about your body? Did this change at all after having undergone breast cancer treatment? What was this like before your diagnosis?

Have you struggled with your weight or body prior to being diagnosed with breast cancer? [If yes] How so? Can you please describe?

Can you recall any event in your past that you believe impacted your relationship to your body, body image or self-esteem? Eating/food? Physical activity? (For example, is there a time or specific formative relationship, where you recall being made to feel badly (e.g., judged) about your appearance? About what you ate (e.g., judged, controlled)? How about in relation to being physical (e.g., judged, embarrassed)?

*Thank you for sharing that information with me. I know it can be difficult to discuss these sensitive issues so I appreciate your openness. If you are okay to continue, I would now like to ask you about your available social support.*

What type of social support do you have in your life?

Do you believe that your social supports play a role in your exercise, eating, or other lifestyle behaviours?

Who is the person whom you rely most on for support?

Does he/she do things that interfere with or discourage you from behaving in healthy ways, or ways that would help you achieve your health goals?

Does he/she do things that encourage or support you to behave in healthy ways, or ways that would help you achieve your health goals?

*We are just about done, but first I would like to finish by asking some questions about any previous attempts you have made in terms of living healthier, and what your hopes are going forward. This information will give us some direction as to what might be most and least helpful for you in the present program.*

In the past, if you have ever made attempts to lose weight, be more active, or live a healthier lifestyle more generally, what have been the most significant challenges?

In the past, have you ever achieved a weight-loss or exercise goal, even if temporarily? If so, why do you think you were successful? Why do you think you were unable to sustain this progress?

What are you most hoping to get out of this program (i.e., what are your goals)?

What do you feel would be most helpful or motivating for you in achieving and maintaining these goals, long-term?

Is there anything else that you would like to share, that you think might help us better understand you and how to best support you in achieving your lifestyle goals throughout this program?

## **2. Midway-Intervention Interview**

*Thank you for taking the time to speak with me today. The purpose of this call is to understand and gain insight into your thoughts regarding the healthy weight management groups so far. By knowing how you feel you are progressing throughout the group sessions, we will be in a better position to help you make use of the group to address your specific concerns and to help you develop realistic goals for yourself while participating in the group.*

*This process is entirely voluntary and you do not have to respond to any question if you do not wish to. In total, this interview should take no more than 45 minutes, and with your permission, I would like to audio-record it. [If participant agrees, start recording.]*

*Great, to begin, I am interested to know:*

How are you finding the group thus far?

Has there been anything about the group that you have found particularly helpful so far? (Probe re: both group support and intervention model/theory) Unhelpful? (Probe)

What would you say are your biggest challenges or barriers currently to maintaining a healthy weight or lifestyle in general?

*As I mentioned, achieving a healthy weight or lifestyle extends beyond behaviour, and often involves deeper concepts, like body image, which can be especially important for women, and breast cancer survivors in particular. If you are comfortable, I would like to ask you about your feelings about your body and weight.*

How do you feel about your weight at this moment in time?

How do you feel about your body?

*Now I will ask some questions about the intervention so far?*

Do you feel comfortable in the group sessions? Please elaborate. What could be done to make you (and others) feel more comfortable?

What do you find is helpful about the program so far? What do you find not helpful?

Are there any particular insights that you have gained from participating thus far? (Probe about relationship to self, body, food)

Can you give an example of a time when you successfully implemented some of the strategies that were raised in the group?

Do you have an example when you could not successfully implement a strategy or achieve a goal? How did you handle that?

Now that we are midway through the intervention, are you finding that your leading a healthier lifestyle from when you first started? Please explain.

Are your attempts to lose weight different now than they were during previous attempts to lose weight? If so, how are they different?

What do you feel would be most helpful or motivating for you in achieving and maintaining these goals, long-term?

Is there anything else that you would like to share, that you think might help us better understand you and how to best support you in achieving your lifestyle goals throughout this program?

### **3. Post-Treatment Interview**

*Thank you for taking the time to speak with me today. This interview should take approximately 45 minutes to complete and, with your permission, will be audio-recorded. We are conducting these interviews to supplement the questionnaires you completed since this is such a new program and there is a lot to be learned from participants about how they found the group. The information we obtain through these interviews will be grouped together and used to inform and improve the program in the future. This interview will be used for this purpose only and will be confidential.*

*May I audio record this interview? [If yes] Great. If at any point you would like us to pause, or for me to pause the recorder – please let me know.*

*I would now like to ask you some questions that you were asked prior to participating in the lifestyle group, to see how your behaviours and views might have changed or stayed the same.*

At this point, do you consider yourself to be someone who leads a healthy lifestyle? Have you noticed a change in your lifestyle after participating in the group? Please explain

How would you describe your current lifestyle?

Diet:

What are your eating patterns (how many meals per day, typical daily intake)?

How would you describe your relationship to food?

What are your favourite (both healthy and unhealthy) and least favourite foods?

Exercise:

What are your physical activity patterns (how often and what type of activity)?

What is your favourite and least favourite type of physical activity?

Do you feel that you are living a healthier lifestyle now, after having participated in the healthy lifestyle group? Please explain.

- If so, what occurred throughout your participation that has led to this progress?
  - How confident are you that you can maintain such progress? How do you plan on doing so?

If not, why do you feel that your participation did not lead to any significant changes?

What would you say the biggest challengers or barriers might be for you going forward in maintaining a healthy weight or lifestyle in general?

How do you currently feel about your weight? Has this changed at all after having participated in the lifestyle group?

How do you currently feel about your body? Has this changed at all after having participated in the lifestyle group?

Who is the person whom you rely most on for support?

Do you believe that your social supports play a role in your exercise, eating, or other lifestyle behaviours?

Does he/she do things that interfere with or discourage you from behaving in healthy ways, or ways that would help you achieve your health goals?

Does he/she do things that encourage or support you to behave in healthy ways, or ways that would help you achieve your health goals? [Would it have been helpful to have this person involved somehow throughout their involvement in the healthy lifestyle intervention (in group or outside of group) and if so, how might this have been?]

*Please share with me your experience of the program overall*

What was it like to take part in this program?

In what ways was the program helpful to you? How so?

What did you like most? What did you like least?

Which session or group topic did you like most? Please elaborate.

Which session or topic did you like the least? Please elaborate.

What were your expectations going into the program? (probe re: whether these were met).

In what way did the program fall short of your expectations?

Please share what you felt was missing from the program. What would you have hoped to focus on more?

Can you think of any modifications that we could make to some of the sessions in order for them to be more relevant to your situation?

What, if any, were the challenges to your participation?

*Please share with me your experience with your group facilitators*

How did you find the involvement of your group facilitators?

What other support from the facilitators do you think would be beneficial to future participants?

*Please share with me any other thoughts*

Is there anything else you would like to share with us about your experience in this program? Or in relation to future directions for the program?

#### **4. Three-Month Post-Treatment Interview**

*Thank you for taking the time to speak with me today. This interview should take approximately 45 minutes to complete and, with your permission, will be audio-recorded. We are conducting these interviews to supplement the questionnaires you completed since this is such a new program and there is a lot to be learned from participants about how they found the group. The information we obtain through these interviews will be grouped together and used to inform and improve the program in the future. This interview will be used for this purpose only and will be confidential.*

*May I audio record this interview? [If yes] Great. If at any point you would like us to pause, or for me to pause the recorder – please let me know. So my first question.....*

*Please share with me how you are feeling about your lifestyle at this time now that it is three months after the intervention.*

Did the program help you maintain any changes now after 3 months? Please elaborate.

Which session or group topic did you feel has helped you the most after the intervention finished?

Please share what you felt was missing from the program. What would you have hoped to focus on more?

If you can think back to the pre-treatment interview and your expectations of the intervention, do you think you were successful in achieving in what you were most hoping to achieve (i.e., what were your goals)? Refer to notes to remind them if they don't recall.

*Please share with me your experience with your group facilitators*

Do you feel confident to implement your personal goals without the help of the group facilitator?

*I would now like to ask you some questions that you were asked prior to participating in the*

*lifestyle group, to see how your behaviours and views might have changed or stayed the same.*

Do you consider yourself to be someone who leads a healthy lifestyle? Please explain.

How would you describe your current lifestyle?

Diet:

What are your eating patterns (how many meals per day, typical daily intake)?

How would you describe your relationship to food?

What are your favourite (both healthy and unhealthy) and least favourite foods?

Exercise:

What are your physical activity patterns (how often and what type of activity)?

What is your favourite and least favourite type of physical activity?

Do you feel that you are living a healthier lifestyle now, after having participated in the healthy lifestyle group? Please explain.

If so, what occurred throughout your participation that has led to this progress?

- How confident are you that you can maintain such progress? How do you plan on doing so?

If not, why do you feel that your participation did not lead to any significant changes?

Do you expect to encounter any challenges or barriers in a few months from now? What about in a year?

How do you currently feel about your weight? Has this changed at all after having participated in the lifestyle group?

How do you currently feel about your body? Has this changed at all after having participated in the lifestyle group?

*Please share with me any other thoughts*

Is there anything else you would like to share with us about your experience in this program? Or in relation to future directions for the program?

Table 1.

*HLM-ABC Pilot General Structure*

<b>Session Numbers</b>	<b>Group Topic</b>
<i>Session 1</i>	Introduction and Orientation to the HLM-ABC Basic Principles: Balance (psychological, physiological, systemic) & Moderation
<i>Session 2</i>	Intuitive Eating
<i>Session 3</i>	Let's Get Moving
<i>Session 4</i>	Food & Mood
<i>Session 5</i>	Motivation and Decisional Balance
<i>Session 6</i>	Barriers and Promoters to Change
<i>Session 7</i>	Self-Care (discussion based)
<i>Session 8</i>	Body-Image (discussion based)
<i>Session 9</i>	Reviewing the Overall HLM-ABC
<i>Session 10</i>	Booster Session- Open Support
<i>Session 11</i>	Booster Session- Open Support
<i>Session 12</i>	Booster Session- Open Support

Table 2.

<i>Narrative Construction Features*</i>	
<b>Narrative Feature</b>	<b>Description</b>
<i>Narrative Complexity</i>	Thick or thin descriptions Generality vs. specificity (of details) Singular or multiple subplots Layers or not Degree of detail and dialogue (e.g., “I said/she said”)
<i>Narrative Arc</i>	Beginning-middle-end structure (linear or not) Shape of the narrative Rising and falling actions
<i>Narrative Tone</i>	The genre/pervasive feeling that runs through what is said (e.g., tragedy or adventure, hopelessness, despair, optimism, excitement, etc.)
<i>Agency</i>	The degree of agency or authorship they possess in their self-characterization Sense of control vis-à-vis events in their life/world Internal vs. external locus of control
<i>Characterization</i>	The way they characterize themselves (e.g., victim, hero, etc...) Self-portrayals vis-a-vis existing archetypal characters
<i>Autobiographical reasoning</i>	The degree of sophistication and connection of events (e.g., part-whole, event-life) Degree to which individual events are seen as part of a bigger picture or seen as contributing to the development of the self
<i>Narrative openness vs. foreclosure</i>	Views of the future and past events How is the author operating in reference to the past, present, future? Sense of dwelling on the past or hopefulness/hopelessness about the future
<i>Master narratives</i>	References to larger stories (e.g., religion, culture, or family) with which they identify and inform the meaning-making process
<i>Telltale motifs or metaphors</i>	Comparisons Rich language Running through participant’s narrative Are they complex, inter-related, self-aware?

\*Narrative features adapted from Randall (2015) and Ramsey & Bleiszner’s (2013) “grammar of resilience”



Table 3.

*Participant Demographics*

<b>Participant Number</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Diagnosed BC Stage</b>	<b>Treatments</b>
P1	44	Caucasian	Stage III	Bilateral Mastectomy Chemotherapy Radiation
P2	56	South Asian	Stage II	Single Mastectomy Chemotherapy Radiation Hormonal Therapy
P3	42	Caucasian	Stage III	Single Mastectomy Chemotherapy Radiation Hormonal Therapy Herceptin
P4	37	Caucasian	Stage II	Bilateral Mastectomy Chemotherapy Radiation Hormonal Therapy