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A Review of Factors Contributing to the Shortage of Palliative Care Service for Adolescent and Young Adult Oncology Patients

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A REVIEW OF FACTORS CONTRIBUTING TO THE SHORTAGE OF PALLIATIVE CARE SERVICE
FOR ADOLESCENT AND YOUNG ADULT ONCOLOGY PATIENTS

A Dissertation

Presented to the Faculty of

Antioch University Seattle

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In Partial Fulfillment

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By

Erin K. Harper

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A REVIEW OF FACTORS CONTRIBUTING TO THE SHORTAGE OF PALLIATIVE CARE SERVICE
FOR ADOLESCENT AND YOUNG ADULT ONCOLOGY PATIENTS

This dissertation, by Erin K. Harper, has been approved by the Committee Members signed below who recommend that it be accepted by the faculty of the Antioch University Seattle at Seattle, WA in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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ABSTRACT

A REVIEW OF FACTORS CONTRIBUTING TO THE SHORTAGE OF PALLIATIVE CARE SERVICE
FOR ADOLESCENT AND YOUNG ADULT ONCOLOGY PATIENTS

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Adolescent and young adult oncology (patients aged 15–39 years old) is an emerging group of patients that are recognized to have distinctive qualities concerning their cancer treatment, including intensified psychosocial needs compared to their adult and child counterparts (Bleyer, 2012). The quality of life for adolescent and young adults during and after cancer treatment is disproportionately worse than what is reported by adults and children and the incidence of cancer in this population is steadily growing (Bleyer, 2011, 2012; Pritchard, Cuvelier, Harlos, & Barr, 2011; Rosenberg & Wolfe, 2013; Siegel, Naishadham, & Jemal, 2013; Wein, Pery, & Zer, 2011). Palliative medicine refers to an interventional service that specifically targets improving a patient's quality of life throughout their care and has been specifically tailored in the oncology treatment guidelines and care principles for adults and children. The healthcare system, however, has been slow to notice how palliative medicine could positively contribute to adolescent and young adult oncology care. Consequently it has been under considered for this patient group. It has yet to be studied in depth as a viable and beneficial service to this cohort. Using a comprehensive literature review, this dissertation explores

current shortages in palliative medicine among the adolescent and young adult oncology population. Employing multiple search modalities for key terms of the research topic resulted in 28,832 article returns. Titles and abstracts were reviewed and 36 articles were used in the literature review along with seven grey literature publications. Aspects of palliative care delivery and quality were investigated. Several themes emerged from the literature as well as specific clinical considerations for working with this patient group. Systemic barriers influencing the identified shortages were also examined. Recommendations for remediation are discussed where applicable, as well as the current state of addressing or not addressing each shortage. The role of psychologists in palliative medicine and care of adolescent and young adult oncology patients is also discussed. By illuminating the shortages in palliative care service to the adolescent and young adult oncology population, this dissertation can act as a stimulus to guide the creation of treatment guidelines or assist in future service and program development having proactively identified areas in need of attention. This dissertation is available in open access at AURA, <http://aura.antioch.edu/> and Ohio Link ETD Center, <https://etd.ohiolink.edu/etd>

Keywords: adolescent and young adult, oncology, cancer, palliative care, palliative medicine, AYAO

Dedication

I wish to dedicate this dissertation to my brother William and my grandmother Alice; one who inspired my work, and the other who unconditionally supported my journey. I also dedicate this research work to the adolescent and young adults affected by cancer, along with their families and friends. My hope is that this work will inspire care standards that promote the emerging, complex, promising and rich human being inside each one of them, no matter their place in treatment.

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Introduction

Cancer is the leading cause of health-related deaths among the adolescent and young adult demographic, and incidence has steadily increased over the past 25-years (Bleyer, 2012; Palmer & Thomas, 2008; Rosenberg & Wolfe, 2013; U.S. Department of Health and Human Services, 2006). It has been estimated that 70,000 15–39 year olds are diagnosed with cancer annually (Bleyer, 2012). This figure is approximately eight times greater than for children under the age of 15. In the past decade, the adolescent and young adult (AYA) demographic, defined in the United States as oncology patients who are 15–39 years old, has emerged as a group in need of increased attention from the medical community and its overseeing bodies. Medical service, psychosocial support, and clinical trials and research are among the areas in greatest need of development and improvement for this patient group (Livestrong Young Adult Alliance, 2007). The historic care of these patients has typically been divided between pediatric and adult services causing AYA-specific needs to go undetected. The AYA oncology population and its particular needs stand out for a variety of reasons, primarily related to advancements in medical oncology, an increase of managed care in the community and changes in the landscape of cancer; that is, more occurrences of disease and patients presenting with more advanced disease. Incidents of cancer among this population are on the rise (Mukherjee, 2010; Siegel et al., 2013). While other life-threatening diseases have been managed and even cured over the century, cancer remains a disease that we have neither vaccinations against nor health protocols to stop its spread.

Cancer is a disease often more associated with aging, however, a substantial amount of time, resources, research and funding has historically been dedicated to the younger pediatric population attempting to earn back their unlived years (Ferrari et al., 2011; Nathan, Hayes-Lattin, Sisler, & Hudson, 2011; U.S. Department of Health and Human Services, 2006). Similarly, because cancer is more prevalent in the over 40 population and affects a greater number of individuals in old age, most oncology research, care, and cure efforts have been directed toward the adult and older adult population (Bleyer, 2011; D. Clark, 2007; Mukherjee, 2010). However, AYAs are a patient population that bridges pediatric and adult age groups but have not experienced the same advocacy, funding, research interest nor medical commitment. As a result of resource allocation, clinical focus, and medical advancements, remarkable progress has been made in cancer treatment and survival of children under age 15 and in adults over the age of 40. Little to no improvement in cancer survival rates nor improvement in survival status has been observed for AYAs in nearly forty years (Bleyer, 2012).

Researchers have indicated multiple reasons for this diminished rate of improvement ranging from AYA tumor biology to the allocation of national funds for cancer research (U.S. Department of Health and Human Services, 2006; Wein et al., 2010). However, with a large and increasing number of AYAs presenting with cancer, there has also been a corresponding and increasing trend of young patients surviving cancer or living longer with advanced disease when provided with appropriate care and surveillance (Bleyer, 2011; Siegel et al. 2013; Thornes, 2001).

The Children's Hospital of Philadelphia carried out a multidimensional retrospective study of their supportive care services program. The program served all children, adolescents and young adults with progressive chronic diseases who were thought to have a life expectancy of less than six months, with the majority of services being provided in the patient's home. In the most recent period studied for their review, 68 patients were referred to and followed by the supportive care services program of which 75% were from the oncology service. Unexpectedly, two years after the start of the research project, over a quarter of the patients were still living with progressive or terminal disease (Bello Belasco, Danz, Drill, Schmid, & Burkey, 2000).

Current research estimates that nearly 90% of children with special healthcare needs now are living past their 21st birthday (J. K. Clark & Fasciano, 2013), thus it is becoming more common for these young adults to be living with serious long-term illness. One physician described adults who continue to survive well with chronic illness as "the fruits of our labors [who] deserve continued expert medical care as young adults and adults." (Thornes, 2001, p. 26). To sustain progress in extending longevity in life-limiting illness, medical and psychosocial needs that arise from a cancer diagnosis, treatment, and subsequent effects must be appropriately and adequately addressed. Researchers stress that AYA patients require a different set of provider clinical skills from those routinely used in younger pediatric and adult oncology and more support tailored to their developmental needs (D'Agostino, Penney, & Zebrack, 2011; Ferrari et al., 2011; J. K. Clark & Fasciano, 2013; Morgan, Davies, Palmer & Plaster, 2010; Rosenberg & Wolfe, 2013).

Factors Influencing the State of Affairs

Physicians and other medical providers often lack awareness of the current state of healthcare for this patient group in spite of the growing, although still small, number of research studies and reports highlighting the minimal survival rates and millions of patient years-of-life affected for AYAs (Bleyer, 2012). Most medical providers are not trained to identify and treat this population as a distinct patient group with specific medical and psychosocial needs. This is typically because patients are dichotomized into either pediatric or adult oncology programs and are assimilated into or concealed within the dominant culture of the care setting (Pritchard et al., 2011). As a result, the provider clinical skills that would be gained through increased contact, interest, education, and practice in working with a critical mass of AYA patients is largely missing. Clinicians and researchers have been unable to develop an appropriate in-depth baseline of care for AYA oncology patients (Palmer, Mitchell, Thompson, & Sexton, 2007; Thomas, Seymour, O'Brien, Sawyer, & Ashley, 2006; Palmer & Thomas, 2008). Health care professionals may underestimate or ignore the impact of cancer on this age group as a consequence of the medical culture, system structure, lack of personal knowledge, or education. Cumulatively, this combination of factors has resulted in many AYAs not receiving adequate attention or appropriate care (Cherny, 2009; Cherny & Catane, 2003; Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Wein et al., 2010).

The reasons AYAs have experienced worse outcomes in cancer survival rates and survival improvement are varied and complex. These causes span the biopsychosocial spectrum and are politically influenced. From a medical viewpoint, AYA patients

generally present with cancers that are less common than those typically identified in either pediatric or adult medical oncology. Cancers in the AYA age group tend to be more aggressive and more rare (Bleyer, 2012). AYA patients tend to present with later stage disease compared to their younger and older counterparts, which may be a result from a delay in diagnosis or a misdiagnosis (Rajani, Young, McGoldrick, Pearce, & Sharaf, 2011). A survey of 400 teenage and young adult cancer patients attending the Teenage Cancer Trust's annual conference in 2010 revealed that these young people visited their general practitioner an average of five times before their symptoms were taken seriously or diagnosed accurately given the background of multiple physical changes already occurring in this age group (Rajani et al., 2011). It has been noted that because of the normal physical and developmental changes already taking place in AYA patients, the pharmacokinetics of cancer treatment is less precise and the biological response less well understood, potentially contributing to worse overall outcomes (Albritton & Bleyer, 2003; Coccia et al., 2012; Thomas, Albritton, & Ferrari, 2010; U.S. Department of Health and Human Services, 2006; Wein et al., 2010). This general lack of knowledge is further compounded by minimal guidance for how to treat cancers in this age group, which is thought to be a result of less research and less access to clinical trials for AYAs nationwide. Moreover, reduced access to quality treatment or placement in a less appropriate treatment setting are thought to be factors in the worse outcomes for this patient group. (Albritton & Bleyer, 2003; Bleyer, 2011, 2012; Rajani et al., 2011, U.S. Department of Health and Human Services, 2006; Whiteson, 2003).

The psychosocial conditions of this age group are also believed to have an impact on the poor outcomes observed in this patient population. Adolescent and young adults tend to lack medical insurance resulting in no or less consistent contact with a primary care provider. The cost of medical care is also thought to be a deterrent for AYAs in seeking and following-up with medical care or taking medication as prescribed. Adolescent and young adults are more likely to ignore unusual physical signs and symptoms due to the potential financial burden or to the invincibility attitude common in this age group (Albritton & Bleyer, 2003; Morgan et al., 2010). Adolescent and young adults and healthcare providers both tend to attribute signs and symptoms to growing pains or other expected physical developmental changes. Lifestyle choices, including drinking or drug or tobacco use, can also be a deterrent to AYAs seeking medical help or can be a barrier to treatment adherence and follow-up (Morgan et al., 2010). For the most part, AYAs generally have a poor record of adherence to treatment and treatment follow-up compared to either children or older adults (Albritton & Bleyer, 2003; Bleyer, 2011, 2012; Coccia et al., 2012; Livestrong Young Adult Alliance, 2007). This lack of treatment compliance may be due to AYAs being more mobile and transitory and being less concerned with their own mortality.

The poor survivorship outcome observed in the AYA patient population is also influenced by the negative effects on, and the disruption of, appropriate psychosocial and physical development. A cancer diagnosis can interrupt the individuation and character-building a patient has been cultivating and shaping since their early teenage years, creating a disruption in social and personal development. In many cases this

means, having to move back in with parents or family, to rely on others, and to question beliefs about themselves and their worldview. A cancer diagnosis as an AYA can interrupt success and functioning in later adulthood because a diagnosis at this age often impacts education and occupation or vocation at critical points in a patient's life. Quality of life (QOL) can feel quickly degraded as increasingly complex treatment strips patients of their ability to shape their social world, reach milestones, experience transitions, and discover their place and path. Researchers have observed that as an outcome of these issues, AYAs experience increased anxiety and depression compared to their younger or older counterparts (Corey, Haase, Azzouz, & Monahan, 2008; Rosenberg & Wolfe, 2013; Zebrack, 2011;). The combination of these factors influences treatment and may contribute to a patient's poorer QOL if not properly addressed across the cancer care continuum.

Long-Term Consequences

With a greater likelihood of presenting with later stage disease, AYAs have been more difficult to treat, commonly with fewer desired outcomes. Generally, they experience a more complex course of medical care; they have an increased chance of medical and psychological co-morbidities; and they face broader psychosocial issues. The effects at this age can be much farther reaching than diagnosis in childhood or as an older adult and often have a large impact on more than just the patient and family. A 2008 analysis of data recorded between 2000–2007 under the National Surveillance, Epidemiology and End Results Registry (SEER) Program determined that, despite representing only 5% of all cancers diagnosed across the lifespan, the diagnosis of

cancer among AYAs affected more than three million patient-years-of-life (Bleyer, 2012). According to Bleyer the AYA years-of-life affected by a cancer diagnosis was four times higher than what other children and early teenagers experience. For the AYA population, patient-years-of-life affected equates to a longer course of treatment and longer recovery times, as well as increased and more serious late effects from treatment. Patient-years-of-life affected also includes developmental stagnation, increased duration of psychosocial burden, and more adverse impact due to extended time out of school and work. The years-of-life affected not only directly impacts the patient and his or her family, but also puts an increased strain on medical system costs and resources. In many cases, the AYA patient is delayed in becoming a contributing and participating member of the community and greater society.

In the latest investigation using data from SEER, it was discovered that six of the 24 most commonly diagnosed cancers for this age group had a 5-year patient survival rate of less than 50% (Bleyer, 2011). Cancers accounting for this low survival rate include: acute myeloid leukemia, acute lymphoid leukemia, rhabdomyosarcoma, lung carcinoma, adrenocortical carcinoma, or hepatic carcinoma. An analysis of data reporting the most frequently diagnosed adult cancers in 2014 identified that two of the 10 most common cancers, which are lung or bronchus and pancreatic cancer, historically have had less a than 30% chance at 5-year survival (American Cancer Society, 2013, 2014).

Additional analysis of the SEER data described above reveals that 25% of the cancers most commonly diagnosed in AYA have a 5-year survival rate of less than 50%.

Only 20% of cancers most commonly diagnosed in adulthood have a 5-year survival rate under 50%, indicating a relatively poorer survival for AYAs. Moreover, the data shows that nearly a fifth of AYA patients diagnosed with cancer presented with distant disease at their initial diagnosis. Influencing factors such as AYA patients commonly hesitating to seek treatment or a delay in accurate medical diagnosis make it more likely that this age group will present with distant disease at diagnosis. Bleyer's (2011) pioneering investigation also indicated that a quarter of the AYA patient population presenting with distant disease at diagnosis had less than a 30% chance at 5-year survival. Adjusting this period of investigation (Bleyer, 2011) into an annual estimate suggests that approximately 3,000 AYA patients per year will present with distant disease at diagnosis and about 700 of those patients will have a less than 30% chance of surviving past five years.

Studies used to support the National Comprehensive Cancer Network's ([NCCN], 2012) guideline on AYA oncology indicate that patients who survive childhood or adolescent cancer continue to confront health issues after diagnosis. In one of these studies, 73% of the 10,397 survivors who were less than 30 years from diagnosis, reported having a chronic health condition, and 42% of those patients reported having severe, disabling or life-threatening conditions. The mean age of the survivors included in this study was 29.2 years old (Oeffinger et al., 2006). Additionally, compared with the general population, AYA cancer survivors are at significantly higher risk for developing a secondary cancer either as a result of treatment or a second primary tumor (NCCN, 2012). Some researchers estimate that between 10–40% of AYAs will ultimately develop

incurable disease after primary treatment (NCCN, 2012; Schrijvers & Meijnders, 2007). From this data, it is reasonable to predict that AYA patients with complex or advanced disease could significantly benefit from more precise, data-driven care that addresses their unique medical and psychosocial needs.

Current Organizational Responses

In the wake of increasing awareness of the overall poorer health status of AYA relative to other oncology age groups, responses from the medical community and advocate groups have varied. One recent effect has been an overall increase in AYA-specific oncology programs across the United States. The first programs of this kind began at the University of Texas M.D. Anderson Cancer Center and Dana Farber Cancer Institute. Since their establishment, several others have launched nationwide. Programs of this kind often enhance the delivery of biologically-based medicine by offering psychosocial services while providing an age-appropriate care environment. In an effort to increase AYA-specific services, the Teen Cancer America program, a branch of the Teenage Cancer Trust program in the United Kingdom, was created in 2012 to provide strategic guidance to hospitals to help establish specialist units and services for this age group. In summer 2014, Teen Cancer America reported that more than 30 hospitals in 20 states were in discussion with the organization about developing services for this patient group (Davies, 2014). In addition to site-specific, medically-based programs, there has been a growing range of online resources for this patient group. Examples include access to overnight camps, academic scholarships, encouragement to accept changes in appearance, as well as financial help to meet a family's basic needs related to

a cancer diagnosis. Tailored websites include: Stupid Cancer, Critical Mass, Livestrong's Planet Cancer, Rise Above It, and The SAM fund and Ulman Cancer Fund.

In the past few years there has been an increase in support for AYA oncology from government and non-government groups. Specifically, the National Cancer Institute (NCI) has increased its sponsorship for clinical research related to AYA oncology, and has a comprehensive website offering guidance, information, and education regarding AYA oncology (Livestrong Young Adult Alliance, 2007). Advocates affiliated with the Children's Oncology Group stress the need for more clinical trials for this age group and also encourage flexibility in eligibility for clinical trials and surveillance programs already in existence (Nass & Wilder-Smith, 2013). Professional organizations such as Critical Mass: The Young Adult Cancer Alliance have been steadily working to help establish recommendations for the medical, psychosocial, and community care of AYAs as well as for research efforts specific to this patient group (U.S. Department of Health and Human Services, 2006). Most notably, in January 2012, the National Comprehensive Cancer Network released its first clinical practice guidelines regarding the delivery of medical care for this patient group. The release of this publication helped establish AYAs as a major oncology patient group and highlighted the necessity for a specific and separate care pathway for them (NCCN, 2012).

A community of healthcare advocates has responded to the unique and often unmet needs of this patient group by establishing the Change It Back: Health Care Rights Initiative—Centers of Excellence Program. This is the first organized attempt at specifying standards of care for AYAs. The objective of this initiative is to improve health

and survivorship outcomes and elevate the quality of services available to the AYA oncology population by recognizing programs that have demonstrated success in meeting the care standards for this group (Health Care Rights Initiative, 2012). Criteria which have been specified to receive designation as a “Center of Excellence,” however, do not explicitly enumerate palliative medicine, a service widely identified to improve patient health outcomes. While its theory, practice, and expertise could be usefully applied and beneficial to this patient population, palliative medicine has gone unrecognized as a critical component to excellent care service for this group. (Pritchard et al., 2011; Rosenberg & Wolfe, 2013).

Why Palliative Care?

Unlike the leading biomedical and cure-based focus of medical oncology, palliative care addresses symptoms and side effects of cancer care that affect a patient’s current QOL while considering future outcomes. This care modality is important for AYAs who tend to experience a greater reduction in their QOL while receiving treatment, in part due to psychosocial and developmental changes and missing out on events such as graduations, dances, and parties in which they are unable to participate (Albritton & Bleyer, 2003; S. George & Bradbury, 2010; Morgan et al., 2010; Smith et al., 2012). Not addressing the treatment effects that physically affect functioning or limit participation in developmental tasks and social events can have enduring negative consequences for the AYA patient (J. K. Clark & Fasciano, 2013; U.S. Department of Health and Human Services, 2006; Whiteson, 2003). Additionally, the future-minded orientation of palliative care is important for the AYA patient with regard to making

health care decisions and offering services that protect future functioning by introducing interventions in anticipation of patient changes or challenges (Morrison & Meier, 2004; National Consensus Project, 2013; Rosenberg & Wolfe, 2013; Thornes, 2001).

The National Consensus Project (NCP), a collaborative organization of multiple partners working to establish standardized care and guidelines to provide palliative care, describes palliative care as:

patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice. (NCP, 2013, p. 14)

The organization's definition is based on the World Health Organization's (WHO) definition of palliative care (World Health Organization [WHO], 2014b, Appendix A) and has been adopted for use by the United States Department of Health and Human Services, Centers for Medicare & Medicaid Services and the National Quality Forum (NCP, 2013). WHO (2014b) includes a specification beyond this definition by stating that palliative care "may also positively influence the course of illness . . . and is applicable early in the course of illness . . . in both the prevention and relief of suffering . . . or to manage distressing clinical complications" (para. 1).

To this end, palliative care is life-enhancing. Its role is to support living until death by working with the patient to better manage the impact of their disease on their life. It emphasizes quality of living, provides anticipatory guidance, and communicates and promotes decision-making within a relatively uncompromising medical system

historically focused on the physical illness (Levy et al., 2009; Meier, 2011; Morrison & Meier, 2004; NCP, 2013). Palliative care is an invaluable medical service that is well-suited to meet the underserved needs of the AYA oncology patient. As advocacy groups seek national appeal to improve recognition, research, treatment, and surveillance of AYA oncology patients, palliative care should be stressed as a service that can be central in meeting the biopsychosocial needs of this patient population and influence more positive health outcomes and survivorship.

Personal Relevance

I am researching AYA oncology and palliative care and the questions raised therein because of a personal family connection with the subject. Conversations with family member(s) affected by cancer helped seed the prospect of writing on this topic and the point of view of the investigation. Having witnessed a family member who was profoundly affected by a cancer diagnosis at 19 years old, and the continued effect of the disease six years later, I first-handedly experienced the change that occurs in the unwell person and the immediate family because of life-threatening long-term illness and the challenges that follow. As a sibling to an AYA significantly challenged by cancer, I am keenly aware that there is much more that can be done to help patients and their families during and after treatment. Further, that care can be timed, tailored, and implemented in a manner that enables everyone to function as well as possible no matter the AYAs place in treatment or the outcome. I write as an author and beneficiary of the results of this investigation. A portion of the writing and opinions expressed in

this body of work are informed by my closeness with the subject and are intended to support or supplement the results of the review.

Background

The following review of literature will discuss what palliative care is generally understood to be and how it differs from hospice care. In addition, the history of palliative care, the developments that have advanced its practice, and the two existing divisions of palliative medicine, pediatric and adult will be discussed. It will also explore the need for palliative care to serve the emerging adolescent and young adult (AYA) oncology patient group and why palliative care is best suited for this population as well as what is currently absent in the research. Finally, the review will investigate how palliative care practice has advanced alongside the rising awareness of AYA, and what should be done to serve this group more effectively using the palliative care approach.

What Exactly Is Palliative Care?

Palliative care is a philosophy and model of healthcare service that serves patients with life-threatening, complex, terminal and/or debilitating illnesses. Palliative care considers both patient and family needs with an essential focus on achieving and supporting the patients' best-possible quality of life (Irwin & von Gunten, 2010; Meier, 2011; NCP, 2013). Palliative care anticipates, prevents, and relieves suffering, through effective management of pain or other distressing symptoms, by bringing together practitioners in multiple disciplines to address and support physical, psychosocial, and spiritual care, coordinate comprehensive care, and facilitate patient access to information and choices (Morrison & Meier, 2004; National Institute for Clinical Excellence, 2004; NCP, 2013; WHO, 2014b). Palliative medicine can be provided concurrently with treatment for curative-intent or with life-prolonging treatment, as

well as during clinical trials; it can also be the primary care modality. An advantage of palliative care is that it can help patients better tolerate treatment and recover from treatment, and help patients have more success with difficult treatment routines (O'Shea, 2013). It is structured to provide care, support, and benefits to patients and families regardless of disease stage, place in the course of treatment, or the need for other therapies (Billings, 1998; Levine et al., 2013; Levy et al., 2009; National Institute for Clinical Excellence, 2004; NCP, 2013; WHO, 2014b).

Palliative care is indicated when patients experience uncontrolled symptoms or side effects, medical or psychosocial distress, serious comorbid physical or psychosocial conditions, or for patients who have complex, progressive, or advanced disease, unusual treatment burden, or treatment fatigue. Palliative care is also warranted if the patient or family voices concerns about the disease's course or treatment decision-making, or when palliative care services are explicitly requested (Levy et al., 2009). Medical conditions appropriate for palliative care include: conditions for which curative treatment is possible, but may fail; illnesses requiring intensive long-term treatment, with the goal of maintaining quality of life (QOL); and progressive conditions in which treatment is primarily palliative after diagnosis. Conditions causing severe non-progressive disability, but that create increased vulnerability to health complications, are also appropriate for palliative medicine (Himmelstein, Hilden, Morstad Boldt, & Weissman, 2004).

A comprehensive assessment with the oncology patient and his or her family is the foundation to providing targeted quality palliative care and forms the basis of the

plan for care (Morrison & Meier, 2004; NCP, 2013; Smith et al., 2012). The assessment should include a survey of a patient's physical and psychological symptoms, functional and developmental status, readiness for advanced care planning, social, cultural, and spiritual preferences, and strengths and future goals, as well as what the patient values regarding personal commitment to his or her care (NCP, 2013). Researchers agree that core components in the practice of palliative care include: open communication and active listening, providing information and education, supporting informed decision-making, multidisciplinary care coordination to include community medical resources, facilitating seamless transitions across care settings, encouraging patient autonomy, and allowing the patient and family to set the philosophy for how to live with incurable disease (Bello Belasco et al., 2000; Levine et al., 2013; Morrison & Meier, 2004; O'Shea, 2013). These features are essential to maximizing quality of life with illness.

The potential significance palliative care has on patient health and wellness, when coordinated and appropriately applied, has recently been documented on a worldwide scale. In 2014, the World Health Organization (WHO) released the first-ever publication capturing the progress and innovation of palliative medicine and related patient statistics in a multi-country investigation. The Global Atlas of Palliative Care at the End of Life (WHO, 2014a), highlighted models with limited funding and limited material resources that have been successful in diverse settings around the world. This report details programs that follow palliative medicine's philosophy of care and documents the value communities have placed on palliative care service (PCS), and its

sustainability when adapted to meet the needs of a specific community. The authors of this report estimate that if palliative care were to be used on the basis of need, not just in response to specific diagnoses or prognoses, its services would be indicated for 20 million people. The call for increased access to and delivery of palliative care both in the United States and worldwide is a marked shift from formerly predominant negative beliefs about palliative medicine (Cherny, 2009; Cherny & Catane, 2003; Fadul et al., 2009).

Historically, the term palliative care and perceptions of its practice have been synonymous with the phrases “terminal care,” “end of life care,” “hospice care,” and “comfort care.” The lack of agreement, understanding, and inconsistency in conceptualization has led to the examination of how palliative medicine is perceived and defined independently of other supportive care services (Billings, 1998; Kang & Feudtner, 2012). As a result of this observation, palliative medicine has constructed and clarified its philosophy, structure, principal components, goals, purpose, and place in health care services. It is now widely held that the practice of palliative medicine encompasses end of life and hospice care as a feature of its service; however, the role of palliative care is neither designed nor intended to be exclusively for patients who are near the end of life or dying (Meier, 2011; Morrison & Meier, 2004; Pritchard et al., 2011; Rosenberg & Wolfe, 2013; WHO, 2014b).

How are palliative care and hospice different. Palliative care embraces the hospice philosophy of care to provide coordinated, compassionate, patient-family centered care, but seeks to bring this approach to a wider group of patients beyond

those near end of life (Billings, 1998). The objective of palliative care is that its principles are layered within the general operation of healthcare and can be performed in a primary, secondary, or tertiary fashion (Irwin & von Gunten, 2010; Meier, 2011). Researchers on the subject describe primary palliative care as a philosophy of practice and basic skills, such as communication and symptom management, that all physicians and health care workers with direct access to patients should embody. Secondary palliative care includes collaboration with specialist-level palliative experts who help coordinate and direct care for complex patients or patients with medical comorbidities requiring increased surveillance. Tertiary palliative care incorporates research, education, training, and advocacy and is carried out within the greater scope of palliative medicine (Irwin & von Gunten, 2010; Meier, 2011). More recently, palliative care has worked to position itself so that it can be increasingly integrated into primary medicine and across treatment settings (Billings, 1998; D. Clark, 2007; Levy et al., 2009; Morrison & Meier, 2004). Where palliative care programs and hospice programs differ in practice is in the care location, timing of care, and eligibility for services.

Unlike hospice care, palliative care is not reserved for the terminally ill nor does it require a prescribed estimate of remaining life for its services to be accessed. In fact, it was those patients not meeting the hospice eligibility requirement but still in need of coordinated specialist-directed care that led to the rapid growth of palliative care in the United States (Meier, 2011). Ideally, palliative medicine is a care intervention based on patient needs, that extends across the course of illness, and is coordinated with anti-cancer or disease-modifying treatments. This is a blended approach in which

oncology physicians and palliative care workers co-manage the care of the patient (Billings, 1998; Irwin & von Gunten, 2010; Meier, 2011).

Since palliative care is designed to be available to anyone at any time in his or her illness, it requires clinicians and health care workers of the practice to be “future-minded” about their patients. In this framework, palliative care differs from hospice because it provides anticipatory guidance with regard to physical and psychosocial effects of a disease after illness or when illness is stabilized (J. K. Clark & Fasciano, 2013; Levine et al., 2013). Rosenberg and Wolfe (2013) state, palliative medicine is essentially designed to “develop interventions to foster more functional outcomes during and after cancer” (p. 46). A tenet of palliative care is to communicate with the patient about considerations and choices based on the projected future health and functioning of that individual (Kang et al., 2005; Meier, 2011; Thornes, 2001). Hospice focuses primarily on comfort and quality of life at the end of life, while palliative care focuses on providing the best QOL for patients and families during treatment, with a healthy future in mind.

To promote the best possible QOL, palliative care is ideally carried out at the patient’s home where psychosocial factors are generally more positive (Bello Belasco et al., 2000, Meier, 2011; Michaud, Suris, & Viner, 2007; Thornes, 2001; WHO, 2014a). For patients who receive at-home care, a primary objective of palliative care “is to help the patient return to a level of functioning that allows for self-care and increased medical independence” (Connor, 2010, p. 284). This care is rooted in the efforts of multiple disciplines working together to achieve improved quality of functioning and engagement

consistent with the patient's capacities and present and future goals. Hospice home care also participates in healthcare intervention according to a patient's QOL and goals, but, it maintains a greater focus on the relief of physical suffering at the end of life and preparation for death (Connor, 2010).

Palliative Care History and Developments

From the time of Hippocrates, the so-called "Father of Medicine", and the advent of the Hippocratic Oath, the principals of medicine have upheld two overall goals: to reduce or relive suffering and to cure disease (Irwin & von Gunten, 2010; Morrison & Meier, 2004). However, modern-day medicine has tended to concentrate primarily on only one of the two goals—to cure disease. In the 1960s, through the pioneering work of oncology nurse Cicely Saunders, attention to and treatment of the suffering of patients was brought back into the spotlight. This subject became a focus of intellectual discourse and study among a small group of healthcare workers.

Cicely Saunders was one of the first to write about and conduct research on terminally ill patients, starting with her publication in 1959 titled "The Management of Patients in the Terminal Stage." In 1967, she opened the first ever independently operated hospice facility, St. Christopher's Hospice in London (D. Clark, 2007; Pritchard et al., 2011). Her efforts were a response to the public and professional interest in cancer which, at the time, was primarily focused on curative treatment. She recognized that suffering might result inadvertently by the efforts to control disease where sometimes the treatment came at the cost of the patient's psychological, social, and spiritual wellbeing (D. Clark, 2007; Irwin & von Gunten, 2010). As a result of the

narrowed medical efforts and attention that focused on curing cancer, individuals without a chance for a cure or who were thought to be dying were often overlooked, frequently being told there was no more help. St. Christopher's Hospice was established to support these patients and was the source and start of organizational and clinical studies that played a central role in the advancement of palliative care (D. Clark, 2007).

The term palliative care was first introduced by Canadian physician Balfour Mount in 1974 (D. Clark, 2007). The term "palliate" derives from the Latin term *pallium* which means "to cloak" or "cover." The original meaning of this word caused palliative care to be viewed disapprovingly by the medical community suggesting it only "covered up" the real problem (Billings, 1998; Irwin & von Gunten, 2010). Despite some negative perceptions, hospice and palliative care was having success with patients and families because palliative care practitioners use periods of health or stability to actively and collectively plan for potential health changes as well as help bring some sense of control to the uncertainty of severe and complex illness (D. Clark, 2007; R. George & Hutton, 2003). With this success, some instead viewed the approach as "covering-up the suffering [rather than covering up the real problem] and letting the patient experience the best quality of life possible" (Irwin & von Gunten, 2010, p. 277). The success of the London-based St. Christopher's Hospice stimulated an expansion in hospice development throughout the United Kingdom peaking in the 1980s, when approximately 10 new hospices were being opened annually (D. Clark, 2007).

The development of palliative care has been a "bottom-up" process with only a few individuals championing the field and its associated professional development, and

calling for professional and public acknowledgement of this healthcare approach for the medically complex and terminally ill. The efforts of advocates, including Cicely Saunders, Margaret Bailey, and Eric Wilkes, in the United Kingdom during the 1960s, achieved success when in 1976 the first hospital-based palliative care team was established at St. Thomas Hospital in London (D. Clark, 2007). Ten years later, in 1987, The Royal College of Physicians in Great Britain recognized palliative medicine as a separate medical specialty (D. Clark, 2007; Irwin & von Gunten, 2010; NCP, 2013). An review of hospice-based medical services in the United Kingdom in 2004 determined there were 196 hospice inpatient units, 341 day-care service programs, 237 hospital-based care programs and 324 hospice at-home programs, a remarkable increase in just four decades (D. Clark, 2007).

More than ten years passed after the first independently-supported hospice house was established in the United Kingdom before similar services were offered in other European countries: Sweden (1977), Italy (1980), Germany (1983), Spain (1984), Belgium (1985), France (1986), and Netherlands (1991) (D. Clark, 2007). As in the United Kingdom, other countries began embracing palliative medicine as an established and recognized medical specialty. Approximately ten years after The Royal College of Physicians in Great Britain recognized palliative medicine as a specialty, the Royal College of Physicians and Surgeons in Australia and New Zealand followed suit in 1998. Similarly, in 1999, the Royal College of Physicians and Surgeons and the College of Family Physicians of Canada established their first postgraduate training in palliative medicine (D. Clark, 2007; Irwin & von Gunten, 2010; NCP, 2013).

In addition to the rise in development of palliative care and hospice programs and recognition of palliative medicine within the professional-medical community, an increase in international collaboration has been observed. These collaborative efforts promote interests, goals, guidelines, and research imperatives in palliative and hospice care. The United Kingdom, as with almost all other palliative care and hospice advancement, led the way with the formation of the Association for Palliative Medicine for Great Britain and Ireland in 1985 (D. Clark, 2007). Soon afterward, in 1988, the European Association for Palliative Care was established and ten years later, in 1999, the International Association for Hospice and Palliative Care was formed (De Lima, 2010). Elsewhere, the Asia Pacific Hospice and Palliative Care Network was established in 2001 with the Latin American Association for Palliative Care following in 2002, and the African Association for Palliative Care in 2003 (D. Clark, 2007; De Lima, 2010).

The first collaborative organization of this kind in the United States began with the establishment of the National Hospice and Palliative Care Organization in 1978. Despite the enthusiasm demonstrated by early establishment of this progressive organization, development of this specialty appears to have been slower to develop in the United States than in other medically-developed nations. Palliative medicine did not gain traction in the United States until the 1990s when a report published by the Institute of Medicine (IOM) in 1997 titled "Approaching Death: Improving Care at the End of Life" stimulated professional discussions and an increased interest in the field. Similar reports by the IOM followed in 2001 and 2003. In 1995, The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) aimed to

improve end-of-life care for adults through a multisite, hospital-based investigation carried out in the United States (Connors et al., 1995). Similar projects followed, and in the mid-1990s, the Robert Wood Johnson Foundation funded the Promoting Excellence in End of Life Care program to address areas of care and treatment in need of improvement for palliative and hospice patients, and to support initiatives and innovative models for better care (D. Clark, 2007; Kang & Feudtner, 2012).

In response to the professional and academic interest in hospice and palliative medicine, the Center to Advance Palliative Care was founded in 1999 by the Robert Wood Johnson Foundation. This program has increased the availability and expertise of palliative care across the United States by providing comprehensive training and mentorship at every stage of program development. It also has helped to create sustainable inpatient and outpatient palliative care programs (Kang & Feudtner, 2012). Simultaneously, the Academy of Hospice Physicians, which was formed in 1988, officially changed its name in 2000 to the American Academy of Hospice and Palliative Medicine to incorporate the burgeoning interest in palliative care (D. Clark, 2007). Following what other countries had done 20 years earlier, in 2006 the United States formally approved, through the American Board of Medical Specialties, the creation of Hospice and Palliative Medicine as a subspecialty, a move that increased the legitimacy of the field (D. Clark, 2007; Irwin & von Gunten., 2010).

Following this development, the Accreditation Council for Graduate Medical Education began developing and accrediting fellowship programs that targeted training in hospice and palliative medicine in 2007 (Abraham, 2011; Kang & Feudtner, 2012; NCP,

2013). In 2008, the American Board of Internal Medicine began certifying medical practitioners in palliative and hospice care, but only under co-sponsorship of one of the other nine medical practice boards (Abraham, 2011). As of early 2010, there were 74 active palliative care fellowship programs in the United States, an increase from 53 in 2005 and 17 in 2000, together offering a total of 181 fellowship positions and 27 research roles (Abraham, 2011; Morrison, Maroney-Galin, Kralovec, & Meier, 2005). A study published in 2005 using data obtained from the American Hospital Annual Survey, revealed that 25% of hospitals in the United States surveyed in the year 2003 offered pediatric and adult palliative care programs, a rate increase of 10% over three years (Morrison et al., 2005). This trend has remained relatively steady, with research publications reporting that approximately 50–70% of hospitals with 50–300 beds serving adults or children currently have palliative care programs in place (Abraham, 2011; Feudtner et al., 2013; Meier, 2011; Morrison et al., 2005). The observed growth in hospital programs and practitioner specialization in palliative care signals increasing openness to this type of care suggesting this is the appropriate time to assess and shape its development.

As palliative medicine developed and delivery became more widespread, its structure and services, like in most other medical practices, have become dichotomized and specialized as separate pediatric and adult medical models. Over time, most palliative care services have developed to meet the different needs, complexities, goals, and health prognoses of each set of these patients. For example, pediatric palliative medicine, in comparison to adult service, has tended towards more innovative

advancements in its practice to meet the changing landscape of disease and prognosis in this age group (Crane, 2011; Spathis, Harrop, Elverson, & Lapwood, 2012). A sensitivity to younger patients' un-lived-years and family participation in all phases of care may be some of the reasons for unequal progress (Crane, 2011; O'Shea, 2013; Spathis et al., 2012). A brief examination of the different core features of palliative medicine in both systems is necessary to help build the foundation for AYA care, care which requires specific palliative practices to meet their particular needs, complexities, goals and health prognoses. Their treatment should not have to fall onto either side of the division.

Adult palliative care. The number of hospital-based adult palliative care programs has more than doubled across the United States since the early 2000s (Feudtner et al., 2013). The emergence and development of palliative care and hospice, as it is known today, grew primarily out of oncology care with the help of work by Cicely Saunders. Subsequent, to the formative work by Cicely Saunders, the discipline of adult palliative medicine has historically focused primarily on the care of patients with cancer (Clark, 2007; National Institute of Clinical Excellence, 2004). Patients served by palliative care in either a hospital setting or in a hospital-based program are on average age 60–65 years old and tend to have more medical co-morbidities than younger patients (Rosenberg & Wolfe, 2013).

Adult palliative care is positioned to help serve the AYA population because of its prolonged focus on and expertise in oncology care and increased experience with co-occurring medical conditions. Adult palliative care also has more clinical experience involving intimate partners, significant others, or spouses in treatment and planning.

This is a distinguishing characteristic of the adult palliative care model applicable to caring for AYAs (Thornes, 2001). Attributes of adult-oriented healthcare that differ from pediatric healthcare include a patient's expectation of autonomy, a patient's search for reasonable answers, a multidisciplinary approach, and regular engagement in the course of becoming old (J. K. Clark & Fasciano, 2013). The practice, encouragement, and management of patient autonomy should be a central element in palliative care with AYA, and the adult service method is well positioned to guide care with this patient group utilizing the approaches listed in this paragraph.

Pediatric palliative care. Pediatric palliative care has been slower to take shape than its adult counterpart with the majority of hospital-based programs having been established beginning in the late 1990s and early 2000s (Feudtner et al., 2013). Despite its later emergence in the field of medicine, pediatric palliative care has experienced ongoing, increasingly responsive advances to developments in medicine and technology. These advances have contributed to the long-term survival of children with chronic and complex medical disease. Improvements however do not relieve them from the nature of their disease, which can make children prone to repeated life threatening complications or life-long complications (Crane, 2011; Himmelstein et al., 2004). Children typically receiving palliative care are likely to have increasingly complex disease, use many healthcare resources, and be prone to frequent hospitalizations (Feudtner et al., 2013).

A distinguishing feature of palliative medicine practice in pediatric oncology is that most parents and families using this service wish to seek and attempt every

possible cure-directed treatment (Crane, 2011; O'Shea, 2013). Gawande (2010) writes, "rarely is there *nothing* more that doctors can do . . . we want these choices . . . we don't want anyone to limit them" (para. 80). This desire for treatment, for giving effort, and for hope was observed in a study by Aetna Insurance in 2004. Aetna allowed a small group of policy holders with a life expectancy of less than a year to continue ongoing clinical treatment while also receiving hospice. Examination of this concurrent care option demonstrated that patients were significantly more likely to add hospice or similar at home services, with the number of patients using this service nearly tripling in two years. Later, the same effect of tripling enrollment in hospice was also observed with a larger group of policy holders who were no longer offered active clinical treatment, but instead a palliative approach to treatment and care was applied (Gawande, 2010).

Palliative medicine validates these study observations by aligning with the strong patient desire for maintaining hope through continuous care. This desire has recently been recognized at the level of the United States national health administration (Crane, 2011). With the introduction of The Affordable Care Act of 2010, it is now possible for pediatric patients to receive treatment with curative intent concurrently with palliative care under the Concurrent Care for Children Requirement (Crane, 2011; Gawande, 2010; Kang & Feudtner, 2012; Patient Protection and Affordable Care Act, 2010). Similar to the Aetna pilot, this means that patients and families do not have to forgo "hope" and active treatment to receive palliative or hospice treatment but, that both practices can work simultaneously for the patient's health and wellbeing. This legal requirement

has proven an enormous advance for palliative medicine because for the first time, the benefit of palliative care is receiving wider national recognition and the service is being accessed as it's intended to serve the patient.

Pediatric palliative care is family-centered, interdisciplinary, developmentally-oriented, consistent, and cautious in practice, accordingly staff on pediatric palliative care teams must possess basic knowledge and experience in child development and family systems (J. K. Clark & Fasciano, 2013; Himmelstein et al., 2004; Kang et al., 2005). The pediatric palliative team often has more experience with supporting transitions to home or outpatient care, adult service or hospice than palliative care teams for adults (Thornes, 2001). Pediatric palliative care teams also have a broader more diverse approach to bereavement service that includes adults as well as young children, such as other pediatric oncology patients, siblings, and classmates in the bereavement process. (Himmelstein et al., 2004).

Just as with the adult model, the pediatric palliative care model and skill set have elements that are suitable for or can be tailored to serve the AYA population. This model would prepare team members to be more adept at responding to and managing repeated complications experienced throughout an adolescent or young adult's development. Practitioners trained in the pediatric model are likely better equipped to work with the AYA population because they have shown the ability to navigate and embrace the rapid changes in pediatric oncology over the past two decades. With an intensified focus on the AYA population, similar rapid changes are expected to take place. Additional approaches and competencies fundamental to pediatric palliative care

that would be relevant to AYA care include: knowledge of age-specific physiologic differences, knowledge of anticipated developmental changes, awareness of a patient's social role and social identity in the face of illness, and the ability to maintain a focus on growth and development while also facing the potential for the patient's death (Levine et al., 2013; Howk & Wasilewski-Masker, 2011). Pediatric patients are often involved with PCS for a prolonged period, and practitioner's knowledge to navigate patient and family relationships, school and social systems, developmental tasks and desires, care coordination and transition, as well as the psychosocial challenges of prolonged illness would be invaluable skills to facilitate the development of PCS for AYA oncology patients.

Blending both approaches for AYA patients. A 2013 publication emphasized that 90% of children with special health care needs are now living past their 21st birthday, and a half million of these young adults are entering the adult healthcare system annually (J. K. Clark & Fasciano, 2013). Many of these young people report feeling cast adrift despite the increasing frequency of youth with serious illness living longer and continuing to require routine and specialized care (J. K. Clark & Fasciano, 2013; Thornes, 2001). Palliative care is a service that could be designed to meet the biopsychosocial needs of these "adrift" patients, as well as newly diagnosed AYA patients, providing a central anchor among this group. "Young adulthood is the crossroads where childhood disease transitions into adult-like patterns" (J. K. Clark & Fasciano, 2013, p. 2), and it requires extensive expertise in medical and social management. Pediatric and adult palliative care approaches, services, and structure each have elements that can help in

the formative development of PCS for AYA patients, and both are appropriate for meeting some of the unique needs of this patient group.

In the initial phases of tailoring palliative care to AYAs, direction will need to come from both the pediatric and the adult palliative care philosophies and models of care. Historically adult service has a stronger focus on treating cancer and thus can potentially contribute more knowledge about a palliative orientation to patient care in the treatment of cancer. Pediatric service has experience in how to better address and care for the patient's continued psychological and physical development throughout the course of illness and into recovery (Siegel et al., 2013; Spathis et al., 2012). Pediatric palliative service is more developed and experienced with family-centered care, a principle that could merge with the practice and encouragement of patient autonomy and health care decision-making which is integral to adult service. Adolescents and young adults, however, have distinct needs which will not be met by knowledge or expertise from either pediatric or adult services alone.

As mentioned, pediatric and adult palliative care practices both have elements that can beneficially contribute to the emerging development of palliative care for AYA patients. However, some considerations stand out to suggest the need for a separately-skilled service group to meet AYA needs. Adolescents and young adults demonstrate distinctive cancer biology and treatment response when compared to either pediatric or adult patients (Bleyer, 2012). These differences require greater specific medical knowledge of the cancers most common to this group of patients, which are a combination of both pediatric and adult cancers (Siegel et al., 2013). The

latest report of cancer statistics in the United States using data from multiple national health organizations indicated leukemia and brain or central nervous system tumors, the leading types of cancer causing death in AYA males aged 20–39, are also the same leading types causing death in males 20 years and younger. Conversely, breast cancer, the cancer causing most deaths in AYA females aged 20–39, was the same leading type of cancer causing death in older females aged 40–59 (Siegel et al., 2013, Appendix B). Adolescent and young adult physiology along with ongoing changes in growth and development may cause different pharmacokinetic responses and side effects to treatment drugs than those observed in adults or pediatric patients with the same cancer type. Additionally, when the types of cancers, disease expression, and demands of care become more complex and multidimensional, implementing PCS for the AYA patient group is uncharted and unfamiliar. Consideration for AYA and the unique medical oncology care that is required extends beyond the complexities of biological or biomechanical aspects of illness.

Pediatric palliative care teams generally have less expertise and experience working with young adults, patients who might prefer more independence than the strong family-model typical of pediatric care (Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Thornes, 2001). Similarly, adult palliative care teams may have considerably less experience and expertise working with younger AYA who are frequently treated within the pediatric service. Also, adult palliative care teams have less experience and can be less well equipped to care for more active young people (Thornes, 2001). Adult medical systems expect that the individual is capable and able to navigate through assorted and

often fragmented care, while pediatric medical systems may leave a young adult with little opportunity for collaboration in the direction and construction of their medical care (Ferrari et al., 2011).

What Features of Palliative Care Make It Exceptional?

Despite some of the divergent approaches to patient palliative care between the pediatric and adult subdivisions, there are features from each that when combined make palliative care very suitable for the AYA population. Palliative medicine aims to provide continuity of care in a vastly complex system and makes expertise in collaborative communication, information sharing, and joint decision making a priority. It is especially well-equipped to assist patients and families to identify treatment goals and merge these with goals outside of healthcare, in an effort to maintain a holistic care approach (Meier; 2011; NCP, 2013; Rosenberg & Wolfe, 2013; Smith et al., 2012). Palliative care teams also have a strong commitment to assist in the adaptation and implementation of comprehensive care plans in the patient's home and community. Palliative service teams often have more time available than other treatment teams to plan for medical and psychosocial problem-solving with patients, families, and homecare providers and to help with symptom management at home. With wide-ranging knowledge of community resources and relationships with multiple social systems, the palliative care team can link various care providers to work together for the patient and his or her goals (Bello Belasco et al., 2000).

Palliative care teams are prepared, through education, experience and availability, to support parents and siblings of increasingly ill AYA patients, and are

skilled at working with positive and negative coping mechanisms of families and patients. Because palliative care recognizes the positive relationship between family well-being and patient health, care for the patient in tandem with care for the family is a critical aspect of whole-person care (O'Shea, 2013; Thornes, 2001). Palliative care service teams also have specific training in communication, especially about grief and grieving the loss of function, missed activities and milestones, and changes in social networks as well as special training on end-of-life communication (J. K. Clark & Fasciano, 2013; Rosenberg & Wolfe, 2013). Finally, compared to most medical services, the PCS model generally allows more time to spend with a patient listening, reflecting, educating, and answering questions. Researcher and author Eileen O'Shea (2013) states, "listening is probably the most important gift palliative care specialists can provide to patients and their families" (p. 40).

What needs further attention. Despite the growth and advancement in palliative medicine since its start in the 1960's, it is still not reaching all the patients who need its service. The Global Atlas of Palliative Care at the End of Life (WHO, 2014a) reports that if all patients in need of palliative care received service, palliative care would be in demand by over 20 million people every year. In the AYA population, the need for PCS is not strictly tied to an imminent expectation of death, as many patients have recurring needs over many years (Thornes, 2001). Cancer diagnoses for this patient group in the United States will likely trend upwards because many more youth and young adults are able to access medical services due to implementation of the Patient Protection and Affordable Care Act in 2013 (Patient Protection and Affordable Care Act,

2010). Consequently, a growing cohort of AYAs will be in need of PCS and most likely for prolonged periods of treatment.

In the larger medical arena, palliative care is still in its infancy but is slowly being recognized for its objectives, efforts, positive benefits, and health outcomes. Palliative medicine is particularly useful for chronic, complex, or life-limiting diseases but has yet to be recognized by some medical disciplines as an essential care service, for numerous reasons, related to individual, divisional, systemic, and political conditions which will be discussed later. Over the past decades palliative care resources directed at the establishment and provision of PCS have been expended in a greater effort to overcome the established barriers such as lack of staffing and training, insufficient funding and support, and misinformation that influences biases, than to expand palliative care in new directions. Thus efforts to develop AYA specific care have not gained momentum, recognition has been slow to progress and little research has been conducted addressing details and deficiencies of PCS for AYA patients. Currently, only one program, the Teenagers and Young Adults with Cancer Professional Group, has recognized and documented the role and value of PCS for AYAs and has developed a comprehensive palliative care guideline for use by professionals and patients served by the Teenage Cancer Trust of Great Brittan (Smith et al., 2012, Appendix C).

How Has Palliative Care Fared in the Recent Progresses?

The first-ever National Comprehensive Cancer Network (NCCN) clinical practice guideline on adolescent and young adult oncology, released in 2012, made recommendations spanning the cancer care continuum and included items such as

fertility and behavioral considerations. The guidelines state that critical components to improving the delivery of state-of-the-art care to this patient group include a need for increased enrollment in clinical trials, a multidisciplinary approach to treatment, and that specific attention be paid to the special physical and psychosocial issues of AYAs (Coccia et al., 2012; NCCN, 2012). Notably, the clinical practice guidelines also highlight clinical considerations for palliative care and end-of-life care. These recommendations state that palliative care should be introduced earlier in treatment for enhanced symptom management and psychosocial support to provide the best possible care for the patient. Additionally, the recommendations propose that efforts should be made to normalize palliative care as a common and expected service of oncology (NCCN, 2012).

The NCCN's clinical guideline publication is rooted in the increased research on AYA oncology and task groups championing the distinctiveness of this patient group. One of these working groups, The Adolescent and Young Adult Oncology Progress Review Group, conducted a research portfolio analysis using the National Cancer Institute (NCI) database and the International Cancer Research Portfolio to identify recent projects that address AYA oncology issues. The analysis identified that the number of AYA research projects increased for all government and non-government funding organizations between 2002–2005, nearly tripling in the three year period (Livestrong Young Adult Alliance, 2007). In an effort to develop a national agenda for AYA issues, the group has made broad medical, service, and research recommendations with hopes to advance progress in the field. To assess how well research has been addressing these recommendations, the Progress Review Group divided the research

projects included in the portfolio analysis into their five recommendation topics based on content and fit. The two recommendation topics most closely aligned with palliative medicine and the purpose of this dissertation had the least amount of research between the years 2002–2005. None of the 38 studies in the two recommendation topics seemed clearly to address palliative care for the AYA group leaving AYAs with complex illness understudied and consequently, unrecognized in need of better service. This absence of awareness is in contrast to the mindset taken on by society and healthcare systems that Ferrari et al. (2011) noted “have accepted a disproportionate allocation of resources to children and their families (e.g., research efforts and staff ratios) and greater amounts of time given in support and interaction with patients and families” (p. 4851), despite childhood cancers accounting for less than 1% of the total cancer burden.

The 2014 PubMed database listed 362 research articles supported by the NCI that were relevant to adolescent and young adult cancers. However, based on a review of the study titles, none seemed to clearly address the subject of palliative care. To date, there have been only three publications in the United States on the topic of palliative care and AYA treatment, all of which were published within the past six years (Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Wein et al., 2010). It appears that despite the increased support for, research into, and awareness and knowledge of AYA oncology, palliative care continues to be overlooked as an appropriate and desirable service for this age group.

With the slow but increasing attention, examination, and research being devoted to the 15–39 years of age AYA, there is a growing body of evidence extolling the use and

benefit of PCS for this patient population. Healthcare providers are becoming aware that this patient group presents with less common cancers and more late-stage disease; encounters metabolic and pharmacologic differences in treatment response and experiences increased late-effects and years-of-life affected by treatment. They show the least improvement in care and treatment and have the lowest survival rates when compared to the pediatric and adult oncology population (Bleyer, 2011; Rosenberg & Wolfe, 2013; Pritchard et al., 2011; Wein et al., 2010). AYAs also demonstrate increased rates of anxiety and depression compared to their younger or older counterparts, with up to 90% of survivors showing increased expression of PTSD symptoms. An insufficient amount of resources is directed toward the complex needs of AYA patients (Bleyer, 2011; Rosenberg & Wolfe, 2013; Pritchard et al., 2011; Wein et al., 2010).

The goals and intent of palliative care are aligned with specific medical and psychosocial care needs for this oncology age group as discussed in this paper. Palliative care also effectively supports the objective of optimizing QOL in treatment and post-treatment which is an outcome particularly important for the AYA group but is not always considered in many current treatment approaches (NCP, 2013). In total, very little has been investigated or published to date regarding the blending of AYA oncology treatment and palliative care services in either the United States or worldwide. The few publications that address palliative care and AYA draw primarily from pediatric and adult palliative care and tend to be anecdotal, thus making only general recommendations outlining what should be included in PCS and the reasons why it's important (Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Wein et al., 2010).

United States government and non-governmental organizations have made only general recommendations regarding palliative care for this patient group but have pressed to establish evidenced-based standards of care to optimize treatment outcomes (NCCN, 2012; U.S. Department of Health and Human Services, 2006). AYA guidelines issued by the NCCN in 2012 which primarily provide medical directives regarding screening, assessment, treatment related issues, and survivorship care, contain only suggestions regarding PCS that include early introduction of palliative care and developing best practice standards. The articles by Rosenberg and Wolfe (2013) and Pritchard and colleagues (2011) maintain that a greater understanding of palliative care's implementation, utilization and mechanism of action is required for services to be ultimately effective in this patient population, but, supporting organizations have given little attention or thought to the gaps and challenges of reaching these goals.

To date, there has been no systematic examination of the factors that contribute to the scarcity of quality palliative care for the AYA oncology patient group nor of the reasons hospital systems and care programs may encounter difficulty in effectively delivering palliative care to this group. An examination of the quality and delivery of palliative care to AYAs is necessary to uncover and address weaknesses of service to patients with increased complexities where better outcomes in health and personal care have been unsatisfactory.

Palliative care is not just for the terminally ill or dying but should be considered across the cancer care continuum as recommended by NCCN and expert authors on the subject. "Consensus is growing that AYA patients should have access to palliative care

services from the time of diagnosis until the time of death or cure” (Coccia et al., 2012, p. 1144; Pritchard et al., 2011). For palliative care to become more fully and successfully integrated into the standard AYA oncology care, practitioners and patients must reject the misconception that it is only for the dying. A thorough review of literature is warranted to identify and anticipate what factors contribute to poorer quality of service and what factors can make a transition to integrated care difficult if not addressed.

Purpose of This Study

At present there are few studies that explore the relationship between AYA oncology and palliative care, typically documenting only why this service is essential and what practices should be included. Authors have not specified why such a beneficial service has not been utilized to its fullest potential or what considerations would need to be made in providing this service to AYAs. All aspects of AYA palliative care, including negative factors or barriers to implementation and quality of service, should be assessed. These factors need to be addressed and analyzed in order to design an effective and efficient regime that will have clinical and patient success.

By investigating factors contributing to the shortage of quality palliative care and its delivery, the purpose of this analysis is to understand the hidden complications that might be encountered in providing palliative care services to AYAs. This dissertation will also document clinical considerations of offering palliative care services to this group. This analysis will inform program design and help reduce the likelihood of dissatisfaction with service delivery, that the program will not be successful, or of overall program

breakdown; any of which could perpetuate underuse of this desirable and much needed service.

By informing program design and program delivery, this investigation may also identify provider and service roles that constitute optimal care and treatment for this patient group. Specifically, the role of psychologists in palliative care serving AYAs will be explored and discussed. Several researchers propose that there are multiple ways psychology can positively influence treatment and recovery in the care of AYA patients (Golijani-Moghaddam, 2014; Zebrack, Mathews-Bradshaw, & Siegel, 2010; Zebrack et al., 2013). While historically psychologists have not been a central part of palliative care (Golijani-Moghaddam, 2014; Payne & Haines, 2002), this analysis will derive from the existing literature how psychology contributes to the long-term care of oncology patients with life-altering disease and its role with AYAs. This discussion will also highlight ideas for future research, clinical training, and education for psychologists, and possible concepts regarding the growth of psychology into this specific field.

Study Rationale

This dissertation intends to shape palliative care practices that will lead to increased use of and support for such specialty programs that will ultimately increase patient satisfaction and positive health outcomes during treatment and into the patient's future. Currently, however, neither academic literature nor medical research details why palliative care is not being fully utilized with AYAs who could greatly benefit from its services. AYAs should receive the best care possible and applicable to them, to help remedy past inattention and poorer health outcomes, and to reduce their

years-of-life affected by cancer. It is important to reverse trends in lack of palliative care treatment options to this population for this reason. As yet, this sort of an investigative review has not been conducted covering this patient population, and significant information and insights will likely be gathered.

Study Goal

The central goal of this analysis will be to examine and document factors contributing to shortages in the delivery and quality of palliative care to the AYA population and determine reasons they might exist. The intent is to identify what must be considered to implement palliative care for AYAs and to document potential challenges to the implementation. Outcomes of this analysis are expected to establish a framework of what constitutes quality service which will support the development of AYA palliative care programs. Both service delivery and program quality are equally important to provide the best care to AYAs and ensure that the programs have the greatest chance at sustainability and patient benefit.

Study Significance

“Standards should be based on available evidence, best practices, and expert opinion, with the expectation that they will evolve as the evidence base matures” (U.S. Department of Health and Human Services, 2006, p. 15). The results of this analysis can be useful to government and non-government organizations attempting to develop standards of care for the AYA population, as well as to medical systems or individual hospitals attempting to integrate PCS with AYA treatment protocols. The value of examining factors that contribute to the shortage of quality palliative care and its

delivery is to better structure a comprehensive framework of care for this distinct patient population. This examination can help to develop effective and reliable standards of care, preserve the principles of care practice that guide palliative and uphold appropriate application of palliative medicine in a diverse and frequently disconnected medical system. Ultimately, this analysis will shed light on the reasons palliative care has not been adequately pursued for this patient group and what to expect or consider if choosing to offer this care service to AYAs.

Research Methods

A literature review is a survey of scholarly articles, books, dissertations, government and non-government publications, conference proceedings, and other sources of information which are relevant to a specific issue, research question, area of research, or theory. A literature review draws together multiple sources of information on a specific subject, often bridging between disciplines when specific literature is scarce. By surveying a broad scope of information, a literature review provides an overview and evaluation of significant literature on a specific subject. A literature review includes a critical analysis of information, opinions, and conclusions contained in the cited works that are then drawn together under the context of the research question. It can also provide new insights and interpretations, identify gaps in the literature, and provide direction for future research (Aveyard, 2010; Hart, 1998).

A comprehensive literature review was conducted investigating what is potentially missing in the quality and delivery of palliative care to adolescent and young adults (AYA) and what factors contribute to the absence. This was accomplished by doing a search of applicable databases, journals, and professional organization publications using the guidance of the research question: "What factors contribute to the shortage of quality palliative care and its delivery for adolescent and young adult oncology patients?" A literature review is the best approach to address the research question because it assembles information in support of investigation and evaluation on subjects where correlated research is limited or not yet explored (Aveyard, 2010; Rhoades, 2011). Also, according to Rhoades, literature reviews are important to the

academic and clinical community in ways that are aligned with the goals for conducting scientific research. Rhoades (2011) states that findings can: guide the decision making process of practitioners, administrators, and parents; facilitate the development of practice guidelines; strengthen advocacy capacity; guide practitioners into new lines of inquiry; facilitate the direction of research by determining next steps; review and expand the topical lexicon; and highlight future research needs (pp. 61–62).

The challenge of using a literature review to answer this research question is that the findings are derived from some sources that do not directly investigate the study subject of AYAs and palliative care. Due to the wide scope of investigation needed in order to generate a sufficient base of literature related to this subject, some conclusions or evaluative statements may be weaker than conclusions drawn from empirically tested or primary sources. However, the challenge posed in this research methodology is mitigated by the transparency and explicitness of the search strategy and thus, critical replication to examine any limitations is possible. Making clear statements regarding where in the review or how the review is challenged, weakened, or limited will inform critics of the work how much to interpret and conclude from the analysis (Kahn, Kunz, Kleijnen, & Antes, 2003).

Strategy

The literature review was conducted by searching scholarly articles, books, government and non-government publications, and dissertations, and made use of grey literature. Grey literature is considered work that is not normally subject to peer review, editorial requirements, or publication demands, examples include institutional or

technical reports, working papers, conference proceedings, and other documents (Hemingway & Brereton, 2009; Neely et al., 2010; Rhoades, 2011). To capture the whole picture of the subject under investigation, the search and screening strategy was cross-disciplinary and involved multiple search procedures that included, hand searching key journals and books, accessing electronic databases, investigating reference lists, investigating publications from key organizations, scanning the World Wide Web, and using other tactics that were needed (Rhoades, 2011; University of Strathclyde, n.d.).

The databases used in the investigation were PsychInfo (psychology), PubMed (biomedical), EBSCOhost (psychology and behavioral sciences), CINAHL (nursing), ProQuest (doctoral dissertations and master's thesis), EJC (electronic journal center), and Google Scholar. A preliminary investigation identified key journals on the topic of adolescent and young adult oncology and palliative medicine. These included: Journal of the National Comprehensive Cancer Network, Journal of Adolescent and Young Adult Oncology, Clinical Oncology in Adolescents and Young Adults, The Journal of Supportive Oncology, Journal of Supportive Care in Cancer, American Journal of Hospice and Palliative Medicine, Cancer, Journal of Clinical Oncology, Journal of Palliative Medicine, Journal of Palliative and Supportive Care, European Journal of Cancer Care, European Journal of Cancer, Journal of Palliative Care, Palliative Medicine, Journal of Pediatric Oncology Nursing, Journal of Cancer Survivorship, Journal of Cancer Treatment Reviews, Archives of Pediatric and Adolescent Medicine. Articles were tracked and sorted using the EndNote program (Endnote Version X7.2.1).

Screening phase one. The databases and named journals, as well as others found to be pertinent, were screened for articles on the study subject by searching the keywords relevant to the research question. The search terms included any combination of the following: palliative care/ advanced care/supportive care, terms which are used synonymously, and adolescent and young adult, AYA, adolescent, young adult, teenagers or oncology, cancer, chronic illness. Each database was searched separately using the search filter options: peer-reviewed, years 1998–2014, English language, and any combination of the search terms that yielded results. Searches were conducted using advanced search options screening only titles, titles and abstracts, keywords, or article subjects for the search terms. Many of the journals identified a priori were accessed using the Electronic Journal Center and searched using the key terms or hand screened following the outlined protocol.

To be considered in the review, scholarly articles and publications that met the keyword search terms must have first contained some information relevant to answering the research question. To determine this, publication titles were screened to identify if two or more of the variables of interest contained in the research question were clearly addressed. For the purposes of this research, the variables under examination are defined as follows:

- Adolescent and young adult patients: patients who are first diagnosed with cancer between the age of 15 and 35 years old (Bleyer, 2012).
- Palliative care and palliative medicine: an approach to medical and health care for patients with advanced or life-limiting illness that improves quality of

life through early detection, relief, and prevention of suffering in the areas of physical, psychosocial, and spiritual living (WHO, 2014b).

- Oncology: the division of medicine concerned with the study and treatment of tumors and hematological malignancies (National Cancer Institute, n.d.).

Other terms close in subject to the variables of interest were permitted, these included: teenagers and chronic illness. When a comprehensive search of the databases was completed, the articles that met phase one criteria for inclusion proceeded to phase two of the screening process.

Screening phase two. In the second stage of screening, research studies that appeared to address two or more of the variables of interest, evidenced by their title content, were reviewed for alignment with the research question by examining abstracts. This was determined by whether a research study met the inclusion criteria without meeting the exclusion criteria. If it did, articles were considered in the literature review. Additionally, the references section of articles that met the established inclusion criteria were reviewed for additional material fitting the purpose of the proposed investigation. All articles identified in this manner were subject to the same two phase screening procedure described.

Inclusion criteria. Articles that contained one or more of the following elements were incorporated in the literature review study: have a primary focus on oncology, signal a greater focus on palliative care, include some components of palliative care service or delivery in the research question or background, and expressly focus on patients aged 15–39 years old or when more than fifty percent of participants fall within

the AYA age range. Palliative care, advanced care, or supportive care must have been an element of the research study and specified as a focus in the abstract. Examination of the selected articles commenced when a saturation of the literature was reached.

Randolph (2009) describes that saturation is a point reached when no additional articles come to light that contribute additional relevant information to the literature base.

Exclusion criteria. Research studies selected in phase one of the screening process were rejected in phase two based on the exclusion criteria or if they were determined not to contribute significantly to the body of literature collected for this review. After review of the abstract, articles were rejected if any one of the following conditions were present in the research study: it did not discuss or investigate services, features, or delivery of palliative care, it had a greater focus on hospice care, or when half of the participants of a research study did not fall within the 15–39 age range.

Screening phase three. In addition to empirical research, publications on the topic have also been released by recognized organizations central to the subject under study. These organizations include: The Teenage Cancer Trust; Critical Mass: The Adolescent and Young Adult Cancer Alliance; and the National Hospice and Palliative Care Organization. Publications from these organizations and other work, including books, dissertations, and other grey literature, were evaluated for fit and inclusion in the literature review. Inclusion of these writings were not held to the strict inclusion or exclusion criteria outlined above but, were assessed based on specific subject relevance and contribution. These works were data mined for information to supplement existing

research or research conclusions, or to introduce information not addressed by the research base.

Sorting screened documents. The research studies, publications, and relevant literature were categorized according to the main variable under investigation addressed by the authors. Documents were sorted and classified as primarily addressing the quality of palliative care, the delivery of palliative care or both. Documents were then further classified as primary, secondary, or tertiary to the delivery and/or quality of palliative care based on the professional judgment of the author of this dissertation. Key publications, writings that investigate and discuss both adolescent and young adult oncology and palliative care in the same report were a fourth classification.

Analysis

Publications were evaluated by extracting pertinent information regarding (a) the delivery of palliative care, (b) components of palliative care comprising its quality, (c) new insights or conclusions on the topic, and (d) what has been identified as needed or absent in services for this patient group. Emerging topics that recurred across publications included in this review were recorded, and then aggregated into broader combined themes for analysis. The results from the literature review discuss what is missing, why deficiencies exist, what changes are needed to promote improvement, and the reasons improvement is worthwhile.

In an effort to get the most out of the limited existing research, the literature review included a mix of empirically based research and less rigorously judged literature of several varieties. The data and interpretations drawn from these sources are

presented in a written narrative format, specifically in the form of a meta-ethnography. According to Harden (2010), “in a meta-ethnography, the synthesis goal is to achieve a greater understanding or conceptual development than can be found in any individual study” (p. 4). This is achieved by drawing out data and material from individual studies and writings and formulating a new interpretation or insight that interlaces information and concepts across the evidence base to form a new line of inquiry (Harden, 2010; Neely et al., 2010).

The cross-disciplinary investigation of data and published material and its interpretation and analysis provided the scaffolding for a discussion of the role of psychologists in palliative care with this population. Areas in AYA oncology and palliative care where psychologists can be of assistance, ways in which they can help, and the potential benefit of employing psychologists in this specific setting (to include what psychologists can bring to the overall care of patients receiving this service) is discussed. This dissertation highlights the specific value of employing psychologists in this treatment approach and how doing so will enhance palliative care service (PCS) to AYAs and their families.

Results

The research databases and journals named in the previous section were searched for articles related to the subject under investigation. Additional journals referred to in the search included: The Milbank Quarterly, The Lancet, The Lancet Oncology, The New England Journal of Medicine, Adolescent Health, Medicine and Therapeutics, The Journal of Adolescent Health and the Critical Mass publication library was searched. In Phase 1 of the research, a total of 28, 832 article titles that matched the keywords and search criteria were identified. Of these, 474 articles contained two or more of the variables of interest in the title and seemed related to the subject under study. Articles that appeared to meet Phase 1 criteria were reviewed a second time for relevance to the research question and 108 articles were eliminated, leaving 366 to be considered in Phase 2. Articles were excluded because the primary topics such as fertility, clinical trial enrollment, sexuality and dating, support groups and peer camps were unrelated to the goals of this study. In summary, only 0.01% of articles searched in the first phase of research were deemed to be possibly related to the topic of adolescent and young adult oncology and palliative care.

In Phase 2, abstracts of the 366 articles were studied to determine alignment with the research question, and many articles were about young adult survivors of childhood and teenage cancer. Numerous articles documented clinical trial enrollment as well as transitions in care setting for adolescent young adult oncology patients. Multiple articles on adolescents did not provide an explicit statement of the age range represented so it could not be determined if they fit the age criteria used for this

literature review. Many of the articles specific to cancer and palliative care that used a research group were made up of patients with a mean age of 60 years old and so they exceeded the determined adolescent young adult (AYA) age range. Excluding the articles described above left only 56 of the articles that entered in Phase 2. Reevaluation of these 56 articles using the detailed World Health Organization (WHO) definition of palliative care resulted in the elimination of a further 20 articles that focused on important issues of this age group, but not specifically palliative care service (PCS) or delivery or elements related to palliative care. In total, 36 articles were selected in Phase 2 for detailed review and analysis in an effort to address the research question. Review of the reference lists from these 36 articles did not uncover any additional articles that needed to be screened. In Phase 3, seven “grey literature” publications were added and used in the literature review (see Appendix D).

Information related to the research question was highlighted from each article. Relevant, recurrent data and descriptions were extracted, then merged and coded using the QDA Miner Lite analysis software (QDA Miner 4 Lite). Codes without sufficient content or significance to answering the research question were deferred to the section on future directions for the subject. Topics that were suspended include palliative care philosophy for the treatment of AYA, issues in transitional care, patient and family tracking and monitoring, and others (see future directions section). Remaining codes were collapsed where appropriate and then organized into themes. The data,

Figure 1. PRISMA Flow Diagram, literature screening and exclusion process

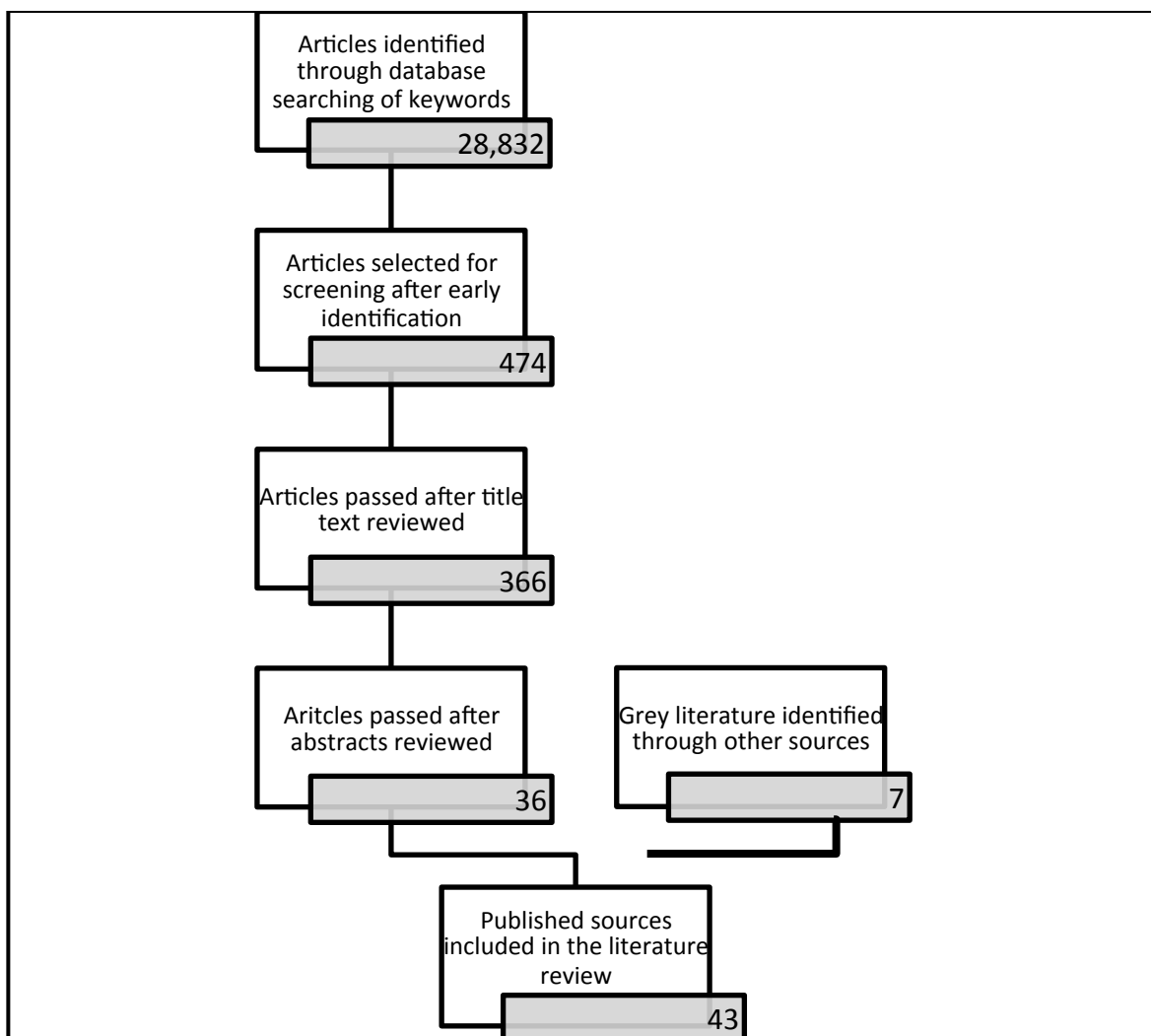


Figure 1. PRISMA Flow Diagram detailing the screening and exclusion process for the literature review. Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement," by D. Moher, A. Liberati, J. Tetzlaff, and D.G. Atlman, 2009, *BMJ*, 339:b2535. doi: <http://dx.doi.org/10.1136/bmj.b2535>. Reproduced with permission, BMJ Publishing Group Limited License no. 3853161296128.

descriptions, and information isolated was analyzed and deconstructed to answer the research question. The contributions of psychology were considered throughout the gathering and analysis of information on the topic.

The content and findings going forward are broad and varying. Some identified shortages and remediation recommendations may not apply to established palliative care or AYA oncology programs because they already have these elements and recommendations in place or accessible. In an effort to assist oncology treatment programs to better serve the needs of AYAO patients, by implementation or integration of palliative care, issues and recommendations raised in this paper describe what is typically missing in existing treatment programs, what services can be beneficial, and the potential challenges in integrating a palliative care approach. In providing comprehensive documentation of areas or features of palliative care that are currently insufficient for adolescent and young adult oncology (AYAO) patients, the intention of this dissertation is to help guide the development of a palliative care pathway for this patient group at the programmatic and national standards level. This is essential for providing AYAO patients state-of-the-art care. The goal of the following review is to uncover the complexities of providing palliative care to AYAO and call attention to how palliative care should serve and engage differently with this unique group of patients.

Results From the Literature Review

Overall, several significant themes in quality and delivery of palliative care to AYAO emerged as absent, lacking, or needing greater development to provide more comprehensive and appropriate palliative services to this population. Additionally arising from the literature review are specific clinical considerations for working with this group. These clinical considerations will provide for focused care from the palliative medicine perspective but have thus far gone unexamined. The shortages, as well as the

current state of addressing or not addressing each shortage and, where applicable, proposed efforts for remediation, will be discussed below. Reasons why these shortages exist were also extracted from the literature and multiple barriers which were identified are discussed in detail.

Quality of palliative care. Thematic areas emerging from existing literature regarding shortages in current quality of palliative care provided to AYAO patients include: research, assessment, palliative care team, education and training, standards and pathways, and program structure. Incorporation of AYA goals and psychosocial development in tailored palliative care is one specific clinical consideration that emerged from within the larger theme of palliative care program structure.

Research into palliative care. A major shortfall identified in the quality of palliative care that teens and young adults receive is the dearth of research on nearly all aspects of the subject under discussion. This lack of research thus also exists for the delivery of palliative care to this population. Multiple authors cite that clinical research is needed to improve and uphold care, guide practice and standardize the proficiencies required, and assess the value and impact of palliative care on patients, families, and institutions (Baker, n.d.; Callaghan, 2007; Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Schrijvers & Meijnders, 2007). Each of these elements, in turn, contributes to the quality of a program and would help structure benchmarks for program control and evaluation. Without focused research, contributions of palliative medicine, such as education and programmatic services that are vital to patient care and overall quality of life (QOL), will remain unidentified. Research can help develop an evidence base

assisting in the establishment of standards of care and program guidelines. Without it, extrapolations from pediatric and adult medicine will continue to influence service to AYA in an incomplete and inaccurate manner. Correspondingly, research into program outcomes could provide supportive evidence of the viability and sustainability of palliative services motivating a national agenda to offer palliative care and justify financing such programs. Without research documenting a positive influence on patient care outcomes and organizational investment, funding and support remains static and palliative care for this population will not evolve.

Assessment of palliative care for AYA. The lack of assessments specifically designed for the AYA with cancer, and limited range of those that do exist, contributes to a scarcity of quality palliative care provided to this patient group. To date, there is no research specifically collecting information from AYAO patients' reports that documents outcomes of PCS, nor are specialized assessments such as patient satisfaction or needs surveys, service satisfaction questionnaires, and mood or symptom screenings distributed in a routine and regular manner to elicit this information. A paucity of assessments designed specifically for palliative care medical practice with AYAO patients is clearly identified in this review. In addition, virtually no AYA specific clinical tools exist to examine the domains of care interlaced in palliative medicine for this group. Examples of domains of care include developmental goals, educational and occupational goals, and the more veiled subjects of psychosocial health such as sexuality and family planning, transitions of care, and readiness to discuss uncomfortable subjects. Family assessments are also routinely left out of patient care practice (Baker, n.d.; Smith et al.,

2012; Wein et al., 2010). Researchers and authors on the topic suggest an urgent need for developing and disseminating precise, tailored assessment and clinical tools to best serve this patient population (Pritchard et al., 2011; Weaver et al., 2015; Institute of Medicine, 2014). Assessments specific to AYAO patients and palliative care are the building blocks for an evidence base that can lead to program formation and development, inform the quality of programs (service use, value, and impact), and help provide individual patient guidance for intervention and monitoring. Without the development of tools for evaluation and measurement of programs and services, palliative care and treatment organization for AYAO is unpredictable and fractional.

Composition of the palliative care team. The absence of a robust multidisciplinary palliative care team that is consistently available to the patient constitutes a key shortage of quality palliative care to the AYAO group. Writers on the subject describe the multidisciplinary team as vital to comprehensive care of this age group and propose that palliative care teams should be minimally comprised of a nurse, social worker, psychologist, palliative care physician, oncologist, and a “key-worker” who advocates and is the point-person for the patient (IOM, 2014; Quinn et al., 2015; Smith et al., 2012; Thornes, 2001; Tsangaris, 2014; Wein et al., 2010; Wiener, Shaw Weaver, Bell, & Sansom-Daly, 2015). To meet the developmental needs and help this group reach expected milestones, an expanded palliative care team is called for (Pritchard et al., 2011). By taking a broader view of the unique needs of AYAO with complex or long-term conditions, one could identify auxiliary services and team members that could benefit AYAO; however as yet, rigorous thought has not been

applied to identifying potential valuable team members. Relationships with providers need to be recognized and created when they don't already exist; to include, but not be limited to, occupational, physical, and recreational therapists, cognitive rehabilitation specialists, vocational counselors, school nurses and a school liaison, fertility treatment specialists, and naturopathic medicine services. Few of these services and personnel are considered to be central to serving AYAO, but this group of patients stands out specifically because of their special psychosocial needs and concerns. Providing practical services through a palliative care approach with a customized team is critical to helping patients have the best quality of life (QOL) and psychosocial outcomes both while receiving care and after treatment has concluded.

For many patients, QOL is measured by less time attending appointments and traveling for care, and spending more time at home. This need extends to the caregivers helping the patient, who endure the financial strain of time taken from work, the cost of travel, and accompanying stressors. A current shortage in the quality of palliative care to this patient group is a lack of online technology and distance service programs used by its professionals. Palliative care for AYAO must have the capacity to deliver service and support virtually, because not doing so fails to leverage a medium of communication AYAs favor and are accustomed to, and treatment will not meet the patient and family's desires to be home (Pritchard et al., 2011). Not only does palliative care need to devise remote healthcare applications and practices but, must also employ recreational support staff who will utilize this platform to improve QOL for patients through peer connections and positive psychosocial encounters such as a live chat room. Palliative

care services will need to employ information/internet technology personnel to help build, manage, and facilitate such services and train palliative care staff to regularly use these virtual communication programs.

Education and training for palliative practitioners. A general lack of education and training on AYAO to palliative healthcare providers results in a shortage of quality palliative care provided to the AYA patient group. Specific, specialized, professional training in the discipline is missing and acutely needed. This training must incorporate teachings from a developmental perspective of care or the quality of care will continue to underperform (R. George & Hutton, 2003; Pritchard et al., 2011; Rosenberg & Wolfe, 2013). Wiener and colleagues (2015) point out that “training in AYA palliative care falls in a void between the adult and pediatric domains” (p. 2) and thus a lack of knowledge, formalized training, and quality support services exists (Weaver et al., 2015). The quality of palliative care hinges on staff education and training, and suffers when deficient, with a result that some referral sources do not utilize palliative care for AYAO due to doubts in the strength of the service (Weaver et al., 2015). The education and training deficit includes failure to work with the family and friends which is known to be key to a patient’s quality of life. Education within the wider medical community is also lacking. Palliative care’s purpose and healthcare perspective to serving this group, and more specifically changing the way practitioners talk about palliative care for AYAO, needs discussion. Palliative care staff must approach, explain, engage, act, and support AYAO care from a developmental viewpoint, but education and training through this lens

remains in critical need of community wide advancement (Bruera & Hui, 2012; Pritchard et al., 2011).

Standards and pathways for palliative care. Defined, accepted, and supported standards and pathways for AYAO palliative care have yet to be established, minimizing the quality of palliative treatment provided to this group. Leading authors on the subject state that standards for AYAO palliative service are urgently needed because the scope and elements of such care have yet to be defined (Barling, Stevens, & Davis, 2012; Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Weaver et al., 2015). In further evidence, Tsangaris and colleagues (2014) claim that “to date, the global development of AYA cancer programs has been ad hoc rather than systematic” (p. 948) just as palliative care treatment practices for this age group have been left up to only a few published expert opinions (Fernandez et al., 2011). Palliative care structure and services tend to be highly variable among cancer centers in the United States, and according to a self-study of seven Teenage Cancer Trust units in the United Kingdom, palliative care policies and operation varied widely amongst treatment programs at these AYAO specific sites (Bruera & Hui, 2012; Grinyer & Barbrachild, 2011).

Building a clear conceptual framework of AYAO palliative care for the provider and patient is essential, and developing guidelines for referral, prioritization of care, and benchmarks for intervention are all necessary components that are now lacking, which potentially results in a deficiency of care for patients in need (Bruera & Hui, 2012; Nayak & Salins, 2011; Pritchard et al., 2011). A tenet of oncology care for AYA is that appropriate comprehensive care must be available; this requires that guidelines must be

developed detailing the palliative care treatment intervention and design. The sensitive and complex nature of the AYAO patient group requires a multilayered and universal care approach. Failure to develop a robust, informed, and accepted palliative care program may inadvertently cause a disservice to the patient or family. Additionally, without standards and pathways there will be no basis for research and program evaluation. As a result, the medical community is unlikely to have sufficient confidence in the service value or to endorse it resulting in less access to quality palliative care for the AYAO patient group.

Structure of palliative care programs. Quality palliative care to the AYAO patient group is deficient because the program structure of palliative care service lacks definition. Program structure is more than just its service divisions; specifically, both research and patients report that the accessibility and availability of PCS programs is an issue that has been regularly overlooked (Grinyer & Barbrachild, 2011; Stinson et al., 2012; Tsangaris et al., 2014; Weaver et al., 2015). Availability encompasses having enough trained staff and appropriate professional support, as well as providing care accommodations to meet AYA social or developmental needs and activities, which are all insufficient in current palliative care programming. Informed opinions suggest specifically assigned AYA clinic days, staff's virtual availability and presence, and the ability to provide care at home are all tied to better program offerings for this patient group (Stinson et al., 2012; Tsangaris et al., 2014; Weaver et al., 2015). Accessibility includes linked services and multidisciplinary care, as well as the capability to deliver care across multiple settings to include the home, outpatient care, and the hospital, a

design as yet neither developed nor coordinated for providing palliative care to this group. R. George and Craig (2009) remark, “the elements of palliative care practice . . . should concentrate ultimately upon creating those opportunities for choices to be made” (para. 21). Palliative care program structure is one opportunity to provide ample choice and diverse care accommodations to AYAO that can directly influence the quality of care and the patient’s quality of life. Without an expertly designed structure addressing issues of availability and accessibility, the palliative care program may fail, and patient care may suffer.

Clinical consideration: AYA development and goals. Authors who are expert in the subject assert that AYAO patients need to be approached and treated from a developmental standpoint of care. Oncology professionals refer to conceptual ideas of individuation, independence, personal evolution, and discovery in discussions of the AYAO developmental frame of care, but research and publications often omit the tangible help and services needed by this group. There are few guidelines or programs in place for young adults intended to maintain and cultivate expected developmental progression, and when necessary reclaim the growth lost to illness and treatment. Furthermore there are even fewer recommendations about the practical or basic services needed throughout care and treatment to support young adult development. In a case study of young adults faced with long-term disease, youth described that the maintenance style of care hindered their ability to meet personal life goals by limiting their independence, education, recreational, and vocational goals (Cook, Siden, Jack, Thabane, & Browne, 2013). Abrams, Hazen, and Penson (2007) write that “adolescents

identified health and normalcy as the most hoped-for-objects” (p. 627) for those who are ill. Offering or creating links to services to help patients be mentally and physically healthy during and after treatment will assist AYAO patients to reach their goals and optimal functioning.

Palliative care services provide the opportunity to implement this approach and to take the position of being proactive, not reactive, in offering assistive services not otherwise accounted for in either traditional medical oncology or supportive services programs. Examples of developmentally oriented services include: genetic and family planning counseling, sex and relationship counseling, financial advising, occupational or vocational rehabilitation, equipment and disability services, cognitive rehabilitation, substance abuse services, education advising and advocacy, and college or career counseling. A one-size-fits-all program of palliative support is not appropriate for this patient cohort, and developmentally-specific care plans should be strongly considered (Fernandez et al., 2011; Goodall, King, Ewing, Smith, & Kenny, 2012). The Individualized Education Program designed for the special education student is a good example of an individual developmentally tailored care plan (U.S. Department of Education, 2000). The palliative care resources required to address healthy development objectives of AYA’s during and after treatment are substantial, and some are necessary only in serving this population. If palliative medicine is to meet the developmental milestones and desires of this age group, links to ancillary services must be current and reliable if they are not built into the fabric of the program. Without developmentally oriented services palliative medicine merely replicates care that treats only the physical body.

Delivery of palliative care. The literature review further illuminated shortages in current delivery of palliative care to AYAO patients. Content areas emerging from this existing literature included: technology, pain and symptom management, community care and care at home, multidisciplinary and coordinated care, and intervention. A clinical consideration emerging from the larger theme of pain and symptom management was control of treatment effects to enhance patient future functioning. Included within the theme of community care and care at home is the clinical consideration of treatment effects on social and peer engagement. Another clinical consideration that came into view was family and relationship disruptions, as well as AYAO psychological health and information needs, both of which emerged from the larger theme of intervention.

Scarcity of technology. The failure to use and integrate technology as a means to facilitate care for this patient group is a shortage in the delivery of palliative care for AYAO. Rosenberg and Wolf (2013) express that providers need to think creatively about innovative ways to provide palliative care to this group, and the use of computer technology is a clear response although not stressed in practice or programs. Writers who have identified the utility of online, social, and information technology for this group underscore that this communication tool needs to be used to the benefit of the healthcare team and patient. In particular, as AYAs are generally a mobile group, technology will help medical services be more portable and offer virtual availability supporting their lifestyle. Without it, AYAO are bound to a fixed system possibly hindering independence, development, and exploration (Fernandez et al., 2011;

Pritchard et al., 2011). While AYAs have expressed a preference for electronic information and collaborating with providers using information technology, many medical services including palliative care do not currently accommodate the delivery of care in this manner (Wiener et al., 2015). Not embracing the use of online, social, and information technology in PCS to this group perpetuates an outdated outlook in an otherwise technologically advancing medical and young adult culture.

Techniques for pain and symptom management. The delivery of palliative care to AYAO is deficient because pain and symptom management, a primary service of palliative care, has not undergone rigorous clinical examination for this patient group and for the most part is inadequately achieved. In a study by Zebrack, Mills, and Weitzman (2007), AYAOs receiving treatment reported that minimizing side effects and symptoms of treatment was the 3rd most important need for this group. Improvements in managing pain, symptom, and stress, and systematic pharmacological management however, continue to be cited as care components of AYAO in vital need of attention by both the medical community and scholarly researchers (Barling et al., 2012; Bruera & Hui, 2012; Wein et al., 2010). Quick and appropriate triage to manage pain and symptoms and the infrastructure to support this care approach is necessary; without it, superior palliative care for this group remains out of reach. Palliative medicine also needs to give specific attention to the manifestation and management of chronic pain in AYAO patients. This has been largely undocumented, but it is presumed that this issue will be more challenging because the drugs used in the course of therapy are increasingly more toxic often causing added pain (Humphrey & Dell, 2015). The delivery

of palliative care to AYAO will be insufficient without expertise in chronic pain management tailored to this population. Pain and symptom management is a core feature of palliative medicine but, because palliative treatment to this group is relatively immature, training and expertise in the basic elements of pain and symptom control, as well as empirically-based examination and evaluation of pain interventions for AYAO remain underdeveloped.

Clinical consideration: Symptom management for future functioning. Keeping in mind that this patient group is at greater risk for latent treatment effects and poorer survivorship status, treatment for AYAO must focus beyond immediate and acute patient care (Bleyer, 2012). As it stands, most patient care is present-focused with much less effort being focused on the future outcomes. As such, patients can be negatively affected by this narrowly focused care approach. Healthcare management of oncology treatment side-effects should concentrate not just on the patient's current experiences but also consider the potential future or long-term effects of treatment. An exceptional paper on palliative care for young people highlights "there is sufficient evidence on the natural history of diseases and knowledge of disorders to allow forward planning" (Thornes, 2001, p. 40). Despite this knowledge, AYAs report that losing the ability to perform activities of daily living independently is a top concern and source of distress (Woodside & Keats, 2013). Reinforcing that these worries are common, an AYAO disease management evaluation revealed that patients and their parents noted the need for practical skills to manage cancer, but this need was not similarly identified by healthcare workers caring for this group (Stinson et al., 2012). Accordingly, to best serve this group

and lessen patient anxieties palliative care must take action and encourage interventions at the time of treatment that will diminish the impact of cancer and treatment side-effects in the future (J. K. Clark & Fasciano, 2013). Adolescent and young adult cancer related fatigue, chronic fatigue, and chronic pain can all have an adverse impact on participation in social settings and personal wellbeing. Amelioration of these symptoms needs to be considered as an expert area for AYAO palliative care and requires additional attention by the medical and research communities. Additionally, strengthening ties with community based disability services, home equipment suppliers, and medication management and supply services all need better development if palliative care is to help AYAO have improved quality of life (Thornes, 2001). Patients may continue to be harmed by cancer long after active treatment has ended, unless palliative care takes steps to teach coping skills, offer education, and suggest treatment options to mitigate any future effects of cancer treatment.

Palliative services for care at home and in the community. A shortage in the delivery of palliative care to AYAO is the deficiency of in-home and community care service. Connor (2010) writes, “the objective of home health care is to help the patient to return to a level of functioning that allows for self-care” (p. 284). While skills for independent care can be modeled, managed, or practiced in the hospital setting, they must be reinforced in the home and community where AYAs carry out their everyday living and where a patient’s social interactions and development actually takes place. Several well regarded authors claim that to better serve AYAO, more effort from institutions and programs to providing services at home and in community settings is

needed and procedures for palliative care at home need to be optimized (Callaghan, 2007; Fernandez et al., 2011; Pritchard et al., 2011). Suggestions for improvement include mobile palliative care teams, support from community specialists, and expanded community partnerships. (Barling et al., 2012; Bruera & Hui, 2012; Grinyer & Barbrachild, 2011; Pritchard et al., 2011).

There is also a scarcity of outpatient centers that offer palliative and supportive care services appropriate for AYAO. In a review of the Supportive and Palliative Care Program at University of Texas M.D. Anderson Cancer Center, Bruera and Hui (2012) identified that, the program's outpatient supportive care clinic received a fifth of its visits from same-day consults or drop-in visits in 2011. The M.D. Anderson Cancer Center is an outstanding example that demonstrates the use and function of community-based services but elsewhere, palliative or supportive care in outpatient clinics generally remains deficient. Most notably absent in palliative care for AYAO patients and their family is respite services; as Thornes (2001) confirms, "appropriate respite provision is a major gap in services" (p. 33) (Barling et al., 2012). For AYAO patients with long-term, complex, and terminal illnesses, respite services available through a palliative care program for the youth and his or her family are essential, as without relief from the round-the-clock-care, relationships, psychosocial health, and QOL unnecessarily suffer.

Clinical consideration: Social & peer engagement. Adolescent and young adult oncology patients who are eligible or already receive PCS are those who tend to have complex, long-term, or co-occurring disease. This group of adolescent and young adult

patients experiences social difficulty and isolation in a manner different from other youths with cancer (Fernandez et al., 2011). The social issues and participation challenges for this group may have a negative impact on mental health and adversely shape their future social life and peer interaction. Loss of social and peer support is often vocalized by AYAO as a consequence of extended treatment. Experts stress that primary aims of palliative care service for this group should be to relieve isolation and social suffering and to optimize opportunity for peer interaction and independence (R. George & Craig, 2009; Pritchard et al., 2011). Guidance needs to be given to patients on how to communicate their experience to peers and to connect as a non-patient, and when possible treatment should be organized around special social events. Additionally, care should be streamlined and provided in the community to reduce frequent medical appointments which can interrupt social opportunities and participation (Callaghan, 2007; R. George & Craig, 2009; Stinson et al., 2012). Adolescent and young adults identify that peer companionship and peer support, as well as participation in typical social experiences, is needed for health and recovery; without these opportunities to individualize and explore the social world, QOL may suffer in treatment and survivorship (Linebarger, Ajayi, & Jones, 2014; Tsangaris et al., 2014). Also, to help peers maintain connection and companionship with patients, AYA specific services will also need to consider intervention and support for friends of patients to include disease and treatment education, emotional support, and opportunities to ask questions (Palmer & Thomas, 2008).

Inadequacy of multidisciplinary and coordinated care. Varied and comprehensive care services as well as coordinated care is lacking in the delivery of palliative care to AYAO. A study of AYAO supportive care needs integrating results from a systematic literature review and qualitative input from AYA cancer survivors, identified that a multidisciplinary team is vital to providing the best patient care, but such a blended team approach is a need that has been largely unfulfilled as yet (Tsangaris et al., 2014). Experts have recognized that comprehensive multidisciplinary care services are necessary to meet the practical and developmental needs of this patient group yet, palliative medicine has not fully anticipated the extent of specialist support needed by AYAO patients and from which they can benefit (Humphrey & Dell, 2015; Michaud et al., 2007; Tsangaris et al., 2014). The desired composition of a palliative care team has been documented among professional researchers, but discussion has been based on adult and pediatric palliative care models which are relatively narrow in scope and don't address AYAO needs (IOM, 2014; Tsangaris et al., 2014; Wein et al., 2010). Consequently, many AYAs report that it is very difficult to get suitable help in supporting their independent living and disease management objectives (Cook et al., 2013). Without expanded multidisciplinary palliative care to address diverse difficulties specific to AYAO, already demanding patient challenges can be magnified, and patients may not experience normal patterns of development.

Coordination of care for this group can be challenging as AYAO patients, more often than not, experience a cross-over in care between pediatric and adult care and between hospital and outpatient settings. Author J. Edwards conveys that effective

liaisonship should be the principal goal of palliative care, and the interdisciplinary functioning of palliative medicine provides an opportunity to link communication across healthcare departments and act as a point of contact for auxiliary services (Edwards, 2001; J. K. Clark & Fasciano, 2013). However, due to the scarcity of PCS for this group, which then is often used only in a consultive capacity, palliative care has yet to take on this needed and relevant role (Cook et al., 2013; Tsangaris et al., 2014). Centralized organized care service for AYAO with complex or long-term disease is unattainable, and services will continue to be directed in a disconnected manner potentially causing detriment to the AYAO patient under care, unless coordinated and unified services are delivered by palliative care and its potential affiliates.

Intervention with palliative care. Early intervention of palliative medicine and discussions around advanced care and end of life planning are two aspects in the delivery of palliative care to AYAO patients identified as unsatisfactory at present. Palliative care is often used in a fragmentary manner and is offered mostly to manage pain and treatment symptoms. Use in this manner limits the impact this intervention service can have on the care and quality of life of the patient, by reducing the opportunities for healthcare choices of patients and families introduced in palliative care as well as reducing guided decision-making over the short and long term (Barling et al., 2012; Wein et al., 2010). The need for early introduction and maximum intervention of palliative care, no matter the patients place in treatment, has been expressed as one of the greatest needs for AYAO (Barling et al., 2012; Bruera & Hui, 2012; Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Wein et al., 2010). Without a change in service timing

and the addition of diverse treatment options as well as making these options more available, the potential benefits of palliative medicine will remain restricted.

Discussions surrounding advance care planning and end of life preferences tend to be deficient for AYAO patients receiving palliative care (Lyon, Jacobs, Briggs, Cheng, & Wang, 2013; Walter, Rosenberg, & Feudtner, 2013; Wiener et al., 2015). Wiener and colleagues (2015) highlight that “the involvement of AYAs in end of life conversations is often under documented, with conversations occurring too close to death” (p. 7).

Guided care planning and end of life treatment discussions should be initiated when the patient is in a relatively healthier state and can make clear informed choices. Predicting the patient’s prognosis is challenging, and treatment decision conversations can be hard, but decisional conflict, uncertainty, or damaging choices may result if these conversations are not introduced early (Lyon et al., 2013, Walter et al., 2013). Likewise, palliative care intervention for this group should also support hope and consider the patient’s life goals after the disease by collaborating with the patient on interventions while still in treatment to meet these goals. This may require palliative services to engage specialists outside the medical model when needed. The when, what, where and how of palliative care intervention for this distinct group of patients requires expert review and analysis to determine changes needed in the prevailing adult and pediatric palliative care models.

Clinical consideration: Family and relationship disruptions. While caring for the AYAO patient, family wellbeing should not be ignored. In a report on palliative care for young people carried out by an expert working party, it was noted that AYAO patients’

suggest families be forewarned of the possible non-medical effects of having an ill family member. Some of the effects include practical and emotional issues such as disruption of family routine, role change, anger, loss of social support and loss of friends (Thornes, 2001). These impacts as well as costs to the family such as loss of work, loss of income, and increased financial strain are noted by other authors on the subject. Increased social isolation and stress and potential long-term comorbidity of issues for family and caregivers who care for AYAO patients are also concerns (Barling et al., 2012; Bello Belasco et al., 2000; Fernandez et al., 2011; Schrijvers & Meijnders, 2007). It is well known that families experience the non-medical aspects of cancer too, with some research indicating siblings of AYAO experience high psychological distress often equal to that of AYAO survivors (Quinn et al., 2015). The family's welfare can have a direct effect on the health of the AYAO patient, and as a majority of patient care is likely to be provided at home after acute phases of treatment, it is important for palliative care to assess the health of the family (Wein et al., 2010). Palliative care will need to treat the family as a unit, evaluating the needs of the family, ensuring the family is offered support, and increasing the availability and accessibility of psychosocial services for family members (Grinyer & Barbrachild, 2011; Palmer & Thomas, 2008). The quality of a patient's life, particularly his or her levels of emotional distress and grief, can be influenced by how they perceive their family to be coping; without a widened approach to care to include the family, palliative care is not fully considering patient wellbeing.

Clinical consideration: Psychological health and information needs. The psychosocial experience of AYAs is a significant aspect of life and wellness that

separates this oncology patient group from children and older adults. AYAs face the challenge of being isolated and excluded from, and left behind their same-age peers, a separation that grows wider as the patient remains ill and peers naturally move ahead in their own lives. Some AYAO patients with long-term disease have only the hospital as their social landscape and live out their social experiences with the staff who care for them (J. K. Clark & Fasciano, 2013). Research by Wiener et al. (2015) describes the palliative care training needs for working with AYAO patients including patient perspectives in the recommendations; notably, AYAs' express distress at losing staff they have bonded with to the clinical rotation system and because of this arrangement, feel a lack of connection and continuity of care. Palliative care needs to acknowledge the lack of connection felt by AYA and model open communication and contact even after staff have moved to a different setting. Continued contact and communication by palliative health care workers is especially important when the AYA can no longer expect a cure; experts identify there is essentially a secondary isolation, from peer-patients and auxiliary staff, when this stage is reached (IOM, 2014). If palliative care does not champion change in the existing patterns of communication and contact, it would be preserving a healthcare model inappropriate for the emotional and social needs of AYAO.

AYAs are in a place in life where self-determination, means of influence, awareness of their impact on others, critical thinking, and worldview are all forming or have begun to take root. This emerging individuation can be diminished or stripped away when AYAO patients are put into an unfamiliar, disorienting healthcare world. The

disorientation may result in patients feeling that they must trust in the guidance of a few medical healthcare providers, with little informed self-guidance or clarity in decision-making and to choose care that may be unclear or conflicting. AYA patients identify the desire to take responsibility for their own health care and decision-making and express the need for increased information sharing and communication to inform their decisions (Tsangaris et al., 2014, Zebrack et al., 2007). However, opportunities for care decision-making may be suppressed because of the acuity of disease at diagnosis or staff who are undertrained on AYAO care options. Palliative care is especially equipped to help establish goals of care and identify areas where care decisions are possible, which must be a top priority for serving this group (Rosenberg & Wolfe, 2013; Wein et al., 2010). Confusion, uncertainty, anxiety, fear, and distress are all correlates of cancer care expressed by AYAO patients; palliative care service has the expertise to help them become confident and knowledgeable of their own healthcare information and provide anticipatory guidance to mitigate these emotional reactions (J. K. Clark & Fasciano, 2013; R. George & Hutton, 2003; Tsangaris et al., 2014). George and Hutton (2003) propose that symptom control creates a decisional space, a practice where palliative medicine excels. Palliative care, however, has yet to profess their service as a tool for psychosocial symptom control or for deterring psychosocial impact of illness with this patient group.

Barriers to palliative care services. The literature review also provided information, research, and data explaining why the shortages identified in PCS to AYAO patients exist. These barriers to implementation or integration of palliative care to this

group were numerous and included: research and clinical trials into palliative care, utilization and application of palliative medicine, communication regarding palliative care, perceptions of palliative care, palliative care within medical culture and settings, resource and financial support for palliative care, and lastly legal implications and advocacy for palliative care.

Research and clinical trials into palliative care. Some of the deficiencies identified in the quality and delivery of PCS to AYAO patients result from there being only limited research or clinical trials on the topics (IOM, 2014; Rosenberg & Wolfe, 2013; Weaver et al., 2015; Wein et al., 2010). A sizeable body of research exists reporting on young adult survivors of childhood cancer but, less research has been conducted with survivors of AYAO and even less has been carried out with AYAO who are on treatment, receiving palliative care, or who would benefit from palliative care service. Wein and colleagues (2010) state that palliative care staff were reluctant to refer or expose critically ill or dying patients to research interventions and additionally, AYA research studies tend to have high attrition rates. Further reasons for the paucity of research are that AYAO remains a relatively unknown or overlooked patient group, assessments or measures have not been devised for this specific group, collection of patient reported outcomes to stimulate development of assessments and research is lacking, and financial resources at the government, institutional, and programmatic level are scarce for research on this subject with this group (IOM, 2014; Pritchard et al., 2011; Weaver et al., 2015).

Evidence of palliative care intervention improving symptom or physical status as well as its favorable impact on the patient's disease experience and reduced late effects of disease will need to be proven to get increased buy-in by programs and practitioners of the 'acute-fix' model and governing healthcare systems of the value of palliative care services for AYAO patients. Investigations and clinical trials of palliative care for AYA will also need to demonstrate savings in medical cost to obtain initial and sustained financial support for research efforts from private institutions and governing bodies. Generally, only interventions with observable patient improvements that positively affect a large cohort of patients and are a low cost to the organization are likely to be preferred for financial and resource support. As such, research and clinical trials are needed to prove the efficacy of palliative care to AYAO patients as well as cost value, but to date, AYAO specific palliative services to study do not exist because there is no empirical support documenting and demonstrating the varied benefits of this care approach.

Utilization and application of palliative medicine. A reason for the shortage in PCS to AYAO patients is the manner in which palliative care is contemporarily utilized in the healthcare sector. At present, PCS is not considered state of the art care nor a core service component for long-term or complex cancer conditions and so tends to be used only in a consultative capacity when needed (Wein et al., 2010). This perception leads to use based on need rather than based on prognosis and thus PCS is introduced reactively rather than proactively (Cook et al., 2013; Manitta, Philip, & Cole-Sinclair, 2010). Applied in this manner, patients, families, practitioners and institutions will never observe the long-term benefit of PCS nor the present-time benefit of having a team of professionals

addressing the whole care of the person, not just the cure. For example, PCS intervention is not often considered when the patient or family is emotionally or behaviorally in need of support, yet palliative care possesses the skilled personnel to address this and other common issues and needs. Although palliative care could be accessed first in such cases, it is often an afterthought when other supportive interventions have been tried. Due to the conventional positioning of palliative care service in the hospital and outpatient settings, the specialization has not been utilized often when a patient's medical care begins (Bruera & Hui, 2012; Pritchard et al., 2011; Wein et al., 2010). Increased presence of palliative care staff on hospital rounds or outpatient tumor boards will allow practitioners to identify AYA/O patients at the outset and provide deliberate help at the start of treatment when it can have its maximum impact.

Communication regarding palliative care. An explanation for some of the identified shortages in AYA/O palliative care is due, in part, to how we communicate about palliative care, or more accurately, that we don't communicate about palliative care soon enough or at all (R. George & Hutton, 2003; Pritchard et al., 2011; Thornes, 2001). Pritchard and colleagues assert not only is there a scarcity of communication about palliative care but there is an overall lack of communication about a patient's illness trajectory or complexity in general, thereby impairing the opportunity for appropriately timed palliative care intervention. R. George and Hutton (2003) emphasize that some think truthfulness (especially worse news) is prophetic, and so declining health is not discussed transparently by the healthcare team, patient, or

family. While this may temporarily postpone distress, it may set the stage for even more difficulty and distress at a later time when health status indisputably changes and some interventional courses of action are unavailable. Missed opportunity for PCS involvement is also due to lack of good communication between health service providers and a lack of normalized protocol to introduce palliative care, as well as an 'acute-fix' focused attitude by programs and practitioners, which neglects communication about the patient 'care' portion of treatment that palliative care satisfies (Michaud et al., 2007; Thornes, 2001). The manner in which specific elements of palliative care, such as its services, use, timing, and benefit, are communicated to other healthcare providers needs to change, as does how practitioner's communicate to patients about their healthcare status or illness impact and the help PCS can offer.

Perceptions of palliative care. Some of the identified shortages in the quality and delivery of PCS to AYAO patients exist because of negative, conflicting, or unclear perceptions of what palliative care is (Pritchard et al., 2011; Weaver et al., 2015; Wein et al., 2010). In some settings, palliative care is believed to be synonymous with hospice care, thereby stigmatizing it as a service only for the very sick and dying and essentially a signal for giving up hope (Pritchard et al., 2011; Wein et al., 2010). Referral sources lack knowledge of what palliative care service is, leading to late referral, underutilization, or missed timeframe for intervention, perpetuating and reinforcing negative ideas about palliative care (Weaver et al., 2015; Wein et al., 2010). Because of the negative connotations ascribed to palliative medicine by patients and medical staff and the lack of knowledge about its services, use, and benefit, negative perceptions are passed on to

patients entering care who may in fact benefit from PCS. Patients have expressed distress at the introduction of palliative care, believing that curative treatment is ending, their oncologist is withdrawing, and that palliative care will quicken death (Pritchard et al., 2011; Wein et al., 2010). These inaccurate perceptions reinforce a cycle of misuse impairing the intent, goal, and purpose of palliative care; the only ones who can begin to break this self-fulfilling cycle are practitioners of palliative care and primary care providers as well.

At present, internal perceptions by palliative care healthcare workers as to what, when, and why PCS can help the AYA patient group may be inconsistent or anecdotal because the role of PCS with AYAO patients is unclear and untested at this time. When palliative medicine describes itself primarily as providing symptom and pain management, referrals to the service are limited to this care and opportunities for palliative services to fulfill a larger role in patient treatment are inadvertently constrained. Some informed authors recommend exploring a new way to discuss and describe palliative care service. Bruera and Hui (2012) suggest as a starting point that an alternative term to palliative care be considered (Barling et al., 2012; Pritchard et al., 2011). To increase utilization and subsequently discover how it will best serve AYAO, palliative healthcare workers must think of and explain to practitioners and patients alike the expanding role of PCS for this group and change the way palliative care is talked about (Barling et al., 2012; Pritchard et al., 2011).

Palliative care within medical culture and settings. A cause for some of the shortages described in PCS for AYAO patients is because of the enduring medical culture

and state of affairs (Edwards, 2001; Irwin & von Gunten, 2010; Michaud et al., 2007; Partridge et al., 2014; Rosenberg & Wolfe, 2013). Medicine and its affiliate institutions are largely cure-directed, acute driven and treat-fix oriented that stifle or, at best, provide less support for appropriate comprehensive services to patients who fall outside this frame of care (Michaud et al., 2007; Weaver et al., 2015). In the prevailing medical system palliative services are often accessed only in response to a drastic deterioration in health status rather than accessed proactively, due partly to medical departments not fully understanding palliative care or being less accepting of PCS. As such, there is a critical need for a paradigm shift in how healthcare conceptualizes, advertises, positions, accesses, and utilizes palliative and supportive services (Cook et al., 2013; Edwards, 2001; IOM, 2014; Partridge et al., 2014). To establish a comprehensive cohesive system of care for all stages of illness and life, the healthcare discipline needs to evolve, incorporating and validating palliative care, hospice, and other supportive services and integrating it across the spectrum of oncology healthcare.

Incorporating and instituting supportive programs such as PCS for AYAO is challenged by constraints in physical, institutional, and staff resources, specifically staff that are expertly trained in oncology and palliative care for this age group (Partridge et al., 2014; Rosenberg & Wolfe, 2013). De Lima (2010) writes that in many cases the development of palliative care has been a bottom up approach reinforced and sustained by advocates of the service and eventually established in institutional programs and policy. However, “palliative care services usually require in-depth and sustained institutional efforts” (Partridge et al., 2014, p. 3331), and without crucial prioritization of

this care model, the healthcare supply and demand, fiscal resources, and commitment are directed back to services of the traditional “acute-fix” healthcare approach (Fernandez et al., 2011; Knapp, Quinn, Murphy, Brown, & Madden, 2010). Recently, governmental and non-governmental recommendations, schools of medicine, the medical community, and advocates are calling for more training and education in PCS (Partridge et al., 2014). However, without acceptance and integration, sustained support, allocation of necessary resources, and sufficient funding for PCS, expert training will be a meaningless effort, and palliative medicine will likely continue to exist on the sideline.

Resource and financial support for palliative care. A lack of financing and resources for palliative care services explains why some of the identified shortages exist in the quality and delivery of PCS to AYAO patients (De Lima, 2010; Knapp et al., 2010; Partridge et al., 2014; Pritchard et al., 2011; Rosenberg & Wolf, 2013). This is a multilayered issue involving systems and structures that govern healthcare service and funding. Most writers on the subject of palliative care state that reimbursement for PCS is insufficient (Fernandez et al., 2011; Knapp et al., 2010; Partridge et al., 2014). Reporting on a survey of 101 cancer centers in the United States, Partridge and colleagues state that poor reimbursement and lack of a reimbursement system were commonly cited as barriers to delivery of palliative care. For palliative care programs to be sustainable and justifiable, United States reimbursement regulations for palliative care will need to be reviewed and modified because the current restrictive referral

requirements and lack of pay for services does not compel use of this healthcare service (Knapp et al., 2010; Partridge et al., 2014).

A lack of pay for services rendered is a challenge of providing palliative care to the AYAO group as is a deficiency in palliative care program funding. Authors on the topic repeatedly emphasize that funding is insufficient, variable, or unreliable (Fernandez et al., 2011; Knapp et al., 2010; Partridge et al., 2014; Pritchard et al., 2011; Rosenberg & Wolf, 2013). In a Florida program directly serving AYA with long-term illness aiming to improve and enhance patients QOL, the most significant obstacle to maintaining the program was funding (Knapp et al., 2010). Funding is a necessity, and it is essential that palliative care is prioritized higher than it currently is in distribution of hospital, institution, or program funds. A consequence of this challenge is that there are limited or insufficient resources allocated or available specific to serving the AYAO patient group (Fernandez et al., 2011; Rosenberg & Wolfe, 2013). The limited resources include a shortage of staff appropriately trained in the palliative care needs of AYAO patients, limited auxiliary programming which are instead tied to the larger institutional service needs exclusive of palliative care, insufficient institutional funding towards palliative care for AYAO, and lack of commitment to launch an AYAO specific palliative care program (Bruera & Hui, 2012; De Lima, 2010; Partridge et al., 2014). Furthermore, there are also programmatic and patient barriers to accessing existing resources, as such as lack of adequate service availability, poor insurance coverage, and prohibited deliveries of interdepartmental services as a policy of institutional organization. For palliative care programming to be successful with the AYAO patient group and to ensure

the best QOL possible, the limitations of resources needed to serve this group will need methodical review.

Legal implications and advocacy for palliative care. One reason for the shortage of PCS in the AYAO setting is due to a lack of regulation supporting expert opinion of the value in integrating or introducing palliative care early or requiring palliative care as part of standard AYA oncology care (Fernandez et al., 2011; Partridge et al., 2014). As efforts to recognize the AYAO cohort and emphasize its various special needs, such as fertility preservation and increased participation in clinical trials, has continued at the government level by various organizations, palliative care programming for this patient group has been in the shadows of these other AYA treatment endeavors (Partridge et al., 2014; Weaver et al., 2015). Hospital accreditation is an area that has not yet been formally considered as an instrument to ensuring PCS be offered or integrated into the treatment regime of this patient group. This course of action has the potential for significant influence on hospitals and institutions because accreditation can be the gateway to government funding, university affiliation and funding, governmental and non-governmental grants, and insurance reimbursement for these establishments. Advocates, AYA champions, and lobbyists are the catalyst to helping promote this need at the local, regional, and federal level and more affirming voices are needed to come forward.

Discussion

This dissertation shows that there are a variety of components of healthcare that have not yet been considered in service to the adolescent and young adult oncology (AYAO) population. Within the overall architecture of oncology treatment strategies for this group, palliative care specifically is lacking and many AYAO patient needs have never been considered as potential palliative care service offerings. When offered, the quality and services of palliative care are generally insufficient in meeting the needs of this patient group. The findings, which illuminate the shortages in palliative care to the AYAO group, are summarized in Table 2, (page 101); as appropriate, clinical considerations specific to an area of care can be found directly below the theme. The few articles currently in circulation that address the subjects of palliative care and AYAO together are generally limited to documentation of what is needed and why (see Pritchard et al., 2011; Rosenberg & Wolfe, 2013; Wein et al., 2010). Although limited, this documentation has provided a basis for recognition and exploration of the benefit and utility of palliative care to this group; yet, these writings do not critically examine application of this service to the AYAO patient cohort. In the course of this dissertation, one additional article on the topic of AYAO and palliative care was published (see Donovan, Knight, & Quinn, 2015). The content of this article is not significantly different from nor does it add to the knowledge base generated by the three most relevant publications captured in the literature review, but is evidence of some, however very small, progress in scholarly acknowledgement of this topic. Existence of these publications helps to legitimize the importance of this dissertation's research

investigation because the literature base remains minimal, at best, and current writings discuss, but do not intensely analyze, changes needed to better serve this group.

Leading organizations and working groups that establish treatment guidelines and standards of care have made recommendations for additions or improvements in adolescent and young adult (AYA) palliative care and have stated the need to move the discipline forward (see IOM, 2014; NCCN, 2012). However, these recommendations are inconsistent with change campaigning, because efforts and resources necessary to address issues or correct problems are insufficient and more importantly are often allocated elsewhere. As yet, the conflicts and challenges to meeting the healthcare initiatives documented for this group have not been examined in detail. Rather than leaving these concepts for change to conjecture and as casual scholarly dialogue, this dissertation can aid in tangible movement and improvement to palliative care for the AYAO group, having illuminated barriers to program and service change not explored by overseeing bodies.

Improvement in palliative care service to AYAO patients requires that AYAs, as a group, be considered differently from existing patient care models. From the findings of this dissertation, several themes signal the need for a strong developmental orientation in palliative care provided among this group, which is currently lacking. Standing out from the findings are the specific clinical considerations for working with this patient group that document the absence of, and need for, a developmental care approach. These are distinct from models of pediatric and adult care and include: AYAO development and goals, symptom management for future functioning, social and peer

engagement effects, and AYAO psychological health and information needs.

Correspondingly, several of the theme areas emphasized in this dissertation inherently contain developmental principles in their content and focus; these include: information technology, palliative services for care at home and in the community, palliative care program structure, palliative care team, and palliative practitioner education and training. By addressing these shortages in care and establishing corrective steps, palliative medicine will subsequently provide intervention with a developmental orientation. There also are opportunities within these care areas to tailor services and support to the specific developmental goals or age-appropriate needs of this unique patient group (see section on palliative care team, community care and care at home for examples). Anchoring palliative care services (PCS) for this group of patients from a developmental framework and intervention practice will help AYAO patients to feel less adrift within a medical system designed largely for either children or adults. As a cardiologist is a heart specialist, a neurologist is a brain specialist, and a pulmonologist is a lung specialist, palliative practitioners can be the patient specialist who will best accomplish this expertise with AYAO patients by engaging in care from a developmental standpoint of services, support, and intervention.

Several critical content areas raised in this dissertation must, at a minimum, be addressed to begin to bring comprehensive palliative care to this patient group to improve overall AYA oncology treatment. Education on palliative theory and its model of care for practitioners, patients, and the healthcare establishment, and education of AYAO patient palliative needs to palliative care practitioners, program directors, and

funding sources is a key step to initiate awareness of and generate support for bringing palliative care to this population. Widespread education will illuminate the importance and value of PCS to this unique patient cohort and will almost certainly stimulate research and change necessary to integrate PCS as a regular fixture of AYA oncology treatment. Funding for research and palliative programming is another essential element to improving palliative care to this group that in combination will help ensure AYAO patients and families desire palliative care and its component services and that it is appropriate, successful, and comprehensive. Generating support for funding is complicated by the measures required to elicit financial backing and other established, more visible programs now taking financial priority. Detailing the developmental and psychosocial needs for this population, current shortages in PCS among AYAO patients, and the unique role of palliative intervention in improving AYAs' quality of life (QOL), patient-years-of-life affected, and patient's successful future functioning will hopefully encourage initial funding for a specialized program of palliative care to this group. Palliative care tailored to the developmental and social conditions of this population must also employ the regular use of information technology in healthcare service to be successful and to communicate with these patients in a manner they are accustomed to and generally prefer. Utilizing contemporary information technology across the healthcare continuum can assist in the progress of several domains of medical and psychosocial care. This can be an uncomplicated gateway to specialized palliative care as information technology and media can be introduced at a relatively low cost, is more

easily disseminated, is often more accessible, and can circumvent some of the institutional delay that is often common in departmental or program adaptations.

The normalization of palliative care among practitioners and in the oncology setting is critical to the success of this service. More specifically, making it a common and expected service of AYA oncology is fundamental to breaking through several of the barriers to palliative medicine that limit its quality and delivery to AYAO patients across the healthcare spectrum. Taking steps to normalize palliative services in the care of AYAO patients would help remediate several of the issues to providing care illuminated in the literature review findings such as reducing negative perceptions of palliative care, enhancing communication regarding palliative care, improving utilization and application of palliative medicine, helping to reshape palliative care within medical culture and settings, and open opportunities for research and clinical trials into palliative care and their accessibility. Likewise, taking steps towards improvement in any one of these barrier content areas would not only remediate the presenting issue but also help to normalize PCS in the healthcare setting. This dissertation is a tool to help stimulate the development of a systematic palliative care pathway for AYAO patients and guide the creation of standards of care in this domain that will influence the regular and expected presence of palliative care in AYAO healthcare.

Taking the initial steps to introduce and standardize specialized palliative care for AYAO patients can be facilitated with guidance from adult and pediatric palliative services. Several elements from each program of care will help form the knowledge base to serve this unique oncology cohort across settings and for extended periods of time,

but the course of program development cannot rely only on the practice and expertise of these treatment subspecialties. The shortages investigated in this dissertation exist, in part, because the current design and clinical proficiency within pediatric and adult service divisions do not provide a complete and appropriate model of care for the AYAO population. To implement a structured and standardized palliative care intervention program for the AYAO group, recognition of its value to care as well as research, funding, and education apportioned to the pediatric and adult palliative subspecialties will similarly need to be allocated to AYAs. Designing a palliative care program and clinical practice regime that is precise and tailored to AYAO patients will help bring treatment in line with the full-scale services and skilled, informed care available in pediatric and adult service. Drawing on the findings of this dissertation, the treatment community as a whole can ultimately provide to AYAO patients the full benefit that palliative care offers.

This dissertation emphasizes not only the importance and value of integrating palliative care with AYAO treatment, but also considers patient and healthcare conditions should the status quo as reflected in the findings go forward. Each shortage of the quality and delivery of palliative care to AYAO patients, as well as the barriers leading to these shortages, will require rigorous, detailed examination in the effort to mitigate the issues at any level of care. Having investigated the topic of palliative care for AYAO patients beyond the existing body of literature to reveal what is missing from treatment quality and delivery, and why it is missing, this dissertation has extended the research base and helped validate the need with the intention of stimulating critical

thought and inspiring future research that will prompt programmatic, institutional, local, and national action. The findings will help form a basis for a new program of care as yet not sufficiently considered by many scholars or healthcare institutions. The practitioner expertise, approach to, and extent of service that palliative medicine can offer to the AYA population is vital and valuable to shaping focused whole-person, patient-centered-care helping to overcome the poorer treatment outcomes AYA patients have historically experienced and to create more successful results and improved quality of living no matter at what point the AYA patient is in treatment.

Psychology's Role and Contribution to Palliative Care With AYA Patients

It is not only common knowledge but it is also well documented that many cancer patients, and AYA in particular, experience a psychological reaction to cancer which can be magnified by a long-term or complex course of disease (Abrams et al., 2007; J. K. Clark & Fasciano, 2013; Connor, 2010; Irwin & von Gunten, 2010; IOM, 2014; Zebrack et al., 2013). Historically, the field of psychology and its practitioners have had little awareness of or involvement in palliative medicine during the majority of its development. Research and theoretical psychologists have examined the experiences surrounding death and dying, but direct clinical work with severely ill patients did not become frequent practice until recently (Golijani-Moghaddam, 2014). There are many reasons thought to account for psychology's distance from palliative care which include palliative practitioners views that mental illness should not take precedence in care regimes of severely ill patients, lack of referral for psychological services, members of the palliative team assuming for themselves the duty of psychological counseling, and

psychology having unclear roles and boundaries regarding their place in palliative care (Golijani-Moghaddam, 2014; Payne & Haines, 2002).

The majority of psychologists who responded to a 2010 survey of members of the British Psychological Society working in specialist palliative care were often the first staff members in their position within palliative care and had been working in this capacity an average of only six years (Golijani-Moghaddam, 2014). Collectively, contributions of psychologists to palliative care delivery throughout different points of care were identified by the survey respondents and are summarized in Table 1. Because palliative care and psychology have only recently been aligned there is insufficient data to establish baseline metrics to determine or demonstrate what psychological services are of most benefit to the patients in palliative care. Consequently, there is a lack of evidence as to what psychotherapeutic approaches are most appropriate and efficacious in palliative care to any population not just the AYA cohort (Golijani-Moghaddam, 2014). Some therapeutic approaches such as Acceptance and Commitment Therapy, narrative-based therapies, Motivational Interviewing, and cognitive-behavioral therapy have been suggested as appropriate in palliative care and care at the end of life (Kasl-Godley, King, & Quill, 2014).

Detailed examination of palliative medicine's expanding expectations and role in healthcare has helped illuminate specific skills, roles, and competencies psychologists possess that can independently contribute to enhancing palliative medicine and care at the end of life in their own right. Specifically, in a recent article by Donovan and colleagues (2015), the authors highlighted that advance care planning with AYA patients

Table 1

Contributions of Psychologists to Palliative Care Delivery

Intervention point	Role/contribution of psychologist
1. Prior to life-limiting illness	Health promotion Advance care planning Public awareness and education programming
2. After diagnosis	Supporting patients and their families Offering consultation/training for professionals Facilitating patient-professional communication
3. During advanced illness/dying	Psychosocial work with patients and their families Interventions addressing: - anticipatory grief and adjustment reactions - Existential and spiritual issues - Mental disorders - Pain and physical symptom management - Advance care planning - Life review - Unresolved life concerns
4. Bereavement	Identifying bereaved persons at risk Grief therapy

Note. From "Practitioner psychologists in palliative care: Past, present, and future directions," by N. Golijani-Moghaddam, 2014, *Counselling Psychology Review*, 29(1), p.35. Reproduced with permission, ©British Psychological Society.

is distinct from other ages in going through the process of healthcare decision-making and is an area where psychology can aid and excel (Kasl-Godley et al., 2014; Payne & Haines, 2002;). In one of the earliest writings on the contributions of psychologists in palliative care, Payne and Haines (2002) identify four broad domains of palliative care where psychologists can contribute specific clinical expertise: direct clinical services, education and teaching, support or supervision at the organizational level, and psychological research methods and approaches. Many patient and professional services occupy each of these domains reinforcing that psychological presence in

palliative care is active, considerable, valuable, and ultimately necessary for optimal patient care.

The services and skills psychologists can contribute to the general field of palliative care that have already been documented in previous academic work can be found in Payne and Haines, 2002; Kasl-Godley et al, 2014; Golijani-Moghaddam, 2014; Haley, Larson, Kasl-Godley, Neimeyer, and Kwilosz, 2003. While the background and framework of this research topic allow the reader to infer that there are essential roles for psychologists, the findings of this literature review highlight aspects of care that are unsatisfactory and can clearly benefit from the help and expertise of psychologists operating from a psychological framework inspiring richer comprehensive care for remediation of these shortages. This dissertation will elaborate on the specific contributions psychology can make as partners or team members of palliative care in the treatment and care of AYAO patients throughout each of the four domains suggested by Payne and Haines (2002).

In direct clinical service, distinctive ways in which a clinical psychologist can help serve the AYA population is through teaching communication skills and self-advocacy to patients and families; providing academic assistance in the form of assessments, educational plans, and school accommodations; providing neurocognitive services in the form of assessments and rehabilitation plans; and communicating and coaching on the subject of family planning, relationships, and sexuality. Psychologists are also skilled in providing guidance on adjustment, self-care, coping and problem-solving skills, and non-opioid pain management practices such as distraction techniques, breathing

exercises, meditation, guided imagery, and stress management methods. At the organizational level, psychologists in palliative care can help serve particularly by providing peer support and bereavement services to other healthcare staff serving AYAO, engaging in program and service development, and in helping craft and manage programmatic change which is to be expected in a new field of operation. Psychologists can be of use in research by isolating and studying issues or areas related to palliative care for AYA in need of further investigation; developing diverse assessments principally, neurocognitive and academic measures for AYA patients, tailoring health surveys for caregivers and families of chronically ill AYA; as well as auditing and evaluating programs and services specifically serving AYAO in palliative care. In the area of education and teaching concerning AYAO and palliative care, psychologists can contribute their unique skill in communication training for patients and medical staff and to educate clinicians about the distinct developmental and social health needs of this patient group at any stage of disease.

In addition to the four clinically-associated palliative care domains described above, psychologists can also contribute in the realm of law, advocacy, and policymaking related to palliative care and AYAO. In the domain of law, advocacy, and policymaking psychologists should establish themselves in the working groups that determine standards and guidelines governing program requirements and development, as well as lobby and advocate for increased insurance coverage of palliative care services and increased patient accessibility of diverse services that are covered by private and government-subsidized insurance.

The psychologist roles and recommendations identified above are suggestions that will need to enter into an iterative process of research and reform to develop psychology's "best fit" to benefit AYAO with complex treatment regimes. Payne and Haines (2002) conclude, "the distinctive contributions of psychologists comes not from any single task they undertake, but from the base from which they work and their overriding perspective . . . their distinctiveness comes from their training" (p. 403). Beyond the scope of this dissertation, a detailed concise overview of the competencies necessary to work with palliative care patients of all ages across the disease continuum can be found in the research article by Kasl-Godley et al. (2014), as well as in the Clinical Practice Guidelines for Quality Palliative Care, Third Edition (2013).

There currently is a great opportunity for psychologists to positively influence patient care in palliative medicine and to guide integration of this care service into oncology. To date, there are only limited, certified post-doctoral training opportunities in palliative medicine and those that exist have limited access, are not oncology intensive, and focus on a cohort of older patients (Kasl-Godley et al., 2014). Psychologists need further training in palliative medicine to understand its components and complexities, as well as its position and potential effect in the medical care model, and to study with expert practitioners of the field (Golijani-Moghaddam, 2014). For psychologists serving the AYAO population specifically, there are multiple, diverse skills and services extending beyond the niche of psychological counseling and intervention that could be offered to help foster healthier young adults during and after treatment.

Summary

Current areas of deficiency in palliative care among the adolescent and young adult oncology patient demographic are identified utilizing a systematic, targeted review of existing literature on the topic. Because of the dearth of publications addressing both subjects together as one conceptual care practice (see Donovan et al., 2015; Pritchard et al., 2011; Rosenberg & Wolfe, 2013; and Wein et al., 2010), opinions, information, research, and data were collected from a diverse assortment of literature that contained elements of AYAO and palliative care or indirectly approached both subjects in the same publication. The review yielded two major segments of deficiency or under-development, those of palliative care quality and palliative care delivery. Multiple independent themes were present in each category, and within several of the themes, specific clinical considerations for working with AYAO patients by way of a palliative care approach were illuminated. A third major intent of the literature review was to identify barriers leading to the shortage of palliative care to AYAO patients, and findings determined that there are several causes. See Table 2 for a table of the overall findings of this dissertation.

Each of the themes is defined and summarized based on the literature review and examined through a broad lens of personal observations and experience in the clinical setting as well as writings on the AYA oncology population, their unique medical, psychosocial, and developmental needs. The state of addressing or not addressing the deficiencies in the care of AYAO patients is discussed and recommendations for remediation are made where applicable.

Table 2

Literature Review Findings

Themes		
Quality of Palliative Care	Delivery of Palliative Care	Barriers to Palliative Care
<ul style="list-style-type: none"> • Research into PC • Assessment of palliative care for AYA • Composition of the palliative care team • Education & training for palliative practitioners • Standards and pathways for palliative care • Structure of palliative care programs <ul style="list-style-type: none"> ○ <i>Clinical consideration: AYA development & goals</i> 	<ul style="list-style-type: none"> • Scarcity of technology • Techniques for pain & symptom management <ul style="list-style-type: none"> ○ <i>Clinical consideration: Symptom management for future functioning.</i> • Palliative services for care at home & in the community <ul style="list-style-type: none"> ○ <i>Clinical consideration: Social & peer engagement.</i> • Inadequacy of multidisciplinary & coordinated care • Intervention with palliative care <ul style="list-style-type: none"> ○ <i>Clinical consideration: Family & relationship disruptions.</i> ○ <i>Clinical consideration: Psychological health & information needs.</i> 	<ul style="list-style-type: none"> • Research & clinical trials into palliative care • Utilization & application of palliative medicine • Communication regarding palliative care • Perceptions of palliative care • Palliative care within medical culture & settings • Resource & financial support for palliative care • Legal implications & advocacy for palliative care

Although palliative medicine is becoming more accepted in the overall medical arena, a focus on AYA patients is needed because their needs significantly differ from those of children or older adults with cancer. The need for specialized support and intervention is magnified when AYA patients are faced with a complex course of disease, long-term treatment, or incurable disease. Palliative care is one solution to helping this population, but this intervention has not been methodically examined, specifically tailored, nor constructively applied to this patient group as of yet. A variety

of reasons accounts for the absence of palliative care to this group. The factors identified as barriers will remain barriers in the future if not remediated within the healthcare community that comprise these domains. Shortages in AYA/O PCS may be an inadvertent outcome due to limited recognition of the service option or simply a direct result of today's healthcare climate. To amend the palliative care service offerings and accessibility to this underserved group of patients, reducing shortages in education and funding is a top priority. This dissertation highlights the absence, shortage, or suboptimal elements of PCS for AYA/O patients with the intention to reverse these trends and help guide the development of a blueprint of palliative care for patients at the institutional, local, and national level. With this dissertation being a step forward, there is more yet to be done.

Study Limitations

Several factors limited the breadth of the literature review and the extent of the resultant findings. Principally, there were a very small number of empirically-based, peer-reviewed publications on the combined topics of palliative care and adolescent and young adult oncology. In addition to the three articles written directly on the topic of PCS and AYA/O captured in the literature review, one more relevant summary by Donovan et al. (2015) discussing both issues was published following the data collection period. The content supplied in this newly circulated article did not add any significant new data or discussion beyond the other cited articles. As a result of the scarcity of research publications on the combined subject of palliative care and AYA oncology, flexible parameters for article inclusion were needed to generate a base of literature

which to draw from. Articles not expressly addressing palliative care, but that touched on elements of this care service with AYAO were included. For example, publications addressing general palliative care deficiencies and merging this with the body of work written on AYAO were relied on, and studies with a greater focus on “teenagers/adolescents” were used. Consequently, the findings of this dissertation need to be applied thoughtfully, guided by informed processes, because the limited research base required skilled extrapolation and interpretation to bridge the gaps and isolate the conclusions.

In recent years, palliative medicine has gained traction in the healthcare arena as a beneficial intervention service beyond end-of-life care. As palliative care is finding its place and standing in current medical practices, it has been an ever-changing care concept during the duration of the writing of this dissertation. Because the landscape of palliative medicine is changing in response to patient and organizational advocacy, this dissertation’s findings, which define, identify, and resolve the existing shortages, may not apply to programs that are aware of and adapting to healthcare trends in this field. As the existing palliative care model is ever-shifting, the literature review that forms the basis of this dissertation is a snapshot at one point in time and the findings are contextual.

Future Directions

Many aspects of palliative care for AYAO patients were discussed in this dissertation and the literature review results. Even so, there are elements that did not have enough content or discussion published in the literature used in this review to

influence the findings. These elements, however, are in need of further inquiry and should be pursued in the future as this area matures. Examples of topics specific to AYAO and palliative care that came to light and should be considered for future study are:

Table 3

Subjects for Future Investigation

Physical	<ul style="list-style-type: none"> • chronic pain • chronic fatigue • memory changes experienced by AYA • patient engagement in exercise and physical activity • experiences and challenges of disfigurement and disability
Developmental	<ul style="list-style-type: none"> • study of substance use and abuse trends for AYAO with complex or advanced disease • examining the need for and barriers to continued education and academic accommodations • patient occupational retention
Social	<ul style="list-style-type: none"> • issues of family planning • investigation of support and intervention for AYAO who are young parents with young children
Medical System	<ul style="list-style-type: none"> • patient and family tracking and monitoring • differences in palliative care needs between younger and older AYAO • differences in needs at various stages in treatment • issues in transitioning care settings or healthcare teams • advocacy

Unless these topics are recognized and incorporated into future investigations, this population may continue to be underserved because each topic is substantial, and one or more of these topics may impact AYAO patients who need specialized help.

Chronic pain is an especially vital subject as medical management of pain in this population is challenging, and unmanaged pain many have burdensome, long-term consequences for AYAO patients. Investigations will need to begin with literature reviews of the topics listed above, and additional research needs to determine if experiences are different for AYA patients with complex or long-term oncology needs. Direct patient research after the knowledge base has been acquired will need to take place in an effort to form a distinct and measurable foundation for these topics and for meaningful, sustained study and research.

Multidisciplinary research across the palliative care spectrum is the primary action needed for the AYAO group at present, and following the line of inquiry outlined above is recommended for the numerous issues raised in the findings of this dissertation. For the future of this care service and its viability, it is necessary that experts design a palliative care philosophy and palliative care training, guidelines, and standards specifically for the adolescent young adult oncology population. This is a growing cohort and remains the only group of patients without specialization and specificity of care in palliative medicine. The reader can review palliative care treatment guidelines and standards of care for pediatric, adult, and geriatric patients from WHO, NCP, and the National Hospice and Palliative Care Organization resources.

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APPENDIX A

World Health Organization: Definition of Palliative Care

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

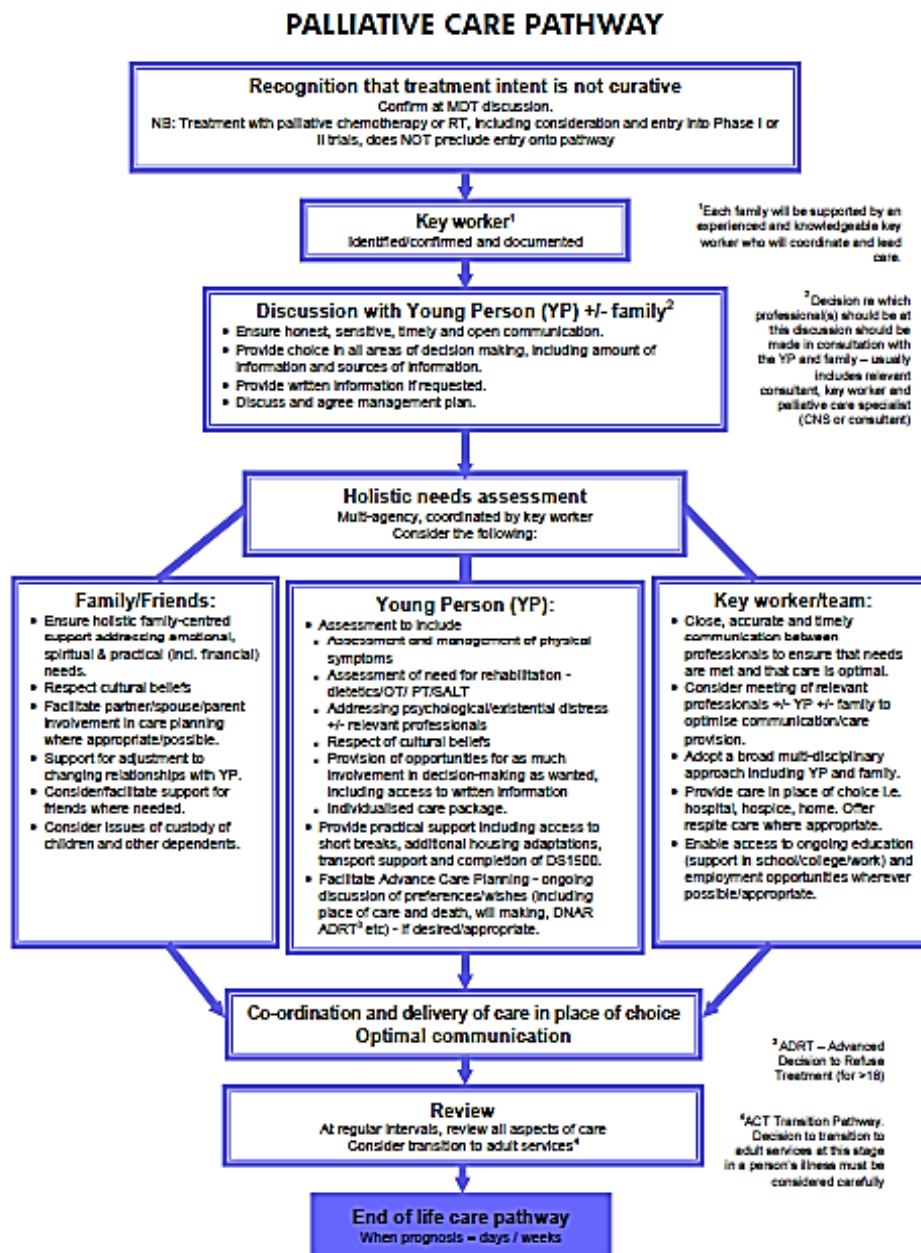
Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

World Health Organization. (2014). WHO definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>. Reproduced in accordance with the WHO copyright notice, <http://www.who.int/about/copyright/en/>

APPENDIX B

Teenage Cancer Trust: Palliative Care Pathway



Smith, S., Case, L., Waterhouse, K., Pettitt, N., Beddard, L., Oldham, J., . . . Siddall, J. (2012). *A blueprint of care for teenagers and young adults with cancer*. Manchester, England: Teenage Cancer Trust. Retrieved from <https://www.teenagecancertrust.org/about-us/what-we-do/professional-leadership/professional-resources>. Reproduced with permission from the Teenage Cancer Trust.

APPENDIX C

Leading Types of Cancer Death in the United States

TABLE 7. Five Leading Types of Cancer Death by Age and Sex, United States, 2009

ALL AGES	<20	20 TO 39	40 TO 59	60 TO 79	≥80
MALE					
ALL SITES 296,758	ALL SITES 1,086	ALL SITES 4,256	ALL SITES 54,483	ALL SITES 154,168	ALL SITES 82,765
Lung & bronchus 87,697	Leukemia 330	Leukemia 590	Lung & bronchus 14,960	Lung & bronchus 52,272	Lung & bronchus 20,171
Prostate 28,088	Brain & ONS 281	Brain & ONS 556	Colorectum 5,495	Colorectum 13,200	Prostate 15,099
Colorectum 26,807	Other endocrine system 99	Colorectum 456	Liver & intrahepatic bile duct 4,553	Prostate 11,717	Colorectum 7,652
Pancreas 17,870	Bones & joints 93	Non-Hodgkin lymphoma 305	Pancreas 3,662	Pancreas 9,871	Urinary bladder 4,579
Liver & intrahepatic bile duct 13,035	Soft tissue 83	Lung & bronchus 279	Esophagus 2,615	Liver & intrahepatic bile duct 6,309	Pancreas 4,215
FEMALE					
ALL SITES 270,856	ALL SITES 878	ALL SITES 4,629	ALL SITES 50,579	ALL SITES 127,506	ALL SITES 87,264
Lung & bronchus 70,389	Brain & ONS 241	Breast 1,056	Breast 11,572	Lung & bronchus 39,782	Lung & bronchus 19,188
Breast 40,678	Leukemia 231	Uterine cervix 438	Lung & bronchus 11,174	Breast 17,165	Breast 10,882
Colorectum 25,042	Bones & joints 86	Leukemia 388	Colorectum 4,139	Colorectum 9,968	Colorectum 10,600
Pancreas 17,758	Soft tissue 81	Brain & ONS 333	Ovary 3,189	Pancreas 8,782	Pancreas 6,371
Ovary 14,436	Other endocrine system 63	Colorectum 331	Pancreas 2,523	Ovary 7,171	Non-Hodgkin lymphoma 4,129

ONS indicates other nervous system.

Note: Ranking order excludes "Miscellaneous malignant cancer" and "In situ, benign, or unknown behavior neoplasm."

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APPENDIX D

Phase 2: Research Articles and Publications Selected for Study

Author(s)	Title	Publication Year	Journal or Publisher/Organization
<i>Scholarly Articles</i>			
Abrams, A. N., Hazen, E. P., & Penson, R. T.	Psychosocial issues in adolescents with cancer.	2007	Cancer Treatment Reviews
Barling, J. A., Stevens, J. A., & Davis, K. M.	Adolescents and young adults (AYAs) transition into palliative care: A narrative analysis of family member's stories of place of death.	2012	Journal of Palliative Care and Medicine
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Callaghan, E. E.	Achieving balance: A case study examination of an adolescent coping with life-limiting cancer.	2007	Journal of Pediatric Oncology Nursing
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George, R., & Hutton, S.	Palliative care in adolescents.	2003	European Journal of Cancer
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Gupta, A. A., Edelstein, K., Albert-Green, A., & D'Agostino, N.	Assessing information and service needs of young adults with cancer at a single institution: The importance of information on cancer diagnosis, fertility, preservation, diet, and exercise.	2013	Journal of Supportive Care
Humphrey, L., & Dell, M. L.	Identifying the unique aspects of adolescent and young adult palliative care: A case study to propel programmatic changes in pediatric hospitals.	2015	Seminars in Pediatric Neurology
Jenkins, C. A., Scarfe, A., & Bruera, E.	Integration of palliative care with alternative medicine in patients who have refused curative cancer therapy: A report of two cases.	1998	Journal of Palliative Care
Knapp, C., Quinn, G. P., Murphy, D., Brown, R., & Madden, V.	Adolescents with life-threatening illnesses.	2010	American Journal of Hospice and Palliative Medicine

Linebarger, J. S., Ajayi, T. A., & Jones, B. L.	Adolescents and young adults with life-threatening illness: Special considerations, transitions in care, and the role of pediatric palliative care	2014	Pediatric Clinics of North America
Manitta, V. J., Philip, J., & Cole-Sinclair, M. F.	Palliative care and the hemato-oncological patient: Can we live together? A review of the literature.	2010	Journal of Palliative Medicine
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Pritchard, S., Cuvelier, G., Harlos, M., & Barr, R.	Palliative care in adolescence and young adults with cancer.	2011	Cancer
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Schrijvers, D., & Meijnders, P.	Palliative care in adolescents.	2007	Cancer Treatment Reviews
Stinson, J. N., Sung, L., Gupta, A., White, M. E., Jibb, L. A., Dettmer, E., & Baker, N.	Disease self-management needs of adolescents with cancer: perspectives of adolescents with cancer and their parents and healthcare providers.	2012	Journal of Cancer Survivorship
Trevino, K. M., Fasciano, K., Block, S., & Prigerson, H. G.	Correlates of social support in young adults with advanced cancer.	2013	Journal of Supportive Care

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Wein, S., Pery, S., & Zer, A.	Role of palliative care in adolescent and young adult oncology	2010	Journal of Clinical Oncology
Wiener, L., Shaw Weaver, M., Bell, C. J., & Sansom-Daly, U. M.	Threading the cloak: Palliative care education for care providers of adolescents and young adults with cancer.	2015	Clinical Oncology in Adolescents and Young Adults
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Grinyer, A. & Barbrachild, Z.	Teenage and Young Adult Palliative and End of Life Care Service Evaluation.	2011	Teenage Cancer Trust
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Michaud, P. A., Suris, J. C., & Viner, R.	The adolescent with a chronic condition: Epidemiology, developmental issues and health care provision.	2007	The World Health Organization
Palmer, S. & Thomas, D.	A practice framework for working with 15–25 year-old cancer patients treated within the adult health sector.	2008	On Trac@PeterMac Victorian Adolescent and Young Adult Cancer Service
Smith, S., Case, L., Waterhouse, K., Pettitt, N., Beddard, L., Oldham, J., . . . Siddall, J.	A blueprint of care for teenagers and young adults with cancer.	2012	Teenage Cancer Trust
Thornes, R.	Palliative care for young people aged 13–24.	2001	Joint Working Party on Palliative Care for Adolescents and Young Adults

Appendix E

List of Abbreviations

AYA -	Adolescent and young adult
AYAO -	Adolescent and young adult oncology
PCS -	Palliative care service
QOL -	Quality of life
NCCN -	National Comprehensive Cancer Network
WHO -	World Health Organization
NCI -	National Cancer Institute
IOM -	Institute of Medicine
SEER -	Surveillance Epidemiology and End Results study
NCP -	National Consensus Project

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