

EXPLORING THE LIVED EXPERIENCE OF VISUAL CREATIVE EXPRESSION FOR
YOUNG ADULT CANCER SURVIVORS

by

AMY ROSE GREEN

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Abstract

The purpose of this research was to contribute experiential understanding of the lived experience of creative expression (both individually and/or within a therapeutic setting) in the particular context of young adult cancer survivors. It utilized van Manen's (1990) hermeneutic phenomenological approach to answer the following question: "What is the lived experience and lived meaning of visual creative expression for young adult cancer survivors?" Seven young adults (diagnosed with cancer between ages 18 to 35) were engaged in two conversations (one main interview and one check-in interview) about their creative expression experiences. Participants were also invited to reflect on their insights, ideas, and experiences of creative expression through emails to the researcher. A thematic reflection and guided existential reflection (based on the four lifeworlds of lived body, lived time, lived space, and lived relation) were utilized to further understand, organize, and reveal the ways the participants experienced the phenomenon of creative expression. In line with van Manen (1990), data analysis was conducted through the writing and re-writing of findings in a reflective and vocative manner. Seven themes were uncovered that could be organized into the four lifeworlds: lived time involved being in the flow; lived body involved allowing the body to express itself and renegotiating control; lived space involved being impacted by a permanent change to the environment; and, finally, lived relation involved being seen, respect for the art as other, and giving back. The seven themes within these four life worlds intertwined to embody two additional themes: increased self-understanding and healing the mind and body.

As the first study to explore the lived experience of visual creative expression specifically for young adult cancer survivors, this research begins to fill a large gap in the literature. Findings suggest that visual creative expression can be a meaningful and impactful

experience for young adult cancer survivors, and that this experience espouses both similarities and differences from experiences of creative expression for older adults that have been previously described in the literature. Specific recommendations are made for future research, in addition to implications for practitioners working with the young adult cancer survivor population.

Preface

This research was approved by the University of British Columbia's Behavioural Research Ethics Board. The certificate number of the ethics certification obtained was H12-02385.

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Dedication

“The essence of all beautiful art, all great art, is gratitude”
(Friedrich Nietzsche, 1844-1900)

This work is dedicated to the seven young adults who so openly shared their stories with me. They inspired, challenged, and moved me, and I am sincerely grateful to each of them.

Chapter One: Introduction / *Preparing the Canvas*

The practice of healing through art is one of the most deeply rooted practices in cultures throughout history and across the world (McNiff, 2004). As Judith Rubin, past president of the American Art Therapy Association, eloquently stated, “from the soothing of David’s biblical harp to the catharsis of classic Greek drama, the arts have offered solace to those under stress” (Rubin, 2006, p. 9). In contemporary society, creative expression through the visual arts appears to be a significant human experience for individuals, and one that many turn to in times of trauma, illness, and painful experiences (Green, 2011). For example, survivors of the atomic bomb in Hiroshima submitted artwork by the thousands in response to an invitation by the Japanese Broadcasting corporation (NHK, 1977), welcoming the opportunity to cope with their sorrow and make amends with those who had been killed (Schonberger, 1978). Similarly, after 9/11, individuals and communities across the US made memorial quilts, decorated a Statue of Liberty replica, and created resiliency sculptures, turning to art as part of the grieving, healing, and meaning-making process (National September 11 Memorial & Museum). And, finally, of a smaller scale but certainly no less meaningful, following his diagnosis of Hodgkin’s Disease at age 26, renowned Canadian artist Robert Pope turned to art as a way to explore and represent his experiences of healthcare and healing as a cancer patient (Robert Pope Foundation, 2010). In 1991, his paintings came together to compose the compelling visual narrative, *Illness and Healing, Images of Cancer*, which remains an influential text across the globe.

In the years since Pope’s narrative was published, health practitioners and researchers have increasingly documented the benefits of creative expression for cancer survivors (Stuckey & Nobel, 2010). Within the oncology literature, visual creative expression, both individually and with an art therapist, has been shown to offer a wide range of psychological and physiological

benefits for cancer survivors at all stages of medical care (Stuckey & Nobel, 2010). Empirical studies have supported a link between visual art therapy interventions and decreased anxiety and depression for cancer survivors (Monti et al., 2006; Nainis et al., 2006; Puig, Lee, Goodwin, & Sherrard, 2006). Additionally, Nainis et al. (2006) found that, following a one-hour art therapy intervention, adult cancer patients ($N=50$) reported significant improvements in pain, tiredness, drowsiness, lack of appetite, shortness of breath, and overall wellbeing. Qualitative studies have also supported the use of visual art therapy interventions for cancer survivors. For example, Luzzatto and Gabriel (2000) evaluated a 10-week group art therapy program for post-treatment cancer survivors, wherein participants utilized various art materials, explored different techniques for facilitating meaning-making, and developed personally symbolic images. Based on written questionnaires, the authors found that the 70 adult participants reported improved mood and feelings, increased self-awareness, and improved attitudes towards others (e.g. more trust, and increased respect and compassion).

Because creative expression appeared to be a significant and beneficial phenomenon for cancer survivors, I became curious about the lived experience and lived meaning of creative expression for this population. Although not a cancer survivor myself, I am an amateur artist who uses creative expression for self-care, and a counsellor-in-training who regularly utilizes art therapy techniques with my clients. Thus, exploring the lived experience of creative expression was of particular interest to me. Lived experience refers to “our immediate, pre-reflective consciousness of life” (van Manen, 1990, p. 35) and, once intentionally reflected upon, the meaning of lived experience (i.e. lived meaning) can be understood and illuminated. Explorations of lived experience and lived meaning are commonly associated with phenomenological approaches to research – studies that aim to uncover the “essences” of a phenomenon that

contribute to an understanding of its meaning (Randles, 2012; van Manen, 1990). Such research may be particularly relevant in the creative expression field in light of a quote from Stuckey and Nobel (2010), who reviewed the current literature in art and healing and stated that:

Art and health have been at the center of human interest from the beginning of recorded history. Despite that fact, and despite the invested effort and growth of knowledge in each arena, it is interesting the we often still find ourselves struggling with the “fundamentals” of art and health and their meaning in society (p. 254).

Because research questions involving lived experience are best explored through phenomenological methods (van Manen, 1990), I turned to the literature and identified two phenomenological inquiries on the lived experience and lived meaning of visual creative expression specifically for cancer survivors (Lane, 2005; Reynolds & Lim, 2007a; 2007b). One additional phenomenological study explored the lived meaning of creative expression for individuals with disabling chronic illness, which included some participants with cancer (Reynolds & Prior, 2003). These studies attempted to facilitate understanding of the phenomenon of creative expression as it is lived and understood by cancer survivors. However, limitations in the existing body of research point to a need for further phenomenological understanding of creative expression. Firstly, in all three studies, the researchers included pre-determined questions in their phenomenological interviews about the ways that creative expression contributed to health and wellbeing for cancer survivors. For example, Lane (2005) asked, “How did you heal yourself with art?” Such questions pre-assume that the lived experience of creative expression is a healing one for cancer survivors. Future phenomenological studies could avoid such leading questions, focusing solely on the experience as it is lived by participants. Additionally, only one of these studies (Lane, 2005) espoused van Manen’s (1990) hermeneutic

phenomenology. This methodology is particularly appealing due to its accessibility and pragmatic orientation (Nicol, 2010). Furthermore, its attention to expressive, vocative writing offers an especially meaningful way to describe lived experience, which may be especially relevant to the dynamic experience of creative expression.

Finally, although none of these studies *excluded* younger adults, none were conducted specifically with the young adult cancer survivor population (aged 18-35). In fact, the mean age of participants (when reported) typically ranged from the late 40s to the 60s. Further phenomenological research that explores the experience of creative expression specifically for young adult cancer survivors fits with the analytic strategy of varying the example, with the goal of furthering phenomenological understanding (van Manen, 1990). This research may be particularly relevant, because the young adult cohort represents a unique survivorship population with distinct experiences and needs (Kent et al., 2012). For example, young adult survivors are faced with the difficult task of balancing their illness-related needs and constraints with normative developmental tasks (Elad, Yagil, Cohen, & Meller, 2003; Weissberg-Benchell, Wolpert, & Anderson, 2007), and a cancer diagnosis and its often intense and lengthy treatment process may disrupt the transition to adulthood process for young adults (Treadgold & Kuperberg, 2010). Other specific challenges particularly relevant to young adult survivors include: premature confrontation with mortality (Zebrack, 2011); uncertainty about disease recurrence (Elad et al., 2003; Zebrack, 2011); sexuality and fertility concerns (Elad et al., 2003; Schover, 1999); increased dependency on parents and others (Elad et al., 2003; Zebrack, 2011); changes in physical appearance and body image concerns (Elad et al., 2003; Zebrack, 2011); disruptions in social life, school, and employment (Elad et al., 2003; Zebrack, 2011); feeling different from healthy peers (Elad et al., 2003); and the re-negotiation of goals and dreams (Elad

et al., 2003). Some evidence even suggests that young adults experience physiological and psychological impacts of cancer more severely than other age groups; in fact, one study revealed that the highest prevalence of distress in a large sample of adult cancer survivors aged 19-95 years ($n = 4496$) was amongst those between 19-29 years (Zabora, Brintzenhofezoc, Curbow, Hooker, & Piantadosi, 2001).

Both the National Cancer Institute (NCI) in the US (2004; 2006) and the Canadian Cancer Society (CCS; 2009) recently released reports that referenced young adult cancer survivors as the understudied or “orphaned” cohort, and have called for a significantly more robust effort towards understanding and supporting this distinct population. Perhaps in response to these oft-cited reports, recent years have witnessed an emergence of research with young adult cancer survivors (Hall et al., 2012). This being said, gaps continue to exist in the literature, and research that investigates creative expression specifically with the young adult population is nearly nonexistent. A notable exception is a pilot program funded by the BC Cancer Agency in 2011 that involved an arts-based support group for young adults with cancer (Prins Hankinson, 2011). Although this study provided preliminary support for group-based art therapy for young adults with cancer, it is clear that more research with young adult cancer survivors and, more specifically, on the lived experience of creative expression with this population, is needed.

Research Problem and Research Question

Although recent phenomenological research has explored the lived experience of visual creative expression for cancer survivors, no existing phenomenological studies have been conducted solely with young adult survivors. In fact, research in the oncology field in general has tended to ignore this unique population. Finally, methodological flaws and gaps in existing phenomenological studies create concerns about the trustworthiness of findings from such

research, and call for further phenomenological research. In response to these gaps and concerns, I employed a hermeneutic phenomenological approach (van Manen, 1990) to explore the lived experience and lived meaning of creative expression specifically for young adult cancer survivors. Specifically, the research question that was considered and reflected upon was: What is the lived experience and lived meaning of visual creative expression for young adult cancer survivors?

To answer this research question, I drew upon van Manen's (1990) hermeneutic phenomenology, which calls for an integration of the "reductio" (phenomenological reduction that involves exploring and understanding a phenomenon unencumbered by assumptions and biases) with the "vocatio" (the vocative use of language and text to reveal the essences of a phenomenon). Inspired by van Manen's unique approach, I attempted to create a vocative and rich text to represent the experience of creative expression as it is lived by young adult cancer survivors.

Implications

The importance of doing phenomenological research lies in the need to uncover the essential elements of a phenomenon (Colaizzi, 1973). To foster a deeper understanding of creative expression, the intention of this study was to return our attention to the phenomenon as it is lived, using verbal descriptions from participants as the main source of data, and attempting to remain as close to the experience and meaning systems of the participants as possible. Furthermore, it hoped to extend existing phenomenological knowledge by exploring the lived experience and lived meaning of creative expression in the particular context of young adult cancer survivors, illuminating further phenomenological insight. Such research was viewed as essential in helping us comprehend and grasp what creative expression means to young adult

cancer survivors. Such an investigation was construed as being helpful to art therapists, counsellors, and other health professionals working with this population in becoming more intentional in their practices. For example, it was anticipated that results might encourage mental health professionals to enhance their clinical interactions by incorporating art techniques into their therapeutic sessions, or by encouraging clients to engage in creative expression during their leisure time.

Chapter Two: Review of the Literature

In this chapter, I examine research in the two overarching areas of cancer in young adulthood and creative expression/art therapy to demonstrate the meaningfulness and appropriateness of the research question. I then examine the existing research on creative expression/art therapy in the context of oncology in the hopes of bringing together these two fields to provide support and rationale for the current study.

Young Adult Cancer Survivors

Young adulthood is characterized by a myriad of developmental transitions, major decisions, and psychosocial transformations (Elad et al., 2003; Young et al., 2011). However, although the majority of young adults expect to navigate certain life-related changes – such as decisions about employment, education, and intimate relationships – most, on the other hand, do not expect to confront a cancer diagnosis. Yet, approximately 2,075 young adults between the ages of 15-29 in Canada (CCS, 2009), and nearly 70,000 young adults between the ages of 15-39 in the United States (NCI, 2006) are diagnosed with cancer each year. This is equivalent to approximately 200 young adults per day.

These statistics highlight the relevance of selecting young adult cancer survivors as the context for the current study. In this section of the literature review, I develop this relevance further by highlighting the unique experiences and psychosocial concerns pertinent to this population. Additionally, I explore the research on psychosocial interventions with this age group, identifying gaps in the literature that point to a need for further study. This provides a segue into the following section; namely, creative expression/art therapy in oncology. Firstly, however, I provide definitions for key terminology (namely, young adulthood in the context of

cancer and cancer survivorship), and my rationale for how I defined these terms in the proposed study.

Defining Young Adulthood in the Context of Cancer

Within the cancer literature, young adulthood has been defined as multiple different age ranges, including 15-29 (CCS, 2009; NCI, 2004), 15-39 (NCI, 2006), 20-44 (BC Cancer Agency; BCCA, 2005), and 19-35 (Prins Hankinson, 2011). Defining the age range of young adults in oncology has been a challenge in the literature, and some studies are limited in that they simply refer to “young adults” or “adolescents and young adults” without specifying a specific age range (Geiger & Castellino, 2011). After careful contemplation, the current study defined young adulthood as between the age range of 18-35. The rationale for this inclusion criterion included: (a) 18 is the age of when most individuals have graduated from high school, and begin to embark on many young adulthood tasks, and (b) 35 falls in the middle of past inclusion criteria.

Although many studies combine older adolescents (e.g. aged 15-17) with young adults (often referring to this group as “AYAs”, or “adolescents and young adults”) (NCI, 2004), I did not include adolescents in the proposed study. It is important that the proposed study remains dedicated to the unique and distinct experiences that encompass the young adult survivorship population, given that this population has been traditionally under-recognized in the literature. A limitation I have identified in the literature is the tendency of some articles to generalize findings from studies that included only adolescents to young adults (e.g. Treadgold & Kuperberg, 2010), or to report the results for these two age groups together (NCI, 2004). Thus, as much as possible throughout this literature review, when detailing various studies, I explicitly stage the age ranges used. Furthermore, although a substantial and rich body of research has explored young adult

survivors of childhood cancer (Zebrack, 2011), encompassing this research is beyond the scope of this review.

Because 18-35 encompasses a large age range, it is important to note that there is a breadth and diversity of lived experiences encompassed by this age group. Lifestyle, relationships, sexuality, education, and career issues comprise stark contrasts within the range of young adult experiences (Treadgold & Kuperberg, 2010). For example, an 18-year-old survivor might be in her first year of university and living at home with her parents, while a 35-year-old survivor might be well established in her career, married, and even have children of her own. Thus, although several similar experiences unite this age group (for example, the NCI's Adolescent and Young Adult Oncology Progress Review Group argued that most cancer patients up to age 40 feel they have more in common with younger versus middle-aged or older patients), it is important to keep in mind the concurrent differences.

Defining cancer survivorship. Currently, cancer survivorship can be conceptualized as a process, not an end state or outcome. However, it has not always been defined this way. Indeed, until approximately 30 years ago, the standard medical definition of survivor held that only those who had been free of cancer for at least five years could be deemed survivors (Rowland, 2007). In 1985, physician Fitzhugh Mullan wrote about his experiences of living with cancer for the *New England Journal of Medicine* in an effort to redefine the course of cancer from one that focuses on the binary notion of “cured” or “not cured”, to one that focuses on the ongoing experience of cancer survivorship. Furthermore, in 1986, Mullan, along with other cancer survivors and healthcare professionals, founded the National Coalition for Cancer Survivorship (NCCS), which declared that a person was entitled to call him or herself a survivor “from the moment of diagnosis and for the balance of his or her life, regardless of the ultimate cause of

death” (Rowland, 2007, p. 29). More recently, Adams (1991) asserted that “cancer survival is an ongoing process that begins when the initial cancer diagnosis is made” (p. 107) and Zebrack (2000) offered a similar definition of cancer survivorship as “not just a single event with a certain end but an enduring condition characterized by ongoing uncertainty, potentially delayed or late effects of the disease or treatment, and concurrent psychosocial issues” (p. 238). In line with Mullan (1985), Adams (1991), and Zebrack (2000), the current study conceptualized cancer survivorship as an ongoing process.

Mullan (1985) was the first to conceptualize cancer survivorship by stages, asserting that survivorship is characterized by acute survival (the medical stage), extended survival (remission, or completion of the rigorous medical stage), and permanent survival (when activity or recurrence of the disease is minimal, but other long-term, secondary effects arise). In 1991, Adams conceptualized cancer survival as a process that is ongoing across the phases of diagnosis, treatment, rehabilitation/continuing care, post-treatment/remission, and recurrence/advanced disease (Adams, 1991). While many needs overlap across these phases (for example, the need for psychosocial support) many needs are also distinct (Adams, 1991). For example, an individual in the treatment phase may be concerned with navigating different treatment options, whereas an individual in the advanced disease stage may be emotionally and physically preparing for the dying process. The current study included participants who were currently in the rehabilitation/continuing care or post-treatment/remission phases of survivorship; however, in line with its conceptualization of cancer survivorship as an ongoing process, it explored participants’ creative expression experiences from any stage of survivorship.

A new paradigm of cancer survivorship is gradually emerging in North America (Shermak, 2008). Earlier detection rates and medical advances in cancer treatment mean that

more and more cancer survivors are part of the social landscape, which, in turn, means there is a growing population of cancer survivors to draw knowledge from (Shermak, 2008). With this increased knowledge has emerged a debate about the use of the word “survivor” to describe those who have had, or currently have, cancer (Shermak, 2008). Indeed, individuals who have experienced cancer may reject the label of “survivor” for failing to account for the possibility of recurrence (Kaiser, 2008; Khan, Harrison, Rose, Ward, & Evans, 2011), for being overly “heroic” (Kaiser, 2008), for being too public of an identity (Kaiser 2008; Khan et al., 2011), for implying a high risk of death that was not reflective of their experience (Khan et al. 2011), or for suggesting that cancer survivorship is dependent on personal characteristics (Khan et al., 2011). At the same time, Park, Zlateva, and Blank (2009) found that survivor identity is associated with active, rather than passive, involvement and better psychological well-being. In line with Park and his colleagues (2009), the use of the term “survivor” in the current study was meant to imply active engagement. Furthermore, it embraced a construction of survivorship that recognized the ongoing effects of cancer, and the diversity in how individuals who have faced or are facing cancer define themselves as survivors (Kaiser, 2008).

Cancer Discourses: The Young Adult Paradox

The cancer experience is largely defined and understood in terms of middle and later adulthood (Kent et al., 2012). At the same time, younger children, like older adults, are more likely to be highlighted in common cancer discourses than young adults (Thomas, Seymour, O’Brien, Sawyer, & Ashley, 2006). This generation gap has been referred to as “diapers vs. dentures” (Kent et al., 2012, p. 272) or as the “grey zone” (Thomas et al., 2006), and may result in young adults feeling and getting lost in the cancer care system (Kent et al., 2012; Thomas et al., 2006). For example, it can be disconcerting for a young adult to be placed on a cancer ward

occupied by mainly younger children or older adults (Grinyer & Thomas, 2001). Moreover, cancer outcomes in adolescents and young adults are underperforming those experienced by both their pediatric and older adult counterparts (Thomas et al., 2006). In fact, the average improvement in survival rates for adolescents and young adults from 1973-2001 (based on data from the US) was about half that seen in children and older adults (Bleyer, Budd, & Montello, 2006; Thomas et al., 2006). Certainly this is influenced by biological factors, such as the relative rarity of individual cancers in older adolescents and young adults. However, this is also influenced by social factors. For example, young adults may face several challenges in receiving timely diagnoses, as even health care providers may express incredulity at the possibility that a young adult could have cancer (Kent et al., 2012). Furthermore, caught between two worlds, adolescents and young adults have the lowest rate of primary care use amongst all age groups, and are less likely to participate in and have access to clinical trials that could help improve their long-term outcomes (Bleyer, et al., 2006). Young adults are also less likely to be referred to cancer centres, less likely to receive treatments aimed specifically at their age group, and more likely to be treated by physicians who are less educated in the biology of cancers that affect this age group (Bleyer et al., 2006).

A shift in the existing cancer discourse has occurred in the past 10 years as increasing attention has been paid towards the physical and psychosocial needs of adolescent and young adult cancer survivors (Treadgold & Kuperberg, 2010). This new focus has been reflected in, and perhaps influenced by, the US National Cancer Institute (NCI) who, in 2006, published a report from the Adolescent and Young Adult Oncology Progress Review Group, highlighting the unique challenges faced by young adult cancer survivors. Similarly, in 2009, the Canadian

Cancer Society's publication, *Canadian Cancer Statistics*, featured "Cancer in Adolescents and Young Adults (15-29 Years)" as its special topic.

Psychosocial Concerns for Young Adult Survivors

According to the Canadian Cancer Society (2009), coexisting education, work, lifestyle, and psychosocial needs during the formative stage of young adulthood contribute to the complex needs of cancer survivors from this age group. Similarly, Thomas et al. (2006) argued that the distinct physical, emotional, and social concerns facing young adults with cancer remain amongst the most challenging faced by patients, families, and health-care providers alike. Certainly, a cancer diagnosis and its often intense and lengthy treatment process may disrupt the transition to adulthood process for young adults as they are forced to manage normative developmental tasks (such as shaping independent lives, building careers, and starting families of their own) with the challenges of facing a cancer diagnosis (Rabin, Simpson, Morrow, & Pinto, 2011). Such challenges include, for example, disruptions in education and employment trajectories (Rabin et al., 2011), and significant financial burdens as young adults who may be independent and/or raising young families may lack financial stability as they are forced to take time off work (Kent et al., 2012). Two challenges that have been cited as being particularly salient for young adult cancer survivors are: (1) increased concerns about fertility, body image, and sexual dysfunction (e.g. Rabin et al., 2011); and (2) shifting social relationships (e.g. Kent et al., 2012). These psychosocial challenges are elaborated upon in the subsequent sections.

Fertility, reproduction, and body image concerns. Infertility and reproductive issues are pertinent for both young men and women who have experienced cancer, and have been explored in several qualitative studies (e.g. Kent et al., 2012; Chapple, Salinas, Ziebland, McPherson, & Macfarlane, 2007; Connell, Patterson, & Newman, 2006). For example, Chapple and her

colleagues (2007) interviewed 21 young men aged 16-26 previously treated for cancer about their fertility issues. The authors found that uncertainty about future fertility was a source of distress for some young men, and many were unprepared for the process of sperm-banking or found this topic difficult and embarrassing. Additionally, they noted that a few participants would have benefited from counselling around this topic.

In turning to the body image literature, the physical implications of cancer treatments can create significant difficulties as some young adult survivors are forced to adjust to amputations, obvious scarring, or other physical changes that set them apart from their peers during a period of life when individuals may be particularly concerned with their physical appearance (NCI, 2004). In 2010, Snobölm and her colleagues utilized a phenomenological method to describe the essence of how young adults with cancer experienced their bodies. Twelve young adults (six female) aged 22-35 with varying diagnoses were interviewed about their experiences of their bodies, and asked to draw their body as they saw it before and after their cancer diagnosis. From this data, the authors identified five themes: (1) “Experience of physical body change”, which included the difficulties participants experienced with, for example, losing their hair or living with scarred bodies; (2) “Experience of discomfort”, which included lack of energy, physical pain, and difficulties in unifying their body and soul; (3) “Experience of body at the moment without reflecting on the disease and treatment”, which included participants’ difficulties in reflecting on their bodies in the present, as opposed to pre-cancer; (4) “Experience of body image”, which included both participants’ yearning for what was once “normal”, and their experience of their bodies’ ability to handle the stress caused by cancer; and (5) “Experience of grasping the illness”, which included the difficulties participants faced in understanding that their bodies had cancer, even when they experienced no physical symptoms. Overall, the participants

experienced both physical changes and emotional and mental reactions in response to these changes, and described how their bodies, which they previously took for granted, had become a threat to them and something they had to re-negotiate their understanding of.

Shifting social relationships. Based on the large-scale Australian *Cancer Survival Study* ($N = 1,453$), Hall and her colleagues (2012) investigated the psychosocial wellbeing of a sub-set of young adults aged 18-40 ($N = 58$). When compared to 58 randomly selected older adults (aged 64 years or older), matched for gender and cancer type, the authors found that young adults reported slightly worse social functioning than older adults. Indeed, challenges in familial, peer, and romantic relationships have been noted throughout the literature (Zebrack, 2011). For example, after receiving a cancer diagnosis, young adults may experience increased dependence on their parents during a time of life where they desire increased autonomy and independence (Thomas et al., 2006).

Furthermore, adolescents and young adult cancer survivors may withdraw from healthy peers who they no longer relate to (NCI, 2004), which can result in a diminished social network and resulting emotional and developmental consequences (Treadgold & Kuperberg, 2010). Isolation and alienation are commonly reported by young adults, as they may miss out on or delay “normal” experiences such as dating, moving out on their own, attending university, pursuing employment, and getting married or having children (Zebrack, Hamilton, & Smith, 2009). Furthermore, adolescents and young adults may struggle with the decision about when, and if, to share information about their cancer with friends, peers, new acquaintances, and employers (Zebrack, 2011). Perhaps most concerning is their decision regarding disclosure to dating partners (Zebrack, 2011). Young adult survivors may feel unattractive towards the

opposite sex and fear exposing any physical imperfections to those they are attracted to (Evan, Kaufman, Cook, & Zeltzer, 2006).

Impacts on mental health. Overall, existing research has shown that most adolescent and young adult cancer survivors are psychologically well-adjusted (Zebrack, 2011). However, many young adult survivors may experience an array of mental health issues, including anxiety, depression, feelings of isolation, vulnerability, distress, and, guilt (Marcus et al., 2010; NCI, 2004). In fact, some studies have found that, when compared to older adults, young adult cancer survivors experience higher rates of distress (Stava, Lopez, & Vassilopoulou-Sellin, 2006; Zabora et al., 2001). For many survivors, these concerns may become particularly salient following acute treatment, when longer-term consequences and issues that may not have been addressed or processed during treatment arise (Kelly, Gibson, Langeveld, & Arbuckle, 2008). Furthermore, among cancer survivors, feelings of uncertainty about the future is a substantial concern, which in turn can lead to psychological distress and emotional costs (Decker, Haase, & Bell, 2007; Halliday & Boughton, 2011).

Psychosocial Wellness for Young Adult Cancer Survivors

Momentum is gaining for providing and researching age-appropriate services for young adult survivors, and research findings have supported various psychosocial interventions for young adult cancer survivors (e.g. Canada, Schover, & Li, 2007; Elad et al., 2003; Zebrack, Oeffinger, Hour, & Kaplan, 2006). Although this trend is without question crucial, I believe it is important not to pathologise every young adult cancer survivor – many go on to lead healthy, productive lives following cancer treatment (Zebrack, 2011). In fact, much research suggests that young adults who have survived cancer are generally as psychologically and emotionally adjusted as their healthy peers (Canada et al., 2007; Elad et al., 2003). However, the breadth of

aforementioned concerns led me to wonder about the potential benefits of various psychosocial supports for young adult cancer survivors. I imagine that even those who are well-adjusted might benefit from ongoing psychosocial support. Certainly, age-appropriate interventions have the potential to minimize negative effects and support positive psychosocial adjustment for young adult survivors (Zebrack, 2011). In making this assumption, a second important consideration is brought to light; namely, although many psychosocial interventions can enhance quality of life and provide opportunities for personal growth for young adult survivors, these interventions should be offered in accordance to the survivor's personal readiness (Zebrack, 2000).

Retreats and peer support groups. Currently, few cancer centres in Canada have support groups open to young adult cancer survivors (CCS, 2009). This being said, national organizations such as the Lance Armstrong Alliance in the US and Young Adult Cancer Canada (YACC) are providing much-needed support for young adult cancer survivors and their families, who, for too long, have navigated the health and psychosocial systems in isolation (CCS, 2009). For example, since 2007, YACC has offered retreats where young adults can come together and gain support from other survivors. Research has revealed that retreats offering opportunities for peer connection and educational workshops may be particularly beneficial for young adult cancer survivors and provide experiences that may promote successful achievement of age-appropriate tasks (Zebrack, 2006). For example, Elad et al. (2003) found that an 8-day adventure jeep trip was a beneficial experience for young adult survivors (aged 20-29; $N = 17$). During the trip, young adults were provided opportunities for physical challenges in a group setting, upon which they reported improvements in self-confidence, independence, and social contacts. Furthermore, the trip served as a catalyst for continued group support: participants continued to meet and recruit other young adult cancer survivors into their group activities after the trip's completion. In

a different study, Zebrack and his colleagues (2006) found that the Young Adult Survivor Conference, a 4-day retreat, designed as an educational and support experience for young adults¹ in the post-treatment phase of survivorship, provided an opportunity for young adults to discuss survivorship issues and build connections with other cancer survivors. These studies provide support for the benefits of peer support for young adult cancer survivors; however, more research specifically with young adults is needed.

Online support groups are a rapidly growing support option for young adult survivors. Zebrack (2008) found that, out of 217 young adult cancer survivors (aged 18-40), 95% had used or wanted to use Internet sites that offer cancer education or support that is appropriate to their age group. Online support groups offer several benefits, including: cost effectiveness, bringing large groups of survivors together and thus increasing opportunities for support, overcoming geographical constraints for survivors in rural communities, maintaining anonymity, and overcoming physical limitations (e.g. from invasive treatments) that can prevent some survivors from attending face-to-face groups (Treadgold & Kuperberg, 2010).

Counselling and psychotherapy. In his survey of the needs of young adult cancer survivors between the ages of 18 to 40, Zebrack (2008) found that 76.3% out of 217 respondents wanted mental health counselling; similarly, Merckaert et al. (2010) found that younger adults were more inclined to desire psychological support than older cancer survivors. However, despite research findings that psychotherapy may have a positive impact on emotional distress (e.g. Andersen et al., 2004), a minority of cancer survivors in general are offered (Pascoe, Edelman, & Kidman, 2000) or seek mental health counselling (Nekolaichuk, Cumming, Turner, Yushchyn, & Sela, 2011). In looking specifically at young adult survivors, Zebrack (2008)

¹ Although the lower age limit was not specified in the article, survivors were as old as 39.

found that 38.6% out of 158 young adult survivors who wanted mental health counselling experienced an unmet need for this service. Furthermore, Pascoe, Edelman, and Kidman (2000) conducted a survey at oncology outpatient departments ($N = 504$; aged 20-93 years) and found that the majority of cancer survivors with clinically significant anxiety and/or depression had not received any counselling or psychological treatment. Promisingly, of the 17% of their sample who had received individual counselling, 86% reported that they had found the experience “extremely” or “reasonably” helpful. However, because the median age of participants in this study was 62 years, findings cannot easily be generalized to the young adult survivor population.

In 2006, Osborn, Démoncada, and Feuerstein conducted a meta-analysis of randomized, controlled studies to investigate the effects of cognitive behavioral therapy (CBT) on depression, anxiety, pain, physical functioning, and quality of life (QOL) in adult cancer survivors. CBT is a psychotherapeutic intervention typically involving stress management and problem-solving, with the assumption that unhelpful cognitions can be monitored and altered to facilitate positive behavior change (Osborn et al., 2006). Participants with all types of cancers, ranging in age from 18-84, and from eleven studies in total were included in their analysis. The average length of follow-up was 7.9 months. The authors concluded that CBT is effective for short-term improvement (<8 months) of depression, anxiety, and QOL in cancer survivors, and has long-term effects (>8 months) on QOL. They also found that individual interventions were more effective than group interventions.

The mean age of participants in Osborn and her colleagues’ meta-analysis, when reported, fell into the 40s and 50s. Indeed, I identified very limited research that explored psychotherapy specifically with the young adult cohort. A notable exception is Canada, Schover, and Li (2007), who found that a psychosexual counselling intervention (2 sessions with both educational and

supportive components) was helpful for adolescents and young adults (aged 15-25 years) who were currently being treated for cancer or had been treated for cancer in the past five years. Of the 21 participants, about half were female, and half were randomly assigned to a control waitlist condition (these participants started the counselling intervention 3 months after the “immediate-start” condition). All participants completed self-report questionnaires just prior to the intervention, after the final session of the intervention, and 3 months following the intervention. Compared to the control condition, the immediate-start condition had more knowledge about the effects of cancer on sexuality and fertility ($F = 5.24, P = 0.040$), greater confidence in dating situations ($F = 12.21, P = 0.004$), and less emotional distress ($F = 42.24, P = 0.001$). Furthermore, after both groups had completed the intervention, the authors combined the two groups to increase power in further analyses of the efficacy of the intervention. From baseline to post-intervention they found a significant increase in cancer-related sexual knowledge, an increase in confidence about general appearance, a decrease in participants’ concerns about being able to express affection and about feeling attractive to others, and a decrease in the overall number of sexual concerns. Although the small sample limits confidence that changes in the group were due to the intervention, the results provide preliminary evidence that psychosexual counselling is an important component of young adult cancer care.

A significantly more robust body of psychological intervention research has looked at survivors during active treatment, and less research has examined survivors as they transition into the post-treatment phase (e.g. see Osborn et al.’s meta-analysis, 2006). An exception is a recent study by Marcus and his colleagues (2010), who examined whether a telephone counselling program could improve psychosocial outcomes among early stage breast female cancer survivors entering post-treatment. The intervention included 16, 45-minute telephone

sessions delivered over 12 months by professional telephone counselors in psychosocial oncology, and results from the intervention group ($N = 152$) were compared to results from a minimal intervention control condition ($N = 152$). The authors found significant decreases in sexual dysfunction and significant increases in personal growth in individuals in the intervention compared to the control condition. Furthermore, when dichotomized at cutpoints suggestive of the need for a clinical referral for distress or depression, the control group showed no change in these areas at 18 months, whereas the intervention group showed a 50% reduction in both (distress, $p = 0.07$; depression, $p = 0.06$). However, because only 13.2% of this study's sample was under 40 years old, again there are limitations in our ability to generalize results to the young adult population.

Summary

In light of the diverse and distinct challenges and mental health concerns faced by young adult cancer survivors, it is important that interventions are available that promote social support, decrease distress, and provide opportunities for young adult cancer survivors to make meaning of their experiences (Zebrack, 2000). More research on such interventions is needed, and several leading researchers and national cancer agencies have called for an increased commitment to psychosocial advocacy for the young adult cohort (CCS, 2009; NCI, 2004). As indicated previously, limited research has investigated psychosocial interventions specifically for the young adult cohort. I found that, although many studies with adult cancer survivors do not *exclude* younger adults, the mean age of participants (when reported) often falls in the 40s, 50s or 60s (e.g. see Osborn et al.'s meta-analysis, 2006). Furthermore, most studies on the outcomes of psychological interventions for cancer survivors have been conducted with women and, more specifically, women with breast cancer (e.g. see Osborn et al.'s meta-analysis, 2006).

Finally, research about the potential benefits of psychosocial support for people with cancer has focused largely on group and individual interventions (e.g. peer support groups or individual psychotherapy) that are based on verbal expression (i.e. talking) (Collie, 2003). However, creative- and arts-based interventions are available and may even have advantages over other services that depend on verbal communication. For example, visual creative expression can facilitate emotional expression and communication, and promote personal growth and meaning-making (Geue, 2010). Indeed, such interventions may be particularly beneficial for young adult cancer survivors, but more research is needed to better understand the experience of creative expression and creative interventions for this population. Thus, in the following section, I will explore research on the use of art and art-based interventions within in the oncology literature, after providing an overview of the phenomenon of creative expression.

Visual Creative Expression

In this section, I draw upon research from the disciplines of therapeutic creative expression and art therapy to provide a broad understanding of creative expression as a phenomenon. I will begin by providing a historical overview of creative expression as a healing agent and the emergence of art therapy as a formal profession. A comprehensive review of the history of art therapy and the various art therapy schools of thought is beyond the scope of this review, and readers are guided to Junge (2010) and Karkou and Sanderson (2006) for a more thorough overview. I then distinguish therapeutic creative expression from art therapy, and provide a rationale for my decision to include participants who have engaged in either for the proposed study. I then review the available creative expression and art therapy research, highlighting empirical/outcomes research, process research, and lived experience research.

Historical Perspectives

The use of art for therapeutic and healing purposes has existed for centuries (Karkou & Sanderson, 2006), dating back to the cave paintings of Lascaux, Native American sand paintings, and Navajo dream catchers (Rubin, 2004). Philosophers, authors, and artists alike have long recognized the healing and communicative powers of art. As early as 1886, the influential German philosopher Friedrich Nietzsche stated that, “Art approaches as a saving sorceress, expert at healing” (as cited in McNiff, 2004). Leo Tolstoy viewed art as an indirect means of communication between individuals (Levinson, 2003). And, famous artists like Vincent Van Gogh, Jackson Pollock, and Frida Kahlo used art as a means to cope with their pain and anguish (Rubin, 2004).

When compared to the old-age association between art and healing, the field of art therapy itself is relatively new (Malchiodi, 2006). In the realm of psychotherapy, Sigmund Freud and Carl Jung are largely credited for first integrating the visual arts with the psychological (Junge, 2010). Freud’s notion that art provided access into the unconscious, and, later, Jung’s interest in the psychological meaning of images influenced many psychiatrists to begin using art in their diagnostic and analytic work. In North America, art therapy as a distinct field formally emerged in the 20th century with the work of Margaret Naumberg and Edith Kramer, who helped shift the focus from art as a diagnostic tool to art as a therapeutic process (Junge, 2010). The past decade has witnessed extraordinary growth in the art therapy field; however, this growth has been coupled with confusion about what, exactly, art therapy is (Junge, 2010). Although some view art therapy as simply a technique or set of tools, it is, in fact, “a unique profession, in that it combines a deep understanding of the creative process with an equally sophisticated comprehension of psychology and psychotherapy” (Rubin, 2010, p. xxvi). In line with Rubin’s

definition, the American Art Therapy Association (AATA, 2011) defines visual art therapy as the therapeutic use of art media, images, and the creative process, within a professional relationship, to “improve and enhance the physical, mental and emotional well-being of individuals of all ages” (Art therapy, para. 1). Today, art therapy is used with children, adolescents, families, adults, couples, and groups to help individuals suffering from a wide variety of concerns, including schizophrenia, trauma, grief, depression, and illness (Rubin, 2004).

Therapeutic Creative Expression vs. Art Therapy

According to Edith Kramer (1958), an early pioneer in the art therapy field, the process of creative expression is inherently healing. Similarly, Naumberg (1966) viewed art as a form of symbolic communication that facilitates emotional expression, and has the potential to bring new insights and understanding. Indeed, many art therapists today hold the belief that creative expression in and of itself is therapeutic (e.g. McNiff, 2004; Rubin, 2004).

This being said, Dalley (1984) argued that there are fundamental differences between individual creative expression and creative expression as used in a therapeutic setting. Some art therapists believe that, as healing as individual creative expression is, it is not necessarily therapeutic in and of itself (Patterson et al., 2011). Certainly, the elegance of art therapy is that it provides a safe and respectful environment, within a predetermined framework, to use creative expression for the particular purpose of developing a deeper sense of personal understanding (Davis, 2004). Indeed, while the art materials provide a medium for the externalization of emotions and feelings, the art therapist provides the context within which the client can feel safe to explore what has been externalized (Wood, 1998). The art therapist brings with him or her the capacity to help clients work with subtle communication expressed in the artwork and explore

deeper emotions (Wood, 1998). Meaning in artwork can then extend from interaction and dialogue between art therapist and client (Davis, 2004).

Although I acknowledge that there are certainly differences between creative expression undertaken individually and creative expression undertaken in a therapeutic setting, I chose to explore creative expression in both contexts in the proposed study. This decision is supported by the claims of Shaun McNiff, an international leader in the arts and healing field, who stated that:

Art adapts to every conceivable problem and lends its transformative, insightful, and experience-heightening powers to people in need. Many of us explore the healing power of art on our own, while others do it with the guidance and in the safety of therapeutic relationships. The medicines of art are not confined within fixed borders. Wherever the soul is in need, art presents itself as a resourceful healer (McNiff, 2004, p. 5).

Furthermore, existing research has supported the therapeutic qualities of creative expression in both of these contexts. Collie and her colleagues (2006) used narrative methods to explore how women with breast cancer used not only art therapy, but also independent creative expression, to address needs that arose for them following their cancer diagnosis. The authors found few differences between the women's stories about art therapy versus individual creative expression. However, they stressed that all women who participated in creative expression outside of art therapy had a witness or recipient to their artwork, which was an important component of the therapeutic experience.

Creative Expression and Art Therapy Research

In recent years, research interest has intensified within the art therapy and creative expression fields (Moon, 2000). However, the body of literature that has accumulated since art therapy's inception is still rather minimal (Slayton, D'Archer, & Kaplan, 2010). Some art therapists view research as being incongruent with their healing aims and the essence of the creative process (Deaver, 2002; McNiff, 2004). The reluctance of some art therapists to engage

in research endeavors may be grounded in a lack of training in research methodology, or by the fear that all research methods are grounded in an overly objective, evaluative approach that conflicts with the subjective, nonjudgmental nature of art therapy (Deaver, 2002). This being said, research has become a priority in the art therapy profession (Deaver, 2002). Many art therapy researchers have called for more practical, theory-building, and institutional research foundations in order to enhance clinical practice, define the theoretical underpinnings of art therapy, and bolster the identity of art therapy as a profession (Deaver, 2002).

In the late 1990s, researchers argued that art therapy research was limited by its overwhelming tendency to focus on the analysis of art products (Ball, 1998; Malchiodi, 1998). Studies focusing solely on the art product have been criticized for removing artwork from its context; that is, the creative process (Ball, 1998). A key shift in research in the past 10-15 years is its movement away from the art product to the art process (Karkou & Sanderson, 2006). In line with this trend, increasingly more empirical studies on the outcomes and effects of creative expression and art therapy have emerged. Furthermore, exploratory studies on both the process of art therapy and the lived experience of creative expression in a variety of contexts have become more prevalent. This being said, there remains a need for more research in all of these areas.

Empirical research. Despite lack of an obvious adaptive or evolutionary reason why humans are drawn to creative expression, this phenomenon appears to have many benefits for various individuals. Recent empirical studies have revealed the physiological effects of creative expression. For example, Drake, Coleman, and Winner (2011) demonstrated that visual creative expression improved mood to a greater extent than a writing exercise. Similar studies have shown that visual creative expression improved mood significantly more than various forms of distraction (e.g. completing word puzzles) (Bell & Robbins, 2007; De Petrillo & Winner, 2005).

In turning to the art therapy literature, several researchers have emphasized the importance of providing evidence for the effectiveness and outcomes of art therapy (Slayton, D'Archer, & Kaplan, 2010). Outcome studies are concerned with the results of a process, and whether or not art therapy has achieved the objectives it set out to achieve (Kapitan, 2010). Outcomes research has also been defined as a systematic approach to measuring short- and long-term outcomes of care, and incorporating the subjective and objective experiences of clients, therapists and/or providers (Julliard, 1998). Such research is important because, although art therapists believe intuitively that art therapy works, because little research has demonstrated the efficacy of art therapy, the profession is at a disadvantage when presented to the general public, employers, insurance companies, and clients themselves, who may be unclear about what art therapy is (Kapitan, 2010). Furthermore, it is important to investigate whether there is any evidence of what works and does not work in art therapy (Kapitan, 2010), whether art therapy has effects on certain variables and preconditions, and whether health benefits are short-term or sustained (Stuckey & Nobel, 2010).

In 2010, Slayton and her colleagues conducted a review of studies published between 1999-2007 that measured outcomes of art therapy effectiveness with all ages of clinical and nonclinical populations. Studies that combined art therapy with other expressive arts therapies (e.g. music therapy) were excluded from the review, as were studies that examined the impact of art activities without the presence of an art therapist or qualified clinician. Through their analysis, the authors identified 7 detailed qualitative studies, 13 single-subject pre-posttest designs, 4 studies using control and treatment groups without random assignment, and 11 controlled clinical trials with randomized assignment to groups. From their review, the authors concluded that, although more research is needed, “a small body of studies now exists in which art therapy as a

treatment modality has been isolated, measured, and shown to be statistically significant in improving a variety of symptoms for a variety of people with different ages” (p. 115). However, Slayton et al. (2010) highlighted several complications in their review that are typically encountered in art therapy outcomes research. For example, there remains a lack of standardized reporting and control groups, and a trend of using anecdotal case material as opposed to measured results. Furthermore, often only ambiguous descriptions of study procedures were provided.

Process research. In 1998, Malchiodi asserted that the process is the most important component of art therapy, as opposed to solely seeking to find meaning in or interpret the art expression itself. However, systematic research investigating the art therapy process appears to be the most absent in the art therapy literature. Although a well-defined and descriptive definition of the art therapy process could not be identified, Hill and Williams’ (2000) oft cited definition of the counselling process as the “overt and covert thoughts, feelings, and behaviours of both clients and therapists during therapy sessions” (p. 670) lends itself well to art therapy.

Most existing studies of the art therapy process have been in the domain of narrative case studies. These case studies have been criticized for providing only anecdotal information from the perspective of the art therapist. Thus, several researchers in the art therapy field have called for more systematic research on the process of art therapy (e.g. Ball, 2002; Malchiodi, 1998). Patterson et al. (2011) used grounded theory to explore art therapists’ perspectives of the process of creative expression and art therapy. Findings revealed that art therapists, without exception, believed in the intrinsic value of creative expression.

In a different study, Ball (2002) studied the art therapy process by observing 50 individual art therapy sessions with five emotionally disturbed children over the course of one year.

Additionally, she interviewed the residing art therapist about her understanding of the therapeutic process in a total of 11 comprehensive meetings. The focus of Ball's investigation was inspired by her observation that art therapists were unable to fully describe the intricate experience of change in art therapy. Thus, Ball systematically analyzed the interactions between the art therapist, client, and creative expression in order to identify moments of change in the art therapy process. Using one case example, Ball concluded that, "the mystery of change centered mainly around the emotional aspect of the therapeutic experience and the mutual influence of therapist and client" (p. 91).

Lived experience research. Over the past two decades, phenomenological studies have been utilized to explore the lived experience of creative expression with a variety of individuals; for example, a woman who had been sexually abused (Quail & Peavy), international students enrolled at university (Davis, 2010), and individuals in mental health recovery (Van Lith, Fenner, & Schofield, 2011). These studies are reviewed in more detail below.

Quail and Peavy (1994) used a phenomenological approach to explore the meaning revealed in a client's descriptions of her experience of artwork created in art therapy over time. After participating in a 16-week art therapy group for women who had been sexually abused, the participant was interviewed in the presence of her artwork until she had conveyed everything she wanted to (in a total of five interviews). During the interviews, the participant was asked about her lived experience of the artwork in therapy, what she could remember about the making of, looking at, and discussion of her artwork, and her experience of the art therapist and group members. Findings revealed that the participant worked intentionally towards connecting with and expressing her inner emotions and experiences. Once the client let go of her expectations to create a perfect aesthetic representation of her inner visual image, which was supported in part by

the art therapist's tacit and direct guidance, meaning emerged and formed in the artwork. From this, "the client experienced increasing awareness and understanding. There was excitement, a sense of discovery" (p. 49).

More recently, Davis (2010) utilized a phenomenological approach based on a hermeneutic grounded theory methodology to investigate the lived experience of art therapy for 19 international students at an Australian university. Part of her research entailed retrospective phenomenological interviews; additionally, her analysis included the recording of observed behaviour and the audio-recording of in-session discussion to add to hermeneutic insights. Findings revealed that art therapy provided a context for exploring autonomy, identity, and the expression of emotions in relation to sojourn adjustment.

Also recently, Van Lith and her colleagues (2011) explored the role of creative expression in the mental health recovery process. The authors interviewed 18 participants who had attended art-based programs in two psychosocial services in Australia. An interpretive phenomenological analysis was conducted in order to understand the lifeworld of and how meaning occurred for participants. The authors grouped the 11 identified themes into three categories: (1) Qualities conducive to the art-making context, (2) How the art making process benefits mental health recovery, and (3) How the image benefits mental health recovery. The first category included aspects of the service-delivery context, including: feelings of belonging and security provided by the setting, having a facilitator who provided guidance and support, and experiencing group connectedness through acceptance and encouragement. The second theme encompassed aspects of the creative expression process that participants believed benefited mental health recovery, including: using art to create balance and wellness, becoming absorbed in the creative process to enable wholeness and perspective, releasing tensions through art, and creating a will to achieve

and keep developing through the challenges and rewards experienced in creative expression. Finally, the third category involved the ways the image gave back to the participant, including: the image providing insights about emotions and wellness, gaining a sense of validation through reflection on personal meanings reflected in the artwork, and gaining encouragement and motivation from others as friends and family celebrated the participants' artwork.

Research that has explored the lived experience of creative expression in the context of oncology and chronic illness has also emerged in the past couple decades. This research is discussed in the following section on creative expression and art therapy in oncology.

Creative Expression and Art Therapy in Oncology

Over the past two decades, increasing attention has been paid to the use of creative expression and art therapy as psychosocial interventions for individuals with cancer, at all stages of medical care (Geue, 2010). In 2010, Geue and her colleagues examined 17 studies published between 1999 and 2009 (excluding case studies) that investigated the effectiveness of art therapy (in the form of painting or drawing) with adult cancer patients. The authors noted that every paper they examined illustrated art therapy's positive effect(s) on participants in some way.

In the following section, I turn to the creative expression and art therapy in oncology literature. I outline the therapeutic potential of creative expression in this context by reviewing the available literature, and describe one available example of art therapy specifically with young adult cancer survivors and one example of creative expression with a young adult cancer survivor in the popular press. Additionally, I review phenomenological studies particularly relevant to the proposed study that explored the lived experience of creative expression with cancer survivors. I also describe a theoretical perspective on creative expression and healing. In doing so, I hope to

paint a picture of the current discourse about how visual creative expression is experienced by and can be helpful for young adult cancer survivors.

Therapeutic Potential of Creative Expression and Art Therapy in Oncology

What is the potential for creative expression and art therapy in oncology? Quantitative studies have revealed art therapy's potential to improve psychological and physical symptoms in cancer patients, and to improve quality of life (Geue, 2010). Furthermore, qualitative investigations have described art therapy's facilitation of emotional expression and communication, and promotion of personal growth and meaning-making (Geue, 2010). These areas will be elaborated on below.

Improving psychological and physical symptoms, and quality of life. There is an expanding body of literature that supports art therapy's potential to positively impact depression, anxiety, stress, fatigue, somatic symptoms, self-esteem, and quality of life (QOL) in cancer survivors (Svensk, 2009; Thyme et al., 2009). For example, Bar-Sela and his colleagues (2007) found significant improvements in depression scores and, to a lesser degree, fatigue scores, following an art therapy intervention for cancer patients undergoing chemotherapy treatment. In a different study, Svensk (2009) found that women with non-metastatic breast cancer who participated in five individual art therapy sessions significantly improved in self-reported quality of life compared with a control group. Monti et al. (2006) reported similar improvements in key aspects of quality life in the intervention group in their randomized controlled trial of mindfulness-based art therapy for women with cancer.

In a qualitative study, Luzzatto and Gabriel (2000) described an art therapy intervention, called The Creative Journey, which was designed for patients of all ages, with all types of cancer, and who were outpatients and had completed their initial course of treatment. Following the 10-

week intervention, 70 patients completed written questionnaires based on two questions: what did they find helpful, and what did they find unhelpful. Findings revealed that most participants emphasized a change towards more positive moods and feelings, an increase in self-awareness, and more trust, respect, and compassion for others. The authors concluded that The Creative Journey intervention could help post-treatment cancer survivors integrate their cancer experience into a new identity. However, the evaluation procedures were not well documented in this study; thus, findings must be viewed as anecdotal evidence (Collie, 2003).

Facilitating emotional expression and communication. A cancer diagnosis creates a range of difficult issues and emotions in individuals, many of which are difficult to address. However, avoiding the expression of such feelings can have detrimental consequences (Borgmann 2002). Creative expression offers a non-intimidating, sensory means for individuals with cancer to externalize and express difficult emotions (Malchiodi, 2008). Indeed, deeply emotional or traumatic experiences, such as those that may accompany the cancer survival journey, may be difficult to access with words alone because, as Bessel van der Kolk (1996) argued, traumatic and highly emotional memories may be initially organized on a perceptual, rather than verbal, level. In other words, when people remember a traumatic event or experience, their implicit memory of trauma (that which is sensory and emotional) may be excluded from explicit memory storage (that which is verbal and composed of facts and ideas) (Malchiodi, 2008). Thus, the resulting implicit memory may not be felt at a conscious level (Swallow, 2002). In addition, Broca's area, the part of the brain in the left hemisphere that controls language, shuts down, causing the experience and feelings to be stored as sensations and images in the right cerebral hemisphere, and not readily communicated through language (Malchiodi, 2008). Thus, verbal therapies alone may not be adequate to facilitate emotional expression in cancer survivors,

because when people are asked to simply think or talk about their intensely emotional or traumatic experiences, the verbal left hemisphere is activated first, and censorship may occur.

However, during creative expression, individuals can express emotional material that might not have been expressed otherwise (Naumburg, 1966). Similarly, during art therapy, individuals are given the opportunity to first express themselves through art, and then to reflect on their creative expression verbally, so that both hemispheres of the brain are activated and previously unconscious material becomes available to the conscious mind (Dalley, 1984). Findings in the literature support art therapy's facilitation of emotional expression. For example, Borgmann (2002) found that art therapy with women diagnosed with cancer promoted self-expression; similar findings were reported by Collie and her colleagues (2006), who looked at both individual creative expression and creative expression in art therapy settings.

Insight and meaning-making. Through the process of using art materials to facilitate the expression of cognitions and emotions on a symbolic level, a sense of distance is created that helps people express difficult emotions in a way that feels safe (Ferris & Stein, 2002). Once internal suffering has been given an external form, it can be explored and understood. Over time, the externalization of emotions and experiences through art can lead to new insights and perceptions that in turn lead to healing and growth (Malchiodi, 2008). Furthermore, creative expression and art therapy can be important avenues for meaning-making. In a well-designed study, Collie and her colleagues (2006) found that creative expression, both individually and with an art therapist, was a valuable means for meaning-making in women with cancer, and promoted four different storylines: Art and Art Therapy as a Haven, Getting a Clearer View, Clearing the Way Emotionally, and Enhancing and Enlivening the Self.

Creative Expression and Art Therapy for Young Adult Cancer Survivors

Although several existing studies on the use of art therapy with adults with cancer do not *exclude* young adults, very few focus specifically on the age range of 19-35. In fact, in the majority of studies I examined, the mean age of participants, when reported, fell in the 40s, 50s or 60s (e.g. Monti et al., 2006; Puig et al., 2006; Svensk, 2009). A notable exception is a pilot program funded by the BC Cancer Agency in 2011 that involved an arts-based support group for young adults with cancer (Prins Hankinson, 2011). Six individuals aged 22-33 participated, and findings from surveys conducted with participants following the intervention revealed that all participants felt supported in the group and would recommend the group to others (Prins Hankinson, 2011). Although this study provided preliminary support for group-based art therapy for young adults with cancer, it did not employ a rigorous methodology and is not published in a peer-reviewed journal; thus, it is not well positioned to garner attention. It is clear that more research on creative expression and art therapy with young adult cancer survivors is needed.

In turning to the popular press, Robert Pope (1956-1992) was a dedicated and famous Nova Scotian artist who died of Hodgkin's Disease at the young age of 36, and who turned to creative expression following his cancer diagnosis. Pope is well known for his rich body of visual artwork that explores his experience of healthcare and healing as a cancer patient (Robert Pope Foundation, 2010). His thoughtful, expressive, sometimes painful, and sometimes celebratory representations of his experiences through drawings and paintings have been exhibited nationally and internationally. They also comprise the moving visual narrative, *Illness and Healing, Images of Cancer* (1991), which has informed current thinking about illness and healing. This narrative is used as a text in medical schools across the country, and invites

reflection about how art can be used as a healing tool for those facing illness. In the words of Pope:

Art is a powerful preventive medicine. Looking at a picture is like walking through an endless series of doors, with each succeeding door leading us deeper and deeper into a rich experience. This journey stimulates our minds, our emotions, our souls; it makes us more alive. Ultimately the esthetic experience heals us and makes us whole (Pope, 1991, p. 137).

The Lived Experience of Creative Expression in Oncology and Chronic Illness

The current study can be understood in terms of other phenomenological studies that have revealed insights into the lived experience of creative expression in the context of cancer and chronic illness. Three identified published studies have made valuable contributions to the literature by exploring in-depth experiences of cancer survivors in creative expression activities (Lane, 2005; Reynolds & Lim, 2007a; 2007b; Reynolds & Prior, 2003). Other related studies have investigated the lived experience of creative expression for individuals with other health concerns (Reynolds & Vivat, 2008; Reynolds, Vivat, & Prior, 2011). Although one strategy in phenomenological research is to delay the review of pertinent phenomenological research until after analysis (Nicol, 2001), I have chosen to review this literature prior to beginning the proposed study in order to gain as deep an understanding of creative expression as possible. The steps taken to limit any pre-assumptions this may cause are discussed in the methodology section of this proposal.

Frances Reynolds is a researcher in the occupational therapy field whose research focuses mainly on the meanings of creative activities for people with physical health concerns, mental health issues, or who are struggling with the adversities associated with ageing. She also explores the role creative activities play in maintaining identity and well-being. In the past 10 years, Reynolds has utilized interpretive phenomenology to explore the lived experience of creative expression for individuals with a variety of health concerns, including chronic fatigue syndrome

(Reynolds & Vivat, 2008), arthritis (Reynolds, Vivat, & Prior, 2011), chronic illness and disability (Reynolds & Prior, 2003), and cancer (Reynolds & Lim, 2007a; 2007b).

Reynolds and Vivat (2008) explored the initial motives for women living with chronic fatigue syndrome in taking up leisure creative expression (mainly textiles, but also painting, pottery, and card-making), and then investigated how creative expression had influenced their subjective well-being. Interviews with 10 women were analyzed using interpretive phenomenological methodology, and results showed that women turned to creative expression after they accepted the long-term nature of their illness because it was perceived as being manageable within their health constraints. Creative expression was also seen as being a means of emotional exploration and self-expression. Once visual creative expression was established as a leisure activity, the authors found that creative expression contributed to the women's subjective well-being by increasing satisfaction in daily life and creating positive self-image. The authors also discovered that creative expression facilitated feelings of hope, and increased contact with the outside world from the confines of home. In terms of this last theme, contact was rarely achieved in the literal sense, but rather through reviving memories and sharpening appreciation of the environment inside and outside the home. Distinct and overlapping themes were discovered in an additional study wherein Reynolds, Vivat, and Prior (2011) explored whether and how leisure visual creative expression provided a coping resource for older women living with arthritis. Again, utilizing interpretive phenomenological analysis, the authors found that participants ($N = 12$) experienced creative expression as a way of controlling pain (through deep concentration and use of colour and imagery), as encouraging sustained attention away from the body and its limitations, and as developing positive identity and self-esteem.

In turning to Reynolds' work in the context of cancer, two recent overarching studies provided valuable information on the lived experience of creative expression. In the first of these, Reynolds and Prior (2003) interviewed 30 women with chronic illness (including, for example, arthritis and multiple sclerosis in addition to cancer) in order to explore the meanings and functions of leisure creative expression (specifically textile arts) for these individuals. Five additional women contributed written narratives, comprising a total sample of 35 women. Results showed that textile arts helped women distract thoughts from their illness, express grief, fill an occupational void, increase their sense of control, increase mindfulness, enable revisiting of priorities, enable flow and spontaneity, facilitate joy and humour, build a positive self-image, increase new social relationships, and contribute to others. Additionally, because illness often creates uncertainty about the future, creative expression helped many participants make plans for the future and increased their determination to cope and recover. Based on this study, the authors published an additional article that focused on four case studies of participants living with cancer in order "to situate the phenomenon in its real life context" (Reynolds & Prior, 2006). The research questions that guided this inquiry were: What experiences encourage some people to create visual artwork in daily life when living with cancer? In what ways does visual creative expression in daily life support identity maintenance/reconstruction after a cancer diagnosis? The authors found that creative expression enabled personal growth, while at the same time re-establishing their familiar identities and maintaining previously important aspects of their lives. The authors concluded that their study showed how a meaningful activity like creative expression could play a substantial role in helping individuals resist being defined by their illness, and for facilitating personal and social coping.

In 2007, Reynolds and Lim published two articles based on a study that explored accounts of 12 women diagnosed with cancer who engaged regularly in art as a leisure activity. The authors' goals were to investigate how creative expression contributed to the women's subjective wellbeing (2007a) and to explore the personal motives and contextual influences of the women in taking up creative expression (2007b). The authors found that art symbolized the cancer experience for participants. Furthermore, similar to past studies, they found that creative expression focused attention on life experiences other than cancer, maintained personal identity and self-worth, and preserved an "able" social identity.

Reynolds and her colleagues' wide range of publications on the lived experience of creative expression have contributed invaluable understanding of the phenomenon of creative expression. However, their research left me with a few questions. Firstly, much of Reynolds' work has been conducted largely with the textile arts. Although this was done with the goal of focusing on a shared artistic medium, I was curious about the lived experience of other forms of creative expression. Certainly, every art medium has unique capabilities and limitations, and each has a different effect on emotions (Malchiodi, 1997). For example, watery paint, due to its uncontrollable nature, can elicit intense emotions (Malchiodi, 1997), whereas clay, which clients can throw, smash, or pound, can assist with the expression of anger (Sherwood, 2004). Furthermore, Reynolds' work is almost exclusively focused on the experiences of women. Thus, I became curious about the experiences of their male counterparts. Finally, her studies looked at creative expression solely undertaken as a leisure activity. While this research is certainly valuable because it informs us about the lived experience of creative expression in participants' everyday lives, I wondered about the lived experience of creative expression in therapeutic settings.

Lane's (2005) study began to answer my curiosities by exploring the lived experience of art and healing for 63 participants (both men and women) in the Arts and Healing Medicine Program at the University of Florida. Lane's study did not focus solely on one type of visual creative expression; at the same time, it also encompassed dance and writing. These forms of creative expression may differ from the visual arts. Participants included hospitalized patients ($N = 23$), artists ($N = 18$), family members ($N = 12$), and healthcare providers ($N = 10$). This well-designed study continued for four years, until data saturation was reached, and Lane closely followed van Manen's (1990) hermeneutic phenomenology by writing and re-writing the participants' stories several times to grasp the essence of the revealed themes. She uncovered eight, non-linear themes of healing in art: (1) Going into darkness (most people began with an experience of pain, articulating loneliness, fear and grief), (2) Going elsewhere (the person begins to leave the pain behind), (3) Making art as a turning point and becoming immersed in the creative process, (4) Slipping through the veil (participants go deeper into themselves), (5) Surrendering to the process and know what to do to heal, (6) Embodying spirit, and (6) Experiencing transcendence (feeling connection with something larger than themselves).

In reading the work of both Lane and Reynolds and her colleagues, I was struck by the depth and diversity of the therapeutic benefits of creative expression. The findings revealed that artistic endeavors addressed two main tasks for cancer survivors: namely, coping with/managing the constraints of illness while building a satisfying life that breaks out of the confines composed by cancer (Reynolds & Prior, 2003). However, I was also left wondering if the lived experience of creative expression is the same for younger adults, because the mean age of participants in all of these phenomenological studies ranged from the late 40s to 60s. With the goal of furthering phenomenological understanding, further research might vary the example (van Manen, 1990) by

exploring creative expression specifically with the young adult cancer survivor population. Furthermore, the aforementioned studies looked at art-making leisurely (e.g. Reynolds & Prior, 2003) *or* in a specific art therapy program (Lane, 2005). I anticipated that it might be useful for further research to investigate creative expression in both settings, allowing participants to determine how they defined creative expression in their lives (whether engaged in spontaneously in leisure time, or pursued with an art therapist). Finally, I argue that all of the aforementioned studies did not rigorously follow a phenomenological method in that they asked pre-determined questions about the experience of creative expression. For example, Lane (2005) asked participants “How was the process of making art an experience of healing?”, and Reynolds and Lim (2007a) asked participants “In what ways has your artistic work helped you manage/live with your health problems?”. Further phenomenological studies could aim to remain more open to the lived experience of creative expression by avoiding such leading questions.

A Theoretical Perspective on Creative Expression and Healing

Shaun McNiff is an internationally recognized leading figure in the arts and healing field. He is past president of the American Art Therapy Association, and has written numerous books on the process of creative expression and healing. In his book, *Art Heals: How Creativity Cures the Soul* (2004), he offered his progressive theoretical views on the field of art therapy. For example, he stressed that: (1) imagination is a powerful force for transformation,(2) the psychological interpretations of artwork is an outdated tradition that must be challenged,(3) even disturbing images have inherent healing properties, (4) group work can be incredibly healing as people create alongside and interact with each other, and (5) “total expression” can be achieved by combining creative expression with movement, storytelling, and drumming. In the context of

illness, McNiff argued that individuals experiencing medical traumas want to be actively involved in and enhance their healing process through creative expression.

Summary

In sum, there are many psychological and physical impacts associated with cancer; these impacts are unique and distinct amongst the young adult survivor population. Creative expression, which has been utilized as a healing process for centuries, is emerging as a meaningful avenue for cancer survivors at all stages of medical care. Quantitative, qualitative, and theoretical research has helped paint a picture of the therapeutic potential of creative expression and art therapy in the oncology field. However, very limited research has investigated creative expression and art therapy specifically with young adult cancer survivors. Thus, I became curious to know more deeply what experiential meaningfulness occurs in visual creative expression for this population, and I wanted to communicate this experience to others. I anticipated that a hermeneutic phenomenological inquiry could provide a meaningful means to achieve this goal, because it centres around vocative writing, aims to involve readers, and facilitates personal knowing (van Manen, 1990). And so, the research question formulated for reflection and exploration was: “What is the lived experience and lived meaning of visual creative expression for young adult cancer survivors?”

Chapter Three: Methodology / *Medium*

Medium - A specific substance an artist uses to create her artwork.

The present study employed a hermeneutic-phenomenological method to answer the following research question: What is the lived experience and lived meaning of visual creative expression for young adult cancer survivors? In the following chapter, I situate the current study, and provide a background to phenomenological philosophy and phenomenological methodology. I then introduce van Manen's hermeneutic phenomenology, and articulate a rationale for my decision to utilize this particular research method to answer the question of interest. Additionally, I provide a detailed breakdown of the two types of inquiry activities utilized in van Manen's hermeneutic phenomenology: empirical and reflective methods (2011). In doing so, I describe how I will address van Manen's research activities, while adhering to the spirit of van Manen's methodology (by addressing the "reductio" and the "vocatio"). Finally, I outline ethical considerations, in addition to the epistemic criteria used to ensure the truthfulness of the proposed inquiry.

Situating the Inquiry

Research methods are mediums for carrying out certain kinds of research questions (van Manen, 1990). In other words, the research question, not the method itself, should serve as the starting point for any inquiry (van Manen, 1990). This being said, "there exists a certain dialectic between question and method" (van Manen, 1990, p. 2). Thus, I turned to the potential methodologies I could utilize to answer the current study's question (what is the lived experience and lived meaning of visual creative expression for young adult cancer survivors?) It was clear that a quantitative approach would not produce the depth of information sought, and would be inadequate to explore the diverse experience that is creative expression. In deciding which

qualitative approach to espouse, I concluded that a phenomenological study was highly suited to explore the lived experience of creative expression. According to Edmund Husserl (1970b) – the 20th century father of the philosophical school of phenomenology – phenomenology is the study of the lifeworld as we immediately experience it. Studies using phenomenological methodologies aim to articulate a deeper understanding of the meaning of everyday experiences. This is in line with the goal of the current study, which is to elucidate a more profound understanding of creative expression as it is experienced by young adult cancer survivors.

Phenomenological Philosophy

Phenomenological research is founded on and rooted in phenomenological philosophy (Dowling, 2007). Phenomenology arose as a philosophy with the fundamental work of Edmund Husserl (1859-1938) in pre-World War I Germany, and continues to occupy an important position in modern philosophy (Dowling, 2007). Husserl (1970a) argued that the “lifeworld” (*Lebenswelt*), or the “world of immediate experience” (p. 188) is pre-reflective and naïve. The goal of phenomenology is to get at this world of human experience without letting pre-conceptions and theoretical notions getting in the way (van Manen, 1990, p. 184). To achieve this rigorous study of lived experience, Husserl developed the idea of “phenomenological reduction”, wherein the phenomenologist reduces the world as it is considered in the natural attitude, and meets the phenomenon in an unbiased and free manner (Dowling, 2007). The focus of Husserl’s phenomenology was largely descriptive –he sought to arrive at and describe an essential understanding of a phenomenon that was free from assumptions and biases (Fleming, Gaidys, & Robb, 2002).

Martin Heidegger (1889-1976), also a German philosopher, was influenced by Husserl’s work (Nicol, 2001). Like Husserl, Heidegger was concerned with the study of lived experience;

however, unlike Husserl, his hermeneutic phenomenology emphasized the importance of understanding or interpretation over description (Dowling, 2007). The most important component of Heidegger's hermeneutic phenomenology is the meaning of Being (van Manen, 1990). To get at the meaning of Being, the phenomenologist must cycle between pre-understanding and understanding (the hermeneutic circle) (Dowling, 2007). Indeed, whereas Husserl believed that truth was accessed through phenomenological reduction, Heidegger maintained that truth was accessed through hermeneutic interpretation (Cohen & Omery, 1994).

Phenomenological Methods of Inquiry

The philosophies of Husserl and Heidegger are frequently used to underpin qualitative research; however, neither of these philosophers developed specific research methods (Fleming et al., 2002). According to Giorgi (2000), researchers and psychologists can ground themselves in phenomenological philosophy; however, in order for human science research to be performed, the insights from phenomenological philosophy must be developed into a workable model for scientific practice. Currently, there are many different approaches to phenomenological research. Each approach has both overlapping and distinct features, and each is influenced by the strand of phenomenological philosophy to which it adheres (Dowling, 2007). For instance, the descriptive phenomenological research approach, which is linked to Husserl's philosophy and was developed by Amadeo Giorgi and his colleagues in the 1970s, is characterized by rigorous, analytic research steps (Giorgi & Giorgi, 2003). Giorgi's human science approach maintains that phenomenological research is pure description, and that the object of this description is fully achieved by directly grasping the essential structure of a phenomenon as it appears in consciousness (van Manen, 1990). Alternatively, interpretive phenomenology, which is linked to Heidegger's philosophy, is less concerned with description, and more concerned with grasping

the meaning of a phenomenon with the purpose of understanding lived experience (Crist & Tanner, 2003). This method of phenomenology is concerned with language and dialogical reflection, and maintains that interpretation is an inevitable and, in fact, desirable component of phenomenological inquiry.

Van Manen's hermeneutic-phenomenological approach to research. Canadian phenomenologist Max van Manen developed a hermeneutic phenomenological research model that combines both descriptive and interpretive phenomenology (Dowling, 2007). His approach has been utilized by researchers in education, nursing, and counselling psychology, and is particularly appealing due to its accessibility, pragmatic orientation, and attention to phenomenological writing (Nicol, 2010).

Van Manen's (1990) approach is composed of an interplay amongst six research activities: (1) turning to a phenomenon which seriously interests us and commits us to the world, (2) investigating experience as we live it rather than as we conceptualize it, (3) reflecting on the essential themes which characterize the phenomenon, (4) describing the phenomenon through the art of writing and rewriting, (5) maintaining a strong and oriented pedagogical relation to the phenomenon, and (6) balancing the research context by considering part and whole. Additionally, van Manen (2011) distinguishes between his methodology and the methods used to undertake this methodology. Firstly, the general attitude of van Manen's methodology is reflected by the "reductio", which involves suspending our everyday "natural attitude", and by the "vocatio", which allows meaning to "speak" through the vocative power of writing and language (van Manen, 2011). Secondly, his method involves two types of inquiry activities: empirical and reflective methods. Empirical methods serve to generate data by allowing for the exploration of prereflective experiential material pertinent to the phenomenon of interest. Reflective methods

serve to analyze data by allowing for the interpretation of the meaning associated with the phenomenon (van Manen, 2011).

Van Manen's hermeneutic phenomenology is especially appropriate to undertake the proposed research endeavor, which wonders about the lived experience of creative expression for young adult cancer survivors. Hermeneutic phenomenology is the study of lived experience, and of the inner perceptual world of human beings (Nicol, 2001). Creative expression is one such lived experience that is often taken for granted; thus, it may be meaningful to transform this lived experience into a textual expression of its essence. Indeed, van Manen (1990) takes the approach that, at its core, hermeneutic phenomenology is a textual activity. Bringing language and thoughtfulness to a phenomenon through expressive, vocative writing may be a meaningful way to substantiate the richness that is creative expression. Furthermore, in attempting to describe creative expression without the distortion of pre-existing conceptualizations or theories, I may be able to articulate it in such a way that creative expression is recognized in a deeper, more profound manner (Nicol, 2001).

Empirical Methods (Data Generation)

Situating the researcher: turning to the nature of lived experience. Because the starting point of hermeneutic phenomenological research is "ego-logical" (van Manen, 1990, p. 54), my own personal experiences, interests, and training provided an initial source of data for the present study. Keeping in line with van Manen (1990), it was important for me to reflect upon my own lived experiences, for they are accessible to me in a way that no one else's are, and may possibly reflect the experiences of others. According to van Manen (1990), "to be aware of the structure of one's own experience of a phenomenon may provide the researcher with clues for orienting oneself to the phenomenon and thus to all the other stages of phenomenological research" (p. 57).

Thus, the following section highlights my personal “lived-experience description” (van Manen, 1990, p. 63), which provided a starting point for me to orient to the phenomenon of interest, and assisted me in recognizing the assumptions and pre-dispositions I brought to this study.

Lived-experience description. Visual creative expression has speckled the canvas of my life since I could hold a pencil. Childhood creative expression experiences splash through my memories in vivid colour, and testaments to my creativity are physically present to this day in the watercolor paintings, patchwork quilts, and lopsided pottery dishes that my parents have sentimentally preserved. My most vibrant creative expression memories lie in the summers of 1998 to 2002, when my favourite aunt joined my sister and me in painting a wildflower garden onto the fence at her cabin. Each summer we added larger-than-life daffodils, daisies, and our own botanical species to the previously dull and lifeless posts, simultaneously creating some of the most joyous memories of my youth. Certainly other forms of artistic expression were important components of my childhood, as I played piano competitively since the age of seven, and participated regularly in community and highschool theatre productions. However, the pressure of performance characterized by these other art forms set visual creative expression apart. When I painted or drew I was not evaluated by a terrifying piano adjudicator, or at risk of forgetting my lines. I was free to express myself fully and without fear of judgment.

When I left home for my undergraduate degree and entered young adulthood, creative expression became a friend I fell out of touch with. I knew she’d be there if I ever needed her, but frequent visits were rare. I dabbled here and there when inspiration was particularly strong, but often found myself abandoning half-finished paintings, frustrated that they were not “perfect” replications of my inner vision. It was only recently, since starting my MA in counselling psychology, that I re-embraced the visual arts. Lessons from professors and clinic supervisors

about “self-care” and “counsellor burn-out” led me to dig out the dusty easel from under my bed and put a paintbrush to canvas again – not worrying about perfect replications, but rather using creative expression as an emotional release.

Furthermore, as I progressed through the counselling program, I became more and more interested in using art therapy techniques with clients. In my practicum placement, where I worked mainly with teenagers, I used art on a regular basis. I was continually amazed by the things youth could say with brushstrokes that they could not say with words, and by the depth of emotions they could access through visual art. Although I have not personally worked with young adult cancer survivors, my interest in creative expression for this population sprouted from inspiring conversations with and workshops led by art therapists who have. A respected art therapist in my community who works in the oncology field told me anecdotally that young adult cancer survivors respond to creative expression in a way that is very unique from children or older adults. This led me to wonder what distinctively characterizes the experience of creative expression for young adult survivors. Although not a cancer survivor myself, as a young adult, I feel connected and relatable to this age group.

Creating the above lived-experience description helped me orient myself to creative expression as a lifelong artist, young adult, and counsellor-in-training who is deeply interested in the phenomenon for personal and professional reasons. Based on my lived experience, my initial and overarching assumption was that creative expression could be a helpful, beneficial, and meaningful experience for young adult cancer survivors. I also anticipated that the experience of creative expression would be unique for young adults as compared to other age groups. Furthermore, I held the assumption that creative expression could offer a means for young adult survivors to express and experience powerful emotions that accompany a cancer diagnosis.

Finally, I assumed that creative expression could be a form of self-care for young adult survivors. I recognized that these assumptions were influenced by my personal experiences, and by the themes I have identified in the literature. I also realized that measures needed to be taken to ensure that these experiences and pre-understandings enhanced, rather than hindered, the research process.

The reductio. The “phenomenological attitude” which was first articulated in Husserl’s (1913/1983) foundational work, involves “bracketing”, wherein a researcher suspends his or her biases and assumptions in order to more fully understand the essences of a phenomenon (Gearing, 2008). However, the process of reduction involves more than a straightforward formula of setting aside assumptions and acknowledging subjective bias (Finlay, 2008). Indeed, van Manen (1990) argued that, “if we simply try to forget or ignore what we already ‘know,’ we may find that the presuppositions persistently creep back into our reflections” (p. 47). Van Manen identified four levels of reduction –or “reductio” (2011) – to help the researcher suspend prejudgments and restore openness.

Firstly, heuristic reduction involves setting aside “taken-for-grantedness” and adopting a mood of wonder. I attempted to achieve this level of reductio by continually confronting the phenomenon of creative expression with open curiosity and childlike wonderment. Secondly, hermeneutic reduction involves overcoming the subjective biases and frameworks that would prevent the researcher from being open to the phenomenon of interest. This does not mean that the researcher should aim for objectivity or detachment (Finlay, 2008); rather, it involves “the researcher engaging in a certain sense of wonder and openness to the world while, at the same time, reflexively restraining pre-understandings” (Finlay, 2008, p. 2). Before undertaking data collection, I identified several of my assumptions, which helped me remain open to the

phenomenon, and prevented me from assuming an understanding of creative expression based on my own expectations. Furthermore, I bracketed the knowledge I had obtained from reviewing pertinent phenomenological studies so that I could approach my data with fresh eyes. Once I started data generation and analysis procedures, I refrained from looking back upon these studies until I was finished these processes, with the understanding that doing so could influence my understanding of this study's data. Thirdly, phenomenological reduction encompasses an unpacking of the existing theories and conceptualizations for the given phenomenon. To achieve this level of reductio, in the literature review, I examined available theories, and discussed the body of literature on creative expression. In line with van Manen (2011), who argued that the most useful way to bracket theoretical meaning is to examine it, I also reviewed existing theories for any insights or phenomenological understanding. Finally, eidetic reduction entails the researcher looking past the particularity of the lived experience towards possible universal aspects and themes. The goal of eidetic reduction is not to identify immutable generalizations, but rather to begin to develop patterns of meaning (van Manen, 2011). I began to achieve this level of reductio by comparing the phenomenon of creative expression with young adult cancer survivors to the phenomenon of creative expression with cancer survivors of other ages. Additionally, using the eidetic technique of "variation in imagination" (van Manen, 2011), I compared the phenomenon of visual creative expression within other contexts, such as chronic illness or mental health.

Throughout the research process, I continually engaged in these levels of reduction in a fluid and circular process. I maintained an ongoing dialogue with myself, continually reflecting on the biases I brought to this study. For example, mid-way through one of my interviews, I

realized my assumption that most people are told at some point in their lives that they cannot “do” art. In recognizing this, I tried to ensure I did not ask leading questions around this belief.

Investigating experience as it is lived. Data on the lived experience of creative expression was generated primarily through young adults cancer survivors’ experiences as they were revealed to me through unstructured interviews and email texts. Additional sources of data that informed the proposed study included fictional and non-fictional texts, and other forms of popular media (e.g. young adult cancer survivor blogs).

Participants. Seven young adult cancer survivors who had engaged in visual creative expression were interviewed on at least two occasions. Seven participants falls in line with the average number of participants suggested by Langdrige for phenomenological data analysis (2007). Participants were diagnosed with cancer between the ages of 18-35, had engaged in visual creative expression following their cancer diagnosis either individually and/or in a therapeutic setting, and had found creative expression to be an important part of their cancer journey. The rationale for the age criterion of 18-35 was previously discussed in this paper, as was the rationale to explore creative expression in both individual and art therapy settings. At the time of the first interview, however, all participants were over 19 years of age, as this is the age of majority in British Columbia. Furthermore, although English was not the first language for two participants, all young adults spoke English well enough to participate fully in the research.

Young adults self-identified as cancer survivors, which is conceptualized in the current study as an ongoing process, not an end state or outcome (Adams, 1991; Mullan, 1985; Zebrack, 2000). In other words, cancer survival can be seen as a process that is ongoing across the phases of diagnosis, treatment, rehabilitation/continuing care, remission, and recurrence/advanced disease (Adams, 1991). This inquiry focused on young adults who were currently in the

rehabilitation/continuing care and post-treatment/remission phases of the survival process. The rehabilitation/continuing care phase is defined as the period wherein cancer therapies shift from an inpatient to outpatient basis, and cancer patients are focused on achieving optimal functioning within the constraints of their illness as they reintegrate back into family and community lives (Adams, 2001). The post-treatment/remission phase is defined as the period wherein cancer survivors focus on readjustment and re-adaptation as they transition from cancer patient to off-patient survivor (Adams, 2001; Zebrack, 2006). The rationale for the decision to include only individuals in these two phases is twofold. Firstly, the advanced physical and medical challenges that characterize the diagnosis, treatment and recurrence/advanced disease phases might have placed constraints on clients' ability to participate in the current study. Secondly, being in the rehabilitation/continuing care and post-treatment/remission phases of survivorship allowed for emotional distance from the stress of early diagnosis and active treatment, and allowed for more room for reflection (Reynolds & Prior, 2006). However, participants reflected on creative expression engaged in while in and after treatment.

Recruitment. I recruited participants by sending recruitment letters (see Appendix A) and recruitment posters (see Appendix B) to various organizations and agencies that serve young adult cancer survivors in Canada, including the Callanish Society, the BC Cancer Agency, the Arts in Medicine program at the Cross Cancer Institute, and Cancer Care Manitoba. I contacted art therapists and coordinators at these agencies, who physically posted or distributed my posters. Furthermore, art therapists from some of these agencies passed along my study information to their colleagues. Additionally, I recruited participants online through Young Adult Cancer Canada (YACC) and Stupid Cancer, by posting my information on their Facebook pages and

public blogs, and contacting their administrators who emailed out my information to their email lists.

I provided contacts from the aforementioned organizations with information about the research project, including its significance, methods, level of involvement required from the research participants, and potential outcomes. The various organization workers were informed that their decision to pass along information about the study was completely voluntary. Interested participants were asked to initiate contact with me via email or telephone, wherein I responded to their inquiries, informed them of the purpose of the study, and conducted screening interviews (see Appendix C). Interviews were then arranged with individuals who met the screening criteria and were interested in participating. All participants were invited to bring pieces of artwork, or photographs of their artwork, that they had created throughout their cancer journey with them to the interview.

Interviewing: the personal life story. In line with van Manen (1990), the current study utilized research interviews “as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience” (p. 67). The focus of the interviews was on the lived experience of creative expression for participants, and my general goal was to encourage participants to describe, through specific examples and anecdotes, what creative expression was like for them as young adult cancer survivors.

Meetings were scheduled at participants’ convenience, and took place over a four-month period. Each participant met with me two times, except for one participant who met with me once and conducted our second check-in via email. First interviews ranged from 1 to 1½ hours (except for the participant who met with me once, wherein the first interview lasted 2 hours). Second interviews ranged from half an hour to 1 hour. All conversations were audiotaped and

transcribed by myself. Three first interviews were conducted in person at a quiet and confidential location of the participants' choosing (e.g. the participant's home or a private office at UBC); due to physical distance, the remaining four first interviews were conducted via Skype with video conferencing. Two of the second check-in interviews were conducted in person and four via Skype. As previously noted, one participant completed her check-in via email. As compensation for their participation, all young adults received \$40: \$30 for the initial interview, and \$10 for the second check-in interview.

The first interviews began with a review of the consent form, which included consent to audiotape the interviews (see Appendix D). It also included consent from participants to have their artwork photographed (if they had any with them). I emphasized the voluntary nature of all aspects of the interview and measures of confidentiality. When participants choose to complete the interviews via Skype, they were mailed or emailed a copy of the consent form. Signed consent forms were returned to me in self-addressed stamped envelopes that were provided to participants. Once I obtained consent, participants were asked to complete a basic demographics form (see Appendix E). I then introduced the interview as a knowledge-generating undertaking motivated by a mutual curiosity between myself and participants about the phenomenon of creative expression (Nicol, 2001). The interview included a few open-ended questions based on the lived experience of creative expression for participants (see Appendix F), but my general goal was to continually encourage participants to tell me, through the use of specific examples, what the experience of creative expression was like for them in their lives. I drew on my counselling training to build rapport with each participant and remain attuned to his or her non-verbal behavior.

Each participant was initially asked to tell me about themselves and their cancer journey, with the goal of encouraging the participants to create their own narrative (Reynolds & Prior, 2003). They were then asked: “Tell me how visual creative expression is part of your life, and how it relates to your journey as a cancer survivor?” A subsequent question was: “After your cancer diagnosis, when did creative expression first become an important part of your life?” If participants had personal artwork with them, I asked them about the experience of creating that particular piece, and, in line with Quail and Peavy (1994), I asked participants how they experienced their artwork in the research context with me. All participants were asked to recall other experiences and stories of creative expression, drawing upon thoughts, feelings, and body sensations (Lane, 2005). As I interviewed participants, I continually attempted to bring them from the general to the concrete, asking them to “think of a specific instance, situation, person, or event” (van Manen, 1990, p. 67); additionally, participants were encouraged to describe, rather than explain, their experiences.

Throughout the interviews, my role was to keep the question (i.e. the lived experience of creative expression) open, and to keep participants and myself oriented to the substance of this experience. This was not always easy – participants often digressed into other stories related to their cancer journey. I would engage in these digressions with participants for a short while, and would then gently bring them back to the phenomenon of interest. This required using open-ended questions about the specific experiences of creative expression, utilizing what Gadamer (1975, p. 330) calls the “art of questioning” and describes as “being about to go on asking questions, i.e., the art of thinking”.

Approximately one month following the first interview, I conducted a second check-in interview with participants, which was also audiotaped. I choose to interview each participant

twice because van Manen (1990) suggests that multiple interviews allows for time for reflection on the texts and transcripts, supporting “as much interpretive insight as possible”. During the second check-in interview, preliminary themes for each individual participant were discussed and reflected upon in a conversation between participants and myself. Together, in a “collaborative hermeneutic conversation” we interpreted the significance of the themes in relation to the original research question (van Manen, 1990). I asked participants: “Is this what the experience was really like for you?” (van Manen, 1990, p. 99). I also asked each individual if there was anything he or she would add to or take away from the text.

A final point of contact was made when I sent a condensed version of the study’s results section (highlighting the study’s nine themes) to each participant. Participants were invited to respond to the following question for each theme: “Does at least part of this theme resonate with you?” At the end of this narrative, they were also asked, “Do you see these themes as, overall, representing the lived experience of creative expression?” Participants were also invited to provide any overall comments, which were incorporated into the present study, and used to re-write and refine the themes.

Texts: sources of lived experience. Various types of texts are sources of data that may contain speculative accounts of lived experience that are valuable for phenomenological inquiries (van Manen, 1990). For this reason, at the end of the first interview, participants were invited to email me any thoughts, feelings, and/or experiences in relation to creative expression that occurred between this interview and our second point of contact. Although this was completely optional, all participants emailed me to some capacity about their creative expression experiences between the first and second interviews.

Additionally, I identified blogs and fictional texts that spoke to creative expression and/or cancer survivorship (particularly during young adulthood) as additional sources of data. Finally, in the spirit of hermeneutic phenomenological research, I attempted to live with open wonder and curiosity about the phenomenology of creative expression, remaining attuned to aspects of this phenomenon as it spontaneously arose in my life. I kept notes and took photographs about the ways I remained attuned to creative expression in my life.

Data Analysis: Hermeneutic Reflection and Writing

Data analysis was undertaken with the goal of capturing the essence of creative expression for young adult cancer survivors. In line with van Manen's hermeneutic phenomenology, reflective methods (i.e. thematic reflection and existential reflection) and writing methods were utilized to interpret the aspects of meaning associated with creative expression, and to gain more direct contact with creative expression as it is lived (van Manen, 1990).

Thematic reflection. Because human science research is concerned with meaning, and, indeed, to be human is to desire meaning, thematic reflection was undertaken in the current study with the goal of trying to “unearth something ‘telling’, something ‘meaningful’, something ‘thematic’” (van Manen, 1990, p. 86) in the various experiential accounts. van Manen (1990) argues that “in order to come to grips with the structure of meaning of the text it is helpful to think of the phenomenon described in the text as approachable in terms of meaning units, structures of meaning, or themes” (p. 78). Thus, while reading and re-reading the transcripts, I worked to develop themes in order to “reflectively [analyze] the structural or thematic aspects” (p. 78) of the experience of creative expression for young adult cancer survivors. When turning to the interviews (which were transcribed verbatim), emails, and other sources of data, I continually asked myself: What is the essence of creative expression being reflected here? How

can I capture this essence in a theme? I also used the following phrase to focus my analysis: “The lived experience of creative expression for young adult cancer survivors involves: _____.”

I read all transcripts several times for familiarity, taking note of any sentences or phrases that seemed particularly noteworthy in clarity or revelatory nature (Nicol, 2010). Next, I analyzed the documents using van Manen’s (1990) three approaches toward isolating thematic aspects of a phenomenon. Firstly, utilizing the wholistic/sententious approach, I attended to the entire text, attempting to generate a narrative (paragraph) that captured the fundamental meaning of the text as a whole. Next, utilizing the selective/highlighting approach, I read the text again and highlighted phrases that seemed particularly revealing about creative expression. Finally, utilizing the detailed/line-by-line approach, I carefully examined each individual sentence or sentence cluster, generating thematic statements about what each sentence or sentence cluster revealed. Undertaking each of these approaches helped me reflect and meditate on the lived meaning of creative expression, and begin to identify broader themes. Furthermore, I attempted to determine whether or not each preliminary theme was essential (van Manen, 1990). To do so, I asked the following question: “Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? Does the phenomenon without this theme lose its fundamental meaning?” (p. 107). I also created charts and diagrams of themes to work with them in visual form, which helped me to further cultivate meaningful descriptions.

Guided existential reflection. To continue the process of data analysis and thematic reflection, I utilized a guided existential reflection based on the four lifeworlds: lived body, lived time, lived space, and lived relation (van Manen, 1990). These lifeworlds are experienced by all people, regardless of their culture, ethnicity, or gender; indeed, all individuals live corporeally, temporally, spatially, and relationally (van Manen, 2011). Thus, these four existentials were

particularly useful in my reflection for the current study, because the lived experience of creative expression is understood more richly when this existential ground is considered. I asked myself, for example: “What meaning was there for participants in a space that was altered by their artwork?”, “In what ways did participants feel creative expression in their bodies?”, and “How did participants’ experience of creative expression interact with time?” I used these questions to further refine and expand upon the themes I had identified during the thematic reflection. I then sorted the data and organized the themes around the four lifeworlds, and further refined the themes by ensuring that each lifeworld was represented as fully as possible.

Writing as analysis. Writing is not simply a component of van Manen’s hermeneutic phenomenology; it is, in fact, its essence. Thus, for the current study, I engaged in a process of writing and re-writing in order to become more united with the lived experience of creative expression. Firstly, after each participant’s initial interview, I composed a first linguistic transformation, or phenomenologically sensitive paragraph, in the attempt to capture the thematic statements for each participant (van Manen, 1990). I discussed these texts with participants during the second check-in interview. These hermeneutic conversations served as the starting point for participants to share additional insights about the nature of creative expression in their lives. After all of the second interviews were completed, I wrote and re-wrote, further refining and re-defining the themes. In the process of writing, I sought to do more than simply communicate the content of the transcribed interviews and other texts I was working with. Rather, I attempted to create a textual quality wherein the reader’s understanding of creative expression was amplified. I also ensured that each participant’s voice was represented in each of the study’s themes.

The vocatio. The core purpose of hermeneutic phenomenology is to reveal a phenomenon's essential qualities through a rich, vocative text (Nicol, 2010). Certainly, when qualitative descriptions of human experience integrate aesthetically textured descriptions, it can deepen the sense of understanding in the reader (Todres, 1998). Thus, the final linguistic transformations involved representing the data in an expressive, aesthetic, and vocative text. This does not mean that structure was ignored; rather, both the thematic aspect of the text (*what* the text says) and the mantic aspect of the text (*how* the text speaks) were crucial to this hermeneutic phenomenological inquiry (van Manen, 1997).

In order to accomplish a vocative form of writing, I attended to van Manen's (1997) five textual features: concreteness, evocation, intensification, tone, and epiphany. Firstly, concreteness refers to a phenomenon being placed concretely in the lifeworld so that readers may identify closely with the text (van Manen, 1997). To achieve concreteness, I used specific descriptions from interview transcripts to help readers understand creative expression in an accessible way (Nicol, 2008). Furthermore, I used anecdotes from participants, gathered from their interviews and other texts (e.g. emails) in order to better articulate the phenomenon of interest, keeping van Manen's (1990) warning in mind:

Anecdotes... are not to be understood as *mere* illustrations to "butter up" or "make more digestible" a difficult or boring text. Anecdote can be understood as a methodological device in human science to make comprehensible some notion that easily eludes us (p. 116).

Secondly, evocativeness involves vividly bringing forward images and sensations that encourage the reader to reflect on and wonder about the phenomenon (van Manen, 1997). To achieve this textual feature, I attempted to use descriptive, rather than plain, language that speaks closely to the nature of the participants' lived experiences as possible. Thirdly, intensification involves giving words their full value (van Manen, 1997) – I attempted to achieve this by

carefully selecting language that kindles visual imagery. I also threaded metaphors, particularly art-related metaphors, throughout the text (Nicol, 2008). Next, tone refers to the creation of an overall text that speaks to readers in a stirring, non-cognitive manner (Nicol, 2008; van Manen, 1997). Because this fourth textual feature alludes to the text as a whole, it is difficult to pinpoint the exact mechanisms I used; however, I attempted to create an overarching tone that speaks to readers personally, so that they might engage in a meaningful dialogue with the text (Nicol, 2008). Finally, if I achieved van Manen's first four textual features, I might have created a text that encourages an epiphany, which refers to a sudden understanding, or feeling of being changed by what one has read (Nicol, 2008). According to van Manen (1997), "this experience is so strong or striking that it may stir us at the core of our being" (p. 364). For readers of this study, this could mean comprehending the lived experience of creative expression for young adult cancer survivors in a new and moving way.

The four existentials used to guide my reflection (lived body, lived time, lived space, and lived relation) acted as a useful framework for organizing my findings. According to van Manen (1990), "phenomenology offers accounts of experienced space, time, body, and human relation as we live them" (p. 184). Because all humans are understood to experience these four lifeworlds, they were used to identify essential moments in the participants' creative expression experiences that were meaningful in relation to their cancer journeys.

Ethical Considerations

This inquiry shared general ethical considerations common to other research endeavors in human science research. These included declaring participants' right to withdraw at any time, identifying possible risks or consequences for participating, and outlining measures to protect confidentiality (Nicol, 2001). In the current study, using pseudonyms and altering any identifying

information in the storing and presentation of the findings maintained confidentiality.

Furthermore, all transcribed interviews and photographs of artwork were stored in a password-protected file on an external hard-drive, and secured in a locked cabinet.

During the research interviews, I emphasized to participants that they needed only share what they felt comfortable. As a counsellor-in-training, I was equipped with skills that helped me establish a safe environment within the research setting. I also created a list of supportive community resources that I could have provided to participants; however, none expressed interest in this, and I learned that all of my participants were already well resourced with support systems in their communities.

A final ethical consideration pertinent to the proposed study involved incorporating art into the research endeavor. Because I invited participants to bring artwork to the research interviews, it was crucial that I understood the rights and autonomy of artwork (Moon, 2000). Most importantly, I did not attempt to interpret the participants' artwork, because this can have malevolent aspects for the artists (Moon, 2000). This being said, the interpretation of images is unavoidable, for simply *looking* at a piece of artwork involves an interpretation of what one sees (McNiff, 2004). However, I attempted to maintain an attitude of "humility and awe as contrasted to authority and omniscience" (McNiff, 2004, p. 78) when engaging in dialogue with participants about their artwork.

Expressions of Rigour

Qualitative research espouses multiple standards, or criteria of rigour, to ensure its quality or trustworthiness (Morrow, 2005). Each specific strategy used to demonstrate trustworthiness should be a reasoned one, and should reflect the method and paradigmatic underpinnings of the research study (Morrow, 2005; Whitehead, 2004). Thus, the epistemic criteria for the proposed

study conformed to the primary assumptions of hermeneutic phenomenological inquiry. I used a framework proposed by de Witt and Ploeg (2006), who based their five “expressions” of rigour on (a) van Manen’s scholarship, (b) their review of the phenomenological nursing literature, and (c) Madison’s criteria of rigour for hermeneutic phenomenology. I used these five expressions (balanced integration, openness, concreteness, resonance, and actualization) to ensure the rigour and legitimacy of the proposed study. Additionally, I attended to the moral criteria of the proposed study.

Balanced integration. This first expression of rigour refers to (a) intertwining findings with the philosophical concepts of the study’s research topic and methods, and (b) finding a balance between the participants’ voices and the philosophical explanation (de Witt & Ploeg, 2006). I achieved the former by articulating the general phenomenological philosophy of the study, and the fit between hermeneutic phenomenology and the research question. Additionally, I integrated theoretical explanations with the study’s findings in the Discussion section, and balanced these explanations by ensuring that the participants’ voices were reflected at all times throughout the presentation of findings.

Openness. The notion of openness encompasses the open attunement toward the phenomenon of interest that the phenomenological researcher adopts and maintains throughout the entire research process (de Witt & Ploeg, 2006; van Manen, 1990). This expression of rigour first involves acknowledging and understanding one’s own preconceptions and assumptions (Whitehead, 2004), which I acknowledged in my lived-experience description. As previously described, I also attended to van Manen’s (2011) four levels of *reductio* to help me recognize biases, suspend judgments, and restore openness throughout the research process.

The concept of openness also involves opening up the study to scrutiny (de Witt & Ploeg, 2006). Firstly, drafts and final versions of findings were collaboratively discussed with my research supervisor and colleagues, which was invaluable in generating deeper insights and understandings (van Manen, 1990). Additionally, an art therapist with extensive experience working with cancer patients and survivors – and, specifically with young adult cancer survivors – read a draft of my findings, offering her comments. I invited all of these individuals to share how the descriptions did or did not resonate with their own experiences. In response to their comments, themes were “examined, articulated, re-interpreted...and reformulated” (van Manen, 1990, p. 100).

Furthermore, as noted, initial drafts of the study’s findings were presented to participants in a process termed by van Manen (1990) as the “validating circle of inquiry” (p. 27). Through this process, I looked for the symbolic act of “nodding” in recognition (the “phenomenological nod”) from participants, which involves an act of recognition towards a text that has revealed something both new and familiar. During the check-in interviews, when we discussed the first linguistic transformations of our conversations, all participants “nodded” as they read or heard the narratives. For example, one participant responded:

I felt like a lot of those things were really accurate, and so, um, I don’t think when I said them I realized how clear I was being, but hearing them from your mouth, it’s like, “Oh yes, yes, I felt that way (*laughs*).

After reading or hearing the linguistic transformations, it appeared that participants were reminded of other instances of creative expression, or had more room to open up and expand upon previously discussed experiences. One participant wrote in an email: “I loved reading my words interpreted by you, very respectful, flowing and bright. I have attached (*in an email*) a document with a few comments on it. But mostly it was very succinct”. Expansions such as those

proposed by this participant were used to further articulate the themes.

Later, participants were sent a condensed draft of the results, and were asked to reflect on whether or not the nine themes resonated with them, and whether or not the narrative as a whole represented their lived experience of creative expression as a young adult cancer survivor. This was completely optional; however, all participants responded. Some participants provided comments, which, again, were used to refine and re-write the themes. All participants agreed that, overall, the presented themes represented the lived experience of creative expression. After reading the narrative, one participant wrote:

I resonated with every theme. Using art to work with the crazy journey of cancer is deep work, and it creates such rich, rich material. Your ability to pull out the themes that you did was impressive, and well done.

Concreteness, resonance, and actualization. Concreteness and resonance (i.e. epiphany) were previously discussed when I outlined van Manen's five features to create a vocative text. De Witt and Ploeg's (2006) final expression of rigour, actualization, involves the future realization of the resonance of study findings. Certainly, the interpretation of the phenomenological text is always open, "because the conversation to understand and reveal meaning is perpetual" (Nicol, 2001, p. 90). To encompass this expression of rigour, I will hold a temporal understanding of the data, recognizing that research represents merely a snapshot view about a phenomenon (Whitehead, 2004). Indeed, over time, each person's understanding and interpretation of a text will change. This fits with the purpose of phenomenology, which is not to achieve a final interpretation, but rather to explicate the meanings of experiences as we live them, now, in our everyday lifeworld (van Manen, 1990).

Moral criteria. I attempted at all times to engage with participants in a respectful way. It appeared that engaging in the research process was a helpful and meaningful experience for

many participants. For example, one participant wrote to me in a follow-up email: “Definitely a meaningful experience for me, and helpful in reminding me about my joie de vivre!” Another participant said about her experience in the study: “It’s actually pretty good, because it really, um, kind of, uh, helped me just to put some words and some perspective on this. I never thought so much about the art therapy”.

Chapter Four: Results

In this chapter, I attempt to paint a vibrant picture of the lived experience and lived meaning of creative expression for young adult cancer survivors. Firstly, I introduce the seven young adults who shared their stories with me, briefly considering their cancer journeys and their experiences with creative expression. I then identify commonalities in their stories as young adult cancer survivors, based on the four lifeworlds of lived time, lived body, lived space, and lived relation. Understanding their lives as cancer survivors provides a framework for the next section, wherein I explore the themes that say something meaningful and important about the lived experience of creative expression.

Certain logistical considerations have been undertaken throughout this chapter. Firstly, anecdotes from participants have been edited in the following way: an ellipsis indicates that words have been removed for clarity or readability, square brackets with italicized font indicate my contributions to the conversation, rounded brackets with italicized font indicate non-verbal body language or specify what was being referred to, and square brackets with non-italicized font indicate that I have changed words (e.g. the pronoun) for readability or confidentiality.

Participants

Seven young adults – six females and one male – agreed to meet with me and share their stories for this study. At the time of the first interview, participants ranged in age from 23 to 35, with an average age of 28. Participants were diagnosed with cancer between the ages of 18 to 34, with an average age at diagnosis of 25. Each participant had been diagnosed with a different type of cancer, including: Hodgkins Lymphoma, Non-Hodgkins Lymphoma, Germinoma Brain Cancer, Breast Cancer, Primary Mediastinal Lymphoma, Nasal-Pharyngeal Carcinoma, and

Melanoma. Certainly, different types of cancer resulted in differing experiences; however, all participants expressed many similar subjective experiences throughout their cancer journeys.

The palette of types of creative expression participants engaged in was diverse and colourful, and included (but was not limited to): photography, ceramics, knitting, crocheting, art journaling, videography, painting, sketching, collaging, tattoo-design, mandala-colouring, and stone carving. All participants engaged in more than one type of visual creative expression. Furthermore, all participants except one had engaged in creative expression both individually and with an art therapist (either individually and/or in a group). The remaining participant had not had access to art therapy during her cancer journey; however, she said that, “I wish it was something that was offered to me”.

Creative expression played varying roles in participants’ lives. For some, creative expression was their passion and even career. Others had not engaged in creative expression for many years – even since childhood – before their cancer journeys. For one participant, this “re-discovering” did, in fact, lead to her craft turning into a profession. There was also diversity across the participants’ individual characteristics. These differences are not important in terms of the study’s results and purposes, and are offered for descriptive purposes only. Participants were currently living in various locations across Canada and the United States, and had diverse cultural backgrounds (including Asian, Columbian, Hispanic, and European). All participants were currently completing or had previously completed some form of post-secondary education. Two participants were married, and one of these participants had a child.

I have decided not to use names as I discuss these young adults’ experiences, firstly to ensure confidentiality, but also because my goal is to capture the lived experience of creative expression by weaving the participants’ voices together. In fact, I was inspired by one of the

study's participants, who used a similar technique in one of her cancer advocacy projects (a theatre piece that captured the experience of cancer). She described her method as follows:

We...picked part of somebody's story, and you have to like break apart the story into, um, something that's unrecognizable, so that they *might* tell it's their story...it would just be like a little whisper, like "Oh, I know, that was my story..." and then you braid it in with someone else's story. So it's recognizable, but not totally like "Aghhhhh!" (*makes gasping sound*).

A Portrait of Cancer Survivorship During Young Adulthood

The seven young adults' stories are unique and personal, each encompassing its own distinctive colours, textures, and styles. However, across the lived existentials of body, time, space, and relation, similarities are revealed amongst their stories that can be merged and combined into a portrait of cancer survivorship during young adulthood.

Lived time. Young adulthood is a time of life when one is expected to be healthy, vibrant, and productive. Thus, cancer presented a threat to the "normal" young adult trajectory; during cancer, participants' lives were "put on hold". One participant laughed as she described her first reaction to her diagnosis: "It wasn't like 'Oh my god, I have cancer'. No, it was like, 'Oh my, I can't finish my final semester'". Another participant recalled how she had just graduated from high school and was preparing to "move to Hawaii" to "pick macadamia nuts and travel and have a lot of fun" when she found the lump in her neck. Thus, when all her friends were "off doing other adventures, going to college and travelling", cancer became her own "wild adventure and education". Yet another participant recalled:

I should be announcing that I have a baby, not, you know, "I have a tumor...?" That's what my friends were doing, they're like, "Oh, I got engaged! Oh, you know, I'm having a child!" It's like, "Oh, I have a 50/50 chance to live..."

Many also faced a "you're too young for this" mentality – disbelief from others and themselves that cancer could, indeed, happen to them. This sometimes resulted in a delay in diagnosis. Many participants had to advocate for themselves to receive a timely and accurate

diagnosis; one participant recalled that, “I can...only imagine if I’d, if I didn’t insist that, that it’s not allergies...”

All participants had vivid recollections of various “cancer dates” – they could tell you the exact date, and sometimes the exact time, when, for example, they first learned they had cancer, or when they had their first chemotherapy treatment. Young adults also became acutely aware of the limits to time; indeed, each came face to face with his or her mortality. One described how, “chemo therapy doesn’t work on melanoma...so if it were to travel to my lungs or something, that’s pretty much a death sentence”. Time also took on a different meaning during the cancer journey. For some, time slowed down completely; for others, it took on an intensity that was like nothing they had experienced before.

Finally, there was also a sense of permanence to cancer; although it would not always *define* participants’ identities, it would always be *part* of participants’ identities. Many felt that who they were before cancer was very different than who they were currently, and who they would be in the future. One participant quoted a line from *Tuesdays with Morrie*, saying that “Once I learned how to die, I learned how to live”.

Lived body. Perhaps the most “obvious” characteristic of cancer (and, indeed, cancer *treatment*) was its impact on the body. Participants underwent chemotherapy, radiation therapy, and surgeries. They experienced pain and scarring, some lost their hair, many lost weight, and some lost partial functioning of certain body parts. One participant proclaimed that “chemo...steals your heart, steals your soul for a moment”. Another participant described the impact that cancer treatment had on her body:

I was in this world of being jabbed with needles, getting a spinal tap...getting blood drawn and then, you know, getting blood transfusions, and then passing blood clots. Like it’s just a gross, gross time. Your hair falls out, and your nose hairs fall out so you’re constantly sniffing...it’s just, it’s gross. Cancer is just gross.

For many, their cancer diagnosis also resulted in body image and sexuality concerns. One participant said: “When you’re sick, people don’t view you as a sexual being. Like, you’re no longer a woman, you’re a child”. There was often a sense of loss for their pre-cancer bodies. One participant said:

I still try to deal with the, for example, my short hair. Because I always had long hair...so, I think what is hard is like self-esteem and self-image, that I have to learn now to deal with...starting over with this new body...there are a lot of different things that always...remind me of the fact that my body’s not the same as before.

Following their cancer diagnoses, some participants also experienced a newfound appreciation for their bodies. One young adult described how her cancer journey helped her recognize that “my body’s precious and taking care of it...” Cancer also impacted the emotions in the body. One participant described how, as her body was busy “trying just to, to fight”, the emotional impact became “really, really hard”. Indeed, almost every participant used the word “scared” or “scary” at some point during our conversations to describe his or her cancer experience. At the same time, the body experienced joyful and hopeful emotions. One participant recalled: “I was throwing up, I was having pain, I was, like sometimes I would be crying...but then there were just so much positive things that would just, um, like cover right over it...”

Lived space. During cancer treatment, participants’ environments were altered as they spent more time in the hospital and clinical settings. As young adults, some participants suddenly found themselves surrounded by older adults, in a different stage of life from them. One participant described her experience:

...being the youngest person on the cancer ward, like all of my roommates they were these little old ladies, and it was, I mean they were nice, but it’s really, really hard to be like, “Wow, I’m the only young person here”. That’s really weird.

Another participant recalled being thankful she was treated in the adult cancer clinic, because it was much closer to her home. She also believed she got “special treatment” because she was so much younger than everyone else. However, she reflected:

I was 18 but treated in the [adult] cancer clinic, so it was all elderly people mostly...I always wonder if I had been treated with more young people, cuz I was like right on that cusp...it was interesting being so young and being around such different energy.

Many participants also experienced a newfound appreciation for the world around them. One participant said that, post-cancer, all his “priorities are different from what they were”. Similarly, cancer impacted the way participants interacted with their worlds. One participant shared how, throughout her life, she had often faced judgment for being “too happy, too positive”. However, she shared animatedly about how her cancer experience gave her an “‘All Access Pass’ to enjoying life,” giving her the strength to “shine as bright as [she] want[ed] to shine”.

Lived relation. A cancer diagnosis shifted participants’ relationships with others. All participants described feeling different or isolated from same-aged peers in some way. One participant, who learned that his wife was pregnant on the same day he was diagnosed with brain cancer, recalled his experience of starting a family during this time:

Being new parents combined with the cancer diagnosis treatment and all of that was – and is – kind of sets us apart from all of our peers, really. We have a lot of friends who are having kids at this time too, or have toddlers or etc., and we don’t quite fit in with them.

Some participants recalled how certain important others in their lives disappeared, at least temporarily, during their cancer journey. One participant recalled that “a lot of friends just were not there, were not up to the challenge”. Additionally, sometimes close others did not react to participants in a way they deemed most helpful. For example, one participant recalled how, with the exception of one distant relative who had recently been treated for prostate cancer, nobody in her family would address “the fact that [she] might die”. This same participant recalled how,

when at the doctor's office, her family would take over, so she was unable to express her concerns and questions – particularly around issues of cancer's impact on her sexuality and fertility.

At the same time, participants also received an abundance of care and support from certain others in their lives. Doctors, nurses and other therapists were commended for their help and support; for example, one participant said, "my chemotherapy nurse was lovely and magical and amazing". Family and friends also played important roles. Although some participants experienced increased reliance on parents and others during a time of life when they preferred increased independence, the care from others was deeply appreciated. One participant spoke about her sister, saying: "I couldn't have done it without her. And she was the one who kicked my ass too, whenever I got too, like, you know, down". Another participant recalled: "throughout the whole, the whole journey...what I've realized and what I've learned the most is how...much I appreciate those people who were with me during those hard times". Furthermore, most participants were heavily involved in the young adult cancer community, and had strong social connections with other young adult cancer survivors.

Many participants also recalled feelings of responsibility for making others worry about them, or recalled wanting to care-take for those who were impacted by their cancer diagnosis. One participant's voice wavered as she shared: "It's always the hardest thing of, of my cancer experience, or the thing that still tugs on my heart...is my impact on my parents". Another participant recalled how she delayed telling her friends about her diagnosis because "it was just too hard to tell them". She also recalled how she was scheduled to get her biopsy results back the same week her father was visiting her family from abroad. She noted: "I was just really

scared...if the biopsy results was bad...that it would just ruin the whole, um, atmosphere, um like the whole pleasant thing, like the family thing”.

It was within this portrait of cancer survivorship that these seven young adults experienced creative expression. With this in mind, I will now turn to the themes I have revealed that say something about these young adults’ lived experience of creative expression.

The Lived Experience of Creative Expression for Young Adult Cancer Survivors

My goal was to extract more direct contact and connection with the experience of creative expression as it is lived by young adult cancer survivors (van Manen, 1990). I read and re-read interview transcripts, emails, and other texts, utilized van Manen’s three approaches toward isolating thematic aspects of a phenomenon, and engaged in a guided existential reflection to articulate nine common themes (see Figure 1). As I worked to solidify these themes, I kept van Manen’s (1990) words in mind:

Phenomenological themes are not objects or generalizations; metaphorically speaking they are more like knots in the webs of our experiences around which certain lived experiences are spun and thus lived through as meaningful wholes (p. 90).

The themes or “knots in the web” I have articulated were drawn out with care and confirmed by the participants themselves. Furthermore, although these themes appear to say something important about the lived experience of creative expression, they certainly do not encompass the entirety of this experience. Quotes from two participants articulate the impossibility of capturing the essence of creative expression. One said that: “You’re actually just trying to put something to words that is, that’s bigger than you...it’s really more about something that has its own soul.” Another participant reiterated, saying that: “It (*creative expression*) feels like something that is without words, like so much of art, you can’t explain the process.”

In the following sections, I attempt to develop a narrative that elucidates the themes while remaining attuned to the fundamental quality of creative expression. To do this, I organized the themes around the four lifeworlds of lived time, lived body, lived space, and lived relation, because the lived experience of creative expression can be understood more richly when this existential ground is considered. Certainly, all participants experienced creative expression through interactions with time, their bodies, the environment, and other people. Although the themes are organized into the four different lifeworlds, each theme incorporated aspects of time, body, space, and relation. Certainly, these four existentials are present at all times and cannot be completely teased apart from each other. Furthermore, although these themes are presented in a linear fashion, participants talked about their experiences in a circular design, traveling freely amongst the ideas represented in the various themes.

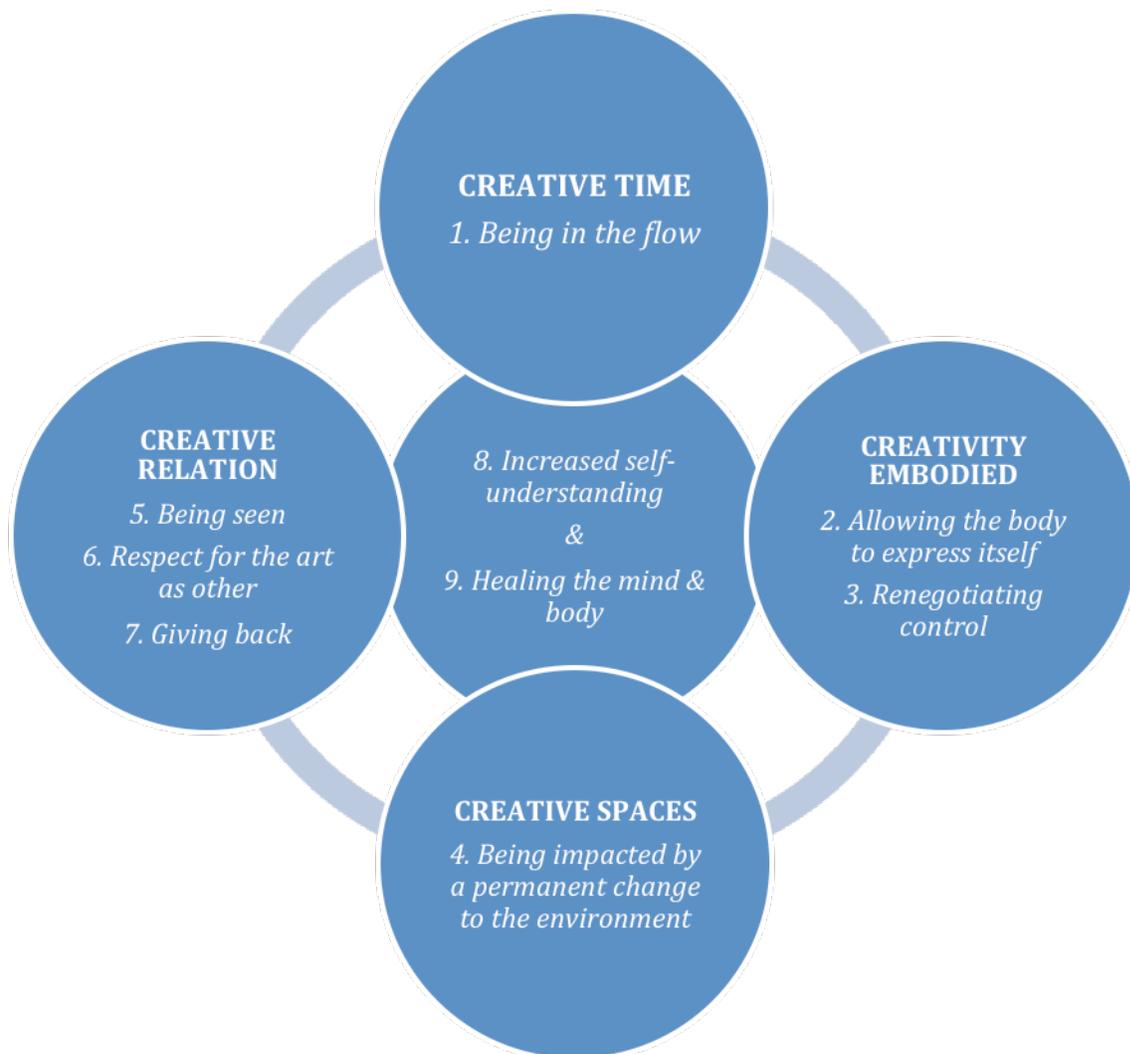


Figure 1. Nine themes representing the lived experience of creative expression for young adult cancer survivors across the four lifeworlds of lived time, lived body, lived space, and lived relation.

Creative Time

Being in the flow. All participants described ways that creative expression allowed them to get into the “zone” or the “flow”, recounting this experience as “peaceful”, “relaxing”, “kind of like a nap”, and something to “lose myself in”. At the same time, creative expression was described as a time of being “concentrated” and “focused”. Time lost its meaning. One participant described the irony and essence of “losing track of time” as a photographer:

When you enter the dark room, you can't even see out a window, so you don't know what time it is. You look at the clock all the time if you're true processing, cuz you have to time it, but you're looking at the clock, and you're not registering what time it is...So it could be like 10:30 p.m., and you haven't eaten all day, but you don't feel hungry.

Indeed, like this participant forgot to eat while in the dark room, the feeling of timelessness was tied to the participants' bodies, environments, and relations with others; not only did time seem to disappear, so did the world around them. One participant said that, while engaged in creative expression, "I don't realize that I'm moving". Another recalled his experience during a group art therapy activity:

I think I really started tuning out the rest of the group, because there was a lot of, there was sort of a lot of noise, people were talking as they were doing it. And...it got sort of quiet...

Similarly, another participant said:

At the exact time that I'm creating it, in that moment in the zone, I'm really disconnected to everyone, so it's like a hiatus away from people.

Creative expression allowed young adults to "become really mindful", "meditative", and "present"; it was a time when they didn't ruminate about the past or future, but instead "could just relax, and not worry, and not think too much." One participant said: "When I get into my art, it's usually quite passionate...it's really freeing...I don't over-think it". This state of mindfulness or not "over-thinking" was sometimes surprising; said one participant:

The last half hour I was sort of just in this, almost like a trance...I wasn't really thinking about it, but I, um, yeah...I was in "art mode". It was kind of incredible because I didn't think that was possible for me. And I had, uh, never experienced anything like it before.

Particularly during active cancer treatment, the flow of creative expression became a safe haven for some participants, away from the painful effects of cancer. It was a time of "not thinking about either the pain, or not thinking about the treatment, or not thinking about anything else, just being concentrated on what you are doing". One participant said: "That's when it helped...this little, I don't know, half an hour, 20 minutes, when I was not thinking, 'Ok I have

cancer, and I'm going through this". Another participant felt similarly, recalling what creative expression meant for her when cancer became too overwhelming:

I didn't even want to think about it too much, and all I could do was just pick up my (*knitting*) needles and just forget about it. Especially if it was like a complicated pattern, um, something I had to pay attention to, I could just lose myself in it."

Flow appeared to be closely entangled with a sense of enjoyment. One participant described creative expression as her "joie de vivre"; others described it as "fun", "rewarding", and "fulfilling". Metaphors such as "like a breeze" and "a tropical getaway" were also used to describe the warm, happy feeling creative expression often offered participants. As participants recalled their experiences of creative expression in conversation with me, they smiled, made excited hand gestures, and laughed. It appears as though creative expression was a time that was cherished and meaningful, often bringing out a playful or youthful side of participants. One participant said repeatedly throughout our interviews that colouring mandalas while she was undergoing cancer treatment was a pleasant and enjoyable pastime. Another participant described what art was about for her:

To just enjoy it. To somehow just enjoy the ride and get it out, and make a big mess – if that feels good, like, how to make a big mess. And I've done that, like I've made like whoooooogsh!! (*makes a "whoosing" sound and gestures around the room, demonstrating the mess she makes in her space*).

Letting go of self-judgment: a prerequisite to and consequence of flow. All participants talked about a belief, present at some point in their lives, that they weren't able to "do" (at least certain kinds of) art. For some, this was a self-script they encountered during childhood that had shifted, or gradually had begun to shift, in adulthood. Said one participant:

I remember when I was younger, I thought if I'm not a painter or something like that you're not an artist, but I've totally changed my, changed my opinion...I think everyone's an artist, and we all have our own creative capabilities...we're just creative in lots of different ways."

This being said, some level of self-judgment, worry, or frustration with the look of one's creations speckled each participant's story to some degree. In order to really get into the flow, it appeared that participants first had to let go of this self-judgment, or the need for their art to look a certain way. In other words, they had to stop focusing on the final art product in order to truly immerse themselves in the process. This was sometimes difficult. One participant said:

I hadn't done anything that I could call creative, probably since, I dunno, Grade 8 art class, and, I wasn't, like, against art or anything, I just didn't think that I could do it, and I still don't, don't get me wrong, like I can't (*laughingly*), but, I realized when I did it the first time, um, I really struggled with it at first, but when I really got into the zone, I, really it kind of blew my mind.

Another participant described an experience of creating with clay during an art therapy activity:

I found it really hard, (*laughs*), really challenging, because, I don't have any inspiration, I don't know what I'm gonna do, and it's in a realm that I'm not familiar with at all, um, and I've never done. But, you know...she (*the art therapist*) had told us, like "Don't worry if, don't worry about making it look good," which, for me, is always like a huge thing, I guess, with creative expression. So, I kinda let that go, and, and, um, which was hard to do (*laughs lightly*).

One participant stressed that it is important "to shut off the analytical side so you can just make it". She continued:

I think that that's what...stops a lot of people from allowing the art to be therapeutic, is they, they judge it, and they analyze it, and then it's no longer therapeutic...it becomes more a burden. Like I've sat here with friends during art night, and they just, they won't allow themselves to let go, it's about "It needs to be perfect". And I'm like, it doesn't. It's just about the process.

It also appears that this process was cyclical – letting go of judgment helped participants get into the flow, and being in the flow helped facilitate even less self-judgment. One participant spoke quickly and excitedly as she recalled one experience with creative expression:

It's so much about the process, of like, "It doesn't have to look a specific way". I might have an idea, but I don't get attached to it. And then when you're in the flow, maybe with a

glass of wine, (*laughs*), it turns off. The critical side too...and you just get, get into the flow of it.

Creativity Embodied

Allowing the body to express itself. Art provided a medium for young adult survivors to express their emotions, cognitions and their cancer experiences. A particularly poignant description from one participant captures how art helped her tell part of her cancer story:

Art allows another voice within me to speak, when words are not enough. It helps to uncover stories I didn't even know were lurking, as illustrated in the piece entitled "Baby Bird" with the picture of me as a baby and my mom holding me juxtaposed over the words "cancer". When I created this image something deep within me was revealed and I found a story I didn't even know I was holding in my heart.

Other participants echoed this idea that art was an accessible and powerful way to express themselves; for example, one participant said that "it's easier to put something in colours than to put it in words", and, as she described the experience of showing one of her paintings to her art therapy group, she said that "I didn't have to say more, it was really very obvious (*from the dark, thick layers of paint*) that I wasn't feeling well."

It appears that this self-expression moved something deep within participants' bodies. It was a form of internal release. One participant noted that, "knowing how much story lies in our body", art provided a way for her to "tap into the body". In my conversation with another participant, she said that art helped her "get [her] insides out". When I reflected back to her that "maybe the art was a way to, like you said, put your insides out, put it on the paper", I unintentionally made a purging motion from my mouth with my hands. She laughed as she then responded, "I like that motion of just vomiting, that's exactly what it is".

Creative expression offered a way to "let out" both the difficult and uplifting emotions that accompanied participants' cancer journeys. One participant said that, "I can easily check into my heart through art...and it easily brings emotion for me when I'm making it". One participant

explained the physical movement of her knitting as contributing to the process of emotional expression, saying that, “stabbing my knitting needles through the yarn became my rosary and my way through grief”. This same participant noted that, “it definitely helped me knit out my sadness, my frustration, my joy, my triumph, you know, all of that”. During the interview experience itself, emotions came easily for many participants as they reflected upon and shared their artwork with me. Voices quavered, eyes misted over, and sometimes tears were shed.

As one participant pointed out, experiencing emotions through creative expression was not always “soothing and pleasant”. Indeed, it could sometimes be “painful”. Some participants described how supportive others helped ease this process. For example, one participant noted that the presence of an art therapist made emotional expression safer, saying that, with her therapist, “I just experienced my emotions, and know that she’s not going to react, and she can handle it”. Another recalled a particularly strong memory after creating an art piece dedicated to her cancer journey: “I remember sitting here and I was making this...and just collapsing on the ground, and just like weeping and sobbing and weeping, and I remember my boyfriend at the time came in and held me”.

Although creative expression could indeed be painful at times, again, it appears that it was still safer than words. For example, one participant said:

I was probably able to write, but that’s pretty painful. When you just articulate words, uh, you really have to go to a very conscious mind and say, “Ok, this is what is, it’s going, it’s happening”. And then paint, it’s kind of an easy way of going through these emotions without thinking too much about it.

Renegotiating control. Many participants described cancer’s physical and emotional impacts on the body as something that could often not be controlled. For some, when facing this uncontrollable experience, creative expression became a way to take back control, often providing a sense of purpose and usefulness. For others, or at other times, creative expression

became a way to accept and surrender to the uncontrollable nature of cancer. Either way, creative expression allowed participants to re-negotiate control in the way that they needed to.

In regards to the former, one participant described art as “something to hold onto...when everything’s wooshing by”. Another participant said that:

My cancer got rid of all those other things that I could call mine, and, and things that make [me] me, you know? It got rid of them. Martial arts went away, I didn’t volunteer anymore, I lost my hair, I lost my eyebrows, you know, I lost 10 pounds...um, all these things that were defining me, I couldn’t do or even see in myself anymore. But [knitting], it didn’t go away. That was like the one thing cancer couldn’t touch.

Creative expression also helped many participants take control of their physical reactions to cancer treatments. One participant said, “You’re going to feel fidgety, and this is something small, you know...that your body can handle and do”. Furthermore, some participants described how cancer is often accompanied by physical scars and ailments that are out of their control. One participant recalled how, in designing and getting his “cancer tattoo” he finally was able to control a permanent “scar” to his body:

I’ve experienced pain and scarring from my, like, my surgery and from my post-surgery effects and stuff, [right], but it was, it’s completely different when you, when it’s happening because you want it to, and, like it still hurt, but it was, uh, I dunno, it’s like it really felt like I was taking control.

Another participant described how, although she could not control the impacts cancer had on her body, art helped her have power over her reaction to it. When she created an art piece dedicated to her lymph nodes, she said that, “it felt like really a powerful thing, to say like, ‘I love my lymphnodes’, you know? This like, really honouring them, um, honouring my body”. Additionally, particularly during active treatment, creative expression became a way to control or safely contain overwhelming emotions. One participant described this as a way to stay “sane”. She went on to describe this phenomenon in the following way:

I could just...box up those feelings, um, it wasn't really bottling, it was just boxing them up, putting them on a shelf for now, I could take it down later and deal with it. But right now I could just lose myself in...the mundane things like, you know "knit 4, pearl 5, turn, you know, on the right side blah blah blah". It was a neutral place to be. And that was really what I needed, when I, especially when I was feeling down or frustrated or sad.

Also especially during active treatment, having control over and choosing to engage in creative expression appeared to provide some participants with a sense of purpose and usefulness. For example, one participant described how, while she was in the hospital, she was too tired to do mostly everything. However, in choosing to "start drawing and colouring" she said, "at least you feel like you're not just here, suffering." Another participant reiterated:

It gave me a feeling of, "productive fidgeting" is what I also like to call it. You know, instead of shaking my foot or, you know, drumming my fingers against the windowsill, or pacing back and forth, cuz I didn't even have the energy to do that, I could just do something and feel, feel useful.

On the flip side of the same coin, sometimes creative expression helped participants realize and accept their inability to control everything. It became a way to let go of control. For example, one participant described how, post-cancer treatment, she had lost some dexterity in one of her hands. She recalled an art therapy exercise where, at first, she "was not using it (*her hand*) because [she] was scared...it would look clumsy". However, she said when she let go of her need to control "the physical part", it "really did a lot for [her]". Furthermore, another participant said that: "I want to control everything, but it doesn't work (*laughs*)...when you are obviously, coping with cancer, you want to still control things, but you don't have control anymore". However, this participant's engagement with creative expression offered a space where she could let go – in fact she *had* to let go – of control. She said: "This is pretty much my definition of art: it's something that you can't control".

Creative Spaces

Being impacted by a permanent change to the environment. Participants spoke about how, as one participant articulated, “putting something on a piece of paper, or any kind of art that you’re doing, it’s permanent.” One participant noted how creating permanence was particularly important during cancer treatment, when her life seemed especially *impermanent*. She said, “I found it important to have documents of that time with photographs”. As I sat in conversation with this participant, she showed me photograph after photograph taken while she was in active cancer treatment. She alternated smiling and laughing with becoming serious and teary-eyed as she shared how she used the power of her camera – a Pentax she’d received from her father when she was only 8 years old – to capture both the “shitty” and hopeful moments. She described how she took photos in a “panic”, because her life was threatened, and she was “trying to remember things”.

Participants often found the final products of their creativity aesthetically and artistically pleasing. One participant joyfully recalled her experience of watching her videography creation, saying that “I love the beginning, so I was like ‘Yes! Like, yes!’” During a different research interview, I commented to a participant that she was smiling as she looked at her art and shared it with me. She replied, “I think I’m just happy with the colour arrangement”.

Displaying their artwork in important spaces gave participants a sense of happiness, strength, and comfort. For example, one participant described how she would display her knitting creations around her hospital room while she was undergoing chemotherapy:

It brightened the room, it made the hospital room a little bit more “me” and less clinical...it was nice to have something absolutely frivolous that had no, you know, purpose. So, you know, even though it *did*, it was nice to know that, oh, this wasn’t for if you stopped breathing...it was there just to make me happy, and that was the only real use it had. Um, so it was just, it gave me something nice to look at.

Some participants displayed their creations in their homes. For one participant, having her watercolour painting in her bedroom was “calming”. She explained: “When I look at it, I know what I’m capable of, and I see what I’ve gone through...I did manage”. Another participant joyfully shared with me a painting of a “vulnerable tree” that “stays in [her] bedroom” because it gives her the strength to “shine” and keep “reaching, and striving to be in the light”. For another participant, his creation – a tattoo he designed himself – would forever be stamped on his body.

He said:

I think about it, sometimes, when I’m meditating, I’ll think about it, and think about what it represents, really. And, uh, I still look at it, not everyday, but I look at it in the mirror and stuff...I definitely get comfort out of that.

Participants also often took pride in and experienced a sense of accomplishment from their creations. This was largely tied to others seeing their work (which will be explored further during the “being seen” theme), but could also be experienced independently from others. For example, one participant, although typically critical of her artwork, referred to one of her paintings, saying that: “I think I have some things that I’ve done that I’m really proud of, and this is one of them. I think, ‘Oh my God, this is just enough to be beautiful’”. Another participant felt similarly about one of her pieces created for an art education class, saying: “I was so happy with how this turned out, and this was just a small little assignment that was literally supposed to be a small collage, and it turned out to be this thing that I really, really love”.

Contrarily, sometimes participants’ creations were not ones they wanted to look at on a daily basis. For example, in regards to one of her pieces that was blatantly about cancer, one participant said:

I wouldn’t have the cancer thing in my room. Like, I’m done with that, right? Like that was like therapeutic and, and satisfying, but I don’t find that a piece of artwork that I’d like to look at.

Similarly, some art was a painful reminder of cancer. For example, one participant described how, with the exception of one painting, all of her artwork was either left at the hospital, or was “in a pile” and unexposed at her house. She said that, “for some reason...I don’t want to see them”, noting that they represented “kind of a hard memory”. Another participant spoke of the way an unfinished knitted sweater reminded her of the painful effects of chemotherapy:

I was working on a sweater...and it has these really intricate cables. And my mind was kind of fuzzy, like my memory wasn’t the best, so I realized that I crossed the cables the wrong way several times, or I just didn’t work that cable pattern at all in places, so I remember that just really getting to me, because I was like, “But, I had this memorized! Why is this a problem now?” And the problem wasn’t with the knitting...it was just another thing that, that chemo ruined for me, um, and it was really frustrating, and I can’t even look at the sweater to finish it, it just gets me so mad...it was such an awful reminder...

Creative Relation

Being seen. An important part of creative expression was showing one’s creations to others. Indeed, in the research context with me, participants were often excited and very open about showing and sending me their artwork. I recall being awed as I sat with one participant in her office, surrounded by a sea of artwork – paintings, art journals, ceramics, and binder after binder of records of her artwork. This participant said that, “being seen is the whole thing about art for me, a way to share and be seen in a different way”.

It was important for many participants to have a place to “celebrate” their work. Positive affirmations from others often filled participants with a sense of pride. One participant said that “being seen is so, so powerful, and to be seen and validated that people think it’s beautiful...” Another participant created a large videography project (centred around a cancer theme) for a university class, and described showing the finished product to her class as the “climax”. She appreciated the support she received from her classmates and professor, and smiled as she

described this part of the project as “heart-swelling”. Yet another participant described how this celebration piece was empowering:

It was nice when people would say, “Oh, that’s a really nice hat”, like chemo hats, and I would say, “Oh, thanks, I made it myself”. All of a sudden the focus was shifted from, “Oh, this girl is sick”, to “Wow, look at, you know, holy cow, she has cancer *and* she’s still making her own stuff!”

Often, sharing one’s work was a means to connect with others. For example, one participant said that, when others would see her knitting in the doctor’s office waiting room, they would “tend to talk to [her] a little bit more”. Another participant noted how he would often talk about his cancer tattoo with other survivors who had cancer tattoos. Art also created a way to relate with others about their own experiences with cancer. One participant recalled how the man working at a printing company was moved by her photographs:

I was picking them (*her prints*) up and, I was about to leave and he’s like “You know, I’m really happy with these prints, they look really good”. And I was like, that’s so amazing! And I felt so good, and then I felt compelled to tell him the story...he was like “Yeah, my wife...works with cancer patients and I really love that you’re making art about this”. That was really, really nice. And that’s the kind of reaction I hope people could have, not his connection to it, but his opening up about it.

Showing one’s work involved a level of vulnerability. Sometimes, prior to showing their work, participants worried about how others would react. Two participants who created cancer-themed art for fine arts classes noted that, in showing their work in class, sometimes their classmates were “uncomfortable” with such meaningful, deep art. One noted being largely disappointed about others’ reactions to her cancer-themed photography:

The class critiqued it, they at the end, they were like, “Yeah, I’m sorry that we can’t say so much about it, it’s just very *heavy*, and we don’t know what to say” you know, or whatever...For someone to just see a photograph and not even meet her (*the subject in her photography*), and then be speechless because there’s a photograph of her bald or her giving herself medicine through her needle...it sucks that they can’t even say anything about it.

The other participant recalled:

...and then I get up and explain, and they're all like (*makes surprised facial expression, laughs*). So that time I, I felt judged, but not because of my art, but because of my vulnerability. Like my willingness to be vulnerable.

Other participants also experienced upsetting interpretations or reactions to their work from close others in their lives. One participant said:

My brother took one look (*at her painting*), he still laughs about it, and that was pretty hard, but um, he has also the right to just not see anything in it. Like, that's the thing with art, it's like once it is out there, you cannot control what's going in the minds of others....

Of course, participants were seen by me in the research context. As they showed me their artwork, I responded. Although I attempted not to judge or interpret their work, some level of interpretation was inevitable, for simply *looking* at a piece of artwork involves an interpretation of what one sees. In reference to their work, I sometimes made comments such as "I find that so moving", "It's really quite stunning", and "That's beautiful". I realize that this may have contributed to feelings of pride in participants, similar to feelings of pride they experienced in the past from being seen. However, comments referring to the aesthetic appeal of their artwork may have made participants feel misunderstood at times about the intended meaning of their work.

Respect for art as other. Creative expression was viewed as something that had a life of its own. Art would appear, sometimes without a plan; like one participant said, "pieces just come together really like, like magic almost". Another participant reiterated as she described her experience of finding the "perfect match" of colours as she created mandalas, saying that "it's just like...so incredible, like magic like I got that". Yet another participant expressed her belief that art has its own "soul". When referencing one of her watercolour paintings, she gave artistic credit over to the art, saying: "I didn't do it, it was the colour itself just moved". It was clear throughout her interviews that she had a special and deep relationship with this particular painting; she spoke fondly about it on many separate occasions, expressing admiration for the

way the colours moved with independence and ease. Another participant's recollection of creative expression was similar:

Slowly the image, the sculpture, started becoming something (*laughs lightly*) and it was twirly and it wasn't what I had planned, but it started to look really uniform, and I was surprised with how specific it was, I thought that it would be more crazy looking.

Art products were also seen as physical entities that were separate from, yet connected to, participants. One participant became acutely aware of this intimate connection between art and himself as he had his own tattoo design marked permanently on his body. Participants also had respect for their artwork. Indeed, art products were saved and protected, either stored away, thoughtfully given away to others, or displayed for others to see. One participant recalled an experience with stone carving, where she described the irony of working with an art medium: "You're treating something with such reverence, like if I would drop that, it would break, yet I'm rasping away at it, you know?"

The sensual aspects of art were important. Indeed, some participants described the importance of being able to hold, touch, and feel art. For one participant, this was particularly special in the face of her cancer treatment:

Cancer is just gross. You know, um, and here was something *soft* and pretty and happy that I could touch. And it kind of made up for that gross stuff that I was feeling, having to swallow, you know, pills with really bitter aftertastes, and, you know, getting pinched and prodded. And here was something, you know, almost angelic in my hands...

Giving back. All participants used creative expression to give back to others and the world in some way. As participants spoke to me about the ways they used their art to give back, their bodies reflected the pride and joy they felt around this topic: faces lit up, voices became more animated, and smiles were shared. They recalled ways they used art to give back in the past, shared ways they were currently giving back, and expressed dreams about how they hoped to

contribute in the future. This theme sang boldly to me as I listened to the participants' stories; I felt energized as they painted pictures of hope, compassion, and inspiration.

Firstly, many participants used art as a form of cancer advocacy. One participant photographed individuals wearing fake moustaches and used these images to create posters for prostate cancer awareness. Another designed various knitting patterns (including one of a lymph node awareness ribbon) wherein a portion of the proceeds went to a cancer charity. Yet another submitted one of her paintings to an art contest that was raising money to support cancer patients.

Additionally, many participants were engaged in projects where they helped other cancer survivors tell their stories. One participant created a videography project for a university class wherein she interviewed several survivors about cancer's impact on their body image and sexuality. She described this experience:

What was powerful about it was that I felt I could convey their stories to other people, um, as well as mine. So it was kind of having that support network behind me, and, yeah...that added on the feeling of, like I, I need to do this. It's something that I, that I owe to them.

Similarly, another participant created a photography project wherein she photographed cancer survivors centred around something meaningful to them and their journey. In undertaking this endeavor, she explained that her "intention was to bring humanity to the illness" and, in helping others tell their stories, she said, "I think that gives them a sense of control and, um, self respect or something".

Participants also used their art pieces as a way to express gratitude and care for others. One participant gave away most of her artwork to the friends and family who cared for her during cancer treatment – it was important for her to give them a token of her appreciation. Another made "chemo hats" for others going through cancer treatment. She articulated how giving away hats was not only a way to help others, but also contributed to her own feelings of usefulness:

Like it just made me feel, like, I could do something for somebody, you know? I, I'm not a doctor, I don't know, you know, I don't know what do to, I can't heal you, but I could at least make you feel...warm. I could make you feel loved, cared for.

Participants also encouraged other cancer survivors or people in their lives going through a difficult time to utilize creative expression in their own healing journeys. For example, one participant gave a friend who had recently undergone surgery some of her art supplies, because “she was saying like she was tired and couldn't do much, so I gave her the rest of the mandalas”. Similarly, another participant encouraged her mother-in-law, an “amazing watercolour painter” who had recently completed cancer treatment, to “paint out [her] sadness”. Yet another participant shared his experience of recently attending a young adult cancer retreat as a peer supporter. While there, he participated in an art therapy activity and used self-disclosure to encourage others to let go of self-judgment when engaging with art:

I was like, “You know, even if it doesn't look good, um...this can be a really powerful thing, and don't think that just because you can't draw, um, that doesn't, that isn't what this is about. This isn't an art contest. It's about expression.” And, uh, and I like to tell people that...I like to make sure that they know that I'm not an art person...cuz a lot of people aren't, and, as a non-art person...I know what it's like to, to find out about it and experience it and, um, and what it, what it can give you...what it can really bring out.

Another participant was making it her mission to “preach the gospel of knitting”. At the time of the second interview, she was preparing to present a talk at a local cancer support club about how she “knitted circles around cancer”. She noted how this was like a “dress rehearsal” for her, because, she said:

My real pie in the sky dream is to do a Ted Talk about how I used my knitting...to get through, through chemo. It wasn't diet, it wasn't exercise, honestly most days it was just, you know, it was just finding meaningful work to do. And I'd love to talk about that in front of an audience.

Creative Lifeworlds Intertwined

Increased self-understanding. The four lifeworlds interacted to make the experience of creative expression for young adult cancer survivors one in which increased self-understanding

and self-awareness occurred. Additionally, self-understanding: A) occurred over time (Lived Time), B) was felt in participants' bodies and occurred because the body could express itself through art (Lived Body), C) was available because creative expression was something physical and permanent participants could reflect on (Lived Space), and, D) occurred through narrative with oneself, with the art as its own entity, and with others (Lived Relation).

Firstly, increased self-understanding occurred over time. For some participants, this process happened more explicitly when they were post-treatment or in remission. One participant noted that she didn't think as "critically" about the art she created during treatment, but the creative expression she engaged in while in remission was more of a "reflective practice". Another participant felt similarly, saying that, although she engaged in a great deal of creative expression while in treatment, it wasn't until about five years later that she "started to really...formally explore [her] cancer experience with art". She explained that the art she created during treatment was "satisfying to be creating something", and "was just about *doing* it"; however, art she created later on "was super validating and powerful" because, she said, "I realized how much insight I gained after the fact". This being said, when she reflected on an art journaling entry she created during treatment while in the research context, she was able to make meaning of it. She noted that, "I don't remember it being like, 'This was the story I was telling at the time'...but in my journal you can totally see that that was what I was talking about, right?"

Secondly, increased self-understanding was felt in participants' bodies and occurred because the body could express itself through art. One participant explained how creative expression helped her to unravel a narrative:

As I'm making it, the narrative comes...the art lets different parts reveal themselves. The story I go in trying to tell changes in the process. And then I am like, "Ohhh, yeah, this is like the story that I have now told.

Thirdly, increased self-understanding was available because creative expression was something physical and permanent participants could reflect on. One participant described an experience in art therapy when she sculpted her heart of clay, saying that: “To see it real in front of me, I was able to understand...how much weight was in there”. Another participant stressed that, during an art therapy exercise, she did not intend to make something meaningful; however, she later realized that: “When you put it down on paper, you can be like, ‘Oh, ok that’s how I see myself’”. This process was sometimes surprising. For example, one participant described how, while she was working on an art piece, she suddenly noticed that it was much more colourful than past pieces she had created during her cancer journey. She said that:

It just made me realize probably, um...I’m not as dark inside as I think...there is some hope somewhere, even if I don’t acknowledge it, and my rationality says to me, “No, everything’s dark, this sucks, fuck!” (*laughs lightly*) There is something inside of me that, I dunno, it’s powerful and it’s colourful, and it has hope and light.

Finally, increased self-understanding occurred through narrative with oneself and others. Participants gained awareness and understanding by reflecting on their artwork through self-reflection, writing, and, perhaps especially, in conversation with others. One participant blogged about her experiences with knitting, and it appears as though this helped her realize just how impactful creative expression was for her. Several participants incorporated text into their art; one participant noted that this was often her way to find meaning in her work. Finally, engaging in a narrative with others about one’s artwork was particularly important in increasing self-understanding. One participant explained:

To explain it to others, um, I found that to be one of, one of the best parts. Because I was almost, as I was explaining it to others, I sort of learned about what I had created, it was like, it was like I was explaining it to myself.

Participants explained how other people sometimes pointed out things about their art products that they were not aware of, helping them gain deeper self-understanding. For example,

one participant recalled how, when her art therapist noted how dark her paintings were, she became “aware how...deep it was...how dark [she] was feeling in the moment”. Furthermore, through the process of giving back and sharing others’ cancer stories, self-awareness was enriched. One participant who participated in a theatre project (which included visual art aspects) that was inspired by cancer survivors’ stories expressed how, in telling others’ stories, she too was impacted: “It was a really powerful opportunity to share, to share stories, and always, every time I did it I learned something new about myself”

Additionally, increased self-awareness appeared to unfold in the research context with me as participants reflected on their experiences with creative expression. Their narratives with me were rich and thoughtful, and they shared insights that I was often inspired and moved by. One participant shared how she had never reflected on one of her paintings in such depth until she talked about it with me, saying that, “Now I just see how meaningful it was. I see it really much more meaningful now than I thought that it was, actually”. Similarly, as one participant explained a collage he had created, he came to a new realization: “You know, the whole thing is probably about frustration and anger...it’s more about frustration and anger than it is about anything else”. Yet another participant reflected upon some of the text in one of her pieces during our research conversation, saying that: “There’s the words ‘love, light, and hope’ which I think are really important. That’s what I really believe in”.

Healing the mind and body. The four lifeworlds also interacted to make the lived experience of creative expression one in which healing – of the mind and body – could occur. One participant described how creative expression helped her to heal in a way that reflects each of these lifeworlds. She discussed how she first went through the “process” of making the art (lived time), wherein she felt “all these emotions” and a “physical response” (lived body),

followed by feelings of “vulnerability” in sharing her physical product (lived relation and lived space). She then reflected on how she came to increased self-understanding, which greatly impacting her healing process:

If you reflect on it afterwards it's like...you go to a place where you're more self-aware. You learn more about yourself, what triggers you, and what um, yeah what causes those emotions to come out. [*So it helps you develop a new level of understanding about yourself?*] Yeah...um, and I guess that's how I heal, is through the learning process.

When art was all about the flow and the art process over the art product, or, as one participant put it “just being in it and not having to worry about the end result”, it appears that participants were able to create in a more therapeutic way. One participant talked about the art she created for an Art Education Class (wherein she dedicated all of her work to her cancer journey), saying that, “this was all about the process, so I could do no wrong...so that was, I think, really healing...to just make it”. Another participant echoed her sentiments; when asked what the experience of creating was like for her once she could let go of “worrying about making it look good”, she answered that “you sort of get into this ‘zone’, I think. And, that in itself is really, like, um, restorative, it's...really healing in itself”. Yet another participant said simply that “the act of creating is good for the soul”.

Participants found creative expression's ability to help the body express itself to be “therapeutic” and “helpful”; one participant described how her art helped her make “records of [her] emotions”, which was important because she believed “it's really healthy to not bottle things up”. Another participant reiterated these beliefs as he described the way that art helped him let out his feelings:

I just knew throughout the experience – and I still do – that if you're feeling something, you have to, you have to let it out, because pretending is not...it's not going to be helpful in the long run. Because the shit is going to come back later, bigger.

Participants also recalled how having physical control of their art – when so many things in life were out of control – was helpful. One participant said that: “I could control the way I told my story, and in that regained some freedom”. Similarly, another participant stated:

It was like coming back to myself, and remembering something that seemed like I had forgotten about it, because I lost my voice – metaphorically, not physically – um, and my family would speak to my doctors for me, and wouldn’t let me get a word in [yeah], and, so, creating something that communicated...was a way of me finding myself again.

Through the lived experience of creating, participants also experienced growth and forward movement. One participant said that, “you come to this end point where you are changed from when you first started”. Another participant described how, in expressing her fear through her art, and by seeing the darkness of the paint in front of her, she was able to acknowledge “the fact that [she] had good reason to be sad”. By doing so, she was able to “move a bit forward...from being numbed”. Finally, as another participant so poignantly said: “Making art I think was probably the biggest thing that has helped me to become complete, or maybe just put me on the road to becoming complete”.

Some participants were inspired through their interactions with creative expression to move forward in their lives with new goals and dreams. One participant’s videography project for a university class (which focused on cancer survivors’ experience of their sexuality) caught the attention of her professor, who encouraged her to apply for a Master’s program. As she shared this exciting news with me during our second interview, she expressed how exhilarated she felt about creating future projects, saying that, “I’m so fascinated by each person’s individual self expression of their own journey”. Post-cancer, another participant was pursuing her knitting as a career. In an essay that she sent to me, her words were full of inspiration and passion as she

described how creative expression filled her with a sense of power: “There’s still more beauty for me to knit, if cancer didn’t stop that, nothing else will. I am a knitter, I can do anything”.

Chapter 5: Discussion

*“Art does not reproduce the visible; rather, it makes visible”
(Paul Klee, 1879-1940)*

I arrived at this study from a place of curiosity and wondering about the lived experience of creative expression for young adult cancer survivors. After consulting the relevant literature, generating and analyzing new data, engaging in a thematic and existential reflection, and writing and re-writing to arrive at what I modestly hope is a rich and meaningful text, new insights were revealed to me about the phenomenon under investigation. My goal is to help readers develop a deepened and perhaps more thoughtful understanding of the lived experience of creative expression for young adult cancer survivors. Of course, this intention is speckled with the understanding that the lived meaning of creative expression I offer throughout these pages could never fully capture this phenomenon.

During my process of writing and re-writing, I was reminded of a term I learned during an undergraduate English Literature course: *ekphrasis*. In Greek, this word means “description”; in English it refers to a text that offers a vivid description of a visual piece of art. In relating to visual creative expression, and attempting to describe its essence through text, I have indeed engaged in a form of ekphrasis. Although I did not offer a description of one piece of art (following the example of, say, Dante Gabriel Rossetti’s sonnet entitled “For *Our Lady of the Rocks* by Leonardo da Vinci”), I did use narrative to make sense of a visual experience. In undertaking such an endeavor, Benton (1997) suggests that text and art “together thus become more than they are apart; each illuminates the other” (p. 375).

Throughout this chapter, I begin by offering a summary of the current study’s findings, followed by my perspective as the eighth young adult who participated in this research. I then

discuss this study's contributions to the literature, discussing the meaning and significance of noteworthy findings. I follow this by examining limitations of the current study, and offering potential routes for further research. Implications for counselling practice are then suggested before I conclude with my final "sketch" of ideas.

Summary of the Inquiry

In this hermeneutic phenomenological study, I engaged in multiple conversations with seven young adults who had participated in visual creative expression – either individually and/or in a therapeutic setting – throughout their cancer journeys. These young adults came from diverse backgrounds, and varied in their previous engagement with creative expression. Yet, all of these individuals turned to creative expression in some way – from knitting to tattoo designing – after they came face-to-face with the life threatening experience that is cancer.

Over the course of four months, I spoke with each participant on multiple occasions: six engaged in two face-to-face interviews, while the seventh met with me once for a longer period of time and then followed up with me thoroughly through email. Our conversations resulted in nearly 14 hours of audiotaped storytelling, reflection, questioning, elaboration, laughter, and a few tears. In pursuing this research, I encountered something that van Manen (1990) has also uncovered in his phenomenological research: participants appeared to "invest more than a passing interest in the research project in which they have willingly involved themselves" (p. 98). I witnessed participants express care for the subject and research question; for example, they were excited to show me examples of their creativity, gave me hard or electronic copies of their artwork, invited me to art events in the community, sent me narratives they had composed about the phenomenology of interest, and linked me to their websites or blogs. It appeared as though

they truly wanted me to capture a full and meaningful picture of the way they experienced creative expression.

A thorough thematic analysis and guided existential analysis, followed by a process of writing and re-writing, led me to nine vibrant themes that I hope say something evocative about the lived experience of creative expression. These themes encompass how participants experienced creative expression through the four lifeworlds of lived time, lived body, lived space, and lived relation. When reflected on in this way, it appears that the experience of creative expression was one that involved: A) being in the flow, B) allowing the body to express itself, C) renegotiating control, D) being impacted a permanent change to the environment, E) being seen, F) respect for art as other, and G) giving back. Furthermore, these themes can be seen as intricately intertwining to create an experience wherein increased self-understanding and healing of the mind and body occurred. Certainly the description and interpretation I have offered is not perfect, for “no explication of meaning is ever final, no insight is beyond challenge” (van Manen, 2011). Rather, it invites and challenges the reader to stay as attuned as possible to the various ways that creative expression is experienced, and to the infinite possible explanations of those experiences (van Manen, 2011).

The Eighth Participant

I am the eighth young adult who participated in conversations with the study’s participants. Participants affected me, as I likely affected them. I am not a cancer survivor, so I certainly approached the experience of creative expression from a different lens; however, the participants’ stories often resonated with and moved something deep within me. They reminded me of my own passion for creative expression, inspired me to engage in artistic pursuits, and supported and challenged some of my biases about the creative experience.

Important to this inquiry was my continual openness and wonderment towards the phenomenon of interest. I jotted down quotes I overheard in everyday conversation around creative expression, and reflected on my own experiences with art. Furthermore, I was serendipitously invited to partake in an online trial art therapy program being piloted through CancerChatCanada. My role as a participant was to provide feedback to the facilitators and designers of this program so they could develop an effective computer-based tool for art therapy that could be offered online for cancer patients and survivors. I tremendously enjoyed participating, and found that, upon reflection of some of the artwork I created, I came to increased self-awareness and new, sometimes surprising, understandings. Throughout the data generation process, I also attempted to come into closer contact with the experience of cancer itself, by reading fictional and non-fictional cancer-related accounts, and chatting with a colleague who works as a counsellor at the BC Cancer Agency.

I resonate with a quote from van Manen (2011), who noted that: “In some sense the phenomenologist is like an artist and an author. Just as a painter draws the world so the phenomenologist tries to use words to evoke some aspect of human existence in a linguistic image”. In reading this assertion, I drew parallels between the participants’ experiences of creative expression and my own lived experience of writing this thesis document. This experience occurred over time; unquestionably, I often felt stuck, but for many wonderful moments I found myself in the flow. Like this study’s participants, I too slipped into flow more easily when I could quiet my inner critic and just let the process unfold. My thesis-writing experience also encompassed a renegotiation of control; at times I felt powerful as I sat down in front of my computer, at others I had to release trying to control the way each sentence unfolded. As I finished various chapters, I often felt a sense of pride and accomplishment as I read the final

products of my labour. Furthermore, sharing my work with others affirmed my hard work, at the same time influencing and helping to refine it. Finally, in some small way, this work also allows me to give back to the young adult cancer community – a community without whose openness and generosity I would not have been able to complete this work.

Contributions to the Creative Expression Literature

This research contributes to the creative expression literature in several novel and exciting ways. Firstly, as previously noted, both the Canadian Cancer Society (CCS; 2009) and the National Cancer Institute (NCI) in the US (2004; 2006) have called for increased research on and support for young adult survivors. In 2011, a new journal was introduced, entitled, *Journal of Adolescent and Young Adult Oncology*, which reflects this rapidly growing discipline. In fact, the number of journal articles identified by the search term “adolescent young adult cancer” increased from about 250 per year prior to 2007 to 4045 in 2009 (Bleyer, Albritton, Barr, Lewis, & Sender, 2011). This growth is certainly significant; however, this search term still yields substantially less than the 7000-7500 articles the search term “children cancer” identifies (Bleyer et al., 2011). It is clear that more research is still needed with this population; however, the current study contributes to the “emerging buds and blossoms” of young adult oncology (Bleyer et al., 2011, p. 13).

Moreover, this study was the first of its kind to explore the lived experience of visual creative expression specifically within the context of young adult cancer survivors. Thus, it begins to fill a large gap in the literature. Findings indicate that creative expression with young adults shares several similarities with, as well as some differences from, creative expression for older adult populations. Some pertinent contributions of the current study in regards to these similarities and differences are discussed in more detail below.

Being in the Flow

The concept of flow has been studied in depth by Csikszentmihalyi (1997), who described flow experiences as moments wherein “what we feel, what we wish, and what we think are in harmony” (p. 29). Similarly, Amundson (2009) described flow as an instance wherein a person is fully engaged in an activity. Some of the descriptors Amundson used in relation to flow are ones that were utilized by participants in the current study; for example, “peaceful” and “time stands still” (p. 135). Many experiences of flow have been identified in the creative expression and cancer literature. For example, in Lane’s (2005) hermeneutic phenomenological study, she described how creative expression involves the participant becoming “immersed” in some kind of creative process. Furthermore, Reynolds and Prior (2006) engaged in a qualitative study in order to understand whether women living with cancer ($N = 10$; average age of participants was 47-57) who engaged in visual creative expression described experiences associated with the flow state. Similar to the current study, Reynolds and Prior found that, during creative expression, participants experienced concentration, a sense of altered time, and a reduced awareness of environment.

Csikszentmihalyi (1997) asserted that flow tends to occur when one is faced with a clear set of goals. However, in line with Reynolds and Prior (2006), participants’ experiences in the current study did always clearly reflect this aspect. Indeed, participants often spoke about art taking on a life of its own; furthermore, rather than enacting firm plans, participants often allowed images to evolve naturalistically, and frequently engaged in a process of artistic “play” and discovery. This being said, certain art projects were more explicitly linked to clear goals. For example, when one participant knitted chemo hats for fellow survivors, it appears she had a goal to make others feel warm and loved. Similarly, when other participants created art projects for

university classes, they clearly had the goal to complete their assignments while also, it appears, saying something meaningful about their cancer experiences. Thus, it seems that flow can manifest itself in different ways. Like Amundson (2009) described, “in some instances it can be a ‘whitewater’ experience where there is challenge and focused effort and in other instances it can be a peaceful steady forward movement” (p. 135). Furthermore, the current study appears to be novel in suggesting that letting go of self-judgment is a prerequisite to and consequence of flow in relation to creative expression. Although other studies have referenced participants who faced self-judgment around art (e.g. Collie et al., 2006;), this study appears to be unique in linking the release of this judgment to an experience of flow. These findings invite us to expand upon Csikszentmihalyi’s definition of flow.

Allowing the Body to Express Itself

Georgia O’Keefe, the famous American artist, once said that, “I found I could say things with color and shapes that I couldn’t say any other way - things I had no words for”. These sentiments were echoed almost word for word by some of this study’s participants. Indeed, several published studies have indicated that art helps adults (e.g. Collie et al., 2006; Singh, 2011; Vianna et al., 2013) and adolescents (e.g. Baerg, 2003) express and explore emotions and cognitions related to their cancer journeys. The current study validates and adds to this rich body of literature. The neuroscience literature helps explain how creative expression facilitates emotional expression. When an individual experiences a crisis or stressful life event, the higher verbal functions in the cerebral cortex become less accessible (Hass-Cohen, 2008b). Thus, when facing a stressful life event like cancer, a person may be left without words to describe his or her experience. Creative expression offers a way for individuals to access their non-verbal emotions through art; thus, it is perhaps not surprising that participants in the current study found creative

expression to be an accessible way to uncover and release emotions from deep within their bodies.

The finding that young adults were able to express themselves through art when words were not available relates to what van Manen (1990) calls epistemological silence – the kind of silence we are confronted with when we face the unspeakable. As van Manen (1990) expressed, “the experience of something that appears ineffable within the context of one type of discourse may be expressible by means of another form of discourse” (p. 113). Indeed, it appeared that for the participants in this study, their experiences of cancer were often “unspeakable”; however, they could express their stories and feelings through their art when words were just not enough.

Being Seen and Giving Back

Past studies have revealed how creative expression involved and impacted social relationships for cancer survivors in some way (e.g. Reynolds & Lim, 2007b; Reynolds, Lim, & Prior, 2008). Results from the current study are similar to some of these findings; for example, past research has found that participants dedicated artwork, or used art products as gifts to reciprocate care, to others (e.g. Reynolds and Lim, 2007b; Vianna et al., 2013). However, it appears that, in some ways, creative expression played a different role for young adults in terms of their lived relation to others. For example, in Reynolds and Lim’s (2007b) study (wherein the average age of participants ranged from the late 40s to 50s), they described how art-making provided a shared interest with others that was not cancer-related; in other words, they noted that art-making helped participants “resist being overly defined by cancer” (p. 6). This aspect of creative expression was not explicitly found in the current study. In fact, many young adults used creative expression to share with the world what they had gone through, using art as a form of cancer advocacy to tell their own and other survivors’ stories. This appears more in line with

research conducted by Baerg (2003) with adolescents ($N = 2$; age 15 and 16), wherein she found that showcasing their creative work as part of a “healing arts gallery” was an important component of the creative experience. Similarly, breast cancer survivors may use their art for activism. Indeed, Collie and her colleagues (2011) found that breast cancer survivors often used art as a way to give back to the breast cancer community, experiencing self-transcendence through altruism. More research is needed to better understand the role of cancer advocacy through creative expression for young adult survivors.

Self-Understanding

In line with findings from the current study, past research has revealed that creative expression facilitates increased self-understanding and awareness for cancer survivors. For example, Collie and her colleagues (2006) found that creative expression helped women with cancer gain a clearer view of what they were experiencing, and helped them engage in a process of meaning-making. Of particular importance to self-understanding for participants in the current study was the experience of engaging in a narrative with oneself and others about their art products. The neuroscience literature helps to explain this phenomenon. When emotions are expressed through art, individuals are then able to reflect on what they are feeling and create new meanings (Hass-Cohen, 2008a). Being able to put words to and explain emotionally charged experiences promotes the integration of unconscious bodily memories into more conscious personal narratives (van der Kolk & Fisler, 1995). This, in turn, results in an integration of the right and left hemispheres, promoting meaning-making and increased self-awareness (Hass-Cohen, 2008a). In coming to increased self-understanding, perhaps participants also engaged in a process of reformulating their identities. Indeed, one participant noted that her art helped her create a “reflection of how I view myself”, because, she said:

People who are ill can lose track of their self image. Like, how they see themselves, and how other people see them changes so much, so I think that's a huge impact on how you feel about yourself.

According to McNutt (2013), art-making and the art therapy process is one way in which the cancer survivor can “take inventory of her pre-cancer identity and synthesize it with new notions of identity” (p. 130). McNutt also argues that this reformulation of identity is integral for survivors to be able to move forward from their illness.

For some participants in the current study, increased self-understanding occurred more explicitly when they engaged in creative expression post-treatment compared to while they were in active treatment. This appears to make sense, given that, while in treatment, participants often faced overwhelming physical and emotional demands that created less space for self-reflection. This finding contributes to the literature by suggesting that, in the context of young adult cancer survivorship, experiences such as creative expression that foster increased self-understanding can unfold differently depending on the stage of survivorship.

Healing the Mind and Body

Cancer during young adulthood impacted participants emotionally and physically. They experienced pain and uncertainty, and they came face-to-face with their own mortality. As part of their cancer journeys, creative expression provided an experience wherein healing of the mind and body could occur. Indeed, the National Center for Complementary and Alternative Medicine (NCCAM) considers the expressive therapies to be mind-body interventions because they are designed to facilitate the mind's capacity to influence the body (in Malchiodi, 2005). Again, the neuroscience literature helps explain this process. Hass-Cohen (2008a) has coined the term “art therapy relational neurobiology principles” (ATR-N), and she and her colleague explain that, because ATR-N approaches “ignite implicit memory and trigger integrated right and left

hemispheric functioning”, this, in turn, may “decrease the stress response, regulate disturbing emotions, increase a sense of mastery and control, and expand relation interconnectedness” (Bridgham & Hass-Cohen, 2008). Perhaps it is no wonder that the young adults in this study described creative expression as “therapeutic” and “healing”.

Limitations

Before addressing this study’s limitations, it is important to again reflect upon its purpose. According to van Manen (1990), “meaning questions can never be ‘solved’ and thus done away with...they can be better and more deeply understood...and they will need to be appropriated, in a personal way, by anyone who hopes to benefit from such insight” (p. 77). In other words, it was not my intention to provide a finalized answer, hypothesis or theory to represent the phenomenon of creative expression for young adult cancer survivors. Nor was it my goal to uncover themes that could be generalized to the entire population of young adult cancer survivors. Certainly this study’s findings are limited to the stories of the seven young adults who spoke with me, and to the extent to which I was able to reflect upon and express their ideas through writing. However, it is believed that this work offers an experiential understanding of the phenomenon of creative expression that can speak to shared meanings and understandings.

Firstly, the opening question within this study’s first interview posed a limitation. By asking participants to tell me about their cancer “journeys”, I inadvertently imposed a metaphor onto them about a journey that they may or may not have related to. Alternatively, I might have avoided the use of such a metaphor, and instead allowed metaphors to arise spontaneously in our conversations (if at all). Furthermore, the fact that four interviews were conducted via Skype while three interviews were conducted in person is a limitation of the current study, because these two interviewing formats created different research experiences. This being said,

conducting interviews by Skype in the current study was beneficial in that it allowed for the inclusion of participants from various geographic locations across North America. Furthermore, Hanna (2012) suggested that software such as Skype are the most feasible alternatives to in person interviews, and are more effective than telephone interviews because they allow for synchronous interaction between researcher and participant, maintaining the visual and interpersonal components of the conversation. However, Skype interviews created a few restrictions. Firstly, there were some unforeseen technological “glitches” experienced during two of the Skype interviews, wherein the video conferencing technology stopped momentarily, or the audio system skipped. Although these interruptions were always brief, they slightly interrupted the flow of the research experience. Furthermore, when it came to the transcription process, during two audiotaped Skype interviews it was sometimes difficult to hear what the participant was saying (e.g. there was sometimes a “fuzziness” to their speech) Thus, this may have created an issue where a certain phrase or word was missed. Finally, perhaps Skype interviewing created an atmosphere less conducive to spontaneous interactions about participants’ creative expression experiences; at the same time, it appeared to foster an environment that was very focused on the research conversation, with less room for distraction.

Although the participants in the current study represented a diversity of cultural backgrounds and other individual characteristics, only one male voice was included. This was solely an issue of recruitment – only one male participant who fit the criteria for this study approached me with an interest to participate. Perhaps this is because males are less likely than females to turn to creative expression following a stressful life circumstance such as cancer, or are less willing to share their perspectives in a research context. Regardless of the reason “why”, future research would be well-served to include a broader male perspective. Geue and her

colleagues (2012) found that the most successful form of recruitment for males for an art therapy intervention was invitation letters by post, which was not utilized in the current study; thus, this is useful information for future researchers hoping to recruit a larger male sample.

Engaging in a guided existential reflection was both a strength and a limitation of the current study. Certainly, reflecting on the data in this way helped me engage closely with the phenomenon of interest, and ensure that I was capturing the ways in which creative expression was experienced through time, body, space, and relation. This being said, I realize that there are other ways in which individuals may experience their worlds. Furthermore, as Nicol (2001) pointed out, using a guided existential reflection shaped the study's findings by suggesting a theory for the way humans live and experience themselves (i.e. through time, body, space, and relation). It also potentially constrained the analysis such that the themes a priori ended up representing these existentials. In doing so, it challenges phenomenology's epistemological stance as a theory-free way of knowing.

Directions for Future Research

Further phenomenological research is always called for; thus, future hermeneutic phenomenological studies that explore the lived experience of creative expression are warranted (Nicol, 2001). Future research might investigate different types of creative expression; for example, music, drama, and writing. Although several participants in the current study recalled experiences with these types of creativity, the focus was mainly on visual creative expression. I am especially curious about the lived experience of music for young adult survivors. Music involves both listening and creating components; thus, it could be especially dynamic and novel to understand this experience further. Future research could also focus on the particular themes articulated in the current study. For example, one might investigate the experiential quality of

giving back, and, more specifically cancer advocacy, through art, because this appears to be particularly salient for the young adult population. It could be meaningful to further unpack the meaning young adults prescribe to their experiences of cancer activism through art.

The lived experience of online blogging is also of interest, as survivor-initiated “cancer blogs” have recently become popular communication tools (Thielst, 2007). Cancer blogs are personal online websites wherein users personalize their sites with photographs and links, and are given the opportunity to share narratives via text, pictures, and videos (Keim-Malpass et al., 2013). Indeed, blogging integrates several aspects of creative expression, including writing, visual design, and photography. Furthermore, blogs provide a means for cancer survivors to share personal experiences, find emotional support, and expand their cancer-related knowledge (Thielst, 2007). Keim-Malpass and her colleagues (2013) analyzed the naturalistic narratives from 16 online blogs published by young women diagnosed with cancer (aged 23-39 years), in order to better understand aspects of disease and survivorship. Using this methodology, the authors were able to determine dimensions of persistent problems that young women faced during and post treatment, which they wrote about in their blogs. This research indicates that young adults are, indeed, utilizing blogs to reflect on and share about their experiences. A next step for researchers is to better understand the lived meaning of this blogging experience.

Implications for Counselling Practice

Findings from this study have several exciting implications for counsellors and other practitioners working with young adult cancer survivors. First and foremost, this research suggests that turning to creative expression following a cancer diagnosis can be a meaningful and impactful experience for young adult cancer survivors. This has implications for counsellors and agencies who work with this population, who want to provide more supportive avenues for these

individuals. One of this study's participants had never been offered art therapy throughout her cancer treatment. This participant turned to creative expression on her own, and experienced a healing experience individually. However, others may not be as inclined to, or perhaps even think to, turn to creative expression without some outside encouragement, and could miss out on a potentially meaningful and healing experience. Thus, art therapy offered through counsellors and agencies might play an important role in introducing young adults to the healing potential of creative expression, and continually support them through this medium.

Furthermore, many individuals in our society have adopted the belief that they are not "creative" or cannot produce something that is "artistic" (Malchiodi, 2005). Indeed, every participant in the current study believed, in the past and/or presently, and at least to some capacity, that they could not "do" art. Yet, all participants were able to let go of their beliefs and self-judgment, at least temporarily, in order to get into the flow of art and experience increased self-understanding and healing. Furthermore, Malchiodi (2005) noted that those who engage in art more extensively (e.g. through occupational pursuits) may be so worried about the artistic outcome of their work that they have difficulty surrendering to the creative process. Pablo Picasso himself said that, "It took me four years to paint like Raphael, but a lifetime to paint like a child". Some participants in the current study also experienced this phenomenon. This is useful information for art therapists and other practitioners who utilize creative interventions, who may encounter resistance or anxiety from clients around creative expression. Firstly, it is important for practitioners to facilitate a non-judgmental and supportive environment wherein creative expression can unfold. Secondly, participants in the current study recalled how fundamental their art therapists were in encouraging them not to worry about the artistic outcome. Knowing that participants found it helpful for therapists to engage in a dialogue about the importance of the art

process over the art product is important information for art therapists and other practitioners.

This being said, creative expression will not be a good fit for all young adult survivors, so when approaching clients with creative expression interventions it is important to always keep the client's agency at the forefront of the dialogue.

Another implication for practitioners lies in creative expression's ability to provide a safe container for emotions. A common assumption is that creative therapies are largely utilized as a form of catharsis (Malchiodi, 2005). Indeed, much research shows that creative expression helps individuals express emotions (e.g. Collie et al, 2006; Vianna et al., 2013), and findings from the current study add further explanations to this body of literature. However, this is only one aspect of how creative expression is used in art therapy. In fact, according to Malchiodi (2005), in art therapy, "self-expression is used as a container for feelings and perceptions that may deepen into greater self-understanding or may be transformed, resulting in emotional reparation, resolution of conflicts, and a sense of well-being" (p. 9). In the current study, the theme of "renegotiating control" revealed that, when engaging in art individually, several participants spontaneously used art as a way to control and contain emotions. This finding has implications for practitioners looking to provide clients with coping strategies to deal with the stressors of cancer.

Additionally, findings from this study revealed that creative expression engaged in both individually and within a therapeutic environment were meaningful avenues for meaning-making and healing. These findings were in line with Collie and her colleagues (2006), who used narrative methods to explore how women with breast cancer used not only art therapy, but also independent creative expression, to address their needs that arose following their cancer diagnosis. These authors found few differences between the women's stories about art therapy versus individual creative expression. This is certainly not to say that individual creative

expression is the exact same experience as or a replacement for art therapy. However, it is important to know that creative expression engaged in individually can be deeply impactful in the face of a cancer diagnosis. Practitioners working with creative expression interventions could work with art both in their practices, and by inviting and encouraging their clients to engage in creative pursuits during their leisure time. Furthermore, Collie and her colleagues stressed that all the women who participated in creative expression outside of art therapy had a witness or recipient to their artwork. The current study uncovered similar findings. Thus, it is important for practitioners to be aware of the importance of “being seen” and “giving back” when working with clients who engage in creative expression individually.

Finally, although it appears creative expression can promote wellbeing and healing for young adult cancer survivors in many ways, findings indicate that, at times, both the process and products of creative expression can present challenges. Firstly, findings from this study reveal that the process of creative expression can sometimes be “painful”, and facilitate difficult emotions. Additionally, art products were sometimes tough reminders to participants about the constraints cancer had placed on their lives. Indeed, according to Hass-Cohen (2008), activating visual images of painful or traumatizing memories can be sometimes be emotionally overpowering and may reawaken amygdala fear responses. Thus, it is pertinent that practitioners who utilize creative expression techniques are aware of the non-verbal power of art, and that they help facilitate a healing experience by coupling fear-arousing emotions with new and positive sensory experiences (Hass-Cohen, 2008). Furthermore, findings reveal that sometimes art products were misinterpreted by others, or perceived by others as being too “heavy”, which was a difficult experience for some participants. It could be important for counsellors to remain cognizant of and engage in an open dialogue with clients about these potential reactions prior to

beginning the creative process, and to continually check in with clients about any disappointing interactions with others (including the practitioner him or herself) during and after various creative endeavors.

The Final Sketch

Keeping in the spirit of ekphrasis, I end with a poem that integrates words and phrases from this study's participants in order to say something about the lived experience of creative expression in a new, yet familiar, way.

“When I Create”

When I create
I lose track of time, the world disappears
As I dive into the yellows, blues, and reds
I uncover stories I didn't know I was holding in my heart.

When I create
My emotions ooze out
And I create my way through my sadness, frustration, and triumph
Because it's easier to express through colours than through words.
But, sometimes I don't know what to do with these emotions
So I create to gain distance from them
And my art becomes something to hold onto
When everything around me is whoosing by.

When I create
I permanently change the world, and thus I am changed
My art gives me strength, gives me comfort
And I often find beauty
Where before there was none.
But sometimes my art makes me anxious, makes me scared
So I put this art safely on a shelf
To revisit when I'm ready.

When I create
I don't always know how the process will unfold
The colours seem to move by themselves, like magic.
Sometimes I'm surprised
By the image that reveals
But that's my definition of art – it's something you can't control.

When I create
I am not alone
Art herself is an angel, an angel with a soul
And there are others too
I create to be seen by them, and to cherish them
To understand my story, and tell their stories too.

When I create
I find myself
And become more aware of the person I could be.
When I create, I am complete
Or at least on the road to becoming complete.
When I create, I can do anything.

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Appendices

Appendix A: Recruitment Letter

Recruitment Letter to Community Organizations and Agencies

Principal Investigator: Dr. Richard Young, Professor, Ph.D.; Department of Educational and Counselling Psychology, and Special Education; Faculty of Education; University of British Columbia (UBC)

Co-Investigator: Amy Green, M.A. Candidate; Department of Educational and Counselling Psychology, and Special Education; Faculty of Education; UBC

Department/Institution: Department of Educational and Counselling Psychology, and Special Education; University of British Columbia

Project Title: Exploring the Lived Experience of Visual Creative Expression for Young Adult Cancer Survivors

Research Funding: Social Science and Humanities Research Council of Canada; University of British Columbia

Dear [insert name of person/organization],

My name is Amy Green and I am a second year M.A. student in the Community Counselling Program at the University of British Columbia (UBC). As part of my requirements for a degree in a Master of Arts, **I am conducting a research study on the lived experience of visual creative expression for young adult cancer survivors.** I am contacting you to see if (name of organization) is interested in helping me recruit participants for this research project. I hope to interview a minimum of 7 young adults between the ages of 19-35 who have engaged in visual creative expression (including, for example, painting, drawing, sculpture, wood-carving, ceramics, crafts, and textiles) following their cancer diagnosis. Potential participants can be in the rehabilitation/continuing care or post-treatment/remission phases of cancer survivorship. All participants will be compensated with \$40 for their time: \$30 for an initial interview, and \$10 for a follow-up interview.

If you would like to learn more about my research, I would be happy to meet with you in person, talk with you on the phone, communicate with you via email, or send you a copy of my entire research proposal. The following provides some background information on who I am, why I am passionate about this research topic and why I believe it is an important and valuable topic of exploration. Finally, I will outline what participation in the research will entail.

Importance and Purpose of the Study:

The goal of this study is to learn more about the lived experience of visual creative expression for young adult cancer survivors. Creative expression, both individually and with an art therapist, has been shown to be a meaningful and helpful experience for people living with and healing from cancer. However, little research has been conducted solely with the young adult population; in fact, this age group has been referred to as the “orphaned cohort”. Thus, the aim of this study is to learn what the phenomenon of creative expression means to young adult cancer survivors.

Who is conducting this Study?

I will be the primary researcher for this study, working under the supervision of Dr. Richard Young at UBC. I am currently a second year M.A. student in Counselling Psychology, and hold a Bachelor's degree in Psychology.

What is Involved?

Interested participants can reach me at the contact information included below. Once they contact me I will conduct a preliminary phone-screening interview to ensure they are eligible for the project and have a clear understanding of what it entails. If we both agree to proceed, participants will be invited to meet with me at an interview location of their choosing; alternatively, if physical distance is a constraint or if it is the participant's preference, interviews can be conducted via Skype. Participants will be asked to complete a brief demographics form, and then engage in an open-ended interview. Interviews will last approximately 1-2 hours, and participants will be informed that they need only share what they feel comfortable. Following this interview, participants will be invited to email me about any experiences of creative expression that arise in the coming two months. I will then conduct a follow-up interview where I will check in with participants about emerging themes, and invite them to expand upon any information they shared in their emails. **All participants will receive \$40 for their participation**, as well as bus tickets to and from the interview or parking reimbursement as required.

Dissemination of Information, Consent and the Right to Withdraw:

The information I gather will be included in my final thesis and potentially in additional articles that may be published in academic journals, or presented at future research conferences. I am happy to forward a copy of my final findings to your organization. **The identities of all participants will be kept strictly confidential** and will not be revealed in any document. Participants will be identified by pseudonyms. Consent to participate in this study is completely voluntary and participants can stop an interview at any time or refrain from answering any interview questions. Participants are also free to withdraw from the study at any time without explanation.

Contact Information:

Your assistance and support in recruiting participants would be greatly appreciated. If you have any questions, concerns, or would like to speak to me further, you can reach me at:

xxxx@xx.com or xxx-xxx-xxxx.

Kind regards,

Amy Green

Appendix B: Recruitment Poster

Were you diagnosed with cancer between age 19-35?
Did you engage in creative expression following your diagnosis?
Would you like to share your experience?

The University of British Columbia is conducting a study on the experience of visual creative expression for young adult cancer survivors. Creative expression can include anything from painting to wood-working to sketching, and can be engaged in either leisurely, professionally, or within a therapeutic setting. You are eligible to participate if you are currently in the rehabilitation or post-treatment phases of your cancer journey.

What will I have to do? Participation will include two individual interviews and an invitation to email me about your creative expression experiences.

Why should I participate? You will receive \$30 for the first interview, and \$10 for the second interview as compensation for your time. Additionally, this is your opportunity to give voice to your experiences!

For more information contact Amy Green at

Appendix C: Screening Questions

Participant Screening Questions

I will begin by thanking potential participants for taking the time to contact me, and explain that I will need to ask them a few questions to determine their eligibility. All callers will be reminded that all information shared on the phone and throughout the study will remain confidential. With their permission, I will ask the following questions:

- 1) How did you hear about the study?
- 2) Do you read, speak, and write enough English to participate in the study?
- 3) Do you self-identify as someone who had, or currently has, cancer? What type of cancer do you/did you have? How long has it been since you were diagnosed?
- 4) Have you engaged in visual creative expression and/or art therapy following your cancer diagnosis? Do you believe this was/is important in your life?
- 5) Would you feel comfortable talking about your experience of creative expression in relation to your cancer journey?
- 6) The initial interview will range from 1-2 hours depending on how much you would like to share. I will also be contacting you for a follow up discussion once I have finished the first draft of an analysis of our interview. Is this ok with you?
- 7) At the end of the first interview I will invite you to email me about any insights, ideas, or impressions in relation to creative expression. This is completely optional. Is this something you would be interested in?
- 8) Why do you want to participate in this study?
- 9) Do you have any questions for me?
- 10) If you are still interested and able to participate, let's arrange a meeting time and place that works for you. You are invited to bring pieces of your art (or photographs of your art) to the interview with you; this may help remind you of specific creative experiences during the interview process, but is completely optional.

Appendix D: Consent Form**a place of mind**

THE UNIVERSITY OF BRITISH COLUMBIA

Title of Study: Exploring the Lived Experience of Visual Creative Expression for Young Adult Cancer Survivors

Principle Investigator: Dr. Richard Young, Professor, Ph.D.; Department of Educational and Counselling Psychology, and Special Education; Faculty of Education; University of British Columbia (UBC)

Co-Investigator: Amy Green, M.A. (Candidate), Department of Educational and Counselling Psychology, and Special Education; Faculty of Education; UBC.

Contact Information: xxx-xxx-xxxx or xxxxx@xx.com

This research is part of Amy's thesis requirement for completing a Master of Arts (M.A.) in the Counselling Psychology Program. Upon completion, the thesis will be a public document that can be viewed through the UBC library.

Sponsor: This research is funded by the Social Science and Humanities Research Council of Canada (SSHRC)

Why we are doing this research? The purpose of this study is to learn more about the lived experience of visual creative expression for young adult cancer survivors. Creative expression through the visual arts, both individually and with an art therapist, has been shown to be a meaningful and helpful experience for people living with and healing from cancer. However, little research has been conducted solely with the young adult population; in fact, this age group has been referred to as the “orphaned cohort”. Thus, the aim of this study is to learn what the phenomenon of visual creative expression means to young adult cancer survivors.

What happens if you agree to participate? If you choose to participate, you will be asked to complete a brief demographics form, and then engage in an open-ended interview. You will be invited to talk about your visual art experiences since you were diagnosed with cancer. The interview will last approximately 1-2 hours, and you will only need to share what you feel comfortable. Following this interview, you will be invited to email me about any experiences, insights, ideas, or impressions in relation to creative expression in the months following the first interview. Approximately two months following the first interview, I will contact you for a follow-up interview, where I will check in with you about any emerging themes from the first interview, and invite you to elaborate on any ideas expressed in your emails. This second discussion will take approximately 45 minutes to one hour. Finally, you will be invited to comment on the final analysis of our interviews, which will take approximately 30 minutes.

Study Results: Information gathered from the interviews will be analyzed and put together for a final research essay that will be used to complete the school requirements of the co-investigator. The information may also be shared at meetings and conferences and may be published in academic journals or magazines for other people to read. Your name will not be shared in any presentation or publication.

Potential Risks: We do not anticipate any possible risks from participating in this study. There is a possibility that some of the questions we ask or the topics we discuss may seem personal or uncomfortable. You need only discuss what you feel comfortable, and can end an interview at any time. If a topic comes up that you would like support for, we will have a list of community agencies and supportive services that can offer additional support.

Potential Benefits: This research will contribute to the knowledge base on the lived experience of creative expression for young adult cancer survivors. This knowledge will help inform psychosocial support, particularly in counselling and art therapy, for young adult cancer survivors.

Confidentiality: All interviews will be audiotaped and transcribed. All information gathered throughout the study that is related to your identity will be kept confidential and will not be shared with anyone without obtaining your permission first. Any and all data that is gathered will be kept in a locked filing cabinet. Transcribed interviews will be encrypted and saved on an external hard-drive that is protected by a password that will be known only to the principal and co-investigator. Your name will not be identified on any of these documents; rather you will be asked to choose a pseudonym to protect your identity (alternatively, the researchers can select a pseudonym for you). It is UBC's policy that after five years, all data will be destroyed.

With your consent, any artwork you bring with you to the interview will be photographed. This is completely optional and voluntary.

There are three exceptional circumstances under which confidentiality cannot be maintained: 1) If there is reason to suspect physical, mental or sexual child abuse; 2) If there is serious risk of suicide and/or self harm and 3) If the participant presents a clear and imminent threat to someone else or society at large. If at any point the researcher assesses the participant's self disclosure to indicate any one of these three situations, the researcher will be obliged to intervene and take necessary precautions to ensure the safety of participants. Interventions may include, but are not exclusive to: emergency services, the Ministry of Child and Family Development, and counselling support services. Participants will always be informed of the precautions that are being taken and will be given the option of accessing these services themselves with the support of the investigator.

Remuneration or Compensation: As compensation for your time spent participating in this study, you will receive \$40 for your participation (\$30 for the initial interview, and \$10 for the follow-up interview), as well as bus tickets to and from the interview or parking reimbursement as required. Should you choose to withdraw from an interview at any point, you will still receive your full compensation for that interview.

Contact for Information about the Study: If at any point before, during, or after the study you have any questions, please feel free to contact the principal investigator or co-investigator. Their contact information is on the first page of this document.

Contact for Concerns about the Rights of Research Participants: If at any point you have questions or concerns about your rights as a research participant, please feel free to contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598. If long distance, e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Consent and the Right to Withdraw: Consent to be part of this research study is completely voluntary. You can choose to withdraw at any time with no explanation and with no consequences. You have the right not to answer any questions you do not want to answer, and can take a break at any time during the interview.

Signature:

I understand the information provided for the study “Exploring the Lived Experience of Creative expression for Young Adult Cancer Survivors” as described in this consent form.

Your signature below indicates that you have received a copy of this consent form for your own records.

1. “I consent/I do not consent (please circle one) to my participation in this study.”
2. “I consent/I do not consent (please circle one) to having my artwork photographed.”

Signature of Participant

Date

Printed Name of Participant

Check box if you are interested in receiving a summary of the research findings.

Signature of Investigator: “These are the terms under which I will conduct research.”

Signature of Investigator

Date

Appendix E: Demographics Form

Participant Demographics Form

Please answer the following questions by filling in the blank sections and circling answers where appropriate. If you need any help, please feel free to ask the researcher. If there are any questions that you feel uncomfortable answering, you have the right to leave them blank.

All information provided will be kept strictly confidential.

Thank you for your participation!

1. Pseudonym chosen: _____
2. Date of Birth: _____
3. City you live in: _____
4. Gender: a) Male b) Female c) Other _____
5. Cancer type: _____
6. What stage of survivorship do you self-identify with?
 - a. Rehabilitation/Continuing care
 - b. Post-treatment/Remission
7. Relationship status:
 - a. Married/Common-law
 - b. Committed relationship
 - c. Divorced
 - d. Single
 - e. Widow/Widower
8. Who lives in your household? (please specify their ages and relationship to you, but no names): _____
9. Highest level of education completed:
 - a. Elementary
 - b. High school
 - c. Post-secondary diploma
 - d. Undergraduate degree
 - e. Graduate degree
10. Current employment/career: _____
11. How did you hear about this study?

Appendix F: Interview Protocol

First Interview

All participants will first be asked: “Tell me about yourself.”

All participants will then be asked the question:

“Tell me how creative expression is part of your life. How it relates to your journey as a cancer survivor?”

After this is discussed, I will pose the following question:

“Take a moment and think about any strong memories you have about creative expression since your cancer diagnosis. Can you tell me about it in a way that I would feel I am experiencing it myself? For example, what was the process like? What did you see? How did you feel? What did you hear? Smell?”

I will then continue asking for more specific examples. If all of a participant’s experiences are positive, I will ask if he or she can think of a negative creative experience. Similarly, if all of a participant’s experiences are negative, I will ask if he or she can think of a positive creative experience. I will also ask all participants:

“Do you remember when creative expression first became important in your life? Can you tell me about that experience?”

Participants who bring artwork (or photographs of artwork) with them to the interview will be asked:

“What was your experience of creating this particular piece of artwork?” and “How do you experience the artwork now, in the research context with me?”

I will conclude the interview by asking participants if there is anything else they would like to say about their experiences of creative expression. I will also ask what the interview experience was like for them.

Second Interview

I will initially present my preliminary understandings of our first conversation, and ask for clarification of any material that might be unclear. I will then ask participants about any insights, reflections, or ideas that emerged between the first and second interviews, and if they would like to elaborate on anything from their emails (if applicable). I will tentatively present the emerging themes that I have identified, and ask participants: “Is this what the experience of creative expression is really like for you?”