

A Heuristic Arts-based Study on the Impact of Long-term and Late Effects of Cancer on  
Adolescent and Young Adult Cancer Survivors

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A Thesis Submitted in Partial  
Fulfillment of the Requirement  
for the Master of Arts in Art Therapy Degree

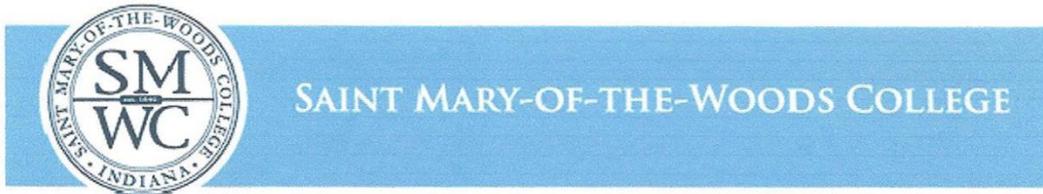
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INSTITUTIONAL REVIEW BOARD APPROVAL

Saint Mary-of-the-Woods College

Graduate Program in Art Therapy



**MEMO**

To: Jill McNutt, MA, ATR-BC, LPC, ATRL  
Lisa Kolodziej, Graduate Student  
From: LampriniPantazi, Ph.D., & Chair of the Human Subjects  
-Institutional Review Board  
Date: June 24<sup>th</sup>, 2014  
Re: Human Subjects Institutional Review Board Application

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Thank you for submitting a Human Subjects proposal entitled “**A Heuristic Arts-based Study on the Impact of Long-term and Late Effects of Cancer on Adolescent and Young Adult Cancer Survivors.**”

The Institutional Review Board (IRB) of Saint Mary-of-the-Woods College has **approved your research.** Unless renewed, this approval will expire on August 8<sup>th</sup>, 2015.

If any changes need to be made during implementation of this research project, please submit those changes to the IRB for its approval. Also, if any incidents occur, please notify the IRB as soon as possible.

We wish you success with your research project.

Institutional Review Board members:

A handwritten signature in blue ink, appearing to be 'Lamprini Pantazi', written over a horizontal line.

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## ABSTRACT

The adolescent and young adult population is an overlooked group when it comes to resources for coping with the distress of having and surviving cancer. Although the art therapy literature documents the value of art therapy for children and adults with cancer, few resources focus on the usefulness of art therapy in addressing the needs of survivors of adolescent and young adult cancers. Through an arts-based heuristic inquiry, the researcher, a survivor of adolescent cancer, re-envisioned and recreated a personal image that held great meaning in her experience of cancer survival. Following Moustakas' (1990) six phases of heuristic inquiry, the researcher investigated the usefulness of personal art making for coping with the lasting effects of a cancer diagnosis. As a result, the researcher noted three major themes relating to body image and identity, interruption, and acceptance. The researcher discusses these themes and the implications they may have for other survivors of adolescent and young adult cancers. The researcher offers recommendations that may provide a starting point for the utilization of art therapy with this population.

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## CHAPTER I

### **Introduction**

The researcher, age 28, is a young adult survivor of adolescent cancer, diagnosed at age 14, and treated between the ages of 14 and 15. As a result of her personal journey with cancer, the researcher has experienced physical and psychological late and long-term effects, including, but not limited to, depression, anxiety, chronic pain, and worry about fertility. The researcher has utilized personal art making throughout her late teens and young adulthood in order to express feelings surrounding her cancer survival and to deal with the changes and lasting effects brought on by having cancer at a young age.

During her Clinical II (AR-535) course in the fall of 2012 at Saint Mary-of-the-Woods College, the researcher created an art response to a unit assignment involving research on art therapy for general adolescent issues. In this drawing, she noted that she had utilized the same style of artwork that was common for her as a teenager. In addition, she had often represented some type of uncertainty, unknown, longing, or sadness within her work at that time. Creating this new image allowed the researcher to feel a heightened sense of ownership over those turbulent years, and inspired the researcher to begin viewing her old artwork from a slightly more mature perspective. For this reason, the researcher arrived at the idea of conducting a heuristic inquiry in which she would revisit and re-envision some of the artwork that was created during her late teens. Through this creative process, the researcher will identify the long-term and late effects of her cancer survival.

### **Statement of the Problem**

The “long-term” and “late” effects of a cancer diagnosis and its treatment can persist long after the disease itself has gone into remission. While the lasting effects of a cancer diagnosis

and its treatment are often discussed amongst cancer survivors, and are acknowledged in the research literature, the general public is often unaware of the existence of such effects. The treatment focus tends to be placed on coping with the illness itself versus coping with survival and tending to cancer's lasting effects.

The adolescent and young adult population is an often overlooked group when it comes to resources for coping with the distress of having and surviving cancer at a young age.

Although the art therapy literature has documented the effectiveness of art therapy for children and adults with cancer, few resources focus on the use of art therapy in addressing the specific needs of survivors of adolescent and young adult cancers.

### **Research Question**

The researcher conducted an arts-based heuristic inquiry into the experience of cancer survival as well as the long-term and late effects of the illness. The researcher re-created one piece of artwork, originally created during her early young adulthood, which allowed her to express feelings related to the personal impact of cancer survival and the late and long-term effects she experienced. The researcher performed a systematic, self-reflective exploration of her personal art making experiences in order to investigate the usefulness of personal art making for coping with the effects of cancer survival. This study was guided by the question, "*What can I discover about the long-term and late effects of cancer survival when I immerse myself in the process of art-making?*"

### **Basic Assumptions**

The researcher's basic assumptions for this study were that: (a) art making was a useful, therapeutic coping mechanism for dealing with illness, trauma, and feelings of distress; and (b)

some symptoms and themes (i.e. worry, anxiety, depression, etc.) were likely to be expressed in ways that were identifiable within the artwork.

### **Purpose of the Study**

The purpose of this research was to increase insight and understanding of the impact of the long-term and late effects of cancer survival on adolescent and young adult cancer survivors. The researcher intended to investigate the usefulness of personal art making as a method of addressing and coping with the long-term and late effects of cancer survival in adolescent and young adult survivors.

### **Hypotheses**

The researcher hypothesized that:

1. Fully immersing herself in this art-exploration would increase her insight and understanding of the long-term and late effects of cancer survival, as evidenced by the findings of the heuristic inquiry.
2. The creative process would allow her to integrate past experiences as an adolescent and young adult cancer survivor into the present, increasing feelings of ownership and peace with her cancer journey as evidenced by personal insight and discoveries noted throughout and following the art making process.

### **Definitions**

The Centers for Disease Control and Prevention (2004) and the National Cancer Institute (n.d.) defined a “cancer survivor” as an individual from the time a cancer diagnosis is received, and throughout the remaining years of his or her life. However, the term was defined differently for the purpose of this study.

**Cancer survivor.** An individual who has received and been treated for an initial cancer diagnosis, and is no longer in active treatment for the initial illness.

**Long-term effects.** Medical, physical, and/or psychological symptoms that may arise during active cancer treatment and persist after the initial cancer treatment has ended.

**Late effects.** Medical, physical, and/or psychological symptoms and conditions that may not be present during active cancer treatment, but may appear months or even years after the initial cancer treatment has ended.

**Psychological long-term or late effects.** Responses that are psychological or emotional in nature and may be attributed to the experience of cancer (i.e., anxiety, depression) (Stein, Syrjala, & Andrykowski, 2008).

**Adolescent and young adult.** The Adolescent and Young Adult Oncology Progress Review Group, the National Cancer Institute, and the LIVESTRONG Young Adult Alliance (2006) defined the adolescent and young adult age group as those aged fifteen through thirty-nine years. However, these terms were defined differently for the purpose of this study.

**Adolescent.** An individual during the time period between the ages of thirteen and eighteen years.

**Young adult.** An individual during the time period between ages eighteen and thirty-nine years.

## **Limitations**

The researcher acknowledged the limitations of this study. The researcher is a young adult survivor of adolescent cancer, and has had personal experience utilizing art making as a coping mechanism and stress reliever. This heuristic inquiry was limited to the sole experience of the researcher. The artwork utilized in the study was solely that of the researcher, and may

not necessarily be characteristic of the artwork of other survivors of adolescent or young adult cancers. The researcher's experience of cancer and late and long-term effects may be different than other young survivors, and may not be generalized to encompass the experiences and feelings of other survivors of adolescent and young adult cancers. Additionally, the researcher had planned to hold an exhibition of the artwork created during this heuristic study to a group of adult cancer survivors, as well as provide a qualitative exhibition survey for participants. Due to the inability to gain approval from the exhibition site, the researcher was unable to incorporate the planned exhibition and survey into the current research study.

### **Ethical Implications**

This heuristic study was expected to pose low or minimal risk to the researcher. As the researcher engaged in the heuristic study, anticipated risks included the researcher's unpleasant responses to subject matter that may be personally difficult or emotion laden in nature. The researcher planned to protect and help herself should any adverse thoughts or feelings arise by discussing these personal or private issues with her personal therapist, a licensed clinical social worker (LCSW).

**Researcher bias.** The researcher's outlook on the usefulness of art-making as a coping strategy to deal with the long-term and late effects of cancer may have been biased due to her previous experiences with utilizing art to cope with her own diagnosis, as well as the long-term and late effects she has experienced. As a cancer survivor, as well as the subject of this heuristic inquiry, the researcher noted her personal investment in the research. Additionally, the researcher has received education and training as an art therapist, and recognized her general acceptance for the use of art making to cope with physical and emotional challenges.

**Justification and Merits of the Study**

There were several research studies into the needs, health worries, quality of life, and long-term and late effects of childhood or adolescent cancer for the adolescent and young adult age groups. There was also literature addressing the usefulness of art therapy for children and adults with cancer, as well as with adult cancer survivors. At the time of this research study, there appeared to be very limited resources or information regarding the use of art therapy to address the specific needs of survivors of adolescent or young adult cancer.

According to Seitz et al. (2011), adult survivors of cancer diagnosed during the adolescent years reported impaired general and health-related life satisfaction when compared with the general population. This was found to be a result of somatic and psychological late effects, symptoms of depression and anxiety, and lack of posttraumatic growth. According to Wallace (2007), cancer challenges the trajectory of achievement of normal adolescent goals and development. A cancer diagnosis during the adolescent period may result in greater dependence on parents, poor body image, lack of self-worth, and affected peer relationships. Art therapy can provide a safe outlet for the expression of feelings and emotions tied to the cancer experience. Creating builds confidence and promotes self-esteem, while the art product itself may provide valuable insight into one's emotions and experiences.

## CHAPTER II

**Review of the Literature****The Physical Late Effects of Cancer on Adolescents and Young Adults**

Long-term survivors of cancer at a young age, treated with chemotherapy and/or radiation therapies, are vulnerable to a variety of adverse health effects, which may not be detected until years after treatment has ended. The risks of complications generally increase depending on the types and dosages of chemotherapy drugs received, the site(s) exposed to radiation therapy, the dosages of radiation received, the amount of treatments of received, and the age at exposure to cancer treatments. Because cancer treatments can lead to numerous health complications, it is important for young survivors to receive regular health screenings and be monitored regularly by health professionals (Mulrooney, Neglia, & Hudson, 2008).

Overall, cancer treatments may have long-term effects on a variety of bodily systems. Depending on their treatment protocol, young cancer survivors may be at higher risks for cardiovascular effects, including heart disease and stroke, reduced pulmonary function, and metabolic disorders, including obesity and hypertension. The endocrine system may be compromised, resulting in growth hormone abnormalities, thyroid problems, abnormal adrenal function, hormone deficiencies, and changes in the onset or progression of puberty (Mulrooney et al., 2008).

Secondary cancers are a life-long concern for virtually all cancer survivors. Survivors who have received radiation therapy typically have a greater risk of developing secondary cancers than those who have not been treated with radiation. Breast cancer is a significant risk for female survivors of childhood or adolescent cancer who have received radiation to the chest.

Survivors of leukemia or brain tumors who have been exposed to cranial radiation are at risk for tumors of the central nervous system (Mulrooney et al., 2008).

**Fertility and reproductive issues.** Adolescent and young adult cancer survivors often face an increased risk of fertility concerns when compared with the general population.

Receiving chemotherapy, radiation, surgery, or a combination of these treatments prior to the reproductive years puts young cancer survivors at a significantly greater risk of infertility.

Cancer treatments may have a variety of effects on the reproductive function of adolescent and young adult cancer survivors (Barton et al., 2013; Jacobs & Pucci, 2013). Concerns may include, but are not limited to androgen deficiency and hypogonadism in men and ovarian failure, low ovarian reserve, and premature menopause in women (Jacobs & Pucci, 2013). Additionally, cardiac or pulmonary damage as a result of cancer treatments can put female survivors at a higher risk of pregnancy complications. Radiation to the abdominal or pelvic region may increase the risk of prematurity or low birth-weight in babies born to female survivors (Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004).

In a survey of young adult survivors diagnosed with cancer during adolescence, infertility was reported by 14.5% of participants (Dieluweit et al., 2010). After interviewing young adult survivors, Zebrack et al. (2004) reported gaps in participants' knowledge about the effects of their cancer treatments on fertility and reproduction. More than half of the participants expressed uncertainty about their abilities to have children. The researchers reported that only about half of the participants interviewed had been informed about the potential effects of cancer treatments on their fertility.

Two major themes were reported by the young adult survivors in this study. The first dealt with concerns and knowledge regarding fertility status and reproductive capacity, the

potential impacts of undergoing cancer treatments on fertility, knowledge about fertility preservation and options for having children, and the impact of this information on relationships with spouses or partners. Some female participants expressed that the concerns and uncertainty surrounding their fertility had created tension and adverse feelings between them and their spouses. The second theme identified participants' concerns about children and parenting, as well as their feelings about the possibility of not becoming parents. Participants expressed concerns about having healthy children, passing on an increased risk of cancer, or being overly vigilant about their children's health (Zebrack et al., 2004).

**Sexual dysfunction.** Adolescent and young adult cancer survivors are at an increased risk for issues with their psychosexual development and sexual functioning, which may negatively impact the formation of intimate and romantic relationships (Jacobs & Pucci, 2013). Cancer treatments can damage the physiological systems that dictate healthy sexual function and response. These include the hormonal, vascular, neurologic and psychological elements of sexual function (Zebrack, Foley, Wittmann, & Leonard, 2010).

The loss of a normal menstrual cycle during cancer treatments may be seen as a significant and emotional loss for some young females. Young males may experience embarrassment due to the inability to control nocturnal emissions or erections resulting from treatment. Feelings of embarrassment or shame may also occur as the body is scrutinized by health professionals during treatments, hospital stays, and check-ups (Kelly, 2013). These issues may impact emotional well-being as well as perceptions of body image. A negative body image may affect sexual well-being and feelings of attractiveness (Jacobs & Pucci, 2013). Sexual dysfunction may also be associated with psychological impairments or negative feelings related to quality of life (Zebrack et al., 2010).

After surveying a sample of adolescent and young adult cancer survivors, van Dijk et al. (2008) noted that half of the participants reported feeling sexually attractive only seldom to never. Half of the participants reported feeling almost no sexual attraction to others, and reported that they felt satisfied with their sexual lives only seldom to never. Twenty percent of participants reported feeling that their sexual lives had been limited due to illness. These feelings were related to difficulties with expressing emotions, having scars, uncertainties about their bodies, and potential fertility issues.

### **Psychological Late Effects and Emotional Concerns**

The psychological consequences of cancer on young survivors may include depression, anxiety, or other mental health disorders (Mulrooney et al., 2008). In a survey of children and adolescents who had survived cancer, Eilertsen, Rannestad, Indredavik, and Vik (2011) found that emotional problems were consistently reported by survivors themselves, as well as by parents and teachers. After screening for anxiety in a sample of adolescent cancer patients currently undergoing treatment, Wu, Sheen, Shu, Chang, and Hsiao, (2013) reported that 11.5% of participants received high scores for anxiety, nearly 11% scored high for social anxiety, and nearly 21% reported a high level of worry.

After assessing a sample of adolescent survivors of childhood cancer, Kahalley et al. (2013) reported that psychological concerns were identified in 82% of participants. Out of those that were referred for follow-up services, 40% exhibited psychological concerns that had not been previously identified. Based on this finding, the authors suggested that adolescent cancer survivors may experience clinically concerning psychological symptoms that frequently go unidentified and untreated.

After conducting interviews with a sample of young adults that had been diagnosed with cancer during adolescence, Wicks & Mitchell (2010) identified the perception of loss of control due to illness as a major theme. The participants reported that this lack of control left them feeling frustrated, angry, and/or inadequate. Because cancer interferes with an adolescent's ability to lead a normal life, receiving a cancer diagnosis, dealing with an unpredictable treatment schedule, and experiencing the effects of treatment on one's appearance and sense of well-being are likely to challenge one's perceptions of control. The authors suggested that it may be difficult for adolescents with cancer to gain confidence in their independent decision making skills, as many health-related decisions are made by others. Some participants reported that their desire for control caused them to become non-compliant with receiving treatments or medication, while others reported that feeling they had no control caused them to become less involved in treatment decisions (Wicks & Mitchell, 2010).

**Altered self-image.** Changes in appearance and self-image are of great concern for young cancer patients and survivors, particularly adolescents. The adolescent period is marked by an increased awareness of one's appearance due to cognitive and physical developments and increased and sexual awareness. Dissatisfaction with one's appearance can greatly impact body image and self-esteem (Taylor, Pearce, Gibson, Fern, & Whelan, 2013; Wallace, Harcourt, Rumsey, & Foot, 2007).

Virtually all types of cancer treatments can cause changes to one's appearance, including scars, hair loss, weight loss or gain, and deficits in growth. The resulting appearance changes of cancer treatments may be of enormous concern to adolescents, impacting their self-esteem and social functioning. After conducting interviews with a sample of adolescent cancer survivors, Wallace et al. (2007) noted that appearance changes due to cancer treatments were typically

more concerning for young females than for males. Because the males interviewed were younger than the females, the authors suggested the difference may be a result of differences in maturity levels. However, the researchers mainly attributed this finding to the different societal meanings that appearance typically has for males and females.

Despite numerous painful or uncomfortable procedures and side-effects, several of these adolescent female survivors reported that hair loss was the worst part of their cancer treatment, and was the one aspect of having cancer that caused them the most anxiety. Participants expressed the importance of trying to remain “normal” in the eyes of others. However, hair loss, which is commonly associated with chemotherapy, was an obvious indication of their illness allowing others to identify them as “different.” In order to “blend in,” the participants relied on hats, scarves, and wigs, and reported that they would not go out in public without covering their heads. Many reported that they disliked going out in public alone, even when their heads were covered. Although the participants attempted to blend in by covering their heads, the authors noted that this actually drew attention towards them, resulting in impacted self-esteem and self-image.

**Posttraumatic stress.** According to the *DSM-IV-TR* (American Psychiatric Association, 2000), being diagnosed with a life-threatening illness or learning that one’s child has a life-threatening illness are traumatic events that may be associated with the risk of developing Posttraumatic Stress Disorder (PTSD). The degree of severity and threat posed by the illness are essential predictors of PTSD symptoms. Symptoms of PTSD have been noted in survivors of childhood and adolescent cancers as well as in their parents (Kazak et al., 2001; Pelcovitz et al., 1998).

The overwhelming emotional impact of being faced with a life-threatening illness during adolescence, as well as the nature of cancer treatments pose sources of trauma at an age that is not typically associated with serious life threats. The emotional trauma associated with cancer is likely to impact or impair the major developmental tasks of adolescence, separation from family and identity formation. According to Pelcovitz et al. (1998), survivors of adolescent cancer described their parents as caring, but over-protective. At a time when independence and control become increasingly important, adolescents with cancer are forced to become more dependent on their parents. In response, parents may become overly protective as a way to deal with the trauma presented by their child's illness. At the same time the cancer patient is dealing with their illness, peers are dealing with issues related to autonomy and identity formation. Adolescents with cancer are forced to begin dealing with adult situations and responsibilities, while their peers are typically not. Peer relationships are often disrupted, and adolescents with cancer frequently reported feelings of isolation (Pelcovitz et al., 1998).

Pelcovitz et al. (1998) compared a sample of adolescent cancer survivors with a sample of physically abused adolescents, as well as a control of the same age group. The authors reported that nearly 35% of the cancer survivors met the criteria for PTSD, when compared with only 7% of the abused adolescents, and 4% of the control group. All of the adolescent cancer survivors reported that the symptoms they experienced directly stemmed from their diagnosis or treatment. In a sample of young adult cancer survivors, Kazak et al. (2001) found that a substantial portion of participants experienced at least some symptoms of PTSD. Many participants reported that they had re-experienced the trauma of their cancer diagnosis and treatment. While slightly over 6% of young adult participants met the full diagnostic criteria for PTSD, over 63% fulfilled the requirements for Criterion B of the diagnostic criteria for this

disorder, and 31% reported symptoms of arousal. In a sample of pediatric and adolescent survivors, only 4.5% met the full criteria for PTSD, while 50% met the requirements for Criterion B, and nearly 29% reported arousal.

Additionally, Pelcovitz et al. (1998) reported that the mothers of those adolescent cancer survivors who had PTSD also met the criteria for this disorder. In a sample of mothers of pediatric and adolescent cancer survivors, Kazak et al. (2001) reported that nearly 11% met the full criteria for a PTSD diagnosis, over 95% met the requirements for Criterion B of the diagnostic criteria for this disorder, and 51% reported symptoms of arousal. Although mothers may have developed these symptoms in response to the trauma of having a sick child, a lifetime history of PTSD in mothers or a chaotic family life may have increased the risk of PTSD in young survivors (Pelcovitz et al. 1998).

Levels of family functioning may also contribute to the development of PTSD in young cancer survivors. Alderfer, Navsaria, and Kazak (2009) discovered a high rate of self-reported difficulties in the functioning of families of adolescent cancer survivors. The authors reported that adolescent survivors who met the criteria for a PTSD diagnosis typically came from families that had trouble responding appropriately to and expressing emotion with one another, had difficulty problem-solving, and were either over- or under-involved in one another's interests.

**Survivor's guilt.** Survivor's guilt refers to the feeling of guilt that may arise after surviving a traumatic event such as cancer. Survivor's guilt is commonly experienced by survivors of accidents, war, natural disasters, and acute or long-term illnesses. Cancer survivors of various ages may ask themselves questions about why they got cancer, and may struggle with feelings of guilt for having survived cancer when many others do not. These questions carry with them a sense of guilt and sadness (Keene, Hobbie, & Ruccione, 2007; Wertich, 2014). In

adolescent and young adult cancer survivors, the experience of survivor's guilt may lead to feelings of pressure to live one's life to the fullest, or prove to oneself that he or she is worthy of surviving (Langeveld & Arbuckle, 2008). Survivors may also experience guilt related to the burden they believe their limitations may place on loved ones, or the fact that cancer may be passed on genetically to their children (Keene, Hobbie, & Ruccione, 2007).

**Worries.** In a survey of young adult survivors who had been diagnosed with cancer before age nineteen years, Langeveld, Grootenhuis, Voûte, de Haan, and van den Bos (2004) did not note any significant differences in the general health concerns between the survivors and the control group. However, survivors reported a greater degree of worry about certain life aspects than the control group, including their health in comparison to peers, their fertility, obtaining life or medical insurance, and finding or changing jobs. In contrast with the control group, survivors worried less about the appearance of their bodies, headaches and common illnesses (i.e., the flu or a cold), losing friends, and dying.

As far as cancer-related concerns went, 54% of young adult survivors expressed worries about cancer recurrence, and 50% reported worries about developing a secondary cancer. Forty-three percent of survivors expressed concerns surrounding the health of their future children. Female cancer survivors reported more cancer-specific worries and lower levels of physical functioning than males. The authors suggested that this difference may be attributed to the idea that women are typically more inclined to report their symptoms than men (Langeveld et al., 2004).

### **Social Adjustment and Relationship Impairment**

Stam, Bultz, and Pittman (1986) investigated the prevalence of psychosocial problems among a sample of adult cancer patients. The participants reported experiencing the most

difficulties with family/significant other concerns, including impairments in relationships and familial roles. Likewise, survivors of adolescent and young adult cancers often experience social late effects that can continue into adulthood. These may include delayed social development, and differences in family life and living conditions when compared with peers that have not had cancer (Dieluweit et al., 2010).

A life-threatening illness such as cancer during adolescence increases dependence on parents and caregivers, while decreasing participation in normal peer activities. After surveying young adult cancer survivors diagnosed during adolescence, Dieluweit et al. (2010) reported that the rate of those individuals living with their parents decreased less with age for survivors than for peers who had no history of cancer. A higher number of male survivors reported that they were still living with their parents than did female survivors.

Feelings of isolation are common among both adolescent and young adult cancer survivors (Gould, 2010; Hall et al., 2012; Pelcovitz et al., 1998). When compared with older adult cancer survivors, Hall et al. (2012) found that survivors of cancer diagnosed during young adulthood reported lower levels of social functioning. The authors suggested that the effects of cancer contributed to young adults' impaired abilities to participate in normal social activities.

**Marriage and divorce.** Young adult cancer survivors may face higher risks of divorce or separation than young adults without a history of cancer. Uncertainty over the health of a partner, issues with sexual functioning and fertility, as well as physical, emotional, and financial stressors may contribute to instability and marital distress. The stressors of a cancer diagnosis during young adulthood, coupled with the demands of having young children and lower job security may strain the relationships of young couples who do not yet have the psychosocial or

financial resources to handle the burden of this life-changing event (Kirchhoff, Yi, Wright, Warner, & Smith, 2012).

Kirchhoff et al. (2012) recognized significant gaps in knowledge about the impact of cancer on the social and marriage outcomes of young adult cancer survivors. After surveying a sample of survivors who had been diagnosed during early adulthood, the authors reported that while young adult cancer survivors tend to get married at similar rates, they are more likely to divorce or separate than are young adults without a history of cancer. Twenty-one percent of the survivors surveyed had been divorced, compared with nearly 11% of young adult participants without a history of cancer.

Female survivors of cancer diagnosed during young adulthood may face a higher risk of divorce or separation than male survivors. Kirchhoff et al. (2012) reported that 21% of female survivors had been divorced compared to 13% of male survivors. The authors suggested that the amount of daily activities that fall disproportionately on women (i.e. childcare, housework), coupled with a cancer diagnosis may result in a greater disruption in young families where the female partner has cancer. The authors also reported that female survivors of ovarian and cervical cancers were twice as likely to be divorced than controls. Issues with fertility and sexual functioning are more common to these types of cancer and likely contribute to higher levels of marital stress, particularly in couples who are actively trying to conceive.

### **Employment and Finances**

When compared with older adult cancer survivors, Hall et al. (2012) reported that young adult survivors experienced greater levels of financial burden. Cancer treatments and their resulting health impairments can have negative impacts on employment. Young adult survivors may not be able to work due to the impacts of cancer on their overall health, or may have to

leave jobs where the nature of work poses consequences to their health. Young adults are often limited as to the amount of welfare benefits they can claim and receive, having paid little or no taxes (Grinyer, 2007; Taylor, Pearce, Gibson, Fern, & Whelan, 2013). Young adults are less likely to be financially independent or have their own private health insurance than older cancer survivors, and may also be caring for their own dependent children (Hall et al., 2012). Large medical expenses due to cancer treatments and doctors' visits are likely to result in financial difficulties, leading young adults to use their savings and borrow money. As a result, young adult cancer survivors are more likely to be in debt than their older counterparts (Hall et al., 2012).

### **Positive Effects of Survivorship**

Despite the challenges, impairments, and worries that may be experienced as a result of a cancer diagnosis and treatment, young cancer survivors may also identify positive aspects of cancer survival and ways in which having cancer has allowed them to achieve personal growth and development. Wicks and Mitchell (2010) reported that young adult survivors of adolescent cancer felt more confident, focused, and/or motivated as a result of completing their cancer treatments. These survivors also expressed feeling that they had matured more quickly than their peers, and that their relationships with family and friends had been strengthened.

Wallace, Harcourt, Rumsey, and Foot (2007) found that female survivors of adolescent cancer expressed an increased appreciation for and enjoyment of life. Participants identified how their overall views on life had shifted as a result of having and surviving cancer, allowing them to see things more positively, put things into perspective, and become less upset with everyday stressors. Participants also felt stronger, more confident, and better equipped to deal with difficult situations. Although they recognized these gains, the participants still conveyed

awareness that something had been lost, and expressed a sense of longing for a time when those everyday stressful situations would have been of more importance.

In their interviews with female survivors of adolescent cancer, Wallace et al. (2007) noted two themes regarding appearance. Participants reported feeling a shift in their perceptions of their own appearance after having cancer. They tended to view their appearances in a different light than they had prior to having cancer, and expressed a newfound appreciation for their bodies and their looks. Hair re-growth was a large factor in this shifting perspective. Participants also reported feeling differently about the way society values appearance. The concept of appearance seemed of less importance after having cancer than it had before. Participants reported having being treated differently based on their altered appearances, and expressed that this helped them to appreciate the importance of not passing judgment or valuing others based solely on appearance. Additionally, this led participants to express their individuality more often or more boldly than their peers and to worry less about fitting in or ‘following the crowd’ (Wallace et al., 2007).

### **Art Therapy with Cancer Patients and Survivors**

**Adults.** Nainis et al. (2006) reported that adult cancer patients’ participation in art therapy sessions resulted in reductions in cancer-related symptoms, including anxiety, tiredness, pain, fatigue, breathlessness, loss of appetite, and insomnia. Art making may offer a welcome distraction for cancer patients by temporarily drawing one’s attention away from treatments or overwhelming emotions. During art therapy sessions, cancer patients are encouraged to speak openly and find their own meanings within their artwork. The art may become a vehicle for the expression of feelings, fears, and concerns (Nainis, 2008).

Art therapy may encourage cancer patients and survivors to strengthen or re-construct their personal identities through the creative expression of transformation brought on by the experience of having cancer (Luzzatto & Gabriel, 2000). Malchiodi (2011) explained that art therapy may be utilized to address recurring topics that arise, specifically in women who have had cancer. These include body image as a result of illness or treatments, coping with the ongoing physical, psychological, and interpersonal effects of a life-threatening illness, and questions about life's meaning and why they became ill.

The art making process may also assist cancer patients and survivors in the decision-making process that is important to their treatment and recovery. Art making reduces stress, while allowing cancer patients and survivors to externalize their emotions. This may provide distance from overwhelming thoughts and feelings, allowing patients and survivors to see situations more clearly or from different perspectives (Czamanski-Cohen, 2012).

**Children.** Art therapy may allow children with cancer to express their feelings of anxiety, anger, or desperation, and may provide support and prevent traumatization in children who are undergoing intrusive or painful medical procedures (Günter, 2000; Favara-Scacco, Smirne, Schilirò, & Di Cataldo, 2001). Favara-Scacco et al. (2001) reported that art therapy administered before, during, and after painful medical procedures reduced anxiety and increased cooperation in children (aged between two to fourteen years old) with leukemia. The researchers utilized visual imagination to provide distraction, medical play to offer control, structured drawing activities to allow for the containment of anxiety, free drawing to allow participants to externalize feelings of fear and confusion, and dramatization to encourage the acceptance of physical changes in the body. The researchers noted that the parents of children who received art therapy expressed that they too felt better able to cope with the experience of having their

children undergo painful procedures. The researchers also reported that participants or their parents requested art therapy whenever the procedure needed to be repeated.

**Adolescents and young adults.** Although the use of art therapy with pediatric and adult cancer patients and survivors has been documented, there appears to be a gap in the literature when it comes to the use of art therapy specifically with adolescent and young adult cancer patients and survivors. After searching multiple databases, this researcher found limited published information on the use of art therapy with this population.

Gould (2010) reported on expressive art workshops for teenage and young adult cancer survivors that were held in London, England, and conducted by the Teenage Cancer Trust charity. These workshops were led by an artist who was diagnosed with HIV and had utilized personal art making to cope with her diagnosis and health concerns. The group atmosphere provided an opportunity for participants to share their feelings and experiences, and allowed them to connect with peers that have had similar experiences.

Baerg (2003) described the beneficial effects of art therapy for two female clients, 15-years-old and 16-years-old, undergoing cancer treatments. The 15-year-old client, who had been diagnosed with breast cancer, utilized a drawing journal to document her experiences and feelings. The 16-year-old client, who had been battling her cancer since the age of 6, utilized poetry to respond to her experiences of growing up with cancer.

Baerg (2003) noted that art therapy allowed these two clients to become actively involved in their own healing processes. Through their art, they explored their cancer journeys, learned to express unspoken feelings and thoughts, and responded to the effects they experienced from their diagnoses and treatments. A public display of artwork was another valuable part of the therapeutic journey for both of these adolescents. The public forum allowed them to feel

confident telling their stories and to take ownership of their cancer journeys, while having those journeys acknowledged, and even celebrated by others. Baerg (2003) noted that the arts had allowed them to journey, “through the rolls of patient, victim, and sufferer, to that of survivor” (p. 73).

For art therapists that may work with this population, Baerg (2003) suggested giving clients some private time during the first session in order to allow them to get used to the idea of expressing themselves on paper. If a client is at a loss for what to create, an assignment may be suggested, such as making something that described what it was like hearing his or her cancer diagnosis for the first time, or creating something that described what made him or her unique. Giving a simple directive can provide comforting structure for clients that may feel hesitant about making art. The researcher also suggested encouraging clients to respond to their own artwork in order to discover personal meaning and insight, and asking questions that encourage deeper exploration. For example, the therapist may ask the client how a particular drawing or poem might have been different if it had been created six months previously, or how the same drawing or poem may change if done a year later.

**Implications for art therapy.** How adolescent and young adult cancer survivors cope with and view their experiences of having cancer may affect their personal outcomes, including feelings of anxiety or resilience (Wu et al., 2013). Since a cancer diagnosis may lead to feelings of lack of control, offering choices and encouraging decision-making may strengthen young cancer patients’ and survivors’ abilities to cope with cancer and its effects (Wicks & Mitchell, 2010). Art therapy interventions that offer opportunities for independence and personal decision-making, or that are designed to develop or enhance problem-solving skills may be beneficial for this population.

Adolescents and young adults may identify aspects of positive change and personal growth as a result of their cancer journeys (Wallace et al., 2007; Wicks & Mitchell, 2010). Art therapy with this population may potentially focus on assisting young cancer survivors to recognize the positive aspects of having survived cancer, including greater maturity and wisdom, closer relationships, and increased personal strength. Art therapy may also focus on assisting survivors as they develop their self-identities in relation to having cancer, or as they work to redefine themselves as survivors, rather than victims.

In their interviews with adolescent cancer survivors, Wallace et al. (2007) noted that participants felt that they would have benefited from speaking with other adolescent cancer survivors about their experiences, both at diagnosis and during treatment. Participants felt that only those who had also experienced cancer could truly understand what it was like and what they were going through. This may suggest that group art therapy experiences would be of great assistance for young cancer survivors.

## CHAPTER III

**Methodology****Arts-based Heuristic Inquiry**

The researcher revisited one piece of artwork that she initially created at age nineteen. The researcher chose this piece of artwork because it held personal significance in her experience of life as a young adult survivor of adolescent cancer. The researcher re-envisioned and re-created this work of art, and analyzed the art making process according to the six phases of heuristic inquiry (Moustakas, 1990). These are (a) initial engagement (with the artwork), (b) immersion (in the process of creating), (c) incubation, (d) illumination, (e) explication (identifying central themes and meaning within the artwork), and (f) creative synthesis (as expressed as a narrative and/or artwork).

**Initial engagement.** According to Moustakas (1990, p. 27), the task of the researcher during the initial engagement phase was to discover an interest or passion that holds both personal implications and important social meanings. Self-dialogue and self-exploration allows the researcher to discover the research question. Engagement with a question that holds personal meaning was a process that required inner receptiveness, a willingness to enter fully into the theme, and a willingness to reach inward to find awareness and knowledge.

**Immersion.** During the immersion phase (Moustakas, 1990, p. 28), the researcher lives and experiences the question. The process of immersion allowed the researcher to expand upon his or her knowledge and understanding of the topic and question.

**Incubation.** During the incubation phase (Moustakas, 1990, p. 28-29), the researcher retreats from the intense immersion and focuses on the question. While the researcher becomes

detached from involvement with the question, knowledge and understanding may develop outside of the researcher's immediate awareness

**Illumination.** When the researcher is open and receptive, the process of illumination (Moustakas, 1990, p. 29-30) occurs naturally. This process involved new awareness or knowledge of the question and experience. The illumination phase may bring corrections to distorted meanings or allow for the disclosure of hidden meanings. The researcher may find new awareness, modification of old understanding, synthesis of fragmented knowledge, or a new discovery of something that was beyond the researcher's immediate awareness

**Explication.** Explication (Djuraskovic & Arthur, 2010; Moustakas, 1990, p. 30-31) was the process of examining themes that surfaced during the illumination phase. The researcher examines what has awakened in his or her consciousness in order to understand its meaning. The researcher utilizes focusing, soul-searching, and self-disclosure, recognizing that meanings are unique to one's experience and internal frames of reference. The researcher tends to his or her own awareness, feelings, thoughts, beliefs, and judgments, identifying new views or explanations.

**Creative synthesis.** During the final stage of heuristic inquiry, the researcher integrates his or her findings and discoveries into a creative synthesis (Djuraskovic & Arthur, 2010; Moustakas, 1990, p. 31-32). This was typically done by means of a narrative, poem, story, drawing, painting, or some other creative form. The creative synthesis was a portrayal of a human experience in its entirety.

### **Pre- and Post-Reflection**

In addition to the heuristic inquiry, the researcher performed a pre-and post-reflection, which focused on her reactions to and impressions of her original artwork. Before beginning the

heuristic inquiry, the researcher reflected on how this image felt to her at the present time, eight years after it was originally created. The researcher also noted memories and thoughts that surfaced while reflecting on the image. These were expressed as a word reflection. After the heuristic inquiry was performed, the researcher completed a post-reflection focusing on her original artwork, and utilizing the same method. Data from the pre-and post-reflection was analyzed in order to compare and contrast the researcher's feelings toward the original image before and after completion of the heuristic inquiry.

### **Analysis of the Data**

The reflective journal kept by the researcher during the heuristic inquiry was analyzed and data was coded in order to group data into similar categories. The reflective journal was divided into excerpts. Each excerpt was assigned an initial code, and then further analyzed to identify its main theme. Each excerpt was then assigned a source code reflecting its main theme. Through immersion in the data, the process of reading and re-reading, codes were combined into overarching themes that emerged from an analysis of the data (see Table 1). The researcher's codes for depression, sadness, anxiety, worry, and frustration were combined and labeled with the code feelings, as each pertained to an emotional state.

### **Validity and Reliability**

According to Douglass & Moustakas (1985), heuristic research has an inherent validity, as it is conducted through an authentic self-process, one which is self-directed, self-motivated, and open to spontaneous shifts. The six phases of heuristic research identified by Moustakas have been utilized by researchers in various fields, including education (Kahakalau, 2004), counseling psychology (Djuraskovic & Arthur, 2010), and the creative arts therapies (Coles, 2014; Fenner, 1996; Woods & Springham, 2011).

Table 1

*Coding of the reflective journal.*


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<u>Excerpt I.D.</u>	<u>Code(s)</u>	<u>Source(s)</u>
IE-1	D	B
IE-2	A	H
IE-3	J	H
IM-1	F	E
IM-2	A/D/I	C
IM-3	D/J	H
IM-4	D/H/M	C/G
IM-5	E/F	C/G
IM-6	G	A
IM-7	C/G	A
IN-1	D	F
IN-2	D/F	C
IL-1	I/K/L	A
IL-2	D/H	C
EX-1	K	G
EX-2	D/F/K	C/G
EX-3	D/J	H
EX-4	D/F	G/H
EX-5	D/F/H/M	C/G

## Coding Key

A	Acceptance
B	Anticipation of research
C	Body image
D	Feelings
E	Feeling different
F	Grief/loss
G	Identity
H	Interruption
I	Maturation
J	Physical pain
K	Positive growth
L	Self-awareness
M	Self-esteem

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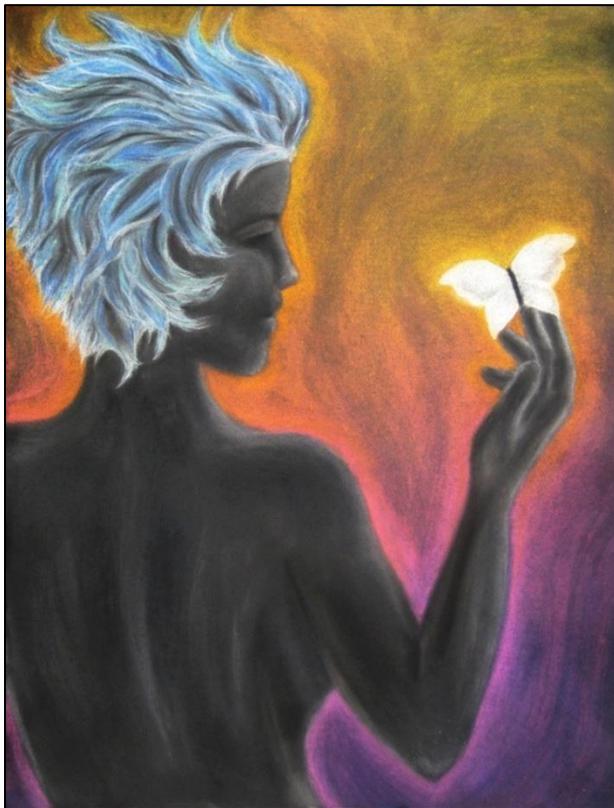
Throughout the duration of this heuristic inquiry, the researcher was able to address and discuss certain feelings and issues that arose with her personal therapist, a Licensed Clinical Social Worker (LCSW). The therapist reflected back issues and concerns to the researcher, allowing the researcher to gain some objective distance, increasing the validity of the findings of the heuristic inquiry.

## CHAPTER IV

**Results of the Study****Results of the Arts-based Heuristic Inquiry**

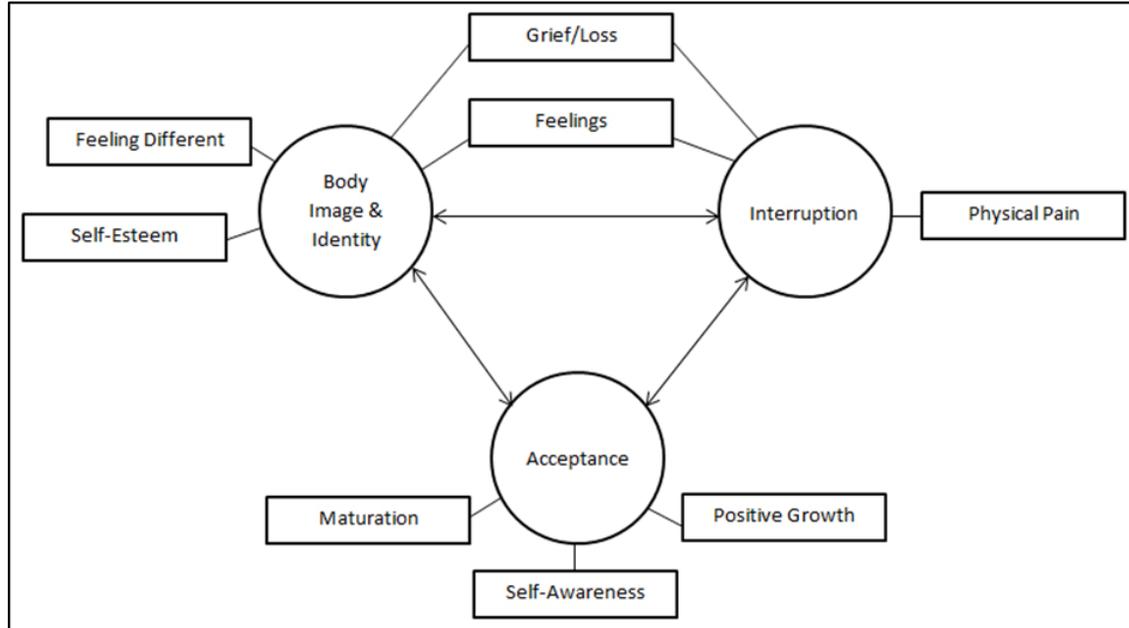
As part of the arts-based heuristic inquiry, the researcher re-envisioned and recreated an image that was initially created by the researcher at age nineteen. Figure 1 shows a photograph of the new image created by the researcher during the heuristic inquiry.

Figure 1. Drawing created by the researcher as part of the arts-based heuristic inquiry.



Three major themes relating to the researcher's personal experience of cancer survival emerged from the findings of the heuristic inquiry and included (a) body image and identity, (b) interruption, and (c) acceptance. Figure 2 details the thematic analysis of the data from the researcher's reflective journal which documented the arts-based heuristic inquiry.

Figure 2. Thematic analysis.



**Body image and identity.** Upon analysis of the reflective journal, the researcher noted a strong relationship between body image and identity, with the two codes appearing eight times each, and appearing together in the same excerpt five times. Because of this, body image and identity were combined and noted as the first major theme of the thematic analysis. The theme of body image and identity was noted in the researcher's enduring feelings surrounding hair loss due to chemotherapy, as well as the recognition that much of her personal identity had been based on her hair.

My long hair was a huge part of my identity since I was little. I was always the girl with the long hair. Then I lost it ... When I was told definitively that I had cancer, my first response was a question about losing my hair (excerpt IM-5).

After struggling to re-grow my hair long, I never felt right until I cut it short. I felt like I had more freedom to experiment and this helped me find a new identity ... Funny how so much of how I identified always was, and is sort of again, in my hair (excerpt IM-7).

***Feeling different.*** Upon reflection, there were many times when the idea of fitting in or feeling “different” from peers came through in excerpts related to body image and identity. Feelings of being different came through as the researcher continued to reflect on losing her hair.

I struggled to hide the fact that I had lost my hair by wearing a wig, until it started growing back. Then I struggled to fit in as I began high school wearing scarves because I didn't want wig tape to damage my new hair, and I couldn't play volleyball with a wig (excerpt IM-6).

***Self-esteem.*** Body image and identity issues were noted by the researcher to have impacted her self-esteem moving forward from cancer treatments.

Body image issues in general are often a source of anxiety or worry for teen girls. Having cancer and all the physical changes that can come with the territory can really exacerbate it. Having cancer on top of this for me, I feel highlighted my hair, my body, created insecurities, and set me up for some ongoing issues with the way I see myself (excerpt EX-5).

***Feelings.*** Feelings regarding body image and identity came through as the researcher began to create hair on the figure as she immersed herself in the art making process. The researcher noted the emotional effects of losing her hair at age fourteen.

Thinking about how big an impact losing my hair had on me. I really struggled. When it happened, as well as when it started growing back, I would cry so often about it. I had a difficult time leaving the house because of it. After I started high school, I would often miss school in the mornings because I was in such bad shape. My family was sponsored by Make-a-Wish and we went on a trip to Hawaii right before I turned fifteen. It was amazing, but even there I had a day where I struggled for the same reason. I feel like this

sole thing was behind the majority of my self-esteem, self-identity, and body image issues (excerpt IM-4).

**Grief and loss.** Feelings of grief and loss for her hair after having lost it as a result of chemotherapy were noted by the researcher to have contributed to other body image issues she experienced throughout the years after her diagnosis. This came through in the following excerpt, as the researcher noted that these issues still have some effect on her.

I've always felt that a lot of the body image issues I experienced stemmed from the loss I experienced with my hair. I talked about body image with my therapist after I realized that this process had stirred up feelings in me surrounding body image issues. The more I thought about it, I realized that these issues have changed over the years, mostly for the better, but they never really left me. My therapist provided insight that it was likely not only my cancer experience that made me susceptible to these issues, but that the experience seemed to bring these things to the forefront (excerpt IN-2).

**Interruption.** Interruption related to feelings that the researcher's "normal" life trajectory had been interrupted by the cancer diagnosis and treatment, as well as ongoing cancer care and follow-up testing.

I have noted some instances in which my "normal" life was interrupted. To this day, with various annual tests staggered so I go to the hospital approximately three times a year, life still gets interrupted. Sometimes I'm not feeling equipped to handle thinking about my cancer, yet there are always reminders (excerpt EX-3).

**Feelings.** Feelings, particularly of sadness, came through as the researcher reflected on emotions that came up while engaging in the heuristic study. These were noted by the researcher to have been interruptive of everyday life at the time the research was being conducted.

In the incubation phase [of this research study], when I was away from my work, I noticed that I felt down very often for no apparent reason. I feel like putting myself back in that space and thinking about all of my experiences led to these feelings of sadness (excerpt EX-4).

***Grief and loss.*** Feelings of loss through as this excerpt continued as the researcher noted some of the reasons for her current feelings of sadness, including thoughts about the perceived loss of normalcy, as well as personal identity.

I have really been noticing all of the losses I experienced. My hair. Feeling like I missed out on a normal transition from childhood to adulthood. Growing up fast was just kind of thrown upon me. Instead of doing normal things, I was deeply depressed and found it difficult to leave home. I think my depression came partly from recognizing and feeling that loss of normalcy, as well as my identity, and I just didn't know how to deal with it (excerpt EX-4).

***Physical pain.*** In addition to emotional responses, the idea of interruption reflected in chronic physical pain which could not be ignored as the researcher immersed herself in the process of art making. The researcher noted awareness of the pain beginning to intensify as she worked on the particular area of the figure where she felt the pain in her own body.

Pain in my neck and right shoulder is kicking in. This is a reminder of my old image and of chronic pain I have lived with since around age 18. I attribute this to surgery on the right side of my neck. Doctors have not found anything wrong through testing, and it is frustrating to be told there is nothing that can be done to help it. It is always there, always interrupts my activities, and always happens when I draw or paint ... Funny that

this is kicking in right as I am working on [the neck and shoulder] area of the figure (excerpt IM-3).

**Acceptance.** Acceptance of the past and the researcher's experiences as a cancer patient and survivor, as well as acceptance for the researcher's current state of cancer survival were identified in several excerpts and were often linked to feelings of being more mature or self-aware, or noticing that growth had occurred.

**Maturation.** Feelings of increased maturity came through as the researcher reflected on her finished drawing during the illumination phase.

Thinking about the image I just made ... I definitely feel more grown up now. I feel like even my art work is more grown up and mature than it used to be (excerpt IL-1).

**Self-awareness.** Feelings of having achieved greater self-awareness came through in the same excerpt, as the researcher continued to reflect on her artwork.

I feel like [creating this drawing] has given me an increased feeling of self-awareness, and the colors that surround my figures remind me of energy. I feel like the image represents having gained greater awareness of who I am. I can see this in the figure's relationship to the butterfly, representing my connection to animals and my love for living things (excerpt IL-1).

**Positive growth.** The idea of achieving positive growth was also noted in the same excerpt, as the researcher sensed that her ongoing struggle with depression had improved over time.

My new figure feels much more alive. And likewise, I feel so much more alive now than when my first image was made. I was so deeply depressed back then. Although I still

deal with these issues, it's obvious to me that [my depression] has lifted tremendously since that time (excerpt IL-1).

### Results of the Pre- and Post-Reflection

Figure 3 shows a photograph of the original image created by the researcher in 2005, at Figure 3. Original drawing created by the researcher.



nineteen years of age. Prior to immersion in the arts-based heuristic inquiry, the researcher generated a list of reflective words while meditating on this image. The researcher engaged in another word reflection following the arts-based heuristic inquiry. The comparison of pre-and post-reflective words may be seen in Table 2.

Upon analysis of the pre- and post-reflection, the researcher noted a difference in the words that were chosen. The pre-reflection suggested feelings of sadness, loneliness, isolation, and longing for something, while the post-reflection suggested a more optimistic view.

Table 2

*Comparison of the pre- and post-reflection*


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<u>Pre-Reflection</u>	<u>Post-Reflection</u>
Expressive	Expressive
Vibrant	Vibrant
Bold	Bold
Movement	Moving
Brightness	Bright
Glowing	Glowing
Dark	Colorful
Intense	Fiery
Contrast	Sunset
Angst	Warmth
Gloomy	Passionate
Dismal	Emotive
Sadness	Courageous
Anxious	Confidence
Heavy	Beauty
Pain	Strength
Burning	Powerful
Longing	Vitality
Pondering	Energy
Forming	Thoughtful
Lonely	Future
Emptiness	Optimistic
Forlorn	Secure
Alone	Tranquility
Introverted	Serene
Unknown	
Uncertain	
Vastness	
Hiding	
Covered	

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Words such as courageous, confidence, powerful, and strength suggested a shift in the researcher's awareness of her personal accomplishment having lived through cancer, and seeing herself as a stronger person. In contrast with pre-reflection words such as anxious, intense, and heavy, post-reflection words such as warmth, tranquility and serene suggested a feeling of calm

when viewing the image. The overall comparison of the pre- and post-reflections suggested a positive reaction to an image that originally conjured feelings of sadness and isolation.

## **Discussion**

### **Body Image and Identity**

The theme of body image and identity came up several times during the researcher's experience as she engaged in this heuristic inquiry. Feelings surrounding this theme often centered on the emotional impact of hair loss due to chemotherapy. As a 14-year-old, much of the researcher's concept of personal identity was based on her long hair, something that she was known for by family and peers. The loss of that identifying factor appeared to greatly impact the researcher's self-concept and self-esteem.

The researcher believed that losing her hair caused her to stand out from her peers, and attempted to hide her hair loss by covering her head so as not to be seen as different or draw unwanted attention toward her. The feelings that came through during this heuristic inquiry correspond with those of the adolescent female cancer survivors interviewed by Wallace et al. (2007), who reported that hair loss was the worst, and most anxiety provoking aspect of cancer treatment. Hair loss is an obvious indication of illness which allows those undergoing cancer treatments to be viewed as different. This group of young survivors reported the importance of remaining normal in the eyes of others, attempting to "blend in" by covering their heads. By doing so, Wallace et al. (2007) suggested that the survivors may have actually drawn more unwanted attention towards them, resulting in impacted self-esteem and self-image.

The researcher believes that her experience of having cancer and losing her hair created insecurities surrounding her appearance, leading to a personal ongoing struggle with body image issues and low self-esteem. Prior to engaging in this heuristic inquiry, the researcher believed

that the body image issues she had experienced as a teenager had been mostly resolved, but the themes identified in this study have demonstrated the degree of persistence that these issues may have.

### **Interruption**

The theme of interruption came through in the heuristic inquiry as the researcher reflected on ways that her normal course of life was interrupted by a cancer diagnosis, as well as ongoing interruptions involving doctor's visits and testing long after her cancer went into remission. The researcher also noted the immediate interruption of chronic physical pain as she engaged in the art making process. As presented in the review of the literature, the idea of one's normal life being interrupted by cancer continues in various ways long after the initial diagnosis is received and treatment is completed. Interruption can present in the form of emotional or physical reminders, including, but not limited to post-traumatic stress, impaired social or physical functioning, relationship or marriage stress, worry and anxiety surrounding health, fertility, and cancer recurrence, and the difficulties of financing medical insurance and ongoing preventive testing.

### **Acceptance**

Baerg (2003) stated that art therapy allowed two teenage cancer survivors to become actively involved in their own healing processes, exploring their journeys and expressing their emotions through their work. Baerg noted that engaging in the arts allowed these survivors to take ownership of their experiences, allowing them to journey, "through the rolls of patient, victim, and sufferer, to that of survivor" (p. 73). The results of this heuristic study support Baerg's statement, as acceptance, positive growth, maturation, and improvement in feelings of depression were reflected in the data. The researcher also noticed a shift in her own awareness

upon analysis of the pre- and post-reflections. The researcher noted that she was able to recognize the fact that she had lived through cancer as an accomplishment, and began to see herself as a stronger person as a result of her engagement in the artistic process.

### **Recommendations**

As initially planned by the researcher, it is recommended that the art created during this heuristic inquiry be exhibited to a group of adult cancer survivors, and that a qualitative exhibition survey (see Appendix A) be utilized with informed consent (see Appendix B) in order to gain feedback from participants about their own cancer journeys. Due to the nature of heuristic research, the results of this study were limited solely to the researcher's personal feelings and involvement. Holding an exhibition for and surveying other cancer survivors would provide richer data, and would allow for the identification and comparison of themes suggested by participants with the themes identified by the researcher during this heuristic study. This may provide insight as to how themes identified by a survivor of cancer during adolescence differ from or are similar to themes identified by survivors diagnosed at different life stages.

Due to the limited nature of this heuristic inquiry, the results of this research study cannot be generalized to encompass the feelings and experiences of other cancer survivors. Therefore, it is also recommended that an art therapy focus group be conducted for other survivors of cancer during adolescence or young adulthood. This would provide an opportunity for other members of this population to create and reflect on their own artwork in response to their experiences of having and surviving cancer. Data provided by this group could then be compared and contrasted with the data from this heuristic inquiry in order to identify similar or different themes.

Body image and identity issues resulting from hair loss have been highlighted in the results of this heuristic inquiry, as well as in the reports of other female survivors of adolescent cancers (Wallace et al., 2007). It is highly recommended that adolescents and young adults, particularly young girls who are undergoing cancer treatments receive therapeutic services in order to address the emotional issues that may surface as a result of hair loss and/or other body changes. Beginning these services at the time of active treatment may increase the ability to cope with and express feelings regarding these losses or changes, while encouraging and supporting healthy levels of self-esteem. It is also highly recommended that therapeutic services continue after treatment has ended in order to address long-term and late effects and the emotional impact of having and surviving cancer, as well as to provide support while the individual adjusts to life after cancer.

Art therapy may provide a non-threatening modality for addressing sensitive issues brought on by having cancer, as well as for increasing and sustaining self-esteem. With the support of a trained art therapist, it is recommended that adolescents and young adults undergoing cancer treatments create personal artwork about their experiences, their emotions or worries, or the illness itself. Creating art about an illness as it is being experienced has the potential to be healing for the artist. Chambala (2008) reported that drawing or painting one's anxiety allowed art therapy group participants to identify personal strengths through creative expression, while drawing or painting coping strategies allowed participants to leave with tangible reminders of useful coping strategies.

It is also recommended that adolescents and young adults affected by cancer create self-portraits during their cancer journeys with the support of a trained art therapist. Self-portraiture can encourage self-reflection and acceptance, which may be of assistance for young cancer

patients and survivors. According to Alter Muri (2007), creating a self-portrait can provide an opportunity to step back from and reflect on one's experiences. Self-portraits may allow the artist to express and acknowledge feelings and emotions, while the artwork itself may provide containment for these emotions, helping the artist to gain some reflective distance. Although self-portraiture was not necessarily the intention of the images shared by the researcher in this study, each image provided a visual representation of the researcher's state of being at the time of its creation. This allowed for reflection and encouraged identification and appreciation of the researcher's current state of cancer survival.

Finally, it is recommended that other individuals who choose to engage in heuristic research meet with a personal therapist during the research process. The support of the therapist, as well as the opportunity to speak with an unbiased third party during this heuristic inquiry was believed to be extremely valuable to the researcher, particularly for its ability to provide reflective distance from the research material.

### **Conclusion**

The results of the heuristic inquiry support the researcher's hypotheses that immersion in the art making process would increase personal insight and understanding of the long-term and late effects of cancer survival, as well as that the creative process would result in insight and discoveries which would increase feelings of ownership and peace with her cancer journey. The researcher identified three major themes relating to her past experience as well as her current state of cancer survival as a result of the heuristic inquiry. These were body image and identity, interruption, and acceptance.

The researcher also noted a shift in her own awareness as a result of engaging in the art making process, as evidenced by the analysis of the pre- and post-reflections. The researcher

identified having gained the ability to view surviving cancer as a personal accomplishment, and began to see herself as a stronger person as a result of re-envisioning and re-creating her earlier artwork. This suggests the potential of personal art making for supporting adolescents and young adults affected by cancer on their journeys, for providing the reflective distance necessary to separate themselves from the emotions and challenges they may face as a result of their diagnoses and treatments, and to create and define their lives on their own terms moving forward as survivors.

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Appendix A  
**Qualitative Exhibition Survey**

Title of Research: *A Heuristic Arts-based Study on the Impact of Long-term and Late Effects of Cancer on Adolescent and Young Adult Cancer Survivors*

Study co-researcher: Lisa Kolodziej

Research study site: Cancer Resource Center

Some questions modified or adapted from: *Cancer Survivors Survey of Needs* (Mayo Clinic Cancer Center, n.d.)

**Demographics**

1. Age: \_\_\_\_\_ 2. Gender: \_\_\_\_\_ 3. Age at diagnosis: \_\_\_\_\_

4. Type of cancer: \_\_\_\_\_

5. Type of treatment(s) received (please circle all that apply)

Surgery      Chemotherapy      Radiation Therapy      Hormone Therapy

Other (please specify): \_\_\_\_\_

6. Are you currently receiving cancer treatments? (please circle one)      Yes      No

7. Approximately how long has it been since your last treatment? \_\_\_\_\_

8. Is your cancer currently in remission?      Yes      No

9. Do you consider yourself to be a “cancer survivor?”      Yes      No

**Effects of Cancer**

10. Have you experienced any physical long-term or late effects from your cancer treatment that are physical in nature? (i.e. pain, fatigue, bodily changes, fertility or sexual issues)

Yes      No      If you answered “Yes,” please describe:

11. Have you experienced any long-term or late effects from your cancer treatment that are emotional in nature? (i.e. depression, anxiety, guilt, uncertainty, worry, fear of recurrence)

Yes            No            If you answered "Yes," please describe:

12. Have you experienced any social impairment as a result of your cancer diagnosis or treatment? (i.e. feeling lonely or isolated, difficulty participating in social activities, difficulty managing household/caring for family, separation/divorce)

Yes            No            If you answered "Yes," please describe:

13. Have you experienced any financial or work-related concerns as a result of your cancer diagnosis or treatment? (i.e. debt from medical bills, difficulty obtaining insurance, loss of employment, difficulty obtaining/maintaining employment)

Yes            No            If you answered "Yes," please describe:

14. Generally speaking, do you tend to associate more positive feelings or more negative feelings with your cancer experience?

Positive            Negative            Both Positive and Negative            Neutral

15. Has having/surviving cancer changed the way you view or feel about yourself (positively and/or negatively)?

Yes            No            If you answered "Yes," please explain:

16. Has having/surviving cancer changed your views or appreciation of life in general (positively and/or negatively)?

Yes            No            If you answered "Yes," please explain:

17. Have you recognized any positive aspects of having/surviving cancer?

Yes            No            If you answered "Yes," what are they?:

18. What do you feel have been your biggest sources of strength, hope, or inspiration throughout your cancer journey?

Please use the space below to provide any additional comments, feelings, or insights you would like to share about your personal experience with cancer:

**Art Exhibition**

19. Upon viewing the artwork, did you have an emotional response or connection to the images?

Yes          No          If you answered “Yes,” please explain:

20. Do you feel that you can relate to the artwork?

Yes            No            Please explain why or why not:

Please use the space below to provide any additional comments, observations, or personal reflections you would like to share about the art exhibit:

## Appendix B Consent to Participate

You are invited to participate in a research project investigating the long-term and late effects of cancer among adolescent and young adult survivors. The artwork on display was created by the researcher as part of a heuristic arts-based inquiry into the researcher's experience of cancer survival. The purpose of the art exhibition and survey is to identify and understand themes relating to the cancer experience among adult cancer survivors. This research study will partially fulfill the requirements of the AR591 Thesis Research and Writing course for Lisa Kolodziej, a graduate student pursuing a Master of Art in Art Therapy degree at Saint Mary-of-the-Woods College.

The procedure involves minimal risk for the participants, as no identifying information will be collected in the survey, and pseudonyms will be utilized in the research report. Participation in this research study is likely to increase knowledge and understanding about the experience of long-term and late effects among cancer survivors of various age groups. Only the researcher will have access to the completed forms, which will be kept in a secured location.

Your contribution to this research is entirely voluntary, and completion of this exhibition survey signifies your consent to participate. You have the right to decline participation in the survey by not returning the form. You also have the right to skip any questions you do not wish to answer. You may withdraw from this study at any time, without penalty, by notifying the researcher.

This study was approved by the Saint Mary-of-the-Woods College Human Subjects Institutional Review Board on June 24, 2014.

If you have any questions or concerns about this study, you may contact the researcher at any time. If you would like to make an inquiry to someone other than the researcher, you may contact the researcher's supervisor, or the chair of the Human Subjects Institutional Review Board.

### **Co-researcher**

Lisa Kolodziej

### **Primary Researcher**

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### **Chair, IRB**

Dr. Lamprini Pantazi, PhD.

Chair, Human Subjects Institutional Review Board

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My signature below indicates that I am 18 years of age or older, I have been informed about the nature and purpose of this study, I consent to participate, and have received a copy of this consent form.

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Signature

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Date

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Co-researcher Signature

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Date