


# Day-to-Day Decision Making by Adolescents and Young Adults with Cancer

Journal of Pediatric Hematology/  
Oncology Nursing  
2022, Vol. 39(5) 290–303  
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Hematology/Oncology Nurses  
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DOI: 10.1177/27527530211068718  
journals.sagepub.com/home/jpo



Kimberly A. Pyke-Grimm, PhD, RN, CNS, CPHON<sup>1,2,3</sup> ,  
Linda S. Franck, PhD, RN, FAAN<sup>3</sup>, Bonnie Halpern-Felsher, PhD, FSAHM<sup>4</sup>,  
Robert E. Goldsby, MD<sup>5</sup>, and Roberta S. Rehm, PhD, RN, FAAN<sup>3\*</sup>

## Abstract

**Background:** Adolescents and young adults (AYAs) with cancer must negotiate the transition between childhood and adulthood while dealing with a life-threatening illness. AYA involvement in decision making varies depending on the type of decision and when decisions occur during treatment, and evidence suggests that AYAs want to be involved in decision making. **Objective:** To explore involvement of AYAs with cancer in day-to-day decisions affected by their cancer and treatment. **Methods:** This qualitative study used interpretive focused ethnography within the sociologic tradition, informed by symbolic interactionism. Semi-structured interviews and informal participant observation took place at two quaternary pediatric oncology programs. **Results:** Thirty-one interviews were conducted with 16 AYAs ages 15 to 20 years. Major day to day decision-making categories identified included: (1) mental mindset, (2) self-care practices, (3) self-advocacy, and (4) negotiating relationships. Participants described how they came to grips with their illness early on and decided to fight their cancer. They described decisions they made to protect their health, how they advocated for themselves and decisions they made about relationships with family and friends. **Conclusions:** Through day-to-day decisions, participants managed the impact of cancer and its treatment on their daily lives. Research should focus on developing and implementing interventions to empower AYAs to participate in day-to-day decisions that will affect how they manage their cancer, its treatment and ultimately their outcomes. **Implications for Practice:** Healthcare providers can facilitate AYA's participation in day-to-day decision making through encouraging autonomy and self-efficacy by providing support and through effective communication.

## Keywords

adolescent and young adult, cancer, decision making

## Introduction

The National Cancer Institute defines the adolescent and young adult, commonly referred to as AYA, as those individuals between 15–39 years of age. In the United States in 2020, there were estimated to be approximately 89,500 new cancer diagnoses in this age group, or five percent of all new cancer cases diagnosed at any age. The 5-year relative survival rate for these AYAs is approximately 85% (National Cancer Institute, 2020).

Adolescence and young adulthood is characterized by the interplay of rapid changes in physical, cognitive and emotional function coincident with demands to maintain and/or develop, independent decision making, school or workforce skills, relationships and lifestyle choices (Arnett, 2000; Zebrack, 2011). AYAs between the ages of 15 and 25 years, experience a time of transition, and cancer and cancer treatment can have an impact on this stage of development for these vulnerable patients

(Kim et al., 2016; Larouche & Chin-Peuckert, 2006; Morgan et al., 2010; van Riel et al., 2014; Woodgate, 2005).

<sup>1</sup>Stanford Children's Health, Department of Nursing Research and Evidence-Based Practice, Palo Alto, CA, USA

<sup>2</sup>Division of Hematology/Oncology, Department of Pediatrics, Stanford University School of Medicine

<sup>3</sup>Department of Family Health Care Nursing, San Francisco School of Nursing, University of California, San Francisco, CA, USA

<sup>4</sup>Department of Pediatrics, Division of Adolescent Medicine, Stanford University, School of Medicine, Stanford, CA, USA

<sup>5</sup>UCSF Benioff Children's Hospital, San Francisco, CA, USA

\*Professor Emeritus.

### Corresponding Author:

Kimberly A. Pyke-Grimm, PhD, RN, CNS, CPHON, Department of Nursing Research and Evidence-Based Practice, Stanford Children's Health, 750 Welch Road, Palo Alto, CA 94304, USA.

Email: kimpgrimm@gmail.com

AYAs with cancer face unique challenges. Studies have shown limited improvement in outcomes compared to the same diseases in younger and older individuals (Keegan et al., 2016; Smith et al., 2010; Tricoli & Bleyer, 2018). Medication non-adherence is also a leading concern when caring for children and adolescents with any chronic illness, including cancer and hematopoietic stem cell transplant. (Bhatia et al., 2015; Landier et al., 2017; McGrady et al., 2015; Morrison et al., 2017; Psihogios et al., 2020). Optimal involvement of the AYA in treatment decisions and illness management support adherence to medical treatment (Albritton & Bleyer, 2003; Sawyer & Aroni, 2005).

There is often a short window of time available to make decisions about cancer and treatment. This stressful characteristic of cancer is especially challenging for adolescents and young adults. The stress of making these decisions includes facing pain, loss of friendships and activities, loss of potential, changes to their body or in body image and even the possibility of death (Bellizzi et al., 2012; Zebrack & Isaacson, 2012). Optimal decision-making requires a balanced relationship between the decision-making input from the deeper socio-emotional centers of the limbic system (rapid, reactive, automatic and intuitive) with the cognitive control system of the prefrontal and parietal cortex (reasoning, analysis and reflection) (Diekema, 2020). The limbic system develops much sooner than the cognitive control systems, with the limbic systems nearly fully developed by mid adolescence, whereas the cognitive control systems are not fully developed until the mid-20s (Blakemore & Robbins, 2012). This is the basis for the adolescent predisposition for risk-taking, stimulus seeking behavior and heightened emotional reactivity (Crone & Dahl, 2012; Guyer et al., 2016; Pfeifer & Blakemore, 2012). When triggered by stressful or anxiety provoking stimuli, the socioemotional response of the limbic system may overwhelm and shut down the nascent cognitive control system. The stress generated by cancer related decisions in AYAs might preferentially trigger the deeper emotional regions of the brain leading to poor decision quality (Kann et al., 2016; Morris et al., 2018; Ravindranath et al., 2020).

Adolescent and young adult treatment decision making (TDM) has been studied within multiple contexts: clinical trials, survivorship, fertility, advance care planning, relapse and end-of-life (Barakat et al., 2014; Davies et al., 2018; Frederick & Mack, 2018; Hinds et al., 2005; Ingersgaard et al., 2018; Jacobs et al., 2015; Lyon et al., 2013, 2014; Mack et al., 2019; Miano et al., 2020; Miller et al., 2013; Needle et al., 2020; Pearce et al., 2016; Pyke-Grimm et al., 2020; Stein et al., 2014; Theroux et al., 2021) illustrating AYAs are capable of participating in cancer-related decision making throughout the illness continuum. Adolescents and young adults are able to participate in

complicated decisions that take into account risks both to themselves and others, including understanding the consequences of decisions (Hinds et al., 2005; Lyon et al., 2013, 2014). Mack et al., (2019) reported decisional regret in almost one quarter of AYAs about cancer treatment decisions. Decisional regret was also associated with increased anxiety, depression and poorer prognosis. Younger AYAs were more likely to be less involved in decision making than they preferred. Pyke-Grimm and colleagues (2020) three dimensions of treatment decision making heuristic model helps to describe the impact of TDM. Experience for example, enables the AYA to become involved in TDM about their cancer treatment. Improvements in decision quality, decision outcomes and the decision-making process have been reported in intervention studies focused on supporting adolescent decision making (Lyon et al., 2013, 2014).

Shared decision making is an important tenet of patient-centered care, involving a partnership between the provider and patient in making treatment decisions (Godolphin, 2009) that can reduce decisional conflict and improve knowledge (Wyatt et al., 2015). Research has also documented a loss of control in decision making for AYAs (Coyne et al., 2014; Wicks & Mitchell, 2010). AYA involvement in decision making varies depending on the type of decision and when decisions occur during treatment (Hinds et al., 2005; Miller et al., 2013; Pyke-Grimm et al., 2020). AYAs want to be involved in their decision making (Davies et al., 2018; Keim-Malpass et al., 2016; Mack et al., 2019; Maslak et al., 2019; Miano et al., 2020; Pyke-Grimm et al., 2020; Ruhe, Badarau, et al., 2016; Tenniglo et al., 2017) for major decisions (Pyke-Grimm et al., 2020) and also for minor or supportive care decisions (Darabos et al., 2021; Pyke-Grimm et al., 2020; Ruhe, Wangmo, et al., 2016; Weaver et al., 2015) relating to their cancer treatment. There is limited understanding of the role of AYAs with cancer in day-to-day decisions. It is important to understand their role since collaborating with AYAs and families in this effort encourages AYA's independence and self-efficacy in decision making and managing their care. Therefore, the purpose of this analysis was to explore the day-to-day decision making by AYAs in relation to their cancer and treatment.

## Method

### *Study Design and Participants*

The data for this analysis were acquired as part of a larger study to explore the experiences of AYAs' involvement in decisions about their cancer treatment (Pyke-Grimm et al., 2020). This was a qualitative study, using interpretive focused ethnography in the sociologic tradition, informed by the theory of symbolic interactionism.

Features of focused ethnography include a problem-focused and context-specific approach, involving participants with knowledge about a specific phenomenon (Knoblauch, 2005). Bronfenbrenner's Bioecological Theory of Human Development (Bronfenbrenner, 1979) and Bandura's Self-Efficacy Theory (Bandura, 1977) served as sensitizing theories for this study. For additional details about the methods see Pyke-Grimm et al. (2020). AYAs who were receiving cancer treatment within one year of diagnosis were purposefully sampled from two quaternary pediatric oncology programs in the Western USA. Institutional Review Boards at both centers reviewed the study (study numbers: 34399 and 13-11242).

Primary inclusion criteria were AYAs who: (1) were ages 15 to 25 at the time of the interview (the upper age limit typically cared for at these pediatric institutions), (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 such as whether to enroll in a clinical trial, a surgical treatment decision or other treatment decision such as radiation therapy versus surgery. Exclusion criteria included experiencing relapse, receiving end-of-life care, non-English speaking, or unable to physically or mentally participate in the interview. The AYA provided written, informed consent or, the parent provided consent with assent from the AYA. In some interviews (12/31) parents were present if preferred by the participant, however the interview questions were directed to the participant.

### Data Collection

Prior to the interview, participants completed an 11-item demographic questionnaire with questions about age, level of education, ethnicity, race, marital status,

household members, employment and educational status. The interview guide included open-ended, semi-structured questions (Supplemental Appendix 1) designed to elicit the experience of TDM, actual involvement in the decision, the factors influencing the decision, level of involvement in current TDM, and how having cancer and receiving treatment affected their day-to-day decisions. Initial questions were broadly focused on the time of diagnosis. Questions then focused on a recent major treatment decision, how they had participated in that decision and what influenced their decision-making role. Other questions probed aspects of everyday life, and how their cancer affected daily decisions about school and social life. Follow-up probes were used to encourage more detail and target specific areas or topics mentioned. A pilot study of four cancer survivors diagnosed with cancer as an AYA served as the basis for development of the interview guide. These data are not included in this study. An AYA Advisory Council at one of the participating sites reviewed the interview guide for this study and provided feedback prior to its use.

Rigor was improved by conducting second interviews with the same participants (all but one) to elaborate and verify findings from the first interview. The transcript or digital recording of the first interview was reviewed by the first author (KPG). Questions were then developed to explore further their individual responses and to verify initial findings. These questions helped to form the interview guide for each participant's second interview (a median of 22 days after the first interview). The first author (KPG) conducted member checking of preliminary data with six participants relating to the accuracy of the data to help establish credibility and trustworthiness (Lincoln & Guba, 1985). Fifteen of the 16 participants were interviewed twice and a single AYA was interviewed once (total 31 interviews). COREQ (Consolidated Criteria for Reporting Qualitative Research) was used as a guide to ensure the quality of the findings (Tong et al., 2007).

Interviews were conducted in private when participants were either inpatient or outpatient. The mean length of the first and second interviews were 64 min (range 30–97) and 60 min (range 37–97), respectively. A \$25 gift card was provided for each interview as a token of appreciation. Immediately after each interview, field notes were dictated. Reflexive notes were also recorded to explore potential biases or other nonverbal experiences that might influence the interpretation of the transcripts. The recordings were professionally transcribed and reviewed for accuracy by the first author (KPG).

### Data Analysis

All transcripts were reviewed on multiple occasions with analysis of transcribed interviews occurring simultaneously with new interview data collection. Open and

**Table 1.** Participant Characteristics.

Characteristic	n (%)
Age at 1st interview (mean)	17.3 yrs
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)
Diagnosis (n, %)	
Leukemia	7 (44)
Lymphoma	3 (19)
Bone Tumor	6 (37)

focused coding was performed on the transcripts and codes were combined into categories. To promote rigor, findings were reviewed with members of the research team during analysis. This included routine meetings with the senior author (RSR) during analysis. Transcripts and field notes written by the first author (KPG) were analyzed to capture and focus important findings. Analytic memos about meanings derived from the data were written during the analytic process. The software ATLAS-ti (Cope, 2014) was used to assist coding of transcripts and combining codes into larger categories for data analysis and organization.

## Results

Participant characteristics are reported in Table 1. The 16 participants were ages 15 to 20 years old at the time of the interviews. All had participated in a major cancer treatment decision. The average time from diagnosis to the first interview was 5.4 months (range 1.4–9.7 months).

The participants identified day-to-day decisions they made in the course of their daily lives that were related to their cancer and treatment. For example, managing their cognitive (thoughts and beliefs) responses to their cancer and treatment, how they cared and advocated for themselves, as well as how they navigated relationships with others. The decisions described were related to issues they dealt with on a daily basis, were not major treatment decisions (Pyke-Grimm et al., 2020), and sometimes were made in collaboration with others.

Within this context of day-to-day decisions, we identified four major categories affected or influenced by their cancer or treatment: (1) mental mindset, (2) self-care practices, (3) self-advocacy, and, (4) navigating relationships. These categories represent how the participants responded to their new environment: cancer and its treatment, and the day-to-day decisions they made. It was striking how inextricably important peer relationships were to AYAs and how decision making played out

within the categories of both self-advocacy and navigating relationships. The major categories and category definitions of day-to-day decision making for AYAs are presented in Table 2.

### Mental Mindset

AYAs described early on that they decided to accept the reality and meaning of their diagnosis, leading to the conscious decisions to fight the cancer, proceed with treatment and “stay strong” for themselves and others. This also included the changing nature of their relationships such as with their family. As AYAs learned what to expect, they became reconciled to what they had to do to get through their treatment. One participant described how she made the decision to stay strong at the time of her diagnosis.

...that it (cancer) 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 f\*\*\* you, cancer, and we're going to say f\*\*\* 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 (name of cancer). You could be told a worse diagnosis. You could also be told that you're going to be dead in a week. (*Female, 19 years*)

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 and do what they needed to do to get it (treatment) over with. It was a mental mindset or decision that helped them to accept and move on with their treatment in order to get back to their life as they knew it. They wanted to get back to their life but recognized that they first needed to get through the treatment. During the interviews, participants did not describe experiencing denial, however some described feelings of shock and disbelief at diagnosis.

### Self-Care Practices

Participants took responsibility in carrying out physical self-care activities related to their cancer and treatment. They chose to participate in a variety of self-care activities such as implementing regimens related to their radiation treatment, monitoring themselves for physical changes (i.e., fever or bruises), drinking fluids to stay hydrated, fertility preservation injections, administering their own chemo (intravenously via their central line) at home and managing their central line and pain management.

**Table 2.** Categories Related to Day-to-Day Decision Making Reported by AYAs with Cancer.

Category	Category definition
Mental mindset	Decisions related to attitude(s) about their cancer and/or treatment.
Self-advocacy	Decisions related to acting on behalf of themselves in the context of managing their health care needs.
Self-care practices	Decisions related to the practical aspects of their physical care.
Navigating relationships	Decisions related to managing or maintaining their relationships.

These were decisions they made independently after initial education from health care providers (HCPs). One participant described how he cared for his central line.

They told me how to flush it (PICC line) and lock it and then change the caps and all that....I did it once or twice when my parents were sleeping, 'cause like they needed it. So I was like I'll just like do it. So it's nice to know. I like to know because it's like it's cool to know and then if the doctor's asking questions, you know what they're talking about." (*Male, 16 years*)

Another participant described how he took responsibility to apply topical anesthetic to his port site in preparation for blood draws.

I wake up at 6am and put on lidocaine cream and the home nurse will come and draw the labs. It's so different every day. You don't know what it's going to be like so you kind of just have to roll with the punches. (*Male, 15 years*)

They partnered with nurses on how best to access their ports: "Well, I've kind of learned from getting my port accessed so many times like what works for me best, like the size needle and how they hold my port." They monitored their blood counts and made decisions about daily activities based on blood results:

When my platelets are low I can't ride it (bike) because they don't want me to fall or anything like that... I always ask and they usually tell me just like five of the counts that are most important, like the hemoglobin, the platelets and the ANC and like two other ones. And that usually helps me gauge when I'm able to do certain stuff. (*Male, 17 years*)

They described engaging in additional self-care practices, like choosing to participate in physical activity, and physical therapy as part of their treatment plan. One participant who had undergone limb salvage surgery for osteogenic sarcoma recounted the following experience with his physical therapist:

I can decide do I want to go hobble around and run around when it's half healed or do I want to take it easy, slowly get this thing back to normal and heal it, be patient. And that's just on me. (*Male, 18 years*)

Other examples of how they took on responsibilities of self-care included driving themselves to clinic appointments and scheduling their own appointments.

## Self-Advocacy

AYAs developed self-advocacy skills during their treatment. Within the context of self-advocacy, managing their health needs included preventing illness or complications and treatment facilitating behaviors. Managing their healthcare needs was often nuanced by the developmental context of the AYAs life and friendships.

**Preventing Illness or Complications.** Daily decisions and self-advocacy often centered around their cancer or treatment. They made a range of decisions in response to their restrictions to prevent illness or complications. Some actions, like screening for illness were purely preventive, but others were a compromise. Some chose not to take a chance, following the rules about activity restrictions due to their low blood counts. They first asked if people were unwell and avoided crowds, to stay safe. They communicated with friends and family about where they could and could not go, or what activities they could participate in and reminded people to wash their hands. Family (parents) often supported these restrictions and suggested alternative activities. Their friends respected their needs and were flexible in modifying their plans such as visiting them at their home rather than going out to public or crowded places. Friends were often protective, keeping them safe from potential infections.

... I was neutropenic at the time so I couldn't go out, without my mask and everything. And I, want to be with my friends and then they're going to the movie theaters, to watch *Captain America: Civil War*. And they were inviting me to come. Like do I make that decision, yes or no? And I did – I went with them, but I made sure I let them know my situation and I wore my mask and my friends, they were just being a wall just from everyone else from the outside. (*Male, 20 years*)

The participant describes a compromise of how allowing, encouraging, or using friends to act as a "wall," kept him safe from others. There were two goals related to peer support: advocating for the protection of their health and assuring that they received the social support they needed as an AYA.

Maintaining a semblance of normal life and relationships with friends were important. It was sometimes challenging and awkward to advocate for themselves. One participant recounts his decisions related to an experience with friends.

When I got back from the hospital, my friends threw me a birthday party and half of the friends who were there were sick. I didn't want to like leave right away. It's like you know, I can't be here at all. But at the same time, I was just sitting there and like just dreading. It's like just please don't cough in my direction. I mean, I got home

that night, like the first thing I did was like strip off everything, jump straight into the shower, take a nice long bath, go downstairs, have like a— *Emergen C*— just take one of those and then just like went straight to bed. (*Male, 18 years*)

**Treatment Behaviors.** Decisions and behaviors related to their treatment varied depending on their experiences. They advocated for themselves when it came to side effects and symptoms of their treatment. Fatigue was experienced by the majority. They worked with the healthcare team in making decisions about antiemetics to mitigate nausea. They developed self-advocacy skills as they became experienced:

Like even if I'm not involved in the decision, I want to know what the decision is... In the beginning they'd be like, "Okay, we're going to give you Ativan, Zofran and this, one for nausea." And I'd be like, "Okay, wait. I don't think I want to do Ativan because last time I did it I didn't feel so good." And then kind of like just let them know that's what happened and then they're like, "Oh, okay..." (*Male, 18 years*)

They were proactive in making decisions about medications: requesting medications, suggesting changes to medications, participating in deciding what medications to take and asking questions about side effects or interactions of medications.

They negotiated their care and role with parents. Occasionally, the participant's preference for their care was in conflict with their parents' preference. Several participants for example, chose to manage their symptoms with medical marijuana, which initially caused tension with their parents. They had to negotiate with their parents and self-advocate for using it:

"Look, Mom, this (marijuana) helps with this and this and this," she was still like, "No." .... Well, the thing is, it wasn't like she was like disappointed that I wanted to do it. It was nothing like that. It was just more of like, "I heard this is bad. I don't want my son taking it, especially in the situation that he's in." (*Male, 18 years*)

The participant also partnered with the HCPs to try to convince his mom he needed it.

One AYA described her conflict with her parent over symptom management and how she managed it by advocating for herself:

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. (*Female, 15 years*)

After another AYA, in becoming experienced with his cancer and treatment, was able to advocate for care with his parents to bring him to the hospital for a transfusion. This was a decision he made.

Like some mornings I'll wake up and I'll feel really weak. And so I'll watch throughout the day and then like if I get a little headache and it doesn't go away, I'll know and be like, "Hey, we need to go in because my blood count is low."... They'll just say okay and then we'll all go in. (*Male, 16 years*)

Participants communicated with HCPs, advocated for themselves and took control requesting chemotherapy be delayed in some situations, be given in the outpatient setting or requested the chemotherapy schedule be rearranged to allow for socialization with friends and family.

Like one day I was having really bad fevers and I said, "I really don't think having chemo when I'm having five to seven fevers like in 24 hours is a good idea," and I really pushed to have it delayed a day. ... And we came to a nice common compromise that we would just wait a day. (*Female, 19 years*)

Another participant advocated with her mom, to change her chemotherapy schedule.

We didn't want to have to come on the weekends because we have like church and stuff and like my friends are like out of school and I want to hang out with my friends and do other stuff like that. And so, we were trying to get like the time that I would come up here changed like a day or two back. (*Female, 15 years*)

Participants became experienced with their care and learned to advocate for themselves with parents, friends and HCPs.

### **Navigating Relationships**

Participants described their changing interpersonal relationships with family and friends and the decisions they made within these contexts.

**Retreating to Family.** At the time of diagnosis, they retreated from the outside world and to their family during treatment, spending more time with them. Parents were especially important in offering strength, support and advocacy. Participants often listened to family, seeking their opinions. They accepted and appreciated family members' participation in their care, and

their input, and for the most part, parents were present during their hospitalizations and clinic visits. They became closer to their family, more open, and even developed deeper relationships. One participant described how her daily routine and relationship with her family had changed.

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. (*Female, 15 years*)

Another participant commented about how cancer had 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. (*Female, 19 years*)

During this period of time, participants described how relationships changed from what they had previously been. They regressed to spending more time with family during this early diagnosis and treatment period, as they learned about their disease, treatment, self-care and vulnerabilities. They were gathering information before making decisions. They made allowances and compromises by spending more time in their family environment and accepted this. This was a lifestyle change for them. As they gained more knowledge, self-care and self-advocacy skills they were able to reconnect with peers and connect with their HCPs within the context of daily decisions. These were changes that occurred with experience, over time.

**Relationships with Friends.** Cancer physically changed the participants, leading to a substantial change in lifestyle, self-identity, appearance, and activities. These changes influenced decisions they made about their relationships with friends.

Participants talked about their appearance, and hair loss in particular. One described losing her hair as the worst part of her 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. For one participant, 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. One participant was afraid of being seen by others unless they were close friends. She chose to avoid these types of situations and activities. Revealing their baldness was commonly reserved for those they felt comfortable with or only at home with close friends or family. One participant 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." Other participants were confident in their appearance and did not care who saw them bald. For two females, their hair loss was not a reason to restrict activities or alter with whom they felt comfortable. One AYA embraced and wanted to show off being bald as it brought awareness to cancer- her cause.

Daily decisions and behaviors related to relationships with friends were manifested in different ways and affected their social life. For some, activity restrictions related to blood counts were not too much of an imposition and their decisions were situational: "...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." For other participants, however, the benefits (usually socialization) outweighed the risks of not following the rules. 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 were evident.

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." (*Nonbinary, 18 years*)

Their decisions about hanging out with friends involved weighing the options.

Sometimes my need for socialization overrides that (fatigue) cause I knew I was probably neutropenic over the weekend but I still went to (place) 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. (*Nonbinary, 18 years*)

Their decision making involved juggling their health, and friendships including maintaining peer support. These two different goals influenced their decisions, and one goal superseded the other at one time or another.

The frequency of contacts and communication with friends, both in person or social media decreased. They did not always know what to talk about and limited what they told friends about their cancer, usually choosing only to share details with close friends. One

participant 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 an athlete and since cancer, had experienced severe physical deconditioning. He did not reply to their offers to visit, using the excuse that he couldn't see them due to his low counts.

Decisions about the type and use of social media varied. Social media did allow the participants to stay connected and up to date with and receive support from friends and family, to some extent.

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. (*Female, 17 years*)

However, for some participants 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."

## Discussion

This focused ethnographic analysis of the day-to-day decisions experienced by AYAs with cancer identified four main categories: (1) mental mindset, (2) self-care practices (3) self-advocacy and (4) navigating relationships. The findings suggest that the day-to-day decisions AYAs with cancer experience are nuanced within the context of their developmental stage. The findings also expand upon the heuristic model of decision making in AYAs with cancer described by Pyke-Grimm et al. (2020). The participants' descriptions of their roles in day-to-day decisions, the importance of these decisions highlighted by the types of decisions discussed, and how they took control of many daily decisions relatively early on in their disease trajectory, support and expand upon the model.

AYAs with cancer identified changes in their way of life and described how they managed these changes by participating in day-to-day decisions to cope with their cancer and treatment. These day-to-day decisions they experienced were influenced by their cancer and its treatment. These decisions included managing their symptoms, advocating for protecting their health and attempting to meet their social needs. Participants' routines and activities were disrupted, they were challenged to find their new "cancer normal" way of being and they described adapting to and managing their new life. Cancer became just another part of the mosaic that made up their unpredictable lives. These findings are consistent with prior research that maintain it is important for young people with cancer to regain a sense of normality

through everyday activities (Gibson et al., 2016; Graetz et al., 2019).

During treatment, AYAs utilized both independent and collaborative approaches to decision making with parents and HCPs, as they assumed responsibility for self-care practices. As self-advocacy skills developed, they communicated with their parents and HCPs about their care and management. Learning practical skills to advocate for themselves and practice symptom self-care supports empowerment (Stinson et al., 2012) and might enhance the therapeutic relationship. Making decisions about managing their disease allowed them to retain some of their independence and made them more confident. Promoting their involvement in daily decisions might increase their feelings of being in control and lead to enhanced self-efficacy and empowerment over their disease and treatment. Through self-advocacy participants were able to re-gain independence at a time when being independent was impacted due to their illness. Schreiner et al., (2020) reported AYAs description of "living well" included, having autonomy over their body and being able to make their own decisions.

Development of mature socialization is a critical developmental task during this adolescent and young adult stage of life. Cancer often impedes the development of creating and sustaining a network of peers, close friendships and romantic relationships as participants retreat to their family for support. Their relationships with peers change, often becoming distanced as they miss social events and simply spending time with them. Participants drew a connection between socialization and their physical vulnerability. They attempted to balance protecting their health with the need for socialization. Sometimes they chose to take risks, violate their restrictions and see friends, prioritizing their emotional well-being. Other times they prioritized their physical vulnerability by keeping friends at bay. A common theme from multiple studies is that cancer and its treatment negatively affect AYAs' peer relationships (Bellizzi et al., 2012; Fladeboe et al., 2020; Larouche & Chin-Peuckert, 2006; Rosenberg et al., 2014; Zebrack et al., 2014) and life experiences, causing isolation and alienation (Belpame et al., 2017; Hokkanen et al., 2004; Levin Newby et al., 2000). Alternatively, improved relationships with family and friends was reported by some participants, supporting previous study findings (Kuntz et al., 2019; Straehla et al., 2017).

It is well known that AYA's are very aware of their body image but the addition of cancer to this developmentally normal concern makes it much more complicated (Stinson et al., 2012). AYAs with cancer 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). The participants were concerned with



their identity and body image and this sometimes affected their choices about with whom, where and how much they would socialize. Sometimes, due to body image concerns, they limited socialization with peers more than what was imposed upon them by their cancer treatment. Discussion and support of these developmental issues with the AYA and their family might help their adaptation (Zebrack & Isaacson, 2012).

As many as 90% of 18-29-year-olds use social media (Perales et al., 2016) and most of the participants in this study did as well. AYAs with cancer use social media to research their illness, develop peer and support relationships and to express themselves (Fladeboe et al., 2020; Nesby & Salamonsen, 2016; Perales et al., 2016). Participation in social media can empower patients to communicate with their HCP, asking questions and participating in decision making (Benetoli et al., 2018; Smailhodzic et al., 2016). Most participants used social media to keep them connected with friends and to maintain friendships. Social media participation was not all positive, however, as for some it was a reminder of what they were missing out on leading to avoidance and possibly exacerbating social isolation.

As the care of AYA's with cancer transitions to primarily outpatient settings, the importance of self-care advice increases in parallel. Mobile phone ownership is nearly universal (Pew Research Center) in AYAs so there is opportunity for technology to have an impact on this population. Day-to-day decision making might be supported by current technology for example that has been developed for symptom management (Jibb et al., 2017; Macpherson et al., 2014), physical activity (Götte et al., 2018; Hooke et al., 2016; Le et al., 2017; Mendoza et al., 2017) and medication adherence (Bhatia et al., 2020; Jupp et al., 2018; Linder et al., 2019; Wu et al., 2018). It will be important to determine how this technology impacts care and how it might facilitate AYA decision making and promote their role in managing their healthcare.

In this study, the novel descriptions of how the participants demonstrated self-advocacy skills and agency as they made decisions and managed their lives is a contribution to the literature. This is similar to reports of AYAs taking control by making decisions and managing their lives as much as the impact of cancer on their life will allow (Davies et al., 2018). Overall, our study extends previous research and creates awareness of the types of day-to-day decisions AYAs are involved in related to their cancer and treatment.

### *Implications for Practice and Research*

During the early phase of their cancer treatment the participants faced developmental challenges while dealing with their cancer. Our findings suggest there is opportunity to

support AYAs with cancer early in their disease trajectory. We need to ask how, when and to what extent can AYAs participate in day-to-day decisions and what AYA characteristics influence their decision-making preferences and outcomes. Based on the participants' reported changing relationships with friends and family, peer support in the form of social media or support groups might be important interventions for AYAs.

Nurses are in a unique position to assess the needs of the AYA and develop a relationship with them to facilitate the empowerment process around decision making, knowing AYAs may be selective about decisions they choose to participate in. AYAs also need information if they are to be actively engaged in making decisions. Healthcare professionals can empower the AYA by building strong relationships, understanding their informational needs and creating effective communication processes in order to support daily decision making.

Research to improve decision-making comfort and competency might lead to improved medication adherence for AYAs taking an increased role in managing their care. The participants described decision making as it related to their self-advocacy skills and self-care practices. Understanding what facilitates the development of self-advocacy skills for example, such as the role of experience, time, specific HCP or parent factors highlight the importance of further research on AYAs experiences with daily decision making. Optimizing AYAs' choice, control and ability to participate in these decision-making processes, is key, and requires effective communication and the provision of information by HCPs. Decision making by AYAs and their families to manage the cancer experience both at home and in hospital must be further investigated to understand the role of family in the care of the AYA with cancer. The experiences of AYAs should be examined prospectively using a longitudinal design to examine developmental and decision-making changes that take place over time. Research might focus on understanding what encourages and supports AYAs involvement in decision making, how we can best engage them in day-to-day decision making and the outcomes of these decisions. Developing, testing, and implementing interventions to promote their participation in day-to-day decisions to manage their disease and treatment and its impact on their lives might be informed by these findings. Future interventions could also be aimed at empowering and promoting self-advocacy in the AYA and navigating the negotiation of their role with their health care team and family (parents).

### *Limitations*

This study had several limitations. First, the interviews were conducted in a single geographic area, so the participants' views may not reflect those in other parts of the

country nor other cultural, racial and socioeconomic groups. Second, it is unknown the effect of the parents' presence during some of the interviews. Third, recall bias is inherent. Fourth, the participants age range of 15–20 years might be viewed as a limitation as responses of older AYAs were not captured. Finally, our participant sampling was purposive in nature and participants were selected by the treatment team who may have been biased in their choice of AYAs to approach to participate in the study.

## Conclusion

Day-to-day decision making centered around the AYAs mental mindset, physical self-care practices, self-advocacy skills, and navigating changing relationships. The daily decisions AYAs made were influenced by their cancer and treatment and affected numerous aspects of their lives. Their decision-making involvement sometimes included collaborating with family (parents) and HCPs. Understanding AYAs day-to-day decisions allows HCPs to better understand how they experience their illness and how we might best support them. The description of the participants' self-advocacy skills is an important finding and investigating what supports self-advocacy in this population and its outcomes could be beneficial. The degree to which they participated in self-care practices and developed self-advocacy skills within the context of cancer, supported independent behaviors during a challenging developmental stage. Healthcare providers can promote AYA's involvement and autonomy in daily decision making by providing support and empowering them, using effective communication directed at the AYA, and encouraging partnership in their health care.

## Acknowledgments

The authors wish to thank the participants and members of the clinical teams at both sites for their contributions to this study.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The research described in this article was funded by an individual National Research Service Award from the National Institute of Nursing Research, grant number 5F31NR015951 and an American Cancer Society Predoctoral Award.

## ORCID iD

Kimberly A. Pyke-Grimm  <https://orcid.org/0000-0001-6396-7460>

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