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Dimensions of Treatment Decision Making in Adolescents and Young Adults With Cancer

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Dedication

This dissertation is dedicated to my family, who provided me unconditional support and love during this journey through my doctoral education: my children, David, Laura and John and my husband, Paul.

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Abstract

Dimensions of Treatment Decision Making in Adolescents and Young Adults With Cancer

Kimberly A. Pyke-Grimm

Adolescents and young adults (AYAs) with cancer are encouraged or expected to be involved in treatment decision making (TDM). There is limited research on whether and how they want to be involved in TDM. Treatment outcomes in the AYA group have improved minimally compared to their older and younger peers. They experience treatment non-adherence rates as high as 60% that can lead to increased risk of relapse. Open communication, positive family relationships and involvement of the AYA in treatment decisions and illness management could support treatment adherence. However, there is insufficient research exploring the AYA's involvement in TDM.

Focused Ethnography within the sociologic tradition informed by symbolic interactionism was used to explore and describe AYAs' experiences with cancer TDM. Semi-structured Interviews and informal participant observation were used. Thirty-one interviews were conducted with sixteen AYAs between the ages of 15 and 20 years. Participants were asked to reflect on a major recent treatment decision making experience (e.g., clinical trial or surgery) and other treatment decisions made since. Analysis included field notes, analytic memos and coding of interview transcripts. The research was conducted at two pediatric institutions.

Three dimensions related to AYAs' involvement in cancer TDM were identified: 1) becoming experienced with cancer, 2) import of the decision and 3) decision making roles. AYAs' preferences for participation in decision making may vary over time and by type of decision. Parents play a particularly important supportive role. Categories related to their new way of being were also identified and centered around not being able to do what they used to do, changing interpersonal relationships and living with uncertainty. Participants described spending more time with family who provided strength, support and advocacy. They described various strategies for dealing with cancer, and how they decided which activities to participate in, or avoid. Future research is needed to focus on developing and implementing interventions to assist AYAs to develop decision making skills and be involved in decisions about their care, as well and enable AYAs to feel less isolated and facilitate their adjustment to their new “cancer normal.”

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Chapter One

Introduction

More than one million cases of cancer are diagnosed annually in adolescents and young adults (AYAs) around the world. Cancer is the leading cause of death due to disease in AYAs living in economically leading countries. In American AYA males, cancer is the second most common cause of death, after suicide and the most common cause of death in AYA females (Bleyer, Barr, Ries, Whelan, & Ferrari, 2017). AYA patients have shown limited improvement in outcomes compared to the same diseases in younger and older individuals (Albritton, Caligiuri, Anderson, Nichols, & Ulman, 2006; Bleyer et al., 2017; Bleyer, Ulrich, & Martin, 2012).

AYA cancer patients live in a world between pediatric and adult age groups with differences in their brain development, physiology and the biology of their cancer in comparison to younger and older patients (Bleyer et al., 2008). This study is focused on the younger AYA group (15-25 years). This age group is burdened not just by cancer, but by dealing with the normal developmental challenges of adolescence and young adulthood; the progression of which is influenced by dependence on family and healthcare providers (HCP), brain development, and parental protectiveness (Coyne & Gallagher, 2011).

Non-adherence to treatment in AYAs with cancer has been reported to be as high as 60%, (Festa, Tamaroff, Chasalow, & Lanzkowsky, 1992; Landier et al., 2017; Phipps & DeCuir-Whalley, 1990; Smith, Rosen, Trueworthy, & Lowman, 1979; Tebbi et al., 1986) and can cause a higher risk of cancer relapse (Butow et al., 2010). For the younger AYA, open communication, positive family relationships and involvement of the AYA in treatment decisions and illness management support adherence to medical treatment (Albritton & Bleyer, 2003; Sawyer & Aroni, 2005).

Few studies of treatment decision making (TDM) have solely focused on adolescents or the young adult age group. Whether and how involvement in TDM impacts AYAs and their parents has not been examined. As a result, it is necessary to first understand the AYAs' involvement in TDM and factors that influence how they approach TDM. Focusing on this issue will help to achieve the goal of understanding the process and outcomes of decision making in this population.

The first chapter of this dissertation is an introduction to my phenomenon of research, followed by three articles that have been formatted for a specific journal, and finally a discussion chapter. The first article presents an integrative review of published literature on AYA involvement in cancer treatment decision making. The second article describes three dimensions of TDM in the AYA with cancer: becoming experienced with cancer, import of decision, and decision making styles. The third article presents the AYAs' perception of the impact of having cancer during the acute phase of their cancer treatment, focusing on three main areas: you can't do what you used to do, relationships change and living with uncertainty. The final chapter addresses how the study aims were met, limitations, implications for nursing practice and areas for future research.

Purpose and Aims

The purpose of this study was to explore, from the perspective of the AYA (age 15-25 years) with cancer, their involvement in TDM, and the influence of family in cancer TDM. Focused ethnography in the sociological tradition was used, based on a symbolic interaction framework. Ethnography in this tradition usually focuses on studying shared cultural and social phenomena, rather than cultural groups per se, as in the classic anthropological tradition (Wall, 2015). The interaction between family, culture and community is likely to be very important for how and whether AYAs are involved in TDM and ethnography is well suited for this type of inquiry. Preparation for this study included conducting a pilot study with four AYA cancer survivors and attending a conference for AYA survivors of cancer (CancerCon). This helped to solidify recruitment strategies, refine interview questions and practice analysis techniques, and inform the direction of this dissertation study. The specific aims of this study were to:

1. Describe the AYAs preference for and actual involvement in their cancer TDM, including factors that influence TDM about their cancer.
2. Explore the types of treatment and non-treatment decisions in which AYAs do and do not want to be involved.
3. Examine how AYAs interact with family, especially parents, in making treatment decisions.

Background and Significance

Treatment Decision Making and Cancer Outcomes. Rates of non-adherence to medication in young people with cancer are between 27% and 60% (Festa et al., 1992; Landier et al., 2017; Phipps & DeCuir-Whalley, 1990; Smith et al., 1979; Tebbi et al., 1986) leading to increased risk of cancer relapse (Butow et al., 2010). Open communication, positive family relationships and involvement of the AYA in treatment decisions and illness management support adherence (Albritton & Bleyer, 2003; Sawyer & Aroni, 2005) whereas paternalistic relationships with health professionals may reduce treatment adherence by AYAs (Kyngas, Hentinen, & Barlow, 1998). Unfortunately, we lack an understanding of the extent to which and how AYAs want to be involved in their treatment decisions, and the best way to incorporate these preferences in treatment decision making. Supporting AYAs in achieving their desired level of participation is therefore expected to optimize relationship building and trust with healthcare providers (HCP).

The participation of young people in TDM may have numerous potential benefits including improved autonomy, efficacy, sense of control and increased adherence to medical management. (Barakat, Schwartz, Reilly, Deatrick, & Balis, 2014; Butow et al., 2010; Coyne et al., 2014; Coyne & Gallagher, 2011; Kelly, Mowbray, Pyke-Grimm, & Hinds, 2017; Ruhe et al., 2016; Snethen, Broome, Knafl, Deatrick, & Angst, 2006).

I posit that if AYAs were more comfortable with and involved in making their own informed decisions, rather than being overly reliant on (or limited by) their parents and healthcare providers, and if they took more control over their health related decisions they would likely improve their treatment adherence and have better outcomes. However, we lack data about why, how and under what circumstances AYAs make cancer related treatment decisions, which I sought to discover in this study.

AYA Treatment Decision Making in Cancer. Despite evidence and guidelines supporting TDM, scholars continue to debate whether young people are equipped to make rational decisions because their behavior is impulsive, emotional and reactive (Crone, 2009; Paus, 2005; Steinberg, 2005). Adolescents slowly develop frontal lobe function, with the locus of decision making moving first to the deeper, rapidly maturing emotional areas such as the limbic system, leading to decisions characterized by risk taking and stimulus seeking behavior (Blakemore & Robbins, 2012). Cognitive maturation follows later, with fronto-cortical areas establishing control of processes such as planning and weighing of risks and benefits (Christakou et al., 2013). The age when children and adolescents are competent to engage in the informed consent process for research participation (important instances of TDM) for example is controversial (Kauffman & Banner Jr., 1995; Wendler & Shah, 2003). Weithorn and Campbell (1982) suggest that children above 14 years of age are competent to analyze the primary issues of consent and there is agreement that children develop capacity for autonomous thought and to assent to their own care some time prior to 18 years of age (Coyne, 2008; Coyne & Gallagher, 2011).

During cancer treatment, families make important decisions at key points throughout the disease trajectory such as at diagnosis or disease recurrence (Stewart, Pyke-Grimm, & Kelly, 2012). These decisions are complicated by the high level of novel information, uncertainty, risk, emotional stress and the need to make decisions quickly (Kodish et al., 2004; O'Connor, 1997). Current recommendations state that children should be involved in decisions when they are able to do so and would like the choice to participate (Conway et al., 2006; Hinds et al., 2001; Spinetta et al., 2003; United Nations, 1989; Zwaanswijk et al., 2007). Organizations such as the Children's Oncology Group, the American Academy of Pediatrics and the National Health Service of the United Kingdom encourage child involvement in TDM (Joffe et al., 2006; Masera et al., 1997; Spinetta et al., 2003). Although recommendations are that children be encouraged and supported to participate in TDM (Spinetta et al., 2003; United Nations, 1989) guidelines about when and how to involve children and adolescents in TDM are mostly opinion based and are not routinely followed (Unguru, Sill, & Kamani, 2010).

Preferences of AYAs for their level of involvement in TDM may vary for many reasons (e.g. stage of illness, seriousness of condition, type of decision) thus participation may be seen as an ongoing process that varies with the situation (Coyne & Harder, 2011). Concordance between desired and actual TDM roles improves satisfaction with decision making and trust in clinicians (Angst & Deatrick, 1996; Kirschbaum & Knafl, 1996). However, there are reports that children and adolescents with cancer frequently do not participate in TDM to their level of preference and comfort (Unguru, 2011; Zwaanswijk et al., 2007). Their preference for involvement in TDM varies, from no involvement at one end of the spectrum to making most if not all of the decisions at the other (Broome, Richards, & Hall, 2001; Coyne & Gallagher, 2011; Knopf, Hornung, Slap, DeVellis, & Britto, 2008; Snethen, Broome, Knafl, Deatrick, & Angst, 2006). AYAs report they preferred to have their physician or parents decide about their treatment (Ellis & Leventhal, 1993; Stegenga & Ward-Smith, 2008) or believed there was no real decision to make (Coyne, Amory, Kiernan, & Gibson, 2014). Barakat and colleagues (2014) reported that the majority of AYAs had minimal or no role in making the decision about Phase III clinical trials and other studies suggest most did not want sole responsibility for making decisions (Dunsmore & Quine, 1995; Unguru et al., 2010). In contrast, other studies report AYAs preferred to be or were fully engaged in the decision (Weaver et al., 2015) or made the final decision with parental assistance (Zwaanswijk et al., 2007). Having autonomy in decision making about participating in clinical trials was very important to most AYAs in a study conducted by Pearce et al. (2016).

Although studies focus primarily on the child or adolescent, making the findings difficult to apply to the AYA population, it is clear that there is dimensionality to their involvement in TDM. There are situations when they do not want to assume responsibility for making a decision such as close to the time of diagnosis (Stegenga & Ward-Smith, 2008; Weaver et al., 2015), and other situations, such as at the end of life, when they want the responsibility of making treatment decisions (Hinds et al., 2005; Miller et al., 2013).

Complex Relationships With Parents and HCPs. Another key aspect of the multi-dimensional phenomenon of AYA TDM is the complex relationships AYAs have with parents and HCPs. Their participation in TDM is complex because of the triangular interactions between the child/AYA (patient), HCP and parents, and variables including culture, age, experience with illness, and where on the continuum of care the AYA is. Parents assume an executive or gatekeeper role, deciding what the young person should and should not be told to protect him/her from material deemed to be too upsetting (Young, Dixon-Woods, Windridge, & Heney, 2003). There is a wide variation in opinion among parents and HCPs regarding whether and how much children should be involved in making decisions about their own healthcare. HCPs may under or overestimate the child's ability to understand complex issues such as treatment, research and consent (Coyne & Gallagher, 2011). The degree of involvement by children in their own TDM is often determined by the attitudes of the HCPs and parents, not the child's ability (Coyne, 2008; Martenson & Fagerskiold, 2008) demonstrating an imbalance of power between the child and parents/HCP.

Young people will often defer to their parents or physicians for multiple reasons including: wishing to avoid conflict, deference to others' knowledge or experience, or fear of losing emotional, physical or financial support. Additional reasons for young people to not dissent may include agreement with the parent or choice for the parent to make decisions. When adolescents' preference is for TDM by parent or HCP it may be due to the complexity of the issues (Knopf et al., 2008).

In addition to the parent-child and parent-HCP relationship, another critical relationship in the AYA TDM environment is the AYA with the HCP. The complex interaction between the three main parties: the AYA, the parent and the clinician contribute to the complexity, variation and difficulty in studying this phenomenon. As clinicians have usually not met the patient and family prior to the crisis, they may be unable to estimate the child's ability to deal with and understand complex issues such as treatment, research and consent. Obviously, the imbalance of power between the young people versus the parents and clinicians means their participation is likely under external control. In a study of the attitudes of pediatric oncologists, de Vries found that some physicians assess adolescents as not capable of meaningful participation; some did not always provide adolescents with all the information necessary to make an informed decision and some felt that proxy consent from parents was sufficient (de Vries, Wit, Engberts, Kaspers, & van Leeuwen, 2010).

There are no known interventions to support AYA TDM and little outcome data on the effect of involvement in TDM on AYAs and their parents. A critical impediment to this research is the lack of in-depth descriptions about AYAs' preferences and involvement in TDM. Taken together, there is limited understanding about the preferences and role of the AYA in TDM involvement.

Gaps in TDM Knowledge. Despite the progress that has been made in the field of cancer-related decision making, there are still major gaps in knowledge (Unguru, 2011) about the perspectives of the AYA. These include gaps in our understanding of the AYA's voice and preferences for TDM, the involvement of AYAs in the TDM process and factors that contribute to or impede this process. Whether and how young people's involvement in TDM impacts AYAs and their parents has not been examined. Demonstration of outcomes of TDM participation are lacking, especially related to congruence between desired and actual TDM roles. Most studies of decision making focus on cancer research participation and end-of-life decisions; are cross-sectional or retrospective; or focused on the parents' or clinician's perspective, rather than AYA's. Most research has primarily focused on children not AYAs with cancer, especially in terms of their input regarding treatment choices and outcomes such as adherence to treatment (Buchanan, Block, Smith, & Tai, 2014). Furthermore, few studies address how AYA's approach TDM or interact with their family to make treatment decisions (Barakat, Schwartz, Reilly, Deatrick, & Balis, 2014; Coyne et al., 2014; Pearce et al., 2016).

To provide individualized care to AYAs with cancer and their families, clinicians must understand the range of factors that influence their involvement in TDM. The knowledge gained through this research will help better understand the TDM process in AYAs with cancer and their preferred level of participation. Results could empower clinicians to sensitively assist AYAs to participate in TDM and help them develop appropriate interventions. Such research is expected to improve the AYAs relationship with HCPs and improve both their and their family's well-being. The short-term goal of this proposed research is to describe the AYA's involvement in cancer TDM and the factors that influence their participation within the context of family. The long-term goal of this program of research is to develop and test evidence-based interventions aimed at supporting and enhancing shared decision making for the AYA population with cancer.

Theoretical Foundations

Two formal theories: Bronfenbrenner's bioecological theory of human development and Bandura's self-efficacy theory informed the research question; to explore the AYAs' involvement in cancer treatment decision making. These theories are complementary to each other in explaining the phenomenon under study and each offers a unique contribution to understanding AYAs with cancer and their involvement in treatment decision making within the context of cancer and family.

Bioecological Theory of Human Development. Bronfenbrenner's bioecological theory (Bubolz & Sontag, 2008) proposes behavior and development as intertwined functions of the personality and the environment and posits that human behavior can be interpreted based on interactions in social structures of community, society, economics and politics that are named ecological levels (or spheres). These levels are defined as: individual, family, peer group, school and community and visualized as a series of nested structures, each contained within a larger one and are identified as: microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979). A later construct, the chronosystem, examines the influence of changes and continuities over time (Bronfenbrenner, 1986). These levels identify factors that play a (if not the) primary role in influencing the developing person as well as influencing the other levels. The maturing person (AYA) is portrayed as not just a passive actor that is at the mercy of the environment, but as a developing actor who interacts with the environment and, in turn, affects or restructures that environment. Essentially, the interaction between the individual and the environments is bidirectional or reciprocal. The ecological system is not a stagnant structure, as it includes interaction between local environments and more distant influences such as the culture of the society the AYA lives in, government policies, or available funding for care (Bubolz & Sontag, 2008).

Bronfenbrenner's diagram has been modified and applied to the AYA with cancer (Appendix A). There are many interactions between members of the microsystem and mesosystem. It is within the microsystem where the immediate context of development involving person-to-person interaction occurs. The model is the relationship and interaction between systems where the AYA is the focus. The microsystem includes relationships between the AYA and family and the HCP. The newly diagnosed AYA with cancer experiences totally new mesosystem interactions, including the new environments of the hospital and other places where they interact with HCPs. They experience new microsystems such as their hospital room or clinic visits. This can have profound effects on the existing family microsystem and their interaction with the AYA on many levels including TDM. Inadequate and unsatisfactory involvement in TDM is an emerging clinical problem (Unguru, 2011), which may benefit from analysis and intervention. The microsystem is where most time, socialization and development takes place with the family.

Adjunct Theory

Theory of Emerging Adulthood. Although Bronfenbrenner was a developmental psychologist, his focus was on the developing human being and the immediate settings within which the developing person lives and interacts. However, the concept of development and developmental tasks is not well addressed in Bronfenbrenner's bioecological theory. Arnett's (2000) developmental theory offers important conceptual perspectives for understanding AYA development and TDM.

Over the last 50 years, sweeping cultural and economic changes have led to the emergence of a defined prolonged period called adolescence and young adulthood. Previously, this transition from child to adult roles was very short and discreet. The increasing complexity of life in industrial societies has required more education and time for social and economic maturation prior to full emergence of the adult. Associated with this is continued delay of the median age of marriage and age of first child bearing (Arnett, 2000).

Arnett proposed a developmental theory of emerging adulthood as the period from late teens through the twenties, with particular focus on those between 18-25 years of age (Arnett, 2000). In present day, emerging adults have lost the constraining role requirements that were common in previous eras. They are no longer expected to work at a young age, marry or have children early in life. They are allowed a wide latitude to try new things and behaviors, therefore there is a huge variability in their lives and activities. Although these people would not describe themselves as 'adolescent' they usually do not call themselves adult either.

A natural outgrowth of this change is that their definition of this interval, and when they have matured to adulthood, is not so much related to an age or career achievement but more to the development of aspects of their character such as, accepting responsibility for one's self, making independent decisions and being financially independent. Self-sufficiency is a common thread to these criteria. Certain high-risk behaviors also occur more frequently in emerging adults. This may be related to their exploration of their identity, but also could have a biological basis in the primacy of the limbic system over the frontal lobes, a period of time when the frontal seat of sober second thought takes a backseat to the demand for stimulation characterizing limbic predominance (Arnett, 2000).

Taking over decision-making, and increasing complexity of decision-making is a hallmark of the process of maturation (Leffert & Petersen, 1999). Increased autonomy, authority and responsibility is not absolute nor irreversible, for in a state of stress or high risk decisions, emerging adults will often turn to parents for guidance (Grinyer, 2004). This is true in a situation of acute disease such as cancer (Smith et al., 2012). The period of adolescence is a time of intense developmental activity, when if illness such as cancer occurs maturational processes may be slowed down, halted or even reversed (Stern et al., 2010).

The development of independent decision making may be delayed by the diagnosis of cancer. These patients feel they have lost control over their life leading to attempts to regain control even if only just in a limited way and may experience feelings of anger (Albritton & Bleyer, 2003; Stern et al., 2010). Adolescents want to be like their peer group, and cancer makes this difficult (Wicks & Mitchell, 2010). During the process of cancer therapy, the ability to make decisions and advocate for autonomy may increase with experience with the illness (Hinds et al., 2005; Zwaanswijk et al., 2011). Arnett's theory of emerging adulthood is specific to the development of the AYA population and is used in conjunction with Bronfenbrenner's bioecological theory.

Theory of Self-Efficacy. Bandura's self efficacy theory is concerned with the individual's core belief in their ability to perform a specific behavior or task which is defined as self-efficacy (Appendix B) (Bandura, 1977). Albert Bandura proposed self-efficacy as a mediator of powerful behavior. The theory was derived from social cognitive theory in the 1970's and posits the triangular and reciprocal interactions between person, behavior and environment, known as triadic interchange, as the foundation for reciprocal determinism. Reciprocal determinism is the belief that personal factors such as behavior and cognition and the environment operate and influence each other interactively (Bandura, 1977). Self-efficacy beliefs are involved in motivation, moods, attitudes and the willingness to perform health-promoting behaviors (O'Leary, 1985; Strecher, DeVellis, Becker, & Rosenstock, 1986).

The theory of self-efficacy provides a useful framework for understanding AYA participation in TDM. Inadequate and unsatisfactory participation in TDM is a well-recognized clinical problem, which may benefit from considering it as just another health behavior amenable to analysis and modification in the context of self-efficacy theory. Adolescents and young adults may believe that participation in TDM will result in them being more satisfied with the experience of cancer. They may believe, however, that they are not capable of participating in TDM to the extent that they might prefer; leading to the undesirable outcome of perceiving that their fate and cancer experience is in the hands of external forces (e.g. parents and physicians), in turn, leading to frustration, dissatisfaction with care and possibly noncompliance with medication. The degree to which the AYA with cancer prefers to be involved in the TDM process, their actual involvement and self-efficacy may be closely interrelated and amenable to therapeutic intervention. This may lead to increased involvement in the TDM process.

Alone, these theories are not adequate to provide enough guidance for TDM and even the two together are not comprehensive in completely explaining the phenomenon. Therefore, theoretical frameworks and a construct related to decision making also inform and elaborate further on relationships and concepts about the phenomenon of the AYA with cancer and TDM (Appendix C). These decision making theoretical frameworks and constructs include: Degner's Control Preferences Construct, O'Connor's Model of Decisional Conflict, and Kahneman and Tversky's Prospect Theory.

These theories informed the approach to TDM by providing a frame of reference for development of interview guides, making observations and points to focus on during the analysis. The interview guides, for example, included questions related to what types of decisions AYAs want to be involved in making; what influences their involvement in TDM and how they interacted with family and their HCPs to make these decisions. The individual's (AYA) interactions with the microsystem (parents/HCPs) informed the analysis. They lay a solid foundation that allowed potential areas of interest to be explored and the elaboration of relevant concepts.

Methods

Focused ethnography was chosen as the methodology for this study for its emphasis on understanding everyday life from the perspective of those who live it (Reeves, Kuper, & Hodges, 2008). Focused ethnography provides an excellent, rich data source on the group, culture, community and social situation of the subject. Listening to the AYA speak of their ordinary experiences allow us to better interpret their lived experience, and understand their world. I entered their world by spending time with the participants and observed them informally in the clinic or hospital to understand their experiences, perspectives and interactions.

Ethnography employs a mix of very detailed open-ended (semi-structured and/or conversational) interviews, review of relevant documents and materials, and participation in the participant's environment. The emphasis is on exploration of the nature of the participant's world rather than testing hypotheses about it (Reeves et al., 2008). In this way, ethnography provides rich data on the group, culture and community of the subject, which is exactly what is important to this investigation informed by Bronfenbrenner's and Bandura's models. Ethnography has been shown to be useful in a number of studies of healthcare and healthcare practice (Holloway & Wheeler, 2010; Wall, 2015) but not yet in assessing TDM to our knowledge. In this study, I used focused ethnography in the sociological tradition based on a symbolic interaction framework (Polit & Beck, 2004) to explore the symbols and meaning of the everyday lives (Blumer, 1986) of AYAs within the context of their treatment for cancer and the TDM that occurs.

Major patterns, processes, domains and typologies become known through the iterative analysis process. In the data analysis I looked for outliers, variations in process or outcomes. Interviews and field notes were analyzed. To better interpret the human lived experience, it entailed listening to the AYA speak of their ordinary every-day experiences to understand more about their world.

Setting and Sample

Setting. The setting was two large quaternary care university teaching hospitals in the San Francisco Bay Area. Both pediatric oncology centers treat AYAs and one of the two has an official adolescent young adult cancer program.

Sampling Strategy. The purposive sampling plan included AYAs undergoing active treatment for any diagnosis of cancer who have had a major treatment decision made within one year of their diagnosis. Major treatment decisions include clinical trial enrollment consideration; surgical treatment options and experimental therapy. The researcher assumed that the participants shared a common cultural viewpoint such as their developmental level, experience with cancer and the need to make cancer treatment decisions and therefore focused on their similar behaviors and experiences (Morse, 1987; Wall, 2015).

Inclusion Criteria. The inclusion criteria were individuals who: were between 15 and 25 years of age; were currently undergoing cancer treatment; have had a previous major treatment decision made within the past year; speak and understand English; agreed to participate in one to two interviews lasting approximately 45 minutes to one hour each and provide informed consent to participate (participants who are 18 years of age or older) or assent obtained from themselves (participants less than 18 years of age) and consent from their parent(s)/guardians(s).

The age selection criterion of 15 to 25 years of age is based on the following rationale. The low end of the age criteria is based on the definition of AYA (Coccia et al., 2014) and age 25 is typically the upper age limit of admission to a Children's Hospital. Children below the age of 18 are considered minors and it is required that parents provide consent on their behalf. The decision point of enrolling the child in a clinical trial or surgical treatment choices (i.e. limb salvage versus amputation) for example are considered to be a major decision and definite decision point in treatment at which a decision is required.

Fifteen of the sixteen AYAs were interviewed twice. The second interview allowed time to confirm and elaborate evolving findings. The multi-site approach facilitated participant enrollment and transferability of findings.

Recruitment and Procedures

Participants were recruited from the oncology programs of two university affiliated regional pediatric institutions. Eligible participants were identified by the staff in the Pediatric Oncology Clinics and Inpatient Units. Members of the treatment team initially introduced the study to prospective parents and AYAs; if they were interested in possibly participating, I then introduced myself to discuss the study further and answered any questions.

After consent was obtained, a demographic questionnaire was completed with the participant (Appendix D). Interviews were conducted with each AYA in the outpatient setting, in a private room or in their hospital room depending on convenience and participant preference. The interview was conducted using an interview guide (Appendix E) with additional questions as appropriate. At the end of each interview, I asked permission of participants to contact them for a second interview. Participants were given a gift card worth $25 per interview for their time and participation in the study.

Data Collection

Ethnographers usually use multiple methods of data collection to develop their understanding of the everyday life of those whom they study. These methods include participant observation and interviewing. Data generation included interviews, observations, field notes, and memos.

Interviews. Interviews were conducted privately with each participant. An open-ended, semi-structured interview guide was used to initiate and guide the interviews conducted by myself. The interview guide was reviewed by the AYA Council at one of the recruitment sites for wording, clarity and content. Two members of the Council, who were young adults and who had been treated for cancer were advisors to the project.

AYAs were asked to: reflect on a major treatment decision that was recently made and others that have been made since; what this experience meant to them; discuss what their preferred and actual involvement was; explore what types of decisions they want to be involved in making; and how they interacted with family to make these decisions. The guide consisted of open-ended questions, which allowed for in-depth exploration of specific areas. To as great an extent as possible, the participants were encouraged to speak about ordinary, specific episodes and situations in their lives rather than discussing abstract concepts (Benner, Tanner, & Chesla, 1998). With the AYA's permission, interviews were audio-recorded and transcribed verbatim.

Observation. Observation is critical to qualitative research methodology, because what people do is at least as important (if not more important) as what they say (Hammersley, 1998). Data were gathered noting observations made during the interview including descriptions of the field site, participant and nonverbal responses to questions. Field notes of behavior are very important because behavior is not included in an audio recording and this important channel of communication is essential to consider. This also draws the researcher's attention to any signs of distress that might indicate whether a certain line of questioning is appropriate or should be returned to at another time.

Field Notes. Field notes are an important part of ethnographic research (Maanen, 1995). They are brief descriptions of events, observations and notes to self about what occurred and further questions to explore. Field notes were written after the fact and often written as a narrative summary to highlight the overall picture or key points (Wolfinger, 2002).

Field notes were dictated following each interview and included a description of: the field site, respondent and the overall flow of the interview. They also included: key insights, salient and interesting points, main issues and themes, any problems, new information and concepts or events that emerge from the interview. Field notes were kept in a word document on an encrypted computer.

Data Analysis

Verbatim transcripts of the audio-recorded interviews, field notes and memos constituted the data for analysis. Analysis began following the first interview and continued simultaneously with data collection. I reviewed transcripts from each interview for accuracy by listening to the interview and compared it to the transcript. Field notes and memos were generated and reviewed multiple times during the analysis. The transcripts were read and reread to develop a deep understanding of the meaning. Interviews were compared and contrasted within and between cases.

Coding: Coding generated the scaffolding upon which the analysis was built. Through the process of coding the events recorded in the interview or observation, they were turned into data and analysis began (Charmaz, 2014). Early decisions made in coding shaped the later analysis about the critical, fundamental conceptual categories. Through the process of constant comparison of data, the ethnographic researcher identifies what is important to the participants and can focus on that area. First attempts at coding followed the data closely. The initial codes were temporary or ‘provisional.’ They were modified by constant comparison and subsequent new data. They remained provisional as the researcher was opened to the identification of new meaning and interpretation over time. As codes evolved or remained true to their data and, essentially, proved their worth by showing they reflected some important element of truth in the data, they were retained. Areas where the codes are deficient were filled in with potential new codes (Charmaz, 2014).

Previously interviewed participants were asked to discuss or consider the preliminary analysis and verify the relevance of the analysis. Regular face-to-face meetings with my dissertation chair facilitated collaborative analysis and refinement of data-gathering techniques.

Memo Writing. The memo is the unit of analysis that mediates the transition from an interview or transcript to a body of analysis. Memos are a note based on a phrase or idea that occurs to the researcher while contemplating the database that is developed from the transcripts. Memos can be an identification of or a comment on a major finding, the beginning of a category or they can be focused on a particular aspect. Writing analytic memos can help immensely in writing the results and provide the basis for analysis and the report.

Rigor. During the data analysis process, it is important to maintain utmost rigor, and intent and spirit of the methodology used in the study. The use of terms such as validity and reliability, which are common in quantitative research, are inappropriate for use in qualitative research, unless the criteria for their application is true to a qualitative perspective. Qualitative and quantitative research come from different backgrounds and worldviews. The researcher must remain true to these epistemic traditions and their output should be judged using the appropriate criteria (Leininger, 1994).

There is debate about how to establish validity in qualitative research. While some claim it is futile to strive for certainty in science (Maxwell, 1990; Whittemore, Chase, & Mandle, 2001) it is necessary to balance the coexistence of rigor and subjectivity and even creativity in the qualitative scientific process (Johnson, 1999).

Numerous scholars have contributed to the development of validity criteria or criteria for rigor (Lincoln & Guba, 1985; Maxwell, 1990; Sandelowski, 1993; Whittemore et al., 2001). Whittemore, Chase and Mandel (2001) developed primary and secondary criteria for assessing qualitative research to enhance rigor. Primary criteria, including credibility, authenticity criticality and integrity, are necessary but not sufficient for overall qualitative inquiry. Credibility is the degree to which the results of the research reflect the experience of the participants. Authenticity is closely linked to credibility and involves presenting results of research that reflect the participants' perspective (Sandelowski, 1986)). Criticality is evidence of critical appraisal such as searching for alternative explanations, biases and exploring negative instances. Integrity is represented through repeated checks of interpretations as well as humble presentation of findings. Interpretation must be validly grounded in the data.

Whittemore et al.'s (2001) secondary criteria are more flexible but narrower benchmarks of quality. They include explicitness, vividness, creativity, thoroughness, congruence, and sensitivity. Explicitness suggests the researcher has identified their methodological decisions, interpretations, and biases. Vividness is the ability to highlight important features, capturing the essence of the phenomenon without overwhelming with detail (Sandelowski, 1986). Creativity is innovative organization, presentation and data analysis. Complete sampling, data adequacy and comprehensiveness of approach and analysis are described in terms of thoroughness. Congruence is the parallels between the research question, method and findings, between data collection and analysis, between this and previous studies and between the findings and practice. Sensitivity refers to sensitivity to the human, cultural, and social context in which the research is performed (Whittemore et al., 2001).

The following illustrate how these validity criteria were applied to this study of AYAs' involvement in treatment decision making. Credibility was enhanced through careful systematic data collection from multiple sources. Authenticity was enhanced by discussing preliminary findings and analysis with participants (member checks). Criticality was supported through research team debriefing sessions where the procedures, data, analysis, and interpretation was discussed. To promote integrity, review of the data was collaborative with team members. Transcripts were reread, compared and contrasted throughout the study. In an attempt to achieve thoroughness, perspectives from AYAs of different ages were sought. To improve rigor, second interviews were conducted with participants, field notes were taken, participants were asked to verify the relevance of emerging findings (member checking) and informal participant observation was conducted.

Reflexivity. An ethnographic researcher must be aware that they can never be completely objective because they bring their own biases and experiences to any interaction. By consciously being reflexive, the researcher tries to be aware of these things and how they might shape their own thoughts, interpretations and conclusions about the activities they are witnessing (Hammersley & Atkinson, 1995). Reflexivity is the process whereby a researcher evaluates and meditates on the decisions, interpretations and experiences they experience while performing their research to understand their role and function as both researcher and respondent (Charmaz, 2014). It is an important aspect of rigorous qualitative research as the researcher develops into an effective practitioner in this process by developing awareness of how the researcher's interests, positions, and assumptions affect the process (Guba & Lincoln, 1994).

Without this self-awareness and analysis, the researcher risks simply retelling the participant's story from their own perspective (Charmaz, 2014). I wrote reflexive notes as part of the field notes. This allowed me to check in with myself, and allow for more personal processing. The researcher can examine their position in terms of attitudes, beliefs and how this may affect one's research as well as what they would do differently and whether a question should be included or not.

Human Subjects

Informed Consent. Informed consent in qualitative research is mandated to be somewhat open ended, for the researcher cannot know exactly what will happen during their participation in an activity and the possible outcomes, especially because adaptability and flexibility are encouraged in the process (Eisner, 1991). Performing research on children (who by definition are classified as vulnerable) requires commitment to researcher reflexivity and continuously maintaining safety, dignity, and the child's voice. There are both procedural ethics and ethics in practice (Guillemin & Gillam, 2004) that are areas of ethical concern when working with children. They include: informed consent and assent, protection from disclosure, awareness of power imbalances and how the child is represented. Consent and assent with children is better approached as a process versus a single event (Warin, 2011).

In this study, I reviewed the consent document with the participant and/or parent. Consent/assent language was aimed at the 6th grade level. The participant was given the opportunity to ask questions or decline to continue with the informed consent process. The participant was given the opportunity to read the consent or to have the consent read to him/her. All questions and concerns were addressed before the consent was signed. The participant was reminded that their participation was voluntary and they may stop the interview process at any time. Written and verbal consent (greater than18 years of age) and assent (less than 18 years of age) was reviewed at the beginning of the interview and continuously monitored during the process. The AYA had the opportunity to withdraw consent/assent in private when parents had left the investigator with the participant.

Confidentiality. Threats to confidentiality are especially prominent in presenting the results of qualitative research, and merit direct discussion with participants during the consent process (Morse, 2007). Participants described by listing demographic identifiers may make it possible for those who know the person participating in the study to then identify them. If the quoted words, stories and images of participants are published these are other threats to confidentiality, as someone who knows them may be able to identify them even without including the name or other HIPPA protected identifiers (a unique ID or pseudonym).

Strategies for protecting confidentiality in the dissertation study included: the 1) de-identification of all research data (questionnaires and interviews) and patients were labeled or referred to by using a unique assigned study ID and, pseudonyms were used in reporting; 2) all notes, consents, audio recordings of interviews and any other identifying information were kept in a secure, locked filing cabinet. Audio recordings were transcribed into a password protected, whole disc encrypted computer and then erased from the recording device; 3) limited access to locked/encrypted materials with only myself and dissertation chair having access; and 4) all study materials will be securely deleted at the end of the study once analysis and publication is complete, An electronic contact list was maintained on the encrypted computer for administrative purposes and for future contact in the analysis process. It will be destroyed at the end of the study.

Fieldwork Ethics. In the interview context, issues of power may exist. Power balance issues are present in all human interactions, including the transaction of the interview (Nunkoosing, 2005). Interviewees often consider the interview as a potential threat in addition to an opportunity to be heard (Schwalbe & Wolkomir, 2002). Even though the interviewer needs the participation of the participant (and therefore is at the participant's mercy) this power differential in favor of the participant may not be perceived by the participant (Becker, 1970). In fact, the interviewer may be interpreted as a potential threat, who may discover hidden secrets of the vulnerable participant. The interviewer may hold a certain amount of power, as the initiation and chooser of the time and place and possibly a representative of a higher authority. It is often beneficial to deliberately present as less powerful or give up some of their power to the interviewee (Kleinman, Copp, & Henderson, 1997). Power is multifaceted and sometimes difficult to assess and the interviewer may never be able to place themselves on an even footing with the research participant (Glesne & Peshkin, 1992). In this study it was important to develop a trusting relationship with the participant from the beginning (using my skills as a clinician and researcher) by slowly and carefully building a relationship characterized by rapport, respect and safety in the relationship (Karnieli-Miller, Strier, & Pessach, 2009; Nunkoosing, 2005).

Key Findings

The sample consisted of 16 AYAs (9 males, 6 females and 1 non-binary) who were interviewed on two separate occasions with the exception of one participant who was interviewed once. Thirty-one interviews were conducted. The first lasted a mean of 64 minutes. The second lasted a mean of 60 minutes. Participant characteristics are presented in Table 1.

A range of topics were discussed including family involvement in making decisions, decisions made at home and in hospital, their decision making style for various types of decisions, influences on their treatment decisions, how their cancer or treatment affected decisions that came up in their daily life as well as relationships with others including friends, family and HCPs. Based on the data, the analysis focused initially on describing three identified dimensions of AYA decision making. The first dimension, “becoming experienced,” was identified as an important phenomenon that the AYAs lived through. They sought information about their disease and treatment from various sources, became engaged as an active participant in care, learned through observation or participation in repetitive events such as anti-nausea administration, participated in discussions with their healthcare team and came to understand the various roles that individuals play in the hospital and healthcare system. They also determined care preferences, learned to advocate for themselves and manage their care.

The second dimension, “import of decision,” delineated how the AYA distinguished decisions. A multitude of decisions were discussed and ranged from supportive care type decisions (i.e. symptom management), anesthesia versus moderate sedation decisions for procedures (i.e. lumbar punctures and bone marrows), decisions about fertility preservation, decisions made about clinical trials often early after diagnosis, and life altering, irrevocable surgical decisions. While some were considered inconsequential, others were considered to be of great consequence and important. Interestingly, some of the consequential decisions often were perceived to require little deliberation, being described as a ‘no brainer’.

The third dimension, “decision making roles,” described the types of decision making roles the AYA assumed in various decisions. For some, they considered themselves the ultimate decision maker when it came to decisions of higher magnitude. They remembered (or believed) they decided by themselves. The majority sought information and collaborated with their parents and/or HCPs in making decisions. There was a group of AYAs, who were too overwhelmed or distressed to participate in making decisions, for which their parents often assumed an active role in decision making with HCPs.

Overall, the AYAs had positive relationships with their HCPs, communicated with the team on rounds and asked questions if they had them. They were often involved in self-management both in the hospital and at home and wanted to be informed and involved in making decisions about their care. These finding are consistent with previous studies, in that the AYA wants to be informed and participate in decision making (Barakat et al., 2014; Pearce et al., 2016).

The interviews largely focused on the role of the AYA in treatment decision making, the various types of decisions they experienced as well as how decisions were made within the context of family (parents). Findings also related to the impact of cancer on the AYA. These findings were uncovered while exploring in depth questions about decision making. The second research paper therefore focused on findings describing the AYAs' view and management of their lives within the context of cancer. Categories identified related to their new way of being and centered around not being able to do what they used to do, changing interpersonal relationships and living with uncertainty. The category, "you can't do what you used to do," encompassed their change in activity level and appearance as a consequence of the side effects of treatment. They relinquish much of their normal routine like attending school and socializing with friends and participating in their usual activities. They experience this as a profound loss.

"Relationships change," another category describes how their relationships with friends, family and HCPs evolve. They retreat to family who provide strength, support and advocacy and spend less time with friends. They sometimes feel like a burden to friends and others and describe how they missed out on important, normal activities. They missed school and socializing with friends. Social media helped some of them to stay connected with friends.

The category of "living with uncertainty" is pervasive for these AYAs. They encounter uncertainty in the form of not knowing the outcome of their surgery in terms of physical limitations, potential side effects of treatments, waiting for results of diagnostic tests and procedures, and the threat of recurrence. They also lived with uncertainty in terms of returning to their life and interacting with others who may have moved on, as well as their future plans.

This study has extended the body of knowledge related to understanding AYA involvement in cancer treatment decision making. The following articles describe the state of the science related to AYA involvement in TDM, identify the dimensions of AYA treatment decision making that may interact with each other (or not), and their “cancer” normal for these AYAs.

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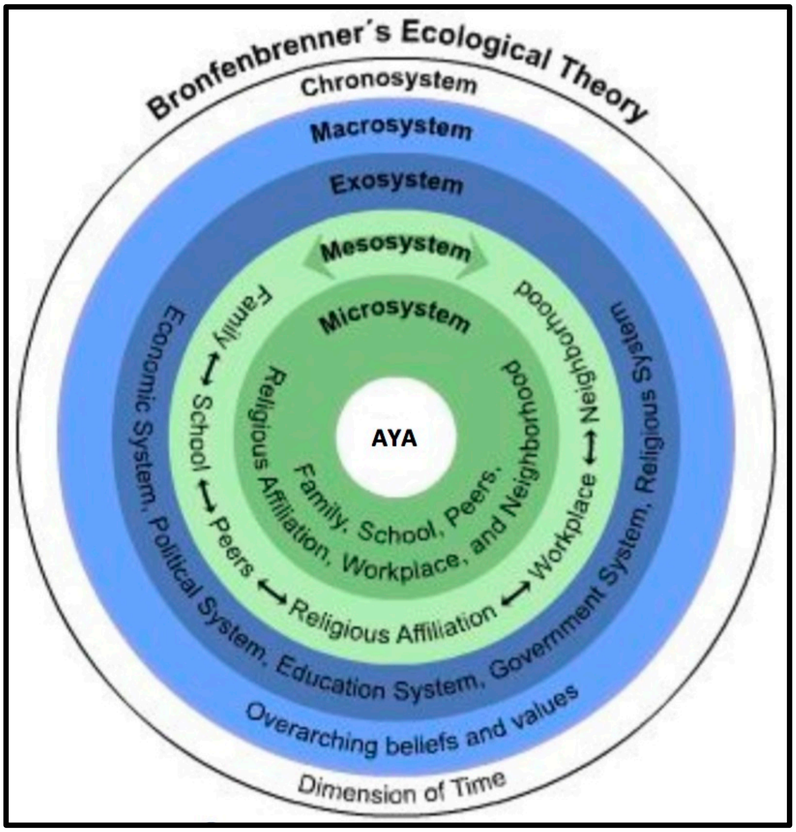
Appendix A

Bronfenbrenner's Bioecological Theory of Human Development



Modified from (Horsey, 2014)

Appendix B

Bandura's Self-Efficacy Theory

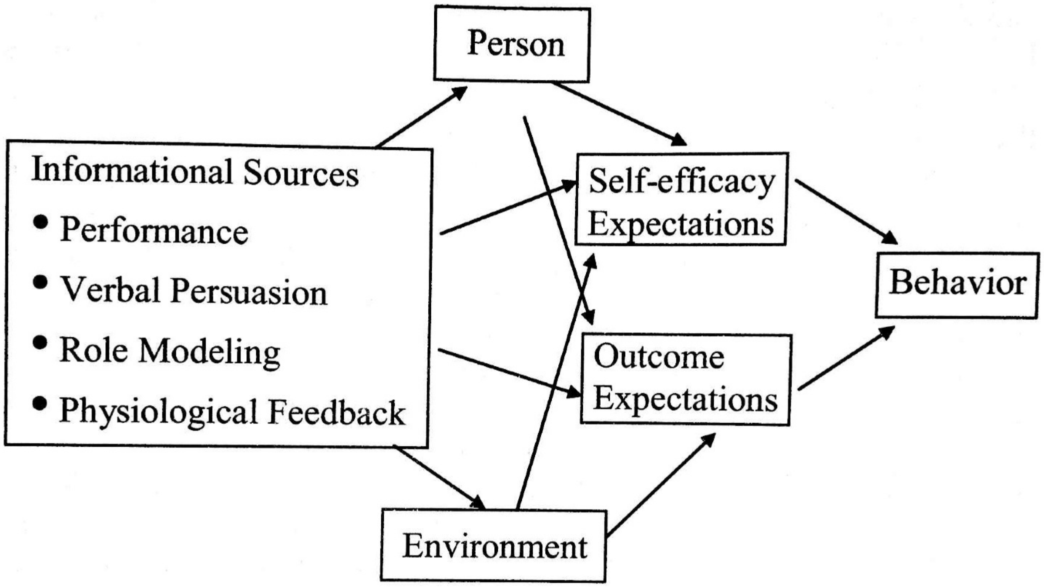
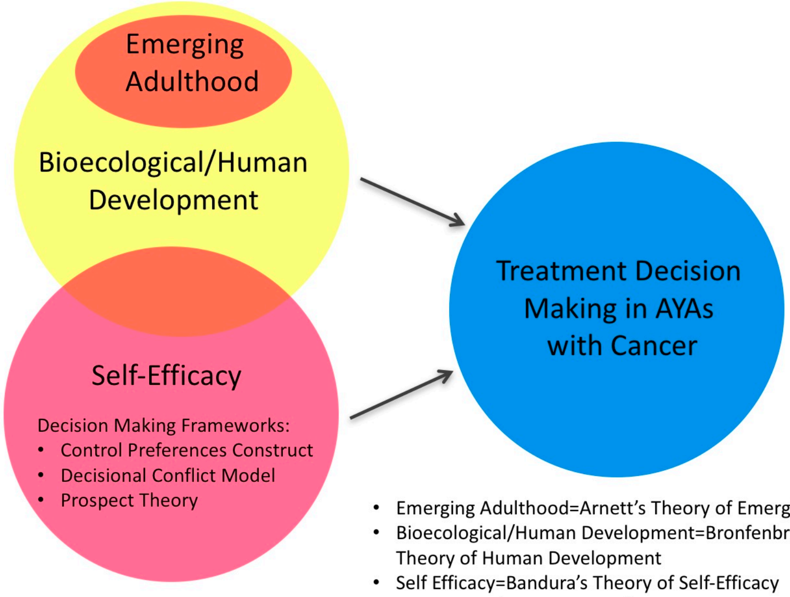


FIGURE 10.1 Self-efficacy.

(Resnick, 2008, p 190)

Appendix C

Relational Diagram of TDM in AYAs With Cancer: Bronfenbrenner’s Bioecological Theory of Human Development, Bandura’s Theory of Self-Efficacy and Decision Making Frameworks



- Emerging Adulthood=Arnett’s Theory of Emerging Adulthood
- Bioecological/Human Development=Bronfenbrenner’s Bioecological Theory of Human Development
- Self Efficacy=Bandura’s Theory of Self-Efficacy
- Decision Making Frameworks:
  - Degner’s Control Preferences Construct
  - O’Connor’s Decisional Conflict Model
  - Kahneman and Tversky’s Pospect Theory

Created by K. Pyke-Grimm, 2015

Appendix D

Demographic Questionnaire

Date: _________ Interview ID #_________

1. What is your age?_________

2. What is your gender?
☐Male ☐Female

3. What is the highest level of education you have completed?
☐Pre-high school ☐Some high school
☐High school degree ☐Vocational school degree
☐Community college degree ☐University degree
☐Post graduate education or degree

4. What is your ethnicity/race?
☐Asian/Pacific Islander ☐Black or African American
☐White ☐Hispanic or Latino
Other:_________

5. What is your current marital status?
☐Divorced ☐Living with another
☐Married ☐Separated
☐Single, never married ☐Widowed

6. How many children do you have? _________

7. What are the ages of your children? _________

8. Describe (without naming names) who lives in your household (for instance, 2 children, husband, 1 brother, 1 roommate, 2 parents) ___________________________

9. Employment status:
☐work full time ☐work part time
☐not working ☐homemaker
☐a student

10. Are you currently in school?
☐Yes ☐No
Grade level: _________

11. Are you experiencing any of the following today:
pain: yes/no
nausea: yes/no
vomiting: yes/no
fatigue: yes/no
difficulty concentrating: yes/no
changes in activity level: yes/no

Appendix E

Adolescent and Young Adult Interview Guide

Hello. Thank you for agreeing to participate in this study about decisions that were made about your cancer treatment. Please be assured you can stop the interview at any time, ask questions at any time, or if there are things or events you do not want to talk about that is okay. I may also take notes during the interview and the interview will be audio-recorded.

We are interested in learning about how decisions are made about cancer treatment when you are a teenager or young adult. Tell me about yourself. Before we get started talking about the particular decision about your treatment I'd like you to tell me the story of what's happened since you were diagnosed with cancer.

Thank you! That really helps me get a sense of what you and your family have experienced. When I talked to you earlier, you mentioned decisions about your cancer treatment were made (such as at diagnosis) can you tell me about that? Now I'd like to focus on the experience of making the treatment decision.

1. You mentioned a decision was made about your cancer treatment (such as at diagnosis, surgical). Can you tell me **e**verything you can remember about what making that treatment decision was like.

- Who was involved in making the decision and how? (probe-what about your parents or family?)
- What kinds of things did you think about?
- What kinds of things were you feeling?
- Did you talk with anyone about the decision?
- What kinds of things did you talk about?

2. Sometimes when people look back at a decision made long ago sometimes they wish things were done differently or sometimes they are satisfied with how things were done.

- When you look back at this decision, how do you feel?
- Would you liked to have been involved in making this decision differently than you actually were? If so, can you please describe how?
- How were you actually involved in this decision? Can you please describe how you were involved?

3. What would have helped you to be more involved in making this decision, if anything?
4. What prevented you from being involved in making this decision, if anything?
5. What could have helped to support you and guide you through this decision?
6. Are there decisions being made about your care currently or since that decision was made? If yes, can you give me an example? How were you involved in those decisions?
7. What types of decisions would you like to be involved in making?
8. What types of decisions do you not want to be involved in making?
9. What about the day to day decisions about your care (e.g. to use an EMLA patch for an IV start)? How are you involved with those? Can you please give me an example?
10. What about the decisions that you are involved in making that are not related to your care? Tell me about those.
11. How does your cancer or treatment affect decisions that come up in your daily life.
12. I'd like you to think about how your family makes decisions in general. Can you please give me an example about how they made decisions about you before you were diagnosed with cancer.
13. What are some decisions (treatment or non-treatment related) you think you will be making in the future?
14. When you think about decisions in the future, how do you think you will be involved in making these decisions.
15. As you approach the future what role do you think your parents will play in your decisions about your cancer and your life?

Closing Questions

16. What advice would you give another teenager who was diagnosed with cancer at your age about making decisions about their treatment?
17. Is there anything else you would like to tell me about your experience in how these decisions were made when you think back, or since that time up until now?
18. Is there anything else I should ask you?
19. Last question: What was it like to participate in this study?

Thank you so much for your time and thoughtfulness in answering my questions.

Table 1

Demographic and Clinical Characteristics of the 16 Study Participants

Characteristic	
Mean age in years at 1st interview (range)	17.3 (15-20)
Gender (n, %)	
Male	9 (56)
Female	6 (38)
Non-binary	1 (6)
Race (n, %)	
White	6 (37.5)
Hispanic	2 (12.5)
Asian	4 (25)
Multiracial	4 (25)
Cancer Diagnosis (n, %)	
Leukemia	7 (44)
Lymphoma	3 (19)
Bone Tumor	6 (37)
Mean Months from Diagnosis to 1st interview (range)	5.4 (1.4-9.7)
Treatment Decision (n, %)	
Clinical Trial enrollment	10 (63)
Radiation Therapy vs Surgery	1 (6)
Surgical Options	5 (31)

Chapter Two

Treatment Decision Making Involvement in Adolescents and Young Adults With Cancer: An Integrative Review

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Abstract

Problem Identification: Involvement in TDM is generally considered to be a key element of patient and family centered care and positively impact outcomes. However, for adolescents and young adults (AYAs) with cancer, little is known about the current state of knowledge about their perspective on and involvement in TDM or the factors influencing the AYAs' TDM involvement.

Literature Search: An integrative review focused on AYAs between 15-21 years, their involvement in TDM, and factors influencing their involvement was carried out using the MEDLINE, PsycINFO, CINAHL, and Web of Science databases.

Data Evaluation: Of the 4047 articles identified, 21 articles met the inclusion criteria and were critically appraised.

Synthesis: Five themes were identified: 1) AYAs' preferred/actual/perceived involvement, 2) age/cognitive maturity, 3) disease/illness factors, 4) information/communication and 5) relationships, roles and perspectives of parents/healthcare providers. AYA involvement in TDM varies depending on the magnitude of the decision, and when it occurs. Findings suggest the AYAs' role in decision making is situational and often evolves over time to become more active.

Implications for Research: Research is needed to further understand AYA's preferences for TDM, the type and degree of their involvement, and the interactions between factors that contribute to or impede AYA involvement in TDM.

Knowledge Translation: Nurses must consider illness factors, the AYAs' preferences, and the importance of the role of family in TDM.

Keywords: adolescent and young adult, pediatric oncology, decision making, patient participation, patient involvement

Introduction

In the USA, approximately 70,000 cases of cancer are diagnosed each year in people between 15 and 39 years of age, a group defined as adolescents and young adults (AYAs). While cancer survival rates have generally improved for pediatric and adult patients, those for AYA cancer patients have not kept pace. This lack of progress is most evident for AYAs between 15-25 years (Albritton, Caligiuri, Anderson, Nichols, & Ulman, 2006; Bleyer, Ulrich, & Martin, 2012). They are confronted not just by cancer, but by dealing with normal developmental challenges, the progression of which is affected by dependence on family and healthcare providers, and parental protectiveness (Coyne & Gallagher, 2011).

An important reason for AYAs' poorer outcomes is non-adherence to cancer treatment. Non-adherence rates as high as 60% have been reported (Festa, Tamaroff, Chasalow, & Lanzkowsky, 1992; Phipps & DeCuir-Whalley, 1990; Smith, Rosen, Trueworthy, & Lowman, 1979; Tebbi et al., 1986), which can lead to cancer relapse (Butow et al., 2010). Participation of AYAs in treatment decision-making (TDM) may support adherence to medical treatment (Albritton & Bleyer, 2003; Sawyer & Aroni, 2005).

A core principle of patient and family-centered care is to empower patients and families and build their confidence so they can make decisions about their healthcare (American Academy of Pediatrics, 2012). AYAs with cancer are increasingly encouraged or expected to be involved in TDM by organizations such as the National Comprehensive Cancer Network and the Children's Oncology Group. Professional organizations, government agencies, and ethical as well as legal perspectives promote the inclusion of children and adolescents in TDM. However, guidelines about when and how to involve children and adolescents in TDM are mostly opinion-based with little empirical support, and evidence suggests they are infrequently followed (Unguru, Sill, & Kamani, 2010).

Understanding AYAs' preferences is key to changing healthcare delivery to improve participation in decision making, satisfaction with the process of decision making, compliance with the therapeutic plan, and ultimately to improve outcomes for AYAs with cancer. To understand the AYAs' involvement in TDM and factors that influence how they approach TDM, we conducted an integrative review of the literature. Since most pediatric oncology units primarily care for patients up to age 21, in this review, we focused on the 15-21-year-old age group. The aims of the review were to determine the following: 1) the current state of knowledge about 15-21-year-old AYAs with cancer and their perspective on and involvement in TDM, 2) factors influencing the AYAs' TDM involvement, such as their age, developmental stage, and phase in the continuum of care, and 3) their TDM involvement within the context of their family and with their healthcare providers (HCPs).

Background

Cancer treatment for AYAs requires families to make challenging decisions throughout the disease trajectory, including at the time of diagnosis, disease recurrence, therapeutic changes in options, and at the time of end of life care (Stewart, Pyke-Grimm, & Kelly, 2012). Current recommendations state that young people should be involved in decisions when they are able to do so and choose to participate (Joffe et al., 2006; Masera et al., 1997; Spinetta et al., 2003).

A key aspect of the phenomenon of AYA TDM is the triangular relationship between the patient, HCP, and parents. Parents often assume a gatekeeper role, deciding what the child may be told to protect him or her from upsetting information (Young, Dixon-Woods, Windridge, & Heney, 2003). Stewart et al. reported variability in the degree to which parents involved their child in TDM. Parents focused on whether participation in TDM was in their child's best interests, allowing more involvement in older children and less involvement when they prioritized sparing the child from distress (Stewart et al., 2012).

Young people commonly defer to parents or physicians for TDM for multiple reasons, including feeling pressured, wishing to avoid conflict and deferring to others' knowledge or experience (Knopf, Hornung, Slap, DeVellis, & Britto, 2008). Healthcare providers may not be able to accurately estimate young people's cognitive development and therefore their ability to participate or understand issues of TDM (Coyne & Gallagher, 2011). The imbalance of power between young people and parents and clinicians means their participation in TDM is likely under external control. In a study of the attitudes of pediatric oncologists, de Vries found that some physicians do not believe adolescents are capable of meaningful participation, do not always provide adolescents with necessary information and believe that proxy consent from parents is sufficient (de Vries, Wit, Engberts, Kaspers, & van Leeuwen, 2010). However, the American Academy of Pediatrics (2012) policy statement advocating patient and family-centered care makes recommendations to support effective partnerships between children, parents and families, and their healthcare providers.

When children, adolescents and young adults participate in treatment decision making (TDM) they may benefit in multiple ways. These could include improved sense of control and autonomy, improved efficacy and improved adherence to medical treatment (Barakat, Schwartz, Reilly, Deatrick, & Balis, 2014; Butow et al., 2010; Coyne et al., 2014; Coyne & Gallagher, 2011; Kelly, Mowbray, Pyke-Grimm, & Hinds, 2017; Snethen, Broome, Knafl, Deatrick, & Angst, 2006). Participation in TDM could be overly demanding (Ruhe, 2016a). However, research results about why, how and under what circumstances AYAs make cancer-related treatment decisions are unavailable. There are no reviews to our knowledge that examine the research literature as a whole to guide practice and further research on AYAs' preferences and involvement in TDM or influencing factors.

Methods

Whittemore and Knafl's (Whittemore, Chase, & Mandle, 2001) methodology for conducting an integrative review served as the framework for this article. AYAs were defined as being between the ages of 15 and 21 years. Because many studies included participants younger than age 15, they, and people of the AYA age group, were collectively referred to as "young people." Treatment decision-making was defined as decisions surrounding treatment or research aimed at curing or delaying cancer progression, diagnostic, therapeutic, procedure or supportive care choices.

A systemic search of the literature was undertaken using the following databases: MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, and Web of Science. All databases were searched from their inception through June 8, 2017. An initial scoping search led to the exclusion of Sociological Abstracts as it did not yield any unique, relevant articles. Reference lists of relevant articles were examined to find additional references. The search strategy did not specify narrative or other integrative reviews but did include systematic reviews or meta-analyses. A combination of database index terms and keywords were used to ensure maximum recall of relevant articles, targeting three main concepts of the search: TDM, AYA age group, and childhood cancer. Non-English articles were excluded. See Appendix A for details of the search strategy.

Articles identified by the search strategy underwent further screening according to the inclusion and exclusion criteria (see Figure 1). The following inclusion criteria were used: 1) original quantitative, qualitative, and mixed methods studies that included AYAs between 15-21 years of age with cancer, 2) studies primarily included cancer patients if they included other chronic illnesses, 3) procedures, methods, and analysis clearly described, 4) studies that examined the AYAs' involvement or perspective in TDM regarding their cancer treatment. The exclusion criteria were: 1) studies of AYAs who had only completed therapy (survivors) or studies focused solely on TDM related to fertility preservation and, 2) non-systematic reviews, editorials, or case reports.

Data extraction included reviewing the articles for the purpose statement and description of design, sample, variables measured, data collection, analysis, main findings, and limitations (see Table 1). The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) was used as a guide for reporting the studies (Moher, Liberati, Tetzlaff, & Altman, 2009). Thematic analysis was used to synthesize the findings (Lucas, Baird, Arai, Law, & Roberts, 2007). The Mixed Methods Appraisal Tool (MMAT) was used to assess the methodological quality of the articles (Pace et al., 2012; Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009). This tool allows analysis of multiple study types, including 1) mixed methods, 2) qualitative, 3) randomized controlled, 4) non-randomized and 5) observational descriptive. The MMAT scores range from 0-4, with 0 indicating no criteria met and 4 indicating all criteria met. The determination of the final included studies were performed by one author (KPG). Two of three authors (KPG, KPK, RR) scored each article using the MMAT. Differences of opinion were discussed until consensus was achieved. Data analysis entailed developing categories of findings and identifying important themes by collapsing similar results and comparing findings between studies.

Results

The search identified 4047 possible studies. After removal of duplicates and further review of abstracts and full study reports in accordance with the inclusion and exclusion criteria, 21 articles met the inclusion criteria and were selected for critical review: 15 were qualitative, and six were quantitative (Table 2). Figure 1 shows the PRISMA flowchart. Two of the articles were secondary data analyses. The years of publication ranged from 1993-2017. Two articles exclusively reported on AYAs (15-24 years) and 19 articles included children age 14 years and under in addition to the target group of AYA. Across the 21 studies, age ranged from age 7 to 24 years of age. The studies took place in European and English-speaking countries, including the United Kingdom (2), The Netherlands (n=3), Switzerland (n=2), Australia (n=2), Canada (n=1) and the United States (n=13). Two of the 21 studies were multi-site and conducted in two different countries (Table 1). The 21 studies included participants who were receiving treatment for cancer, no longer receiving therapy (survivors), or diagnosed with a different chronic illness. The types of decisions described in the studies were primarily related to research participation (Phase I, II or III trials) (8), end of life decisions, where there may have been an option to participate in a Phase I clinical trial (2), and treatment decision making in general (i.e. at diagnosis, treatment, relapse and supportive care) (11).

The MMAT study quality scores ranged from 2-4 (0-4 scale). Three studies were assessed to be of high quality (score=4), 15 were judged as moderate quality (score=3) and three as lower quality (score=2). All 21 studies were included so as to be comprehensive in examining the scope and depth of the phenomenon (Noblit & Hare, 1988) (Table 2).

Five major themes were identified from the 21 studies, reflecting the AYAs' involvement in TDM or influencing factors: 1) AYAs' Preferred/Actual and/or Perceived Involvement, 2)

Age and Cognitive Maturity, 3) Disease and Illness Factors, 4) Information and Communication, and 5) Relationships, Roles, and Perspectives: Parents and Health Care Providers. The themes relate to the degree of involvement in TDM (theme 1) and the factors influencing TDM (themes 2 through 5). Each theme is described in detail below.

AYAs Preferred, Actual, and/or Perceived Involvement in Treatment Decision Making.

Young people with cancer did not always participate in TDM to their level of preference and comfort (Unguru, 2011; Zwaanswijk et al., 2007) and they varied in their preference for involvement in TDM, from none at one end of the spectrum, to making most of the decisions at the other. No matter what the AYA's role in decision making, the family was usually involved to some extent.

Responses ranged from completely deferring decision making to others, to independently making decisions. In three of the 21 studies, young people described how they preferred to have their physician or parents decide about their treatment (Ellis & Leventhal, 1993; Stegenga & Ward-Smith, 2008). Ellis and Leventhal (1993) reported that most wanted the physician to make all of the decisions. Some young people believed there was no real decision to make because the only choice is to proceed with life-saving therapy (Coyne, Amory, Kiernan, & Gibson, 2014). Similarly, Barakat and colleagues (2014) found that the majority of AYAs had little or no role in TDM about Phase III clinical trials. Unguru et al. (2010) also reported that young people perceived they had little or no role in the decision to participate in research. Five studies identified young people's preference to collaborate with their parents and providers (Dunsmore & Quine, 1995; Kelly, Mowbray, Pyke-Grimm, & Hinds, 2017; Ruhe et al., 2016a; Unguru et al., 2010; Zwaanswijk et al., 2011); most wanted to be informed (Zwaanswijk et al., 2007) but did not want sole responsibility for making decisions (Dunsmore & Quine, 1995; Unguru et al., 2010).

Some young people preferred to be or were fully engaged in the decision (Weaver et al., 2015) or made the final decision with parental assistance (Zwaanswijk et al., 2007). Two studies reported that young people wanted to be either more informed or more involved than they actually were in decision making (Dunsmore & Quine, 1995; Unguru et al., 2010). Having autonomy in decision making related to clinical trials was very important to most AYAs in a study conducted by Pearce et al. (2016). In seven articles, altruistic motives were a reason for participating in clinical research (Barakat, Schwartz, Reilly, Deatrick, & Balis, 2014; Broome, Richards, & Hall, 2001; Hinds et al., 2005; Miller et al., 2013; Pearce et al., 2016; Read et al., 2009).

Investigators reported situations when young people did not want to assume responsibility for making the decision, such as at or close to the time of diagnosis (Stegenga & Ward-Smith, 2008; Weaver et al., 2015). At diagnosis, there was often an urgency to start treatment while young people were too ill to participate in discussions or decision making (Barakat et al., 2014; Zwaanswijk et al., 2007). There were also situations when they did not want to surrender the control of TDM, such as at the end of life (Hinds et al., 2005; Miller et al., 2013). Barakat and colleagues (2014) reported the AYA recalled minimal or no role in clinical trial TDM, though their parents recalled substantial efforts to involve the AYA. AYAs and parents had markedly different memories of the same event, and AYAs experienced regret for not being involved as they would have preferred.

Age and Cognitive Maturity. Eight of the studies reviewed showed that age and cognitive maturity were factors influencing whether young people are involved in TDM. Five studies reported increased age and maturity was associated with increased decision involvement (Barakat et al., 2014; Coyne et al., 2014; Ellis & Leventhal, 1993; Unguru et al., 2010; Zwaanswijk et al., 2011). Unguru et al. (2010) reported age was associated with the types of decisions, roles performed, and physicians' willingness to discuss decision making, with older children being more likely to be involved in TDM. In Zwaanswijk et al's (2011) study, parents, patients, and survivors uniformly recommended that young children (<12 years) not be involved in TDM (OR=0.1, CI 0.0-0.2), but preferred that adolescents (> 12 years) be involved (OR=18.2, CI 6.8-48.4). Patient age was the main factor associated with information and preferences to participate in decision making. Ellis and Levanthal (1993) found young people believed the patient should be at least 16 years of age to participate in making minor treatment decisions. Barakat and colleagues (2014) reported that cognitive and emotional maturity facilitated involvement in Phase III clinical enrollment decisions.

In contrast, several studies showed that age *was not* associated with family decision-making patterns such as exclusionary, informative, collaborative and delegation (Snethen, Broome, Knafl, Deatrick, & Angst, 2006). Weaver and colleagues (2015) also found no correlation between age, time on treatment, new or relapsed disease, and decision-making preference, although their study consisted of only 40 participants. Dunsmore et al. (1995) in their study of 51, 12-24-year-olds with cancer reported age was not correlated with decision making.

It was not possible to determine from the studies if preferences for TDM were based on age or experience with cancer and cancer treatment or other factors. Younger patients may have been diagnosed with cancer for a longer period of time than older AYAs who were diagnosed recently and so may acquire experience beyond their years.

Disease and Illness Factors. Fifteen articles reported findings relating young people's disease and illness factors to TDM involvement. The young people's symptoms, seriousness of the condition, and urgency of the decision were barriers to their participation in TDM (Barakat et al., 2014; Broome et al., 2001; Zwaanswijk et al., 2007). Prognosis also determined whether young people were included in TDM. Parents did not want young people to participate if they had a moderate (OR=0.5) or unclear (OR=0.2) prognosis (Zwaanswijk et al., 2011). Barakat (2014) highlighted acute emotional or physical stress as a limiter of AYAs' involvement and participation in decision making. These studies demonstrate that the emotional or physical state of young people can influence the actual TDM role they assumed.

Additional factors influenced young people's choice or actual participation in TDM. Young people classified decisions as minor (delivery of care, decisions about pain management and antiemetics) or major (decisions about treatment protocols) (Coyne et al., 2014; Ruhe et al., 2016b; Tenniglo et al., 2017). They also considered major decisions not to be decisions at all because there was only one obvious choice and refusal was not an option (Coyne et al., 2014). Decision making involvement was situational; young people preferred to participate in minor or supportive care decisions, if they felt well, but left most major decisions to the HCP (Ruhe et al., 2016b; Weaver et al., 2015). Kelly et al. (2017) also reported that most young people did not want to make "big" decisions.

TDM involvement was often dependent on the stage in the disease trajectory. In one study, 85% of young people reported they made the final decision about a Phase I cancer study (Miller et al., 2013). These young people had all experienced the standard diagnosis and management, so they would be classified as "experienced," no matter what their chronological age. Other researchers found decision making shifted from the parents or HCP to young people later in the disease trajectory (Hinds et al., 2005).

Information and Communication. In seventeen studies, young people and families referred to information seeking, information exchange and communication with the healthcare team in the context of decision making. Limited knowledge of the disease and treatment were important barriers to participation in decision making (Coyne et al., 2014; Stegenga & Ward-Smith, 2008; Zwaanswijk et al., 2007). Ellis and Levanthal (1993) found that although most young people with cancer wanted the doctor to make all decisions, those who had less understanding of their diagnosis were less likely to want to be involved in making decisions compared to those with more understanding ($p=0.039$). Alternatively, Coyne et al. (2014) reported young people identified 'receiving information' as an important determinant of their participation in shared decision making, and that adolescents were unsatisfied with their participation in decision making, claiming they were limited by parents and HCPs. Ruhe et al. (2016b) found that parents actively limited information that could be upsetting or related to prognosis, therefore limiting the knowledge young people needed to participate in TDM.

In Zwaanswijk's (2011) study, 60% of young people felt it was important to receive information even if they did not want it at the time. They also thought the patient should participate in medical decision making. Pearce et al. (2016) reported that AYAs thought effective communication, information availability and the opportunity to ask questions was important for them to participate in trials. A trusting relationship with their HCPs allowed good communication and encouraged trial participation.

In contrast, Stegenga and Ward (2008) found that receiving information and being informed was important to young people, but not necessarily linked to decision making. They studied adolescents within six months of diagnosis, finding their desire for information was not a desire for control but simply a desire to understand; they believed the healthcare team should make the decisions.

Relationships, Roles, and Perspectives: Parents and Health Care Providers. Eighteen studies discussed how the relationship or role of the parent or HCP influenced young people's involvement in TDM. Ruhe (2016b) reported that physicians and parents regulate young people's participation in decision making. Young people were restricted by the parents' and physicians' culture.

The most frequently reported factor by young people, parents, and physicians in making decisions was consideration of and sensitivity to others (Hinds et al., 2005). Young people relied on their parents to protect them and trusted them to make decisions in their best interests (Broome & Richards, 2003). Young people trusted HCPs because they assumed they were experts (Coyne et al., 2014). They wanted support or preferred shared decision making with family and clinicians (Coyne & Gallagher, 2011; Zwaanswijk et al., 2007).

Snethen and colleagues (2006) described four family patterns of decision making in the context of clinical trials. Parents whose goal was to protect young people and excluded them from participation in TDM were identified as exclusionary. Parents who preferred to have their young people understand the issues and the meaning of the decisions were identified as informative. Parents whose children tended to be older adolescents compared to the members of other groups and who advocated active participation by young people were identified as collaborative. Finally, parents who approved the choice to be made but turned over the actual decision to the young people were identified as delegators.

Collectively, these findings highlight the complexity of the triadic relationship between the provider, parent, and young people. Young people's involvement in TDM was related to many variables, including age, experience with illness, and their progress on the continuum of care.

Discussion

The findings in this review demonstrate that the young people's actual TDM involvement varies based on their chronological and developmental stage, disease state, previous experience with disease, type and magnitude of the decision, and decisional and family context. Preferences for their level of involvement in TDM varies during cancer treatment for many reasons (e.g. stage of illness, seriousness of condition, type of decision); thus, participation appears to be an ongoing process that varies with the situation (Coyne & Harder, 2011).

In this integrative review, five themes were identified about young people's involvement or perspectives in TDM regarding their cancer treatment. Treatment decision making is situational as there are some decisions young people are comfortable making and others they are not, with varying degrees of involvement from parents or HCPs. Decisions they are more comfortable with include minor decisions about care delivery (Coyne et al., 2014), whereas for decisions of tremendous consequence, such as those at the time of diagnosis, they are more likely to defer to their parents or providers.

Decision making is a process that evolves over the course of the young person's disease trajectory. They enter into the illness journey with little or no understanding of their disease, with their experiences providing a rapid education. Later in the course of the disease, when many of these young people experience complications and face a decision about alternative treatment or end of life care, they have become knowledgeable and more assertive about their involvement in decision making (Bluebond-Langner, Belasco, & DeMesquita Wander, 2010; Hinds et al., 2005; Lyon, McCabe, Patel, & D'Angelo, 2004; Miller, 2009; Miller et al., 2013; Miller & Harris, 2012; Miller, Reynolds, & Nelson, 2008).

Early in the disease trajectory, the degree of involvement by young people in their own TDM is determined primarily by the attitudes of the HCPs and parents, not by the young person's ability (Coyne, 2008; Martenson & Fagerskiold, 2008). Even when young people are competent to make treatment decisions, they still want support and prefer shared decision making with family and clinicians (Coyne & Gallagher, 2011; Pearce et al., 2016; Zwaanswijk et al., 2007).

This review identified contradictory findings regarding the association of age with TDM. Bluebond-Langer (2010) argues that relying on chronological age or developmental stage to determine how to involve young cancer patients in decision making is unreliable because of the marked inter-individual differences in rate and stage of development. Recently diagnosed patients, no matter what age, may still be in the passive, early state of decision making. If they are experiencing substantial suffering or stress, even the most mature adolescents are likely to rely on relatives or other proxy decision makers (de Vries et al., 2010). Day (2016) also reported in a systematic review that adolescents' ability to participate in TDM and discussions, as determined by their HCP, is determined by their maturity and/or disease experience and not their age. The studies reviewed did not provide this distribution of experience of the sample, so this likely interaction cannot be identified. Future studies should be sure to assess the complexity of the patient experience in addition to the participants' chronological age.

How information is provided and the degree to which parents and HCP directly communicate with young people is an important factor in determining involvement in and experience of TDM (Stegenga & Ward-Smith, 2008; Zwaanswijk et al., 2007). For some young people, receiving information and communication defines their level of involvement in decision making. For adolescents, lack of information is a barrier to active decision making. Adolescents living with chronic illness value clear and straightforward technical information (Britto et al., 2007; Britto, Cote, Horning, & Slap, 2004; Dunsmore & Quine, 1995; Knopf et al., 2008). Less than 20% of adolescents "preferred patient led decision making;" the majority do not want to direct decision making authority or to make the final decision (Britto et al., 2004; Knopf et al., 2008). Knopf and colleagues (2008) suggest this may be due to their recognition of how complex and life-threatening the decisions really are. This finding is supported by recent research (Kelly et al., 2017) suggesting that during cancer treatment, young people may prefer information exchange and communication to being involved in actually making treatment decisions.

The findings of this integrative review clearly indicate that treatment decision making is not one-dimensional. The findings suggest there is an interaction between age, previous cancer experience, and decision making. Studies support the finding that TDM patterns change over time, as individuals become experienced with their disease and their evolving relationships with HCPs matures (Dixon, 1996; Thorne & Robinson, 1988). Many of these studies examine characteristics of young people or decision making in one dimension, rather than identifying the many factors that modify the situation. An 18-year-old, for instance, who is newly diagnosed with cancer **may be** naïve, but a 10-year-old may be very experienced, having lived with cancer for the past five years. Important dimensions that must be considered in studying or advocating for AYA involvement in TDM include age, experience with the illness, low-risk decisions versus high-risk decisions and decisions with a clearly identified best option versus no best option.

Any effort to involve young people in TDM must take into account the parents' perspectives and their role in the care and treatment of their children. Bluebond-Langner (2010) reported that parents feel strongly that the responsibility for the decision rests with them. More research is needed to determine how the AYA with cancer interacts with their family to make treatment decisions, for instance, how each negotiate their roles, given findings suggesting that decision making by the AYA and their families is a dynamic, social process.

Limitations

The findings of this integrative review should be considered in light of several limitations. For example, most of the included studies included participants who were younger and older than the AYA age range. Because most of these studies did not report findings for subsamples, it was not possible to determine how the reported results were similar or different with respect to age or condition. Another limitation was the lack of consistency in how TDM was defined, making it challenging to interpret and compare findings across studies. Many of the studies were retrospective, with participant recall of their TDM experiences, potentially leading to recall bias. Other methodological concerns included weaknesses across methods (i.e. whether or not quantitative studies had adequate sample sizes, and qualitative studies were conducted with adequate rigor). Finally, most of the studies had inadequate representation of minority groups.

Implications for Nursing

The findings of this integrative review provide nurses with a comprehensive summary of the state-of-the-science with respect to AYA experience of TDM and influencing factors. In caring for AYAs, nurses must consider multiple factors, such as age, disease, treatment trajectory, and relationships with parents and HCP when encouraging AYAs to participate in decision making. Nurses must also be mindful that the AYAs' role in TDM may be both situational and evolve over time to become more active. Recognizing the role of family in TDM is essential.

Future research investigating our understanding of the AYA's voice and preferences for TDM, the actual involvement of AYAs in the decision-making process, and the interactions between factors that contribute to or impede this process is warranted. Studies including relevant outcomes of TDM participation are lacking, especially related to congruence between desired and actual TDM roles. Important next questions include: 1) How do AYAs want to be involved in TDM? 2) What types of decisions do AYAs want to be involved in? 3) How do AYAs negotiate their role and involvement in decision making? and 4) When does a transition of decision making authority take place from the parent(s) to the AYA?

Conclusion

The findings of this review suggest young people's role in decision making evolves over time to become more active, but is situational. The findings highlight the importance of the role of family and relationship with the HCP throughout their continuum of care. Barriers and facilitators to shared TDM include factors associated with the AYAs' preferences, age, disease, and relationships with family and providers. Involvement in decision making can be especially challenging for the AYA with cancer due to their diagnosis of a chronic, potentially life-threatening illness, family influence, their developmental stage, and desire to transition to an independent young adult. Future research would help to identify important areas to focus interventions, in turn moving forward the science directed to the care of the AYA with cancer.

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Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
1. Barakat et al., 2014, United States	To describe how AYAs and parents make decisions about Phase III clinical trials from the perspective of family decision making patterns, variables that influence the involvement of the AYA in TDM and barriers and benefits (attitudes) to participation in a clinical trial. The second goal was to determine the value of the Pediatric Research Participation Questionnaire (PRPQ) in measuring attitudes about clinical trial enrollment in AYA oncology. Study Design: Qualitative. Interview guides using semi-structured questions. Review of the PRPQ.	N=13 AYAs (15-23 years of age), diagnosed with cancer and offered a phase III clinical trial within the past 3-21 months. N=16 primary caregivers N= 11 primary healthcare providers	The semi-structured interview guide for the AYA and parents included questions related to their memories of the diagnostic meeting, their interpretation of the TDM process for that family, an estimate of the involvement of the AYA in the decision to enroll (or not) in the phase III clinical trial, and factors influencing their involvement. Physicians were asked how they orchestrate the diagnostic meeting and their opinion about what factors primarily influence the AYAs involvement in TDM. All 3 groups were asked to interpret and comment on the PRPQ. Group or individual interviews were conducted with the AYAs and their caregivers. Individual interviews were conducted with providers. Participants completed the PRPQ which measures the perceived benefits and barriers to clinical trial enrollment. The interviews were audio-taped and transcribed. Audit trails were maintained about coding decisions. Two coders were used to ensure reliability in coding. Constant comparative methods were used. The fraction of the participants supporting each pattern of themes was analyzed with reference to the participants' age (at diagnosis) and whether they enrolled in a clinical trial or not.	1. 38.4 % of AYAs endorsed "AYA abdicates to caregiver," having no or a minimal (30.8%) role, conveying a sense of resignation, viewing themselves as dependent. Only 2 AYA (15.4%) believed they collaborated in the decision Most caregivers (43.7%) supported the AYA in making decisions and providers (54.5%) supported a caregiver-based and AYA-approved approach to decision making. 2. Identified themes that influence AYAs' involvement in decision making included 1) acute stress limited their participation; 2) increased maturity (developmental, cognitive or emotional) was associated with increased involvement. 3. Barriers to deciding to enroll in a clinical trial included the need for more procedures, the potential to increase the length of treatment, and believing standard treatment and clinical trials have the same outcome. 4. A few AYAs indicated that cancer caused them to become more mature. 5. Providers noted that AYAs' involvement had a positive impact on adherence. 6. Altruism was identified as a perceived benefit to enrollment. 7. AYAs, caregivers and providers suggested minor modifications to the PRPQ.	Small numbers, only 13 AYA's participated. Very large age range, from age 15 to 23 years. This is a very large developmental interval with even smaller numbers representing different ages. Single center 77% of the participants were white.

Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
2. Broome & Richards, 2003, United States	To describe how children's and adolescents' relationship with adults, parents, and researchers influenced their involvement in clinical research. Study Design: Qualitative-semi-structured interviews and narrative analytic techniques. The data were collected as part of a larger study.	N=34 children or adolescents. Participant (age range 8-22 years) had a diagnosis of diabetes or hematologic cancer. All were enrolled in a clinical trial within the last 2 months. 39 mothers, 14 fathers and 19 siblings were interviewed. At least one parent of each child/adolescent participated	An interview guide with 26 open-ended questions was used to ask participants about their recollection of their research experience. Each participant was interviewed individually, lasting between 30-60 minutes. Interviews were transcribed and a template was used to guide coding. The specific aims and structured interview guide were used to organize the template. Three interviews were conducted initially and then the template was modified. Demonstrated rigor by having 2 members of the research team review each transcript twice. They identified recurring as well as unique themes, patterns, comparisons and contrasts.	1. Nine themes were identified in the larger study relating to children's perceptions of their involvement in clinical research. This article focuses on three of the nine themes related to the participants' relationship with parents and clinicians/investigators: Faith in parents: participants believed their parents would protect them, research, and make the correct decision while involving them in the process. They used words like trust, communication and love when they talked about their discussion with their parents about making a decision to participate in the research study. Parents respect what the child wants if they did not agree with the parents or declined to participate in a research study. They would want to know the parents' reasons for the decision to participate and they were certain their parents would want to know their reasons for wanting to participate or not. Relationships with investigators: For children with cancer the investigator usually approached the parent and child simultaneously. This was different than for children with diabetes where the investigator almost always approached the parent first. Most of the time, lengthy discussions with the researcher preceded the joint decision by the parent and child to participate in the research. 2. Parents were the primary influence in the child/adolescents' decision making process.	The larger study the data came from was not specified nor referenced. The participants were English speaking and primarily Caucasian (74%) thus limiting ethnic diversity. This was a single site study.

Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
3. Broome, et al., 2001, United States	To describe children's and adolescents' experience and understanding of the clinical research in which they were involved. Study Design: Qualitative-semi-structured interviews using narrative analytic techniques. They compared three groups of children and adolescents: those with cancer, those with diabetes, and those who had a bone marrow transplant.	N=105 family members, including the child with the illness, mothers, fathers, and siblings. N=34 (children and adolescents). Participants (age range 8-22 years) diagnosed with diabetes, or hematologic malignancy and enrolled in a clinical trial.	Six members of the research team conducted tape-recorded in-depth interviews lasting for 30 minutes to 1 hour using a standard interview guide with 26 open-ended questions about the participant's understanding of the clinical research experience. Field notes were recorded. Interviews were transcribed verbatim. Two authors read the transcripts noting themes, patterns, comparisons and contrasts. Rigorous approach to data coding and analysis, 2 investigators read, reread and coded the data. The team created a coding template. The data were collected as part of a larger study.	1. Nine themes were identified relating to the participants perceptions of their involvement in research. This article focuses only on the child's and adolescent's perceptions about research. The nine themes included: 1. Their understanding of research 2. How they differentiate between research and treatment. 3. Their involvement in the decision to participate. 4. The child's perception of what happens when the child and his/her parent disagree about research participation. 5. Faith in the parents. 6. Relationships with members of the research/medical team. 7. Options for treatment if the child decides not to participate in the clinical study. 8. Incentives to participate. 9. How the child talked about aspects of his/her life outside the trial: Understanding of research was related to the age, previous experience with research and the specific diagnosis. Younger children were less likely to know the risks of research although they could discuss the benefits and goals of research. Patients with diabetes could differentiate research from treatment better than those with cancer. There was a wide range of involvement in the decision to participate without clear relationships between the disease, reason for involvement and age. Age and diagnosis were influential in predicting what a child could describe about the research and consent processes. When they were older they were able to describe more.	The sample was fairly homogenous with 74% of the participants being Caucasian. A single site (in the Midwest) participated in the study.

Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
4. Coyne, Amory et al, 2014, Ireland	To explore children's cancer experience and shared decision making (SDM) from the perspective of the child, their parents, and healthcare providers. To describe all groups perceptions of the child's involvement in SDM. To describe factors that facilitate or impede children's participation in SDM. Study Design: Qualitative-Grounded theory.	Three groups of participants: N=20 children (7-16 years of age) with various types of cancer, on therapy and within 6 weeks to 1 year of diagnosis. N=22 parents (5 fathers, 17 mothers) of the children with cancer. N=40 healthcare professionals. Single center (Children's Hospital) in Ireland. Interviews took place on the inpatient unit.	Interviews were audio-recorded and transcribed. The interview questions encompassed the following topics: the children's involvement in 1) information sharing, 2) decisions at home 3) decisions while hospitalized, the decision making process; the 3 groups were asked about 1) their preferences for decision making and 2) their perceptions of the rights and abilities of the children. Analysis of audio-recorded interviews of hospitalized children, using a grounded theory approach. Analysis was consistent with a grounded theory approach: using constant comparison of data, open-coding, writing memos and the development of categories. Rigor was achieved through a second person coding the data and then with the compilation of the list of categories they were reviewed again by 2 members of the research team for agreement.	1. The majority of participants categorized decisions as either minor (related to the delivery of the care) or major (related to the decision to treatment and treatment protocol) medical decisions. 2. Most major decisions were made by the HCP but were discussed with parents. They believed there was "no real decision" to be made by the parents or children. 3. For 'big' decisions about treatment, refusal was simply not an option because cancer was life-threatening. 4. Parents agreed that children should not participate in major decisions, as there was no option to refuse. 5. Children understood they had "no choice" and trusted their parents to make decisions in their best interest, and HCPs, who were the experts. 6. Because of the rigid treatment protocols, parents and their children believed there were no decisions to be made. 7. HCPs and parents agreed that the child had a limited role in decision making. Participation by the child in minor or everyday decisions was acceptable as long as it did not affect the outcome or protocol. 8. Children's involvement in minor decisions was often dependent on their physical well-being, understanding, maturity, personality, emotional state, coping abilities and disabilities. 9. Children (7-11 years of age) seemed satisfied with their level of involvement in decision making. Adolescents (12-16 years), however, were frustrated with their lack of control over decision making.	Mostly mothers (77%) participated in the study, which could bias the findings. Most were Caucasian. This data was solely collected in Ireland, which may reflect cultural differences unique to their geographic location. It is unknown if the protocols were research protocols or standard of care, or if there a choice between options.

Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
5. Dunsmore & Quine, 1995, Australia	To highlight the information and decision making needs and preferences of adolescents with cancer, whether those needs were being met, and implications. Study Design: Cross-sectional, exploratory, and descriptive. Focus groups were used to develop the 42- item self-administered questionnaire. The questions were both open and closed ended.	N=51 The age group was 12-24 years (mean age 18 years). Participants had multiple cancer types. Patients were either on therapy (10/51) or off therapy (41/51). Participants were recruited from a teenage cancer camp in Australia (1992).	Responses to the open ended questions were analyzed using content analysis. Frequencies of the responses were calculated. Coding categories were developed from the responses to the questions. Chi square test was applied as appropriate.	1. Participants wanted to be more informed and involved than they were in decision making. 2. Even though they preferred more involvement in decision making, most did not complain about who actually made the decision. They average age was 12 years at diagnosis so they recognized they were young, but now that they are older they say they would have done things differently. 3. They especially wanted to know if treatments were failing, prognosis was poor, or if they were going to die. 4. Approximately 50% wanted themselves, parents and physicians to be involved in TDM; 20% wanted only themselves and the physician to be involved, excluding the parents. 5. 50% of participants thought decision making should involve themselves, parents, and physicians, but only 6% said that is actually what happened (chi-square=52.46,df=6,p=.0.00). 6. In general they did not want the sole responsibility for making decisions. Those participants who did (6/51) had relapsed. 7. Most participants (78%) preferred to speak with a physician about cancer and treatment, followed by another teenager with cancer (76%) and then parents (71%). 8. Most preferred a participatory style of communication with their healthcare providers to gain information and to make decisions.	Most participants were off therapy so this may influence their decision making preferences and recall compared to those receiving therapy with more recent experiences. This study is retrospective. The participants are approximately 5.3 years on average from diagnosis so there may be recall bias.

Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
6. Ellis & Leventhal, 1993, United States	To determine the information needs and decision making preferences of children with cancer and their parents. Study Design: Cross sectional survey.	N=50 Children/Adolescents N=60 Parents All child/adolescent participants with cancer, age 8-17 years, were screened and asked to participate until 50 surveys were completed. It was a single center study, at a major metropolitan pediatric oncology center, serving a predominantly African American population. Nearly all (94%) participants were non African American.	Variables included age, sex, race, phase of disease, and diagnosis. They used pilot interviews to develop the survey. Based on their pilot testing, they limited the survey (132 items) to age 8 years and older. The parent survey was developed from the child's survey and consisted of 186 questions. The survey took 1 hour to complete. Participants completed the survey either in the clinic or at home. They analyzed the questions for consistency, if the question was confusing and test retest reliability. Responses were compared between children and their own parents. They also examined age, sex, parental education and diagnosis, and phase of disease. They compared parents' survey items between mothers and fathers.	1. African-American participants were less likely to agree to the study, and if they did, were less likely to actually to complete the survey. 2. 63% knew their diagnosis of cancer. 86% of the participants were involved in research but only 38% of them knew it. 4. 89% of patients wanted the doctor to make all the decisions. 5. 69% of the parents wanted the doctor to decide about their child's treatment. 6. 72% of patients and 80% of parents believed they had the right to refuse curative therapy for otherwise fatal disease. 7. Children who had less understanding of their diagnosis were less likely to want to be involved in making decisions than those with a complete understanding (p=0.039). 8. Patients thought they should be at least 16 years old to make even minor decisions about medical care.	Only 6% of participants were African Americans despite the large percentage of African Americans in the drawing population. The results are not necessarily reflective of the setting's population. Participants were English speaking only and primarily white males. The surveys were lengthy and took one hour to complete. For children and even adults, this a long time to focus on answering questions.

Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
7. Hinds et al., 2005, United States and Australia	To identify preferred end of life choices in children and adolescents with advanced stages of cancer. Factors considered by patients parents and physicians in making these choices were also considered. Study Design: Descriptive: children and adolescents were interviewed in person within 7 days of their participation in 3 types of end-of-life decisions (Phase I trial, initiation of terminal care, DNR) to identify their care preferences and the factors that influenced their decisions. Factors considered by parents, patients and physicians were compared.	Children/adolescents= 20. They were between 10-20 years of age (mean-17 years) with a refractory solid tumor, brain tumor or leukemia. 17/20 participants were white. Parents=19 Health care providers (physicians)=14 One-third of the patients who were invited to participate declined. Two groups were interviewed at 2 sites: St Jude's Children hospital, Tennessee and Sydney Children's Hospital, Australia.	A 6-item interview guide was developed and field-tested prior to use. Participants were interviewed individually. Three of the authors conducted the interviews. They used Ethnograph (software program) to organize the data and coded every phrase. Two members of the study team reviewed the first three interviews and developed first level codes and a code dictionary. The rest of the team used the code dictionary to complete a semantic content analysis.	1. Children and adolescents can participate in end of life decisions. 2. 90% of participants accurately recalled the 2 or 3 options presented to them. 3. Participants identified death as an outcome. 4. Participants considered the outcomes/impact of their decision on others. 5. Participants were able to consider more than one element at a time in the complex decision making process. They were able to take into account these elements into the decision. 6. A factor influencing participants' and parents' decision making was altruism. 7. A frequently reported factor by patients/parents/physicians was consideration of and sensitivity to others. Human relationships strongly influence end-of-life decisions. This is in contrast to developmental theories. 8. Participants' perspective is important to parents and physicians and does affect how decisions are made.	Only 2 sites participated in the study. A small number of individuals per group participated. Some of the participants had CNS tumors and had cognitive deficits so may not recall events accurately.

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8. Jacobs et al., 2015, United States	To describe congruence between adolescents' end of life preferences with parents who participated in the Advance Care Planning intervention arm (session 1 only) of a 2-arm RCT. To describe the practitioners end of life thoughts for themselves and patients via a post-hoc survey. Study Design: Survey Participants who received the intervention, which consisted of a 3-session interview with a facilitator focusing on 1) advance care planning, 2) respecting choices 3) completion of 5 wishes. Each weekly session lasted 60 minutes. The providers and nurses completed the post-hoc survey electronically.	17 adolescent/family dyads N=34 participants The adolescents were between 14-21 years of age with a range of cancer diagnosis. Most (70%) were on therapy and the remainder were survivors of cancer.	Dyad pairs completed the surveys individually. SAS was used to analyze the data. Data was recoded into dichotomous variables: very important or important, or otherwise. Congruence between the adolescents' and parents' survey responses was examined using Kappa statistics.	1. Most adolescents (70%) felt it appropriate to discuss end of life decisions if dying, followed by at any time point (38%). 2. 89% felt it important to be pain free, be at peace spiritually, for the doctor to be honest, to know my treatment choices and be able to stay at home. Most preferred to die at home (65%). 3. Most (71%) had never heard about an advance directive or completed one. 4. 53% had never talked with anyone about their end of life preferences; they believed it important that their family know about their wishes. 5. 88% felt their parents would respect their medical wishes. 6. Adolescents and parents agreed that understanding treatment choices and being physically comfortable were important. 7. Less than half of the providers and nurses believed that children less than 18 years of age who knew their wishes should complete an advanced directive. 8. 77% of the providers would refer a patient to a trained team to discuss advanced directives. They agreed that being pain-free and at peace spiritually were important.	The group of adolescents were extremely heterogeneous with regard to disease and age. 70% were in active treatment with the rest in follow up; 1/3 had experienced relapse. It was a single site study. Preponderance of African-American (58%) so may not reflect Caucasian, Asian or Hispanic findings well.

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9. Kelly et al., 2017, United States.	To determine how children and adolescents viewed their involvement in treatment decision making. Study Design: Qualitative study using interactive interview techniques. Purposive sampling was used.	N=29 children and adolescents between 9-17 years of age. Participants had various cancer diagnoses. Participants ranged in age, ethnicity, diagnosis, treatment experience and time since diagnosis (up up ≥ 24 months). Almost half were female and < 13 years of age.	Twenty participants were initially interviewed using interactive techniques. Cards describing different degrees of TDM involvement were used to conduct the interview. Ten additional interviews were conducted to confirm results using new cards summarizing preliminary findings and member checking. Interviews were audio-recorded. Interviews were conducted in the clinical setting or home. Constant comparative analysis was used. The first author conducted the initial analyses. All authors participated in reviewing coding decisions and achieved consensus agreement.	1. “Having a say as I need at this time” is the primary construct that represents the child’s and adolescent’s communication preferences. The type of treatment decision or child’s illness state influenced the construct. Having the say they wanted led to improved satisfaction, less fear and more comfort with their decisions. 2. Participants often reported parents and physicians acted in their best interest. 3. Excessive information at introductory visits was confusing and frightening. Some AYA wanted to be educated about their treatment plans. 4. Most participants did not want to make decisions they felt were “big“ or consequential. They often felt there was no real decision to be made. 5. Wanting less say than others was a function of their trust in their parents’ and their doctors’ knowledge about their disease and treatment. 6. They identified frequent shared decision making with parents and doctors. 7. There was a wide variety of preferred involvement, volume of information and participation in treatment discussions.	The study was retrospective and included those who were > 24 months since diagnosis. A description of whether the participants were receiving or had completed therapy was not provided. The order of presentation of the laminated cards was not specified and could have influenced the participants’ responses.

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10. Miller et al., 2013, United States	To examine adolescent patients' perspectives of their understanding and decision making about a pediatric Phase I cancer study. This study was part of a larger study including parents. Study Design: qualitative Descriptive Structured -open and closed ended questions. They video-taped and audio-taped their Phase I study informed consent conference as part of the larger study. Interviews conducted related to the informed consent conference and the decision process. Interviews took place within a week (mean of 6 days) of the informed consent conference.	N=20 Age of participants was 14-21 years with multiple cancer types. Multicenter (6 children's hospitals in the US) sample of parents considering enrolling a child in a Phase I study. If the parent agreed, then the child was asked for assent. The selection process was unspecified.	Interviews using a structured interview with open and closed questions were conducted. The interview questions were related to Phase I treatment participation. They generated descriptive statistics of the closed-ended question (mean, standard deviations and range). Open-ended questions were coded by 1 study team member and verified by another member. The frequency of responses was calculated for each coded category.	1. 100% of participants knew that a Phase I trial was discussed. 2. 85% (17/20) of participants reported they made the final decision about enrollment in the study. 3. 10% (2/20) reported being a partial decision maker. 4. 75% of participants identified that a reason for participation was the potential to lengthen their life or cure them. It offered them hope. 5. 45% participated because there was no other option. 6. 20% participated because they wanted to help the science or other people. 7. 90% felt the trial would provide medical benefits. 8. 65% stated they did not know if their treatment would benefit them medically. 9. 25% stated that participation in the Phase I trial could reduce their quality of life due to side effects. 10. 15% identified they may spend more time in the hospital because of participation in the study.	The sample size was small. Most of the participants were white males.

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11. Pearce et al., 2016, United Kingdom	To explore the perceptions and experiences of AYAs participating in clinical trials. To explore perceptions and experiences of health professionals involved in the care of AYAs with regard to their participation in clinical trials. Study Design: Interpretive qualitative semi-structured interviews using narrative methods. Triangulation of the data from the AYA and health professional datasets was conducted.	N=21 (AYAs) aged 15-24 years of age with primary bone cancer (Ewings or Sarcoma) participated. Participants were eligible to participate in one of two bone or soft tissue clinical trials. All patients who met criteria were invited to participate in the study. N=18 (health professionals) who recruited or were involved in the care of these participants.	Transcripts were analyzed using an interpretive approach including constant comparison methods. A theoretical framework emerged. Data from both groups (AYA and health professionals) were analyzed separately. Two of the authors coded the data and two of the other authors validated the coding.	1. Some AYAs thought clinical trials were the same as chemotherapy, others as alternative treatment. 2. Both AYAs and health professionals valued face to face conversations and teaching. 3. Altruism and the trusting relationship with health professionals were powerful determinants of the decision to participate in a trial. 4. The Clinical Nurse Specialist role of educator was appreciated by the AYA. 5. Support from family, peers and health professionals was critical to decision making. 6. AYA appreciated communicating with peers with similar experiences. 7. AYAs recognized the benefit of being treated in a specialized setting. 8. Randomization and clinical equipoise are concepts difficult to understand. 9.Prolonged hospitalizations are burdensome. 10. AYAs wanted to return to a normal life.	This study was retrospective. Participants were either on or off therapy and results from these two groups were not differentiated. 21 of 34 eligible participated (62%). It was a single center site. Racial and socioeconomic data were not provided.

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12. Read et al., 2009, United States & Canada	To determine personal factors (attitudes) of AYAs about their own experience in healthcare research and the decision to participate in research. To compare AYA responses to parental responses. Study Design: It is a secondary analysis of questionnaire data. The original study was about the return of research results. 86 AYAs and 409 parents participated in this study, which was conducted at 5 different centers in Canada and the United States.	N=21 (AYA participants). They were 12-22 years of age (median age was 18). N= 31 parents If the children and parents recalled participation in health research in the initial study they were selected for analysis.	The questionnaires for the AYAs and parents were developed using the Dilman method and validated using focus groups, followed by expert review and finally a pilot study. There was a wide range of how participants were selected and administered the questionnaire. SAS was used with appropriate statistics. Pearson's chi square test was used to assess the association between demographics and attitudes to clinical trial participation. Multivariate analysis was used to generate potential hypotheses.	1. 26% of the AYA participants thought that participating in research would help them. 2. 67% of AYAs thought participating in research would help others. 3. Main deterrent to participating in research identified by 45% of AYAs was that research would take up too much time. 4. Having too much to think about was identified by 36% of AYAs and 47% of parents as an impediment to participation. 5. Parents who were young, Black or less educated were more likely to decline research participation for their AYA. Otherwise there were no other demographic associations.	There was no length of time specified for the time between the diagnosis, and the day of being offered the clinical trial and the date of completing the questionnaire. The questionnaires were anonymous so there was no way to verify if the AYA had actually participated in a clinical trial. The data was based on the participant's memory, with potential for recall bias.

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13. Ruhe et al., 2016a, Switzerland	To explore patient's perspectives in pediatric oncology on participation in discussions and decision making surrounding their cancer diagnosis	N=17 (AYA participants). They were between 9 and 17 years of age and receiving oncology treatment at Swiss centers. 6 girls, 11 boys time from diagnosis between 3 weeks to 2 years.	Data was a sub-set of a larger mixed methods project whose aim was to investigate how decisions were made in pediatric oncology in Switzerland and the extent to which children were included. The quantitative part of the project surveyed pediatric oncologists and parents (not reported in this article). The qualitative part was composed of face to-face interviews with minor patients using a semi-structured guide adapted by the interviewer. Transcripts were coded and analyzed qualitatively using MAXQDA software.	1. The main topic; participation in healthcare, comprised three themes: (a) participants' role in medical communication and decision making, (b) the toll of participation, and (c) participants' thoughts and opinions about participation. 2. The degree of involvement in medical communication varied with some patients being directly involved while others participated to a lesser extent. 3. Several of the participants were present at these discussions and became active by asking questions which ranged from inquiring about side effects to another treatment possibility. 4. They highlighted being involved in minor choices, such as whether they preferred liquid drugs or tablets or undergoing a procedure with or without anesthesia. 5. They reported making decisions together with parents and/or a physician on the few occasions when they participated in more than a minor decision such as choosing to enter a trial or fertility preservation. 6. Most reported being satisfied with the level of their participation. 7. Some stated that information was not at all times entirely comprehensible. 8. Receiving information or making a decision was sometimes burdensome and even stressful. 9. They believed that involvement in their health care was natural. 10. If only parents talked to the physician, the child was suspicious things were hidden. 11. Preferences with regard to participation also fluctuated in the same patient. 12. Participants reported valuing when they were able to choose their preferred level of involvement.	4 children out of 21 refused the interview, leading to the sample of 17. 1 interview was not recorded or transcribed because the recorder failed. The manuscript does not state whether initial codes/readings were reviewed by one or more than one author. It only states English translations of quotes in other languages were checked by 2 authors. Swiss children only, therefore likely limited racial representation although racial makeup not reported. Only the more articulate children might have participated. Treating oncologists recruited the children so might have selected the ones they liked or were more positive. There may have been selection bias. Small sample with wide range of ages and times since diagnosis.

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14. Ruhe et al., 2016b, Switzerland	To learn how patient participation is accomplished in pediatric oncology. Study Design: a subgroup analysis of a larger mixed methods project conducted in 8 Swiss centers. Semi-structured one-to-one interviews to explore communication, decision making, patient involvement and inclusion of children in TDM. A subset of the qualitative data subset from the larger mixed methods study is presented. This article focuses on the theme of "Patient Participation". Other themes are reported in other articles.	N=17 participants (9-17 years old and on treatment), 19 parents and 16 oncologists were interviewed.	Data was a subset of a larger mixed methods project whose aim was to investigate how decisions were made in pediatric oncology in Switzerland and the extent to which children were included. The semi-structured interview was performed individually and lasted between 20 min and 2 hours. The primary language of the child was used and included German, French, Italian or English. Tape recorded interviews were transcribed and subjected to thematic analysis by at least two researchers. Findings were presented to a third researcher. Disagreements were resolved by consensus. MAXQDA software was used to assist analysis. This article just reports the theme of "Patient Participation".	1. 17/21 children agreed to participate (81%) in the study. 2. Children are involved in their care in variable ways. 3. Children's participation is controlled or regulated regularly by parents and physicians. 4. Children's participation is influenced by other factors such as culture, circumstance, physician preference. 5. Most times that patients' preferences were taken into account were decisions about symptom management. There were few instances where patient preference was taken into account for the "more essential" decisions such as switch from regular to high-risk treatment. 6. A very common form of participation for children is to observe or overhear discussions between parent and physician. 7. In many cases there is little or no room for choice when adherence to treatment protocols was critical.	4/21 patients refused to participate. It is possible interviewing in 4 different languages may have led to miscommunication. Some parents could not participate because a common language could not be found. Participants were selected by their oncologist so substantial selection bias is possible or even likely. Some oncologists refused to participate and allow their patients to participate. It is possible their decision-making interactions may be substantially different.

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15. Snethen et al., 2006, United States	To describe within and across families patterns of decision making when the child is a participant in a clinical trial. Study Design: Secondary analysis (qualitative) of a larger study of ill children and their parents about their experience with research (NIH funded study). 34 families participated.	N=14 family units N= 15 children/AYAs (5 children between 8-11 years, 6 children between 12-15 years and 4 AYAs between 16-20 years). N =28 parents Families who had children between 10-20 years of age with chronic illness who participated in a clinical trial were interviewed. The types of chronic illnesses included: cancer (9), bone marrow transplant (3) or diabetes (3).	Parents and children/AYAs were interviewed as part of a larger study. A subset of this data underwent secondary analysis. A semi-structured interview guide was followed and thematic analysis was conducted. The researchers developed a template to help with identifying important issues. Case studies were developed for each family unit and were part of the data analysis. Matrices were developed allowing comparisons within and across family units and contributed to rigor by preventing bias. Authors discussed the cases until they came to a consensus.	1. Patterns of decision making were based on the parents' goal in the decision making process, the child's level of involvement, and the parents' perceptions of their roles in the decision making process. Informed consent is a complex experience and not linear. 2. Patterns of decision making were identified: Exclusionary, Informative, Collaborative and Delegated. Exclusionary decision making: The parent protects the child who is not involved in decision making. Informative: Parents want the child to understand the situation, the child learns, and the parents make decisions and inform the child. Collaborative: Parents empower the child and support the child in making the final decision. These children were older, 17-20 yrs. Delegation: Parents screen information and want the child to make the decision with the parents' approval. These children were younger. 3. The analysis showed there was no specific pattern of decision making that related to age.	The participants' education and cultural diversity were not discussed in relation to the findings. The sample was primarily white (approximately 66%) which may have biased the results. Small sample size with few participants in each chronic illness group.

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16. Stegenga et al., 2008, United States	To determine if the research question was appropriate and if adolescents can provide rigorous data. Study Design: Qualitative-pilot, exploratory using phenomenological methods and semi-structured interviews.	N=3 adolescents between 13-15 years of age, diagnosed with cancer within the previous 4-6 months.	The interviews were audio-taped, transcribed and underwent content analysis. The interviews ranged from 15-40 minutes (mean 27 minutes). Both investigators reviewed the transcripts. Inter-rater agreement was initially 90%.	1. The only decision early on was whether or not to treat the cancer and everything else should be left to the doctors. 2. Three themes were identified: The adolescents believed decisions should be made by the health care team who were most knowledgeable. "The desire for information was not described as a desire for control." They wanted information; to know what was going on and what to expect even thought they knew they had no control. Family and friends provided support.	This was a pilot study with only 3 participants at a single center. Single interviews were conducted. No demographics were reported other than their age and gender. The focus of the study was on the time close to diagnosis and the number of participants were only 3, so major limitations in terms of the transferability of findings.

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17. Tenniglo, et al., 2017 The Netherlands	To determine supportive care topics important to patients and parents and their preferred role in decision making. Study design: Qualitative. In person and on-line focus groups. Online focus group participants responded to posted topics or to other participants' comments. The questions for the online focus group were derived from the traditional focus group questions.	N=18 parents (9 mothers, 9 fathers) N=11 patients (mean age of 15 years, range 12 -18 years at time of diagnosis) from 2 months after treatment initiation to 6 months after termination of treatment 54% had ALL.	Two in-person (parent) and one anonymous, on-line (patient) focus group were conducted at two different pediatric oncology sites. Data were analyzed using thematic analysis. The traditional focus group sessions were audio-recorded. The on-line focus group data were entered into the software Atlas.ti. Patient questions in the online focus group were derived from themes developed from the traditional parental focus group.	Three themes were identified: 1. Communication between patients and physicians, the provision of information and psychosocial care. 2. Patients and parents were both involved in the management of medications such as antiemetics. 3. Parents and patients wanted to be involved in medication management. 4. Parents and patients preferred involvement in topics such as choice of analgesics or anti-emetics but not in more 'medical' topics such a febrile neutropenia or choice of antibiotics. 5. Although there was great demand for information at diagnosis, they had minimal time or energy to look for it.	1. Online focus group questions were set in advance, so little opportunity for new themes to emerge. 2. Online focus group questions came from parental in-person focus groups, so themes unique to patients may have been missed. 3. No pilot testing of questions. 4. Recruitment was through a patient cancer association so participants may be a biased subset. 5. No racial or socioeconomic data so applicability to other populations is questionable.

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18. Unguru et al., 2010, United States	To determine what children with cancer understand about the oncology research they participated in, research-related treatment and their preferences for involvement in decision making. Study Design: Mixed methods. Face to face audio-recorded interviews using a semi-structured tool were conducted; a Quality of Assent instrument was administered. Single site (large metropolitan oncology program).	N= 37 The participants were age 7-19 years at the time of their diagnosis and had a variety of cancer diagnoses. All children who had signed a research assent form from 2005 to 2007 were eligible, but further selection criteria were not elaborated upon. The authors reported the clinical characteristics of the non-responders were not different from those of the 60% of the total who responded to the request to participate.	The research team developed a 69-item "Quality of Assent " instrument consisting of open- and closed-ended questions, modeled after the "Quality of Consent" Instrument (Joffe et al, 2001). Content validity, clinical relevance, clarity, comprehension, acceptance, and children's comprehension of the questions were either reviewed by experts in the field or pilot tested with a convenience sample of cancer patients (n=4) or healthy peers (n=4). Questions related to their comprehension of the research (familiarity, knowledge, awareness, understanding, appreciation), and preference for involvement in the research (this section of the instrument was assessed in those ≥14 years old. Interviews were conducted privately with participants and lasted les than 30 minutes. Only one interviewer (Unguru) read each question aloud to the participant. Interviews were transcribed and the content was verified. The first author coded for common themes from the qualitative (open-ended) questions. Analysis (using SPSS software) included descriptive, exploratory tests, parametric and nonparametric statistics. Linear regression analysis of the quantitative data was used to determine the patterns and trends of understanding and preferences. Open-ended questions were coded for common themes; no specific software was mentioned.	1. 51% were unaware their treatment was research. 2. 86% did not understand the physician's explanation about the trial. 3. Most enrolled in trials to help future children (73%) and to get better (70%). 4. Children with specific diseases such as Hodgkin's disease, germ cell tumors and leukemia were more aware of the research compared to those with different diagnoses. Age was no influence. 5. 50% reported they felt they had little or no role in the decision. 6. Only 62% believed they were free to dissent from trial enrollment. 7. Age was not correlated with the types of decision made, roles performed in the decision to enroll in research, or physicians' willingness to discuss decision making 8. 88% did not discuss their decision-making involvement with their parents; 71% did not discuss this with the physician. 9. 54% of children had not talked to their parents or physician about making decisions about their care; those who did (71%) were ≥ 14 years of age and parents did not include them in decision making. 10. Most children (60%) wanted to be involved in decisions (mean 14.5 years), 40% wanted a little involvement (mean age 12 years) and none wanted to make decisions on their own. They preferred collaborative decision making with their parents (97%) and physician (94%).Very few (11%) discussed increasing their role in decision making with their parents and physicians. 11. Suggestions to doctors to improve TDM involvement were to talk not only to parents but to children, ask for their opinion, explain things in an understandable way and not treat them like children.	Participants were enrolled in a variety of clinical trials (Phase I-III, pilot and biology). Unclear length of time since diagnosis. Some children were interviewed > 2 years after their research study enrollment. This was only a single center study. There was a mix of various scenarios of interviews, in private lounge, before or after a clinic, on a separate day, or as an inpatient. Content-validity studies showed poor inter-correlation between items that were being summed to generate various scores. Cronbach's alpha was 0.62. Because these were person-to-person interviews, the children's responses may be what they perceived the interviewer wanted to hear rather than their true belief. Children may have confused clinical care with research care.

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19.Weaver et al., 2015, United States	This study investigated medical decision-making preferences of adolescent oncology patients and their perception of parental and clinician behaviors that support their preferred level of decision-making involvement. Study Design: Qualitative study using a 4-question interview guide and qualitative analysis of transcripts.	N=40 English-speaking participants age 12-18 years. Participants were asked about their preferred decisional role on a recent decision. Participants were diagnosed or relapsed within 6 months of the study.	The first author performed all interviews, which were transcribed and analyzed using the software Atlas.ti. 2 blinded team members coded the transcripts. Intra-rater and inter-rater reliability was calculated. Variables included a 3-variable ordinal scale and a 4-variable “non-ordinal” decisional preference category score. Statistical tests such as chi-square or Kruskal-Wallis were used as appropriate.	1. 40% African-American, 20% Hispanic, 2.5% Asian and 37.5% Caucasian. 2. 60% Male. 3. 60% had leukemia/lymphoma, 32.5% with a solid tumor and 7.5% neuro-oncologic. 4. 85% had a new diagnosis and 15% were in relapse. 5. 12.5% picked their involvement based on the situation, 22.5% preferred to be passive, 22.5% had a mid level of involvement and 42.5% preferred to be fully engaged in the decision. 6. No statistically significant relationships were identified between decision-making preference and age, time on treatment, new or relapse disease, treatment location, or sex. 7. Phrases about parental support fell into 4 common categories, (Behavior, Attitudes, Learning and Legacy). 8. Clinician behaviors identified to support decision making (facing the patient, listening, “advocating for honesty” and giving “encouragement, respect and hope.” 9. Adolescents’ perspective on decisions is dependent on their relationship with their parent and physician. 10. Decisions are described as ‘situational.’	The population was only English speaking. Only the patient perspective was studied their memory may be flawed. Correlation with parent or clinician perspective would have improved reliability. Refusal rate was 17-33% (29% overall), leading to bias. 17/40 interviews were not performed alone, so the presence of a parent or grandparent could have biased the responses. The numbers in each category were very small, making the statistical power very low. The failure to identify any relationship with age or time on treatment is likely a reflection of this low statistical power and should not be a conclusion.

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20. Zwaans-wijk et al., 2007, The Netherlands	The study was developed to investigate the preferences of childhood cancer patients, survivors and parents for communication, information and decision making. Study Design: Qualitative. Participants participated in an iterative, asynchronous web-based focus group.	N=25 child/adolescent participants on therapy (7) and off-therapy (18); n=11 parents. Three groups participated in the study: 1. Children and adolescents receiving treatment for cancer- 7 patients (age 8-17 years). They were diagnosed 6 weeks to 1 year prior to the interview. 2. Parents (11) of these children/ adolescents receiving treatment. 3. Survivors (18) from 8-17 years of age who were off therapy and treated in the previous 5 years. Recruitment was by personal request and email solicitation from 2 Dutch oncology units.	Online focus groups were conducted separately with the children and adolescents who were on therapy, by age: 8-11 and 12-17 years of age; parents, and survivors of cancer (8-17 years of age). Questions were posed on-line daily for 5 days related to the participants' experience at diagnosis, how information was exchanged between the parent and child participant, their preferred participation in decision making, how physicians and nurses participated in communication and roles about the child's care that parents and the child assumed at home. On day 6 and 7, participants could pose questions they considered relevant in communication. The researchers functioned as moderators, asking questions and clarifying feedback. Participants who were not participating were sent email reminders. Transcripts were thematically coded by 2 investigators who independently read and developed a coding scheme. Coding was discussed by the investigators until there was consensus.	1. They wanted open communication between the healthcare providers and themselves. 2. All 3 groups expressed a desire for reassurance, support and empathy from Health Care Providers. Trust in the HCP was an important part of the relationship. 3. The participants generally stressed that the child patient has a basic right to full information about their illness and treatment. Participants do vary in the amount and kind of information they want. Some children wanted to be present during the physician consultations, while others preferred to communicate with their parents. 4. Clarity of information was important and the ability to ask questions and receive information should be adapted to the patient's age and cognitive abilities. 5. Children prefer to receive only general information at the time of diagnosis. They would like more detailed information later. 6. Majority of participants prefer decisions to be made collaboratively with the patient, parents and HCPs. 7. Survivors and adolescent patients believed that they should make the final decision and that parents could provide assistance with making the decision. 8. Being too ill to participate, not trusting the physician, and inadequate knowledge of the disease and treatment were important barriers to participation.	This online focus group allowed participants to see the other participants' responses, so there may have been a herd mentality on certain topics, where the first posters may sway the rest. The anonymity could allow sharing of passwords so unauthorized participants may have contributed. Small numbers of patients still on therapy (7) participated, meaning results were more likely to reflect past experiences, rather than current dilemmas. Authors don't report the attrition rate i.e. how many participants continued to participate over the course of the 7-day online focus group.

Treatment Decision Making Involvement in Adolescents and Young Adults with Cancer-Table 1

Authors, Year, Country	Purpose and Design	Population/Sample	Variables/Data Collection and Analysis	Main Findings	Limitations
21. Zwaans-wijk et al., 2011, The Netherlands	Investigate preferences for communication and associated variables of children undergoing cancer treatment, parents and survivors of childhood cancer (treated within the previous 5 years). Communication aspects included healthcare provider empathy (affective communication), information exchange (give information to patient and parents simultaneously or not), to give info only if asked, and if patient should participate in TDM. Study Design: Questionnaire using a random selection of 10 out of 200 vignettes (hypothetical situations). The variables of the vignettes selected randomly (>4608 combinations). Preferences measured using visual analogue scale.	N= 34 children with cancer (age 8-16 years). N=59 parents N=51 survivors (8-16 years of age at the time of diagnosis, currently 10-30 years of age). Patients and parents participated in the study immediately after a 'decisive consultation' which occurred on average 113 days after the diagnostic consultation. 3 Dutch Oncology Centers participated.	This study was part of a larger multicenter study on communication in pediatric oncology. Questionnaires were distributed either in person or by mail. Only 35.2% consent rate from cancer survivors. 72.3% of actively treated patients and 66.3% of parents consented. This was a unique protocol. The questionnaire included vignettes involving factors such as diagnosis, treatment, prognosis, illness stage, child age, emotionality, physical condition and amount of parent pre-existing knowledge of the illness. A set of vignettes was randomly screened for consistency and the presence of the factors. The vignettes were also pilot tested. Each participant was given 10 unique vignettes to review. Variables associated with in the 3 groups' preferences about medical communication were investigated. Deconvolutional analysis using multivariate techniques were utilized. Multiple regression analysis was performed to account for the fact that each participant scored 10 vignettes. There was no evidence that responses differed among the 3 oncology centers. Linear regression was performed to analyze the provider empathy score; logistic regression analyses was used for the remaining variables.	1. Healthcare provider empathy was very important, especially when dealing with treatment failure and end of life. At diagnosis, empathy was not important. 2. Information should be given to both the parent and child simultaneously if the child is older. If the child is younger or more frightened, the information should be given first to the parents so that patients are shielded. 3. Younger and frightened patients should only receive information when they explicitly ask for it. Older children should receive the total information without asking. 4. Parents want to receive bad prognosis information first and separately from children. 5. Younger children were recommended to not be involved in treatment decision-making. For older patients involvement in treatment decision making was preferred. Parents preferred that patients who were easily frightened or whose prognosis was poor or unknown not be included in treatment decision making. 6. In agreement with current guidelines, increasing patient age was the primary association with information giving and preferences to participate in decision making.	Hypothetical situations may not represent what is actually done in real life. The survivor group was 2-14 years from diagnosis with potential for recall bias. The treatment and parent groups were asked to participate in person, but the survivors were invited by mail; therefore, this may account for the much lower participation rate of the survivors.

Table 2
Quality Assessment of Research Reports

Article	**Type of Method**	**MMAT Quality Score**
1.Barakat et al. 2014	Qualitative: Content Analysis	3
2. Broome et al., 2003	Qualitative: Narrative Analytic Techniques	3
3. Broome et al., 2001	Qualitative Narrative Analytic Techniques	3
4. Coyne et al., 2014	Qualitative Grounded Theory	3
5. Dunsmore and Quine, 1995	Quantitative	2
6. Ellis and Levanthal, 1993	Quantitative	3
7. Hinds et al., 2005	Qualitative: Descriptive	3
8. Jacobs et al., 2015	Quantitative: Descriptive	2
9. Kelly et al., 2017	Qualitative: Descriptive	4
10. Miller et al., 2013	Qualitative: Descriptive	3
11. Pearce et al., 2016	Qualitative: Narrative	4
12. Read et al., 2009	Quantitative: Descriptive (*secondary analysis*)	3
13. Ruhe et al., 2016a	Qualitative: Thematic Analysis *Part of a mixed methods study*	3
14. Ruhe et al., 2016b	Qualitative: Thematic Analysis *Part of a mixed methods study*	3
15. Snethen et al., 2006	Qualitative: Thematic Analysis (*secondary analysis*)	3
16. Stegenga & Ward-Smith, 2009	Qualitative: Phenomenolgy	3
17. Tenniglo et al., 2017	Qualitative: Thematic Analysis	2
18.Unguru et al., 2010	Quantitative: Descriptive	3
19 Weaver et al., 2015	Qualitative Semantic Analysis	4
20. Zwaanswijk et al., 2007	Qualitative: Focus Groups: Thematic Analysis	3
21. Zwaanswijk et al., 2011	Quantitative – Vignette method	3

Scale ranges from 0-4: 4=highest score.

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Appendix A

Study Selection

Search Strategy

The research question was broken down into three main concepts: cancer and related diseases, TDM, including patient participation and informed consent, and the AYA age group. Each of these concepts was searched using a combination of database index terms and extensive keywords. The main concepts were combined to find only articles that included all three concepts. Then limits were placed to exclude publication types and concepts outside the scope of this research, for example review articles that are not meta-analyses or articles on decisional support in non-medical environments.

In stepwise fashion, the study selection process included the following:

- The title and abstracts of the publications identified by the searches were reviewed for inclusion and exclusion criteria.
- Full text articles that fulfilled these criteria were obtained and reviewed once again, applying the inclusion and exclusion criteria.

The inclusion criteria were:

- Original quantitative, qualitative and mixed methods studies that included AYAs between 15-21 years of age with cancer,
- Procedures, methods, and analysis clearly described,
- Studies that examined the AYAs' involvement or perspective in TDM regarding their cancer treatment,
- Studies primarily included cancer patients if they include other chronic illnesses.

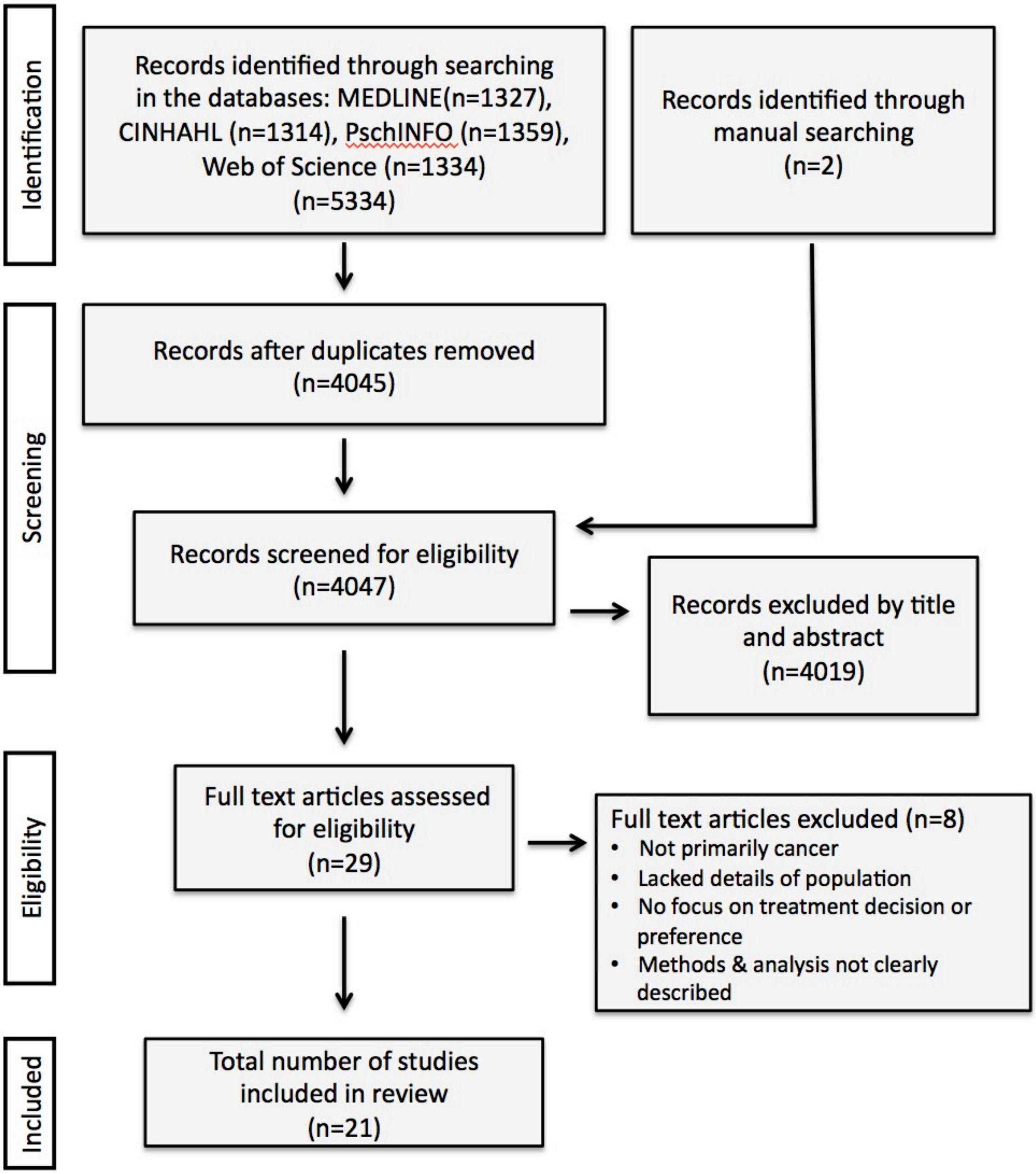
The exclusion criteria were:

- Studies in which the data pertain only to patients who had completed therapy (survivors) or were related to fertility preservation.
- Reviews, editorials, or case reports.

Reference lists of articles that met the inclusion criteria and publications of researchers in this area were reviewed for completeness. Figure 1 illustrates the process and outcomes of the sample selection protocol.

Figure 1

Study Selection Process: PRISMA Diagram



Chapter Three

Three Dimensions of Treatment Decision Making in Adolescents and Young Adults With Cancer

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Abstract

This study explored the involvement of adolescents and young adults (AYAs) in cancer treatment decision making (TDM). AYAs experience treatment non-adherence rates as high as 60%, which can increase the risk of relapse. Open communication, positive family relationships and involvement of the AYA in treatment decisions and illness management support adherence to medical treatment. Using interpretive focused ethnography, we conducted one to two interviews with 16 AYAs (total 31) receiving cancer treatment within one year of diagnosis. Participants reflected on a major recent TDM experience (e.g., clinical trial or surgery) and other treatment decisions. We identified three dimensions related to AYAs' involvement in cancer TDM: 1) becoming experienced with cancer, 2) import of the decision and 3) decision making roles. AYAs' preferences for participation in decision making may vary over time and by type of decision. Parents play a particularly important supportive role in decision making for AYA patients.

Key words: adolescent and young adult, cancer, treatment decision making

Background

Cancer is the leading disease-related cause of death among individuals diagnosed with cancer between 15-39 years of age, defined as adolescents and young adults (AYAs) by the National Cancer Institute {Albritton, 2006 #240}. Progress in improving the cancer survival among AYAs has fallen behind that of their younger and older peers (Bleyer, Ferrari, Whelan, & Barr, 2017; Lewis, Seibel, Smith, & Stedman, 2014). The cause for this disparity is likely to be multifactorial, but treatment nonadherence may play a significant role. Patient discomfort with their participation in decision making may be a key factor in nonadherence; therefore, research to improve their engagement in and satisfaction with their decision making could improve these outcomes (Coyne, Amory, Kiernan, & Gibson, 2014). The American Academy of Pediatrics (2012) policy statement advocating patient and family-centered care recommends effective partnerships between children, parents and families, and their healthcare providers resulting in shared decision making.

AYAs with cancer are a distinct subgroup that requires focused care for the unique biological and psychosocial challenges they face during treatment. Adherence to therapeutic regimens, such as medication taking or attending medical appointments, is difficult for AYAs (Bleyer, Barr, Ries, Whelan, & Ferrari, 2017; Kondryn, Edmondson, Hill, & Eden, 2011). Across many studies and forms of cancer, rates of nonadherence to medication in AYAs with cancer are between 27% and 63% (Festa, Tamaroff, Chasalow, & Lanzkowsky, 1992; Phipps & DeCuir-Whalley, 1990; Smith, Rosen, Trueworthy, & Lowman, 1979; Tebbi et al., 1986). Nonadherence can lead to increased risk of cancer relapse (Butow et al., 2010). Open communication, positive family relationships and involvement of the AYA in treatment decisions and illness management support adherence to medical treatment (Albritton & Bleyer, 2003; Sawyer & Aroni, 2005), whereas paternalistic relationships with health professionals may reduce treatment adherence by adolescents (Kyngas, Hentinen, & Barlow, 1998).

Shared decision making in pediatrics is a collaboration that optimizes the involvement of the patient, to the extent they can participate, the parent/family, and the clinician to make healthcare decisions together, while remaining true to medical science and the values and goals of the patient and family (Coyne et al., 2014; Kane, Halpern, Squiers, Treiman, & McCormack, 2014; Kon, Davidson, Morrison, Danis, & White, 2016). As interest in applying shared decision making to pediatrics is relatively recent (Wyatt et al., 2015), there is inconsistency in the definition, interpretation and approach to shared decision making amongst different clinicians and researchers. (Elwyn et al., 2012; Makoul & Clayman, 2006).

Participation in treatment decision making (TDM) in children, adolescents and young adults may have numerous potential benefits, including improved autonomy, efficacy, sense of control and increased adherence to medical management. (Barakat, Schwartz, Reilly, Deatrick, & Balis, 2014; Butow et al., 2010; Coyne et al., 2014; Coyne & Gallagher, 2011; Kelly, Mowbray, Pyke-Grimm, & Hinds, 2017; Ruhe et al., 2016; Snethen, Broome, Knafl, Deatrick, & Angst, 2006). Participation in decision making could also be stressful and taxing (Ruhe et al., 2016). However, we lack data about why, how and under what circumstances AYAs make cancer-related treatment decisions.

Current recommendations state that children and AYAs should be involved in medical decisions when they are able to do so and would like the choice to participate (Conway et al., 2006; Fern et al., 2013; Hinds et al., 2001; Joffe et al., 2006; Masera et al., 1997; Spinetta et al., 2003; United Nations, 1989; Zwaanswijk et al., 2007). Guidelines about how and when to involve children and adolescents in TDM, however, are mostly clinical or editorial, with little empirical support (Unguru, Sill, & Kamani, 2010).

One challenge AYAs face during their treatment is determining the degree of involvement they prefer when making treatment decisions. Younger AYAs live in a world between childhood and adulthood. Few studies of TDM have solely focused on this age group. Barakat and colleagues (2014) described how AYAs and parents make decisions about Phase III clinical trials and reported that barriers to AYAs' involvement in decision making included acute stress. Increased maturity (developmental, cognitive or emotional) was associated with increased involvement. Pearce et al. (2016) reported having autonomy in decision making was important to the AYA with cancer and found that support from family, peers and health professionals was critical to decision making.

Investigators report that children and adolescents with cancer frequently do not participate in TDM to their level of preference and comfort (Unguru, 2011; Zwaanswijk et al., 2007). They vary in their preference for involvement in TDM, from no involvement at one end of the spectrum, to making most if not all of the decisions at the other (Broome, Richards, & Hall, 2001; Coyne & Gallagher, 2011; Knopf, Hornung, Slap, DeVellis, & Britto, 2008; Snethen et al., 2006). Kelly et al. (2017) reported that most (80%) of the 9-17 year olds they interviewed did not want to or could not make treatment decisions. Rather, these findings suggest they wanted information about their cancer and treatment, to be part of discussions, and to have a say and be asked what they think.

Early in the cancer treatment, parents often take control of critical decision making, but as adolescents become experienced with cancer, they often want or demand to participate in TDM (Miller, 2009; Miller, Reynolds, & Nelson, 2008), including end-of-life decisions (Miller

& Harris, 2012). Studies of shared decision making in children and adolescents suggest they differentiate between major decisions, which they believe are not really decisions at all, and minor decisions, decisions about how care is delivered, that they want to participate in. Adolescents are often dissatisfied with their role in TDM and feel a sense of powerlessness (Coyne et al., 2014).

The participation of children, adolescents and young adults in TDM is complex because of the triangular interactions between the AYA (patient), healthcare provider (HCP) and parents. Parents assume an executive or gatekeeper role, deciding what the child should and should not be told to protect him/her from material deemed to be too upsetting (Young, Dixon-Woods, Windridge, & Heney, 2003). HCPs may under or overestimate the child's ability to understand complex issues such as treatment, research and consent (Coyne & Gallagher, 2011). The degree of involvement by children in their own TDM is determined by the viewpoints of the parents and HCPs, not the child's ability (Coyne, 2008; Martenson & Fagerskiold, 2008), demonstrating an imbalance of power between them and their parents and HCPs (Scherer, 1991; Susman, Dorn, & Fletcher, 1992).

Young people will defer to their parents for multiple reasons, including wishing to avoid tension or conflict with parents, recognizing parental judgment, experience and knowledge, or fear of losing parental emotional, physical or financial support. When AYAs are competent to make treatment decisions, they still want support and prefer shared decision making with family and clinicians (Coyne & Gallagher, 2011; Zwaanswijk et al., 2007). When adolescents' preference is for TDM by a parent or HCP it may be due to the complexity of the issues (Knopf et al., 2008).

Despite the progress that has been made in the emerging field of cancer-related decision making, there are still major gaps in knowledge about the perspectives of the AYA. These include gaps in our understanding of the AYA's voice and preferences for TDM, the involvement of AYAs in the decision making process, and factors that contribute to or impede this process. Demonstration of outcomes of TDM participation are lacking, especially related to congruence or lack of congruence between desired and actual TDM roles. Most studies of decision making focus on cancer research participation and end-of-life decisions; many are cross-sectional or retrospective, or focused on the parents' or clinician's perspective, rather than the AYA's. Research has primarily focused on children or adolescents and there is much to learn about AYA patients with cancer, especially in terms of their input regarding treatment choices and outcomes such as adherence to treatment (Buchanan, Block, Smith, & Tai, 2014). Furthermore, few studies address how AYAs approach TDM or interact with their family to make treatment decisions (Coyne et al., 2014).

The purpose of this qualitative study was to explore, from the perspective of younger AYAs with cancer, their involvement in cancer TDM. Specifically, we sought to address the following three aims: 1) describe the AYAs' preference for and actual involvement in their cancer TDM, including factors that influence TDM about their cancer, 2) explore the types of treatment and non-treatment decisions in which AYAs do and do not want to be involved, and 3) examine how AYAs interact with family, especially parents, in making treatment decisions. The knowledge gained through this study will help clinicians and researchers better understand the TDM process in AYAs with cancer and their preferred level of participation. These results could, in the long term, empower clinicians to sensitively assist AYAs to participate in TDM and help them develop appropriate interventions. These interventions may also improve the AYA's relationship with HCPs and improve both their and their family's well-being.

Methods

Study Design

In this study, we used focused ethnography in the sociological tradition, based on a symbolic interaction framework, including interviews and informal participant observation, to explore AYAs' experiences with TDM related to their cancer therapy. Ethnography has been described as the study of social interactions, society and culture through direct experience in social situations (Atkinson, Coffey, Delamont, Lofland, & Lofland, 2001; Gubrium & Holstein, 1999). The goal of ethnography is to develop an intimate understanding of how people see their world (Hammersley, 1998). Ethnography provides a rich data source from the group, culture and community of the participants in the study.

Focused ethnography typically centers on studying shared cultural and social phenomena, rather than cultural groups, as in the classic anthropological tradition (Wall, 2015). Culture can be described as the patterns of behavior, customs, ideas, beliefs and knowledge of a group of people (Roper & Shapira, 2000). Focused ethnography is problem-focused and context-specific, with a limited number of participants. In comparison to conventional ethnography, focused ethnography usually takes place over a short interval, but produces a large amount of data that requires intensive analysis (Knoblauch, 2005).

Focused ethnography was well suited to understand the human experiences of AYAs with cancer and their level of involvement in the TDM process (Prus, 1996). Listening to the AYAs speak of their experiences allowed us to interpret their everyday life experience, and understand their world. The first author entered their world by spending time interviewing the participants and observing them informally in the clinic or hospital setting to understand their experiences, perspectives and interactions.

The theory of symbolic interactionism informs ethnography in the sociologic tradition. In symbolic interactionism, a person's sense of meaning is interpreted through social interactions, communication and understanding of verbal and non-verbal symbols (Blumer, 1969). People form meanings through interactions with others, and their own recurrent self-reflections (Licqurish & Seibold, 2011). The meaning of situations and relationships strongly influences decisions and actions (Blumer, 1969). Bronfenbrenner's (1979) Bioecological Theory of Human Development and Bandura's (1977) Self- Efficacy Theory served as sensitizing theories for this exploration of AYA's involvement in TDM in the context of being treated for cancer.

Study Participants

The purposive sampling plan included AYAs receiving treatment for cancer within one year of diagnosis at two quaternary pediatric oncology programs in the western United States. Inclusion criteria for the purposive sample were AYAs who: 1) were between the ages of 15 and 25 at the time of the interview, 2) were receiving initial active treatment for cancer 3) had been diagnosed with cancer between one month and one year prior to the interview, 4) had experienced a major cancer treatment decision including but not limited to: whether to enroll in a clinical trial, a surgical treatment decision or other treatment decision such as radiation therapy versus surgery, 5) were able to speak English, and 6) provided informed consent or assent to participate. AYAs were excluded from participating if they experienced a disease relapse or were receiving end-of-life care, self-identified as non-English speaking, or were not physically or cognitively able to participate in an interview.

Members of the treatment team approached potentially eligible AYAs and/or their parents about their willingness to participate in the study. The first author then met with the eligible AYA and his/her parent(s) as appropriate to review the study in more detail. Written informed consent was obtained from the parent or AYA and assent from the AYA when necessary. A total of 17 AYAs were approached for study participation. One male declined to participate because he did not want to talk. Participants were given a gift card worth $25 per interview as compensation for their time and participation in the study. We obtained institutional review board approval at each treatment center.

Demographic Questionnaire and Interviews

The first author collected all data. She is a pediatric oncology nurse who has experience with conducting interviews in this population. After consent was obtained, an 11 item demographic questionnaire was developed that included questions about age, level of education, ethnicity, race, marital status, household members, employment status and if they were currently in school was completed with the AYA. Participants were screened for current symptoms, and if present they had the choice to reschedule the interview.

Interviews were guided by open-ended and semi-structured questions that explored the AYA’s experience with treatment decision-making, the nature of their involvement in the decision, what influenced this decision, their current level of involvement in making treatment decisions and how their cancer or treatment affected decisions that came up in their daily lives. The interview guide (available upon request) was informed by a pilot study of four cancer survivors (not included in the current study) who had been diagnosed with cancer as an AYA. Members of an AYA Advisory Council at one of the participating centers reviewed the interview guide and provided feedback.

Second interviews were conducted with 15 of the16 participants to expand upon and verify preliminary findings. The guide for each participant's second interview was developed after the first interview to ask clarifying questions, explore further questions more deeply and to conduct member checking of preliminary findings. The first author also conducted formal member checking toward the end of data collection with six of the participants.

Interviews were conducted in a private setting on either the outpatient or inpatient unit. Most interviews were conducted privately, except for 12 that were conducted in the presence of a parent. The interviews were audio-recorded with the AYA's permission.

The interview guide consisted initially of broad questions about when participants were diagnosed with cancer. Early in the interview, questions focused on a recent major treatment decision, how they participated in the decision and what influenced their role in decision-making. Other questions centered on everyday life, including decisions AYAs made about how to incorporate considerations related to their cancer into their school and social life. Probes were used to elicit additional detail related to specific questions, for example, "can you tell me more about that," or "give me an example." The participants seemed interested in and comfortable with the questions asked. If they were not sure of what was being asked they asked for clarification or indicated through their non-verbal expressions that they did not understand the question.

Data Analysis

The audio-recorded interviews were professionally transcribed verbatim and reviewed for accuracy by the first author. Field notes were taken by the first author following each interview and transcribed. The transcripts were reviewed multiple times and analysis was conducted iteratively throughout and after data collection.

Coding was performed on the transcripts, focusing on the feelings, actions, decisions and interactions of participants (Prus, 1996). Transcripts were coded and codes combined into categories. To ensure rigor, findings were discussed to consensus with members of the research team during the analysis period, including semi-weekly meetings with the senior author during periods of active analysis. Reflexive notes were written into field notes by the first author. By consciously being reflexive, we tried to be aware of biases and our own experiences and how they might shape our thoughts, interpretations and conclusions about the activities witnessed during data collection and analysis (Hammersley & Atkinson, 1995). ATLAS-ti (Meadows & Dodendorf, 1999) was the software used as a platform for data analysis and organization.

Findings

Patient Characteristics

A total of 16 AYAs participated in the study (Table 1).

Table 1
Demographic and Clinical Characteristics of the 16 Study Participants

Characteristic	
Mean age in years at 1st interview (range)	17.3 (15-20)
Gender (n, %)	
Male	9 (56)
Female	6 (38)
Non-binary	1 (6)
Race (n, %)	
White	6 (37.5)
Hispanic	2 (12.5)
Asian	4 (25)
Multiracial	4 (25)
Cancer Diagnosis (n, %)	
Leukemia	7 (44)
Lymphoma	3 (19)
Bone Tumor	6 (37)
Mean Months from Diagnosis to 1st interview (range)	5.4 (1.4-9.7)
Treatment Decision (n, %)	
Clinical Trial enrollment	10 (63)
Radiation Therapy vs Surgery	1 (6)
Surgical Options	5 (31)

Fifteen AYAs were interviewed twice and one was interviewed once for a total of 31 interviews. Their age at the time of cancer diagnosis ranged from 14.7 - 20 years old. The average age at the time of the first interview was 17.3 years (range 15.2-20.6 years). Six participants were White, four were Asian/Pacific Islander, four were multiracial, and two were Hispanic. The diagnoses included acute lymphoblastic leukemia (n=6), acute myeloblastic leukemia (n=1), lymphomas (n=3), osteosarcoma (n=5), and Ewing sarcoma (n=1).

For ten participants, a major decision they faced was whether to participate in a clinical trial either at diagnosis (n=9) or later in their treatment (n=1). For five participants, the major decision involved choosing between surgical options, and, for one participant, a major treatment decision was choosing between surgery or radiation therapy.

The average time from diagnosis to the time of the first interview was 5.4 months (range 1.4 - 9.7 months). The second interview took place on average 26 days after the first interview (range 1-74 days). The interviews lasted on average 64 minutes (range 30-97 minutes) for the first interview and 60 minutes for the second interview (range 37-97 minutes). Only one AYA declined to participate in the study when asked.

Dimensions of Decision making

We identified three dimensions of decision making for AYAs' involvement in cancer TDM: 1) becoming experienced with cancer, 2) import of the decision, and 3) decision making roles (Table 2).

Table 2
Dimensions of Treatment Decision Making

Dimension	Definition
Becoming Experienced With Cancer	Relates to the AYAs' experience over time. At diagnosis they are naive and inexperienced. They are new to the cancer experience. Over time they gain experience with decision-making and learn about their disease and treatment.
Import of Decision	Relates to how the AYA determines what decisions are more important than others. This may relate to the consequences or potential outcomes of the decision. It also relates to how easy or hard the decision was to make.
Decision Making Roles	Relates to the type of decision making role that AYAs assume in various treatment decisions or care preferences. This may include an active, collaborative or passive role.

Figure 1 illustrates the dimensions as axes in three-dimensional planes. Here, we dissect this complex web of interactions in a way that allows each of these three dimensions to be illuminated singly and to be understood before generalizations and potential interventions can be considered.

Figure 1

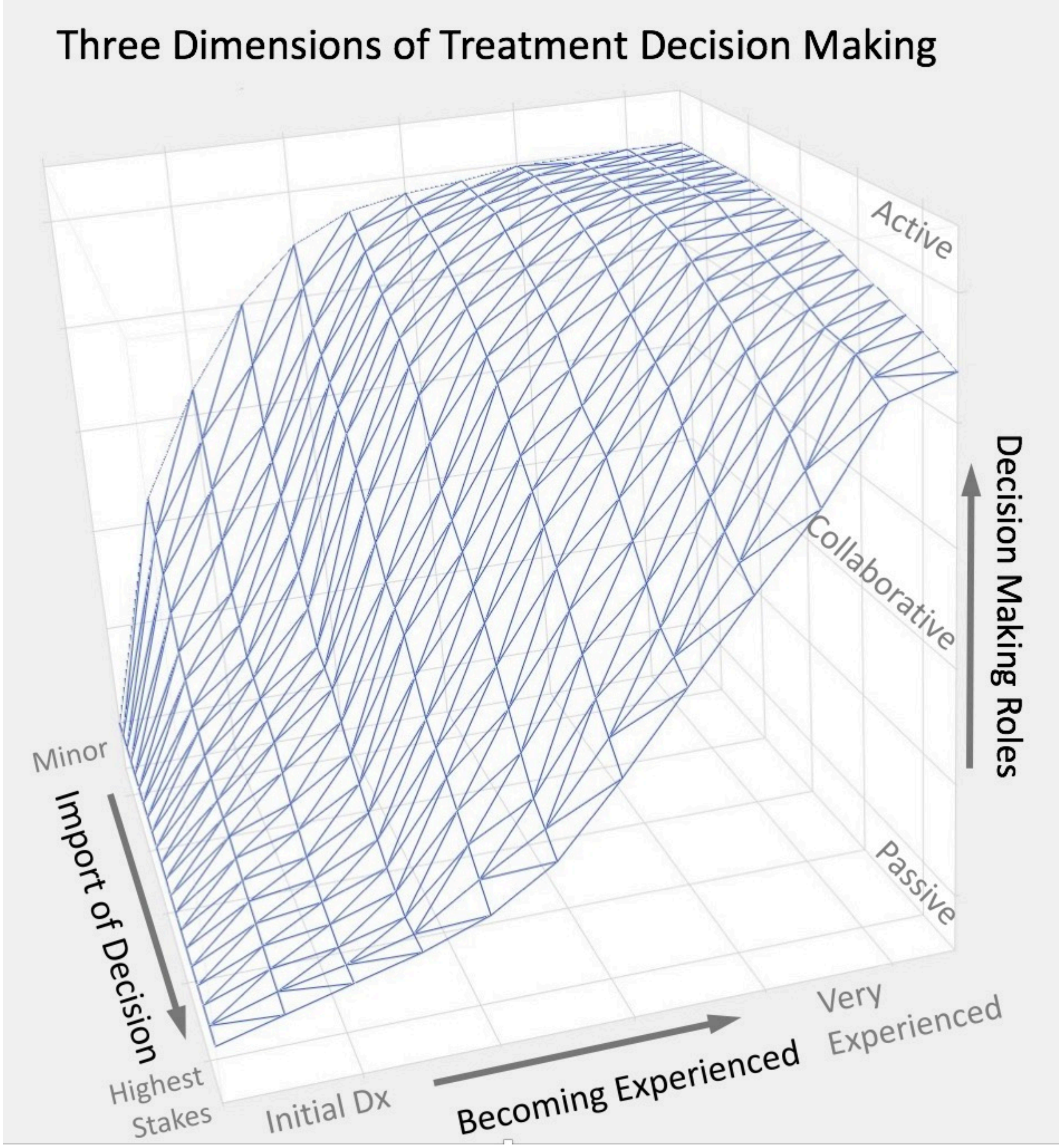

Figure 1. Dimensionality is portrayed in three different axes.

Dimension 1: Becoming Experienced with Cancer

Receiving the diagnosis. Shortly after diagnosis, AYAs often described themselves as sad, angry, frightened, in shock, and unable to retain information. It felt “surreal” and they thought they might die. One AYA stated,

> …and you’re so just trying to wrap your head around the fact that you are sick and that you have to do this. It’s kind of like, I can’t make a decision. As a 15-year-old, I was like, I can’t make a decision right now.

Initially, events were often happening quickly, such as diagnostic procedures and decisions such as whether or not to enroll in a clinical trial. Over time, and at their own pace, the AYAs became experienced with cancer and its treatment. Cancer evolved from an amorphous threat to something of more substance that they could understand and interact with. One AYA recounted her experience as follows:

> The more you get into it, the more it becomes real and the more it like is actually what’s happening. Like once you finally understand that this is something you have to do, then over time you’ll get more and more - you’ll get more comfortable ‘cause you’ll know what happens, like how to go about doing things and stuff.

*Seeking informat*ion. Participants became actively engaged in their own care. They often sought information and gained knowledge about their condition and options for treatment. They asked family, but rarely friends, for their advice or opinion, and searched the internet to better understand their condition and treatment. More than half of the AYAs (9/16) mentioned they used the internet to look up information about their disease and/or its treatment. One participant described her need for information in the following way: “They tell you not to Google things but

I don’t like that advice because then I have no idea what I’m walking into, right? So, I did a lot of research.”

Another AYA described how she used the internet for information: “I think what someone recommended was ‘don’t go online and search for these things ‘cause you’re only going to scare yourself.’ But I think sometimes I just did anyway. It was mostly kind of out of curiosity.”

Over time, they understood more about their condition and became more comfortable with their understanding of cancer. A participant said:

> Because now it’s like I kind of know everything. I don’t know everything, but I know a lot more. When they say stuff, I can think about it and connect it with other things, and so I don't have to look up every term that they say now. In the beginning, I was so confused the entire time they were talking.

Information was important in making decisions: “I’d rather go on too much information that has the potential to be scary than walking into a situation not knowing what I’m getting into at all. Because then I’m dependent on their explanation.”

Once satisfied with the amount of information, the need for more information decreased over time. As one AYA remembered,

> Because in the beginning I had less questions, and then I peaked in questions and I had to do lots of Googling and reading of like PubMed and stuff, and now I have less questions.

Wanting to know about the treatment options and the time spent researching these options was also related to the importance of the decision. One AYA described how it was important to “Do your research so that you know what you’re getting into… ‘cause I don’t think you can make informed decisions if you don't know what is going on." Making the right decision was important.

Living with cancer. Participants learned about their care through observing their HCPs as they delivered care to them and other patients, and by listening to discussions during bedside rounds or clinic visits. They learned a new language. Being part of discussions and listening even helped them to be less scared. Most participants asked their HCPs questions directed at the plan and side effects of treatment, usually focused on the effects in the immediate future.

In contrast to wanting information and being part of discussions, another participant described how she wanted information on a "need to know" basis only. She advocated for herself the right to self-regulate, so if the discussion became too much for her she would be able to remove herself without having to explain. She describes, "sometimes it's a little hard to (say) 'get out', 'cause I don't want to be mean or anything, be like 'I don't want to hear this.' But I'm getting better at standing up for myself."

For some who were less engaged early on, they became more engaged over time. They participated more in discussions and asked questions, when they had them. Others commented that decision making increased over time because they had more information and became more knowledgeable.

Participants became experienced at determining their care preferences. One AYA, for example, explained how with experience and trying different options for accessing his subcutaneous injection port, he found what worked best.

> At one point, I was using that [topical anesthetic cream] and the cold spray, but then I stopped that because, for some reason. I don't know. And then I used ice once and then - yeah, but then now, I just decided that I'm just going to use the cream.

Becoming experienced also included learning how to identify and respond to illness symptoms and manage their care. The AYAs often learned the common side effects of their treatment and would notify the team or their parents if they were experiencing them. One 16-year-old described how she managed her symptoms at home:

> If I didn't feel well, I would try to see if the medication is working, see if they try to make me feel better. But if I feel like there’s definitely something wrong, then I immediately call the oncologist….and like one case was that I wasn't feeling very well, kept throwing up. I don’t think I can take my antibiotic or take any more food in ‘cause I feel like I will vomit it back up.

Developing an understanding of roles of healthcare team members. As they became more knowledgeable about their disease and treatment and learned the language of their illness, participants learned how to communicate with team members: “Cause like I didn’t know how to explain stuff to doctors and how I feel about it at first.”

They also became discriminating, realizing that different physicians or team members have different expertise. AYAs therefore learned whom to talk with about different issues or if they had specific questions. One participant described how, before making the decision about which surgical procedure to undergo, it was important to get the surgeon’s opinion and determine his experience with the different surgical options: “Because my decision was mainly influenced by what my surgeon felt most comfortable doing and my personal research on what I wanted.”

Dimension 2: Import of Decision

Distinguishing different types of decisions. AYAs described types of decisions, and how meaningful they were in their treatment, as easy versus hard, big versus little, and major versus minor, and framed them in terms of consequences or impact on themselves and their future. Decisions ranged from supportive care decisions, sometimes regarded as care preferences and considered to be of lesser consequence, to more momentous, life-threatening decisions of greater consequence—such as whether or not to have surgery, or participate in a clinical trial—that involved others' assistance or input. AYAs could distinguish the import of different types of decisions and compare them based on the magnitude or type of decision. When they compared a clinical trial or surgical decision to supportive care decisions, the former were often described in terms of being life-altering or threatening and longer term. One AYA compared deciding on a surgical option to that for a supportive care decision in the following way:

> Well this [surgery for osteosarcoma] is just going to last much longer. I'll have this my whole life, whereas anti-nausea medication is specifically for this, like a specific connection. Like once this [nausea] is gone, that is going to be gone, but this [surgery for leg] will continue.

Another AYA agreed with this distinction:

> I think for something like the clinical thing [trial], it's just something on a much larger scope. Like this is the treatment that I'll be going down for three years. You know, I want to be able to like weigh the options myself. But then for something like nausea, it is maybe an afternoon of uncomfortableness and then the next day it just kind of repeats. But like I don't think you really get the same chance with a clinical trial. The clinical trial, I think it is a much bigger decision.

A 19-year-old commented about the distinction between decisions of different import in the following way.

> But for example, with the port, if I want to count to three, then I suddenly decide I don't want to count to three, that's fine. With the surgery, if I'm like I want a reverse and then a month later I'm like, "Oops, so can I get the other version instead?" that's not going to work. So, they're not like the same kind of choices.

In contrast, several AYAs did not view clinical trial enrollment as a major decision. Sometimes, making these decisions involved trusting providers and involving others. AYAs explained how there were not always a lot of decisions to be made during their treatment. Once you start cancer treatment, you follow the preset treatment plan. For them, most decisions were not really big decisions.

> I haven't actually had any big decisions to make since the decision [surgery versus radiation] of that shoulder thing. It's kind of like there aren't as many places where I can make decisions, simply because its just that's how it goes, you know?

Some decisions, even if major, have only one obvious choice in the view of the AYA, so are sometimes described by them as a 'no-brainer.' For example, for one 15-year-old, the decision to undergo fertility preservation was easy and her choice.

Two participants described decisions they did not want to be involved in making. One AYA described decisions related to stem-cell transplant and the other described decisions about advance directives that he had been given information about. These decisions about what might happen in the future made the AYAs uncomfortable.

Minor decisions. Minor decisions revolved around preferences for care or symptom management and did not involve long-term consequences. Early on and throughout their treatment, AYAs were involved in making supportive care type decisions related to their cancer treatment. These care preferences included their involvement in symptom management (i.e.

nausea, pain, and mucositis), how to access their port, nasogastric or gastrostomy tube insertion, and procedure-related decisions (i.e. bone marrow biopsy or lumbar puncture). They became engaged in participating in these types of decisions relatively soon in their cancer experience: classifying them as minor or little. AYAs, for instance, described how they partnered with the nurse practitioner to determine their best antiemetic regimen during their chemotherapy infusions, or with the anesthesiologist to determine the best type of anesthesia for a procedure.

For some of their care it did not always matter if they were asked their opinion. The decisions were simple. It was more important that the HCP "get it right." For instance, for procedures like accessing their port or starting an IV, they wanted the nurse to do whatever he or she needed to do to be successful.

Intermediate decisions. These were decisions that were not minor, were important, but not necessarily life threatening, such as fertility preservation, self-management decisions, or the decision to electively admit oneself to the hospital. In the context of day-to-day decisions, one AYA described how she knew when she needed to go to the hospital and made the decision to advocate for admission when necessary:

> A lot of times I choose to be like "I need to go to the ER right now." That's a decision 'cause I usually am the one who like says tapping out, like I need to go to- I need to see it, I need to put myself in the hospital 'cause that's what I need to feel better.

Major decisions. Major decisions were critical, where the consequences will last a lifetime, such as choosing between various limb salvage surgical options or amputation. As described above, AYAs were readily able to distinguish these decisions as being higher stakes, with greater consequences and different from other decisions they participate in.

Dimension 3: Decision-Making Roles

Deciding to fight. Some AYAs described their decision making involvement as a conscious decision or mental mindset to decide to fight, with the goal to beat the cancer, or to "stay strong" for themselves or others. Accepting or addressing the reality and meaning of their diagnosis was an early decision. They made the decision to address their diagnosis and go ahead with treatment. As AYAs became familiar with what to expect, they became reconciled to what they had to do to get through their treatment. One AYA described how she made the decision to stay strong at the time of her diagnosis.

> …that it wasn't going to phase me no matter what, and especially in front of my parents. I was not going to be the one to cry and say "why me?" That was a decision I decided that today, yes, you were told a terrible thing. Today you are going to be strong. Today we're going to say fuck you, cancer, and we're going to say fuck you, cancer, to the very end and even afterwards we're not going to cry and say "why me?" because there's much worst things to happen than to be told you have Hodgkin's lymphoma. You could be told a worse diagnosis. You could also be told that you're going to be dead in a week.

Throughout their care, participants commented on how they were going along with the treatment plan, were going to "stick with it," "carry on" and "see it through." They decided to persevere.

AYAs' decision making roles varied depending on the type of decision and when these decisions occurred during their treatment course. For decisions related to whether to enroll in a clinical trial or other types of treatment choices (i.e. surgical or radiation therapy) for their cancer, most AYAs said they were involved in making the decision, but define this in different ways. Some of their decision making roles can be described in terms of a continuum: active, passive, or collaborative. Supportive care and symptom management decisions were located at the minor end of the continuum, and were typically AYA-led. More momentous decisions, with potential long-term consequences such as limb salvage, were located at the major end of the continuum and required more consultation and consideration. These types of decisions were more collaborative or led by parents or HCPs. Participants were able to distinguish treatment decisions from care preferences.

Active Role (decision made by themself). For surgical decisions, two AYAs with osteogenic sarcoma said they "made the decision." Both participants were almost 18 years old at the time of the decision. As young adults, they were the primary decision maker when it came to their cancer treatment. It was "my choice," "my body" and it was happening to them. They listened to the physician's recommendations, asked questions, weighed the options, researched the topic, and made the best decision for themselves. They accepted this role and responsibility.

Family had a role in supporting them in their healthcare decisions. Their parents assumed the primary supportive role but the AYAs did accept input from HCPs as well. They did not often turn to their friends or extended family for assistance in making treatment decisions but usually kept them informed if the friend was considered to be close. One AYA commented:

> Sometimes it's nice to have input, like the input of the surgeon and the input of my parents and the input of the Internet and the input of other people. But I do think in the end, it's still my decision.

Time was an important modifier for those who were involved in treatment decisions that were not required at the time of diagnosis. For these two participants, who had osteosarcoma and whose surgery did not take place for several months into their treatment they had time to think about and research their surgical options:

> It did give me time to like come to a good decision… but it was enough time that I didn't feel like I was stressing to like learn stuff. Like I didn't feel like I was cramming for a test.

Making these decisions, for the AYA participants, meant taking ownership and actively seeking information from multiple sources, educating themselves and talking to providers, family and sometimes friends. Consequently, they felt comfortable and in charge of these decisions.

Collaborative role (decision made by themselves and the parent(s) and/or their physician(s)). More than half of the AYAs (10/16) made the major treatment decision in collaboration with their parents and/or HCPs. There was a consensus: the AYA, parents and most often HCP participated and agreed on the treatment. When clinical trials were being discussed, parents wanted the AYA to be included in the discussion. In some cases, the physician recommended a certain treatment and the participant went along with the recommendation. There was no obvious relationship between age and the choice of a collaborative or passive role.

Parents encouraged AYA participation in discussions, making decisions about clinical trials and choosing between surgical options. Parents looked out for the AYA's best interests and were their advocates and protectors during their diagnosis and initial treatment. The AYAs accepted and appreciated their parents' involvement. The AYAs trusted their parents and doctors to act in their best interests. One participant said:

> At the time, it was just I don't really know what's going on right now. Like the doctors, they know a lot more than me. I think I just placed my trust in them and kind of did what they say is best for me as well as I can.

The contrast between the previous quote and the next illustrates the spectrum of involvement of the AYA in decision making, especially in the initial phases. One participant described her role and that of others in making decisions about her care:

> When the doctors talked to us, they talked to all three of us, my parents and me, not just my parents. They would include me in the conversation…so all the doctors and myself and my parents decided radiation would be better.

Participants described their overall trust in the team they had during their treatment. They recognized that their physicians have knowledge and experience in dealing with cancer and respected this. They expressed positive feelings about their relationship with their team and they developed close relationships with those with whom they interacted regularly. As young adults, they came to rely on these relationships with physicians during times of TDM. Another participant explained: "I had the freedom to do whatever I thought was best, but I also had other people influencing me and helping me decide which was best." Parents typically maintained an active role in the decision making process: "Even though I'm an adult and I'm in control of what happens, I still go with what my parents tell me on a lot of things. I'll never make a decision without asking other people on this stuff."

Passive role (decision made by parent(s) and/or their physician(s)). For four AYAs, their parents mostly made the decision about their cancer treatment. For this group, treatment decisions related to whether to enroll in a clinical trial at diagnosis. Factors about the disease or illness influenced decisions they were part of making. The AYAs often did not want the responsibility or were too overwhelmed or ill to participate.

> I didn’t really like to hear what was happening. I just didn’t want to face the music. So I didn’t really participate in that much of the talking for a while, just ‘cause I didn’t like to hear what they had to say, I guess.

At the time of diagnosis and during early treatment planning, some participants recalled a sense of urgency. Things happened quickly due to the acuity of their condition and, for the most part, there were no major, or optional, decisions to be made. They were either too ill or overwhelmed to participate in discussions about their treatment and recall their parents either made the treatment decision with the physician or were simply told by the treatment team what needed to happen. A few participants were not present for or did not remember the initial treatment decision being made during the early discussions. They were informed about the plan and accepted it. As one AYA stated: “I trust doctors and I trust my parents too, ‘cause my parents, they would never like make a decision to hurt me even though it may feel like it’s a hard situation.”

Factors Influencing Decision Making Roles

AYAs exerted control over decision making, but also described an interactive relationship between themselves and their HCPs. As one participant explained: “I do like them [HCPs] being direct and I like them talking to me instead of my parents and I like them talking to me like I know what they’re talking about.”

For some, turning 18 was when the conversations about their care were more directed at them. They felt it was their decision to make.

> Beforehand, being 17, I would still be like, “This is my choice, my body. This is happening to me. I want to be able to decide.” But just turning 18, the effect of all the

> doctors and everybody, when I was 17, even though my penny for my thoughts was important, it was still like they would tell my mother.

He went on to elaborate how being treated and talked to like an adult influenced his involvement in decision making: “I guess you could say just being talked to seriously is what made me like, yeah, I want to choose for myself, and this should be about my choice.” This is an example of how the development of meaning in a situation is influenced by interactions with others, and self-reflection.

Occasionally, the AYA’s preference for their care was in conflict with their parents’ preference. Several AYAs for example, chose to manage their symptoms with medical marijuana, which initially caused tension with their parents. One AYA described her conflict with her parent over symptom management.

> Every night before bed, I take a Benadryl, just because it helps me sleep and it makes- sometimes if I wake up in the middle of the night nauseous, that is not fun at all, so I would take one to help that. He [parent] told me, “Don’t take them. You don't need them.” I told him to stick it because I was going to do it anyway. For me, it’s like if he doesn’t want me to take it, then that’s his problem, not mine, because I need it. And I'm one of those people that I don’t take something if I don't need it.

AYAs described how it was important to have a safety net when making decisions or someone checking their decisions to make sure they did not make an unacceptable decision.

> It really depends on what kind of decision it is. I feel like if it’s my body, it’s my decision, full stop, unless it’s something like I’m going to jump into lava so, you know. But on less ridiculous things, it is my opinion that if it’s my body, then it’s my decision on what to do with it.

Another AYA agreed with wanting a backstop to their decisions.

> You're exposed to so many learning opportunities and you're able to make mistakes and have a net underneath you. Because my age, again, and in pediatrics, I get to have a really nice cushy net if I make a bad decision because I'll have people saying that was a - before actually anything happens, to say, "No, that's a bad decision, that's a bad choice."

Being involved in decision making was not always easy. One AYA described his experience with making treatment decisions after his diagnosis: "Well scared like oh-oh. And then like all these – like they're showing me the paper and that's when I'm like these are my big boy decisions here." He went on to elaborate:

> Just nervous because, usually, my mother does all this stuff but now I have to do this stuff from now on and I have to get used to this. So, the first time you're always nervous but then I guess you might start getting used to it and you just treat it as normal.

Overall, participants often felt involved in their decision making because they were informed about the treatment plan, felt listened to, were part of discussions and felt comfortable asking questions or making suggestions. One participant explained what helped her to be involved in making decisions: "My primary doctor. She always thinks that my opinion counts and she always makes it open for me to make any suggestions."

All groups wanted to be included in things that affected them, especially major decisions. Even though the AYA may not have made the final decision, most felt they were involved and had a voice in the decision. One AYA commented how he felt that he had more say over time because he became more knowledgeable and experienced and the team respected him. Over time their involvement in decision making either stayed the same or increased.

Discussion

Although some recent studies have sought to understand AYAs' participation in their care, including their role in TDM (Barakat et al., 2014; Pearce et al., 2016), few studies of cancer TDM have focused specifically on the perspective of the AYA, their experience, or their interactions with family. This study used interpretive focused ethnography to further our understanding of the AYA's involvement in cancer TDM and how decisions are made within the context of family, during the acute phase of treatment. Interviewing AYAs provided a unique opportunity to learn about their involvement in cancer decision making while on therapy. Our findings indicate that decision making by the AYA and their families is a complex, dynamic, social process.

An important finding is that TDM is multidimensional and includes the AYA's experience with cancer, the import of the decision and their decision making roles. Identifying these three important dimensions contributes to an increased understanding of AYA cancer TDM.

During the initial stages of treatment, the AYAs were naïve to cancer. In accordance with previous research by Tenniglo et al. (2017), patients must negotiate a major change in their life circumstances during the initiation of their treatment. The subset of participants who felt that they had no choice but to trust the physician during the initial tumultuous phases of cancer diagnosis and major decision making responded in a manner similar to the initial stage in healthcare relationships of naive trust described by Thorne and Robinson (1988). Day and colleagues (2016) described adolescents' experience at this time as a loss of control and agency. They are overwhelmed, pressured for time and unable to make decisions.

Over time and at different rates, AYAs learn the nuances of their disease and treatment and gain experience with it. Becoming experienced includes learning about what cancer entails.

AYAs wanted and sought varying amounts of information, ranging from wanting only essential information with no details, to seeking information from multiple sources to help them make a surgical decision. They often sought information about their condition and/or treatment from the internet, educated themselves and took responsibility in reporting symptoms or asking questions related to their care. They wanted to know what was going to happen (the plan) and how decisions were going to impact them in their near future, as is also reported in other studies (Ruhe et al., 2016; Stegenga & Ward-Smith, 2008). These findings are consistent with those of other researchers who report that young cancer patients and survivors emphasize information exchange, asking questions, and the accessibility of the healthcare team (Zwaanswijk et al., 2007), and that the AYA's development of trust and rapport was necessary to enable communication and decision making about clinical trial participation (Pearce et al., 2016).

AYAs could distinguish important major cancer treatment decisions from minor supportive care decisions that typically occurred more frequently or daily. In Coyne's (2014) study, children and adolescents made a similar distinction between what they referred to as major and minor decisions. The urgency and seriousness of the AYA's condition influenced their TDM role at the time of diagnosis. Similar to other studies, there was often a sense of urgency and immediacy with little time to think (Broome et al., 2001; Pearce et al., 2016). At diagnosis for instance, depending on the disease, there was urgency to start treatment and for illness reasons, the AYA may not be able to, or chose not to, participate in discussions or decision making.

Importantly, however, most AYAs experienced either a collaborative (10) or passive (4) role in making major treatment decisions and appeared content with this role. Very few were active (2). In the passive group, several participants recalled neither being involved nor present during initial treatment discussions. They were eventually informed about the treatment decision (whether to participate in a clinical trial) but did not recall or have a role in decision making other than they agreed with and went along with the decision. These findings are consistent with studies reporting parents may take control of critical decision making early in the cancer treatment (Miller, 2009; Miller et al., 2008) or where parents and HCPs were clearly the main decision makers (Coyne, 2008; Coyne et al., 2014). Some AYAs' involvement in making treatment decisions evolved over the course of their disease trajectory to become more active. Perhaps it is their experience with cancer that influences their role in TDM. It would be important to explore this further in future research.

A range of AYA decision making roles and degrees of parental involvement in decision making were identified. Decision making roles were examined in the context of the type of decision. For supportive care type decisions, the AYAs were active in making most of these decisions. Sometimes they consulted with their parent(s), but for the most part, they made these decisions independently or in collaboration with a HCP. In general, the participants were more active in making these less consequential decisions about supportive care or "lower" risk type decisions about their care. This finding is consistent with those of Tenniglo et al. (2017), who reported similar findings in patients who were 12-18 years old, and Ruhe et al. (2016), who studied younger children and adolescents, and found that both participated in symptom management related decisions.

The role of family in making major decisions was important to the AYA. This suggests we must interpret recommendations to involve AYAs as much as possible, with caution, because it may not be their preference and could actually contribute to further stress. It may be helpful to foster collaboration between AYAs and their parents. Even though AYAs after age 18 are considered (young) adults, their families are very important in making these decisions so should be encouraged to participate. If AYAs are cared for in adult facilities, where the model is to solely discuss healthcare with the patient, then families may be excluded and the AYAs may not receive the developmentally appropriate support they need.

Degner and Beaton (1987) developed the "Control Preferences Construct," which describes the degree of control that an individual wants in TDM, as located along a continuum of keeping, sharing or giving away control to HCPs. This is a useful framework to conceptualize AYA and parental TDM. We were able to extend Degner's findings to further explain factors, such as age, time since diagnosis, and individual preferences, that influenced the degree of desired control, and how that desire might change over the course of time and experience. We found for decisions that involved treatment options (i.e. surgical decisions) a few older AYAs described themselves as the primary decision maker and accepted this role and responsibility. For AYAs who assumed a more collaborative role with their parents or HCPs, or for other reasons were not able to participate in discussions about cancer treatment decisions, parents included or attempted to include them in these discussions related to cancer TDM. A few participants assumed a more passive role at diagnosis due to stress or illness. This finding is similar to that of Barakat et al., (2014), who reported AYAs' clinical trial involvement was limited by acute stress/distress, physical illness and reduced health-related quality of life. The findings from this study extend the findings from a study by Kelly et al. (2017) that showed that children and adolescents' involvement in treatment discussions were influenced by what was happening to the child at the time, such as their clinical situation.

Some AYAs prefer that their parents make an important decision. This is not uncommon during the early phases of the disease; however, as they progress through the cancer experience, most AYAs naturally start taking more control over decisions. If they do not make this progression, there might be developmental issues that should be explored. This might be due to lack of knowledge or support, a cognitive inability or a timid personality. If there is a remediable deficiency, this should be addressed, but if none is found, their preferences should be respected. Forcing their participation or making them feel inadequate can generate distress. Also, it is possible that adherence and other outcomes may be optimized if there is congruence between their preferred type of participation and their actual participation in the TDM process.

The timing of the decision might have an effect on the AYA's decision making experience and role. The experience of decision making for those who considered participation in a clinical trial was somewhat different compared to those who were involved in making a surgical decision. For most participants, the need to consider whether to enroll in research trials occurred almost immediately after diagnosis. In contrast, the actual treatment decisions, such as surgical or radiation therapy, did not occur for several months after starting treatment, allowing time to consider and explore the options.

This study contributes to our perception of treatment decision making as something that evolves over the course of the AYA's cancer disease trajectory. The progress the AYA make along each dimension may be independent of each other, or, more likely they may interact as the AYA develops experience with their cancer. Experience allows the AYA to participate and become engaged in decision making about their cancer treatment. AYAs were able to distinguish the dimension of the "import of the decision" very readily and early on. They articulated and openly discussed a range of decisions from those that were of lesser import, such as supportive type care decisions about symptom management, through to life changing decisions about their cancer treatment, such as deciding on a surgical option or whether to enroll in a clinical trial. The dimension of “decision making roles” varies depending on the type of decision and where the AYA is on the “becoming experienced with cancer” dimension.

Many AYAs were involved in important discussions and decisions about their care. These experiences may facilitate decisional confidence and a more active role in subsequent decision making. Taking the lead in day-to-day decisions about supportive care or symptom management might improve long-term adherence with medical management. The practice they experience in making healthcare decisions, the positive feedback and acknowledgement of their importance in the process may lead the AYA to commit to increased adherence.

Several AYAs recounted experiences of conflict with the parent about their symptom management. These situations occurred, for instance, when the AYA was using marijuana for symptom management and the parent believed this was a bad, illegal or immoral thing to do. These families seemed to have developed, an uneasy truce where the parent continued to disapprove, but the AYA continued to use the substance in question. The discordance between parent and AYA leads to negotiation of the AYA’s role in TDM and emphasizes how decision making is a social process, highlighting the complicated dynamics of the family. The topic of this conflict and negotiation may be important for further exploration.

The three dimensions of treatment decision making can be considered as the three axes (x, y, and z) in a three dimensional graph (see figure 1). A specific AYA cannot be considered as a single point on the graph, but as projected on the three-dimensional surface. This understanding may display the typical trajectory of AYA cancer patients. When they are newly diagnosed most are naïve and tend to be passive. After gaining some experience, they assume an active role with minor decisions but are still relatively passive or collaborative with major decisions. Some AYAs, especially those with complicated illness trajectories, may reach a point through their experiences where they are actively involved in important decisions such as choosing end-of-life care or participation in a Phase I trial. Visualizing where the AYA is on this topographical graph may help care givers and AYAs understand their position in the TDM continuum and could be an important tool for HCPs and AYAs. Further studies could help validate this potential model and determine how it interacts with social processes affecting the AYA, family, the healthcare team and cancer treatment, and variables such as age, gender, prognosis, phase in treatment and, information needs and desire for information.

This study used ethnography in the sociology tradition based on a symbolic interactionism framework (Polit & Beck, 2004). In-depth interviews focused on revealing the meaning of decision-making for the AYA. Understanding the meaning was the essence of understanding the AYA's behavior. As young people beginning to take charge of their own lives and health, the meaning of making cancer-related decisions was intimately tied to their development, both as AYAs, and as patients being treated for a potentially life-threatening illness. The meaning of decision making involvement was influenced by their experience, ranged from active, collaborative or passive, the import of the decision and type of decision. At this critical time in their care, meanings were influenced by interacting with parents and HCPs, and for many leading them to become more active over time, and to determine how involved they wanted to be as time went on.

Study Limitations

This study had several limitations that could have influenced the findings. AYAs may have been wary about sharing negative information about the TDM experience and therefore offer socially acceptable responses, particularly as it relates to communication and trust in the treatment team. To mitigate this, the first author was supportive and accepting of their responses.

It is unknown if the presence of parents at some of the interviews affected the AYA's responses. Brief interruptions during some of the interviews, by the nurses to provide care also may have influenced their responses. Only AYA views were elicited, so alternate perspectives of AYA TDM from parents or HCP were not included in the analyses. Although the sample was somewhat diverse, there is a need for further research with diverse ethnic and racial samples, such as including African American and Native American participants.

Another limitation was the viewpoint of the researchers. During study recruitment, the first author was employed part-time as a Clinical Nurse Specialist at one of the institutions where the study took place. She was not involved in the clinical care of the participants, but this role did give her "insider status" with knowledge of their clinical status, which may have introduced bias in analyzing the data. To address this, the team made a point of discussing her involvement and reached consensus on important findings. Finally, this study was conducted at two geographically close oncology programs. It is possible that approaches to involving AYAs in TDM may vary by geographic region.

Implications for Practice and Research

The findings from our study suggest that experience, import of the decision, and decision making roles are dimensions that impact the AYA's involvement in decision making and may change over time and depending on the decision. Healthcare providers should assess and consider where the AYA is on these three dimensions when decisions are being made. Their approach to the AYA and their care should be tailored to where the AYA is on these three dimensions.

Our study findings also highlight the important role of parents in decision making and the relationship with HCPs throughout the continuum of care. This message may be especially important for adult focused HCP's, where incorporating family into discussions with a legally competent young adult may not be routine. Partnering with the AYA, and also the parents, is critical to determining their role in their child's cancer decision making and how best to facilitate this. This is an opportunity for HCPs to promote quality patient and family-centered care.

Although various professional groups have endorsed position statements and recommendations for inclusion of AYAs in TDM, these guidelines have not been translated into practical recommendations. To "operationalize" these recommendations, hospital policies and standards of practice need to be developed that are tailored for the different developmental levels of patients in the AYA population.

Additional research focusing on how these three dimensions interact is warranted. Understanding the roles of the AYAs, parents and HCPs, and their perceptions surrounding AYA decision making would be useful for designing interventions. Therapeutic approaches tailored to the individual needs of the AYA can encourage optimal participation and eventually improve psychological and treatment outcomes. It is also necessary to examine decision making over time, in longitudinal studies, to determine if there are changes in AYAs' decision making, and whether their participation in TDM correlates with long-term outcomes. It would be useful to investigate whether or not the use of decision aids developed for the AYA are of benefit in assessing their preferences for decision making. Understanding how to engage AYAs in different types of decision making and self-management decisions related to their care is another area worthy of investigation as they ultimately prepare to transition to an independent adult cancer survivor.

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Chapter Four

My Cancer Normal: How Adolescents and Young Adults Manage Their Unpredictable Lives With Cancer

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Abstract

Purpose: Adolescents and young adults (AYAs) with cancer are at risk for psychological stress and poorer treatment outcomes compared to younger and older peers. The study was conducted to better understand treatment decision-making experiences of AYAs. This paper reports how cancer affects decisions that come up in their daily lives.

Design and Methods: Focused ethnography within the sociologic tradition informed by the framework of symbolic interactionism. Semi-structured interviews and informal participant observation took place at two quaternary pediatric oncology programs.

Results: Thirty-one interviews conducted with 16 AYAs between the ages of 15 and 20 years. Categories identified were 1) not being able to do what they used to do, 2) changing interpersonal relationships, and 3) living with uncertainty. Participants described spending more time with family who provided strength, support and advocacy. They described various strategies for dealing with cancer, and how they decided which activities to participate in, or avoid. They sometimes felt like a burden to others and missed out on normal activities, including school and socializing. Social media helped them stay connected with friends.

Conclusions: AYAs exhibited resilience and adapted to manage the impact of cancer on their lives. Research should focus on developing and implementing interventions to enable AYAs to feel less isolated and facilitate their adjustment to their new “cancer normal.”

Practice Implications: Provide support, give AYAs as much control as possible and encourage them to participate in as many of the things they used to do before. This should facilitate feelings of control and self-efficacy.

Key words: adolescent and young adult, cancer, treatment decision making

Background

The National Comprehensive Cancer Network (NCCN) guidelines highlighting the unique needs of adolescents and young adults (AYA) for oncology care (Coccia et al., 2012; Coccia et al., 2014), and their guidelines for patients (National Comprehensive Cancer Network, 2017) provide information on how both physical and psychosocial issues are an important aspect of AYA care. Over the past 10-15 years, there has been substantial recognition of the special concerns of adolescents and young adults (AYA) with cancer, defined as young people aged 15-39 years old. These concerns have been the basis of a proliferation of research and recognition by clinicians, researchers and organizations. Researchers at the basic, translational and clinical levels highlight the needs of the AYA population to a much greater extent than ever before.

When individuals are diagnosed with cancer, it is a shock to their perception of their invulnerability and threatens their self-esteem. They often see themselves in comparison to others, and identify compromises in their quality of life. Cancer therapies are notable for causing changes in psychological status and physical appearance, which may be irreversible (i.e. amputation). Even after the cancer is cured there are long-term sequelae that include delay or nonattainment of education and career goals and long-term health complications (Wong et al., 2017; Zebrack & Isaacson, 2012). Cancer is even further complicated when it occurs in an adolescent or young adult who is negotiating the transition between the child world and the adult world at the physical, psychological, financial, educational and emotional levels. The normal developmental milestones they should be attaining may be delayed or, in some cases, forfeited (Barr & Bleyer, 2017). The developmental milestones that are necessary to become an independent adult include the development of resilience and self-sufficiency, both of which are severely impacted by the cancer experience and enforced or increased dependence on the family

(Institute of Medicine, 2014).

Studies of cancer survivors show that most are well adjusted (Bellizzi et al., 2012; Kazak et al., 2010). However, there are reports that up to 44% of AYA survivors of cancer have post-traumatic stress symptoms (Kwak et al., 2013). Belizzi and colleagues (2012) found in their study of AYA cancer survivors that 69% reported negative financial impact, and reported negative impact on their appearance (62%), control of their lives (47%), work plans (35%), and their relationship with their spouse/significant other (25%). Compounding these problems, existing supportive care services are generally inadequate for AYAs with cancer (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Hall et al., 2012; Keegan et al., 2012; Zebrack, 2009).

There are gaps in our understanding of how cancer and its therapies affect the development of the AYA physically, emotionally and psychologically. This time period has many demands for development, including maintaining activities, developing independence, developing a positive attitude, developing school or workforce skills and maintaining or developing current and new relationships (Institute of Medicine, 2014; Zebrack & Isaacson, 2012). Few studies have focused on the impact of cancer on all of these areas of development and how the healthcare system can improve the prognosis of these patients and their families.

This analysis is from an ethnographic study with the overall goal of understanding the experiences the of AYAs' involvement in cancer treatment decision making. Here, we report findings on how cancer and treatment affect decisions that come up in their daily lives, and how cancer related decisions impact their lifestyle.

Methods

We used focused ethnography in the sociologic tradition, informed by symbolic interaction. Bronfenbrenner's Bioecological Theory of Human Development (Bronfenbrenner, 1979) and Bandura's Self-Efficacy Theory (Bandura, 1977) served as sensitizing theories for this study. AYAs who were currently receiving treatment for cancer and within one year of their diagnosis were purposefully sampled from the population of two quaternary pediatric oncology programs in the Western USA. Both participating centers provided institutional review board approval for the study.

Inclusion criteria for the purposive sample were AYAs who: 1) were between the ages of 15 and 25 at the time of the interview, 2) were receiving active treatment for cancer 3) had been diagnosed with cancer between one month and one year prior to the interview, 4) had experienced a major cancer treatment decision including but not limited to: whether to enroll in a clinical trial, a surgical treatment decision or other treatment decision such as radiation therapy versus surgery, 5) were able to speak English, and 6) provided informed consent or assent to participate. Exclusion criteria included; experiencing relapsing disease, receiving end-of-life care, non-English speaking, or unable physically or mentally to participate in the interview. Seventeen AYAs were offered study participation. A single male declined to participate because he was not interested in talking.

Members of the AYA's treatment team approached potential participants and/or their parents to determine whether they would be eligible and willing to participate. Subsequently, the AYA and/or parents reviewed the study information in more detail with the first author. The AYA provided written, informed consent or, if appropriate, the parent provided consent with assent from the AYA.

Prior to beginning the interview participants completed an 11 item demographic questionnaire (developed for this study) with the first author that included questions about age, level of education, ethnicity, race, marital status, household members, employment status and if they were currently in school. If participants endorsed on the survey feeling poorly or other symptoms they were given the opportunity to reschedule the interview.

The interview guide consisted of open-ended, semi-structured questions (available upon request) designed to understand the experience of the AYA with TDM, their actual involvement in the decision, the influences of the decision, their level of involvement in making current treatment decisions, and how having cancer or being under treatment affects the decisions that that they experience on a daily basis. Initial questions in the interview guide were broadly focused around the time of diagnosis. Questions then focused on a recent major treatment decision and how they had participated in that decision and what influenced their decision-making role. Other questions probed about everyday life, and how their cancer affected everyday decisions made about school and social life. Follow-up probes were used to encourage more detail and target specific areas or topics mentioned. The participants appeared comfortable with the content of the questions and were interested in the interview process. They were comfortable to ask for clarification when they were not sure of what was being asked and indicated through verbal or nonverbal cues their comprehension of the questions. A pilot study of four cancer survivors diagnosed with cancer as an AYA served as the basis for development of the interview guide. An AYA Advisory Council at one of the participating sites reviewed the interview guide and provided feedback.

Rigor was improved by attempting to conduct second interviews with all the participants to elaborate and verify findings from the first interview. The transcript or audio recording of the first interview with each participant was reviewed. Questions were developed to explore their individual responses more deeply and to conduct a member check of the findings from the first interview. These questions helped to form the interview guide for each participant's second interview. Six of the participants also participated in formal member checking of preliminary data. Fifteen of the 16 AYAs were interviewed twice and a single AYA was interviewed once (total 31 interviews).

Interviews were conducted in a private location in the hospital when participants were either inpatient or outpatient. Most interviews were conducted in private by the first author, a pediatric oncology nurse with interviewing experience. The interviews were audio recorded with the AYAs permission. The mean length of the first interview was 64 minutes (range 30-97) and of the second interview was 60 minutes (range 37-97). A $25 gift card was provided for each interview as a token of appreciation.

Immediately after each interview field notes were dictated for transcription. Reflexive notes were also recorded for later analysis to explore potential of biases or other nonverbal experiences that may influence the interpretation of the transcripts. Audio recordings of the interviews were professionally transcribed and reviewed for accuracy by the first author. All transcripts were reviewed on multiple occasions with analysis of transcribed interviews occurring simultaneously with new interview data collection. Focused coding was performed on the transcripts and codes were combined into categories. To ensure rigor, findings were discussed with members of the research team during the analysis period. This included semi-weekly meetings with the senior author during periods of active analysis. Transcripts and field notes were analyzed along with memos written by the first author to capture and focus important findings. The software ATLAS-ti (Meadows & Dodendorf, 1999) was used to assist coding of transcripts and combining codes into larger categories for data analysis and organization.

Findings

As shown in Table 1, the 16 participating AYAs were between 15 and 20 years old at the time of the interviews. The participants had various malignancies: leukemias (n=7), osteogenic sarcoma (n=5), Ewings sarcoma (n=1), and lymphomas (n=3). All AYAs had participated in a previous major cancer treatment decision, such as whether to enroll in a clinical trial, a surgical treatment decision or other treatment decision such as radiation therapy versus surgery. The average time from diagnosis to the first interview was 5.4 months (range 1.4-9.7 months).

Table 1

Demographic and Clinical Characteristics of the 16 Study Participants

Characteristic	
Mean age in years at 1st interview (range)	17.3 (15-20)
Gender (n, %)	
Male	9 (56)
Female	6 (38)
Non-binary	1 (6)
Race (n, %)	
White	6 (37.5)
Hispanic	2 (12.5)
Asian	4 (25)
Multiracial	4 (25)
Cancer Diagnosis (n, %)	
Leukemia	7 (44)
Lymphoma	3 (19)
Bone Tumor	6 (37)
Mean Months from Diagnosis to 1st interview (range)	5.4 (1.4-9.7)
Treatment Decision (n, %)	
Clinical Trial enrollment	10 (63)
Radiation Therapy vs Surgery	1 (6)
Surgical Options	5 (31)

My “Cancer Normal”

AYAs expressed how having cancer affected their everyday decisions and focused on the impact of cancer on their lives when they discussed their views, decisions, and management of their lives within the context of cancer. They also identified changes in their way of life since being diagnosed with cancer and described how they managed these changes. Types of changes were consistently identified across interviews. The phrase, “my cancer normal” represents their new way of being. Within this context, we identified three major categories of data that provided the organizing framework for the analyses: 1) you can’t do what you used to do, 2) relationships change and, 3) living with uncertainty. These areas related to how the AYAs responded to their new environment and the decisions they made to manage their illness. The AYAs described many situations in which they were adapting to and managing their new life with cancer and their desire for normalcy. They expressed a range of responses to the impact cancer had on their lives and strategies they employed to adapt. Cancer was now part of the mosaic that made up their unpredictable and ever-changing life experience during this period in their disease trajectory.

You Can’t Do What You Used To Do

The AYAs’ experienced a change in activity level and overall involvement in activities, and this was often a consequence of the side effects they experienced from their cancer treatment. The side effects influenced how the AYAs felt, looked and in what activities they could participate in. Participants experienced side effects such as nausea, vomiting and fatigue. Some described how they partnered with their nurse practitioner in trying to determine the best combination of antiemetics to control their nausea and vomiting. One AYA described her initial chemotherapy treatment and its impact: “…incredibly nauseated, incredibly fatigued, incredibly like not great, like someone had taken a hammer and hit me all over." She elaborated on how she now defined feeling good:

> …my bar for feeling good has gotten way low. I would say any time that I'm not having a headache I feel great,... my "I feel good" right now is way different from the "I feel good" of two years ago, because I am tired all the time. Or "I feel awake" is totally different than what that feeling used to be, or "I have energy" is way different… I think it's more of you get used to things. So, if you're used to always feeling tired, then that's normal instead of – and feeling not tired, even if you're still not feeling great, feels better anyway so it's all relative.

For the AYAs, days after receiving chemotherapy often consisted of recovering from their treatment. They describe how they try to make the most out of their good days, by doing schoolwork, going for walks and moving around instead of laying around and not doing anything. Fatigue was described and experienced by the majority of participants. Most also experienced a reduction in their activity level and were not able to participate in physical and recreational activities they had once enjoyed. They described their lives as "boring" compared to the active lives they led before they were diagnosed. They described how their lives were before having cancer and how having cancer has changed their lives now. They did not want to be in the hospital any more than they had to and preferred to be home. They wanted to get treatment over with and move on with their lives. Being alone and managing time in their own head made them sad. Being at home was preferred and therapeutic, for example: "I think just being in a hospital makes you feel a little bit more… vulnerable, whereas … home is like actually the place where I kind of start recovering again."

Participants described how cancer changed them physically, leading to a significant change in their lifestyle, their self-identity, appearance, and activities they did or did not participate in. Several AYAs described themselves as athletic or participating in a sport routinely prior to their diagnosis. Now, due to the physical limitations of their disease and side effects of treatment, they were losing weight, had low blood counts and fatigue. They stopped participating in certain activities.

> … That's just going to be hard for me to go back and try to retrain myself to be a different athlete.… I'm not as strong as I was and so I'm going to have to reteach myself like the basics because I'm not as powerful as I was.

Another AYA described how his lifestyle had changed. "Before all of this I was out working out in the gym. But then with the hospitalization now I had to stop. Now I'm just sitting down, laying down or just either watching TV or on my laptop."

Participants talked about their appearance, and in particular, their hair loss, a side effect of the treatment. One AYA described losing her hair as the worst part of her cancer treatment. They often chose to wear wigs, beanies or hats to appear normal and unnoticed. They commented that they became self-conscious when other people were looking (staring) at them. Through their interaction with others and self-reflection they developed a new meaning about their appearance. For one AYA, being stared at was one of the toughest parts about having cancer, "I'm just like you guys, I just have something wrong." Their hair loss also sometimes made it awkward to be around others. "I'm not hiding it [hair loss] or anything. But at the same time, just kind of helps me feel more … normal. Yeah, if I had eyebrows… I can wear the beanie and not even notice a difference."

One AYA was afraid of being seen by others who knew her unless they were her close friends. She chose to avoid these types of situations, affecting the activities she participated in. Often, allowing themselves to be bald was reserved for those they knew or felt comfortable with and often only at home with close friends or family. One AYA commented: "…I feel more comfortable with my family and I just go bald and like have fun. And here (hospital) it feels a little awkward to have my hat off. I don't know. So, I just keep it on."

For several participants, however, it did not matter who saw them without hair. They were confident in their appearance. For two females, their hair loss was not a reason to restrict their activities or whom they felt comfortable with. One AYA embraced and wanted to show off being bald as it brought awareness to cancer, her cause.

Because of their treatment schedule, unplanned hospitalizations and experiencing the side effects of treatment, they had to give up much of their normal routine and activities. Participants expressed, like one young woman, that they "live a different kind of life now." Another young man said that cancer treatment was "all consuming." The AYAs tried to keep busy, distract themselves and keep from being bored. For some there were issues of mobility, physical strength, losing weight, not feeling well, and fatigue that impacted their feeling of isolation and inability to participate in the activities or hobbies they used to do. One AYA, who had played the violin since she was eight years old, felt she had to give it up because she was just too tired to play in the orchestra. She said that what she missed most were her friends, more than actually playing the violin.

During the acute phase of their treatment activity, restrictions were imposed on AYAs, often due to low blood counts that could make them vulnerable to infection. Family (parents) often supported and enforced these restrictions and suggested alternative activities. For most, when it came to school for example, these restrictions meant either not attending school at all, participating in on-line classes, homeschooling, or for some, deferring their plans for college. Not attending school with friends was a loss for them. They especially missed seeing friends and social interaction. They looked forward to returning to school where they could see their friends whom they missed: “I feel weird saying that I miss school and stuff, but I do ‘cause I don’t have anything to do all day. But I miss seeing people all the time.”

Another AYA described what he was missing out on:

> … just talking with teachers, having conversations, seeing friends, hanging out with friends at lunch, the jokes, laughter, company in general. … Not seeing people…missing dances, missing graduation. ... Senior trip, seeing everybody go to Hawaii and you’re stuck in bed. …Man, this sucks. This really sucks. This is my senior year. I … didn’t get to go to graduation. I missed my last dances.

AYAs put activities that they used to do, such as group activities, on hold due to low blood counts or because events took place outside a safe range from the hospital. Sometimes their autonomy and independence were threatened.

> … this whole treatment makes me feel like a baby in a way... And what I mean by a baby is like when I’m in a wheelchair, my mom has to wheel me around and when I get mouth sores from methotrexate, I have to eat Spaghettios and Mac and Cheese.

For safety reasons they sometimes needed help.

> I think the worst part was needing someone to help me shower and it’s oh, my gosh. I went from being able to shower by myself to having someone help me and pretty much hold my hand to get in there, which is just horrible. I didn't like it at all.

Daily decisions often centered around their cancer or treatment. There was a range of choices they made in response to the restrictions in their activities. Some AYAs took control and chose not to take a chance and get sick. They followed the rules related to their restrictions in activities and communicated with friends their need to be careful, not get sick and where they could and could not safely go. Their friends respected this and were flexible in modifying their plans such as hanging out at their home rather than going out to public or crowded places. Friends were also often protective of them when they went out publically, keeping them safe from potential infections.

> I don't really go out as much anymore, just 'cause I've realized I'm not missing much at this point. 'Cause if I go out there, I'm going to be on crutches, have the chance of getting sick, and it's I guess hazardous.

For some, the restrictions were not too much of an imposition on their lifestyle: "…when my white blood counts are low, I just make sure when I go out with my friends that I'm not sharing drinks and food and touching stuff in public." For others, however, the benefits sometimes outweighed the risks when it came to not following the rules of restrictions related to their treatment. The benefits usually involved socializing and seeing friends. They sometimes had conflicting priorities, respecting their restrictions on the one hand and seeking social support from friends on the other. The importance and meaning of friendship was evident. Sometimes participating in the activity was worth the risk.

> If I really want to do it or if I haven't done something like that in a while …. Like I hadn't hung out with people offline in a while so I was okay, this is worth it… instead of "I'm going to sit in the house and try not to get sick."

Weighing the options applied to hanging out with friends.

> Sometimes my need for socialization overrides that (restrictions) ‘cause I knew I was probably neutropenic over the weekend but I still went to (X) to sit in a crowded theater and watch my friend’s movie because I wanted to and he was going to be there and I needed to see people face to face.

They advocated for themselves and took control requesting chemotherapy be given in the outpatient setting or during the week to allow for socialization with friends and participation in activities on the weekend. They also worked with providers to arrange chemotherapy around holidays so they could celebrate the holidays at home, spending time with friends and family.

Relationships Change

Retreating to family. The AYAs described their interpersonal relationships with family, friends and their healthcare providers. The AYAs retreated from their interactions with the outside world and to their family during treatment, spending more time with them compared to before their diagnosis. Family, and in particular parents, were important in offering strength, support and advocacy. They often listened to family, seeking their opinions. The participants accepted and appreciated family members’ participation in their care, and their input, and for the most part, parents were present during their children’s hospitalizations and clinic visits. They spent more time with family than they did prior to cancer, and less time with friends. They commented on how their relationships changed and they became closer with their family, more open, and even began to know them better. One AYA described how her daily routine and relationship with her family had changed since her cancer diagnosis.

> I’m home more than I used to be, I guess. Because I’d always like be gone. … And then I’d come home and I’d just do my homework, then I’d go to bed. So I really wouldn't talk to my family that much and then I’d be gone on the weekends with my friends. So, I

> guess I'm closer with my family now … I have more time to spend with them.

Another AYA commented about how cancer has brought her closer to her family.

> I think we have never spent so much time together, me and my mother and my father, and I think my dad would even say this is, despite how bad this would be, it's a horrible situation, he's very thankful for the opportunity to have time with me and like spend time in this life. Weirdly enough, we've never had situations where we're … together and we can have conversations and talk back and forth for hours.

Relationships with friends. Friends were an important part of the AYAs' lives. They talked openly about friends and close friends, and how their relationships had changed over time since their diagnosis. Friends were initially very supportive: "…when I first shaved my head, six of 'em were over at the house, and they shaved their heads with me." Nevertheless, frequent hospital appointments and an unpredictable and inflexible schedule, restrictions from low counts, and the need to avoid crowds and public places resulted in them becoming socially distanced from peers.

> I can't meet with friends that frequently because I will have hospital appointments all over the place and then there will be quick changes to my schedule … I don't know that day if I will feel good or not.

The frequency of contacts and communication with friends, either by way of social media or in person, decreased. When AYAs were in contact, they did not always know what to talk about and limited what they told friends about their cancer. They were reserved in who they talked with about their cancer and usually only shared details about their cancer and treatment with close friends. They were also protective of and defended their friends.

> I feel like it's hard on them, really hard on them, seeing me go through this… And I

> just don't really want to put them through it as well… And I try to stay positive all the time.

When they "hung out" with friends they often talked about "normal things." However, three participants described feeling like a burden to friends and were not invited to do things as often. As one young woman recounted,

> Because people don't invite me to do things anymore, which makes me really sad, … Well they don't invite me to go places. They don't call me and be, "Hey, do you want to go hang out sometime?" …It could be that they're busy or it could be that they don't like me or it could be that like they have other things to do or maybe they think that "oh, you have cancer so you don't want to go places" and stuff like that. I don't know.

When asked if she reached out to them, she responded: "No, because I get too nervous that they don't like me. Yeah. So, it's an unfortunate feedback loop…"Another AYA had similar feelings.

> I feel like a burden and even if I'm not. It's because if I hang out with somebody on the weekend, it's just my mind. I think oh, they could've done something really fun instead of sitting in their garage with me, you know. And it sounds morbid and sad but – and I'm okay with it 'cause it's just how it is.

One AYA controlled how often he saw friends, stating that he did not want his friends to visit him in the hospital and see him in his new condition. He had been a football player and since cancer, had lost weight and muscle, and physically changed. He deliberately avoided texting them back if they offered to visit him in the hospital. He told them he couldn't see them due to his low counts. He preferred to socialize with friends at home.

The AYAs felt they were missing out on things that they should have been a part of such as going off to college. One AYA described his life now as "living in limbo." They did not hear from those friends who were away at college as often.

> It was especially tough for me because all my friends left for college and if I was in high school still. I'm glad I'm done with high school, but if I was in high school still, I'd have all my friends who live around here still here.

Social media did allow AYAs to stay connected and up to date with friends and family, to some extent. Through social media, the AYAs were able to communicate instantly with friends as well as receive support.

> I keep up with everybody, of course, and people talk to me all the time. I'm not isolated from the world. … If I didn't have my phone and stuff I'd probably - I don't know I'd probably be really depressed, I guess, 'cause I have people talking to me all the time.

However, for some AYAs social media was a double-edged sword:

> I try to stay away from social media 'cause sometimes it makes me "dang, I wish I was doing that stuff, like hanging out with my friends", but it also helps me keep in touch with people.

Participants noticed that friends fell away over time.

> I feel - they don't really talk to me, they don't really text me that much anymore, but I don't really text a lot of people that much anymore either. So I guess they don't really know how to talk to me sometimes, just 'cause they don't want to upset me or put me over the edge, I guess. But I'm still me. You can still talk to me.

Meeting others with a similar experience was appealing for some and allowed them to feel less alone or isolated. They were open to talking to others who were going through the same thing. It was reassuring to see others doing well who were going through something similar. Not all AYAs, however, were interested in talking with others just because they had cancer. They would find it awkward.

The AYAs described important, close relationships they developed with nurses and other members of the healthcare team. For example, they made special connections with certain nurses and allowed themselves to connect with someone they didn't know. These relationships were often unique because the team members joked with them, were positive and direct in their approach, or talked with them about things other than their cancer. They were interested in them as a person. One AYA commented on his relationship with the nurses: "I try to just talk to them (nurses), give them a hard time, hope they give me a hard time back."

Living With Uncertainty

Despite getting used to having cancer, the unpredictable nature of cancer left participants with uncertainties about their future. These uncertainties took the form of their future in general, future activities, as well as recurrence of their disease. They lived with uncertainty in several aspects of their life and it took many forms. For instance, it related to their treatment and was expressed as not knowing the outcome of their surgery or participating in a clinical trial. Uncertainty also related to potential side effects or late effects of the treatment now or in the future, as well the possibility of recurrence of their disease or physical handicaps. They worried about the results of scans and other diagnostic tests and were reassured when reports were negative for findings. One AYA commented: "If I go in and they scan my chest and they see something there [cancer recurrence], then April suddenly isn't the end date."

Participants wanted to get through their treatment. One AYA was scared to miss his chemotherapy appointments, but was reassured over time with the news of good results. "I'm scared to miss my chemo because what if it comes back, what if it comes back right now, what if it comes back tomorrow?"

For those who had undergone limb surgery, there were uncertainties about relearning activities and what they would be able to accomplish physically in the future:

> Well I'm going to be a gimp, I guess. Like this knee, like what I read, like people go on hikes and stuff but I just don't know yet. …like it would kind of stink if I was the guy that everybody was waiting up for socially.

For others, it meant relearning activities they had once been familiar with or returning to activities such as sports.

Uncertainties also related to psychosocial aspects of their lives. When the AYAs thought about entering back into life, they considered how they would manage different social interactions. They did not want to be treated or thought of differently because they had cancer.

> …but this scar and what happened to my leg is going to be the sole thing to remember it by, so if that's as close to normal as I can get it, then that's as close to normal I can feel and be. And I just don't want people to say, "Oh, Paul, he had cancer." That's what they associate with me and they think of me and then they think of oh, he went through all this treatment and that sucks, whereas I just want to be Paul.

Another AYA described her concerns about how she would manage her appearance when she went back to college after treatment.

> I'm a little worried 'cause I'm is this where I wear the wig all the time … and do I have to put makeup on? It's a weird feeling to think that you go back –you find your new normal and it's not actually going back to normal. What will be my new normal?

Participants did not think too far into the future and talked more about the here and now. They wanted to go back to school or college after treatment, play sports again, see their friends more or just get their driver's license. Several participants, however, commented on their thoughts about the more distant future and plans for a family with some uncertainty:

> Hopefully I'm healthy, hopefully I will still be healthy and so be good with – and have a family. Hopefully they will be healthy too and be able to do the stuff that I wanted to, stuff like that.

Another AYA commented: "…even though I know it's not a hereditary disease, it will be always in the back of my head, right?"

Discussion

This focused ethnographic analysis of the psychosocial issues and strategies used by AYAs with cancer while receiving treatment within their first year of diagnosis identified three main categories: 1) you can't do what you used to do, 2) relationships change and 3) living with uncertainty.

Previous research indicates that AYAs have unique psychosocial needs, often involving school, friends, and a normal routine (Zebrack & Isaacson, 2012). The findings from our study suggest that AYAs with cancer, however, spend a large amount of time away from school, friends and their normal routine. The changes their bodies and psyche experience lead to changes in their relationships with others and loss of normal experiences and personal control. Cancer takes an emotional toll. Due to their often intensive and extended treatment, their school and academic pursuits were altered, interrupted or postponed. They wanted to go back to school, play sports again, and hang out with friends. This lifestyle change was a loss for them and their desire to be normal and return to normal activities was evident.

In addition to the physical changes, AYAs experienced disruption in their routine and an alteration in activities, some of which they were no longer able to do. They were challenged with finding their new “cancer normal.” They described their response to these situations and strategies they used to navigate and manage the unpredictable nature of their illness and its treatment. Their identity and body image was compromised by the side effects of treatment and they learned new strategies to deal with these changes. These findings are consistent with those of other studies (Brown, Pearce, Bailey, & Skinner, 2016; Larouche & Chin-Peuckert, 2006; Wallace, Harcourt, Rumsey, & Foot, 2007). This study however added to our understanding of the AYAs day-to-day decisions, living with uncertainty, and how this affected their everyday lives.

The conceptual and coping strategy of normalization is useful in describing families of children with chronic illness and their need to redefine and reframe their family and child's identity and interactions with others (Deatrick, Knafl, & Murphy-Moore, 1999; Morse, Wilson, & Penrod, 2000; Rehm & Bradley, 2005). Characteristics of normalization include: 1) acknowledging the problem, 2) choosing to adopt a normalcy framework, 3) acting in a way consistent with normalization, 4) creating treatment regimens consistent with normalcy, and 5) interacting with others based on the assumption the child and family are normal (Deatrick et al., 1999). Robinson reported that life for families and individuals with chronic illness is initially problem saturated “with little life beyond the problem.” The process of normalization allows them to persevere because they can focus on hope and wellness and what they can do rather than what they cannot do (Robinson, 1993). Constructing and living a "new normal" has also been described in families of children with cancer (Clarke-Steffen, 1997). This construction of “new normal” was based on the AYAs cancer experience when their previous normal was not appropriate for their current life situation.

Normalization is a useful framework for understanding the AYAs’ response to their cancer. The AYAs in this study had a desire to be normal in the face of the challenges they experienced due to their cancer. Even though they recounted examples of how their lives were affected by their cancer and its treatment and how “it sucked,” not all aspects of their cancer were completely negative. They conveyed numerous examples of beneficial effects of the cancer situation including improved relationships with family and their care team. They exhibited resiliency, self-determination and agency and stated how they got used to their new lives. These findings may be helpful when intervening and developing policies and best practices to assist AYAs in mastering self-management and becoming independent.

Other researchers have demonstrated the importance of normality (Belpame et al., 2017; Wallace et al., 2007). Belpame (2017) described a last phase of acceptance of the consequences of their disease during which AYAs focus on evolving toward a new normal life. Overall, our study extends previous research on normalization and establishes the importance of developing awareness and interventions to improve the function and quality of life of AYA patients.

For AYAs, meeting the milestone of becoming independent during this developmental stage of their life, in addition to having cancer, proved difficult. They found themselves retreating to their families. Their need for dependence because of their cancer made it difficult and their response was contrary to what AYAs would prefer or typically do at this stage of development. While AYAs are generally learning to separate from their parents and become independent (Arnett, 2000) the AYAs did value their close relationships with parents and their important role as a source of support. In this regard, our findings support and extend findings of other researchers (Belpame et al., 2017; Kyngas, Hentinen, & Barlow, 1998; Zebrack, Mills, & Weitzman, 2007). These findings have also contributed to our further understanding of the importance of family during crisis and illness for the AYA. HCP's must be aware that the increased involvement of family is necessary, common, but not necessarily welcomed by the AYA, who are in the process of establishing their independence. Despite some misgivings, participants generally welcomed and depended on parents, though tried to assert their independence as they could.

The AYAs were concerned with their identity and body image and this sometimes determined with whom, where and how much they would socialize. These were internal decisions they made in spite of the external restrictions that were imposed upon them due to the side effects of their cancer treatment. Previous research has shown that AYAs with cancer are extremely aware of their body image and have difficulty remaining active, maintaining their independence and dealing with side effects of therapy (Belpame et al., 2017; Wallace et al., 2007; Woodgate, 2005; Zebrack & Isaacson, 2012). Support to improve coping and self-efficacy may help AYAs cope with these issues (Zebrack & Isaacson, 2012).

Development of mature socialization is a critical developmental task of adolescence. The development of a robust network of peers, close friendships and romantic relationships is critical to the development of normal psychosocial functioning (La Greca & Harrison, 2005). Cancer prevents or impedes these developing relationships at this critical time. In this study, AYAs had a need for social support, but found that often their relationships with peers changed over time and they missed out on social events and spending time with friends. They became socially distanced from friends. A common theme amongst AYAs from multiple studies is that cancer and its treatment negatively affect peer relationships (Bellizzi et al., 2012; Larouche & Chin-Peuckert, 2006; Zebrack, Kent, Keegan, Kato, & Smith, 2014). AYAs are unable to participate in normal life experiences, which leads to feelings of isolation and alienation (Belpame et al., 2017; Levin Newby, Brown, Pawletko, Gold, & Whitt, 2000).

Social media helped to keep AYAs connected with friends and to maintain friendships. Most AYAs participated in social media of one form or another. For some, however, it was a reminder of what they were missing out on and for this reason it was difficult to participate in social media. For AYAs, connecting with others living with cancer was thought to be helpful and something some (but not all) were interested in doing.

The AYAs had fears about the unknown and their future related to their cancer. They articulated living with uncertainty both in the short and long term and gave examples of what that uncertainty looked like. This has not previously been described to our knowledge. Uncertainty was pervasive. Other researchers have reported how illness and treatment-induced uncertainty is memorable to older AYAs as a major stressor when they are asked to reflect on their cancer treatment experience (Greenberg & Meadows, 1992; Novakovic et al., 1996; Stewart, 2003; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Investigators have also emphasized the uncertainty that children and AYAs must cope with in order to manage their illness (Donovan, Brown, LeFebvre, Tardif, & Love, 2015; Koocher & O'Malley, 1981; Stewart, 2003) and report that levels of uncertainty do not diminish with the passage of time as AYAs progress past diagnosis and treatment (Decker, Haase, & Bell, 2007).

Study Limitations

This study had several limitations that could have influenced the results. First, the interviews were conducted at two sites in the same general geographic area, so the AYAs' views may be reflective of the practices at these institutions and not of other pediatric oncology programs throughout the country. Second, the first author was employed part time as a Clinical

Nurse Specialist at one of the institutions where data collection took place, though she was not directly involved in the clinical care of the participants. The first author was conscious of her position both as a clinician and researcher. This unique position was discussed with the senior author and considered during the data collection and analysis phases of this research. The first author's clinical experience improved her ability to understand the AYAs' background and experience with cancer during the interviews. Third, AYAs may be wary about sharing negative information about the TDM experience and therefore offer socially acceptable responses, particularly as they relate to communication and trust in the treatment team. Fourth, the study was a retrospective view of recent AYAs experiences. Fifth, only the AYAs views were analyzed during this study so the views of the parents and providers were not included. Sixth, the sampling strategy purposely focused on AYAs themselves, since this perspective has not been commonly studied previously. Future studies should include the perspectives of the parents and treatment team in this process. Seventh, even though the participants were ethnically diverse, these results do not necessarily reflect cultural, racial and socioeconomic diversity, as small samples can usually only identify commonalities, not differences between cultural groups. Finally, the effect of the presence of parents during some of the interviews is unknown, but their presence does emphasize the importance of family to AYAs within the context of living with cancer.

Implications for Practice and Research

Our findings suggest that there is opportunity for improvement in the care we provide AYAs with cancer early on in their disease trajectory. Support services should be available to help AYAs conquer the numerous and challenging tasks of development they face while dealing with their cancer. Peer support in various forms may be an important intervention for some AYAs.

The nurse is in a unique position to assess the needs of the AYA and provide individualized care. Nurses often get to know the AYA and can advocate and share their assessment with the healthcare team and together with the team, determine interventions for the AYA. Developing a relationship with the AYA to facilitate the empowerment process around decision making is essential. Healthcare professionals should help the AYA become empowered and develop self-efficacy by building strong relationships, understanding their informational needs and creating effective communication processes. Training staff to communicate effectively, share information and promote self-efficacy would be useful for the AYA during their cancer treatment. Assessing outcomes of these types of interventions is important.

Communication is also a critical tool to assist AYAs in coping with uncertainty (Brashers, 2001; Hogan & Brashers, 2009). One of the essential functions of communication in oncology is managing uncertainty (Epstein & Street Jr, 2007). Clear, sensitive, and accurate information provided by healthcare providers as a part of their open communication reassures, comforts and results in peace of mind (Decker et al., 2007; Sisk, Mack, Ashworth, & DuBois, 2018). Support and appropriate information provision may improve the adaptation of AYAs to their cancer circumstances.

Finally, there is a need for further research in this area. Coping strategies used by AYAs and their families to manage the cancer experience must be investigated to understand the role of family in the care of the AYA with cancer. It is also important to determine which interventions are successful from a patient and family-centered perspective. Future interventions should be aimed at empowering and promoting self-efficacy in the AYA. The experiences of AYAs should be examined prospectively using a longitudinal design to examine developmental, normalization, and decision making changes that take place over time.

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Chapter Five

Discussion

The overall goal of this dissertation study was to understand from the AYA perspective, their level of involvement in TDM and within the context of the family. The participants appeared to find this research interesting and willingly shared their experiences. Sixteen out of sixteen participants agreed to a second interview. Even though one of the sixteen participants agreed to a second interview, we were unable to arrange for the second interview before the end of her therapy. Only one AYA declined to participate in the study. The high response rate may reflect the parents' and AYAs' view of the importance of this topic. The AYAs were mostly eager to talk and tell their story.

The main findings from this study pertain to the AYA's involvement in treatment decisions that include decisions related to: their cancer treatment, day-to-day care decisions, and their daily life at home. This chapter will include a discussion about the following: 1) meeting the specific aims, 2) the limitations of the study and, 3) practice and research implications.

Specific Aims

Aim #1. To describe the AYA's preference for and actual involvement in their cancer TDM, including factors that influence TDM about their cancer.

There are several key findings under this aim. There was a range of involvement of the AYA in TDM. Decision making preferences and involvement are highly personal and vary between individuals, at different times, and in different situations. Overall, the AYAs felt informed, part of discussions and viewed themselves as sharing in or making treatment decisions. They wanted to be informed and involved in decisions about their care and were given opportunities to participate if they wanted to. In some cases, they elected not to participate in making decisions about their actual cancer treatment. This was typically due to feeling overwhelmed or severe illness around the time of diagnosis.

Parents and HCPs made efforts to include them in decisions in the initial stages of their cancer treatment and throughout their daily care. Styles of decision-making varied from there being no decision to make (either there was a single option or the other options were obviously unacceptable), accepting the decision, through to being involved in discussions, to assuming a shared or primary role in decision making. The AYAs' preferences for participation in decision making varied over time and by type of decision. Overall, AYAs became more active in making decisions about their care over time. AYAs provided rich descriptions of factors that influenced their decisions. These will be the subject of a future paper.

Most AYAs were either collaborative (10) or passive (4) in their role in treatment decision making and appeared content with this role. Very few were active (2). The role of family was very important to the AYA in making decisions. We must be careful in interpreting recommendations to involve AYAs because it may not be their preference and could be more stressful. Fostering collaboration between AYAs and their parents as major decisions are made may be useful. Although people older than 18 are considered young adults, their families are important in making these decisions so should be encouraged to participate. If AYAs are cared for in adult facilities, where the model is to solely discuss healthcare with the patient, then families may not be included and the AYAs may not receive the appropriate support they need.

These findings are concordant with evidence from previous investigators and studies. Several studies report most young people wanted to be informed (Zwaanswijk et al., 2007) but did not want sole responsibility for making decisions (Dunsmore & Quine, 1995; Unguru, Sill, & Kamani, 2010). Young people have previously been found to collaborate with their parents and providers (Dunsmore & Quine, 1995; Kelly, Mowbray, Pyke-Grimm, & Hinds, 2017; Ruhe et al., 2016a; Unguru et al., 2010; Zwaanswijk et al., 2011).

The AYAs' role in decision making may depend on many factors, including their previous experience, where they are in the disease trajectory and type of decision being faced. In this study a small group of participants (4), were unable to, or chose not to participate in making treatment decisions at the time of diagnosis due to similar factors. Similar to findings reported in other studies, AYAs did not want to assume responsibility for making decisions at or close to the time of diagnosis (Stegenga & Ward-Smith, 2008; Weaver et al., 2015) and most wanted to share in decision making (Weaver et al., 2015). Barakat and colleagues (2014) found that the majority of AYAs had little or no role in TDM about Phase III clinical trials. They described how young people's symptoms, seriousness of the condition and urgency of the decision are barriers to the child's participation in TDM.

Perhaps with effective interventions that include communication strategies or decision aids, AYAs would be able to achieve a more active role in decision making if that was their preference. Interventions may change the way AYAs are involved in making treatment decisions or change the way they are involved in deciding about care preferences.

Aim #2. To explore the types of treatment and non-treatment decisions in which AYAs do and do not want to be involved.

The AYAs described the cancer treatment decision they experienced and were able to clearly convey their role in this decision. These decisions included whether to participate in a clinical trial or deciding between surgical options. They also readily elaborated on the decisions they made related to their care preferences. Occasionally, they had difficulties in identifying day-to-day decisions or supportive care type decisions that were part of their cancer treatment and needed prompting. Others were able to identify supportive care or symptom management type decisions and described how they were offered treatment choices such as various options about accessing their port or the choice between anesthesia or moderate sedation for a procedure.

The decisions they described varied. During treatment and depending on the circumstances, patients were faced with minor decisions such as nausea management and port access, a challenge they were likely to master early on. The AYAs were also faced with the need to make life-changing decisions such as to enter into a clinical trial within the first few days of diagnosis or to have limb salvage surgery.

When the participants discussed everyday, usually minor decisions at home, related to their cancer or treatment they were able to recount experiences about how cancer related decisions impacted their lifestyle, including socialization, relationships with their family and friends, and their current activities. Their lives were different from before cancer; now unpredictable and uncertain. The description of their involvement in important treatment decisions was different than the decisions they made about everyday life that was influenced by their cancer treatment. These everyday decisions did have importance for their cancer treatment and quality of life, including taking into account such varying factors as their susceptibility to infection, energy levels and need for social support when deciding on whether to engage in social and school activities. The contrast of these types of decisions influenced by their cancer treatment has extended our knowledge about the range of decisions they encounter both in the hospital and at home.

The AYAs were able to distinguish between important treatment decisions and care preferences. They were able to acknowledge the importance or severity of what they considered major or significant decisions about their care. They described the clinical trial or surgical decisions as being of a greater magnitude or of more consequence compared to the everyday supportive care decisions they were routinely involved in. This may account for why most collaborated with their parents or providers in making the major types of decisions. Other investigators have noted similar findings. Coyne et al., (2014) noted that young people classified decisions as minor (delivery of care) or major (decisions about treatment protocols). Ruhe et al., (2016b) described how youth were involved in minor choices and Kelly and colleagues (2017) reported that most youth did not want to make "big" decisions. Investigators have found that young people prefer to and do participate in supportive care decisions such as decisions about pain and nausea management (Ruhe et al., 2016b; Tenniglo et al., 2017).

This study contributes to our increased understanding of treatment decision making as something that evolves over the course of the AYAs cancer disease trajectory. Young people enter into the illness experience with little to no understanding of their disease, with their experiences providing a rapid education. They quickly learn and become involved in supportive care decisions early on. Supportive care decisions are much more frequent, often occurring on a daily basis. It is likely AYAs quickly realize they can make choices in these situations that are not irrevocable. If they make a decision that doesn't go so well, they have another opportunity tomorrow or with the next dose. In contrast, major decisions (clinical trial versus standard care or amputation or limb salvage) occur much less frequently AND have long lasting consequences.

Three individual dimensions of AYA cancer decision making were identified: 1) becoming experienced with cancer, 2) import of the decision, and 3) decision making roles. I attempted to consider them individually, but always had to return to describing them in the context of the other dimensions. I found they could not be discussed in isolation because they interact with each other. The three individual dimensions can be considered as the three axes (x, y, and z) in a three dimensional graph. A specific AYA cannot be considered as a single point on this graph, but rather projected on a three-dimensional surface. For example, the AYA may be highly experienced in making decisions about self-care or symptom management, but at the same time might have limited experience with other aspects of cancer care, and prefer to be collaborative or passive with major decisions. Visualizing where they are on this topographical graph may help care givers and AYAs understand where they are in decision making.

This three dimensional understanding may also help to display the common trajectory of AYA cancer patients. When they are newly diagnosed most are naïve and tend to be passive. After gaining some experience, they assume an active role with minor decisions but are still relatively passive or collaborative with major decisions. Some AYAs, especially those with complicated illness trajectories, may reach a point through their experiences where they are actively involved in important decisions such as choosing end-of-life care or participation in a Phase I trial.

The paper written about the three dimensions of decision making evolved to explore the relationship between experience, being able to distinguish the import of the decision and the AYA's decision making style. These dimensions are described in chapter three of this dissertation. It is also important to note that several participants gave examples of future decisions that made them uncomfortable and that they did not want to be involved in making. This included the examples of advance directives and stem cell transplant.

The findings highlight the multifactorial and ever changing landscape of decision making for the AYA. The description of the three dimensions of AYA decision making contribute to how we can understand decision making at various stages of the AYAs cancer experience. Further studies could help validate this potential model and determine how it interacts with social processes affecting the AYA, family, the health care team and cancer treatment, and variables such as age, gender, prognosis, phase in treatment and information needs.

Aim #3. To examine how AYAs interact with family, especially parents, in making treatment decisions.

It was evident from the interviews with the AYAs that they want feedback from their parents in making treatment decisions. The AYAs preferred parental involvement and appreciated their support in TDM. AYAs preferred that parents were involved and present for discussions. They trusted their parents, listened to them and wanted their input and opinions about their care. Parents also offered support and strength. For only a few (2), AYAs who assumed an active role in decision making, their parents assumed more of a supportive role, since they took the lead. Siblings, extended family members and friends had little or no role in their decision making.

HCPs must consider parental involvement in decision making. Existing literature support these findings. Even when youth are competent to make treatment decisions, they still want support and prefer shared decision making with family and clinicians (Coyne & Gallagher, 2011; Pearce et al., 2016; Zwaanswijk et al., 2007). Young people rely on their parents to protect them and trust them to make decisions in their best interests (Broome & Richards, 2003). This finding may be important for clinicians caring for adults, where including family in discussions with a young adult patient who is legally competent may not be the norm.

Many AYAs were involved in important decisions about their care and their parents included them in discussions and in making decisions. These experiences may translate into decisional confidence and a more active role in decision making. For the day-to-day decisions about supportive care or symptom management in the hospital, they often took initiative in making these decisions, with little or no input from families. It is possible that their participation in low risk self-management decisions might be useful to improve long-term adherence with medical management. The practice they receive in making their own healthcare decisions, the positive feedback and acknowledgement of their importance in the care process may lead to the AYA being more willing to commit to adherence. Of course, this would require further study.

Several AYAs mentioned occasional disagreements with parents about how they preferred to manage their symptoms. These disagreements occurred, for instance, about the use of marijuana with the parent having negative feelings that the use of marijuana was bad or illegal. As the AYA persisted, the parents would come to accept that the AYA was going to continue to use marijuana in spite of the parent's misgivings.

The frequency with which they must negotiate their role in making decisions when there is discordance between the AYA and parents has increased our understanding of how decision making is a social process, highlighting the complicated dynamics that occur within the family. The topic of conflict and how this is negotiated by the AYA may be an important area for further exploration.

During this acute phase of their cancer treatment, the AYAs often retreated to their family, becoming closer to their parents and siblings. This is contrary to what typically happens during this stage of development, when AYAs become increasingly independent and their peer group is very important. The AYA may have to cope with substantial feelings of loss of these important external relationships. They may also feel that having to depend on their family is a sign of failure to become an adult. All of which may add to the risk of stress and sadness during this difficult time. The findings from this study have contributed to our further understanding of the changing role of the AYA and family, and importance of family during crisis and illness for the AYA. HCP's must be aware that the involvement of family is common and beneficial. This may be an area requiring extra sensitivity from professional staff.

Psychosocial issues relating to the impact of cancer on the AYA were uncovered and explored. Key findings included social distancing from friends, impact of the disease and treatment side effects on their physical appearance, uncertainty about their outcomes, their desire to be normal and how they adapt to their "cancer normal." Peers were an important part of their lives, and communicating through social media helped to keep them connected to friends.

Participants wanted to get their treatment over with and to return to their lives. They had a desire to be normal. These findings are consistent with the literature (Belpame et al., 2017; Decker, Haase, & Bell, 2007; Donovan, Brown, LeFebvre, Tardif, & Love, 2015; Kumar & Schapira; Wallace, Harcourt, Rumsey, & Foot, 2007; Woodgate, 2005; Zebrack & Isaacson, 2012) however this study added to our understanding of the AYAs day-to-day decisions, living with uncertainty, and how this affected their everyday lives. AYAs endorsed and revealed thoughts about living with uncertainty, both in the short and long term. This has not previously been described to our knowledge. They articulated examples of uncertainty that affected many aspects of their lives related to anticipating diagnostic tests, the threat of recurrence, not knowing what physical limitations they would have, how they would manage social interactions and how their cancer would affect their future. Uncertainty was pervasive in many aspects of their lives.

Study Limitations

This study was conducted at two pediatric oncology programs in Northern California. It is plausible that the practices and approaches to care may have been unique to these programs and may not reflect practices in other parts of the United States. It is also possible that approaches to involving AYAs in TDM may vary by cultural or in geographically disparate centers.

Social desirability may have played a role in how participants responded to questions. The AYAs may have been wary about sharing negative information about the TDM experience and produced socially acceptable responses, particularly as it related to communication and trust with HCPs. In an attempt to alleviate this concern, the first author explained confidentiality and developed trust during the face-to-face interviews. Conducting a second interview also facilitated trust and follow-up with developing ideas.

The first author was employed as a nurse on one of the units, even though she was not involved in the direct care of the participants in the study, her role as a clinician may have influenced the interpretation and processing of the data. The research team, with no direct interactions with the participants, were aware of this and assisted in maintaining neutrality and objectivity. Only the AYAs' views were analyzed during this study. Family members, such as parents will be interviewed in future research to gain perspective across developmental stages and levels of interaction.

Practice and Research Implications

Some of the practical implications of these findings include how we approach AYAs and their families about decision making and how we message decision making. Determining AYAs level of involvement which might change by situation and over time is important to evaluate on an ongoing basis. Effectively assessing their desire for TDM involvement and communicating their preferences to the team is important to providing patient and family-centered care. A critical first step is to assess where the AYA is in the decision making and on the experience continuum. Once the clinician understands where the AYA is, the clinician can help the AYA get to where they want to be. Developing a tool to assess and communicate their preferences is an example of a simple intervention. Requesting their presence and including AYAs in discussions where decisions of all types are discussed and made, such as at bedside rounds, or during consent conferences, and determining the amount and type of information they need or want in order to make decisions is important to their "becoming experienced."

Assisting AYAs along their experience journey to develop decision making skills and be involved in decisions about their care is essential. AYAs should be given opportunities to participate in decision making, either major or minor and work in partnership with the team and their family. An important way for the AYA to feel respected and their input valued is to make efforts to include them in decision making and discussions. Their participation will help to facilitate communication amongst the team and build relationships. If AYAs can participate to the degree that they desire, this may help to improve treatment adherence, which could be the focus of a future study.

Likewise, HCPs have an obligation to communicate in a clear, accurate and therapeutic way. Developing the qualities and skills to promote good communication to facilitate decision making is important in our role and helps to decrease uncertainty. One of the basic ways to improve uncertainty is to optimize communication between the patient and the healthcare team (Brashers, 2001; Hogan & Brashers, 2009). It is possible that improving communication will improve patient satisfaction and their ability to cope with challenges. Identifying best practices in the care of this patient population is an important overall goal.

The findings from this study have highlighted important areas for future research. AYAs may not feel they have the skills or abilities to be involved in decisions, which may influence the role they assume. Developing effective interventions (to educate and to increase their comfort in making decisions) may impact their desire to be involved in health care decisions. It also may make them more aware of the variety of roles they could take in decision making.

For major treatment decisions, healthy peers were not involved in making the decision. However, some AYAs were interested in speaking or meeting other AYAs who had cancer. It would be very interesting to study the intervention of providing early exposure to a cancer-experienced peer on TDM engagement and levels of stress and anxiety in the AYA population.

There are additional opportunities for conducting research in this area. Connecting measurement to patient and family outcomes is essential. Future research might focus on the measurable impact of interventions on the AYA and family such as their level of satisfaction, self-efficacy, self-management and treatment adherence as a result of the AYAs role in decision making. Examining outcomes relative to AYAs involvement is important to determine. In Kelly et als. (2017) study they found that children and adolescents for example, reported that "having a say" improved their satisfaction, comfort with decisions and reduced fear.

This study was an appropriate initial step before extending to triads including parents and providers. Understanding the role of family in TDM and how the AYA negotiates their role within the context of family is important. Investigating how to optimally provide patient-centered and family-centered care to promote decision making in AYAs and identifying if parents' decision making preferences influenced, or were the same or different from their AYAs warrants study.

Understanding the temporality of treatment decisions is another area that requires further exploration. In this study, some of the participants were involved in major decision making early on after diagnosis, whereas others were involved later on in their treatment. Investigating how these experiences are similar or dissimilar would be helpful in order to tailor interventions to the AYA.

It would be useful to investigate whether or not the use of decision aids developed for the AYA are of benefit in assessing their preferences for decision making. The sample was limited to English speaking participants because of limited resources in this study, we hope to include other language groups in future studies. Finally, conducting prospective research at multiple sites with diverse samples on the topic of decision making in the AYA would also be beneficial. These will be fruitful areas for my program of research going forward.

Conclusion

The use of focused ethnography, as a method to study the phenomenon of AYA cancer treatment decision making, was useful in describing the nature of decision making in AYAs, and the contextual factors that influenced their experiences. Health care providers must help AYAs to participate in decision making to the extent that they desire. Empowering them to become involved may foster a sense of control, self-efficacy, personal growth and even improve adherence. It is important to understand the needs and preferences of the AYA when it comes to decision making. Facilitating AYAs to have some choice and control and the ability to participate in the decision making process, if they desire, is key and requires effective communication and the provision of information. AYAs in this study wanted to be involved in decisions and informed about their care. Collaborating with them in this effort encourages their independence and self-efficacy in managing their care now and in the future.

Understanding their concerns and desires in order to assist them from a psychosocial point of view is also important. As HCPs, we should attempt to minimize the disruption to their lifestyle and work to keep their routine as normal as possible. This is challenging in our current health care system. Providing emotional support and meeting their information needs helps to empower them during their cancer experience.

Developing ongoing and predictable relationships with AYAs builds trust, respect, collaboration and shared decision making. The unique needs of the AYA demand that we understand how best to care for and serve this population. The often active and supportive role of the parents in the care of these individuals cannot be over looked and is important to understand especially as these individuals transition into adulthood as cancer survivors. Understanding how best to partner with both parents and the AYA is essential to providing both patient and family-centered care.

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