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“Improving to where?” Understanding Survivorship Trajectories
among Adolescents and Young Adults after Hematopoietic Cell Transplantation

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Nursing

by

Eden Rose Brauer

2016

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ABSTRACT OF THE DISSERTATION

“Improving to where?” Understanding Survivorship Trajectories
among Adolescents and Young Adults after Hematopoietic Cell Transplantation

by

Eden Rose Brauer

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2016

Professor MarySue V. Heilemann, Chair

Despite the prevalence of hematological malignancies during early adulthood, very little is known about the hematopoietic cell transplantation experience among adolescents and young adults, and even less is known about their transition from the completion of therapy to long-term survivorship. Therefore, this dissertation research explored the experiences of critical transitions in early survivorship, such as discharge to the home setting, involvement of an informal caregiver at home, the trajectory towards self-care, and reentry to work and school, among a sample of adolescents and young adults after hematopoietic cell transplantation.

Grounded theory, influenced by Constructivism, guided all aspects of the study design. In-depth interviews, using a semi-structured interview guide, were conducted with 18 adolescents and young adults, who had received autologous or allogeneic hematopoietic cell transplantation for primary hematologic malignancy at age 15-29 years and were 6-60 months post-treatment. Interview transcripts were systematically analyzed to identify emergent

categories and generate theory.

Findings from this study highlight participants' experiences across three critical transitions in early survivorship. The first two transitions are sequential and have psychosocial, emotional, and behavioral components, while the third is not sequential and is more focused on an unfolding perspective. The transitions are: 1) a shift from hospitalization to the home and high reliance on informal caregivers; 2) attempts to resume previously normal activities, such as work and school; and 3) an emotional and existential shift involving a reconceptualization of the perception of the future. Participants described the context in which these transitions occurred, specific challenges they faced, and adaptive strategies they developed.

While the findings cannot be generalized to all adolescent and young adult survivors of hematopoietic cell transplantation, this study provides insight into the trajectory towards self-care, the reliance on informal caregivers, and the experiences of critical transitions in early survivorship. The findings also shed light on the extensive, unexpected, and persistent life disruptions that participants experienced. By exploring deeper understanding of the survivorship trajectory of adolescents and young adults after hematopoietic cell transplantation, these findings can be used to inform clinical practice, guide future research, and shape policy.

The dissertation of Eden Rose Brauer is approved.

Patricia A. Ganz

Carol Pavlish

Huibrie C. Pieters

MarySue V. Heilemann, Committee Chair

University of California, Los Angeles

2016

Dedication

This work is dedicated to the young adult participants who shared their time and story with me.

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Curriculum Vita

Education

Masters of Science in Nursing	University of California, Los Angeles	2009
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Registered Nurse, California. License Number: 760704	2009-Current
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Nurse Navigator, Adolescent and Young Adult Oncology Program (part-time) 2015-2016
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- Provide comprehensive assessment and follow-up care for patients at diagnosis, active treatment and transition to survivorship, including education on fertility preservation education and family building options, sexual health, and symptom management.
- Participate in design, implementation and evaluation of various research projects.

Clinical Nurse I/II, Bone Marrow Transplantation/Hematology (full-/part-time) 2009-2013
City of Hope National Medical Center

- Provide nursing care for the complex needs of adult stem cell/bone marrow transplant patients, including the conditioning period and the acute and chronic recovery phases.

Research and Administrative Experience

Research Assistant (part-time) 2014-Current
UCLA School of Nursing

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- “Winging it”: How older breast cancer survivors persist on aromatase inhibitors* by Eden **Brauer**, Patricia A. Ganz, and Huibrie C. Pieters. Submitted to *Journal of Oncology Practice* 2016
- “Winging it”: How older breast cancer survivors persist on aromatase inhibitors* by Eden **Brauer** and Huibrie C. Pieters. Podium presentation at Western Institute of Nursing conference (presented by Huibrie C. Pieters). 2016
- Distress in AYAs with Cancer: Components and Covariates*. Bianchetti, M., Morgan, D., **Brauer**, E., Macpherson, C. F., Hu, J. Siegel, S., Malvar, J., & Sposto, R. Poster presentation at Critical Mass Young Adult Cancer Alliance Conference. 2015
- Millennials, Malignancy and the Changing Timetable of Adulthood: Nursing Implications*. Poster presentation at Western Institute of Nursing conference. 2014
- Global Research: Ethical Considerations for Nurse Researchers*. Podium presentation at Western Institute of Nursing conference. 2014
- Millenials and Malignancy: A Constructivist Grounded Theory Approach to Cancer among Adolescents and Young Adults*. Poster presentation at Qualitative Health Research (QHR) conference. 2014
- Survivorship Issues for AYAs after Hematopoietic Cell Transplantation: A Focused Review of the Literature*. Poster Presentation at Critical Mass Young Adult Cancer Alliance Conference. 2014
- The CHOICES Project: Methodology by Walter R. Allen, Ophella C. Dano, and Eden **Brauer** in Allen, W. R., Kimura-Walsh, E., & Griffin, K. A. (eds.). *Building CHOICES: How underserved students and high schools construct college preparatory opportunities*. New York: Info Age Publishing. 2009

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Introduction to the Dissertation

Background and Significance

Cancer is the leading cause of non-accidental death among adolescents and young adults (AYAs) in the United States (U.S.) (Bleyer, Budd, & Montello, 2006; Nass et al., 2015). Approximately 70,000 AYAs, defined by the National Cancer Institute (NCI) as individuals aged 15-39 years, are diagnosed with cancer each year, which is nearly six times more than children under 15 years (Nass et al., 2015; National Cancer Institute, 2014). Improvements in early detection, treatment modalities, and supportive care have contributed to lower rates of cancer deaths and dramatic increases in cancer survivors generally (DeSantis et al., 2014; Kohler et al., 2015). In fact, approximately 66% of patients are living at least five years after diagnosis (Kohler et al., 2015; McCabe, Bhatia, et al., 2013; Siegel, Miller, & Jemal, 2015). However, survival improvements for AYAs have lagged behind younger and older cohorts according to U.S. Surveillance, Epidemiology, and End Result (SEER) data (Bleyer et al., 2006). Specifically, AYAs had dramatically higher survival rates than other age groups in the 1970s and 1980s, but more recently these rates have stagnated while rates in younger children and older adults have improved (Adolescent and Young Adult Oncology Progress Review Group [AYAOPRG], 2006). The relative lack of improvement among AYAs has triggered concern among both the pediatric and adult worlds of oncology. In response to these findings, the NCI convened the Adolescent and Young Adult Oncology Progress Review Group (AYAOPRG). At this meeting, AYAs with cancer were designated as a vulnerable population, warranting specific attention. A call for targeted cancer research with AYAs was made to improve understanding of the underlying reasons for the significant outcome disparities observed in AYAs compared to other age groups (AYAOPRG).

Definition of AYA

In 2006, the progress review group defined AYAs broadly as individuals diagnosed with cancer between 15 to 39 years of age (National Cancer Institute, 2014). The rationale for this wide age range was to include the entire spectrum of patients that showed a lack of improvement in survival. In addition, the AYAOPRG (2006) argued that, compared to other age groups, AYAs share certain circumstances on the cancer journey such as delays in treatment, lack of clinical trials, and the need to balance treatment with life-stage factors, such as school, work, and young families. However, there has also been scientific support for the use of subgroups within this broad AYA definition to account for variation in experiences; this also expanded theoretical support for acknowledgement of the heterogeneity in this group (Arnett, 2014; Phillips-Salimi, Lommel, & Andrykowski, 2012). Recently, Institute of Medicine (IOM) working groups revisited this topic and decided to maintain the current definition, but also recommended that the age range be modified depending on the specific objectives of the research project (Smith et al., 2016).

Intersection between Cancer and Life Stage

In general, AYAs are an extremely healthy group, with virtually all adolescents aged 10 to 17 years (98.1%) and young adults aged 18 to 24 years (96.3%) reporting excellent, very good, or good health (Mulye et al., 2009). This norm of good health makes a cancer diagnosis during this life stage even more alienating. AYAs with cancer face competing demands between needing to attend to the developmental tasks of their age while simultaneously needing to be dependent on family and healthcare providers due to the imposition of a cancer diagnosis (Corbeil, Laizner, Hunter, & Hutchison, 2009). While there is undoubtedly wide variation within the AYA population, the central conflicts of the “AYA paradox” (Kent et al., 2012) include

balancing needs for autonomy with increased dependence on family. AYAs also confront maintaining engagement in education or occupation despite being in treatment. They face the continual processes of social development, sexual maturation, and intimacy while also facing isolation, the threat of infertility, alterations in body image, and uncertainty regarding the future (Ettinger & Heiney, 1993; Thomas, Seymour, O'Brien, Sawyer, & Ashley, 2006). From a life course perspective, the intersection of a cancer diagnosis with the developmental tasks of young adulthood can significantly impact social and emotional development, which may result in high levels of distress, and may hinder successful transition to adulthood (Zebrack, 2011).

Current State of the Science

The call to action from the NCI spurred considerable progress in the field of AYA oncology over the last decade, particularly in raising awareness and recognizing AYAs as a distinct patient population with specific needs, circumstances, and health risks. Research on AYAs has proliferated as evidenced by an exponential increase in scientific articles on AYAs and even the development of a scientific journal devoted to the discipline. In addition, specialized clinical programs and services have emerged across the country to support AYA patients in a variety of settings (Smith et al., 2016). At the same time, advocacy efforts have come together to form a strong national presence that can influence policy at multiple levels. Despite this recent activity, the discipline of AYA oncology is still in its infancy and many challenges remain. For example, funding mechanisms for AYA services are sparse because research has not yet demonstrated the value that such efforts add. Training programs that are specific to AYAs are also needed to equip health care providers with evidence-based skillsets and expertise to promote the health and wellbeing of these patients.

Gaps in the Current Literature

As noted, since the initial publication of outcome disparities by the NCI, the interest in AYAs with cancer has increased substantially. In 2013, the National Cancer Policy Forum of the IOM convened two complementary workshops to synthesize the state of the science regarding the unique needs of AYAs and identify major research gaps. Findings from these workshops highlighted survivorship as a key area for future research. Requests emerged to focus specifically on mitigating late and long term effects, addressing psychosocial issues and improving quality of life among AYA survivors (Nass et al., 2015). Similarly, a recent review in *JAMA Pediatrics* on the field of AYA oncology called for an increase in research on AYA survivorship with particular attention to psychosocial needs and critical transitions along the cancer continuum (Barr, Ferrari, Ries, Whelan, & Bleyer, 2016). Another important gap in the extant literature is the lack of research on variations within the AYA population, such as specific treatment and disease subgroups. Therefore, further research is needed, particularly in the area of survivorship, to advance the science and provide evidence for optimal interventions. Such work, especially if it includes input from AYAs themselves, holds promise to enhance quality of care and ultimately improve outcomes for this population.

Purpose of the Study

Using an inductive, qualitative approach, this study focuses on a specific subset of AYA survivors, those who have undergone hematopoietic cell transplantation (HCT) as a treatment for hematological malignancies. Leukemia and lymphoma represent two of the most common cancer types among AYAs and may require HCT as part of treatment (Baker, Armenian, & Bhatia, 2010; Barr et al., 2016). Aiming to restore hematopoietic function, HCT requires a conditioning

regimen of high-dose chemotherapy with or without radiation therapy followed by transplantation of bone marrow or stem cells from a donor (allogeneic) or self (autologous) (Wood & Lee, 2011). This process involves a prolonged hospitalization, with a significant period of intensive supportive care, symptom management, and close monitoring of infections and other complications such as graft-versus-host disease. Once blood counts recover, patients are discharged to the local community with their informal caregivers. Over the long term, HCT survivors face substantial long-term physical and psychological morbidity, even beyond ten years since treatment (Baker et al., 2010; Majhail & Rizzo, 2013; Sun et al., 2011; Sun et al., 2013). Despite the prevalence of hematological malignancies in early adulthood (Barr et al., 2016), very little is known about the HCT experience among AYAs, and even less is known about their transition from therapy to long-term survivorship. Therefore, this dissertation research explored the experiences of critical transitions in early survivorship, such as discharge to the home setting, involvement of an informal caregiver at home, the trajectory towards self-care, and reentry to work and school, among a sample of AYAs after HCT.

Specific Aims

The specific aims developed to guide this study were as follows:

- SA1. To explore and describe the meaning of the AYAs' relationship with an identified informal caregiver(s) during the recovery phase following HCT;
- SA2. To explore the AYAs' processes of regaining independence and resuming self-care, including barriers and facilitators, after HCT;
- SA3. To describe the meaning and experience of these processes in relation to health-related outcomes or associated risks while taking into account the AYAs' social, emotional, psychological, and behavioral functioning or wellbeing;

SA4. To develop a practical framework grounded in the experiences of a sample of AYA survivors of HCT that can inform long-term risk reduction and health promotion interventions for this population.

Overview of the Dissertation: Three Manuscripts

My dissertation research is presented in three independent data-based manuscripts. In the first manuscript, I explored the transition from acute hospitalization for HCT to the home setting and focused specifically on the experiences of relying on informal caregivers during early recovery. Participants described living in a highly restricted world when they first went home, which they called a personal, but protected “bubble.” Despite a desire to be alone, they were dependent on not just one, but several informal caregivers for physical, emotional, and practical needs. Thus, the dynamics of teams of informal caregivers became a focus. Over time, tensions escalated in the confines of the bubble, but ultimately participants accepted their situation as a means to an end.

In the second manuscript of this dissertation, I examined the search for normalcy, which consisted of attempts to return to work or school after treatment. Participants in this sample were in school, employed, or both at the time of diagnosis; therefore, the return to school or work was inextricably linked to a sense of normalcy. The search for normalcy involved several steps, starting with early forays into the outside world, then feeling left behind, rushing to catch up, and finally, struggling to keep up. For some, this process left them unable to rebound and caused them to realize that adjustments were necessary. The context in which they attempted to return to work or school, specific challenges they faced on the path, and strategies they developed in these environments were crucial elements of this paper.

In the third manuscript, I have presented an analysis of the impact of the cancer experience on the AYAs' sense of life potential and their perception of the future in early survivorship after HCT. I have focused on how the AYAs in this sample, prompted by a pivotal shift in their perception, described their reconceptualizations of the future. This shift caused them to realize the lifelong nature of cancer survivorship. In response, participants engaged in adaptive strategies, such as bracing for "something bad" and "rolling with the punches" to adjust to this new reality. Moving forward, however, was complicated by a nagging tendency to wonder about what their life would have been like without a cancer diagnosis.

Specific explanations of the methodology used for each analysis, Grounded Theory influenced by Constructivism, is addressed in each manuscript. Therefore, I will not address methodological issues here. As is fitting, each paper includes a tailored discussion section plus sections on implications and conclusions.

Together, these three manuscripts provide insight into the experiences of a sample of AYA survivors of HCT and the complex issues they face when attempting to move forward with their lives following treatment. In a final conclusion chapter after the third manuscript in this dissertation, I will provide broader perspective on the findings presented, suggest overall implications of this dissertation as a whole in terms of clinical practice, and highlight important areas for future research.

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Zebrack, B. J. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer*, *117*(10 Suppl), 2289-2294. doi:10.1002/cncr.26056

First Manuscript

“A Group Effort”: Understanding the Dynamics of Informal Caregiving
for Adolescents and Young Adults after Hematopoietic Cell Transplantation

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Abstract

Background: Hematopoietic cell transplantation (HCT) is a life-saving treatment for hematologic malignancies, but is associated with significant morbidity that necessitates an informal caregiver. The developmental aspects of the adolescent and young adult life stage may complicate dependence on an informal caregiver during recovery, but virtually no research has explored this phenomenon.

Objective: The objective of this qualitative study was to explore the transition from dependence on an informal caregiver to self-care during the immediate post-treatment period from the perspectives of adolescents and young adults.

Methods: We used Grounded Theory methodology, influenced by Constructivism, to conduct in-depth, semi-structured interviews with a total of 18 adolescents and young adults who were 6-60 months post-HCT. Interview transcripts were systematically analyzed to construct a rich and nuanced understanding of adolescent and young adults' experiences of informal caregiving and dependence as well as progress towards self-care after HCT.

Results: The transition from hospitalization for HCT to the home began with participants immediately retreating to a "bubble" of isolation, in which they relied on informal caregivers rather than professionals for caregiving. Participants described the dynamics of teams of caregivers, rather than single individuals. Despite interpersonal conflicts and frustration in the bubble, participants were ultimately willing to accepted rely on others as a means to an end.

Conclusions: The shift in care responsibilities from medical personnel to informal caregivers was distressing but seen as necessary. Despite a desire for freedom, participants were aware of their vulnerability and generally complied with the restrictions of post-HCT recovery.

Implications for Practice: Our findings raise questions about traditional conceptualizations of

informal caregiving dyads after HCT and their applicability to the experience of AYAs. We also found high variability in transition to self-care with respect to time since treatment. The transition from acute HCT hospitalization to recovery in the home setting represents a time of high dependence for AYAs on their caregivers during which all parties may benefit from supportive interventions.

Introduction

The diagnosis of cancer during the adolescent and young adult (AYA) life stage can result in extensive life disruption and deficits across a wide range of health outcomes (Nass et al., 2015). Leukemia and lymphoma, two of the ten most common cancer types among AYAs, account for 30% of cancers in 15-19 year olds and 23% of cancers in 20-29 year olds (Bleyer, O'Leary, Barr, & Ries, 2006). Hematopoietic cell transplantation (HCT), a standard treatment for leukemia, lymphoma, and other hematological malignancies, aims to restore hematopoietic function by transplanting stem cells from one's self (autologous) or a sibling or human leukocyte antigen-matched (HLA) unrelated donor (allogeneic) after a conditioning regimen of high-dose chemotherapy and sometimes total body irradiation as well (Wood & Lee, 2011). HCT has demonstrated tremendous promise as a life-saving treatment for malignancies that are common during young adulthood. However, high rates of morbidity, mortality, and long-term sequelae associated with HCT mandate that patients identify an informal caregiver as part of the pre-HCT screening process (Be the Match; Cooke, Grant, Eldredge, Maziarz, & Nail, 2011). It is expected that even an uncomplicated HCT course will necessitate the commitment of an informal caregiver. For AYAs recovering from HCT, the transition to self-care can be a developmentally disruptive, prolonged, and challenging period of uncertainty, isolation, and dependence on an informal caregiver, about which very little is known.

The term, "informal caregiver," refers to an unpaid family member or friend who provides health-related assistance to someone with a chronic health problem that is unable to care for him/herself independently (Family Caregiver Alliance). The estimated 44 million informal caregivers in the U.S. have been described as an extension of the health care workforce (Feinberg, Reinhard, Houser, & Choula, 2011). According to recent estimates, family caregivers

who live with those they provide care for spend just over 40 hours per week on caregiving, the equivalent of a full-time job (National Alliance for Caregiving, 2015).

Informal caregiving specifically after HCT has been compared to “opening Pandora’s box” (Sabo, McLeod, & Couban, 2013) and “riding a rollercoaster in the dark” (Wilson, Eilers, Heermann, & Million, 2009). It requires the acquisition of specific knowledge (e.g., health risks associated with immunosuppression and pancytopenia) and skills (i.e., dietary restrictions and meal preparation, maintenance and care of vascular access devices, medication schedules, infection precautions) to ensure safety in the home (Cooke et al., 2011), but is also an emotional endeavor rife with uncertainty and fear for both the patient and the caregiver. In addition, the caregiving demands after HCT may persist for several years (Boyle et al., 2000; Cooke et al., 2011). The work of caregiving not only impacts the patient’s health outcomes, but has also been shown to take a severe toll on the physical and mental health of the caregiver (Bishop et al., 2007; Reinhard, Given, Petlick, & Bemis, 2008; Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). Studies suggest that many caregivers feel unprepared for this role and face increased risk of distress and burnout (Cooke et al., 2011; Reinhard et al., 2008; van Ryn et al., 2011), depression and anxiety (van Ryn et al., 2011), and low quality of life (Bishop et al., 2007; Cooke et al., 2011; Sabo et al., 2013; Vanderwerker et al., 2005). Aside from the physical and psychological effects, caregiving for HCT recipients requires extraordinary time commitments and financial costs (Majhail et al., 2013; Meehan et al., 2006). While meeting these obligations, many informal caregivers also struggle to maintain employment, reporting missed days, leaves of absence, and reduced productivity in the workplace (Cameron, Franche, Cheung, & Stewart, 2002; Family Caregiver Alliance). Given their level of responsibility, informal caregivers may seriously affect HCT outcomes (Frey et al., 2002; Reinhard et al., 2008).

Very little is known about AYAs' experiences with informal caregiving after HCT. The interaction between the developmental tasks of the life stage and the dynamics of the informal caregiving relationship has not been explored. The AYAs' transition to self-care in the post-treatment phase is a critical period with broad implications for long-term wellbeing (Hewitt, Greenfield, & Stovall, 2006; Park, Zlateva, & Blank, 2009; Thorne & Stajduhar, 2012). AYAs are particularly vulnerable in this transition due to high-intensity treatments, increased risks for long-term effects, and a wide array of unmet physical, psychological, social, and information needs (Keegan et al., 2012; Nass et al., 2015; Smith et al., 2013).

The "AYA paradox" (Kent et al., 2012) describes the tension between the psychosocial aspects of the AYA life stage, such as establishing independence, discovering one's identity, and exploring a wide range of future possibilities (Arnett, 2014), coupled with the simultaneous need to rely on an informal caregiver during and after treatment. While decreasing reliance on their caregivers after HCT is developmentally appropriate, virtually no research has explored AYAs' experiences of dependence on informal caregivers after HCT and how this impacts their recovery trajectory. Thus, the purpose of this qualitative analysis was to explore AYAs' perspectives of their transition to self-care and their relationships with informal caregivers as they recovered from HCT.

Methods

Design

We utilized a qualitative, inductive approach to gain an in-depth understanding of AYAs' perspectives and experiences with informal caregivers post-HCT. Grounded Theory methods (Corbin & Strauss, 2008), influenced by Constructivism (Charmaz, 2014), provided systematic yet flexible guidelines for all aspects of this study. Approval was obtained from the institutional

review boards of the City of Hope National Medical Center and the University of California, Los Angeles.

Recruitment

AYAs who received HCT in the inpatient setting for treatment of a hematologic cancer and were 6 to 60 months post-HCT at the time of the study were identified from the patient population of a national comprehensive cancer center in Southern California (Figure 1). Key variables were reviewed in the medical records to verify the eligibility of potential participants. Only participants whose primary cancer diagnosis was hematological, who were 15 - 29 years at the time of HCT and at least 18 years at the time of interview were eligible. Those who had relapsed since HCT, had a history of more than one HCT, could not speak English, or were cognitively impaired were excluded. Eligible patients who were deemed medically complex (such as pending results or recent hospitalizations) or were receiving follow-up care at another facility were not approached. Ultimately, 59 introductory letters were mailed inviting participation in the study. After a response rate of 5%, we followed up selectively by either a phone call or an in-person approach at scheduled clinic appointments. For patients receiving active care at the institution (defined as seen within the last 2 years), permission from the primary hematologist was obtained before initial contact.

Simultaneous Data Collection and Analysis

After receiving written informed consent, intensive interviews were conducted by the first author with each participant either in person or via telephone depending on participant preference. A semi-structured interview guide, based on findings from a previous pilot study on AYA cancer survivors by the first author, was developed to enhance consistency of data collection (Table 1). Open-ended questions and probes focused on the transition to self-care, the

relationship with informal caregiver(s), and the experience of acute recovery in the home setting. With participants' permission, interviews were digitally audio-recorded and were on average 102.4 minutes (range: 56.4 – 164.2). Then, recordings were transcribed verbatim by a professional transcriptionist, checked for accuracy and de-identified. Additional data collection consisted of a Demographic Questionnaire created by the research team and the abstraction of relevant clinical variables from the medical record, such as age, primary cancer diagnosis, transplant type, and time since HCT. After protocol-driven procedures were completed, participants received a \$50 gift card to compensate them for their time.

Data collection and analysis occurred concurrently to allow for constant comparison (Charmaz, 2014; Corbin & Strauss, 2008). Data analysis began with coding, which allowed us to link concrete description to theoretical insights (Charmaz, 2014). Starting with initial coding of each individual transcript, we studied the emerging data and began to conceptualize ideas using gerunds to bring attention to participants' actions. Next, we used focused coding to develop the most salient codes and identify tentative categories to form a theoretical foundation. The strategy of theoretical sampling narrowed our focus in further data gathering to refine and fill out emergent categories and help answer analytic questions. This analytic process continued until major theoretical categories were deemed saturated and robust and no new properties emerged (Charmaz, 2014). The strategies of memo-writing and diagramming were central to all stages of our analysis and allowed for theoretical exploration, refinement, and abstract interpretation (Charmaz, 2014). Rigor was enhanced during data analysis in that a minimum of two independent qualitative researchers were engaged in multiple rounds of collaborative coding and analysis at each stage of the process. A software program, Atlas.ti, was employed for initial coding, focused coding, early memo-writing, and network diagramming to explore tentative

categories, their properties and dimensions, as well as to support overall data management and organization (Atlas.ti).

Results

This paper focuses on the transition from acute HCT hospitalization to the home setting among a sample of AYAs (N=18), and the resultant shift in dependence from hospital personnel to informal caregivers. Sample characteristics are listed in Table 2. Through analysis, three major categories were developed in the data. The first category, *Retreating to “my own little bubble,”* referred to the way that participants retreated into extreme isolation after discharge from the hospital into what was called a protective “bubble.” The second category, *Interactions with informal caregivers in the bubble,* described the dynamics of caregiving relationships and included three sub-categories: “A group effort:” *Teams of informal caregivers,* “No longer surrounded in the Safety:” *Loved ones instead of professionals,* and *Nowhere to vent: The bubble as pressure cooker.* The third category, *The bubble as a means to an end,* referred to the way participants reflected on the purpose of the bubble.

Retreating into “My Own Little Bubble”

Although they were no longer hospitalized, the AYAs in this study acknowledged they were living in a highly restricted version of reality, what one called “the small portion that was accessible to me.” During this time, the home setting represented the participants’ entire world. They were aware of their vulnerability and retreated immediately into isolation or, what multiple participants termed, the “bubble.” According to one participant, the bubble provided safety and protection:

I can't be around people. I can't live in the outside world. I'm in my own little world, my own little bubble, and I feel safe. And once I go out, it's like I'm allowing [myself] to get

hurt. And I don't want that. So, I keep myself away in my own little bubble.

For the AYAs of our sample, the bubble was a self-enforced form of extreme isolation. Many spoke of isolating themselves in their rooms most of the time, as one participant recalled, “I literally stayed in my room, stayed in my room. I did not want to go outside, didn't want to do anything, and just stayed in my room.” Another confided, “I just wanted to be in my room and sleep and just think. [...] You just want to be alone.” Participants described eating meals in their bedroom, away from family. Aside from follow-up medical appointments, they stayed home almost exclusively and refused to leave the house, even for a short walk. In addition, several participants also spoke of refusing any type of physical affection (hugs, kisses, hand holding) from parents or significant others during this time.

For many, the bubble was a source of comfort, offering safety but also control of personal boundaries. One participant recalled that in the hospital,

People come in and come out, and you don't really have privacy. I mean you can't lock your door, obviously. And so you can't necessarily bar anybody either. I mean they have to do their job, right? [...] The point was it was my bed. No one was coming in. It was my room. I got to control it. I got to shut the door, and nobody could come in. So, I was really freaking excited. It was my space, and I got to reclaim it. [...] And you don't necessarily even get to control who touches you. [...] So I was just like, ‘No. I need a bubble. I need my personal bubble, and don't come into it.’

Interactions with Informal Caregivers in the Bubble

Despite their strong desire to be alone, participants freely admitted that they could not

take care of themselves at home and accepted their dependence on informal caregivers while in the bubble. All participants recalled conversations with their oncologists about the requirement for an informal caregiver prior to HCT. For many, the decision was clear, as one said, “a no-brainer.” However, participants also acknowledged that they did not fully comprehend the caregiver role when it was first explained, as one shared,

Kind of like every other thing that’s said to you during the cancer process, it goes through one ear and out the other because it’s so much information all at once. So, these things didn’t really hit me until I was going through them and I realized how sucky it really was.

In cases where participants lived far from home at the time of diagnosis, caregiving required either the participant or the caregiver(s) to uproot their lives in order to be close. For example, several parental caregivers traveled across state and country borders or took time off of work during acute treatment. Many reported that their informal caregivers quit their jobs or schooling entirely, while others struggled to balance competing responsibilities.

Participants returned home with extensive physical issues including overwhelming fatigue, weakness, and medication side effects. Without an informal caregiver helping him, one participant explained, “I could have slept all day.” Fatigue and weakness resulted in high dependence on caregivers for basic care. One participant explained,

I didn't have the strength to go upstairs anymore. I had to use the downstairs shower.

They had to clean it every time because usually I would have an episode of vomiting or loose stools. And [long pause] sometimes bathing was an issue, where I wasn't strong enough to hold myself.

Participants recalled numerous challenges at home, such as being unable to pour their own drinks, open bottles, pick something up off the ground, or use the stairs more than once per day. One described the “mental preparation” required just to stand up from bed each morning. Some felt unsafe with respect to falling or slipping without their caregiver nearby.

Participants also depended on caregivers to convince or even “force” them to engage in healthy behaviors, such as taking a short walk, eating and drinking water adequately, and taking their many medications as prescribed. This was because, as one participant explained, “I didn’t have a nurse there.” With respect to eating, participants explained that caregivers not only obtained food at a grocery store and prepared it according to specific dietary restrictions, but they also offered considerable encouragement to ensure it was eaten. As one participant mentioned, “Eating is probably one of the most hard things to do after a transplant.” Another participant described how her caregiver helped her in various ways, such as “getting food, getting my medications, just being there, bringing me water, making me get up and walk around.”

In most cases, caregivers were also responsible for maintaining extraordinary medication schedules. One participant had a medication schedule of “70 pills a day,” which meant taking multiple medications nearly every waking hour. In addition, some participants needed caregivers to administer intravenous medications through vascular access devices. One participant was amazed at his mother’s ability to take control over his medications saying, “She knows my pills. She knows which ones I take in the morning, afternoon, and nighttime. You know, I wake up in the mornings. They’re ready in a little cup. I’m like, ‘Man, what time did she come in?’” When another participant started losing track of his pills, his caregiver developed a color-coded schedule system using a whiteboard to prevent missed doses. Participants also spoke at length about their caregivers’ cleaning and housework responsibilities. Overall, participants

acknowledged, some tearfully, the extraordinary responsibilities that their caregivers had assumed.

“A group effort”: Teams of informal caregivers.

While most participants (n=14/18) identified a parent as their primary caregiver, they also reported extensive needs across life domains and generally believed that no single caregiver could meet them all. Therefore, the majority of participants (n=15) described teams of caregivers rather than a single person, with one participant explaining, “It was a group effort.” This division of labor typically involved parents handling practical, medical and financial tasks and advocating on their young adult child’s behalf, while intimate partners, siblings, very close friends, and even a pet provided emotional support, distraction, and companionship. In addition, many participants spoke of different loved ones filling caregiver roles at different times along their trajectory, such as during the inpatient stay versus recovery at home. For example, several participants spoke of barriers for certain caregivers to come to the hospital, such as parents who could not drive and a mother who was breastfeeding a newborn. Others explained how friends or intimate partners assumed responsibilities when parents had to resume other aspects of their lives. Another participant relied on his mother early in recovery because she was a retired registered nurse, but after he returned to college, his roommate accompanied him to medical appointments for moral and informational support.

Participants realized that dividing responsibilities across a team of caregivers brought together an array of strengths, attributes, and qualities to get them through recovery. As one participant explained this division between her parents, “I can turn to one or the other based on my own needs.” Similarly, another participant described how her mother and husband supported her in different ways:

Usually when you're married, you always think your husband's going to be the one that's going to take care of you and be that one. But, for me, it wasn't like that. It was like, okay, my mom understands me more. [...] She understands it more than my husband can be there for me. Because, from my husband, I felt more like he was just there to love and just cheer me up, but he couldn't be there to help me get through it physically. So, my mom was always the one I always looked for to having around me all the time. She would stay the night with me and stuff like that. And she would pray with me and just make sure that I felt good.

Other participants described how a team of caregivers provided secondary, or more peripheral caregiving of the overall family unit. A participant, whose baby sister was born while she was undergoing treatment, identified her mother as her primary caregiver while noting that her grandparents came from another state to care for the baby and her other young siblings so her mother could be by her side. Another participant described how his siblings pitched in to help his mother, who was also a caregiver to her own mother.

No longer “surrounded in the safety:” Loved ones instead of professionals.

Despite the advantages of a team of trusted caregivers, the shift from depending on clinical professionals to entrusting care to loved ones also brought on new fears and increased distress. Although informal caregivers were sometimes present during hospitalization, they were typically not involved in care management. Thus, the transition to the home resulted in anxiety, with one participant stating, “We [had] too many questions. Like, there wasn't a doctor to just like pull into the room and be like, ‘Hey. She's got a little cough.’ [...] We were kind of like panicky. You know, we weren't surrounded in the safety.” For many, the hospital was associated

with safety, and one participant likened it to a “vacation” because she worried less in the hands of professionals.

Parents as informal caregivers.

While participants expressed gratitude for the support they received while in the bubble, their increased reliance on caregivers brought distinct challenges, especially when the caregiver was a parent. Of note, no participants in this study were parents themselves. The AYAs in this sample explained that the shift in caregiving responsibility to their parents also meant a return to dependence on those who cared for them as children. However, in many cases, the need for physical, emotional, and practical support from their caregiver overrode the desire for independence they had felt before cancer. One participant reminisced,

Going off to college, I was like, ‘No. I don't want my parents. I don't need to talk to them.’ It's just, you know, I wanted freedom. I wanted adulthood. And then getting the cancer, obviously I was like, ‘I want my mommy.’

For others, living under their parents’ roof again signified a distressing loss of independence and privacy. One participant described her frustration after she and her husband moved back in with her parents saying, “It sucks to feel not independent.” Others described their parents’ overbearing worry as the most challenging aspect of this phase, with one participant explaining how he filtered his own emotions to “accommodate” his mother’s anxiety.

The dynamics of caregiving exacerbated family conflicts and relationship tensions that existed prior to diagnosis. One participant spoke of having to rely on a mother she never got along with:

It wasn't like we bonded over this, you know, tragic thing. It was more like the problems

that were conflicting, were conflicting on top of this cancer. [...] I think the severity of it got worse, because the tensions were higher. [...] And then, I'm just on all these meds and trying to stay sane. And a lack of sleep on both ends. And just, it wasn't a good mixture.

Another participant described how emotions escalated because her illness forced her divorced parents to interact. She explained, "The problem, of course, is that they had to be together in a room with me. [...] Unfortunately, it's just a really pressured situation. You know, their only child is sick." Thus, caregiving contributed to feelings of distress in contexts of previous familial or relational dysfunction.

Some participants found the parental caregiver relationship challenging once their need for help decreased. As their level of dependence waned, some reported difficulty overcoming regressive behaviors and establishing new relationship dynamics with parents. As one participant shared,

I am feeling better, I don't have the same dependency on my parents. However, we do seem to be locked into a pattern almost. So, I do need to just learn who I am again, I guess, so that I am not always acting like a young child in front of them. You know, it's easy to revert to that. It's easy to be playfully young in front of them. 'Daddy, buy me this,' or, 'Mommy, get me a sandwich,' or, you know, whatever - kind of just child-like almost, deliberately childlike and immaturely childlike. [...] But I'm not in that anymore. That's not my age, and now I'm not a cancer person either. So, you know, it's just hard to figure out what our dynamics are now.

Intimate partners as informal caregivers.

The dynamics of informal caregiving between AYAs and their intimate partners also presented unique challenges. During treatment and acute recovery, some intimate relationships persisted, some dissolved, but no new intimate partnerships were formed. In the bubble, participants felt incapable of the tasks of relationship maintenance. Social support and physical intimacy seemed impossible, and participants often felt unworthy of their partners. One explained, “I just don’t feel good enough, I guess you could say, for my wife.” Another participant who referred to her boyfriend as “my biggest emotional support” offered him an exit from the relationship,

I actually had said to him, ‘It’s okay if you want to break up with me. I totally understand. I don’t want to put any pressure on you.’ [...] I feel like it kind of sped up things. Like, how serious we would be. Because before, we were just dating like, four months. So, it was all like, just lighthearted, and wasn’t super serious. And then, like, I was diagnosed. And he was like, ‘I want to be with you through this.’ So, that stepped it up.

Overall, participants adamantly expressed that they did not want their partners to stay in the relationship out of pity. Also, participants did not expect partners to quit work, school, or postpone life plans on their behalf, which differed slightly from expectations for parental caregivers.

Most participants struggled with body image issues, as one participant would not video-chat with his long-distance girlfriend of eight years to avoid “letting her see me like that. [...] Like, if I didn’t like how I looked, I didn’t want people to see me like that. I would look at myself in the mirror, and I would like go into some depression mode.” Participants also admitted to

having low to no interest in physical affection or sex, but attempted to maintain intimacy as a way to counteract the imbalance that caregiving put on their relationships. Unfortunately, many AYAs in our sample faced challenges with sexual dysfunction, as described by one who felt the side effects of his medications, explaining “I’d be ready to like get down to business, and I wasn’t able to function. Like, I’d just feel like numbness all over my body.” Participants also reported difficulty with loss of libido and the energy demands of intimacy. One explained, “I was probably just more worried about being tired. A lot of the drugs that I’d taken, and radiation, and chemotherapy like, do really diminish sex drive. By a lot. To the point where it’s just non-existent.”

The interpersonal interactions of intimate relationships were also difficult for participants. They felt drained, exhausted, and unable to reciprocate emotional support. For example, some participants struggled to sympathize with their partners’ seemingly trivial problems. As one recalled,

[My girlfriend] called me, talking how her and her best friend were fighting. And I was sitting there, nauseated, getting platelets through an IV. And I was like [...], ‘Do you realize how insignificant your little argument with your friend is here?’

Participants also expressed concern about the immense burden of caregiving on their intimate partners. They observed the toll their illness took on these loved ones and felt the overwhelming responsibility was unfair. As one participant described what he observed in his girlfriend,

People will tell caregivers, ‘Oh, that’s so great that you’re doing this.’ There’s always though a tinge of like, ‘Well, it’s expected that you’re going to do this.’ And that’s- That

can be hard after a while. For a caregiver to feel like, ‘Well, this is my obligation. And I need to do this. And I need to do it well. And if he gets sick, or if there’s something that isn’t sterile at home, or if I’m not quick enough to make a meal, or take care of his needs, he’s going to get sick and it’s my fault.’ There’s *that* level of stress!

For those intimate relationships that endured, participants expressed appreciation for their partners, but also admitted the imbalance that caregiving created in their relationship, recognizing that “it’s not rainbows and lollipops.”

Nowhere to vent: The bubble as emotional pressure cooker.

Over time, the confines of the bubble and exclusive interactions with caregivers felt more constrictive and resulted in heightened emotions, specifically frustration, anger and guilt. Participants typically lived with more than one person during recovery, reporting an average of 3.9 people in a household (range: 2-7). Thus, participants had very little time alone and nowhere to vent. In addition, many pointed out that their typical outlets for stress, such as playing basketball, paintball, going to the shooting range, or meeting friends for happy hour, were off limits due to restrictions and limitations.

No time alone: Suffocating in the bubble.

Many participants felt frustrated and even suffocated by their lack of alone time. Informal caregivers left them for only brief periods and checked in frequently while gone. As one participant explained, her family left her for “probably like 30 minutes by myself, but they won't leave me longer than that and they're constantly calling me when they're gone.” Another participant, who requested a weekend of “alone time,” away from her “hovering” parents, recalled,

I wanted freedom, so I was like, ‘Mom, please rent me a hotel room for a weekend.’ And so I wanted two nights at the hotel room without Dad, without Mom, just me at the hotel room, because at the apartment, Mom and Dad were both there. And I didn't take my IV stand with me. So, I had to get like a hotel hanger, and I had to put the IV on the hotel hanger, and then I actually hung it from a picture frame so that it would drip down and come up. [...] It was such ridiculousness. I mean like I must've stood on the bed like 20 minutes, trying to get the hotel hanger to hook into the picture frame, because you can't do it from the sprinkler system because that will set off the sprinklers. They have a big old sign right next to it that says, ‘Do not hang things.’ And then, by that time, I panicked. And so I ruined the whole thing by calling my Dad at like 10:00 p.m. and being like, ‘Can you come sleep with me in the hotel room?’ And so he comes over and sleeps in the other double bed. Apparently that was too much freedom. [...] I guess maybe [I wanted] just time alone. I mean I guess my parents hovered, I guess. I mean they're concerned, obviously. And I must have just felt like they were around too much.

“And then the anger comes out:” Emotional outbursts directed at informal caregivers.

Most participants resigned to the fact that their health and caregiving needs compromised their freedom, but some also voiced frustration about the confines of the bubble, their dependence on other people, and their lack of privacy. In fact, some participants described lashing out or “snapping” at their caregivers, with one sharing,

I would all of a sudden wake up and- I mean, I'm sure it was the pills, just in my brain. Just frustrating me. But I would wake up and just start yelling at my mom. I don't know why. And I'd yell at my wife's mom. I'd yell at my wife. And I don't even know why I

would do it, to tell you the truth. [...] I was just getting frustrated with people being around me all the time. [...] It wasn't their fault. But it was just my anger in general. [...] Even though they're doing the right thing, and they're helping you. [...] Like, the cabin fever, claustrophobic. Like, it just felt like everything was kind of shrinking down and closing in on me. [...] I just felt like I was a child again. [...] And then, the anger comes out. You don't *want* to direct it at anybody. But [the caregiver is] the first person you see in the morning. It was either my mom, her mom, or [my wife].

Participants felt caught off guard and surprised by these emotional outbursts. They described a constant mixture of strong, percolating emotions that would occasionally erupt in an uncontrollable way. In many instances, the caregiver was simply in the line of fire and not the direct source of their frustration. However, others did voice specific complaints about their caregivers, such as hovering, worrying, and nagging, but at the same time, felt guilty because their caregivers were doing so much for them. As conflicts escalated for one participant, he wondered if his family actually wanted him to get well. Tired of his “fits” and “tantrums,” he explained, “[They said], ‘We don't know what's wrong you anymore.’ I'm like, ‘I just want to get out of the house, get away from you guys.’”

“I'm not sick anymore:” Unburdening their informal caregivers.

As they grew aware of the physical, emotional and financial impact of their HCT on their caregivers' lives, participants were profoundly moved, but also felt guilty. One participant struggled with the impact of caregiving on his younger, teenage brother, who drove him across the city to his appointments despite not having a driver's license and sacrificed his own college

scholarship to drop out and take care of him. He explained, “I feel like I delayed his life, like I burdened him with that. I appreciate what he did, you know, but I just feel like he was held back because of me.” As a way to unburden their caregivers, many participants felt compelled to prove they were no longer sick. Another participant described a similar desire to relieve his parents of their worry:

I feel like, thanks to them, I'm here. [choking up] But now I try to show them that I'm doing great, so it has to stay that way. [...] In my attitude, by always making jokes, showing them that I'm working out, that I feel great, that I can do things. [...] Show them that that old kid that I was, sitting down on the couch, who was sick, is not sick anymore. I'm not sick. That's all. I'm not sick anymore.

Participants also tried to protect their caregivers from the difficult emotional aftermath of their illness. As one explained, “They’re already seeing enough. Why put them through any more? [...] I’m not going to tell her the deep, deep dark secrets of what I was feeling if I knew it was going to affect her.” Some participants spoke of letting down their families by simply being diagnosed, explaining that no parent should have to hear their child has cancer. Others created distance in their relationships to reduce the “suffering” their disease caused others. Some even withheld negative information, such as news of disease progression, from their families. Therefore, proving to caregivers that they were no longer sick was a common attempt to deal with feelings of guilt, break away from their caregivers and reclaim some level of independence. In addition to unburdening, participants also decreased reliance on caregivers when caregivers themselves had to return to work or tend to other responsibilities.

The Bubble as a Means to an End

As long as participants were in the bubble and highly dependent on their caregivers, they felt they were not leading a normal life of a young adult and had not moved beyond the cancer experience. Therefore, the bubble was also associated with frustrated dissatisfaction. In part, this stemmed from the inability to give attention to broader life plans, such as resuming work, school, or social relationships, during immediate post-HCT recovery. Participants described feeling “trapped” and likened the bubble to “house arrest” or “prison.” One participant elaborated, “Obviously, it’s better than being in the hospital, but, the mindset was still, ‘I’m still a prisoner. This is not the way I should be living.’” Despite feeling dissatisfied with the isolation and dependence, participants accepted the bubble as a means to an end.

Aware of potential threats to their health after HCT, participants tried to live cautiously and realized that heavy restrictions and reliance on caregivers were necessary to protect their health as well as their future potential. They saw the bubble as instrumental to getting back to their pre-diagnosis lives. As one participant explained, “I wanted to re-engage where I left off when I got sick and try as much as possible to just go on normally as if it hadn't happened.” Participants were motivated by the belief that this sheltered period of recovery would allow them to eventually fulfill their potential, with all of their abilities and life plans still intact. Therefore, they were willing to endure the extreme isolation of the bubble and accept extensive help from caregivers because they understood this situation to be temporary and worthwhile.

Discussion

Diagnosed as AYAs, participants in our study were on the brink of self-discovery, in the process of establishing independence, and immersed in identity exploration when a cancer diagnosis changed their world. Their willingness to isolate themselves in a “prison”-like bubble after HCT was predicated on the assumption that rest and recovery would return them to where

they left off. Thus retreating into “my own little bubble” for a finite period represented a compromise through which participants attempted to preserve their future potential for a “normal” life.

From the AYAs’ perspective, the transfer of care from medical professionals to informal caregivers was a necessary, but emotionally demanding change. It was followed by extended time in a bubble that offered safety and privacy, but also intensified isolation and dependence on informal caregivers. Our findings are consistent with previous studies about informal caregiving after HCT in which responsibilities stretch far beyond providing meals, helping with hygiene, and transportation and include the provision of complex medical care, emotional support, and patient advocacy (Cooke et al., 2011; Sabo et al., 2013). In the bubble, participants interacted almost exclusively with informal caregivers. The smallness of their world resulted in some emotional eruptions because participants had nowhere else to vent, but generally they acquiesced to the restrictions that their recovery demanded.

From the perspectives of the AYAs in our sample, the process of decreasing reliance on an informal caregiver was much more gradual and complicated than the abrupt separation from the medical team at the end of treatment. Only when participants’ physical health improved and they were able to be more independent with basic self-care did they begin to fully comprehend the contributions of their caregivers. They were painfully aware of the impact of their cancer on their caregivers, citing physical, emotional, and financial sacrifices their loved ones had made on their behalf. This led to a compulsion to try to unburden their caregivers by shedding their sick identity when they could, engaging in healthy activities and holding back from expressing negative emotions. The notion of unburdening is similar to the concept of “protective buffering” (Langer, Brown, & Syrjala, 2009) and is consistent with Forinder and Posse’s study (2008) on

adolescent HCT survivors. Unburdening holds particular significance when it coincides with developmental expectations of independence.

The division of caregiving labor across a team in our sample may have also been a strategy to minimize burden on any single caregiver. Even though they typically identified a primary caregiver, such as a parent or intimate partner, these AYAs recognized that a range of different people in their lives supported them in different ways. These team caregiving arrangements also fluctuated over time as circumstances changed. For example, several friends or intimate partners assumed responsibilities when parental caregivers had to return home or tend to other responsibilities. This finding of team caregiving arrangements is significant when situated within the broader HCT literature. The demands of informal caregiving have been fairly well-documented for younger and older groups of HCT survivors, with the pediatric literature focused on parental caregivers (Forinder, Claesson, Szybek, & Lindahl Norberg, 2015; Forinder & Norberg, 2014; Lindahl Norberg, Mellgren, Winiarski, & Forinder, 2014; Riva et al., 2014; Rodday et al., 2012; Virtue et al., 2014) and studies on adults reporting on spousal caregivers and the impact of HCT on marriage (Cooke et al., 2011; Jia, Li, Chen, & Cao, 2015; Langer, Abrams, & Syrjala, 2003; Meehan et al., 2006; Rexilius, Mundt, Erickson Megel, & Agrawal, 2002; Sabo et al., 2013; Wilson et al., 2009). In both cases, research portrays the relationship between survivor and caregiver as strongly dyadic, either between parent and child or between spouses, even if other caregivers contribute as well. The studies on adults after HCT and their caregivers also describe a predominantly middle-aged, white, married, heterosexual point of view that may not pertain to AYAs. Our results suggest that neither the one-to-one parent-child dyads in the pediatric literature nor spousal dyads in the adult literature describe the unique caregiving configurations of the AYA HCT experience accurately.

Instead, the AYAs in our sample benefitted from more fluid teams of caregivers rather than individual caregivers. By drawing support from multiple people in their lives, they acknowledged the limitations of specific relationships and avoided overburdening any single person. Relying on a parent required sacrificing recently established independence and sometimes triggered regressive relationship dynamics. Meanwhile, relying on friends, roommates, or intimate partners as caregivers placed overwhelming demands on non-familial, less committed relationships. Therefore, the distribution of informal caregiving responsibilities described by our AYA sample across a team of loved ones may reflect the open-endedness of young adulthood and ultimately promote developmental growth in the context of long-term survivorship.

Progression out of the bubble and subsequent decreased reliance on caregivers did not necessarily correspond to time since HCT. In other words, the AYAs in our sample did not consistently describe a linear recovery trajectory of steady improvement in self-care. Rather, participants reported high variability in self-care functioning across the sample, with little relationship to time since HCT. The bubble period began with acute recovery in the home setting immediately following HCT hospitalization. While some gradually emerged out of the bubble as their ability to do self-care improved, many participants found themselves stuck in the bubble or caught in a pattern of returning to the bubble after setbacks. Many participants continued to experience considerable limitations in their daily activities regardless of time, but particularly as late effects started to emerge. Therefore, decreased dependence on caregivers and the ability to care for oneself were not guaranteed eventualities and successful transition to self-care was likely dependent on other factors, aside from time since HCT.

Limitations

This is the first study to explore AYAs' relationships with their informal caregivers after HCT. However, despite the novel nature of this research, the findings must be considered in the context of several methodological limitations. First, the retrospective design required participants to pull up memories of their experiences, opening the door for potential recall bias. Given the qualitative nature of the study design, the purposive sampling technique, the sample size of 18, and the fact that all participants had survived and were currently in remission, the results are not generalizable to the larger population of AYAs after HCT. Additionally, our findings are limited to the experiences of AYA patients who were treated at a single institution, a national comprehensive cancer center in Southern California and should be considered as such.

Conclusions

Despite growing interest in the AYA oncology population, current knowledge on the relationship between AYAs and their informal caregivers is extremely limited. Our findings have implications for clinical practice for AYAs undergoing HCT. First, it is important to recognize various members of a team of caregivers identified by AYAs and involve them in follow-up care as much as possible. By recognizing the variation in multiple caregivers, clinicians can strive to understand specific roles and provide more tailored information and support. Furthermore, for example, it may also be helpful for clinicians to provide guidance on "alone time" when appropriate to allow AYAs some personal space.

Our findings serve as a preliminary basis on which to build larger, multi-institutional studies to better understand the recovery trajectory of the immediate post-treatment period among AYAs after HCT. Our results also suggest that issues of long-term HCT survivorship and their impact on informal caregivers may extend beyond 5 years, indicating a need for long-term, longitudinal studies. Future research should include the perspectives of the informal caregivers

themselves as well. Based on the significant involvement of caregivers across the HCT trajectory, future studies should also examine possible relationships between caregiver qualities and patient outcomes. Of note, researchers have begun to test a needs questionnaire for caregivers of AYAs with cancer, but to date, the evaluations of the tool's acceptability are limited and reflect only the input of parental caregivers (Carey, Clinton-McHarg, Sanson-Fisher, & Shakeshaft, 2012). Our findings challenge the appropriateness of conventional dyadic models of caregivers and patients for the AYA population. Ultimately, better understanding of the unique aspects of informal caregiving for AYAs after HCT will not only help support successful transition to self-care and reduce developmental disruptions for these patients as they embark on long-term survivorship, but it will inform the design of future randomized controlled trials to enhance development of needed interventions.

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Table 1: Example Questions from the Semi-Structured Interview Guide

Area of Focus	Examples of Questions and Probes
<p>Relationship with informal caregiver(s)</p>	<p>When people are preparing to go through a transplant, they are often asked to identify a caregiver. Tell me about your experience with that.</p> <p>Who would you say was your primary informal caregiver?</p> <p>Did you have other informal caregivers? If so, who?</p> <p>Who selected your informal caregiver? <u>Prompt:</u> If it was you, how did you select your informal caregiver? <u>Prompt:</u> What factors did you consider when selecting this person?</p> <p>Tell me about your informal caregiver. <u>Prompt:</u> Describe your relationship prior to your diagnosis. <u>Prompt:</u> Did you live together? <u>Prompt:</u> How often did you talk? <u>Prompt:</u> How or in what ways did you rely on them?</p> <p>What did it mean to you to have this person designated as your caregiver? <u>Prompt:</u> What did you need help with? <u>Prompt:</u> What helped? What made things harder? What/who got in the way? <u>Prompt:</u> How did your caregiver fit into this? Tell me about what your informal caregiver did when you left the hospital.</p> <p>How did you view your relationship with your caregiver at this point? How did you see yourself in relation to your caregiver?</p> <p>Over this time, tell me about any changes that occurred in your relationship with your informal caregiver. <u>Prompt:</u> What happened? <u>Prompt:</u> Why do you think that happened?</p>
<p>Transition to self-care</p>	<p>How do you feel about your level of independence now? How well do you feel you are able to take care of yourself now? <u>Prompt:</u> How does this make you feel? <u>Prompt:</u> Tell me about a time when you felt very independent. What happened? <u>Prompt:</u> Tell me about a recent time when you felt very dependent? What happened?</p> <p>Now (currently) who do you rely on most? Why? How do they help you (physically, emotionally, financially)?</p>

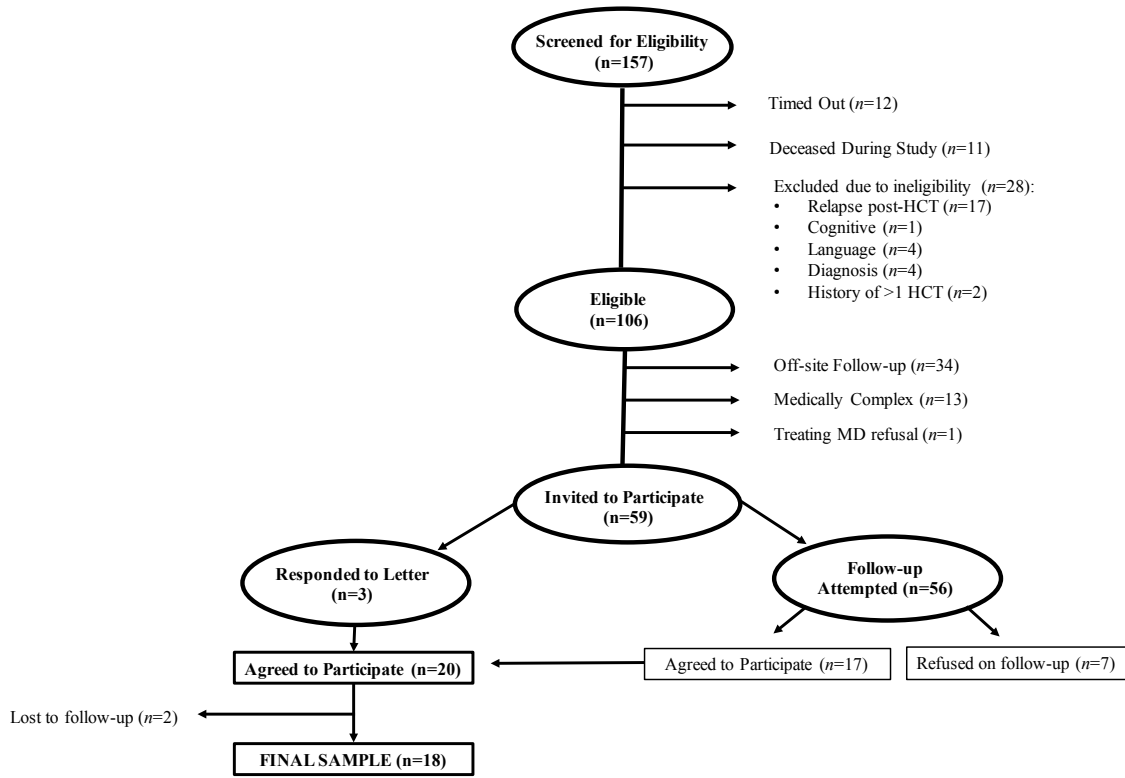
	Is there something that your caregiver(s) can do that would be more helpful?
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Table 2: Sample Characteristics (N=18)

Characteristic	Mean	Range	n
Mean Time since HCT (months)	32.8	(8-60)	
Mean Age at HCT (years)	23.3	(18.5-29.7)	
Mean Age at Study (years)	26	(19.8-34.6)	
Gender			
Male			11
Female			7
Ethnicity			
White/Caucasian			7
Hispanic/Latino			8
Asian/South Asian			3
Diagnosis			
Hodgkin's Lymphoma			2
Acute Myeloid Leukemia			10
Acute Lymphoblastic Leukemia			5
Non-Hodgkin's Lymphoma			1
HCT Type			
Allogeneic, HLA-Matched Unrelated Donor			9
Allogeneic, Sibling Donor			3
Allogeneic, Cord Blood			3
Autologous			3
Primary Caregiver			
Mother			10
Father			2
Both Parents			2
Friend			1
Intimate Partner			2
Sibling			1
Living Situation at Study Enrollment			
Family of Origin (Parent(s) and Siblings)			10
Roommate(s)			1
Spouse/Partner			5
Spouse/Partner and Family of Origin			1
Extended Family			1
Highest Level of Education Completed			
Some high school			1
High School			2
Some college			9
4-year college			5
Graduate degree			1
Current School/Employment Status			
No School and Unemployed			6
Student (full or part-time)			5
Employed (full or part-time)			6
Student and Employed			1

Total Annual Household Income	
Don't Know	5
\$19,999 or less	4
\$20,000 - \$49,999	5
\$50,000 - \$74,999	3
\$75,000 - \$99,999	0
\$100,000 or more	1
Relationship Status at Study Enrollment	
Not in a significant relationship	8
In significant relationship, not living together	4
Living with spouse/partner	6
Marital Status at Diagnosis	
Never Married	17
Married	1
Marital Status at Study Enrollment	
Never Married	14
Married	4

Figure 1: Study Recruitment Diagram



Second Manuscript

“From Snail Mode to Rocket Ship Mode”:
Adolescents and Young Adults’ Experiences of Returning to
Work and School after Hematopoietic Cell Transplantation

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Abstract

Background: Return to work and school after treatment is an important indicator of normalcy in cancer survivorship. Minimal data exists on experiences related to returning to school or work as an adolescent or young adult after cancer. Hematopoietic cell transplantation is an intense treatment for hematological malignancies and is associated with extensive life disruption, including forced leaves from school and work. Resuming these activities may pose particular challenges to adolescents and young adults after hematopoietic cell transplantation.

Methods: Grounded theory, influenced by Constructivism, guided all aspects of the study design. In-depth interviews were conducted with 18 adolescents and young adults, who were 15-29 years when they underwent hematopoietic cell transplantation for hematologic malignancy and were 6-60 months post-treatment at the time of the study. Interview transcripts were systematically analyzed to identify interrelated categories and ultimately to develop a theoretical framework rooted in the participants' experiences.

Results: All participants were in school, employed or both at diagnosis; therefore, the return to school or work was inextricably linked to a sense of normalcy. The search for normalcy involved several steps starting with early forays into the outside world, followed by feeling left behind, rushing to catch up, and struggling to keep up. For some, this process left them unable to rebound. Participants described the context in which they attempted to return to work or school, specific challenges they faced, and strategies they developed in these environments.

Conclusions: Better understanding of psychosocial late effects, specifically related to school and work trajectories after cancer, is critical to survivorship care for adolescent and young adult cancer survivors. Findings are discussed in the context of important opportunities for clinical management, age-appropriate interventions, and implications for future research.

Background

With 14.5 million cancer survivors in the United States (U.S.) currently, cancer survivorship is considered a public health concern (DeSantis et al., 2014). Due to advancements in early detection, treatments, and supportive care, this number continues to rise and is estimated to exceed 19 million by 2024 (DeSantis et al., 2014; McCabe et al., 2013). According to the recommendations of the Institute of Medicine, cancer survivorship care should include management of late effects in the psychosocial domain, such as employment and work-related issues (Hewitt, Greenfield, & Stovall, 2006). Resuming normal activities, such as working, is an important dimension of psychosocial recovery in cancer survivorship (Feuerstein, 2009; Katz, 2015). Beyond the economic benefits, employment may also provide a sense of normalcy and purpose for many survivors, who derive self-esteem, a sense of identity, and social capital from work (Feuerstein, 2009; Kennedy, Haslam, Munir, & Pryce, 2007). Therefore, the inability to work after cancer can have psychosocial as well as financial consequences (Katz, 2015; Landwehr, Watson, Macpherson, Novak, & Johnson, 2016; Mehnert, 2011). Return to work is a complex health outcome that is influenced by disease, treatment, physical, psychological, and workplace factors (McGrath et al., 2016; Mehnert, 2011). However, for survivors of adolescent and young adult (AYA) cancers, the meaning and impact of cancer on school and worklife are not well understood.

From a developmental perspective, the AYA life stage is characterized by identity exploration, self-focus, and instability as life plans are being continuously revised to clarify goals and possibilities for the future (Arnett, 2014). Many AYAs are in the process of completing formal education or vocational training, but current research suggests that most balance work at the same time. In a study with 1,029 18-29 year olds, 78% reported they believed a college

education is essential to success in life (Arnett & Schwab, 2012). However, 70% of the sample also reported they were balancing the demands of college with paid employment and, in fact, 59% worked at least 20 hours per week (Arnett & Schwab, 2012). Indeed, entering the workforce is an important milestone of this life stage. From the age of 18 to the age of 29, the average American holds eight different jobs, but many of these jobs offer low wages and have little relevance to their long-term career goals (Staff, Messersmith, & Schulenberg, 2009; United States Department of Labor, 2012). AYAs may also have unique financial debts from credit cards, student loans and new mortgages (Landwehr et al., 2016). Cancer in AYAs can impact not only return to work, but also a range of outcomes related to education, employment, finances, and a broader career trajectory.

Over the past decade, AYA oncology has emerged as a distinct discipline, but late effects in social functioning, particularly schooling and work outcomes, remains an understudied area. The available literature has shown that AYA survivors have consistently reported extensive unmet needs related to educational aspirations, employment, and financial stability during the post-treatment phase (Corbeil, Laizner, Hunter, & Hutchison, 2009; Hauken, Larsen, & Holsen, 2013; Miedema, Easley, & Robinson, 2013). In addition, work-related changes, such as taking a leave of absence, reductions from full-time status, and job switching due to physical demands, are problems for AYAs due to the repercussions of cancer and its treatments. In one study, 523 AYAs ranked finances, control over life, and work plans as areas of life most negatively impacted by cancer (Bellizzi et al., 2012). Furthermore, according to the Behavioral Risk Factors and Surveillance System (BRFSS) survey, AYA survivors have been significantly more likely to be unemployed compared to age-matched peers without cancer (Tai et al., 2012).

More aggressive cancer treatment regimens have also been associated with more significant challenges during reentry, poorer social functioning, and may also influence work outcomes among AYAs (Siegel et al., 2012; Stanton, Rowland, & Ganz, 2015). Hematopoietic cell transplantation (HCT) is an intense treatment that aims to restore hematopoietic function by transplanting stem cells from oneself or a donor after a conditioning regimen of high-dose chemotherapy with or without total body irradiation (Wood & Lee, 2011). Physical, psychological and social effects of this treatment persist for many years, if not the remainder of life (Jones, Parry, Devine, Main, & Okuyama, 2015; Sun et al., 2013). Past studies show no differences in employment between survivors of bone marrow transplant (the early name for HCT) and matched controls after 10 years and suggest that 67-78% had returned to work by one-year post-treatment (Bush, Donaldson, Haberman, Dacanay, & Sullivan, 2000; Chao et al., 1992; Lee et al., 2001). However, it is likely that older studies do not reflect the significant advancements in HCT supportive care and HLA-matching, and thus do not take into account the more recent growing population of HCT survivors. More current research on HCT indicates long-term challenges in work and career, such as job insecurity, financial losses, physical and mental barriers, and career derailment; they also suggest that these stresses contribute to poorer quality of life (Hamilton et al., 2013; Johansson, Larsen, Schempp, Jonsson, & Winterling, 2012; Stepanikova, Powroznik, Cook, Tierney, & Laport, 2016).

In general, very little is known about the experience of returning to work or school as an AYA cancer survivor, but particularly after intense treatment regimens such as HCT (Institute of Medicine, 2013; Katz, 2015). In the National Cancer Institute's Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study of 463 AYAs, respondents who endured more intensive treatment (which likely describes HCT) were four times more likely to

report that cancer had a negative impact on their plans for school and work compared to those that received less intense treatments (Parsons et al., 2012). Furthermore, those who endured more intensive treatments and quit work or school immediately after diagnosis (also reflective of our sample) were less likely to return to work within 15 - 35 months. Risk for post-treatment unemployment or inability to resume schooling was also associated with specific blood diseases, such as acute lymphocytic leukemia and non-Hodgkin's lymphoma, compared to other cancer types. Therefore, these findings are particularly relevant to AYA survivors of HCT, who endure intensive therapy as well as extensive and often persistent life disruption.

Another limitation of the existing research is that returning to work is often conceptualized as a binary variable, with inadequate examination of the grey area of this phenomenon, such as the AYAs' experiences of returning to work but struggling due to "joblock," or the inability to change jobs, compromising aspirations, or failing to reach their potential (Institute of Medicine, 2013; Nass et al., 2015). The AYAHOPE study revealed that more than 72% of the AYAs who worked or attended school full-time prior to diagnosis were able to resume these activities 15 - 35 months later, but most of these individuals reported problems on their return (Parsons et al., 2012).

There is a lack of insight about the factors that influence AYAs' decisions to return to work or school, the particular challenges of initial reentry, as well as experiences related to functioning and sustaining their engagement in work and school after intense treatments like HCT. Therefore, the purpose of this analysis was to gain a nuanced understanding of AYAs' experiences of resuming activities related to work and school after HCT.

Methods

Setting and Recruitment

Following institutional review board approval, we identified eligible participants from the pool of HCT recipients at a national comprehensive cancer center in Southern California through medical chart review and consultation with treating hematologists (Figure 1). Eligible patients were between 15 – 29 years when they received a single bone marrow or stem cell transplant for a primary diagnosis of a hematologic cancer and were 6 – 60 months post-HCT at study enrollment. Exclusion criteria included a history of previous HCT, relapse of disease after HCT, non-English speaking, or less than 18 years of age at the time of the study. Of the 106 eligible patients, we did not approach those that were considered medically complex, defined by pending results or recent hospitalization for HCT complications (n=13), those that were receiving follow-up care at another location (n=34), or those whose hematologist did not provide permission (n=1). Invitations to participate were mailed to the remaining 59 potential participants. This was followed by telephone or face-to-face contact at scheduled appointments in the outpatient clinic to discuss possible recruitment.

Study Procedures

After obtaining informed consent, participants completed a socio-demographic questionnaire followed by an in-depth interview conducted by the first author, either by telephone or face-to-face in a convenient, private location of the participant's choosing. Findings from a previous pilot study by the first author with AYAs was used to develop a semi-structured interview guide for the current study. Questions were designed to allow participants to go deeper into topics and areas that mattered most to them (Table 1). With participants' permission, interviews were digitally audio-recorded, transcribed verbatim by a professional transcriptionist, checked for accuracy and de-identified. The duration of interviews was on average 102.4 minutes (range: 56.4 – 164.2). Detailed, reflexive field-notes were kept to document non-verbal

aspects of interactions, general impressions of the interviewer, and methodological issues that arose during interviews. After the protocol was complete, participants received a \$50 gift card to compensate them for time and travel.

Data Collection and Analysis

Grounded theory, influenced by Constructivism, provided a systematic yet flexible set of methodological guidelines for all aspects of the study design (Charmaz, 2014). Using this inductive, qualitative approach, data collection and analysis occurred concurrently to develop early theoretical insights that were rooted in participants' words and could guide subsequent data gathering (Corbin & Strauss, 2015). A systematic coding process was done wherein labels of analytic meaning were attached to segments of data throughout the transcripts. At every stage of coding and analysis, a minimum of two independent qualitative researchers collaborated to enhance rigor. We engaged in constant comparative analysis that involved multiple steps. First, we performed initial coding using gerunds to focus our emphasis on participants' actions while staying close to the data itself. Next, we used focused coding to identify and then develop the most salient codes from among all initial codes; these were sorted and used to synthesize larger amounts of data to form tentative categories that reflected the main phenomena in the data (Charmaz, 2014). The strategy of theoretical sampling was used to focus successive interviews on aspects of experiences that were not well understood from data from previous interviews; it also helped to elaborate upon and refine major categories as well as the relationships between the categories (Corbin & Strauss, 2015). At every level of analysis, the techniques of memo-writing and diagramming were central to the exploration of analytic hunches, development of abstract categories, and integration of ideas related to meaning of the data (Charmaz, 2000). Analysis continued until there was consensus that major theoretical categories were saturated and robust.

Descriptive statistics were used to characterize the demographic and clinical characteristics of the sample. A software program (Atlas.ti) was used for data management and organization.

Results

This analysis focused on the transition into the “outside world” and the overarching process of “searching for normalcy” among a sample of AYAs recovering from HCT. Since all of the participants in this study considered the normal environment of their pre-diagnosis lives to include school, work, or some combination of both, the “search for normalcy” occurred in these familiar settings. Searching for normalcy was characterized by a sequence of steps, starting with 1) Early forays into the outside world, 2) Feeling lost or “left behind,” 3) Rushing to “catch up,” 4) Struggling to keep up, and 5) “I just couldn’t rebound.” Having to make adjustments (Figure 2). This process involved attempts to resume life paths that were halted abruptly at diagnosis.

Sample Characteristics

A total of 18 eligible AYAs participated in the study. Sociodemographic and clinical characteristics of the sample are listed in Tables 2 and 3, respectively. At diagnosis, 83% (n=14) participants were enrolled in school, either high school or undergraduate college, and many were also employed (n=10). By the time of the study, some participants had attempted to return to school (n=8), some had attempted to return to work (n=7), and some planned to return to school within the next few months (n=2). Only one participant was managing both school and work, and admitted he had only been doing so for two weeks. There was a considerable range in the time since HCT that participants attempted to return to work or school, with one resuming work approximately three months post-HCT while a small number beyond the third year of recovery had not yet attempted these activities. Of note, many AYAs who resumed school did not return

to the schools where they were enrolled at diagnosis, but instead were attending new schools that were more conveniently located to caregivers and the transplant center.

“Hit and Miss:” Early Forays in the “Outside World”

As AYAs in this sample considered going back to school or work, they focused on small but significant signs of their progress. Within this gradual process, they relied less and less on caregivers for basic activities of daily living (eating, bathing, dressing, and toileting). Some even started to cook for themselves, manage their own medications, or go to follow-up appointments alone. However, participants also described an extremely unpredictable daily existence, as one participant explained, “It was hit and miss. Certain days, I would be ready to take on the world. Certain days, I’ll be like, ‘Leave me alone. Could I just stay in bed?’” This variability complicated participants’ ability to make long-term plans or resume activities outside of the home, such as work and school. One stated, “I just don’t know when I’m going to have a good day or a bad day,” while another spoke of periodic “lulls” when he felt he could not do anything.

During this time, participants experimented with occasional ventures outside the home. These early forays brought feelings of elation as participants experienced their first contact with outside-world normalcy. One participant said,

The more I live in the real world, and the more I’m just kind of moving forward, the better I feel, which makes me feel like I’m getting better, even if I may not be physically or mentally.

These forays outside the home often involved revisiting experiences and locations that were important in their pre-diagnosis lives. After attending a game of his favorite professional baseball team, another participant said, “That was the first place I had gone where there was a lot of

people. [...] It felt really good. I felt like my life was at least on a goal back to normal, gradually.” Another participant shared the excitement he had about performing music on stage with his death-metal band,

It made me feel great inside. It made me feel like I still had it in me. [...] I never told my doctor. I felt like it was something I had to do. Like, I felt it inside even though I was risking myself. But it made me feel great.

However, early forays into the outside world caught participants unprepared, both physically and emotionally, at times. For example, one participant reported going to a bar with his girlfriend on a very cold night; unfortunately, it was followed by a nearly two-month readmission to the hospital for pneumonia. Starting to drive again also posed challenges for several participants, with one admitting, “I shouldn’t have driven because I was still really weak and really tired. And sometimes I’d be a little bit loopy from the medication. And I couldn’t pay as much attention as I should have.” While the outcomes were not always perceived as positive or successful, early forays into the outside world helped participants delineate new personal limitations and survey the aftermath of what had just happened in a broader context.

Feeling Lost or Left Behind

As participants increased their interactions with the outside world, they wished to minimize the impact of their illness on their lives by putting their cancer experience behind them and moving forward “as if it hadn’t happened.” As long as they remained disconnected from the people, places, and activities of their pre-cancer lives, participants felt frustrated and far from normal. As one participant commented,

I went through nine months of extreme dependence where I couldn't do anything on my own. [...] I felt like I wanted to sort of branch out and move away from that as quickly as possible. I saw it as like the first step on the return to normalcy.

On their path to normalcy, participants wanted to re-engage with the familiar environments of work or school. However, the unexpected detour of cancer left them feeling somewhat lost because they found themselves navigating a changed reality. Here, they felt alienated from their former selves. One participant recalled,

Life just didn't fit into the puzzle that it had before. I just didn't feel like I belonged in society anymore. I felt like I was too different. Like, I couldn't respond to things that people normally get happy about, or sad about. And I couldn't be a friend to the friends who had been a friend to me. Because whenever they complained about their problems, I could only think about myself. And how their problems weren't really that bad. [...] It was hard to be the person I was before. And I didn't know what person I was left to be. I just- I was lost.

It was common for participants to feel that peers had moved forward and accumulated life experiences without them. One participant described, "My friends, they have girlfriends. My friends are getting married, getting engaged, having kids, all that stuff. I want it to happen to me someday. We'll see." Another participant compared herself to her friends in college: "Everybody is just moving on with their lives, but I'm just like, in my house, just relaxing and not doing anything super productive." Participants watched their friend groups become "sparser and sparser" as peers moved on to college, then graduate school, and marriage, and left them behind.

Many participants found it difficult to relate to what should have been common experiences of young adulthood. For example, one participant struggled to relate to her friends when they commiserated about “the freshman fifteen,” a term she did not understand. Another participant concluded,

I can only be around cancer or sick people who can relate with me now. I cannot relate with, you know, ‘Oh, yeah. I got a tattoo. Yeah. I got laid. Yeah. We went to this concert. We went to see Pitbull, went to Cabo, went to Hawaii, went to all this.’ ‘I went through a blood infusion. I went through a CAT scan, and they opened me up. I have a hole in my stomach. What's that? Nevermind.’

Participants also compared themselves to what they understood to be the normal sequence of milestones within young adulthood, or “the regular flow of things,” such as completion of higher education, establishing a career path, home ownership, exploring intimate partnerships, or starting a family. Feeling behind with respect to these achievements triggered feelings of jealousy, anger, and depression. One participant admitted that her envy prevented her from being happy for her friends as they graduated from college. Another participant said she was “really mad at having to stop my life completely” just when her music career was starting to take off. For many, feeling behind brought out deeper fears of failing.

Through all this cancer experience, [the fear of death has] been there but that's never something like, oh, my God, I'm going to die. [...] What scared me was not being able to finish school, to be left behind, to kind of have my life be ruined from all this, and then being able to say, 'Yeah. I was in college once. I didn't make it. Now I'm working some dead-end job, and my life is miserable.' That, to me, is worse than death. [...] That was

what scared me more, was the thought of failure rather than the thought of death.

Comparisons with their pre-cancer selves, their peers, and their perceptions of the “normal” AYA timeline left participants feeling derailed. As depicted in Figure 2, this feeling of being behind was a driving force in their search for normalcy as they tried to locate the life they remembered.

“From Snail Mode to Rocket Ship Mode:” Rushing to Catch-up

Rather than give up on their potential or accept deviation from the “normal” timeline, many participants responded to feeling behind with a fierce determination to “catch up.” This was characterized by a rush to make up for “lost” or “wasted” time, in an effort to restore their pre-cancer life path. One participant contrasted this rush to the slow pace of treatment:

When you’re in the hospital, they’re telling you, ‘Take your time. Take it easy.’ So, I went from going through snail mode to going in rocket ship mode. That is just two very big extremes.

This sense of urgency to get on with life, work, and school came from within; participants admitted that neither their family nor the medical team pressured them into resuming activities quickly. After being “obsolete for a while,” many participants admitted they were “chomping at the bit” and “begging” or even “harassing” their medical teams to allow them to return to school or work as soon as possible. Despite advice to “take it easy,” their need to rush superseded a more gradual approach, as one participant explained, “I had to do what helped me get through the process, get through the post-cancer part.”

Danger in “dwelling.”

The idea of catching up provided a sense of hope. They wanted to believe that their pre-diagnosis life and their future potential, as they had imagined it for themselves, were both still possible. Most participants worried that if they analyzed their situation too much, they would never move on from it. In this vein, participants avoided connecting with other AYAs with cancer, worrying that doing so would hold them back. One recalled, “I didn’t have any interest in connecting with other cancer patients my age.” Another who had been volunteering with a community-based cancer support network said, “I recently stopped doing that because I felt like, if I continue, I’m just going to constantly stay in that mindset that cancer’s always going to be around me. And I didn’t want that.” Another explained,

I kind of hesitated to connect [...] with young cancer people in treatment and survivors. I just felt like people there were so caught up in their experience and in their treatment, and it sort of was like a dominating force in their lives. And I just did not want to be like that. So, it kind of felt like going back. It kept me engaged in this world that I didn’t want to be in.

Participants also rushed to catch up because they feared that the window to reclaim their potential would close if they waited too long. One participant worried, “If I don’t push myself enough, I just won’t go back to the point where I was before.” Similarly, another participant explained,

I felt the rush. [...] I’m like, ‘I need to go and get on with my life already. [...] And then I was worried that if I waited too long, I would lose that ambition. Like, it would just get to a point where I’m like, forget it. [...] And I didn’t want that for myself.

These fears fueled the urgency to return to school and work. One participant elaborated, I was really determined to catch up, so I actually went to summer school. [...] So, I would say that I maybe overcompensated for my time that I was away. So, this was stupid. I don't know why I did this, but I accepted four jobs. Yeah. I don't know why I did that. [...] Part of it, I think, was you missed out on something and you've got to make up for it kind of mentality. Part of it was just enjoyment. I was back at school. I could handle this job. I can do this for this professor. I could take this class. It was really darn cool. Like, it was just exciting. And part of it, I think, was maybe to prove something, not that I had necessarily lost independence, but I felt like it. And so now I had to compensate by doing a job, being independent, earning my own money, paying my own way, being equal or being adult, whatever that meant. So, it was a – I don't know. I just had no impulse control, perhaps. So, I just dove in the deep end, and it was sink or swim.

Advantage of returning to previous school and work environments.

In some cases, the rush back involved an attempt to salvage the work or school circumstances of their pre-diagnosis lives. In many cases, our sample felt a strong sense of loyalty to the affiliations that had supported them through diagnosis and treatment. Indeed, participants who were able to return to the same school or work settings tended to have a smoother transition than those who started in new places. As one participant said, "I have connections with the professors there. [...] So, to try and recreate that [somewhere new], I think it would be impossible." They preferred to return to familiar settings where they had proven their work ethic and established their reputation before cancer but this was not always possible,

especially for those returning to school. Furthermore, they appreciated working with people who knew them before cancer and felt more confident that they were being evaluated on merit and the quality of their work rather than pity.

In contrast to school, the rush back to work was often driven by more practical concerns, such as finances, health insurance and secure employment. Those that returned to the same jobs received flexible accommodations and collegial support. For example, one participant explained that his boss allowed him to return full-time so that he would benefit from full-time salary and health benefits, even though he “knew that I wasn’t going to be at full capacity and so he would let me leave early and stuff. You know, they were really easy on me. They didn’t make me do much work.” One participant received his own private office so he could rest and concentrate, while another appreciated the flexibility he had to attend appointments in the middle of the day across the city at the transplant center. Such support made participants feel valued as employees, even though they required flexibility.

Interestingly, using hindsight, several participants expressed regret about rushing , acknowledging that they were not ready to return physically or emotionally. Despite their many reasons for rushing, they also admitted that doing so added difficulty to the reentry process. Instead, they believed a longer period of physical and psychological rehabilitation would have been beneficial.

Struggling to Keep Up

After diving “into the deep end,” participants struggled to maintain the fast pace they had adopted to catch up and stay afloat at school or work. Attempts to “sink or swim” revealed new illness issues not previously faced in the home setting. Aside from general recommendations to be cautious, AYAs in our sample received minimal guidance about reentry into school or work

from their medical team. According to participants, the experience of returning to school and work was significantly complicated by four major barriers: forced breaks, susceptibility to illness, fatigue, and cognitive changes (Figure 2).

The impact and consequences of forced breaks.

Participants were not able to stay in school while undergoing treatment and many were forced to withdraw mid-year. Unfortunately, these abrupt departures from school resulted in distressing losses in academic credits and financial investments due to rigid school policies. Many participants described their frustration at seeing their hard work, course credits, and tuition payments go “down the drain” due to forced breaks. One college student explained that she

had to withdraw from that whole semester, that whole year that I was there. And pay the fee of attending the school when I didn't even get credit for being there, because I missed finals. [...] It was basically, ‘Hey, you missed finals. That’s how our grading system works. There’s no exception about it. And here’s your five, ten thousand dollar fee that you owe.’

At diagnosis, most participants were too overwhelmed to comprehend the impact their illness and treatment would have on their school trajectory. Many participants lacked support in requesting formal medical leaves from school and communicated with their schools after it was too late. Hoping his treatment would be short enough not to require a formal leave from school (such as “a few rounds of chemo”), one participant decided to stop going to class and did so “without telling them anything.” He said,

It ended up being, no, this time, they want to do the chemo, the radiation, and the bone marrow transplant. So, that time, everything changed and I ended up staying in the

hospital a lot longer. And I remember I emailed the Office of Admissions like, 'Okay. It's been like so many quarters. Now I want to try to come back.' They're like, 'Oh. Well, you didn't tell us. You didn't take a leave of absence. So, you're no longer a student here.' And I got really depressed.

One of the most difficult aspects of forced breaks was the lack of continuity when resuming coursework that built on previous curriculum. Interruptions between courses that were inter-related or part of a sequence made seamless transitions back to school close to impossible. Significant breaks in school ultimately resulted in academic distress and even failures that caused participants to doubt their abilities, intellects, and futures. One participant elaborated,

It wasn't so much the health that was affecting me. It was the big gaps I was taking between classes really made my classes difficult academically. [...] And on top of that, I'd just finished all this transplant and all these side effects and stuff. So, my brain is still like half-functioning. It became too difficult. So, I failed a good amount of classes. And, again, it was one of those things that got really depressing for me because I was worried that, if it kept going, if you fail so many classes, you're going to get kicked out of school. And then, at that point, you know, you start feeling stupid when you keep taking a class over and over and you keep failing it.

While some participants considered the option of starting over, fresh, or anew (e.g., repeating courses, changing majors), many pointed out that doing so would diminish their pre-diagnosis accomplishments, create financial barriers, and set them back even further from their goals. Being diagnosed during a natural break (i.e., summer vacation or between high school and college) made financial and academic logistics easier to coordinate, but also tended to accentuate

separation from their peers who had clearly moved on to the next stage. Lack of continuity was a challenge specific to school and was not as detrimental for participants returning to work settings.

Susceptibility to illness.

Participants explained that their weakened immune system, increased risk for infections and subsequent hospitalizations, as well as heightened anxiety about exposure to “germs” further complicated their return to school and work. Many participants experienced devastating readmissions to the hospital for pneumonia, fevers, and infections. Frequent illnesses contributed to worry as participants tried to differentiate the symptoms of common colds from more serious health concerns such as relapses. One participant recalled that sickness dominated his first year back to school, reporting that “every single person that I encountered who was sick, I caught the sickness.” Nonetheless, one participant forced herself to attend class during a bout with shingles, wrapped in a blanket but unable to concentrate. Susceptibility to illness also increased anxiety about the school or work environment itself as a health threat. Another participant recalled the impact of this worry on her ability to focus,

I tried taking a class and I couldn't do it. I couldn't focus because I was like, what if somebody's sick sitting next to me? I'm going to get sick, and I'm going to end up in the hospital and not finish this class. So, I just stopped the class. I couldn't focus, so I dropped it. I wasn't ready to be out yet. And I still feel like that. I'm not ready.

Fatigue “with its own capital ‘F’”

Simply attempting to participate in school or work involved increased activity levels, which resulted in tremendous rises in fatigue. Participants explained that attending a single class

involved a long list of mental and physical tasks, such as getting ready for school, commuting, parking, walking to class, possibly climbing stairs, concentrating in class, socializing with classmates, and commuting home. This left participants exhausted. One commented,

[The fatigue] has taken on a different entity than the cancer. [...] It's so persistent that it's become its own capital 'F' Fatigue rather than a capital 'C' Cancer. [...] Same thing with stamina and energy - capital 'E,' capital 'S' kind of situation. [...] How do I deal with the fatigue? Is my fatigue too much today? Can I do this, or is my fatigue a problem for me?

Many participants spoke of coming home after school or work and collapsing. One recalled, "It would make me so tired that pretty much all I would do is go to work. Even though I was leaving early, I'd go home and fall asleep. I didn't have the strength to do much else."

Participants discussed strategies they developed out of necessity to manage fatigue and make reentry to work or school possible. A few participants utilized assistive devices to increase independence, such as one participant who used a wheelchair to conserve energy at a large college campus. He explained, "It wasn't that I couldn't walk. I could walk, but I would take a few steps and then I just felt like I ran a marathon." However, participants sacrificed healthy behaviors, such as adequate exercise and sleep, and resorted to skipping classes due to fatigue. Participants also adjusted their schedules to build in recovery time, such as avoiding classes two days in a row because "back-to-back was too much. I just couldn't rebound." Interestingly, online classes were not considered an acceptable option to most participants because they sought the normalcy of attending classes in-person.

Cognitive changes: "chemobrain."

Our sample struggled with post-HCT cognitive changes, particularly in memory and concentration. These changes became more apparent as participants increased their mental workload in school or a job. Participants described the experience of “chemobrain” as more elusive than other side effects because it was difficult to understand, predict or self-manage. As one participant shared, “When I tell anybody that like, ‘I forgot something.’ They’re like, ‘Oh, you know, I forget all the time.’ I’m like, no. This isn’t normal. It’s completely blank.” Another described her experience simply, “I just can’t seem to have that control over my mind, to pay attention to just like, one thing. It’s always kind of going in other directions.”

In general, participants felt quite comfortable initiating discussions about chemobrain with their health care providers, unlike other treatment effects such as sexual or psychological issues. However, they typically received vague input, especially in relation to reintegration at school or work. As one participant reported,

They say like, ‘It’s normal. It’s to be expected.’ And they don’t really have much information. I guess because it’s not very well researched. And they said it should get better, but I’ve heard anecdotal stories on the Internet from people who’ve said it hasn’t gotten better. Over like, five years. They still had like, holes. And I feel like it’s getting worse. Which is no good. And that’s really worrisome. Because it makes my life harder. I have to do things twice. Or I forget completely to do something. And then, it makes things difficult later. Or I’m at the store, I buy stuff, and I completely forget what I had gone to get. Which is a normal experience. But when it happens all the time, it’s really frustrating.

Particularly at school, cognitive deficits in memory and concentration added a significant layer of difficulty. One participant who was a graduate student reported how it put her at a disadvantage. Classes that required rote memorization posed more challenges than writing classes. Many spoke of feeling slower in their thinking and struggling to work under pressure, such as exams or deadlines. One participant shared her experiences,

I'm finding that I'm having memory problems, which is really hard to deal with. I lose my train of thought a lot. I have like, mild aphasia, where I forget words. Like, 'refrigerator.' I forget 'refrigerator' at least once a week. And it's really weird. It's always there. I always use that word. But sometimes it's just like, gone. And yesterday actually, I had a math exam. And I completely forgot how to do a section of problems, which I had done the homework for like, three days before. So, I should have known it. But it was completely gone. [...] It just doesn't stick. And that had really never been a problem for me before. Because I'm a teach-it-once-and-it-sticks. [I felt] really bad. Like, I feel like my memory is getting worse. Which it shouldn't be. They put me on Adderall to help with the chemobrain. Because apparently that helps some. And it does. It definitely makes me better able to participate, and be able to figure out what's going on in class. Because I don't think I'd be able to concentrate for that long. One, because it's tiring. And two, because it's a lot for my brain to do, I guess, at this point. But this was the first time that I had just completely lost something. [...] I just looked at the problem. Like, I did this. I know how to do this. But I can't- How- How- What's the first step? I can't remember. What am I doing?

Feeling disheartened about her memory issues, this participant left the exam without mentioning her experience to her professor.

As they struggled to understand this baffling side effect, many participants developed their own strategies to address chemobrain, such as writing daily lists, keeping a calendar, and setting reminders. Participants also shared their symptoms with their loved ones to reduce confusion and embarrassment, as one said, “Every one of my friends, and my boyfriend, and my family kind of knows that I have those slip-ups.” Some participants utilized their school’s disability services, but often did not find the offerings helpful for their situations. One participant explained that she received additional time for exams, but did not find this effective because she still could not recall information.

Cognitive changes were also emotionally disturbing. Participants felt “frightened” by their forgetfulness and inability to focus. This was especially true for participants who were not aware of the cognitive risks of HCT. One participant recalled,

I would study and study, and then I'd go take a test and I'd completely bomb it, just couldn't retain some things. [...] During finals, I was just a complete mess. I thought that I had one final for anthropology on Thursday. Turns out it was Wednesday. So, I had been studying for the wrong test. And started out towards the one building, and it was in a different building. And that morning, I was just panicking, trying to last-minute study, and I put metal inside a microwave. I mean just like stupid stuff I have no clue how I did. So it was just chemobrain, but I didn't really realize what was going on.

Another participant described the particular stigma of chemobrain as a young adult, explaining, “I’m 25. I shouldn’t have issues like this.”

While these strategies helped participants compensate for these issues, many reported surprise at the worsening of their cognitive symptoms over time. They worried about the long-term impact of treatment on their mind and how this might affect their future potential. One said “I’m just worried about not doing as well as I could in school, which will set me up for not as good opportunities as I would have had if I had not had these mental issues.”

“I just couldn’t rebound:” Having to make adjustments

As participants attempted to resume work and school, they were not discouraged by initial barriers. Rather, they were determined to test various strategies to increase their chances for success. However, after repeated disappointments and failures, some participants ultimately admitted that they could not proceed in the current situation and recognized a need for adjustment.

Questioning the “normal” timeline.

After running into numerous challenges, some participants stepped back and questioned the pace they had set for themselves. They contemplated whether pursuing a “normal” timeline was actually an important or reasonable goal. As one participant shared,

I can't say that anybody thinks of me badly for not graduating in four years. But apparently I think badly of myself, and there's no reason to. I mean it was out of my control. It wasn't because I slacked off or didn't go to class or anything like that. It's just because I thought four years was important, and that is completely arbitrary. And so the expectation of four years for college for that bachelor's, I mean why? Why are we so married to that idea? I mean like why is the idea of four years so important? And it's so hugely important especially to, I think, a young adult. And I don't know why. I guess it's society's idea. But the fact that I didn't graduate in four years, I mean that was like

complete upheaval in my life. And why?

Another participant reiterated this questioning when he said, “You’re fed by the spoonful, since you’re like, fourth grade. [...] Like, get your grades, go to college, get married. That’s the meaning of life. All of it, like- And it’s like, ‘Well, if I don’t go to college, can I still have a good life?’” As participants faced a barrage of obstacles at school and work, some began to question societal expectations and the normative timeline they had been holding on to. While not all participants engaged in this inquiry, those that did often reached new lows about their futures. As one simply realized, "I can't be whatever I want anymore."

Discussion

Our findings are among the first to articulate AYA cancer survivors’ experiences with the process of returning to work and school after cancer treatment. In particular, the experience of returning to college is not well studied. Furthermore, virtually no research has examined these attempts among the subset of AYAs who have undergone HCT. Our analysis reveals that AYAs were driven to return to school and work by a deep desire for normalcy, but were met with immense challenges, a lack of preparation, and a need for specific guidance from health care and education professionals to facilitate this important step of survivorship.

Rush and Regret: Deciding to Return to Work or School

The transition from active treatment to the post-treatment phase is challenging and complex for AYAs (Barnett et al., 2016; Hauken et al., 2013; Keim-Malpass & Steeves, 2012; Miedema, Hamilton, & Easley, 2007; Millar, Patterson, & Desille, 2010). Feeling left behind from their peers and their pre-diagnosis selves, participants in our study rushed back to school and work impulsively, taking on too much too quickly while facing overwhelming responsibility

and mounting complications. In most cases, the decision to return to work or school was driven by a powerful desire to get back to normal life rather than feeling physically, emotionally, or cognitively prepared. They did not consider their readiness and they did not pause to develop a plan. Relying largely on self-evaluation, participants tended to overestimate their functional abilities. This is consistent with other studies on return to work among adult cancer survivors (Parry, Morningstar, Kendall, & Coleman, 2011; Stergiou-Kita et al., 2016), but our findings suggest that AYAs may be particularly at risk for these overestimations because of their developmentally driven determination to catch up with peers and the fear that they will lose their ambition if they do not push themselves hard enough. In our sample, overestimations and lack of preparation for return to school and work resulted in glaring mismatches between expectations and reality, as suggested by Hauken and colleagues (2013). These mismatches seem to have contributed to distress in our AYA sample. As they resumed school or work, participants engaged in a process of trial and error to accommodate new limitations, but they also experienced feelings of regret, demoralizing struggles, and even failures.

Many participants in our study actively sought permission to return to work and school from medical teams, but reported that they received vague guidance about how to implement this decision in light of lingering health issues. Many struggled with the dilemma that their medical team did not understand the rigidity of school requirements, while school-based disability offices and counseling services seemed ill-equipped to deal with the complexity of cancer survivorship. The missing links between medical providers and school officials are likely to hinder success among this vulnerable group of AYAs who have survived cancer only to confront multiple barriers when regaining entry to a “normal” life. Thus, coordination across these transitions warrants further attention.

Return to Work

Employer support is critical to successful transition back to work (Stergiou-Kita et al., 2016). Participants in our study who returned to work described largely positive experiences. However, they relied on the kindness and empathy of bosses and colleagues, rather than knowledge of their rights as employees, entitlements for accommodations, or specific policies intended to protect cancer survivors in the workforce. This finding indicates that AYAs need additional support in connecting to resources on legal and policy aspects of work protection and disability.

Return to School

Since our study focused on the younger end of the NCI AYA age range of 15-39 at time of diagnosis, our findings provide rare insight into the experience of returning to college after treatment. While similar to the process of returning to work in some ways, the return to college presented unique challenges. In fact, resuming college after a prolonged recovery period was impossible for some, even many years after HCT. Lost credits and tuition and the impact of mid-year, forced breaks were much more destabilizing experiences for our sample than were losses due to breaks from work. This likely reflects a difference in our sample's perceptions of these roles with school connected to career and long-term life potential and a job seen as a temporary source of income.

Cognitive effects of treatment, or what many participants referred to as “chemobrain,” were particularly challenging in the school setting. While many mentioned strategies they relied on, such as list making for help with memory recall, task efficiency, and working under the pressure of deadlines, participants clearly desired more support in this area. Participants needed practical guidance and insight about what to expect in relation to their cognitive function in the

future. For some in our sample, the experience of “chemobrain” triggered profound feelings of self-doubt which provides insight into a phenomenon common to AYA cancer survivors. In a recent study, 2,589 survivors who were diagnosed with cancer between the ages of 11-21 were significantly less likely than sibling controls to have attained post-high school education, to be employed full-time, to be married, or to be living independently; these social outcomes were related to neurocognitive symptoms, such as task inefficiency (Prasad et al., 2015). Furthermore, unemployment was significantly associated with psychological distress, particularly depression among this large sample of AYA survivors. In accordance with the National Comprehensive Cancer Network’s guidelines for AYAs, neuropsychological evaluation is recommended to identify deficits in this area (Coccia et al., 2012). Our findings suggest that neuropsychological burden may thwart AYAs’ attempts to resume formal schooling, pursue career opportunities, and establish independence as adults, and necessitates individualized intervention.

Financial Consequences

Challenges in resuming roles at school and work have been found to be chronic stressors that can potentially influence quality of life, psychological distress, and “economic survivorship” for AYAs (Hamilton et al., 2013; Kwak et al., 2013; Yanez, Garcia, Victorson, & Salsman, 2013). Indeed, the personal struggles of our sample with work and school involved deep concerns about their future financial wellbeing. Using data from the Cancer Surveillance System of Western Washington, a population-based cancer registry, and state bankruptcy records, Ramsey and colleagues (2013) found that adults with cancer were 2.65 times more likely to declare bankruptcy than adults without cancer and bankruptcy rates were 2-5 times higher among 21-35 year old cancer survivors (Ramsey et al., 2013). Studies have also shown that AYAs are more likely to forego medical care due to cost when compared to older groups or age-matched

peers (Kirchhoff, Lyles, Fluchel, Wright, & Leisenring, 2012; Weaver, Rowland, Bellizzi, & Aziz, 2010). Each of these issues further emphasize the importance of addressing work and school issues with AYA cancer survivors in ways that matter to the AYAs in order to enhance, rather than ignore, their ability to cope with their complex financial challenges.

Recommendations for the Return to School and Work

The return to school or work for AYAs, particularly after an intensive, life-disrupting treatment like HCT, represents a major transition in early survivorship that necessitates coordinated support to reduce distress and facilitate successful reentry. Currently, many AYAs receive a “green light” from their medical teams to resume activities, but virtually no other guidance. Meanwhile, school policies are inflexible and disability programs offer accommodations that do not alleviate the most significant barriers they face. Unsurprisingly, this disjointed approach results in distress and difficulty for AYAs who are trying to return to these settings.

Our findings demonstrate a need for multi-disciplinary, AYA-specific services not only during acute treatment but during major transitions of survivorship. Once they are struggling, AYAs tend to seek assistance from school services because they see these issues as purely “school-related.” However, expertise related to cancer survivorship, particularly late effects, is needed to develop realistic, meaningful plans that leave room for adjustments, but ultimately enhance options for success, not failure. Key opportunities for communication or counseling exist when AYAs are “begging” to return to school or work. These moments can lead to larger conversations and prepare AYAs before they “dive in the deep end” on their own. In particular, more formal coordination is needed between health care and school personnel to facilitate the return to college. Pediatric care models often contain school reintegration programs that provide

support for children in K-12 schooling to minimize the effects of breaks in education. Based on our findings, we recommend school and work reintegration support for AYAs that is tailored to the specific demands of higher education, early workforce status, and young adult developmental needs.

Support is warranted at multiple phases of this process and should begin well in advance of actual return to school or work, especially in relation to dealing with fatigue. In accordance with the American Society of Clinical Oncology (ASCO) guidelines, cancer survivors should be routinely screened for fatigue and treated when appropriate (Bower et al., 2014). Anticipatory guidance that promotes realistic expectations particularly related to fatigue can help AYAs during planning and preparation stages of reentry. In addition, moderate levels of physical activity as well as cognitive behavioral therapy and mind-body interventions may reduce symptoms for AYAs who continue to experience fatigue after treatment (Bower et al.).

AYAs may also benefit from rehabilitation services such as physical or occupational therapy or neurocognitive training to improve function and acquire coping strategies as they prepare for work or school (Syrjala, Martin, & Lee, 2012). For example, occupational therapy can offer personalized evaluation to identify deficits and teach interventions, such as mental games, puzzles and exercises, that can be practiced at home for the management of chemobrain. Outpatient occupational or physical therapy may be especially valuable to AYAs who attend clinics without formal AYA services. Another promising but relatively untapped area is the use of internet-based programs (Syrjala et al., 2011), apps, or video game technology, which can be used with cell phones, tablets and computers to deliver health interventions, particularly among survivors who have grown up in the digital age. Such interventions could offer, for example, game-style remediation of chemobrain. They could also be used to help AYAs compensate for

memory issues by managing and organizing their lives (e.g., lists, schedules, reminders) as they resume school or work.

Support is also needed at the time of reentry as AYAs adjust to a new setting. Strategies to maintain healthy behaviors such as moderate exercise and adequate sleep and nutrition through this transition are needed (Syrjala, Martin, & Lee, 2012). Guidance on energy conservation and building recovery periods into their schedules can help AYAs create sustainable plans. Over time, it is important to reassess the manageability of a workload in relation to other life factors, identify specific stressors and evaluate mental health and well-being through this adjustment period. Online education may become a more acceptable, more “normal” option as it becomes more ubiquitous. Possible advantages to online education programs include the lack of a commute which could reduce energy demands of school, as well as self-pacing options to control the rates of information transmission in cases of cognitive changes.

While several AYA programs have emerged over the last decade (Barosh et al., 2015; Ferrari, et al., 2010; Reed, Block, & Johnson, 2014; Smith et al.; 2016), many focus on support during acute, often inpatient treatment. Thus, high-quality AYA survivorship care for outpatients remains a challenge. The wide-reaching impact of cancer on the lives of AYAs demands input from a multi-disciplinary team of health care providers, such as oncologists, nurses, social workers, financial counselors, physical and occupational therapists, psychologists, as well as non-medical professionals, such as lawyers and school officials, who can collaboratively facilitate successful transitions across the AYA cancer trajectory. On a broader level, health care providers should be involved in advocating for and shaping policies in school and employment settings to ensure reasonable accommodations and protections for survivors.

Disinterest in Fellow AYA Peer Support

An important and unexpected finding of this study was participants' lack of interest in connecting with fellow AYA cancer survivors. Research in AYA oncology has overwhelmingly supported the notion of peer support – both AYAs' desire for it and the added benefit it provides (Hauken et al., 2013; Kent et al., 2012; Mattson, Demshar, & Daly, 2013; Thompson, Palmer, & Dyson, 2009; B. Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006; B. J. Zebrack et al., 2013). However, our participants felt alienated from other AYAs with cancer because the HCT experience was so unique. They even lacked interest in peer support with other AYAs undergoing HCT, explaining that the HCT trajectory is highly variable and individual. They also felt that dwelling with fellow survivors would prevent them from normalizing and moving forward. While a few participants considered serving as a mentor figure to other AYAs in the future after their own issues were more resolved, they were not interested in being the mentee or the recipient of support.

This disinterest in peer support is somewhat perplexing given the strong consensus for peer support in the AYA literature; this can be interpreted in several ways. It may reflect the need for research on specific subgroups (i.e., based on disease type, treatment type, or narrower age groups) within the greater AYA population, recognizing the heterogeneity of these patients and their cancer experiences. It may also underscore the profound isolation of the HCT experience. AYAs who have undergone HCT may still reap benefits from peer support, but may have specific preferences that could make it more appealing. For example, internet-based support options may limit the need for travel and may also allow connections beyond a single institution. Support that is built around more “normal” activities, such as outdoor adventures or social outings, may have less stigma than traditional peer mentorship programs.

Limitations

The findings of this study should be considered in light of several limitations. Although the sample was diverse across some demographic factors, participants were from a single specialized institution, recognized as a national comprehensive cancer center, in the Western United States. While the 6-60 month span provides insight into various experiences along the HCT trajectory, the cross-sectional design is not reflective of longitudinal trends. In addition, retrospective reporting allows for the possibility of bias. Many participants in this study underwent extensive treatment prior to HCT, and therefore, disruption in work and school trajectories is not necessarily a direct result of HCT. It was, however, of concern to this sample and therefore, it was salient to this analysis. It is also important to note that because of the younger age of our sample with respect to the National Cancer Institute definition of AYA (15-39) (Smith et al., 2016), our findings are disproportionately focused on school rather than work.

Implications for Future Research

Our study indicates that our sample of AYAs had a tremendous desire to return to the normalcy of work and school after HCT, but needed additional support with planning reentry and adjusting to these settings. A recent systematic review on psychosocial outcomes in AYA cancer survivors highlighted the need for more quantitative studies using validated instruments (Barnett et al., 2016). In particular, current research has not captured or begun to quantify lost opportunities or derailed career trajectories due to cancer among AYAs. It is important that future work include the collection of longitudinal data that tracks outcomes in relation to developmental changes over time. In light of our unexpected finding regarding peer support, future research on AYAs should continue to explore differences across important AYA subgroups to develop risk profiles and identify areas of greatest need. Finally, future research should inform the development of optimal models of survivorship care, particularly the

management of psychosocial late effects, for AYAs after treatment and during major transitions such as reentry to work and school.

Conclusions

According to the Institute of Medicine's seminal report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (2006), cancer survivorship care should include several key elements, including interventions to address late effects in the psychosocial domain. Despite proliferating interest in AYA oncology over the past decade, reentry into work and school and subsequent attainment of education and career goals represent an important yet virtually unknown area of AYA cancer survivorship (Barnett et al., 2016; Nass et al., 2015). A recent report from an Institute of Medicine (2013) working group on AYAs identified psychosocial late effects, specifically related to school and work trajectories after cancer, as an area in need of further attention. The current analysis identified important contextual factors in the decision to return to school and work (feeling left behind and trying to catch up) as well as specific barriers faced by AYAs. We have presented important opportunities for clinical management of AYA survivors as well as future research in this area. It is critical to understand the challenges AYAs face in cancer survivorship in order to improve long-term social outcomes for this vulnerable population.

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Table 1: Excerpt from Semi-Structured Interview Guide

Area of Focus	Examples of Questions and Probes
Resuming activities	<p>After you finished your treatment, what were the biggest challenges you faced at that time?</p> <p><u>Prompt:</u> If you returned to work/school, when did you and what was it like?</p> <p><u>Prompt:</u> If you were able, what hobbies/interests were you able to dive into again?</p> <p><u>Prompt:</u> If not, why not? What was different? How did that feel?</p> <p>Can you please tell me about any things that continue to be challenging since having HCT?</p> <p><u>Prompt:</u> What has been the most challenging or difficult and why? (socially, emotionally/psychologically, behaviorally)</p>
Perspectives on cancer, HCT, and health	<p>How often do you think about your cancer and transplant experience?</p> <p><u>Prompt:</u> When you do think of it, what comes to mind?</p> <p>How do you feel about your health now?</p> <p><u>Prompt:</u> What does “being healthy” mean to you now?</p>

Table 2: Sociodemographic Characteristics (N=18)

Characteristic	n
Sex	
Male	11
Female	7
Ethnicity	
White/Caucasian	7
Hispanic/Latino	8
Asian/South Asian	3
Living Situation at Study Enrollment	
Family of Origin (Parent(s) and Siblings)	10
Roommate(s)	1
Spouse/Partner	5
Spouse/Partner and Family of Origin	1
Extended Family	1
Highest Level of Education Completed	
Some high school	1
High School	2
Some college	9
4-year college	5
Graduate degree	1
Total Annual Household Income	
Don't Know	5
\$19,999 or less	4
\$20,000 - \$49,999	5
\$50,000 - \$74,999	3
\$75,000 - \$99,999	0
\$100,000 or more	1
Current Relationship Status	
Not in a significant relationship	8
In a relationship, not living together	4
Living with spouse/partner	6
Current Marital Status	
Never Married	14
Married	4

Table 3: Clinical Characteristics (N=18)

Characteristic	n	Mean	Range
Age at HCT (years)		23.3	18.5 – 29.7
Age at Study Enrollment (years)		26.0	19.8 – 34.6
Time since HCT at Study Enrollment (months)		32.8	8 – 60
Primary Cancer Diagnosis			
Acute myeloid leukemia	10		
Acute lymphoblastic leukemia	5		
Hodgkin's lymphoma	2		
Non-Hodgkin's lymphoma	1		
HCT Type			
Allogeneic, HLA-Matched Unrelated Donor	9		
Allogeneic, Sibling Donor	3		
Allogeneic, Cord Blood	3		
Autologous	3		

Figure 1: Summary of Recruitment

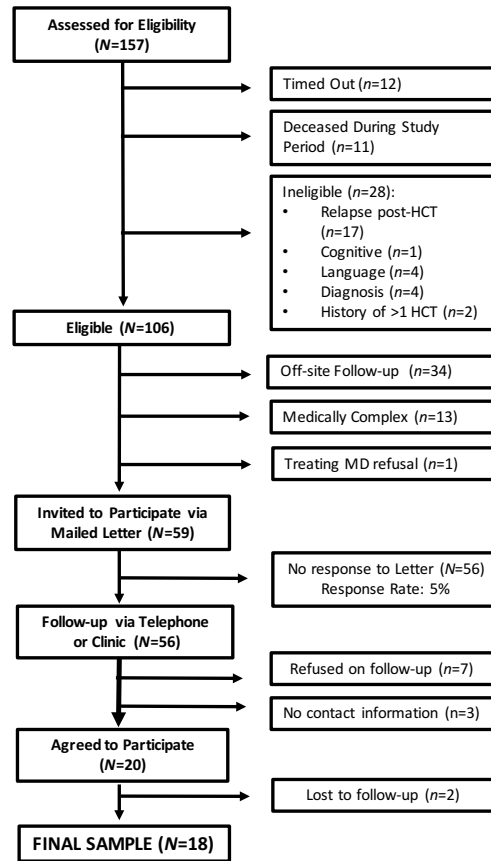
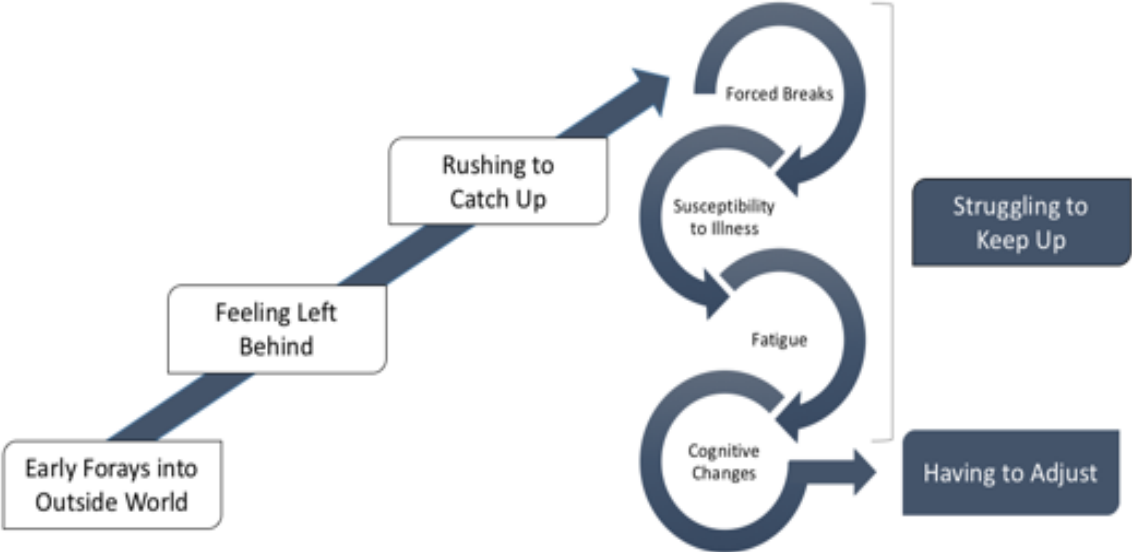


Figure 2: Searching for Normalcy in the “Outside” World among AYAs after HCT



Third Manuscript

“Improving to where?” Facing the Future among Adolescents and Young Adults
in Early Survivorship after Hematopoietic Cell Transplantation

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Abstract

Background: Despite the prevalence of hematological malignancies in early adulthood, very little is known about hematopoietic cell transplantation among adolescents and young adults, and even less is known about their transition from the completion of therapy to early survivorship. In this qualitative analysis, we investigated the impact of the cancer experience on sense of life potential and perception of the future from the perspectives of adolescents and young adults in early survivorship after hematopoietic cell transplantation.

Methods: In-depth interviews were conducted with adolescents and young adults who underwent allogeneic or autologous hematopoietic cell transplantation between the ages of 15-29 years and were 6-60 months post-treatment. De-identified interview transcripts were systematically coded based on Constructivist Grounded Theory methodology to identify emergent categories and generate theory. A sociodemographic questionnaire and a quality of life tool (RAND Short Form-36 [SF-36]) were administered to collect other descriptive data.

Results: Eighteen adolescents and young adults participated and described their reconceptualizations of the future. The process began with a pivotal, existential question, “Improving to where?” In response, participants engaged in “bracing for something bad” and “rolling with the punches” to adjust emotionally. However, moving forward was complicated by a tendency to “wonder what if.”

Conclusions: Adolescents and young adults who undergo hematopoietic cell transplantation face significant risks for late effects in survivorship. Age-appropriate interventions are needed to support these survivors as they manage their fears while enhancing health and wellbeing.

Introduction and Background

Improvements in early detection, treatment modalities, and supportive care have resulted in lower rates of cancer deaths and dramatic increases in cancer survivors, with approximately 66% of patients living at least five years after diagnosis (Kohler et al., 2015; McCabe, Bhatia, et al., 2013; Siegel, Miller, & Jemal, 2015). Currently, there are more than 14 million cancer survivors in the United States (U.S.) and this number is expected to exceed 19 million by 2024 (DeSantis et al., 2014). Across cancer types, the most rapid improvement has been observed in hematopoietic and lymphoid malignancies due to advancements in treatment protocols (Siegel et al., 2015).

Hematopoietic cell transplantation (HCT) has become a standard treatment for several hematologic malignancies. Based on data from the Center for International Blood and Marrow Transplant Research from 1968 to 2009, there are approximately 108,900 HCT survivors, including 67,000 autologous and 41,900 allogeneic, in the U.S., with an expected 2.5-fold increase by 2020 (242,000 survivors) and 5-fold by 2030 (502,000 survivors) (Majhail et al., 2013). Better HCT outcomes have been attributed to refined clinical practice, such as the reduction of treatment-related mortality, reduced-intensity conditioning regimens, enhanced patient-donor human leukocyte antigen (HLA) matching, and better timing of HCT (Baker, Armenian, & Bhatia, 2010; National Marrow Donor Program [NMDP], 2012).

Leukemia and lymphoma represent two of the most common cancer types within the adolescent and young adult (AYA) age range and often require HCT as part of treatment (Baker et al., 2010; Barr, Ferrari, Ries, Whelan, & Bleyer, 2016). Although many more patients are undergoing and surviving HCT, long-term HCT survivorship remains a relatively new frontier. Many HCT survivors face substantial long-term physical and psychological morbidity, even

beyond ten years since treatment (Baker et al., 2010; Majhail & Rizzo, 2013; Sun et al., 2011; Sun et al., 2013). Despite the prevalence of hematological malignancies in early adulthood, very little is known about the HCT experience among AYAs, and even less is known about their transition from therapy to long-term survivorship. In this qualitative analysis, we explored the impact of the cancer experience on sense of life potential and perception of the future from the perspectives of AYAs in early survivorship after HCT.

Methods

Procedures and Participant Recruitment

Qualitative methodology, guided specifically by Constructivist Grounded Theory (Charmaz, 2014), was used to study the transition to survivorship after HCT from the perspectives of a sample of AYAs. Eligible participants were age 15 – 29 years old when they received an autologous or allogeneic HCT as treatment for a primary hematological cancer. At the time of the study, they were 6 – 60 months post-HCT and at least 18 years old. Patients who had relapsed since HCT, had a non-hematological primary diagnosis, had a history of more than one HCT, were cognitively impaired or unable to speak English were excluded.

After approval from institutional review boards was obtained, we assessed 157 patients for eligibility through medical record review (Figure 1). Of these, 12 timed out, 11 expired during the study period, and 28 were deemed ineligible. Of the remaining 106, 13 were considered medically complex (e.g., recently hospitalized, results of possible relapse pending) and 34 were receiving follow-up care elsewhere. We mailed invitations to participate to 59 individuals, which yielded a 5% response rate. We attempted to follow up with the remaining 56 individuals via telephone or in-person at regularly scheduled clinic appointments about their interest in participation. Reasons for direct refusal included concerns about “not having enough

time” and “not wanting to talk about it.” The option to conduct the interview portion of the protocol over the phone was amended once the study was underway based on participant request because appointment days tended to be long and exhausting and many participants lived considerable distances from the transplant center.

Data Collection and Analysis

After obtaining informed consent, in-depth interviews were conducted by the first author (EB) either in-person in a private consultation room or over the telephone depending on the participant’s preference. Open-ended questions and prompts that explored the impact of the cancer experience on participants’ perceptions of their life trajectories as well as their futures was explored using a semi-structured interview guide (Table 1). The average length of the interviews was 102.4 minutes (range: 56.4 – 164.2). With participants’ permission, interviews were digitally audio-recorded, transcribed verbatim by a professional transcriptionist, and de-identified.

Clinical variables were abstracted from medical charts. In addition, a sociodemographic questionnaire and a quality of life tool (RAND Short Form-36 [SF-36]) were administered. The RAND SF-36 consists of 36 items in eight sub-scales to assess physical functioning, role-physical, pain, vitality, social functioning, role-emotional, mental health, and general health perceptions (Ware, Kosinski, & Gandek, 1993, 2000). Aggregates were created from sub-scale scores to form a Physical Component Summary (PCS) and Mental Component Summary (MCS) (Ware, Kosinski, & Keller, 1994). Population norms for young adults (age 18-34 years) were used as a reference, with standardized norm mean scores of 50 and a standard deviation of 10 (Ware et al., 1993, 2000).

Grounded theory methods, influenced by Constructivism, provided flexible yet systematic guidelines for all aspects of study design (Charmaz, 2014). Data collection and analysis occurred concurrently to allow for constant comparison that focused data gathering as analysis advanced. This concurrent process continued until major theoretical categories were saturated and robust. A systematic coding process began with initial coding, followed by focused coding to identify emergent categories (Charmaz, 2014). Analytic techniques such as field-notes, memo-writing, diagramming, and network mapping were implemented through each stage to deepen analysis and raise the level of abstraction. Advanced analysis allowed for the refinement and “filling out” of major categories and the relationships between them to sharpen theoretical insights and integrate ideas. To enhance methodological rigor, two or more independent qualitative researchers collaborated in each stage of coding and analysis. Atlas.ti software was utilized for data management (Atlas.ti).

Results

In this analysis, we focused on how a sample of AYAs faced their futures as they moved beyond acute recovery, reentry and into early survivorship after HCT. They described a pivotal shift in their understanding of the impact of their cancer and HCT experience (“Improving to where?”) that transformed their perception of their future from being wide open with potential to one of narrowed possibilities. In response to this new reality, participants reconceptualized their future by using two main adaptive strategies: 1) bracing for “something bad” and 2) “rolling with the punches.” However, the prospect of a lifetime of health problems left participants frequently wondering what their lives would have been like without cancer (Figure 2).

Sample Characteristics

The 18 participants in our sample were, on average, 23.3 years of age at HCT (range: 18.5-29.7) and 26.0 years at study enrollment (range: 19.8-34.6). The average time since HCT was 32.8 months (range: 8-60). Their diagnoses included acute myeloid leukemia (n=10), acute lymphoblastic leukemia (n=5), Hodgkin's lymphoma (n=2), and Non-Hodgkin's lymphoma (n=1). Participants underwent allogeneic HCT using HLA-matched unrelated donors (n=9), sibling donors (n=3), and cord blood (n=3) as well as autologous HCT (n=3) in the inpatient setting. Additional sample characteristics are listed in Table 2.

Rand SF-36 Results

Results from the Rand SF-36 for study participants are reported in Table 3. Participants in this study reported lower than average scores across all sub-scales and both composite-scores when compared to a normative population of 18-34 year olds. In particular, the lowest scores among participants were in the physical functioning and role-physical subscales, indicating limitations and problems due to physical health, and the general health perception subscale, which evaluates current health as well as likelihood for health to improve in the future.

“Improving to Where?”: A Shift in Perception about the Future

While recovering after HCT, participants attempted to re-engage in the activities of their pre-diagnosis lives, first regaining independence with self-care and then attempting to return to school or work, and to resume social interactions. However, at each point in the process, they faced unexpected, troubling, and surprisingly persistent challenges. Participants spoke about these challenges with a somber familiarity, pointing out how the repeated experience of having to tackle new obstacles complicated their recovery. One participant explained, “It’s not like, oh, it happened and then I got over it. It’s like it kept interfering in my life.” Another stated, “Getting

your life back just wasn't the same. It wasn't like, 'Okay, let's wrap it in a pretty little bow and go to the next thing.' It was hard."

Because they were dealing with so much difficulty, many were confused by the positive feedback they received at follow-up appointments from their medical teams who said, "You're getting better. You're doing a lot better than you were before. Everything looks good."

Participants were assured that their disease remained in remission, but at the same time, they observed pervasive physical and psychological effects of their cancer experience. These included pain, anxiety, sexual dysfunction, abnormal liver function, chronic graft-versus-host disease, avascular necrosis, and the inability to work or in many ways, enjoy life. Thus, they found themselves pondering whether the state they were in post-treatment was indeed the desired outcome from the medical team's perspective. These reflections occurred at different times for different participants, but the underlying shift in perception was salient across the sample. Many participants described a pivotal moment in early survivorship when they questioned what "doing well" and "improving" after treatment really meant, as one participant vehemently asked, "Improving to where?"

Until this point, participants had assumed they would eventually achieve a full restoration of health and resume a pre-diagnosis life trajectory. This was based partly on what they described as hopeful but unrealistic expectations set by their medical team, who shared stories of "extraordinary" rather than typical cases. The discordance between their expectations for a "normal life" and their lived reality triggered an internal, existential crisis. One participant described the shock she felt when she learned about the daily life of a HCT survivor 11 years after treatment, who had to nap for an hour during his lunch break and nap for another hour before dinner with his family just to get through the day. These moments of understanding

seemed to come suddenly, allowing participants to see their health-related progress in a new context with different points of reference, that of cancer survivorship. They described how a new reality was sinking in, as one participant said, “This is the way my life is now” while another admitted, “I’m not normal anymore, like I was.”

For the participants, cancer was now a disease that would never really end and would require consideration in life decisions as well as active management. One participant explained, “You can’t really tell when the treatment part is over. Like, I did the chemo. I thought that was it. Then I had to do the radiation part. I thought that was it. Then I had to do more stuff. So, it’s hard to tell a cancer patient, ‘You don’t need treatment anymore. You’re fine for the rest of your life.’”

For the first time since diagnosis, they understood cancer would be an integral part of their identity. One participant called it “just one more thing that defines me,” equating it to her height or hair color.

Adapting by Bracing for “Something Bad”

The realization that cancer was going to “keep interfering” with their lives cast a new shadow on the future. As one participant explained, “It’s just very long and slow, and it probably will just continue like this. I will get minutiae-ly better as time goes by, but it won’t be fast. It won’t be significant.” Participants reported persistent anxiety from the time of diagnosis onwards, but their anxiety was different as they moved forward in their recovery. One explained that it “seems to have affected me more now that everything seems to be over.” Participants described a shift in their anxiety from fears about recurrence to a disturbing uncertainty about the future. They focused particularly on HCT-related health risks which they saw as “a necessary

price to pay for still being alive,” but also a source of never-ending worry. Specifically, participants were afraid of the late effects of treatment, such as secondary malignancies, cardiovascular and pulmonary toxicities, cataracts, premature ovarian failure and infertility, and shortened life spans. As one participant explained, “They start telling you about risks, about further cancers and tumors, because of the radiation. And infertility. Just so many things that get pushed into your brain. You’re trying to process it, and just trying to not freak out at the same time. Because it’s a lot of information. And you think, ‘Well, there is a possibility. Like, what if it happens to me?’ I mean, I never thought I’d get cancer, but I got it.”

For many, these fears manifested as a sense that “something bad was going to happen” (Figure 2). One participant said, “You just have to watch for everything, and you have to pretty much protect against everything and just accept that, truthfully, this is not the last time I'm going to be sick. I'm only 26. So, there's a long life with a lot of health problems coming up, unfortunately, and that's just how it's going to be. Like I said, I've just aged.” This was perceived as an inescapable fate that always loomed in the background. Many participants described a cyclic pattern of highs and lows that characterized their cancer trajectory thus far. They understood that lows would inevitably follow more positive periods and therefore, braced themselves. As one participant reported, “I hate not knowing something, because that's what starts [my anxiety]. If I don't know something, my brain's like filling in the blanks and the end. [...] I'm the kind of person that likes to think about all the possibilities as if they're true. And that makes me like really anxious.” They expected their “luck to run out” at some point, but had no idea when or how it would happen. As one participant shared, “Every day of my life, everything that I do, I'm constantly worrying and thinking. [...] It's hard. It sucks to have to live your life constantly afraid of what's going to come.” Because participants were “constantly analyzing”

every possible outcome, a relentless anxiety seeped into other areas of their life and they found themselves bracing for the future.

Adapting by “Rolling with the Punches”

Realizing their cancer experience would never be finished resulted in emotional distress that at times completely overwhelmed participants, particularly with respect to the future. One participant wondered, “I just didn’t know what the future held for me. You know, am I ever going to work again? Or am I just going to be bedridden my whole life? You know, I was taking seventy pills a day. I’m like, am I going to take seventy pills a day for the rest of my life?” Until this point, participants did not consider the possibility that cancer could leave permanent imprints on their lives. They expected to have a fresh start after treatment. However, with this realization they saw a changed future, what one described as “a very dirty clean slate.” The open-ended future of their pre-diagnosis life was now riddled with a barrage of health risks and limited by the confines of cancer, as one participant acknowledged, “Some things you just can’t do, some things can’t happen.”

In order to face their futures and move forward, participants adapted by “rolling with the punches” to manage anxiety and adjust to this new reality (Figure 2). They recognized their lack of control as well as the inevitability of “punches” or setbacks, such as readmissions, late effects, and narrowed opportunities. By “rolling” rather than resisting, participants approached their future within the circumstances of reality, preparing for punches and minimizing their harm by letting go of or adjusting expectations. However, these strategies also meant that participants now factored their cancer experience into nearly all life decisions.

“Rolling with the punches” involved three specific strategies for this sample: “defining my own pace;” planning realistically;” and “getting practical.” “Defining my own pace” rather

than that of their peers or former selves meant bringing their health needs to the foreground and making accommodations. It also liberated participants from conventional expectations of young adulthood. “Planning realistically” referred to a strategy that reflected an aversion to long-term planning. As one participant justified, “[Planning is] getting in the way of yourself. Because I guess planning is expectations. And expectations, when they are not met, create disappointment.” Instead, participants preferred to structure their lives in smaller time increments, such as months or academic semesters, without looking beyond, to avoid long-term goals and dreams.

“Getting practical” involved reprioritization with cancer in mind. For example, participants spoke about how their cancer experiences influenced their long-term career aspirations. While a few felt that cancer reaffirmed their previous goals with new clarity, most changed direction completely. Many now felt it was more important to select careers based on practical aspects, such as health benefits and physical tolerability, rather than pure interest. Participants expressed practical concerns about adequate salary and insurance coverage in the event of future health problems. As one participant shared, “When I’m looking at my career and planning out my life, in the back of my mind I always think, ‘Okay, am I going to be making enough money if something happens to me?’” In addition, many participants attributed changes in career aspirations to cancer-related physical limitations. One explained, “I need to look for something that my body can tolerate. So, now it's like I have to lay out certain options, what I can do and what I cannot do.” One participant gave up the dream of teaching early education, despite just finishing her degree, because the active teacher role would require sitting cross-legged on the floor and carrying young children, all of which she could not tolerate. Another explained her rationale when considering a variety of jobs:

I can't really do much. It's not like I can go back to like a fast food place because I can't

do any of that physical stuff. You know, that fast food work, that's like a lot of lifting and carrying, and I can't do that. I can't do that because I can't carry more than five pounds. And then even going back to the bank, [...] even that, I wouldn't be able to do because it was carrying the money, and the money is heavy. The coins and all the bills, that's pretty heavy. And I wouldn't be able to. And, it's a lot of bending over and picking up, and I'm not able to do any of that. So, it's tough. Even if it was an office job, I'm not able to sit for a long period of time because, when I get up, my hip hurts or my feet will get swollen. It's just like so many things that I just can't. I can't even if I wanted to. Even if I wanted a desk job, I can't. I can't.

Similarly, many participants described “getting practical” in their approach to intimate relationships. Specifically, many now sought intimate partners who would be able to handle future cancer-related issues, both emotionally and financially.

Wondering “What if I hadn’t had cancer?”

Amidst these attempts to manage their fears of the future, many participants described a nagging undercurrent of wondering, “Where would I be today if I didn’t get sick? What if I hadn’t had cancer?” As much as they tried to keep these thoughts at bay, many admitted that thoughts about the “what-if factor” and “the alternate universe” occurred frequently. Part of this wondering stemmed from a curiosity to know the person they were growing into just before they were diagnosed. As one participant explained,

I was done with high school. I was moving to a new place. I was starting to become a real adult. [...] It’s harder for me to tell how much of the person that I am today is because of [cancer] and how much is because of other factors. Maybe if I had been 25 instead of 18,

I would've had a better sense of the person that I really was before, the sort of adult that I was before I had the diagnosis whereas, for me, it's like it came right on the cusp of real adulthood.

It was common for participants to try to understand the extent to which the cancer experience shaped their life trajectory. Wondering “what if” often involved attempts to separate the specific effects of cancer from the developmental changes that were occurring at the same time (and would have unfolded without cancer). For example, one participant explained that because of her family history of anxiety, “I could've been non-cancer, 26, and still have the same anxiety. So, that's kind of a question you can't answer, unfortunately.”

Unanswered and often unanswerable questions characterized the experience of wondering “what if?” Participants believed strongly that without cancer, their lives and futures would look substantially different and their interest in these unfulfilled life paths lingered. They denied dramatic changes to their core self; as one participant pointed out, he did not become a “crazy risk taker” or “completely carefree” after facing his mortality. However, they ultimately believed their life trajectory had changed course and now pointed to a different future. From this new vantage point, the presence of cancer was permanent, no matter their disease status, and their sense of potential was no longer limitless.

Discussion

The focus of this analysis is on a critical turning point in early survivorship for a sample of AYAs recovering from HCT. “Improving to where?” emerged as an important question and referred to a theme that participants confronted at some point during their recovery. Once this question was raised, it was pervasive and led participants to realize the lifelong nature of cancer

survivorship. Some participants described this understanding as a shock and others described it more as a new reality that dawned on them. Regardless, it debunked previous expectations of returning to “normal.” The process of understanding the meaning of this theme resulted in psycho-emotional turmoil for participants of varying degrees and ultimately required them to re-conceptualize their futures.

Founded Fears

Participants in our sample did not automatically understand cancer as a chronic disease. It was at some point after acute treatment when they were well into early survivorship that they figured out that cancer and its sequelae were going to be with them for years to come. With this understanding came the belief that “something bad” was going to happen in due time as a result of their treatment. While much research on cancer-related anxiety focuses on fears of recurrence (Koch, Jansen, Brenner, & Arndt, 2013; Mehnert, Koch, Sundermann, & Dinkel, 2013), participants in our study distinguished their anxiety as related to late effects of treatment and a lifetime of elevated health risks.

Unfortunately, other research suggests that these fears are well founded for many reasons (Baker et al., 2010; Bukowinski, Burns, Parsons, Perentesis, & O'Brien, 2015; Lee et al., 2016). In general, cancer survivors have elevated risk of secondary malignancies due to their genetic predisposition as well as their previous cancer treatment (McCabe, Bhatia, et al., 2013; Robison & Hudson, 2014), but little is known about survivorship risks among AYAs. A history of low clinical trial enrollment has resulted in a lack of knowledge regarding the specific pharmacokinetics of cancer therapies in the context of AYA development and disease biology (Bleyer, Budd, & Montello, 2006). However, limited evidence suggests that AYAs often have less responsive diseases and require more intense regimens than younger age groups, thereby

possibly increasing their risk for more severe treatment-related toxicities (Bukowinski et al., 2015). In one of the few studies to examine late effects among those diagnosed as AYAs rather than childhood cancer survivors, AYAs who were treated between ages 15 and 39 years were nearly 60 percent more likely to develop a secondary cancer when compared to the general population (Lee et al., 2016). Furthermore, this figure stands in contrast to survivors treated after age 40 who were only 10 percent more likely to develop another malignancy. In addition to the risks associated with AYA survivorship, the treatment of HCT also carries significant long-term health risks, including late relapse, secondary cancers, late infections and organ toxicity, regardless of the age at treatment (Baker et al., 2010; Majhail & Rizzo, 2013; Sun et al., 2013).

Greater insight into our sample comes with the results of the SF-36 which have demonstrated lower than average scores across all sub-scales and both composite scores when compared to a normative population of young adults aged 18-34 years, particularly in the physical areas as well as general health perceptions. Gross comparisons with a cohort of adult survivors of pediatric HCT (n=214) who were on average 11.9 years (range: 1.8-17.9) at HCT, 28.7 years (range: 18.8-45.9) at the time of the study, and 16.2 years (range: 5.2.-28.9) since HCT indicate comparable mean MCS (50.4) but notable differences in the mean PCS (51.1), and physical subscales of physical functioning (89.1), role-physical (84.5), and bodily pain (79.2) (Sanders et al., 2010). In addition, there was a stark contrast in the general health perception subscale between the sample of adult survivors of pediatric HCT (70.1) reported by Sanders et al. (2010) and our sample (36.4). This subscale addresses current health as well as the belief that health will improve in the future. The low scores in general health perception reported by our sample are concerning and may reflect their future-oriented anxiety and the looming expectation for “something bad.” The relatively average MCS reported by our sample is somewhat

unexpected given that AYAs tend to report poorer mental health outcomes than comparison groups such as healthy controls, siblings, and older survivors (Sansom-Daly & Wakefield, 2013). Furthermore, adult HCT survivors also face significant psychological challenges, such as anxiety and depression and distress (Rusiewicz et al., 2008; Wells, Booth-Jones, & Jacobsen, 2009). Persistent distress among HCT recipients has been linked to negative outcomes such as poor physical functioning (Sherman, Simonton, Latif, Spohn, & Tricot, 2004), lower health-related quality of life (Bevans et al., 2014) and decreased survival (Loberiza et al., 2002; Park et al., 2010).

The combined risks of AYA survivors of HCT make them a particularly vulnerable group with extensive survivorship needs for the remainder of life (Bukowinski et al., 2015). Our findings provide deeper insight into this group's distress about future health risks, their gaps in awareness, and need for risk-based information and long-term support. Tailored education about therapy-related health risks and strategies to promote healthy behaviors may improve personal risk awareness, reduce anxiety, and empower AYA survivors to serve as their own health advocates (Landier et al., 2015). Furthermore, treatment summaries and survivorship care plans are useful tools to equip AYAs and their health care providers to monitor therapy-related risks over time and minimize the impact of long-term complications.

Lost Future

The unexpected change in life direction that resulted when participants realized that cancer survivorship was a lifelong endeavor brought anxiety and distressing uncertainty about the future. No longer could they imagine a future untouched by cancer. Instead, they perceived a narrowing of options and a future of fear. From a developmental perspective, the AYA life stage, what some have called “emerging adulthood,” is characterized by identity exploration,

instability, self-focus, high hopes, big dreams, and freedom (Arnett, 2014). As such, participants' pre-diagnosis sense of "normal" was fleeting and undefined, but their future was full of possibility. Participants did not grieve an old normal, but rather an imagined self and future that they would never know or live out. This finding intersects with themes of grief for a "real" identity (Forinder & Posse, 2008) and new life (Stephens, 2005) in other HCT populations. Thus, because their sense of normal was so undefined at diagnosis, the concept of "new normal" in cancer survivorship may not reflect the AYA experience and warrants further study as it is used commonly in research and clinical settings.

Conclusion

A decade ago, the National Cancer Institute and Livestrong Foundation convened the Adolescent and Young Adult Oncology Progress Review Group (2006) to harness research efforts on the AYA population. While research in AYA oncology broadly has surged, the area of AYA survivorship remains in its infancy. For example, much of the current knowledge on AYA survivorship has been extrapolated from studies on survivors of childhood cancer, an arguably distinct patient population (Kinahan et al., 2015). As recommended by the Institute of Medicine, risk-based protocols should guide survivorship care to support high-risk subgroups and optimize use of resources (McCabe, Partridge, Grunfeld, & Hudson, 2013). However, it is also critical to develop interventions that support survivors in moving forward, specifically managing anxiety about the future, through a lifetime of known risks.

Despite limitations of small sample size from a single institution and cross-sectional data, this study makes a unique contribution by enhancing our understanding of cancer survivorship among a specific subgroup of AYAs. Future research on AYA survivors should include larger, multi-institutional cohort studies of AYAs to identify the particular risks associated with AYA

survivorship. Nevertheless, in providing rich data from the perspectives of AYAs themselves, our results lay early groundwork that can inform psychosocial interventions targeted at this particularly complex population.

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Table 1: Excerpt from Semi-Structured Interview Guide

Area of Focus	Example Questions and Probes
Impact of cancer experience	<p>Tell me about any things that continue to be challenging since having HCT.</p> <p><u>Prompt</u>: What has been the most challenging or difficult and why? (socially, emotionally/psychologically, behaviorally)</p> <p>Looking back, how has this overall experience (cancer/transplant) affected the flow of your life?</p> <p>Since being discharged from the hospital, what has been the biggest change for you socially (Resuming social roles)?</p> <p><u>Prompt</u>: Emotionally/psychologically (Fear, anxiety, depression, PTSD, resilience, post-traumatic growth)?</p> <p><u>Prompt</u>: Behaviorally (physically, risk-taking, health behaviors)?</p>
Reflecting on the present and the future	<p>Think about your life now. Has it changed because of your transplant? If so, how?</p> <p>How, if at all, has having cancer affected how you think about the future?</p> <p><u>Prompt</u>: How has it affected your future plans?</p> <p>What would you tell someone who was just starting out on their journey of transplant and beyond?</p>

Table 2: Sociodemographic Characteristics (N=18)

Characteristic	n
Sex	
Male	11
Female	7
Ethnicity	
White/Caucasian	7
Hispanic/Latino	8
Asian/South Asian	3
Highest Level of Education Completed	
Some high school	1
High School	2
Some college	9
4-year college	5
Graduate degree	1
Total Annual Household Income	
Don't Know	5
\$19,999 or less	4
\$20,000 - \$49,999	5
\$50,000 - \$74,999	3
\$75,000 - \$99,999	0
\$100,000 or more	1
Current School/ Employment Status	
Enrolled in school (part- or full-time)	5
Employed (part- or full-time)	6
Enrolled in school and employed	1
Neither in school, nor employed	6
Current Relationship Status	
Not in a significant relationship	8
In significant relationship, not living together	4
Living with spouse/partner	6
Current Marital Status	
Never Married	14
Married	4

Table 3: RAND SF-36 Component Summaries and Subscales

Scale	Total (N=18)	
	Mean	SD
PCS	37.5	14.0
MCS	45.7	11.0
Physical functioning	37.3	18.0
Role-physical	34.0	17.4
Bodily pain	47.2	13.5
General health perception	36.4	14.9
Vitality	45.3	10.3
Social functioning	41.4	14.5
Role-emotional	39.1	13.2
Mental Health	46.8	12.1

Abbreviations: RAND SF-36, RAND Short Form-36; SD, standard deviation; PCS, physical component summary; MCS, mental component summary.

Figure 1: Summary of Study Recruitment

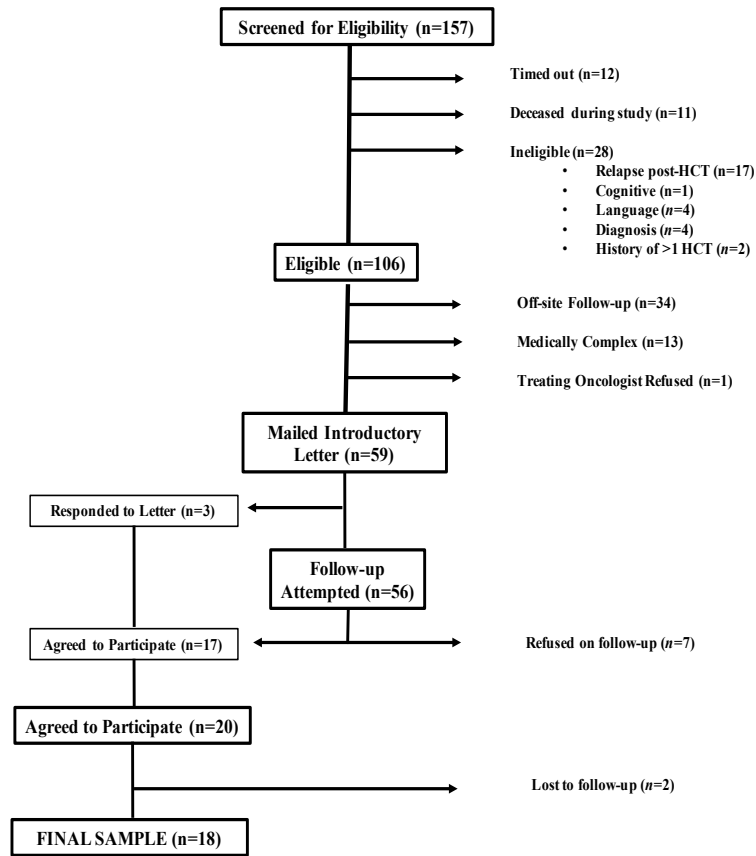
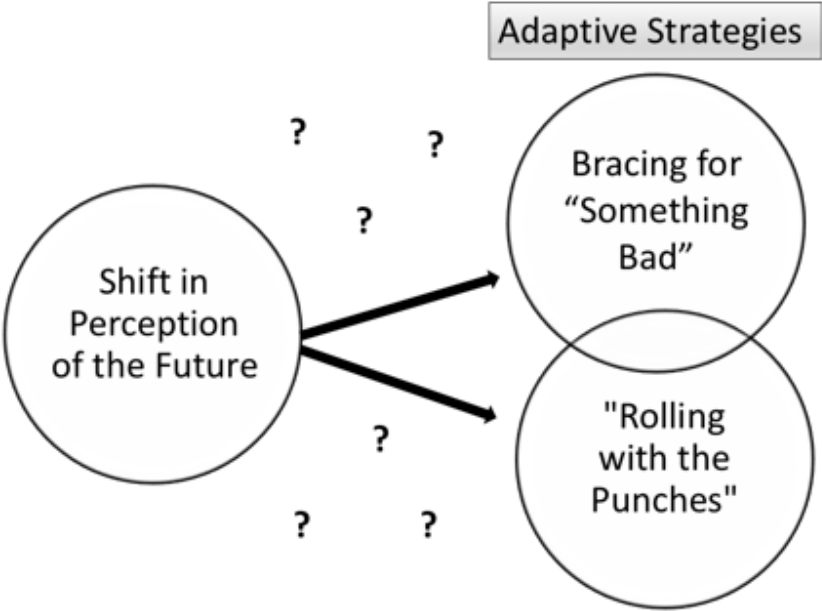


Figure 2: Reconceptualizing the Future Through Adaptive Strategies among AYA Survivors of HCT



Conclusion to the Dissertation

Over the past decade, the interest in AYAs with cancer has proliferated, but major gaps in current research and clinical knowledge remain (Nass et al., 2015; Smith et al., 2016). The experiences of specific subgroups of the AYA population, including HCT recipients, have not been well studied, despite consistent recognition of these patients as one of the most vulnerable and acutely ill cancer populations (Bevans, Mitchell, & Marden, 2008). While the findings cannot be generalized to all AYA survivors of HCT, this study provided insight into the trajectory towards self-care, the reliance on informal caregivers, and the experiences of critical transitions in early survivorship. The findings also shed light on how a cancer diagnosis and the high intensity of HCT results in extensive and persistent life disruption that is unexpected and difficult to overcome. By providing deeper understanding of the survivorship trajectory of AYAs after HCT, these findings can be used to inform clinical practice, guide future research, and shape policy.

Implications for Clinical Practice

The particular focus on the transition to self-care of this study will aid nurses and other health care providers as they promote the health status of AYA cancer survivors through the transitions of early survivorship and over the long term. An important finding from this study was the AYAs' reliance on teams of informal caregivers rather than single individuals. It is important for health care providers to acknowledge the various members of a caregiving team and ensure that all members feel prepared and well connected to resources to reduce caregiver burden, burnout and distress. The members of the team may also change over time and therefore, the caregiver who accompanies an AYA to appointments may not necessarily be the one who is performing care responsibilities at home. Nurses in a variety of clinical settings will come into

contact with AYA survivors and their caregivers. Assessment of caregiving relationships, including screening for highly distressed caregiving arrangements, should be part of routine follow-up care.

Another implication for clinical practice was the need for support during major transitions. In particular, participants in this study reported difficulty maintaining positive health behaviors, such as adequate sleep and exercise, proper nutrition, and stress management, during reentry to work and school settings. Although this represents a very new area of research, data from other studies suggest that unhealthy lifestyle behaviors are common among AYA cancer survivors (Warner et al., 2016). For example, their use of alcohol is equivalent to age-matched controls (Institute of Medicine [IOM], 2013). Studies have also demonstrated significantly higher rates of smoking and obesity among AYA cancer survivors when compared to those without a history of cancer (Tai et al., 2012; Warner et al., 2016). Such adverse health behaviors may have dire consequences for AYA cancer survivors. Alcohol may increase the risk for myocardial dysfunction, liver damage, osteoporosis, as well as other cancers; tobacco may exacerbate cardiac and pulmonary toxicities and increase lung cancer risk, while drug use can worsen mental health issues, such as depression, anxiety, and post-traumatic stress disorder (IOM, 2013). Interventions specifically tailored to AYAs are needed to help incorporate healthy behaviors into their lifestyle as they resume social roles and increase activity levels. AYA nurse navigators may be instrumental not only in supporting successful transition in the short-term, but also in establishing lifelong healthy behaviors.

As the AYA movement gained traction over the past decade, several AYA programs have emerged in medical centers across the country. These programs vary significantly in design, scope, and approach and the evaluation of such models is an important priority for the field

(Smith et al., 2016). Our findings indicate that AYA survivors have extensive needs across physical, emotional, and practical domains and reaffirm the necessity for comprehensive survivorship care as an essential component of any AYA care model. This is in line with current recommendations regarding supportive care by the National Comprehensive Cancer Network (Coccia et al., 2012) and criteria for the distinction of AYA Center of Excellence (Smith et al., 2016).

Finally, the AYAs in our study spoke of significant anxiety and worry throughout their cancer trajectory. Other studies on AYA cancer survivors have also reported psychological morbidity, which includes depression, anxiety, and low self-esteem (Langeveld et al., 2003) and identified vulnerable AYA subgroups at high risk of post-traumatic stress disorder (Rourke, Stuber, Hobbie, & Kazak, 1999) and suicide (Recklitis, Lockwood, Rothwell, & Diller, 2006). While many participants sought out professional psychological support in the post-treatment period, they also described limitations on these services due to providers' lack of knowledge about cancer survivorship. The AYA cancer experience presents unique challenges and survivors will benefit from psychological support services that are specifically tailored to the needs of AYA cancer survivors and reflect knowledge of cancer diagnoses, treatments, and associated risks. Psychological support for AYAs should also provide strategies to manage anxiety in different situations and help AYAs identify alternate outlets for stress.

Implications for Future Research

By examining the experiences of a specific treatment group (AYAs after HCT), this study makes a unique contribution by presenting our findings in the context of the broader AYA literature. An important next step for research in AYA oncology is to build knowledge about the unique aspects of being diagnosed with cancer during the AYA life stage rather than extrapolate

from data on adult survivors of childhood cancer. While the robust datasets available on pediatric survivors have provided a useful starting point, it is essential for researchers to pool resources and join efforts to develop similar repositories of information about AYAs specifically.

Increasing enrollment of AYAs in clinical trials is another priority that will advance the science of AYA oncology substantially. Expanding the AYA oncology knowledge base will allow researchers to describe the heterogeneity of the AYA population, a group of patients that spans a wide age range, a variety of diagnoses, and inhabits diverse life circumstances.

Our findings demonstrated the devastating impact of late effects among survivors of a high-intensity treatment. Basic and translational research on the unique biology of AYA cancers as well as specific hormonal and pharmacological aspects of AYA development may help identify more appropriate therapies as well as opportunities to reduce exposures and ultimately minimize adverse effects over the long term. Large, longitudinal studies are needed to identify the specific late effects experienced by AYAs and develop evidence-based risk profiles. Studies on psychosocial late effects are also needed, especially beyond five-years post-treatment. The development, implementation, and evaluation evidence-based interventions for AYA survivors, using randomized controlled trials, are high priorities for research (McCabe et al., 2013).

Because AYAs are technologically savvy (or digital natives), the use of virtually delivered interventions and electronic survivorship care plans shows tremendous promise.

Implications for Policy

The findings of this study have important implications for policy. At the micro level, it is important for policies in school and work institutions to support AYAs who are transitioning to these settings after treatment while continuing to manage physical and psychosocial issues. Specific policies should be reviewed and amended to facilitate successful transition and

minimize added financial burden. Health care providers with expertise in AYA oncology can advocate by serving as liaisons to provide input into medical leave and reentry policies that are both physically realistic and financially manageable for AYAs in higher education. Through these relationships, they can also ensure that the accommodations of school-based disability services intended to support AYAs actually reflect and address their needs. Policies in the work setting often exist, but the AYAs in this study seemed to be unaware of their rights and protections as employees. Therefore, it is important to recognize that many AYAs are new to the workforce and may need additional support in navigating these channels.

On a macro level, policy is needed to minimize the immense financial burden of cancer on AYA survivors. Prior to the passage of the Patient Protection and Affordable Care Act (ACA), young adults were the most underinsured age group in the United States (Bleyer, O'Leary, Barr, & Ries, 2006) and nearly two of five (39%) young adults ages 19 to 29 years were without health insurance (Collins, Robertson, Garber, & Doty, 2012). Lack of insurance has been linked to delays in diagnosis (Martin et al., 2007), delays in receiving treatment (Burg et al., 2010), and decreased survival in AYAs with cancer (Kent, Sender, Largent, & Anton-Culver, 2009). While the ACA has expanded much needed insurance coverage for AYAs, particularly for those who are 26 years and younger, the impact of this policy on specific outcomes, including access, quality, finances, and health, has not yet been reported and requires further analysis.

Summary

The experience of cancer and its treatment during the AYA life stage results in significant life disruption and deficits across a wide range of health outcomes. High-intensity treatments, increased risks for long-term effects, and a wide array of unmet physical, psychological, social, and information needs complicate the survivorship trajectory for AYAs. Despite growing

awareness of these issues, current knowledge on AYAs' transition to survivorship and self-care is extremely limited (Hewitt, Greenfield, & Stovall, 2006; IOM, 2013). This study reported useful insight into the survivorship needs and experiences of a particularly vulnerable subset of AYAs. In addition, findings provided rich understanding of critical transitions in the post-treatment period of AYAs after HCT: the sequential transitions described in the first and second manuscripts of recovery with the help of informal caregivers at home and then reentry into the outside realms of school and work, as well as the transition in the third manuscript of integrating the cancer experience into a broader life vision for the future. All three transitions have broad implications for long-term health and wellbeing and represent opportunities for targeted interventions and future research. Nurses are well-positioned to lead efforts in survivorship care, research and advocacy for AYA survivors to minimize the impact of late effects and support AYAs in moving forward with their lives.

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