

UNDERSTANDING THE PSYCHOSOCIAL IMPACT OF CANCER IN ADOLESCENCE  
AND YOUNG ADULTHOOD: A MIXED-METHODS ASSESSMENT OF THE  
PERSPECTIVES OF PATIENTS, SURVIVORS, AND HEALTHCARE PROFESSIONALS

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## General Introduction

Imagine this: you are in your second year at university, settling in after a rough start to living away from home for the first time, when a routine trip to student health for a persistent cold gradually transforms into exhaustive testing and then – a cancer diagnosis. You move back home with your parents, in shock, life seemingly on hold, trying to adjust to your new “normal.” You push through your appointments, surrounded by adult patients thirty years, or more, older than you are and feeling very much alone. Friends start to drift; they don’t understand what’s happening. Then comes remission. Incredible, you feel relief and joy, but with it comes crippling fear, loneliness, and a daily struggle to make sense of what you just went through, and uncertainty as to how far behind you now are, in relation to your original plan and in relation to your friends and classmates. For the estimated 7,600 adolescents and young adults (AYAs; 15-39 years) diagnosed with cancer annually across Canada, this is an all too common narrative (Canadian Partnership Against Cancer; CPAC, 2017).

Although this accounts for only 4% of all new cancer diagnoses, it is associated with a disproportionately large impact on personal, societal, and socioeconomic levels (CPAC, 2017). The purpose of this general introduction is to help broadly orient the reader to the topic of cancer in adolescence and young adulthood. We begin with a discussion of cancer incidence and distribution, followed by a review of psychosocial care in oncology including distress, coping strategies, illness centrality, uncertainty, and social support as it pertains to AYAs. This is followed by a discussion of key survivorship issues for AYAs, including ongoing distress, post-traumatic stress and growth, fertility issues, health behaviours, and the challenges of transitioning from active care to survivorship. We then consider patient and healthcare professional perspectives in understanding AYA oncology, and novel treatments that have

emerged to meet growing needs. Conceptual frameworks and models are then presented. Finally, with this broad orientation, the three research studies completed to expand upon current knowledge are examined.

### **Cancer incidence and distribution rates in AYAs**

The Canadian Partnership Against Cancer (CPAC, 2017) recently compiled the most comprehensive overview of cancer incidence and mortality in individuals aged 15-39 years. Taking a bird's eye view, the six most frequent cancers diagnosed in AYAs, cumulatively accounting for over 80% of diagnoses, are thyroid cancer, breast cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, testicular cancer, and melanoma. However, it is testicular cancer, Hodgkin lymphoma, bone sarcomas, and cervical cancer that can be described as predominantly AYA cancers, because age-specific incidence for these cancers peak in the 15-39 year range (CPAC, 2017). There is also variability in cancer distribution by age, with distinct cancer incidence rates for the subgroups of 15-29 years, 30-39, and over 40 years. In terms of incidence, cancer rates for AYAs are on the rise (CPAC, 2017). The past two decades have seen an 18.2% and 11.9% increase in the 15-29 and 30-39 age groups, respectively. Conversely, there has been a 2.2% decrease in cancer incidence in the over 40 group. Sex differences in AYAs were examined in the Cancer in Young Adults in Canada Report (Theis, Nishri, Balh, Ugnat, & Marrett, 2006). Notably, this publication defined the young adult range as 20-44 years. The researchers found that, specific to this age frame, young adult women bore a greater disease burden than did men, accounting for nearly two-thirds of the cancer cases diagnosed. This was largely attributed to a higher incidence of sex-specific cancers for women of this age, mainly cervical, breast, ovarian, and uterine cancer. In this 20-44 age range, cancer was found to be

responsible for 32% and 11% of potential years of life lost in young women and men, respectively (Theis et al., 2006).

There is considerable variability in AYA age frames not only in Canadian research, but also internationally. The American based Adolescent and Young Adult Oncology Progress Review Group (2006) identified that AYAs diagnosed between the ages of 15 and 39 years account for approximately 6% of all new cancer diagnoses. Additionally, this age frame has the greatest gap in survival improvement, with 5 years survival rates that are lower as compared to other age ranges (Bleyer, Viny, & Barr, 2006; Hampton, 2005). In the United States, population-based incidence, survival, and mortality rates were examined using the AYA age frame of 15 to 29 years from 1975 to 2000 (Bleyer, O'Leary, Barr, & Ries, 2006). Among key findings, the authors reported that the types of cancer diagnosed in this age frame were unique, that cancer incidence increased progressively over this period though recently the increase began declining at the high end of the age range, that males were at an increased risk of developing cancer and overall had a poorer prognosis than did females (Bleyer et al., 2006).

Alston, Geraci, Eden, Moran, Rowan, and Birch (2008) examined cancer incidence rates in British teenagers and young adults diagnosed between 1979 and 2003. The authors selected the age range of 13 to 24 years using a morphology-based diagnostic scheme, as the distribution of cancers in those aged 13 and greater is more similar to young adults than it is to younger pediatric patients. Cancer classified as leukemias, lymphomas, central nervous system, bone, and germ cell tumours, melanoma cancer, and thyroid, ovary, cervix, and colon/rectum carcinomas were found to increase over time whereas stomach and bladder carcinomas decreased (Alston et al., 2008). These findings are consistent with cancer incidence and survival among patients 15 to 19 years of age in Europe since the 1970s (Steliarova-Foucher et al., 2004). Although the reasons

for outcome disparities in AYAs are not clear, Albritton and Bleyer (2003) suggest that differences may be at least partially attributable to biological differences. Specifically, it is notable that AYA cancers are largely attributable to environmental or inherited factors, and that same cancer diagnosed in a younger as opposed to the older patient may require unique treatment approaches.

Taken cumulatively, these national and international reports highlight several key issues. Firstly, the distribution of cancers, and types of cancers diagnosed in AYAs are specific to this age range. Secondly, there has been a consistent increase in cancer incidence rates among AYAs in the last quarter century. Thirdly, gender differences in incidence rates are present. Thus, from a biological and epidemiological perspective, the evidence overwhelmingly supports the need to examine AYAs as not only a distinct subgroup, but also one with further subgroups within it.

### **Psychosocial care for AYAs**

Being diagnosed with cancer as an adolescent or young adult is not only distinct from biological and epidemiological perspectives, but also from a psychosocial perspective. The last fifteen years have seen increased recognition and awareness of the specialized biopsychosocial needs of AYAs, and with that came a growing body of research literature, changing care practice guidelines, and the emergence of grass-roots organizations to meet these needs (Bleyer, 2002; Corsini & Ammerman, 2008; Pentheroudakis & Pavlidis, 2005; Thomas et al., 2006; Zebrack et al., 2006). Broadly speaking, AYAs diagnosed with cancer have consistently been found to be at increased risk of psychosocial problems and increased life disruptions, including but not limited to increased depression and anxiety symptoms, poorer quality of life, poorer body image, poorer sexual functioning, increased financial concerns, and increased physical pain (Blank & Bellizzi, 2006; Harrison & Maguire, 1995; Hall, Boyes, Bowman, Walsh, James, & Girgis, 2012; King,

Kenny, Shiell, Hall, & Boyages, 2000; Kroenke et al., 2004; Mor, Allen, & Malin, 1994; Parker, Baile, Moor, & Cohen, 2003; Wenzel et al., 1999). However, the increased recognition of AYA oncology as a specialized field has arguably brought with it as many questions as it has answers. To better understand AYA psychosocial care and needs, the following section first broadly reviews psychosocial oncology and the evolution of distress measurement. With this contextual understanding, psychosocial literature specifically related to cancer in AYAs will then be addressed, including coping strategies, illness centrality, the role of uncertainty, fertility, and social support.

As defined by the Canadian Association of Psychosocial Oncology (CAPO, 2018):

“... psychosocial oncology is a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer.”

One of the first and still most prevalent measures of psychosocial care is the umbrella term of “distress.” The concept of distress is notably broad, in that it is comprised of psychosocial, practical, and physical concerns (Cancer Journey Action Group, 2009) and deals with all aspects of social, emotional, and quality of life issues (CAPO, 2018). Distress prevalence has been increasingly researched in the cancer population, with recent evidence suggesting that significant levels of distress affect 35 to 45% of cancer patients and up to 58% of palliative care patients (Bultz & Carlson, 2006; Carlson & Bultz, 2004; Potash & Brietbart, 2002; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Thanks to the growing awareness of patient psychosocial needs, in 2005, the Canadian Strategy for Cancer Control (CSCC)

(Rebalance Focus-Action Group, now known as Cancer Journey Action Group) officially recognized distress as a key measure by which to gauge patient functioning. In this capacity, distress was referred to as the “sixth vital sign” joining the ranks of temperature, blood pressure, heart rate, respiration, and pain (National Pharmaceutical Council, 2001). Consequently, distress was elevated to the status as a critical and central measure by which to gauge patient functioning. This change also reflects an increasingly holistic and comprehensive approach to cancer care, evolving from prevention and continuing on to bereavement (CAPO, 2018).

Notably, we know that levels of distress are most likely to increase when an individual appraises a situation (consciously or unconsciously) and concludes that the threat he or she is feeling cannot be diminished (Fitch, Porter, & Paige, 2008). Given that the cancer journey is fraught with difficult and challenging situations, the nature of which changes over time as new challenges present, there are clearly many opportunities for distress to manifest. It is therefore accepted that all patients require some level of distress screening, and that there is value to periodic (rather than a single point) evaluation (see Figure 1).

### **Coping strategies**

Cancer is a life-changing illness; it substantially alters the patient’s way of life, view of the world, and how the individual interacts with others (Kynge et al., 2001). Consequently, cancer patients report using a plethora of coping methods and resources to adjust to a cancer diagnosis and treatment, and the challenges presented at each step of the way. Kynge et al. (2001) examined how young adults (aged 16 to 22 years) managed the onset of cancer using a qualitative, interview methodology analysed using content analysis. Respondents were categorized as using emotion-focused, appraisal-focused, and problem-focused coping strategies. Among the main coping strategies that emerged were social support and attempts to return to a

“normal life.” Other identified resources included belief in oneself, belief in God, a fighting spirit, and discussions with family and friends. Additionally, returning to a sense of normalcy and to a routine way of life was a commonly reported coping strategy, helping AYAs come to terms with their cancer diagnosis and to accept cancer as a component of their lives (Corey, Haase, Azzouz, & Monahan, 2008). More recently, Trevino et al. (2012) invited young adults (aged 20-40 years) with advanced cancer to participate in structured clinical interviews to assess coping strategies and their relationship with psychosocial distress. Interviewers read aloud to participants the items of the Brief COPE scale, the Prolonged Grief Disorder Scale, the McGill Quality of Life Questionnaire, and the single item McGill physical well-being scale. Using principal components factor analysis, the authors were able to identify six coping factors: support seeking, respite seeking, acceptance, proactivity, distancing, and negative expression. Proactive coping (directly approaching stressors) and distancing (avoiding stressors) emerged as the strongest factors. In terms of relationships between coping factors and psychosocial distress, increased negative expression was associated with increased grief, whereas increased support seeking was associated with increased anxiety. Although promising, the authors noted the small sample size ( $n = 53$ ) and need to replicate the findings (Trevino et al., 2012). Taken cumulatively, emerging research evidence supports the use of diverse coping strategies to manage the aftermath of a cancer diagnosis, treatment, and associated psychological distress. However, further research is warranted to expand the research, to connect these findings with the broader literature on well-being outcomes, and to operationalize information to be clinically valuable as an evaluation or intervention tool.

**Illness centrality**

Accepting cancer as a component of life, and adjusting to this identity reconstruction, can be a challenging process for cancer patients and survivors. This process has been conceptualized within the literature as illness centrality, and is formally defined as “the extent to which one’s core self is now situated in the context of cancer” (Park, Bharadwaj, & Blank, 2011). Park et al. (2011) theorized that how an individual adapts to a cancer diagnosis, and the extent to which the diagnosis becomes an enmeshed part of his or her self-definition, may be an important predictor of coping and well-being. To that effect, the authors investigated how well-being was associated with illness centrality (Park et al., 2011). Regression analyses indicated that increased illness centrality was associated with decreased well-being, specifically decreased mental health-related quality of life, decreased positive affect, increased negative affect, increased intrusive thoughts, and decreased life satisfaction; illness centrality was found to be unrelated to physical health-related quality of life and post-traumatic growth (Park et al., 2011). This provides preliminary evidence of the importance of assessing illness centrality, however, the research was conducted with a sample of young and middle-aged adults, indicating the need to replicate findings in an AYA sample to assess the generalizability of results.

**Uncertainty**

Uncertainty is a fundamental component of each cancer journey, with cancer survivors reporting uncertainty to be a prominent concern (Donovan, Brown, LeFebvre, Tardif, & Love, 2015; Gil et al., 2004; Garofalo, Choppala, Hamann, & Gjerde, 2009; Lie, Larsen & Hauken, 2017). Uncertainty is theoretically characterized by three central components: probability, temporality, and perception (Decker, Haase, & Bell, 2007). For the AYA cancer patient, the probability of illness recurrence or treatment effectiveness, the temporal instability of symptom



and treatment pace and frequency that renders future planning difficult, and perceptions and appraisal of the cancer experience can all contribute to uncertainty. One study identified five key areas of uncertainty: when the diagnosis was first conferred, first interactions with the healthcare system, living with cancer, adjusting to the impact of cancer treatments, and managing changes in, and withdrawals from, social networks (Lie et al., 2017). The tripartite model of uncertainty also recognizes uncertainty as existing in three major areas, mainly medical, personal, and social anxiety (Donovan et al., 2015). Donovan et al. (2015) examined messages on an online forum, and found medical uncertainty to be a predominant thread throughout discussions. Uncertainty in illness is of concern, as it is associated with stress response and consequently, leads to anxiety, distress, fear, and defensive coping (Barron, 2000; Decker et al., 2007; Friedman, Freyer, & Levitt, 2006; Haase, 2004). Uncertainty has also been linked to anger, irritability, decreased self-esteem, vulnerability, and an increased need for information (Campling & Sharpe, 2006).

Due to these potentially negative consequences, Decker et al. (2007) sought to address uncertainty in newly diagnosed AYA cancer patients, as well as those one to four years since diagnosis, and five or more years since diagnosis. The authors did not find significant differences in overall uncertainty across the groups, but rather, found item differences reflecting changing uncertainty concerns over time. Specifically, newly diagnosed survivors endorsed unpredictability items relating to pain, changes over the course of the illness, staff responsibilities due to the unfamiliar environment of the oncology ward, and uncertainty as to when they could return to previous self-care levels. In survivors considered long-term, and diagnosed five or more years earlier, uncertainty levels were significantly higher for items including how illness impacts daily life, uncertainty in predicting the length of illness, having unanswered questions, and the success of treatment. Perhaps surprisingly, the group one to four

years since diagnosis had lower levels of uncertainty on individual items. Some uncertainty regarding the meaning behind pains experienced, the unpredictable nature of physical distress, and the way in which illness course changes over time was reported (Decker et al., 2007). These findings are significant in that they highlight that uncertainty is of key concern to AYAs with cancer and that rates of uncertainty may wax and wane over time. Additionally, AYAs five years or greater since the time of diagnosis endorse high levels of uncertainty, solidifying the need to assess the long-term implications of cancer treatment. Similarly, Garofalo et al. (2009) found that the end of active treatment was associated with a “honeymoon” period. As patients moved into survivorship, the authors found increased uncertainty and decreased well-being. Although the reasons for this decline are poorly understood, the authors emphasized the importance of considering the impact of uncertainty on quality of life across the cancer trajectory (Garofalo et al., 2009).

### **Social support**

Studies examining social support and its relationship to symptom distress in AYA cancer patients are notably sparse (Corey, Haase, Azzouz, & Monahan, 2008). Corey et al. (2008) theorized that, consistent with the Adolescent Resilience Model, increased perceived social support would decrease cancer-related distress. The authors specifically examined social support provided by friends, family members, and healthcare providers. Results support the importance of perceived social support from multiple sources as a predictor of mental health in cancer patients. Adolescents and young adults with peer connections were also found to be more hopeful (Saba, 1991). The need for ongoing research into this field is strongly advocated, as social support is a critical component of psychosocial care for AYA cancer patients, providing an opportunity to share thoughts, feelings and experiences (Corey et al., 2008; Kyngäs et al., 2001).

Social support is also a crucial component of helping AYAs to cope with significant life changes and disruptions such as a cancer diagnosis (Corey et al., 2008; Haluska, Jessee, & Nagy, 2002).

### **Key Survivorship Issues for AYAs**

Both cancer incidence rates and survival rates are on the rise in AYAs, resulting in an increased number of individuals living with the long-term sequelae of a cancer diagnosis and treatment (Canadian Cancer Statistics, 2007). Cancer survivorship research emerged as a distinct field when it became apparent that the needs of this growing population were poorly understood (Rowland, 2008). One of the most notable terminology changes was the adoption of the term “survivorship” to denote a period beginning at the time of diagnosis and progressing for the remainder of the lifespan, rather than a period beginning at the end of active treatment (Rowland, 2008). The terminology shift was designed to help healthcare professionals embrace a model of care that acknowledge the individual needs and desires of the patient in the long-term treatment plan, to ensure a broader continuum of care, and to help dispel the use of more negative labels. Although some conflict remains regarding the appropriateness of the term “survivor,” it remains the prevalent terminology in the academic literature. The following section, therefore, focuses on examining notable issues central to AYA cancer survivorship, mainly ongoing distress, post-traumatic growth, fertility, health behaviours, and transitioning from active to follow-up care.

### **Distress in AYA Survivorship**

Boyes et al. (2011) sought to address the gap in survivorship knowledge by assessing the prevalence of anxiety and distress, as well as factors correlated with anxiety and distress, in adult cancer survivors at six months post-diagnosis. A total of 1,360 individuals completed the questionnaire. Whereas the majority of participants reported low levels of anxiety and/or depression on the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), a

considerable 28% ( $n = 369$ ) reported levels that were considered borderline clinical or clinical (score 8-11 or 12-21 out of a possible 21, respectively). Specifically, this consisted of 24% meeting anxiety criteria, 14% depressive criteria, and 10% mixed anxiety-depressive. The authors also found that individuals with higher levels of anxiety and/or depression were more likely to be younger, living alone, less active, currently smoking, had a history of mental health issues, and low levels of perceived social interaction. Type of cancer was also associated with distress, in that individuals diagnosed with lung cancer or melanoma were more likely to report anxiety than were those diagnosed with prostate cancer. Additionally, individuals receiving chemotherapy in the month prior were more likely to meet criteria for depression. The research findings support that health behaviours, social, and psychological factors showed greater association with psychological morbidity than either disease or individual characteristics (Boyes, Girgis, D'Este, & Zuca, 2011). The need for ongoing assessment of distress symptoms into survivorship is also supported, given that more than a quarter of respondents reported significant anxiety and/or depression levels.

### **Post-Traumatic Stress and Growth in AYA Survivorship**

Whereas post-traumatic stress refers to the feelings of fear and anxiety that may follow a life-threatening experience such as cancer diagnosis and treatment, post-traumatic growth refers to personal growth or gain subsequent to the negative experience (Jim & Jacobsen, 2008). Theoretically, when an individual changes the meaning or interpretation of his or her trauma to encourage or maintain positive assumptions about themselves and the world, and this new positive is greater than what was present before the traumatic experience, then post-traumatic growth is thought to be occurring (Jim & Jacobsen, 2008). Post-traumatic growth is frequently reported by cancer survivors, and is generally categorizable within one of the following three

areas: increased social resources (relationships with family and friends improved, love for family and friends deepened), increased personal resources (compassion and concern for others increased, improved outlook on life), and improved coping skills (improved stress management, ability to accept challenges as they present themselves and to accept life circumstances)

(Adapted by Jim & Jacobsen, 2008 from Schafer & Moos, 1992).

In regard to post-traumatic stress, cancer was only explicitly deemed a stressor with the adoption of the DSM-IV (APA, 1994), thereby validating the experiences of cancer patients and helping to foster an interest in research (Sumalla, Ochoa, & Blanco, 2009). In cancer survivors, post-traumatic stress symptomology often includes symptoms related to intrusive thoughts, such that being reminded of cancer may lead to high distress, and recurrent, distressing thoughts of cancer may intrude during daytime as well as in dreams (APA, 1994). Emotional numbness and avoidance are also commonly reported, whereas symptoms such as arousal and hyper-vigilance have proved difficult to measure given a potential overlap with residual treatment side-effects (APA, 1994; Jim & Jacobsen, 2008).

Few studies have examined these positive and negative impacts of a cancer diagnosis and treatment in a single sample (Bellizzi & Blank, 2007; Helgeson, 2010; Park & Blank, 2012). Jointly examining potential positive and negative impacts is important, as focusing solely on one or the other may lead to biased findings. To this effect, Park and Blank (2012) summarized the literature and noted that positive changes yielded no significant independent results when positive and negative impacts were simultaneously tested. The authors reflected that these findings may partially be due to methodological flaws and testing biases, and stressed the need for further research examining how well-being relates to positive and negative changes. Consistent with these objectives, Park and Blank (2012) assessed positive and negative changes

as manifested across a range of life domains, examined how these changes were related to an adjustment to cancer, and examined whether positive changes were able to buffer the relationship between negative change and adjustment. Findings revealed that whereas all participants identified some degree of change, “no change” was also commonly reported suggesting the need to research this minimal change group. Additionally, the negative change was fairly infrequently reported, suggesting the importance of focusing on the issues reported by this subgroup. Endorsed to a greater degree were positive changes. However these positive changes remained only modestly related or unrelated to adjustment indicators. Conversely, despite the relative lack of frequency of negative changes reported, they remained robustly associated with adverse events. Finally, positive changes were not found to buffer the relationship between negative change and adjustment. The authors suggest that future research would benefit from conjointly examining positive and negative changes reported by cancer survivors, rather than considering them to be distinct entities (Park & Blank, 2012).

### **Fertility**

One of the areas in which uncertainty is frequently experienced is that of fertility. Infertility is rarely a definitive diagnosis, in that healthcare providers report there is often no certain way of determining the extent of damage to the reproductive system that will occur over the course of treatment (Lee et al., 2006; Nieman et al., 2006). Consequently, future predictions regarding fertility are not only difficult but also largely unreliable (Lee et al., 2006).

This uncertainty and inability to provide accurate prognoses have been reported as part of the reason why the topic of fertility is infrequently broached with patients (Quinn et al., 2009). Additional reasons include a lack of physician knowledge, perceived cultural or language barriers, and the belief that discussing fertility preservation may add increased stress to an

already stressful situation (Quinn et al., 2009). For patients with a poor prognosis, physicians also report reluctance to discuss fertility preservation with the underlying logic being that fertility discussion is futile when lifespan expectation is brief.

From a patient perspective, this physicians' discomfort with discussing fertility issues and fertility preservation have detrimental repercussions. Most notably, AYAs often remain uninformed regarding their fertility status and fertility preservation options, and discovering their potential fertility impairment may come as a surprise (Canada & Schover, 2005; Gorman, Bailey, Pierce, & Su, 2012). Additionally, adolescents and young adults have clearly articulated their desire for information regarding fertility and report being frustrated with the perceived lack of choice or control (Gorman et al., 2012). In one study completed with female patients, it was reported that whereas most women perceive parenthood to be an important part of life, the ability to bear children might hold even greater meaning for cancer survivors (Schover, 2005).

Patients also report a great deal of ongoing uncertainty when coming to terms with fertility in survivorship. Patients report awareness that a fertility discussion at or near the time of diagnosis would be difficult, but still state that it was desired (Gorman et al., 2012). Common questions survivors may pose themselves include whether there is a risk of passing on a "cancer gene" to their child, whether their body is strong enough to cope with the demands of pregnancy, possible elevated risk of cancer recurrence due to pregnancy strain, concerns regarding the ability to conceive a "normal" child, and future concerns regarding personal risk of mortality and living long enough to raise children, among others (Halliday & Boughton, 2011).

Recent data collected from Canadian fertility clinics further emphasizes that AYA cancer patients are not accessing services at a level commensurate to incidence rates (Loren et al., 2013; Yee, Buckett, Campbell, Yanofsky, Barr, 2012; Yee, Buckett, Campbell, Yanofsky, & Barr,

2013). Notably, males are accessing fertility clinics more than females. This is likely because, as compared to harvesting eggs, sperm banking is a non-invasive, lower cost procedure which is more widely accessible and, as such, it is much less likely to lead to treatment delays.

Taken cumulatively, the need for increased information, discussion of fertility preservation options, availability of accessible fertility clinics, and associated emotional and practical support for all AYA cancer patients are strongly advocated (Gorman et al., 2012; Halliday & Boughton, 2011). However, considerable gaps in practice remain (CPAC, 2017).

### **Health behaviours in AYA survivorship**

Adolescent and young adult cancer survivors are at an elevated risk for long-term health complications. Addressing modifiable risk factors, such as smoking status, alcohol consumption, drug use, and physical activity level, can help to attenuate health risks. Specifically, low alcohol consumption, exercise, and smoking abstinence have been associated with increased quality of life, decrease in some long-term side effects, and preliminary evidence supports a decrease in cancer recurrence risk, chronic disease, mortality, and the diagnosis of a second primary cancer (Blanchard, Courneya, & Stein, 2008; Brown et al., 2003; Jones & Demark-Wahnefried, 2006; World Cancer Research Fund, 2007). Similarly, AYA survivors are at increased risk of cardiovascular disease, weight gain, and fatigue, all of which can be attenuated by healthy behaviours and aggravated by unhealthy behaviours (Rabin, 2011).

Given the importance of, and consequences associated with, modifiable risk factors, Rabin (2011) recently reviewed the health behaviours of cancer survivors currently in adolescence and young adulthood. Compared with the general population, AYA survivors were found to have lower current smoking rates with approximately 17% being current smokers and 28% being previous smokers (Emmons et al., 2002; Oeffinger et al., 2001; Rabin & Politi, 2010).



These survivors are also less likely to begin smoking, less likely to smoke as compared to their siblings, and for smokers, more likely to want to quit (Emmons et al., 2002). A similar pattern was found for alcohol and drug abuse, with approximately 3% of AYA cancer survivors engaging in high levels of use; this is lower than what is recorded in the general population (Rabin & Politi, 2010). Though these statistics are promising, they nonetheless indicate that a significant portion of AYAs continues to engage in risky behaviours.

Rabin (2011) also reviewed demographic, medical and healthcare, social cognitive, and distress-related variables impacting modifiable risk factors such as smoking status, alcohol, and drug use. Demographic variables associated with a less healthy lifestyle included male gender and being at the older end of the AYA age spectrum, whereas a healthy lifestyle was associated with the ongoing ability to work, higher education, and increased income. Increased contact with healthcare providers, greater concern over health, and greater importance placed on health were all associated with increased healthy behaviours. Finally, the AYA's social network has also been found to impact behaviours, such that heavy smoking in peers was associated with increased AYA smoking, whereas having primarily non-smoking peers was associated with greater attempts to quit. Understanding the links between modifiable risk factors and associated factors is important when attempting to design and implement effective intervention and treatment programs.

The physical activity levels of AYAs with cancer have been increasingly researched in recent years, both in reference to activity levels and the benefits of physical activity in survivorship. General guidelines recommend 75 minutes of vigorous (or 150 minutes of moderate) exercise per week (US Department of Health and Human Services, 2008); individuals are then classified as sedentary (little to no exercise), insufficiently active, active within the

guidelines, or active above the guideline recommendations. A recent study categorized 23.5% of AYA survivors as sedentary, 25.2% as insufficiently active, 22.3% as within guidelines, and 29.1% as exceeding guideline recommendations (Bélanger, Plotnikoff, Clark, & Courneya, 2011). Additional studies using these guidelines identified between 37.6% and 47% of AYA survivors as physically active (Bellizzi, Rowland, Jeffery, & McNeel, 2005; Coups & Ostroff, 2004; Florin et al., 2007; Haskell et al., 2007; Rabin & Politi, 2010). Studies using more lenient definitions of physical activity reported that between 65% and 82% of AYA survivors were physically active (Cox et al., 2009; Oeffinger et al., 2001), with one online study reporting physical activity levels of 80% in AYA cancer survivors (Finnegan et al., 2007).

Consideration of the physical activity level of AYA cancer survivors is important, in light of recent work associating positive outcomes with physical activity and negative outcomes with the lack thereof. Specifically, Bélanger et al. (2011) found that AYAs who were active within or above guidelines were more likely to report greater health-related quality of life and self-esteem, as well as lower levels of stress and depression. The authors also found that these relationships were stronger for individuals who had received chemotherapy treatment as opposed to those who had not. Specifically, for previous chemotherapy patients at any level of physical activity, meaning even for individuals in the “insufficiently active” category, these positive benefits were evidenced. Love and Sabiston (2011) examined the relationships among physical activity, social support, and post-traumatic growth. The authors found that physical activity moderated the relationship between social support and post-traumatic growth, such that the relationship between social support and post-traumatic growth was stronger for those who were less active and weaker for active individuals. The authors suggest that physical activity may serve to foster post-traumatic growth in AYA cancer survivors independent of social support (Love & Sabiston,

2011). Conversely, individuals with low physical activity levels (and categorized as sedentary or insufficient activity) may be at increased risk of poorer health-related quality of life, poorer cancer-related disease outcomes, increased risk for other chronic diseases, and greater risk of premature mortality (Bélanger et al., 2011).

Demographically, active cancer survivors are more likely to be younger, have a higher level of education, non-smoking, wealthier, to have greater general health, lower body mass, and fewer comorbidities (Bélanger, Plotnikoff, Clark, & Courneya, 2012; Blanchard et al., 2002; Courneya, Vallance, Jones, & Reiman, 2005; Jones, Courneya, Vallance, & McBride, 2006; Karvinen et al., 2007; Karvinen et al., 2009; Keats, Culos-Reed, Courneya, & Murnaghan, 2007; Stevinson et al., 2009). Although research examining the factors contributing to increased physical activity is sparse, two recent studies conducted by Bélanger et al. (2011, 2012) have examined the issue. Bélanger et al. (2012) sought to examine physical activity determinants in AYA cancer survivors. Using path analysis, the authors found significant contributions from affective attitudes, education level, overall general health, and intention. The variance in the latter (intention) was in turn largely explained by perceived behavioural control and both instrumental and affective attitude. As such, interventions designed to help increase physical activity may benefit from fostering strong intentions in clients. Preliminary research also suggests a preference among AYA cancer survivors for engaging in physical activity with family and friends, rather than solitary (Bélanger et al., 2011), and greater perceived self-efficacy and autonomous motivation were also associated with increased exercise (Rabin, 2011). Together, these findings may help to guide future interventions for AYA cancer survivors.

### **Transitioning from Active Care to Survivorship Care**

As was expressed by Rowland (2008) “being cancer free does not mean being free of cancer.” Although a time of celebration, transitioning from active care to survivorship can also be fraught with challenges. Notably, patients may feel concern over losing the support of the oncology department, apprehension surrounding their monitoring and survivorship care, experience fears of cancer recurrence (now that they are no longer actively “fighting”), and coping with the long-term effect of the cancer and cancer treatments, among other issues (Rowland, 2008).

For AYAs, research examining the transition is notably lacking with much of the evidence being anecdotal (Soliman & Agresta, 2008). Consequently, Thompson, Palmer, and Dyson (2009) used a qualitative, focus group methodology to assess issues associated with transitioning from active therapy into follow-up care. Concerns centre on finishing treatment, ongoing health concerns, and directions for the future. More specifically, the finishing treatment category included concerns with moving to what was perceived as a less structured model of care. Ongoing health concerns voiced included the risk of a cancer recurrence, fatigue, and fertility; participants noted that these topics were discussed at the onset of treatment but not since that time. In regard to future directions, participants voiced that cancer had put a stop to many aspects of their lives. Challenges and uncertainty regarding relationships, employment, and educational pursuits were noted (Thompson et al., 2009). Thompson et al. (2009) reflected on the clinical implications of their research, addressing practical suggestions to guide the transition from active therapy to follow-up. These suggestions including fostering an ongoing relationship between the patient and their oncologist, providing the necessary supports to aid the AYA with re-integration, conducting regular psychosocial assessments with appropriate supportive care options, surveying of late effects of treatment, ensuring young survivors remain connected to

other survivors, helping with the return to schooling or employment, and ensuring a transitional care plan is in place.

In terms of the latter, the need to ensure a transitional care plan is in place was echoed by Casillas et al. (2011) who surveyed AYA's to assess their confidence in managing their survivorship care. The authors found that survivors generally lacked the necessary information, mainly lacking pertinent documentation such as medical record copies (33%), treatment summaries (48%), and survivorship care plans (55%). Additionally, the authors classified 41% of respondents as having "low confidence in managing survivorship care." Lack of confidence in survivorship care was also found to be especially salient for ethnic minorities, who were therefore considered a high-risk group.

Given that the population of AYAs requiring long-term survivorship care is increasing, the need for both medical and psychosocial follow-up advocated. Consequently, the need for research examining survivorship care planning and awareness of this across ethnicities is increasingly reported (Casillas et al., 2011). An important component of this research and planning is eliciting the perspectives of AYAs as well as healthcare providers and ensuring consistent goals across these groups.

### **Evaluating the Perspectives of AYA Patients and Healthcare Providers**

The need to elicit patient feedback to help guide the creation and implementation of healthcare services is being increasingly recognized (Fallon, Smith, Morgan, Stoner, & Austin, 2008; Zebrack et al., 2006). The importance of actively involving patients is especially important when working with AYAs with cancer, as their needs remain poorly understood. Although research on this topic is notably sparse, three studies addressing the issue have emerged in recent years: each will be discussed.

Although previous research has examined and assessed universal needs in cancer patients, research focusing on the needs of AYA patients was noted to be lacking (Zebrack et al., 2006). Zebrack et al. (2006) therefore assessed the noticeably absent perspective of AYAs with cancer as well as clinical oncology professionals with the goal of understanding the unique needs and characteristics of young adult cancer subgroup. A total of 40 oncology health professionals and 37 AYAs contributed information; the Delphi method was used to develop group consensus regarding the importance of responses, and to rank order responses. The authors found that although there were areas of considerable agreement in terms of priority needs for AYAs in treatment as well as survivors off treatment, there were also clear areas of difference. Notably, for AYAs in treatment, the importance of opportunities to meet other patients or survivors was listed as a top priority by AYAs themselves and psychosocial professionals, but ranked third for physicians and nurses behind support from family and friends, and individualized written disease information. The latter was, however, ranked second for all groups (see Zebrack et al., 2006 for a full review of findings). Zebrack et al. (2006) reflected that the purpose of the research was to help generate questions for further exploration and areas of potential exploration. Arguably, a first step may be understanding how the needs of AYAs are perceived by a larger and broader sample of AYAs and healthcare professionals.

A second attempt to address AYA perspectives was conducted by Fallon et al. (2008) who sought feedback from AYAs about the “Adolescents with Cancer” continuing education professional development module. Respondents articulated topics including the importance of humour, appropriate knowledge of cancer treatment and side effects, clinical, counselling, and psychological skills, and knowledge of key issues such as fertility, sexuality, risk-taking behaviours, healthy living, and so forth. Although many of these topics were already contained

within the draft model, others such as the importance of a sense of humour were novel. This research helps to demonstrate how a combined, patient vetted and professionally researched approach to the development of educational modules and programs may be beneficial.

Finally, the healthcare professional perspective on cancer in AYAs was researched by Gibson et al. (2012) as they queried the key competencies necessary to care for AYAs with cancer. This research is important, as little to no evidence exists to describe the specialist role of professionals in AYA cancer. The authors, therefore, sought to assess what it is that makes a healthcare professional suitable and competent to work with AYA cancer patients. Data were generated over the course of two workshops. Findings from the first workshop highlighted the importance of tailored expertise in paediatric and adult cancers, an understanding of cancer, and ensuring appropriate disease information is delivered, respectively. In the second workshop, participating healthcare professionals placed greater emphasis on the need for advanced communication skills, honesty, and the necessary skill and ability to help empower AYA patients, respectively.

Through this research, Gibson et al. (2012) support the need to formalize education in the speciality of AYA cancer, and to ensure the appropriate progression from novice to expert for healthcare professionals treating this unique population. Consider the example of communication. Healthcare professionals working with AYA cancer patients require the unique skill of not only communicating with the patients, but oftentimes, with the parents of the AYA as well (Gibson et al., 2012). The authors, therefore, suggest that the communication needs of AYAs are unique to this population, and significantly different from the communication needs of other age groups (Hall, 1999; Gibson et al., 2010).

### *Novel treatments for AYAs*

As adolescent and young adult cancer patients and survivors are increasingly recognized as a group with unique needs, so too are healthcare providers and patients themselves exploring novel treatments to meet these needs. Novel treatments including a therapeutic music video intervention, psychoeducational video games, Photovoice project, and network focused nursing are therefore briefly summarized and reviewed.

Interventions are ideally designed to address the critical needs of a population in question – in this case, AYA cancer patients and/or survivors. Arguably, key goals to consider for the AYA population include targeting coping, autonomy and personal identity development, stress management, and social support (Docherty et al., 2012). With this goal in mind, Burns, Robb, Phillips-Salimi, and Haase (2010) conducted a preliminary investigation of the use of therapeutic music video intervention for AYAs undergoing stem cell treatment. Grounded in the Adolescent Resilience Model (Haase, 2004) as well as the Contextual Support Model of Music Therapy (Robb, 2000), study results supported the therapeutic music video intervention as an effective manner in which to buffer stem cell related challenges, and supported the need for a larger scale randomized intervention.

Docherty et al. (2012) proceeded to conduct this larger investigation and compared weekly use of the therapeutic music video intervention as compared to the control condition of a low-dose audiobook. Data were collected from the parents of the AYA undergoing stem cell treatment rather than the AYA themselves, likely due to the debilitating nature of the treatment. Groups were qualitatively assessed to determine whether individuals in the experimental condition experienced reduced illness-related distress, improved coping and family environment, and increased perceived social support, derived meaning, resilience, and quality of life. Three



core themes emerged from the data: (1) helpfulness and meaningfulness of the therapeutic music video intervention for AYAs (2) helpfulness and meaningfulness of the therapeutic music video intervention for parents of AYA cancer patients and (3) the ability to participate in the project while undergoing stem cell treatment.

From each core theme, several subthemes emerged. The first core theme included subthemes discussing the mechanisms by which AYA suffering is reduced during the intervention, the perceived benefits of the intervention, and the manner in which the intervention helped to connect the AYA with family, peers, and healthcare professionals. The second discussed parental benefits, such as reduced parental suffering, the creation of a DVD legacy, and the opportunity for the parent to support the AYA during treatment. Finally, discussion of the third theme included subtopics describing how participants arrived at the decision to participate in the research, and suggestions regarding how to ameliorate the therapeutic music video process. Taken cumulatively, this research provides preliminary support for AYA and parental benefits, as the therapeutic music video intervention appears to create a non-threatening environment in which both parties can begin to discuss the cancer experience (Docherty et al., 2012).

Similar positive findings have emerged regarding the potential benefits of a video game methodology. Kato and Beale (2006) explored the impact of a psychoeducational video game about cancer in a sample of 43 AYA cancer patients with a variety of diagnoses, with the goal of assessing interest in such a game. The majority of participants demonstrated moderate interest, but willingness, to partake in a video game based on cancer knowledge. Based on this preliminary interest-based survey, Beale, Kato, Marin-Bowling, Guthrie, and Cole (2007)

assessed the use of the newly developed “Re-Mission” video game, designed to encourage, guide, motivate, and support appropriate self-care in AYAs during cancer treatment.

Participants were randomly assigned to the experimental or control condition. In the experimental condition, participants were provided with the Re-Mission game as well as a recreational game and asked to play for a minimum of one hour weekly over a three-month period. Participants in the control condition were given the same instructions as to the frequency of play, but provided only the recreational video game. Cancer knowledge questionnaires were also completed by participants at baseline, and one and three months post-baseline. Although the majority of participants in the experimental condition infrequently played the Re-Mission game (*mean* = 3.63 hours), a significant increase in cancer knowledge was nonetheless found. The authors suggest that the greater gain in cancer-related knowledge may also reflect increased information seeking from other sources, such as the internet or from healthcare professionals. Overall, these results suggest that a video game methodology may be an effective way of stimulating cancer-related knowledge and positive self-care behaviours in AYA’s.

An additional novel intervention, Photovoice, has shown promising results with young adult cancer survivors of childhood cancer (YACS) and warrants consideration for AYA patients and survivors. Photovoice has been effectively implemented with marginalized populations to assess social and environmental conditions, and is strongly rooted in theory and a participatory research methodology (Wang, Morrel-Samuels, Hutchinson, Bell, & Pestronk, 2004). The Photovoice project was recently attempted with YACS, providing the opportunity to photograph and explore cancer survivorship themes (Yi & Zebrack, 2010). Each participant was asked to select a partner (spouse, friend, family member) and given a digital camera. The intervention consisted of seven meetings, during which topics to photograph were discussed, and the

photographs taken were then discussed at the subsequent meeting (see Yi & Zebrack, 2010, for a full review of Photovoice methodology). The research yielded themes including culture, health, reflection on positive cancer impacts, and a lost childhood. The Photovoice methodology appears to be a successful means by which to allow YACS to process and explore thoughts and emotions related to the cancer experience.

In addition to novel interventions, network-focused nursing represents an innovative move towards holistic nursing care for AYAs in that it considers and attends to the patient's social network. The concept of a network-focused nursing emerged out of Denmark, with the goal of ensuring AYAs diagnosed with cancer are supported in maintaining and strengthening their social networks, and facilitating the development of new social networks while undergoing cancer treatment (Olsen & Harder, 2009, 2011). Network-focused nursing practices include ensuring AYA inpatients share a room with other AYAs, supporting significant others and allowing for "parent-free time" as is needed, inviting peers to remain in the unit with the AYA, and ensuring a multidisciplinary professional network is available to provide support as needed. At the request of the AYA, nurses are also prepared to speak with teachers and/or fellow students to inform them of the AYAs illness, describe the goals of fostering a supportive network, and arrange and chair networking meetings (Olsen & Harder, 2009, 2011). Specifically, networking meetings are an opportunity for the AYA to gather family, friends, and significant others in one room to hear about their diagnosis, treatment plan, and what to expect over the coming months. These guests are also informed as to how they can support the AYA throughout the cancer journey (Olsen & Harder, 2009, 2011).

The concepts of network-focused nursing and networking groups are empirically grounded. Research suggests that over time and with greater treatment duration, the social

network of the AYA diminishes (Enskar, Carlsson, Golsater, & Hamrin, 1997; Neville, 2005). This is of concern, as one of the most challenging aspects of survivorship cited by AYAs is that of trying to “catch up” socially (Neville, 2005). In addition to the social challenges, it is recognized that in order to suitably treat AYAs, healthcare providers need to be aware of the impacts of cancer on normative adolescent and young adult development (Bleyer, 2002). This is particularly salient when we consider that AYAs are faced with a “dual crisis” at time of diagnosis – meaning that the cancer diagnosis and treatment threatens both the health of the AYA and threatens age-appropriate developmental goals from being achieved (Novakovic et al., 1996; Olsen & Harder, 2009).

In addition to the novel interventions on which preliminary research is emerging, there are a multitude of additional interventions that have yet to be researched and are, therefore, lacking empirical evidence regarding efficacy. These include, but are not limited to, the impact of online communities (stupidcancer.com, young adults cancer Canada), the use of personal blogs as a way of communicating with family, friends, and the online community regarding the cancer diagnosis and treatment, peer matching programs (Immerman Angels, Canadian Cancer Society), and adventure therapy programs (Survive and Thrive Expeditions, First Descents), among others.

Many of these programs and initiatives are AYA-created and led resources, representing a grassroots attempt to ensure the needs of the AYAs themselves, and peers, are met. Arguably, this may reflect the inability of structured, healthcare organizations to recognize and meet these needs in a sufficiently timely manner. Alternatively, it may be a reflection of the developmental stage of AYAs, and a productive, constructive approach to active coping. Regardless, further

research is required to help qualify, and quantify, the short and long-term impact of such novel and innovative resources on AYAs at different stages in the cancer trajectory.

### *Conceptual frameworks and models*

At its most basic, a conceptual framework or model helps us to learn about, and understand, the topic at hand. Often representing a combined quantitative and qualitative approach, it is critical to guiding empirical research as it provides an overarching view of how multiple aspects of inquiry relate to one another. Specifically, a framework or model can help clarify findings by connecting previous literature with new findings, can support or help disprove new theories, and can guide further directions for research.

In psychosocial care, conceptual frameworks and models are also used to guiding program planning, educational services, and research initiatives. However, given the relative novelty of AYA psychosocial oncology, there is a paucity of suitable and comprehensive models. Those available, mainly a dimensional overview of AYA psychosocial issues (Zebrack et al., 2007), the Supportive Care Framework for Cancer Care proposed by Fitch (1994), Rowland's developmental model of adaptation (1989), and the Adolescent Resilience Model (ARM) (Haase, 2004), will be reviewed. Borrowing from associated literature, the Circumplex Model of Affect (Russell, 1980) and the Well/Ill-Staying/Moving Model (WISM; Røysamb & Nes, 2018) will be presented. Notably, the goal of reviewing these models and frameworks is to provide a broader context by which to understand and conceptualize AYA care.

Zebrack and colleagues (2007), guided by the Chesler and Barbarin Stress-Coping Model (Chesler & Barbarin, 1987), organized the psychosocial issues of young adult cancer patients and survivors along 5 key dimensions: intellectual, practical, interpersonal, emotional, and existential. The intellectual dimension references issues such as the amount of information the

cancer patient is interested in receiving, or the manner in which he or she prefers information to be communicated. The practical dimension includes issues relating to the experience of being hospitalized and treated and the likely disruptions in school or occupation. The interpersonal dimension largely focuses on relationships with others including peers, parents, and healthcare professionals. Issues relating to psychological and emotional distress, as well as actual and perceived support, are considered to be part of the emotional dimension. Finally, spiritual and existential concerns have been recognized as core components of the Stress-Coping Model, including the issues of facing uncertainty, desire for hope, and psycho-spiritual adaptation. Each dimension is thought to reflect key issues facing the AYA cancer patient and survivor. The strength of this model resides in its ability to clearly organize the cancer experience into observable categories, and to ensure the multifaceted needs of the patient are understood. However, it is not focused on interactions among or within dimensions, as dimensions are regarded relatively independently. For example, the relationship between psychological distress and school or work, or the relative importance of intellectual issues compared to emotional issues. This broad categorization of dimensions suggests that this model is best utilized as a comprehensive organizational structure.

The Supportive Care Framework for Cancer Care proposed by Fitch (Fitch, 1994; Fitch, Porter, & Page, 2008) is a theoretically based approach, derived from extensive patient and family interviews, surveys, and consultation sessions with interdisciplinary professionals. This model was designed to aid oncology healthcare providers in organizing and imparting relevant and essential information to patients. The framework includes seven key dimensions: (1) psychological, relating to self-worth, coping, and body image; (2) social, relating to relationships, family, and occupation; (3) spiritual, relating to suffering, pain, and meaning in

life; (4) informational, relating to the provision of disease, symptom, and treatment information; (5) practical, relating to finances, legal concerns, and childcare; (6) emotional, relating to sentiments such as fear, anger, despair, or hopelessness; and (7) physical, relating to symptoms such as nausea, pain, or fatigue (Fitch et al., 2008; see Figure 2). Fitch and colleagues (2008) further expanded the framework by articulating needs relating to each dimension. For example, the spiritual dimension includes the individual's need to assess the purpose and meaning in life, whereas the needs in the information dimension relate to reducing confusion, anxiety, fear, and distress through information acquisition (see Fitch et al., 2008 for full evaluation). It integrated pertinent information on the proportion of patients requiring various types of services connected with these needs, and provides further guidance on types of services or activities consistent with a supportive care model (Figure 1). The strength of this framework rests in its ability to guide healthcare professionals in understanding the diverse needs of cancer patients, and providing clear guidelines as to how to attempt to meet those needs. To this effect, the authors reflected that this model is best suited for program planning, as the basis for research, or as a guideline by which to organize and implement educational and psychosocial care (Fitch et al., 2008). This framework is not specific to AYAs, though it could theoretically be tailored for any age range. As it stands, however, specific needs do not take into account the uniqueness of the AYA cancer patient and survivor. Additionally, as was noted above, this comprehensive organizational framework of needs does not delineate the relationships among the needs.

Rowland (1989) summarized three overarching variables impacting the ability of a patient to adjust to a cancer diagnosis and treatment: the sociocultural context, medical context, and individual psychological context. The former refers to learned cultural beliefs and social attitudes towards cancer, specifically relating to how a person views not only themselves but also

their illness. The medical context references cancer stage, type, site, and related diagnostic and treatment considerations. Finally, Rowland (1989) focuses on the individual psychological context, meaning the characteristics of the individual related to how they adapt to a cancer diagnosis and treatment. Rowland further specifies that the individual psychological context contains three sub-variables affecting overall adjustment to cancer, mainly the developmental stage of the individual, and the individual's intrapersonal and interpersonal styles, respectively. Rowland's developmental model of adaptation posits that, although no two patients will have the same experience, cancer causes similar or common disruptions in patients at similar developmental stages. As such, examining the developmental life stage of the patient helps to define which disruptions need to be addressed (Rowland, 1989).

Rowland identified four stages of adulthood, identified as the young adult (19 to 30 years), the mature adult (31 to 45 years), the older adult (46 to 65 years) and the aging adult (aged 66 years or greater). Within each stage of adulthood, developmental tasks, common tumours, disruptions of illness (including altered relationships, dependence-independence, achievement disruptions, body image and integrity, and existential issues), and interventions are discussed. Of note, the author does recognize the flexibility within these proposed stages, and the clear possibility that an individual may present within a life stage outside of the age range proposed.

Given the present focus on cancer in AYAs, the developmental stage and adaptation for patients identified by the model as young adults and mature adults is most pertinent and will be briefly discussed (Rowland, 1989). In young adulthood, developmental tasks include autonomy development, achieving intimacy and sexual identity, the progressive tampering of egocentric tendencies, completion of formal education, career development, and identity development. In



contrast, in the mature adult stage developmental tasks are more likely to include a focus on personal growth and the stabilization of personal identity, the consolidation of career goals, and a focus on social and emotional tasks relating to family and childrearing. Consider now disruptions due to illness associated with these stages. Illness disruptions in young adulthood may include a strain on established and evolving relationships, the recurring need to depend on others when autonomy was just beginning to be developed or solidified, the need to adapt expectations relating to current and future achievement related goals, changes to body image and often self-image, uncertainty regarding sexuality and fertility, and existential worry regarding issues such as risk of recurrence. Given the expected flow from the stage termed young adulthood to that of mature adulthood, the author notes that the illness disruptions categorizing the former may also be evidenced in the latter stage (Rowland, 1989). In addition, issues such as fears of abandonment, changes in family structure, role changes and reversal within the family, concerns regarding returning to work and illness-related costs, the physical impact of illness on the body, sexuality concerns and the exacerbation of existing sexuality problems, the existential questioning of life's purpose and personal spiritual and religious beliefs. For a more extensive overview of the developmental model, refer to Rowland (1989).

Rowland's developmental model of adaptation (1989) has much strength. It recognizes that a cancer diagnosis and subsequent treatment threatens not only the immediate goals of the cancer patient, but also future goals and aspirations. Accordingly, understanding the developmental stage of the individual and where the individual is situated in reference to key life domains cannot only help interpret the current impact of, and adjustment to, cancer, but also help to anticipate potential problem areas and appropriate interventions. Practical application of same might include a bio-psycho-social evaluation to help assess the current life stage of the patient,

and current and anticipated disruptions and challenges due to cancer. A potential weakness of the model, however, is the lack of current research integrating the life stages and developmental issues described. It would be beneficial to integrate relevant research on exercise, post-traumatic growth and resilience, or the impact of social media on interpersonal functioning, for example.

Grounded in lifespan development theory and meaning-based models, the Adolescent Resilience Model (ARM) (Haase, 2004) proposes that the protective factors, risk factors, and outcomes are related, and knowledge of the interrelationships can help to guide effective interventions for adolescents with cancer. Resilience is proposed to be a positive health concept, defined as “the process of identifying or developing resources to flexibly manage stressors to gain a positive outcome and a sense of confidence, mastery, and self-esteem” (Haase, 2004 p. 290). The ARM is therefore designed to describe the mechanisms necessary to enhance positive outcomes for AYA cancer patients.

The ARM is broadly composed of protective factors (individual, family, social), risk factors (individual and illness related), and outcomes (see Figure 3). Protective factors include positive coping, deriving meaning, positive family atmosphere, family support and resources, social integration, and healthcare resources. Risk factors include defensive coping, uncertainty in illness, and disease and symptom-related distress. Finally, outcomes included in the model consist of resilience and quality of life. The authors suggest that using the ARM as a guide, intervention studies may benefit from targeting multiple ARM concepts at once or targeting specific concepts as a way of identifying the impact on outcomes. The strength of the ARM resides in its recognition of the significant impact of positive health concepts, and practical considerations of how these concepts are amenable to change and improvement. This research is novel and as of yet in preliminary stages, but suggests a clear, theoretically grounded way in

which to approach the psychosocial treatment of adolescents with cancer. For the purposes of the present research, this model is limited by its focus on adolescence. Further evaluation to integrate concepts central to the individual, such as personality and subjective well-being, would be valuable.

Consider now the value of a Circumplex Model of Affect (Russell, 1980), which suggests that two basic neurophysiological systems are responsible for all affective states. Although there has been variability in the descriptive labels applied to the axes, the two-dimensional model of arousal by valence is strongly supported across the literature (Lang, Bradley, & Cuthbert, 1998; Larsen & Diener, 1992; Watson, Wiese, Vaidya, & Tellegen, 1999). Using a circular, two-dimensional image, valence (pleasure-displeasure continuum) is represented by the horizontal axis and arousal (alertness) the vertical axis (Posner, Russell, & Peterson, 2005; see Figure 4). For example, the center point represents a moderate level of arousal and a neutral valence, whereas the top-right quadrant would indicate high arousal and positive affect. As such, emotions can be represented as complex interactions between the valence-arousal dimensions, which are neurophysiological, and cognitions, which are neocortical (Posner et al., 2005). The CMA arose from discontent with the longstanding categorical approach to emotions, wherein emotions were treated as discrete categories with separate neural structures and pathways. The CMA represents a dimensional model, based on the premise that emotions emerge from neurophysiological systems that are overlapping with one another. Furthermore, a dimensional approach helps to make sense of high co-morbidity of psychiatric diagnoses. Since it was originally proposed, the Circumplex Model of Affect has garnered considerable research attention and empirical support; it incorporates interdisciplinary data on affective states derived from developmental research, neuroimaging studies, and behavioural genetics (Posner et al.,

2005). This model is empirically strong, well-grounded theoretically, and incorporates up to date interdisciplinary research. It is focused on addressing emotional states, but has not integrated the factors that impact emotional states, such as changes in life circumstance or illness. For this, we turn to the Well/Ill-Staying/Moving (WISM) model.

The WISM model (Røysamb & Nes, 2016, 2018) incorporates emerging research on psychiatric disorders and types of wellbeing, as well as the influence of genetic factors on same. The authors describe WISM as a two-dimensional circumplex model, partly derived from the CMA (Russell, 1980), with the vertical and horizontal axes represented by stability-change, and positive-negative, respectively (see Figure 5). At the core of the WISM model is the premise of goal states as central to human motivation. As such, the WISM model proposes four quadrants: well-moving (change, positive, approaching goal state), well-staying (stability, positive, goal state achieved), ill-staying (stability, negative, absent goal state), and ill-moving (change, negative, threatened goal state). Notably, the emergence of a serious illness, such as cancer, which often evokes fear, anger, and anxiety, would be considered ill-moving. This is an exciting, promising new field of research. However, the novelty of this model means that much of the relationship between genetics, environment, well-being, and ill-being remains to be assessed and understood. Specific to this research, to the best of our knowledge this model has yet to be used to conceptualize the impact of a cancer journey from illness onset to termination, be it in pediatric, AYA, or adult populations. Similarly, whether or not it has merit in guiding programming or interventions in oncology remains to be seen.

Each conceptual framework and model warrants careful consideration when attempting to research the psychosocial needs of AYA cancer patients and survivors. However, the relevance and appropriateness of one model above the other largely depend on the specific topic being

addressed, and whether the model is to be used for primarily research or clinical purposes.

Within the present context, the purpose of understanding these models is to guide and anchor our understanding of the completed AYA research within broader theoretical constructs, and to consider how these models might be helpful in contextualizing our research findings.

### *In Summary*

The purpose of this general introduction was to help orient the reader to the impact of a cancer diagnosis, treatment, and long-term effects in adolescence and young adulthood. The review of cancer incidence rates demonstrates how cancers diagnosed in the AYA age frame offer a distinct biological presentation, as well as a distribution of cancer types specific to this group. Psychosocial oncology has firmly taken grasp as a distinct discipline from medical care, and yet one that arguably warrants equal attention for cancer patients. Distress measurement emerged as a key patient indicator, serving as a broad, approximate gauge of well-being. However, it quickly became evident that understanding and measuring distress was but the proverbial tip of the iceberg, and it paved the way for decades of research assessing the impact of cancer, treatment, and survivorship, as well as predictors of well-being and well-being outcomes. As the literature expanded, so too came the growing awareness of the impact of cancer, adjustment processes, well-being, and the needs of AYA cancer patients and survivors as equally distinct, and largely specific to this age frame. Understanding these variables is critically important, as with this understanding comes the ability to develop and tailor appropriate support services and models of care for this population. As such, literature reviewing the perspectives of AYA patients and healthcare providers was discussed, along with novel treatments for AYAs, and conceptual models and frameworks by which the information provided could be organized.

Although the AYA oncology field has come a long way, much work remains. The most recent Canadian report on Adolescents and Young Adults with Cancer (CPAC, 2017) emphasizes the need for AYA-specific data to guide our understanding of distress and psychosocial supports needed, improved understanding of treatment wait-times and fertility preservation, research and education including best cancer control practices and access to clinical trials, assessment of end-of-life care and symptom management. The same report highlighted the need for AYA-specific survivorship research, to query post-treatment access to education and employment opportunities, improved understanding of late effects, access to rehabilitation services and the ability of available services to meet needs, quality of life measures, and models of survivorship care (CPAC, 2017). Notably, these are proposed as merely a first line of research goals and knowledge needs, not an exhaustive list.

After considering gaps in current knowledge and advocated next steps, the purpose of this dissertation was to examine AYA oncology from three distinct yet connected standpoints, using a multifaceted research approach to add to the current literature in the field. To this effect, three research studies were conducted. The first study assessed the impact of an AYA cancer documentary film as an awareness and teaching tool for healthcare providers. From a healthcare provider perspective, there is a lack of specialized education or training to educate professionals of issues specific to the experience of cancer in AYAs. Consequently, the extent to which healthcare providers perceive themselves as capable of caring for this population, and their perceptions of the key issues facing AYAs, is largely unknown. The second assessed subjective well-being in AYAs and its relationship with personality and well-being outcomes. From an AYA perspective, emerging research studies attempt to understand the psychosocial impact of cancer in this age range. However, comprehensive evaluations of psychosocial adaptation are

notably lacking from the literature. Finally, given the emergence of increasingly novel interventions and activities for AYA patients and survivors, the third study assessed the impact of an adventure therapy program – Survive and Thrive Expeditions – on adolescent and young adult cancer patients and survivors. Adolescents and young adults have increasingly turned to novel interventions to help cope with the psychosocial impacts of a cancer diagnosis and treatment. However, the majority of interventions lack any formal evaluation. Evaluations are necessary components of novel interventions, helping to assess crucial factors such as impact, efficacy, and how interventions could be improved to meet participant needs.

ARTICLE 1:  
CANCER IN YOUNG ADULthood: HOW DO HEALTHCARE PROVIDERS PERCEIVE  
THE EXPERIENCE?

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### **Abstract**

The goal was to assess the perceived ability of healthcare professionals to discuss adolescent and young adult oncology (AYAO) specific issues, and the use of a documentary film as awareness and teaching tool. Healthcare professionals and students ( $n = 81$ ) were recruited during training sessions at three Canadian cancer centres and invited to complete a brief questionnaire before and after viewing a documentary film depicting an outdoor expedition for AYA cancer patients. Demographics, work experience, and self-perceived AYAO knowledge was assessed pre-film. Understanding of AYAO needs, emotions, and life issues was queried using a 5-pt ordinal scale and using open-ended questions both pre- and post-film. Post-film, respondents were asked to reflect on whether they had learned anything new (yes/no). Medical staff and students reported a statistically significant increase in understanding of AYAO emotions, needs, and life issues from pre- to post-film, with 96% of the sample reporting they learned something new from viewing the film. Qualitative data support an increased post-film recognition of isolation as a key emotion and decreased emphasis on the treatment-related concerns as key life issues. Notably, the need for support was well recognized both pre- and post-film. This research provides preliminary support for the use of film as a teaching tool. Further research is warranted to explore short and long-term benefits from the patient and professional standpoint.

## Introduction

The present research strives to assess the perceived ability of healthcare professionals to discuss cancer-related concerns with adolescent and young adult cancer patients (AYAs) aged 18-39 years and to assess the impact of an AYA cancer documentary film as an awareness and teaching tool for healthcare providers.

It is now widely recognized that the 7,600 AYAs diagnosed with cancer across Canada each year require care that is not only specific to their stage of life but also delivered by suitably trained healthcare providers and offered in appropriate settings (Canadian Partnership Against Cancer, 2017). Although AYAs represent 4% of the cancer population, it is the altered distribution of cancers, biological differences, psychosocial challenges, and treatment issues specific to this age frame that call for the need for a distinct discipline to ensure the medical and psychosocial needs of AYA's are met (Canadian Partnership Against Cancer, 2017; D'Agostino, Penney, & Zebrack, 2011). However, meeting these guidelines is challenging. Centralized treatment facilities for AYAs are lacking, with patients largely triaged to paediatric or adult care (Bleyer, Budd, & Montello, 2006; Burke, Albritton, & Marina, 2007; Olsen & Harder, 2009, 2011). This is problematic, as AYAs do not fit in either of these treatment centers.

Similar to the manner in which paediatric and geriatric oncology care are medical specialities with tailored education, there is a clear need to ensure healthcare professionals treating AYAs are appropriately trained to meet the distinct needs of this population (Barr, Rogers, & Schacter, 2011; Hayes-Lattin, Mathews-Bradshaw, & Siegel, 2010; Robison, 2011). However, there is a notable lack of information on training programs and standards for AYA healthcare professionals (Zebrack, Matthews-Bradshaw, & Siegel, 2010; Robison, 2011). Additionally, with healthcare professionals treating AYA oncology patients mainly at non-

specialized facilities, they are likely to have limited experience with this population (Ferrari et al., 2010; Tsangaris et al., 2014).

Preliminary research suggests that those actively working with and treating AYAs develop a more solid understanding of AYA needs. Zebrack et al. (2006) conducted a novel assessment of the perceived medical and psychosocial care needs of AYAs as reported by healthcare professionals and assessed the degree to which these perceptions were consistent with those reported by AYAs themselves. Included in the research were 37 AYA patients and 40 oncology healthcare professionals who identified the needs of AYA cancer patients and who were asked to rank their importance accordingly. Specific categories emerging from the research included biomedical needs, supportive care needs, other psychosocial needs, and long-term survivorship needs. The authors reported a fairly high level of agreement between AYAs and the healthcare professionals treating them and noted that this might be due to the professionals' high levels of AYA involvement in cancer advocacy work, education initiatives, and the provision of services (Zebrack et al., 2006). This research is promising, as it suggests that those actively working with AYAs are able to gain insight into the unique psychosocial needs of this population. However, a clear gap remains: Healthcare providers, be it nurses, oncologists, or supportive care workers, without specialized training or AYA experience, may be ill-equipped to meet the distinct needs of the AYA patient who presents on their caseload.

Although academic and clinical communities have only recently begun to delineate the distinct medical and psychosocial needs of AYAs and the ability of healthcare professionals to address these needs, the grassroots AYA self-support community has flourished in the past decade. Organizations ranging from small individual operations and inspirational blogs to large-scale non-profits organizing retreats and nation-wide events have popped up, offering services to

AYA patients and survivors. One of the greatest success stories belongs to Young Adult Cancer Canada (YACC; [youngadultcancer.ca](http://youngadultcancer.ca)), the brainchild of young adult cancer survivor Geoff Eaton and based in St. John's Nfld, YACC organizes retreats and gatherings nationwide as well as volunteer events and fundraisers including "Shave for the Brave" and a blog for sharing patient profiles. Smaller, individually run websites and blogs giving a personal voice to the AYA cancer experience from diagnosis, through treatment, and sometimes through an advanced metastatic cancer diagnosis, include Lacuna Loft ([lacunaloft.com](http://lacunaloft.com)), Anna Craig: My Journey with Stage 4 Breast Cancer ([annacraigblog.wordpress.com](http://annacraigblog.wordpress.com)), Nalie ([nalie.ca](http://nalie.ca)), and quite literally thousands more.

Social media has played a substantial role in disseminating resources, links, and articles, with most organizations boasting a Facebook and Twitter contact in addition to a webpage. Furthermore, novel initiatives such as a weekly radio show ([StupidCancer.com](http://StupidCancer.com)), peer matched support ([Imerman Angels; imermanangels.org](http://ImermanAngels.org)), and brief films ([Wrong Way to Hope: Survive and Thrive Expeditions; survivethrive.org](http://WrongWaytoHope.org)) help peers to feel connected and outsiders to gain perspective on the AYA cancer experience. However, research examining the impact, effectiveness, and clinical utility of such tools are frequently lacking. Long-term sustainability of resources is also questionable, in that the majority of organizations are small-scale and volunteer based.

Consider now the use of film. The first journal article focusing on film as a teaching tool in psychiatry was published in 1979 (Fritz & Poe, 1979). Since then, this type of "popcorn prescription" has become an increasingly popular and potentially powerful teaching tool, as films have the ability to highlight the critically important patient perspective and voice in a field that is historically more disease-focused (Alexander, Pavlov, & Lenahan, 2007; Banos & Bosch, 2015;

Ber & Alroy, 2001; Cappelletti, Sabelli, & Tenutto, 2007; Kumagai, 2008; Pescosolido, 1990; Volandes, 2007). Specifically, the patient narrative can help broaden a healthcare provider's perspective from the physiological, biological disease process to include the social and psychosocial considerations of living with illness (Kumagai, 2008; Volandes, 2007). It can help healthcare professionals understand that illness has an impact on the whole person, as well as their family (Weber & Silk, 2007). It brings an individual and social perspective to an abstract nosological classification (Cappelletti, Sabelli, & Tenutto, 2007). With respect to AYA oncology, both large-scale organizations and small grassroots initiatives have turned to film over the past decade to give the AYA cancer movement a voice. From short vignettes to in-depth documentaries, AYA's are on video, online, telling their stories and experiences.

One such AYA is Michael Lang, an adventure guide, filmmaker, and cancer survivor who has created a series of documentary films focusing on various aspects of cancer in AYA. His documentary film, "Wrong way to hope: An inspiring story of young adults and cancer" (WW2H) follows a group of young adult cancer patients and survivors as they kayak the Owyhee River deep in the South East Oregon desert. The young adults face the physical challenges of navigating the river over the course of the eight-day trip, as well as the emotional and psychosocial challenges of connecting with other patients and survivors and sharing and discussing information about their cancer journey. The WW2H film offers raw insight and a much-needed patient perspective on the impact of cancer in young adulthood.

In summary, we now know that AYA oncology requires recognition as a specialized discipline, in that the biological and psychosocial needs of this group are different. However, given the relatively low number of AYA oncology patients seen across Canada, specialized treatment centers and healthcare professionals with expertise in AYA care are sparse. Providing

AYAO training is especially challenging, as this is a multidisciplinary field. Healthcare providers come from medical (physicians, oncologists, radiation therapists, nurses), psychosocial (psychology, social work, spiritual care), and administrative (managers, support staff including administrative assistants and receptionists) disciplines, as well as students in training. With these disciplines comes a difference in education, training, and daily work tasks. Preliminary research by Zebrack et al. (2006) supports that healthcare professionals with experience working with AYAs have a better understanding of the needs of this patient group. However, healthcare providers typically have limited exposure to AYA specific training, or experience with AYA patients (Bleyer, Budd, & Montello, 2006; Burke et al., 2007; Ferrari et al., 2010; Olsen & Harder, 2009, 2011; Tsangaris et al., 2014). With the emergence of AYAO as a distinct field comes the use of novel approaches to learning, such as film. Film has had a longstanding teaching role in medicine, in that it can help professionals to gain the critical patient perspective. Film has been shown to be an effective teaching tool that could provide an important patient voice (Kumagai, 2008; Volandes, 2007; Weber & Silk, 2007). However, the use of films in a teaching or educational capacity for AYA cancer, to the best of our knowledge, has not been evaluated. When Lang planned a North American release of the WW2H film that included screenings at three healthcare facilities in Canada, the opportunity to assess the documentary film as a teaching tool presented itself. As such, the author arrived at an agreement with Lang to conduct a brief pre-post survey at three of the screening sites.

We aimed to assess the impact of the film on self-reported measures of AYA understanding using both quantitative and qualitative research approaches. To do so, we first sought to characterize the sample and understand the relationships among demographic and work experience variables. As many AYA patients are seen and treated by healthcare

professionals with varying levels of experience in oncology overall, and with AYAO oncology in particular, we aimed to assess relationships between sex, age, experience (number of years as a healthcare professional, number of years in oncology, and percentage of time spent with young adults) and self-reported understanding of key topics for AYAO's (treatment decisions, management of side effects, fertility issues, and psychosocial concerns), and group (medical, psychosocial, student). With this basic understanding of sample characteristics, we aimed to address the following hypotheses:

*Hypothesis 1:*

We expected that understanding of the emotional experience, life issues, and needs of AYAO patients would vary by discipline. As we are querying understanding of psychosocial topics, it was expected that the psychosocial professionals would report the significantly higher level of understanding pre-film than the remaining groups. Individuals in the student group were expected to have the least amount of formal or informal training in AYAO, and we hypothesized they would report a significantly lower level of understanding pre-film than the remaining groups.

*Hypothesis 2:*

There is considerable evidence supporting the impact of film-based interventions on knowledge, perceptions, and behaviours (Chiasson, Shaw, Humberstone, Hirshfield, & Hartel, 2009; Huebner, Rullo, Thoma, McGarrity, Mackenzie, 2013; Kumagai, 2008; Volandes, 2007). As such, we expected that a documentary film allowing healthcare professionals to gain a patient AYAO perspective would significantly increase self-reported understanding of patient life issues, needs, and emotions from pre-test to post-test across all discipline groups.

*Hypothesis 3:*

Across disciplines, healthcare providers typically have limited exposure to AYA specific training, or experience with AYA patients (Bleyer, Budd, & Montello, 2006; Burke et al., 2007; Ferrari et al., 2010; Olsen & Harder, 2009, 2011; Tsangaris et al., 2014). Pre-film qualitative reflections on the key issues facing AYAs would, therefore, be based on this limited knowledge. The film intervention provides a patient-perspective to the knowledge base of healthcare providers. It is hypothesized that this patient perspective, as presented by the film intervention, would result in a difference in the key issues qualitatively reported from pre-film to post-film.

**Methods****Study Setting**

Data were collected at three Canadian cancer centres: Princess Margaret Hospital (Toronto, Ontario), Cross Cancer Centre (Edmonton, Alberta), and the Alberta Children's Hospital (Calgary, Alberta). This study was independently approved by Lakehead University and Thunder Bay Regional Health Sciences Centre research ethics boards. Prior to each WW2H film screening, the research ethics board at each site was contacted to obtain consent to administer the research project questionnaires.

**Participants**

Healthcare practitioners working or training in cancer care at each site were invited to view the WW2H film screening and participate in the research. This included medical (oncologists, radiation therapists, nurses, students), psychosocial (psychologists, social workers, nutritionists, spiritual care chaplains, students) and administrative professionals working within cancer care.



### **Pre-test/post-test design**

The single group pre-post design methodology involved collecting information pre-film, and immediately post-film viewing with the goal of evaluating changes in participants' perceptions. There are notable drawbacks to this research design including the lack of a control group or random assignment. The single group pre-post design is not an authentic experimental design, in that it lacks the rigour to establish a causal link between the intervention and the outcome. However, this research approach was selected for practical reasons in that it presented the only viable method of collecting data on this previously unexamined and important issue. The pre-post design is a viable way of examining changes in knowledge, for exploratory purposes, on little-known topics (The Pell Institute, 2017).

### ***Recruitment***

In the weeks prior to each screening, each site was responsible for emailing staff to advise them of the coming screening, as well as the option to participate in the research study. The film screenings were advertised as "Lunch and Learn" sessions, with two screenings taking place at each site from 12:00 to 12:30 and 12:30 to 1:00, respectively. This timing is consistent with the lunch hour limitations of healthcare professionals, who seldom have a full 60-minute break. The WW2H screenings were also advertised using posters at each site.

### ***Procedure***

Michael Lang was present at each screening and served as a research assistant to coordinate the on-site data collection. A research package including an information letter (see Appendix A) and paper surveys to be completed prior to the film and after the film (see Appendix B and C) were placed at each seat in the screening room. As they entered, healthcare professionals were asked to read the information letter and, if they choose to participate,

complete the pre-film questionnaire. This was reiterated prior to starting the film. The post-film questionnaire was clearly marked, with instructions not to open it until after viewing the film. After the film ended, participants were instructed to complete the post-film survey during the question and answer period. Considering the low-risk nature of the research, and efforts to ensure respondents remained anonymous, the information letter clearly detailed that consent would be implied from questionnaire completion. In summary, each 30-minute session was structured as followed: viewers entered, were seated, and completed the pre-film questionnaire in the first 5 minutes. The WW2H film ran for 20 minutes. The final 5 minutes post-film allowed for question period and survey completion.

### ***Measures***

Pre- and post-questionnaires were necessarily brief due to the limited amount of time before and after viewing the film. Each questionnaire, therefore, required approximately 2 to 4 minutes to complete.

#### **Characterizing the sample.**

Demographic and work-related questions were used to characterize the sample. Assessed were age, sex, work discipline (medical, psychosocial, students), number of years working as a healthcare professional, number of years working in oncology, and percentage of time spent with young adults. Perceived ability to discuss key topics - treatment decisions, management of side effects, fertility issues, psychosocial concerns with AYA patients – was rated on a 5-point ordinal scale (1 = poor, fair, satisfactory, good, 5 = excellent). These questions were presented to participants in the pre-film questionnaire.

#### **Assessing AYAO understanding pre and post-film.**

This research was largely exploratory in nature, intending to assess how healthcare providers perceived their understanding of emotional experience, life issues, and needs of AYAO's, and how viewing the WW2H film impacted this. Given this aim, existing questionnaires were not found to be suitable. The quantitative and qualitative questions first evolved organically, from a discussion between the author and Michael Lang when the concept of evaluating the impact of the WW2H documentary film was originally proposed. The author (a clinical psychology doctoral student), Lang (WW2H film creator and AYA cancer survivor and advocate) and a supervising clinical psychologist specializing in oncology then proceeded to develop and finalize questionnaire wording. Questionnaire development was guided by Burgess' "A general introduction to the design of questionnaires for survey research (2001). Specifically, research aims were decided, population and sample identified, the procedure for collecting questionnaire data was decided, followed by questionnaire design and research ethics board review and approval of the questionnaires. The questions were reviewed for face validity.

The AYAO understanding scale included three questions, querying the self-perceived understanding of the (1) needs, (2) life issues, and (3) emotions of AYAO patients and survivors, rated on a 5-point ordinal scale (1 = poor, fair, satisfactory, good, 5 = excellent). These questions were presented to respondents in both the pre and the post-questionnaire. The scale had a minimum score of 3 and a maximum score of 15.

The AYAO understanding scale questions were also developed into qualitative, open-ended questions. Respondents were asked what they perceived as the three main (1) needs, (2) life issues, and (3) emotions AYAO patients and survivors have throughout their cancer experience. Again, these questions were presented to respondents in both the pre and the post-questionnaire.

**Assessing learning post-film.**

A single yes/no item was used to assess whether respondents believed they learned anything from watching the WW2H documentary film.

**Quantitative Data Coding and Analysis**

Quantitative data were coded numerically and entered into SPSS 25.0 for analysis. Demographics and frequencies were first used to characterize the sample. Sex differences across groups were examined using chi-square analyses. Differences in age and experience (number of years as a healthcare professional, number of years in oncology, and percentage of time spent with young adults) across groups (medical, psychosocial, student) were examined using one-way analyses of variance with post-hoc comparisons using Tukey HSD test. Finally, Pearson Product Moment Correlations were used to assess any relationships between experience variables (number of years as a healthcare professional, number of years in oncology, and percentage of time spent with young adults) and self-reported understanding of key topics for AYAO's (treatment decisions, management of side effects, fertility issues, and psychosocial concerns).

**Hypothesis one and two.**

Hypothesis one stated that self-reported understanding of the needs, life issues, and emotions of AYAO patients would vary significantly across groups. Hypothesis two stated that self-reported understanding of patient life issues, needs, and emotions from pre-test to post-test would increase across all discipline groups. Hypothesis one and two were tested concurrently: independently modelled repeated measures mixed-design analyses of variance were used to explore the impact of the film intervention on self-reported knowledge variables (model 1: needs, model 2: emotions, and model 3: life issues) pre and post-film while also looking at the impact of group (medical, psychosocial, and student) for each of the variables. Each model included two

independent variables (group as the between-subjects variable and time pre-post as the within-subjects variable) and one dependent variable (self-reported knowledge). This analysis examines main effects for each independent variable and interaction effects. More specifically, it will tell us whether there was a change in self-reported knowledge from pre to post (main effect for time), a difference between groups (main effect for group) and whether changes over time are different for the groups (interaction effect). To identify where the significant differences lie, follow-up pairwise comparisons were conducted with Bonferroni corrections applied to these analyses. The assumption of homogeneity of variances (that comparison groups have equal variance) was assessed using Levene's Test of Equality of Variances. Homogeneity of intercorrelations is the assumption that intercorrelations among levels of time (within-subjects variable) should be similar for the levels of the group (between-subjects variable); this was tested using Box's M statistic.

### **Qualitative Data Coding and Analysis**

Before and after viewing the film, respondents were asked to write what they perceived to be the three main emotions, needs, and life issues of young adult cancer patients.

Qualitative data were coded using thematic analysis (Braun & Clarke, 2006). Among other strengths, thematic analysis is a flexible approach to qualitative coding that is relatively easy to learn and apply, allows for the key features of large sets to be summarized, and is able to highlight data similarities and differences (Braun & Clarke, 2006). Notably, this is also a coding methodology that is accessible to researchers with minimal qualitative research experience.

Qualitative data were interpreted by a clinical psychology doctoral student, and reviewed by a licensed clinical psychologist, guided by Braun and Clark's (2006) breakdown of the "Phases of Thematic Analysis" and the "15-Point Checklist of Criteria for Good Thematic

Analysis.” The first step, transcription, had the writer accurately transcribe data from the paper questionnaires and become familiar with the data. Coding was the second step in the process. As responses were typically single words, synonymous words and concepts were amalgamated to generate distinct initial codes. This allowed us to compare the frequency of codes from pre to post. The next step was searching for themes; comprehensively collating codes and translating groups of codes into themes accomplished this. With the preliminary themes, step four focused on reviewing the themes and ensuring preliminary themes were well grounded in codes and raw data. Step five focused on analysis. This included ensuring that the themes made sense and creating a clear story about the data, finalizing the themes, and naming the themes. The final step in thematic analysis focuses on producing the written report. At this step, the data is considered in light of the research questions and broader literature in the field.

As an additional analytic tool, Wordles were created to provide visual representations of changes in code frequency for each question (needs, emotions, and life needs). Wordles are visual representations of words within a body of text with increased font size used to demonstrate increased word frequency (McNaught & Lam, 2010). They are created using an online platform, wherein responses are pasted into the designated section and automatically generated. Specifics of the “word clouds” such as layout, font, and colour can be individualized.

Wordles can be considered “communicative artifacts” in that they allow the user to create an image that is meaningful, represents the text, and to communicate same to the user (Feinberg, 2010). Notably, Wordles were created for pleasure in that fonts were designed to be aesthetically pleasing (rather than primarily legible) and colour is used with whimsy rather than strict purpose (Feinberg, 2010). Given the basic structure of Wordles, a longer word (e.g.

Information) that appears the same number of times as a shorter word (e.g. Data) may appear more prevalent, simply by taking up more space (Feinberg, 2010).

Wordles are recognized as a valuable tool for preliminary analysis of data in that they highlight key differences and points of interest, but also as a validation tool to support and confirm findings from other analytic tools (McNaught & Lam, 2010). Wordles can be used to examine content, for basic comparative analysis, and in iterative design in that it can be used to compare word clouds over time (Tang, 2014). As with any analytic technique, it is important to consider the suitability of the data and to ensure conclusions are not overdrawn.

### **Hypothesis three.**

Hypothesis three states that the qualitatively reported main needs, life issues, and emotions of AYAO patients reported pre-film would partially differ from those reported after the film intervention. This hypothesis was examined in several ways:

1) We compared the frequency of codes pre-film, and post-film for the questions of main emotions, main life issues, and main needs of AYAO patients, respectively.

2) Wordles were created to provide visual representations of changes in code frequency for each question (needs, emotions, and life needs).

3) We compared differences in themes pre-film, and post-film for the questions of main emotions, main life issues, and main needs of AYAO patients, respectively.

## **Results**

### **Characterizing the Sample**

Eighty-one healthcare professionals viewed the film and completed the pre-post questionnaires. Participants included 48 medical staff (physicians, nurse practitioners, nurses), 10

psychosocial care staff (psychology, social work, spiritual care), and 23 who identified as students. Questionnaires were numbered with a total of 110 distributed. Sixteen questionnaires were not returned. Six questionnaires were removed as participants indicated they work in disciplines without direct patient contact (e.g., administration), and an additional seven questionnaires were not included due to missing data. As such, the participation rate was calculated to be 74%. Respondents included 70 females (86.4%). Average age of respondent at survey completion was 37.5 years. Respondents reported an average of 10.5 years as a healthcare professional, with 6.7 of those in oncology. A chi-square test was performed and no relationship was found between sex and group,  $\chi^2(2, N = 81) = .159, p = .925$ .

Similarities and differences across groups were examined using one-way analyses of variance with post-hoc comparisons using Tukey HSD test. As compared to both the medicine and psychosocial groups, the student group was younger, had fewer years of experience, less oncology experience, and spent less time with AYA's (see Table 1). Pearson product-moment correlations were used to examine the relationship between experience and the ability to discuss AYA topics (see Table 2). Whereas increased experience was associated with the increased self-reported ability to discuss treatment issues, side effects, and fertility issues, self-reported ability to discuss psychosocial concerns was only positively associated with increased time spent with AYA patients.

Of the respondents, 79.0% (n = 64) indicated their practice would change as a result of viewing the film, whereas 13.6% (n = 11) selected they were unsure. Finally, 7.4% of respondents (n = 6) stated their practice would not change. A review of qualitative responses for these individuals showed that one provided no explanation; one indicated they were not working



with patients; and four felt that they were already understanding and meeting the needs of their AYA patients.

Table 1

*Group Characteristics Compared Using One-Way Analysis Of Variance*

	Total Sample <i>M (SD)</i> <i>N = 81</i>	Medicine <i>M (SD)</i> <i>N = 48</i>	Psycho-social Care <i>M (SD)</i> <i>N = 10</i>	Students <i>M (SD)</i> <i>N = 23</i>	<i>df</i>	<i>F</i> <sup>1</sup>	<i>p</i>
Age	37.52 (13.11)	41.90 (12.75)	44.90 (9.21)	25.17 (4.13)	2, 23.40	47.91	<.001
Years as a healthcare professional	10.47 (10.90)	14.85 (11.80)	9.40 (4.95)	1.78 (1.74)	2, 22.15	36.67	<.001
Years in the oncology field	6.66 (8.06)	10.09 (8.68)	5.15 (3.13)	.15 (.43)	2, 20.45	42.34	<.001
Percentage of time spent with young adults	17.60 (19.89)	21.72 (17.92)	30.30 (30.33)	3.48 (7.60)	2, 21.86	20.00	<.001
Treatment decisions	2.94 (1.26)	3.38 (1.10)	3.50 (1.19)	1.78 (0.80)	2, 23.63	25.85	<.001
Management of side effects	3.27 (1.38)	3.92 (1.11)	3.00 (1.05)	2.04 (1.15)	2, 24.10	21.05	<.001
Fertility issues	2.50 (1.25)	2.60 (1.18)	3.80 (0.79)	1.70 (0.97)	2, 27.95	20.95	<.001
Psychosocial concerns	3.10	3.27	4.40	2.17	2,	21.41	<.001

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(1.30) (1.11) (0.70) (1.23) 28.86

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Levene’s test of homogeneity of variances was significant for all ANOVA’s, therefore Welch’s statistic was reported.

Table 2

*Pearson Product Moment Correlations Examining the Relationship between Experience and the Ability to Discuss AYAO Topics, n = 81*

	Number of years as a healthcare professional	Number of years in oncology	Percentage of time spent with young adults
Ability to discuss:			
Treatment decisions	.308**	.364**	.502**
Management of side effects	.393**	.447**	.397**
Fertility issues	.261*	.261*	.231*
Psychosocial concerns	.104	.181	.377**

**Hypothesis one and two.**

Hypothesis one and two were tested concurrently: independently modelled repeated measures mixed-design analyses of variance were used to explore the impact of the film intervention on self-reported knowledge variables (model 1: life issues, model 2: needs, and model 3: emotions) pre and post-film while also looking at the impact of group (medical, psychosocial, and student) for each of the variables.

*Model 1:*

A repeated measures mixed-design ANOVA was conducted to assess the impact of the group (medical, psychosocial, student) on participants’ self-reported understanding of the needs

of AYA O patients, across two time periods (pre-film, post-film). There was a significant interaction between the group type and time, Wilks Lambda = .922,  $F(2, 78) = 3.291$ ,  $p = .042$ , partial eta squared = .078. There was also a significant main effect for time, Wilks Lambda = .619,  $F(2, 78) = 47.981$ ,  $p < .001$ , partial eta squared = .381. The main effect comparing groups was also significant,  $F(2, 78) = 9.541$ ,  $p < .001$ , partial eta squared = .197, suggesting a difference in understanding by group at both time points. Based on estimated marginal means with a Bonferroni adjustment for multiple corrections, at time one the student group scored significantly lower than both the medicine (mean difference =  $-.792$ ,  $SE = .248$ ,  $p = .006$ ) and supportive care (mean difference =  $-1.600$ ,  $SE = .370$ ,  $p < .001$ ) groups. At time two, only the significant difference between the student and psychosocial group remained (mean difference =  $-.839$ ,  $SE = .294$ ,  $p = .017$ ). The significant main effect for time was then examined. Again based on estimated marginal means with a Bonferroni adjustment for multiple corrections, there was a significant increase in self-reported understanding of needs from pre to post-film for the medicine group (mean difference =  $.771$ ,  $SE = .130$ ,  $p < .001$ ) and the student group (mean difference =  $1.261$ ,  $SE = .188$ ,  $p < .001$ ) but not for the psychosocial group (see Figure 1).

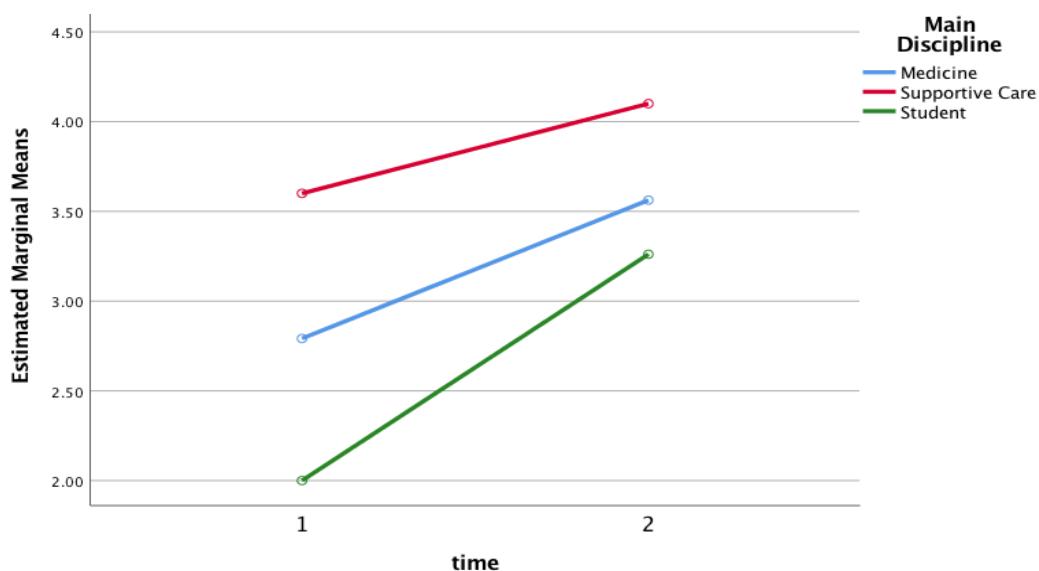


Figure 1. Understanding of needs plotted by main discipline.

*Model 2:*

The impact of the group on participants' self-reported understanding of the emotional experience of AYA patients, across two time periods, was assessed using a repeated measures mixed-design ANOVA. There was a significant interaction between the group type and time, Wilks Lambda = .887,  $F(2, 78) = 4.954$ ,  $p = .009$ , partial eta squared = .113, and a significant main effect for time Wilks Lambda = .685,  $F(1, 78) = 35.813$ ,  $p < .001$ , partial eta squared = .315. Based on estimated marginal means with a Bonferroni adjustment for multiple corrections, there was a significant increase in self-reported understanding of emotional issues from pre to post-film for the medicine group (mean difference = .875,  $SE = .125$ ,  $p < .001$ ) and the student group (mean difference = 1.130,  $SE = .181$ ,  $p < .001$ ) but not for the psychosocial group. The main effect comparing groups was also significant,  $F(2, 78) = 12.273$ ,  $p = .009$ , partial eta squared = .114, meaning there was a difference in understanding by group at both time points. Estimated marginal means with a Bonferroni adjustment for multiple corrections was applied to examine group differences. At time one, the supportive care group reported significantly higher understanding than the medicine (mean difference = 1.071,  $SE = .353$ ,  $p = .001$ ) and student groups (mean difference = 1.452,  $SE = .384$ ,  $p = .001$ ) groups. There were no significant differences at time two (See Figure 2).

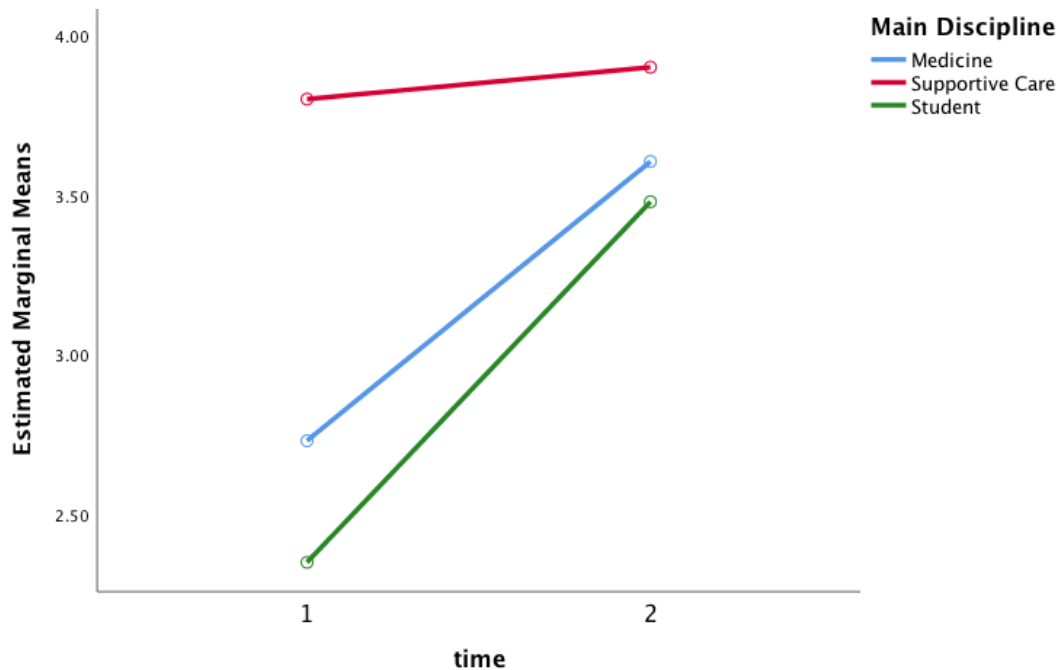


Figure 2. Understanding of emotions plotted by main discipline.

*Model 3:*

The final repeated measures mixed-design analyses of variance explored the impact of the film intervention on self-reported knowledge of life issues pre and post-film while also looking at the impact of the group. There was a significant interaction between the group type and time, Wilks Lambda = .919,  $F(2, 78) = 3.446$ ,  $p = .037$ , partial eta squared = .081, and a significant main effect for time Wilks Lambda = .679,  $F(1, 78) = 36.855$ ,  $p < .001$ , partial eta squared = .321. Based on estimated marginal means with a Bonferroni adjustment for multiple corrections, there was a significant increase in self-reported understanding of life issues from pre to post-film for the medicine group (mean difference = .875,  $SE = .124$ ,  $p < .001$ ) and the student group (mean difference = 1.043,  $SE = .180$ ,  $p < .001$ ) but not for the psychosocial group. The main effect comparing groups was also significant,  $F(2, 78) = 7.574$ ,  $p = .003$ , partial eta squared = .137, meaning there was a difference in understanding by group at both time points. Estimated marginal means with a Bonferroni adjustment for multiple corrections was applied to

examine group differences. At time one, the supportive care group reported significantly higher understanding than the medicine (mean difference = .871,  $SE = .350$ ,  $p = .045$ ) and student (mean difference = 1.426,  $SE = .382$ ,  $p = .001$ ) groups. There were no significant differences at time two (see Figure 3).

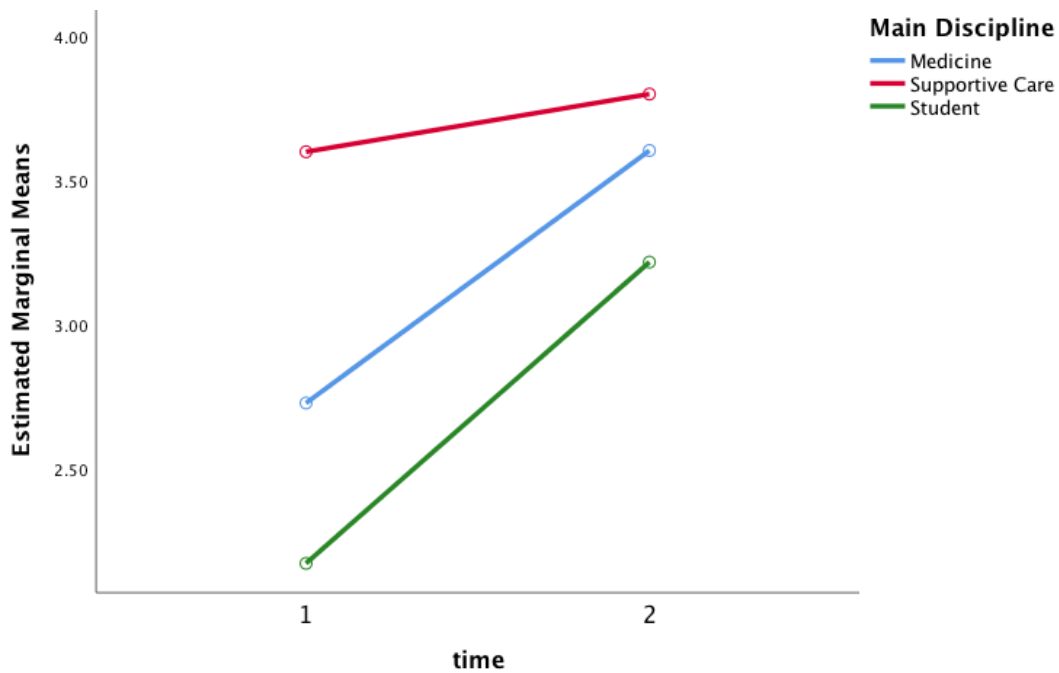


Figure 3. Understanding of life issues plotted by discipline.

**Qualitative analyses**

**Hypothesis three.**

Hypothesis three states that the qualitatively reported main needs, life issues, and emotions of AYA0 patients reported pre-film would partially differ from those reported after the film intervention. To examine this exploratory hypothesis, we first compared the frequency of codes pre-film, and post-film for the questions of main emotions, main life issues, and main needs of AYA0 patients, respectively.

The top five prevalent codes for the main emotions, needs, and life issues of young adult cancer patients (from the viewers’ perspective) are presented below (see Table 4). Notably, fear was the most prevalent emotion listed before viewing the film (67.9%), however, after viewing the film isolation ranked first (63.0%). Support was reported as the most prevalent need both before and after viewing the film (69.1% and 84.0%, respectively). Finally, both pre and post film, interpersonal difficulties was rated the most prevalent life issue by healthcare professionals (40.7% and 62.4%).

Table 4

*Top 5 Reported Needs, Emotions, and Life Issues of AYA Patients and Survivors, As Reported By Healthcare Professions*

	Emotions: <i>n</i> (%)	Needs: <i>n</i> (%)	Life Issues: <i>n</i> (%)
Pre-film	Fear: 55 (67.9%)	Support: 56 (69.1%)	Interpersonal difficulties: 33 (40.7%)
	Anger: 37 (45.7%)	Information: 27 (33.3%)	Fertility problems: 29 (35.8%)
	Depression: 23 (28.4%)	Compassion: 16 (19.8%)	Employment: 21 (25.9%)
	Confusion: 24 (29.6%)	Social Network: 15 (18.5%)	Treatment: 14 (17.3%)
	Isolation: 18 (22.2%)	Counselling: 10 (12.3%)	Image: 12 (14.8%)
Post-film	Isolation: 51 (63.0%)	Support: 68 (84.0%)	Interpersonal difficulties: 52 (64.2%)
	Fear: 50 (61.7%)	Social Network: 29 (35.8%)	Loss of identity: 37 (45.7%)

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Anger: 40 (49.4%)	Information: 15 (18.5%)	Isolation: 30 (37.0%)
Depression: 32 (39.5%)	Hope 9 (11.1%)	Employment: 10 (12.3%)
Confusion: 14 (17.3%)	Feeling Heard 9 (11.1%)	Moving forward: 9 (11.1%)

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Wordles were then created represent and contrast pre-post qualitative codes for emotions (see Figures 4 and 5), needs (see Figures 6 and 7), and life issues (see Figures 8 and 9). In regard to emotions, ‘fear,’ ‘anger,’ ‘depression,’ ‘confusion,’ ‘hopelessness,’ ‘isolation’ and anxiety stood out pre-film, with additional responses reported a minority of times. The wordle changed substantially post-film, with ‘isolation’ clearly dominating the image, followed by ‘fear,’ ‘depression,’ and ‘anger.’ It was evident that a greater number of codes were endorsed pre-film, whereas post-film the majority of respondents focused on four common emotions.

In regard to the main needs of young adult cancer patients, at both pre and post ‘support’ was the most prevalent code, though it increased in prevalence at the post. Pre-film, ‘information,’ ‘compassion’ and ‘social network’ were also moderately reported. Post-film, however, the need for a ‘social network’ had increased significantly in prevalence, and ‘information’ had decreased.

The greatest variety of codes was evident in response to the final question, “what are the 3 main life needs of young adult cancer patients.” Prior to viewing the film, ‘interpersonal difficulties,’ ‘fertility problems,’ ‘employment,’ and to a lesser degree ‘treatment’ were the most prevalent codes. Post-film, we see a greater variety of codes endorsed to a lesser degree. Although ‘interpersonal difficulties’ was still the most prevalent response, it was followed by ‘loss of identity,’ ‘isolation’ and a variety of low to moderately endorsed codes. As such, it



appears that whereas responses were more restricted pre-film, post-film there was a greater awareness and reporting of a broader variety of life issues.

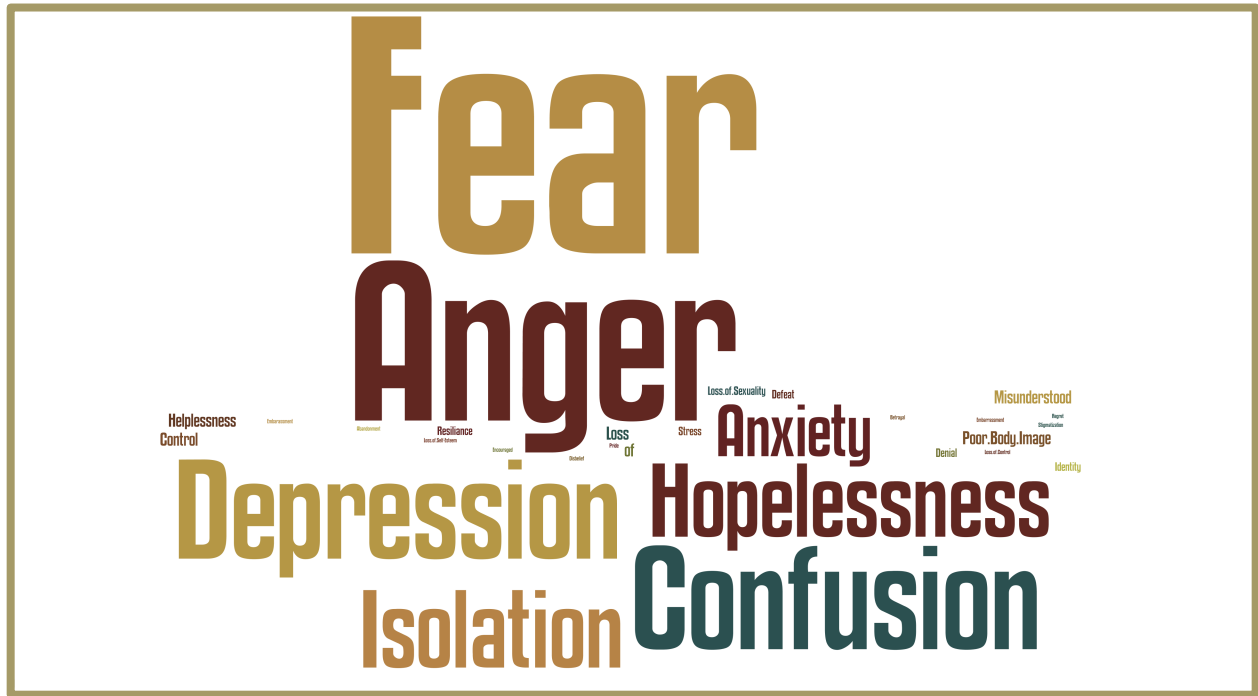


Figure 4. “Wordle” depiction of AYA O emotions reported by healthcare practitioners pre-film.



Figure 5. “Wordle” depiction of AYA O emotions reported by healthcare practitioners post-film.



Figure 6. “Wordle” depiction of AYA needs reported by healthcare practitioners pre-film.



Figure 7. “Wordle” depiction of AYA needs reported by healthcare practitioners post-film.

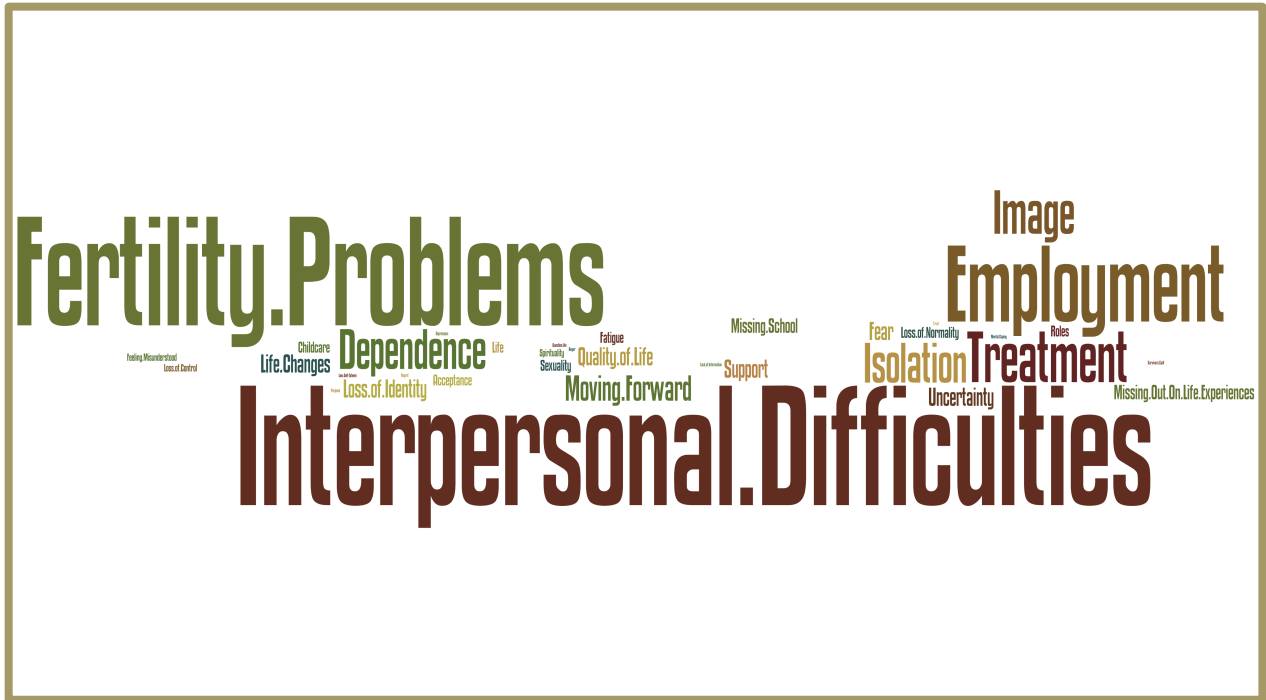


Figure 8. “Wordle” depiction of AYA life issues reported by healthcare practitioners pre-film.

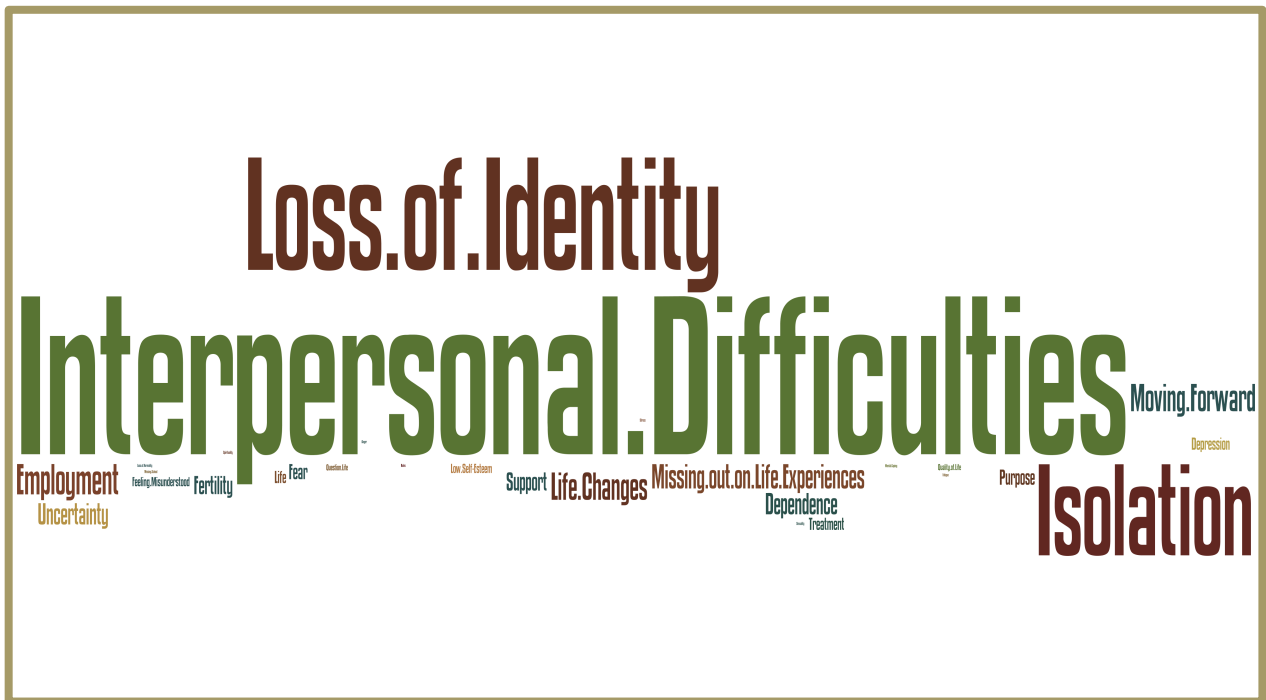


Figure 9. “Wordle” depiction of AYA life issues reported by healthcare practitioners post-film.

Finally, we compared differences in themes pre-film, and post-film for the questions of main emotions (see Table 5), main needs (see Table 6), and main life issues (see Table 7) of AYA/O patients, respectively. Theoretically, if all 81 participants provided 3 individual responses for each question pre and post, we would expect 243 responses pre and post for emotions, needs, and life issues respectively. However, actual totals range from 189 to 232. There are two reasons for this. Firstly, some respondents provided fewer than three responses for each question pre and post. Secondly, in the event that the respondent provided highly synonymous answers, such as fear and afraid listed as emotions, it was counted only once.

Prevalence of codes changed from pre- to post-film, but themes remained relatively stable. As such, the themes provided are valid for both pre- and post-film responses. Emotions were categorized under the headings of loss, positive emotions, interpersonal emotions, forceful/externalizing negative emotions, passive/internal negative emotions, and anxiety and fear related negative emotions. There was an increase in endorsement of the ‘interpersonal emotions’ category, and decrease in the ‘anxiety’ and ‘fear’ related negative emotions category from pre to post. Needs were categorized under the headings of ‘support from others,’ ‘treatment-related issues,’ ‘future orientation,’ and ‘self-concept.’ From pre- to post-film, there was increased endorsement of the ‘support from others’ category and ‘self-concept’ category, as well as a slight decrease in the ‘future orientation’ category. Life issues were categorized as ‘emotional/existential,’ ‘relationship issues,’ ‘changes/issues in daily life,’ and ‘treatment-related issues.’ There were notable pre-post changes for each category; increased prevalence for the ‘emotional/existential’ and ‘relationship issues’ categories, decreased prevalence for the ‘changes/issues in daily life’ and ‘treatment-related issues’ themes.

Table 5

*Thematic Organization of Emotions Codes*

Themes		Codes	Prevalence	
			Pre-film <i>n</i> = 222	Post-film <i>n</i> = 232
Emotions	Loss	Loss of control, loss of identity, loss of sexuality, loss of self-esteem, loss of body image confidence	12 (5.4%)	11 (4.7%)
	Positive emotions	Gratitude, hope, encouraged/motivated, pride, courage, strength, resilience/determination	4 (1.8%)	3 (1.3%)
	Negative emotions, forceful/externalizing	Anger, frustration, resentment, bitterness	38 (17.1%)	42 (18.1%)
	Negative emotions, internal passive	Depression/sadness, despair, sorrow, helplessness, hopelessness, disappointment, feelings of inadequacy	49 (22.1%)	49 (21.1%)
	Negative	Fear, scared/afraid, anxiety, worry,	94	66

emotions, internal fear / anxiety related	concern, stress, vulnerability	(42.3%)	(28.4%)
Interpersonal emotions	Feeling misunderstood, stigmatization, ostracized, abandonment, missing out, relationship challenges, isolation	25 (11.3%)	61 (26.3%)

Table 6

*Thematic Organization of Needs Codes*

	Themes	Codes	Prevalence	
			Pre-film <i>n</i> = 189	Post-film <i>n</i> = 206
Needs	Support from other	Support from peers/physician/other cancer patients/family, love, social network, relationships, bonding, understanding/non-judgmental acknowledgement of their situation, compassion, empathy, emotional support, encouragement, belonging, feeling heard/being listened to, candid	97 (51.3%)	120 (58.3%)

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	discussion, comfort		
Treatment- related issues	Trust in healthcare team, information/knowledge, education, treatment options, health care, medication, pain control, changes in physical appearance, well-being/good health, dealing with side-effects, interventions, changes in sexuality	52 (27.5%)	36 (17.5%)
Moving ahead / Future orientation	Counselling/grief work/therapy/psychosocial support, guidance, opportunities to take risks, financial resources/employment/career, sense of normalcy, independence, maintaining dignity, purpose, time, space, goal adjustment, moving forward, separate living from cancer	23 (12.2%)	23 (11.2%)
Internal / Self-concept	Self-acceptance, self-awareness, hope/optimism/positive outlook, identity, coping mechanism, control, presence, strength, will to fight, courage, being able to express oneself,	17 (9.0%)	27 (13.1%)

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spirituality

Table 7

*Thematic Organization of Life Issues Codes*

	Themes	Codes	Prevalence	
			Pre-film <i>n</i> = 214	Post-film <i>n</i> = 222
Life Issues	Emotional/ Existential	Feeling misunderstood, loss of control, loss of identity, sense of self, depression, defeat, believing in hope, fear of death, recurrence, mortality/end of life, uncertainty, loss of direction, isolation, loneliness, regret, anger/frustration, low self- esteem, spirituality, finding a sense of purpose, mental coping, survivor guilt, trust, stress, questioning life/purpose of life,	41 (19.2%)	100 (45.0%)
	Relationship Issues	Interpersonal difficulties, loss of friends, family relationships, dependence, loss of independence,	58 (27.1%)	76 (34.2%)



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	being a burden to others, acceptance, support, roles		
Changes / Issues in Daily Life	Missing school/education, missing out on life experiences, feeling left behind, employment, financial issues, career, moving forward, picking up again/moving on, sense of future, childcare, loss of normalcy, life changes – transitioning/adjusting/putting life on hold, staying motivated	50 (23.4%)	39 (17.6%)
Treatment- related issues	Fertility problems, body image, lack of information, dealing with treatment/side effects/sickness, surviving, fatigue/loss of strength, sexuality, quality of life, living, shortening of lifespan	65 (30.4%)	7 (3.2%)

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The final research goal was to assess whether respondents believed they had learned something from watching the WW2H documentary film. Across the total sample, 96.3% ( $n = 78$ ) said they had gained new knowledge of the AYA cancer experience. These numbers varied slightly by group (see Table 8).

Table 8

*Increase in AYA knowledge*

Did you learn anything about AYAs with cancer that you did not know before watching the film?	Total Sample <i>n</i> = 81	Medical Staff <i>n</i> = 48	Psycho-social Care Staff <i>n</i> = 10	Students <i>n</i> = 23
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
Yes	78 (96.3%)	46 (95.8%)	9 (90.0%)	23 (100%)
No	3 (3.7%)	2 (4.2%)	1 (10.0%)	-

**Discussion**

The goal of this film intervention was not to provide in-depth training to healthcare professionals. Rather, a critical first step is for healthcare providers to be aware of AYA’s as a distinct population, and to have general knowledge and awareness of unique AYA needs. This research supports that many healthcare professionals feel ill-equipped to address the key issues faced by young adults. However, a brief film intervention can be an effective way of increasing short-term self-reported understanding.

Before viewing the film, the groups reported differences in self-reported ability to discuss key topics with AYAs. The medical group scored themselves highest on the ability to discuss treatment decisions and management of side effects. However the psychosocial group had the

greatest confidence in their ability to discuss both psychosocial concerns and fertility issues. The latter is surprising, in that fertility is predominantly a medical issue. However, lack of discussion about fertility and fertility preservation is a critical and ongoing issue with one medical chart review finding that documented discussions of fertility risk, fertility preservation and referral to a fertility specialist occurred in 26%, 24%, and 13% of cases respectively (Quinn et al., 2009). Although the need to discuss fertility considerations with AYAs is clearly advocated (D'Agostino, Penney, & Zebrack, 2011; Wallace, 2011), comfort doing so on the part of medical staff may be lacking.

Groups had different levels of understanding of the emotions, needs, and life issues toward pre-film, which impacted post-film responses. Specifically, the student group reported the lowest level of pre-film understanding for emotions, needs, and life issues, whereas the psychosocial group reported the highest. From pre-film to post-film, the medicine and student groups reported significant increases in knowledge. Simply put, the psychosocial group feels like they “get it” even before the film, whereas the medical and student groups reported positive change in knowledge. However, 96% of respondents stated that they gained new knowledge as a result of watching the film. The adage “if you don’t know that you don’t know, you think you know” may hold true here. The WW2H film provided an easily viewed presentation of some potentially new information that was readily digested and resulted in viewers reporting, “I didn’t know, and now I know.”

The qualitative element to this research was largely exploratory. However results support a moderate shift in the perceived emotional experience, needs, and life issues of AYA patients reported from pre-film to post-film. Notably, from pre- to post-film, isolation was recognized as a primary emotion, support and the need for a social network both increased in prominence as

key needs, and the life issues of interpersonal difficulties and loss of identity increased in prevalence. When considered in the broader context of the qualitative results it is evident that viewing the film had a notable impact on the understanding of the AYA cancer experience. However, we don't know to what degree, if at all, reported concepts are consistent with what young adults with cancer report as their main emotions, needs, and life issues.

There were notable strengths and limitations to the research. Data collection across multiple sites resulted in a respectable sample size, and the mixed quantitative-qualitative methodology was a significant strength given the novel and exploratory nature of the research. The strength of the research could have been improved by implementing a long-term follow-up to assess change in perceptions over time, as well as a control group for comparison. Although valuable next steps, this was not viable for the current project. A further limitation of the research was the unequal and group sizes. However, this may also reflect the nature of attendance at such hospital events. Psychosocial care teams are typically much smaller than medical teams, and at many hospitals, may only consist of one or two people. From a statistical viewpoint, with a larger group size it would be important to assess experience, including overall experience, time in oncology, and experience with AYAs in particular, as potential confounding variables. Given the interdisciplinary nature of oncology care, it is possible that experience is more important to assess than discipline. Secondly, although the Bonferroni adjustment for multiple corrections was applied, it can be argued that the scope of analysis is not supported by the sample size. Moving ahead, a larger sample size would alleviate these concerns. Finally, the results suggest that the questions assessing main needs, emotions, and life issues have yielded very similar results, and may not be independent. There would be value to either 1) re-wording

the questions to ensure they query distinct concepts; or 2) combining the questions into a single factor of “knowledge”.

### **Future research**

As our preliminary findings support the benefits of an AYA documentary film as a teaching tool, several next steps are recommended. Firstly, it would be beneficial to more broadly solicit both positive and negative feedback and commentary on the film. A more open-ended line of questioning might allow for disclosure of positive and negative feedback that was not present in the original research, and could help to guide further research and film initiatives. Secondly, a follow-up at six months post would allow the sustainability of information and concepts to be assessed. We also suggest assessing the extent to which young adults themselves report emotions, needs, and life issues in line with those reported by healthcare professionals. Finally, the strength of the pre-post research could be improved by implementing an e-learning pilot project, using the Solomon four-group design pre-post research methodology. Specifically, as a component of e-learning and ongoing training, recruit healthcare professionals to view the film online. Participants would then be randomized into one of four groups: 1) pre-test, treatment, post-test; 2) pretest, post-test; 3) treatment, post-test; and 4) post-test only. This is a complex design, but it results in improved statistical power, and greater internal and external validity (Lavrakas, 2008).

Notably, this is but one film, and the author fully understands that little can be said about a one-time exposure to some potentially new information as being key and essential to making lasting change. In fact, we do not have a measure of lasting change. However, a patient’s story or a collection of patients’ stories can be a powerful thing when presented in an easily digested fashion. This is also consistent with preliminary research identifying the value of film as a

teaching tool in healthcare (Alexander, Pavlov, & Lenahan, 2007; Pescosolido, 1990; Volandes, 2007).

It is concluded that films portraying a patient perspective may offer a valuable and much-needed insight into the psychosocial implications of cancer for young adults, providing a valuable point of reference in clinical care. Given an ever-increasing budget-conscious healthcare system, and the limited time of healthcare professionals, offering brief films may present a feasible, low-cost approach to providing introductory information. This type of learning activity could be readily added to existing staff-education modules, to be viewed by staff as a personal development exercise when their schedule permits.

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**List of Appendices**

## *Appendix A: Information Letter*



### **Study Title** Cancer in Young Adulthood:

How is the Experience Perceived by Healthcare Providers?

Welcome to the screening of “*The Wrong Way to Hope: An Inspiring Story about Young Adults and Cancer*,” also known as *WW2H*.

We invite you to participate in a brief research study to help us assess the beliefs of healthcare providers regarding cancer in young adulthood, and the potential impact of the film on these perceptions.

#### **What participating in the research means:**

- You will be asked to complete a questionnaire twice, once immediately before and once immediately after the film. Each questionnaire will take 2-4 minutes to complete.
- The questionnaires ask about your perceptions of the young adult cancer experience and your comfort with this topic.
- This research is being administered at all WW2H screening sites between September 2011 and September 2012.

#### **Information about participating in the research:**

- Please do not write your name on the questionnaires. All information collected will be kept free of any identifying information, and you will, therefore, remain anonymous in any publications or presentations of research findings.
- You can choose not to participate by leaving the forms blank, or not returning the forms.
- You can choose not to participate in the research and still enjoy the WW2H film.
- To withdraw from the research, simply do not complete the questionnaires forms or do not return them. As you are not writing your name on the questionnaires, you will not be able to withdraw from the research after it is submitted.

#### **Information about the research:**

- There are no immediate benefits to participating. However the information collected will help us evaluate the impact of the WW2H film and the perceptions of health professionals in the field.
  - This research is being conducted by Liane Kandler, graduate student at Lakehead University, under the supervision of Dr. Scott Sellick, Director of Supportive and
-

Palliative Care at the Thunder Bay Regional Health Sciences Centre. These individuals, as well as a student researcher, are the only individuals who will have access to the research data.

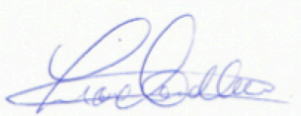
- This project was reviewed by, and received ethics clearance through, the Office of Research Ethics at Lakehead University and the Thunder Bay Regional Health Sciences Centre Research Ethics Board.

#### Contact information

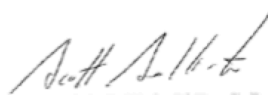
- If you have questions about the research, would like to withdraw from the research, or would like the results from the research study when they are available, please contact Liane Kandler in Thunder Bay, Ontario, Canada, at the Supportive Care Program at 807-684-7310 ([kandlerl@tbh.net](mailto:kandlerl@tbh.net)).
- If you have any concerns regarding your rights as a research participant, or wish to speak to someone other than a research team member about this research project, you are welcome to contact:
  - Office of Research  
Lakehead University  
955 Oliver Road  
Thunder Bay, ON P7B 5E1  
Tel.: (807) 343-8283  
Fax: (807) 346-7749
- All research data will be kept for 10 years, as is required by the research ethics review process.

Thank you for taking the time to consider this research. Please do not hesitate to contact me, Liane Kandler, or my supervisor, Dr. Scott Sellick, if you have any further questions. We can be reached by calling 1-807-684-7310 or toll-free at (877) 696-7223.

Sincerely,



Liane S. Kandler, M.A.  
Graduate Student Researcher  
Supportive Care, TBRHSC  
Tel: 807.684.7310  
E-mail: [kandlerl@tbh.net](mailto:kandlerl@tbh.net)



Scott Sellick, PhD., C. Psych  
Director, Supportive Care  
Supportive Care, TBRHSC  
Tel: 807.684.7305  
E-mail: [sellicks@tbh.net](mailto:sellicks@tbh.net)

*Appendix B: Pre-Questionnaire*

**Wrong Way to Hope**

**Please complete the questions below – To keep the information anonymous, do not write your name on these sheets. Thank you for your help!**

**Questions about your discipline:**

1. What is your discipline?

Medicine:

- Physician
- Nurse Practitioner
- Nurse
- Other: \_\_\_\_\_

Supportive Care:

- Psychology
- Social Work
- Spiritual Care
- Other: \_\_\_\_\_

Administration:

- Administrative Employee
- Other: \_\_\_\_\_

Other:

- Student \_\_\_\_\_
- Other: \_\_\_\_\_

2. Do you work mainly in the oncology field?

- Yes
- No  
If No, in what field?  
\_\_\_\_\_

3. How many years have you been working as a healthcare professional?  
\_\_\_\_\_

4. How many of these years were spent primarily working in the oncology field?  
\_\_\_\_\_

5. While working in the oncology field, approximately what percentage of your time was spent working with young adults (18-44 years)?  
\_\_\_\_\_

(0-100%)

**Questions about you:**

1. Year of birth?  
\_\_\_\_\_

2. Sex?

- Male
- Female

**Questions about your work experiences:**

Based on your work experience and training received to date, how would you rate your ability to discuss the following topics with young adult cancer patients?

1. Treatment decisions

Poor	Fair	Satisfactory	Good	Excellent
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Management of side effects

Poor	Fair	Satisfactory	Good	Excellent
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Fertility issues

Poor	Fair	Satisfactory	Good	Excellent
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Psychosocial concerns

Poor	Fair	Satisfactory	Good	Excellent
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PID

**Wrong Way to Hope**

**Please complete the questions below – To keep the information anonymous, do not write your name on these sheets. Thank you for your help!**

---

1. What do you believe are the three main emotions young adults feel throughout their cancer experience?
  - a. \_\_\_\_\_
  - b. \_\_\_\_\_
  - c. \_\_\_\_\_
  
2. What do you believe are the top three life issues that young adults deal with throughout their cancer experience?
  - a. \_\_\_\_\_
  - b. \_\_\_\_\_
  - c. \_\_\_\_\_
  
3. What do you believe are the top three needs of a young adult throughout his or her cancer experience?
  - a. \_\_\_\_\_
  - b. \_\_\_\_\_
  - c. \_\_\_\_\_

Please select the option that best describes what you believe your understanding to be:

	Poor	Fair	Satisfactory	Good	Excellent
1. My understanding of the <b>emotional experience</b> of being diagnosed with cancer in young adulthood is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My understanding of the <b>life issues</b> that face young adults with cancer is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My understanding of the <b>needs</b> of young adults with cancer is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for your participation! Please enjoy the film, and complete the second short questionnaire after the viewing.**

PID



*Appendix C: Post-Questionnaire*

**PART 2:**

To be completed after viewing the film -  
please do not open until after!

**Wrong Way to Hope**

Please complete the questions below – To keep the information anonymous, do not write your name on these sheets. Thank you for your help!

1. What do you believe are the three main emotions young adults (18-44 years) feel throughout their cancer experience?

a. \_\_\_\_\_

b. \_\_\_\_\_

c. \_\_\_\_\_

2. What do you believe are the top three life issues that young adults deal with throughout their cancer experience?

a. \_\_\_\_\_

b. \_\_\_\_\_

c. \_\_\_\_\_

3. What do you believe are the top three needs of a young adult throughout his or her cancer experience?

a. \_\_\_\_\_

b. \_\_\_\_\_

c. \_\_\_\_\_

Please select the option that best describes what you believe your understanding to be:

	Poor	Fair	Satisfactory	Good	Excellent
1. My understanding of the <b>emotional experience</b> of being diagnosed with cancer in young adulthood is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My understanding of the <b>life issues</b> that face young adults with cancer is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My understanding of the <b>needs</b> of young adults with cancer is...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PID

**Wrong Way to Hope**

**Please complete the questions below – To keep the information anonymous, do not write your name on these sheets. Thank you for your help!**

---

1. Did you learn anything about young adults with cancer that you did not know before watching the film?

- Yes (please identify what you learned below)
- No (please identify why not in the space below)

- a. \_\_\_\_\_
- b. \_\_\_\_\_
- c. \_\_\_\_\_

2. Do you believe your practice will change as a result of having watched this film?

- Yes
- No
- Unsure

Please elaborate:

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**Thank you for taking the time to complete these questions! We appreciate your participation. If you have any questions or comments, be it about the questionnaire or the film, please do not hesitate to contact us.**

PID
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ARTICLE 2:  
PREDICTORS OF WELL-BEING IN ADOLESCENT AND YOUNG ADULT CANCER  
PATIENTS

Liane S. Kandler

Lakehead University

### **Abstract**

Personality, positive and negative affects, and cancer coping in adolescent and young adult (AYA) cancer patients was assessed, as a way of comprehensively understanding predictors of well-being/distress and social support. A total of 128 AYAs were recruited online and completed the online questionnaire. Demographics, basic medical history, and use of psychosocial characteristics were measured to characterize the sample. Personality (neuroticism, extraversion), affects (positive affect, negative affect, satisfaction with life), cancer coping (impact of diagnosis, adjustment to cancer, illness centrality) and well-being/distress outcomes (anxiety, depression, spiritual well-being, positive change, and negative change) were queried. Maximum likelihood factor analysis yielded a two-factor solution of subjective well-being (positive affect and negative affect) and a two-factor solution for cancer coping (positive and negative coping style). Personality, positive and negative affect, and positive and negative cancer coping styles were all significant predictors of distress. However, significant predictors of social support included only neuroticism and positive cancer coping style. This research provides preliminary support for the importance of considering personality and positive and negative affect in oncology research, as a way of guiding person-centered psychosocial care and support. Further longitudinal research is warranted to examine positive and negative pathways to well-being and social support.

## Introduction

The purpose of this research was to assess positive and negative dimensions of personality, subjective well-being (SWB) and cancer coping style as they relate to well-being/distress outcomes, as a way of guiding survivorship care in adolescent and young adult (AYA; aged 18-39 years) cancer patients and survivors. Notably, AYAs are diagnosed with a life-changing illness during what is arguably one of the most productive and rapidly-changing life periods. As a function of this, they have been found to be at increased risk for psychosocial problems and life disruptions, including depression and anxiety symptoms, poorer quality of life, greater life disruptions, poorer body image, poorer sexual functioning, increased financial concerns, and increased physical pain (Blank & Bellizzi, 2006; Hall, Boyes, Bowman, Walsh, James, & Girgis, 2012; Harrison & Maguire, 1995; King, Kenny, Shiell, Hall, & Boyages, 2000; Kroenke et al., 2004; Lang, David, & Giese-Davis, 2015; Lang, Giese-Davis, Patton, & Campbell, 2018; Mor, Allen, & Malin, 1994; Parker, Baile, Moor, & Cohen, 2003; Wenzel et al., 2003). In summary, cancer is a life-altering experience with considerable negative repercussions.

The negative repercussions of a cancer diagnosis are well documented; an interest in understanding potentially positive outcome is increasing. Two recent studies have attempted to examine predictors of well-being and post-traumatic growth in young and middle-aged cancer patients and survivors (Park, Bharadwaj, & Blank, 2011; Park & Blank, 2012). Notably, this research represents an important step forward, in that the authors attempted to assess how multiple known psychosocial factors impact well-being outcomes.

Using a cross-sectional design, Park, Bharadwaj, and Blank (2011) examined illness centrality and cancer openness/disclosure as predictors of 7 facets of well-being, mainly physical and mental health-related quality of life, post-traumatic growth, positive and negative affect,

intrusive thoughts, and satisfaction with life in a sample of 167 participants. Independent regression analyses were conducted for each of the 7 facets of well-being, assessing the predictive value of illness centrality, openness/disclosure, and the interaction term between them. The authors found that whereas increased illness centrality was adversely related to most well-being measures, increased openness/disclosure was positively associated. These findings support the need to continue to examine the relationships between illness centrality and openness/disclosure and facets of well-being. Arguably, this research would also benefit from an understanding of how the variables examined relate to other known factors impacting well-being, including social support and distress.

Park and Blank (2012) used a similar methodology to assess effects of cancer treatment. The authors reflected that cancer survivors frequently report both positive and negative changes in their lives as a result of their cancer experience, and sought to examine how these changes related to six measures of well-being, mainly positive and negative affect, mental and physical health-related quality of life, satisfaction with life, and spiritual well-being. A total of 237 young and middle-aged cancer survivors (zero to four years since diagnosis; mean age 45.3 years) participated in the research. Regression models for each of the six well-being variables were computed, with positive change, negative change, and their interaction term examined as predictors of well-being. Negative change emerged as a consistent predictor of all well-being variables examined, whereas positive change was associated only with positive affect and spiritual well-being. The authors highlight the need for additional research focusing on positive and negative change as a way of understanding the psychosocial impact of cancer.

The research conducted by Park et al. (2011) and Park & Blank (2012) arguably represents the most comprehensive available examination of psychosocial well-being variables in

young and middle-aged adult cancer patients and survivors. However, known factors influencing well-being in oncology patients were lacking from both research studies, including global distress, social support, perceived life stress, and cancer coping (Blank & Bellizzi, 2006; Corey, Haase, Azzous, & Monahan, 2008; Decker et al., 2007; Gil et al., 2004; Saba, 1991). In addition, this research lacks grounding in the broader subjective well-being (SWB) literature.

Although a relatively novel term in the oncology literature, SWB has been extensively researched (Diener, Heintzelman, Kushlev, Tay, Wirtz, & Luter, 2017; Stones, Kozma, McNeil, & Worobetz, 2011). Broadly, SWB is “defined as people’s overall evaluations of their lives and their emotional experiences” (Diener et al., 2017). In other words, our well-being is subjective, in that it is based on how we cognitively evaluate our life, circumstances, emotional experiences. Subjective well-being has been defined as an umbrella term that incorporates positive affect, negative affect, and life satisfaction; these facets of SWB have been shown to be separable in factor analyses and to have distinct relationships with outcome variables (Diener et al., 2017). Although the construct of SWB is generally stable over time and resistant to life changes, significant life changes such as acquired disability may have a long-term impact (Diener et al., 2017). As such, it is reasonable to suggest that the potential long-term medical and psychosocial repercussions of a cancer diagnosis and treatment would have a similar impact on SWB.

Understanding SWB is important, as individuals with higher SWB tend to score higher on positive outcome measures, including improved social relationships, health, and life longevity (Diener et al., 2017). But what causes an individual to report high or low SWB? Genetic models have been found to account for up to 40% of the variability in SWB (Roysamb, Nes, & Vitterso, 2014). Personality traits are thought to have a long-term impact on maintaining stable levels of SWB (Stones et al., 2011), and as such warrant consideration when examining well-being



outcomes. However, genetic and personality research is limited by challenges with delineating the gene-environment interaction; an individual's environment and choices may, in turn, alter genetically inherited traits (Roysamb et al., 2014). In addition, some outcomes of SWB have also been found to be predictors, further complicating our understanding. Consider for example social relationships. Social relationships are thought to not only be a positive outcome associated with high SWB, but also a significant cause of SWB (Diener & Seligman, 2002). Within the oncology literature, social support plays a similar dual role. Social support has been researched as a coping strategy in AYAs (Corey, Haase, Azzouz, & Monahan, 2008; Kyngäs et al., 2001). However, social anxiety, social withdrawal, and lack of connection with or support from peers have also been researched as cancer outcomes (Boyes, Girgis, D'Este, & Zuca, 2011; Donovan, Brown, LeFebvre, Tardif, & Love, 2015; Lie, Larsen & Hauken, 2017). Taken cumulatively, this research evidence supports the need to assess social support in AYAs as it relates to both SWB and well-being outcomes.

Consider now the Circumplex Model of Affect [CMA] (Russell, 1980) and the Well/Ill-Staying/Moving (WISM) model of well-being and ill-being (Røysamb & Nes, 2018) as ways of conceptualizing the concepts of SWB, personality, and cancer coping. The CMA uses a circular, two-dimensional image, wherein valence is represented by the horizontal axis, and arousal is represented by the vertical axis. Valence is conceptualized as a pleasure-displeasure, attraction-aversion continuum, whereas arousal is considered a sense of alertness or energy, such as high to low activation. The CMA suggests that these neurophysiological valence-arousal dimensions classify emotions along the circumplex model, as opposed to distinct emotions having distinct neural pathways. Furthermore, it is posited that the individual, subjective experience of an emotion represents complex interactions between the valence-arousal dimensions (which are

neurophysiological) and cognitions (which are neocortical) (Posner, Russell, & Peterson, 2005). Quadrants can be simply conceptualized as positive-active, positive-passive, negative-passive, and negative-active. Similar to the CMA, the WISM model plots stability-change on the vertical axis and positive-negative on the horizontal. Quadrants are then labeled as well-moving, well-staying, ill-staying, and ill-moving (Røysamb & Nes, 2018). If the models were to overlay one another, the positive-active quadrant of the CMA would match up with the well-moving quadrant of the WISM, the positive-passive with the well-staying, the negative-passive with the ill-staying, and the negative-active with the ill-moving. If we apply these models to categorizing our constructs of personality, SWB, and cancer coping, we would expect neuroticism, negative affect, and negative cancer coping to be represented on the left of the model, with extraversion, positive affect, and positive cancer coping on the right half of the model.

In summary, AYAs who survive a cancer diagnosis and treatment will go on to live perhaps 40, 50, or 60 years, during which time they will attempt to manage the potentially significant after-effects of cancer. Meeting not only their immediate medical needs, but also their complex psychosocial needs, is therefore critical (Canadian Partnership Against Cancer, 2017). How best to provide psychosocial support to these patients has been increasingly studied. However, much of the literature examines a small subset of specific psychosocial variables in relative isolation from broader constructs known to impact well-being/distress, such as personality and satisfaction with life.

It is important to consider the role of SWB and personality when examining coping styles, social support, and outcomes in cancer patients and survivors: People not only react to their circumstances and environments, but also shape them. As such, it is reasonable to suggest that an individual's personality and SWB will impact how they experience their cancer journey.

Social support also warrants careful consideration, in that research supports its dual role as both a predictor of well-being and an outcome itself. Specifically, social support has been examined as an outcome of SWB, as well as a coping strategy and an outcome variable in the oncology literature (Boyes et al., 2011; Corey et al., 2008; Diener & Seligman, 2002; Donovan et al., 2015; Kyngas et al., 2001; Lie et al., 2017). Furthermore, emerging research is now identifying and attempting to understand distinct positive and negative pathways to well-being outcomes (Park, Bharadwaj, & Blank, 2011; Park & Blank, 2012). This is consistent with the SWB literature, which emphasizes the need to assess positive and negative affect pathways (Diener et al., 2017). Theoretically, this division of constructs into positive and negative dimensions is also consistent with CMA and WISM models.

The purpose of this research was therefore to assess positive and negative predictors of well-being/distress outcomes and social support in AYAs. To do so, a two-step approach was utilized. Step one was to use maximum likelihood factor analysis (MLFA) to reduce the data to positive and negative factors. Consistent with the literature, distinct positive and negative factors were expected to emerge from MLFA of subjective well-being measures, cancer coping variables, and well-being outcome variables. More specifically, the following hypotheses were posited:

- 1) MLFA of subjective well-being measures would yield a two-factor solution, with positive affect on one factor, negative affect on a second factor, and satisfaction with life loading on both factors;
- 2) MLFA of cancer coping measures (illness centrality, mental adjustment to cancer, and distress due to traumatic events) would yield distinct positive and negative coping styles;

3) MLFA analysis of well-being/distress outcomes measures (anxiety, depression, positive and negative change, spiritual well-being, and perceived stress) would yield positive and negative outcomes.

Step two of the research was assessing distinct positive and negative predictors of well-being /distress outcomes and social support, by comprehensively examining the predictive value of personality (neuroticism, extraversion), the SWB factors, and cancer coping factors. This was exploratory, in that specific predictions could not be put forth until after the factor analytic models were completed. However, broadly speaking, we hypothesized the following:

4) That personality measures, SWB factors, and cancer coping factors would all remain significant and independent predictors of well-being/distress outcomes.

5) That personality, SWB factors, and cancer coping factors would all remain significant and independent predictors of social support.

### **Method**

Individuals diagnosed with cancer between the ages of 15 and 39 years and over the age of 18 at time of survey completion were eligible to participate in the research by completing an online questionnaire. This study was independently approved by Lakehead University and Thunder Bay Regional Health Sciences Centre research ethics boards.

### **Recruitment**

Recruitment occurred exclusively online. A Facebook page dedicated to the research was created, as was a twitter profile for the researcher. Digital posters advertising the research were created and distributed through both platforms. Posters, and research blurbs were submitted to popular websites geared towards young adult cancer patients and survivors, such as Young Adult Cancer Canada and Stupid Cancer. Finally, the writer composed several blog posts focusing on

the impact of cancer in adolescence and young adulthood and promoting participation in the research. Individuals interested in completing the questionnaire were asked to email the researcher. Data collection occurred over a 10-month period, from September 2014 to July 2015.

### **Procedure**

Individuals interested in participating in the research were asked to email the researcher for additional information. This procedure was put in place 1) to ensure participants could save their progress and complete the questionnaire in several sessions; 2) to allow researchers to send email reminders to prompt respondents who did not complete the questionnaire; 3) to protect copyrights by ensuring measures were shared only with eligible participants. Individuals who requested information were emailed the information letter, which explained the purpose of the questionnaire, the expected length of time required to complete the questionnaire, prize incentives, and so forth (see Appendix A). Included in this was the personalized link to the online questionnaire; Consent was implied by completion. The questionnaire was created using FluidSurveys ([www.fluidsurveys.com](http://www.fluidsurveys.com)). FluidSurveys allowed for the online data to be stored on a Canadian server, thereby ensuring it was not subject to U.S. security laws.

To encourage participation, respondents who chose to provide contact information at the end of the questionnaire were entered into a random prize draw to win one of three prizes: a \$250.00 grand prize, \$100.00 second place prize, and \$75.00 third place prize, to be distributed as a VISA gift card or gift card to any retailer (such as Chapters, Amazon) that offered the option of purchasing online. Notably, a second questionnaire was embedded within the first to collect this identifying information, thereby ensuring that identifying information could not be linked to questionnaire responses.

## Measures

### **Characterizing the sample.**

Demographic information, cancer-related health information, and use of psychosocial support services was obtained using a questionnaire developed by the investigator. Demographic variables included age, sex, ethnicity, country of residence, smoking status, alcohol consumption, drug use, education, income, and marital status. Cancer-related variables included age at the time of the first diagnosis, stage at the time of diagnosis, type of cancer, current treatment status, types of treatments received, and co-morbid conditions. Finally, psychosocial support variables queried types of psychosocial support received (in-person individual or group, online formal or informal, support from family and friends), use of the Internet to seek cancer-related health information, and what was found to be most helpful (see Appendix B).

### **Measures of subjective well-being.**

Life satisfaction was assessed using the Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). This is a five-item measure querying the extent to which individuals are satisfied with their lives, rated on a seven-point scale from (1) strongly disagree to (7) strongly agree (see Appendix C). For the present sample, internal consistency reliability was very good ( $\alpha = .882$ ).

Positive and negative affect was measured using the Positive and Negative Affect Schedule (PANAS-X; Watson & Clark, 1994). The PANAS-X consists of 60 items, with subscales of positive affect, negative affect, fear, hostility, guilt, sadness, joviality, self-assurance, attentiveness, shyness, fatigue, serenity, and surprise. Each item was rated on a five-point scale ranging from (1) very slightly or not at all to (5) very much. Participants were asked

to reflect on the extent to which was the listed emotion experienced in the past few weeks (see Appendix D). For the purposes of the present research, we focused on the positive affect and negative affect subscales; internal consistency for these subscales was strong at  $\alpha$ s = .881 and .886, respectively.

### **Personality measure.**

The NEO Five-Factor Inventory-3 (NEO-FFI-3) is a 60-item scale designed to measure the five broad personality domains: neuroticism ( $\alpha = .891$ ), extraversion ( $\alpha = .871$ ), openness ( $\alpha = .776$ ), agreeableness ( $\alpha = .772$ ), and conscientiousness ( $\alpha = .833$ ). Respondents were asked to rate items on a 5-point scale from strongly disagree to strongly agree. The reliability and validity of the NEO-FFI-3 is strongly supported (Costa & McCrae, 2010). For the purposes of the present research, we focused on neuroticism and extraversion subscales. Due to copyright, the measure was not attached.

### **Measures of cancer coping.**

A single-item model of illness centrality was developed by Park, Bharadwaj, and Blank (2011) and replicated for the present study (Appendix E). Park and colleagues (2011) reviewed the literature and concluded that information on how post-cancer identities are formed is sparse. Individuals diagnosed with cancer can ostensibly begin to distance themselves from cancer once they are in remission or survivorship. An individual may choose to become a cancer advocate, occasionally participate in awareness and fundraising events, connect with peers, or attempt to distance themselves from cancer associations and this period of illness. The cancer diagnosis may be integrated into their core identity, or remain a relatively minor component of how they see themselves. If the cancer experience can be separated to some degree from one's identity,

then the extent to which it remains central was thought to be important. The authors theorized that an individual's illness centrality – the extent to which cancer is central to one's identity and one's core self - would be associated with adjustment outcomes in survivorship (Park et al., 2011). To test this hypothesis, they created a single-item measure, modelled after the efficacy of single item-measures of centrality used to evaluate religiousness and ethnicity (see Greenfield & Mark, 2007; Richman, Kohn-Wood, & Williams, 2007; and Yip, Gee, & Takeuchi, 2008 in Park et al., 2011). Participants were asked “how much is your current identity centered around your cancer experience” with response options along a 5-point scale ranging from 0 (not at all) to 4 (totally). Consistent with their hypothesis, Park et al. (2011) found that increased illness centrality was associated with decreased mental health quality of life, decreased positive affect, increased negative affect, increased intrusive thoughts, and decreased life satisfaction. The authors advocate for continuing development of psychometrically sound measures of illness centrality, be it the single-item measure presented here or a multi-item design.

The Impact of Events Scale, Revised (IES-R; Weiss, 2007) is a 22-item measure that was used to assess self-reported, subjective distress due to traumatic events. Items were rated on a five-point scale ranging from (0) not at all to (4) extremely, and subscale scores for intrusion ( $\alpha = .882$ ), avoidance ( $\alpha = .801$ ), and hyperarousal ( $\alpha = .850$ ), as well as the total scale score ( $\alpha = .932$ ), were calculated (see Appendix F). A total score above 24 suggests that the respondent has symptoms of PTSD ( $n = 19$ ; 14.8%), score of 33 and above is associated with a probable PTSD diagnosis ( $n = 9$ ; 7.0%), and a score of 37 or greater suggests significant PTSD symptoms at a severity high enough as to impact immune system functioning ( $n = 18$ ; 14.1%).

Coping was assessed using the Mini-Mental Adjustment to Cancer Scale (Mini-MAC; Watson, Greer, & Bliss, 1989). The Mini-MAC is a very well recognized, extensively used 29-



item measure that assesses five coping strategies: helplessness- hopelessness ( $\alpha = .905$ ), anxious preoccupation ( $\alpha = .877$ ), fighting spirit ( $\alpha = .609$ ), cognitive avoidance ( $\alpha = .793$ ), and fatalism ( $\alpha = .646$ ; Zucca, Lambert, Boyes, & Pallant, 2012). Psychometric properties of the Mini-MAC have been extensively evaluated, and supported (Watson, Law, Santos, Greer, Baruch, & Bliss, 1994). Each item was rated on a four-point scale ranging from (1) definitely does not apply to me too (4) definitely applies to me (see Appendix G).

The single-item measure of illness centrality, the IES-R, and the Mini-MAC were grouped under the heading of “cancer coping” in that they measure the direct impact of cancer, and how the individual has (or hasn’t) managed in coping with it.

#### **Well-being/distress measures.**

Positive and negative changes were assessed using an edited version of the Perceived Benefits Scale (Carver & Antoni, 2004), supplemented with additional items addressing existential beliefs and health behaviours (Bellizzi, Miller, Arora, & Rowland, 2007), that was first developed and utilized by Park and Blank (2012). Of note, the 22 items were assessed for positive and negative change on a 7–point scale ranging from much worse now, to no change, to much better now. Scoring followed the guidelines described by Bellizzi et al. (2007) wherein positive and negative scores were separately calculated. For example, all neutral and negative scores were coded as 0, and positive scores coded as 1 = “a little bit better,” 2 = “better,” and 3 = “much better” in order to calculate mean positive change. For the present sample, Cronbach’s alpha for positive and negative change was .897 and .884, respectively (see Appendix H).

Spiritual well-being was assessed using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp; Peterman, Fitchett, Brady, Hernandez, & Cella,

2002). This measure consists of 12 items scored from (0) not at all to (4) very much and assesses the respondent's spiritual well-being over the past seven days ( $\alpha = .853$ ; Appendix I).

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is a 14-item emotional distress screening tool that has been widely used with cancer patients (Carroll, Kathol, Noyes, Wald, & Clamon, 1993; Razavi, Delvaux, Farvacques, & Robaye, 1990; Sellick & Edwardson, 2007), and has demonstrated strong psychometric properties (Mykletun, Stordal, & Dahl, 2001). The items equally load on anxiety and depressive subscales, and can be combined to form a distress score. Each item is scored on a 4-point scale ranging from 0 to 3, and scores above 11 on either scale or 8 on both scales is considered to be within a probable risk range, therefore warranting follow up (see Appendix J). The internal consistency reliability for the present sample was very good ( $\alpha = .888$ ).

The Perceived Benefits Scale (positive and negative change), spiritual well-being as measured by the FACIT-Sp, and anxiety and distress subscales of the HADS were grouped under the heading of "well-being/distress", in that – although they have been extensively used with cancer patients - they broadly measure an individual's well-being/distress rather than direct repercussions of cancer and how they were managed.

### **Social support measure.**

The Social Provisions Scale (SPS; Russell & Cutrona, 1984) measures social support, and specifically queries current relationships with family, friends, co-workers, and so forth. The measure consists of 24 items, each rated from (1) strongly disagree to (4) strongly agree and yields the following 6 subscales: guidance ( $\alpha = .850$ ), reassurance of worth ( $\alpha = .787$ ), social integration ( $\alpha = .803$ ), attachment ( $\alpha = .745$ ), nurturance ( $\alpha = .814$ ), and reliable alliance ( $\alpha =$

.784). Substantial research supports the reliability and validity of the instrument (Russell & Cutrona, 1984) (see Appendix K).

### **Data Coding and Analysis**

Quantitative data were coded numerically and entered into SPSS 25.0 for analysis. Descriptive and frequency analyses were used to characterize the sample by demographics, medical characteristics, and psychosocial care. Relationships among measures of personality, SWB, cancer coping, well-being outcomes, and social support were examined using Pearson Product Moment Correlations.

Hypotheses one, two, and three stated that factor analysis of each set of measures (SWB, cancer coping, and well-being outcomes) would yield positive and negative dimensions. For hypothesis 1, the 20 items of the PANAS and the five items of the Satisfaction with Life scale were included. For hypothesis two, we included the single item-measure of cancer identity, the Mini-Mental Adjustment to Cancer subscales (Helplessness-Hopelessness, Anxious-Preoccupation, Fighting Spirit, Cognitive-Avoidance, Fatalism), and the Impact of Events subscales (Intrusion, Avoidance, Hypervigilance). Finally, hypothesis three included the Hospital Anxiety and Depression Scale subscales (anxiety and depression), the Perceived Benefits Scale subscales (positive and negative scales), and the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale. For each hypothesis, the measures were independently subjected to maximum-likelihood factor analysis (MLFA) with oblique rotation. For each MLFA, the Kaiser-Meyer-Olkin measure of sampling adequacy (Kaiser, 1974) and Bartlett's test of Sphericity (Bartlett, 1954) were used to assess the suitability of factor analysis.

Hypotheses four and five stated that personality measures, SWB factors, and cancer coping style factors would significantly predict well-being/distress outcomes and social support.

Specifically, to test hypothesis four we entered extraversion and neuroticism at step one, positive affect and negative affect factors at step two, and positive and negative cancer coping at step three of a hierarchical multiple regression, to assess how much of the variance in the well-being/distress outcome could be explained by the model and to assess the relative contribution of each independent variable. The same sequence of variables was entered for hypothesis five, to assess how much of the variance in social support could be explained and the independent contribution of each variable. For each model, preliminary analysis was conducted to ensure the assumptions of normality, linearity, multicollinearity, and homoscedasticity were not violated.

## **Results**

### **Participant Characteristics**

One hundred and twenty-eight young adults (78.9% female) completed the online questionnaire. Mean age at diagnosis was 27.7 years ( $SD = 6.3$ ; range 15-39 years), whereas mean age at survey completion was 32.8 years ( $SD = 6.3$ ). The sample was primarily Caucasian (86.7%) and identified English as their first language (92.2%). Approximately half of the respondents were married or in a common-law relationship (51.6%) with 26.6% identifying as single, 16.4% as in a committed relationship, and 4.7% as separated or divorced. Over a fifth of the sample reported completing an undergraduate (23.4%) or graduate (24.2%) degree. Only 5 participants (3.9%) reported being current smokers, and the majority reported not drinking (37.5%) or consuming 4 or fewer drinks per week (46.9%). For additional demographic information, (see Table 1).

Table 1

#### *Demographic characteristics of participants*

<i>Mean <math>\pm</math> SD</i>	Range
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Age at survey completion	32.8 ± 6.3	21-56 years
	<i>N</i>	(%)
<b>Sex</b>		
Male	27	21.1%
Female	101	78.9%
<b>Marital status</b>		
Single	34	26.6%
Committed Relationship	21	16.4%
Married/Common-Law	66	51.6%
Separated/Divorced	6	4.7%
Missing	1	0.8%
<b>Education completed</b>		
Middle school	1	0.8%
High school	6	4.7%
Some college	16	12.5%
College graduate	20	15.6%
Some university	9	7.0%
Undergraduate degree	30	23.4%
Some graduate school	11	8.6%
Graduate degree	31	24.2%
Other	4	3.2%
<b>Ethnicity</b>		
White/Caucasian	111	86.7%

Latin American / Hispanic	5	3.9%
Asian	4	3.1%
Black / African American	2	1.6%
First Nations / Metis	2	1.6%
Other	4	3.1%
English first language		
Yes	118	92.2%
No	10	7.8%
Household income (CAD)		
<\$25,000	21	16.4%
\$25-50,000	22	17.2%
\$50-100,000	42	32.8%
>\$100,000	33	25.8%
Missing	10	7.8%

In regard to cancer diagnosis and treatment, breast cancer (31.3%), testicular cancer (14.8%), Hodgkin's lymphoma (7.8%) and leukemia (7.8%) were the most commonly reported cancer diagnoses. The majority of the sample reported having undergone surgery (74.2%), chemotherapy (75.0%) and radiation therapy (50.8%) to treat their cancer, with 43.0% reporting they are currently in treatment, and 42.2% is expecting to undergo treatment in the coming months. For additional medical information on the sample, (see Table 2).

Table 2

*Medical characteristics of participants*

	Mean $\pm$ SD	Range
Age at diagnosis	27.7 $\pm$ 6.4	15-39 years
Hospital Anxiety and Depression Scale		
Anxiety subscale	8.3 $\pm$ 4.5	0-19
Depression subscale	5.0 $\pm$ 3.9	0-15
Total scale	13.3 $\pm$ 7.7	0-31
	<i>N</i>	%
Hospital Anxiety and Depression Scale		
Low distress (Score on both anxiety and depression subscales $\leq$ 8)	63	50.4%
Possible case (Score on either subscale $\geq$ 8)	23	18.4%
Probable case (Score on both subscales $\geq$ 8 or on one or more subscales $\geq$ 11)	39	31.2%
Stage of disease at diagnosis		
Stage 0	6	4.7%
Stage 1	26	20.3%
Stage 2	31	24.2%
Stage 3	40	31.3%
Stage 4	11	8.6%
Missing	14	10.9%

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Type of cancer		
Breast	40	31.3%
Testicular	19	14.8%
Hodgkin's Lymphoma	10	7.8%
Leukemia	10	7.8%
Thyroid	7	5.5%
Sarcoma	7	5.5%
Brain	6	4.7%
Colorectal	6	4.7%
Cervical	4	3.1%
Ovarian	4	3.1%
Lymphoma	3	2.3%
Melanoma	3	2.3%
Squamous cell carcinoma	2	1.6%
Non-Hodgkin's lymphoma	2	1.6%
Other	5	4.0%
Type of treatments received in past		
Radiation therapy	65	50.8%
Chemotherapy	96	75.0%
Surgery	95	74.2%
Hormone therapy	28	21.9%
Bone marrow / stem cell transplant	9	7.0%
Type of treatments I am presently undergoing or scheduled		

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Radiation therapy	-	-
Chemotherapy	19	14.8%
Surgery	7	5.5%
Hormone therapy	30	23.4%
Bone marrow / stem cell transplant	-	-
Types of treatment I will require in the coming months		
Radiation therapy	6	4.7%
Chemotherapy	16	12.5%
Surgery	16	12.5%
Hormone therapy	24	18.8%
Bone marrow / stem cell transplant	1	0.8%
Smoking status		
Current smoker	5	3.9%
Non-smoker	123	96.1%
Drinking status		
Non-drinker (0 drinks/week)	48	37.5%
1-4 drinks/week	60	46.9%
5+ drinks/week	17	13.3%
Missing	3	2.3%
BMI Category		
Underweight, BMI under 18.5	8	6.3%
Normal weight, BMI 18.5-24.9	58	45.3%
Overweight, BMI 25.0-29.9	32	25.0%

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Obese, BMI 30 or greater	27	21.1%
Missing	3	2.3%

In terms of psychosocial services, 37% of respondents reported trying individual counseling and finding it either very helpful or extremely helpful. Similarly, the majority of respondents reported that connecting with other cancer patients or survivors in person (74.8%) or online (46.8%) was very or extremely helpful. The majority of respondents had not tried group counseling (70.6%), online one-to-one counseling (93.7%), or online group counseling (88.6%). See table 3 for additional information.

Table 3

*Use of psychosocial services: Have you used any of the following resources?*

	No, did not try	Yes, it was extremely helpful	Yes, it was very helpful	Yes, it was somewhat helpful	Yes, it was slightly helpful	Yes, but it was not at all helpful
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
One to one, in person counseling (n = 127)	53 (41.7%)	23 (18.1%)	24 (18.9%)	14 (11.0%)	8 (6.3%)	5 (3.9%)
Group counseling, in person (n = 126)	89 (70.6%)	12 (9.5%)	9 (7.1%)	8 (6.3%)	5 (4.0%)	3 (2.4%)
One to one counseling,	118	2	1	3	1	1

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online ( <i>n</i> = 126)	(93.7%)	(1.6%)	(0.8%)	(2.3%)	(0.8%)	(0.8%)
Group counseling, online ( <i>n</i> = 123)	109 (88.6%)	1 (0.8%)	3 (2.4%)	4 (3.3%)	3 (2.4%)	3 (2.4%)
Connecting with other cancer patients and survivors, in person ( <i>n</i> = 127)	12 (9.4%)	59 (46.5%)	36 (28.3%)	14 (11.0%)	6 (4.7%)	0
Connecting with other cancer patients and survivors, online ( <i>n</i> = 126)	39 (31.0%)	43 (34.1%)	16 (12.7%)	21 (16.7%)	4 (3.2%)	3 (2.4%)
Searching for information online ( <i>n</i> = 127)	6 (4.7%)	31 (24.4%)	35 (27.6%)	34 (26.8%)	19 (15.0%)	2 (1.6%)

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**Hypothesis One**

The 20 items of the PANAS and the five items of the Satisfaction with Life scale were subjected to a maximum-likelihood factor analysis (MLFA). Prior to performing the analysis, the suitability of the data for factor analysis was assessed. The Kaiser-Meyer-Olkin value was .86, exceeding the recommended value of .6 (Kaiser, 1974) and Bartlett’s test of Sphericity (Bartlett, 1954) reached statistical significance ( $p < .001$ ), thereby supporting the suitability of factor analysis. The MLFA revealed the presence of five factors with Eigenvalues exceeding 1, explaining 31.8%, 14.6%, 6.5%, 6.0%, and 4.5%, respectively. However, examination of the scree plot emphasized a two-factor solution (see Figure 1; Table 4). The two-factor solution explained a total of 46.5% of the variance. To aid in the interpretation of these factors, an oblique rotation was performed. Satisfaction with Life items loaded on the first factor of low negative affect, and a second factor of high positive affect. The correlation between the two factors was weak ( $r = .388$ ). Consistent with the literature, these results provided support for the use of positive affect and negative affect as separate scales (Watson, Clark, & Tellegen, 1988).

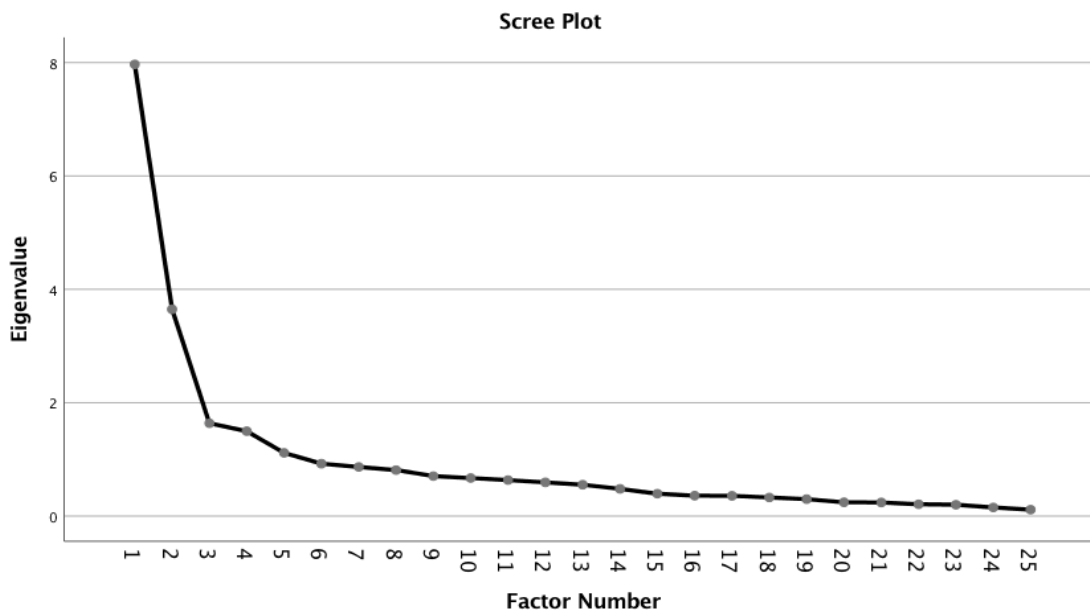


Figure 1. Scree plot depicting MLFA of subjective well-being variables

Table 4

*Pattern and Structure Matrix for MLFA with Oblim Rotation of Two Factor Solution of SWB variables*

Item	Pattern coefficients		Structure coefficients		Communalities
	Component	Component	Component	Component	
	1	2	1	2	Extraction
S-Ideal	<b>.569</b>	<b>.397</b>	<b>.684</b>	<b>.562</b>	.612
S-Excellent	<b>.615</b>	<b>.292</b>	<b>.700</b>	<b>.471</b>	.568
S-Satisfied	<b>.556</b>	<b>.366</b>	<b>.662</b>	<b>.527</b>	.561
S-Important	<b>.493</b>	<b>.216</b>	<b>.556</b>	<b>.359</b>	.352
S-Change	<b>.288</b>	<b>.297</b>	<b>.374</b>	<b>.380</b>	.220
N-Distressed	<b>-.790</b>	-.094	<b>-.817</b>	-.323	.676
N-Upset	<b>-.738</b>	-.059	<b>-.755</b>	-.273	.573
N-Guilty	<b>-.529</b>	-.007	<b>-.531</b>	-.161	.282
N-Scared	<b>-.682</b>	.076	<b>-.660</b>	-.122	.441
N-Hostile	<b>-.635</b>	.046	<b>-.622</b>	-.139	.389
N-Irritable	<b>-.517</b>	-.230	<b>-.584</b>	-.380	.390
N-Nervous	<b>-.509</b>	.185	<b>-.455</b>	.038	.238
N-Ashamed	<b>-.525</b>	.022	<b>-.519</b>	-.131	.270
N-Jittery	<b>-.412</b>	.056	<b>-.396</b>	-.063	.159
N-Afraid	<b>-.654</b>	.115	<b>-.621</b>	-.075	.398

P-Excited	.083	<b>.691</b>	.283	<b>.715</b>	.517
P-Strong	-.117	<b>.710</b>	.089	<b>.676</b>	.470
P-Enthusiastic	.040	<b>.803</b>	.273	<b>.815</b>	.665
P-Proud	-.047	<b>.681</b>	.150	<b>.668</b>	.448
P-Alert	.064	<b>.391</b>	.178	<b>.409</b>	.171
P-Inspired	-.137	<b>.784</b>	.091	<b>.745</b>	.572
P-Attentive	.172	<b>.482</b>	.312	<b>.531</b>	.309
P-Determined	-.128	<b>.707</b>	.078	<b>.670</b>	.464
P-Active	.133	<b>.518</b>	.284	<b>.557</b>	.327
P-Interested	-.015	<b>.678</b>	.182	<b>.674</b>	.454

## Hypothesis Two

Maximum-likelihood factor analysis (MLFA) with oblique (Oblim with Kaiser Normalization) rotation was used to examine the relationship between measures assessing the impact of cancer. The following measures were included in the MLFA: single item-measure of cancer identity, Mini-Mental Adjustment to Cancer subscales (Helplessness-Hopelessness, Anxious-Preoccupation, Fighting Spirit, Cognitive-Avoidance, Fatalism), Impact of Events subscales (Intrusion, Avoidance, Hypervigilance). The Kaiser-Meyer-Olkin value was .78, exceeding the recommended value of .6 (Kaiser, 1974) and Bartlett's test of Sphericity (Bartlett, 1954) reached statistical significance ( $p < .001$ ), thereby supporting the suitability of factor analysis. The MLFA revealed the presence of three factors with Eigenvalues exceeding 1, explaining 44.9%, 18.3%, and 12.6% of the variance, respectively. However, examination of the scree plot emphasized a two-factor solution (see Figure 2; Table 5). The two-factor solution

explained a total of 63.2% of the variance. To aid in the interpretation of these factors, an oblique rotation was performed. The first factor reflected high illness centrality and a negative preoccupied dwelling on cancer; this factor was labeled negative cancer coping. The second factor reflected low illness centrality, and a positive acceptance and movement, and was labeled positive cancer coping. There was a weak, negative correlation between the two factors ( $r = -.207$ ), supporting the separate factors.

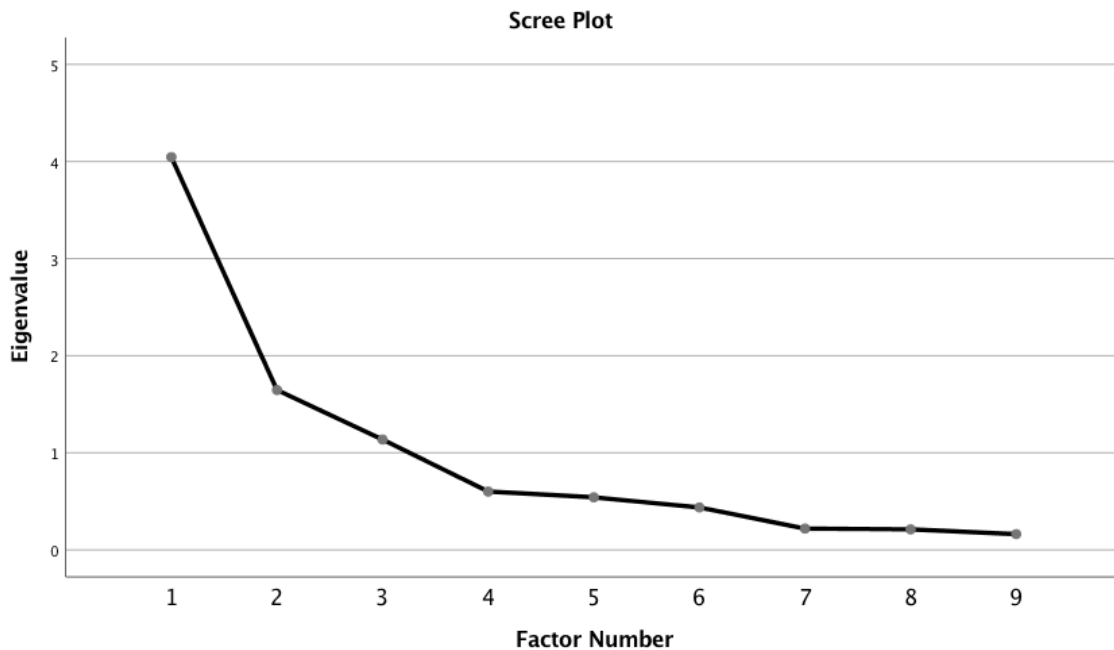


Figure 2. Scree plot depicting MLFA of cancer coping variables

Table 5

Pattern and Structure Matrix for MLFA with Oblim Rotation of Two Factor Solution of Cancer Coping variables

Item	Pattern coefficients		Structure coefficients		Communalities
	Component	Component	Component	Component	
	1	2	1	2	Extraction
Illness	<b>.506</b>	-.107	<b>.527</b>	<b>-.207</b>	.289



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Centrality					
IES Intrusion	<b>.923</b>	.229	<b>.878</b>	.047	.821
IES	<b>.766</b>	.172	<b>.732</b>	.021	.564
Avoidance					
IES	<b>.904</b>	.046	<b>.895</b>	-.135	.803
Hyperarousal					
MAC	<b>.364</b>	-.011	<b>.366</b>	-.083	.134
Cognitive					
Avoidance					
MAC	<b>.615</b>	<b>-.482</b>	<b>.710</b>	<b>-.603</b>	.728
Helpless-					
Hopeless					
MAC	<b>.712</b>	<b>-.388</b>	<b>.778</b>	<b>-.478</b>	.715
Anxious-					
Preoccupation					
MAC Fighting	.019	<b>.642</b>	-.108	<b>.638</b>	.407
Spirit					
MAC Fatalism	.024	<b>.548</b>	-.084	<b>.543</b>	.296

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### Hypothesis Three

Well-being outcomes measures were subjected to MLFA with oblique rotation. Included in the analysis were the Hospital Anxiety and Depression Scale subscales (anxiety and depression), Perceived Benefits Scale (positive and negative scales), and the Functional

Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale. The Kaiser-Meyer-Olkin value was .73, exceeding the recommended minimum value of .6 (Kaiser, 1974) and Bartlett’s test of Sphericity (Bartlett, 1954) reached statistical significance ( $p < .001$ ), thereby supporting the suitability of factor analysis. The MLFA revealed the presence of one factor with an Eigenvalue exceeding 1, explaining 54.4% of the variance (see table 6). All variables loaded substantially on this factor, reflecting high anxiety and depression scores on the HADS, negative PBS score, low spiritual well-being, and low PBS positive score.

Table 6

*One Factor Solution of Well-Being Outcome variables*

Item	Factor Matrix Component 1
PBS_Negative	.698
PBS_Positive	-.367
HADS Anxiety	.725
HADS Depression	.882
FACIT Spirituality	-.542

In summary, the MLFA models allowed the data to be reduced into five variables: positive affect, negative affect, positive cancer coping, negative cancer coping, and difficulty with cancer adjustment. Regression factor scores were saved for use in the final regression models to test hypotheses 4 and 5. Regression scores is a refined method that is compatible with oblique rotation, whereas alternatives such as Bartlett scores and Anderson-Rubin scores are less suited (DiStefano, Zhu, and Míndrilă, 2009).

**Hypotheses Four and Five**

Hierarchical multiple regression was used to predict cancer adjustment and social support, respectively. In the first model, extraversion and neuroticism were entered at step 1, explaining 45.4% of the variance in the cancer adjustment. The positive affect factor and negative affect factor were entered at the second step, with the model then explaining a total of 67.0% of the variance. Positive cancer coping and negative cancer coping factors were entered at the final step. The total variance explained by the model was 76.1%,  $F(6, 117) = 66.12, p < .001$ . In the final model, all predictors remained statistically significant, with negative cancer coping factor recording a higher beta value ( $beta = .352$ ; see Table 7).

In the second model examining social support, extraversion and neuroticism were entered at step 1, explaining 18.1% of the variance in the outcome factor. The positive affect factor and negative affect factor were entered at the second step, with the model then explaining a total of 27.9% of the variance. Positive cancer coping and negative cancer coping factors were entered at the final step. The total variance explained by the model was 38.3%,  $F(6, 121) = 12.52, p < .001$ . In the final model, two predictors remained statistically significant, with positive cancer coping factor recording a higher beta value ( $beta = .32$ ) than the neuroticism measure ( $beta = -.20$ ; see Table 8).

Table 7

*Results from hierarchical regression analyses showing personality, SWB, and cancer coping style as predictors of distress in AYA cancer patients*

Steps	Measurement	Unstandardized		Standardized	$p$	F	$R^2$	$\Delta R^2$
		coefficient		coefficient				
		B	SE	$\beta$				

1	-	-	-	-	-	50.387***	.454	-
	Constant	.477	.503	-	.345			
	Neuroticism	.080	.011	.503	.000			
	Extraversion	-.081	.016	-.360	.000			
2	-	-	-	-	-	63.491***	.670	.216
	Constant	.054	.400	-	.893			
	Neuroticism	.047	.009	.294	.000			
	Extraversion	-.039	.013	-.173	.004			
	Negative affect	-.487	.061	-.506	.000			
	Positive affect	-.112	.060	-.114	.064			
3	-	-	-	-	-	66.122***	.761	.091
	Constant	.471	.352	-	.183			
	Neuroticism	.023	.009	.143	.009			
	Extraversion	-.036	.012	-.161	.002			
	Negative affect	-.298	.059	-.308	.000			
	Positive affect	-.153	.053	-.156	.004			
	Coping Negative	.339	.055	.352	.000			
	Coping Positive	-.158	.054	-.150	.004			

**Note:** B, unstandardized beta; SE, standard error;  $\beta$ , standardized beta; p, significance level, F, F statistic;  $R^2$ , variance;  $\Delta R^2$  change in variance; \*\*\* $p < .0001$

*Table 8*

*Results from Hierarchical Regression Analyses Showing Personality, SWB, and Cancer Coping*

*Style as Predictors of Social Support in AYA Cancer Patients*

Steps	Measurement	Unstandardized		Standardized	<i>p</i>	F	R <sup>2</sup>	ΔR <sup>2</sup>
		coefficient		coefficient				
		B	SE	β				
1	-	-	-	-	-	14.995***	.193	-
	Constant	86.542	6.262	-	.000			
	Neuroticism	-.661	.135	-.401	.000			
	Extraversion	.277	.193	.118	.154			
2	-	-	-	-	-	13.303***	.302	.109
	Constant	91.292	6.607	-	.000			
	Neuroticism	-.436	.138	-.264	.002			
	Extraversion	-.083	.201	-.035	.682			
	Negative affect	2.758	.905	.276	.003			
	Positive affect	1.949	.903	.192	.033			
3	-	-	-	-	-	12.518***	.383	.081
	Constant	92.426	5.918	-	.000			
	Neuroticism	-.327	.142	-.198	.023			
	Extraversion	-.211	.194	-.090	.278			
	Negative affect	1.885	.980	.189	.057			
	Positive affect	1.559	.881	.154	.079			
	Coping Negative	-.505	.922	-.051	.584			
	Coping Positive	3.526	.895	.321	.000			

**Note:** B, unstandardized beta; SE, standard error; β, standardized beta; p, significance level, F, F statistic; R<sup>2</sup>, variance; ΔR<sup>2</sup> change in variance; \*\*\**p*<.0001.

## Discussion

The purpose of this research was to assess personality, affect, and cancer coping style as they relate to well-being outcomes and social support, as a way of guiding survivorship care in adolescent and young adult (AYA; aged 15-39 years) cancer patients and survivors. Consistent with SWB literature, factor analysis yielded two distinct dimensions of a negative affect and positive affect. However the satisfaction with life scale loaded on both affective dimensions rather than creating a third (Diener et al., 2017; Stones et al., 2011). These factors were labelled negative and positive affect, respectively. The factor analysis of measures of cancer coping also yielded two dimensions. Negative cancer coping was characterized by high illness centrality, high cancer intrusiveness, high avoidance, hyperarousal, strong endorsement of helplessness-hopeless feelings, feelings of anxious-preoccupation, and attempts at cognitive avoidance. Conversely, positive cancer coping dimension was characterized by fatalism and a fighting spirit; mainly, accepting the disease while also perceiving it as a challenge. Notably, low levels of anxious-preoccupation and helplessness-hopelessness also loaded on this second factor. These factors were labelled as negative and positive cancer coping. Notably, anxious-preoccupation and helplessness-hopelessness also loaded negatively on this second factor, suggesting low levels of anxious-preoccupation and helplessness-hopelessness is associated with positive coping.

In the context of the CMA (Russell, 1980) and the WISM (Røysamb & Nes, 2018) models, we see that the dimensions are consistent with the affective horizontal axis split, but the factor analysis did not support further differentiation by valence, or change and stability vertical axis.

It was expected that well-being/distress outcomes would also yield a two-factor solution characterized by positive versus negative outcomes. However, the analysis supported a single

factor solution, hence distress. Notably, only one measure of positive change was included in the analysis. Moving ahead, it will be important to ensure a range of outcome measures is included in the research to fully capture the well-documented negative repercussions of cancer, as well as possible positive aspects of growth, change, and resilience.

In the first hierarchical regression model, higher neuroticism, lower extraversion, higher negative and positive affect, higher negative coping, and lower positive coping strategies were all found to be significant predictors of increased distress. It is unclear why both negative affect, and to a lesser extent positive affect, were both associated with increased distress. One possible explanation is multicollinearity; a strong correlation amongst predictor variables can cause a change in the beta coefficient. If we look back to the correlational relationships, PANAS positive was significantly correlated with Extraversion and Neuroticism ( $r = .318$  and  $.502$ ), whereas PANAS negative was significantly associated with only Neuroticism ( $r = .459$ ).

Social support was assessed in the second hierarchical regression model. Social support is arguably critical and central to AYA care, in that lack of connection with other AYA cancer patients and survivors, feelings of isolation, and difficulty maintaining connection with family and friends who struggle to make sense of chronic illness in this age frame are commonly reported concerns (Abrams, Hazen, & Penson, 2007; Evan & Zeltzer, 2006; Morgan, Davies, Palmer, & Plaster, 2010). These findings suggest that individuals who have moved into a stage of acceptance and forward movement, and who report lower neuroticism, are likely to have stronger social supports. Given the cross-sectional nature of the research, it is also quite possible that – as has been previously documented (Diener & Seligman, 2002) – social support plays a reciprocal role in that individuals with greater perceived social support are more able to take positive steps to accept and cope.

There are notable limitations to this research. This study focused on a specific age range, AYAs, yet the sample had considerable diversity in terms of the type of cancer, age at diagnosis, and treatment outcomes. The diversity, relatively small sample size, and cross-sectional study design meant the data was not suitable for structural equation modelling. Future studies could aim to assess changes in affect and cancer coping over time longitudinally, and as it relates to cancer characteristics in AYAs, and for cancer patients in other age groups. Furthermore, a longitudinal study following patients from diagnosis onwards would also be an important step in helping us to understand bi-directional relationships such as social support, and to help us understand the suitability of measured variables as a comprehensive model. It would be helpful to categorize and track changes using the WISM model. Specifically, can we differentiate well-being outcomes associated with the ill-staying, ill-moving, well-moving, and well-staying quadrants? Would these classifications overlap with the CMA?

In addition, the strength of the data rests upon the measures used to examine the constructs. Whereas measures like the HADS (Zigmond & Snaith, 1983) and the Mini-MAC (Watson, Greer, & Bliss, 1989) have strong reliability and validity, the single item measure of illness centrality is quite novel, and would benefit from additional psychometric validation (Park et al., 2011). Similarly, the emphasis on measures of negative outcomes of cancer means that measures of positive adjustment and growth are lacking (Haase, 2004). Notably, although measures of cancer coping and measures of distress were so grouped following careful consideration of what the individual items and subscales measure, and how they relate to one another, it could be argued that there is value to examining alternative groupings. Consider once again the multiple roles of social support. Social support has been found to be a positive outcome of high SWB as well as a cause of SWB (Diener & Seligman, 2002), a positive coping



strategy for AYAs (Corey, Haase, Azzouz, & Monahan, 2008; Kyngäs et al., 2001), and low social connectedness has been examined as a cancer outcomes (Boyes, Girgis, D'Este, & Zuca, 2011; Donovan, Brown, LeFebvre, Tardif, & Love, 2015; Lie, Larsen & Hauken, 2017). As such, we acknowledge that there is flexibility in theoretical groupings, and it is possible measures being examined as predictors or outcomes may in fact have multiple roles.

In spite of the limitations to the present research, these findings represent an important first attempt to merge existing literature on personality and SWB with cancer coping and well-being outcomes variables that are typically relegated to the oncology literature. Recognizing that an individual diagnosed with cancer brings with them their personality, their unique viewpoint of the world, and how they interact with it, it an important step. In turn, these characteristics will arguably impact how an individual copes with life-changing events such as cancer diagnosis and treatment. There is a balance to understanding an individual at the time of diagnosis, as well as understanding how a major life event such as cancer changes their perception of the world. This is not to suggest that pushing through the negative implications of cancer to find positive growth is the goal. Feeling negative emotions, grieving the loss of normality, and coping with the significant life change cancer represents – these are important. Rather, it is to suggest that if we understand the individual's characteristics and current state, we are in a better position to meet them emotionally, and to support them. This is targeted, informed, psychosocial care.

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**List of Appendices**

*Appendix A: Information Letter*

Dear Potential Participant,

If you were diagnosed with cancer between the ages of 15 and 39, no matter how old you are now, then you are eligible to participate in this research.

We are trying to understand the impact of cancer in adolescence and young adulthood. To do so, we have put together a questionnaire asking about:

- Basic information about you, your cancer, and any formal therapy or support you may have received
- What you believe the key emotions, life issues, and needs of an adolescent or young adult cancer patient are
- Your life satisfaction, distress, emotions, stress, social support, and any uncertainty you might be experiencing
- Your quality of life, physical activity level, and the extent to which cancer is a significant part of your life
- Positive or negative life changes that have occurred since your diagnosis

This study is being conducted by Liane Kandler (Doctoral Student in Clinical Psychology at Lakehead University in Thunder Bay, Ontario, Canada), Dr. Scott Sellick (Director, Supportive and Palliative Care, Thunder Bay Regional Health Sciences Centre, Thunder Bay, Ontario), and Dr. John Jamieson (Professor, Psychology Department, Lakehead University). Only these individuals will have access to the research data. These researchers have no conflicts of interest to disclose.

Participation in this study is completely voluntary. All information collected is confidential. To participate, simply complete the questionnaire.

The questionnaire is long, and has approximately 250 questions. It is estimated that it will take about 30 to 60 minutes to complete. Because of the questionnaire length, you have the option of starting the questionnaire and returning to it at a second point in time to finish.

This research is considered low risk, and is not expected to result in harm. However, it is noted that discussing sensitive topics such as your personal cancer experience may be intimidating and/or distressing. If you are uncomfortable answering the questions, you can decide not to or stop at any time. If answering the questions is distressful for you, please consider consulting reaching out for a medical or psychological consult. There are no direct benefits to participating in the research. However your responses will help us to understand what adolescents and young adults with cancer are facing, and how resources and tools can be better tailored to meet your unique supportive care needs.

To say thank you for your time and your valuable feedback, at the end of the questionnaire you will have the option of being entered into a random prize draw. You will be eligible to win one of three prizes, a grand prize valued at \$250.00, second place prize of \$100, and a third place prize of \$75.00. You will have the option of receiving the prize amount as a VISA gift card, or as an online gift certificate to a store of your choice.

This study has received ethics approval from Lakehead University and the Thunder Bay Regional Health Sciences Centre. This research was funded by a Doctoral Scholarship from the Canadian Institute of Health Research, awarded to Liane Kandler.

For information on the study, to obtain a copy of the results, or if you had any further questions, please contact Liane Kandler at [lkandler@lakeheadu.ca](mailto:lkandler@lakeheadu.ca)

If you have any concerns regarding your rights as a research participant or wish to speak to someone other than a research team member about this research project, you are welcome to contact any of the research boards who reviewed the application

1) Chair, Research Ethics Board. Thunder Bay Regional Health Sciences Centre. 980 Oliver Road, Thunder Bay, Ontario P7B 6V4. Tel: 807-684-6422; Fax: 807-684-5904.  
ResearchEthics\_Chair@tbh.net

2) Office of Research Services, Lakehead University. 955 Oliver Road. Thunder Bay, Ontario. P7B 5E1. Phone (807) 343-8934. Fax (807) 346-7749

All research data will be kept for 7 years, as is required by the research ethics review process.

Thank you for taking the time to consider this research!

(To participate and begin the questionnaire, click next)

### *Appendix B: Study Specific Questionnaire*

#### Study Specific Questionnaire

The following study-specific questionnaire contains three sections. The first section queries demographic information, the second cancer-related personal health information, and the third asks about your thoughts regarding the key emotional issues, life issues, and needs that adolescent and young adult patients experience.

Please note: The actual questionnaire will be online. As such, the following reflects only the questions, but not the actual questionnaire formatting.

#### **SECTION 1: DEMOGRAPHIC INFORMATION**

Date of birth: Year, Month, Day

Sex: Male, Female

Marital status: Single, Married, Separated, Divorced, Widow/er, Common-law, Committed relationship

Living arrangements: I live alone. I live with other people (not alone)

What is the highest level of education you have completed? Elementary school (Grades 1-6), Middle School (Grades 7-9), High School (Grades 10-12), Some college, Completed college, Some university, completed university, some graduate school (Master's degree, Doctoral degree), Graduate school completed.

I mainly identify with the following ethnicity: White/Caucasian, First Nation, Metis, Arab/Middle Eastern, Southeast Asian, South Asian, Chinese, Latin American/Hispanic, Black/African American, Other:

My total household family income is approximately: Amount/currency (given different currencies, participants will be asked to write their income and indicate the currency).

My primary source of income is: My work/employment, Student loans or financing, parents or guardian, partner or spouse, disability benefits, social assistance, pension or retirement benefits, other:

Is English your first language?

If not, what is your first language?

How tall are you?

How much do you weigh?

What is your current smoking status? I am currently smoking, I am smoking but trying to quit, I recently quit smoking, I quit smoking 6 months ago or more, I have never smoked

Note: For current smokers / trying to quit – approximately how many cigarettes a day do you smoke?

In an average week, how many alcoholic drinks do you consume? (numbers 0 through 40)

In an average week, how many times do you use recreational drugs (marijuana, non-prescription medication, etc.)? (numbers 0 through 21)

**SECTION 2: CANCER-RELATED HEALTH INFORMATION**

How old were you when you were diagnosed with your first cancer?

What type of cancer were you first diagnosed with?

What stage of cancer were you first diagnosed with? 0, 1, 2, 3, 4

Were you diagnosed with second cancer?

If so, what type of cancer was the second you were diagnosed with?

For your second cancer, at what stage of disease were you diagnosed? 0, 1, 2, 3, 4

What types of treatments have you had in the past, or are you expected to have in the coming months:

I have received these treatments in the past.

I have been informed that I will need to receive these treatments in the coming months

Radiation

Radiation

Chemotherapy

Chemotherapy

Surgery

Surgery

Hormone Therapy

Hormone Therapy

Bone Marrow / Stem Cell Transplant

Bone Marrow / Stem Cell Transplant

Have you used any of the following professional or semi-professional support resources?

For each resource used, participants will be asked to rate how helpful the resource was on a scale of (1) not at all helpful to (5) extremely helpful.

	Yes	No	Was not available
One on one, in person counseling			
Group counseling, in person			
One on one, online counseling			
Group counseling, online			
Searching for information online			
Connecting with other patients online			
Other:			
Other:			
Other:			

**SECTION 3: AYA CANCER EXPERIENCE**

1. What do you believe are the three main emotions young adults feel throughout their cancer experience?

a. \_\_\_\_\_

b. \_\_\_\_\_

c. \_\_\_\_\_

2. What do you believe are the top three life issues that young adults deal with throughout their cancer experience?

a. \_\_\_\_\_

b. \_\_\_\_\_

c. \_\_\_\_\_

3. What do you believe are the top three needs of a young adult throughout his or her cancer experience?

a. \_\_\_\_\_

b. \_\_\_\_\_

c. \_\_\_\_\_

*Appendix C: Satisfaction with Life Scale (SLS)*

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item.

- |                              |       |   |
|------------------------------|-------|---|
| 1=Strongly disagree          | _____ | In most ways my life is close to ideal                      |
| 2=Disagree                   | _____ | The conditions of my life are excellent                     |
| 3=Slightly disagree          | _____ | I am satisfied with life                                    |
| 4=Neither agree nor disagree | _____ | So far I have gotten the important things I want in life    |
| 5=Slightly agree             | _____ | If I could live my life over, I would change almost nothing |
| 6=Agree                      |       |   |
| 7=Strongly agree             |       |   |



*Appendix D: Positive and Negative Affect Scale (PANAS-X)*

Table 1 *Sample PANAS-X Protocol Illustrating "Past Few Weeks" Time Instructions*

This scale consists of a number of words and phrases that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent you have felt this way during the past few weeks. Use the following scale to record your answers:

1 very slightly or not at all	2 a little	3 moderately	4 quite a bit	5 extremely
<input type="checkbox"/> cheerful	<input type="checkbox"/> sad	<input type="checkbox"/> active	<input type="checkbox"/> angry at self	
<input type="checkbox"/> disgusted	<input type="checkbox"/> calm	<input type="checkbox"/> guilty	<input type="checkbox"/> enthusiastic	
<input type="checkbox"/> attentive	<input type="checkbox"/> afraid	<input type="checkbox"/> joyful	<input type="checkbox"/> downhearted	
<input type="checkbox"/> bashful	<input type="checkbox"/> tired	<input type="checkbox"/> nervous	<input type="checkbox"/> sheepish	
<input type="checkbox"/> sluggish	<input type="checkbox"/> amazed	<input type="checkbox"/> lonely	<input type="checkbox"/> distressed	
<input type="checkbox"/> daring	<input type="checkbox"/> shaky	<input type="checkbox"/> sleepy	<input type="checkbox"/> blameworthy	
<input type="checkbox"/> surprised	<input type="checkbox"/> happy	<input type="checkbox"/> excited	<input type="checkbox"/> determined	
<input type="checkbox"/> strong	<input type="checkbox"/> timid	<input type="checkbox"/> hostile	<input type="checkbox"/> frightened	
<input type="checkbox"/> scornful	<input type="checkbox"/> alone	<input type="checkbox"/> proud	<input type="checkbox"/> astonished	
<input type="checkbox"/> relaxed	<input type="checkbox"/> alert	<input type="checkbox"/> jittery	<input type="checkbox"/> interested	
<input type="checkbox"/> irritable	<input type="checkbox"/> upset	<input type="checkbox"/> lively	<input type="checkbox"/> loathing	
<input type="checkbox"/> delighted	<input type="checkbox"/> angry	<input type="checkbox"/> ashamed	<input type="checkbox"/> confident	
<input type="checkbox"/> inspired	<input type="checkbox"/> bold	<input type="checkbox"/> at ease	<input type="checkbox"/> energetic	
<input type="checkbox"/> fearless	<input type="checkbox"/> blue	<input type="checkbox"/> scared	<input type="checkbox"/> concentrating	
<input type="checkbox"/> disgusted with self	<input type="checkbox"/> shy	<input type="checkbox"/> drowsy	<input type="checkbox"/> dissatisfied with self	

*Appendix E: Illness Centrality*

Single item measure of illness centrality

How much is your current identity centered around your cancer experience?

(0) not at all            (1) slightly            (2) moderately            (3) greatly            (4) totally

Retrieved from Park, C. L., Bharadwaj, A. K., & Blank, T. O. (2011). Illness centrality, disclosure, and well-being in younger and middle-aged adult cancer survivors. *British Journal of Health Psychology, 16*(4), 880-889. doi: 10.1111/j.2044-8287.2011.02024.x

*Appendix F: Impact of Events Scale (IES)*

Impact of Events Scale - Revised (IES-R)

Identifier

Date

Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to (your problem), how much were you distressed or bothered by these difficulties? This assessment is not intended to be a diagnosis. If you are concerned about your results in any way, please speak with a health professional.

0 = Not at all    1 = A little bit    2 = Moderately    3 = Quite a bit    4 =Extremely

1	Any reminder brought back feelings about it	Please select ... ▼
2	I had trouble staying asleep	Please select ... ▼
3	Other things kept making me think about it	Please select ... ▼
4	I felt irritable and angry	Please select ... ▼
5	I avoided letting myself get upset when I thought about it or was reminded of it	Please select ... ▼
6	I thought about it when I didn't mean to	Please select ... ▼
7	I felt as if it hadn't happened or wasn't real	Please select ... ▼
8	I stayed away from reminders about it	Please select ... ▼
9	Pictures about it popped into my mind	Please select ... ▼
10	I was jumpy and easily startled	Please select ... ▼
11	I tried not to think about it	Please select ... ▼

12	I was aware that I still had a lot of feelings about it, but I didn't deal with them	Please select ... ▼
13	My feelings about it were kind of numb	Please select ... ▼
14	I found myself acting or feeling like I was back at that time	Please select ... ▼
15	I had trouble falling asleep	Please select ... ▼
16	I had waves of strong feelings about it	Please select ... ▼
17	I tried to remove it from my memory	Please select ... ▼
18	I had trouble concentrating	Please select ... ▼
19	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart	Please select ... ▼
20	I had dreams about it	Please select ... ▼
21	I felt watchful and on guard	Please select ... ▼
22	I tried not to talk about it	Please select ... ▼

Avoidance	0
Intrusion	0
Hyperarousal	0
Total Mean IES-R Score	0
Total IES-R Score	0

Document Version: 1.4  
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*Appendix G: Mini Mental Adjustment to Cancer Scale (mini-MAC)*

	<b>Definitely does not apply to me</b>	<b>Does not apply to me</b>	<b>Applies to me</b>	<b>Definitely applies to me</b>
1. I have been doing things that I believe will improve my health (e.g. I have changed my diet)	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
2. I feel I can't do anything to cheer myself up	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
3. I feel that problems with my health prevent me from planning ahead	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
4. I believe that my positive attitude will benefit my health	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
5. I don't dwell on my illness	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
6. I firmly believe that I will get better	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
7. I feel that nothing I can do will make any difference	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
8. I've left it all to my doctors	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
9. I feel that life is hopeless	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
10. I have been doing things that I believe will improve my health (e.g. exercise)	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>

	<b>Definitely does not apply to me</b>	<b>Does not apply to me</b>	<b>Applies to me</b>	<b>Definitely applies to me</b>
11. Since my cancer diagnosis I now realize how precious life is, and I'm making the most of it	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
12. I've put myself in the hands of God	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
13. I have plans for the future (e.g. holiday, jobs, housing)	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
14. I worry about the cancer returning or getting worse	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
15. I've had a good life — what's left is a bonus	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
16. I think my state of mind can make a lot of difference to my health	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
17. I feel that there is nothing I can do to help myself	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
18. I try to carry on my life as I've always done	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	3 <input type="radio"/>
19. I would like to make contact with others in the same boat				
20. I am determined to put it all behind me	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
21. I have difficulty in believing that this has happened to me	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
22. I suffer great anxiety about it	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
23. I am not very hopeful about the future	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
24. At the moment I take one day at a time	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
25. I feel like giving up	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
26. I try to keep a sense of humour about it	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
27. Other people worry about me more than I do	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
28. I think of other people who are worse off	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>

	<b>Definitely does <i>not</i> apply to me</b>	<b>Does <i>not</i> apply to me</b>	<b>Applies to me</b>	<b>Definitely applies to me</b>
29. I am trying to get as much information as I can about cancer	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
30. I feel that I can't control what is happening	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
31. I try to have a very positive attitude	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
32. I keep quite busy, so I don't have time to think about it	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
33. I avoid finding out more about it	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
34. I see my illness as a challenge	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
35. I feel fatalistic about it	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
36. I feel completely at a loss about what to do	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
37. I feel very angry about what has happened to me	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
38. I don't really believe I have cancer	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
39. I count my blessings	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>
40. I try to fight the illness	1 <input type="radio"/>	2 <input type="radio"/>	3 <input type="radio"/>	4 <input type="radio"/>

(Watson and Greer, 1988)

*Appendix H: Adapted Version of the Perceived Benefits Scale*

	Much worse now	Worse now	A little worse now	No change	A little better now	Better now	Much better now
My ability to be assertive							
My ability to recognise strengths							
My sense of self-worth							
My sense of control over life							
My beliefs in own judgments							
My ability to take care of myself							
My relationships with family							
My relationships with friends							
My appreciation of life							
My sense of closeness with God							
My sense of purpose in life							
My spirituality							
My beliefs about the goodness of people							
My beliefs about the safety of the world							
My beliefs about the fairness of the world							
My communicating with others							
My use of medications or supplements (vitamins, etc.)							
My life style and pace of life							
My ability to manage stress							
My diet and nutrition							
My exercise							
My reading or use of the Internet to gather health information							
My getting enough sleep							
My use of alcohol							



*Appendix I: Functional Assessment of Chronic Illness Therapy: Spiritual Well-Being  
(FACITSp)*

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

		Not at all	A little bit	Some- what	Quite a bit	Very much
Sp1	I feel peaceful .....	0	1	2	3	4
Sp2	I have a reason for living.....	0	1	2	3	4
Sp3	My life has been productive .....	0	1	2	3	4
Sp4	I have trouble feeling peace of mind.....	0	1	2	3	4
Sp5	I feel a sense of purpose in my life .....	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort .....	0	1	2	3	4
Sp7	I feel a sense of harmony within myself .....	0	1	2	3	4
Sp8	My life lacks meaning and purpose.....	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs.....	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs .....	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs....	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay .....	0	1	2	3	4

*Appendix J: Hospital Anxiety and Depression Scale (HADS)*

Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response. Please complete this form and return it to reception.

*Tick only one box for each section*

**1. I feel tense or 'wound up':**

Most of the time .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A lot of the time .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Time to time. Occasionally .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**8. I feel as if I am slowed down:**

Nearly all the time .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**2. I still enjoy the things I used to enjoy:**

Definitely as much .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not quite so much .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only a little .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hardly at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**9. I get a sort of frightened feeling like 'butterflies' in the stomach:**

Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Occasionally .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quite often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. I get a sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Yes, but not too badly .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A little, but it doesn't worry me .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**10. I have lost interest in my appearance:**

Definitely .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't take so much care as I should .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I may not take quite as much care .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take just as much care as ever .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4. I can laugh and see the funny side of things:**

As much as I always could .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not quite so much now .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely not so much now .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**11. I feel restless as if I have to be on the move:**

Very much indeed .....	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Quite a lot .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not very much .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**5. Worrying thoughts go through my mind:**

A great deal of the time .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A lot of the time .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
From time to time but not too often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only occasionally .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**12. I look forward with enjoyment to things:**

As much as I ever did .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather less than I used to .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely less than I used to .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hardly at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**6. I feel cheerful:**

Not at all .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most of the time .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**13. I get sudden feelings of panic:**

Very often indeed .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quite often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not very often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**7. I can sit at ease and feel relaxed:**

Definitely .....	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Usually .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not at all .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**14. I can enjoy a good book or radio or TV programme:**

Often .....	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not often .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very seldom .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Appendix K: Social Provisions Scale*

Instructions: In answering the following questions, think about your current relationships with friends, family members, co-workers, community members, and so on. Please indicate to what extent each statement describes your current relationships with other people. Use the following scale to indicate your opinion.

<u>STRONGLY DISAGREE</u>	<u>DISAGREE</u>	<u>AGREE</u>	<u>STRONGLY AGREE</u>
1	2	3	4

So, for example, if you feel a statement is very true of your current relationships, you would respond with a 4 (strongly agree). If you feel a statement clearly does not describe your relationships, you would respond with a 1 (strongly disagree).

	<u>Rating</u>
1. There are people I can depend on to help me if I really need it.	_____
2. I feel that I do not have close personal relationships with other people.	_____
3. There is no one I can turn to for guidance in times of stress.	_____
4. There are people who depend on me for help.	_____
5. There are people who enjoy the same social activities I do.	_____
6. Other people do not view me as competent.	_____
7. I feel personally responsible for the well-being of another person.	_____
8. I feel part of a group of people who share my attitudes and beliefs.	_____
9. I do not think other people respect my skills and abilities.	_____
10. If something went wrong, no one would come to my assistance.	_____
11. I have close relationships that provide me with a sense of emotional security and well-being.	_____
12. There is someone I could talk to about important decisions in my life.	_____
13. I have relationships where my competence and skill are recognized.	_____
14. There is no one who shares my interests and concerns.	_____

	<u>Rating</u>
15. There is no one who really relies on me for their well-being.	_____
16. There is a trustworthy person I could turn to for advice if I were having problems.	_____
17. I feel a strong emotional bond with at least one other person.	_____
18. There is no one I can depend on for aid if I really need it.	_____
19. There is no one I feel comfortable talking about problems with.	_____
20. There are people who admire my talents and abilities.	_____
21. I lack a feeling of intimacy with another person.	_____
22. There is no one who likes to do the things I do.	_____
23. There are people who I can count on in an emergency.	_____
24. No one needs me to care for them.	_____

Scoring:

A score for each social provision is derived such that a high score indicates that the individual is receiving that provision. Items that are asterisked should be reversed before scoring (i.e., 4=1, 3=2, 2=3, 1=4).

1. Guidance: 3\*, 12, 16, 19\*
2. Reassurance of Worth: 6\*, 9\*, 13, 20
3. Social Integration: 5, 8, 14\*, 22\*
4. Attachment: 2\*, 11, 17, 21 \*
5. Nurturance: 4, 7, 15\*, 24\*
6. Reliable Alliance: 1, 10\*, 18\*, 23

ARTICLE 3:

SURVIVE AND THRIVE EXPEDITIONS: EXPLORING THE IMPACT OF AN  
ADVENTURE THERAPY PROGRAM ON ADOLESCENT AND YOUNG ADULT CANCER  
PATIENTS AND SURVIVORS

Liane S. Kandler

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### Abstract

Novel approaches to meet the distinct psychosocial needs of adolescent and young adult cancer patients and survivors are emerging, but rarely evaluated. This article describes the experiences of young adults with cancer who participated in an adventure therapy program, Survive and Thrive Expeditions. A qualitative descriptive design was used to assess the perspectives of Survive and Thrive participants. Respondents were invited to complete an online survey with open-ended questions at three-time points: In the week prior to leaving on the expedition ( $n = 22$ ), and both immediately ( $n = 20$ ) and six months after returning ( $n = 17$ ). Participant reflections of the adventure therapy, and perceptions of the main needs, emotions, and life issues faced by young adults throughout their cancer experience were queried. The importance of peer connections, the impact of being isolated in nature as well as the beauty of nature, and personal growth and reflection were reported as key benefits from participating. Main emotions reported by young adults included anger, sadness, and isolation. Main life issues included practical concerns, treatment effects, and impact on relationships. Finally, main needs included support, and a desire to move ahead. This research supports the benefits of Survive and Thrive Expeditions for adolescent and young adult cancer patients and survivors. Further research examining the potential long-term benefits of participating, and surveying a broader sample, is warranted.

## Introduction

The purpose of the present research is to assess the impact of an adventure therapy program – Survive and Thrive Expeditions – on adolescent and young adult cancer patients and survivors. The life-threatening diagnosis of cancer is difficult at any age, however for individuals diagnosed in adolescence or young adulthood (AYA) between the ages of 15 and 39 years it can be especially arduous. Specifically, AYA cancer patients and survivors have been found to have increased depression and anxiety symptoms, poorer quality of life and greater disruptions in life, poorer body image, poorer sexual functioning, increased financial concerns, lower social functioning, increased information needs, and increased physical pain (Blank & Bellizzi, 2006; Hall, Boyes, Bowman, Walsh, James, & Girgis, 2012; Harrison & Maguire, 1995; King, Kenny, Shiell, Hall, & Boyages, 2000; Kroenke et al., 2004; Lang, David, & Giese-Davis, 2015; Lang, Giese-Davis, Patton, & Campbell, 2018; Mor, Allen, & Malin, 1994; Parker, Baile, Moor, & Cohen, 2003; Wenzel et al., 1999). The challenges associated with coping with a cancer diagnosis and treatment as an AYA also include developing adaptive coping strategies (Kynge et al., 2000), maintaining low illness centrality (Park, Bharadwaj, & Blank, 2011), fostering a greater tolerance for uncertainty given the high degree of uncertainty in chronic illness (Decker, Haase, & Bell, 2007), and maintaining social support (Corey, Haase, Azzouz, & Monahan, 2008; Haluska, Jessee, & Nagy, 2002). A recent scoping review found that adolescents and young adults were at increased risk of depression, anxiety, and distress (Lang et al., 2015). Notably, this age-effect remained consistent regardless of minority group, race, or tumor group (Lang et al., 2015). Distress has also been found to be an ongoing concern, with 28% of AYA reporting clinical or borderline clinical levels of anxiety and depressive symptoms into survivorship (Boyes, Girgis, D’Este, & Zucca, 2011). Boyes et al. (2011) also found greater distress to be

associated with a younger age, living alone, being less physically active, currently smoking, having a history of mental health issues, and low levels of perceived social interaction. This is consistent with findings that AYA cancer survivors, as compared to older adult cancer survivors or cancer-free AYA peers, are more likely to experience psychological morbidity (Lang et al., 2016). Perhaps not surprisingly, and maybe more so than for any other age range, peer support has also been deemed an invaluable resource in helping AYAs cope with the diagnosis, treatment, and survivorship (D'Agostino, Penney, & Zebrack, 2011; Hollis & Morgan, 2001; Treadgold & Kuperberg, 2010). However, geography presents an additional challenge to peer support, in that the physical distance to travel to access traditional counseling resources may not be feasible (Campbell, Phaneuf, & Deane, 2004). Furthermore, one study found that, even a year post diagnosis, a considerable percentage of AYAs reported unmet informational needs (57%) and counseling needs (41%; Zebrack et al., 2014). Online support groups, blogs, informational resources, and chat boards for AYA cancer patients and survivors have increased in prevalence, creating opportunities for peer-to-peer communication. Content analysis provides preliminary support for these online venues as a platform for AYAs to discuss and cope with difficult emotions, exchange information, share experiences, and help user identify and create a new “normal” (Love et al., 2012). In many ways, it allows users to feel part of an online community, arguably providing a sense of belongingness. Although online connections are not necessarily seeking to replace genuine face-to-face interactions, and robust efficacy data is sparse, the increasing number of support groups, services, and interventions available online speak to interest in online resources (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Klemm et al., 2003; Rabin, Dunsiger, Ness & Marcus, 2012; Valle, Tate, Mayer, Allicock, & Cai, 2013).



Taken cumulatively, there is a significant body of research supporting the unique, and difficult, psychosocial challenges and needs of AYA cancer patients and survivors.

Thanks to this growing body of research evidence, the complex and distinct psychosocial needs of AYA cancer patients have been increasingly recognized, and generally deemed underserved (Adolescent and Young Adult Oncology Progress Review Group, 2006; Albritton & Bleyer, 2009; Canadian Cancer Society, 2009; Canadian Partnership Against Cancer, 2017; Robison, 2011). In part because of the relative scarcity of a cancer diagnosis in AYAs, specialized, coordinated, and integrated medical and psychosocial care are lacking (Sutcliffe, 2011). From a psychosocial perspective, this includes access to AYA-specific support resources, access to AYA-specific information, resources to assess fertility options and discuss sexuality, resources to support vocational and educational pursuits, and financial support (D'Agostino, Penney, & Zebrack, 2011). Providing quality care is also especially difficult given that AYAs are a very heterogeneous group, diagnosed with a wide range of cancers and facing a broad range of psychosocial challenges based on their chronological age and stage in life (Robinson, 2011). Countries around the world, including Canada, are therefore striving to establish and implement a nationwide strategy for AYA cancer care (Robinson, 2011).

As an alternative to traditional individual and group therapy models, novel treatments have been increasingly piloted to meet the distinct psychosocial needs of AYAs (Beale, Kato, Marin-Bowling, Guthrie, & Cole, 2007; Burns, Robb, Phillips-Salimi, & Haase, 2010; Enskar, Carlsson, Golsater, & Hamrin, 1997; Neville, 2005; Olsen & Harder, 2009, 2011; Yi & Zebrack, 2010). A case in point would be the therapeutic music video intervention that was piloted with AYAs undergoing stem cell transplants and found to be effective in buffering stem cell related challenges (Burns, Robb, Phillips-Salimi, & Haase, 2010). A psycho-educational video game

designed to guide, motivate, and support appropriate self-care for AYA's during cancer treatment also significantly increased cancer-related knowledge and positive self-care behaviours (Beale, Kato, Marin-Bowling, Guthrie, & Cole, 2007). Other novel treatments successfully piloted with AYA cancer patients and survivors include Photovoice, and network focused nursing techniques. Photovoice allocates participants with a digital camera and asks participants and a partner to photograph particular themes and to discuss the images at group meetings (see Yi & Zebrack, 2010, for full review of Photovoice methodology). When implemented with AYAs, the photovoice project yielded themes relating to culture, health, reflections on positive cancer impacts, and a lost childhood, suggesting this methodology to be a successful way for AYAs to explore cancer-related thoughts and emotions (Yi & Zebrack, 2010). Finally, network-focused nursing places a clear emphasis on ensuring the social networks of AYAs are not only supported, but also maintained during cancer treatments (Olsen & Harder, 2009, 2011). This includes practices such as inviting peers to remain on the unit with AYAs, enforcing periods of "parent-free" time, and ensuring staffs are available to speak with family, friends, and teachers as to how the AYA can be supported during cancer treatments. This initiative is important, given that the social network of the AYA has been found to diminish over time and with greater treatment duration (Enskar, Carlsson, Golsater, & Hamrin, 1997; Neville, 2005). Whereas these novel and adventure-based treatments have at least preliminary supporting evidence, a multitude of AYA-led initiatives have, as of yet, to be researched. For example, peer-matching programs (Immerman Angels), online support communities (stupidcancer.com, Young Adults Cancer Canada), and individual blogs (Nalie.ca, LacunaLoft.com). Arguably, many of these resources have emerged out of a perceived lack of appropriate, available, and accessible AYA resources, thereby representing a grassroots, patient-led approach to resource development. One recently

piloted way to bring together young adults from across North America has been through adventure therapy programs.

Adventure therapy is broadly defined as the “deliberate, strategic combination of adventure activities with the therapeutic change processes with the goal of making lasting changes in the lives of participants” (Gillis & Ringer, 1999, p. 29). It is a therapeutic modality that allows participants to push personal and physical boundaries in a calculated manner, under the guidance of outdoor guides and counselors. Adventure therapy programs have been successfully piloted with a number of groups, including at-risk youth and individuals with mental health problems (Autry, 2001; Groff & Kleiber, 2001), with the research typically consisting of a mixed qualitative-quantitative approach. Although results vary depending on the group of participants, themes emerging from the research globally relate to the development of skills and competence, empowerment, the facilitation of emotional expression, and the importance of social interaction with similar peers (Autry, 2001; Groff & Kleiber, 2001; Stevens et al., 2004). The short and long-term impacts of adventure therapy have also undergone scrutiny. Using meta-analysis, Bowen and Neill (2013) attempted to assess the relative efficacy of adventure therapies in facilitating change across program outcomes from 197 adventure therapy studies. Their findings support that, in regard to facilitating short-term positive change, adventure therapy is moderately effective. Notably, the authors also noted age-related treatment effects in individuals over the age of 18 reporting stronger positive outcomes (Bowen & Neill, 2013). A challenge, however, is the lack of easily comparable data in the adventure therapy field, given low sample sizes and the lack of standardized outcome measures (Neill, 2003). Some estimates are suggesting that as few as 1% of adventure therapy programs are actually represented by the compiled data (Neill, 2003). As an additional consideration, adventure therapy typically places

emphasis on the “adventure” component of the experience as a key healing or therapeutic factor when the individual is confronting their respective issues (Beringer & Martin, 2003). The physical, natural environment is often relegated to a simply unfamiliar environment that changes the comfort level of the participant, may increase anxiety and risk, and foster change (McKenzie, 2000). However, the natural environment itself as a healing factor is supported within the literature (Frederickson & Anderson, 1999; Frumkin, 2001), and the need to accept a paradigm shift with equal emphasis on the healing power of natural environments and well as human factors is strongly advocated (Beringer & Martin, 2003; Beringer, 2004). This approach represents a holistic approach to understanding the impact of the environment as an equal factor in facilitating positive growth and change.

Research evidence provides preliminary support for the benefits of adventure therapy for oncology patients and survivors. Stevens et al. (2004) employed a health-related quality of life perspective to qualitatively examine the impact of an adventure therapy expedition for adolescents with cancer. Developing connections and emotional bonds with peers and with nature, developing a sense of “togetherness” or partnership, re-building a personal sense of self-esteem that had been impacted by cancer, and creating new memories, were the four primary themes that emerged from the research. Overall, the experience was viewed positively; results support the benefits of adventure therapy for health-related quality of life. An adventure therapy program for teenagers with cancer in New Zealand found similar results, with quantitative data supporting increased resilience and qualitative data supporting themes including being oneself, support from peers, and a strong sense of pride (Wynn, Frost, & Pawson, 2012). Research also supports the short-term benefits of adventure therapy to increase physical activity levels in young

adult cancer survivors. However, the authors advocate for the further research assessing how to maintain these gains in the long term (Gill, Goldenberg, Starnes, & Phelan, 2016).

These results are promising. However, there are many other adventure therapy programs for AYAs that have yet to be evaluated. One such program is Survive and Thrive Expeditions (STE), a non-profit organization created by an AYA cancer survivor, Michael Lang, who, after cancer treatments, realized that he would need to take active steps to take back his perceived control of life or risk ongoing distress. With this, STEs was born with the mission statement of helping “young adult cancer survivors identify, process, and apply life lessons through adventure activities.” A variety of expeditions, including rafting, kayaking, canoeing, and sailing are open to young adults aged 18 to approximately 40 years. Although informal participant feedback has described the STE experience in overwhelmingly positive terms, with comments often referring to the experience as powerful, life-changing, a wonderful bonding experience, and incredible (<http://www.survivethrive.org/about-us/participant-experiences/>), formal evaluation of the STEs have yet to be conducted.

In summary, being diagnosed with cancer as an AYA is, for most, an interruption in life progress with significant and long-standing effects including distress, decreased quality of life, disconnect from peers, financial concerns, fears of the future and disease recurrence, and disruptions to education and career, among others (Blank & Bellizzi, 2006; Hall et al., 2012; Harrison & Maguire, 1995; King et al., 2000; Kroenke et al., 2004; Parker et al., 2003; Wenzel et al., 1999). Recognition of AYA oncology and psychosocial oncology as a distinct discipline is relatively new, and efforts to meet the needs of the population are emerging but continue to lag, with grassroots organizations and AYA-led initiatives playing a significant role. However, many of these independent resources, such as adventure therapy, lack formal evaluation (Neill, 2003).

This evaluation is critical to our understanding of the role of adventure therapies as a tool to provide AYA peer support and positively impact AYA cancer patients and survivors. We, therefore, aimed to provide a preliminary evaluation of one adventure therapy program, STEs, using a primarily qualitative descriptive research methodology. This study aimed to address the following research questions:

1. *What were the demographic, medical, and psychosocial characteristics of the STE participants?*
2. *What were respondent expectations prior to participating in the STE?*
3. *In the week following return from the STE, what were respondent's reflections on the experience?*
4. *Six months after returning from the STE, what were respondent's reflections on the experience?*
5. *From the perspective of an AYA cancer patient or survivor, what are the main emotions AYAs feel throughout their cancer experience?*
6. *From the perspective of an AYA cancer patient or survivor, what are the main life issues AYAs deal with throughout their cancer experience?*
7. *From the perspective of an AYA cancer patient or survivor, what are the main needs of AYAs throughout their cancer experience?*

## **Method**

### **Participants and Recruitment**

Recruitment to STE programs was conducted by Michael Lang, STE creator, and administrator. Participants were recruited broadly using social media (Facebook, Twitter), word of mouth, and through the Survive and Thrive Cancer Programs website

([www.survivethrive.org](http://www.survivethrive.org)). Individuals interested in participating in the adventure therapy contacted Lang to discuss expedition details and, if interested, were asked to complete registration forms and medical clearance forms. This discussion ensured that individuals were suitably prepared for the potential physical and psychological rigors of participating in one of the four available expeditions. Notably, only one aspiring participant to date was deemed unsuitable for the expedition.

A total of five STEs took place between July 2013 and to October 2014; all cancer patients and survivors participating in these 5 STEs were invited to participate in the first survey. The original email invitation to participate consisted of the information letter (explaining the general purpose of the research, what the surveys queried, and information on the researchers) and link to the survey. This email was sent to STE participants by Michael Lang, thereby ensuring that the personal information of STE participants was not shared with the researchers without consent; follow-up time 2 and 3 surveys links and information letters were emailed directly by the researchers to respondents who agreed to participate. At each time point, non-responders were emailed a second time after 2-3 days, and a third and final time after 6-7 days. Respondents were advised that they would be entered into a random prize draw (\$50.00 gift certificate at time one, \$75.00 gift certificate at time two, iPod nano at time three). Online questionnaire was administered using the FluidSurveys platform ([fluidsurveys.com](http://fluidsurveys.com)).

### **Description of the Survive and Thrive Expeditions**

Survive and Thrive Expeditions included in this research were rafting the Grand Canyon (rafting expedition), sailing the Discovery Islands (sailing expedition), and kayaking the lower Owyhee River (kayaking expedition): each will be briefly discussed and compared. The rafting expedition was a 7-day river trip on a motorized craft, travelling 188 river miles. Days were

spent exploring the breathtaking landscape, canyons, ruins, and streams of the Grand Canyon, Arizona. The trip was offered at the cost of \$1700.00 to participants (plus travel expenses). The sailing expedition was a 7-day trip around the Discovery Islands (British Columbia), at the cost of \$440.00 (plus travel expenses) to participants. Days were spent in tasks such as learning basic navigation and sailing, whale watching, camping each night ashore, and hiking to inland locations. Finally, the Owyhee River kayaking expedition spanned 8 days, with participants navigating 72 km of Class 1 to 3 rapids, experiencing the pristine scenery, and exploring canyons and landscapes across Idaho and Oregon. This expedition was offered at the cost of \$660.00 to participants (plus travel expenses). Maximum number of participants on each expedition also varied, with 8 to 12 participants welcome on the kayaking and sailing expeditions, and 20 to 24 on the rafting. By providing a selection of STE opportunities, potential participants are able to choose a trip that fits with their interests, physical abilities, and availability. Consider for example that navigating the Grand Canyon in a motorized craft is perhaps less physically daunting than independently kayaking the Owyhee River and its rapids. However, for some there is also appeal to be able to navigate a solo kayak, as opposed to spending travel time in close proximity with peers in a raft or sailboat.

In terms of personnel, STE founder and adventure guide Michael Lang, his wife and fellow guide Bonnie Lang, 2 to 4 additional outdoors guides (at least one of whom has emergency medical training), and a psychosocial support person participated in each expedition as well. As expeditions can be challenging both physically and psychologically, participants were invited to bring a friend or partner with them for support. Fundraising was available to those for whom the cost was a barrier, and participants were responsible for travel expenses to



the departure city. Medical clearance was required for AYA cancer patients and survivors prior to participating.

Across all expeditions, there was an emphasis on exploring psychosocial skills (including daily quiet time, daily personal journaling, guided meditation, storytelling, creating a mission statement for life), connecting with other cancer patients and survivors, sharing personal stories and experiences, and focusing on living well with and post-cancer. Expeditions also incorporated a 24-hour period of isolation from peers, allowing time for in-depth personal reflection. Finally, although there were individual elements to each STE, each expedition also emphasized working together as a team, communication with peers, and social skills. In summary, STEs use a combination of travel, adventure, physical challenges, reflection time, and exploration of the cancer journey to help AYA cancer patients and survivors to open up to one another and to themselves, to connect with one another, and to take dedicated time in nature to process the impacts of cancer diagnosis and treatment.

### **Study Design**

A qualitative descriptive (QD) research methodology was selected, as the primary goals of the research were descriptive in nature. Specifically, QD is the method of choice when seeking a straight-forward description of events/interventions, when researchers are attempting to delineate the basic who/what/where of interventions/events, when the goal is to develop/refine interventions/questionnaires, and when examining a poorly understood phenomenon (Kim, Sefcik, & Bradway, 2016; Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). A QD research methodology also allows for the integration of quantitative and qualitative data collection methods.

The study used an online survey administered at three-time points: time 1 (in the 10 days prior to leaving for the STE), time 2 (in the week following the STE), and time 3 (6-7 months after returning from the STE). Eligibility for the study included: (a) cancer patient or survivor between the ages of 18 and 45 years (b) participant in a Survive and Thrive expedition. Ethical approval for this study was granted by the Thunder Bay Regional Health Sciences Centre and by Lakehead University (Thunder Bay, Ontario).

### **Instruments**

The majority of questions were developed specifically for this study. Consistent with a qualitative descriptive research methodology, the questions were designed to elicit straight information on the participant characteristics, their expectations of the STE, their perceptions after participating in the STE, and their perspectives on the AYA cancer experience. Questions were designed and reviewed by the author (a clinical psychology doctoral student), Michael Lang (STE organizer), and a clinical psychologist specializing in oncology care. Questionnaire development was guided by Burgess' "A general introduction to the design of questionnaires for survey research (2011). Specifically, research aims were decided, population and sample identified, the procedure for collecting questionnaire data was decided, followed by questionnaire design and research ethics board review and approval of the questionnaires.

The time 1 questionnaire assessed:

1. *Demographic information (age, sex, marital status, education completed, ethnicity, household income);*
2. *Medical information (age at diagnosis, stage of disease, type of cancer, cancer treatments received and expected, smoking status, drinking status);*

3. *Psychosocial information (distress as measured by the Hospital Anxiety and Depression Scale - HADS; use of individual counseling, group counseling, and online supports);*
4. *Open-ended questions querying respondent expectations prior to participating in the STE (what participants hoped to gain by participating in the STE, any concerns or fears going into the expedition, what they were most excited about, and what they were least excited about);*
5. *Open-ended questions querying the AYA cancer experience (what are the three main emotions, life issues, and needs of a young adult throughout his or her cancer experience).*

The time 2 questionnaire assessed:

1. *In the week following return from the STE, what were respondent's reflections on the experience (what, if anything, they felt they gained from participating, what was most challenging, what was most rewarding, what had the greatest impact, any perceived individual change, what was enjoyed the most, and what was enjoyed the least).*

The time 3 questionnaire assessed:

1. *Six months after returning from the STE, what were respondent's reflections on the experience (what, if anything, they felt they gained from participating, what was most challenging, what was most rewarding, what had the greatest impact, any perceived individual change, what was enjoyed the most, and what was enjoyed the least);*
2. *Open-ended questions querying the AYA cancer experience (what are the three main emotions, life issues, and needs of a young adult throughout his or her cancer experience);*
3. *Distress as measured by the Hospital Anxiety and Depression Scale.*

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) has been widely used with cancer patients and is considered to be a reliable screening tool (Carroll, Kathol, Noyes, Wald, & Clamon, 1993; Razavi, Delvaux, Farvacques, & Robaye, 1990; Sellick & Edwardson, 2007). Large-scale sample data support the strong psychometric properties of the HADS, based on factor structure, internal consistency, and intercorrelations (homogeneity) of subscales (Mykletun, Stordal, & Dahl, 2001). The HADS consists of 14 items, with 7 items each loading onto anxiety and depressive subscales. Each item is scored on a 4-point scale ranging from 0 to 3, allowing for a maximum score of 21 on each subscale, and a maximum total score of 42. A score above 10 on either scale is thought to be indicative of probable emotional distress. Similarly, scores of 8 or above on both scales are also considered to be within probable risk range. The HADS takes approximately three to five minutes to complete, and was administered in the online questionnaires at time one and time three.

### **Data Coding and Analyses**

Demographic, medical, and psychosocial data was coded numerically and entered into SPSS 25.0, and used to describe overall sample characteristics. Respondent expectations prior to participating in the STE, and reflections in the week after returning as well and 6 months post were queried using open-ended questions. Responses were analyzed using thematic analysis (Braun & Clark, 2006). Specifically, thematic analysis phases consist of: 1) developing a familiarity with the data 2) creating preliminary codes 3) searching for themes within the codes 4) reviewing these themes 5) generating clear definitions and names for the themes and 5) producing a final report (Braun & Clark, 2006). Thematic analysis, wherein themes are directly derived from the data, is consistent with a qualitative descriptive research methodology (Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Participant responses of main emotions,

needs, and life issues experienced by AYAs throughout their cancer experience were coded in a more basic manner, as the questions yielded single-word responses. As such, again consistent with a qualitative descriptive research methodology, our goal was to ensure codes were directly derived from the data, with a focus on summarizing and categorizing the data (Hsieh & Shannon, 2005; Sandelowski, 2000). All qualitative data was coded, classified, and interpreted by a clinical psychology doctoral student, and reviewed by a licensed clinical psychologist.

## Results

### Sample Characteristics

A total of 22, 20, and 17 respondents completed the survey at time 1, 2, and 3, respectively. Detailed demographic data, as well as medical health information and use of psychosocial support services for participants, are presented in Tables 1, 2, and 3. At time one, the mean age of our sample at the time of diagnosis was 28.8 years ( $SD = 5.3$ ) and mean age at the time of the expedition was 32.5 years ( $SD = 5.4$ ). Our sample was well educated with the majority having completed an undergraduate or graduate degree. However, household income was less than \$75,000 for over 80% of the sample. More than half the sample (68.5%) was diagnosed at stage 1 or 2, and over 70% had completed surgery or chemotherapy in the past. Hospital Anxiety and Depression Scale scores were notably high, with over half of the sample reporting levels of distress that represent probable clinical cases. Half of the sample (50%) reported having attended one-to-one counselling that was helpful to them, and 28% of the sample reported attending group counselling that was helpful.

Table 1

#### *Demographic Characteristics of Respondents*

	Time 1	Time 3
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	( <i>N</i> = 22)	( <i>N</i> = 17)
	<i>N</i> (%)	<i>N</i> (%)
<b>Age at expedition</b>		
Mean ± SD	32.5 ± 5.4 years	-
Range	20-41 years	-
<b>Sex</b>		
Male	7 (31.8%)	3 (17.6%)
Female	15 (68.2%)	14 (82.4%)
<b>Marital status</b>		
Single	17 (77.3%)	13 (76.5%)
Married/Common-Law	3 (13.6%)	2 (11.8%)
Separated/Divorced	2 (9.1%)	2 (11.8%)
<b>Highest level of education completed</b>		
High school	2 (9.1%)	0
College	2 (9.1%)	1 (5.9%)
Undergraduate degree	11 (50.8%)	9 (52.9%)
Graduate degree	7 (31.8%)	7 (41.2%)
<b>Ethnicity</b>		
White/Caucasian	20 (90.9%)	16 (88.9%)
White/Asian	1 (4.5%)	1 (5.6%)
Missing	1 (4.5%)	1 (5.6%)
<b>Household income (CAD)</b>		

Less than \$25,000	5 (22.7%)	4 (18.1%)
\$25,000 to \$75,000	10 (45.5%)	10 (45.5%)
Greater than \$75,000	3 (13.6%)	1 (4.5%)
Missing	4 (18.2%)	1 (4.5%)

Table 2

*Medical and Psychosocial Characteristics of Participants*

	Time 1 (N = 22) N (%)	Time 3 (N = 17) N (%)
<b>Age at diagnosis</b>		
Mean ± SD	28.8 ± 5.3 years	-
Range	17-38 years	-
<b>Hospital Anxiety and Depression Scale</b>		
Anxiety subscale (Mean ± SD)	8.6 ± 3.5	8.6 ± 3.9
Depression subscale (Mean ± SD)	4.8 ± 3.2	5.0 ± 3.6
Total scale (Mean ± SD)	13.5 ± 5.6	13.6 ± 6.3
Score above threshold = probable distress	12 (54.5 %)	10 (58.8%)
<b>Stage of disease</b>		
Stage 0	1 (5.3%)	0
Stage 1	4 (21.1%)	3 (21.4%)
Stage 2	9 (47.4%)	8 (57.1%)

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Stage 3	3 (15.8%)	3 (21.4%)
Stage 4	2 (10.5%)	0
Type of cancer		
Breast	5 (22.7%)	5 (29.4%)
Hodgkin's Lymphoma	3 (13.6%)	2 (11.8%)
Testicular	2 (9.1%)	0
Melanoma	2 (9.1%)	2 (11.8%)
Other (Rectal, Osteo-sarcoma, Seminoma, Non-Hodgkin's Lymphoma, Burkett's Lymphoma, Thyroid, ALL, AML, Cystic Mucinous Neoplasm, Pure Red Cell Aplasia)	10 (45.0%)	8 (47.1%)
Type of treatments received in past		
Radiation therapy	8 (36.4%)	6 (35.3%)
Chemotherapy	18 (81.8%)	14 (82.4%)
Surgery	16 (72.7%)	13 (76.5%)
Hormone therapy	5 (22.7%)	5 (29.4%)
Bone marrow / stem cell transplant	4 (18.2%)	3 (17.6%)
Type of treatments I will need in the coming months		
Radiation therapy	2 (9.1%)	2 (11.8%)
Chemotherapy	1 (4.5%)	1 (5.9%)
Surgery	1 (4.5%)	1 (5.9%)

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Hormone therapy	2 (9.1%)	2 (11.8%)
Bone marrow / stem cell transplant	0	0
Smoking status		
Quit smoking	6 (27.3%)	4 (23.5%)
Never smoked	16 (72.7%)	13 (76.5%)
Drinking status		
Non-drinker (0 drinks/week)	8 (36.4%)	6 (35.3%)
1-3 drinks/week	10 (45.4%)	8 (47.1%)
5+ drinks/week	4 (18.1%)	3 (17.6%)

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Table 3

*Use of Psychosocial Services: Have You Used Any of The Following Resources? (Time 1; n = 22)*

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	Yes, it was very useful	Yes, it was somewhat useful	Yes, it was not very useful	No, did not try	Not offered. However I would like to try
One to one, in person counseling	11 (50%)	2 (9.1%)	2 (9.1%)	7 (31.8%)	0

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Group counseling, in person	6 (28.6%)	3 (14.3%)	1 (4.8%)	10 (47.6%)	1 (4.8%)
One to one counseling, online	0	0	0	19 (100%)	0
Group counseling, online	0	1 (5.3%)	0	18 (94.7%)	0
Searching for information online	0	3 (15.8%)	3 (15.8%)	13 (64.8%)	0
Connecting with others online	2 (10.0%)	5 (25.5%)	0	12 (60.0%)	1 (5.0%)

*Note:* Respondents reported using the following “other” resources: Friends and family, social media, AYA retreats, relaxation/visualization, tai chi, wellness classes, a puppy, mindfulness meditation.

Respondents *would have liked* to have available to them: Peer support from an AYA cancer patient or survivor (online, in person, or by telephone), closer support groups and classes, art therapy.

**Open-ended Questions Assessing the Survive and Thrive Expedition**

Key themes that emerged from open-ended questions at time one (prior to leaving on the expedition), at time two (in the week following their return from the expedition) and at time three (six-months post-expedition) are provided in tables 4, 5, and 6, respectively. Before leaving on the expedition (time 1), participants aimed to connect with nature, connect with peers, to encourage personal growth, to face their personal fears, and to enjoy a break from daily life. Although most participants reported no fears or concerns about the trip, some reflected practical concerns (such as the ability to physically keep up, and the rigors of living outside) and concerns about connecting with peers. Participants reported the greatest excitement for being in nature and meeting and connecting with peers, whereas they had the least excitement for practical issues

such as the physically demanding aspects of the trip and living outside, and least excitement for emotional concerns related to connecting with peers, opening up, and discussing their cancer.

Table 4

*Respondent Perceptions of the STE Prior to Participating*

Open-ended questions	Key themes	Expanding on key themes
Q1: What did you hope to gain from participating in the STE?	Connecting with nature	Desire to connect with nature, enjoy the beauty of nature, to enjoy and be amazed by beautiful scenery
	Connecting with others	Wanting to connect with other adolescent and young adult cancer patients and survivors, to connect with others who have had similar experiences and similar stories, to gain connections and support from individuals facing similar challenges
	Personal growth	Desire to reflect and gain personal insight into their cancer experience, desire to be inspired, to challenge myself, a place to grow and heal
	Break from daily life	Wanting to take a break from the “insanity” from daily life, a vacation, time away from the routines of daily life
	Facing fears	Wanting to face and conquer personal fears, to be adventurous and to regain a sense of adventure
Q2: From what you	No concerns	No concerns or fears reported.
	Practical	Concerns related to ability to meet the physical demands of

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<p>know about this trip, is there anything you are concerned about or afraid of?</p>	<p>fears</p> <p>Interpersonal concerns</p>	<p>the expedition, fears related to local wildlife, concerns that weather may be poor, and concerns from with distance from specialized medical care</p> <p>Moderate nervousness with meeting new people, concerns regarding the ability to connect and communicate with others</p>
<p>Q3: What are you most excited for?</p>	<p>Being in nature</p> <p>Meeting and connecting with peers</p>	<p>Excitement to be spending such a great deal of time in nature, for the adventure, for the ability to explore</p> <p>Excitement to connect with other adolescent and young adult cancer patients and survivors</p>
<p>Q4: What are you least excited about?</p>	<p>Nothing</p> <p>Practical concerns</p> <p>Emotional concerns</p>	<p>“Nothing”</p> <p>Concerns related to the physical challenges of the trip and sleeping outside, dealing with both hot and cold temperatures</p> <p>Feeling hesitant to discuss their feelings, their cancer experience, concerns that they might not connect with others</p>

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Immediately after returning from the expedition (time 2), participants reflected that they gained valuable connections with peers, personal growth including increased strength and

confidence, gained an appreciation for nature, time to reflect on life and life choices, and inspiration to move ahead (Table 5). The most rewarding aspects of the STE expedition were identified as the newly developed peer network, pushing personal physical limits, experiencing the beauty of nature, and the assigned quiet time to self-reflect. In contrast, the most challenging aspects of the STE discussed by participants were the physical such as fatigue and exhaustion, interpersonal challenges relating to minor conflict between group members, facing personal fears and anxieties, and practical issues related to the lack of privacy and living in the wilderness. Respondents reflected that connecting with others, being in nature, alone time to reflect, and group activities were expedition highlights that had the greatest impact on them. Consistent with this, the majority of respondents reported feeling that they had changed in various ways as a result of the STE, with only two respondents stating that they were not sure. Finally, respondents were asked to comment on what they enjoyed the most and least. As was reported previously, connecting with peers, spending time in nature, and personal growth were identified as the most enjoyable aspects of the trip. In regard to the least enjoyable, it is notable that the majority of respondents reported “nothing.” However, some respondents reflected that practical concerns associated with physical challenges and living in nature were not enjoyable. Difficulty connecting with the group and peers, and discomfort with an underlying religious tone to some conversations were also reported by a minority of group members. As general comments, the majority of participants provided overwhelmingly positive feedback.

Table 5

*Respondent Perceptions of the STE in the Week Following Participating*

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Open-ended	Key themes	Expanding on key themes
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questions

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<p>Q1: What, if anything, did you gain from participating in this “Survive and Thrive” expedition?</p>	<p>Meeting and connecting with peers</p> <p>Personal growth</p> <p>Nature</p> <p>Reflection</p> <p>Moving ahead</p>	<p>Connecting with other survivors, great conversations with individuals and the group, meeting beautiful people, making new family and friends, feeling as though their personal community expanded</p> <p>Increased sense of personal strength and confidence, increased self of accomplishment</p> <p>Gained the ability to connect with nature, appreciation for the natural wonders, an increased connection with nature</p> <p>Time to reflect on life, consider life choices, connect with personal spirituality</p> <p>Expedition was a source of inspiration to develop support initiatives in their hometowns, a feeling of hope moved ahead from the realization they were not alone</p>
<p>Q2: What was the most rewarding part of the experience?</p>	<p>Peer network</p> <p>Physical</p> <p>Nature</p>	<p>Connection with others was extremely rewarding, moving from strangers to friends and family, being part of a community that understands</p> <p>Respondents reported that the trip was a chance to accomplish physically demanding activities, to push personal limits, and to affirm themselves physically</p> <p>Experiencing the beauty of nature, being able to experience nature for an extended period of time, and being</p>

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		disconnected
	Reflection	Respondents were rewarded by the quiet time, time to reflect, to think about self, to learn about self, and to consider who they are and the plans moving ahead
Q3: What was the most challenging part of the experience?	Physical	Personal physical challenges, significant fatigue, that a great deal – perhaps too much – was packed into each day
	Interpersonal challenges	Challenges emerging from cultural and political differences among group members, feeling as though some group members were hostile, and feeling as though there could have been greater intervention by group facilitators
	Personal fears	Anxiety about the trip, trying to let go of personal issues holding them back, and the difficulty of having “tough” conversations
	Practical issues	Lack of privacy, lack of private moments, the great amount of time spent in the group, the challenges of living outside including bugs, wildlife, and poor weather, the lack of control over food/diet
Q4: What had the greatest impact on you?	Connecting	Power of hearing others stories, being inspired by the strength of other’s, learning from others, connecting with others, bonding with others in the group
	Nature	Being in nature, the positive energy from being in the

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		wilderness, nature’s beauty, the impact of being in nature
	Alone time	Periods of alone and solo time identified as being greatly beneficial, including the solo time outside, morning reflection, other periods alone
	Group activities	Organized activities such as hiking, journal time, and receiving letters from loved ones had a great impact
Q5: Do you think you have changed as a result of participating in this expedition? If so, how?	Yes	Overwhelmingly, respondents felt that they had changed as a result of participating in the expedition, including feeling more confident in self and personal choices, more patient, feeling motivated to help others, more connected with others, more relaxed and at ease, more compassionate, gaining a fresh perspective on how to live life, and desire for nature to be a part of their life
	Don’t know	Two respondents reflected that they were unsure if they had actually changed as a function of participating
Q6: What did you enjoy the most?	Connecting	Exchanges with the group, connecting with others, sharing stories, meeting new friends
	Nature	Being in nature, connecting with nature, enjoying the experiences outside
	Personal	Challenging myself, focusing on the present moment,

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	growth	opening my eyes to new experiences, looking at my life
Q7: What did you enjoy the least?	Nothing	Nothing, enjoyed it all
	Practical concerns	Some of the food/lack of vegetables, food allergy contamination issues, local insects, and wildlife, cold, heat, rain, physical exhaustion
	Interpersonal	Not feeling connected with the group, not feeling connected with one particular individual, feeling as though most group members were focused on the positive and, therefore it was hard to share more negative emotions, feeling as though group members did not realize not everyone is cured, feeling as though I was not welcome to share pain, that those still grieving and struggling felt “overwhelming excluded” by the positive focus
	Faith	The focus on Christianity and discomfort with the concept of others saying they will “pray for you,” discomfort with the religious component
Q8: Any other comments or thoughts you would like to share?	Positive feedback	“Highly recommended,” “best decision I have made in a long time,” “these young adult programs are immensely important,” “I loved it all so much,” “trip of a lifetime,” “grateful to be a part of it.”
	Neutral /	“I am less interested in the young adult cancer community,”

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Negative feedback	“I had to carve what I needed out of the itinerary provided,” “I felt very much excluded from the guidance of the organizers which focused on building positive goals while some of us were still in the process of grieving our loss.”
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Approximately 6 weeks after returning from the expedition, participants were once again asked to reflect on the experience by answering the same open-ended questions that were posed at time 2 (see Table 6). Respondents reflected that peer connections were gained from participating, were the most rewarding part of the experience, had the greatest impact on them, and were enjoyed the most. When queried how respondents felt they had changed as a result of participating, personal growth was one of the key themes that emerged. Personal growth was also reported as a theme for what was gained from participating. Interestingly, respondents reflected that the physical challenges of the trip were both the most challenging and most rewarding aspects of the STE. Participants also reflected that connecting with nature was very rewarding, whereas other challenging aspects of the experience included internal challenges such dealing with strong emotions, practical concerns associated with living in nature and dealing with the elements, and interpersonal challenges such as being part of the group at all times, and one participant reflected feeling excluded from the group. In addition to peer connections, respondents discussed being in nature and alone time to reflect as aspects of the trip that had the greatest impact on them. Increased perceived personal strength was also reported as one of the key ways in which respondents felt changed by the trip. In terms of what was enjoyed the most and the least, in addition to peer connections, being in nature, planned activities, and alone time to reflect were highlighted as most enjoyable, whereas least enjoyable aspects of the trip included practical concerns associated with the food restrictions and living in nature, personal



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	challenges	personal limits
	Connecting with nature	Experiencing the great outdoors, the beauty of nature, connecting with nature
Q3: What was the most challenging part of the experience?	Physical challenges	Facing personal physical limitations, feeling physically exhausted
	Internal challenges	Feeling very emotional, difficulty in letting go of negative emotions like fear and anger and moving forward, introspection, saying goodbye,
	Practical concerns	Dealing with the elements, feeling cold, being sunburnt, having to portage, rainy weather
	Interpersonal	At times hard to be around a group of people so much, feeling as though I had little in common with the group, feeling excluded from the group, feeling like leaders did little to intervene
Q4: What had the greatest impact on you?	Peer connections	Sharing with others, talking to others, hearing the stories from other participants, friendships, affirmations
	Nature	The immensity of nature, beauty of nature, cliff jumping, “whenever I am having a tough time, I think of the scenery that day...”
	Alone time	Solo time, personal reflection time

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		feelings
	End	Leaving new friends, the end
	Interpersonal	Challenging to interact with one participant, in particular, challenging to interact with the group
Q8: Any other comments or thoughts you would like to share?	Positive feedback	The trip changed my life, it was a good/great/wonderful/terrific program and experience, one of the best decisions I ever made, a beautiful and rich experience, very important to my healing and facing life
	Negative feedback	One individual expressed concern with the group dynamics, and reported feeling alienated by the group

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**Open-ended Questions Assessing the Main Emotions, Life Issues, and Needs of AYA Patients and Survivors**

Coding and analysis of what respondents identified as the main emotions, life issues, and needs that young adults deal with throughout their cancer experience at time one (prior to the STE) and again at time three (approximately 6 months post) are provided in tables 7, 8, and 9, respectively. In regards to emotions, at both time points, respondents identified feeling isolated, externalizing emotions such as anger and frustration, and negative internalized emotions such as sadness, fear, hopelessness, and anxiety. Only at time one did participants report positive emotions, and the traumatized theme.

Table 7

*What Do You Believe Are The Three Main Emotions Young Adults Feel Throughout Their Cancer Experience?*

<i>N</i> (%)	<b>Time 1:</b> Before leaving on the STE (66 responses)	<i>N</i> (%)	<b>Time 3:</b> Follow-up 6 months post STE (51 responses)
Isolation 7 (10.6%)	Lonely (2), alone (1), isolation (1), feeling alienated (1), not understood (1), feeling different (1)	Isolation 9 (17.6%)	Isolation (4), loneliness (3), feeling different from peers (1), abandonment (1)
Positive 4 (6.1%)	Courage (1), Joy (1), Hope (1), Grateful to be alive (1)	-	-
Negative: Externalizing 12 (18.2%)	Anger (9), frustration (3)	Negative: Externalizing 9 (17.6%)	Anger (7), frustration (2)
Negative internal: Sadness 12 (18.2%)	Sadness (4), depression (2), grief (2), sorrow (1), shame (1), failure (1), loss (1)	Negative internal: Sadness 8 (15.7%)	Sadness (3), grief (3), numbness (1), shame (1)
Negative internal: Fear 12 (18.2%)	Fear (10), frightened (1), scared (1)	Negative internal: Fear 14 (27.5%)	Fear (13), fear of the unknown (1)
Negative internal: Anxiety 11 (16.7%)	Anxiety (6), uncertainty (2), worry/stress (2), confused (1)	Negative internal: Anxiety 6 (11.8%)	Anxiety (4), stress (1), uncertainty (1)
Traumatizing 4 (6.1%)	Shock (1) disbelief (1), whirlwind (1), cursed (1)	-	-
Hopelessness 4 (6.1%)	Helplessness (1), powerless (1), how fragile life is (1), vulnerability (1)	Hopelessness 5 (9.8%)	Why me (2), futility (1), vulnerability (1), surrender (1)

Life issues identified by STE participants remained largely unchanged from time one to time three, with the core themes of practical concerns, treatment effects, relationships, and psychological issues. Participants reported practical concerns related to financial independence and career development and maintenance. Treatment effects included trying to maintain independence, changes in physical health and appearance, fertility, and pausing and questioning

life. Relationship issues included concerns with romantic relationships and changes in relationships with family and friends. Finally, psychological issues included dealing with isolation and adjusting to a new life. At time one, participants also reflected psychological issues related to survival and mortality, whereas at time three concerns with future anxiety were communicated.

Table 8

*What do you believe are the three Main Life Issues that Young Adults Deal with throughout their Cancer Experience?*

Time 1: Before leaving on the STE (66 responses)			Time 3: Follow-up 6 months post-STE (51 responses)		
<i>N</i> (%)	<i>N</i> (%)		<i>N</i> (%)	<i>N</i> (%)	
Practical concerns 21 (31.8%)	Financial 12 (18.2%)	Financial concerns (10), financial instability (1) economical (1)	Practical concerns 18 (35.3%)	Financial 10 (19.6%)	Finances (5), health insurance/money (2), financial hardship (1), financial uncertainty (1), access to resources (1)
	Career 9 (13.6%)	Developing and maintaining a career (9)		Career 8 (15.7%)	Career (5), putting career on hold/starting later (1), career interruptions (1), getting established in a career (1)
Treatment effects 18 (27.3%)	Independence 4 (6.1%)	Lack of independence (4)	Treatment effects 13 (25.5%)	Independence 5 (9.8%)	Trying to keep independence (2), trying to maintain day to day living (1), getting back to normal (1), having strength to meet goals (1)
	Physical health / appearance 4 (6.1%)	Changes in physical health (2), loss of mobility / health (1), impact of treatments (1)		Physical health / appearance 2 (3.9%)	Body changes and scars (1), changes in physical ability (1)



	Fertility 6 (9.1%)	Fertility (5), possibility of infertility (1)		Fertility 5 (9.8%)	Fertility problems (3), ability to have children (1), negative impact on sexuality (1)
	Pausing and questioning life 4 (6.1%)	Putting life on hold (1), losing time at a critical point in life (1), questioning life (1), questioning identity (1)		Pausing and questioning life 1 (2.0%)	Changes in values and priorities in life (1)
Relationships 16 (24.2%)	Relationships with family/friends 12 (18.2%)	Relationships with family/friends (9), loss of ability to connect with peers (1), dealing with emotions and reactions of others (1), social ridicule (1)	Relationships 13 (25.5%)	Relationships with family / friends 10 (19.6%)	Relationships with family / friends (7), changes in friendships (1), how you will be seen socially because of cancer (1), learning who your friends are (1)
	Romantic relationships 4 (6.1%)	Dating/discussing diagnosis with partner (3), impact on intimate relationships (1)		Romantic relationships 3 (5.9%)	Romantic relationships (2), how to meet new people or make it work (1)
Psychological issues 11 (16.7%)	Survival and mortality 4 (6.1%)	Anxiety about death (1), mortality (1), life is fragile and we are not invincible (1), survival (1)	Psychological issues 7 (13.7%)	Future uncertainty 2 (3.9%)	Fear of recurrence (1), searching and finding negative information online (1)
	Isolation 3 (4.5%)	Feeling isolated (2), emotional vulnerability (1)		Isolation 3 (5.9%)	Isolation (2), feeling alone (1)
	Adjusting to life 4 (6.1%)	Trying to maintain normalcy (2), constant living with uncertainty (1), lack of control (1)		Adjusting to life 2 (3.9%)	Future life, children, work (1), future (1)

The main needs of young adults throughout their cancer experience also remained consistent from time one to time three, with the global themes of support, practical concerns, treatment-related needs, and needs related to moving ahead. Specifically, support was the most heavily endorsed need with over half of the sample identifying the sub-themes of emotional support, support from family and friends, support from other survivors, physical support, and other supports. Practical concerns at both times were associated specifically with financial needs, whereas treatment-related needs included access to quality healthcare services, and access to appropriate treatment information. Finally, the global theme of moving ahead included the subthemes of engaging in healthy living activities, and a desire to look ahead and look forward.

Table 9

*What do you believe are the Three Main Needs of Young Adults Throughout their Cancer Experience?*

Time 1: Before leaving on the STE (66 responses)			Time 3: Follow-up 6 months post-STE (51 responses)		
N (%)	N (%)		N (%)	N (%)	
Support 34 (51.5%)	Emotional support 5 (7.6%)	Emotional support (3), love (1), care (1)	Support 29 (56.9%)	Emotional support 3 (5.9%)	Emotional support (2), love (1),
	Support from family/friends 14 (21.2%)	Support from family and friends (12), a partner/spouse (1), surround self with supportive people (1)		Support from family and friends 11 (21.6%)	Support from family and friends (8), social support (1), true friends (1), quality support system (1)
	Support from other survivors	Meet other survivors (4), people you can relate to (2), cancer counselling (1),		Support from other survivors	Network of other young adult cancer patients (5), face to face interaction with other

	9 (13.6%)	patient groups (1), socializing (1)		8 (15.7%)	young adult cancer patients (2), retreats with other young adult cancer patients (1)
	Physical support 2 (3.0%)	Physical support and care (1), help for everyday chores (1)		Physical support 2 (3.9%)	Practical support for daily tasks like cooking and cleaning (1), exercise support (1)
	Other support 4 (6.0%)	Pet (1), no judgment (1), community support (1), stable support (1)		Other supports 5 (9.8%)	Community support (2), one to one counselling (2), environment that makes you comfortable to share (1)
Practical concerns 9 (13.6%)	Financial / career 9 (13.6%)	Financial support (5), money (1), financial and medical coverage (1), accommodations from work and school (1), maintaining independence (1)	Practical concerns 6 (11.8%)	Financial 6 (11.8%)	Financial (5), access to financial and health insurance resources (1)
Treatment-related needs 9 (13.6%)	Healthcare 4 (6.0%)	Access to high-quality healthcare team (3), knowing how to navigate the healthcare system (1)	Treatment-related needs 6 (11.8%)	Healthcare 3 (5.9%)	Access to excellent medical care (1), a good medical team to help feel secure (1), information about adolescent and young adult cancer specific resources (1)
	Information 5 (7.6%)	Understanding fertility options (2), understanding all treatment options (1), information (1), access to all information despite young age (1)		Information 3 (5.9%)	Information and resources (1), information, as we often don't know what is happening or why (1) advice or direction from someone who has been there (1)
Moving	Healthy living	Healthy living support (3),	Moving ahead	Healthy living	Space and time to process,

ahead	9 (13.6%)	keeping busy / hobby (3),	10 (19.6%)	3 (5.9%)	think, and feel (1), safe
14 (21.2%)		physical activity (1),			physical activities (1),
		staying as active as			learning skills to get through
		possible (1), relaxation (1)			treatment and beyond (1)
	Looking ahead	Hope (2), moving forward		Looking ahead	Learning to accept (1),
5 (7.6%)		(1), mini-rewards every		7 (13.7%)	learning to become
		few weeks (1), get away			empowered (1), acceptance
		from it all sometimes (1)			(1), having something to look
					forward to (1), being patient
					with yourself (1), chance to
					be yourself (1), independence
					(1)

**Discussion**

Participant perceptions of the STE were examined by analyzing qualitative feedback at three-time points: prior to the expedition, immediately after returning, and six months after returning. In addition to examining the questions separately, and by question, our analyses identified global themes emerging from these questions: peer connections, the impact of nature, and personal growth and reflection. Arguably, these global themes can be considered to be of greatest importance to respondents in that they repeatedly emerged as positive aspects of the STE; each will be discussed.

Consistent with existing literature, study findings highlighted the importance of connecting with other AYA cancer patients and survivors in a meaningful way, in an isolated, technology-free environment (D’Agostino, Penney, & Zebrack, 2011; Hollis & Morgan, 2001; Treadgold & Kuperberg, 2010). Secondly, participants extolled the virtues and impact of being in nature, connecting with nature, and being isolated in a beautiful remote environment. This theme is also consistent with a significant body of research highlighting nature as a healing

factor in adventure therapy (Beringer, 2004; Beringer & Martin, 2003; Frederickson & Anderson, 1999; Frumkin, 2001). Specifically, participants referred to the scenery across trips as breathtaking and amazing, and reported an increased connection with nature, positive energy from being in the wilderness, and continuing to use visual imagery of scenery viewed as a coping strategy.

Finally, across measurement time points and questions, participants reported how the STE provided the opportunity for personal growth and reflection. The nature of the growth varied substantially by the participant, and included increased personal strength and confidence, challenging self, reflecting on life and next steps, increased self-confidence, and ability to focus my energy on goals. There appeared to be the greatest endorsements of this theme at time three, six months after returning from the STE. These findings clearly support the significant and ongoing impact of STE.

Notably, not all comments and feedback from participants were positive, in that a minority expressed concerns with the arduous physical challenges associated with living in the wilderness, interpersonal challenges associated with peers, feeling alienated by a positive focus, and the faith-based conversations. Although positive feedback certainly highlights the strengths and impact of a program, negative feedback is invaluable to understanding potential areas of weakness, promoting reflection, and creating opportunities for growth. As such, these areas of concern will be discussed.

With regard to the physical rigors of the STE, cancer patients and survivors arrive at different points in their treatment and recovery and with unique physical limitations. Prior to the expedition, being clear with participants regarding potential physical challenges is critical. This might include suggestions for participants to gently increase their activity level prior to the

expedition. For example, asking daily walkers to add 10 minutes to their walk. During the trip, facilitators and guides also have a role here in promoting positive morale and encouraging participants to do their personal best, while understanding and remaining aware of personal limitations. From an organizational point of view, the question becomes – is the STE “too” arduous? Is there benefit to further balancing the physical rigors with increased periods of mindfulness, self-reflection, or rest?

In regard to peer conflict, there is always the potential that one or two participants on each trip do not ‘connect’ as others do and as they would have liked. This can be further isolating, and especially frustrating when living in such close quarters and contact, and when you are very much unable to remove yourself from the situation. This is reflected in individuals reporting that they did not feel connected with the group, and with one particular individual feeling hostility from some group members and feeling as though facilitators could have done more to intervene. During the trip, the presence of a psychosocial care professional as well as guides with experience facilitating can help to temper interpersonal disagreements. It is also worthwhile to consider general guidelines to continue to manage same, so that isolated individuals are encouraged to continue to find connections, however tenuous, with their peers and facilitators. This might include introducing candid discussions early in the trip on respect for peers and respect for differences of opinion, as well as ongoing individual or group discussions as needed to navigate minor stressors as they emerge, and before they escalate.

Feeling alienated from the group due to a perceived pressure to remain positive is a separate issue. A number of participants reflected that it was challenging to share negative emotions given the positive, feeling as though they were not welcome to share their pain, and feeling “overwhelming excluded” by the positive focus. Cancer patients and survivors

participate at different stages of treatment, meaning whereas some may be coping with the aftermath of a diagnosis and treatment and well into remission, others may still be very much entrenched in the reality of living with cancer. Some may be striving to remain focused on the present and future, whereas others may be healing by mourning their losses and pain. During the expedition, it will be important for facilitators to both practice and model for participants how to give space and value to all emotions, thereby respecting the individuals' emotional journey. Prior to the expedition, there may be value in ensuring that group leaders are familiar with classic principles of group therapy (Vinogradov & Yalom, 1989) to allow them to focus on verbal and non-verbal interactions within the group as a way of facilitating same.

Finally, individuals stated they were uncomfortable with the focus on Christianity, including the promise of others to pray for them. Notably, although the Survive and Thrive website currently states a core philosophy of "Love God. Love People.", the religious beliefs of the organizers was not publicly reflected when this research was completed, and may have come as a surprise to participants. Transparency is advocated here; the extent of religious discussion may vary depending on the participant group, however the extent to which religious discussion is initiated by facilitators can be communicated to potential participants. As was stated above, if religious beliefs of all faiths are welcome and tolerated, group therapy skills might help facilitators to model tolerance and manage potential discord.

In summary, the negative feedback provides the opportunity to reflect on aspects of the STE that may have been challenging, frustrating, or potentially harmful for participants. Action may not always be required, but reflection is always wise.

What participants perceived as the main emotions, needs, and life issues facing AYA cancer patients and survivors was also assessed. Key main emotions included feelings of

isolation, fear, sadness, and anxiety. In regards to main life issues and needs, the importance of support and relationships was reported, reflecting similarity with STE open-ended questions listed above. Respondents also indicated the clear importance of practical concerns and treatment-related needs. Notably, there was little variation in responses from time one to time three. This is partially attributable to the phrasing of the questions, in that the main needs, emotions, and life issues “throughout” the cancer journey were queried, rather than the primary concerns at a particular point in time. This phrasing was selected as participants were at different points of their cancer journey when they partook in the STE, and the goal was to assess whether participating in an STE – and connecting with other AYA patients and survivors – resulted in a change in global impressions of needs, life issues, and emotions faced.

### **Study Limitations and Future Directions**

Although based on a relatively small sample size, we were able to conduct a fairly in-depth investigation of the perceptions and impact of participating in an STE. Additionally, the generalizability of these findings are strengthened by being collected from Survive and Thrive participants from five separate expeditions over a two-year period. Second, the demographic and psychosocial characteristics of participants indicate a sample that is primarily Caucasian, highly educated, with a history of counseling, and with ongoing distress (over half reported probable clinical distress as based on the HADS). This sampling bias may reflect the types of individuals who are most likely to choose to participate in adventure therapy program, as opposed to relying solely on more traditional psychosocial tools or supports. Finally, the online questionnaire format with open-ended questions employed in the current study allowed for participants to easily complete the measure from the comfort of their home and at their convenience, and allowed for assessment at multiple time points. However, it did not provide the depth of an individual



interview in that the vast majority of responses received were single word responses or very brief.

In terms of next steps, a larger sample size would allow us to examine participant characteristics, satisfaction, and differences across expedition type. Additionally, in an effort to understand group dynamics, there would be value to obtaining the perspectives of support people who participated in the STE in the research, rather than focusing solely on AYA cancer patients and survivors. This would perhaps also allow for a more comprehensive evaluation of the constructive criticism that was received. A larger sample size would also allow us to assess whether there are specific elements of the STE methodology that distinguish it from other AYA adventure therapy programs. Future research would benefit from attempting to delineate the impact of key themes on participants, and expanding the research to include additional quantitative methods. Additionally, further qualitative examination using open-ended interviewing would allow for more in-depth examination of the main needs, emotions, and life needs of AYAs throughout the cancer experience, and help to advance our understanding of the distinct needs of this population.

### **Summary**

Consistently, and with few exceptions, participants reflected that participating in the STE was beneficial to them, and continued to impact them positively even six months after returning. It may be difficult to delineate the specific aspects of the STE that contributed to this positive feedback. However, key themes consistently emerging from the data included the impact of peer connections, the impact of connecting with nature, and personal growth and reflection. These findings support the beneficial impact of adventure therapy for many AYAs, and the importance of evaluating novel approaches to care.

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**List of Appendices**

*Appendix A: Email to potential participants*

Dear Potential Participant,

You are invited to participate in a research study examining the impact of Survive and Thrive Expeditions on adolescent and young adult participants.

We are trying to understand how the participating in a Survive and Thrive Expedition impacts the individual. To do so, we have put together three questionnaires, one to be completed in a week or so before you leave on the trip, the second to be completed in the week or so following your return from the expedition, and the final to be completed approximately 6 months after the expedition.

The purpose of asking you to fill out a questionnaire at each of these times is so we can assess who you are before going on the Survive and Thrive Expedition, as well as any actual or perceived changes immediately after and in the long term.

The questionnaires ask you for:

- Basic information about you, your cancer, and any formal therapy or support you may have received.
- Any distress you might be experiencing, your social support, any uncertainty you might be experiencing, positive or negative life changes that have occurred since your diagnosis, how you are coping, and the extent to which cancer is a central part of your identity.
- Open-ended questions about the expedition, and your thoughts and impressions.

This study is being conducted by Liane Kandler (Doctoral Student in Clinical Psychology at Lakehead University in Thunder Bay, Ontario, Canada), Dr. Scott Sellick (Director, Supportive and Palliative Care, Thunder Bay Regional Health Sciences Centre, Thunder Bay, Ontario), and Dr. John Jamieson (Professor, Psychology Department, Lakehead University). Only these individuals will have access to the research data. These researchers have no conflicts of interest to disclose.

Participation in this study is completely voluntary. All information collected is confidential. To participate, simply complete the questionnaire at each time point.

The questionnaires may be long for you, and is estimated that each questionnaire will take about 30 to 45 minutes to complete. Because of the questionnaire length, you have the option of starting the questionnaire and returning to it at a second point in time to finish if you are completing it online, or we would happily send you an addressed and stamped return envelope if you prefer a paper copy.

To say thank you for your time and your valuable feedback, at the end of each the questionnaire you will have the option of being entered into a random prize draw.

For those who complete the first questionnaire, we will randomly pick a winner for a \$25.00 gift card for your choice of Chapters/Indigo, Canadian Tire, or Amazon.

For those who complete the first and second questionnaire, we will randomly pick a winner for a \$50.00 gift card for your choice of Chapters/Indigo, Canadian Tire, or Amazon.

Finally, for those who complete all three questionnaires, we will randomly pick a winner for a 16G iPod nano in the colour of your choice, and personally engraved, valued at \$149.00 plus tax.

This research is considered low risk, and is not expected to result in harm. However, it is noted that discussing sensitive topics such as your personal cancer experience may be intimidating and/or distressing. If you are uncomfortable answering the questions, you can decide not to or stop at any time. If answering the questions is distressful for you, please consider consulting reaching out for a medical or psychological consult. There are no direct benefits to participating in the research. However your responses will help us to understand what adolescents and young adults with cancer are facing, and how resources and tools can be better tailored to meet your unique supportive care needs.

This study has received ethics approval from Lakehead University and the Thunder Bay Regional Health Sciences Centre. This research was funded by a Doctoral Scholarship from the Canadian Institute of Health Research, awarded to Liane Kandler.

For information on the study, to obtain a copy of the results, or if you had any further questions, please contact Liane Kandler at [lkandler@lakeheadu.ca](mailto:lkandler@lakeheadu.ca)

If you have any concerns regarding your rights as a research participant or wish to speak to someone other than a research team member about this research project, you are welcome to contact any of the research boards who reviewed the application

1) Chair, Research Ethics Board. Thunder Bay Regional Health Sciences Centre. 980 Oliver Road, Thunder Bay, Ontario P7B 6V4. Tel: 807-684-6422; Fax: 807-684-5904.  
[ResearchEthics\\_Chair@tbh.net](mailto:ResearchEthics_Chair@tbh.net)

2) Office of Research Services, Lakehead University. 955 Oliver Road. Thunder Bay, Ontario. P7B 5E1. Phone (807) 343-8934. Fax (807) 346-7749

All research data will be kept for 7 years, as is required by the research ethics review process.

To participate in this research, please reply “yes” to [lkandler@lakeheadu.ca](mailto:lkandler@lakeheadu.ca) and indicate whether you would prefer to receive the questionnaires by email or as paper copies.

If you choose not to participate, please reply “no” and we will avoid bothering you with any further emails.

Thank you for taking the time to consider this research!

*Appendix B: Study specific questionnaire*

Study Specific Questionnaire

The following study-specific questionnaire contains two sections. The first section queries demographic information, and the second cancer-related information.

**SECTION 1: DEMOGRAPHIC INFORMATION**

Date of birth: Year, Month, Day

Sex: Male, Female

Marital status: Single, Married, Separated, Divorced, Widow/er, Common-law, Committed relationship

Living arrangements: I live alone. I live with other people (not alone)

What is the highest level of education you have completed? Elementary school (Grades 1-6), Middle School (Grades 7-9), High School (Grades 10-12), Some college, Completed college, Some university, completed university, some graduate school (Master's degree, Doctoral degree), Graduate school completed.

I mainly identify with the following ethnicity: White/Caucasian, First Nation, Metis, Arab/Middle Eastern, Southeast Asian, South Asian, Chinese, Latin American/Hispanic, Black/African American, Other:

My total household family income is approximately: Amount/currency (Canadian, US)

My primary source of income is: My work/employment, Student loans or financing, parents or guardian, partner or spouse, disability benefits, social assistance, pension or retirement benefits, other:

Is English your first language?

If not, what is your first language?

What is your current smoking status? I am currently smoking, I am smoking but trying to quit, I recently quit smoking, I quit smoking 6 months ago or more, I have never smoked

Note: For current smokers / trying to quit – approximately how many cigarettes a day do you smoke?

In an average week, how many alcoholic drinks do you consume? (numbers 0 through 40)

In an average week, how many times do you use recreational drugs (marijuana, non-prescription medication, etc.)? (numbers 0 through 21)

**SECTION 2: CANCER-RELATED HEALTH INFORMATION**

How old were you when you were diagnosed with your first cancer?

What type of cancer were you first diagnosed with?

What stage of cancer were you first diagnosed with? 0, 1, 2, 3, 4

Were you diagnosed with a second cancer?

If so, what type of cancer was the second you were diagnosed with?

For your second cancer, at what stage of disease were you diagnosed? 0, 1, 2, 3, 4

What types of treatments have you had in the past, or are you expected to have in the coming months:

I have received these treatments in the past.		I have been informed that I will need to receive these treatments in the coming months	
<input type="checkbox"/>	Radiation	<input type="checkbox"/>	Radiation
<input type="checkbox"/>	Chemotherapy	<input type="checkbox"/>	Chemotherapy
<input type="checkbox"/>	Surgery	<input type="checkbox"/>	Surgery
<input type="checkbox"/>	Hormone Therapy	<input type="checkbox"/>	Hormone Therapy
<input type="checkbox"/>	Bone Marrow / Stem Cell Transplant	<input type="checkbox"/>	Bone Marrow / Stem Cell Transplant

Have you used any of the following professional or semi-professional support resources? For each resource used, participants will be asked to rate how helpful the resource was on a scale of (1) not at all helpful to (5) extremely helpful.

	Yes	No	Was not available
One on one, in person counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Group counseling, in person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
One on one, online counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Group counseling, online	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Searching for information online	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Connecting with other patients online	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Appendix C: Open-Ended Questions*

- 1) Time one (Baseline)
  - a. What do you hope to gain from participating in this “Survive and Thrive” expedition?
  - b. From what you know about this trip, what are you concerned about, or afraid of?
  - c. From what you know about this trip, what are you most excited about?
  - d. From what you know about this trip, what are you least excited about?
  - e. Any other comments or thoughts you would like to share?
  
- 2) Time two: (Short-term post) – To be completed within 1 to 10 days of returning from the Survive and Thrive expedition
  - a. What did you gain from participating in this “Survive and Thrive” expedition?
  - b. What was the most rewarding part of the experience?
  - c. What was the most challenging part of the experience?
  - d. What had the greatest impact on you?
  - e. How do you think you have changed as a result of participating in this expedition?
  - f. What did you enjoy the most?
  - g. What did you enjoy the least?
  - h. Any other comments or thoughts you would like to share?
  
- 3) Time three (Long-term post) – to be completed within 6 and 7 months of returning from the expedition.
  - a. What did you gain from participating in this “Survive and Thrive” expedition?
  - b. What was the most rewarding part of the experience?
  - c. What was the most challenging part of the experience?
  - d. What had the greatest impact on you?
  - e. How do you think you have changed as a result of participating in this expedition?
  - f. What did you enjoy the most?
  - g. What did you enjoy the least?
  - h. Any other comments or thoughts you would like to share?



## General Conclusion

Thanks to nearly two decades of research, AYAs diagnosed with cancer are now increasingly recognized as forming a discrete subset of cancer patients, with specialized psychosocial and medical needs (CPAC, 2017). However, with this recognition comes the responsibility of ensuring evidence-based information and programs are available to meet AYA needs, and to educate AYA care providers. To this effect, this dissertation consisted of three separate studies, each providing a different lens by which to examine the AYA oncology care. In this final chapter, each study is summarized, their respective take-home messages are presented, and future research directions are then discussed. This information is then contextualized within broader theoretical models of oncology care, with the goal of looking ahead to next steps.

### **Summary 1 - Cancer in young adulthood: How do healthcare providers perceive the experience?**

The first study assessed the perceived ability of oncology healthcare professionals to discuss cancer-related concerns with adolescent and young adult cancer patients (AYAs) ages 18-39 years, and to assess the impact of an AYA cancer documentary film as an awareness and teaching tool for healthcare providers. With growing recognition of AYA oncology as a specialized discipline came the need to ensure healthcare providers treating this subgroup of patients were comfortable meeting their age-specific needs. However, with very few centralized treatment facilities for the 7,600 AYAs diagnosed annually across Canada, AYAs were found to be treated by paediatric or adult oncology professional who often lacked specialized training, or experience, with this patient subgroup (Bleyer, Budd, & Montello, 2006; Burke et al., 2007; Ferrari et al., 2010; Olsen & Harder, 2009, 2011; Tsangaris et al., 2014). Additionally, providing and evaluating training can be challenging, as oncology healthcare professionals come from

diverse disciplines, including nursing, social work, psychology, occupational therapy, dietitians, radiologists, and oncologists, to name a few. Emerging research suggests that even in the absence of formal training, healthcare professionals with experience working with AYAs have a better understanding of the needs of this patient group (Zebrack et al., 2006) suggesting the value of awareness and exposure as natural teaching tools. With this was borne the idea of looking at film as a teaching tool. Historically, films have been found to provide the critically important patient perspective, bringing individual and social perspectives and thereby broadening the healthcare provider's perspective (Banos & Bosch, 2015; Cappelletti et al., 2007; Kumagai, 2008; Volandes, 2007). The documentary film "Wrong Way to Hope: An Inspiring Story of Young Adults and Cancer" (WW2H) was evaluated as a teaching tool for a total of 81 oncology healthcare professionals using a brief pre-post survey methodology.

This research yielded several important findings and take-home messages. First, many oncology healthcare professionals feel ill-equipped to address the key issues faced by young adults. However, a brief film intervention can be an effective way of increasing short-term self-reported understanding, with 96% stating they gained new knowledge from watching the film; Long-term impacts have yet to be assessed. Second, healthcare professionals with more years of experience in healthcare, in oncology, and more time spent with AYA oncology patients, respectively, reported increased ability to discuss treatment decisions, management of side effects, and fertility concerns. However, higher self-reported ability to discuss psychosocial concerns with AYAs was associated only with increased time spent with AYAs. This adds credence to the claim that increased experience and exposure to this subgroup of patients is associated with increased self-reported understanding (Zebrack et al., 2006). Third, comparisons across groups of healthcare professionals (medical, psychosocial, students) supported significant

self-reported gains in AYA knowledge for medical and student group from pre- to post-film, but not for the psychosocial group. Reasons for the lack of significant self-reported gains for the psychosocial care are unknown and warrant further investigation. Fourth, qualitative assessment of key AYA issues pre and post-film support a moderate shift in perception of what these key issues are. Mainly, there appeared to be a shift in the healthcare professional's "lens" as a function of gaining AYA perspective through film.

Further research is necessary to assess the suitability of the WW2H film as a formal teaching tool. These promising research findings support the dissemination of the film across for oncology healthcare professionals and students in training. This might include viewing and discussing the film more informally, such as during screening events or lunch and learn sessions, or as fodder for discussion in more formal academic settings. The goal is not to provide a comprehensive education, but rather to stimulate widespread discussion and awareness of the distinct AYA needs. The evaluation of potential long-term gains in perspective, and the comparison of alternative documentary films as teaching tools, warrants investigation. Furthermore, behavioural research would allow us to assess whether viewing the film contributes to actual change in clinical consultations.

### **Summary 2 - A comprehensive evaluation of the psychosocial experience of cancer in adolescence and young adulthood**

The purpose of this research was to assess positive and negative dimensions of personality, affect, and cancer coping style as they relate to cancer adjustment and social support, as a way of guiding survivorship care in adolescent and young adult (AYA; aged 15-39 years) cancer patients and survivors. Our research included 128 AYA cancer patients and survivors who completed an online survey assessing demographic information, medical information,

psychosocial support, personality, affect, cancer coping, and cancer adjustment measures.

Several key findings emerged from the data. First, 50% of respondents reported elevated levels of distress as measured by the Hospital Anxiety and Depression Scale. Despite this, uptake of formal psychosocial support was fairly low, with in-person one-to-one counselling and group therapy attempted by approximately 60% and 30% of the sample, respectively. Uptake of online support was even lower; only 7% of participants had attempted individual counselling, and 12% group counselling. This tells us distress in survivorship remains high, and that uptake of professional psychosocial supports is low. Second, our findings support that, when entered into a hierarchical regression model, extraversion, neuroticism, positive affect, negative affect, positive cancer coping, and negative cancer coping all remained statistically significant predictors of distress AYA cancer patients. Third, our final hierarchical regression model found that higher positive cancer coping, and lower neuroticism, were significant predictors of higher perceived social support. Feeling socially supported is especially challenging during cancer, a time that is often characterized by social awkwardness, isolation, and withdrawal.

Based on these findings, we propose the following recommendations. Although it is rational to expect that an individual's personality and individual traits will impact all aspects their lives, including their response to a cancer diagnosis and treatment, we do not routinely, formally assess personality in clinical care. To quote Sir William Osler, "The good physician treats the disease; the great physician treats the patient who has the disease." In other words, we need to treat the patient who has cancer, not just the cancer, thereby provide the whole-person context to the disease. The cancer, although it may certainly feel all-consuming at times, is but a part of what makes that person who they are. From research and clinical perspectives, assessing and integrating information about the person themselves, and their unique perspective, is

advocated. In the context of research, this might include broader measurement of personality and SWB. In the context of clinical care, this might include administering basic screening measures to all patients to assess not only distress as a vital sign, but also SWB, social supports available, or personality. This in turn enables a holistic approach to oncology treatment. Arguably, treating the individual rather than the disease is consistent with the client- and family-centred care approach that is advocated across Canada (Gregus, 2016).

### **Summary 3 - Survive and Thrive Expeditions: Exploring the impact of an adventure therapy program on adolescent and young adult cancer patients and survivors**

Connecting with peers is a critical component of AYA psychosocial care (D'Agostino, Penney, & Zebrack, 2011; Hollis & Morgan, 2001; Treadgold & Kuperberg, 2010). However, given the geographical vastness of Canada and the relative scarcity of a cancer diagnosis in this age frame, it is common for AYA patients to complete their treatment without meeting a similarly aged peer (CPAC, 2017). Adventure therapy programs are one of several alternative treatments that's have emerged, allowing patients and survivors to push personal and physical boundaries while connecting with peers to achieve therapeutic change (Autry, 2001; Groff & Kleiber, 2001). The purpose of this study was to qualitatively assess the impact of Survive and Thrive Expeditions (STE) adventure therapy programs on adolescent and young adult cancer patients and survivors. Participants from five STEs were invited to participate in the research by completing an online survey in the week prior to leaving on the expedition (time 1;  $n = 22$ ), in the days following their return (time 2;  $n = 20$ ) and 6 months after their return (time 3;  $n = 17$ ). At time 1 the survey queried participant characteristics (demographics, medical, psychosocial), expectations for STE expedition, perceptions of AYA needs, emotions, and life issues, and

distress. Impressions of the STE expedition were queried at time 2 and 3, with time 3 also reassessing perceptions of AYA needs, emotions, and life issues, and distress.

This research yielded several important take-away messages. First, at time one and three, over half the sample reported significant levels of distress. This supports the need to assess and treat distress not just at time of diagnosis and treatment, but ongoing into survivorship. Second, key themes emerging from the qualitative data highlighted benefits of the STE as being peer connections, the impact of being in nature, and personal growth and reflection. Although this research requires replication and further examination, these preliminary results represent a first attempt to document the benefits of adventure therapy for AYAs. Notably, the importance and benefits of forging peer connections (D'Agostino, Penney, & Zebrack, 2011; Hollis & Morgan, 2001; Treadgold & Kuperberg, 2010), the healing power of nature (Frederickson & Anderson, 1999; Frumkin, 2001), and the benefits of positive growth post-cancer (Park, Bharadwaj, & Blank, 2011; Park & Blank, 2012) are well documented in the literature. As such, we propose there is preliminary evidence to support the benefit of adventure therapy, specifically STE, for some AYA cancer patients and survivors.

As a next step, it would be valuable to employ mixed method-quantitative-qualitative assessment tools to more broadly assess participant characteristics and potential short as well as long-term benefits of participating. For example, consider measuring personality and SWB prior to participating as predictors of well-being outcomes. Consider qualitatively evaluating the strength and impact of the connection to the peer group as a predictor of the impact of the STE. Consider as well the use of in-depth individual and group interviews to allow for depth of data collection. Groups, when successful in facilitating connectedness and belongingness, can be

incredibly powerful. However, for individuals who participate in STEs but remain disconnected from peers, it will be important to assess whether participation is still beneficial.

### **Musings: Comparing studies**

Having individually summarized the research studies, we aimed to address the following cross-study comparisons: 1) how do the main needs, emotions, and life issues reported by healthcare professionals (study 1) compare to those reported by AYAs (study 3); 2) based on results from the 3 studies, what can we say about social support?

Studies 1 and 3 requested that healthcare providers and AYAs, respectively, reflect on the main needs, emotions, and life issues of AYAs with cancer. In study 1, healthcare providers were asked to reflect on these questions before and after viewing the *Wrong Way to Hope* film; we focus on post-film unless explicitly stated. In study 3, AYAs completed the same questions before participating in the STE, and again 6 months post. There was relatively little shift in AYA responses from pre-to 6 months post-expedition; we will focus on the latter. In regard to emotions, both groups of respondents emphasized fear, anger, and sadness as prevalent. However, AYAs also reported considerable isolation and loneliness; healthcare professionals reported these interpersonal emotions considerably more post-film than pre-film. As for needs, support was recognized by both groups of respondents as the primary need. However, whereas AYAs then reported more frequently on the need to move forward, followed by practical concerns and treatment related needs, healthcare professionals cited treatment related needs, needs related to ones self-concept and self-awareness, and then the needs associated with moving forward. In regard to life issues, AYAs reported practical concerns, equally followed by relationships and treatment effects, and finally psychological issues. Healthcare professionals pre-film reported treatment related issues, relationships issues, changes in daily life, and

emotional/existential issues. There was a significant shift post-film, with emotional/existential issues reported as most prevalent, and treatment related issues as least prevalent. Notably, whereas AYAs on the STE were well into survivorship or long-term treatment, in hospital healthcare professionals typically see AYAs who are in active treatment. As such, some of the difference in perspective might be attributable to this very different time perspective.

These findings suggest that, generally speaking, there is considerable overlap between what healthcare providers and AYAs generally perceive as the main needs, emotions, and life issues of AYAs. This is promising, especially considering the relative novelty of the AYA-oncology discipline. However, the prevalence of themes reported by healthcare professionals and AYAs varied. Additionally, increased prevalence does not necessarily reflect increased importance; it would be helpful to attempt to assess relative importance in addition to frequency. Consider now how the Supportive Care Framework (Fitch, 1994; 2008) could be used to guide further research. Rather than broadly assessing needs, emotions, and life issues, it would be beneficial to assess needs in each of the framework dimensions, mainly, emotional, practical, informational, spiritual, social, physical, and psychosocial. By querying same at different points in the cancer journey, and asking participants to reflect on the relative order of importance of each, it would allow a more fluid representation of AYA needs and how they change over time. The Survivor's Unmet Needs Surveys (SUNS; Campbell et al., 2010) would be a useful tool. The 89 items on the SUNS use a 0-4 scale (no unmet need to very high unmet need) to assess unmet needs of cancer survivors related to emotional health, access and continuity of care, relationships, financial concerns, and information. Finally, an increased and diverse sample size would also address our main limitation: the AYA sample was quite small, and taken from a



subset of participants no longer in active treatment, physically fit enough to participate in a wilderness expedition, and motivated to connect with peers.

Consider now the manner in which social support was a central topic addressed across all three studies. A total of 58.3% of healthcare professionals in study 1 highly recognized support from others as an AYA need, and relationship issues (34.2%) as a prevalent life issue. In study 3, AYAs also recognized isolation as a prevalent emotion (17.6%), relationships as a life issue (25.5%), and support as the most frequent need (56.9%). Prior to participating in the STE, some AYAs voiced a hope of connecting with others and excitement to meet and connect with peers. When asked to reflect on the same questions six months post, AYAs wrote extensively on the value of connecting with other survivors, the value of the peer network, the power of being with others and bonding with the group, the value of learning from and being inspired by peers, the group exchanges, and more. Aspects of social support were reported as something gained from participating, the most rewarding part of the experience, what had the greatest impact, and what was enjoyed the most. Interestingly, challenges associated with connecting with peers, feeling hostility from group members, feeling excluded from the group were reported as some of the most challenging parts of the STE, and what was enjoyed the least. To this effect, for an individual who was unable to meaningfully connect with the group, a decreased interest in the young adult cancer community was reflected in the general feedback. These findings demonstrate that although select participants voiced an interest in connecting with peers before the expedition, it was overwhelmingly reported as a positive repercussion after the STE. When an individual didn't feel connected with the group, it seemingly had a significant negative impact on their overall experience. For these individuals, the intervention may have been iatrogenic.

In study 2, we found that higher social support (as measured by the Social Provisions Scale; SPS; Russell & Cutrona, 1984) was correlated with lower neuroticism (NEO-FFI-3; Costa & McCrae, 2010), lower negative affect (PANAS-X; Watson & Clark, 1994) lower helpless-hopeless/anxious-preoccupation/cognitive avoidance (Mini-MAC; Watson, Greer, & Bliss, 1989) lower subjective distress (IES-R; Weiss, 2007), lower distress (HADS; Zigmond & Snaith, 1983), fewer negative changes (PBS; Carver & Antoni, 2004), and less stress (PSS; Cohen, Kamarck, & Mermelstein, 1983). Higher social support was also correlated with higher extraversion (NEO-FFI-3; Costa & McCrae, 2010), increased positive affect (PANAS-X; Watson & Clark, 1994), higher life satisfaction (SWLS; Diener, Emmons, Larsen, & Griffin, 1985), increased fighting spirit/fatalism (Mini-MAC; Watson et al., 1989), and increased positive changes (PBS; Carver & Antoni, 2004). Furthermore, lower neuroticism and higher positive coping (based on the composite factor of low illness centrality, positive acceptance, and positive movement) were significant predictors of increased social support in a regression analysis.

In summary, across these three studies, and consistent with existing research literature, social support has shown itself to be a robust variable, serving as both predictor and outcome (Boyes et al., 2011; Corey et al., 2008; Diener & Seligman, 2002; Donovan et al., 2015; Fitch, 2008; Kyngas et al., 2001; Lie et al., 2017). The importance of considering the complex role of social support is incorporated in the dimensional overview of AYA psychosocial issues (Zebrack et al., 2007), the Supportive Care Framework (Fitch, 2008), Rowland's developmental model of adaptation (1989), and the Adolescent Resilience Model (Haase, 2004). Whereas the ARM looks at the positive impact of social support as a resilience factor, the frameworks and dimensional approaches recognize the importance of social support. If we consider the developmental model of adaptation, an individual's interpersonal style within their psychological

context is thought to affect their overall adjustment to cancer. Consider now the WISM model, which posits that goal states are central to human motivation and change. How can the social network of an ill-staying patient support them, even if the individual has no desire to engage? Were STE participants who were forward and positive thinking and able to connect meaningfully with peers in well-moving and well-staying quadrants? Were participants who remained focused on ongoing negative challenges, emotions, and felt disconnected from peers in ill-staying and ill-moving quadrants? It is important to reflect that being in an ill-staying or ill-moving state is just that – a reflection of an individual’s current state – rather than a positive or negative judgment. Just as it is necessary to grieve after a loss, or to feel difficult emotions, arguably so too is it necessary for an individual to acknowledge and process the myriad of emotions that accompany a cancer diagnosis and subsequent treatment. Simply put, it is okay to feel what you feel, and important to understand how current feelings and state of mind might impact connections with family, peers, self-perspective, and the individual’s surrounding environment.

Herein rests the question: given the positive impact of meaningful social support and connectedness, and the potentially deleterious impact of poor social support and connectedness, how can social support be prioritized within AYA oncology care? Novel approaches such as network focused nursing (wherein a clear emphasis is placed on ensuring the social networks of AYAs are not only supported, but also maintained during cancer treatments; Olsen & Harder, 2009, 2011) represent an attempt to meet this need within the healthcare system. However, the concept of network-focused nursing remains in its infancy, and has yet to be broadly implemented. Grassroots organizations, be it STE, Young Adult Cancer Canada, or peer-to-peer connections facilitated by Imerman Angels to name but a few, prioritize connectedness with peers. However, these are community-based resources meaning that whether or not an

individual is able to access them may requires the individual to reach out and do so on their own. With the widespread availability of internet access and online platforms geared towards AYAs, the possibility of connection is arguably greater than at any other point in the past. However, for an AYA in active treatment, or who feels disconnected from peers, making overt efforts to develop a social network may not be possible. And as we saw from pre-post STE feedback, although AYAs to some extent recognized the desire to connect with peers pre-STE, the true value of same was reported after those meaningful connections were formed post-STE. So we turn again to the question – how can social connectedness be prioritized? Arguably, it comes back to caring for the individual with cancer, rather than solely treating the disease. If we can recognize distress as a vital sign in cancer, why not recognize the importance of ongoing assessment and evaluation of psychosocial variables such as social support to the same extent?

### **Looking ahead: How can care models shape our perspective**

We now aim to stimulate discussions in two key areas. One, how can the Tiered Model of Supportive Care (Fitch, 2000) and the Supportive Care Framework (Fitch, 1994) be adapted for AYA oncology and used to practically guide, and set standards for, AYA care? Two, how can the WISM model (Røysamb & Nes, 2018) help to guide AYA care?

The Supportive Care Framework (Fitch, 1994) states that a cancer diagnosis and treatment is life changing, in that it impacts and creates social, psychological, spiritual, physical, emotional, informational, and practical needs. From this emerged the Tiered Model of Supportive Care (Fitch, 2000), which suggests basic screening of all patients for need and information, many patients referred for assessment and intervention, some patients receiving early intervention tailored to need, and a few patients receiving a referral for specialized services. These models represent an important first step towards acknowledging the importance of

psychosocial screening of all patients. However, the implementation of the model is open to interpretation. What amount of basic information do you provide at the first step? What do we screen for, and using what tools? When do you screen? In addition, this model requires that oncology care centres have resources in place to meet the whole-person needs of the cancer patient; this is not always the case. Even when patients are in need of basic psychosocial support, there is incredible diversity in services available across provinces and Canadian centres are not always able to provide this care. Sufficient resources to meet the needs of those in crisis is often so challenging, that preventive care or support for emerging distress at times seems implausible. Arguably, this is a poor standard of care. From a clinical practice perspective, consider shifting the mindset from providing staggered, need and crisis-based care to providing ongoing assessment and support addressing all aspects of the Supportive Care Framework. Essentially, screening broadly, re-screening intermittently, and ensuring regular availability of supports to individuals is advocated as a minimum standard of care. This is truly representative of prevention and support-based models of care.

Now, contemplate the means by which the Supportive Care Framework and the Tiered Model of Supportive Care (Fitch, 1994, 2000) could be tailored for AYA care. To begin, consider the integration of both models: At the most basic tier, ensure all new patients are screened for general as well as AYA-specific needs across all domains of the Supportive Care Framework, and continue to periodically assess same over the course of treatment and into survivorship. Secondly, for AYA's specifically, the developmental stage of the patient must be considered as they move through treatment and into survivorship; the demands of cancer can significantly disrupt typical developmental life course (D'Agostino, Penney, & Zebrack, 2011; Docherty, Kayle, Maslow, & Santacroce, 2015; Evan & Zeltzer, 2006). Third, the Canadian

Partnership Against Cancer (Adolescent and Young Adults with Cancer, 2017) advocates the need to strengthen research evidence to help develop evidence-based standards and practices for AYA oncology. An AYA specific distress measure – the first of its kind – is under development thanks to a Canadian research team operating in partnership with the Australian based “CanTeen” organization (CPAC, 2017). However, AYA specific measures of other dimensions, be it social, psychological, spiritual, physical, emotional, informational, or practical needs, have yet to be developed. Notably, AYA validation and norms for existing instruments are also lacking.

Our final goal was to open the discussion on how the Well/Ill-Staying/Moving (WISM) model (Røysamb & Nes, 2018) could be used to guide AYA oncology care. The WISM model (Røysamb & Nes, 2018) is a two-dimensional circumplex model represented by stability-change and positive-negative axes, and built upon current understanding of the genetic and environmental influences on SWB, the relationships between SWM and mental health disorders, and, in part, the Circumplex Model of Affect (Røysamb & Nes, 2018). The authors integrated current literature on psychological, mental, social, hedonic, and eudaimonic well-being as well as SWB (Røysamb & Nes, 2018). With this, they created a four-quadrant structure, with the quadrants defined as well-moving (change, positive, approaching goal state), well-staying (stability, positive, goal state achieved), ill-staying (stability, negative, absent goal state), and ill-moving (change, negative, threatened goal state). At the very core of the model is the concept that individuals have goal states, needs, or ideas (Røysamb & Nes, 2018). Consider the goal state of health. Individuals who are well-staying perceive themselves as being in stable good health (e.g., the cancer patient in long-term remission, the healthy and fit 40-year-old). Individuals who are well-moving are in the process of moving towards good health, and thereby in a period of

growth and change. For example, the new runner who signed up for her or his first 5km, the cancer patient who just finished their last treatment and is anticipating remission, or the new mother who is slowly recuperating. Anxiety, danger, and fear characterize those in the ill-moving state, such as individuals awaiting oncology test results, or those trying to come to terms with fears of recurrence in survivorship. Finally, the ill-staying state is one characterized by sadness and hopelessness – stuck in the negative. Consider the oncology patient who has lost hope, or is newly diagnosed and still in shock.

The strength of the WISM model in healthcare is the ability to conceptualize the individual's current goal state, thereby integrating a comprehensive view of the patient. There is a tendency in the healthcare system to “silo” patient care. We refer those in pain to the pain specialist, in distress to the psychologist, in financial need to the social worker, and on it goes. Depending on the services available, and the caseload of each discipline, wait times may vary. Attempts are then made to connect these respective healthcare professionals, be it through team rounds, notes, or charting. However, the experience of pain, of social isolation, of nausea, of anxiety – they are not felt in isolation, but rather they are interconnected with other aspects of well-being and physical health. How do we ensure we conceptualize and care for the individual as a whole, rather than treating segmented aspects of presenting concerns? It is here that using the WISM model is advocated.

Consider how the WISM model could be adapted for the oncology field and for AYA oncology in particular. Perhaps more than any other life stage, AYA is strongly characterized by internal and external change, transition, and growth. For an AYA diagnosed with cancer, understanding their state at just prior to the time of diagnosis – be it well-staying, well-moving, ill-moving, or ill-staying – can help to guide treatment and care. Consider the challenges of

motivating an ill-staying individual to treatment, and the level of support they may require, as compared to an individual who was well-staying. As an individual proceeds through their cancer journey, understanding the cancer-related, and non-cancer-related factors that impact their ability to cope, to adhere to treatment, to present for appointments, to care for self, to connect socially with others, to feel supported, and so forth, are – arguably – as important as understanding their type and stage of disease. With this information, we can provide multi-faceted support to the individual, help the individual feel supported, help them manage and process their pain and experiences when they shift into ill-moving or ill-staying, and, when ready, help guide them back to well-moving and well-staying.

As we conclude, the words of Hippocrates of Cos (c. 460 BCE – c. 370 BCE) seem especially relevant: “It is more important to know what sort of person has a disease than to know what sort of disease a person has.” In essence, understanding the individual who was diagnosed with cancer is at a minimum equally important, if not more so, than understanding their disease itself. This insight is critical if we are to provide quality healthcare that encompasses and prioritizes not only medical needs but equally emphasizes caring for the patient as a whole person.



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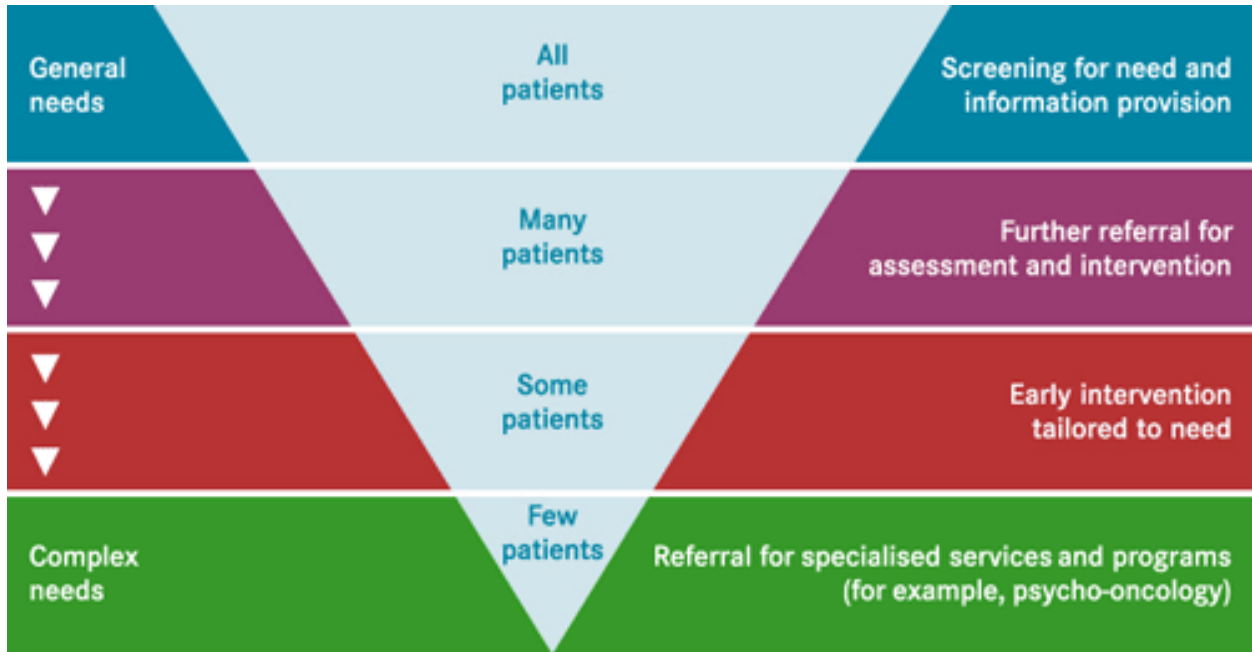
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**Figures**

**Figure 1: Tiered Model of Supportive Care**

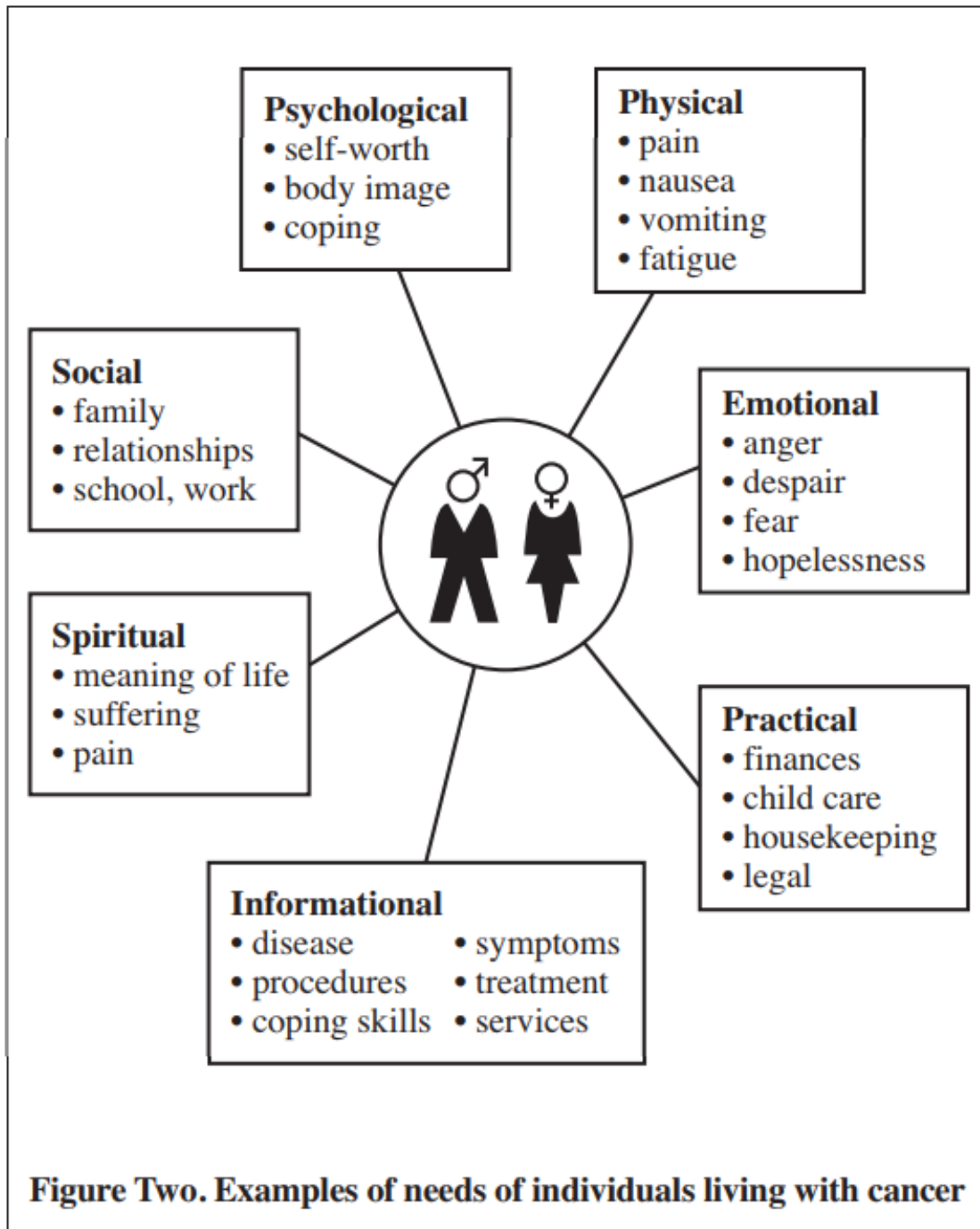
Tiered Model of Supportive Care



Model adapted by Supportive Cancer Care Victoria from Fitch, M. 2000. Supportive care for cancer patients'. *Hospital Quarterly*, 3, 39-46.



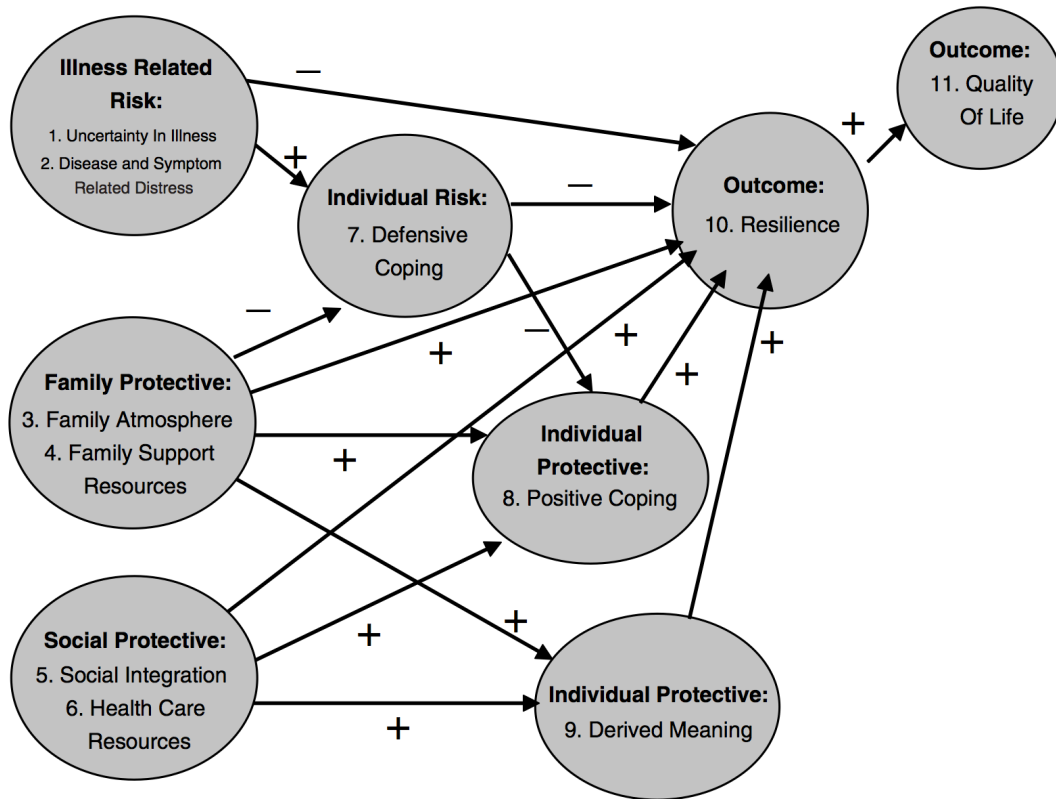
*Figure 2: Supportive Care Framework*



Fitch, M. (2008). Supportive care framework. *Canadian Oncology Nursing Journal*, 18, 6-14. doi:10.5737/1181912x181614

*Figure 3: Adolescent Resilience Model*

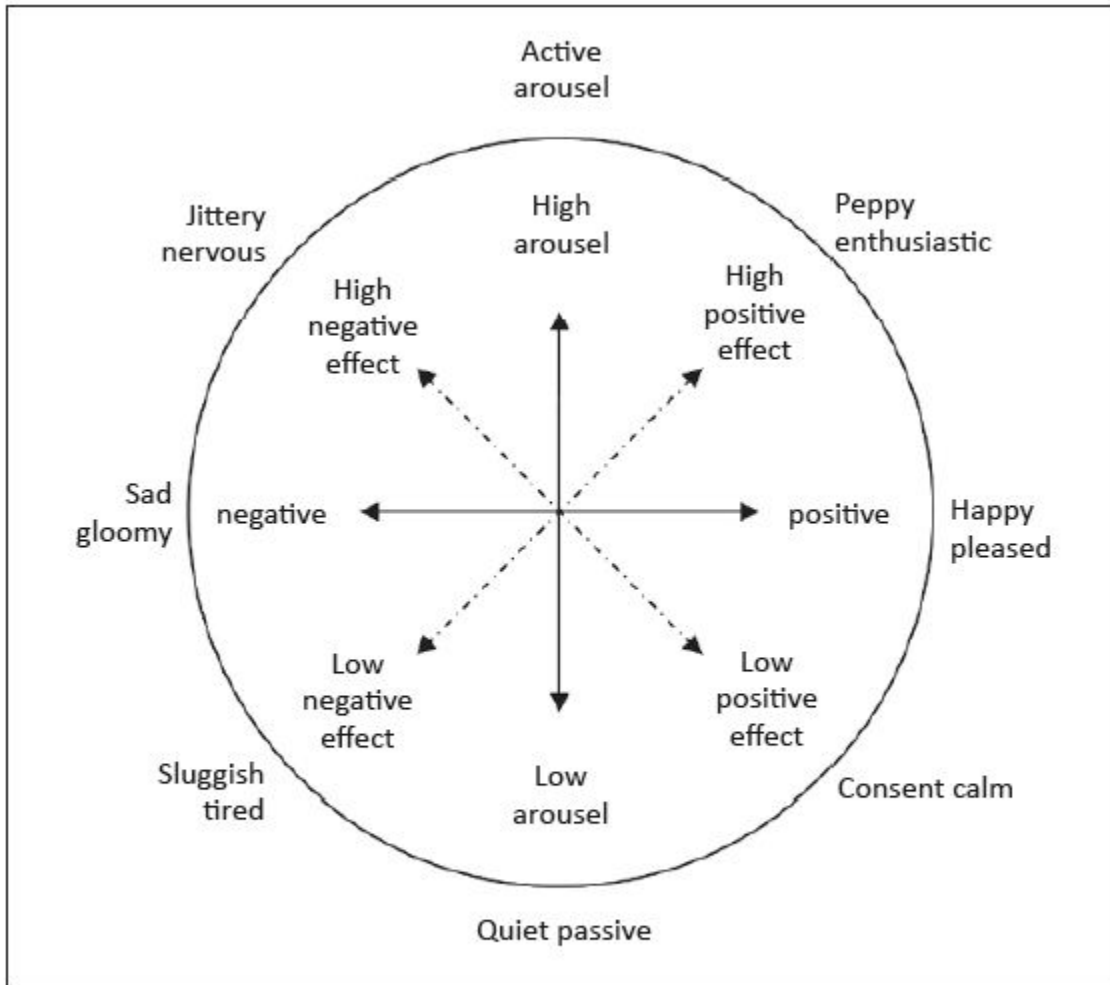
Adolescent Resilience Model (ARM)



Haase, J. E. (2004). The adolescent resilience model as a guide to interventions. *Journal of Pediatric Oncology Nursing*, 21, 289-299. doi: 10.1177/1043454204267922

**Figure 4: Circumplex Model of Affect**

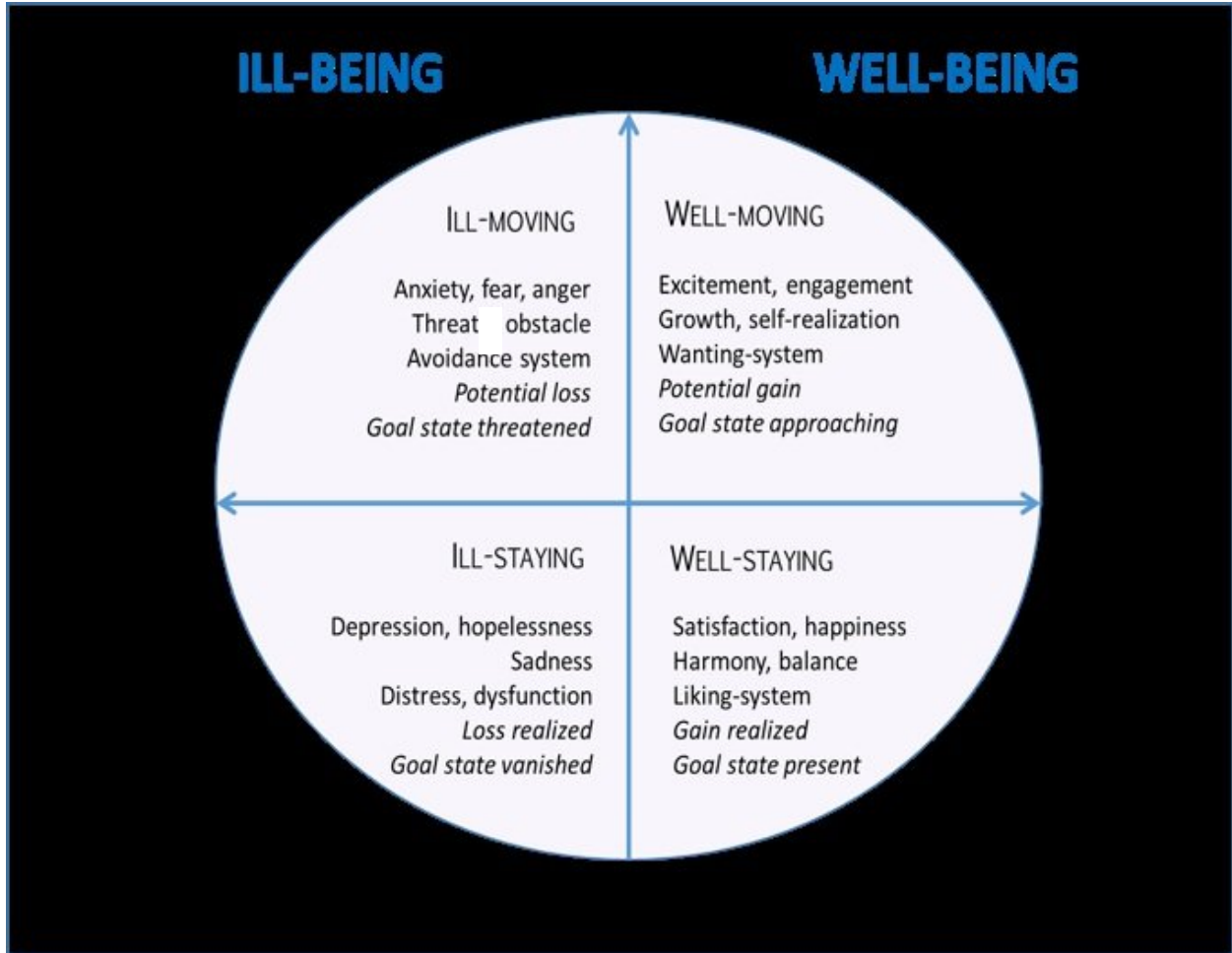
Circumplex Model of Affect



Source: Russell, J.A. (1980). A circumplex model of affect. *Journal of Personality and Social Psychology*, 39, 1161–1178.

**Figure 5: Well/Ill-Staying/Moving Model**

Well/Ill-Staying/Moving Model



Røysamb, E., & Nes, R. (2018). *Genes, environment and core features of eudaimonic well-being*. In J. Vitterso (Ed.), *Handbook of eudaimonic well-being* 233-252. Springer.