

A NARRATIVE CARE INTERVENTION TO SUPPORT THE POST-CANCER
TREATMENT TRANSITION FROM PRIMARY TO FOLLOW-UP CARE: ANALYSIS OF
OUTCOMES AND CONTENT

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Abstract

The needs and ways of supporting individuals during the transitional phase after completion of treatment for primary cancer are less well-studied compared to other phases of the cancer journey. It is important to better understand this transitional juncture as it is one where individuals experience pronounced distress and grapple with various existential concerns. Thus, the current study implemented and evaluated a narrative care-informed intervention, the Narrative Care Interview (NCI), to allow participants to story their experience of being diagnosed with and treated for a primary cancer and to share their outlook on life moving forward. The NCI's goal was to support participants in constructing a cohesive narrative that incorporated their confrontation with cancer into their broader life story, with the intention of aiding adaptation to cancer-related changes.

The study's primary objective was to evaluate the NCI's effectiveness and acceptability by assessing whether it led to any changes on various relevant psychosocial variables including resilience, overall affect, quality of life, anxiety and depressive symptoms, self-efficacy, life satisfaction, and perceived personal meaning, and by assessing treatment satisfaction. A secondary objective was to better understand changes in self, life-perspective, and outlook on relationships during the transition following treatment.

Twenty-seven adults who had completed treatment for primary cancer within the past two years completed questionnaires assessing the variables listed above and participated in the NCI, and 20 participants completed the post-intervention questionnaires. Results showed a moderate improvement in social wellbeing and a generally favourable review of the NCI. With respect to the secondary objective, a modified grounded theory analysis of interview content led to the development of the core category, 'Transience as a Catalyst for Change,' which consisted of

three main categories: Woundedness and Healing; Refining and Solidifying Identity; and Maximizing Time. The core category, or theory of change, represented realizations about the impermanence of life, health, and time, which sparked changes in participants' sense of self, life-perspective, and outlook on relationships. Overall, the current study demonstrated the potential utility and benefit of a brief, narrative care-based intervention in providing support to individuals during the uncertain transitional period between primary cancer treatment and follow-up.

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Chapter 1: Introduction

Cancer is one of the foremost health issues facing Canadians, with one in every two individuals expected to be diagnosed with the illness at some phase of their life and one in four expected to die from cancer (Cancer Statistics at A Glance, 2020). While some disease sites, such as lung and pancreas, are associated with much higher mortality rates than other cancers, such as thyroid and prostate, the number of individuals surviving more than five years beyond their diagnosis has been continually increasing and mortality rates overall have been declining steadily since 1988 (Canadian Cancer Statistics, 2018). However, the incidence rates of some cancers, for instance melanoma in males and uterine cancer in females, are increasing (Canadian Cancer Statistics, 2017). Nonetheless, improvements in prevention strategies, screening procedures, and treatment modalities have greatly contributed to higher rates of ‘survivorship,’ and the number of individuals living long past their cancer diagnoses will likely continue to rise (Canadian Cancer Statistics, 2018). As such, it is important to continue striving to understand the challenges facing cancer survivors, and to develop and provide resources to address their post-treatment needs.

Challenges and Needs Associated with Cancer Survivorship

The concept of cancer ‘survival’ was proposed in 1985 by a physician who had personally been diagnosed with cancer in an attempt to explain the experiences both of individuals who had been ‘cured,’ and of those who continued to live with some form of the disease (Mullan, 1985). Importantly, Mullan noted that those who had been ‘cured’ continued to experience various functional and psychosocial problems thereafter, and in fact shared concerns similar to individuals living with chronic disease (Mullan, 1985). He in effect drew a separation between individuals who have experienced cancer and those who have not. It was also Mullan

who suggested that the word “survival” be applied even in cases where individuals were considered to be ‘cured,’ due to the lasting effects of a cancer diagnosis on one’s life, and encouraged the study of cancer survivorship as its own unique and significant concept as an important addition to research on cancer treatment (Feuerstein, 2007). According to Mullan (1985), there are three phases, or “seasons of survival”: 1) acute (ranging from diagnosis to completion of active treatment); 2) extended (ranging from the end of active treatment or remission to the end of follow-up medical examinations); and 3) permanent survival (encompassing the period during which an individual is disease-free for a prolonged period of time and is unlikely to experience a recurrence).

As per the Canadian Cancer Society, ‘net survival’ refers to “an estimate of the percentage of people who are alive at some point in time after their cancer diagnosis” (Cancer Statistics at a Glance, 2020). Though there has been some debate on how to define survivorship, in research it has frequently been referred to individuals who are alive for five years or longer after their diagnosis (Cancer Statistics at a Glance, 2019). Others have rejected this characterization, opting to view survivorship as “the period of health and wellbeing experienced by survivors after active cancer treatment (and before diagnosis of recurrence or a new malignancy)” (Rowland, Hewitt, & Ganz, 2006, pp. 5101), as a way to foster hope in newly-diagnosed patients and to improve physician-patient communication (Hoffman, 2004). In the present research, the latter view of survivorship was adopted.

There now exists a growing area of research related to cancer survivorship, following Mullan’s calls for examining and understanding the noteworthy challenges which survivors face (e.g., Rowland, Hewitt, & Ganz, 2006). It has indeed been found that long-term cancer survivors (i.e., generally those individuals living more than five years post-treatment) experience

exacerbated distress in relation to ongoing existential, physical, and emotional concerns associated with having endured a highly stressful and often traumatic life event (Philip & Merluzzi, 2016). For instance, a significant number of such survivors, approximately 20% according to one study, have reported experiencing depression during the later post-treatment period (Philip, Merluzzi, Zhang, & Heitzmann, 2013). In addition, some research suggests that anxiety can be an even bigger problem than depression for long-term cancer survivors, when compared to healthy controls (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). Fear of recurrence is another prominent concern for many cancer survivors (Thewes et al., 2011). Indeed, in one study of long-term cancer survivors (5 years or longer post-diagnosis), 87% reported experiencing low fear of recurrence, while 9% reported moderate fear and 4% reported high fear of recurrence (Koch-Gallenkamp et al., 2016). Factors associated with increased risk of developing moderate or high fear of recurrence were being female, younger, closer to diagnosis (5-7 years after diagnosis), and socially isolated, and having a lower education level (Koch-Gallenkamp et al., 2016). Results from another study showed that factors associated with increased fear of recurrence differ between young survivors, or those diagnosed between the ages of 15 and 39, and older survivors, such as being less than five years out of treatment and having had surgery, respectively (Shay, Carpentier, & Vernon, 2016).

Notably, the transitional period beginning just after active cancer treatment has ended (i.e., encompassed by Mullen's extended survival period) has been found to be one of particularly pronounced vulnerability (Hewitt, Greenfield, & Stovall, 2006; Rowland et al., 2006), though arguably less research has been conducted in relation to this point in time specifically (Stanton, 2012). The term 'transition' is used here to signify "the psychological process involved in adapting to [a] change event or disruption," (Kralik, Visentin, & van Loon,

2006, pp. 322). This term has been used widely in healthcare and illness research to describe a passage between two events or time points, characterized by some form of transformation and inner reorientation, during which an individual learns to adapt to new circumstances (Kralik et al., 2006). This process is most often thought to be non-linear (Kralik, 2002; van Loon, & Kralik 2005), and will be discussed further below. The months immediately following completion of active cancer treatment have also been referred to as a “re-entry phase” (Mullan, 1984).

Concerns common across different cancer types following active treatment include anxiety, fatigue, sleep disturbance, cognitive difficulties, pain, and limitations in sexual functioning (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010), as well as practical concerns such as decreased ability to work (Hauglann, Benth, Fossa, & Dahl, 2012). For example, the presence of depressive symptoms found among women with breast cancer were indeed found to be highest during the first year post-treatment, as compared to other points in the treatment trajectory, with rates as high as 30% immediately following the end of treatment (Harrington et al., 2010). The same review of research found that anxiety rates of women with breast cancer were also highest within the first six months post-treatment (between 45-48%) (Harrington et al., 2010). One particular study found distinct trajectories of distress among women with breast cancer: 33% of participants experienced distress from diagnosis to the end of treatment, followed by a decline in distress; 15% experienced greater distress from the point of treatment completion to six months thereafter (i.e., the re-entry phase); and 15% experienced consistently high distress throughout the study (Henselmans et al., 2010). Similar patterns of higher incidence for symptoms closer in proximity to the end of treatment were found for gynecological cancers (Harrington et al., 2010). Other significant challenges facing individuals during the post-treatment transitional period can include the loss of support provided by medical

professionals during active treatment, difficulty returning to previous roles in various contexts (e.g., at home and at work), potential decline in interpersonal support, and persistent side-effects of treatment (e.g., fatigue, difficulty sleeping, gastrointestinal issues, and cognitive deficits) (e.g., Ahles & Saykin, 2007; Costanzo et al., 2007; Ganz et al., 2004; Stanton et al., 2005; Talcott et al., 2003). Indeed, two major reports have corroborated the many complex psychosocial challenges and fears that survivors face at the treatment-to-survivorship transitional juncture, some of which are not yet fully understood, including difficulty managing the impact of certain treatments (e.g., impact on body image), worry about potential long-term side-effects (e.g., infertility), and other emotional consequences such as symptoms of posttraumatic stress (Hewitt et al., 2006; Reuben, 2004). According to one of these comprehensive reports on cancer survivorship, conducted by the American National Research Council, appropriate care and support during this transition is of utmost importance to patients' long-term health, for instance serving to provide knowledge about future risks, as well as follow-up care that will aid patients' continued physical and emotional well-being (Hewitt et al., 2006).

Considering the presenting concerns outlined above, as well as the importance of preparing individuals to cope with these concerns, findings from two largescale American surveys of posttreatment cancer survivors are particularly troubling. Results of these surveys indicated that: out of the 89% of individuals who endorsed one or more physical concerns (e.g., pain), only 67% received appropriate care; out of the 90% who endorsed one or more emotional concerns (e.g., lost sense of identity, grief about other patients dying), only 45% received appropriate care; and out of the 45% of individuals who endorsed one or more practical concerns (e.g., financial problems), only 36% received appropriate care (Beckjord et al., 2014). Importantly, individuals who were further from the time of their diagnosis were more likely to

receive care, as were those with physical complaints when compared to individuals with emotional concerns (Beckjord et al., 2014). Indeed, it has been found that patients are often not adequately prepared by healthcare professionals to cope with the many challenges that may arise during the re-entry phase (e.g., Janz et al., 2008; Arora et al., 2002). In another investigation of breast cancer survivors' symptoms and needs, 51% reported having at least one unmet 'supportive care need,' most commonly in the healthcare system/information domain, followed by the psychological domain (Cheng, Devi, Wong, & Koh, 2014). It appears that effective supports and interventions to help individuals cope with the many psychosocial concerns that often arise during the immediate posttreatment period are urgently needed.

Supporting Patients During the Treatment-to-Survivorship Transition

Though there is a pertinent need for interventions for cancer survivors during the transitional period after treatment completion, until recently the majority of effort had been applied toward creating and evaluating interventions for patients during the treatment period, with conflicting evidence regarding efficacy (Andrykowski & Manne, 2006; Faller et al., 2013; Lepore & Coyne, 2006). However, within the last few years more attention has been directed at supporting individuals during the re-entry phase of cancer survivorship, as per the recommendations made over a decade ago by the National Research Council (Hewitt, Greenfield, & Stovall, 2006). Numerous interventions have focused on promoting behavioural change, such as promoting weight management in breast cancer survivors, and these have been found to lead to short-term increases in physical activity (e.g., Bluethmann, Vernon, Gabriel, Murphy, & Bartholomew, 2015). Several studies have also implemented psychoeducational, Cognitive-Behavioural Therapy (CBT)-, Acceptance and Commitment Therapy (ACT)-, and Mindfulness-Based Stress Reduction (MBSR)-informed interventions to support cancer

survivors with respect to psychosocial concerns such as quality of life and anxiety (e.g., Arch et al., 2019; Arch et al., 2012; Arch & Mitchell, 2015; Dow Meneses et al., 2007; Jones et al., 2013; Lengacher et al., 2009; Penedo et al., 2007). One review found that psycho-oncological interventions for survivors, including individual and group psychotherapy and psychoeducational programs, produced small to medium effect sizes in relation to variables such as emotional distress, depression, anxiety, and quality of life (Faller et al., 2013). These effects were found to be sustained six months posttreatment, and in some cases even longer, as in the case of quality of life after individual psychotherapy interventions (Faller et al., 2013). Relaxation training was also associated with small improvements in emotional distress, anxiety, depression, and quality of life at the posttreatment period (Faller et al., 2013). Another study comparing the effects of group-based ACT versus group-based Behavioural Activation demonstrated that both interventions led to decreases in symptoms of anxiety, depression, avoidance, and psychological inflexibility, as well as increases in behavioural activation when compared to a waitlist control group (González-Fernández, Fernández-Rodríguez, Paz-Caballero, & Pérez-Álvarez, 2018).

Researchers have also evaluated the efficacy of using “Survivorship Care Plans,” which were recommended by the National Research Council report (Hewitt et al., 2006), on the transition from cancer patient to cancer survivor. These formal documents, tailored to each patient, were intended to provide a summary of an individual’s diagnosis and treatments, side-effects, follow-up care plans, recommendations for preventative strategies, practical information (e.g., insurance and worker rights), and information regarding available psychosocial services (Hewitt et al., 2006). While some evidence has suggested that these plans may have a positive effect on constructs such as self-efficacy (van de Poll-Franse, Nicolaije, & Ezendam, 2017) and psychological distress (Oancea & Cheruvu, 2016), they have not been shown to significantly aid

individuals in coping with many of the issues they face after primary cancer treatment, including fear of future testing, new cancer diagnoses, and recurrence (Hershman et al., 2013). In addition, these plans may not be sufficient in aiding individuals during the transition between active treatment and survivorship due to the reluctance reported by some oncology specialists to transfer care of their patients, as well as the need for specialized training for primary care practitioners providing care to cancer survivors (Kantsiper et al., 2009).

Other issues with some of the above-mentioned interventions include a predominant focus on breast cancer patients and reliance on multiple sessions, as well as fairly short-term and minimal impact on specific outcomes and overall quality of life of cancer survivors (Faller et al., 2013). Within a fast-paced hospital environment, it is advantageous to implement brief, cost-effective interventions that address the most pertinent needs of patients transitioning out of active treatment. Furthermore, while many of these interventions targeted psychological distress (e.g., anxiety), they did not specifically address the existential and philosophical concerns that individuals at the transitional phase from ‘patient’ to ‘survivor’ often face, which likely play an important role in exacerbating their distress (Kralik et al., 2006; Wexler & Corn, 2012).

Existential concerns are those relating to themes of existence, such as being, death, choice, and meaning (Lagerdahl, Moynihan, & Stollery, 2014). According to Yalom (1980), the four major existential concerns facing humans are death, freedom, isolation, and meaninglessness. One study examined the major existential concerns faced by cancer survivors once they were finished with curative treatment, and found these to be death anxiety, freedom, isolation, and meaning (both losing and gaining meaning in different domains) (Lagerdahl, Moynihan, & Stollery, 2014). This gap in support for patients transitioning out of active treatment, and particularly for those experiencing existential concerns, is significant because

individuals at the posttreatment juncture have specifically identified a need and desire for ‘continuity of care’ after their active treatments are completed, including mandatory holistic follow-up appointments that would provide an opportunity to discuss not only their physical concerns, but their existential ones as well (Lagerdahl, Moynihan, & Stollery, 2017).

Existential Concerns Facing Cancer Survivors

The occurrence of illnesses such as cancer has long been thought to provoke changes in self and life-perspective. Notably, in 1982 Michael Bury brought forth the concept of ‘biographical disruption,’ positing that illnesses, particularly chronic ones like rheumatoid arthritis, cause a disruption in the understanding and organization of one’s everyday life up until that point. One reason for this disruption is likely the confrontation that an individual coping with illness will likely have with pain and suffering, including one’s own and their loved ones’ mortality (Bury, 1982). Under these circumstances, one can see why Bury believed that “a fundamental re-thinking of the person’s biography and self-concept is involved” (Bury 1982, pp. 169) in the process of disruption. Indeed, in the case of cancer, commonly reported existential concerns include fear of death, loss of life meaning, uncertainty, vulnerability, isolation, changes in relationships, loss of or change in social roles and life goals, regrets over one’s past experiences and choices, perceived dependency, and loss of control (Hench & Danielson, 2009; Kissane, 2012).

It is possible that a disruption in one’s sense of self and understanding of their world would be especially pronounced during a major transitional period such as the one faced by individuals transitioning out of active cancer treatment – for instance, as suggested by Stanton, this transition involves the often distressing “loss of the safety net of active medical treatment and the accompanying supportive milieu” (Stanton, 2012, pp. 1216). This loss has even been

reported as a 'sense of abandonment' (Macmillan Cancer Support, 2012). Such periods of transition may also be distressing because of the idea that they challenge one to construct a whole new reality and re-define their sense of self in order to adapt to the resulting disruption (Bridges, 2004; Selder, 1989). However, the construction of a new reality may also help one cope with uncertainty, which is one of the common issues that cancer survivors must reconcile (Selder, 1989).

One possible way to cope with the disruption brought on by a cancer diagnosis may be to search for one's own personal sense of meaning. Meaning in life has been defined as "the extent to which one's life is experienced as making sense, as being directed and motivated by valued goals, and as mattering in the world" (George & Park, 2016, pp. 206). The basic human capacity and need to experience meaning in life has long been discussed in philosophy and by existentially oriented psychotherapists, including the propensity for illness (and in conjunction the concept/possibility of death) to challenge one's own sense of meaning in life (Frankl, 1999; Kissane, 2012; Sherman, Simonton, Latif, & Bracy, 2010; Yalom, 1980). The importance of having life meaning has been highlighted by evidence linking one of four aspects of meaning, namely sense of purpose (with the other three aspects being the presence of values, goals, and the ability to reconcile events which occurred in the past), to longevity in old age (Krause, 2009). Sense of purpose in this study was conceptualized as the belief "that one's actions have a set place in the larger order of things and that one's behavior fits appropriately into a larger, more important social whole" (Krause, 2009, pp. 520). Interestingly, one meaning-making model has suggested that following a stressful life event, meaning can be derived from new appraisals both at a situational level (e.g., why a particular event happened) and at a global level (i.e., altered assumptions about the world and one's own values, such as one's understanding of the concept

of justice) (Park & Folkman, 1997). Distress is thought to occur when these two domains are at odds with one another (e.g., an individual diagnosed with cancer believes that ‘bad’ things happen to ‘bad’ people, but they believe that they are a good person). A process of meaning-making then occurs, in order to reduce the distress, through the altering either of one’s situational appraisals or of their global beliefs (Park & Folkman, 1997).

As a result of their cancer journey, survivors have reported both new meaning-making and loss of meaning in different contexts of their life (van der Spek et al., 2013). Meaning-making has also been characterized as a form of coping, using methods such as benefit-finding in relation to the stressful life event, reminding oneself of those benefits, setting goals to facilitate meaning-making, examining/ordering one’s priorities, and ascribing positive meaning to ordinary things/events that were previously seen as inconsequential (Folkman, 2008). This ‘meaning-focused coping’ has been linked to ‘posttraumatic growth,’ or positive changes such as personal and interpersonal growth following a traumatic life event (Tedeschi & Calhoun, 2004; Hoogland, 2018). Meaning is also involved in one’s ‘sense of coherence,’ or a global orientation characterized by viewing the world and one’s immediate environment as meaningful, manageable, and comprehensible (Antonovsky, 1979). Antonovsky theorized that sense of coherence is linked to both physical and mental wellbeing (1979), though evidence has shown that it primarily affects psychological health (Flensburg-Madsen, Ventegodt, & Merrick, 2005).

In line with lack of coherence being linked to poor psychological health is the idea that one’s self concept and worldview are disrupted by stressful life events such as cancer. ‘Coping,’ or a cognitive process whereby one learns how to tolerate a chronic illness (Bury, 1988), on the other hand, signifies a level of personal growth and sense of coherence (Williams, 2000). It is fair to assume that psychosocial support may be particularly valuable at the posttreatment

juncture, which has been shown to represent a particularly stressful transition for cancer patients, in order to help them cope with the significant existential concerns mentioned above, and to gain a sense of coherence and meaning. These ideas of biographical disruption, meaning in life, and sense of coherence directly relate to the concept of narrative, which is one of the fundamental aspects of human existence.

Narrative

Narrative is defined as “the representation of an event or a series of events” (Abbott, 2002, pp. 12). It is also a way for humans to express and understand their own life and the events that happen to them, in other words as a way of ‘self-creation’ (Randall, 1995). As explained by Abbott, narrative is a way for us to ‘know ourselves’ (Abbott, 2002). Also known as storytelling, narrative is thus an integral part of humans’ daily lives and overall functioning. The concept of narrative identity also stems from the idea that ‘identity is a life story’ that develops throughout the lifespan, in which the individual is the protagonist or main character of their life story (McAdams, 1987). Importantly, identity develops not only through the telling of one’s story, but in the interpretation of what the events in one’s life mean (McAdams, 2013). This interpretation is done through a process termed ‘autobiographical reasoning’ (Habermas & Bluck, 2000), through which an individual reflects upon autobiographical memories to make conclusions about “who they are and what their lives mean” (McAdams, 2013, pp. 279).

Narrative is said to be an instrument of power, because it has the ability to convey meaning, causation (i.e., humans inherently search for the causes of things, and narrative can give the impression of causation by explaining why things happen through ordering events in a consecutive fashion – usually one would assume that the first event in a story leads to the second event), and normalization (Abbott, 2002). In fact, causation (i.e., ordering events in a logical

manner) is thought to be one of the ways that can make stories believable, or normalized.

Organizing events in a coherent fashion, while also incorporating thoughts and feelings about those events, is thought to allow individuals to feel a sense of coherence and ability to exert control over their lives (Polkinghorne, 1991), as well as to aid in identity formation (Habermas & Bluck, 2000; McAdams, 1993; McLean, Pasupathi, & Pals, 2007). Conversely, not structuring events, painful ones in particular, into a coherent narrative is thought to cause negative thoughts and feelings (Polkinghorne, 1991). In fact, evidence has shown that creating a narrative, for instance by writing about one's personal experiences, contributes to improved mental and physical health (Polkinghorne, 1991). In the context of difficult and even traumatic experiences, expressing those experiences through talking or writing has been related to significant improvements in health and well-being (Pennebaker, 1997). Aspects of a 'good' narrative, which can help one to make sense of their experiences, include having a guiding reason leading the story (i.e., a goal), as well as ordering events relevant to the story in a coherent manner (Gergen & Gergen, 1987; Gergen & Gergen, 1988).

The idea of needing to organize life experiences into a coherent narrative relates to the existential concerns of uncertainty and meaninglessness, and humans' difficulty in tolerating these concerns. As one academic has stated, "under stressful conditions, a self-narrative may decompose, producing the anxiety and depression of meaninglessness" (Polkinghorne, 1991, pp. 135). Alternately stated, distress can arise when events occur in life that are unexpected and unexplained. An important related facet of narrative is the mechanism of resolving conflicts in order to achieve closure in one's story – in other words to reduce uncertainty (Abbott, 2002).

Narrative and Illness

Illness narrative can be thought of as the way in which individuals formulate and voice their suffering (Kleinman, 1988), and can be a powerful coping tool (Hyden, 1997). In an example of one of the earlier writings on illness narrative, Frank (1993) noted that one aspect of this type of narrative is ‘epiphany,’ in the sense that the occurrence of illness is life-changing – in other words, it shifts “the fundamental meaning structures” in one’s life (Denzin, 1989, pp. 70), including their sense of self (Frank, 1993). Potential illness narratives that may become apparent include ‘who I have always been’ (i.e., the illness experience helps one realize who they are/have been all along) and ‘who I might become’ (i.e., the illness experience brings about a new identity altogether) (Frank, 1993). Robinson (1990) outlined three trajectories in illness narratives, in the context of multiple sclerosis, as: 1) stable (‘un-story-like,’ resemble medical case histories); 2) progressive (construct the story in a positive manner, for instance with a focus on achieving personal goals); and 3) regressive (the most common in medical settings, with a focus on the illness as a wedge between one’s personal goals and ability to achieve those goals). Another typology of illness narrative suggests the following varieties: illness as narrative; narrative about illness; and narrative as illness (Hyden, 1997). Illness as narrative refers to the case in which one’s narrative contributes to the illness itself and in how the illness impacts one’s life (Hyden, 1997). Narrative about illness is a method of transmitting medical information and knowledge (Hyden, 1997). Lastly, narrative as illness refers to instances where narrative “generates” the illness, for instance when a brain injury hinders the patient from formulating their story (Hyden, 1997, pp. 55). Hyden (1997) posited that these narratives can help individuals in several ways: to change/construct illness (i.e., make sense of it and how it relates to one’s life); to reconstruct a person’s life story to incorporate an illness into their identity/history; to explain/understand the

illness; to assert their identity; and to shift the illness from an individual to collective concept (e.g., by considering the social implications of a certain illness).

Because illness causes a disruption to one's identity, perspective, and relationships, it is important for a process of narrative reconstruction to occur (Williams, 1984). This concept refers to "the reordering of experience as the result of illness," by examining one's beliefs about the cause of their illness, and its impact on their life (Bury, 2001, pp. 274; Williams, 1984). Again, one can see why this would be an important process for individuals ending active cancer treatment, as it is likely a vulnerable time during which they must consider their personal identity, potentially have to establish a new one, or at the very least integrate new facets into their existing identity. Research in the context of the end of cancer treatment has demonstrated that a continuum exists, with one end representing a full embrace of the 'survivor' identity, and the other end representing a resistance to the 'survivor label' (Greenblatt & Lee, 2018). Considering the complexity, significance, and universality of issues related to identity, narrative formation, and illness narrative in particular, the argument can be made that these concepts deserve to be addressed in healthcare settings, in order to support individuals in coping with the challenges brought on by biographical disruptions (e.g., those arising at various points throughout the cancer journey, including at the end of treatment).

Narrative Care in Medical Settings

Concepts related to narrative have more recently begun to be incorporated in medical settings, for instance in the form of narrative care. Narrative care refers to the act of unassumingly and inquisitively listening to an individual's personal narrative, with the intent of guiding them to attain deeper understanding, meaning, and cohesion in their story (Baldwin,

2015). Recent investigations show that narrative care may be an essential part of successful rehabilitation in healthcare settings (Randall, 2016).

While the incorporation of narrative in medical settings is relatively recent (Charon, 2001), the concept of narrative has a long history with respect to promoting psychological wellbeing. Notably, narrative therapy, which informs narrative care, was developed in the early 1990s by White and Epston, who viewed human problems as “arising from and being maintained by oppressive stories which dominate the person's life” (Carr, 1998, pp. 486). These problems occur when one’s lived experience does not accurately match the story that they and those around them articulate regarding that experience (Carr, 1998). According to White and Epston (1990), encouraging individuals to incorporate ‘unique outcomes,’ (Goffman, 1986) or the aspects of their lived experience that are often left out of one’s dominant, ‘problem-saturated’ life story, into their narrative can help them cope with a problem, such as illness, and gain a sense of personal agency. Ascribing meaning to these unique outcomes and constructing a new narrative is particularly important and can lead to positive change in psychotherapy (Angus & Hardtke, 1994). This change occurs after an individual begins to see new ways of problem resolution and in turn becomes more optimistic regarding prospects for positive change. Positive change can be achieved through therapeutic strategies such as elaboration and thematic integration (Angus & Greenberg, 2011). Accessing one’s emotions throughout the process of storytelling is also essential to achieving continuity and coherence in one’s narrative (Paivio & Angus, 2011).

Identification of unique outcomes can be accomplished by externalizing the problematic aspects of one’s story and outlining how these aspects have impacted one’s life and relationships (White & Epston, 1990). Externalizing the problem can encourage open dialogue regarding the

problem and allow the individual to find new, more effective and less stressful ways to cope with the problem (White & Epston, 1990). In the context of traumatic life events like cancer, accessing emotions and ascribing meaning to these events, in the context of a coherent narrative, has been linked to improved health, such as better immune function (Pennebaker & Beall, 1986; Pennebaker, Kiecolt-Glaser, & Glaser, 1988). In line with these principles, the intention of narrative therapy is to make space for the creation of alternative stories, or “reauthoring” (Myerhoff, 1982), that better describe one’s lived experience and in turn provide them with increased sense of control, meaning, and understanding (Carr, 1998). Furthermore, narrative therapy views problems, including illnesses like cancer, as external forces separate from one’s being and aims to highlight this separation so that individuals do not become defined by their problems (Carr, 1998).

According to this understanding of the concept of narrative, narrative care in medical settings could help patients to understand how their illness may have permeated their life story and guide them through retelling their story in a way that externalizes the illness. Revising one’s personal narrative following an experience like cancer treatment is an important step toward moving forward by providing a sense of self-coherence conducive to adaptive coping (Borden, 1992). This can be done through strategies such as oral storytelling, with the guidance of semi-structured, open-ended questions (Mathieson & Stam, 1995), or in writing (Bolton, 1999). Indeed, a review of narrative care in cancer support found that this approach can help patients to cope with the illness in a variety of ways, including helping them to distance themselves from difficult situations (akin to White and Epston’s “externalizing the problem”), organize their thoughts and experiences, and more coherently integrate events with their previous life experiences (Carlick & Biley, 2004). Another evaluation of a nurse-led narrative care

intervention implemented during cancer treatment demonstrated a significant positive effect on patients' mood and stress level (Croghan, Evans, & Bendel, 2008). This intervention consisted of a 10-week storytelling group where participants were given instruction on how to form, tell, and retell their stories with the support of other group members, as well as a facilitator (Croghan et al., 2008).

Based on the existing research, it is reasonable to predict that narrative care will also be associated with positive psychosocial changes in cancer survivors during the posttreatment period. Indeed, research has demonstrated that discovering meaning after experiencing cancer, including experiencing growth, increased life meaning, and restored 'just-world' belief, is associated with better adjustment for cancer survivors (Park, Edmondson, Fenster, & Blank, 2008). In the current study, we aimed to utilize the concept of narrative care in the development of a brief, one-session intervention to support cancer patients during the posttreatment period. Of particular interest in the current investigation was the exploration of possible changes in self, life perspective, and outlook on relationships as a result of one's experience with cancer diagnosis and treatment, and thus the current study's analysis of the intervention content (i.e., participant interview data) focused on this domain.

The Current Study

The current study focused on implementing and evaluating a narrative care-informed interview as an intervention designed to provide an opportunity for participants to express their posttreatment reactions and to aid participants in meaningfully integrating the experience of cancer into their life narrative so that they may be better able to adapt to cancer-related changes. The intervention was specifically designed to address the pressing demand for a feasible, cost-effective response to the need for psychosocial care during the posttreatment transitional period

from cancer ‘patient’ to ‘survivor.’ The primary objective of the study was to evaluate the acceptability and effectiveness of the intervention, as well as to summarize participant outcomes on various psychosocial factors before and after the intervention and any potential benefits gained by participants. It was hypothesized that there would be an improvement in the following variables after the intervention compared to prior: resilience, overall affect, quality of life, anxiety and depressive symptoms, self-efficacy, life satisfaction, and perceived personal meaning. A secondary objective was to analyze the content of the participant interviews in order to understand participants’ perspectives on changes in self, life perspective, and outlook on relationships resulting from one’s experience with cancer.

With respect to the first study objective of evaluating the effectiveness and acceptability of the intervention, quantitative analyses were conducted to determine any changes in the constructs measured before and after the intervention, as well as of participants’ ratings of the intervention. For a fuller picture of the intervention’s acceptability and potential utility and benefits, qualitative methods were utilized to analyze participant comments to open-ended questions in the intervention evaluation survey, as well as any verbal feedback provided at the end of the interview itself. Further qualitative methods were employed to address the second objective of identifying changes resulting from the cancer experience.

Chapter 2: Methods

Participants

Participants were 27 patients with non-metastatic cancer who had a range of disease types and had completed their primary treatments at the Sunnybrook Health Sciences Centre, Odette Cancer Centre (OCC). Eligibility criteria included the following: 1) patients had been diagnosed with a primary cancer (i.e., non-metastatic); 2) all primary treatments, including surgery, chemotherapy, and/or radiation therapy were completed within the past two years prior to participating in the current study (this timeframe was originally within six months and then expanded to two years); 3) individuals were not attending ongoing psychotherapy or counselling while participating in the study; and 4) participants were able to read, write, and converse in English.¹

Procedure

This study was reviewed and approved by the research ethics boards at Sunnybrook Health Sciences Centre and York University prior to participant recruitment. A purposive sampling strategy (Battaglia, 2011) was employed to recruit participants at the Sunnybrook OCC, with the aim of obtaining a broad range of participants representing varied age, gender, and cancer groups. Firstly, OCC radiation oncology team members (i.e., oncologists, nurses, and radiation technicians) were asked by the research team to approach patients who met the study's eligibility criteria to gauge their interest in participating. The radiation therapy team was enlisted to help with recruitment because radiation therapy is most commonly the last form of treatment

¹ Due to difficulty with recruitment, exceptions were made in the case of the third eligibility criterion for two individuals willing to participate in the study. One participant was attending monthly visits with a psychiatrist at the Sunnybrook Patient and Family Support Program (PFS) but was enrolled in the study after noting that she believed it would be worthwhile for herself and for others to share her experience as a younger woman diagnosed with rectal cancer. Another exception included a young woman with breast cancer who was attending ongoing Cognitive Behavioural Therapy at a private clinic since before her diagnosis.

received following surgery and/or chemotherapy. As such, potentially eligible patients (i.e., those with non-metastatic disease who were close to the end of their radiation therapy treatments) were approached by OCC radiation oncology staff members and asked whether they were interested in speaking with a research assistant about “an end-of-treatment conversation” research study being offered by the Patient and Family Support Program. A research team member then had a brief conversation with amenable patients to provide an overview of the study, answer questions, obtain contact information of interested potential participants, and provide information about available psychosocial support resources, if requested or deemed appropriate (e.g., Patient and Family Support services or Wellspring Cancer Support programs). The script for this conversation is provided in Appendix A. Research assistants also offered a flier to all individuals, which provided a brief summary of the study, as well as contact information for the research coordinator (I.I.). This flier is provided in Appendix B. Other recruitment strategies included attending follow-up clinics and asking oncologists to approach patients who had previously completed treatment about interest in participating in the study and posting fliers for the study around the hospital.

Interested potential participants were informed by the research assistants that they would be contacted over the phone by the study’s research coordinator, who would provide more detailed information about the study, answer questions, and conduct a brief screening questionnaire to ensure eligibility. The Telephone Screening Questionnaire is provided in Appendix C. Non-eligible individuals, as well as those who were not interested in participating in the study, were informed about potential resources for psychosocial support as part of the screening telephone call. At the end of the screening procedure, eligible individuals’ mailing addresses were obtained so that the study’s consent form could be mailed to them, and a date for

the interview at Sunnybrook was set, approximately three to four weeks after the telephone screening in order to provide sufficient time for completion of the consent process and pre-interview questionnaire package. For convenience, most interviews were scheduled on days when participants had other appointments at the hospital. Eligible and interested individuals were informed that they would be contacted by email approximately one week following the screening telephone call to check whether they had received the consent form in the mail and were able to send a signed copy to Sunnybrook. Two copies of the consent form, as well as a stamped return envelope, were sent to all potential participants. Potential participants were also informed that the two pre- and post-interview questionnaire packages could take up to 40 minutes to complete, and that the interview could range from 30 minutes to 90 minutes in length, depending on how much they feel comfortable sharing.

Once the research coordinator received confirmation that the consent form had been signed and returned to the hospital, a link to the first online survey was emailed to the participant. Participants without Internet or email access also had the option of completing a paper version of the questionnaire packages. The period after the pre-interview survey was sent and before the interview was completed was considered Time 1, followed by the interview at Sunnybrook, which was considered Time 2. The expected time interval between Time 1 and Time 2 was two to three weeks. After the interview, participants were provided with a full-day hospital parking voucher worth \$26. There was no other compensation for participating in the study.

All interviews were audio-recorded, and later transcribed verbatim. All but one of the interviews were conducted by the research coordinator/writer (I.I.).² At Time 3, two weeks after

² One study interview and one pilot interview were conducted by the writer's supervisor, K.F.

the interview, a link to the post-interview questionnaire package was emailed or mailed to participants. Participants were asked to complete the survey at their earliest convenience, preferably within a week. All pre- and post-interview questionnaire packages, demographics questionnaires, audio-recordings, and interview transcripts were identified by participant numbers only. A file linking names and participant numbers was stored solely on-site at Sunnybrook, and all paper documents (e.g., consent forms, Telephone Screening Questionnaires, Demographics Questionnaires) were stored in a locked filing cabinet inside a locked office at Sunnybrook. A secure survey tool called Limesurvey, access to which was provided by the Sunnybrook Research Institute Practice-Based Research and Innovation Strategy grant supporting this study, was used to create and distribute the online surveys.

Narrative Care Interview

The semi-structured Narrative Care Interview (NCI) was designed specifically for this study and included questions related to one's experience of being diagnosed with cancer, undergoing treatment, and looking toward life beyond cancer. The interview was based on appreciative inquiry principles, which outline a manner of asking questions that promotes new ideas and possibilities for action (Whitney & Cooperrider, 2011). According to Whitney and Cooperrider (1998), appreciative inquiry is "an organization[al] development philosophy and methodology that can enhance the organization's capacity for ongoing adaptability" (pp. 17) that focuses on a strengths-based approach to change as opposed to more traditional problem-based approaches, such as action research (Egan & Lancaster 2005). This methodology has been utilized by varied organizations (e.g., companies, hospitals, non-profit organizations) (e.g., Cram, 2010; Havens, Wood, & Leeman, 2006; Ryan, Soven, Smither, Sullivan & VanBuskirk, 1999) to promote positive change through the implementation of four phases: 1) interviewing

members of the organization about their experiences, in order to learn about ‘the best of what already exists’ within the organization; 2) prompting individuals to consider what their ideal vision of the organization would be; 3) developing a framework that focuses on the core strengths of their ideal vision for the organization; and 4) applying the vision in order to achieve positive change (Whitney & Cooperrider, 1998).

Core principles, or process variables, of appreciative inquiry relevant to the current study include the following: 1) constructionist; 2) simultaneity; 3) poetic; 4) anticipatory; 5) positive; and 6) enactment (Whitney & Trosten-Bloom, 2003). The constructionist principle refers to the idea that reality as experienced by humans is subjective and is created socially through language and conversation (Whitney & Trosten-Bloom, 2003). In other words, individuals create meaning through discourse. The simultaneity principle suggests that the process of inquiry, or asking someone a question, alone can create change (Whitney & Trosten-Bloom, 2003). The poetic principle purports that storytelling serves as a means to gather information, both in terms of facts and emotions, that helps individuals understand one another (Fifolt & Lander, 2013). The anticipatory principle states that positive change occurs and is driven by people’s and organizations’ positive images of the future (Whitney & Trosten-Bloom, 2003). The positive principle suggests that “positive questions lead to positive change” (Whitney & Trosten-Bloom, 2003, pp. 54-55). Lastly, the enactment principle refers to the idea that “positive change occurs when the process used to create the change is a living model of the ideal future,” or a sort of self-fulfilling prophecy (Whitney & Trosten-Bloom, 2003, pp. 54-55). Appreciative inquiry has been criticized for focusing solely on the positive and failing to address problems (Egan & Lancaster 2005; Patton 2003); as such, the NCI also included questions regarding issues and concerns that individuals experienced throughout their cancer journey and how they coped with those issues.

Also, because the NCI was intended to provide a brief interpersonal context where the individual's experiences with cancer were acknowledged, it was deemed necessary to be inclusive of *all* types of experiences shared, negative as well as positive. Thus, the NCI focused individuals on their resilience and ability to problem-solve while also giving them an opportunity to have more negative experiences heard and validated. The NCI questions are provided in Appendix D.

Measures

The online questionnaire battery was designed to assess participants' psychosocial and physical functioning and well-being before and after the NCI, in terms of resilience, overall affect, quality of life, anxiety and depressive symptoms, self-efficacy, life satisfaction, and perceived personal meaning. The wording of some items was edited to suit the posttreatment period. The following measures were included in the pre-interview questionnaire package, at Time 1, in the following order: (1) Brief Resilience Scale (BRS: Smith et al., 2008); (2) Positive and Negative Affect Schedule (PANAS: Watson & Clark, 1988); (3) Functional Assessment of Cancer Therapy – General, excluding the Emotional Well-Being subscale (FACT-G: Cella et al., 1993); (4) Generalized Anxiety Disorder 7-Item Scale (GAD-7: Spitzer, Kroenke, Williams, & Löwe, 2006); (5) Cancer Behavior Inventory (CBI: Merluzzi, Nairn, Hegde, Martinez Sanchez, & Dunn, 2001); (6) Patient Health Questionnaire 9-Item Scale (PHQ-9: Kroenke, Spitzer, & Williams, 2001); (7) Satisfaction with Life Scale (SWLS: Diener, Emmons, Larsen, & Griffin, 1985); (8) Perceived Personal Meaning Scale (PPMS: Wong, 1998). At Time 2, before the interview commenced, participants were asked to complete a brief demographics questionnaire on paper to fully ensure security of their personal information. The same questionnaires listed above were included in the Time 3 post-interview questionnaire package, in addition to a

Treatment Satisfaction Questionnaire. A summary of the measures collected at each time point is provided in Appendix E. The above-mentioned questionnaires are provided in Appendix F.

Demographics

Demographic information collected immediately prior to the NCI included age, ethnicity, highest level of education, employment status, relationship status, socioeconomic status, number of children, cancer diagnosis, and treatment history. The Demographics Questionnaire is provided in Appendix G.

Resilience

Resilience was measured using the 6-item BRS (Smith et al., 2008). Items such as, “I have a hard time making it through stressful events,” were rated on a 5-point scale (1 = “strongly disagree” to 5 = “strongly agree”). This scale was designed to measure one’s ability to recuperate from stress, including stress resulting from illness, and has been shown to have good psychometric properties in terms of the following measures: internal consistency, construct validity, content validity, reproducibility reliability, and interpretability (Windle, Bennett, & Noyes, 2011). In a review of fifteen scales measuring resilience, the BRS was rated among the top three in terms of psychometric rigour, despite one criticism that the scale focuses on personal agency while overlooking familial and community support (Windle, 2011). Nonetheless, the BRS has been used in cancer research to measure patients’ and survivors’ ability to bounce back from stress (e.g., Eicher, Matzka, Dubey, & White, 2015; Lim, Shon, Paek, & Daly, 2014). As per the literature, a scale score was obtained by calculating an average for the six item responses, after all reversed items were obtained. A higher scale score indicated better resilience.

Cronbach’s alphas for the pre- and post-BRS, respectively, were 0.87 and 0.73.

Affect

Participants' overall affect was measured using the PANAS (Watson et al., 1988), which consists of two 10-item scales measuring positive and negative affect. Participants were asked to rate the extent to which they experienced different emotions (e.g., "Interested," "Irritable") on a 5-point scale (1 = "very slightly or not at all," to 5 = "extremely") within the past two weeks. Total scores were computed for both subscales, ranging from 10 to 50 points. For the Positive Affect Score, a higher total score indicated more positive affect, while for the Negative Affect Score, a higher total score indicated higher levels of negative affect. Researchers have validated this scale among numerous different cultures and have consistently found it to exhibit good psychometric properties (e.g., Crawford & Henry, 2004; Terracciano, McCrae, & Costa, 2003). Cronbach's alphas for the pre- and post-Positive Affect Scale, respectively, were 0.89 and 0.85, and 0.88 and 0.83 respectively for the pre- and post-Negative Affect Sale.

Quality of Life

Quality of life was measured with the widely used FACT-G (Cella et al., 1993). Three of the four subscales, including the Physical, Social/Family, and Functional Well-Being subscales were used, while the Emotional Well-Being subscale was excluded after being deemed repetitive with some of the other mood/affect-related measures included in the questionnaire packages. Each subscale included seven items, rated from zero ("not at all") to four ("very much") for total scores ranging from zero to 28. Sample items for the Physical, Social/Family, and Functional Well-Being subscales included, "I feel ill," "I feel close to my friends," and "I am content with the quality of my life right now," respectively. Total scores for each subscale were obtained, with higher values on the Social/Family and Functional Well-Being subscales indicating better quality of life in those domains, and higher values on the Physical Well-Being subscale indicating lower quality of life in that domain. This scale has been shown to have good psychometric properties,

including validity, reliability, and sensitivity to change (Cella et al., 1993). Support for its good psychometric properties has also been shown in culturally diverse populations and specific cancer groups (e.g., Campos, Spexoto, Serrano, & Maroco, 2016; Yost et al., 2012). Cronbach's alphas for the pre- and post-Physical, Social/Family, and Functional subscales, respectively, were as follows: 0.79; 0.86; 0.84; 0.83 0.87; and 0.90.

Anxiety

Symptoms of Generalized Anxiety Disorder were measured using the GAD-7 (Spitzer et al., 2006). Participants were asked to rate how much they were bothered by seven anxiety-related symptoms, such as “trouble relaxing,” from zero (“not at all sure”) to three (“nearly every day”). It also included one item that assessed the impact of these symptoms on one's daily functioning. Summed total scores ranged from zero to 21, and a score of ten or higher is considered to indicate a potential case of Generalized Anxiety Disorder, according to guidelines set by Spitzer and colleagues (2006). This scale was initially shown to have good reliability and criterion, construct, factorial, and procedural validity in a sample of patients from primary care clinics (Spitzer et al., 2006). A more recent systematic review of self-reported screening tools for Generalized Anxiety Disorder found that the GAD-7 was the best-performing screening instrument when compared to eight others (Herr, Williams, Benjamin, & McDuffie, 2014). The GAD-7 was also shown to have acceptable properties (i.e., sensitivity and specificity) for identifying diagnoses of Generalized Anxiety Disorder at cut-off scores between seven and ten (Plummer, Manea, Trepel, & McMillan, (2016). With respect to cancer populations, the GAD-7 was found to have adequate diagnostic accuracy, with a suggested cut-off score of seven or higher (Esser et al., 2018). In terms of Cronbach's alphas in the current study, they were 0.83 and 0.88 for the pre- and post-scale scores, respectively.

Self-Efficacy for Coping with Cancer

Self-efficacy as related to coping with cancer was assessed using a shortened, 14-item CBI, which was adapted from the second version of the 33-item inventory (Merluzzi et al., 2001). Repetitive or irrelevant items were removed in order to shorten the scale's administration time. One's confidence regarding things such as, "Maintaining a positive attitude," were rated on a 9-point scale (1 = "not at all confident," to 9 = "totally confident"). Items on the CBI fit into six factors, including: 1) Maintaining Activity and Independence; 2) Seeking and Understanding Medical Information; 3) Emotion Regulation; 4) Coping with Treatment Related Side Effects; 5) Accepting Cancer/Maintaining a Positive Attitude; and 6) Seeking Social Support. Both the older version (2.0) and the newer version (3.0) of the CBI, which contains the items included in the current study along with several new items and a new factor, have been shown to have good psychometric properties (Merluzzi et al., 2001; Merluzzi, Philip, Heitzmann Ruhf, Liu, Yang, & Conley, 2018). A mean scale score and mean subscale scores were utilized in the current study, with higher scores indicating greater efficacy for coping with cancer. The pre- and post-scale Cronbach's alphas were 0.93 and 0.88, respectively.

Depression

Depressive symptoms were assessed using the PHQ-9, which is a 9-item screening tool for Major Depressive Disorder in non-psychiatric samples (Kroenke et al., 2001). Items such as, "Feeling down, depressed, or hopeless," were rated from zero ("not at all") to three ("nearly every day"), in terms of how frequently one found these concerns to be bothersome in the past two weeks. An additional item assessed the impact of any endorsed problems on one's daily functioning. In the current study, summed scores of the nine items were calculated; higher scores indicated more depressive symptomatology. This method was chosen according to a meta-

analysis which demonstrated evidence that a ‘summed item score method,’ with a cut-off score of ten as an indication of potential Major Depressive Disorder (Moriarty, Gilbody, McMillan, & Manea, 2015), was better in terms of diagnostic performance as opposed to the algorithm scoring method (Manea, Gilbody, & McMillan, 2015). More specifically, scores between five and nine indicate mild depression, scores between ten and 14 indicate moderate depression, and scores of 15 or higher indicate severe depression (Hinz et al., 2016). Importantly, the PHQ-9 was shown to have good psychometric properties in a large sample of cancer patients with varied diagnoses, in particular good reliability (Hinz et al., 2016). However, factorial analyses in this study indicated that a two-dimensional model (with items 1, 2, 6, and 9 in an ‘affective-cognitive’ factor, and items 3, 4, 5, 7, and 8 in a second ‘somatic’ factor) performed better than a one-dimensional model (i.e., total score) (Hinz et al., 2016). Nonetheless, Hinz and colleagues (2016) suggested using a summed total score, in part because two of the items loaded onto both factors. Lastly, all items were scored higher in the cancer population when compared to the general public, with sleep problems and loss of energy most elevated in comparison (Hinz et al., 2016). In the current study, Cronbach’s alpha was 0.65 for the pre-scale score and 0.88 for the post-scale score.

Life Satisfaction

Life satisfaction, commonly considered to be one’s subjective contentment with their life, was assessed using the 5-item SWLS (Diener et al., 1985). According to Pavot and Diener (1993), life satisfaction is the degree to which one perceives that their life aspirations and successes are met. A 7-point scale (1 = “strongly disagree” to 7 = “strongly agree”) was used to rate one’s agreement with statements such as, “So far I have gotten the important things I want in life.” According to Pavot and Diener (2013), the following categories can be used: scores between 30 and 35 are ‘very high’, (i.e., highly satisfied); scores between 25 and 29 are ‘high’;

scores between 20 and 24 are ‘average’; scores between 15 and 19 are ‘slightly below average’; scores between 10 and 14 are ‘dissatisfied’; and scores between five and nine are ‘extremely dissatisfied.’ The SWLS was found to have good reliability and validity in a sample of patients with non-advanced cancer (Lorenzo-Seva et al., 2019). Results from this study demonstrated that the SWLS was a unidimensional instrument with strong measurement invariance, meaning that the scale was interpreted similarly across gender, age, and tumor localization (Lorenzo-Seva et al., 2019). Lastly, low scores on the SWLS were linked to increased anxiety, depression, and somatization, and decreased quality of life (Lorenzo-Seva et al., 2019). In the current study, summed scores were used, ranging from five to 35. Cronbach’s alphas were 0.84 and 0.84 for the pre- and post-scale scores, respectively.

Personal Life Meaning

Perceived personal meaning in life was assessed using the PPMS, which is comprised of eight items rated on a 9-point scale (1 = “strongly disagree” to 9 = “strongly agree”) (Wong, 1998). Items pertained to personal meaning as perceived overall, as well as in the past, present, and future. Sample items for each timeframe, respectively, were, “My life as a whole has meaning,” “I led a meaningful life in the past,” “At present, I find my life very meaningful,” and “I look forward to a meaningful life in the future.” Though this has not been a widely used measure, one study found it to have excellent reliability (George & Park, 2017). The PPMS was chosen for this study due to its inclusion of different time orientations, which could be relevant to the transitional period between cancer treatment and survivorship being examined in the current study. An average score for the scale was used in the current study, as well as average scores for each of the four timeframes. Cronbach’s alphas for the pre- and post-scale scores, respectively, were 0.95 and 0.96.

Treatment Satisfaction Questionnaire

The 11-question Treatment Satisfaction Questionnaire was developed specifically for this study. It included both quantitative questions (e.g., “The interview gave me more perspective on my experience with cancer,” rated from 1 = “strongly disagree” to 5 = “strongly agree”), accompanied by space for comments, as well as open-ended qualitative questions allowing for participants to elaborate upon their evaluations of the interview and to provide feedback.

Analysis

Quantitative Data Analysis

Descriptive statistics, including means and standard deviations, of all variables were first obtained. In order to address the first study objective of assessing intervention effectiveness, namely by determining whether there were any significant or near-significant differences in the variables measured following the NCI, two-tailed paired-sample *t*-tests were planned to be used. Firstly, data were checked to determine whether the assumptions for conducting a *t*-test were met, including normality of data distribution and homogeneity of variance. For data which met the assumptions, two-tailed paired-sample (i.e., dependent) *t*-tests were performed, and for data which did not meet these assumptions, Wilcoxon Signed-Rank Tests were performed to test the following hypotheses:

$$H_0: \mu_d = 0$$

(There is no difference between variable (i.e., resilience, overall affect, quality of life, anxiety and depressive symptoms, self-efficacy, life satisfaction, and perceived personal meaning) means between the pre- and post-interview time points.)

$$H_1: \mu_d \neq 0$$

(There is a difference between variable means between pre- and post-interview time points.)

Spearman correlations (for non-normal data) between variables of interest were also obtained. An alpha of .05 was used for all significance tests. Means for Likert-scale questions and counts for multiple-choice questions on the Treatment Satisfaction Questionnaire were also obtained, in order to assess acceptability, or participants' reactions to the intervention (Bowen et al., 2009). This was supplemented by analyzing verbal and written participant feedback, as described below. All analyses were conducted using R software.

Qualitative Data Extraction Rule

The first phase of the qualitative analysis entailed reviewing the entirety of each interview transcript in order to identify portions of text within each one that were related to the two areas of interest and study objectives, namely: (1) reflections on and evaluations of the interview itself; and (2) changes in self, life perspective, and outlook on relationships as a result of the cancer experience. In relation to the primary objective, any comments, feedback, objections, or suggestions for improvement related to the interview's structure, benefit, enjoyability, effectiveness, and ability to incite introspection or reflection on one's cancer experience and related learning or change in self and perspective were extracted for analysis.

With respect to the second study objective, the following data extraction rule was developed and employed to guide the selection of text for analysis. Specifically, responses to the questions within the relevant sections of the interview concerning perceptions of change in oneself (i.e., questions pertaining to posttreatment reflection, new learning/meaning-making, and orienting toward the future), or comments concerning change that arose spontaneously during the interview, were extracted for analysis. Both general reflections related to changes in one's sense

of self, life perspective, and/or outlook on personal relationships, as well as anecdotes and examples of thoughts or behaviours that have changed as a result of the cancer experience were included in the analysis. Reflections and examples of a ‘lack of change,’ or a sense of ‘returning to normal’ were also extracted as ‘deviant’ exemplars of the phenomenon of interest. Portions of text related to participants’ reflections on the perceived reasons for any change, or lack thereof, were also included for analysis in order to better understand mechanisms and driving forces behind participants’ experiences of change.

Qualitative Data Analysis

The extracted interview content was analyzed using a modified grounded theory analytic approach, which was first coined in 1967 by Barney Glaser and Anselm Strauss, in order to explore the secondary study objective of understanding cancer survivors’ experiences of perceived changes in self, life perspective, and outlook on relationships following active cancer treatment. As per Birks and Mills (2015), when conducting grounded theory analysis, it is important to first clarify one’s philosophical position regarding knowledge creation (i.e., epistemology) and reality/being (i.e., ontology). Overall, the research paradigm of the current study was interpretivist, which is characterized by a relativist ontology and a subjectivist epistemology (Levers, 2013). Relativism refers to the belief that there is not one ‘true’ reality, but that reality is inseparable from individuals’ experiences; in other words, relativism maintains that each individual experiences their own reality (Guba & Lincoln, 2005). Meanwhile, subjectivism refers to the idea that these multiple realities are socially constructed and mediated by one’s senses (Rehman & Alharthi, 2016). Importantly, while subjectivism does not deny that an objective external reality *could* exist, it posits that the study of that reality is inevitably

“filtered through the lenses of language, gender, social class, race, and ethnicity” (Denzin & Lincoln, 2005, pp. 21; Levers, 2013).

According to Willig (2012), it is also important to distinguish between the realist versus relativist status of the data *and* the status of the analysis of that data. In terms of the data themselves, the writer maintained a relativist position, due to the belief that participants’ accounts of their experiences (i.e., the interview content) reveal information about how they are creating meaning of their life experiences and that the researcher’s goal is to create a comprehensive account of those experiences and related meaning-making (Willig, 2012). With respect to the analysis, it was the writer’s view that it is not possible to unbiasedly represent the participants’ ‘true’ constructions of their own meaning, and thus that the theory produced as part of the grounded theory analysis was influenced by the researcher’s own personal life experiences and implicit biases and views of the world. In sum, the current analysis was based on a phenomenological epistemological framework and thus aimed to understand each participant’s unique subjective experience (Willig, 2012). Specifically, an interpretative phenomenological approach, as opposed to a descriptive one, was employed, which assumes that the researcher is inextricably tied to the process of meaning-making based on the data and cannot produce a “pure description” of another individual’s lived experience (Willig, 2012, pp. 15). In the current context and in line with this approach, it is worthwhile to note that it is likely that the writer’s witnessing of familial experiences with cancer and preceding discussions about those individuals’ experiences with cancer diagnosis, treatment, and survivorship may have influenced which parts of the data stood out or how the data were interpreted. This context relates to the idea that the act of analyzing, or categorizing data, is an embodied activity which influences the quality of categories which emerge from a grounded theory analysis (Rennie & Fergus, 2006).

Furthermore, a primarily inductive approach was applied during the analysis. Consistent with an interpretivist research paradigm, this inductive approach, characterized by a search for patterns in the data, was employed in order to allow for novel information and concepts to be incorporated into the analysis and to produce a more refined understanding of the idea of change as a result of the cancer experience. For instance, participants' backgrounds and demographic information, as well as the entirety of the interviews that incorporated the above-mentioned extracted portions of text, were considered while memo-ing and categorizing, in order to gain a better understanding of perceived change brought on by cancer, and how such change occurs.

Consistent with the original intent of grounded theory, namely to generate a theory from data as opposed to testing previous theory (Glaser & Strauss, 1967), the current investigation aimed to establish a theory explaining the changes in self, life perspective, and outlook on relationships, as perceived by a broad range of participants, as they were experienced during the transitional period from active cancer treatment to longer-term survivorship. 'Theory' in this instance was defined as "an explanatory scheme comprising a set of concepts related to each other through logical patterns of connectivity" (Birks & Mills, 2015, pp. 108-109). According to Birks and Mills (2015), the three factors necessary for the final step of a grounded theory analysis, which is theoretical integration, are: a resulting core category; theoretical saturation of the main categories encompassed by the core category; and analytical memos, as they allow for tracking of the development/evolution of codes and categories and perceived connections and inter-relationships between different codes and categories as new ideas emerge. It should be noted that one important caveat for conducting grounded theory analysis is that there is a paucity of information about the topic of interest (Birks & Mills, 2015), which is a difficult criterion to meet in the broadly researched field of cancer. Nonetheless, it can be argued that grounded

theory analysis was still appropriate in this instance, because as stated previously, there is less known about the experiences of cancer survivors during the transitional period of interest in the current study.

As per Birks and Mills (2015), the following steps/tasks in conducting grounded theory analysis were followed: purposive sampling (i.e., generating data through a varied sample in terms of demographics such as age and cancer site); initial coding (i.e., creating codes and respective labels for each separate meaning-unit within the text); theoretical sampling (i.e., by deciding the order of analysis of the 27 participants' interviews based on the emerging codes); category identification (i.e., grouping codes together into sub-categories); constant comparative analysis (i.e., continuously comparing codes to each other and to sub-categories, and sub-categories to each other throughout the analysis); theoretical sensitivity (i.e., a researcher's personal characteristics and experiences, such as prior knowledge in a particular field, which influence their awareness and ability to make sense of data); intermediate coding (i.e., linking sub-categories to create main categories); deciding on a core category which encompasses the main categories; assessing saturation; and theoretical integration (i.e., presenting the theory and linking it to existing research – as per the Discussion section below). It should be noted that one aspect of grounded theory analysis which the current investigation did not follow was 'concurrent data collection/generation,' as all of the interviews had been conducted (and hence the data collected) before analysis began. The initial goal was to obtain a sample size of 30, under the assumption that this number of participants would be sufficient to perform both of the planned qualitative and quantitative analyses. While there are no guidelines for the number of participants needed for qualitative analyses in particular, it has been found that a sample size as little as six is sufficient to reach saturation, or the point at which no new information emerges

from the analysis (Guest, Bunce, & Johnson, 2006). Furthermore, the researchers aimed to recruit participants with a wide range of experiences, be it in terms of age, cancer site, or gender. It should also be mentioned that six different individuals recruited participants during different times, thus limiting “the use of one’s personal lens” (e.g., in terms of which hospital staff members to approach to request assistance with recruitment) (Fusch & Ness, 2015, pp. 1411), and thereby reducing potential biases in the types of participants recruited.

In terms of specific steps, the writer firstly immersed herself in the data by reading the interview transcripts. Initial analytic observations were noted through memo-ing, which is an essential part of grounded theory analysis (Birks & Mills, 2015). The data extraction rule outlined above was then employed to separate data of interest for the analysis. Based on this data, codes/labels, were generated to capture both semantic and conceptual features of the data. In the current study, a ‘contained’ theoretical sampling strategy was undertaken, where the order of the 27 transcripts analyzed was determined in such a way that each transcript would ‘test’ the emerging theory to see if it held up with diverse participants and whether new codes emerged. The order of interviews transcribed was decided based on constant comparison of the emerging data and an attempt was made to alternate between individuals with dissimilar characteristics such as age, gender, and cancer site. Saturation was reached at participant 14. Two researchers (I.I. and K.F) discussed which portions of text should be extracted, coded portions of data separately, and collaboratively reviewed how meaning-units were labelled and defined. Next, the codes were further examined in order to identify those that shared commonalities of meaning, or existing similarities – permitting coherent, meaningful patterns, or clusters, between the codes to emerge. These clusters were then reviewed, through reflection on the part of the researchers about how they related to each other and to the data as a whole, and were combined into sub-

categories and labelled. The sub-categories were then grouped together into higher-order main categories, which were again labelled. These main categories were then examined and incorporated into one core category which represented the resultant theory of change.

A more descriptive, content analytic technique (Krippendorff, 2004) was applied to the responses to the open-ended Treatment Satisfaction Questionnaire questions, as well as for the reviews and/or feedback given during the interview itself. Such a descriptive, or manifest, analysis focuses on the surface structure of data and aims to remain as close to the explicit meaning of the text as possible, while a more interpretive, or latent, analysis such as grounded theory analysis focuses on the 'deeper' structure of the data and involves more interpretation of the meaning behind the data (Bengtsson, 2016). All qualitative data were managed using N-Vivo software.

Chapter 3: Intervention Effectiveness, Acceptability, and Treatment Satisfaction

Participant Demographics

Twenty-seven participants completed the pre-interview survey and participated in the Narrative Care Interview (NCI), and 20 of those participants completed the post-interview survey. Just under half of participants were female (44% female; 56% male). The majority of participants were Caucasian (74%) and most had a post-secondary degree or higher (74%). Most participants were married (70%). The mean age of participants was 62.8 ($SD = 12.3$, ranging from age 38 to 86 years). Most participants were diagnosed with stage 0, I, or II (67%) non-metastatic cancer. Average time since diagnosis was 11.46 weeks. Two participants (7.4%) were interviewed within two and a half weeks of completing their primary treatment; seven participants (25.9%) were interviewed within three to four weeks; 12 participants (44.4%) were interviewed within five to 10 weeks of having completed treatment; five participants (18.5%) were interviewed between three and ten months following treatment; and one (3.7%) participant was interviewed sixteen months after their treatment ended. Overall, 96.3 percent of participants were interviewed within 10 months of the end of their treatments. A complete summary of demographic characteristics is provided in Tables 1 and 2.

Table 1

Participant Demographic Characteristics (N = 27)

| Variable | <i>M</i> (Range) | <i>SD</i> |
|----------------------------|------------------|-----------|
| Age | 62.78 (38-86) | 12.57 |
| Length of Marriage (Years) | 36.74 (2-60) | 14.64 |
| Variable | <i>n</i> | % |
| Gender | | |
| Female | 12 | 44.44 |
| Male | 15 | 55.56 |
| Ethnic Background | | |
| African | 1 | 3.70 |
| Afro-Caribbean | 1 | 3.70 |

| | | |
|---------------------------|----|-------|
| Asian | 2 | 7.41 |
| Indigenous | 1 | 3.70 |
| South Asian | 2 | 7.41 |
| White | 20 | 74.07 |
| Birth Country | | |
| Canada | 19 | 70.37 |
| Other | 8 | 29.63 |
| First Language | | |
| English | 19 | 70.37 |
| Other | 8 | 29.63 |
| Employment Status | | |
| Employed | 11 | 40.74 |
| Homemaker | 3 | 11.11 |
| Retired | 11 | 40.74 |
| Semi-Retired | 2 | 7.41 |
| Highest Education Level | | |
| Grade 9 | 2 | 7.41 |
| Highschool | 5 | 18.52 |
| College | 5 | 18.52 |
| University | 12 | 44.44 |
| Post-Graduate Diploma | 1 | 3.70 |
| Graduate Degree | 2 | 7.41 |
| Marital Status | | |
| Divorced | 1 | 3.70 |
| Married/Common Law | 20 | 74.07 |
| Single | 6 | 22.22 |
| Children | | |
| No | 6 | 22.22 |
| Yes | 21 | 77.78 |
| Living Situation | | |
| Alone | 2 | 7.41 |
| With Parents | 2 | 7.41 |
| With Partner | 11 | 40.74 |
| With Partner and Children | 8 | 29.63 |
| With Partner and Parent | 1 | 3.70 |
| With Roommate | 2 | 7.41 |
| Income | | |
| No Response | 4 | 14.81 |
| \$0-9,999 | 3 | 11.11 |
| \$10,000-25,000 | 1 | 3.70 |
| \$25,000-50,000 | 7 | 25.93 |
| \$50,000-75,000 | 3 | 11.11 |
| \$75,000-100,000 | 4 | 14.81 |
| \$100,000+ | 5 | 18.52 |

Table 2*Medical Demographic Characteristics (N = 27)*

| Variable | <i>M (Range)</i> | <i>SD</i> |
|------------------------------------|------------------|-----------|
| Age at Diagnosis | 61.87 (37-85) | 12.53 |
| Weeks Since Treatment Completed | 11.46 (2-64) | 13.82 |
| Variable | <i>n</i> | <i>%</i> |
| Type of Cancer | | |
| Anal | 1 | 3.70 |
| Breast | 8 | 29.63 |
| Colorectal | 1 | 3.70 |
| HPV-Related | 1 | 3.70 |
| Lymphoma | 1 | 3.70 |
| Prostate | 9 | 33.33 |
| Rectal | 3 | 11.11 |
| Skin | 2 | 7.41 |
| Urologic | 1 | 3.70 |
| Cancer Stage | | |
| 0 | 1 | 3.70 |
| 1 | 9 | 33.33 |
| 2 | 8 | 29.63 |
| 3 | 4 | 14.81 |
| Not Aware | 1 | 3.70 |
| No Response | 4 | 14.81 |
| Chemotherapy | | |
| No | 16 | 59.26 |
| Yes | 11 | 40.74 |
| Radiation | | |
| No | 1 | 3.70 |
| Yes | 26 | 96.30 |
| Surgery | | |
| No | 15 | 55.56 |
| Yes | 12 | 44.44 |
| Other Treatment | | |
| No | 17 | 62.96 |
| Yes | 7 | 25.93 |
| No Response | 3 | 11.11 |
| Chemotherapy + Radiation | 6 | 22.22 |
| Chemotherapy + Radiation + Surgery | 4 | 14.81 |
| Surgery + Chemotherapy | 0 | 0 |
| Surgery + Radiation | 8 | 29.63 |
| Other Medical Condition | | |
| No | 17 | 62.96 |
| Yes | 7 | 25.93 |

| | | |
|-------------------------|----|-------|
| Mental Health Diagnosis | | |
| No | 22 | 81.48 |
| Yes | 3 | 11.11 |
| No Response | 2 | 7.41 |

Intervention Effectiveness

Means, standard deviations, and correlations between variables of interest are shown in Table 3. While all variables met the homogeneity of variance assumption, all but the pre- and post-BRS and pre- and post-Positive Affect scale scores were non-normally distributed. None of the hypotheses that there would be an improvement on the variables measured following the NCI were supported (including between the CBI and PPMS subscales), except one. The scale for which a Wilcoxon Signed-Rank Test revealed a significant difference between the pre- and post-interview timepoints was the FACT-G Social Well-Being subscale ($n = 20$, $V = 47.5$, $p = 0.05$). The mean pre-interview score was 20.67 ($SD = 5.13$) and the mean post-interview score was 21.55 ($SD = 4.39$). The effect size was 0.43, which constitutes a moderate effect according to Cohen's classification. However, it is important to note that there was a question regarding satisfaction with one's sex life in the questionnaire which was not answered by six participants on the pre-interview survey, and one participant out of the 20 participants who completed the post-interview survey, thus potentially biasing the results. Descriptive statistics were obtained for participants who completed the question versus those who did not, which suggested that there were differences on some variables between the two groups. A summary of these descriptive statistics is provided in Table 4. Notable differences are that participants who did not complete the question pertaining to sexual satisfaction appeared to be older, closer in proximity to the end of their active cancer treatment, have lower positive affect, and have lower functional well-being.

Table 3*Means, Standard Deviations, and Correlations of Study Variables of Interest*

| Variable | Mean (SD) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|-----------------------------------|-----------------|-------|-------|-------|-------|-------|------|-------|-------|------|------|
| 1. BRS-Pre | 3.68 (0.71) | 1.0 | | | | | | | | | |
| 2. BRS-Post | 3.52 (0.51) | .79* | 1.0 | | | | | | | | |
| 3. Positive Affect-Pre | 33.26 (6.73) | .70* | .55* | 1.0 | | | | | | | |
| 4. Positive Affect-Post | 33.20 (5.97) | .43 | .39 | .46* | 1.0 | | | | | | |
| 5. Negative Affect-Pre | 16.93 (5.86) | -.39* | -.64* | -.39* | -.40 | 1.0 | | | | | |
| 6. Negative Affect-Post | 16.25 (4.59) | -.16 | -.39 | -.25 | -.21 | .30 | 1.0 | | | | |
| 7. FACT-G Physical-Pre | 5.63 (4.13) | -.28 | -.59* | -.26 | -.54* | .50* | .45* | 1.0 | | | |
| 8. FACT-G Physical-Post | 5.65 (5.11) | -.29 | -.40 | -.22 | -.50* | .27 | .21 | .65* | 1.0 | | |
| 9. FACT-G Social-Pre | 20.67 (5.13) | .48* | .44* | .37 | .03 | -.14 | .15 | -.28 | -.22 | 1.0 | |
| 10. FACT-G Social-Post | 21.55 (4.39) | .21 | .33 | .14 | .21 | -.17 | .05 | -.32 | -.32 | .82* | 1.0 |
| 11. FACT-G Functional- Pre | 18.56 (5.67) | .70* | .61* | .51* | .32 | -.46* | -.14 | -.38* | -.37 | .71* | .48* |
| 12. FACT-G Functional- Post | 17.60 (6.07) | .63* | .72* | .44* | .45* | -.38 | -.28 | -.68* | -.52* | .41 | .40 |
| 13. GAD-7- Pre | 2.93 (3.38) | -.62* | -.53* | -.46* | -.42 | .75* | .26 | .48* | .42 | -.33 | -.05 |
| 14. GAD-7- Post | 3.00 (3.06) | -.49* | -.50* | -.37 | -.61* | .85* | .45* | .52* | .41 | .05 | .06 |
| 15. CBI-Pre | 7.54 (1.21) | .74* | .73* | .46* | .44* | -.48* | -.10 | -.54* | -.32 | .61* | .46* |
| 16. CBI-Post | 7.51 (0.91) | .31 | .54* | .06 | .22 | -.59* | -.28 | -.39 | -.22 | .48* | .53* |
| 17. PHQ-9- Pre | 4.07 (3.00) | -.62* | -.64* | -.50* | -.57* | .73* | .24 | .71* | .48* | -.35 | -.22 |
| 18. PHQ-9- Post | 4.25 (3.54) | -.57* | -.54* | -.41 | -.67* | .74* | -.08 | .72* | .64* | -.19 | -.26 |
| 19. SLS-Pre | 26.11 (5.55) | .24 | -.02 | .20 | .01 | -.19 | -.07 | -.41* | -.16 | .46* | .49* |

| | | | | | | | | | | | | | |
|-----------------------------------|-----------------|-------|-------|------|-------|-------|-------|-------|-------|------|------|-----|----|
| 20. SLS-Post | 25.85 (5.50) | .37 | .18 | .08 | .37 | -.45* | .12 | -.42 | -.31 | .55* | .56* | | |
| 21. PPMS-Pre | 7.36 (1.31) | .49* | .26 | .23 | .27 | -.10 | .27 | -.20 | -.35 | .73* | .78* | | |
| 22. PPMS-Post | 7.16 (1.37) | .10 | .13 | -.12 | .34 | -.22 | .42 | -.22 | -.47* | .53* | .67* | | |
| | | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 |
| 11. FACT-G Functional -Pre | 1.0 | | | | | | | | | | | | |
| 12. FACT-G Functional -Post | .56* | 1.0 | | | | | | | | | | | |
| 13. GAD-7-Pre | -.71* | -.34 | 1.0 | | | | | | | | | | |
| 14. GAD-7-Post | -.44* | -.26 | .82* | 1.0 | | | | | | | | | |
| 15. CBI-Pre | .76* | .60* | -.65* | -.41 | 1.0 | | | | | | | | |
| 16. CBI-Post | .43 | .47* | -.38 | -.38 | .46* | 1.0 | | | | | | | |
| 17. PHQ-9-Pre | -.69 | -.70* | .79* | .74* | -.71* | -.51* | 1.0 | | | | | | |
| 18. PHQ-9-Post | -.50* | -.61* | .68* | .67* | -.48* | -.49* | .85* | 1.0 | | | | | |
| 19. SLS-Pre | .47* | .19 | -.32 | -.06 | .26 | .04 | -.36 | -.21 | 1.0 | | | | |
| 20. SLS-Post | .67* | .43 | -.50* | -.33 | .44* | .54* | -.57* | -.63* | .61* | 1.0 | | | |
| 21. PPMS-Pre | .59* | .51* | -.25 | -.04 | .54* | .52* | -.46* | -.46* | .40* | .75* | 1.0 | | |
| 22. PPMS-Post | .35 | .40 | -.12 | -.10 | .28 | .43 | -.34 | -.54* | .33 | .74* | .86* | 1.0 | |

Note. * $p < .05$. BRS indicates Brief Resilience Scale; FACT-G indicates Functional Assessment of Cancer Therapy – General; GAD indicates Generalized Anxiety Disorder 7-Item Scale; CBI indicates Cancer Behavior Inventory Scale; PHQ-9 indicates Patient Health Questionnaire 9-Item Scale; SLS indicates Satisfaction with Life Scale; PPMS indicates Perceived Personal Meaning Scale.

Table 4

Descriptive Statistics for Participants Who Completed Question 7 of FACT-G Social Well-Being Subscale

| Variable | <i>Mean (SD) – Participants Who Completed Q7 (n = 21)</i> | <i>Mean (SD) – Participants Who Did Not Complete Q7 (n = 6)</i> |
|-----------------------------|---|---|
| Age | 61.1 (13.36) | 68.67 (7.39) |
| Weeks Since Treatment Comp. | 13.24 (15.24) | 5.25 (2.09) |
| BRS-Pre | 3.75 (0.63) | 3.42 (0.98) |
| Positive Affect-Pre | 34.38 (5.88) | 29.33 (8.57) |
| Negative Affect-Pre | 16.95 (6.30) | 16.83 (4.49) |
| FACT-G Physical-Pre | 5.52 (4.00) | 6.00 (4.98) |
| FACT-G Social-Pre | 20.95 (5.10) | 19.67 (5.57) |
| FACT-G Functional-Pre | 19.00 (5.71) | 17.00 (5.73) |
| GAD-7-Pre | 2.86 (3.31) | 3.17 (3.97) |
| CBI-Pre | 7.67 (0.98) | 7.08 (1.88) |
| PHQ-9-Pre | 3.95 (2.87) | 4.50 (3.67) |
| SLS-Pre | 25.62 (5.78) | 27.83 (4.67) |
| PPMS-Pre | 7.32 (1.37) | 7.50 (1.21) |

Acceptability and Treatment Satisfaction

Results from the Treatment Satisfaction Questionnaire, which 20 participants completed, suggested that participants had an overall positive experience with the NCI. In terms of the first question, which asked whether participants found the interview to be helpful, 18 participants (90%) reported that the interview was “helpful,” whereas two participants (10%) reported that the interview was “unhelpful.” Question two inquired whether participants took away something specific from the interview, and 11 participants (55%) said “yes,” while nine participants (45%) said “no.” The mean score on question three, which asked whether the interview gave

participants more perspective on their experience with cancer (from 1 = “strongly disagree” to 5 = “strongly agree”), was 3.6 ($SD = 0.99$). An average rating of 3.6 ($SD = 0.88$) was also given on the next question, which pertained to highlighting important insights or learnings in relation to one’s experience with cancer. In relation to finding parts of the interview challenging or having opened ‘old wounds,’ respectively, the mean ratings were 2.3 ($SD = 1.03$) and 1.95 ($SD = 1.15$). Most participants ($n = 15$, 75%) reported “no” when asked whether a particular part of the interview stayed with them following the interview, and almost all participants noted that they were not considering doing something differently as a result of the interview ($n = 18$, 90%). All participants reported that the interview was “just the right length.” Lastly, when asked whether all patients at the hospital should have the opportunity to participate in the NCI if desired, the average rating on the scale (from 1 = “strongly disagree” to 5 = “strongly agree”) was 4 ($SD = 1.08$). Verbal feedback provided by participants at the end of the NCI itself offered further evidence of an overall “positive experience” afforded by the interview, as well as several perceived benefits. These findings are outlined below.

Motivation to Participate

When queried about their experience with the interview, many participants ($n = 20$) noted that they were inspired to participate in order to help others, in particular future patients. Even participants who did not report any personal benefits or gains from the interview stated that they felt good about potentially helping someone else through their participation, which made it worthwhile for them. Both a desire to help other patients directly, and more specifically to help improve supports for other patients, were highlighted. Two participants reported wanting to “give back” to the hospital as a whole in return for the lifesaving care they received. However, one participant also discussed the importance of making sure that patients’ stories are heard,

touching upon the importance of narrative care, when she stated, “I hope that it'll help people along the way but I think hospitals are just moving further and further away from that patient... You're just a number. You're a diagnosis and I think this whole part of the experience is lost. The human aspect is getting further and further away.” Another participant, who had experienced a number of challenges before and during his treatments for rectal cancer, such as multiple attempts at various clinics to test for and diagnose his ailments, focused on retelling this difficult journey throughout the NCI, as opposed to focusing on answering the questions about new insights/lessons gained, in part because he perceived this to be his only opportunity to share his experiences with the aim of impelling change for future patients. He stated toward the end of the interview, “One of the reasons I definitely wanted to participate in this was, I was like ‘No, you know what, if the powers that be don't get the feedback then they can't alter their best practices.’” Furthermore, the youngest participant in the study described hoping to help others like her feel less isolated and alone in their experience. Another participant summarized their motivation to participate as follows: “I hope that... somebody can just learn from my experience. If it makes any difference to anybody at all then it's worth it.”

Attitude Toward the Interview

While some participants had a neutral attitude toward the interview, such as, “It was fine,” others had a more demonstrably positive attitude. For example, two participants described the interview as “terrific” and “fantastic,” while no participants expressed a negative view of it. A few participants ($n = 4$) also reported feeling “comfortable” during the interview. One participant stated that the interview was “like therapy” due to the number of insights it helped them to achieve. Other participants ($n = 3$) also highlighted the importance of research overall and how they appreciated such efforts, as it aims to improve the lives of future patients.

Helpful Aspects

Aspects of the interview that participants reported finding helpful included the following: it provided an opportunity to tell their story freely; they felt supported; there was a “good pace” to the interview; the questions were “important;” the open-ended nature of the questions allowed space to think and explore; it provided an opportunity to “verbalize” one’s experience rather than just answer survey questions; it gave one the chance to “organize” one’s experience; and that it pushed one participant “out of [their] comfort zone” in terms of exploring and expressing emotion. In terms of feeling supported, one participant explained, “Yeah, very supportive that the few things I couldn’t explain, you help[ed] me talk about this.” With respect to the nature of the questions, another participant noted, “I think they're all really great questions. I think at the time when I answered each, they, they felt so, like, prolific. Right? But each question was so important to me, I think. Because it was like exactly my journey. Going through this, but like in a nutshell.” Another participant explained the importance of being given the opportunity to tell one’s story, as opposed to choosing numbers on hospital questionnaires to summarize how they are doing: “Putting a number on it's not... just no... I don’t know, just more avenues for people that, that don't have support or recognizing that there are some people sitting in that waiting room who are terrified. It just gets lost I think.” Two other main aspects that participants found “meaningful” were that the interview gave them an opportunity to receive support and to reflect more deeply on their experience. For example, one participant stated:

Being able to talk about it from start to finish and... because I think maybe there are people who don't even get to the point of... they are stuck with the cancer diagnosis and they can't sort of move beyond that so... in this kind of interview you, you bring out a lot of issues that maybe people don't think of... In terms of my experience, I think

listening, having someone to listen to you... I think there's a lot missing in terms of helping people through the process in terms of just listening to their feelings like along the way. If it wasn't for my friends and family there wasn't anybody that sort of asked me except for you, "What's this like for you?" So I just think along the way there weren't enough people that are there to ask questions about how you're really feeling about your diagnosis. It's more how are you feeling about your treatment, you know, managing your side-effects. But not really managing how you're coping. Maybe just even in your interaction with just the general staff... I cannot recall anybody saying, "How is it going?" Or they would all ask, "How are you feeling?"... Like all medical questions. (Female, 71 years old)

Perceived Benefits

Different benefits resulting from the NCI, such as having the opportunity to reflect ($n = 8$), were reported to varying degrees by many of the participants ($n = 21$). One of the benefits was gaining new insights or realizations. Other perceived benefits included feeling "rewarded" and made to feel helpful by participating in the current study to help other patients, overcoming avoidance of discussing difficult topics or challenges in relation to cancer (e.g., "It's made me think about some things I really haven't wanted to think about. And I think it's going to help me in the future. And for that I thank you."), feeling inspired to seek further support, "putting things into perspective," and "reinforcing" what they already knew about themselves and their loved ones. A couple of participants reported feeling that the interview was beneficial because it was "cathartic."

Criticisms and Lack of Benefits

There was a criticism from one participant that some of the questions were repetitive and therefore not all helpful. However, another participant noted that they would have liked more repetition of questions due to their “chemo brain.” Two participants stated outright that they did not gain any new insight from the interview, and several others ($n = 6$) noted that nothing discussed stood out to them as new or particularly important.

Inspired Changes

A number of participants reported that they may change the way they think or do things as a result of the interview ($n = 12$). For example, some participants noted that it is important to share one’s experience and difficulties with others ($n = 4$). This insight was gleaned by one participant through the process of taking part in the NCI: “I’m realizing things and coming to terms with things and understanding things I didn’t even know before, I didn’t know about myself so... I really appreciate this opportunity... Don’t sit and brew. Talk about it, talk, just talk about it. That’s really important and it’s something I never did before.” Having experienced the value of sharing their experience about cancer, some participants referenced the motivation to continue engaging in self-reflection and exploration beyond the interview. Another participant commented that one change they would like to apply moving forward was continued self-reflection. This is shown in the following exchange:

P: I'm sure it's going to make me reflect more, you know... I knew all the answers to these questions. I didn't know you were going to ask them of me, but I think I knew them, so it's nice to hear myself say it out loud.

I: Why do you think that is helpful? Or, nice?

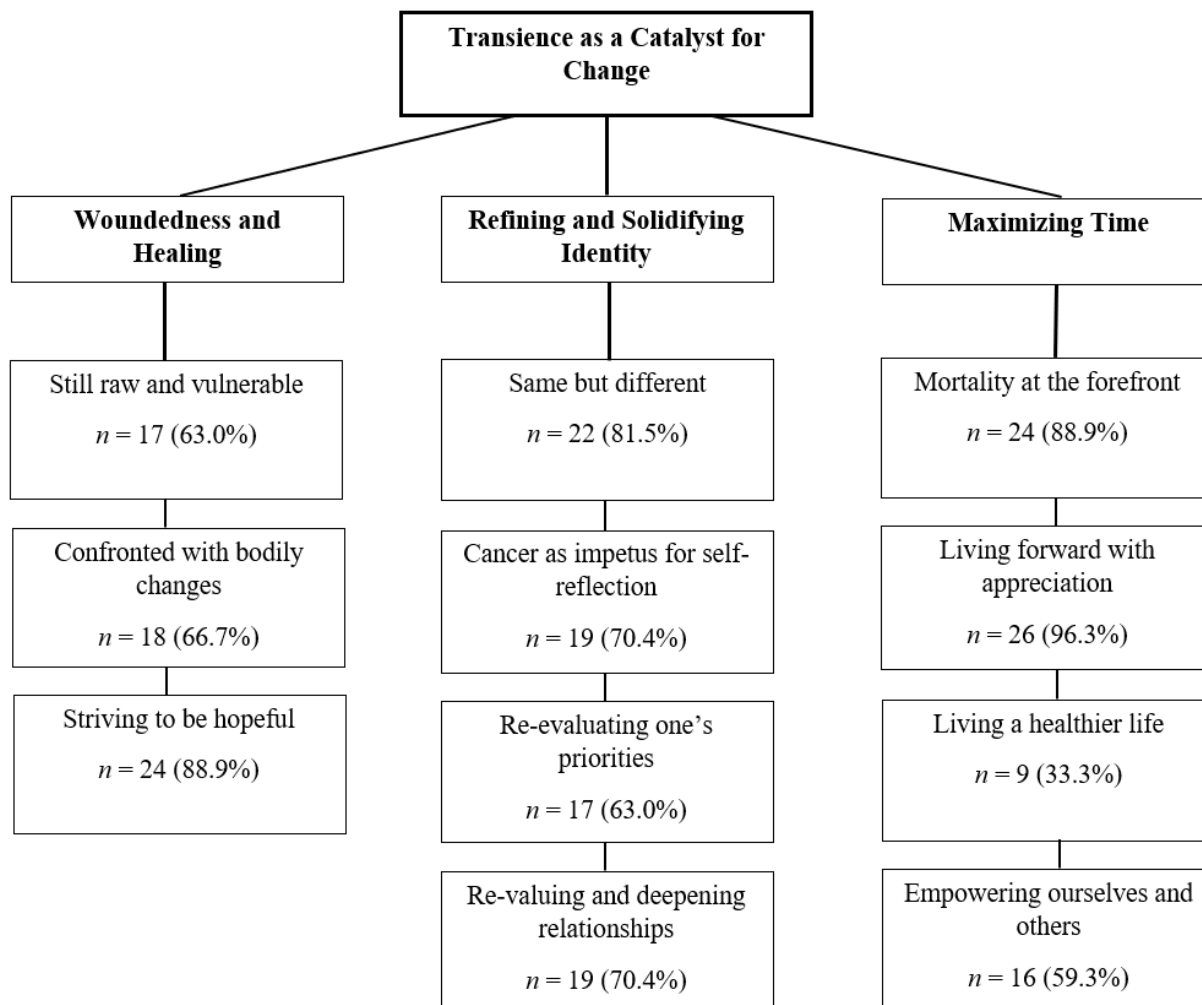
P: Because you hear your narrative, you hear your own story, right? It would be like journaling and then reading your journal entry out loud to yourself. (Female, 40 years old)

A greater focus on one's mental health was also mentioned. In addition to self-reflection and expression, other participants highlighted that they felt more comfortable or motivated to discuss their experience or share their challenges with others and to seek support from others. Lastly, several participants reported feeling inspired to actually get out and help others as a result of realizations made during the interview, for example by volunteering to drive patients to their appointments, reaching out and proactively helping friends, family members, or acquaintances with cancer (e.g., by bringing them food, sending cards), or volunteering their time to share their experiences with patients with similar diagnoses. The desire to share important information and lessons learned through experience was shared by a few participants.

Chapter 4: Perceived Changes in Self, Life Perspective, and Outlook on Relationships:

A Grounded Theory Analysis

A total of 152 meaning units, or codes, were generated from the grounded theory analysis of 27 participant interviews (codes and definitions can be found in Appendix H), which were then grouped into the following 11 sub-categories: 1) Still raw and vulnerable; 2) Confronted with bodily changes; 3) Striving to be hopeful; 4) Same but different; 5) Cancer as impetus for self-reflection; 6) Re-evaluating one's priorities; 7) Re-valuating and deepening relationships; 8) Mortality at the forefront; 9) Living forward with appreciation; 10) Living a healthier life; and 11) Empowering ourselves and others. These sub-categories were further collated into three main categories. The first three sub-categories listed above formed the main category of Woundedness and Healing; the next four sub-categories formed the main category of Refining and Solidifying Identity; and lastly, the remaining four sub-categories formed the main category of Maximizing Time. Finally, the core category of Transience as a Catalyst for Change emerged, which elucidated the experiences of change in self, life perspective, and outlook on relationships experienced by individuals during the transitional period from treatment to survivorship following primary cancer diagnosis and treatment. A summary of the category structure is presented in Figure 1, including the number and percentage of participants who endorsed codes within each sub-category.

Figure 1*Grounded Theory Category Structure*

The core category, Transience as a Catalyst for Change, encompassed the profound alterations experienced by individuals who have been confronted by various types of primary cancers, both mentally and physically, and the many realizations about themselves, life, and relationships brought on by the experience. It spoke to the impermanent nature of things, including health and time, which is a realization that has the power to change one's sense of self, personal goals, attitudes toward others, and daily way of living. This core category also alluded

to the transitional nature of these individuals' current state of existing, somewhere between being treated for a potentially life-threatening disease and hopefully being 'cured' and on the way forward to a 'normal' life.

As exemplified in the main category Woundedness and Healing, many participants reported feeling incredibly vulnerable and sometimes fearful at this uncertain point in their cancer journey, particularly due to lingering physical effects of treatment, as well as the emotional impact of what they have endured throughout months of testing, waiting, treatments, and more waiting. However, there was also a strong desire and striving to remain hopeful and focus on one's resilience and coping while things become more certain, as opposed to merely existing or even suffering. The next main category, Refining and Solidifying Identity, represented the extent of reflection done as a result of one's experience with cancer, as well as changes experienced with respect to one's own sense of self, life priorities, and outlook on relationships, ranging from none at all, which was rare, to monumental. Lastly, the main category of Maximizing Time encompassed changes in the existential realm, revolving around the realization that life, health, and time are truly precious but importantly not everlasting. In turn, these realizations led to shifts in one's emotions, cognitions, and way of doing things.

Woundedness and Healing

Still Raw and Vulnerable

Two participants described feeling more "vulnerable" or "fragile" than they ever have before, and others were overcome by fears about their future, not only in terms of potential recurrences ($n = 9$), but also in reference to how their life and sense of self will be moving forward ($n = 8$). As one participant, who had completed radiation treatment for breast cancer two and a half weeks prior to participating in the NCI, stated:

I think forever and ever you will feel more vulnerable. And you will always, you know, it's at the back of your mind no matter what you do, you can go on, and you can feel positive and, you know, totally enjoy life, but it—for me anyways I think it will always be there... I don't think it'll ever leave me. So, in that way I feel more fragile, a little bit more vulnerable. (Female, 62 years old)

For some participants ($n = 5$), the emotional fallout from their confrontation with cancer was significant and sometimes severe, leading them to experience various difficult emotions, such as loneliness, negative or reportedly “intrusive” thoughts, and in one instance even symptoms associated with depression. Sometimes knowing that these negative changes would fade with time and distance did not help because of expectations they placed on themselves or were placed on them by others. This predicament was exemplified by one of the younger participants who had recently discovered that she would not need to undergo surgery, as previously thought:

I wouldn't say that I'm depressed, but I'm still numb, with very sad emotions. So it's like, people are expecting this really ecstatic response from me, but I just don't have it. And it's not that I'm not happy about it, I'm very happy that I don't have to have surgery, who wouldn't be? But, overall, the amount that it took to go through treatment and... to keep my life as normal as possible and to remain as healthy as possible, like, kicked my ass, physically and emotionally. And emotions are so physical, and when you are tired, you know, its even in your, like, what? Where is my resources? Where's my, you know? And I figured out all these things, it's like, oh, I'm wiped. I'm emotionally wiped. (Female, 40 years old)

Several participants ($n = 11$) spoke about having a “sense of impending doom,” or waiting for or expecting that another terrible thing will happen in their future. For a few

participants ($n = 9$), fear of recurrence (or metastasis for one) was front and centre in their mind; for two others, a broader fear of uncertainty, usually due to continued testing and upcoming appointments which could reveal unwelcome information about the status of their cancer, was more prominent. One participant referred to the stages of treatment and recovery, with their current one being about waiting to gain a sense of certainty: “You probably would have it in the back of your head that it could come back. I guess that’s going to be the next phase, you know, right now I’m waiting for this to be case closed” (female, 67 years old). Other participants spoke about feeling anxious or discouraged after certain expectations they previously held were broken, for instance where they would be in their career, or how long treatment side-effects would last.

These lingering vulnerabilities often resulted in tangible changes in one’s life, such as planning less for the future. As one person who had been diagnosed with colorectal cancer said:

There’s this sense of temporariness that’s... I, I, I just have this feeling that something’s waiting in the wings. It’s a weird feeling but sometimes, sometimes they can be very spooky but then other times now when I’m thinking about it I, I know it’s there, but it doesn’t make any sense. So... I’m not really thinking that far ahead. Which is also something that bothers me because normally I’ve got the next year all planned out. And I don’t have the next month planned out. (Male, 61 years old)

Other disappointing changes, such as delays in getting back to normal, not being able to, or feeling ready to, date, or feeling like one’s life has been derailed by cancer – causing them to fall behind in terms of life progress compared to their peers (as was the case with one younger individual) – were also reported. One participant noted that, “During the experience in particular, you know, you want to be normal so bad. But you're not” (female, 62 years old).

Confronted with Bodily Changes

Several participants ($n = 11$) spoke about their body as different or even foreign to themselves due to the ongoing side-effects and longer-term changes resulting from their cancer treatments. While some participants were pleasantly surprised by the lack of treatment side-effects, others experienced a number of bodily alterations which they found discouraging or distressing because they served as a “reminder” of their cancer. For example, one participant diagnosed with tongue cancer resulting from the human papillomavirus (HPV), who had completed treatment about two and a half months prior to the study, reported struggling with loss of taste and smell, which had significantly impacted his ability to enjoy food; for him, eating was now an “exercise” of necessity rather than enjoyment. He noted that, “I’m hoping that it’s very temporary and that it passes.” Many spoke about such “physical reminders” of their experience, such as thinner hair, poorer eyesight, weight loss or gain, and surgical scars. One participant used the language of feeling “deformed” to describe her post-surgery body, while another reported feeling like “damaged goods.” Another participant who had breast cancer explained that she continued to wear hats to hide her baldness because she did not want others to “feel sorry for” her. Another participant, who was two weeks post-breast cancer treatment stated, “I have put on 20 pounds already and that’s a killer for me... Will it come off, is it a permanent thing for me? I’ve suffered enough, why do I have to go through this too?” For some participants, the physical changes were the only remaining issue they felt they had to contend and grapple with on their way back to ‘normal.’

As a result of these bodily changes, some participants ($n = 4$) were left feeling debilitated, older, and disconnected from their body, and therefore their sense of self. These feelings were often confirmed or exacerbated by changes in everyday abilities and functioning, both with respect to necessary tasks and voluntary but much enjoyed hobbies. One of the younger, single

participants mentioned having to make difficult decisions related to probable future fertility issues. Three participants, all of whom were middle-aged or older men who had prostate cancer, noted struggling with decreased sexual functioning. However, they expressed a greater acceptance of this cancer-related change, viewing it as a trade-off for living longer. For instance, one 77-year-old participant noted that he would have opted out of treatment all-together or would have sought different treatment options had he been younger and faced with the same potential sexual health issues. At his current stage of life, however, he reported heeding the advice of his brother, which was that “If you die, you won’t be able to have sex anyhow.” Overall, while bodily changes and decreases in daily functioning were devastating for a few participants, they were viewed as an ‘acceptable’ compromise for treatment and longevity or as a temporary setback by most.

Striving to Be Hopeful

Despite the challenges brought on by cancer diagnosis and treatment, the majority of participants ($n = 24$) interviewed described being focused on hope for the future and moving past this chapter of their life in a fruitful way. Almost all participants described ‘gaining’ or taking something away from their experience with cancer. A discovery of the extent of one’s resilience and ability to cope with difficulty was a commonly reported gain ($n = 11$), as exemplified by the following statement: “I am a real fighter. And, unknowingly, I [won] the gold medal. Yup... It's nice to know, it's really nice to know. It's really shitty how to get to know it, but, it's nice to know... I prefer to fight than flight. I have a lot of respect for myself” (female, 40 years old). In terms of new insights about oneself, another participant who completed her treatment for breast cancer two months before the study noted that, “I am stronger than I was the day before. I hope

to be stronger tomorrow... That's the whole thing, you have to keep going" (female, 67 years old). The importance of "moving on" was highlighted repeatedly by different participants.

Other important skills discussed were keeping negative emotions in check whenever they arose ($n = 4$), resisting being overtaken by thoughts of recurrence ($n = 4$), and being able to overcome one's fears ($n = 2$). One woman summarized the importance of coping with negative emotions and then moving on:

Thinking of cancer does make me anxious, for sure. You sort of think of the future. That you were always hoping that the future will be good. I mean it is a sad thing to get cancer. There's nothing not sad about it, so. I think I'm managing that part a little bit better, you know, the sadness of having cancer. I think that – I've cried enough about it being sad. I think now I just need to sort of maybe work on the future and feeling more hopeful and you know... putting it behind me. (Female, 62 years old)

Another aspect of Striving to Be Hopeful was learning to face challenges as they come and focusing on the present moment, as opposed to being consumed by unanswered questions, hypothetical situations, and fears. One 79-year-old man reflected upon his experience, noting that, "One of the things I learned is looking back and dwelling on anything that has gone wrong is really counterproductive and it really takes you away from the reality of what's going on tomorrow or today." Importantly, as a result of being in the midst of the transition between treatment and conclusive results about the status of their cancer, some participants ($n = 6$) emphasized the importance of living in the present and not worrying about the future, at least until their future follow-up testing and appointments have passed. One 78-year-old woman in this position explained that her way of thinking and coping had changed in the following way:

“Right now, I’m not thinking farther ‘til I hear from [the] doctor, and then what he says. And what he says I have to accept it... Time will tell... I deal as it comes.”

Adopting a newfound “positive” attitude or strengthening one’s existing commitment to maintaining a positive attitude was a commonly expressed change in one’s outlook toward life following their experience with cancer ($n = 12$). Participants reported realizing that this is a helpful outlook to take because the alternatives are not conducive to moving on with life and living well overall. This was exemplified by the following quote: “With positivity and optimism... it really helped me to move on with my day-to-day life” (male, 56 years old). Another participant concurred, referring to the importance of looking forward to the good parts of life:

You have to... It's a hard one but you have to... You have to look forward, your next lunch, your next supper, your next chocolate bar, right? The good stuff in life. It's not that it's not going to rain on you, but you're not made of sugar... you have to laugh about things. We really joke about life and make it as a positive and not dwell on it in the past and what has been bad. (Female, 67 years old)

This ability to focus on positivity and optimism was thought to help one cope not just with cancer, but with life challenges overall, such as overcoming fear. Related changes in one’s perspective were understanding the benefits of focusing on logical thinking, as opposed to being driven by negative emotions, and focusing on finding and implementing solutions to one’s problems instead of dwelling on those problems. Lastly, some participants ($n = 8$) reported gaining an understanding of the importance of taking care of themselves, without feeling guilty or needing to justify their increased need for self-care.

Refining and Solidifying Identity

Same but Different

When asked to reflect upon changes they experienced as a result of having been diagnosed with and treated for cancer, many participants ($n = 16$) reported believing that they were fundamentally the same person, but five participants (sometimes the same individuals) noted that they were different in terms of their attitudes toward life and what they viewed as important. Some participants, particularly those who had undergone a health crisis in the past, such as prior cancer diagnoses or surgeries for other conditions, stated that their current experience did not result in any significant changes or new lessons learned. Those who could not identify any changes often explained the lack of change by noting that they were already a certain type of person or had certain qualities that ‘would’ probably emerge as important from the experience. For example, one woman who had breast cancer stated, “I’ve always been somebody who’s very appreciative and I appreciate every day, my family, my friends, my job, life. I’ve always been very positive and very appreciative, so I don’t think, I don’t think it’s changed my attitude because I’ve always had that” (female, 48 years old).

Meanwhile, participants who had never experienced any major setbacks in terms of their health tended to experience greater shifts in their sense of self or life perspective. Other participants initially stated that they did not believe they had changed, but upon further reflection, noted some meaningful shifts in their identity, outlook, or way of life ($n = 10$). For example, one 59-year-old man stated, “I don’t know if it’s changed my life, per se... It does, it changes you a little bit. Mostly if your eyes are open and your heart is open, I think it changes you in positive ways.” Referring to the desire to move past the transitional period between her

surgery (i.e., her “new birthday,” which she also called a “rebirth”) and the rest of her life, one woman stated:

I wouldn't say it changed my life. I mean, it has, but I'm past that stage already, because I've done the corrective and the treatments, and I'm looking forward to that birthday, that I can say, I can keep going. Let it be another 15 or 30 or tomorrow, you don't know. It's passed, and we can't live in the past. You have to live forward.

There were some dichotomies in this sub-category, exemplified by one participant stating, “I am a different person,” while another stated that, “I think I’m still basically the same person. But I, I think my perspective about life is different.” Overall, most participants were able to identify some ways in which their identity was refined, solidified, or more rarely, transformed, by their cancer journey.

Cancer as Impetus for Self-Reflection

Many participants described experiencing some form of change within themselves or their lives following their confrontation with cancer. There was a shared sense that cancer is one life event which has the power to change oneself and the way one lives, at the very least by prompting one to engage in introspection and reflection ($n = 9$). As one woman summarized, “You do a lot of reflection on your life after this happens, you know? What am I going to change, what could I do better, you know? Moving forward.” She later stated:

Oh my God, it's impossible for it not to change your life. It is impossible. And probably also the people around you. But more me. I mean, it's, you know, it's my life and it's my cancer. You know, it just, it stops you in your tracks... and you know that's a good thing. It is a good thing. It makes you think about your life, it certainly makes you think about mortality, which is scary. But, I mean, it stopped me, just stopped me dead

in my tracks. But, you know, it makes you reflect on your past, it makes you reflect on your future, you know? So, like it just changes everything. There's just nothing about this experience that is the same afterwards. Which is not a bad thing. It is not a bad thing. It's maybe painful, but it's not a bad thing. (Female, 62 years old)

One 68-year-old man who had prostate cancer went so far as to say that he believed that having cancer causes such a monumental “shake-up” that it unavoidably leads to a reorganization of one's life and sense of self: “My own opinion is if it, if it doesn't shake you up then I think there's something wrong [laughter].” For one participant, his cancer diagnosis was an initial impetus for reflection which led to new insights about himself as a person:

All I, really I've learned about myself is that I don't know myself that well. There [are] parts of me that I didn't even know. Like it's, it's... there's a part of me that's a coward and there's a part of me that's just the opposite but I don't know how they interact... I think I have to spend some more time thinking about getting to know me. 'Cause... a lot of that didn't go the way I would've... if you had asked me two years ago “If this happened, how would you behave?” I wouldn't've, I wouldn't've, I would have been completely wrong. (Male, 61 years old).

This plan and motivation to further engage in self-examination was consistent with the transitional period and signified that the cancer ‘journey’ will likely continue to impact them well beyond this phase. Two participants described being in the process of establishing their ‘post-cancer’ identity to include new insights, changes, and life-lessons they had gained. In addition, consistent with the transitional juncture at which the interview was conducted, a few participants ($n = 3$) engaged in a kind of meta-processing of possible changes during the interview itself as they were invited to consider these topics, some for the first time. Indeed, as

many participants were just coming out of “survival mode” where they were solely focused on their physical healing and well-being, many had not yet had the chance to stop and reflect upon how the experience of cancer had and would affect them mentally.

Interestingly, while there were some reports of negative changes to mood, physical well-being, and lifestyle, as discussed above, many participants ($n = 13$) noted that the changes they experienced were encouraging. For instance, one individual reflected upon their surprise about this occurrence:

It's been the biggest, in a way it's been the biggest change in my life... the biggest change I had for a very long time. I hadn't really thought about that. But it has. And it's not all negative. And actually talking to you helped me realize that. I mean, some of these things are actually good, which hadn't really occurred to me up until our interview. And thinking about it now, I think up until now I've been thinking that basically it's been a, a, a negative thing. But I think there have been some positive things that have come out of it. (Male, 68 years old)

Another participant confirmed having been changed for the better: “Actually it made me better. It made me learn. It made me more appreciative more... Made me open my, my eyes more to life” (male, 75 years old). One younger participant expressed her thankfulness for such positive changes, which would now influence her future:

I honestly think it's just made, it's made me better. Truthfully, honestly like I know this sounds absolutely nuts, I'm glad this happened to me now versus later. Because I think I'm actually a better person. I think I'm a better person to myself. And I think I'm a better person in the sense that I'm more honest with myself about what I wanna do and what I don't wanna do. (Female, 38 years old).

Having experienced an overall “positive mental impact” was a shared experience among three participants, specifically as a result of the reflections they were incited to undergo after being diagnosed. However, another participant believed that the changes they were experiencing at this phase of life would be temporary (e.g., one person’s belief that they would soon “revert to the norm”), while another participant was at the contemplation stage, where they were unsure whether they had or would change or do anything differently in the future. Several participants ($n = 6$) had a sense that something about them was different, but were unable to understand or articulate what that was yet. A common belief was that those alterations in self and/or perspective would become clearer with the passage of time, particularly when further away from treatment.

Re-Evaluating One’s Priorities

An inspiration to re-examine one’s longstanding priorities or question their status-quo was commonly reported among participants ($n = 6$), with some aspects of life or self becoming more important and others falling to the wayside. For many, this was a welcomed change, while for a few others it was difficult to let go of long-held priorities due to comfort and prior investments of time, effort, and resources. One participant spoke about feeling conflicted about his shifting priorities following his diagnosis and the end of his treatments:

It’s helped me reassess what’s important and what’s not important. Part of it is that I’m just not physically able to work right now. It might be a combination of physical and psychological, but work does not really have much appeal at this point, and up until my diagnosis my work was a really big part of my life. It was a really big part of who I am. And [laughter] now it’s not that important. Which in a way, on the one hand

it's kind of liberating. On the other hand, it is upsetting because you know I've been operating in a certain way for a long time. (Male, 68 years old)

The changes in perspective about what is more important than something else were often related to one's values and spending time in a way that is consistent with those values, for example spending time with loved ones versus spending time working, or spending one's time playing versus watching sports. One 56-year-old man explained, "Inside I definitely know that my perspective of things has changed... It's really the value comparison of how much time I spend on one thing versus the other." Age was also linked to existentially-oriented musings, as noted by one man: "It really makes you put your life into perspective. And say, what do you want for the... I'm 60 years old now... I lived over half my life. So... how to live the next..."

In terms of thoughts on *how* to live throughout the remainder of one's life, there seemed to be a consensus on wanting to live in a slower, less stressful, and more balanced way ($n = 12$). The reasons for this desire to live at a slower pace were varied, for example due to new preferences, necessity (e.g., bodily changes), and prevention of future physical and mental problems. 'Doing less' and enjoying simpler pleasures were common ideas, for example:

Just day to day living, you know? I mean. Life itself. It sounds kind of trite. Yeah, just grateful that I'm here and you know, notice the beauty of the sunset. Taking time, time for myself, like I'll sit in an afternoon and read. Which I would have never done. Now I'll say, "Oh, I think I'll sit and read for a while." Yeah, there's nothing pressing and if it doesn't get done today, so, there's tomorrow, the next day. You know, so I'm happier that way. Like, I don't have to do it, I just don't do it. Like, sorry, it's not getting done today. (Female, 69 years old)

One 86-year-old man who had prostate cancer summarized his attitude as:

We're all mortals, you know? We're not going to live forever, so we enjoy each day, as we wake up each morning and enjoy that you're alive, type of thing. That's all. I used to have a more sublime happiness... Now I have more simple pleasures. Just simple things seem more enjoyable than they would have been a number of years ago. Just living a quiet, um, uneventful life [laughter]... That's all.

In line with living a simpler life were realizations about the importance of relationships over "stuff." For example, one 51-year-old woman noted that, "interactions with people are more important than things." Similarly, another woman reported seeing things in a different light in the following way: "I changed the way I looked at material things. Like, if something broke, I don't care anymore. Because I'm not going to be around forever anyway and so, it's stuff. It's all just stuff... I just don't have that same intense caring about things. I care about my grandchildren, like what's important has changed." Conversely, another man stated, "It's actually nice to worry about small stuff," with respect to the idea that spending his time drinking tea or asking his children about what they learned in a specific class is not a 'waste.'

New strategies implemented by participants to allow them to live the kind of life they want to live included setting boundaries with oneself and with others (e.g., scheduling fewer commitments; being upfront about not wanting to do certain activities with one's partner) and working less, as noted above. Prioritizing and protecting one's own time were significant and valued changes for many and were a common thread throughout the analysis. For example, one 68-year-old man who believed that he previously spent too much time appeasing others before taking care of himself, stated, "I'm less willing to waste time... I'm just less willing to sort of put up with certain things in other people that I used to put up with... I'm more aware of what's a valuable use of time and what's not." This idea of becoming 'selfish in a good way' and

prioritizing oneself before spending time with or taking care of others was a notable change among several participants ($n = 7$). Other goals included making a habit of being kind to oneself, being less judgmental toward oneself, doing things one wants to do, and giving oneself permission to say no. With respect to the latter, one 68-year-old woman noted, “Allow yourself to rest, to have a nap, or say ‘No, I’m not actually going to do that.’ You know, giving yourself permission. And I guess, I do give myself lots of permission now not to do things, but in the past, no I would somehow do it, even if I was like falling down from exhaustion.” Ultimately, the lesson for many appeared to be similar to the following quote: “So just...do what makes you happy and help others along the way” (Male, 59 years old).

Re-Valuing and Deepening Relationships

The majority of participants highlighted a change in their consciousness and demeanor toward other people. Firstly, participants reported gaining a deeper understanding of other human beings overall ($n = 4$), and particularly the suffering experienced by others ($n = 5$). There was a sense of wanting to reciprocate the kindness and support received from others, including family, friends, and other patients, and to continue passing this on through good deeds and moral support. An increased awareness of others’ needs was also mentioned, along with instinctual knowledge of how to support and meet those needs. Understanding and being empathetic toward the suffering of others was also a profound change experienced by some participants ($n = 7$). A few participants reflected upon what friends and family who had been diagnosed, treated, lived with, and even died from cancer in the past must have gone through, noting that they had never truly understood their struggles before their own diagnoses. One participant added that they felt better equipped to help support people in their life if or when they are diagnosed in the future. Along with this newfound empathy came a sense of comfort that their own experience was

understood by those individuals. While some participants focused on the encouraging aspects of seeing other cancer patients and survivors within the hospital and their personal lives, such as drawing motivation from their stories of hope and witnessing people “support one another,” others found it “sad” or “depressing” to see how many people have and are suffering. Another common realization expressed was about how difficult it must be for those with less support and resources, reinforcing an appreciation of their luck and privileged circumstances, but also resulting in sorrow for others’ misfortune. One person explained, “It makes you think about that whole humanity thing, right – homeless people – like everything that's wrong with society or could be better. Well that’s in your face here I guess so it kind of brings up those thoughts of societal issues... So... you can't ignore that” (female, 67 years old).

Many participants reported becoming some combination of the following: more thoughtful, compassionate, forgiving, patient, and altruistic, and less critical. Having more faith in people and focusing more on helping others, irrespective of personal gain, were also highlighted. These changes in self were often related to action, such as volunteering, reaching out to friends, and performing ‘random acts of kindness.’ For example, one participant stated, “Even if it’s at my own disadvantage, I try to make other people’s lives better” (male, 77 years old). Another participant reflected on their previous way of being, and how it changed based on their slower pace of living: “I didn't have that much compassion before. Now, I'll remember to actually ask people, “How was your day?” I didn't do that before. Not that I was an extremely selfish person, I was just so on the move...” (female, 40 years old). Others related to this sense of lack of time or necessity to focus on acts or expressions of kindness before, whereas it was considered essential now, regardless of one’s mental or physical state. A focus on altruism and “giving back” were commonly expressed goals by participants ($n = 7$) when thinking about how

they wanted to be and treat others moving forward, for example by volunteering to speak to other cancer patients about their experiences and pass along advice and messages of hope. In terms of another important way to spend one's time, one 77-year-old man noted, "I spend a little more time now trying to make other people happy, especially my family."

In addition to reflecting upon humanity and how to treat others overall, many participants reported noticing changes in how they interact within and view their close relationships. For some participants ($n = 7$), the standout realization or reinforcement of what they already knew was how much they are loved by those around them. Indeed, there was an elucidation of the lengths their loved ones would go to support and help them. As a result, one participant stated, "So you realize how lucky you are to have those relationships" (male, 59 years old). This realization sometimes resulted in a greater appreciation of loved ones and a greater focus on "spending time with" them and nurturing those relationships. "Valuing the time you have together," with respect to one participant's interactions with their children, was another newfound sentiment, as opposed to focusing on achieving a goal during that time, whether that be discipline or improving academic performance. Spending less time and effort arguing was also highlighted as a change for this participant. Lastly, with respect to time, some participants ($n = 5$) noted that it was more important to spend it with others instead of on personal accomplishments. However, while most realizations about their loved ones were positive, one participant reported receiving clarity regarding some surprisingly unsupportive relationships, through unmet expectations such as lack of communication and support. As a result, she stated, "I'm not going to go out of my way for those people anymore, which I always did, so it's kind of made me, it just, it just makes you really appreciate those really good people in your life" (female, 48 years old).

There were some unwelcomed shifts in perspective of relationships and self within those relationships as well, such as being “overprotected,” or made to feel fragile. Being perceived as weak by others and consequently by oneself was another, as one participant explained:

I never get sympathy before [chuckles]. Right? So, because you always appear to be a strong person as a leader, right? But suddenly you need to receive sympathy. Like people say, ‘Oh, I feel sorry to hear that’ or ‘What can I do?’ I know they meant well, but depending on who, receiving that kind of message... suddenly you feel that, ‘Oh, God, I’m weak,’ right? (Male, 56 years old).

One participant reported perceiving a lack of interest from others, noting that they are “going through the motions and then getting away” when asking him how he is doing (male, 61 years old). With respect to changes in self, three others reported finding themselves being less patient and less tolerant of inconsequential problems or complaints. One participant who had rectal cancer explained: “I don't like people who don't respect me [laughs]. I don't have time for them anymore. I noticed that at work a lot, I just, I lost a lot of patience for assholes. I was like, I don't have time for you, I have fucking cancer [laughs].” Overall, these changes signified an increased willingness and ability to stand up, even if only internally, for oneself, one’s time, and one’s needs.

Maximizing Time

Mortality at The Forefront

One of the most prominent changes, reported by 24 out of the 27 participants, was the confrontation with, and subsequent acceptance of, one’s mortality and resulting changes in self and way of life. One of the younger participants who was treated for rectal cancer described her confrontation with death in the following way:

Those numbers are getting better and better, but, you know, the majority of the people I sat with throughout treatment, and saw throughout treatment, may have already passed away. When you come that close to death and you feel death. Like treatment, when I was totally incapable of doing anything, and laying there in bed, you feel death. It's weird, it's very hard to explain. But you feel it, because everything died, they had to kill it. That's what treatment was, so death turned positive is a very new reality... I had to really think about death, before surgery, because you can die on the table. You know, you know, I may not have had the response I did. So, death and being comfortable with death was something I had to work on. And it's a reality, and I was seeing it. Every day, Monday to Friday [during treatment], I was looking at someone in the eyes, who was dying. And when I look in the mirror, I was looking at someone who was potentially dying. And you can say all, you know, you can read the results as much as you want about how cancer treatment is changing, blah, blah, blah. But society has said stamp of death, right? So? So, you confront that really, really soon. You know, even before it is a reality. No one said terminal to me. But now, living with cancer, that changes what death is. How you spend money, how you save money, changes all of that.

On the other hand, one of the older participants had a slightly different take on this confrontation: "When you're young you... think you're immortal. But when you're 77 you know death is approaching. People around me die of, my relatives die 75, 76 with just health issues... And then with the cancer, certainly the thought came – it's happening to you. It can happen to you too. So it's more imminent." Another 86-year-old man commented on how this realization highlighted his humanity and was related to seeing himself as part of the whole and not an

exception, noting that he used to believe that health problems happen to “other people,” and not to himself. With respect to how cancer specifically causes these shifts in perspective, one person explained that, “Mortality is at stake more than it ever is, although tomorrow I could walk out on the street and get hit by a car, but it's not the same... it's something that you have no control over, it's there in your body and you always think ‘Well is this going to be it?’” (female, 71 years old). The fact that one’s assumptive worldview, for instance that one would live a disease-free life, was challenged by a cancer diagnosis created anxiety and distress for some, but also prompted participants to reflect. The notion that longevity is not a given, as one may have previously assumed, was also highlighted. Acceptance of these facts of life often followed, as explained by one participant:

I feel like, if god forbid, I have to go tomorrow, I've done my best. You know, it will be put on my tombstone, we joke about it, we are going to put an ATM machine on our stones, you know, they [her children and grandchildren] would have to come everyday to collect 20 dollars. But you have to joke, you see?... You have to accept these things. (Female, 67 years old).

The unsurprising natural progression from these thoughts about mortality was the realization that life and health are precious. As one does with something precious, the lessons were to appreciate the health and life that you do have, and to make the most of it. Simply that, “We don't know how long we are here, and you have to enjoy every moment” (female, 67 years old). Wanting to experience new things (e.g., travel), follow through on goals (e.g., apply for a promotion that one has put off), and enjoy both daily pleasures and big life events alike were all part of ‘living life to the fullest.’ The meaning and fulfillment of this goal to live a full life was relative to different factors, including one’s age, physical and mental well-being, motivation, and

resources. For instance, one participant with more severe side-effects following treatment for prostate cancer stated:

Once you get back to a state of health and you have your, your energy back, again you have a sense of, don't waste your energy. You know, you now have the energy and you knew what it was like to not have the choice... It's not a, "Oh, the sand is running out of my hourglass." It's just sort of, there are more important things to do in life, to enjoy or to experience than to just be passive. (Male, 60 years old)

"It helped me to live day to day... 'cause yesterday is gone, right? Tomorrow doesn't exist yet. And you can only make that as good as you are today," was another reported lesson resulting in planning life less, because, "Really at the end of the day, we're all going to the same place, right?" (male, 59 years old). Meanwhile, another participant noted that it was important for them to live in the present while also continuing to make long-term plans.

As with life and health, many participants ($n = 9$) discussed the impactful newfound awareness that time is a finite and precious commodity. This is best summarized by the following quote: "Our priorities change a little bit. 'Cause time is all we have, right? You don't own anything. You don't have anything. You have time, is what you have" (male, 59 years old). Another woman called each new day "a gift." Similarly, others had become more conscious about not "wasting" time. Ideas about what constituted "wasting" time differed, with some participants feeling happy in allowing themselves to do less sometimes, while others had the sense that they needed to say "yes" to more experiences. Another participant stated that she gained a better sense about how she would prefer to spend her time, and this allowed her to be "pickier" and say no to experiences and people, like the book club where others always chose books she did not want to read. Ultimately, she noted, "I realize now how much I value time. I

value time more than I ever valued it before. And my own personal time. And I don't feel guilty now, saying 'no, I don't wanna do something.' I don't explain myself anymore" (female, 38 years old).

This idea of protecting the "short" amount of time one has been given was shared by others. Unsurprisingly, many participants ($n = 11$) were spurred into action following this realization and acceptance of the finiteness of time, whether that was to be mindful of their health, spending their money, reaching out to people, pursuing longstanding or new goals, and engaging in more self-care and enjoyable activities alone and with loved ones. "Permitting" oneself to do things, giving oneself "a break," "postponing less," and "seizing the moment" were some of the reported changes made. With respect to the motivation to act and maintain changes, one participant explained:

Everything that I've spoken about I sort of – I incorporate now in my life. And you have to, you know? These are all lessons learned through a difficult experience, so it's a shame not to, you know, not to incorporate them into, you know, the years ahead. It would be such a – it's a waste of all this pain and agony that I've gone through, and all this new insight that I have, not to, you know, not to incorporate that into, you know, the years ahead. So for sure I would want to do that. (Female, 62 years old)

Living Forward with Appreciation

From these profound realizations about mortality and impermanence came alterations in attitude and focus in terms of how to move forward with life for 26 of the 27 participants. A number of participants ($n = 8$) referred to their experience with cancer as a "bump in the road" or a "speed bump" that had temporarily slowed them down or caused a brief interruption in the 'normalcy' of their life. As one woman noted, "This is an obstacle that I have to overcome and I

will and that's it, this is like a bump, this is like a year in my life.” One participant spoke about their aim to return back to life as it was: “I think, you know yes it's been tough and it's been a health hiccup, but I, I wrote my goals up for 2019, and they're back to the same goals I started with in the pre-diagnosis you know” (female, 38 years old). Speaking to the temporal nature of the change, one 41-year-old woman explained:

You know, just gotta enjoy life. Life is short. When you think about it, one word can change your whole life. You know, it's big. It's temporary, but it's still, it changes your life, right?... You live a different life for about a year but then, when you are done, you want to go back to the way your life was before that.

The desire to return to a “normal” or a “new normal” life was pervasive ($n = 12$). In terms of the ‘how’ of moving forward, one 67-year-old man stated, “Pretty much the same as I was, but you know, you could try to make the most of each day the best you can.” Participants saw themselves getting back to “life as usual” by, for example, enjoying their hobbies and spending time with loved ones. For participants whose treatments caused more side-effects, physical improvements were key in order to be able to resume their normal activities. Regaining a sense of normalcy to themselves as a person and to their lives was central to coping with and moving past the “speed bump” that was their cancer diagnosis.

Simply moving on, as opposed to getting stuck in the past, and enjoying life to the best of one's ability was the greatest takeaway for some participants ($n = 7$). One person stated, “One of the things I learned is looking back and dwelling on anything that has gone wrong is really counterproductive and it really takes you away from the reality of what's going on tomorrow or today” (male, 79 years old). In order to move forward, one woman noted learning that, “You just have to let it go and move forward... The way I see it best it's just another chapter in my life...

The world is not gonna stop for anybody. So my life can't stop because I had cancer.” Focusing on ‘filling out bucket lists,’ not being afraid to fail, and becoming more proactive and spontaneous were other changes highlighted. A few participants ($n = 4$) spoke about countering self-created barriers by loosening self-imposed constraints; in other words, “taking the pressure off” and not falling into self- and externally-imposed ‘should’ or ‘have to’ traps.

A number of changes in attitude and outlook reportedly served people well with respect to the intention to make the most of one’s time. Increased gratitude ($n = 9$), appreciation ($n = 7$), and acceptance ($n = 14$) were widely shared sentiments. “I’m just more grateful and appreciative for every day... It just makes me more grateful I think and appreciative of, of what I have and I don't take things for granted like I used to,” is one variation of a common lesson, with this one noted by a 71-year-old retired social worker. Another participant, who had suffered from depression throughout her life stated:

I probably am just more grateful to be alive [laughter]. But I sometimes used to, well especially when I was up and down with depression I used to say, “Ah, life isn’t really worth living. What are we really here for?” So I guess now when you’ve had that, because I remember one night when I couldn’t sleep I guess I was praying and I even wrote [laughter] in my diary, “God, I’m ready to be with you but I don’t want to leave my husband and my family. I realize how much I value life.” And I guess in that way it’s made me realize how precious life is, so I guess sometimes I wasn’t always totally appreciative of it. (Female, 74 years old)

Similarly, another participant described his newfound attitude toward life: “It has changed my life dramatically. Absolutely. I celebrate each day more now. I appreciate each day” (male, 54 years old). In addition to appreciating life, many participants ($n = 7$) mentioned appreciating their

luck, commonly with respect to their treatment outcomes, as well as all of the good things they already had in their life before cancer. Often this appreciation and gratitude was influenced by seeing others around them in the hospital with much worse conditions and prognoses. When asked what about his cancer diagnosis and treatments led to his increased gratitude and appreciation, one participant answered, “Well it makes you look inward for sure... Cancer is very much just the facts, which I like. I like the bottom line. And so it forces you to get to that bottom line pretty quick,” with the bottom line being that “you live or die” (male, 59 years old). Several other participants reported also being primarily thankful that they did not die of cancer and were given a sort of ‘second life.’

Acceptance was another major obstacle and eventual achievement reported by more than half of participants ($n = 14$), which came at different points in their cancer journeys. The same 59-year-old man likened accepting the possible outcomes of a cancer diagnosis and treatment with those of jumping out of an airplane:

Well an analogy, one comparison I made, and I thought about it, and it helped me to just get on the path and go – feel optimism, good about it – I used to go skydiving when I was younger. And I remember the first few times I jumped... you’re jumping out of an airplane, right? So I needed to really get myself right with that... So what I thought of I said well, ‘I’ve had all the training... I understand my equipment, but if something, you know, f’s up and I can’t fix it, I’m gonna die’... So... you have to rationalize... Here we go, right, ‘cause you don’t know at the outset, right? You only know you have a diagnosis; you only know that cancer’s a killer... So, I thought about that and my mindset, and I thought okay, you know? Something happens here... so get, get okay with that.

This example hints at the idea of accepting one's lack of control over some outcomes and being at peace with what may come in the future, as more explicitly stated by this 69-year-old woman:

We aren't in control, control totally of our lives, and I think that's another problem, we want to be in control of everything, about our lives, and I've had to let that go. Because certainly, I couldn't control this cancer thing or the treatments, or how I responded. I couldn't control any of that. So you just have to accept it, do it, go with it, and just hope you'll get through it. Which I think I have, I hope. Hopefully it won't come back.

Newfound acceptance showed up in many ways, from accepting being an “observer” of life and society for a limited time while healing, to learning to live with the side-effects of treatment and bodily changes. On the other hand, some participants continued to struggle with the sense of “unfairness” related to being diagnosed with cancer or the fact that the cancer may recur in the future.

Living a Healthier Life

In the spirit of living forward and making the most of one's time, there was an increased awareness and motivation to live in a healthier way. A few participants spoke about being more careful with their health ($n = 3$), not just in terms of factors related to their cancer diagnosis, but about physical and mental wellbeing overall. For example, one participant spoke about driving slower and drinking less, while another mentioned being more mindful of applying sunscreen regularly. In this way, participants took charge of their health and aimed to prevent future health issues. In addition to physical wellbeing, another participant reported realizing the importance of nurturing her psychological wellbeing after her diagnosis, stating, “be[ing] careful means now don't worry much. Lots of stress, lots of worries will mean crazier sickness.” Other concrete changes included various types of lifestyle modifications. For example, a 71-year-old woman

highlighted the positive changes she had made following completion of her treatment: “I’ve had more positive things come out of it... I changed my diet, I’m in an exercise program now... Not, not that I wasn’t doing that before, but it’s become more important to me now.” She later noted, “I feel very confident that I’m going to move forward and just be healthier than my former self, yeah and be more grateful. That’s the big thing for me, it’s just gratitude for everyday and... I get up in the morning and I’m really positive, I’m going to get out there and move,” highlighting the connection between being physically healthier and gratitude for being alive and well. Greater awareness *and* implementation of healthy lifestyle choices were some of the main shifts experienced by these participants.

Empowering Ourselves and Others

A number of participants ($n = 11$) identified changes in their perspectives about cancer as a disease and about the healthcare system overall, which instilled faith in their ability to heal, and consequently to be able to make the most of the ‘time they have left,’ and prompted them to share helpful lessons gained through their experience with others. Firstly, a few participants ($n = 4$) reported realizing that cancer is ‘the norm,’ as it affects so many more people than they had realized – “Everybody you talk to, everybody knows somebody that has cancer or has been going through cancer.” This included people in their lives that opened up about their own cancer journeys after the participants disclosed their diagnosis. Following his treatment for squamous cell carcinoma, which had spread to his lymph nodes, one participant described the shared understanding and camaraderie between cancer patients:

Having your eyes opened or having stuff happen to you, it helps you to be grateful, to have compassion for others. I think that’s why, I look at people who have cancer or who had cancer, there are no defences with other people who had it or have it. Right,

it's a closed group. I didn't know that up until I had cancer and began meeting people who were in the same boat. Even people who have been cancer-free for 15, 20 years. And often times, often times they can spot you in a crowd. (Male, 59 years old).

While a couple of participants expressed coming out of treatment with concerns about the way the medical system is set up and functions, more participants ($n = 7$) reported having an increased understanding of and sense of security in the healthcare system and providers. For example, one participant noted that, "the overall medical system, it's more efficient than I thought that it was." Another participant explained that their experience helped them to see an important side of medical professionals and other people in general:

Individual people coming and greeting you and saying hello and always being friendly, I mean it's, its pretty incredible... and I also have a lot more faith in people I think, like it's something where just because of the outreach that I had towards me with what I went through is so positive, that's kind of changed my perception of people's mindset a little bit... people were just very sympathetic and empathetic. (Male, 51 years old).

A third important realization participants ($n = 7$) highlighted was that their, as well as society's, view of cancer as a "death sentence" is not always correct and may even be a harmful assumption that many people still hold. As one participant explained, "It's a terrible disease, but it can be overcome. I think we've come a long way medically, and [in the] science field, that cancer isn't as scary a word as it used to be" (female, 51 years old). There was an overall sense of wanting to share vital information which could help future patients, as described by another 56-year-old man who was treated for rectal cancer:

I appreciate a lot more in terms of like what actually happens, so these are the insights I gained... There's treatment, yeah. I think that's the message people need to hear up

front... Because if I don't have cancer why would I pay attention to, worry about the statistic of like cancer treatment cure rate, survival rate. But if you're involved – involved like you are actually a cancer patient, then you start to look at those numbers, right? And then doing treatment, and then you go, 'Oh, it's not too bad.' It is the positive aspect, and also the motivation during the treatment cycle, right?... If you feel like you're, you know, you're losing [the] battle, and there's no light at the end of the tunnel, then you might lose your motivation to continue, right? But if you believe in it, right? Then even though you have some tough side effect then you say, 'You know what? It's expected. Few more weeks I'll be fine.' (Male, 56 years old).

This belief/attitude was one way in which the participant could maximize their – and potentially future patients' – precious time; that is, by spending less time being overcome by fear and more time feeling hopeful and planning for a future beyond cancer. The desire and responsibility to spread awareness about prevention and treatment options (e.g., vaccinations, screenings, etc.), as well as messages of hope, was shared among some participants ($n = 4$), as exemplified by the following quote:

The saying is 'You never know how strong you are until being strong is all you have.' So it's one of those things where you get pushed to the limit and to get through that – it's an accomplishment to get through that... One thing I want to do is to show my kids, that I have a 20 year old and an 18 year old, I wanted them to know if they got diagnosed with cancer, that there is a good chance that with our family history that they will, is that you can fight it and you can get through it. That was always on the back of my mind, to be extremely positive and to show that it can be manageable. (Male, 51 years old).

Indeed, as previously stated, this drive to help others was one of the primary reasons why individuals volunteered to participate in this study.

As evidenced by the above categories, participants were challenged by a number of realizations about time and mortality and consequent questions with respect to their sense of security and previously held assumptions about life and time. Many also underwent a number of alterations in their perceptions of self and their identity, either in becoming an 'updated' version of the person they were before, or by feeling as though they were a whole new person. Outlook on their relationships, priorities, and how to live life were also transformed following their confrontation with cancer. Participants were, in turn, inspired to live life in a meaningful way that would incorporate these changes and allow them to move onward to a new normal.

Chapter 5: Discussion

The posttreatment juncture, during which individuals who have been diagnosed with cancer straddle the line between their identity as a ‘patient’ and a ‘survivor,’ is known to be one of pronounced distress (Hewitt, Greenfield, & Stovall, 2006; Rowland et al., 2006). However, far less attention has been paid to this phase in the field of psychosocial oncology both in terms of understanding needs and providing support. As such, the current investigation sought to implement and evaluate the acceptability and effectiveness of a narrative care-informed intervention in the form of a semi-structured interview, the aims of which were to guide individuals through a narration/telling of their cancer journey, with prompts to reflect upon significant facets of their experience, identify challenges and new learning, and be left with a sense of being heard and understood. In addition to evaluating the acceptability and effectiveness of the intervention, of particular interest was to better understand the changes in self, life perspective, and outlook on relationships which participants perceived to have occurred as a result of their confrontation with cancer.

Results from the Treatment Satisfaction Questionnaire, as well as invitations to comment on and provide feedback at the end of the NCI itself, indicated that the intervention was acceptable to participants, was generally reported as helpful and beneficial, and was recommended as an option for other patients to participate in, if desired. Overall, even participants who did not report any immediate personal benefits gained from the interview conveyed a belief that it could be helpful to others, and that they were therefore pleased to have participated as an act of altruism and contribution to improving the healthcare ‘system.’ Several participants highlighted the perceived lack of easily accessible psychological support available to cancer patients during and immediately following cancer treatment, with some participants

noting a significant gap in care with respect to their psychological wellbeing, in favour of a much greater emphasis on medical outcomes and physical wellbeing. A couple of participants directly spoke about not having been given opportunities to narrate, or to discuss at greater length, different aspects of their cancer journey and life overall during any of their appointments, which they believed would have helped them to cope, or to be directed to appropriate resources. These findings add to the evidence supporting the importance of incorporating narrative into medical care, in order to help individuals make sense of and integrate the oftentimes painful and traumatic experience of having been diagnosed and treated for a life-threatening illness such as cancer (Charon, 2001; Pennebaker, 2000). In fact, while the majority of participants in the current study were well-adjusted and did not report high levels of anxiety, low mood, and other significant physical and psychological difficulties following their treatments, they reported feeling worried about the many other individuals they encountered during their various hospital appointments and treatments who appeared to be faring much worse, in particular those who seemed to have less social support and/or resources.

One of the reported benefits of the NCI, which was also one of the initial goals when creating the intervention, was that it allowed participants to comfortably express themselves and to feel heard and understood. As described by Charon (2001), narrative is inherently crucial to the provision of medical treatment because the act of helping a patient requires the provider to listen to and make sense of the patient's illness story by incorporating their symptoms, personal history, test results, fears, and other psychological aspects of functioning into a coherent narrative; in turn, this "narrating of the patient's story is a therapeutically central act, because to find the words to contain the disorder and its attendant worries gives shape to and control over the chaos of illness," and can therefore be a "transformative" act in itself (Charon, 2001, pp.

1898). In terms of psychological wellbeing and support, narrative is thought to help rebuild a sense of coherent identity, meaning, and order after these have been disrupted by illness (Crossley, 2000). Together, these findings suggest that a narrative care-based intervention such as the NCI could help fill the gap in support for patients, especially during the posttreatment juncture, in addition to encouraging narrative care to become an underlying part of the provision of medical treatment.

A second finding which supports the value of offering the NCI to interested individuals was that a significant improvement was found in terms of social wellbeing following the NCI when compared to before the interview. This finding is important in light of the wealth of literature highlighting the value of having good social support once confronted with cancer, both in terms of good psychological adjustment and even assuaging disease progression (Brandão, Schulz, & Matos, 2016; Gonzalez-Saenz de Tejada et al., 2017; Nausheen, Gidron, Peveler, & Moss-Morris, 2009). One explanation for the improvement in perceived social wellbeing is that the NCI provided participants with an opportunity to reflect upon and realize their social needs and the extent to which the people in their life supported and cared for them. In fact, one of the fuller sub-categories (comprised of 20 codes and four clusters of codes) which emerged from the grounded theory analysis with respect to changes experienced following cancer diagnosis and treatment was *re-valuing and deepening relationships*, which alluded to the notable impact of participants' cancer journeys on their relationships, both in terms of altered perception/attitude (e.g., feeling loved, having increased patience for others) and actual behaviour (e.g., forgiveness, engaging in altruistic acts, spending more time with loved ones). While these realizations and changes of course could have presented themselves and been articulated without participation in the NCI, it is possible that the interview may have helped to deepen and bring them to the

forefront, and in so doing solidified the changes in participants' perceptions of their interpersonal relationships. Considering that a number of participants reported realizing at the end of the NCI how important it is to share one's experiences and difficulties with others, some even calling it "cathartic," and feeling motivated to engage in further storytelling and/or discussions moving forward (e.g., by talking to their friends and family, joining support groups, seeking further psychological support/treatment), it is also possible that some individuals actually acted upon these realizations/intentions following the interview and thus noticed improvements in their social well-being.

The grounded theory analysis conducted in the current study also contributes to the wealth of research which demonstrates that being confronted by an illness such as cancer is a significant life disruption which has the power to change one's sense of self and way of life, even during the transitional phase between active treatment and the return to a 'new normal' life. Indeed, participants identified numerous changes in terms of themselves, their life perspective, and their outlook on relationships, which were already apparent in their awareness and lived experiences soon after they had completed their treatments for a primary cancer, often even before having conclusive results about the efficacy and outcomes of their treatments. These changes were represented by the core category of Transience as a Catalyst for Change, which consisted of three main categories, namely Woundedness and Healing, Refining and Solidifying Identity, and Maximizing Time. The core category, or theory of change, highlighted the impact of confrontations and realizations arising from one's experience with cancer about the nature of life, health, and time, in that none of these precious commodities are permanent and must therefore be treated as 'gifts' to be savoured while they still exist.

Participants spoke about feeling raw and vulnerable following their treatments for various primary cancers and grappling with the *hopefully* temporary psychological difficulties and bodily changes, while striving to maintain hope as a means of helping them to ultimately move forward with their lives. The difficulty in doing so, as well as the mindful effort required to remain hopeful for some participants relates to the concept of liminality, or the uncertainty experienced during transitional phases of life (Dauphin et al., 2020). Liminality first emerged as an anthropological concept to describe the experience of undergoing a ‘rite of passage,’ or transitional period during which one acquires a new social identity or status, such as becoming a parent, and was characterized by three stages – the first being a break from one’s previous position/role, the second being the ambiguous transitional phase, and the third being entry into one’s new position/role (van Gennep, 1960). During the middle, or liminal state, one is described as “being on the threshold of both the old and new, as being in an interim state, thereby positioning them in a state of ambiguity” (Dauphin et al., 2020, pp. 358).

Within the field of cancer research, liminality has been viewed as an ongoing state between being ‘ill’ and ‘well,’ as opposed to being comprised of three separate stages (Little et al., 1998), indicating the significant impact of having had cancer on one’s sense of self. In one investigation looking at accounts of individuals with a history of colorectal cancer, the concept of “cancer patientness” was used to describe the finding that regardless of time passed since treatment completion, individuals positioned themselves and spoke from the perspective of cancer patients whose daily lives were forever altered by their diagnoses (Frank, 1995, pp. 1486). This idea is particularly relevant for individuals who have recently completed treatment and are likely still processing their experience, formulating their ‘new’ identity as a cancer patient/survivor, and devising a path forward. In the current study, many participants spoke about

the belief that they were forever changed in significant ways, even if they could not clearly understand or articulate those changes yet. Some participants also explicitly used the phrase “new normal” to describe their search and goals for a path forward, which has previously been described in the literature as a means of “rebuilding one’s identity and accepting that everyday life will never be quite the same” (Rees, 2017, pp. 244; Denford et al., 2011; Sherman, Rosedale, & Haber, 2012; Trusson, Pilnick, & Roy, 2016). The eagerness to return to a sense of normalcy and routine makes sense in light of previous research indicating that this normalcy is one way to feel a sense of security and purpose (Salander, 2018), and to cope with uncertainty by ascribing meaning to everyday events (Folkman, 1997).

The concept of liminality also relates to the idea of biographical disruption (Bury, 1982), in that one’s life story is often interrupted and broken up by a cancer diagnosis, forcing the individual to live in a sort of limbo until their treatments, tests, and results are completed and known, at least for a while, though for those with pronounced fears of recurrence, distress can last much longer. In the times between the treatments, testing, and outcome appointments there is a great deal of waiting and living with uncertainty, which, according to Mishel’s theory on ‘uncertainty in illness,’ hinders one’s ability to make sense of what is happening to them (Mishel, 1988). In light of these challenges, it is promising that participants in the current study were able to thoughtfully engage in a process of reflection throughout the NCI and to identify a number of alterations within themselves and their lives, suggesting that a process of meaning-making may have been occurring. This finding provides further support for more recent findings which indicate that individuals can cope with uncertainty through meaning-making, especially in the posttreatment period of cancer (Dauphin et al., 2020). In fact, in Dauphin and colleagues’ study (2020) it was discovered that individuals in the posttreatment period still struggled with

coping with uncertainty, but placed a greater emphasis on an “active search and need for closure of the illness trajectory and return to normal life” (pp. 361).

Indeed, despite experiencing some of the well-documented challenges like treatment side-effects and fears of recurrence, many of the participants in the current study focused on reflections about the importance of having an optimistic attitude, as well as a variety of other beneficial changes in their sense of self, outlook on life, and behaviours following their confrontation with cancer. These findings demonstrate the potential influence of the NCI in having encouraged engagement in some of the beneficial processes discussed in Chapter 1, such as adaptation to a biographical disruption through the construction of a new reality and identity (Bridges, 2004; Selder, 1989), establishing a sense of purpose (Krause, 2009), benefit-finding (Folkman, 2008), and posttraumatic growth (Tedeschi & Calhoun, 2004; Hoogland, 2018). Changes in and/or refinements of one’s identity and sense of self were also significant in the current study and are in line with past characterizations of similar concepts, including identity reconstitution (Corbin & Strauss, 1988), restructuring the self (O’Connor, Wicker, & Germino, 1990), reconstructing the self (Loveys & Klaich, 1991), reformulation of self (Morse & Carter, 1996), and reformulation of identity (Fife, 1994) following cancer diagnosis and treatment. It is interesting that the process and outcome of identity change was existent soon following the end of participants’ treatments, who were diagnosed with a wide range of cancer types, despite several participants noting that they were just coming out of a ‘survival mode’ during which they were focused on doing just that – surviving day to day – and did not have much opportunity to reflect upon the gravity of their situation. Interestingly, participants in the current study shared similar types of identity transformations and narratives as those previously described by three breast cancer patients two to five years after their diagnoses, including one where the individual

described experiencing a temporary interruption to the ‘old self’ by the ‘sick self,’ one where the individual felt like an entirely different person five years after their diagnosis, and one where the individual described themselves as a “self in progress” (Shapiro, Angus, & Davis, 1997, pp. 545).

Though the initial aim of the NCI was not specifically to prompt or emphasize identity changes but rather to provide an opportunity for narration and reflection, it does appear to have aided the process of self-transformation, or what Corbin and Strauss have previously called “biographical work” (1988, pp. 69) – at least from the perspective of participants themselves. The focus on guiding participants through a narration of their experience is likely to have had a role in this self-transformation. According to Ochs and Capps (1996), the self and narrative are inextricable because narrative equally emerges from experiences and gives shape to experiences. In fact, one prior model of self-development highlights the importance of storytelling as a means of achieving change and stability in one’s sense of self (McLean, Pasupathi, & Pals, 2007). Storying is a way to express one’s narrative identity, or “a person’s internalized and evolving life story, integrating the reconstructed past and imagined future to provide life with some degree of unity and purpose” (McAdams & McLean, 2013, pp. 233). In turn, narrative identity, particularly when individuals have found meaning in difficult life events, is connected to improved wellbeing and mental health (McAdams & McLean, 2013).

For many participants, the confrontation with one’s mortality and related recognitions about the impermanent nature of health and time were the most prominent changes in outlook on life and subsequent driving forces of change in attitude (e.g., increased gratitude) and behaviour (e.g., reprioritizing self over others, or vice-versa). Importantly, there was an overwhelming sense of wanting to ‘make the most of one’s time,’ and to live a full life in the way one wants to

live it, whether that be to do less or to do more, depending on who the individual was before (e.g., work-driven; hesitant to take risks). This discovery is consistent with previous findings suggesting that self-transformation results from an increased awareness of one's mortality (Coward, 1990), which is subsequently followed by increased self-reflection, awareness, and implementation of changes to one's life and relationships in order to express their new sense of self (Carpenter, Brockopp, & Andrykowski, 1999). While participants noted some expected challenges, particularly so soon after treatment, such as treatment side-effects, uncertainty about upcoming appointments, and fears of recurrence, a majority also reported experiencing and hoping to focus on useful lessons/changes, as opposed to pervasive negative states such as death anxiety, which Yalom (1980) has characterized as a primitive, inescapable dread of nonexistence.

Prior views of death anxiety have centred around the notion that humans must deny death because the idea of not existing is too terrifying (Iverach, Menzies, & Menzies, 2014); however, the ability to use the strategy of denial is 'taken away' once diagnosed with an illness like cancer, thus prompting a reckoning with one's existence and eventual nonexistence. For some individuals, this can result in existential distress, or a painful state which arises following "a stressor that challenges fundamental expectations about security, interrelatedness with others, justness, controllability, certainty, and hope for a long and fruitful life" and can lead to a number of negative mood states (Vehling & Kissane, 2018, pp. 2526). However, more recently the idea that traditional views of death anxiety likely do not fully capture the experiences of cancer survivors has emerged (Vehling & Kissane, 2018). This perspective is consistent with the present study's findings. One recent study found that a reduced sense of purpose was one of two main predictors of increased death anxiety in cancer patients (with the other being fear of recurrence)

(Tang et al., 2011). Importantly, in the current study, most participants did in fact articulate a number of established and/or newfound life purposes. It is important to note that many of the previous studies on these topics were conducted with patients with advanced cancer, while all participants in the current study were diagnosed with a primary cancer. This may help to explain some participants' reported wishes to spread a message of hope, for example that cancer is not a "death sentence" anymore, which contrasts widespread public perceptions (i.e., of individuals who have never had cancer) of cancer and related fears (Robb, Simon, Miles, & Wardle, 2014).

It appears that once the realization that health and time are transient was impressed upon participants, they were prompted to alter their sense of self and the way they do things in a beneficial way. This process had undoubtedly begun for many individuals before participating in the NCI and was indeed evident in their storytelling during the interview. This finding is related to one of the propositions of terror management theory, which aims to explain death anxiety, that impermanence drives a great deal of human behaviour and motivates humans to engage in defensive behaviours to cope with fears about nonexistence (e.g., engaging in healthy habits, suppressing thoughts about death, seeking meaning, relying on social relationships/support) (Lepore & Helgeson, 1998; Pyszczynski, Greenberg, & Solomon, 1999; Sharpe, Curran, Butow, & Thewes, 2018). More beneficial coping strategies such as meaning-making are thought to occur once mortality salience and the threat of dying are more distant (Sharpe et al., 2018), as it did in the current study, further away from diagnosis and after treatment had been completed.

Limitations

First and foremost, it is important to note that many of the participants in the current study were relatively well-adjusted and did not report high levels of psychological distress, including depression and anxiety, neither before nor after participating in the NCI. It is thus

possible that this may account for the lack of significant changes found in terms of the outcome measures examined, including affect, life satisfaction, and self-efficacy. It is also possible that the findings of the grounded theory analysis were skewed in a way that overestimated the prevalence of beneficial changes (e.g., positive outlook toward life) and underestimated the prevalence of adverse changes (e.g., death anxiety) within the broader population of individuals with primary cancer during the posttreatment juncture. This notion potentially illustrates a self-selection bias in the types of individuals who volunteered for the study, with those who experienced more challenges during and soon after their treatments not being willing to participate. In fact, during recruitment, several individuals declined to participate in the study due to their lack of desire or energy to visit the hospital for any extraneous appointments so soon after being there, in many cases daily, for several weeks prior (because most of the participants were recruited at their final radiation appointments). Furthermore, while a wide range of cancer types were represented in the current study, there could have been greater diversity in this and other characteristics, such as socioeconomic status.

Another explanation for the lack of change in terms of most outcome measures examined could be related to the attrition in participants in terms of completing the follow-up questionnaires. Perhaps those who were faring worse or did not like the NCI did not have the time, energy, or desire to complete the post-interview questionnaire battery. Moreover, it could be the case that the one-time interview was not enough to initiate a change in some of the more complicated aspects of the human experience, such as perceived life satisfaction and meaning, or that these changes could not occur within a mere two weeks following the interview. It is probable that individuals would continue to engage in reflection and refinement of their cancer

narrative long after their treatments and follow-up appointments are over. The interview was also not designed as ‘therapy,’ which could have lessened its power to create change.

Another limitation of the study, which could have skewed the finding that there was a moderate improvement with respect to social well-being following the NCI, is that six individuals did not complete a question about their sexual functioning on the social well-being scale before the intervention. Upon further examination, it was discovered that those six individuals were older, closer in proximity to the end of their treatments, had lower positive affect, and had lower functional well-being than participants who did answer the question. It is thus possible that they were fairing worse in this domain, and had they answered the question, the average pre-intervention scale score would have been lower. Lastly, the current study did not follow a true grounded theory analysis method, in that all participants were interviewed before analysis began and it employed a contained theoretical sampling strategy, as opposed to recruiting participants in tandem with an ongoing analysis with emergent findings informing future sampling (Glaser & Strauss, 1967). However, great effort was made to attain a diverse sample which would represent a broad range of cancer types and experiences.

Implications, Future Directions, and Conclusion

The current study adds to the mounting evidence in support of incorporating narrative care into medical settings as a way of addressing mental health needs alongside treatment of disease, in particular during the posttreatment juncture. As highlighted by participants, the findings further bolster the importance of addressing patient needs holistically by focusing on psychosocial support as much as on medical outcomes. The current study suggests that narrative care could benefit individuals especially in terms of improving their social wellbeing and outlook on relationships, as well as to aid in the process of meaning-making, establishing a coherent

sense of self, adopting a beneficial outlook toward their life, and creating a coherent narrative that incorporates their cancer experience into their larger life story. In contrast with prior research which has tended to focus on one type of cancer, the current investigation incorporated the experiences of individuals with various cancer types and found that they shared common concerns and processes of self transformation.

Future studies should focus on how narrative care could be better incorporated into medical and psychological care for cancer patients/survivors, especially those who are more distressed or have fewer social support and/or resources. One way to do this could be to screen for individuals who are more distressed before enrolling them in interventions which aim to help participants create and articulate a coherent narrative about their experience. It is important to find ways of engaging more distressed and high-need participants, for example by offering options for remote participation in mental health support and research studies via telephone or Internet. Encouraging patients' existing healthcare team members to offer opportunities to participate in supports might also be beneficial. Other options are to train healthcare providers, including medical and mental health professionals, in principles of narrative care, such as providing space and time for individuals to share more about their life, their experience with cancer, and how these two domains intersect.

Furthermore, it would be interesting to examine varied factors, such as personality characteristics and previous life experiences, which might influence the extent to which different individuals experience transformation following a cancer diagnosis. One of those factors in the current study appeared to be the existence of previous health conditions or confrontations with major illness; individuals with such prior experiences appeared to be less impacted by their current cancer diagnosis in terms of significant changes in self and way of life, though this was

not studied systematically. It would be worthwhile to continue modifying and evaluating existing narrative-informed interventions like the NCI in order to find better ways of helping individuals integrate their experiences with cancer into their life narratives. For instance, the current intervention's effectiveness and ability to improve participant outcomes might be increased by having more than one session or having more input/guidance from the interviewer with an approach more akin to therapy. It would also be valuable to further investigate the mechanisms of how participants engage in processes such as posttraumatic growth and meaning-making, and whether something like narrative therapy can aid in these processes.

The current study provided a deeper understanding of how participants with varied types of primary cancers perceived themselves, their life perspectives, and their outlook on relationships to have changed soon after having completed their treatments. It was discovered that while still vulnerable following their confrontation with cancer, and consequently death, most participants remained hopeful and were motivated to make sense of the experience and then to move on. A key aspect of their path forward was making the most of their time and living life in the way they want to live it. Participants indeed reported appreciating the space and opportunity to share and reflect upon their cancer journey during the NCI. The current study affirmed the notion that the transitional phase following treatment for primary cancer is one of significant change and necessary integration of one's past, present, and future. Overall, the study's findings indicated that individuals during this juncture may benefit from the opportunity to narrate their cancer journey and path forward.

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Appendix A

Recruitment Script

Hi, my name is _____ and I am a research assistant at the Patient and Family Support Program. I want to talk to you about an opportunity that we have for patients who are finishing their treatments to have an ‘end-of-treatment’ conversation with one of the staff members from our Patient and Family Support Program about their experiences. We are also evaluating this program so there would be some questionnaires to complete before and after the interview. Is this something you might be interested in?

If yes: *Great. Do you mind if I give your name and telephone number to the program coordinator so she can provide you with more detailed information about the study?*

- ➔ Write down name and telephone number on ballot
- ➔ Give flier

If maybe: *I can give you a flier with more information and the research assistant’s contact information. You can call or email if you have any questions or decide that you might want to participate.*

- ➔ Give study flier

Basic info to know:

- “The interview includes questions about your experience with being diagnosed, going through treatment, and looking forward toward life beyond cancer”
- Benefits:
 - Might benefit you to have someone listen to your experience and potentially help you process it
 - Can help us evaluate the interview and make it better so that it can help others in the future
- The two pre-post treatment questionnaires take approximately 30 minutes to complete
- Study is being done to evaluate this end-of-treatment program, which is why they’re asked to complete questionnaires before the interview and two weeks after the interview
- Participants will receive compensation for parking for visit to Sunnybrook for the interview
- Eligibility criteria:
 - Primary cancer (non-metastatic)
 - Done all primary treatments (radiation, chemo, surgery) in the past 2 years

Appendix B

Narrative Care Study Informational Flier



A Research Study:

A Narrative Care Interview to Support
the Post-Cancer Treatment Transition
from Primary to Follow-Up Care

Purpose: To determine whether a single session transition interview aimed at discussing one's experience with cancer and its impact on oneself and one's life is of benefit to patients after they have completed primary cancer treatment.

Participants will be asked to complete two sets of questionnaires before and after attending a 90-minute interview at the Odette Cancer Centre. Total time commitment for this study is approximately 3 hours.

Eligibility: Patients who have completed their full course of primary treatment (including surgery, chemo, and/or radiation) for cancer within the past two years.

Contact: The Principal Investigator for this study is Dr. Karen Fergus, PhD, C.Psych. For questions about this study please call 416-480-6150, ext. 81447 or email the research coordinator at iana.ianakieva@sunnybrook.ca.



Appendix C

Telephone Screening

Screened By: _____ Eligible? Yes/No If No, reason: _____
 Date of Screen: _____

Participant Name: _____
 Email: _____
 Phone: _____

Mailing Address:

*Thank you for taking the time to speak with me today. During this time, I would like to tell you a bit more about the study and ask you some questions to make sure it's a good fit for you. If you have any questions, please feel free to ask at any time. In this study, we will be evaluating a one-session intervention that is meant to support patients in the time shortly after being discharged from treatment for primary cancer. If you agree to participate, in addition to attending an interview at Sunnybrook that will be about 90 minutes long, you would be asked to fill out a series of questionnaires at home about things like your mood and quality of life, before and after the interview. The interview will have questions about your experience during and after treatment, and how it has impacted your life. Does this still sound like something you might be interested in? **Yes/No***

*So first I would like to ask whether you attend any counselling or psychotherapy at this time? **Yes/No***

If Yes: *It is great that you have been able to find support and someone to talk to during this difficult time. However, because in this study we are evaluating an intervention that is designed to do this as well, we are unable to include you. If we did, we would not know whether to attribute any changes to the intervention or to counselling/therapy. Do you have any questions about that?*

If No: *Okay, next I would like to know some details about your cancer treatment:*

type of cancer: _____

Exclusion: Patients with metastatic disease.

type of treatment: _____
completed treatment: **Yes/No**
date of last treatment: _____

Exclusion: Individuals who have not completed all of their primary treatment (chemotherapy, radiation and/or surgery) within the past one to three months.

And lastly, do you have any difficulty with written English? Yes/No

If eligibility criteria not met: *Thank you for answering those questions. Unfortunately, you do not meet the eligibility criteria for the study. Explain why and thank individual for their time.*

If eligibility criteria met: *Thank you very much for providing that information. It looks like you meet all of the eligibility criteria for the study. Are you interested in participating in the study? Okay, so the next step is for me to send you a consent form that will explain the study in more detail, as well as your rights as a participant. It's important to note that you can withdraw from the study at any point and that this will not have any effect on your current or future health care or treatments. If you would still like to participate, please sign this consent form and mail it back using the included envelope.*

In about a week from today, I will follow up by email to make sure that you have received the consent form and that you have signed and returned it. If you have, I will then email you a link to the online survey which I will ask you to complete before coming in to Sunnybrook for the interview. If you have not received the form or had a chance to send it back to me, I will ask you to email me once you do so that I can send you the link to the survey.

Do you have any questions about anything? If not, we can now set up a time for the interview, about three weeks from now to make sure you have enough time to receive the consent form and complete the online survey. Set up date/time for interview.

Would you prefer a phone call or email to set up a time for the interview?

Date of interview: _____

If you have any questions or have to cancel/change the time or date of the interview, you can call me at 416-480-6150, ext. 90504 or email me at iana.ianakieva@sunnybrook.ca.

Appendix D

Narrative Care Interview

Illness period:

- Can you say a little bit about how you came to be diagnosed with cancer?
- What was going on in your life at the time?
- What types of treatments did you receive?
- What was the most challenging thing for you about having cancer? Going through the treatment?
- How did you cope with your illness?
- What helped with your coping (e.g., relationships, resources?) What made it difficult or more challenging?
- In hindsight, is there anything that you might have done differently?

Post-treatment reflection:

- How are you feeling now that your primary treatments (surgery, chemotherapy and/or radiation) are over?
- What is the most pronounced difference for you - between now and before you were diagnosed with cancer?
- How would you say that having cancer has changed *your life* (if at all)? *Yourself*? Your most important *relationships*?
- What do you see as your main challenge right now?

New learning/meaning making:

- Is there anything that could have been done to make your experience better/easier to cope with?
- Did you learn anything new about yourself through your experience with cancer? About your loved ones?
- Did you come to any new insights through this experience?

Orienting toward the future:

- How do you see yourself moving forward?
- Is there anything that you have learned over the course of your illness that you would like to take with you/apply to your life as you move forward?
- Is there anything I didn't ask about, or that you feel is important for me to know about your experience, that you would like to mention?

Appendix E

List of Study Materials and Questionnaires

Time 0: Telephone Screening

Time 1: Pre-Interview Questionnaires

1. Brief Resilience Scale (BRS)
2. Positive and Negative Affect Schedule (PANAS)
3. Functional Assessment of Cancer Therapy – General (FACT-G); Physical, Social/Family, and Functional Well-Being Subscales
4. Generalized Anxiety Disorder 7-Item Scale (GAD-7)
5. Cancer Behavior Inventory (CBI)
6. Patient Health Questionnaire (PHQ-9)
7. Satisfaction with Life Scale (SLS)
8. Perceived Personal Meaning Scale (PPMS)

Time 2: Narrative Care Interview (NCI)

1. Demographics Questionnaire
2. Interview

Time 3: Post-Interview Questionnaires

1. Brief Resilience Scale (BRS)
2. Positive and Negative Affect Schedule (PANAS)
3. Functional Assessment of Cancer Therapy – General (FACT-G); Physical, Social/Family, and Functional Well-Being Subscales
4. Generalized Anxiety Disorder 7-Item Scale (GAD-7)
5. Cancer Behavior Inventory (CBI)
6. Patient Health Questionnaire (PHQ-9)
7. Satisfaction with Life Scale (SLS)
8. Perceived Personal Meaning Scale (PPMS)
9. Treatment Satisfaction Questionnaire

Appendix F

Narrative Care Study Pre- and Post-Interview Survey Measures

Pre-Interview Instructions

The goal of this research study is to help us find out what is the best way to support people with cancer that end treatment and are transitioning back to day-to-day life. When you participate in this survey you will help us improve a narrative intervention (a written tool) to support patients who are transitioning out of treatment. This survey includes: Questions about your mood, coping with your diagnosis, and quality of life.

The survey might take 30 to 40 minutes to finish. Please take your time and answer each question as best as you can. Your feedback is important.

Please complete the survey before coming to Sunnybrook for your scheduled interview. Thank you for taking the time to finish this survey. Participating in this research study is your choice (voluntary). You have the right stop participating in this survey at any time.

Post-Interview Instructions

The goal of this research study is to help us find out what is the best way to support people with cancer that end treatment and are transitioning back to day-to-day life. When you participate in this survey you will help us improve a narrative intervention (a written tool) to support patients who are transitioning out of treatment. This survey includes the same questions as the baseline survey, and questions about your evaluation of the interview.

The survey might take 30 to 40 minutes to finish. Please take your time and give us as many comments as possible. Your feedback is important.

Thank you for taking the time to finish this survey. Participating in this research study is your choice (voluntary). You have the right stop participating in this survey at any time.

Questionnaire 1

| Please respond to each item by circling <u>one</u> number <u>per</u> row | | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|---|--------------------------|-----------------|----------------|--------------|-----------------------|
| BRS 1 | I tend to bounce back quickly after hard times | 1 | 2 | 3 | 4 | 5 |
| BRS 2 | I have a hard time making it through stressful events. | 5 | 4 | 3 | 2 | 1 |
| BRS 3 | It does not take me long to recover from a stressful event. | 1 | 2 | 3 | 4 | 5 |
| BRS 4 | It is hard for me to snap back when something bad happens. | 5 | 4 | 3 | 2 | 1 |
| BRS 5 | I usually come through difficult times with little trouble. | 1 | 2 | 3 | 4 | 5 |
| BRS 6 | I tend to take a long time to get over setbacks in my life. | 5 | 4 | 3 | 2 | 1 |

Questionnaire 2

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you felt this way in the **past 2 weeks**.

| | Very slightly or not at all | A little | Moderately | Quite a bit | Extremely |
|--------------|-----------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Interested | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Distressed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Excited | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Upset | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Strong | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Guilty | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Scared | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hostile | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Enthusiastic | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Proud | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Irritable | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Alert | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Ashamed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Inspired | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Nervous | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Determined | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Attentive | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Jittery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Active | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Afraid | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Questionnaire 3

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

| | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|-----------------------------------|---|---------------------------|-----------------------------|-----------------------|------------------------|----------------------|
| <u>PHYSICAL WELL-BEING</u> | | | | | | |
| GP 1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| GP 2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| GP 3 | Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| GP 4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| GP 5 | I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| GP 6 | I feel ill | 0 | 1 | 2 | 3 | 4 |
| GP 7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

| | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|--|---|---------------------------|-----------------------------|-----------------------|------------------------|----------------------|
| <u>SOCIAL/FAMILY WELL-BEING</u> | | | | | | |
| GS 1 | I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| GS 2 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |

| | | | | | | |
|---------|--|---|---|---|---|---|
| GS 3 | I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| GS 4 | My family has accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GS 5 | I am satisfied with family communication about my illness | 0 | 1 | 2 | 3 | 4 |
| GS 6 | I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |
| Q1 | <i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please <input type="checkbox"/> mark this box and go to the next section</i> | | | | | |
| GS 7 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

Please circle one number per line to indicate your response as it applies to the past 7 days.

| <u>FUNCTIONAL WELL-BEING</u> | | Not at all | A little bit | Some-what | Quite a bit | Very much |
|-------------------------------------|---|-------------------|---------------------|------------------|--------------------|------------------|
| GF1 | I am able to work (include work at home) | 0 | 1 | 2 | 3 | 4 |
| GF2 | My work (include work at home) is fulfilling | 0 | 1 | 2 | 3 | 4 |
| GF3 | I am able to enjoy life | 0 | 1 | 2 | 3 | 4 |
| GF4 | I have accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GF5 | I am sleeping well | 0 | 1 | 2 | 3 | 4 |

| | | | | | | |
|-----|--|---|---|---|---|---|
| GF6 | I am enjoying the things I usually do for fun | 0 | 1 | 2 | 3 | 4 |
| | | | | | | |
| GF7 | I am content with the quality of my life right now | 0 | 1 | 2 | 3 | 4 |
| | | | | | | |

Questionnaire 4

| Over the last 2 weeks, how often have you been bothered by the following problems? | Not at all sure | Several days | Over half the days | Nearly every day |
|--|-----------------|--------------|--------------------|------------------|
| 1. Feeling nervous, anxious, or on edge | 0 | 1 | 2 | 3 |
| 2. Not being able to stop or control worrying | 0 | 1 | 2 | 3 |
| 3. Worrying too much about different things | 0 | 1 | 2 | 3 |
| 4. Trouble relaxing | 0 | 1 | 2 | 3 |
| 5. Being so restless that it's hard to sit still | 0 | 1 | 2 | 3 |
| 6. Becoming easily annoyed or irritable | 0 | 1 | 2 | 3 |
| 7. Feeling afraid as if something awful might happen | 0 | 1 | 2 | 3 |

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all _____
 Somewhat difficult _____
 Very difficult _____
 Extremely difficult _____

Questionnaire 5

This survey will have questions about how confident you are around self-managing different issues and personal behaviours after cancer treatment.

- Please read each separate item.
- Circle a number on the scale that you agree with the most.
- If you circle #1 you are agreeing that you are “not at all confident” that you can manage the behaviour on your own.
- If you circle # 9 you are agreeing that you are “totally confident’ you can manage the behaviour on your own.
- Numbers in the middle of the scale like 4, 5, and 6 mean that you are only “kind of confident (moderately confident)” that you can manage the behaviour on your own.

Please rate all items by circling the most appropriate number below each item. If you are not sure about an item please rate it as best you can.

1. Maintaining independence

| | | | | | | | | |
|-------------------------|---|---|---|-------------------------|---|---|---|----------------------|
| NOT AT ALL CONFIDENT | | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

2. Maintaining a positive attitude

| | | | | | | | | |
|-------------------------|---|---|---|-------------------------|---|---|---|----------------------|
| NOT AT ALL CONFIDENT | | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

3. Maintaining a sense of humor

| | | | | | | | | |
|-------------------------|---|---|---|-------------------------|---|---|---|----------------------|
| NOT AT ALL CONFIDENT | | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

4. Expressing feelings about cancer

| | | | | | | | | |
|-------------------------|---|---|---|-------------------------|---|---|---|----------------------|
| NOT AT ALL CONFIDENT | | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

5. Putting things out of my mind at times

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

6. Maintaining activities (work, home, hobbies, social)

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

7. Trying to be calm throughout medical appointments and not allowing scary thoughts to upset me

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

8. Actively participating in care decisions

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

9. Asking physicians questions

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

10. Seeking social support

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

11. Sharing my worries or concerns with others

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

12. Managing nausea and vomiting (whether or not I have had these problems in the past)

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

13. Coping with physical challenges

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

14. Trying to be calm while waiting at least one hour for medical appointments

| NOT AT ALL CONFIDENT | | | MODERATELY CONFIDENT | | | | TOTALLY CONFIDENT | |
|-------------------------|---|---|-------------------------|---|---|---|----------------------|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

Questionnaire 6

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?

| | Not at all (0) | Several days (1) | More than half the days (2) | Nearly every day (3) |
|--|--------------------------|--------------------------|-----------------------------------|----------------------------|
| a. Little interest or pleasure in doing things. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Feeling down, depressed, or hopeless. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Trouble falling/staying asleep, sleeping too much. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Feeling tired or having little energy. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Poor appetite or overeating. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Trouble concentrating on things, such as reading the newspaper or watching TV. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Moving or speaking so slowly that other people could have noticed. Or the opposite; being so fidgety or restless that you have been moving around more than usual. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Thoughts that you would be better off dead or of hurting yourself in some way. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2. If you checked off any problem on this questionnaire so far, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all
 Somewhat difficult
 Very difficult
 Extremely difficult

Questionnaire 7

Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by marking the appropriate number in the space next to each item. Please be open and honest in your responding.

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Slightly Disagree
- 4 = Neither Agree or Disagree
- 5 = Slightly Agree
- 6 = Agree
- 7 = Strongly Agree

- _____ In most ways my life is close to my ideal.
- _____ The conditions of my life are excellent.
- _____ I am satisfied with my life.
- _____ So far I have gotten the important things I want in life.
- _____ If I could live my life over, I would change almost nothing.

Questionnaire 8

Please take a moment to reflect on what makes your life meaningful to you. Please respond to the following statements as truthfully as you can, and please remember that these are very subjective questions with no right or wrong answers.

| | | | | | | | | |
|----------------------|---|----------|---|-----------|---|-------|---|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
| Strongly Disagree | | Disagree | | Undecided | | Agree | | Strongly Agree |

1. My life as a whole has meaning. 1 2 3 4 5 6 7 8 9
2. I am able to spend most of my time in meaningful activities and pursuits. 1 2 3 4 5 6 7 8 9
3. I led a meaningful life in the past. 1 2 3 4 5 6 7 8 9
4. My entire existence is full of meaning. 1 2 3 4 5 6 7 8 9
5. At present, I find my life very meaningful. 1 2 3 4 5 6 7 8 9
6. I look forward to a meaningful life in the future. 1 2 3 4 5 6 7 8 9
7. I derive a great deal of personal meaning from my past life. 1 2 3 4 5 6 7 8 9
8. I derive a great deal of personal meaning from my future expectations. 1 2 3 4 5 6 7 8 9

Treatment Satisfaction Survey

1) I found the interview to be (please check one):

Helpful Unhelpful

Howso?

2) Was there something specific that you took away from the interview?

Yes No

If yes, please describe.

3) The interview gave me more perspective on my experience with cancer (please circle one):

1
Strongly
Disagree

2
Disagree

3
Neither Agree
nor Disagree

4
Agree

5
Strongly
Agree

Please elaborate:

4) The interview highlighted important insights or learnings in relation to my experience with cancer (please circle one):

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

Please elaborate:

5) There were some parts of the interview that I found challenging or hard:

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

If so, please elaborate:

6) The interview opened up 'old wounds' and that was upsetting:

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

If so, please elaborate:

7) Are there any questions (or parts from the interview) that stayed with you?

Yes No

If yes, what were they and why?

8) Are you considering doing something differently or trying something new as a result of the interview?

Yes No

If yes, please elaborate:

9) The duration of the interview was (please check one):

Too long
 Just the right length
 Too short

10) Based on my experience, I think that all patients should have an opportunity to do a post-treatment transition interview should they wish:

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |

11) Please indicate any ways that you think the post-treatment transition interview could be improved:

Thank you for completing the survey. Please feel free to contact the research coordinator, Iana Ianakieva if you have any questions or concerns.

Phone: 416-480-6150, ext. 90504
Email: iana.ianakieva@sunnybrook.ca

Appendix G

Demographics Questionnaire

Participant ID Number: _____

Today's Date: _____

1) Age: _____ **Date of Birth:** _____

2) In what country were you born? _____

3) What is your first language? _____

4) Ethnic Background:

- Non-Hispanic White or Euro-American
- Black, Afro-Caribbean, or African American
- Latino or Hispanic American
- East Asian or Asian American
- South Asian or Indian American
- Middle Eastern or Arab American
- Canadian Aboriginal or Native American
- Other – please specify: _____

5) Marital Status:

- Single
- Married
- Common Law
- Other – please specify: _____

If in an intimate relationship, length of relationship: _____ Years

If married, length of marriage: _____ Years

6) Do you have children? :

- Yes
- No

If yes, please list gender and age of each:

Gender

Age

| | | |
|--|--|--|
| | | |
| | | |
| | | |
| | | |

7) What is your current living situation?

- I live alone
- I live with a roommate(s)
- I live only with my partner
- I live with my partner and child/children
- I live with my partner and non-family members
- Other – please specify: _____

8) Highest level of education completed:

- No formal schooling
- Primary school
- High-school
- College program
- University degree
- Other – please specify: _____

9) What is your annual income status?

- \$0 – \$9999
- \$10,000 – \$25,000
- \$25,000 – \$50,000
- \$50,000 – \$75,000
- \$75,000 – \$100,000
- \$100,000 – Up

10) What is your usual occupation? _____

- Currently working
- Retired

11) Have you ever been diagnosed with a mental health disorder?

Medical Information:**1) Type of cancer: _____****2) Month and year of cancer diagnosis: _____**

3) Stage of cancer:

- Stage 1
- Stage 2
- Stage 3

4) Age (in years) at time of cancer diagnosis: _____**5) How long ago (in weeks) did you complete active treatment? _____****6) Treatment history****a) Surgery?**

- Yes
- No

If "yes", please specify: _____

b) Chemotherapy?

- Yes
- No

c) Radiation Therapy?

- Yes
- No

d) Other treatment: _____**7. Have you ever had any other major medical concerns/conditions? (Please list).**

Appendix H

Narrative Care Study Sub-Categories and Codes

1. Still Raw and Vulnerable

Cluster 1:

More raw and vulnerable (than before)

Big and small events and everyday occurrences cause more distress than before one's experience with cancer, even despite the person believing they are fine, or should be fine. Some participants feel that this may last forever.

Regretting the delay in getting treatment

The individual wishes they had undergone treatment earlier and regrets not doing so.

Cancer thoughts creeping in

Intrusive thoughts of cancer – these come when not expecting them.

Emotionally wiped

Due to the ongoing ordeal of coping with cancer diagnosis, treatment, and after-effects, the individual feels a sense of emotional fatigue.

Emotionally numb

The individual feels a sense of numbness, lack of emotions, or lack of understanding about their situation and current self.

More emotional

Feeling more emotional, sometimes without apparent reason.

Confused by negative change in self

Changes in self following cancer have been negative, such as lower affect, and are unexpected and unexplained.

Feeling lonely/isolated

The individual feels lonely or isolated in their experience, despite having others around them, for instance because they are in a rarer demographic.

Mixed emotions

A wide range of emotions have been coming up for the individual regarding their experience with cancer.

Depressive symptoms

Symptoms related to depression, such as low mood, irritability, loss of interest in activities, etc. were endorsed.

*Cluster 2:***Sense of impending doom**

Participant has the sense that something will go wrong and is even expecting or waiting for this to occur.

Fear of recurrence

Fear of the cancer returning in the same or different part of the body at any point in the future.

Extrapolating into the future

The individual is fearful of what might happen in the future based on their seemingly inexplicable confrontation with cancer, and thus finds it difficult to fully let go of any worries/negative thoughts about what could happen in the future.

Fear of the uncertainty

The participant is fearful of future problems due to the uncertainty regarding their diagnosis and treatment status, as well as continued upcoming appointments – with the main challenge being the psychological toll this takes on them.

Shattered expectations

One's preconceived worldview, notions, or expectations about how things turn out have been shattered, consequently leading to anxiety or other negative emotions.

Too scary to approach

Participant refers to impending doom or sense of foreboding but then quickly retreats or steps away from it.

Grieving the experience

The individual is in the grieving phase of their cancer journey, focused on reflecting upon and trying to come to terms with the experience.

*Cluster 3:***Planning less**

The ability to plan life too far ahead has been interrupted so the individual is forced to avoid making plans for their future, such as travelling, which may cause distress.

Novel unexpected problems

New, unexpected problems have arisen following cancer.

Normalcy is delayed

The individual feels that they cannot return to normal and live life the way they did before due to continued uncertainty about their diagnosis and treatment success.

Getting left behind

Sadness and grief about having one's life derailed by cancer and getting left behind in terms of life progress compared to one's peers.

Dating is a challenge

Dating has become a challenge due to one's cancer diagnosis and effects of treatment.

Pressure to get better

Experiencing a pressure to be better or to have returned to a normal life or functioning as it was before the diagnosis.

2. Confronted with Bodily Changes

Cluster 1:

Bodily estrangement

Cancer-related physical symptoms/changes are so significant/dramatic as to make one's body feel foreign to oneself.

Bodily hypervigilance

Physical symptoms are cause for concern/anxiety because they serve as a reminder of the cancer.

Damaged goods

The individual feels as though their body is altered in a negative way forever moving forward.

Foregrounding one's body

Since cancer, one has recognized that good health is not necessarily a given, and therefore one needs to make time to focus on/tend to their physical wellbeing/health.

Cluster 2:

Cancer has aged me

The individual feels like they have aged exponentially due to their diagnosis and treatments.

Disconnect between mind and body

Changes to one's body have led to a lack of knowing oneself and one's identity, for example in terms of their body image.

Feeling debilitated

Difficulty bringing oneself to do usual activities.

Change in everyday abilities

Changes in one's daily functioning have occurred, usually in the negative direction, such as decreased physical functioning.

Decreased sexual functioning

The individual has experienced a hinderance to their sexual health and functioning.

Fertility concerns

The individual has been confronted with news about fertility issues, most likely not being able to have children.

3. Striving to be Hopeful*Cluster 1:***Discovering the extent of one's resilience**

The extent of one's resilience, or ability to cope with a difficult situation, has been highlighted through the person's experience with cancer, resulting in increased confidence in one's capacity to cope with challenges.

Keeping negative emotions in check

The individual puts effort into moderating, managing, and/or coping with their negative emotions and feels that this is a very important skill/task.

Compartmentalizing cancer

Striving to not let dark thoughts of cancer or recurrence overtake one, which otherwise will make the whole experience worse.

Overcoming fear

The individual is actively working on overcoming their fears and realizes how important this is to their wellbeing and moving on with their life.

Not worrying about recurrence

The individual is not worrying about recurrence at this time and has decided to take things as they come in the future.

Trying to make sense of the experience

The individual is trying to understand and find meaning in various aspects of their cancer experience.

*Cluster 2:***Taking things as they come**

The individual has decided to accept arising issues in health, work, relationships, and overall functioning as they come instead of worrying about hypothetical situations.

Focusing on the present moment

The individual is focusing on the present moment before future appointments determine their status and next steps, since there is nothing they can change right now about the outcome. This is also a way of dealing with anxiety.

More present

Focusing more on the present moment or being more mindful overall.

*Cluster 3:***Focus on a positive attitude**

A coping strategy where the focus is on having a positive attitude and looking on the bright side of things, as opposed to getting bogged down in one's challenges.

Focusing on the good

Choosing to focus on the positive news of one's diagnosis and/or life overall – 'it could have been worse but it isn't so there is no use in worrying about it right now.'

One of the lucky ones

The individual finds comfort in the fact that there are others who are faring much worse than they are.

Keeping self-criticism in check

The individual has become more aware of self-criticism and tries to keep it in check.

Focusing on the solution

The individual has decided that accepting the situation and focusing on how to fix it is the most beneficial way to cope with cancer, as opposed to wallowing or complaining or fixating on how difficult the experience is.

Focus on logical thinking

Actively trying to engage the logical part of one's brain to make decisions and to cope, as opposed to basing things on emotion.

Focus on self-care

A newfound greater importance placed on doing things for oneself, without guilt or needing to justify these behaviours.

Driven to find new coping strategies

The individual has realized that they do not possess the tools to cope with their current challenges and are motivated to learn new coping strategies to help themselves.

4. Same but Different*Cluster 1:***Same but different**

The person realizes that they are on one level fundamentally the same person, but also different now in terms of their attitude toward life and what is important.

No changes

The individual explicitly states that they have not experienced any changes in themselves or their perspective as a result of their cancer experience.

No obvious changes, expect for...

The participant initially states that they have not undergone any changes as a result of their cancer experience, only to subsequently reflect upon ways in which they have actually changed. (i.e., First impulse is to preserve one's former sense of self).

Same old patterns

The individual believes that people do not change and return to the way they have always been even if temporary changes or desires to change occur.

Self-actualization

The individual feels that they are becoming who they want to be and focusing on how to make their life as fulfilling and/or good as possible.

Emphasizing who I was and am

Aspects of oneself, whether previously in one's awareness or not, have been emphasized by the cancer experience.

I am a different person

The individual feels as though they are a whole different person, mentally, spiritually, and physically.

5. Cancer as Impetus for Self-Reflection

Cluster 1:

Cancer as an impetus for reflection

The experience of cancer caused/prompted the person to reflect on their life, attitudes, and understanding of themselves, and likely led to new realizations or changes in their perspective, the way they live, or in the way they understand themselves or the world around them.

New realizations and insight into the self

Reflecting upon the new insights that one has learned about themselves as a result of having had cancer.

Trying to establish one's post-cancer identity

Not yet being sure who one is as a person following their confrontation with cancer and focusing on finding their new identity.

Increased personal insight

The individual has gained insight into themselves as a result of going through cancer.

Metacognitive processing of changes

The individual is theorizing about mechanisms of change and trying to make sense of the changes they are experiencing following their experience with cancer.

Monumental reorganization of life and sense of self

The occurrence of cancer is viewed as such a significant event that it almost certainly would cause some shift in one's life or the way they understand themselves, either or both in positive

and negative directions. In other words, a monumental reorganization of life or sense of self occurs.

Cluster 2:

Unexpected positive changes

One has surprisingly experienced positive changes out of the challenging/painful experience.

Catalyst for positive changes

Cancer treatment has led to unexpected, surprising positive changes.

Positive mental impact

The individual has noticed that their experience with cancer has had a positive effect on their psychological wellbeing, functioning, and attitude and/or has helped them to make positive changes in themselves.

Cluster 3:

Temporary changes

Some temporary changes in thinking or way of doing things occurs, but eventually things revert to the way they were.

Imperceptible changes

The individual believes that their experience with cancer has probably led to some changes in their life, perspective, or sense of self, but they are not yet able to understand or articulate what those changes are, or believe they will become clearer with the passage of time.

Contemplating change

The individual is contemplating how or whether any changes will occur, but is unsure yet, perhaps due to uncertainties degrading the status of their health.

6. Re-Evaluating One's Priorities

Cluster 1:

Re-evaluating one's priorities

Becoming inspired or motivated to reconsider one's longstanding priorities, values, or convictions and whether these should be shifted based on currently perceived personal significance and potential benefit.

Attention on different priorities

It's not easy to shift one's priorities, especially after having invested in something such as one's career for many years. Thus, a shift in priority may but does not have to include feelings of sadness, loss, or grief.

Changing perspective on what's important

The individual has been prompted to reflect upon what is important to them and their life and has experienced a shift in what aspects of life they find most important.

Questioning the status quo

Rather than be comfortable with the way things are and have always been, taking time to reflect on one's life and how one wants to live it.

*Cluster 2:***Living at a slower pace**

The desire to live at a slower pace, perhaps by doing less or not putting pressure on oneself to be as productive and active as possible at all times.

Doing less

Realizing that it's okay to just do less, whether it be chores, hobbies, activities, work, etc. and putting less pressure on oneself to do as much as they may have done before.

Enjoying simpler pleasures

Simpler pleasures, or everyday things are more appreciated and enjoyable than they would have been in the past.

Desire for a stress-free life

The individual has come to the realization that they would like their life to be less stressful and less complicated.

Finding a better balance

In instances where one does not want to give up a prior priority altogether because they either like it and/or see it as a necessity, there is a desire to ensure time is not over-spent on the previous priority.

Daily worries don't matter as much

Everyday tasks, nuisances, and concerns have become seemingly smaller and less important.

Laissez faire

Becoming more relaxed, doing things at a slower pace, and letting things go.

*Cluster 3:***The material is less important**

Realizing that immaterial things, or 'stuff,' are not that important, so there is less stress when something is broken or lost.

The small stuff is important

While it would have been considered unimportant or a waste of time before, the individual has realized that focusing on little things or spending more time pondering or enjoying small routine things is actually beneficial.

*Cluster 4:***Setting boundaries**

Establishing new boundaries based on newly emerging or more prominent values, interests, and concerns regarding activities, relationships, and time/effort one is willing to devote to those activities and relationships.

Protecting one's time

Related to the realization that time is precious, feeling the need to protect one's time in relation to others. In other words, not wanting to give up too much of one's own time toward dealing with others or managing relationships or others' needs, particularly when they may be considered unworthy of one's time.

Prioritizing one's time

Reevaluating how one wants to spend their time and now prioritizing spending time on different people and/or activities.

Prioritizing myself

The individual has decided to put themselves, including their needs and wants, first before focusing on others.

Selfish in a good way

Focusing on one's own needs and wants before turning to the needs and wants of others, whereas this may have been reversed previously. In other words, attending to personal needs and wants first.

Rethinking the value of work

Work, and relatedly earning money, is less important than it was prior to cancer.

Being kind to myself

The individual has learned to be kind to themselves and give themselves leeway when confronted by setbacks in their goals, functioning, etc.

7. Re-Valuing and Deepening Relationships

Cluster 1:

Increased understanding of others

Due to their experience with cancer, the individual has gained a deeper understanding of others.

Newfound understanding of others' struggles

Gaining a deeper understanding of the suffering or struggles of others, and of cancer patients and survivors specifically.

Cluster 2:

More thoughtful

The participant is more thoughtful of others.

More faith in people

Having an increased belief in others.

Increased compassion

One has developed a greater understanding and compassion, or even empathy, toward others (after being given more time to consider what others are going through and to connect to a universal struggle).

Increased patience

The individual has more patience for people and things, including waiting for appointments.

More forgiving

Being more forgiving of others and oneself about more things than before.

Increased altruism

A greater focus is placed on helping others, whereas previously there would have been greater consideration of personal advancement and needs.

Focus on others

One's focus has shifted to helping others, regardless of any personal benefits.

Less critical of others

The individual has become less critical and more accepting/forgiving of others' flaws.

Cluster 3:

I am loved

Close others' love and care for the individual have been highlighted.

Greater appreciation of loved ones

The individual has come to realize how much they do indeed appreciate close others in their life, or have been made aware of how much more they care about certain people than they did before.

Clarity on relationships

The individual has realized which relationships/people are more reliable and supportive versus those which are not.

Greater focus on relationships

There is an increased focus or care put into certain relationships.

Devoting time to loved ones

The individual has realized that they should, or would like to, spend more time with the important people in their life.

Arguing less

Spending less time or energy arguing, even if others want to engage in an argument, in order to spend one's time in a more enjoyable, peaceful manner.

*Cluster 4:***Being overprotected**

Close others around the individual are very caring and supportive but can move into being overprotective and making the person feel fragile.

Perceived weakness

The individual was confronted with expressed concern and/or empathy from others for the first time, making them feel weak or less of a strong leader figure than they were before.

Perceived lack of interest from others

The individual senses or has noticed signs that some of the people in their life are less supportive or uninterested in remaining in their life.

Diminished patience

The individual has less patience in terms of dealing with other people and certain relationships.

8. Mortality at the Forefront*Cluster 1:***Mortality at the forefront**

The individual's confrontation with cancer caused them to think about their own mortality and become more aware of it and its effect on their life.

Assumptive worldview is challenged

Participants' fundamental assumptions about themselves, their body, their health have been challenged by the diagnosis/treatment.

Longevity not a given

Never having thought that life could be cut short but now recognizing that longevity isn't a given. Once faced with one's own mortality – you cannot undo recognition of death's inevitability.

Life can change on a dime

Having been through a cancer diagnosis reminds one of how life is uncertain – things can change dramatically without a moment's notice.

*Cluster 2:***Life and health are precious**

The realization that health and life are extremely valuable, if not the single most valuable things to us.

Searching for what makes me happy

Focusing on finding what will make one happy in their life.

Living life to the fullest

Focusing on living life as fully as possible by experiencing as many things as one can and enjoying them as much as possible.

Living in the moment

The individual is more willing or motivated to live life to the fullest in the present moment, and on their own terms.

*Cluster 3:***Grateful for time given**

Grateful for time one has been *given*.

Time is a precious commodity

Realizing that time is finite, which contributes to recognizing how valuable it is.

Accepting finiteness of time

Recognizing time is not unlimited, which makes one more respectful of time one has rather than fearful of time running out. The realization is more motivating than paralyzing.

Spurred into action

As a result of one's experience of cancer, the person has become more willing to take action and recognizes that they shouldn't wait because time is finite; this pertains to positive tasks and goals but also less attractive but important goals and tasks.

9. Living Forward with Appreciation*Cluster 1:***Bump in the road**

The cancer experience is seen as an event that caused a temporary slowing down or standstill in one's life, but now that treatment is over the individual believes they can 'return to normal,' or mainly to the way life was before they were diagnosed.

On the road back to normal

The focus is on returning to their life exactly as it was before the cancer diagnosis/treatment.

On the road back to new normal

The focus is on returning to some version of normalcy, with aspects of how one's life was before their experience with cancer, while also incorporating changes in self, others, and life in general which have occurred due to their experience.

Daily life remains unchanged

While the person may have identified some changes in their attitudes or life perspectives, their daily life has reportedly not changed in any notable way as a result of cancer.

*Cluster 2:***Gratitude**

Experiencing a newfound or greater sense of thankfulness/appreciation.

More appreciative

Individual experience with facing one's mortality makes them recognize what they have (versus what they lack), in various life domains.

Appreciating my luck

The individual appreciates their luck in a variety of ways.

*Cluster 3:***At peace**

The individual feels at peace with their life and things that cannot be controlled and accepts what is to come.

Newfound acceptance

An increased acceptance of life circumstances, whether they are positive or negative, and subsequent ability to move forward.

More content

Following one's experience with cancer, the individual feels more content or happy with their life and circumstances.

*Cluster 4:***Living forward**

Focusing on moving forward and not living in the past/not dwelling on the past.

Not afraid to fail

The individual is motivated to push themselves more to do things they would have been afraid to fail at before.

Increased spontaneity

One has realized the importance and/or benefit of being more spontaneous and going with the flow, as opposed to always planning everything in advance.

Other issues seem smaller

Everyday issues and concerns, or even larger life problems seem less important/significant.

Being proactive

Doing things without hesitation.

Loosening self-imposed constraints

Realizing that it's okay to do things one wants to do, which they may normally have stopped oneself from doing.

Caring less what others think

Being less worried or caring less about others' opinions of oneself.

10. Living a Healthier Life

Cluster 1:

Healthy lifestyle modification

The individual has become motivated and/or started to make changes to their lifestyle, for instance by improving their diet, losing weight, focusing on their sleep, and exercising more.

Commitment to new goals

A re-evaluation of one's goals has occurred and has led the individual to set and commit to new goals.

Taking charge of my health

Focusing on being careful with one's health, for example by being vigilant, responsible, and addressing issues when they arise.

More careful

The individual is more careful in terms of their own safety, as well as that of other people and avoids doing things which may put them or others in danger.

More engaged with supports

The individual has begun reaching out to more resources for help.

11. Empowering Ourselves and Others

Cluster 1:

Cancer is the norm

One's own cancer diagnosis has brought on the realization that cancer occurrence is widespread, and some anxiety or worry, but also comfort, is associated with this.

Systemic concerns

Through exposure to different aspects of the healthcare system, the individual has developed worries or frustrations/complaints about some aspect of its functioning.

Increased understanding and security in healthcare providers

As a result of their experience with cancer diagnosis and treatment, the individual has become more aware of how things function in the healthcare system and has gained a greater sense of security in healthcare institutions or specific professionals.

Cancer can be overcome

Despite cancer being a scary, serious disease, the individual has realized that it is possible to come out on the other side and that it can be less scary than anticipated.

Shared experience and shared understanding

Realizing that people who have gone through cancer are a unique group and have a shared bond and understanding of the world/life/themselves that others may not, likely because they have not been exposed to the same challenges and confrontation with mortality. This bond may help individuals to connect on a deeper level, share their own experiences, or feel a sense of support/compassion.

Spreading awareness

Realizing the importance of spreading awareness about cancer and prevention, treatment, and/or coping in order to help others, and feeling motivated to participate in this process.