IMPACT OF YOGA ON QUALITY OF LIFE FOR ADOLESCENT AND YOUNG ADULT NON-CURATIVE CANCER PATIENTS: A PILOT STUDY

by

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DEDICATION PAGE

To my Mum, you have been my strength, support and motivation for all opportunities I have undertaken. Your compassionate heart and positivity will always be my inspiration to live life to its fullest. As always, I “took the road less traveled by, and it has made all the difference”. Love you always and forever.

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ABSTRACT

Four young adult non-curative cancer patients participated in a 7-week home-based Hatha yoga program, completing measures of quality of life (QOL) and program satisfaction. On average, participants engaged in 71.2 minutes per session while adhering to 45% (3.14/7 sessions) of requested frequency, with participants engaging in an average of 71.2 minutes per weekly session. No adverse events were reported. Although no significant changes in QOL were found, meaningful trends were noted. Improved scores were reported for all four participants on functional well-being (p =.066); the Palliative Care Subscale; (p = 0.68); and Meaning and Peace (p = 0.066). Participants noted improvements in flexibility and mindfulness and found the program to be an opportunity to promote self-care. While these preliminary findings are positive, further exploration using larger samples and more rigorous study designs is required.

LIST OF ABBREVIATIONS USED

ADL	Activities of daily living
AYA	Adolescent and young adult
CAM	Complementary and alternative medicine
CCS	Canadian Cancer Society
FACIT-Pal	Functional Assessment of Chronic Illness Therapy – Palliative Care subscale
FACIT-Sp	Functional Assessment of Chronic Illness Therapy – Spiritual subscale
PA	Physical activity
PalS	Palliative Subscale
QOL	Quality of life
RCT	Randomized control trial

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CHAPTER ONE INTRODUCTION

1.1 BACKGROUND

While cancer remains the leading cause of disease-related death in adolescent and young adults (AYA) in Canada (AYA Task Force, 2013), recent medical advancements are allowing AYAs diagnosed with a non-curative cancer to live longer (Oechsle et al., 2011). Unfortunately, despite longer survival times, the quality of life (QOL) of the AYA has not experienced the same level of improvement seen in pediatric and adult oncology patients (Zebrack et al., 2012). This may be attributed to the relative infancy of AYA oncology as a unique domain of care and the current lack of a comprehensive model of supportive care (Fernandez et al., 2011). However, as AYAs typically present with biologically different cancers and encounter psychosocial issues that are developmentally distinct from their younger and older counterparts, there is a clear need for a tailored, age and developmentally specific supportive care plan that meets both the physical and psychosocial needs of the AYA (AYA Task Force, 2013; Coccia et al., 2012; Fernandez et al., 2011). Within the context of *whole* patient care, one method that has been successful in addressing both the physical and psychological effects of cancer is yoga (Boehm, Ostermann, Milazzo, & Bussing, 2012; Lin & Tsauo, 2013; Park, Cho, & Wortmann, 2012; Thygeson, Hooke, Clapsaddle, Robbins, & Moquist, 2010; Geyer, Lyons, Amazeen, Alishio, & Cooks, 2011; Culos-Reed et al., 2012). Yoga is a light form of physical activity (PA) that has been effective in improving QOL in childhood (Geyer et al., 2011) and adult cancer survivors (Lin & Tsauo, 2013) as well as adult non-curative cancer patients (Carson et al., 2007; Chandwani et al., 2012) by reducing their cancer and treatment-related symptoms (Carson et al., 2007; Lin & Tsauo, 2013). Based on these

findings, it is assumed, but yet untested, that yoga will have similar effects in the AYA non-curative cancer patient population. Thus, it is first important to test the proof of concept.

1.2 Implications of a Non-Curative Cancer Diagnosis in AYA

The psychological and physical disease and treatment-related side effects can have a substantial impact on the AYA cancer patient (Wein, Pery, & Zer, 2010). With a lack of AYA specific facilities and a distinct model of care, their unique psychosocial and developmental needs often remain unaddressed or underserved (AYA Task Force, 2013; Zebrack, 2011; Zebrack, Hamilton, & Wilder Smith, 2009). Specifically, AYAs are at a marked developmental cornerstone of their life where they are graduating from high school/post-secondary institutions, embarking on new careers, establishing financial goals to support themselves and their families, and planning for their future (AYA Task Force, 2013; Bhatnagar & Joshi, 2011; Fernandez et al., 2011; McGill AYA Oncology, 2014). In the face of a non-curative diagnosis however, the AYA may struggle with the uncertainty of their disease and may not have the opportunity to experience these key developmental tasks and social changes (George & Hutton, 2003; McGill AYA Oncology, 2014). Consequently, the age-appropriate tasks of establishing meaningful relationships, developing an autonomous identity, and planning for the future are disrupted in both the adolescent (e.g., 15-20 years of age) and young adult (e.g., 21-39 years of age) cancer patient (Fernandez et al., 2011; Zebrack, 2011). Interruption of these tasks results in feelings of distress, anxiety, depression, and extreme isolation in AYA cancer patients (Fernandez et al., 2011; McGill AYA Oncology, 2014; Zebrack, 2011).

Furthermore, physical side effects including fatigue, reduced mobility, pain,

shortness of breath, muscle wasting, anorexia, and poor appetite are commonly reported by the AYA non-curative cancer patient, resulting in a substantial increase in their total suffering (Wein et al., 2010). Cancer-related fatigue is the most commonly reported symptom that affects the AYAs' ability to participate in their activities of daily living (ADL) (Mustian et al., 2013; Oldervoll et al., 2011). Specifically, over 60% of non-curative cancer patients have reported experiencing fatigue which can be further exacerbated by the increased use of commonly prescribed pain medications (Alsharif & Hata, 2013; Banzer, Fuzeki, Bernhorster, & Jager, 2013; Eyigor, 2010; Oldervoll et al., 2011). Losing the ability to independently perform ADL is reported as one of the most distressing concerns in AYA non-curative cancer patients (Wiener et al., 2012).

The substantial impact of the disease and treatment related side effects (e.g., pain, fatigue, nausea, emesis), compounded by the numerous psychosocial issues can greatly decrease the QOL of the AYA non-curative cancer patient. Specifically, the QOL of the AYA non-curative cancer patient is negatively impacted when they are no longer able to maintain their social relationships, feel that their cognitive functioning is declining, and struggle to maintain their pre-diagnosis activity levels (Fernandez et al., 2011). Overall, providing appropriate supportive care for AYA non-curative cancer patients means not only considering their disease-specific medical needs; but it must also address their dynamic and developmentally unique psychosocial needs (Fernandez et al., 2011; Pritchard, Cuvelier, Harlos, & Barr, 2011; Rajani, Young, McGoldrick, Pearce, & Sharaf, 2011; Sender, 2011).

1.3 Definition of Terms

For the purpose of this study, the following terms have been defined as:

ADL. Refers to those physical or social endeavors that an individual normally carries out as they wish (Eyigor, 2010).

AYA. Are those individuals between 15 and 39 years of age (AYA Task Force, 2013; National Cancer Institute of Canada, 2014).

Cancer survivor. Anyone who is alive and continues to function from time of diagnosis and after overcoming a life-threatening disease (Buffart, Galvao, Brug, Chinapaw, & Newton, 2014; National Cancer Institute of Canada, 2014).

CAM. Uses non-pharmacological forms of therapy that are not considered part of traditional medicine; however, it is used as an adjunct treatment to assist in pain and symptom management (Park et al., 2012).

Hatha yoga. Is a gentle form of physical activity that combines various postures and breathing techniques to develop physical, psychological, and spiritual health (Culos-Reed et al., 2012; Ott, 2002).

Palliative care. Is a form of supportive care that aims to maximize the quality of life of the non-curative patient by managing disease and treatment-related symptoms, while providing appropriate physical, psychological, and spiritual support (WHO, 2014).

QOL. Is the extent to which individuals are able to participate in the activities or social interactions that are most meaningful to their well-being (WHO, 2014).

Supportive care. Is a synonym for palliative care with the goal of improving quality of life for patients who are diagnosed with a life-threatening disease. Goals of supportive care are to treat symptoms and side effects of the disease and its treatment (National Cancer Institute of Canada, 2014).

CHAPTER TWO LITERATURE REVIEW

2.1 Historical Perspective on Physical Activity and Cancer

Utilizing PA as an effective adjunct therapy for cancer patients has only emerged within the past 25 years (Jones & Alfano, 2013). In fact, in the not-too-distant past, patients diagnosed with cancer who were receiving cytotoxic therapy were often discouraged from participating in activities related to PA (Henke, et al., 2014; Jones & Alfano, 2013; Oechsle et al., 2011). It was thought that patients receiving cancer therapy needed to conserve their physical power, suggesting inactivity or rest as the most beneficial treatment (Oechsle et al., 2011). However in 1989, two oncology nurses successfully demonstrated that physical exercise for cancer patients resulted in improved cardiovascular capacity, body composition, and decreased feelings of nausea - thus providing the foundation for the development of exercise-oncology (Jones & Alfano, 2013). Since these early findings, a growing body of literature has emerged demonstrating that PA is a safe and effective adjunctive therapy as it is able to reduce/mitigate both the physical and psychological distress associated with a cancer diagnosis and its treatment across patient populations (Carayol et al., 2012; Baumann et al., 2013; Henke et al., 2014; Jones & Alfano, 2013). Overall, PA programs for cancer patients have been found to attenuate the degree of physical deconditioning during cytotoxic therapy. For example, meta-analyses have revealed that patients who are physically active, have a 50% lower mortality rate than those who are inactive (Buffart et al., 2014; Phillips, Alfano, Perna, & Glasgow, 2014). Preliminary evidence has also shown that PA is able to foster enhanced immunity and an improved anti-inflammatory effect (Buffart et al., 2014). The inclusion of increased PA is able to decrease the

systemic inflammatory response, thus reducing the decline in physical function, commonly linked with chronic inflammation (Buffart et al., 2014). This allows the patient to have decreased symptoms of fatigue; as well as, manage chronic or late appearing effects such as heart, lung, endocrine, bone/joint, and memory problems (Buffart et al., 2014; Courneya & Friedenreich, 2011). By maintaining the aforementioned domains, it allows the cancer patient to remain functionally independent, while maintaining QOL (Buffart et al., 2014; Courneya et al., 2011; Henke et al., 2014; Jones & Alfano, 2013; Mustian et al., 2013).

While the literature concerning exercise-oncology strongly supports the benefits of PA for the pediatric (i.e., 0-15 years of age), AYA (i.e., 15-39 years of age), and adult (i.e., 40+ years of age) curative cancer patients; as well as for adult non-curative cancer patients (Buffart et al., 2014; Cournyea & Friedenreich, 2011 Eyigor, 2010; Henke et al., 2014; Jones & Alfano, 2013; Lowe, Watanabe, Baracos, & Cournyea, 2011; Oechsle et al., 2011), it is important to note that as the AYA sub-discipline is only beginning to emerge, the bulk of the literature concerning the AYA cancer patient is dispersed throughout both the pediatric and adult literature.

Although the rationale for the inclusion of PA into the treatment plan for cancer patients has been reported, over half of the individuals diagnosed with cancer are unaware of the potential benefits of participating in a PA program (Banzer et al., 2013; Murnane, Geary, & Milne, 2012; Oechsel et al., 2011). Furthermore, cancer patients remain convinced that physical rest is still the best method to overcome cancer and treatment-related side effects (Henke et al., 2014). These strong-held beliefs remain a substantial barrier to PA engagement (Henke et al., 2014). Regrettably, those patients who are aware of the benefits of PA, and who seek medically prescribed PA programs,

rarely receive detailed recommendations (Cheville, Dose, Basford, & Rhudy, 2012). This disconnect could be due to the fact that not all oncologists/primary physicians/nurses/social workers fully understand the positive impact PA can have on the cancer patient or simply lack the time or experience to provide detailed PA recommendations (Cheville et al., 2012; Eyigor, 2010; Hede, 2011; Irwin & Ainsworth, 2004; Park et al., 2012). The following review will help to shed light on the holistic care that PA can provide for cancer patients across the cancer continuum while highlighting the gap of care for AYA non-curative cancer patients.

2.2 Physical Activity and Cancer

2.2.1 Benefits of Physical Activity and Cancer

Several recent meta-analyses have demonstrated that PA is both a safe and an effective means to help cope with the numerous physical and psychosocial burdens associated with a cancer diagnosis and its treatment both during and following treatment completion (Aznar et al., 2006; Braam et al., 2010; Henke et al., 2014; Jones & Alfano, 2013; Stevinson, Lawlor, & Fox, 2004; Wolin, Ruiz, Tuchman, & Lucia, 2010). Specifically, PA programs have helped to facilitate optimal functioning in a wide range of physical domains including cardiovascular and respiratory function, and mobility for individuals at any age across the cancer continuum (Cheville et al., 2012; Fernandez et al., 2011; Henke et al., 2014; Jensen et al., 2014; Lowe et al., 2011; Oechsle et al., 2011; Robertson & Johnson, 2002; San Juan, Wolin, & Lucia, 2011). PA can also maintain/improve functional capacity (i.e., muscle strength, balance, flexibility, and range of motion to prevent contractures) (Alsharif & Hata, 2013; Cheville et al., 2012; Fernandez et al., 2011; Henke et al., 2014; Lowe et al., 2011; Jensen et al., 2014; Oechsle

et al., 2011; San Juan et al., 2011; Stevinson et al., 2004).

In addition to the physical benefits, PA can assist in improving the psychological symptoms of the cancer patient/survivor by: decreasing sleep disturbance, and improving mood, behaviour, social activity, self-esteem, concentration, and memory (Jones & Alfano, 2013; Robertson & Johnson, 2002). Additionally, PA has been widely reported to improve symptoms of depression, anxiety, and stress (Jones & Alfano, 2013; Mustian et al., 2013). Addressing these adverse psychological symptoms has been found to restore a sense of independence and autonomy in the cancer patient/survivor allowing for QOL to be maintained (Henke et al., 2014; Jones & Alfano, 2013; Mustian et al., 2013). A recent RCT conducted by Henke et al. (2014) examined the impact of a tailored strength and endurance program on QOL in 18 adult (+18 years) lung cancer patients who were receiving palliative chemotherapy. They found significant improvement in physical functioning measures of QOL ($p<0.05$) and noted that non-curative cancer patients who participated in PA while receiving chemotherapy, "were visibly surprised about their improved physical performance, and became more enthusiastic about their re-gained independence" (p.100). Given the range of benefits associated with PA, the inclusion of PA into the comprehensive cancer care plan is encouraged yet not widely adopted (Fernandez et al., 2011; Henke et al., 2014; Mustian et al., 2013).

2.2.2 Determinants of Adoption/Maintenance of Physical Activity Behaviours

Upon learning about the potential benefits of PA, cancer patients prefer that their primary oncologist/physician introduce them to the program (Mustian et al., 2013). As a result, it is critically important that all healthcare professionals, especially primary oncologist/physicians, understand the role of PA in the cancer treatment plan. To outline

patient preferences with regards to time, type, and duration of PA, the literature varies immensely. For example, the literature concerning home-based versus intra-hospital settings and supervised versus independent PA programs for cancer patients, remains inconclusive (Murnane et al., 2012). Preference for type, duration, frequency, and location of PA program are highly dependent on the patient, patient's caregiver/family support, socioeconomic status, the stage of cancer and, symptoms on any given day (Jones & Alfano, 2013; Murnane et al., 2012; Mustian et al., 2013). However, there are specific advantages and disadvantages to the type of PA interventions suggested to cancer patients. For example, Murnane et al. (2012) explored PA preferences (type, location, duration, frequency) through a survey of 92 cancer patients (mean age=58.77 years, range 32-88 years) who were receiving radiotherapy. They found that 53% (48.76/92 participants) of these cancer patients preferred an independent home-based PA programming over PA at cancer centers and local community centers with other cancer survivors. The authors suggested that cancer patients may prefer an independent home-based PA program opposed to a hospital or a group setting because at home they can control when, where, with whom, and how long they perform the PA program. Also, by allowing the cancer patient to perform the PA at home, they may be able to reduce caregiver/family burden because they do not have to travel to a distant location.

Notwithstanding, supervised, hospital-based interventions also have their merits (San Juan et al., 2011). Specifically, it has been proposed that some cancer patients prefer the intra-hospital setting for the following reasons: professional supervision; possible problems that may arise can be addressed immediately; motivational levels can be maintained at a higher level; exercises are more clearly structured; and for younger populations, parental safety concerns can be rapidly addressed and overcome (San Juan et

al., 2011; Winter, Muller, Hoffmann, Boos, & Rosenbaum, 2010).

2.2.3 Guidelines and Recommendations

The American College of Sports Medicine (ACSM) has recently published guidelines for PA and cancer (2013). The ACSM (2013) recommends 150 minutes of moderate or 75 minutes of vigorous aerobic activity combined with strength training, 2-3 times per week, followed by regular stretching for cancer survivors (adult age range 18+ years). The ACSM highlights that participating in PA during therapy, or shortly after therapy, should be appropriate for the functional ability of the cancer survivor (ACSM, 2013). For example, when cancer patients are working on returning to pre-diagnosis PA levels, it is important that they start at a low to moderate intensity, and gradually increase the activity frequency and intensity (Mustian et al., 2013). Interestingly, Carayol et al. (2012) performed a meta-analysis of 17 RCTs that examined the optimal dose of PA for improving psychological well-being in breast cancer patients (median age = 50.5 years). They found that even participating in low intensity exercise (i.e., combination of resistance and aerobic exercises) for 90-120 minutes per week was able to effectively improve QOL and fatigue This demonstrates that even minimal PA participation can have beneficial physical and psychological effects on the cancer patient.

2.3 Physical Activity for Non-Curative Cancer

2.3.1 Benefits of Physical Activity for Non-Curative Cancer

Although the literature concerning the role of PA for the non-curative cancer patient is limited, the early results are promising. Specifically, similar to the curative cancer patient population, emerging research has demonstrated that including a PA program into the supportive care plan can help to manage or improve the physical and

psychological burdens that are experienced by the non-curative cancer patient (Albrecht & Taylor, 2012; Banzer et al., 2013; Eickmeyer, Gamble, Shahpar, & Do, 2012; Lowe, Watanabe, Baracos, & Courneya, 2010; Oechsel et al., 2011; Oldervoll et al., 2011). Importantly, PA has been shown to compliment traditional palliative care (i.e., holistic care that encompasses pain and symptom management and physical, psychosocial, and spiritual support for the patient and their family, WHO, 2013), as it is able to maximize QOL by managing disease and treatment-related symptoms (Alsharif & Hata, 2013; Banzer et al., 2013; Lowe et al., 2011; Oldervoll et al., 2011).

PA as part of the overall supportive care plan for non-curative patients is beneficial for preserving respiratory and circulatory function, offsetting muscle atrophy, reducing joint contractures, and decreasing pain (Alsharif & Hata, 2013; Eickmeyer et al., 2012; Eyigor, 2010; Henke et al., 2014; Jensen et al., 2014). Non-curative cancer patients who participated in a PA program reported reduced lower limb edema, fatigue, dyspnea, and enhanced motor functioning, sense of energy, and mobility (Albrecht & Taylor, 2012; Alsharif & Hata, 2013; Eyigor, 2010; Gulde, Oldervoll, & Martin, 2011; Oechsel et al., 2011). Specifically, it has been noted that muscle strength, flexibility, range of motion, and balance can be maintained with the inclusion of a PA program for the non-curative cancer patient (Alsharif & Hata, 2013). Additionally, PA can offset cachexia by increasing muscle turnover, thus decreasing the degree of physical deconditioning (Alsharif & Hata, 2013; Eyigor, 2010; Oldervoll et al., 2011). Decreasing any one of these physical symptoms can help to mitigate any feelings of dependency that the non-curative cancer patient may be experiencing in relation to caregiver (e.g., family) burden. Overall, including PA into the comprehensive treatment plan appears to attenuate the inevitable functional decline associated with a non-curative diagnosis. By maintaining

functional fitness, it appears to permit a higher level of independence that ultimately leads to an improved QOL (Alsharif & Hata, 2013; Cheville et al., 2012; Eyigor, 2010; Henke et al., 2010; Oechsel et al., 2011).

From a psychological standpoint, PA has been shown to improve mood, cognitive functioning, depression, acceptance, hope for the future, and QOL (Alsharif & Hata, 2013; Banzer et al., 2013; Cheville et al., 2012; Gulde et al., 2011). Banzer et al. (2013) demonstrated that over 80% (N=400) of non-curative cancer patients (18+ years) who participated in PA at least 3 times per week reported improvements in QOL. A PA program was able to provide the non-curative cancer patient with a sense that they are actively participating in their treatment and that they still have control over their bodies (Gulde et al., 2011; Paltiel, Solvoll, Loge, Kaasa, & Oldervoll, 2009). This is because the non-curative cancer patient is able to have an opportunity to be distracted from their disease as well as be provided with an opportunity to set and achieve goals (Gulde et al., 2011).

In addition, PA programs have been reported to allow the non-curative cancer patient a chance to have structure and routine re-introduced back in their ADL (Eickmeyer et al., 2012; Gulde et al., 2011). This was able to remind the patients of their scheduled life before the cancer, offering them a sense of normalcy and providing them with the ability to plan for the future (Gulde et al., 2011). As a result, a sense of identity is restored when non-curative cancer patients are able to continue to plan and participate in their ADL (Gulde et al., 2011).

2.3.2 Feasibility and Physical Activity Preferences for Non-Curative Cancer

Importantly, studies have shown that non-curative cancer patients can safely

engage in light to moderate bouts of PA, and that PA programs do not result in a negative energy expenditure (Banzer et al., 2013; Eyigor, 2010). Likewise, non-curative cancer patients appear to be willing and able to participate in PA programs without experiencing any adverse effects (Albrecht & Taylor, 2012; Alsharif & Hata, 2013; Eickmeyer et al., 2012, Henke et al., 2014). Even patients with 3-12 month life expectancies were able to participate in PA programs and experience QOL benefits (Alsharif & Hata, 2013; Banzer et al., 2013; Oldervoll et al., 2006; Oldervoll et al., 2011;); with those demonstrating the greatest improvements in PA outcomes reporting the most substantial benefit (Banzer et al., 2013).

PA programs are most effective and are reported to have higher adherence rates if they are introduced to the patient shortly after prognosis and if the healthcare provider prescribing PA is familiar with the patient's cancer (Albrecht & Taylor, 2012; Banzer et al., 2013). For example, using a randomized design, Cheville et al. (2012) examined a home-based PA program aimed to improve function, fatigue, and sleep in stage IV (18+ years) lung and colorectal cancer patients (N=66). They found that non-curative cancer patients who were interested in participating in a PA program preferred that their primary oncologist provide specific PA recommendations because the primary oncologists would be familiar with the patient's cancer and treatment history (Cheville et al., 2012). This helps the non-curative cancer patient recognize that the healthcare provider recommending a PA program is aware that modifications to the PA program may be necessary as the non-curative cancer patient's health status changes (Albrecht & Taylor, 2012). In an effort to further increase adherence rates, Cheville and colleagues (2012) also examined how non-curative cancer patients defined PA. They reported that advanced stage lung cancer patients viewed PA as their usual ADL (e.g., cooking, yard work, house

maintenance) (Cheville et al., 2012). The authors concluded that a structured activity that was not consistent with their ADL would be poorly accepted (Cheville et al., 2012). It was also identified that non-curative cancer patients who consider themselves to be non-exercisers, may have difficulty accepting and utilizing a structured PA program (Cheville et al., 2012). To overcome this barrier, it has been suggested that efforts be made to clearly educate the non-curative cancer patient about the beneficial therapeutic effects of a PA program; such as, increased ability to perform ADL independently and improved QOL (Cheville et al., 2012). For example, Henke et al. (2014) implemented a practical walking program that would directly benefit the patient when carrying out ADL. By including a 6 minute walking program, 5 days per week, and a 2 minute stair climbing (10 step staircase) session every other day, patients were able to regain independence through increased mobilization (Henke et al., 2014).

Furthermore, it is important that the PA programs be tailored to the level of physical ability of the non-curative cancer patient (Banzer et al., 2013). Some examples of PA programs that have been well-received by non-curative cancer patients include: walking, cycling, and rowing (Alsharif & Hata 2013). For example, Lowe et al. (2010) surveyed 50 advanced-stage cancer patients (median age = 61 years) and found that PA programs such as walking have been the most preferred according to non-curative cancer patients because this type of program is of minimal cost, can be performed anywhere, and little to no equipment is required (Lowe et al., 2010). Furthermore, Lowe et al. (2010) reported that resistance training was the second most preferred training program. However, only 12% of these non-curative cancer patients were interested in participating in a resistance-training program. This highlights that individuals are interested in participating in an activity to improve their strength; however, the resistance-training

program needs to be made more appealing to this population. A RCT explored PA preferences among 27 cancer patients (median age = 52 years, range 34-69 years) receiving adjunct therapy (Husebo, Karlsen, Allan, Soreide, & Bru, 2014). The authors reported that activities such as walking led to strong participant adherence because of the activities' low cost, ease of use and accessibility, and flexibility in the program to fit the unique needs of each day (Husebo et al., 2014).

In a survey done by Oechsel et al. (2011), it was found that 60-92% (N=53) of non-curative cancer patients (median age = 58 years, range 29-76 years) were interested in an individualized PA program 1-2 times per week. Furthermore, Lowe et al. (2010) reported that 40% of non-curative cancer patients (20/50 participants) preferred to exercise in the morning. It is critical to acknowledge when designing a PA program that non-curative cancer patients who experience fatigue on mild exertion, are bedbound, or are nearing their end-of-life, prefer shorter bouts of exercise multiple times a week as they find this more manageable (Lowe et al., 2010).

Upon examining location (e.g., group setting vs. alone) of PA for the non-curative cancer patient, results are again mixed. Gulde et al. (2011) advocate that non-curative cancer patients would benefit from engaging in a group-based, supervised, PA program. They highlight that non-curative cancer patients are offered an opportunity to meet other cancer patients in a similar circumstance, providing a sense of comfort and unity (Gulde et al., 2011; Paltiel et al., 2009). Moreover, it has been suggested that for optimal physical and psychological outcomes, non-curative cancer patients are encouraged to engage in a group-supervised setting (Banzer et al., 2013). This approach has been suggested because the supervisor/leader of the intervention can monitor the non-curative cancer patient's overall physical effort (Banzer et al., 2013). Conversely, Lowe et al.

(2010) found that 54% (27/50) of cancer patients preferred to participate in a PA program alone, and 84% preferred performing a PA program in their own homes (Lowe et al., 2010). Lowe et al. (2010) suggest that a home-based PA program has the highest adherence because non-curative cancer patients are able to incorporate their PA into their ADL. Specifically, these non-curative cancer patients felt that with a home-based program, there was more flexibility as to when the PA could be completed and how the program could be completed (e.g., alone or with friends and family) (Lowe et al., 2011). Furthermore, the home is the preferred place to perform a PA program because it is a familiar place, where the non-curative cancer patient can maintain their sense of autonomy and dignity (Eyigor, 2010; Lowe et al., 2010). Although home-based programs are preferred, when implementing a PA program for the non-curative cancer patient, weather and climate must be taken into consideration. For example, non-curative cancer patients who live in Canada will be less likely to adhere to a walking program in the winter (Lowe et al., 2010). As a result, PA programs are needed that can also be performed inside the home (Lowe et al., 2010).

Notably, non-curative patients reported that their reasons for avoiding exercise were not related to fear of aggravating symptoms or experiencing any adverse events (Cheville et al., 2012). This is because non-curative cancer patients appear to self-adjust their activity level to be below a threshold that would be perceived to cause adverse symptoms to arise (Cheville et al., 2012). Regrettably, however, increased immobilization is a major risk factor for the progression of deconditioning and some may underestimate the benefits of PA and not do as much as they are able to do (Henke et al., 2014). As a result, when describing PA programs to non-curative cancer patients, key benefits must be highlighted to ensure that they are participating to their fullest physical

and psychological ability of that day. For example, Lowe et al. (2010) focused on the finding that non-curative cancer patients who had a more positive outlook on participating in a PA program, found PA as a means to regain independence, mobility (i.e., slow physical decline), and stability of disease progression.

While multiple suggestions for PA and the non-curative cancer patients have been highlighted, there is insufficient data to make detailed recommendations about specific PA for AYAs with cancer (Lowe et al., 2010). Regrettably, the bulk of the available literature groups AYAs in either the pediatric literature or adult/older adult literature (as detailed in the above reviewed studies). The problem that arises is that these interventions do not highlight or consider the unique needs of the AYA. Most importantly, as the specific ages of cancer groups remain largely unexplored (e.g., pediatric, AYA), it is difficult to say whether or not the types of PA programs for the middle-aged to older adult would be suitable for the AYA.

2.4 Complementary and Alternative Medicine

Public interest in the use of complementary and alternative medicine (CAM) as an adjunct therapy to improve the QOL of all cancer patients has increased in recent years (Culos-Reed et al., 2012; Lewis, de Vedia, Reuer, Schwan, & Tourin, 2003; Lin & Tsauo, 2013; Ross Zahavich, Robinson, Paskevich, & Culos-Reed, 2012). CAM has gained much attention due to its natural, non-invasive, and holistic approach to *patient-centered* care (Lewis et al., 2003). Cancer patients have been reported to engage in CAM with the hopes that this method of therapy can improve survival or minimize chances of reoccurrence (Park et al., 2012). CAM has been also shown to attenuate the physical and psychological symptoms related to the cancer and its treatment (Park et al., 2012).

Specifically, CAM has been shown to reduce stress, anxiety, pain, fatigue, nausea, and vomiting while reducing the need for analgesics in AYA survivors (Park et al., 2012) and adult non-curative cancer patients (Culos-Reed et al., 2012). A unique advantage of CAM is that it has the ability to treat the patient and the disease, through holistic mind and body therapeutic practices (Gallagher, 2011; Lewis et al., 2003). For some, CAM has met the physical, psychological, and spiritual needs of patients where conventional medicine may have fallen short (Gallagher, 2011; Lewis et al., 2003). The desire to have CAM included in the overall supportive care plan is welcomed and recommended for non-curative cancer patients (Gallagher, 2011; Hilliard, 2005; Lewis et al., 2003). This is because by decreasing any one of the previously mentioned symptoms, CAM can help to improve or maintain the non-curative cancer patient's QOL without causing any adverse effects (Hilliard, 2005; Lewis et al., 2003; O'Callaghan, MacCallum, & McDermott, 2004). Where maintenance of QOL is a central goal of any supportive or end-of-life care plan, it seems reasonable to evaluate how CAM can add to the effectiveness of quality care. Currently, most non-curative supportive cancer care models focus largely on treating the disease by managing the cancer and treatment-related effects by conventional medicine (Lewis et al., 2003). As a result, the appropriate transitional support for the patient's physical, psychosocial, and spiritual well-being may be overlooked or unaddressed (Hilliard, 2005).

2.4.1 Yoga as Complementary and Alternative Medicine

The advantage of CAM is that it offers a unique spiritual element, increasing the ability to deliver holistic patient-centered care. Examples of CAM include Tai chi, Qi gong, music therapy, guided imagery, and yoga (Lin & Tsauo, 2013). The reasons for

using CAM as an alternative to traditional forms of PA is that it may lead to higher participation and adherence rates in non-curative cancer population (Culos-Reed et al., 2012; MacKenzie, Carlson, Ekkekakis, Paskevich, & Culos-Reed, 2013). One specific form of CAM that is described as a light form of PA is yoga (Culos-Reed et al., 2012). Yoga is an ancient Indian discipline that means "yoking" or "union", a spiritual practice that strengthens both the mind and body (Carson et al., 2007; Dhruva et al., 2012; Mansky & Wallerstedt, 2006). Two arms of the 8-limbed practice include asana (physical postures) and pranayama (regulation of breath) that are designed to specifically focus on the mind and body connection (Dhruva et al., 2012). With regards to the cancer population, yoga has been chosen over other forms of traditional exercise (e.g., strength, resistance, or aerobic training) because it does not impose a negative energy balance and does not induce weight loss (Banzer et al., 2013). Furthermore, a major benefit of yoga is that it is flexible, adaptable, affordable (Thygeson et al., 2010) and is practiced by all cultural backgrounds (Carson et al., 2007).

While there are several forms of yoga, the post popular in Western culture is Hatha yoga (Carson et al., 2007; Cote & Daneault, 2012; Cramer, Lange, Klose, Paul, & Dobos, 2012; Culos-Reed et al., 2012; Dhruva et al., 2012; Harder, Parlour, & Jenkins, 2012; Lin & Tsauo, 2013; Ott, 2002). Hatha yoga is becoming increasingly popular as a supportive method for cancer care as it combines various postures (asanas) and breathing techniques (pranayama) to develop physical, emotional, and spiritual health (Carson et al., 2007; Cote & Daneault, 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Dhruva et al., 2012; Harder et al., 2012; Lin & Tsauo, 2013; Ott, 2002). As an alternative method for supportive care, Hatha yoga is able to alleviate the demands of cancer therapy and its related side-effects by eliciting similar physical and psychological improvements as seen

in other traditional PA interventions (Culos-Reed et al., 2012). Like traditional PA, Hatha yoga is able to strengthen muscles, enhance flexibility, and improve balance; however, these outcomes are obtained through various postures both in the seated and standing position. This is important because it offers an opportunity for cancer patients to strengthen their muscles in a therapeutic and gentle way, compared to strength and resistance training. For example, Sudarshan et al (2013) found that a once-weekly, 12-week hatha yoga session was able to improve shoulder flexibility in 14 stage I-III breast cancer patients (18+ years). Additionally, Danhauer et al., (2009) provided evidence from a RCT that both during and after receiving cancer treatment, participants (N=44) noticed improvements in muscle strength when participating in yoga. Importantly, enhanced muscular strength is effective in preventing weight loss while undergoing treatment (Danhauer et al., 2009). Not only is yoga beneficial for improving muscular strength, but recent reviews have highlighted that yoga may also be the missing link that will satisfy both the aerobic component typically received from walking; as well as, the strength component gained from resistance training (Culos-Reed et al., 2012; Buffart et al., 2012).

Additionally, the meditative breathing used in Hatha yoga has been shown to calm both somatic and cognitive mechanisms because it focuses on living in the moment (Carson et al., 2007; Thygeson et al., 2010). Dhruva et al. (2012) demonstrated through a RCT that the controlled breathing and meditative techniques used in yoga were able to improve QOL, fatigue, sleep, stress, anxiety, and depression in cancer patients (N=16; mean age = 54.2 years) receiving active treatment. Similarly, Hatha yoga is also associated with improved spirituality outcomes such as, acceptance, forgiveness, empathy, and a profound sense of existential purpose (Thygeson et al., 2010). As a result, a holistic approach to quality care can improve and maintain QOL of cancer patients.

2.5 Yoga as a Supportive Care Intervention Across the Cancer Continuum

Across the cancer continuum (i.e., time of diagnosis through to end-of-life), varying forms of yoga have been shown to improve disease and treatment-related side effects in both curative and non-curative cancer patients (Carson et al., 2007; Culos-Reed et al., 2012; Geyer et al., 2011; Thygeson et al., 2010). Studies have shown that in both males and females, yoga can improve the QOL of curative and non-curative cancer patients by addressing their physical, psychological, and spiritual needs (Carson et al., 2007; Culos-Reed et al., 2012; Boehm et al., 2012; Buffart et al., 2012; Geyer et al., 2011; Lin & Tsauo, 2013; Park et al., 2012; Ross Zahavich et al., 2012; Thygeson et al., 2010). Recent systematic reviews have highlighted that varied forms of yoga are beneficial for reducing cancer related fatigue and for decreasing inflammation and blood pressure; while also improving oxygen uptake, muscular strength, flexibility, and cardio-respiratory fitness (Boehm et al., 2012; Buffar et al., 2012; Chandwani et al., 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Harder et al., 2012; Sadja & Mills, 2013). Similarly, many forms of yoga have contributed to improved sleep, cognitive and social function, decreased stress and anxiety; thus, allowing the cancer patient to experience a sense of relaxation and well-being (Boehm et al., 2012; Buffar et al., 2012; Chandwani et al., 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Harder et al., 2012; Sadja & Mills, 2013).

Kumar and Balkrishna (2009) demonstrated that deep breathing exercises associated with yoga alter the stress-related signaling pathway, which has been suggested to prolong life because it inhibits apoptosis. Physiologically, the meditative and breathing techniques that are applied in yoga are able to decrease metabolism, heart rate, blood

pressure, improve circulation and oxygenation, and breath rate, while increasing alpha brain wave activity, immune and endocrine function (Henke et al., 2014; Lin & Tsauo, 2013; Thygeson et al., 2010).

Evidence from several systematic reviews and meta-analyses of varying yoga studies highlight strong evidence that the inclusion of yoga into the overall supportive care plan for curative and non-curative cancer patients is feasible (Boehm et al., 2012; Buffart et al., 2012; Chandwani et al., 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Harder et al., 2012; Lin & Tsauo, 2013; Sadja & Mills, 2013). Both on and off treatment, various forms of yoga, when included in the supportive care plan for the curative cancer patient, have demonstrated useful adjunct therapies for managing commonly reported physical and psychological symptoms (Boehm et al., 2012; Buffart et al., 2012; Carson et al., 2007; Culos-Reed et al., 2012; Geyer et al., 2011; Lin & Tsauo, 2013; Park et al., 2012; Ross Zahavich et al., 2012; Thygeson et al., 2010). Notable physical improvements were found in strength, flexibility, fatigue, and sleep while psychological benefits commonly reported were improved feelings of body awareness and positive affect, and decreased feelings of stress and anxiety (Boehm et al., 2012; Buffart et al., 2012; Chandwani et al., 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Harder et al., 2012; Lin & Tsauo, 2013; MacKenzie et al., 2013; Sadja & Mills, 2013). Despite variation in the type of yoga intervention (Hatha, Integral, Iyengar, Tibetan, Viniyoga, Vivekanada), duration of session (60-90 minutes), cancer diagnosis, timing of assessment, and duration of program (off treatment 6-26 weeks; active treatment 6-10 weeks), yoga was found to be an effective intervention to improve psychological and QOL outcomes (Culos-Reed et al., 2012; Sadja & Mills, 2013). It has also been highlighted that those who practiced yoga more often had higher self-reported ratings of invigoration, acceptance, and

relaxation on the next day (Lin & Tsauo, 2013). By decreasing these cancer and treatment related symptoms, yoga can instill a sense of wellness, that can inspire the cancer patient to perform their ADLs (Chandwani et al., 2012; Ulger & Yagli, 2010). Furthermore, yoga has been recommended as a viable means to have the cancer patient adhere to a PA program (Culos-Reed et al., 2012; Danhauer et al., 2009; Lin & Tsauo, 2013; Moadel et al., 2007; Ross Zahavich et al., 2012; Sudarshan et al., 2013), which may be key to reducing reoccurrence and lowering overall risk of mortality (Buffart et al., 2012).

Looking at Hatha yoga interventions specifically, Moadel et al. (2007) did a randomized controlled trial examining yoga's ability to promote/preserve QOL in 128 stage I-III breast cancer patients over a 12-week period. They found that there was a beneficial effect on social functioning, as well as enhanced emotional well-being and mood, and that this could potentially act as a means to offset physical/psychological deterioration, and maintain QOL (Moadel et al., 2007). One notable feature of this study is that a 3-month follow-up revealed that the intervention group had maintained their emotional well-being whereas the control group experienced deterioration in overall QOL, mood, and well-being. Similarly, Dhruva et al. (2012) had both curative and non-curative cancer patients do one, 60-minute Hatha yoga class per week and two daily home practices (10-15 minutes) while receiving chemotherapy. Classes were focused specifically on breathing techniques, or pranayama. They reported that class attendance was 100%. Of the 16 participants, control (n = 8) and treatment (n = 8), those practicing yoga noted improvement in stress, sleep disturbance, anxiety, and QOL (Dhruva et al., 2012).

Sudarshan et al. (2013) also examined the impact of Hatha yoga on anxiety, depression, and physical health in stage I-III post-operative breast cancer patients

between 18-70 years of age. The participants did 12 weeks of one yoga session per week with a trained yoga instructor. Assessments were taken on pain and shoulder flexibility. Sudarshan et al. (2013) noted that their participants' pain had decreased and flexibility improved with the inclusion of Hatha yoga.

Furthermore, Mackenzie et al. (2013) utilized an already established community-based Hatha yoga program, Yoga Thrive, to deliver to their study participants (N=66). Mackenzie et al. (2013) was interested in examining affect, mindfulness, health outcomes, mood disturbance, stress, and health-related QOL in individuals with stage II-III cancer. Participants (mean age = 52.88 years) were asked to complete one 75 minute yoga session once a week for seven weeks. Upon examining pre and post program surveys, the authors reported increased energy, improvements in fatigue and mindfulness (i.e., acting with awareness and concentration), and openness to emotions, leading to a decrease in distress (MacKenzie et al., 2013). Similar to findings from Lin and Tsauo (2013), more time spent practicing yoga revealed lower mood disturbances and higher health-related QOL at all time points (MacKenzie et al., 2013).

2.5.2 Yoga as a Supportive Care Intervention for Non-Curative Cancer

Although limited, available research indicates that yoga is also beneficial for alleviating many cancer and treatment-related side effects in the adult non-curative cancer patient. For example, a pilot study by Carson et al. (2007) examined the role of Hatha yoga on non-curative cancer patients (N=13). Through pamphlet distribution to attending oncologists and physicians, Carson et al. (2007) reported data on women with metastatic breast cancer (mean age = 59 years, range 44-75 years) from Duke University Medical Centre concerning the eight-week hatha yoga intervention. The intervention

itself consisted of eight weekly group sessions (four to five patients per group), led by a certified yoga instructor. Each session was 120 minutes and included gentle stretching, and asanas, complemented by breathing exercises (pranayama). Patients were supplied with a yoga mat, a blanket, CDs/audiotapes, and illustrated handbooks to guide them in home practice. Patients were encouraged to spend at least 10 minutes a day practicing yoga strategies on their own, and applications of yoga to daily living were assigned each week.

Carson et al. (2007) demonstrated that Hatha yoga is able to help non-curative cancer patients accept their disease, increase relaxation, and enhance their sense and feelings of invigoration. They also found that participants reported improvements in pain and relaxation; highlighting those who participated in the yoga for a longer period of time experienced more of yoga's beneficial effects (e.g., invigoration, acceptance, relaxation) (Carson et al., 2007). It was also noted that improvements were not only on the same day of yoga practice, but were also carried over to the next day.

Similarly, Danhauer et al. (2009) ran a Hatha yoga program with 44 women who had non-curative breast cancer. They participated in one 75 minute yoga session, once a week, for 10 weeks. Participants were randomized to an intervention group or a control group. They noted that the yoga group reported better mental health, positive affect and spirituality; and decreased levels of depression. Physical benefits for their Hatha yoga intervention included enhanced muscular strength, flexibility, range of motion, energy, relaxation, and an increased sense of well-being, decreased pain, improved sleep quality, stress reduction, and control over physiological parameters.

Furthermore, Ross Zahavich et al. (2012) examined the Hatha yoga program, Yoga Thrive, and its feasibility for prostate cancer patients with curative and advanced

cancer (N=15). Ross Zahavich et al. (2012) utilized the Yoga Thrive program for seven weeks to establish adherence to a PA program, offered to prostate cancer survivors and their support persons, followed by a maintenance phase for weeks 8 – 14 (involving self-selected PA). Similar to outcomes noted by MacKenzie et al. (2013), improvements in mood and decreased levels in fatigue and stress were reported; as well as, significant increases in flexibility. Their concluding recommendations were that future studies should examine the Yoga Thrive DVD for maintenance and at home participation.

2.5.3 Summary of Yoga for Adult Patients Across the Cancer Continuum

Various forms of yoga for the curative and non-curative cancer patient have been effective in improving physical cancer and treatment-related symptoms. Although findings supporting yoga's effect on successfully mitigating physical symptoms are preliminary, available literature supports its beneficial role in improving symptoms related to nausea, vomiting, bowel function, sleep quality, and fatigue (Chandwani et al., 2012; Culos-Reed et al., 2012; Ross Zavhavich et al., 2012). It has also been suggested that a yoga intervention may actually slow the inevitable chronic physical deterioration associated with the disease. This may allow the non-curative cancer patient to independently carry out their ADL for a longer period of time (Carson et al., 2007).

Evidence also exists that non-curative cancer patients and survivors are willing and able to participate in a yoga program from the time of diagnosis until the end-of-life, on or off treatment, in a home-based or supervised yoga program (Carson et al., 2007; Culos-Reed et al., 2012; Geyer et al., 2011; Thygeson et al., 2010). Most importantly, yoga interventions for curative (Sadja & Mills, 2013) and non-curative cancer patients (Carson et al., 2007; Danhauer et al., 2009; Sadja & Mills, 2013) are safe and do not

impose any adverse events (Carson et al., 2007; Chandwani et al., 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Harder et al., 2012; Ross Zahavich et al., 2012).

2.5.4 Yoga for AYAs with Curative Cancer

Available literature regarding the positive benefits of yoga for the pediatric and AYA curative cancer patient is limited. Upon reviewing the literature for AYA specific studies, only one study was found that outlined the role of yoga on AYA cancer survivors (Park et al., 2012). Park and colleagues (2012) highlight that they chose AYA cancer survivors (15-39 years) for their study because young adults report higher levels of distress and are more apt to participate in CAM practices, such as yoga. Participants (n = 286) were, on average, 3.8 years since their diagnosis and 94% had completed primary treatment. They found that 37% of participants reported using CAM approaches and 32% stated they participated in yoga for health reasons. For those who reported engaging in yoga, they found that longer amounts of time spent practicing yoga resulted in better mental health, improved state of mind, and sense of fulfillment with family (Park et al., 2012).

Yoga as a light form of PA has been recently evaluated as an effective means to improve the physical and psychological domains of the pediatric and adolescent cancer patient/survivor (Geyer et al., 2011). Utilizing yoga as an adjunct therapy for these populations has been found to improve strength, balance, pain, and QOL (Geyer et al., 2011). Geyer et al. (2011) discuss the "Bendy Kids Yoga (BKY)" program and its feasibility for improving QOL in pediatric cancer patients. The BKY is an hour-long therapeutic yoga session that consists of stretching, strengthening, balance, breathing, relaxation, and body awareness exercises (Geyer et al., 2011). Three children (ages 5, 6,

and 10,), three adolescents (ages 12, 15, and 19), and 4 parents participated in the BKY yoga study (Geyer et al., 2011). Participants were asked to complete one BKY session per week, for five weeks. The BKY was modified to meet the specific developmental and age-appropriate needs of the patients. For example, the adolescents participated in the postural exercises while the children engaged in yoga games (Geyer et al., 2011). All participants took part in the breathing exercises (Geyer et al., 2011). Children and adolescents reported that they "looked forward to BKY yoga sessions because on both good and tough days, they could always find ways to participate in BKY and always felt better afterward" (Geyer et al., 2011, p. 377). It was highlighted that the flexibility in yoga session structure (e.g., group/individual) greatly assisted the cancer patients in developing friendships and relationships (Geyer et al., 2011). In addition, the BKY offered a time for the family to interact in an activity with their child.

Thygeson et al. (2010) reported similar findings concerning the feasibility of including a Hatha yoga program in the cancer survivor care plan for children and adolescents. Eleven children (6-12 years), five adolescents (13-18 years), and 33 parents/caregivers participated in a single Hatha yoga session. They found that anxiety levels of the adolescent cancer patients/survivors decreased to levels similar to those of healthy high school adolescents.

2.5.5 Yoga for AYAs with Non-Curative Cancer Rationale

Extrapolating from the current literature on yoga in adult non-curative and AYA curative cancer patients, it would seem plausible to suggest that a light yoga program would be a beneficial intervention for the AYA non-curative cancer patient. Yoga may act as a distraction for the AYA non-curative cancer patient because they can participate

in something where they can set goals and experience a sense of normalcy during a very challenging time (Gulde et al., 2011; Wein et al., 2010; Wiener et al., 2012). Yoga provides a sense of control to cancer patients, allowing them to feel as though they are participating in their treatment therapy (Cope, 2002). Regaining a sense of control can assist the AYA non-curative cancer patient in achieving their age-appropriate developmental tasks. Having the AYA non-curative cancer patient participate in a home/hospice-based yoga intervention may also delay or slow their increasing functional impairments (Carson et al., 2007; Hede, 2011; Kumar & Balkrishna, 2009). This could potentially provide the AYA non-curative cancer patient with a sense of increased energy and mental clarity, allowing them to engage in more meaningful endeavors towards the end of their life, attending to their number one wish, the desire to be remembered (Wiener et al., 2012).

2.6 Summary

There is currently an urgent need to establish age-appropriate comprehensive supportive care models for the AYA non-curative cancer patient (AYA Task Force, 2013). At present, no model of supportive care exists for the AYA non-curative cancer patient, and they remain lost between the pediatric and adult cancer care dichotomy (AYA Task Force, 2013). Moreover, the Quality End-of-Life Care Coalition (2012) mission statement asserts the belief that "all Canadians have the right to quality end-of-life care" (p. 1). However, this has not been the case for AYA non-curative cancer patients, as their needs often remain unmet, unaddressed, or underserved (Albritton & Bleyer, 2003). While including PA in the overall supportive care plan for the AYA cancer patient is widely accepted; regrettably, little is known about PA, specifically yoga,

and its role in QOL maintenance in the AYA non-curative cancer population.

2.7 PURPOSE

The primary purpose of this study was to examine the feasibility (e.g., recruitment, retention, and adherence) and safety (i.e., number of adverse events) of a seven-week home/hospice-based instructive Hatha yoga intervention (available on DVD) in AYA non-curative cancer patients. Secondary objectives included the examination of the efficacy of yoga in mitigating cancer and treatment-related side effects through ratings of self-reported QOL.

CHAPTER THREE METHODS

3.1 Study Design

A single-arm, non-randomized, pre and post-test, pilot investigation of a seven-week instructive home-based Hatha yoga program (available on DVD) was conducted. Pre and post program data included measures of QOL specific to palliative disease and spiritual domains. Feasibility (e.g., recruitment, adherence, safety, and retention) was also reported.

3.2 Recruitment

Prior to beginning recruitment, ethical approval was obtained from the Capital District Health Authority (CDHA) and IWK Health Centre's Research Ethics Boards. Once ethical approval was received, participants were recruited via one of two recruitment strategies; physician or self-referral. Medical collaborators at the IWK and CDHA identified and referred eligible participants. Individuals who self-identified to participate in the study were referred to the medical collaborator (R. Rutledge) for eligibility review. Self-identified individuals were also asked to provide a letter of medical approval to participate in the study from their own oncologist/physician.

Several strategies were used to identify participants. Posters (Appendix A, p. 69) advertising the study were placed throughout the IWK and CDHA hospitals as well as on various local, provincial, and national cancer community websites and Facebook pages.

Following participant identification, eligibility screening, and medical approval, the student investigator (SI) contacted potential participants to arrange a meeting at a location of their choice (e.g., home, hospice, video-conference, or phone call) to discuss

the study. During the initial meeting, the SI again reviewed the eligibility criteria and study procedures with the potential participants. Specifically, an overview of the research study, participant expectations (e.g., time commitment, duration of program), potential risks and benefits of participating in the study, and assurance of confidentiality were discussed with the participant. If the potential participant was still interested in participating after discussing the study, they were then asked to sign the informed consent form (Appendix B, p.70) and complete the baseline questionnaire (Appendix C, p.88). Any questions or concerns about the study were answered at that time. Once the consent form was signed, one copy was kept for the research team and one for the participant to take home.

3.3 Participants

Eligible participants were: (a) English speaking; (b) diagnosed with a non-curative cancer and assigned to non-curative or palliative care; (c) between 15-39 years of age; and (d) had oncologist/physician consent to participate. Patients were not recruited to the study if they experienced any medical condition that would contraindicate yoga or if they exhibited significant cognitive limitations (e.g., psychiatric disorders).

3.4 Intervention

A home/hospice-based instructive Hatha yoga DVD was used for the intervention. This style of yoga and format of delivery of the program was chosen due to its popularity among the younger population, its ability to mitigate the commonly reported disease and treatment-related side-effects often overlooked in the AYA supportive care plan, and because of its ease and flexibility of use.

Consenting participants were provided with the instructive Hatha yoga DVD (Yoga Thrive) and the appropriate materials for the program (e.g., yoga mat, yoga block, yoga strap) during or shortly after the initial meeting with the SI. Participants were also made aware that the SI would be contacting them (e.g., e-mail, phone, or text; based on participant preference) to monitor their weekly progress (e.g., track number of weekly yoga sessions completed) and to assess any barriers or obstacles that may need to be overcome (i.e., provide feedback as to how to modify a position to continue with the weekly program in the most comfortable way possible).

Over the course of the seven-week program, participants were asked to complete a minimum of one, 75 minute yoga session per week. The DVD package given to participants included four discs that progressed in difficulty over the seven-week program (Appendix D, p.98. The sessions are broken down as follows:

1. Disc One, Week One, Introducing the Basics, consists of approximately 10 postures and breathing exercises.
2. Disc One, Week Two, Connecting Your Body and Breath, consists of approximately 14 postures and breathing exercises.
3. Disc Two, Week Three, Developing Ease, Stability, Strength, and Flexibility, consists of approximately 17 postures and breathing exercises.
4. Disc Two, Week Four, Opening Your Heart and Chest, consists of approximately 15 postures and breathing exercises.
5. Disc Three, Week Five, Building Relaxed Resilience, consists of approximately 15 postures and breathing exercises.
6. Disc Three, Week Six, Experiencing Meditation in Motion, consists of approximately 14 postures and breathing exercises.

7. Disc Four, Week Seven, Feeling What Your Body Wants, consists of approximately 20 postures and breathing exercises.

If the participant felt capable, they were encouraged to complete additional sessions and record them. Given the individual's ability and variable health status each day, it was understood that the intensity and duration of the Hatha yoga session would be unique to each participant. For example, if a participant was unable to complete the full 75 minute program in a single session, they were encouraged to complete the requested 75 minutes over the course of several days or the week (suggested minimum - 20 minutes/session). Although the Hatha yoga DVD program is designed to gradually increase in difficulty over the seven-week period, the participants were informed that they could choose to complete the level of Hatha yoga that best fit their needs on any given day. For example, if there was a particular session that they most enjoyed, they were encouraged to keep with the session they preferred. Participants were asked to record the number of sessions completed over the course of the seven-week program, as well as the amount of time completed during each session (0-75 minutes). Participants were also asked to record reasons for missed sessions or inability to complete the full 75 minute session.

3.5 MEASURES

3.5.1 Demographics

Baseline *demographic and medical variables* were examined by self-report and included age, sex, cancer diagnosis (date, type), treatment(s) received/ongoing, and medical comorbidities.

3.5.2 Program Feasibility

Recruitment. Sum of the number of individuals who contacted the research team to learn more about the study.

Retention. Was determined by reporting the number of participants who completed the full seven-week study and by those who completed the one-month follow-up.

Adherence. Was calculated by how many full 75 minute yoga sessions the participant completed out of seven. This means that adherence (7/7 sessions) could surpass 100%. As it was anticipated that some participants would not able to complete the full 75 minute session in a single bout, adherence was also calculated by accumulating total weekly session time (i.e., a measure of how many participants met or exceeded the recommended 75 minutes of weekly yoga over the seven-week program duration).

Safety. Safety was assessed on a weekly basis by asking the participants if they experienced any adverse events during their weekly yoga session.

3.5.3 Quality of Life Measures

Participant QOL was assessed by the self-administered Functional Assessment of Chronic Illness Therapy – Palliative Care subscale (FACIT-Pal) and the Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being subscale (FACIT-Sp) (Lyons et al., 2009; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). The FACIT-Pal is a 46-item multi-dimensional measure of health-related quality of life (27 items measure physical, functional, social, and family well-being; 19 items measure advanced cancer domains) (Lyons et al., 2009). The FACIT-Pal subscale was chosen for this study

because it is specific to the advanced cancer population, it addresses both the physical and psychosocial burden of the disease and its treatment related effects (Lien et al., 2011; Lyons et al., 2009; Lin & Tsauo, 2013). In addition, the 12 items from the spiritual component of the FACIT were included to measure the spiritual domains of the AYA non-curative cancer patient (Peterman et al., 2002). The FACIT-Sp subscale (short form, 12 spiritual items) was chosen for this study because it examines the role of spirituality, distinct from religion, in coping with an illness (Peterman et al., 2002). The FACIT-Pal and Spiritual subscale use a 5-point Likert rating scale (0 = Not at all; 1 = A little bit; 2 = Somewhat; 3 = Quite a bit; and 4 = Very much), written at a grade four comprehension level (Peterman et al., 2002; Lyons et al., 2009). Higher scores reported from the FACIT-Pal and Spiritual subscale indicate better QOL (Lien et al., 2011). A most advantageous feature of the FACIT-Pal and Spiritual subscales is that they only take, on average, ten minutes to complete (FACIT Questionnaires, 2014). Due to this specific layout, the FACIT-Pal and Spiritual subscales have been reported to have minimal respondent burden (FACIT Questionnaires, 2014; Lien et al., 2011). Additionally, both the FACIT-Pal and FACIT-Sp report on physical well-being (PWB), functional well-being (FWB), emotional well-being (EWB), and social well-being (SWB) as noted above. Collectively, PWB, FWB, EWB, and SWB make up the Functional Assessment of Cancer Therapy – General questionnaire (FACT-G) (Cella et al., 1993). FACT-G scores have also been reported, as their questions are specific to health related QOL outcomes for those with any form of cancer (FACIT Questionnaires, 2014). For the FACIT-Pal, FACIT-Sp, and FACT-G subscales, a higher score indicates a better QOL (Cella et al., 1993; FACIT Questionnaires, 2014).

3.5.4 Post Program Exit Questions

To gain an increased understanding of the program feasibility and efficacy, three exit questions developed by the SI were administered approximately 30 days after the yoga program ended. The questions were designed to shed light on what motivated the participants to join the study/what made it difficult/easier to participate; if they found the yoga program beneficial or challenging; and if they would recommend this yoga program to others in a similar situation.

3.6 Statistical Analyses

Data collected from the study was analyzed using SPSS Statistics version 21.0 for windows (IBM) and was stored on a secure, password protected computer at the Dalplex. Baseline demographic (e.g., age, sex) and medical (e.g., months since diagnosis, primary tumor type, site of metastases, type and duration of adjuvant treatment, and current medications) data were summarized and presented. Primary outcome measures have been described using frequencies and percentages. Given the small sample, secondary measures (e.g., QOL) were examined using the non-parametric statistic, Wilcoxon Signed-Rank test. While it is recognized that the use of repeated tests increases the probability of Type I error, no statistical adjustment was made. All P values were based on two-sided tests. Significance was set at $p<0.05$ for all tests.

The three exit questions were transcribed verbatim and a simple content analysis was conducted to describe AYA non-curative cancer patient preferences, motives, and barriers to participating in the Hatha yoga program.

CHAPTER FOUR RESULTS

4.1 Participant Characteristics

Participants (N=4) ranged in age from 32 to 38 years of age (M=35.75, SD=1.5). All participants were female and gave informed consent to participate in the study. Individuals who participated in the study had breast cancer (n=3) or lung cancer (n=1). Sites of metastasis included the lungs and lymph nodes.

4.2 Study Feasibility

Recruitment and retention data is summarized in figure 1.

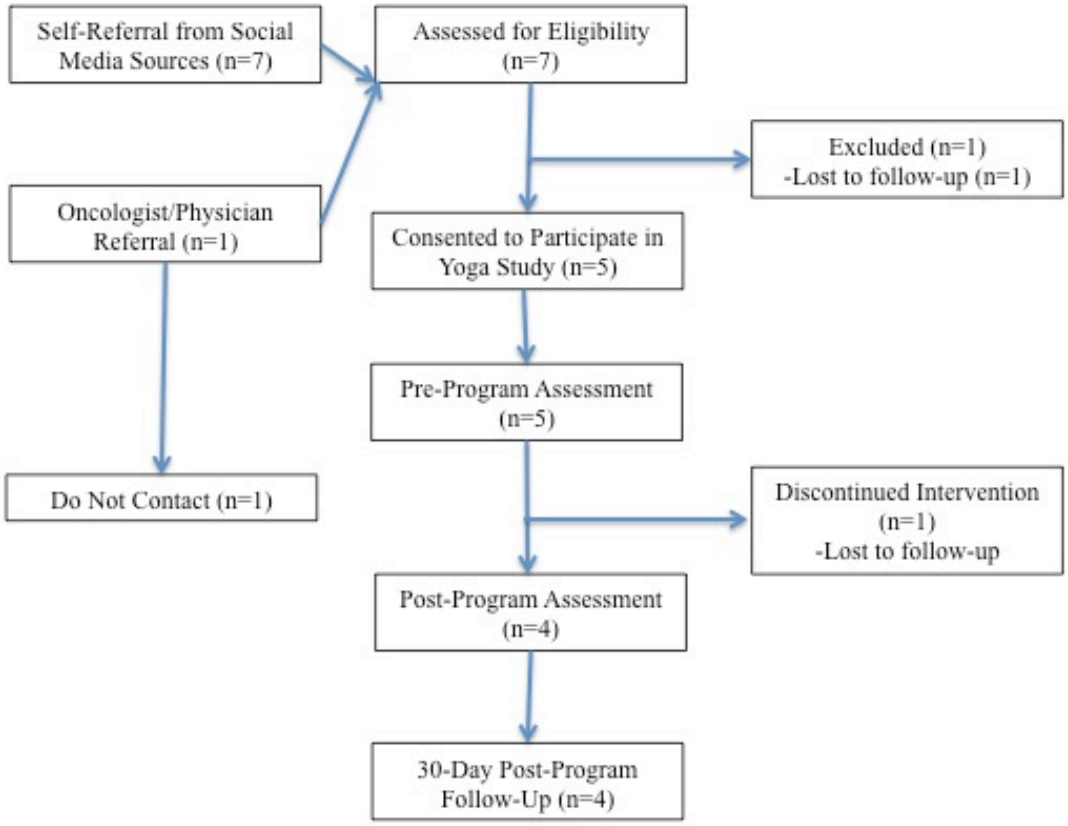

Figure 1 Participant recruitment and retention data.

Recruitment. Physician Referral: One individual was referred to the study by a medical collaborator. Unfortunately, due to declining health, consent discussion was not facilitated, and the potential participant was not considered for the study. *Self-Referral*: Seven additional individuals were self-identified for participation in the study through social media sources (e.g., Facebook and Cancer Community Centers). Out of these seven interested and eligible individuals, one did not complete the consent process, and one was not included in the study because they were currently living outside of North America. Five participants consented to participate in the study; however one individual was lost to follow-up. The four remaining participants completed the Yoga Thrive program in their home.

Retention. Four of five (80%) participants completed both the full seven-week study and the one-month follow-up interview. The fifth participant was lost to follow up (last point of contact was three weeks into study, unable to contact). The following results are presented for the four participants who completed the full study.

Adherence: On average, participants engaged in 3.14 full yoga sessions (45%; range 3 – 7 sessions, on average 71.2 minutes per weekly yoga session) during the duration of the seven-week program. Compiling the total number of yoga sessions completed by all participants (100% adherence = 7, 75 minute yoga sessions per participant, multiplied by 4 participants = 28 yoga sessions), more than half (64%; n=18) of the requested yoga sessions were a full 75 minutes. As anticipated, some participants were not able to complete the full 75 minute session in a single bout, however it is important to highlight that reasons reported for shorter durations were not due to the yoga program, but rather to distractions within the home (e.g., family, pets). Two participants completed the full 75 minutes of yoga each week for seven weeks. The other two

participants completed a total of one and three 75 minute full yoga sessions respectively. Lastly, all participants who engaged in weekly yoga sessions exceeded the minimum requested time of 20/75 minutes per session (only 3 out of 28 sessions were less than 75 minutes). On average, participants who completed less than 75 minutes completed a minimum of 48 minutes.

Reasons for missed yoga sessions were: out of town/on vacation (no DVD or equipment), being sick or having physical pain, and caregiver responsibilities. Six yoga sessions were reported by participants as "did not complete yoga session this week" due to one of the aforementioned reasons for missed yoga sessions.

Safety: No adverse events were reported.

4.3 Quality of Life Measures

Baseline and post-intervention QOL outcomes are summarized in Table 1 (p.41).

4.4 Perceptions of the Yoga Program – 30 day Follow-up

A follow-up phone call was scheduled with each participant approximately 30 days (average 27 days) after study completion. Below are the common categories that were reported by the participants.

Question 1: *What factors motivated you to participate in this yoga study?* Participants indicated that the home-based yoga program was an opportunity for them to improve their health, separate from chemotherapy, radiation, surgery, and medications. It was also an opportunity for self-care, further described as a time to be in their "own world", and "do something for me". Also, participants described themselves as being eager to participate in anything that would make them feel better.

Table 1. *Baseline and Post-Program Mean, SD, Reliability, Coefficients and p values of QOL Measures*

Measure	Pre-test		Post-test		Neg. MR	Pos. MR	Wilcoxon Z	*p*
	M	*SD*	*M*	*SD*				
PWB	3.25	.44	3.57	.40	0.00	3.00	-1.342	.180
SWB	2.75	.62	2.79	.82	2.50	3.50	-0.272	.785
EWB	2.58	.88	2.71	.85	4.50	5.50	-0.184	.854
FWB	2.64	.85	3.21	.83	0.00	10.00	-1.841	.066
PalS	2.93	.46	3.39	.54	0.00	10.00	-1.826	.068
MP	2.78	1.11	3.25	1.00	0.00	10.00	-1.841	.066
Faith	2.06	1.59	2.06	1.31	3.00	3.00	0.00	1.00

Note. PWB, physical well-being; SWB, social well-being; EWB, emotional well-being; FWB, functional well-being; MP, meaning and peace; PalS, Palliative Subscale; *M*, mean; SD, standard deviation; and *p*, probability.

Question 2: *Did you find the yoga program beneficial or challenging?* All participants highlighted that the yoga program was beneficial for improving range of motion. Participants also indicated that they felt better on days they participated in yoga, compared to days they did not. Knowing the benefits of the yoga, they noticed how their body felt on days that they did not participate in yoga. Also, participants noted that they always felt better after completing the yoga session, with regard to both mind and body. Common descriptions after completing a yoga session were a sense of calm and relaxation, as well as a feeling that they did something good for their body.

It was frequently indicated that *Sessions 1 and 2* of the yoga program were too easy, but that *Sessions 3 and 4* were ideal. Those who completed *Sessions 5, 6, and 7*, noted that these "were challenging, but in a good way". Participants indicated that it was difficult to find the motivation to practice yoga on days they were not feeling well, but they were able to overcome this barrier knowing how they would feel afterwards, from previous experience. It was suggested that having reminders, or connecting with others doing the same program (e.g., e-mails, blogging, or texting), might be a nice way to get connected with others, and stay motivated.

The majority of participants noted that it was nice being able to do their yoga program at home. Home-based programming was preferred because not all cancer centers are close to the participants' homes, nor do these cancer centers offer age-specific programs. Also, on days when the participants did not want to socialize, it was an enjoyable way to do something for themselves.

Question 3: *Would you recommend this yoga program to others in a similar situation?* All participants would and have recommended this yoga program to others in a similar situation. The participants enjoyed the flexibility and ease of use of the yoga program. They were able to structure the time and intensity according to how they were feeling on any given day. Lastly, all participants have continued with the yoga program (e.g., once per week) because they agreed that it allows them the opportunity to regain routine in their weekly schedule, to feel a sense of calm and increased awareness (e.g., physically and psychologically), and that they feel better after completing the yoga session

CHAPTER FIVE DISCUSSION

5.1 REVIEW OF FINDINGS

The purpose of this study was to examine the feasibility, safety, and utility of a seven-week home/hospice-based Hatha yoga program for AYA non-curative cancer patients. Four female AYA non-curative cancer patients, varying in age (range 32-38 years of age), type of cancer (e.g., breast, lung), and time since diagnosis participated and completed the seven-week Hatha yoga program.

5.1.1 Feasibility: Recruitment, Retention, and Adherence

Recruitment for participants began in August of 2013; however due to a small provincial population and a very specific and rare cancer patient population (e.g., AYA non-curative cancer patient between 15-29 years of age), early recruitment efforts proved extremely challenging. There are many possible reasons for this. For example, Burke, Albritton and Marina (2007) highlight that AYAs are less likely to be identified as potential participants for AYA research and are less likely to be referred to clinical trials because they are often seeing physicians who are not connected to AYA research. Physicians may also be reluctant to encourage AYAs to become involved in research because little information is known about how varying interventions may help or hinder the AYA due to the infancy of the research in this area. Furthermore, Tonorezos and Oeffinger (2011) note that in addition to the biological and developmental variability across this age group, AYAs face additional challenges within the health care system (e.g., insurance and lack of age-specific treatment and care). Any one of these barriers to access and care could have contributed to low awareness and study participation.

As a result of initial difficulties with recruitment, amendments were made to first expand the study and make it available for nation-wide recruitment. Through cancer community resources (e.g., Facebook and Twitter), self-identified individuals were able to contact the SI and learn more about the study. At the same time, individuals who were older than 29 years of age were contacting the SI to indicate that they would be interested in participating in the yoga study if the age of eligibility were increased. As a result, a second amendment was made to increase the age of eligibility for the study to accept AYA non-curative cancer patients between 15-39 years of age. Returning to the same social media resources, an update was made on the various websites and Facebook pages indicating the new age range. Within minutes of posting the study online, six individuals contacted the SI indicating that they would be interested in participating in the yoga study. Recruitment efforts in recent studies involving AYA cancer patients that used social media have been quite successful. For example, researchers at the University of California examined the role of social media in recruitment efforts of young adult (18-45 years of age) cancer survivors (life stage at diagnosis ≤ 14 years of age) (Gorman et al., 2014). Upon examining national recruitment, social media efforts resulted in better recruitment and participation among the AYA survivors over physician recruitment (Gorman et al., 2014). The researchers were recruiting for two national studies where the first enrolled 82% of eligible participants (204/249) while the second enrolled 59% (295/500) of eligible participants (Gorman et al., 2014). Not only was recruitment accomplished through social media sources, but consent and surveys were also completed electronically (Gorman et al., 2014). Results from this study as well as those recently reported by Gorman et al. (2014) suggest that recruitment and study engagement and adherence may be more successful when web-based communication tools are used.

Importantly, all four participants in the current study were self-identified through social media resources. Common reasons for contacting the SI about the study were that participants were looking for something to improve their health and to separate themselves from the traditional medicine (e.g., chemotherapy, radiation, surgery, medications) that they were already receiving/had received. For future recruitment initiatives, community cancer organizations appear to be viable platforms to connect with and inform AYA non-curative cancer patients of available studies.

With regard to retaining participants, each week the SI contacted (e.g., phone, e-mail, text message, FaceTime, Skype) the participants to check-in on weekly yoga sessions. Although not all participants completed the requested 75 minutes of yoga each week, for seven weeks, weekly contact with participants did serve as an important reminder to take part in their yoga and a means to problem solve with the participants to overcome barriers and acknowledge success.

Upon reviewing what the participants thought of the study during the 30-day follow-up, there was some confusion over the requested adherence. Some individuals thought that the seven-week yoga program simply needed to be completed (e.g., complete seven yoga sessions over an undetermined amount of time). As a result, adherence to the yoga program varied among some participants. Alternatively, the weekly yoga program motivated some participants to engage in additional PA. Moving forward, a clearer description of the yoga program needs to be delivered. However, all participants noted that they have been continuing with the yoga program once per week, which is consistent with findings of other non-curative cancer and PA studies (Albrecht & Taylor, 2012; Oechsel et al., 2011; Oldervoll et al., 2011).

5.1.2 Physical Improvements

Although not an inclusion or exclusion criteria, all participants noted that they did have previous yoga experience. Not all participants indicated that their past yoga experience was beneficial, but they were interested in trying yoga again. Similar studies have indicated that previous yoga experience is related to adherence in a yoga program (MacKenzie et al., 2013). As a result, it is difficult to say whether interest in the yoga study and adherence to the program was due to the yoga program itself, or previous yoga experience.

Upon reviewing weekly check-ins with the participants, it was commonly noted that the participants did not realize how poor their flexibility was prior to beginning the Yoga Thrive DVD. Similar to other yoga studies for individuals at varying stages of their cancer continuum, participants reported that they noticed an improvement in flexibility, range of motion, and balance (Boehm et al., 2012; Buffart et al., 2012; Chandwani et al., 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Harder et al., 2012; Sadja & Mills, 2013; Sudarshan et al., 2013). Participating in the yoga program also made participants aware of the areas that required additional flexibility training and motivated the participant to arrange an appointment with a healthcare professional to improve this 'problem area'. For example, participants noted that they wanted to improve their flexibility so that they could participate in the yoga sessions to a greater extent (e.g., challenge themselves with a more difficult session, or complete the full 75 minute session). This motivation was commonly linked to their desire to take control of their health and do something for themselves. Furthermore, with the notion that they were improving their flexibility and endurance with each week of yoga participation, participants reported their goals for the future week (e.g., more difficult session to complete, length of time participating in yoga session, and number of yoga sessions per

week to complete). The participants forwarded this information to the SI, without any probing. This demonstrates that participants were again interested in planning for the future because they were able to set goals and take control of their health. As Cope (2002) described, yoga provides the opportunity for the non-curative cancer patient to feel as though they are actively participating in their treatment. Although the change in FWB (p=0.066), PalS (p=0.068), and Meaning and Peace (p=0.066), between pre and posttest questionnaires was not statistically significant, all three measures demonstrated a positive trend towards significance. These findings are similar to other studies that have found that participating in yoga slowed/delayed functional impairments, allowing the non-curative cancer patient to participate more fully in their ADL (Carson et al., 2007; Hede, 2011; Kumar & Balkrishna, 2009).

5.1.3 Psychological Improvements

As anticipated, improvements were not solely reported within the physical domain, but were also evident upon reviewing psychological domains. All participants noted that they felt quite relaxed after completing a yoga session. These findings are frequently reported in other studies examining yoga for cancer patients, highlighting that yoga is beneficial for deceasing stress and anxiety, allowing the patient to feel well and relaxed (Boehm et al., 2012; Buffart et al., 2012; Chandwani et al., 2012; Cramer et al., 2012; Culos-Reed et al., 2012; Harder et al., 2012; MacKenzie et al., 2013). Similar to reports from the BKY program developed by Geyer et al. (2011), participants in this study also felt well after participating in yoga, despite how they were feeling before they did their yoga session for the day. Some participants also reported that they felt more aware (e.g., mental clarity), or that their "chemo-brain" had disappeared. As noted by

Wiener et al. (2012), increasing mental clarity may allow the participant to confidently engage in meaningful endeavors.

Interestingly, the positive changes that are most frequently reported among QOL domains in cancer patients include functional and physical well-being (Levine & Balk, 2012). While the positive trends of physical and functional benefits were apparent in this study, it appears that the practice of yoga may also facilitate improvements in spiritual well-being (Bai, Lazenby, Jeon, Dixon, & McCorkle, 2014). These findings are similar to previous research (Thygeson et al., 2010) that also demonstrated an improvement in peace of mind, meaning, and purpose. Importantly, with regard to AYA cancer patients specifically, Smith and colleagues (2013) note that AYAs' spiritual needs are linked to their health-related QOL, and when these needs are not met, it results in worse health-related QOL. That is, spirituality is linked to a more positive well-being because it allows individuals an opportunity to establish meaningful relationships, gives cancer patients a sense of purpose, and enables them to focus on the present (Garssen, Uwland-Sikkema, & Visser, 2014). Although changes in the spiritual domain are not typically seen in the PA literature, yoga offers a uniquely spiritual dimension to PA. While noted changes in the spiritual domain among participants in this study must be read with caution, the yoga program had the potential to contribute to the noted changes in spiritual well-being. Changes in spiritual well-being may also have been due to the particularities of the population under investigation. As one of their needs is to explore end-of-life, the yoga program may have served as an opportunity to self-reflect.

5.1.4 Home/Hospice-Based Program Feedback

Although there is debate over the effectiveness of a home/hospice-based program versus a group-based yoga program, participants of this study indicated that they preferred the home/hospice-based program design. They reported that they enjoyed that they could independently participate in the yoga program when they wanted and with whom. These reports have been commonly noted from other researchers examining PA preferences in the non-curative cancer population (Murnane et al., 2012). Furthermore, a home/hospice-based yoga program offers similar characteristics that have made walking programs popular among the non-curative cancer population (Lowe et al., 2010). For example, the ease of use, low cost, flexible intensity and frequency, and ability to participate anywhere, were commonly reported as positive characteristics by participants of this study. It was stressed by the participants that due to the uniqueness of each day (e.g., feeling well, or not feeling well), they liked how they could incorporate the yoga sessions into their ADL when it best suited their schedule.

Interestingly, although participants indicated that they preferred to participate in the yoga program independently and in their own home, it was highlighted by three of the participants that it would have been nice to get to know others in the study. This way, they could connect with individuals experiencing a similar circumstance, and it would offer them the opportunity to share and relate to others' experiences. Additionally, having the home/hospice-based yoga program available on DVD allowed for individuals who are living in rural or remote areas the opportunity to participate in a program that was aligned with their age-specific needs. As reported by participants living outside urban centers, there are currently no yoga programs available to them, and if there are, these programs typically serve an older cancer population. The problem that was commonly highlighted

was that this difference in age continued to make the participants feel isolated, even though they were among a group of cancer patients. This highlights that the home/hospice-based yoga program was ideal for the participants of this study because they knew it was specifically for individuals of their age and diagnosis. Even this basic information was able to provide the participant with a feeling that they were participating in care that was specific to their physical and psychosocial needs unique to their age and cancer status.

5.1.5 Safety

No adverse events were reported in this study. As was seen in a similar study (Cheville et al., 2012), participants adjusted their level of participation in the weekly yoga sessions below threshold if they felt their participation would cause an adverse event. For example, in this study when a participant did not feel as well as they did the week prior, instead of advancing to the next yoga session (e.g., session 3 to session 4), they would stay with the yoga program that they felt capable of completing. It is also important to note that none of the participants reported any weight loss during the seven-week home/hospice-based yoga program. Although weight stability or gain could be related to other factors such as medications, these findings align with other yoga studies indicating that yoga does not impose any negative energy expenditure (Banzer et al., 2013). Typically with an advanced cancer, due to decreased activity, the muscles will atrophy. Therefore, no reported weight loss could indicate that the participants are maintaining their muscle tone. The increase in functional well-being scores and reported increases in flexibility may also indicate maintenance if not an increase in muscle tone.

5.1.6 In Person versus Home/Hospice-Based Yoga Thrive Program Delivery

As a community-based program, Yoga Thrive has been successful in enhancing participants' energy, mindfulness, openness to emotions, and improved health-related QOL (MacKenzie et al., 2013; Ross Zahavich et al., 2012). Furthermore, this seven-week program delivered in-person has also been found to improve mood, decrease fatigue and stress, and improve participants' flexibility (Ross Zahavic et al., 2012). It was highlighted in these studies that future studies should examine the Yoga Thrive DVD's effectiveness for maintenance and adherence to home-based programming (MacKenzie et al., 2013; Ross Zahavich et al., 2012). Participants were appreciative that the yoga program was made specifically for cancer patients and that they could participate from the comfort of their own homes. Similar to findings from Park and colleagues (2012), participants of this study indicated that they were looking to participate in an activity that would help improve their physical and mental well-being. Participants noted that they had tried previous yoga DVDs, not designed for cancer patients, and did not have as much success. Participants of this study also noted that they enjoyed the level of progression and the varying examples to modify poses. Session 3 was the most preferred session among participants and was typically the 'default' session for days that the participants were not feeling well.

This highlights that the Yoga Thrive DVD may be a feasible alternative for cancer patients living outside of where the Yoga Thrive program is delivered/available. The Yoga Thrive DVD would provide cancer patients with the opportunity to engage in activity that they recognize as an important component to not only tending to their physical and mental well-being, but also as a means to do something for themselves. Similarly, it may be effective to incorporate both the in-person and home-based approach

of the Yoga Thrive program. By introducing the participant to the seven-week program while an in-patient, it would allow the participant to experience the program in a supervised setting. Therefore, as Banzer et al. (2013) highlighted, any potential barriers can be addressed, allowing the participant to engage in the yoga session to their fullest potential. Similarly, if participants had previous experience with the Yoga Thrive program in-person, it may increase their willingness and motivation to adhere to the seven-week program and be better able to complete all seven sessions for 75 minutes. Lastly, participating in the Yoga Thrive program at the hospital, in a group setting, could be an opportune time for the participants to meet others in a similar situation. As noted by Gulde et al. (2011), this commonality can provide comfort and unity, which may be a key component for adherence to the Yoga Thrive DVD after discharge.

5.1.7 Exit Questions and Proposed Improvements

The 30-day post-program follow-up revealed that AYA non-curative cancer patients benefited from participating in the yoga program as a means to feel well (e.g., physically and psychologically) and complete a task to better themselves and that was for themselves (e.g., an activity that they decided to do, something that was not prescribed from their oncologist/physician). All participants indicated that they would recommend the program to others in a similar situation and all have stated that they plan to continue with the program.

Additionally, it should be noted that participants in the present study highlighted that non-physical benefits from participating the Hatha yoga program were: becoming more aware of their body, learning to relax and reach a sense of calm, and regaining control of their bodies.

5.2 STRENGTHS

Gaining support for including PA as part of the overall supportive care treatment plan for cancer patients is challenging because its usability may be dependent on how the programs are initially presented to the patient as well as on the unique patient-disease response (Alsharif & Hata, 2013). However, evidence exists that despite the stage of disease, adult non-curative cancer patients find the inclusion of PA to have a positive impact on their QOL, whether they are receiving hospital, home, or hospice-based care (Alsharif & Hata, 2013). For example, participants of this study indicated that participating in the yoga program was a nice way to relax their mind, but challenge their body, "in a good way". The flexibility and ease of use of the Yoga Thrive DVD appeared to be an ideal fit. Being able to participate when they wanted, and for an amount of time that suited the participants' needs, made the yoga program "less of a chore that they had to do, but something that they looked forward to". Another strength of the home-based program was that transportation was eliminated as a barrier to participation. For example, those living in rural or remote locations had access to a yoga program that they would not otherwise have access to.

5.2.1 Perceived Effectiveness of Yoga

This study was targeted specifically to AYA non-curative cancer patients. Participants of this study are well aware that specific supportive care for the AYA cancer patient, especially the non-curative cancer patient, is only in a developmental stage. As such, the participants took great pride knowing that they are advancing the literature to improve the QOL of others who will experience a non-curative cancer diagnosis at an early age.

With regard to the Yoga Thrive program specifically, it offered the participants something positive for which to plan, and participants were excited about their future. For example, participants indicated that they really enjoyed their weekly session and looked forward to challenging themselves the next week with a session of greater difficulty (e.g., moving from session 3 to session 4).

The design of the Yoga Thrive DVD aligned seamlessly with participants' physical and psychosocial needs. The program is light/gentle in nature, but participants noted the program was "challenging, but in a good way". It was commonly noted that flexibility and balance were improved/improving. As the program is self-directed, participants were able to "go at their own pace", so they were able to progress through the program according to their specific needs. Also, this self-directed approach allowed the participants the flexibility to determine the duration, location, and frequency of yoga participation. Similarly, all participants highlighted that the program was very relaxing and calming, indicating that it was a "perfect release" to feel as though they were improving their health. This sense of re-gained control over their health provided motivation to continue to participate. For example, participants who found a session difficult were optimistic that, with practice, they would get stronger and the sessions would become easier. Some participants became more aware of their body from the yoga program. As a result, some participants engaged in other activities that promote overall body maintenance (e.g., physiotherapy, massage therapy).

5.2.2 Possible Benefits of Study Findings

It is widely recognized that a non-curative cancer diagnosis results in chronic functional decline. Accordingly, the members of the research team respect that 75

minutes of yoga for this population may be too long. However, the literature suggests that non-curative cancer patients are able to complete anywhere between 20-120 minutes of yoga (Thygeson et al., 2010; Carson et al., 2007). As a result, a time frame must be established to determine the duration most optimal for the AYA non-curative cancer patient. Otherwise, we may not have the AYA non-curative cancer patient participating in the yoga program to their full physical potential. In this study however, participants were capable of completing the full 75 minute session. For example, out of a combined possible 28 yoga sessions, 18 were full 75 minute sessions, 3 were between 35-60 minutes in duration, and the remaining 7 were not completed. Furthermore, two participants had full adherence to the requested duration and frequency of the yoga program (e.g., 7, 75 minute sessions were completed in the requested seven-week period of one, 75 minute yoga session per week).

Participants were able to tailor the yoga program on a daily basis depending on their physical strength of that day, allowing the opportunity to make their own decisions free of external control. The study was designed to examine the impact of yoga on the physical and psychological side effects of cancer. Results from this study benefit the AYA non-curative cancer patient because findings support current evidence that the Yoga Thrive program as a home-based intervention is safe and feasible for this population and that it seems to contribute to the maintenance of QOL towards end-of-life. This intervention also examined the tolerance to and preferred duration of the Yoga Thrive sessions and contributes to the advancement of PA programming for the AYA non-curative cancer population.

5.3 Study Limitations

The primary limitation of this study was the lack of a control or comparison group, making it difficult to determine whether the Hatha yoga intervention had an effect on QOL. For example, we cannot confirm whether changes in QOL were due to the yoga program or other factors outside of the yoga program. Moreover, due to the small sample population of AYA non-curative cancer patients, our results are underpowered and preliminary. Nevertheless, while the results of this study did not reach the desired statistical effect on QOL measures, there are positive trends to support a meaningful difference and a rationale for further study (see Table 1).

Likewise, when interpreting our preliminary results on the impact of yoga on AYA non-curative cancer patients, it is important to note that not only was our sample size very small, but the participant ages ranged from 32-38 years of age. As a result, our data may not fully reflect the broader spectrum of the AYA (15-39 years) non-curative patient. Therefore, the question of whether a light Hatha yoga program is a safe, feasible, and efficacious PA option for the AYA non-curative cancer patient needs to be more fully explored.

While recruitment challenges were encountered in this study, with respect to overall study viability, the population does exist, and it may be a matter of tailoring recruitment strategies to both enhance awareness and promote ease of access to the home-based Yoga Thrive program (such as). An interesting finding of this study is that individuals who did participate in the study were referring other individuals in a similar situation to the program, as well as other cancer organizations that support AYA cancer patients.

5.4 Practical Implications and Recommendations for Future Research

In order to better understand the preferences and effects of a yoga program on AYA with non-curative cancer, it will be important to develop and run more rigorous randomized trials with larger numbers. This will help to better validate whether the yoga program was able to improve QOL separate from extraneous influence, and to explore if changes in specific QOL domains are reflective of the age of the sample, rather than the stage of cancer. Similarly, given the early recruitment challenges, a mixed-methods approach may yield more fruitful and contextually rich data.

Irrespective of design, future studies will require more targeted and strategic communication initiatives to make the AYA non-curative cancer population aware of available trials. Another change that could potentially lead to improved recruitment is if the terminology were revised to better reflect the situation of the population rather than the stage of disease. For example, our three identifying terms for eligibility were non-curative, palliative, or advanced. If our study were able to change the criteria nomenclature to words such as relapsed or survivor, we may have been able to recruit more of the non-curative population. For those AYAs who are in denial of their progressing cancer, the use of such descriptive terms may entice AYA cancer patients to participate simply because they are not grouped with the terminally ill. Perhaps encouraging referrals from interested individuals to others in their network may be another way of enhancing recruitment success. To aid in recruitment of younger participants (i.e., 15-30), targeting cancer support groups for youth or social networks frequented by this group may be one way of reaching this population specifically.

Moreover, future studies should focus on social media recruitment as this age group is quite 'connected' to the world through their mobile devices, tablets, and home computers. It was suggested that an application for these devices be used in the future.

Reasons for the inclusion of an application would be its ease of use and its ability to improve access. For example, when a group of young adult cancer researchers from the University of California attempted to recruit participants on a national level via social media, they had an overwhelmingly positive response (Gorman et al., 2014). Simply through the use of social media resources, 82% of eligible participants (204/249) from one study and 59% of eligible participants (295/500) from another study were successfully identified, screened, and examined as participants for the researchers' identified purposes (Gorman et al., 2014).

Aligning with the social media approach, Texas A&M Health Science center School of Rural Public Health has developed a phone application for AYA cancer survivors (15-39 years of age). This application includes features that help the AYA cancer patient monitor PA, diet, nutrition, and well-being (CureSearch for Children's Cancer, 2012). If modified for programs such as this yoga study, the application could also be the method to maintain consistent participant communication. Furthermore, this could hasten the turn-around times for required paperwork in order to participate in the study. This could also result in decreased time from initial expression of interest in the study to the consent and pre-program questionnaire and allow participants to begin the yoga program sooner. When working with individuals with an advanced illness, it is critical that time is optimized. If an application like this were developed for this study, it could also be a way to remind individuals of their progress in the study. For example, there could be a checklist screen (e.g., complete consent form, complete pre-program questionnaire etc.). Similarly, once the participant is ready to begin the yoga program, this same checklist can be included for their participation. The application would also offer the additional benefit logging what session they participated in, the duration of the

session, what symptoms they were feeling, if the session ended short of 75 minutes, and how they felt after the yoga program.

5.5 Conclusions

With the young lives of the AYAs coming to an all too early end, it is essential that methods to enhance the QOL be determined and implemented. This study provides a preliminary understanding of the feasibility and safety of how a light yoga program may improve QOL in AYA non-curative cancer patients. These early findings also demonstrate the potential utility for future studies as this intervention was used without experiencing any adverse events. Furthermore, results of this study are consistent with other studies involving older adult non-curative populations.

Importantly, over the course of the seven-week program, all four participants were able to maintain their FWB, and each participant also experienced enhanced spiritual well-being. Although no statistically significant change was reported in the other QOL domains (e.g., PWB, SWB, EWB, FACT-G, FACIT-Pal), these positive trends suggest that yoga may be a meaningful addition to the overall supportive care plan for the AYA non-curative cancer patient as a means to improve or maintain QOL. Further exploration into the role of yoga in enhancing the well-being of the non-curative cancer patient is warranted.

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DALHOUSIE UNIVERSITY
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Version 2
January 27, 2014

Capital Health

IWK Health Centre

IF YOU ARE…

- **Between 15-39 years of age**
- **Diagnosed with an advanced cancer**
- **And are looking to stretch out your stress…**

YOU MAY QUALIFY FOR A YOGA STUDY!

We are offering a 7-week program examining how yoga can improve quality of life in young adults with advanced cancer.

If you are interested and would like more information, please contact **Hillary Woodside** at (902) 494-2579 or by email at **hillarywoodside@dal.ca.**

APPENDIX B - CONSENT FORM

CDHA CONSENT FORM

Capital Health

Clinical Trial – Consent Form

STUDY TITLE: Impact of Yoga on Quality of Life for Adolescent and Young Adult Non-Curative Cancer Patients: A Pilot Study

CLINICAL STUDY REGISTRATION NUMBER: NCT – 0190 - 1237

PRINCIPAL INVESTIGATOR: **Dr. Rob Rutledge**
Address: Room 2025, Dickson Building
Nova Scotia Cancer Centre
5820 University Ave
Halifax, Nova Scotia, Canada
B3H 1V7
Phone: (902) 473-6185
Email: rob.rutledge@cdha.nshealth.ca

ASSOCIATE INVESTIGATORS: Please see the attached Research Team Contact Page for a full list of investigators for this trial.

Yoga Materials Provided By:

Dr. Nicole Culos-Reed, M.D., University of Calgary

SPARTAN Fitness

PART A.

Clinical Studies – General Information

1. Introduction

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:
- Discuss the study with you;
- Answer your questions;
- Keep confidential any information which could identify you personally; and
- Be available during the study to deal with problems and answer questions.

We do not know if taking part in this study will help you. You may feel better. On the other hand it might not help you at all. It might even make you feel worse. We cannot always predict these things. We will always give you the best possible care no matter what happens.

If you decide not to take part or if you leave the study early, your usual health care will not be affected.

PART B: EXPLAINING THIS STUDY

2. What is the purpose of this study?

Adolescents and young adults who are living with cancer are not benefiting from the same age-appropriate physical and psychosocial care, as are children and older adults. As a result, their unique needs often go unmet or unaddressed. Studies have demonstrated that a lack of age-appropriate care may be responsible for a decreased quality of life. Studies have also shown that physical activity is able to reduce many of the negative side-effects linked to cancer and its treatment (e.g., nausea, vomiting, fatigue). A light form of physical activity that is both safe and manageable for cancer patients is yoga. The purpose of this study is to examine the achievability and safety of a light 7-week home/hospice-based Hatha yoga program (available on DVD) in the adolescent and young adult non-curative cancer population. This study will also examine the ability of yoga to reduce cancer related side effects. Interested participants will be will be self-identified, or will be referred to the study by their primary oncologist/physician.

3. What Is Being Tested?

A yoga program for adolescent and young adult non-curative cancer patients is considered a new area of study for this specific population. However, available studies in the adult advanced cancer population suggest that yoga is a safe and manageable form of physical activity that can reduce side-effects due to cancer and treatment.

4. Why Am I Being Asked To Join This Study?

You are being asked to join this study because you are an adolescent or young adult with cancer and have expressed interest in participating.

5. How Long Will I Be In The Study?

This is a 7-week long study. If you decide to participate, you will be encouraged to complete a minimum of one, 75-minute yoga session per week. You will also be asked to complete one questionnaire before beginning the study, and again after you have finished your 7-week yoga program. The questionnaire will take approximately 10 minutes to complete. Additionally, 30 days after you have finished the study, a member of the investigative team will call you with three follow-up questions. These questions are designed to get a better understanding of your thoughts about the yoga program; likes, dislikes; and if you would recommend this program to someone in a similar situation. This follow-up phone call will take approximately 10 minutes.

6. How Many People Will Take Part In This Study?

This study is taking place in Halifax, Nova Scotia. A total of 10 people are anticipated to participate in this study.

7. How Is The Study Being Done?

Adolescent and young adult non-curative cancer patients will be recruited from both the IWK and Capital Health oncology programs in Halifax, Nova Scotia, as well as other regions across the nation. All consenting participants will receive the same yoga DVD. If you are interested in participating in this study, you will be asked to:

1. Have your primary oncologist/physician provide written consent that you may participate in this study.
2. Sign and return a copy of this consent form; and complete the enclosed pre-study questionnaire.

Once we have received this information, you will be given the instructive Hatha yoga DVD and the appropriate materials for the program (e.g., yoga mat, yoga blocks, yoga strap). Over the course of the 7-week program, you will be asked to complete a minimum of one, 75-minute yoga session per week. If you feel that the 75-minute duration is too long, you may complete the requested 75-minutes over the course of a week (suggested minimum – 20 minutes/session). This

is only a recommendation, you may do more or less depending on how you are feeling. We do however ask that you keep track of the number and duration of your yoga session(s) each week in an activity journal.

The DVD package includes four discs that present an increasingly difficult, 7-week program. An example of the yoga DVD sessions and various poses can be found below.

To gain a better understanding of the usability of the yoga program, the investigative team will administer a follow-up phone call 30 days after you have completed the yoga program. These questions will shed light on what motivated you to join the study; what made it difficult/easier for you to participate; if you found the program beneficial or challenging; and if you would recommend this yoga program to others in a similar situation.

8. What Will Happen If I Take Part In This Study?

Before taking part in this study, your primary oncologist/physician will have identified you for this study based on your age, cancer diagnosis, and Palliative Performance Scale score. After your primary oncologist/physician has identified you as a potential participant, the Student Investigator will then ensure that you meet all eligibility criteria. These measures have been taken to ensure that it safe for you to participate in this home/hospice-based Hatha yoga program. Your primary oncologist/physician agrees that it is safe for you to participate in the yoga program, you will be asked to return the signed medical clearance forms, signed consent forms, and pre-study questionnaire. After we receive these forms, you will be given the Hatha yoga DVD program and all specified yoga equipment as identified in Section 7 “How Is This Study Being Done?”. This study will then proceed as follows:

- Participate in one, 75-minute yoga session per week at home/hospice, for 7 weeks;
- Student Investigator will call you weekly to address any questions or safety concerns;
- Record yoga sessions in activity journal and explain what helped or limited full session completion;
- Fill out post-study questionnaire; and
- 30 days after you complete the study, a member of the investigative team will follow-up with 3 exit questions by phone.

9. Are There Risks To The Study?

While minimal, there are risks with this and any study. To give you the most complete information available, we have listed many *possible* risks, which may appear alarming. We do not want to alarm you but we do want to make sure that if you decide to try the study, you have had a chance to think about the risks carefully. Please also be aware that there may be risks in participating in this study that we do not know about yet.

QUESTIONNAIRE
You may find the questionnaire and interviews you receive during the course of the study upsetting or distressing. You may not like all of the questions that you will be asked. You do not have to answer those questions you find too distressing.

YOGA INTERVENTION
You may experience muscle soreness after completing a yoga session. This is normal, however, if pain persists, you must tell the Student Investigator (Hillary Woodside) or a member of the research team about any new symptoms that don't go away after a couple days of rest.

10. Are There Other Choices?

You are free to seek other opinions or choices if you wish. You do not have to participate in this trial to begin a yoga program or to become physically active. You may choose to speak with your physician, oncologist, or a qualified fitness expert about other yoga or physical activity programs.

11. What Happens at the End of the Study?

This study is being conducted to better understand how yoga can benefit adolescent and young adult non-curative cancer patients. The Student Investigator will call you with follow-up questions 30 days after you have completed the study. The goal of this follow-up phone call is to identify your likes/dislikes and what you would change about the yoga program.

If you would like a summary of the results, please indicate this at the end of consent and a summary will be mailed or emailed to you upon completion of the study. Should you be interested in learning more about the yoga or physical activity options in your area, we encourage you to speak to your physician, oncologist, or a certified fitness professional.

12. What Are My Responsibilities?

As a study participant you will be expected to:

- Have consent from your primary oncologist/physician
- Read and sign the consent form;
- Return the competed questionnaires and written medical clearance from your primary oncologist/physician to the research team;

- Follow the 7-week Hatha yoga program to the best of your ability
- Record your weekly sessions in a journal
- Report any changes to your health during that time of the study to the Principal Investigator
- Report any problems that you experience that you think might be related to participating in the study; and
- Follow the directions of the Principal Investigator to the best of your ability.

13. Can I Be Taken Out Of The Study Without My Consent?

While unlikely, you may be taken out of the study by the Principal Investigator or the Research Ethics Board at any time, if:

- You do not follow the directions of the Principal Investigator and your safety is put at risk;
- In the opinion of the Principal Investigator you are experiencing side effects that are harmful to your health or well-being; and if
- There is new information that shows that being in this study is not in your best interests.

Capital Health Research Ethics Board or the Principal Investigator have the right to stop patient recruitment or cancel the study at any time.

14. What About New Information?

It is possible that new information may become available while you are in the study about some new treatment for your condition. You will be told about any other new information that might affect your health, welfare, or willingness to stay in the study and will be asked whether you wish to continue taking part in the study or not.

15. Will It Cost Me Anything?

Compensation

You will not be paid to be in the study. However, you do get to keep all the yoga equipment provided to you, including: the yoga Thrive DVD, yoga mat, yoga strap, and yoga block.

Research Related Injury

If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. Your signature on this form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate in the study. In no way does this waive your legal rights nor release the Principal Investigator, the research team, the study sponsor or involved institutions from their legal and professional responsibilities.

16. What About My Privacy and Confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. No identifying information (such as your name or hospital number) will be sent outside of this health care facility. If the results of this study are presented to the public, nobody will be able to tell that you were in the study.

However, complete privacy cannot be guaranteed. For example, the investigator may be required by law to allow access to research records. A copy of this consent form will be put in your health record. Your family doctor will be told that you are taking part in this study.

When you sign this consent form, you give us permission to:

- Collect information from you
- Collect information from your health record
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety while participating in this research

Access to Records

The study doctor and members of the research team will see health and study records that identify you by name. Other people, during visits to this health care facility, may need to look at the health and study records that identify you by name. These people might include;

- People and companies working for and with the sponsor inside and outside Canada
- The Research Ethics Board and people working for or with the Research Ethics Board

Use of Your Study Information

The research team will collect and use only the information they need to judge the safety and usefulness of the Hatha yoga program.

You also allow the collection, reporting and transfer of your anonymous personal health information and data from the study to:

The sponsor will use the information collected about you during the study, only for scientific research and development purposes.

This information will include your:

- Age
- Male or female
- Marital status

- Height/Weight
- Education
- Employment status
- Ethnicity
- Medical conditions
- Months since diagnosis
- Primary tumor type
- Site of metastases
- Type and duration of treatment
- Current medications
- The results of tests and procedures you had before and during the study
- Information from the study interviews and questionnaires

Your name and contact information will be kept secure by the research team at within Dalhousie's School of Health and Human Performance. It will not be shared with others without your permission. Information will be kept for at least 7 years as required by law.

After your part in the study ends, we may continue to review your health records for safety and data accuracy until the study is finished.
Information collected and used by the research team will be stored at Dalhousie's School of Health and Human Performance. Dr. Melanie Keats (Co-Investigator) is the person responsible for keeping it secure.

The Research Ethics Board and people working for or with the Research Ethics Board may also contact you personally for quality assurance purposes.

Your Access to Records

You may ask the study doctor to see the information that has been collected about you. You may ask to make corrections to this information by talking with a member of the research team.

17. What If I Want To Quit The Study?

If you chose to participate and later change your mind, you can say no and stop your participation at any time. If you wish to leave the study please inform a member of the research team. A decision to stop participating in the study will not affect your health care. All data collected up to the date you withdraw your consent will remain in the study records, to be included in study related analyses.

18. Declaration of Financial Interest

There is no payment being received by the Principle Investigator or the research team for conducting this study. Neither the Principle Investigator nor the Research Team has a financial interest in conducting this study.

19. What About Questions Or Problems?

For further information about the study call **Hillary Woodside (Student Investigator) OR Dr. Melanie Keats (Co-Investigator).** Ms. Woodside's work telephone number is (902) 494-2579, and Dr. Keats' work telephone number is (902) 494-7173. If you cannot reach Ms. Woodside or Dr. Keats, please refer to the attached Research Team Contact Page for a full list of the people you can contact for further information about the study.

If you experience any symptoms or possible side effects or other medical problems you feel are related to this study, please inform Ms. Woodside or Dr. Keats immediately.

20. What Are My Rights?

Your signature on the form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part as a participant. In no way does this waive your legal rights nor release the involved institution(s) from their legal and professional responsibilities. If you become injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost. You are free to withdraw from the study at any time without jeopardizing the health care that you are entitled to receive.

After you have signed this consent form you will be given a copy. If you have any questions about your rights as a research participant, contact the CDHA **Patient Representative** at **(902) 473-2133**.

In the next part you will be asked if you agree (consent) to join this study. If the answer is "yes", you will need to sign the form.

PART C

21. Consent Form Signature Page

I have reviewed all of the information in this consent form related to the trial called:

Impact of Yoga on Quality of Life for Adolescent and Young Adult Non-Curative Cancer Patients: A Pilot Study

I have been given the opportunity to discuss this study and all of my questions have been answered to my satisfaction.

I agree that my study information may be used as described in this consent form.

This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time without affecting my future care.

_____ Signature of Participant	_____ Name (Printed)	____ / _____ / ___ Year Month Day*
_____ Witness to Participant's Signature	_____ Name (Printed)	____ / _____ / ___ Year Month Day*
_____ Signature of Investigator	_____ Name (Printed)	____ / _____ / ___ Year Month Day*
_____ Signature of Person Conducting Consent Discussion	_____ Name (Printed)	____ / _____ / ___ Year Month Day*

Note: Please fill in the dates personally

**I have had a discussion with the Participant named above and can verify that the participant understands the nature of the study and their participation: Initials_____*

I would like to receive a summary of the study findings. Please send them to me by mail/email at: _____

Please sign both copies of the consent form. Keep one copy for your records and return the second to the research team.

Thank you for your time and patience!

Clinical Trial – Consent Form

STUDY TITLE: Impact of Yoga on Quality of Life for Adolescent and Young Adult Non-Curative Cancer Patients: A Pilot Study

CLINICAL STUDY REGISTRATION NUMBER: NCT-0190-1237

PROJECT #: 1014598

PRINCIPAL INVESTIGATOR: **Dr. Melanie Keats**
Address: School of Health and Human Performance
Stairs House, Dalhousie University
6230 South Street
Halifax, Nova Scotia, Canada
B3H 4R2
Phone: (902) 494 - 7173
Email: melanie.keats@dal.ca

ASSOCIATE INVESTIGATORS: Please see the attached Research Team Contact Page for a full list of investigators for this trial.

Yoga Materials Provided By:

Dr. Nicole Culos-Reed, M.D., University of Calgary

SPARTAN Fitness

CONSENT FORM

Introduction

You are being invited to take part in the research study named above. This form provides information about the study. Before you decide if you want to take part, it is important that you understand the purpose of the study, the risks and benefits and what you will be asked to do. You do not have to take part in the study. Taking part is entirely voluntary (your choice). Informed consent starts with the initial contact about the study and continues until the end of the study. A staff member of the research team will be available to answer any questions you have. You may decide not take part or you may withdraw from the study at any time. This will not affect the care you or your family members will receive from the IWK Health Centre in any way.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

Why are the researchers doing the study?

Adolescents and young adults who are living with cancer are not benefiting from the same age-appropriate physical and psychosocial care, as are children and older adults. As a result, adolescents and young adults are not living as well as they could be with their cancer diagnosis. Studies have also shown that physical activity is able to reduce many of the negative side-effects linked to cancer and its treatment (e.g., nausea, vomiting, fatigue). A light form of physical activity that is both safe and manageable for cancer patients is yoga. The purpose of this study is to examine if a light 7-week home/hospice-based Hatha yoga program (available on DVD) is both enjoyable and safe for the adolescent and young adult non-curative cancer population. This study will also examine if this yoga program can reduce cancer related side effects.

How will the researchers do the study?

The study will run for a total of 7-weeks. Ten (10) participants, in total, from the IWK and Capital District Health Authority in Halifax and other regions across the nation, will be asked to participate in a Hatha yoga program. If you decide to participate, you will be encouraged to complete a minimum of one, 75-minute yoga session per week, which is the exact same program that other consenting participants will receive.

What will I be asked to do?

Before taking part in this study, your primary oncologist/physician must grant you permission to take part in this study. Once we receive a medical approval letter indicating that it safe for you to participate in this home/hospice-based Hatha yoga program, the research team will ensure that you meet all eligibility criteria. If you meet the

inclusion/exclusion criteria listed under "How will the researchers do the study?" and your primary oncologist/physician agrees that it is safe for you to participate in the yoga program, you will be asked to return the signed medical clearance forms, signed consent forms, and pre-study questionnaire (approximately 10 minutes to complete). After we receive these forms, you will then be given the Hatha Yoga Thrive DVD program and all specified yoga equipment. This study will then proceed as follows:

- Participate in one, 75-minute yoga session per week at home/hospice, for 7 weeks;
- Record yoga sessions in activity journal and explain what helped or limited full session completion;
- Fill out post-study questionnaire (approximately 10 minutes to complete); and
- 30 days after you complete the study, the Student Investigator will follow-up with 3 exit questions by e-mail. These questions are designed to get a better understanding of *your thoughts* about the yoga program; likes, dislikes; and if you would recommend this program to someone in a similar situation. This follow-up phone call will take approximately 10 minutes.

The Yoga Thrive DVD

The DVD package includes four discs that present an increasingly difficult, 7-week program. You may chose to stay with the same week for the 7-weeks, or change the discs each week. We ask that you keep track of what disc you used each week, and why. An example of the yoga DVD sessions and various poses can be found below.

What are the burdens, harms, and potential harms?

While minimal, there are risks with this and any study. To give you the most complete information available, we have listed many *possible* risks, which may appear alarming. We do not want to alarm you but we do want to make sure that if you decide to try the study, you have had a chance to think about the risks carefully. Please also be aware that there may be risks in participating in this study that we do not know about yet.

Potential Harms:

QUESTIONNAIRE
You may find the questionnaire and interviews you receive during the course of the study upsetting or distressing. You may not like all of the questions that you will be asked. You do not have to answer those questions you find too distressing.

YOGA INTERVENTION
You may experience muscle soreness after completing a yoga session. This is normal, however, if pain persists, you must the Principal Investigator, a member of the research team, or your primary physician or oncologist about any new symptoms; such as, serious anxiety, persistent pain, or any new symptoms following the yoga sessions that don't go away after a couple days of rest.

What are the possible benefits?

As this is a light physical activity study, you may experience improvements in fitness and quality of life. However, taking part in this study may be of no help to you personally. It is hoped that what is learned in this study will be of future benefit to adolescent and young adults diagnosed with a non-curative cancer.

What alternatives to participation do I have?

You do not have to participate in this trial to begin a yoga program or to become physically active. You may choose to speak with your physician, oncologist, or a qualified fitness expert about other yoga or physical activity programs.

Can I withdraw from the study?

Participation in the study is voluntary (your choice). You may decide not to sign the consent form or you may withdraw (leave) from the study at any time. Your health care will not be impacted based on your decision to participate, or not participate in this study. If you decide to withdraw from the study, any information that you have provided up until that time will not be removed. If the study is changed in any way that would affect your decision to continue to take part you will be told about the changes in a timely manner and may be asked to sign a new consent form.

Your participation could be ended if, in the investigator's judgment, it is in your best interest not to continue or you are unable to complete the study requirements. You will be notified by study staff if this should occur and given information regarding how to contact study staff if you have any questions after you are withdrawn from the study.

Will the study cost me anything and, if so, how will I be reimbursed?

In order to participate in this study, we require a medical approval letter from your primary physician/oncologist. You may be required to pay a small fee for the medical approval letter; unfortunately this will not be reimbursed. There will also be no additional compensation for taking part in the study. You will however, be able to keep all yoga equipment which includes, the yoga Thrive DVD, yoga mat, yoga strap, and yoga block.

Are there any conflicts of interest?

There are no conflicts of interest on the part of the researchers and/or institution to report.

How will I be informed of the study results?

The final study results are group results. Individual results can be made available to you once the study is completed and reported. The results will be mailed to you if you want to receive them. You will be asked to initial the last page and provide contact information indicating if you wish to receive summary of the results.

Once the research is complete will the research intervention be available to me?

After the research is complete, all participants can keep the Yoga Thrive DVD, the yoga mat, yoga strap, and yoga block. Therefore, you have the option to continue the yoga program if you wish.

How will my privacy be protected?

Any information that is learned about you will be kept private. All of the information will be recorded using a unique, computer generated coding number that will not identify you by name. You will not be identified in the publication of results.

All study materials (master lists etc.) will be stored in a locked filing cabinet in the Principal Investigator's (Dr. Melanie Keats, PhD.) research office located within the School of Health and Human Performance at Dalhousie University (Dalplex). Only members of the research team will have access to the study information. Your primary care physician will be notified of your participation in this research study in the event they need to be in touch with the research team. Electronic materials will be stored on secured, password protected computers. The study material will be kept for five (5) years after publication of this research as required by the IWK Research Ethics Board.

What if I have study questions or problems?

If you have any questions or concerns following your enrolment, you may directly contact the Principal Investigator, Dr. Melanie Keats. She may be reached by phone: (902) 494-7173 (Monday-Friday) or by e-mail: melanie.keats@dal.ca. You may also contact the Student Investigator, Hillary Woodside. She may be reached by phone: (902) 494-2579 or by e-mail: hillarywoodside@dal.ca.

What are my research rights?

Your signature on the form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to take part as a subject. In no way does this waive your legal rights, nor release the investigator(s), or involved institutions(s) from their legal and professional responsibilities. If you become ill or injured as a direct result of participating in this study, necessary medical treatment will be available at no additional cost to you. You are free to withdraw from the study at any time without jeopardizing the health care you are entitled to receive.

If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Centre at (902) 470-8765, Monday to Friday, between 9a.m. and 5p.m.

In the next part you will be asked if you agree (consent) to join this study. If the answer is "yes", you will need to sign the form.

Consent Form Signature Page

I have reviewed all of the information in this consent form related to the trial called:

Impact of Yoga on Quality of Life for Adolescent and Young Adult Non-Curative Cancer Patients: A Pilot Study

I have been given the opportunity to discuss this study and all of my questions have been answered to my satisfaction.

I agree that my study information may be used as described in this consent form.

This signature on this consent form means that I agree to take part in this study. I understand that I am free to withdraw at any time without affecting my future care.

_____ Signature of Participant	_____ Name (Printed)	____ / _____ / ___ Year Month Day*
_____ Witness to Participant's Signature	_____ Name (Printed)	____ / _____ / ___ Year Month Day*
_____ Signature of Investigator	_____ Name (Printed)	____ / _____ / ___ Year Month Day*
_____ Signature of Person Conducting Consent Discussion	_____ Name (Printed)	____ / _____ / ___ Year Month Day*

Note: Please fill in the dates personally

**I have had a discussion with the Participant named above and can verify that the participant understands the nature of the study and their participation:*
*Initials*_____

I would like to receive a summary of the study findings. Please send them to me by mail/email at: _____

Please sign both copies of the consent form. Keep one copy for your records and return the second to the research team.

Thank you for your time and patience!

Research Team Contact Page

Impact of Yoga on Quality of Life for Adolescent and Young Adult Non-Curative Cancer Patients: A Pilot Study					
Name	**Role**	**Work Address**	**Telephone Number**	**Pager Number / Cellular Number**	**E-Mail Address**
Dr. Rob Rutledge	Principal Investigator	Nova Scotia Cancer Centre Queen Elizabeth II Health Sciences Centre 5820 University Avenue Halifax, Nova Scotia B3H 1V7	(902) 473-6185	(902) 473-2222 (pager 2126)	rob.rutledge@cdha.nshealth.ca
Dr. Melanie Keats	Co-Investigator	School of Health and Human Performance, Dalhousie University 6230 South Street Halifax, NS B3H 1T8	(902) 494-7173	N/A	melanie.keats@dal.ca
Ms. Hillary Woodside	Student Investigator	School of Health and Human Performance, Dalhousie University 6230 South Street Halifax, NS B3H 1T8	(902) 494-2579	Cell: (902) 449-8116	hillarywoodside@dal.ca

IWK Health Centre

DALHOUSIE UNIVERSITY *Inspiring Minds*

Capital Health

APPENDIX C – QUESTIONNAIRES

PRE-STUDY QUESTIONNAIRE

Study ID: _____

IMPACT OF YOGA ON QUALITY OF LIFE FOR ADOLESCENT AND YOUNG ADULT NON-CURATIVE CANCER PATIENTS: A PILOT STUDY

WELCOME!

Thank you for consenting to participate in this research study. Please remember that all of the information is held in strict trust and your name will **NOT** appear on any public documents. As before, please answer the following questions based on your **present status.** After completing the survey, please return it to the research staff. For further information, or if you have any questions about completing the questionnaire, please speak to the research staff.

DEMOGRAPHIC AND MEDICAL INFORMATION

The following portion of this survey will ask you to provide some information about yourself and your medical history.

Age: _____

Sex: □ Male □ Female

Cancer Diagnosis: _____Date/type: _____

Treatment(s) received/ongoing:

_____

_____

_____

_____

Medical Co-morbidities:

_____

_____

QUALITY OF LIFE QUESTIONNAIRE

The following portion of the questionnaire will ask you to describe how you have felt in the *past 7 days.* Using the scale below, please indicate to what extent each of the following items is true for you. Please note that *there are no right or wrong answers* and no trick questions. We simply want to know how you personally feel. Please circle or mark one number per line to indicate your response as it applies to the *past 7 days*.

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4

Version 1: 2013/06/09

Q1 *Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*

GS7	I am satisfied with my sex life	0	1	2	3	4

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

	ADDITIONAL CONCERNS	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
PAL1	I maintain contact with my friends	0	1	2	3	4
PAL2	I have family members who will take on my responsibilities	0	1	2	3	4
PAL3	I feel that my family appreciates me	0	1	2	3	4
PAL4	I feel like a burden to my family	0	1	2	3	4
B1	I have been short of breath	0	1	2	3	4
PAL5	I am constipated	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
PAL6	I have swelling in parts of my body	0	1	2	3	4
PAL7	My mouth and throat are dry	0	1	2	3	4
Br7	I feel independent	0	1	2	3	4
PAL8	I feel useful	0	1	2	3	4
PAL9	I make each day count	0	1	2	3	4
PAL10	I have peace of mind	0	1	2	3	4
Sp21	I feel hopeful	0	1	2	3	4
PAL12	I am able to make decisions	0	1	2	3	4
L1	My thinking is clear	0	1	2	3	4
PAL13	I have been able to reconcile (make peace) with other people	0	1	2	3	4
PAL14	I am able to openly discuss my concerns with the people closest to me	0	1	2	3	4

SPIRITUAL WELL-BEING

		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

Thank you for taking the time to complete this survey!!!
Your support is greatly appreciated.

Version 1: 2013/06/09

Study ID: _____

IMPACT OF YOGA ON QUALITY OF LIFE FOR ADOLESCENT AND YOUNG ADULT NON-CURATIVE CANCER PATIENTS: A PILOT STUDY

THANK YOU!

Thank you for consenting to participate in this research study. Please remember that all of the information is held in strict trust and your name will **NOT** appear on any public documents. As before, please answer the following questions based on your **present status.** After completing the survey, please return it to the research staff. For further information, or if you have any questions about completing the questionnaire, please speak to the research staff.

QUALITY OF LIFE QUESTIONNAIRE

The following portion of the questionnaire will ask you to describe how you have felt in the *past 7 days.* Using the scale below, please indicate to what extent each of the following items is true for you. Please note that *there are no right or wrong answers* and no trick questions. We simply want to know how you personally feel. Please circle or mark one number per line to indicate your response as it applies to the *past 7 days*.

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

Version 1: 2013/07/01

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

	ADDITIONAL CONCERNS	Not at all	A little bit	Some-what	Quite a bit	Very much
PAL1	I maintain contact with my friends	0	1	2	3	4
PAL2	I have family members who will take on my responsibilities	0	1	2	3	4
PAL3	I feel that my family appreciates me	0	1	2	3	4
PAL4	I feel like a burden to my family	0	1	2	3	4
B1	I have been short of breath	0	1	2	3	4
PAL5	I am constipated	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
PAL6	I have swelling in parts of my body	0	1	2	3	4
PAL7	My mouth and throat are dry	0	1	2	3	4
Br7	I feel independent	0	1	2	3	4
PAL8	I feel useful	0	1	2	3	4

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PAL9	I make each day count	0	1	2	3	4
PAL10	I have peace of mind	0	1	2	3	4
Sp21	I feel hopeful	0	1	2	3	4
PAL12	I am able to make decisions	0	1	2	3	4
L1	My thinking is clear	0	1	2	3	4
PAL13	I have been able to reconcile (make peace) with other people	0	1	2	3	4
PAL14	I am able to openly discuss my concerns with the people closest to me	0	1	2	3	4

SPIRITUAL WELL-BEING

		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

ADDITIONAL COMMENTS

If you would like to comment on the program or share any of your experiences in greater detail, please feel free to use the space below:

_____

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Thank you for taking the time to complete this survey!!!
Your support is greatly appreciated.

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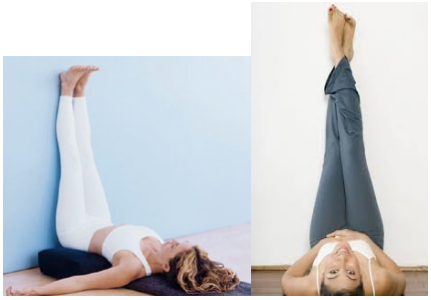
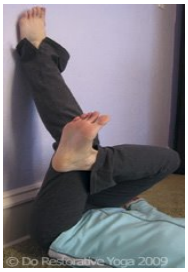
APPENDIX D – YOGA SESSIONS

INTRODUCING THE BASICS, WEEK #1

1. Legs on Wall Release



2. Cross Leg



3. Arm and Shoulder

4. Seated Cross-Legged

5. Seated Side Stretch

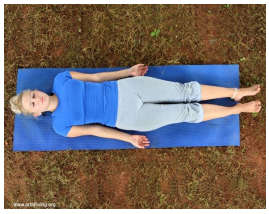
6. Tree Pose

7. Warrior One

8. Pyramid Pose

9. Knees to Belly

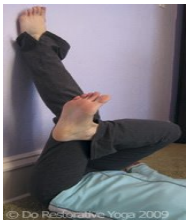
10. Shavasan



CONNECTING TO YOUR BODY AND BREATH, WEEK #2

1. Legs on Wall

2. Cross Leg



3. Arm and Shoulder Release

4. Seated Cross-Legged

5. Seated Side Stretch

6. Cat Dog

7. Mountain Pose

8. Tree Pose

9. High Squat

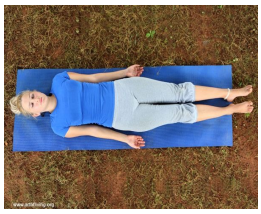
10. Warrior One

11. Little Bridge

12. Knees to Belly

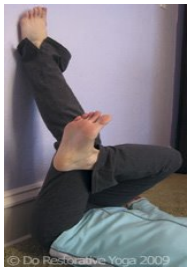
13. Sunrise-Sunset

14. Shavasana



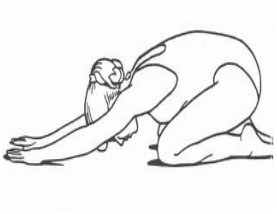
1. Legs on Wall

2. Cross Leg Stretch



3. Cat and Dog

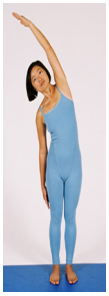
4. Child's Pose



5. Lunge

6. Tarasana

7. Standing Side Stretch



8. Tree Pose

9. Warrior One

10. Pyramid

11. Warrior Three

12. Leg Lift

14. Little Bridge

15. Knees to Belly

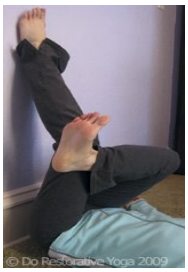
16. Stretch

17. Foot to Sky

Opening Your Heart and Chest, Week #4

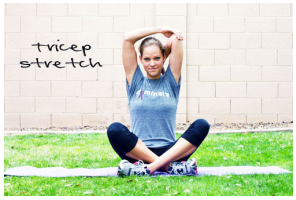
1. Legs on Wall

2. Cross Leg Stretch



3. Seated Arm Stretch

4. Tricep Stretch



5. Behind Back Stretch

6. Wingspan

7. Eagle Stretch

8. Kneeling Side-bend

9. Triangle Pose

10. Tree Pose

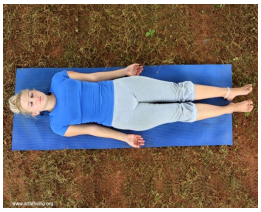
11. Vertical Floor

12. Horizontal Floor

13. Sunrise-Sunset

14. Strap and Foot Lift

15. Shavasana



1. Vertical Floor

2. Runners Pose

3. Reverse Lunge

4. Tarasana

5. Standing Side Stretch

6. Tree Pose

7. Warrior One

8. Pyramid Pose

9. Warrior Three

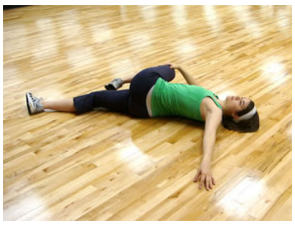
10. Eagle Arms

11. Forearm Plank

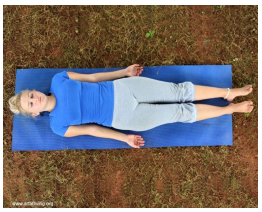
12. Cobra Pose

13. Little Bridge

14. Stretch



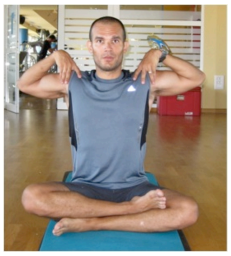
15. Shavasana



1. Legs on Wall

2. Cross Leg

3. Shoulder Twist



4. Side Bend Seated

4. Behind Back

5. Tarasana

6. Chest and Arm Release

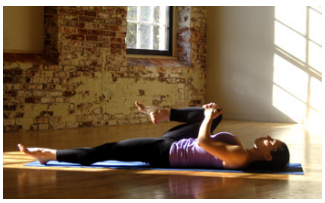
7. One Foot

8. Table Top

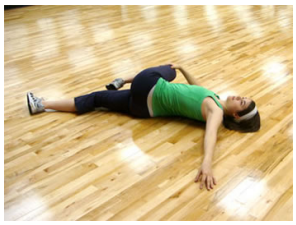
9. Cross Leg Standing Stretch

10. Chair Pose

11. Knees to Belly

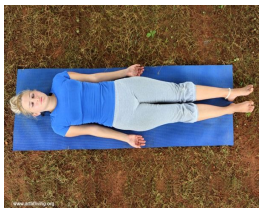


12. Stretch



13. Strap Around Foot

14. Shavasana



1. Vertical Floor

2. Cat and Dog

3. Runners Pose

4. Reverse Lunge

5. Kneeling Side-Bend

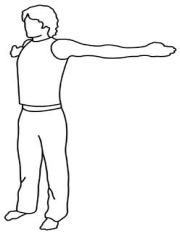
6. Tarasana

7. Tree Pose

8. Warrior One

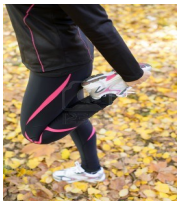
9. Warrior Three

10. Chest Stretch



11. Eagle Arms

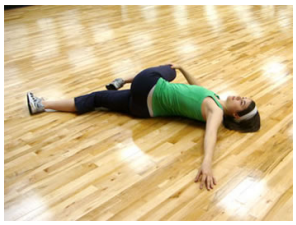
12. One Foot



13. Table Top

14. Sunrise-Sunset

15. Stretch



16. Knees to Belly

17. Knees 90°

18. Little Bridge

19. Leg Lifts

20. Shavasana