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A Developmental Examination of Patient Engagement and Quality of Care in Adolescent Oncology

Elizabeth J. Siembida

University of Connecticut - Storrs, elizabeth.siembida@uconn.edu

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A Developmental Examination of Patient Engagement and Quality of Care in Adolescent
Oncology

Elizabeth Jane Siembida, PhD

University of Connecticut, 2016

The Institute of Medicine places the patient at the center of their high-quality cancer care conceptual framework, arguing that supporting patient engagement within the cancer setting is the highest priority for the improvement of cancer care. Adolescent cancer patients make up a unique cancer group due to tumor biology, specific cancer-related challenges, and social and cognitive factors unique to this developmental period. Within adolescent oncology, there are two main approaches for achieving high-quality care and increased patient engagement – patient-centered care and family-centered care. The current study examined a sample of 80 adolescent cancer patients, and determined how engagement is associated with self-reported quality of care, and the moderating roles of models of care, patient age, and development. A cross-sectional survey design was utilized, and participants were recruited in-person at two metropolitan hospitals. Participants recruited for this study were diagnosed with their most recent cancer diagnosis between the ages of 10 and 20, were at least 3 months from their most recent diagnosis, and had finished active treatment in the last two years (if they were not currently receiving treatment). Overall, the study found no significant relationship between patient engagement and quality of care, and models of care and patient's age and development did not moderate this relationship. However, both patient-centered care and cognitive development were significant predictors of quality of care. Participants reported experiencing patient-centered care more often than family-centered care, but family-centered care was significantly correlated with patient engagement. Finally, cognitive development was the only unique, significant predictor of patient engagement in the current study. These findings demonstrate the necessity of examining

adolescent cancer patients as their own unique group. Patient engagement does not play the same role in adolescents' perceptions of quality of care as we see in adults. Future research will need to further elucidate what aspects of their experience are important in improving quality of cancer care in adolescent cancer patients. The examination of developmental metrics was a novel aspect of the current study, and it exemplified the importance of development in adolescent cancer patients' experience, but also the need to examine multiple developmental metrics.

A Developmental Examination of Patient Engagement and Quality of Care in Adolescent
Oncology

Elizabeth Jane Siembida

B.S., Purdue University, 2011

M.A., University of Connecticut, 2013

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APPROVAL PAGE

Doctor of Philosophy Dissertation

A Developmental Examination of Patient Engagement and Quality of Care in Adolescent
Oncology

Presented by

Elizabeth Jane Siembida, B.S., M.A.

Major Advisor

Keith M. Bellizzi

Associate Advisor

Lisa A. Eaton

Associate Advisor

Thomas O. Blank

University of Connecticut
2016

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Chapter 1

Introduction and Background

A cancer diagnosis at any point in the lifespan has the potential to alter a person's life course trajectory, but when diagnosed during important developmental periods, like adolescence, this alteration can be even more pronounced (Bellizzi et al., 2012). Adolescent cancer patients are part of the broader adolescent and young adult (AYA) cancer population, defined as those individuals diagnosed with cancer between the ages of 15 and 39 (National Cancer Institute [NCI], 2006). It is estimated that about 70,000 AYA individuals will be diagnosed with cancer in the year 2015 in the United States (NCI, 2014).

The focus on AYA cancer patients emerged from a stagnation in long-term survival rates, and reports of patients not feeling like they had a "home" within the oncology setting (NCI, 2006). A number of barriers preventing progress within the AYA cancer population have been identified, including access to care, a high rate of uninsured individuals (although this may be changing with the implementation of the Affordable Care Act), delayed diagnosis, lack of long-term follow-up information, lack of available clinical trials, lack of knowledge of the cancers common among this age group, inconsistent treatment, and limited psychosocial and support services tailored for the AYA population (NCI, 2006).

In response to these trends, the Progress Review Group assembled by the National Cancer Institute (NCI) and LiveStrong (a group focused on the development of healthy lives in cancer survivors) suggested that clinicians and researchers consider even narrower definitions of this broad, inclusive age range by considering key variables such as tumor biology, physical traits, stage of development, and specific cancer-related challenges (NCI, 2006). With both

medical and developmental implications of a cancer diagnosis in adolescence, it is important to consider this smaller subsample of the broadly defined AYA population.

Adolescence is a period of transition from the dependence of childhood to the independence of adulthood, and important cognitive and social factors unique to the adolescent development period may be important to consider when determining patient engagement and quality of care for adolescent cancer patients. Unfortunately, there is not an agreed upon definition of “adolescent” within the medical setting, and varying age ranges utilized in different definitions have made the current literature on adolescent patients muddled (Louis-Jacques & Sample, 2011; Quinn et al., 2011). The lack of a clear definition for “adolescent” and the paucity of research on the physical, cognitive, and psychosocial changes specific to this developmental period make it difficult for healthcare providers to determine the best way to engage patients and provide quality care to this population. What is clear, however, is that a tailored approach is likely necessary.

National medical organizations in the United States, including the American Society of Clinical Oncology (2014) and the Institute of Medicine (2013), have emphasized the importance of improving the quality of cancer care in America, and in 2013 the Institute of Medicine developed a conceptual framework to describe high quality cancer care across the cancer continuum (Institute of Medicine, 2013). A diagram of their framework can be found in Appendix A. According to the Institute of Medicine (2013), “the central goal of its conceptual framework is delivering comprehensive, patient-centered, evidence-based, high-quality cancer care that is accessible and affordable to the entire U.S. population, regardless of the setting where cancer care is provided.” (p. 3) In summary, the six components are engaged patients; an adequately staffed, trained, and coordinated workforce; evidence-based cancer care; a learning

health care information technology system for cancer; translation of evidence into clinical practice, quality measurement, and performance improvement; and accessible, affordable cancer care. A full description of each component can be found in the Institute of Medicine (2013) report.

At the center of this framework is the concept of developing engaged patients. Patient engagement is defined as an increase in “a patient’s knowledge, skills, ability, and willingness to manage his or her own healthcare.” (p.1; Health Policy Brief: Patient Engagement, 2013). Research has found that engaged patients are more likely to receive recommended screening tests, report higher quality care, have lower medical costs, less likely to smoke, less likely to be obese, and report increases in health enhancing self-management behaviors (Greene & Hibbard, 2011; Hibbard & Greene, 2013; Hibbard, Mahoney, Stock, & Tusler, 2007). The main recommendation to encourage patient engagement is for the cancer care team (e.g. oncologists, physician assistants, nurse practitioners, and nursing staff) to provide information, psychosocial support, and financial estimates of cancer care to the patients and their families (Institute of Medicine, 2013). Further, the report suggests that this communication should be facilitated through the use of decision aids and collaboration with patients in the creation of care plans that are respectful of the patient’s values and priorities. As such, both the Institute of Medicine (2013) and the American Society of Clinical Oncology (2014) have focused their recommendations for the development of patient engagement, and subsequently high quality cancer care, on improvement in doctor-patient relationships.

The doctor-patient relationship is the main mechanism through which patients interact with, and understand, their cancer care, and it provides the foundation from which we may be able to improve patient engagement. Although both organizations provide recommendations for

improving this aspect of cancer care, neither discuss the importance of considering differences in preferences for this area according to age, or developmental stage, at diagnosis. Additionally, the framework does not discuss the implications of the legal authority of minor patients. Parents are the legal medical decision-makers for their children under the age of 18 (or 21 years of age in a few states), and they can prevent their adolescent children from playing a role in the decision-making process (Beh & Pietsch, 2004; Hickey, 2007; Moore & Kirk, 2010; Quinn et al., 2011). With adolescence being a time of preparation and transition to adulthood, it is important to examine what characteristics of the doctor-patient relationship are associated with better patient engagement in this population.

There are two main models of the doctor-patient relationship currently discussed in the literature – patient-centered care and family-centered care. Both of these frameworks include some overlapping constructs, but the primary difference is the increased emphasis placed on the role of parents and family members in healthcare decisions within the family-centered model. Because the adolescent development period is characterized by major physical, psychosocial, and emotional changes across this time (Collins & Steinberg, 2006; Steinberg, Cauffman, Woolard, Graham, & Banich, 2009), each of these approaches may be more or less appropriate depending on the context and the adolescent’s development. However, without tailored research examining these models of doctor-patient relationships within the adolescent oncology setting, recommendations for how to interact with these patients to promote patient engagement, and subsequently high quality cancer care, remains a challenge.

This dissertation aims to partially fill this gap by shedding light on important variations in patient engagement and quality of care in adolescent cancer patients. In order to accomplish this goal, Chapter 2 will review the relevant literature and describe the study’s conceptual model.

Chapter 3 will present the study's purpose and research questions, and Chapter 4 will describe the study's methodology and data analysis plan. Finally, Chapter 5 will describe the results of the study, and Chapter 6 will discuss the results in the context of the current adolescent oncology and broader oncology literature, the study limitations, and important future research and clinical directions.

Chapter 2

Review of the Literature

Adolescent Cancer and the Doctor-Patient Relationship

Research focusing specifically on the experience of patients diagnosed with cancer during adolescence is limited due, in part, to issues with the definition of adolescent (Quinn et al., 2011). The limited available research with this population, however, has found that adolescents report both positive and negative experiences due to cancer, and these experiences are both similar and different from their older and younger counterparts.

Adolescent cancer patients report positive and negative outcomes both during treatment and in the years following (Bellizzi et al., 2012; Engvall, Cernvall, Larsson, von Essen, & Mattsson, 2011; Lehmann et al., 2014; Wesley, Zelikovsky, & Schwartz, 2013). Negative outcomes include bodily concerns; problems in social relationships, including later achievement in psychosexual milestones and less likelihood of marriage and parenthood; lower life satisfaction; fertility concerns; and psychological problems (Dieluweit et al., 2010; Lehmann et al., 2014; Seitz et al., 2011). Positive outcomes include a positive view of life, positive view of self, and compassion for others (Lehmann et al., 2014). Additionally, a more positive view about life years after diagnosis was associated with requesting information soon after diagnosis (Engvall et al., 2011). This finding highlights the importance of information provision in the adolescent cancer setting.

One of the main mechanisms through which patient engagement is developed is the provision of quality information concerning cancer, its treatment, and long-term outcomes (Institute of Medicine, 2013). In general, adolescents want information, delivered in a developmentally appropriate manner, concerning cancer as a disease, available treatments,

physical therapy for rehabilitation, complementary and alternative medicine, psychological therapy, fertility status, fertility preservation, long-term effects of treatment, and survivorship care (Aziz, Oeffinger, Brooks, & Turoff, 2006; Ben Arush, Geva, Ofir, Mashiach, Uziel, & Dashkovsky, 2006; Chapple, Salinas, Ziebland, McPerson, & MacFarlane, 2007; Fernandez et al., 2009; O'Connor et al., 2013; Stinson et al., 2012). In response to vignettes of different oncology visits/experiences, adolescent survivors on and off treatment and their parents preferred information to be given to both the patient and the parent simultaneously, but they also reported that an 8-year-old patient should receive information at a different time from their parents as compared to a 12-year-old patient (Zwaanswijk et al., 2011). In interviews with adolescent cancer patients and their parents, Baker et al. (2013) found differences in the priorities of parents and adolescents within the clinical trial enrollment discussion, further highlighting the importance of both family members and patients in the adolescent oncology setting.

Most adolescent cancer patients recognize that their personal preference for how much information they want is subject to change, most often as they age or move through the cancer continuum (Hinds et al., 2005; Zwaanswijk, Tates, van Dulmen, Hoogerbrugge, Kamps, & Bensing, 2007). Adolescent cancer patients also discuss the need to be addressed appropriately, not like a child or an adult, and they report a lack of resources and services targeted directly to their age group (Zwaanswijk et al., 2007; Stinson et al., 2012); they felt as if they were “without a home” (p. 282, Stinson et al., 2012) for their cancer experience. Ethnographic interviews with staff and patients in an adolescent-focused cancer unit in the United Kingdom concurred with these reports because a main benefit of adolescent-focused cancer units was the feeling of shared understanding among the people admitted to and working in the adolescent cancer unit (Kelly, Pearce, & Mulhall, 2004).

In addition to information provision, the Institute of Medicine (2013) highlights the necessity of utilizing shared decision-making practices within the cancer setting. Many adolescent cancer patients, both on and off treatment, report wanting to be involved in decision-making, believe they should make the final decision concerning treatment, and believe they should advocate for themselves (Dunsmore & Quine, 1995; Hinds et al., 2005; Stinson et al., 2012; Zwaanswijk et al., 2007). However, the literature also suggests that there is a discrepancy between the role adolescent patients want to play, the role they actually play, and the role parents and doctors believe they should play (de Vries, Wit, Engberts, Kaspers, & van Leeuwen, 2010; Miller, Baker, Leek, Drotar, & Kodish, 2014; Young et al., 2010). In an observation study of informed consent conferences (ICCs) for a clinical trial, Miller et al. (2014) found that only 43% of the communication within the ICC involved the adolescent patient, the adolescent stated their preference for enrollment in 67% of the ICCs, and the patient was requested to sign the consent form in only 49% of the ICCs.

Talati, Lang, and Ross (2010) provided vignettes to doctors that described medical treatment refusal in minor cancer patients. The vignettes varied in three ways: the diagnosis (poor prognosis with treatment vs. good prognosis with treatment), the age of the patient (11 years old vs. 16 years old), and whether the treatment refusal was made by the patient, the parent, or both the patient and the parent. Overall, doctors were more likely to treat in spite of refusal in the good prognosis vignette, and were more likely to respect the decision of treatment refusal in the poor prognosis vignette. However, across both scenarios, the doctor was more likely to accept the decision of the 16-year-old patient as compared to the 11-year-old patient, particularly in the poor prognosis scenario when the parent wanted to treat but the patient did not. Additionally, over 50% of the doctors said that the 16-year-old patient was the primary

decision-maker whereas 98% of the doctors believed the parent was the primary decision-maker for the 11-year-old patient.

These findings exemplify the importance of examining the doctor-patient relationship within this cancer population. The cognitive and psychosocial changes across this developmental period provide adolescents with an increased ability to make complex medical decisions, but these changes coincide with changes in the still very important parent-child relationship (Benish-Weisman, Levy, & Knafo, 2013; Grotevant & Cooper, 1998; Kagitcibasi, 2003; Tamis-LeMonda et al., 2007). Additionally, as adolescent's transition into adulthood, and the adult healthcare setting, they are expected to begin to make their own, independent healthcare decisions without the help of, or less help from, a parent or guardian. Therefore, the doctor-patient relationship within the adolescent oncology setting provides an avenue through which patient engagement can be developed, and it is important to examine the two most common models for this relationship, patient-centered care and family-centered care, and identify which is most appropriate, and at what times, during the adolescent development period. A comparison of the constructs of these two models of care can be found in Figure 1. Within this figure, constructs that are similar across the two models are shaded in a dark gray, constructs that are similar but still different from each other are shaded in a light gray, and constructs that are different or present in only one model are not shaded. Each model is expanded upon below.

Patient-Centered Care

Patient-centered care has been heavily advocated in the adult medical literature because patients want to feel heard, valued, and empowered to play a role in their treatment (Mullins, Vandigo, Zheng, & Wicks, 2014). Patient-centered care focuses on understanding the whole patient, specifically their values, beliefs, relationships, and environment (Saha, Beach, & Cooper,

2008). Across the number of different models of patient-centered care highlighted in a review, the common core concepts of patient-centered care include: (1) understanding and respecting the patient's values, beliefs, and preferences; (2) provision of information and preventative healthcare; (3) a focus on the doctor-patient relationship, often around sharing power in medical decision-making; and (4) consideration of the patient's environment, such as their relationships with family and friends (Saha et al., 2008).

Adolescents, too, have opinions about their medical care, and often want to play a role in the decision-making process and feel like their values are respected (Coyne, 2006). However, the patient-centered model inherently assumes that patients have the legal authority to make medical decisions, as well as possess the cognitive and psychosocial skills necessary to do so.

Adolescents do not always possess all of the skills necessary to make informed treatment decisions, especially within the emotionally charged situations that often surround major medical decisions (Spear, 2000). This makes it imperative to consider how the preferences of adolescents concerning their involvement in their cancer care vary across the adolescent development period.

A main focus of the patient-centered care model is its emphasis on individually-tailored healthcare, making it applicable to the adolescent chronic illness setting because there is variation in the level of involvement desired by adolescent patients (Taylor, Haase-Casanovas, Weaver, Kidd, & Garralda, 2010). A systematic review of the adult patient-centered literature found an association between the experience of multiple patient-centered care dimensions, such as respect for patient preferences, coordination of care, and involvement of family, and patient satisfaction and self-management behaviors (Rathert, Wyrwich, & Bore, 2012). Rathert et al. (2012) also examined the relationship between individual patient-centered care dimensions and various outcomes. The studies varied in outcomes examined, but respect of patient preferences

and patient involvement was found to be positively associated with outcomes such as lower anxiety, more involvement in medical consultations, and treatment adherence (Rathert et al., 2012).

Adolescents may be able to play a large role in making minor treatment decisions, and allowing adolescents the opportunity to ask questions and gain information about their treatment provides them an avenue towards participation in major treatment decisions (Coyne, Amory, Kiernan, & Gibson, 2014). The provision of information or discussion of preferences is one way in which adolescents can be included in the decision-making process, even if the parents are the ultimate decision makers. Few studies have analyzed this dynamic, but some preliminary evidence suggests that adolescents do not always want to make the final decision, but instead want to feel included (Young et al., 2010). The American Academy of Pediatric Committee on Bioethics (1998) set out guidelines for decision-making in the pediatric setting, and the Committee suggests that children and adolescents should be allowed to participate in decision-making. Unfortunately, most research on decision-making in the pediatric and adolescent medical setting focuses on parents' role in decision-making, leaving out the adolescent patient's role within the decision-making process (Fiks & Jimenez, 2010; Tates & Meeuwesen, 2001).

Family-Centered Care

With the lack of focus on the importance of both the patient and their family members in adolescent healthcare, an alternative model of care that may alleviate these concerns for some patients is the family-centered care model. The family-centered care model developed from research examining the necessity of parents in pediatric hospital settings in both the United States and the United Kingdom (Jolley & Shields, 2009). Even though the presence of parents in

the medical setting has been common practice for decades, research still has not identified the best way for family members to be involved in the care of their adolescent cancer patient.

Frameworks and theoretical considerations have identified five main characteristics of family-centered care (Kuo et al., 2012). Kuo et al. (2012) describe these characteristics in detail, but in summary, doctor-patient relationships grounded in family-centered care principles will (1) provide objective and unbiased information concerning treatment, the diagnosis, and other medical decisions; (2) understand the great amount of diversity in culture, language, and care preferences among those families being treated for cancer, and respect those differences when providing care; (3) be characterized by partnership and collaboration, and treatment decisions are approached with shared goals in mind, and all parties make treatment decisions together; (4) open all treatment decisions to negotiation as care unfolds and outcomes change, and providers and families are flexible and willing to reevaluate treatment decisions if they do not appear to be working in the desired way; and (5) remember and consider that all treatment is conducted in the context of family and community, and ensuring that treatment decisions are respectful of the environment the patient exists in is imperative to quality care.

Systematic reviews of family-centered care interventions in pediatric and adolescent medical settings have found decreased family conflict, better use of health services, improvements in health status, and improvements in family functioning (Kuhlthua et al., 2011; McBroom & Enriquez, 2009). Research conducted in Iran with adolescent cancer patients and their parents found a significant association between adolescents' coping strategies and those of their parents, highlighting the importance of considering the entire family context when making treatment decisions for adolescent cancer patients (Sanjari, Heidari, Shirazi, & Salemi, 2008). Lyon, Jacobs, Briggs, Cheng, and Wang (2013) conducted a family-centered advanced care

planning intervention with adolescent cancer patients. Overall, adolescents and their families who participated in the intervention reported higher levels of congruence on treatment decisions and adolescents reported higher levels of understanding concerning end-of-life decisions.

Although many of the principles of patient-centered and family-centered care are similar, the emphasis they place on the role of the family within the cancer experience marks the major difference between these two models of care. As will be described below, developmental research supports the use of both of these models of care at varying times throughout the adolescent development stage, and in various illness situations. Therefore, research needs to examine which of these models of care are associated with increased patient engagement and, in turn, higher quality of care.

Adolescent Development and Transitional Readiness

Adolescence is a period of development characterized by significant change, and important cognitive and social factors unique to this age group may need to be considered within the cancer setting. Adolescent development researchers are urging for increased focus on this developmental period, suggesting that adolescents should be examined separate from their older and younger counterparts (Grisso & Vierling, 1978; Jensen & Chen, 2013; McCabe, 1996). These recommendations complement the recommendation of the NCI and LiveStrong progress review group to consider narrower distinct groups of patients within the AYA cancer population (NCI, 2006).

Over the course of adolescence, individuals experience a number of physical, cognitive, and psychosocial changes (McNeely & Blanchard, 2009). These changes will impact adolescents' daily lives, their healthcare, and their ability to take on adult responsibilities when they reach 18 years of age. This transition from the dependence of childhood to the independence

of adulthood occurs within the education, financial, and vocational domains of life for most individuals, including cancer patients. However, adolescent cancer patients also need to transition from pediatric to adult healthcare settings, and this transition marks an important change for some of these patients – responsibility for their own healthcare. Although parents may remain involved in healthcare during young adulthood, adolescents still need to prepare for independent medical decision-making and care management. As such, doctors within the oncology setting need to consider all of the physical, cognitive, and psychosocial changes common during this period of development when determining the best ways to provide care.

Adolescents begin to improve their reasoning skills and information processing abilities, and start to gain expertise in areas of interest (Collins & Steinberg, 2006). Abstract and hypothetical thinking improves throughout early adolescence and into middle adolescence, and by late adolescence individuals are able to utilize foresight, plan ahead, and set goals and achieve them (Collins & Steinberg, 2006; McNeely & Blanchard, 2009; Mello et al., 2009; Piaget 1972/2008). Neuroscience research has found that the area of the brain responsible for executive functioning, the prefrontal cortex, develops gradually across adolescence and into young adulthood (Bonnie & Scott, 2013). Specifically, changes in the brain structure account for increases in information processing speed, the ability to do physical and mental work, the ability to plan ahead, and the ability to consider multiple sources of information in decision-making (Keating, 2012; McNeely & Blanchard, 2009; Overton, 1990; Spear, 2000; Steinberg, 2009). Therefore, although adolescent brain function has improved from early and middle childhood, there are still some important functions that are developing as they reach the late stages of adolescence and begin to transition into young adulthood. This makes it difficult for adolescents

to participate in some aspects of medical decision-making without the help of a parent or healthcare provider.

Psychosocial development represents important changes in emotion regulation and social relationships that occur during the adolescent period. Increases in dopamine during early adolescence make individuals prone to risk-taking or sensation-seeking (Chambers, Taylor, & Potenza, 2003), and increases in cortical connections in late adolescence allow higher levels of emotion regulation (Eluvanthigal, Hasan, Kramer, Fletcher, & Ewing-Cobbs, 2007; Steinberg, 2009). The increase in these connections is what allows adults to make logical and rational decisions in the face of emotionally-charged situations, like the diagnosis of a life-threatening illness, something that may be difficult for adolescents to accomplish on their own (Turner-Henson, 2005).

These cognitive and psychosocial changes mark important considerations when analyzing the readiness of an adolescent patient to transfer from pediatric to adult healthcare, an important transition for any individual with special healthcare needs. Adolescents with special healthcare needs that successfully transition to adult healthcare report satisfaction with the increase in control, improvements in health-related quality of life, and improvement in health status (Holmes-Walker, Llewellyn, & Farrell, 2007; McDonagh, Southwood, & Shaw, 2007; Tuchman, Slap, & Britto, 2008). The American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), the American College of Physicians-American Society of Internal Medicine (ACP-ASIM), and the Transitions Clinical Report Authoring Group (TCRAG; 2011) created an algorithm to guide the transition process for adolescent patients with special healthcare needs. Within these guidelines, the authors highlighted the importance of regular (at least yearly) assessments of an adolescent's ability to self-manage their healthcare, ability to live

independently, and identify appropriate educational or vocational training (AAP et al., 2011). These continual assessments across time allow for tracking of the developmental changes common in this stage of development, altering the adolescent's medical involvement accordingly, and stepping away from assuming the development of certain skills based on age ranges. However, research conducted on transition medicine following the publication of these guidelines have found mixed results (Bloom et al., 2012). Although researchers and clinicians agree that transition medicine should be tailored to each individual patient, continue to evaluate the adolescent's self-management abilities, and that the process should start early (Al-Yateem, 2013), large scale surveys of youth with special healthcare needs found that between only 21.6 to 40.0 percent report meeting these transitional goals (McManus et al., 2013; Oswald et al., 2013; Sawicki et al., 2011).

With patient engagement being the center of the Institute of Medicine's (2013) framework for high quality cancer care, it is imperative to consider how to improve engagement in the adolescent cancer population. However, the vast amount of changes that occur during the adolescent development period make it impractical to suggest that only one element of the doctor-patient relationship is satisfactory to improve patient engagement. Therefore, the doctor-patient relationship, the patient's age, and their developmental status all need to be considered when examining patient engagement and quality of care in the adolescent oncology setting.

Study Conceptual Model

Highlighting the importance of examining several potentially relevant factors associated with patient engagement and quality of care in the adolescent oncology setting, a diagram of this study's conceptual model was developed and can be found in Appendix B. As can be seen in the model, the main relationship of interest is the association between patient engagement and

quality of care in adolescent oncology. In addition to support for this relationship in the empirical literature, the Institute of Medicine (2013) framework highlights this relationship as the center of quality of care improvement. However, the literature on adolescents and adolescent cancer patients more specifically suggest that this relationship does not occur in isolation from other important factors, including the model of care utilized in the doctor-patient relationship and the patient's age and developmental status. Therefore, as can be seen in the diagram, this study will also examine the role patient-centered care and family-centered care play in the association between patient engagement and quality of care. Finally, these interactions occur within the context of the patient's age and developmental status. As these two variables are constantly changing, it is important to consider how they relate to all of the variables examined in this study.

The larger goal within the field is to provide high quality cancer care to all cancer patients, and research suggests that engaged patients perceive higher quality care and experience better health outcomes (Greene & Hibbard, 2011; Hibbard & Greene, 2013; Hibbard et al., 2007). However, this research has not considered developmental variability in the ability and desire to be engaged in healthcare. In order to provide high quality care to adolescents, we need to first understand what patient engagement looks like for them, how it's associated with their perception of quality of care, and the role doctors and parents may play in this relationship.

Chapter 3

Present Study

This study examined the relationship between patient engagement and quality of care in the adolescent oncology setting. Additionally, this study explored how the relationship between patient engagement and quality of care is moderated by patient-centered care, family-centered care, age, and developmental stage. The Institute of Medicine (2013) places the engaged patient at the center of their high quality cancer care framework, arguing that supporting patient engagement within the cancer setting is the highest priority for the improvement of cancer care in the United States. Therefore, it is important to consider what specific models of care (i.e. patient-centered care and/or family-centered care) utilized during cancer care in adolescence are associated with higher levels of patient engagement and quality of care.

Currently, there is little research that explicitly looks at the experience of the doctor-patient relationship for adolescent cancer patients (Siembida & Bellizzi, 2015). Additionally, the small, mixed-age samples commonly used in research within this population, and lack of agreement on a definition of “adolescent” makes it difficult to examine whether patient-centered care, family-centered care, or the use of both models of care at different times across the adolescent development period is more appropriate within the adolescent oncology setting (Siembida & Bellizzi, 2015). Finally, decisions made by doctors and family members are often driven primarily by age, but developmental research suggests there is great individual variation in the timing of developmental milestones across this period of the lifespan, making age as a marker for developmental skills potentially inappropriate (Berger, 2005; McNeely & Blanchard, 2009).

Due to these limitations, and a focus in the cancer literature on improvement in quality of care, the first aim of this study was to examine patient engagement and quality of care:

RQ1: What is the relationship between patient engagement and quality of care in the adolescent oncology setting?

Hypothesis 1: Adolescents with higher levels of patient engagement will report higher quality of care.

Since little research has focused on the doctor-patient relationship in adolescent oncology, the second aim of the current study was to examine the frequency of the two most common models of care, patient-centered and family-centered care:

RQ2: What is the frequency of patient-centered care and family-centered care within the adolescent oncology setting?

Hypothesis 2: Family-centered care will be experienced more frequently by adolescent cancer patients.

Research on both patient-centered and family-centered care have found them to be good models of care associated with a number of positive patient outcomes, however, research has not considered how the appropriateness of these models of care for each individual patient may vary as a function of patient age and developmental stage:

RQ3: How does the frequency of patient-centered care and family-centered care vary according to the adolescent patient's age or developmental stage (measured by cognitive autonomy and transitional readiness)?

Hypothesis 3a: The experience of patient-centered care will increase as adolescents get older.

Hypothesis 3b: The experience of family-centered care will decrease as adolescents get older.

Hypothesis 3c: The experience of patient-centered care will increase as adolescents' developmental stage (measured by cognitive autonomy and transitional readiness) increases.

Hypothesis 3d: The experience of family-centered care will decrease as adolescents' developmental stage (measured by cognitive autonomy and transitional readiness) increases.

The limited research available on adolescent cancer patients and the doctor-patient relationship suggests that the experience of patient-centered care, family-centered care, a patient's age, and a patient's developmental stage may all play a role in an individual's engagement in their healthcare. As such, the final aim of this study was to explore how the relationship between patient engagement and quality of care may be moderated by these three variables:

RQ4: How is the relationship between patient engagement and quality of care moderated by patient-centered care, family-centered care, age, and developmental stage (measured by cognitive autonomy and transitional readiness)?

Chapter 4

Methods

Participants

Inclusion criteria for the current study were: most recent cancer diagnosis (either initial diagnosis or recurrence) between the ages of 10 and 20, being at least 3 months from most recent diagnosis, having received active treatment including a form of treatment other than surgery (individuals who had a tumor removed but no other forms of treatment were not considered eligible), and no more than 2 years off active treatment. There was no cap placed on the maximum age participants could be at the time of recruitment as long as they fit all of the inclusion criteria. However, the oldest participant in the current study was 21 years of age at the time of the survey.

The age range of 10 to 20 years of age at diagnosis was chosen in order to account for the developmental changes that occur across this time period, the legal implications of minor patients, and cross-cultural variations in the definition of adolescent patients (JAYAO, 2011). Additionally, patients' most recent cancer diagnosis, either their initial diagnosis or their most recent recurrence, was used to determine eligibility for this study. Therefore, patients could have been diagnosed with cancer prior to age 10, but have experienced a recurrence at age 15 and qualified for participation. Patients were required to be at least 3 months from their most recent diagnosis (either initial diagnosis or recurrence) to allow them to process their diagnosis. By utilizing this inclusion criterion, the prevention and screening stages of the cancer care continuum were not examined. Because these conversations are often conducted in the general practice or pediatric setting, and do not typically include the oncology medical team, these stages were not the focus of the current study. The current project was interested in examining

communication within the oncology setting. Finally, the longer-term survivorship stage of the cancer care continuum was not examined because participants would have had to retrospectively consider their experiences during cancer treatment, and since this could have occurred many years ago, their responses could be prone to bias.

Potential participants were excluded from participation if they did not meet all of the above inclusion criteria, or fit into one of the exclusion criteria categories. Specifically, potential participants were excluded if they: could not read or speak English, were diagnosed with a developmental disorder, or they were diagnosed with a physical disability that would prevent them from completing the survey (i.e. blindness).

To determine eligibility for the study, patient charts were screened for inclusion criteria by the principal investigator and clinical research and nursing staff at the two hospitals. A total of 97 participants fit the inclusion criteria. Of the 97 qualified participants, 86 were approached about the current study. The most common reasons for not approaching qualified participants included appointment cancellations or research staff missing the patient while at clinic. Of those approached, 82 individuals agreed to participate, and 81 participants completed the survey. Therefore, this study had a participation rate of 94.2%. Most participants did not give a reason for refusal, but those that did usually indicated they did not have enough time to complete the survey. Following data collection, one additional participant was eliminated due to missing data. Overall, a sample of 80 individuals was examined for this study. A flowchart describing the recruitment process of the current study can be found in Figure 2.

Participant Recruitment

Participant recruitment occurred from November 2, 2015 to April 1, 2016 at two metropolitan medical centers – Smilow Cancer Hospital at Yale-New Haven and Connecticut

Children's Medical Center (CCMC). Institutional Review Board (IRB) approval was received from CCMC, and honored by the Yale Medical School IRB and the University of Connecticut IRB. Located in southern Connecticut, Smilow Cancer Hospital has a pediatric hematology/oncology program that serves up to 100 new patients every year. The pediatric hematology/oncology program at Smilow Cancer Hospital serves infant, children, and young adult patients who are receiving treatment for cancer. Over the course of study recruitment, 27 patients fit the inclusion criteria for this study, and 25 were approached. Of the 25 individuals approached, 24 agreed to participate in the project, leading to a participation rate of 96.0% at Smilow Cancer Hospital.

As a whole, CCMC serves children and adolescents that require medical care, and it is one of only two free-standing medical centers focused on providing care to pediatric populations in New England. The CCMC hematology/oncology department has a specific program of care dedicated to the treatment and experience of adolescents and young adults diagnosed with cancer, and an estimated 150 patients served in the clinic meet the inclusion criteria of the study. Over the course of recruitment, 70 patients fit the inclusion criteria for this study, and 61 were approached. Of the 61 approached, 57 agreed to participate in this study, leading to a response rate of 93.4% at CCMC.

The recruitment strategies at each site were similar, but varied slightly. At Smilow Cancer Hospital, a nurse practitioner who works with adolescent cancer patients was the main point of contact for recruitment. She screened through the daily appointments on the days she was present in clinic, and the principal investigator came into the outpatient clinic on any day a qualified participant had an appointment. Once at the clinic, the principal investigator also contacted a physician assistant working on the pediatric oncology inpatient floor and asked if any

qualified patients were currently admitted. For those potential participants with outpatient appointments, the nurse practitioner approached them during their clinic appointment and introduced them to the study or gave them the study flyer. The study flyer can be found in Appendix C. If the participant expressed interest, the principal investigator approached the participant, gave more details, consented the participant, and administered the survey on a tablet. Participants who were given the flyer also had the option of texting “adolescent survey” to the principal investigator to indicate interest in the study. For potential participants recruited on the inpatient floor, the physician assistant and the principal investigator approached patients in their hospital rooms and the physician assistant introduced the principal investigator. The principal investigator then gave more background about the study, consented interested patients, and administered the survey on a tablet.

Participant recruitment at CCMC was conducted in-person at the CCMC hematology/oncology clinic. Prior to the start of recruitment, the principal investigator attended a hematology/oncology department staff meeting to introduce herself and the project. Recruitment occurred on all clinic days that had qualifying patients scheduled. At the beginning of each week, the principal investigator screened through the clinic’s weekly appointments and determined who was eligible for the study. Throughout the week, either the principal investigator or a clinical research associate employed by CCMC would recruit participants. Prior to approaching qualified patients, the principal investigator or clinical research associate asked nursing staff or doctors if that day was a good time to approach the patient concerning the study, and asked at what time during their appointment would be the best moment for approach. After identifying the best moment of approach, participants were approached about the study. They were given a brief introduction to the study, consented if interested, and administered the survey on an iPad.

Recruitment was conducted in-person at both Smilow Cancer Hospital and CCMC, and as such, a member of the research team was always present during the survey to answer any questions the participant may have. At the start of the survey, participants were also told that they were able to ask their parent/guardian any questions they may have as well. All participants received a \$20 Amazon gift card for participating in the study.

Data Collection

Data for this study was collected using an online survey developed using Qualtrics. The survey was anonymous; IP addresses were not collected, and email addresses were not linked to individual survey responses. The first page of the survey was an informational page introducing the study, the study's purpose, why the person was directed to the study, and provided information on the compensation they would receive for completing the survey. This page also included contact information for the study research team. A copy of the online survey introduction can be found in Appendix D.

Parents were then directed to the consent page where they read and agreed to their child's participation in the study. Individuals could not continue forward in the survey without agreeing to the consent page. The adolescent participants were then directed to the assent page where they read and agreed to participate in the survey. Participants could not begin the survey without agreeing to the assent page. After consent and assent were obtained, participants were directed to the start of the online survey. Participants moved through the survey one screen at a time, and participants were provided the option to skip any question they were not comfortable answering. The majority of participants completed the survey in 10 to 15 minutes.

Survey Pre-Testing

Because of the differences in reading comprehension and cognitive development among the targeted population, the survey was pre-tested with a small focus group of adolescents. The purpose of the pre-testing focus group was to elucidate whether or not the survey was able to be used with participants in the targeted age range for this study (10-20 years of age at diagnosis). We were specifically interested in making sure that the questions and response items were understandable, and that most participants were able to complete the survey in about 15-20 minutes. All of the measures utilized in this study were previously validated with high school and older populations, so recruitment efforts were focused on participants in the younger range of the target age group. We used a targeted recruitment strategy for the pre-testing focus group, and identified a staff member at a local K-8 school who agreed to work with the research team on identifying potential participants for the pre-testing focus group.

The staff member was instructed to focus on individuals between the ages of 10 and 13, regardless of their medical history. When a potential participant was identified, the staff member contacted the parent and/or guardian and briefly discussed the study, the purpose of pre-testing, the length of the time commitment for their child (about 30 minutes), and compensation for participation. When the parent agreed to have their child participate, the principal investigator met with the participant, explained the pre-testing procedures, and begin the pre-testing process. Consent and assent was received through the online survey, and then participants took the online survey without interruption. This first step monitored how long it took individuals to complete the survey. Once the participant finished taking the survey, the principal investigator conducted cognitive interview testing with the participant, and then gave them their \$20 Amazon gift card. The survey was modified slightly to change terms like “oncologist” or “cancer care team” to more general phrases like “your doctor” or “your medical providers.” Questions related

specifically to a cancer diagnosis (i.e. ‘what was your cancer diagnosis’ or ‘what types of treatment have you received for your cancer’) were eliminated, and one question asking if they had been diagnosed with any chronic illnesses was added.

The cognitive testing was conducted by the principal investigator under the supervision of her major advisor, Dr. Bellizzi, who has previous experience with these procedures. A retrospective verbal probing technique modified for use in childhood populations was used to determine the developmental validity of the survey (Willis & Research Triangle Institute, 1994; Woolley, Bowen, & Bowen, 2004). Following completion of the survey, the principal investigator went back through the survey with the participant and asked the following questions, as appropriate: (1) asked the child to read the question aloud, (2) asked the child to repeat the question in their own words, (3) asked the child to pick the best answer to the questions, and (4) asked the child to explain why they chose their answer (Woolley et al., 2004). Following completion of each cognitive interview, the principal investigator summarized each child’s responses along with her own observations on a question-by-question basis, and these notes were then aggregated across all the pre-test participants (Willis & Research Triangle Institute, 1994).

A total of 4 adolescents were recruited as part of the pre-testing focus group. The pre-testing participants ranged in age from 10 to 17 and there were 2 boys and 2 girls. Two of the pre-testing participants had been previously diagnosed with a chronic illness, including ADHD/ADD and diabetes. It took the participants an average of 11 minutes to complete the survey. The pre-testing focus group had the most trouble on questions concerning transitional readiness, and found the response options for cognitive autonomy the most difficult to understand. Demographic details and survey completion time about each pre-testing participant can be found in Table 1, and the aggregated pre-testing notes and changes made to the survey in

response to the focus group responses can be found in Appendix E. These aggregated pre-testing notes were reviewed by the principal investigator and Dr. Bellizzi, and they determined the appropriate changes to be made to the survey. The final version of the survey used in the current study can be found in Appendix F. The remaining discussion of the study measures represents the final, modified version of each measure based on the pre-testing process.

Measures

Demographic information. The online survey included questions that asked about demographic characteristics of the participants. The demographic characteristics included were age, gender, education, racial/ethnic group, treatment location, cancer diagnosis, age at diagnosis, time since diagnosis, time since end of treatment, type of treatment, and recurrence history. These demographic characteristics were assessed by questions listed at the start of the survey, and participants were instructed to ask their parent or guardian for help if they were unsure of the answer to any of the questions.

Patient engagement. A modified version of the Health Self-Efficacy subscale of the Youth Engagement with Health Services (YEHS!) survey was used to evaluate patient engagement (Sebastian, Ramos, Stumbo, McGrath, & Fairbrother, 2014). The YEHS! survey was developed and validated for use with healthy adolescent populations. Because it was originally developed for use with healthy populations, individual items were modified or eliminated to focus explicitly on care received within the oncology setting. The YEHS! survey included five items, and participants were asked to respond to each item using a 4-point Likert response scale with 1 = Strongly disagree, 2 = Somewhat disagree, 3 = Somewhat agree, and 4 = Strongly agree. Items on this scale included: “I have a safe and trusting relationship with at least one member of your cancer care team” and “I will tell my oncologist my concerns, even if they

do not ask.” The five items were summed to create a patient engagement score, and scores could range from 5 to 20. Higher scores represent more patient engagement. Internal consistency for the present sample was fair, Cronbach’s $\alpha = .76$.

Models of care. Patient-centered and family-centered care were measured using a modified, shortened version of the Give Youth a Voice (GYV) questionnaire (Klassen et al., 2013) and the Measure of Processes of Care (MPOC-20) scale (Klassen et al., 2008). In order to decrease participant burden and eliminate overlapping questions, items most relevant to the theoretical constructs of patient-centered care and family-centered care discussed in the introduction of this proposal were chosen from each measure to create a fourteen item scale with eight questions measuring patient-centered care and six questions measuring family-centered care. Additionally, the questions taken from the MPOC-20 scale were modified to extract the adolescent’s perspective. The original scale was intended for use with parents of pediatric cancer patients.

The instructions asked participants to think about the doctors and nurses who helped during their cancer treatment and identify how often each item happened or did not happen. Participants were asked to respond to each item using a 4-point Likert scale with the following labels: 1 = never, 2 = sometimes, 3 = most of the time, and 4 = all the time. Participants were also able to select ‘does not apply to me’ as a response. An example of an item from each scale include: “allow you to answer questions” (patient-centered care) and “show they care about you and your family” (family-centered care). The scores were summed across all items in each subscale (‘does not apply to me’ responses were given a score of 0 for these calculations). Patient-centered care scores could range from 0 to 32 with higher scores indicating more patient-centered care received. Family-centered care scores could range from 0 to 24 with higher scores

indicating the receipt of more family-centered care. Internal consistency for the present sample on patient-centered care was good, Cronbach's $\alpha = .84$. Internal consistency for the present sample on family-centered care was poor, Cronbach's $\alpha = .68$.

Quality of care. Perceived quality of care, or experience of care, was measured using the self-report Experience of Care Subscale from Sebastian et al.'s (2014) Youth Engagement with Health Services (YEHS!) survey. This subscale was originally developed as part of Hays et al.'s (1999) Consumer Assessment of Health Plans Study (CAHPS), but the current study utilized the question and response format from Sebastian et al.'s (2014) survey because it was tested and validated with an adolescent sample. This scale included five questions that measured adolescent's perceptions of the care they received from their health care providers. Questions were modified slightly to focus them specifically on the oncology setting. Participants responded using a 4 point Likert scale with responses ranging from 1 = Strongly disagree to 4 = Strongly agree. Items from this scale included questions such as "During cancer treatment, did your oncologist or other members of your cancer care team listen carefully to you" and "During cancer treatment, did your oncologist or other members of your cancer care team explain things in a way that you could understand?" The scores were summed across the five items, and scores could range from 5 to 20. Higher scores indicated the perception of higher quality of care. Internal consistency for the present sample was poor, Cronbach's $\alpha = .37$.

Due to the poor reliability for the quality of care measure, exploratory analyses were conducted to determine which item(s), if any, was causing reliability concerns. By looking at item-level specific results, it was determined that the item "Did you have a hard time speaking with or understanding your care team because you spoke different languages" was causing the low reliability in the present sample. This was unsurprising because the majority of the

participants in the current study were monolingual in English, and their doctors also spoke English. A number of participants expressed confusion on how to answer this item as they did not believe it applied to them. Due to the results of both the analyses and the anecdotal evidence of the primary investigator's experience during data collection, this item was removed from analyses. Therefore, perceived quality of care was measured using the modified four-item scale with scores ranging from 4 to 16 and higher scores indicating a perception of higher quality of care. Internal consistency for the modified scale in the present sample was satisfactory, Cronbach's $\alpha = .72$.

Developmental stage. In order to determine if the use of patient-centered care or family-centered care varies according to development, two measures of developmental milestones were included. Development includes a number of important changes across the adolescent period, but for the sake of participant burden, only two areas of development were measured in this study – cognitive development and transitional readiness. Both of these developmental areas are particularly important when examining decision-making and engagement in a health care setting. Cognitive development was measured using the Cognitive Autonomy and Self-Evaluation (CASE) Inventory (Beckert, 2007). The final version of the inventory was tested in a sample of adolescents ranging from 7th grade to college students under the age of 20 and found that the measure was able to discern cognitive differences among this diverse age group (Beckert, 2007). The full inventory includes 27 items grouped into five subscales: evaluative thinking (8 items), voicing opinions (5 items), decision making (6 items), self-assessing (3 items), and comparative validation (5 items). For the current study, only those questions from the decision making and evaluative thinking subscales were utilized, and a total of 14 questions were used to measure cognitive development. Participants were asked to score each item on a 4-point response scale:

never, sometimes, often, and always. Items from each subscale are as follows: “I think about the consequences of my decisions” (evaluative thinking) and “There are consequences to my decisions” (decision making). Scores were summed across the 14 items, and scores could range from 14 to 56 with higher scores indicating higher cognitive autonomy. Internal consistency for the CASE Inventory in the current sample was good, Cronbach’s $\alpha = .85$.

To measure transitional readiness, a modified version of the Transition Readiness Assessment Questionnaire (TRAQ) was used (Sawicki et al., 2011). The TRAQ was developed to assess the readiness of young adults with special health care needs to transition to adult healthcare services and independent living. In order to modify this measure to be used with adolescent cancer patients, where appropriate, individual items were altered or eliminated to focus explicitly on care within the adolescent oncology setting. This measure included 8 items, and participants were asked to respond to each item using a 4-point Likert scale with 1 = never, 2 = sometimes, 3 = often, and 4 = always. Participants were also able to select “My parent/guardian does this” for all 8 questions, and “Does not apply to me” for some of the questions. Example items included “Do you fill out the medical history form, including a list of your allergies” and “Do you apply for a job or college when necessary?” Scores for each item were dichotomized with participants indicating they ‘never’ did the item, their ‘parent/guardian’ does the item, or it ‘does not apply’ to them given a score of 0, and those who indicated doing the item at any level given a score of 1. The dichotomized variables were then summed across all 8 items, and scores could range from 0 to 8. Higher scores indicated participant’s increased readiness to transition to independent living.

Data Analysis

Power analysis. In order to determine the necessary sample needed to test the hypotheses of the current study, a power analysis was conducted using G*Power 3, a statistical power analysis program (Faul, Erdfelder, Lang, & Buchner, 2007). In order to determine the sample size needed for this study, two separate power analyses were run; the first for the multiple linear regression conducted to analyze the first research question, and the second for the multiple linear regression conducted to analyze the fourth research question. For the first power analysis, a linear multiple regression: fixed model, R^2 deviation from zero was selected as the type of test, and an effect size of 0.15 (a moderate effect) was chosen because previous research with the YEHS! scale (Sebastian et al., 2014) found results with moderate to large effect sizes. The alpha level was set at .05, the power was set to .80, and a total of 7 predictors were tested within the final model. With these parameters, G*Power 3 calculated that a total sample of 103 participants was necessary for these analyses. With a final sample of 80 patients, this necessary sample size was not met.

An additional goal of the current study was to explore moderation analyses. Because this was an exploratory aim, a sample size necessary for these analyses was not targeted, however, a second power analysis was conducted to determine the necessary sample size needed to run the moderation analyses with satisfactory power. In order to determine this, a linear multiple regression: fixed model, R^2 deviation from zero was selected as the type of test, and an effect size of 0.15 was chosen, as described above. The alpha level was set at .05, the power was set at .80, and the number of predictors was set at 11 in order to include the need for interaction terms. With these parameters, G*Power 3 calculated that a total of 123 participants was necessary to run moderation analyses with satisfactory power. Because the research question specific to the moderation analyses was an exploratory question, the final proposed sample size for this project

was 103 participants. The final sample size analyzed in this study was 80 participants, and as such, the moderation analyses conducted in this study were underpowered; however, bootstrap samples (as described later in the data analysis section) were utilized to combat this concern. Additionally, due to the scant research conducted with this population and the exploratory aim of this question, these analyses still provide useful information.

Data management. Data management and cleaning was conducted during recruitment and following recruitment completion. At the end of each month of recruitment, data was downloaded from the Qualtrics website and cleaned. The data cleaning process included recoding variables according to the codebook, preparing the data to be uploaded into SPSS, and identifying missing data.

Managing missing data is an important step in the analysis process. Therefore, this study took a conservative approach to missing data. Participants that were missing more than 25% of their data were eliminated from all further analyses. Next, individual items were analyzed for missing data. If an individual item was missing more than 10% of its data, the item was removed from the dataset. Since the variables of interest in this study are created from a combination of items, missing data was also examined at the variable level. To accomplish this, a number of things were assessed. First, if any items were deleted due to missing data, each variable was examined to make sure enough items still remained to lead to reliable analysis of the variable. Each variable needed to have at least 4 items. Next, if participants were missing a score on just one or two items from the measure, scores on the composite variable were calculated by giving the missing items a score of zero. Finally, if across participants more than 10% of the data is missing, then the variable will be eliminated from analysis.

Descriptive statistics and correlations. Before conducting analysis for each of the research questions and hypotheses, descriptive statistics and correlations were examined. Descriptive statistics that were calculated included means and standard deviations for continuous variables, and Ns and percentages for categorical variables. Because the main analytic approach in the current study was multiple linear regression, regression diagnostics were analyzed to determine if any assumptions of the regression framework were violated. Specifically, multicollinearity, Cook's Distance, Mahalanobis distance, homoscedasticity, and distribution of residuals were all analyzed. Both correlations and the variance inflation factor (VIF) were used to assess multicollinearity between the variables of interest in the current study. A cutoff of 2.50 on the VIF was used to determine multicollinearity concerns; if a variable had a VIF above 2.50, then it was examined further for multicollinearity issues.

RQ1 and hypothesis 1. The first research question and accompanying hypothesis aimed to examine the relationship between patient engagement and perceived quality of care. In order to answer this question, a two-step analytical process was used. First, a Pearson correlation coefficient was calculated between patient engagement and perceived quality of care to determine the presence of a significant bivariate relationship. Next, a multiple linear regression model with two steps was developed. The first step included any demographic or illness-related variables found to be significantly associated with perceived quality of care. These significant relationships were determined using Pearson correlations, *t*-tests, and ANOVAs, where appropriate. The second step added patient engagement to the model to determine if patient engagement was a significant, unique predictor of perceived quality of care over and above the control variables.

RQ2 and hypotheses 2. The second research question and its accompanying hypothesis examined the frequency of patient-centered care and family-centered care in the adolescent oncology setting. To answer this question, frequencies and descriptive statistics were calculated. Specifically, the participants' average score for the patient-centered care measure and the family-centered care measure were analyzed, and the percentage of participants who reported experiencing each model of care was analyzed. Results of this analysis indicated if participants experienced one model of care more frequently, less frequently, or at a similar frequency as compared to the other model of care.

RQ3 and hypotheses 3a, 3b, 3c, 3d. The third research question and its accompanying hypotheses examined if the frequency of patient-centered and family-centered care varied based on the patient's age or developmental stage. To answer this question a two-step analysis process was conducted. First, Pearson correlation coefficients were calculated for the following associations: patient-centered care and patient age; family-centered care and patient age; patient-centered care and cognitive development; family-centered care and cognitive development; patient-centered care and transitional readiness; family-centered care and transitional readiness; patient-centered care and patient engagement; family-centered care and patient engagement; cognitive development and patient engagement; and transitional readiness and patient engagement. If significant correlations between the models of care, patient age, the developmental measures, and patient engagement were found, additional analyses were conducted to further explore how the relationship between model of care and patient engagement varies as a function of age and/or developmental stage. A linear regression, moderation framework using the PROCESS macro in SPSS was utilized to examine the relationship between

patient-centered care and family-centered care and patient engagement as a function of age and developmental stage.

If significant correlations were found between patient-centered care and patient age, cognitive development, transitional readiness, and/or patient engagement, the first model examined patient-centered care as the independent variable, patient engagement as the outcome variable, and age, cognitive development and/or transitional readiness as the moderator(s). For this analysis, Model 2 was selected, and 2000 bootstrap samples were calculated. All 95% confidence intervals were bias corrected, and patient-centered care, patient age, cognitive development, and/or transitional readiness were mean-centered. Heteroscedasticity-consistent standard errors were calculated to protect against any violation of the homoscedasticity assumption. Mean centering the predictor and moderating variables allows for the examination of the effect of one variable on the outcome at the mean level of the other variables in the model.

The second model tested the moderating role of patient age, cognitive development, and/or transitional readiness on the relationship between family-centered care and patient engagement. For this analysis, Model 2 was selected, and 2000 bootstrap samples were calculated. All 95% confidence intervals were bias corrected, and family-centered care, patient age, cognitive development, and/or transitional readiness were mean-centered. Heteroscedasticity-consistent standard errors were calculated to protect against any violation of the homoscedasticity assumption. Mean centering the predictor and moderating variables allows for the examination of the effect of one variable on the outcome at the mean level of the other variables in the model.

These models provide information regarding the unique contribution of each model of care on the variance of patient engagement, and will test the interactions between each model of

care and age and development on the variance of patient engagement. A significant interaction implies that one model of care is significantly associated with patient engagement at specific ages and/or developmental stage in adolescent oncology patients.

The main limitation of the PROCESS macro for analyzing moderation is the inability to examine more than one independent variable in the same model. Therefore, if no significant interactions are present, both models of care and developmental measures will be included in a multiple linear regression framework to determine the relationship between these independent variables and patient engagement when examined together.

RQ4. The fourth research question aimed to explore if the relationship between patient engagement and perceived quality of care was moderated by patient-centered care, family-centered care, age, and/or developmental stage. To answer this research question, the PROCESS macro was utilized to run three separate moderation analyses.

The first model tested the moderating roles of patient-centered care and family-centered care on the relationship between patient engagement and perceived quality of care. Before creating the model, bivariate correlations and ANOVAs were conducted with demographic and illness-related variables and perceived quality of care. If any significant relationships were present, the demographic or illness-related variables were included as covariates. The PROCESS model was then constructed with perceived quality of care as the outcome variable, patient engagement as the independent variable, and patient-centered care and family-centered care as the two moderators. Model 2 was selected, and 2000 bootstrap samples were utilized with all 95% confidence intervals being bias corrected. Patient engagement, patient-centered care, and family-centered care were mean centered and heteroscedasticity-consistent standard errors were utilized. Mean centering the predictor and moderating variables allows for the examination of the

effect of one variable on the outcome at the mean level of the other variables in the model. The use of heteroscedasticity-consistent standard errors protects against any violations of the homoscedasticity assumption.

The second model tested the moderating role of patient age on the relationship between patient engagement and perceived quality of care. In constructing this model, demographic or illness-related variables found to be significantly related to perceived quality of care were included as covariates, perceived quality of care was the outcome variable, patient engagement was the independent variable, and patient age was the moderator. For this analysis, Model 1 was selected, and 2000 bootstrap samples were calculated. All 95% confidence intervals were bias corrected, and patient engagement and patient age were mean-centered. Just as in the analysis above, heteroscedasticity-consistent standard errors were calculated to protect against any violation of the homoscedasticity assumption. Because this model has only one moderator, the Johnson-Neyman method was also utilized to determine the zone of significance for the moderator. In other words, if patient age is a significant moderator, the Johnson-Neyman method displays at what age the relationship between patient engagement and perceived quality of care significantly changes.

The final moderation model tested the moderating roles of cognitive development and transitional readiness on the relationship between patient engagement and perceived quality of care. Demographic and illness-related characteristics found to be significantly related to perceived quality of care were included as covariates, and PROCESS Model 2 was chosen as the model. Perceived quality of care was the outcome variable, patient engagement was the independent variable, and cognitive development and transitional readiness were included as moderators. Two thousand bootstrap samples and 95% bias corrected confidence intervals were

calculated. Patient engagement, cognitive development, and transitional readiness were mean centered and heteroscedasticity-consistent standard errors were calculated.

The main limitation of the PROCESS macro for testing moderation is the inability to include more than one independent variable in the same model. Therefore, if there were no significant interactions found in the previous 3 models, a multiple linear regression model will be tested to examine the relationships between each of the main variables of interest (patient engagement, patient-centered care, family-centered care, patient age, cognitive development, and transitional readiness) and perceived quality of care. Demographic and illness-related characteristics found to be significantly related to perceived quality of care were included as control variables in the first model, and the main variables of interest were added in the second model.

Chapter 5

Results

Overall, a total of 81 individuals were recruited for this study, and one was eliminated due to missing more than 25% of their data. Individual items and variables were analyzed for missing data. Based on cutoffs described in the data analysis section above, a total sample size of 80 indicates that an individual item will be eliminated if more than 8 participants do not answer it. No items met this cutoff and, therefore, all items were retained. All variables had at least 4 items, so all variables were retained in the analyses. Next, individual participants were examined to see if they were missing more than two items in a single variable. Two participants were missing data on more than two items for a specific variable, and as such, their scores were not included in analyses that included those variables. Finally, the main study variables were analyzed, and if more than 8 individuals were missing scores, the variables were eliminated. No variables met this cutoff and all were included in the following analyses.

Demographic Characteristics

Information was collected on demographic characteristics and illness-related variables for each participant. Table 2 displays the demographic characteristics of the study sample. Overall, participants were an average of 15.68 (SD = 2.87) years old and had completed 9th grade. The sample had more male participants (N = 46; 57.5%) than female participants (N = 34; 42.5%), and was relatively diverse in terms of racial and ethnic background; sixty-one percent of the sample was white and 39 percent of the sample was from an ethnic minority background. Table 3 displays information regarding the illness characteristics of the study sample. As can be seen in the table, the primary cancer diagnoses included leukemia or lymphoma (N = 47; 59.5%); bone tumors (N = 15; 19.0%); and soft tissue and Kaposi sarcomas (N = 8; 10.1%). On average,

participants were 13.68 (SD = 3.18) years of age at their first cancer diagnosis, and most participants received chemotherapy (N = 78; 97.5%) or surgery (N = 41; 51.2%) as a part of their treatment. Sixty-six percent of participants received more than one form of treatment for their cancer. The sample was relatively evenly split between participants who were receiving active treatment for their cancer (N = 42; 52.5%) and those who had completed active treatment (N = 38; 47.5%), and 21 percent of participants had experienced a recurrence of their cancer.

Because participants were recruited from two different hospitals, participants from each hospital were compared on the main study variables to determine if there were significant differences due to the varying recruitment techniques used at each site. There were no significant differences on any of the main variables of interest between the two hospitals. The variables examined included quality of care, patient engagement, patient-centered care, family-centered care, patient age, cognitive development, and transitional readiness. Therefore, hospital location was not included as a control variable in subsequent analyses, and participants treated at either hospital were examined together, in aggregate.

Finally, *t*-tests, ANOVAs, and Pearson correlations were utilized to evaluate any significant differences in perceived quality of care based on demographic and illness characteristics in the current sample. Table 4 displays the results of these bivariate tests with categorical variables, and Table 5 displays the correlation matrix. Due to the small sample sizes in some of the groups analyzed in the categorical analyses, specifically for the race and diagnosis variables, recoded variables were also analyzed for variation in perceived quality of care based on demographics. Race was recoded to compare individuals indicating a race of White and individuals indicating a race other than White. There were no significant differences in perceived quality of care based on the recoded race variable ($t(78) = 0.57, p = 0.57$). Diagnosis was

recoded to compare individuals with leukemia or lymphoma, individuals with bone tumors, individuals with soft tissue sarcomas, and individuals with all other cancer diagnoses. There were significant differences in perceived quality of care based on the recoded diagnosis variable ($F(3,76) = 4.16, p = 0.009$). The remaining demographic and illness characteristics were not significantly related to perceived quality of care. Therefore, only diagnosis was included as a control variable in all analyses examining perceived quality of care.

Descriptive Statistics of Study Variables

Means, standard deviations, and ranges were calculated for each main study variable and can be found in Table 6. Overall, participants reported high perceived quality of care ($M = 14.88$; $SD = 1.65$) and engagement in their care ($M = 16.24$; $SD = 3.21$). Participants reported experiencing both patient-centered care ($M = 29.35$; $SD = 3.88$) and family-centered care ($M = 21.69$; $SD = 3.00$). In relation to their development, participants were moderately ready to assume the independence of adulthood (Transitional Readiness $M = 4.78$; $SD = 1.99$), and reported a moderate level of cognitive autonomy ($M = 43.76$; $SD = 6.65$).

Research Question 1 and Hypothesis 1

The first research question and its hypothesis aimed to examine the relationship between patient engagement and perceived quality of care. Patient engagement and perceived quality of care were not significantly correlated with each other at the bivariate level ($r = .13, p = .24$). A full correlation matrix examining the bivariate relationships between the main study variables can be found in Table 7.

Prior to interpreting the regression results, regression diagnostics were conducted. First, outliers or cases that may cause undue influence on the model were analyzed through a number of different mechanisms. The standardized residuals were analyzed, and only one residual was

greater than 3.29. Additionally, when looking at the larger standardized residuals as a whole, no more than 5% of the cases had values greater than 1.96. Cook's distance, which measures if a single case has an undue influence on the model, was calculated for all participants, and none exceeded the cutoff of 1. Mahalanobis Distance was calculated, and although a few cases had borderline problematic values (Mahalanobis distances greater than 11), these cases were not significant concerns when analyzing other metrics for outliers so they were considered to be okay for inclusion in the model. The standardized DFBeta was analyzed to determine if any case substantially influenced the model parameters, and two values were larger than the cutoff of 1. However, these cases were not significant concerns when analyzing other metrics for outliers so they were considered to be okay for inclusion in the model. Taken together, no case was considered an outlier, and all cases were retained for the analysis. Finally, multicollinearity was evaluated through VIF values, and none of the values were above the cutoff of 2.50. Taken together, there were no significant outliers and the assumptions were not violated, so no changes were made to the model.

The overall regression model significantly explained 14 percent of the variance in perceived quality of care ($R^2 = .14, p = .02$). However, the inclusion of patient engagement in the second model did not improve the overall variance explained over and above the variance explained by cancer diagnosis ($\Delta R^2 = .003, p = .63$). The full regression model can be found in Table 8. It was hypothesized that adolescents with higher levels of patient engagement would perceive higher quality of care. However, the findings of these analyses do not support Hypothesis 1.

Research Question 2 and Hypothesis 2

The second research question and hypothesis examined the frequency of patient-centered care and family-centered care in the adolescent oncology setting. Participants reported experiencing both patient-centered and family-centered care very often (Patient-Centered Care $M = 29.35$, $SD = 3.88$; Family-Centered Care $M = 21.69$, $SD = 3.00$). In order to determine the frequency at which participants experienced each type of care, participants were categorized into experiencing each model of care or not. A cutoff score was established for each model of care, and this score was equivalent to participants indicating that they experience each item at least “most of the time.” Most participants experienced each model of care most of the time; six participants (7.5%) indicated not experiencing patient-centered care most of the time and 8 participants (10.0%) indicated not experiencing family-centered care. Overall, this indicates that adolescent cancer patients experience patient-centered care more often than family-centered care, however, the majority of participants indicated experiencing both models of care. Hypothesis 2 predicted that adolescents would experience family-centered care more often than patient-centered care. The findings of these analyses do not support Hypothesis 2, but in fact suggest the opposite, that adolescent patients experience patient-centered care more frequently.

Research Question 3 and Hypotheses 3a, 3b, 3c, and 3d

The third research question and its accompanying hypotheses aimed to examine if the frequency of patient-centered care and family-centered care varied based on the patient’s age or developmental stage. The full correlation matrix can be found in Table 7. Overall, patient-centered care and family-centered care did not significantly vary as a function of age (patient-centered care: $r = .04$ $p = .76$; family-centered care: $r = .14$, $p = .22$). Additionally, neither patient-centered care nor family-centered care varied as a function of cognitive development ($r = .20$ $p = .07$; family-centered care: $r = .19$, $p = .10$) or transitional readiness ($r = .09$ $p = .42$;

family-centered care: $r = .19, p = .09$). Hypothesis 3a predicted that patient-centered care would increase as adolescents got older, however the current findings did not support this. Hypothesis 3b predicted that family-centered care would decrease as adolescents got older, however the current findings did not support this. Hypothesis 3c predicted that patient-centered care would increase as developmental stage increased. This hypothesis was not supported by the current findings. Hypothesis 3d predicted that family-centered care would decrease as adolescents' developmental stage increased, but the findings of the current study did not support this.

There are differences as a function of development and model of care in patient engagement. Specifically, patient engagement increased as a function of experiencing family-centered care ($r = .25, p = .03$) and cognitive development ($r = .27, p = .02$). With significant correlations found between patient engagement, the two models of care, and the developmental measures, a moderation framework was analyzed utilizing the PROCESS macro. The full moderation analyses can be found in Table 9.

The first model tested the moderating roles of cognitive development and transitional readiness on the relationship between patient-centered care and patient engagement. Overall, this model explained a significant portion of the variance in patient engagement ($R^2 = 0.11, p = 0.05$), and there was a significant main effect of cognitive development on patient engagement ($b = 0.12, 95\% \text{ CI } [0.01, 0.23], p = .03$). However, there were no significant interaction effects, indicating that neither cognitive development nor transitional readiness moderated the relationship between patient-centered care and patient engagement.

The second model tested the moderating roles of cognitive development and transitional readiness on the relationship between family-centered care and patient engagement. This model explained a significant portion of the variance in patient engagement ($R^2 = 0.14, p = 0.02$). Just

as in the previous model examining patient-centered care, cognitive development was the only significant predictor of patient engagement ($b = 0.13$, 95% CI [0.03, 0.23], $p = .01$). There were no significant interaction effects, indicating that neither cognitive development nor transitional readiness moderated the relationship between family-centered care and patient engagement.

The PROCESS macro does not allow for the examination of more than one independent variable in its moderation analyses. Because the above analyses did not find any significant interaction effects, but in both models cognitive development was a significant, unique predictor of patient engagement, an additional multiple linear regression model was analyzed to examine the role of all four variables together. The results of this regression analysis can be found in Table 10. Overall, the model explained a significant portion of the variance in patient engagement ($R^2 = 0.13$, $p = .04$), and only cognitive development was a significant unique predictor of patient engagement ($b = 0.12$, 95% CI [0.01, 0.23], $p = .03$).

Research Question 4

The fourth research question explored if the relationship between patient engagement and perceived quality of care was moderated by patient-centered care, family-centered care, age, and/or developmental stage. Table 7 displays the correlation matrix between all of the study variables of interest. As can be seen in this table, perceived quality of care was positively correlated with patient-centered care ($r = .54$, $p < .001$), family-centered care ($r = .46$, $p < .001$), and cognitive development ($r = .33$, $p = .003$). Patient engagement was also positively correlated with family-centered care ($r = .25$, $p = .03$) and cognitive development ($r = .27$, $p = .02$). Although not all of the hypothesized relationships were significant, all of the proposed moderation analyses were conducted.

The PROCESS macro for SPSS was utilized to conduct the moderation analyses. The final results for each model can be found in Table 11. The first model tested the moderating roles of patient-centered care and family-centered care on the relationship between patient engagement and perceived quality of care. This model explained 39 percent of the variance in perceived quality of care ($R^2 = 0.39, p = 0.03$), but there were no significant main effects or interaction effects in this model. Therefore, patient-centered care and family-centered care did not moderate the relationship between patient engagement and perceived quality of care.

The second model tested the moderating role of age on the relationship between patient engagement and perceived quality of care. This model explained very little of the variance in perceived quality of care ($R^2 = 0.13, p = 0.29$), and there were no significant main effects or interaction effects in this model. Therefore, patient age did not moderate the relationship between patient engagement and perceived quality of care.

The third model tested the moderating roles of cognitive development and transitional readiness on the relationship between patient engagement and perceived quality of care. This model explained very little of the variance in perceived quality of care ($R^2 = 0.20, p = 0.13$), but there was a significant main effect of cognitive development on perceived quality of care ($b = 0.06, 95\% \text{ CI } [0.001, 0.12], p = .05$). There were not any significant interaction effects in this model. Therefore, cognitive development and transitional readiness did not moderate the relationship between patient engagement and perceived quality of care.

The PROCESS macro does not allow for the examination of more than one independent variable in its moderation analyses. Because the above analyses did not find any significant interaction effects, an additional multiple linear regression model was analyzed to examine the role of all six variables together. The results of this regression analysis can be found in Table 12.

Overall, the model explained a significant portion of the variance in perceived quality of care ($R^2 = 0.40, p < .001$), and the inclusion of the six main variables of interest improved the variance of perceived quality of care explained over and above cancer diagnosis ($\Delta R^2 = .27, p < .001$). Both patient-centered care ($b = 0.15, 95\% \text{ CI } [0.03, 0.27], p = .02$) and cognitive development ($b = 0.06, 95\% \text{ CI } [0.01, 0.11], p = .03$) emerged as significant, unique predictors.

Chapter 6

Discussion

The purpose of this study was to examine the experiences of adolescent cancer patients within the oncology setting, and elucidate variations in patient engagement, models of care, and development across this population. In contrast to the hypothesized relationship, patient engagement did not significantly predict quality of care in this sample of adolescent cancer patients. Instead, patient-centered care was a significant, unique predictor of perceived quality of care, highlighting the importance of the doctor-patient relationship to adolescent cancer patients. Additionally, cognitive development emerged as an important developmental milestone in relation to adolescents' ability to engage in their healthcare and perceive differences in quality of care. The results also found no significant differences in quality of care or patient engagement based on the patient's chronological age. This exemplifies the importance of considering development separate from age. Overall, the results of this study reiterate the necessity of examining adolescent cancer patients separate from their younger and older counterparts, and that the cognitive skills they are developing across this developmental period are important milestones in relation to their cancer experience. The remainder of the discussion will focus on the main study findings, the larger implications of this study within the context of the current literature, the main study limitations, and the significance of this work and future directions.

Main Study Findings

Research question 1. The first research question examined the relationship between patient engagement and perceived quality of care. It was hypothesized that as patient engagement increased, participants would perceive higher quality of care. The findings of the current study

did not support this hypothesis as there was not a significant relationship between patient engagement and perceived quality of care.

Patient engagement has not been examined in adolescent cancer patients, but the current findings do contradict the current literature on patient engagement in the adult healthcare literature (Hibbard & Greene, 2013). An intervention conducted with adult patients who utilize an online medication record to manage at least five medications provided patients the opportunity to log into their electronic medication records, screen the information for accuracy, and communicate any errors or concerns with their pharmacist (de Jong, Ros, van Leeuwen, & Schrijvers, 2016). Individuals who used the patient portal reported significantly more collaborative relationships with their pharmacist as compared to non-users (de Jong et al., 2016). Gagliardi et al. (2016) conducted a systematic review of interventions aimed at increasing patient engagement in arthritis and cancer patients. They reviewed a total of 16 interventions, and 6 studies focused on cancer patients found improvements in decisional conflict, intention, anxiety, and satisfaction with treatment choice following the interventions. With the literature supporting the importance of patient engagement in quality of care, the Institute of Medicine (2013) placed an important emphasis on the development of patient engagement in their framework of high quality cancer care. As outlined in the introduction, however, it is potentially problematic to make sweeping suggestions for all cancer patients. The findings of the current study suggest that patient engagement does not play the same role in perceived quality of care in adolescent patients as it does in adult patients.

Research question 2. The second research question examined the frequency of each model of the doctor-patient relationship, and hypothesized that family-centered care would be experienced more frequently than patient-centered care. This hypothesis was not supported, and

in fact, the opposite was found to be true. Although, overall, participants reported experiencing both patient-centered and family-centered care at high rates, more participants endorsed experiencing patient-centered care. Adolescent cancer patients express a desire for information (Stinson et al., 2012; Zwaanswijk et al., 2007), and a role in decision-making (Dunsmore & Quine, 1995; Hinds et al., 2005; Stinson et al., 2012; Zwaanswijk et al., 2007). Patient-centered care focuses on accurate information provision, shared decision-making, and respect of patients' values and preferences (Saha et al., 2008). Therefore, the increased experience of patient-centered care in this sample of adolescent cancer patients indicates that pediatric oncologists and other members of the cancer care team are recognizing these desires in adolescent cancer patients, and interacting with them accordingly. It is important to note that the patient-centered care and family-centered care measures were highly correlated with each other. This may indicate that these two scales were measuring a similar construct. Further analysis is necessary to determine the exact constructs being measured with these items.

The increased experience of patient-centered care in the adolescent oncology setting, and, as such, an increased role in their own care, is supported by the literature on transition healthcare for adolescents with special healthcare needs (Holmes-Walker et al., 2007; McDonagh et al., 2007; Tuchman et al., 2008). When adolescents with special healthcare needs do not, over time, begin to self-manage their healthcare and transition into the adult healthcare setting with the support of their healthcare provider, they report distress, anxiety, lack of health insurance, and lower standards of care for minority patients (Al-Yateem, 2013; Anderson, Flume, Hardy, & Gray, 2002; Flume, Taylor, Anderson, Gray, & Turner, 2004; Houtrow & Newacheck, 2008; Lotstein, Inkelas, Hays, Halfon, & Brook, 2008; Lotstein et al., 2009; Lotstein, Kuo, Strickland, & Tait, 2010; Lugasi, Achille, & Stevenson, 2011; Okumura et al., 2010; Peter, Forke, Ginsburg,

& Schwarz, 2009; Scal, Davern, Ireland, & Park, 2008; Scal & Ireland, 2005; Shaw, Southwood, & McDonagh, 2004; Watson, Parr, Joyce, May, & Le Couteur, 2011; Wong et al., 2010; Zack et al., 2003). Patient-centered care with its emphasis on shared decision-making and respect of the patients' values and beliefs is a necessary component of helping adolescent cancer patients successfully transition into adult healthcare, when appropriate, and manage follow-up tests and care as they move into survivorship.

Research question 3. The third research question examined if the experience of patient-centered or family-centered care varied as a function of patient age or developmental stage. The four accompanying hypotheses were not supported. Specifically, age was not significantly correlated with either patient-centered care (Hypothesis 3a) or family-centered care (Hypothesis 3b). Patient-centered care did significantly increase as adolescents became more cognitively autonomous or prepared for the transition to adult healthcare (Hypothesis 3c). Finally, family-centered care was not significantly associated with either cognitive development or transitional readiness (Hypothesis 3d). There were, however, variations in patient engagement as a function of models of care and development. Specifically, patient engagement increased as patients reported experiencing more family-centered care, and patient engagement increased as adolescents' cognitive development increased.

The increase in patient engagement as the experience of family-centered care increases suggests that parents can provide an important supportive mechanism through which adolescents can be engaged in their care while also maintaining autonomy (Kuo et al., 2012). Systematic literature reviews of family-centered interventions in pediatric and adolescent medical settings have found decreased family conflict, better use of health services, improvements in health status, and improvements in family functioning (Kuhlthau et al., 2011; McBroom & Enriquez,

2009). Providing adolescents with developmentally appropriate care in conjunction with more illness self-management is an important aspect of aiding adolescents in transitioning to adult healthcare, an area often found to be lacking in previous studies conducted with adolescents with special healthcare needs (AAP et al., 2011; Brooks, Bunn, & Morgan, 2009; Freed & Hudson, 2006; Van Petegem, Beyers, Vansteenkiste, & Soenens, 2012).

To further understand the importance of development in understanding adolescent cancer patients' interactions with their medical care, moderation and regression analyses found that cognitive development was the only unique predictor of patient engagement when examining developmental metrics and models of care. These findings reiterate the importance of examining developmental metrics among adolescent cancer patients, and that their ability to engage in their care is related to their ability to evaluate their actions and make thought-out decisions.

Additionally, the differing patterns in associations among the developmental metrics analyzed and patient engagement suggests the need to measure more than one area of development; adolescent developmental research has found that individuals achieved different developmental milestones at varying times across the adolescent development period (Collins & Steinberg, 2006; McNeely & Blanchard, 2009). Future research should also examine other important developmental metrics such as emotion regulation, changes in peer relationships, sensation-seeking, and changes in the parent-child relationship.

Research question 4. The fourth research question explored how the relationship between patient engagement and perceived quality of care may be moderated by patient-centered care, family-centered care, patient age, and/or developmental stage. Patient engagement was not a significant predictor of perceived quality of care, and none of the examined moderating

variables were found to moderate the relationship between patient engagement and perceived quality of care.

Similar to the results from the first research question, patient engagement appears to play a different role among adolescent cancer patients than it does in adult patients. Additionally, both patient-centered care and cognitive development were significant predictors of perceived quality of care. The increase in experiencing patient-centered care and reported higher perceived quality of care aligns with previous research in adult cancer populations (Rathert et al., 2012). The positive relationship between cognitive development and perceived quality of care highlights the importance of a certain level of cognitive skills in an individual's ability to perceive high quality care (Keating, 2012; McNeely & Blanchard, 2009; Overton, 1990; Spear, 2000; Steinberg, 2009). The different pattern of relationships found in this population of adolescent cancer patients as compared to previous research with adult cancer patients suggests the need to further examine other possible variables (e.g. role in treatment decision-making, information provision, and the role of parents in the treatment experience) that may explain adolescents' perceptions of the quality of care they receive.

Quality of Care in Adolescent Oncology

Adolescents in the current study overwhelmingly perceived receiving high quality cancer care. The perception of high quality of care reported in the current sample may have been due to the data collection procedures. Specifically, adolescents were recruited in the exam rooms of the clinic they received their cancer care. The location of the survey may have caused adolescents to report more positive care than they otherwise would have. However, even in light of this limitation, there was still a small segment of the current sample that reported low levels of

quality of care. For those individuals whose care needs are still not met, we need to better elucidate what factors may be important to them when receiving cancer care.

The Institute of Medicine (2013) placed the development of engaged patients at the center of their quality of cancer care framework, and a number of their priority recommendations focused on delivering accurate and understandable information, patient-centered care, and care that meets patients' needs and values. It is unsurprising that these are the main components of their recommendations given that previous research has found numerous positive outcomes among patients receiving patient-centered care (Rathert et al., 2012). However, as outlined earlier, adolescents are a unique care group with their own needs and expectations. The findings of the current study supported the need to examine adolescents separately from adults, and found that patient engagement is not a main component of perceived quality of care from their perspective. The lack of variability in patient engagement and quality of care within this sample may be one reason for this lack of a significant relationship, but, this still begs the question, however, as to what are the important components of perceived quality of care for adolescent cancer patients. The current study provides a starting point for some possibilities, but further research is necessary.

Adolescents' perceptions of their quality of care significantly increased as a function of experiencing patient-centered care and improved cognitive development skills. The significant relationship with patient-centered care may point to the importance of the doctor-patient relationship in adolescent oncology. Adolescents and young adults with cancer expressed the importance of having autonomy in decision-making around clinical trial participation, and the importance of having family and healthcare professionals as support systems in understanding the clinical trial (Pearce et al., 2016). Young adult survivors of childhood cancer who have

participated in survivorship care were more likely to understand the future health concerns they are at risk for as compared to survivors who have not participated in survivorship care (Ganju et al., 2016). Autonomous decision-making, supportive relationships, and appropriate information provision are all characteristics of patient-centered care.

Adolescent cancer patients also indicate a desire to be involved in treatment decision-making (Hinds et al., 2005; Stinson et al., 2012; Zwaanswijk et al., 2007). However, neither the patient-centered care measure nor the quality of care measure included an item concerning the role of the patient in decision-making. Future research will need to ask specific, targeted questions concerning decision-making as that may be a more important component in adolescent cancer care than other aspects of patient-centered care. Similar to adults, adolescents also want doctor-patient relationships characterized by empathy, open communication, sufficient time with their doctor, and having their questions answered (Hinds et al., 2005; Zwaanswijk et al., 2007; Zwaanswijk et al., 2011). With the exception of a question concerning the amount of time spent with their doctor, the quality of care measure utilized in this study did not examine some of these aspects specifically. It may be that one of these specific characteristics is a more important indicator of quality than all of them as a whole.

The findings of these previous studies suggest that a more nuanced examination of the doctor-patient relationship may be necessary to elucidate what components of their care experience are predictors of higher quality of care in adolescent cancer survivors. The significant, positive relationship between perceived quality of care and cognitive development may also suggest the need for a certain level of cognitive autonomy in order to perceive high levels of quality of care. As discussed in the literature review, across adolescence, individuals begin to improve their reasoning skills and information processing abilities; improve their

abstract and hypothetical thinking; utilize foresight; plan ahead; improve their abstract and hypothetical thinking; utilize foresight; plan ahead; and set goals and achieve them (Collins & Steinberg, 2006; McNeely & Blanchard, 2009; Mello et al., 2009; Piaget 1972/2008). The emotion regulation processes necessary to interact in difficult situations with some level of logic and reason also develop across adolescence (Eluvanthigal et al., 2009). Developmental research suggests that it is important for adolescents to develop these skills within supportive parental and familial relationships (Benish-Weisman et al., 2013; Grotevant & Cooper, 1998; Kagitcibasi, 2013; Steinberg, 2001; Tamis-LeMonda et al., 2007). Therefore, the role and perspective of the patient's parent may be an important source of information in gaining a better insight into the quality of cancer care received by adolescents. Adolescents' coping strategies are related to the coping strategies of their parents (Sanjari et al., 2008), and parents may be better able to describe some of the more nuanced aspects of cancer care, particularly for young adolescents still developing important cognitive skills. Patient engagement is an important aspect of quality of care in adult cancer populations, but the findings of the current study do not suggest the same relationship in adolescent cancer populations. Instead, other aspects of the doctor-patient relationship or the cognitive abilities of adolescents may be important mechanisms to improving quality of cancer care for adolescents.

Patient Engagement and Models of Care

The current study found some varying patterns in patient engagement based on models of care and development. Specifically, patient engagement was significantly correlated with family-centered care and cognitive development, but not patient-centered or transitional readiness. Adolescents and young adults with cancer expressed the importance of having autonomy in decision-making around clinical trial participation, but also the importance of having family and

healthcare professionals as support systems in understanding the clinical trial (Pearce et al., 2016). Family-centered care is characterized by the inclusion of the patient and their family members, and developmental research suggests that as adolescents develop important cognitive and psychosocial skills, the support of parents and other adults is necessary in the face of life-threatening situations (Turner-Henson, 2005). Much like the above discussion concerning perceived quality of care, the findings of this study combined with this past literature suggest the need to explore more specific aspects of the doctor-patient relationship to better determine the mechanisms through which patient engagement can be improved.

Although family-centered care was significantly correlated with patient engagement, only cognitive development emerged as a significant, unique predictor of patient engagement in this sample of adolescent cancer patients. The cognitive development measure utilized in this study examined adolescents' ability to evaluate their thinking and make sound decisions, both important skills to have in order to be engaged in your healthcare. Patient engagement is defined as an increase in "a patient's knowledge, skills ability, and willingness to manage his or her own healthcare" (p.1; Health Policy Brief: Patient Engagement, 2013), and without the ability to think critically and make clear decisions, it would be unreasonable to expect an individual to possess the skills necessary to manage their own healthcare. Previous research suggests that adolescents, particularly those in middle adolescence and older, often have gained the cognitive skills necessary to engage in their healthcare (Billick, Burgert, Friberg, Downer, & Bruni-Solkhah, 2001; Halpern-Felsher & Cauffman, 2001; Weithorn & Campbell, 1982). Specifically, Billick et al. (2001) found that, overall, their sample of pediatric inpatients and outpatients were competent enough to consent to medical treatment at the age of 12. Weithorn and Campbell (1982) found that 14 year olds were just as competent in making informed treatment decisions as adults, but

that 9 year olds were less competent as compared to adults in making informed treatment decisions. Finally, Halpern-Felsher and Cauffman (2001) found that adolescents differed from adults in their ability to perform some, but not all, of the tasks associated with informed decision-making including consideration of options, risks, and long-term consequences. It is imperative that oncologists and other members of the cancer care team continue to recognize the importance of cognitive development, and provide care commensurate with adolescents' cognitive abilities. The findings of this study suggest that oncologists and members of the care team do recognize this as patient-centered care was positively related to cognitive development, and more adolescents endorsed experiencing patient-centered care than family-centered care. Overall, the current study highlights the importance of providing care that is commensurate with adolescents' developmental abilities, and that we need a more detailed examination of the specific behaviors healthcare providers utilize to help foster patient engagement in adolescent cancer patients.

Importance of Multiple Developmental Metrics

A primary aim of the current study was to examine the role of development in the experience of adolescent cancer patients, as most studies focused on adolescent cancer patients do not measure development (Siembida & Bellizzi, 2015). The current findings clearly demonstrate the importance of examining development within adolescent oncology. Cognitive development was the only significant predictor of patient engagement and perceived quality of care, and was significantly correlated with patient-centered care. In contrast, transitional readiness was not significantly correlated with any of the main study variables. Both developmental metrics were significantly, positively related to age, as would be expected, but age was not significantly related to any other variable assessed in the current study. Although the developmental metrics were related to age, age did not play an important role in the other

characteristics of the cancer experience examined. In contrast, the developmental metrics did play an important role. This exemplifies the importance of considering development separate from age.

The differing relationships between cognitive development and transitional readiness and the other variables assessed in the current study highlights the importance of examining multiple metrics of development. Across adolescence, individuals gain important cognitive skills (Keating, 2012; McNeely & Blanchard, 2009; Overton, 1990; Spear, 2000; Steinberg, 2009), develop emotion regulation (Eluvathingal et al., 2007; Steinberg, 2009), renegotiate parent-child relationships (Benish-Weisman et al., 2013; Grotevant & Cooper, 1998; Kagitcibasi, 2013; Steinberg, 2001; Tamis-LeMonda et al., 2007), develop autonomy (Van Petegem et al., 2012), and prioritize peer and romantic relationships (Berger, 2005). All of these changes happen at different times across adolescent development (Collins & Steinberg, 2006; McNeely & Blanchard, 2009), indicating that at any point across this developmental period, an adolescent may be better equipped to handle some situations within their cancer treatment but not others. If the current study measured only transitional readiness, the importance of development in adolescent cancer patients would be greatly reduced; examining only one developmental metric would not provide the entire picture.

Limitations

The conclusions of the current study should be interpreted in light of its limitations. First, the data described in this study was collected cross-sectionally utilizing in-person recruitment technique. The cross-sectional nature of the data precludes the ability to make any conclusions based on the causal effects of the significant relationships, and there is the possibility that the relationships are bi-directional. Additionally, the use of in-person recruitment techniques lead to

a high participation rate among the current sample, lending credence to the generalizability of the study's findings. However, the act of taking the survey in the environment they received their care may prone participants to provide overly positive responses. This limitation may be one reason for the lack of significant relationships found in the current study. Finally, the lack of tailored measurement calls into question some of the conclusions of this study. The measures utilized in this study had satisfactory reliability, but few were developed specifically for use with adolescent cancer patients. The participants in this study expressed that some of the items did not apply to their experience. There is a clear need for measures developed and validated within the adolescent cancer population to better examine these important constructs.

Conclusions and Future Research Directions

The current study analyzed one of the largest samples of adolescent cancer patients found in the current literature. Previous research suggests that adolescent cancer patients are unique from their older and younger counterparts (Siembida & Bellizzi, 2015), and examination of this cancer population was warranted. The current study found that patient engagement was not a significant predictor of higher perceived quality of care, an important finding given the Institute of Medicine's (2013) focus on increasing patient engagement as the first step to improving quality cancer care.

The lack of focus on development within the adolescent oncology literature was also a major barrier to a better understanding of the best care for this population (Siembida & Bellizzi, 2015). Adolescent cancer patients previously reported their desire for developmentally appropriate information (Stinson et al., 2012; Zwaanswijk et al., 2007), and recognize that their preferences and roles will change as they mature (Hinds et al., 2005; Zwaanswijk et al., 2007). The current study aimed to fill this gap by examining two developmental metrics: cognitive

development and transitional readiness. The findings of this study provide important information regarding the role of development in adolescent cancer patient's experience of their cancer care. Cognitive development was a significant predictor of perceived quality of care and patient engagement in the current study; however, transitional readiness was not. Differing patterns in the associations between development and models of care were also found. Taken together, these findings demonstrate the variations in multiple areas of development among adolescents. Developmental literature has found that adolescents mature at varying rates within different developmental milestones (Collins & Steinberg, 2006; McNeely & Blanchard, 2009), and the findings of this study concur. The need to examine multiple measures of development among adolescent cancer patients is clear, and brief screening measures for use within the adolescent oncology clinic setting need to be developed for ease of identification of cognitive developmental skills. The developed screening measure will need to be quick and efficient due to the time limitations places upon each adolescent's clinic visit. The development of such a screening measure is an important next step in this work due to the lack of a significant relationship between chronological age and quality of care, reiterating that age cannot be used as a proxy for development.

Although the findings of this study answer some important questions for the adolescent cancer population, they are only a small part of what needs to be done to better provide adolescent cancer patients with high quality cancer care. The lack of a significant relationship between patient engagement and perceived quality of care in the current study suggests that adolescents may view quality of care differently than their adult counterparts. Future research will need to explore alternative mechanisms for improving care within this population. Additionally, the importance of development within these findings highlights the need for a

better understanding of individual patient's developmental stage. The creation and evaluation of developmental screening measures or other tools will be an important step in aiding clinicians in providing appropriate care to adolescent cancer patients. Finally, this study examines the perspective of the adolescent cancer patient. However, their perspective is not the whole story, and the need for research examining the perspectives of parents and medical providers is needed.

Steinberg and Lerner (2004) said "adolescents represent, at any point in history, the generational cohort that must next be prepared to assume the quality of leadership of self, family, community, and society that will maintain and improve human life" (p. 52). The medical advancements in cancer treatment have allowed for a whole new segment of the adolescent population to live long into adulthood, providing them an increased opportunity for providing this leadership. However, cancer care providers need to recognize the increased, autonomous role these adolescents desire to play to in their medical treatment, and we need to continue to respect the unique characteristics of adolescents and continue to alter their care across this developmental period.

Table 1.
Demographic characteristics of pre-testing focus group

Participant	Gender	Age (years)	Grade	Race	Previous Chronic Illness History	Time It Took to Complete Survey (minutes : seconds)
1	Female	11	6	White	None	7:34
2	Female	10	5	White	ADHD/ADD	12:43
3	Male	12	6	White	None	13:53
4	Male	17	12	White	Diabetes	10:13

Table 2.
Demographic characteristics of sample (N=80)

Variable	M (Range)	SD	N	%
Age	15.68 (10 – 21)	2.87		
Gender				
Male			46	57.5
Female			34	42.5
Education ¹				
Grade 5			9	11.3
Grade 6			1	1.3
Grade 7			7	8.8
Grade 8			5	6.3
Grade 9			14	17.5
Grade 10			9	11.3
Grade 11			12	15.0
Grade 12			3	3.8
High school graduate			9	11.3
Some college courses			11	13.8
College graduate			0	0
Racial/Ethnic Background				
American Indian or Alaska Native			2	2.5
Asian			3	3.8
Black or African American			6	7.5
Hispanic or Latino			20	25.0
Native Hawaiian/Other Pacific Islander			0	0
White			49	61.3

¹Participants were instructed to indicate the highest grade in school that they have completed

Table 3.*Illness-related characteristics of sample (N=80)*

Variable	M (Range)	SD	N	%
Age at first diagnosis	13.68 (5 – 20)	3.18		
Diagnosis				
Leukemia and lymphoma			47	59.5
Central nervous system tumor			4	5.1
Bone tumors			15	19.0
Soft tissue and Kaposi sarcoma			8	10.1
Germ cell cancer			3	3.8
Thyroid cancer			0	0
Melanoma of the skin			0	0
Other			2	2.5
Treatment¹				
Chemotherapy			78	97.5
Radiation			36	45.0
Surgery			41	51.2
Bone marrow transplant			5	6.3
Other			1	1.3
Receiving treatment				
Yes			42	52.5
No			38	47.5
Recurrence				
Yes			17	21.3
No			63	78.8

¹Participants were instructed to choose all treatment options that applied to them, so the N's will add up to more than 80 and the percentages will be greater than 100%

Table 4.

Categorical demographic and illness-related characteristics and their association with quality of care (N=80)

Variable	<i>t</i>-test	<i>p</i>
Gender	.79	.43
Treatment Status	-.10	.92
Recurrence	1.31	.19
Chemotherapy	.98	.33
Radiation	.20	.84
Surgery	1.35	.18
Bone Marrow Transplant	.10	.92

Variable	ANOVA	<i>p</i>
Racial/Ethnic Identity	.90	.47
Diagnosis	4.16	.009

Table 5.

Continuous demographic and illness characteristics and their association with quality of care (N=80)

Variable	1.	2.	3.	4.
1. Quality of Care	1.00			
2. Grade	.06	1.00		
3. Age	-.003	.96**	1.00	
4. Age at Diagnosis	.12	.71**	.74**	1.00

Note. ** = $p < .001$; * = $p < .05$

Table 6.
Descriptive statistics of main study variables (N=80)

Variable	M	SD	Range	Range of Possible Scores
Quality of Care	14.88	1.65	9 – 16	4 – 16
Patient Engagement	16.24	3.21	5 – 20	5 – 20
Patient-Centered Care	29.35	3.88	8 – 32	0 – 32
Family-Centered Care	21.69	3.00	9 – 24	0 – 24
Cognitive Development	43.76	6.65	28 – 56	14 – 56
Transitional Readiness	4.78	1.99	1 – 8	0 – 8

Table 7.*Correlation matrix with main study variables (N=80)*

Variable	1	2	3	4	5	6	7
1. Quality of Care	1.00						
2. Patient Engagement	.13	1.00					
3. Age	-.003	.04	1.00				
4. Patient-Centered Care	.54**	.21	.04	1.00			
5. Family-Centered Care	.46**	.25*	.14	.73**	1.00		
6. Cognitive Development	.33*	.27*	.33*	.20	.19	1.00	
7. Transitional Readiness	.07	-.02	.56**	.09	.19	.21	1.00

Note. ** = $p < .001$; * = $p < .05$

Table 8.

Multiple linear regression with quality of care as the dependent variable, 95% confidence intervals reported in parentheses (N=79)

	B	SE B	t	p
Model 1 ¹				
Constant	15.37 (14.91, 15.83)	.231	66.54	<i>p</i> < .001
Diagnosis1	-1.10 (-2.03, -0.18)	.466	-2.37	.02
Diagnosis2	-1.12 (-2.32, 0.08)	.60	-1.87	.07
Diagnosis3	-1.47 (-2.56, -0.38)	.55	-2.69	.01
Model 2				
Constant	14.91 (14.91, 15.83)	.99	15.08	<i>p</i> < .001
Diagnosis1	-1.07 (-2.01, -0.13)	.47	-2.26	.03
Diagnosis2	-1.09 (-2.30, 0.12)	.61	-1.80	.08
Diagnosis3	-1.42 (-2.53, -0.30)	.56	-2.53	.01
Patient Engagement	0.03 (-0.09, 0.14)	0.06	0.48	0.63

Note. R² = .14 for Model 1 (*p* = .01); R² = .14 for Model 2 (*p* = .02)

¹Diagnosis1 = Bone Tumors vs. Leukemia/Lymphoma; Diagnosis2 = Soft Tissue Sarcomas vs. Leukemia/Lymphoma; Diagnosis3 = Other Diagnoses vs. Leukemia/Lymphoma

Table 9.

PROCESS moderation models with patient engagement as the dependent variable, 95% confidence intervals reported in parentheses (N=78)

	<i>b</i>	SE B	<i>t</i>	<i>p</i>
Model 1				
Constant	16.24 (15.51, 16.97)	0.37	44.36	<i>p</i> < .001
PCC ¹ (centered)	0.14 (-0.04, 0.32)	0.09	1.57	0.12
Cognitive Development (centered)	0.12 (0.01, 0.23)	0.05	2.21	0.03
Transitional Readiness (centered)	-0.13 (-0.57, 0.31)	0.22	-0.60	0.55
PCC X Cognitive Development	-0.01 (-0.04, 0.03)	0.02	-0.38	0.70
PCC X Transitional Readiness	-0.02 (-0.09, 0.13)	0.06	0.31	0.76
Model 2				
Constant	16.30 (15.59, 17.00)	0.36	45.81	<i>p</i> < .001
FCC ² (centered)	0.21 (-0.02, 0.43)	0.11	1.79	0.08
Cognitive Development (centered)	0.13 (0.03, 0.23)	0.05	2.56	0.01
Transitional Readiness (centered)	-0.17 (-0.60, 0.27)	0.22	-0.77	0.45
FCC X Cognitive Development	-0.02 (-0.05, 0.02)	0.02	-1.00	0.32
FCC X Transitional Readiness	-0.01 (-0.13, 0.10)	0.06	-0.19	0.85

Note. R² = .11 for Model 1 (*p* = .05); R² = .14 for Model 2 (*p* = .02)

¹PCC = patient-centered care

²FCC = family-centered care

Table 10.

Multiple linear regression with patient engagement as the dependent variable, 95% confidence intervals reported in parentheses (N=78)

	B	SE B	t	p
Model 1				
Constant	6.56 (-0.04, 13.15)	3.31	1.98	0.05
PCC	-0.01 (-0.28, 0.26)	0.13	-0.09	0.93
FCC	0.26 (-0.09, 0.61)	0.18	1.46	0.15
Cognitive Development	0.12 (0.01, 0.23)	0.06	2.23	0.03
Transitional Readiness	-0.19 (-0.56, 0.18)	0.18	-1.03	0.31

Note. $R^2 = .13$ for Model 1 ($p = .04$)

Table 11.

PROCESS moderation models with quality of care as the dependent variable, 95% confidence intervals reported in parentheses (N=78)

	<i>b</i>	SE B	<i>t</i>	<i>p</i>
Model 1¹				
Constant	15.26 (14.65, 15.87)	0.31	49.76	<i>p</i> < .001
Patient Engagement (centered)	-0.02 (-0.16, 0.11)	0.07	-0.35	0.73
PCC ² (centered)	0.19 (-0.12, 0.49)	0.15	1.21	0.23
FCC ³ (centered)	0.05 (-0.19, 0.29)	0.12	0.45	0.65
PCC X Patient Engagement	0.04 (-0.04, 0.12)	0.04	0.97	0.34
FCC X Patient Engagement	-0.04 (-0.13, 0.04)	0.04	-0.97	0.34
Diagnosis1	-1.01 (-2.16, 0.13)	0.57	-1.77	0.08
Diagnosis2	-0.83 (-2.47, 0.82)	0.82	-1.00	0.32
Diagnosis3	-0.97 (-2.36, 0.42)	0.70	-1.40	0.17
Model 2				
Constant	15.36 (15.07, 15.65)	0.15	105.62	<i>p</i> < .001
Patient Engagement (centered)	0.03 (-0.08, 0.14)	0.06	0.52	0.60
Age (centered)	-0.01 (-0.14, 0.11)	0.06	-0.21	0.83
Age X Patient Engagement	-0.004 (-0.04, 0.03)	0.02	-0.29	0.77
Diagnosis1	-0.92 (-2.02, 0.18)	0.55	-1.66	0.10
Diagnosis2	-1.10 (-3.05, 0.85)	0.98	-1.12	0.27
Diagnosis3	-1.42 (-3.15, 0.32)	0.87	-1.63	0.11
Model 3				
Constant	15.26 (14.92, 15.60)	0.17	89.23	<i>p</i> < .001
Patient Engagement (centered)	0.01 (-0.13, 0.16)	0.07	0.20	0.84

Cognitive Development (centered)	0.06 (0.001, 0.12)	0.03	2.04	0.05
Transitional Readiness (centered)	0.02 (-0.15, 0.18)	0.08	0.20	0.84
Cognitive Development X Patient Engagement	0.004 (-0.01, 0.02)	0.01	0.41	0.68
Transitional Readiness X Patient Engagement	-0.01 (-0.09, 0.06)	0.04	-0.37	0.71
Diagnosis1	-0.90 (-1.97, 0.16)	0.54	-1.69	0.10
Diagnosis2	-0.94 (-2.93, 1.05)	1.00	-0.94	0.35
Diagnosis3	-1.31 (-2.89, 0.28)	0.79	-1.65	0.10

Note. $R^2 = .39$ for Model 1 ($p = .03$); $R^2 = .13$ for Model 2 ($p = .29$); $R^2 = .20$ for Model 3 ($p = .13$)

¹Diagnosis1 = Bone Tumors vs. Leukemia/Lymphoma; Diagnosis2 = Soft Tissue Sarcomas vs. Leukemia/Lymphoma;

Diagnosis3 = Other Diagnoses vs. Leukemia/Lymphoma

²PCC = patient-centered care

³FCC = family-centered care

Table 12.

Multiple linear regression with quality of care as the dependent variable, 95% confidence intervals reported in parentheses (N=77)

	B	SE B	t	p
Model 1 ¹				
Constant	15.36 (14.89, 15.82)	.23	65.94	<i>p</i> < .001
Diagnosis1	-0.93 (-1.88, 0.03)	.48	-1.84	.06
Diagnosis2	-1.12 (-2.30, 0.09)	.60	-1.84	.07
Diagnosis3	-1.46 (-2.54, -0.37)	.55	-2.67	.01
Model 2				
Constant	8.45 (4.91, 11.99)	1.77	4.77	<i>p</i> < .001
Diagnosis1	-0.82 (-1.67, 0.02)	.42	-1.94	.06
Diagnosis2	-0.71 (-1.76, 0.35)	.53	-1.34	.19
Diagnosis3	-0.90 (-1.89, 0.08)	.49	-1.83	.07
Patient Engagement	-0.05 (-0.15, 0.06)	0.05	-0.91	0.37
Transitional Readiness	0.05 (-0.15, 0.24)	0.10	0.47	0.64
Patient-Centered Care	0.15 (0.03, 0.27)	0.06	2.45	0.02
Family-Centered Care	0.09 (-0.07, 0.25)	0.08	1.09	0.28
Cognitive Development	0.06 (0.01, 0.11)	0.03	2.22	0.03
Age	-0.09 (-0.23, 0.04)	0.07	-1.37	0.17

Note. R² = .13 for Model 1 (*p* = .02); R² = .40 for Model 2 (*p* < .001)

¹Diagnosis1 = Bone Tumors vs. Leukemia/Lymphoma; Diagnosis2 = Soft Tissue Sarcomas vs. Leukemia/Lymphoma; Diagnosis3 = Other Diagnoses vs. Leukemia/Lymphoma

Figure 1.

Comparison of the constructs of patient-centered and family-centered care

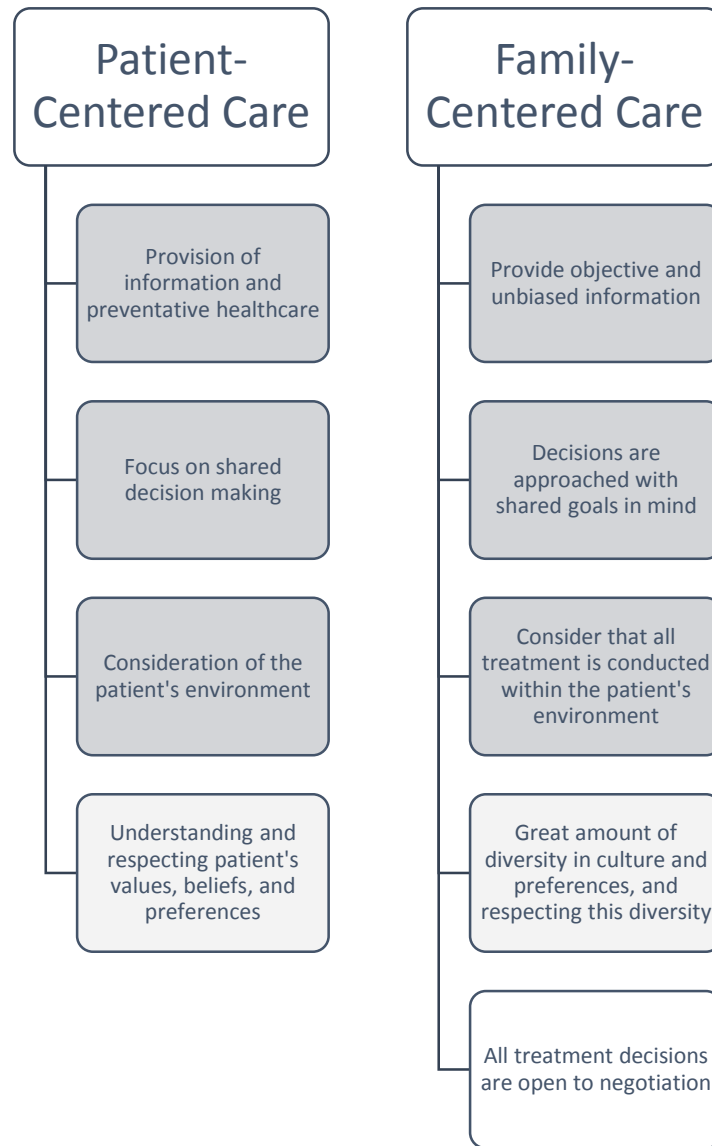
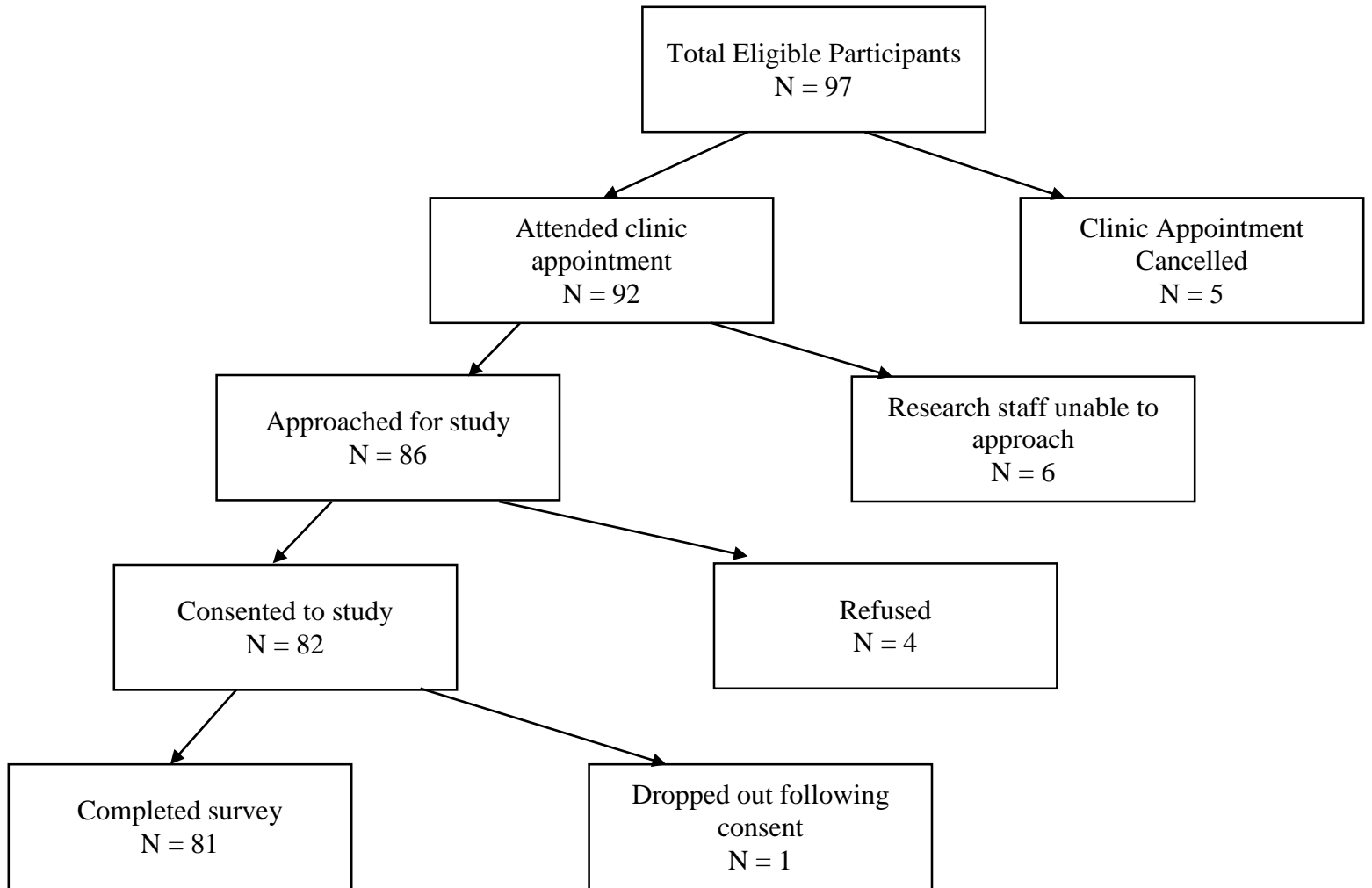


Figure 2.

Flowchart describing recruitment of adolescent cancer patients for the current study



- Participation rate based on total eligible participants: $81/97 = 83.5\%$
- Participation rate based on eligible participants, approached: $81/86 = 94.2\%$

References

- Al-Yateem, N. (2013). Guidelines for the transition from child to adult cystic fibrosis care. *Nursing Children and Young People, 25*(5), 29-34.
- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians, Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 128*, 182-200.
- American Academy of Pediatrics Committee on Bioethics (1998). Informed consent, parental permission, and assent in pediatric practice. *Journal of Child and Family Nursing, 1*(1), 57-61.
- American Society of Clinical Oncology. (2014). The state of cancer care in America, 2014: A report by the American Society of Clinical Oncology, *Journal of Oncology Practice, 10*(2), 119-143.
- Anderson, D.L., Flume, P.A., Hardy, K.K., & Gray, S. (2002). Transition programs in cystic fibrosis centers: Perceptions of patients. *Pediatric Pulmonology, 33*, 327-331.
- Aziz, N.M., Oeffinger, K.C., Brooks, S., & Turoff, A.J. (2006). Comprehensive long-term follow-up programs for pediatric cancer survivors. *Cancer, 107*(4), 841-848.
- Baker, J.N., Leek, A.C., Salas, H.S., Drotar, D., Noll, R., Rheingold, S.R., & Kodish, E.D. (2013). Suggestions from adolescents, young adults, and parents for improving consent in phase 1 pediatric oncology trials. *Cancer, 119*, 4154-4161.
- Beckert, T.E. (2007). Cognitive autonomy and self-evaluation in adolescence: A conceptual investigation and instrument development. *North American Journal of Psychology, 9*(3), 579-594.

- Beh, H.G. & Pietsch, J.H. (2004). Legal implications surrounding adolescent health care decision-making in matters of sex, reproduction, and gender. *Child and Adolescent Psychiatric Clinics of North America*, 13, 675-694.
- Bellizzi, K.M., Smith, A., Schmidt, S., Keegan, T.H.M., Zebrack, B., Lynch, C.F., ... Simon, M. (2012). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*, 118(20), 5155-5162.
- Ben Arush, M.W., Geva, H., Ofir, R., Mashiach, T., Uziel, R., & Dashkovsky, Z. (2006). Prevalence and characteristics of complementary medicine used by pediatric cancer patients in a mixed western and middle-eastern population. *Journal of Pediatric Hematology and Oncology*, 28(3), 141-146.
- Benish-Weisman, M., Levy, S., & Knafo, A. (2013). Parents differentiate between their personal values and their socialization values: The role of adolescents' values. *Journal of research on adolescences*, 23(4), 614-620.
- Berger, K.S. (2005). *The developing person: Through the life span*. New York, NY: Worth Publishers
- Billick, S.B., Burgert, W. III, Friberg, G., Downer, A.V., & Bruni-Solkhah, S.M. (2001). A clinical study of competency to consent to treatment in pediatrics. *The Journal of the American Academy of Psychiatry and Law*, 29(3), 298-302.
- Bloom, S.R., Kuhlthau, K., Van Cleave, J., Knapp, A.A., Newacheck, P., & Perrin, J.M. (2012). Health care transition for youth with special health care needs. *Journal of Adolescent Health*, 51, 213-219.
- Bonnie, R.J. & Scott, E.S. (2013). The teenage brain: Adolescent brain research and the law. *Current Directions in Psychological Science*, 22(2), 158-161.

- Brooks, F., Bunn, F., & Morgan, J. (2009). Transition for adolescents with long-term conditions: Event to process. *British Journal of Community Nursing, 14*(7), 301-304.
- Chambers, R.A., Taylor, J.R., & Potenza, M.N. (2003). Developmental neurocircuitry of motivation in adolescence: A critical period of addiction vulnerability. *American Journal of Psychiatry, 160*, 1041-1052.
- Chapple, A., Salinas, M., Ziebland, S., McPherson, A., & Macfarlane, A. (2007). Fertility issues: The perceptions and experiences of young men recently diagnosed and treated for cancer. *Journal of Adolescent Health, 40*, 69-75.
- Collins, W.A. & Steinberg, L. (2006). Adolescent development in interpersonal context. In N. Eisenberg, W. Damon, & R.M. Lerner (Eds.), *Handbook of Child Psychology: Vol. 3, Social, Emotional, and Personality Development* (1003-1067). Hoboken, NJ: John Wiley & Sons, Inc.
- Coyne, I. (2006). Consultation with children in hospital: Children, parents' and nurses' perspectives. *Journal of Clinical Nursing, 15*, 61-71.
- Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents, and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing, 18*, 273-280.
- de Jong, C.C., Ros, W.J.G., van Leeuwen, M., & Schrijvers, G. (2016). Exploring the effects of patients taking a vigilant role in collaborating on their e-medication administration record. *International Journal of Medical Informatics, 88*, 18-24.
- de Vries, M.C., Wit, J.M., Engberts, D.P., Kaspers, G.J., & van Leeuwen, E. (2010). Pediatric oncologists' attitudes towards involving adolescents in decision-making concerning research participation. *Pediatric Blood & Cancer, 55*(1), 123-128.

- Dieluweit, U., Debatin, K., Grabow, D., Kaatsch, P., Peter, R., Seitz, D.C.M., & Goldbeck, L. (2010). Social outcomes of long-term survivors of adolescent cancer. *Psycho-Oncology*, *19*, 1277-1284.
- Dunsmore, J. & Quine, S. (1995). Information, support, and decision-making needs and preferences of adolescents with cancer: Implications for health professionals. *Journal of Psychosocial Oncology*, *13*(4), 39-56.
- Eluvathingal, T.J., Hasan, K.M., Kramer, L., Fletcher, J.M., & Ewing-Cobbs, L. (2007). Quantitative diffusion tensor tractography of association and projection fibers in normally developing children and adolescents. *Cerebral Cortex*, *17*, 2760-2768.
- Engvall, G., Cernvall, M., Larsson, G., von Essen, L., & Mattsson, E. (2011). Cancer during adolescence: Negative and positive consequences reported three and four years after diagnosis. *PLoS One*, *6*(12), e29001.
- Faul, F., Erdfelder, E., Lang, A.G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical science. *Behavior Research Methods*, *39*(2), 175-191.
- Fernandez, C.V., Gao, J., Strahlendorf, C., Moghrabi, A., Pentz, R.D., Barfield, R.C.,...Kodish, E. (2009). Providing research results to participants: Attitudes and needs of adolescents and parents of children with cancer. *Journal of Clinical Oncology*, *27*(6), 878-883.
- Fiks, A.G. & Jimenez, M.E. (2010). The promise of shared decision-making in paediatrics. *Acta Paediatrica*, *99*, 1464-1466.
- Flume, P.A., Taylor, L.A., Anderson, D.L., Gray, S., & Turner, D. (2004). Transition programs in cystic fibrosis centers: Perceptions of team members. *Pediatric Pulmonology*, *37*, 4-7.

- Freed, G.L. & Hudson, E.J. (2006). Transitioning children with chronic diseases to adult care: Current knowledge, practices, and directions. *The Journal of Pediatrics*, *148*, 824-827.
- Gagliardi, A.R., Légaré, F., Brouwers, M.C., Webster, F., Badley, E., & Straus, S. (2016). Patient-mediated knowledge translation (PKT) interventions for clinical encounters: A systematic review. *Implementation Science*, *11*. Epub ahead of print.
- Ganju, R.G., Nanda, R.H., Esiashvili, N., Switchenko, J.M., Wasilewski-Masker, K.,..., Marchak, J.G. (2016). The effect of transition clinics on knowledge of diagnosis and perception of risk in young adult survivors of childhood cancer. *Journal of Pediatric Hematology and Oncology*. Epub ahead of print.
- Greene, J. & Hibbard, J.H. (2011). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, *27*(5), 520-526.
- Grisso, T. & Vierling, L. (1978). Minors' consent to treatment: A developmental perspective. *Professional Psychology*, *9*(3), 412-427.
- Grotevant, H.D. & Cooper, C.R. (1998). Individuality and connectedness in adolescent development: Review and prospects for research on identity, relationships, and context. In E.E.A. Skoe, A.L. & von der Lippe (Eds.), *Personality development in adolescence: A cross national and life span perspective* (3-37). Florence, KY: Taylor & Frances/Routledge.
- Halpern-Felsher, B.L. & Cauffman, E. (2001). Costs and benefits of a decision: Decision-making competence in adolescents and adults. *Applied Developmental Psychology*, *22*, 257-273.

- Hays, R.D., Shaul, J.A., Williams, V.S.L., Lubalin, J.S., Harris-Kojetin, L.D.,..., Cleary, P.D. (1999). Psychometric properties of the CHAPS 1.0 survey measures. *Medical Care*, 37(3), MS22-MS31.
- Health Policy Brief: Patient Engagement,” *Health Affairs*, February 14, 2013.
- Hibbard, J.H. & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; Fewer data on costs. *Health Affairs*, 32(2), 207-214.
- Hibbard, J.H., Mahoney, E.R., Stock, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research*, 42(4), 1443-1463.
- Hickey, K. (2007). Minors’ rights in medical decision making. *JONA’s Healthcare Law, Ethics, and Regulation*, 9(3), 100-104.
- Hinds, P.S., Drew, D., Oakes, L.L., Fouladi, M., Spunt, S.L., Church, C., & Furman, W.L. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, 23(36), 9146-9154.
- Holmes-Walker, D.J., Llewellyn, A.C., & Farrell, K. (2007). A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15-25 years. *Diabetic Medicine*, 24, 764-769.
- Houtrow, A.J. & Newacheck, P.W. (2008). Understanding transition issues: Asthma as an example. *The Journal of Pediatrics*, 152, 453-455.
- Institute of Medicine. (2013). *Delivering high-quality cancer care: Charting a new course for a system in crisis*. Washington, DC: The National Academies Press.
- JAYAO. (2011). What should the age range be for AYA oncology. *Journal of Adolescent and Young Adult Oncology*, 1(1), 3-10.

- Jensen, L.A. & Chen, X. (2013). Adolescent development in a diverse and changing world: Introduction. *Journal of Research on Adolescence*, 23(2), 197-200.
- Jolley, J. & Shields, L. (2009). The evolution of family-centered care. *Journal of Pediatric Nursing*, 24(2), 164-170.
- Kagiticbasi, C. (2013). Adolescent autonomy-relatedness and the family in cultural context: What is optimal? *Journal of Research on Adolescence*, 23(2), 223-235.
- Keating, D.P. (2012). Cognitive and brain development in adolescence. *Enfance*, 64(3), 267-279.
- Kelly, D., Pearce, S., & Mulhall, A. (2004). 'Being in the same boat': Ethnographic insights into an adolescent cancer unit. *International Journal of Nursing Studies*, 41, 847-857.
- Klassen, A.F., Cano, S.J., Sinha, R., Shahbaz, A., Klaassan, R., & Dix, D. (2013). Is the Give Youth a Voice questionnaire an appropriate measure of teen-centred care in paediatric oncology: A Rasch measurement theory analysis. *Health Expectations*, Epub. doi: 10.1111/hex.12161
- Klassen, A.F., Dix, D., Cano, S.J., Papsdorf, M., Sung, L., & Klaassen, R.J. (2008). Evaluating family-centred service in paediatric oncology with the measure of processes of care (MPOC-20). *Child: Care, Health, and Development*, 35(1), 16-22.
- Kuhlthau, K.A., Bloom, S., Van Cleave, J., Knapp, A.A., Romm, D., Klatka, K., ... Perrin, J.M. (2011). Evidence for family-centered care for children with special health care needs: A systematic review. *Academic Pediatrics*, 11, 136-143.
- Kuo, D.Z., Houtrow, A.J., Arango, P., Kuhlthau, K.A., Simmons, J.M., & Neff, J.M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Journal of Maternal and Child Health*, 16, 297-305.

- Lehmann, V., Grönqvist, H., Engvall, G., Ander, M., Tuinman, M.A., Hagedoorn, M.,... von Essen, L. (2014). Negative and positive consequences of adolescent cancer 10 years after diagnosis: An interview-based longitudinal study in Sweden. *Psycho-Oncology*, 23(11), 1229-1235.
- Louis-Jacques, J. & Samples, C. (2011). Caring for teens with chronic illness: Risky business? *Current Opinion in Pediatrics*, 23, 367-372.
- Lotstein, D.S., Inkelas, M., Hays, R.D., Halfon, N., & Brook, R. (2008). Access to care for youth with special health care needs in the transition to adulthood. *Journal of Adolescent Health*, 43, 23-29.
- Lotstein, D.S., Ghandour, R., Cash, A., McGuire, E., Strickland, B., & Newacheck, P. (2009). Planning for health care transitions: Results from the 2005-2006 national survey of children with special health care needs. *Pediatrics*, 123(1), e145-e152.
- Lotstein, D.S., Kuo, A.A., Strickland, B., & Tait, F. (2010). The transition to adult health care for youth with special health care needs: Do racial and ethnic disparities exist? *Pediatrics*, 126(Suppl 3), S129-S136.
- Lugasi, T., Achille, M., & Stevenson, M. (2011). Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: A theory integrated metasummary of quantitative and qualitative studies. *Journal of Adolescent Health*, 48, 429-440.
- Lyon, M.E., Jacobs, S., Briggs, L., Cheng, Y.I., & Wang, J. (2013). Family-centered advance care planning for teens with cancer. *JAMA Pediatric*, 167(5), 460-467.
- McBroom, L.A. & Enriquez, M. (2009). Review of family-centered interventions to enhance the health outcomes of children with type 1 diabetes. *The Diabetes Educator*, 35(3), 428-438.

- McCabe, M.A. (1996). Involving children and adolescents in medical decision making: Developmental and clinical considerations. *Journal of Pediatric Psychology, 21*(4), 505-516.
- McDonagh, J.E., Southwood, T.R., & Shaw, K.L. (2007). The impact of a coordinated transitional care program on adolescents with juvenile idiopathic arthritis. *Rheumatology, 46*, 161-168.
- McManus, M.A., Pollack, L.R., Cooley, W.C., McAllister, J.W., Lotstein, D., Stickland, B., & Mann, M.Y. (2013). Current status of transition preparation among youth with special needs in the United States. *Pediatrics, 131*(6), 1090-1097.
- McNeely, C. & Blanchard, J. (2009). *The teen years explained: A guide to health adolescent development*. Baltimore, MD: Center for Adolescent Health at Johns Hopkins Bloomberg School of Public Health.
- Mello, Z.R., Bhadare, D., Fearn, E.J., Galaviz, M.M., Hartmann, E.S., & Worrell, F.C. (2009). The window, the river, and the novel: Examining adolescents' conceptions of the past, the present, and the future. *Adolescence, 44*(175), 539-556.
- Miller, V.A., Baker, J.N., Leek, A.C., Drotar, D., & Kodish, E. (2014). Patient involvement in informed consent for pediatric phase I cancer research. *Journal of Pediatric Hematology/Oncology, Epub 02/04/2014*.
- Moore, L. & Kirk, S. (2010). A literature review of children's and young people's participation in decisions relating to health care. *Journal of Clinical Nursing, 19*, 2215-2225.
- Mullins, C.D., Vandigo, J., Zheng, Z., & Wicks, P. (2014). Patient-centeredness in the design of clinical trials. *Value in Health, 17*, 471-475.

- National Cancer Institute. (2014, November 5). *A snapshot of adolescent and young adult cancers*. Retrieved from: <http://www.cancer.gov/researchandfunding/snapshots/adolescent-young-adult#footnote1>
- National Cancer Institute. Closing the gap: research and cancer care imperatives for adolescents and young adults with cancer (NIH Publication No. 06-6067). Bethesda, MD: Department of Health and Human Services, National Institutes of Health, National Cancer Institute, and the LIVESTRONG Young Adult Alliance; August 2006. Accessed January 15, 2015 from: [http://planning.cancer.gov/library/AYAO PRG Report 2006 FINAL.pdf](http://planning.cancer.gov/library/AYAO_PRG_Report_2006_FINAL.pdf)
- O'Connor, N., Graham, D., O'Meara, A., Devins, M., Jennings, V., O'Leary, D., & O'Reilly, M. (2013). The use of complementary and alternative medicine by Irish pediatric cancer patients. *Journal of Pediatric Hematology/Oncology*, *35*, 537-542.
- Okumura, M.J., Kerr, E.A., Cabana, M.D., Davis, M.M., Demonner, S., & Heisler, M. (2010). Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics*, *125*(4), e748-e754.
- Oswald, D.P., Gilles, D.L., Cannady, M.S., Wenzel, D.B., Willis, J.H., & Bodurtha, J.N. (2013). Youth with special health care needs: Transition to adult health care services. *Maternal and Child Health Journal*, *17*, 1744-1752.
- Overton, W.F. (1990). Competence and procedures: Constraints on the development of logical reasoning. In W.F. Overton (Ed.), *Reasoning, necessity, and logic: Developmental perspectives* (1-32). Hillsday, NJ, England: Lawrence Erlbaum Associates, Inc.
- Pearce, S., Brownsdon, A., Fern, L., Gibson, F., Whelan, J., & Lavender, V. (2016). The perceptions of teenagers, young adults and professionals in the participation of bone cancer clinical trials. *European Journal of Cancer Care*. Epub ahead of print.

- Peter, N.G., Forke, C.M., Ginsburg, K.R., & Schwarz, D.F. (2009). Transition from pediatric to adult care: Internists' Perspectives. *Pediatrics*, *123*(2), 417-423.
- Piaget, J. (2008). Intellectual evolution from adolescence to adulthood. *Human Development*, *51*, 40-47. (Reprinted from *Human Development*, *15*, pp. 1-12, 1972)
- Quinn, G.P., Murphy, D., Knapp, C., Stearsman, D.K., Bradley-Klug, K.L., Sawczyn, K., & Clayman, M.L. (2011). Who decides? Decision making and fertility preservation in teens with cancer: A review of the literature. *Journal of Adolescent Health*, *49*, 337-346.
- Rathert, C., Wyrwich, M.D., & Boren, S.A. (2012). Patient-centered care and outcomes: A systematic review of the literature. *Medical Care Research and Review*, *70*(4), 351-379.
- Saha, S., Beach, M.C., & Cooper, L.A. (2008). Patient centeredness, cultural competence and healthcare quality. *Journal of the National Medical Association*, *100*(11), 1275-1285.
- Sanjari, M., Heidari, S., Shirazi, F., & Salemi, S. (2008). Comparison of coping strategies in Iranian adolescents with cancer and their patients. *Issues in Comprehensive Pediatric Nursing*, *31*, 185-197.
- Sawicki, G.S., Whitworth, R., Gunn, L., Butterfield, R., Lukens-Bull, K., & Wood, D. (2011). Receipt of health care transition counseling in the national survey of adult transition and health. *Pediatrics*, *128*(3), e521-e529.
- Scal, P., Davern, M., Ireland, M., & Park, K. (2008). Transition to adulthood: Delays and unmet needs among adolescents and young adults with asthma. *Journal of Pediatrics*, *152*(4), 471-475.
- Scal, P. & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, *115*, 1607-1612.

- Sebastian, R.A., Ramos, M.M., Stumbo, S., McGrath, J., & Fairbrother, G. (2014). Measuring youth health engagement: Development of the youth engagement with health services survey. *Journal of Adolescent Health, 55*, 334-340.
- Seitz, D.C., Hagmann, D., Besier, T., Dieluweit, U., Debatin, K., Grabow, D.,...Goldbeck, L. (2011). Life satisfaction in adult survivors of cancer during adolescence: What contributes to the latter satisfaction with life? *Quality of Life Research, 20*, 225-236.
- Shaw, K.L., Southwood, T.R., & McDonagh, J.E. (2004). Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: Results of a postal survey. *Rheumatology, 43*, 211-219.
- Siembida, E.J. & Bellizzi, K.M. (2015). The doctor-patient relationship in the adolescent cancer setting: A developmentally-focused literature review. *Journal of Adolescent and Young Adult Oncology, 4*(3), 108-117.
- Spear, L.P. (2000). The adolescent brain and age-related behavioral manifestations. *Neuroscience and Biobehavioral Reviews, 24*, 417-463.
- Steinberg, L. (2001). We know some things: Parent-adolescent relationships in retrospect and prospect. *Journal of Research on Adolescence, 11*(1), 1-19.
- Steinberg, L. (2009). Should the science of adolescent brain development inform public policy? *American Psychologist, 64*(8), 739-750.
- Steinberg, L., Cauffman, E., Woolard, J., Graham, S., & Banich, M. (2009). Reconciling the complexity of human development with the reality of legal policy: Reply to Fischer, Stein, and Heikkinen (2009). *American Psychologist, 64*(7), 601-604.
- Steinberg, L. & Lerner, R.M. (2004). The scientific study of adolescence: A brief history. *The Journal of Early Adolescence, 24*(1), 45-54.

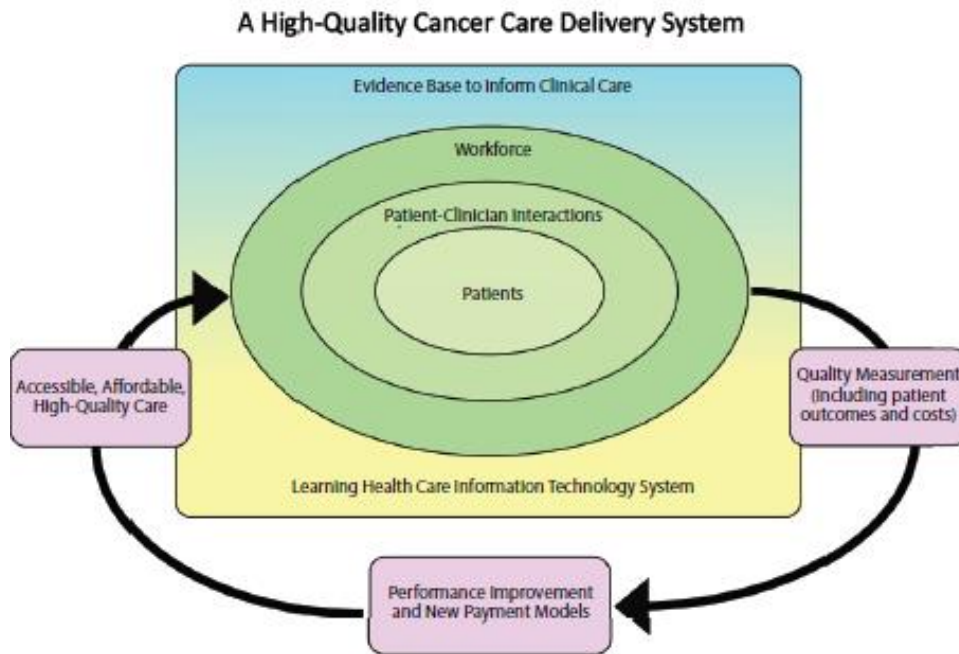
- Stinson, J.N., Sung, L., Gupta, A., White, M.E., Jibb, L.A., Dettmer, E., & Baker, N. (2012). Disease self-management needs of adolescents with cancer: Perspectives of adolescents with cancer and their parents and healthcare providers. *Journal of Cancer Survivorship*, *6*, 278-286.
- Talati, E.D., Lang, C.W., & Ross, L.F. (2010). Reactions of pediatricians to refusals of medical treatment for minors. *Journal of Adolescent Health*, *47*, 126-132.
- Tamis-LeMonda, C.S., Way, N., Hughes, D., Yoshikawa, H., Kalman, R.K., & Niwa, E.Y. (2007). Parents' goals for children: The dynamic coexistence of individualism and collectivism in cultures and individuals. *Social Development*, *17*, 183-209.
- Tates, K. & Meeuwesen, L. (2001). Doctor-parent-child communication. A (re)view of the literature. *Social Science and Medicine*, *52*, 839-851.
- Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., & Garralda, E.M. (2010). Child involvement in the paediatric consultation: A qualitative study of children and carers' views. *Child: Care, Health and Development*, *36*, 678-685.
- Tuchman, L.K., Slap, G.B., & Britto, M.T. (2008). Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development*, *34*(5), 557-563.
- Turner-Henson, A. (2005). Understanding adolescents: A guide for researchers. *Journal of Neuroscience Nursing*, *37*(3), 164-168.
- Van Petegem, S., Beyers, W., Vansteenkiste, M., & Soenens, B. (2012). On the association between adolescent autonomy and psychosocial functioning: Examining decisional independence from a self-determination theory perspective. *Developmental Psychology*, *48*(1), 76-88.

- Watson, R., Parr, J.R., Joyce, C., May, C., & Le Couteur, A.S. (2011). Models of transitional care for young people with complex health needs: A scoping review. *Child: Care, Health and Development, 37*(6), 780-791.
- Weithorn, L.A. & Campbell, S.B. (1982). The competency of children and adolescents to make informed treatment decisions. *Child Development, 53*(6), 1589-1598.
- Wesley, K.M., Zelikovsky, N., & Schwartz, L.A. (2013). Physical symptoms, perceived social support, and affect in adolescents with cancer. *Journal of Psychosocial Oncology, 31*(4), 451-467.
- Willis, G.B. & Research Triangle Institute (1999). *Cognitive interviewing a "how to" guide: Reducing survey error through research on the cognitive and decision processes in surveys*. Short course presented at the 1999 meeting of the American Statistical Association.
- Wong, L.H.L., Chan, F.W.K., Wong, F.Y.Y., Wong, E.L.Y., Huen, K.F., Yeoh, E., & Fok, T. (2010). Transition care for adolescents and families with chronic illnesses. *Journal of Adolescent Health, 47*, 540-546.
- Woolley, M.E., Bowen, G.L., & Bowen, N.K. (2004). Cognitive pretesting and the developmental validity of child self-report instruments: Theory and applications. *Research on Social Work Practice, 14*(3), 191-200.
- Young, A.J., Kim, L., Li, S., Baker, J.N., Schmidt, M., Camp, J.W., & Barfield, R.C. (2010). Agency and communication challenges in discussions of informed consent in pediatric cancer research. *Qualitative Health Research, 20*(5), 628-643.

- Zack, J., Jacobs, C.P., Keenan, P.M., Harney, K., Woods, E.R., Colin, A.A., & Emans, S.J. (2003). Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care. *Pediatric Pulmonology*, *36*, 376-383.
- Zwaanswijk, M., Tate, K., van Dulmen, S., Hoogerbrugge, P.M., Kamps, W.A., & Bensing, J.M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BioMed Central Pediatrics*, *7*, 35-44.
- Zwaanswijk, M., Tate, K., van Dulmen, S., Hoogerbrugge, P.M., Kamps, W.A., Beishuizen, A., & Bensing, J.M. (2011). Communicating with child patients in pediatric oncology consultations: A vignette study on child patients', parents', and survivors' communication preferences. *Psycho-Oncology*, *20*, 269-277.

Appendix A

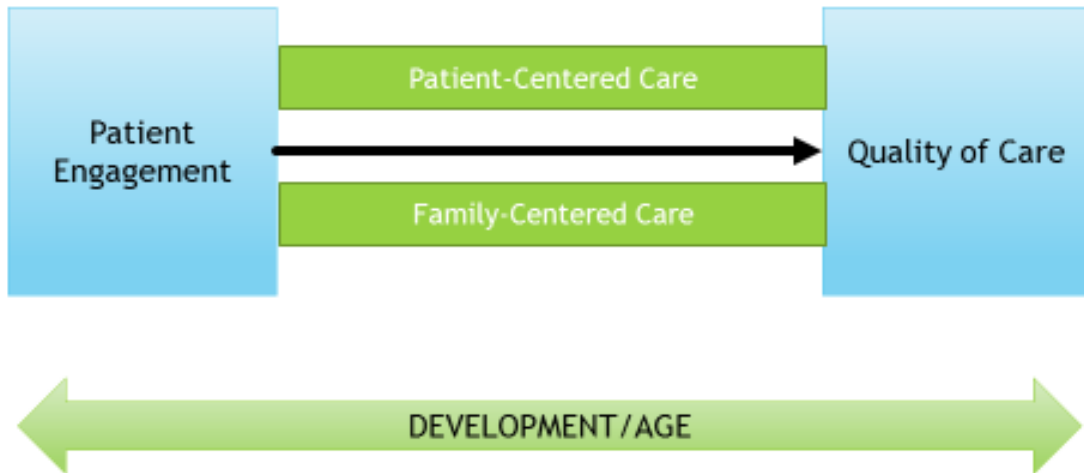
Institute of Medicine's (2013) conceptual framework for high quality cancer care



Appendix B

Study Conceptual Model

Conceptual Model



Appendix C

Recruitment Flyers

Research Study

Smilow Cancer Hospital at Yale-New Haven

Connecticut Children's Medical Center

and

The Department of Human Development and Family Studies at the University of Connecticut

Who is Eligible?

- Adolescents diagnosed with cancer between the ages of 10 and 20
- Cancer diagnosis was at least 3 months ago
- Either receiving active treatment or have finished with active treatment for no more than 2 years
- Must be able to speak and read English

What will you be asked to do?

- Fill out an online survey
- You will receive an email with your survey link and can complete it at a convenient time
- The survey should take no more than 20 minutes to complete

Will I get anything for participation?

- You will receive a \$20 Amazon gift card for completing the survey

**If you have any questions or are interested in participating,
please contact:**

Elizabeth Siembida (Project Manager) at 860-375-4138 or Email:

elizabeth.siembida@uconn.edu

Yale Pediatric Oncology Clinic

Research Study

We're trying to make clinic better and want your feedback!

Who is Eligible?

- Adolescents diagnosed with cancer between the ages of 10 and 20
- Cancer diagnosis was at least 3 months ago
- Either receiving active treatment or have finished with active treatment for no more than 2 years
- Must be able to speak and read English

What will you be asked to do?

- Fill out an online survey
- You will fill out the survey while visiting the clinic on an iPad or tablet OR you can choose to receive a survey link via email and complete it at a convenient time
- The survey should take no more than 10-15 minutes to complete

Will I get anything for participation?

- You will receive a \$20 Amazon gift card for completing the survey

If you're interested in participating while sitting in the waiting room, text "Adolescent Survey" to 774-230-1090 and a knowledgeable individual will come out and meet you.

If you have any questions or are interested in participating at home, please contact:

Elizabeth Siembida (Project Manager) at 774-230-1090 or Email:
elizabeth.siembida@uconn.edu

Appendix D

Online Survey Introduction

Patient Engagement and Quality of Care in Adolescent Oncology

Thank you for your interest in taking part in this study.

Your responses will be useful in examining adolescents' engagement in their cancer treatment, and how this engagement is related to the quality of care received during cancer treatment.

You were directed to this survey because you are a patient at [Name of Hospital]. Your doctor believes that your responses to this survey will be useful in answering the questions of our research study. Before continuing to the survey, please be sure you fit the qualifying criteria:

1. Diagnosed with cancer between the ages of 10 and 20
2. Diagnosed with cancer at least 6 months ago
3. Finished active treatment no more than 2 years ago

If you fit the above criteria, please continue to the survey. Once you finish the survey, you will receive a \$20 Amazon gift card as a thank you for your participation.

Your participation in this survey is strictly voluntary. You are welcome to stop the survey at anytime, and if any question makes you uncomfortable, you are welcome to skip it. If you have additional questions about this study, please contact the Principal Investigator, Elizabeth Siembida at 774-230-1090 or elizabeth.siembida@uconn.edu.

Thank you!

Appendix E

Informed consent form from online survey

A Developmental Examination of Patient Engagement and Quality of Care in Adolescent Oncology

PARENT CONSENT

Aim: To examine the relationship between patient engagement and quality of care in the adolescent oncology setting.

Investigator(s): Dr. Kerry Moss (860) 545-9630
Elizabeth Siembida (774) 230-1090

Purpose of the Research:

Major medical organizations in the United States, like the American Society of Clinical Oncology and the Institute of Medicine, have emphasized the importance of improving the quality of cancer care in America, and one of the major areas of quality cancer care that needs attention is patient engagement. Patient engagement is a patient's ability to understand and manage their own healthcare. Both organizations provide recommendations for improving patient engagement, but neither discusses the importance of considering how it may look different in adolescent patients. Therefore, we would like to examine the relationship between patient engagement and quality of care in adolescent cancer patients. We believe that the opinion of your child will help us to better understand patient engagement and what it looks like in adolescent cancer patients.

Description of the Research:

First, we will ask you (or your child) a few questions about your child. Then, we will show you and your child an electronic device that has the study survey on it. We will ask your child to complete the survey on the screen once.

Your child will be asked to answer a series of questions, and we will explain how to complete the survey prior to your child starting it. This should take no longer than 20 minutes to complete. If you or your child have any questions someone from the study team will be available to you at this time to answer any questions that you may have. For this study we will be asking 103 adolescents from different hospitals to participate.

Potential Risks:

There is a risk of a loss of confidentiality. We will protect against this by using a unique study number that will not contain any identifying information. The questions that are answered on the electronic device will not have any identifying information. If there are any questions on the survey that make you or your child uncomfortable, you do not need to answer.

Potential Benefits:

To individual subjects:

Your child will not benefit directly from participating in this study.
A summary of the study results will be made available to you at the end of the study.

To society:

The study findings may provide valuable information and several benefits including helping doctors and nurses better understand how best to communicate with adolescent cancer patients.

Confidentiality:

Your responses (or your child's responses) will be kept anonymous. The answers provided in this survey will not be associated with your child's identifying information, and following the completion of the research study the data will be kept as long as needed to finish the study then destroyed. Published study results will not reveal who you or your child is/are.

Reimbursement:

Your child will get a \$20 gift card for taking part in the study. There will be no additional cost to you by being part of this study.

Participation:

Your decision for your child's participation is voluntary. If you choose to let your child take part in this study you can take your child out of the study at any time. The medical care your child receives will not be affected in any way by whether your child takes part in this study. New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

Questions:

The principal investigator, Dr. Kerry Moss, is willing to answer any questions you may have about the study, or address any concerns or complaints, and may be reached at (860) 545-9630. Future concerns or questions about this study also may be directed to Dr. Kerry Moss. If you have questions about your child's rights as a research subject, or if you would like to discuss problems, concerns, or questions, obtain information, or offer input about a particular research study, you may call the Institutional Review Board at Connecticut Children's Medical Center at (860)545-9980. In the event of research-related injury, please contact Dr. Kerry Moss at 860-545-9630.

By checking off the box below, I agree that I have read and understood the above study information, and I agree, or consent, that my child may take part in this study.

Appendix F

Assent form from online survey

A Developmental Examination of Patient Engagement and Quality of Care in Adolescent Oncology

ASSENT FORM

Aim: To find out adolescent's involvement in their cancer treatment

Principal Investigator: Dr. Kerry Moss (860) 545-9630

Elizabeth Siembida (774)-230-1090

Why are we doing this study?

Medical organizations and doctors believe that good cancer care includes the patient's involvement in their treatment. We want to see what this involvement looks like in adolescents diagnosed with cancer between the ages of 10 and 20.

We hope the information that you give us will help to find out how adolescents are involved in their cancer treatment.

What will happen during the study?

After reading this page you will be asked to complete the survey on the screen once. You will be asked a series of questions, and we will explain how to complete the survey before you start. The survey will also include directions on how to complete it. This should take no longer than 20 minutes to complete.

Are there good things and bad things about the study?

The survey questions will ask you about you and your cancer treatment. If there are any questions that make you feel uncomfortable, you do not need to answer.

Do you get anything for helping us with the study?

We will give you a \$20 gift card as a thank you for helping us with our study.

Who will know about what I did in the study?

Your answers to these questions will only be seen by the research team. We can use this information to help understand adolescents' involvement in their cancer treatment.

Can I decide if I want to be in the study?

Nobody will be angry or upset if you do not want to be in the study. We are talking to your parent/legal guardians about the study and you should talk to them about it too. If you wish to stop the survey, you may exit it out any point.

If you still want to participate in this study, please check the box below. By checking the box below you agree, or assent, to take part in the study.

Appendix G

Summary of Survey Pre-Testing Focus Group

Survey Measure	Were there any questions on this page that you had trouble understanding?	Were there any response options on this page that you didn't understand?	What would make this question/response option easier to understand?
Demographic Characteristics	<ul style="list-style-type: none"> No issues 	<ul style="list-style-type: none"> No issues 	
Patient Engagement	<ul style="list-style-type: none"> No issues 	<ul style="list-style-type: none"> No issues 	
Patient-Centered and Family-Centered Care	<ul style="list-style-type: none"> The following item was confusing: Look at all the needs of you and your family (for example, emotional or social needs) instead of just physical needs 	<ul style="list-style-type: none"> Original response options (Never, +, ++, Sometimes, +++, +++++, A lot, Does not apply to me) were hard to understand 	<ul style="list-style-type: none"> Change the response options to: Never, Sometimes, Most of the time, All the time, Does not apply to me Rearrange wording order to the following: Look at all the needs of you and your family instead of just physical needs (for example, emotional or social needs)
Quality of Care	<ul style="list-style-type: none"> The following question was confusing: During cancer treatment, did you have a hard time speaking with or understanding your oncologist because you spoke different language. It was unclear the best way to answer when they speak the same language as their doctor 	<ul style="list-style-type: none"> No issues 	<ul style="list-style-type: none"> It was decided that it made sense to add 'does not apply' as a response option to this question
Cognitive Autonomy	<ul style="list-style-type: none"> No issues 	<ul style="list-style-type: none"> The response item 'seldom' was hard to understand. One participant reported having difficulty distinguishing 'sometimes' from 'often.' 	<ul style="list-style-type: none"> Replaced 'seldom' with 'sometimes.' Since only one participant reported difficulty with 'often,' it was kept the same.

Survey Measure	Were there any questions on this page that you had trouble understanding?	Were there any response options on this page that you didn't understand?	What would make this question/response option easier to understand?
Transitional Readiness	<ul style="list-style-type: none"> • Confusion on question: Do you apply for a job or work or higher education • Thought that the use of home and room in the following item made the question difficult to understand: Do you keep home/room clean or clean-up after meals • Confusion on question: Do you call on and use community support services (Ex. Afterschool programs) and advocacy services (Ex. Legal services) when you need them 	<ul style="list-style-type: none"> • In asking questions with the participants, they were answering questions based on how often their parents would do one of the items instead of saying that they (the participant) does not do the item • Thought that a 'does not apply' option would be useful 	<ul style="list-style-type: none"> • Question reworded to: Do you apply for a job or college when needed? • Reworded question to: Do you keep house/bedroom clean or clean-up after meals? • The question regarding community services was eliminated • A response option was added to all questions in this measure that says 'My parent/guardian does this.' • A 'does not apply' option was added to a few questions

Appendix H
Final Survey

Online Survey Examining Doctor-Patient Relationships in Adolescent Cancer Patients

BACKGROUND INFORMATION

Please answer the following questions as best you can. You can also ask your parent or guardian for help if you are not sure what the right answer is.

1. What is the highest grade in school that you have completed?
 - a. Grade 5
 - b. Grade 6
 - c. Grade 7
 - d. Grade 8
 - e. Grade 9
 - f. Grade 10
 - g. Grade 11
 - h. Grade 12
 - i. High school graduate
 - j. Some college courses
 - k. College graduate

2. How old are you? (in years)

3. Which of the following best describes your race?
 - a. American Indian or Alaska Native
 - b. Asian
 - c. Black or African American
 - d. Hispanic or Latino
 - e. Native Hawaiian/Other Pacific Islander
 - f. White

4. What is your gender?
 - a. Male
 - b. Female
 - c. Other

5. Please list where you received your cancer treatment?
 - a. Connecticut Children's Medical Center
 - b. Smilow Cancer Hospital at Yale-New Haven

6. What was your primary cancer diagnosis?
 - a. Leukemia and lymphoma
 - b. Central nervous system tumor
 - c. Bone tumors (e.g. osteosarcoma and Ewing's sarcoma)

- d. Soft tissue and Kaposi sarcoma
 - e. Germ cell cancer (e.g. testicular cancer)
 - f. Thyroid cancer
 - g. Melanoma of the skin
 - h. Other cancer (please describe)
7. How old were you when you were diagnosed with cancer? (in years)
8. What type of treatment did you receive for your cancer? (Check all that apply)
- a. Chemotherapy
 - b. Radiation
 - c. Surgery
 - d. Bone marrow transplant
 - e. Other (please describe)
9. Are you currently receiving active treatment for your cancer?
- a. Yes
 - b. No
 - c. If no, when did you complete active treatment?
10. Have you had a recurrence of your cancer?
- a. Yes
 - b. No

PATIENT ENGAGEMENT

For each of the following statements, please choose the response option that represents your experience during cancer treatment.

1. I will tell my oncologist my concerns, even if they do not ask.
- a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree
2. I talk to my oncologist about different options to address health problems or concerns.
- a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree
3. I make appointments for myself to see my oncologist.
- a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree

4. When I make a plan with my oncologist, I can follow through on the plan at home.
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree

5. I have a safe and trusting relationship with at least one member of my cancer care team.
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree

PATIENT-CENTERED AND FAMILY-CENTERED CARE

Think about the doctors and nurses who have helped with your cancer treatment, and identify how often the following things happen (or do not happen) to you...

1. Allow you to answer questions
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

2. Feel you can trust them
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

3. Show they care about you and your family
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

4. Give you and your parent(s) written information about your treatment
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

5. Let you and your parent(s) choose when to receive information and what type of information you receive
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

6. Talk to you honestly
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

7. Fully explain treatment choices to you and your family
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

8. Trust you know yourself best
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

9. Give you a chance to talk
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

10. Treat you as an individual
 - a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

11. You and family have final say in treatment decisions
 - a. Never

- b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me
12. Look at all the needs of you and your family instead of just physical needs (for example, emotional or social needs)
- a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me
13. Understand your feelings
- a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me
14. Give you a chance to say what you want
- a. Never
 - b. Sometimes
 - c. Most of the time
 - d. All the time
 - e. Does not apply to me

QUALITY OF CARE

For the following items, please select the response option that most closely resembles your experience during cancer treatment.

1. During cancer treatment, did your oncologist or other members of your cancer care team listen carefully to you?
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree

2. During cancer treatment, did you have a hard time speaking with or understanding your oncologist or other members of your cancer care team because you spoke different languages?
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree

- e. Does not apply to me
3. During cancer treatment, did your oncologist or other members of your cancer care team explain things in a way that you could understand?
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree
 4. During cancer treatment, did your oncologist or other members of your cancer care team show respect for what you had to say?
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree
 5. During cancer treatment, did your oncologist or other members of your cancer care team spend enough time with you?
 - a. Strongly disagree
 - b. Somewhat disagree
 - c. Somewhat agree
 - d. Strongly agree

DEVELOPMENTAL STAGE

For the following questions, please indicate how often you do each of the items.

1. I think about the consequences of my decisions.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always
2. I look at every situation from other people's perspectives before making my own judgments.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always
3. I think of all possible risks before acting on a situation
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

4. I like to evaluate my daily actions.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

5. I consider alternatives before making decisions.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

6. I think about how my actions will affect others.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

7. I think about how my actions will affect me in the long run.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

8. I like to evaluate my thoughts.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

9. There are consequences to my decisions.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

10. I can tell that my way of thinking has improved with age.
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always

11. I think more about the future today than I did when I was younger.
 - a. Never
 - b. Sometimes
 - c. Often

- d. Always
12. My decision making ability has improved with age.
- a. Never
 - b. Sometimes
 - c. Often
 - d. Always
13. I am good at evaluating my feelings.
- a. Never
 - b. Sometimes
 - c. Often
 - d. Always
14. I am better at decision making than my friends.
- a. Never
 - b. Sometimes
 - c. Often
 - d. Always

For each of the following statements, please choose the answer that represents your experience during your cancer treatment.

1. Do you keep house/bedroom clean or clean-up after meals?
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
2. Do you use neighborhood stores and services (Ex. Grocery stores or pharmacy stores)?
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
3. Do you help prepare meals/food?
 - a. Never
 - b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
4. Do you fill out the medical history form, including a list of your allergies?
 - a. Never

- b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
5. Do you keep a calendar or list of medical and other appointments?
- a. Never
 - b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
6. Do you request and get the accommodations and support you need at school or work?
- a. Never
 - b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
 - f. Does not apply to me
7. Do you apply for a job or college when necessary?
- a. Never
 - b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
 - f. Does not apply to me
8. Do you get financial help with school or work?
- a. Never
 - b. Sometimes
 - c. Often
 - d. Always
 - e. My parent/guardian does this
 - f. Does not apply to me