

SUPPORTING TRANSITION AND REINTEGRATION

**SUPPORTING ADOLESCENT CANCER SURVIVORS’  
TRANSITION AND REINTEGRATION  
INTO THE EDUCATION SYSTEM**

by

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Submitted in partial fulfillment of the  
requirements for Departmental Honors in  
the Department of Nursing  
Texas Christian University  
Fort Worth, Texas

December 11, 2023

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### **Abstract**

Adolescents and young adults (AYAs) require specific, multidisciplinary care during their cancer treatment and throughout the transition to post-treatment care and survivorship. Currently, there is a lack of research and understanding highlighting the impact of this age-specific and developmentally centered care for adolescents and their return to school post-treatment. Understanding and acknowledging the specific needs of adolescents is crucial to supporting their transition and reintegration back to school after they have achieved post-treatment remission from cancer. Thus, this honors project focused on how providers can improve the transition back to school for this population. Adolescents between 15-18 years of age and off treatment for a minimum of six months who have returned to in-person education participated in either a focus group or individual interviews to evaluate their individual experiences, thoughts, and feelings with the process of returning to school and the support provided to them throughout the process. Interview transcripts were analyzed using thematic content analysis, and eight major themes were identified to inform recommendations for future support of adolescent cancer survivors when returning to school: (1) preparedness; (2) coursework challenges; (3) change and adjustment; (4) consistency and help with adjustment; (5) emotional and social impact; (6) physical impact; (7) normalcy; and (8) positive outlook. These themes form groundwork for age-specific and developmentally informed support when assisting adolescent cancer survivors in their transition from post-treatment to survivorship and returning to school for the first time since diagnosis.

**Table of Contents**

<b>Sections</b>	<b>Page Number</b>
<i>Introduction</i>	6
<i>Review of Literature</i>	6
<i>Adolescent Development</i>	7
<i>Transition</i>	10
<i>Survivorship Experience</i>	14
<i>Readiness to Return to School</i>	16
<i>Barriers to Returning to School</i>	18
<i>Returning to a Sense of Normalcy</i>	20
<i>Literature Review Summary</i>	21
<b>Methods</b>	22
<i>Design</i>	22
<i>Sample and Setting</i>	22
<i>Procedure</i>	23
<i>Recruitment for Individual Participant</i>	23
<i>Interviews and Focus Groups</i>	
<i>Data Collection</i>	24
<i>Data Confidentiality</i>	25
<i>Data Analysis</i>	26
<i>Field Notes</i>	26
<i>Coding and Thematic Development</i>	26
<i>Validity and Reliability with Thematic Development</i>	26
<b>Results</b>	28
<i>Major Themes</i>	28
<i>Theme 1. Preparedness</i>	28
<i>Theme 2. Coursework Challenges</i>	33
<i>Theme 3. Change and Adjustment</i>	35

<i>Theme 4. Consistency and Help with Adjustment</i>	38
<i>Theme 5. Emotional and Social Impact</i>	40
<i>Theme 6. Physical Impact</i>	43
<i>Theme 7. Normalcy</i>	44
<i>Theme 8. Positive Outlook</i>	46
<b>Discussion</b>	47
<i>Strengths and Limitations</i>	53
<b>Implications for Future</b>	54
<b>Conclusion</b>	54
<i>Appendix A: Interview Questions</i>	56
<b>References</b>	57

## **Supporting Adolescent Cancer Survivors' Transition and Reintegration into the Education System**

Cancer is the most prevalent disease-related cause of death in adolescents and young adults (Jones et al., 2020). The advancements in cancer therapies and treatments resulted in the overall 5-year survival rate of all children less than age 19 years to be almost 85% (American Cancer Society, 2022). Intensive cancer therapies and treatments, as well as heightened infection risk due to neutropenia, fatigue, and other cancer-related adverse effects, demand lengthy and intermittent periods of both hospitalization and isolation (Choquette et al., 2016). These are important considerations regarding the transition and school re-entry process for adolescent survivors since these students endure setbacks secondary to their disease.

A cancer diagnosis and the subsequent long-term therapies and treatments negatively affect the advancement and achievement of adolescent developmental milestones (Jones et al., 2020). Attending school and having social interaction with peers gives students a sense of normalcy and hope while adolescent patients are enduring their unique experiences with cancer therapy and treatment (Yi et al., 2016). The return to the educational setting for adolescent survivors is equally critical for this population due in part to their developmental stage and need for independence and acceptance from peers. The academic setting provides opportunities for students to improve and develop their social skills, as well as consider their future endeavors, and research indicates that more prolonged school absences result in more challenges for adolescent survivors regarding school re-entry and overall quality of life (Yi et al., 2015). Difficulties related to school re-entry include feelings of fatigue and general anxiety as well as poor communication between the survivor and the school community. A consistent gap found in the literature suggests that limited services are available for adolescent cancer survivors regarding the hardship of the transition into school re-entry and life after cancer therapy and

treatment. Furthermore, there are knowledge gaps regarding how school re-entry affects adolescent survivors' developing self-identity and personal and social relationships.

A further synthesis and review of the literature showed a lack of transition support and resources related to school re-entry for adolescent survivors of adolescent cancer. The following research question was developed in response to this gap in the literature: How can interprofessional teamwork with education systems to provide support and resources to adolescent survivors of adolescent cancer aid with school re-entry and reintegration following the transition from active treatment to survivorship?

### **Review of the Literature**

Past literature indicates that guidelines have been created to tend to the educational needs of both children and adolescent cancer survivors, but none of the guidelines explicitly address the unique educational needs of adolescent cancer survivors (Rennick & Lee, 2016). Few qualitative studies have been conducted to demonstrate the educational readiness and progression as well as experiences for this population upon reintegration and the transition back to school (Kim et al., 2016). A search of the literature completed using JSTOR, The National Library of Medicine, Springer Link, Psych Lit, CINAHL, Wiley Online Library, and PubMed provided studies that addressed readiness to return to school, barriers to returning to school and returning to a sense of normalcy. Search terms included “adolescence” AND “adolescent development” AND “AYA cancer” AND “adolescent cancer survivor” AND “AYA cancer transition” AND “AYA cancer survivorship” AND “school reintegration” AND “school transition” AND “school preparedness.” Additional terms included “readiness” and “normalcy” to try to bridge the gap in resources that are specifically related to school re-acclimation needed by adolescent survivors and the resources already being provided.

## **Adolescent Development**

Adolescence is marked as the period between childhood and early adulthood (Jackson & Goossens, 2020). The American Academy of Pediatrics (AAP) defines the age range of adolescence as being between 11-21 years old and this transitional time of adolescence serves as a bridge between childhood and adulthood, and this developmental stage is comprised of milestones that are unique to this specific age group (Grubb et al., 2019). The onset of adolescence is characterized by puberty, with the latter years of adolescence focusing on the transition to becoming an adult (Jackson & Goossens, 2020). The AAP states that developmental factors unique to the adolescent population include but are not limited to healthy cognitive, physical, sexual, emotional, social, and psychosocial developmental impacts (Grubb et al., 2019). Furthermore, the AAP discusses how there is a national consensus that the unique needs of adolescents need to be addressed and respected to promote their overall health and wellbeing.

Adolescence marks a critical time regarding the overall development of a young person (Grubb et al., 2019). The AAP describes the need for adolescent-centered physical and mental health promotion, as well as addressing these issues specific to this population (Grubb et al., 2019). There are a variety of health risks that pose a threat to the adolescent population and adolescents may not be prepared to face the challenges specific to their developmental age and stage. Adolescents are more likely to engage in risk-taking behaviors, such as the use of alcohol or tobacco, drugs, or unprotected sex, and these risky behaviors can pose adverse and potentially long-term health consequences. The AAP furthers this statement by discussing other injuries, intentional and unintentional, that adolescents may endure due to risk taking behaviors (Grubb et al., 2019). Such behaviors include motor vehicle accidents, firearm injuries, injuries caused by alcohol or other illicit substances, or homicidal and/or suicidal behaviors and ideations. The AAP



discloses that approximately 72% of deaths among adolescents are attributed to these specific behaviors.

Jean Piaget and Erik Erikson historically described the developmental stages of adolescence (Babakr et al., 2019). Piaget describes four cognitive developmental stages for children, including the sensorimotor, preoperational, concrete operational, and formal operational stages (Babakr et al., 2019). The stage of development defined by Piaget that relates to adolescence is the formal operational stage, which begins around the age of 11 years old. This stage developed by Piaget emphasizes that one's thinking and understanding develop significantly throughout this final stage of psychological development (Babakr et al., 2019). Piaget also describes the formal operational stage as the adolescent's ability to think abstractly and utilize higher-order reasoning and problem solving (Caldeira & Carvalho, 2021). However, these researchers listed previously discovered through research that not all adolescents reach this stage of development in their younger teenage years, partially due to the education system and its lack of emphasis and implementation on critical thinking (Babakr et al., 2019). While Piaget's theories have been used and accepted to define the psychological capacity of children and adolescents, there are shortcomings in his theories when describing adolescents. Researchers have concluded that Piaget's theories overestimate the ability of adolescents (Babakr et al., 2019).

Erik Erikson formulated developmental stages based on age and focused on the entire life cycle. Erikson's Stages of Psychosocial Development are based on Sigmund Freud's Theory of Psychosocial Development using comparison in childhood stages and relating findings to psychosocial development into adulthood (Orenstein & Lewis, 2022). Erikson composed eight developmental stages of individual human development as influenced by varying biological, psychosocial, and social factors throughout one's life (Orenstein & Lewis, 2022). Adolescence is

defined as Stage 5, or The Adolescence Period, and focuses on Identity vs. Identity Confusion. This developmental stage emphasizes that adolescents weigh out their previous experiences while considering societal expectations and their own personal goals to discover who they are on a deeper level. During this stage, the adolescent develops a sense of ego throughout this stage and how the ego helps to develop either fidelity or repudiation. By having a stronger sense of the ego, the adolescent can identify who they are in the world around them (Orenstein & Lewis, 2022). Erikson also claimed that an increased sense of ego beyond that of a healthy amount can lead to dysfunction later in life (Gross et al., 2020).

The general adolescent developmental phase is characterized by the need for peer relationships and social interaction (Orben et al., 2020). Researchers indicated that peer acceptance and influence in adolescence is pivotal in the general development of this age group. The researchers note that social deprivation and isolation have unique effects on both the brain and behavior of adolescents in comparison to other life stages. Social interactions are crucial to the development of adolescents, and adolescence is marked by a sensitive period for social interaction. Psychological and social transformation are changes commonly experienced throughout adolescence, and throughout the teenage years, the social world and peer interactions are more apparent and important. Peer relationships become more complex, and the importance of peer social approval and peer influence become heightened (Orben et al., 2020). Adolescents are more sensitive to peer acceptance, rejection, and approval than children or adults (Orben et al., 2020). Social development is also a characteristic component of adolescent development and is considered a sensitive period for adolescents.

### **Transition**

The adolescent and young adult (AYA) population represents patients initially diagnosed with, enduring treatment for, and transitioning from a cancer diagnosis between the ages of 15-

39 to post-treatment survivorship (Stone et al., 2017). The AYA population faces a unique set of challenges regarding cancer treatment, transition, and survivorship. While substantial advancements in cancer therapy, research, and treatment have caused a decline in cancer mortality rates among this population, AYA patients and survivors endure challenges regarding their disease process (Stone et al., 2017). Researchers have concluded that AYAs diagnosed with cancer are an understudied population, and the unique experiences, care, needs, and outcomes are misunderstood (Smith et al., 2018).

Cancer survivors in the AYA population struggle with social isolation and its subsequent effect on relationships and connectedness with peers (Janssen et al., 2021). The AYA population face common challenges that include loss of control of their life, disruption of developmental milestones, late effects of treatments, social isolation within the healthcare system and with their peers, balancing hope and risks, lack of prognostic information, and uncertainty about the treatments they receive. Specific psychosocial needs help set AYA cancer survivors apart from other survivors. Researchers have discussed how there is insufficient awareness for cancer risks and symptoms among the AYA population, how cancer biology and treatments differ between age groups, the consequences of late effects, and the different transitional phases this population endures (Janssen et al., 2021). The AYA population undergoes different, unique phases of life relating to their developmental stage, all of which are impacted by physical, emotional, cognitive, and social transitions.

A cancer diagnosis during the AYA periods of development increases challenges in their psychological development and interferes with attaining age-specific milestones, resulting in psychological distress, potential deficits, and social issues (Janssen et al., 2021). Normal developmental milestones for this age group, such as identity forming, establishing autonomy, responsibility, independence, completing education, and beginning a career are impacted

negatively by cancer (Janssen et al., 2021). The AYA's social role becomes limited, and these patients have difficulties with maintaining social contacts and an independent life because of cancer treatment. Social roles change as AYAs are unable to participate in the same life activities as their peers. AYAs miss the engagement in normal life experiences and feel isolated and alienated as a result (Janssen et al., 2021). These feelings of isolation and alienation are described as "common" for AYAs since they are set apart from their peers and become more dependent on their parents or caregivers throughout their treatment, causing AYAs to perceive themselves as "different" from their peers because of their cancer diagnosis (Janssen et al., 2021).

Cancer also causes an increase in neurocognitive deficits such as memory problems, decreased attention, and declined executive functioning, all of which impact the AYA's success in the academic or work setting (Janssen et al., 2021). While many AYAs continue and/or return to their academic or employment setting post-treatment, the trajectory of their success may be disrupted due to time missed because of their treatment. Researchers indicate that AYAs educational trajectories are potentially disrupted due to their absences from school or the inability to complete exams (Janssen et al., 2021). Further, AYAs have discussed receiving inadequate educational support throughout the course of their treatment and with returning to school that they need extra support to succeed (Janssen et al., 2021). One qualitative study suggested that Danish AYAs experienced discrepancies and issues with their return to both secondary and higher education from their treatments, lack of understanding from their peers, and other system barriers within their academic system, such as miscommunication (Janssen et al., 2021). These AYAs stated that support from the school and guidance counselors was helpful with their transition back to school and relieving the burden of these factors.

Research revealed that young adult survivors of pediatric cancer suffer from premature aging because of an accumulation of deficits from cancer treatment (Williams et al., 2023). This combination of deficits that results in premature aging is due to host and treatment factors, neurocognition, and mortality. Aging involves tissue and organ dysfunction paired with psychological dysregulation. The researchers suggest that the variability in disease development and functional decline among pediatric cancer survivors is exacerbated and causes molecular damage resulting in premature aging (Williams et al., 2023). The research showed that young adult survivors of pediatric cancer have a higher risk of psychologic frailty, chronic health conditions, neurocognitive impairments, and premature mortality. The researchers state that these factors suggest an accelerated aging phenotype for this group (Williams et al., 2023). As a result, there is a significant impact on school performance. These researchers concluded that these survivors have a high risk of poor educational attainment and are less successful in school (Williams et al., 2023).

Regarding AYA research advancements, the National Cancer Institute supported the Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE) study that addressed gaps in knowledge and research about AYA patients and survivors (Smith et al., 2018). This is the first population-centered cancer registry study that examined care quality with physical and mental health outcomes for AYAs (Smith et al., 2018). The primary goals of the AYA HOPE study were to: (1) determine the feasibility of conducting a US-based study with medical records and survey data from AYAs; (2) determine the impact of cancer on overall medical care, psychosocial and physical functioning; and (3) determine and identify the current gaps, experiences, and needs for cancer care in the AYA population (Smith et al., 2018). The study findings indicated that as cancer occurs in adolescence and/or early adulthood, there is a major concern among patients regarding their educational attainment and professional goals.

AYAs stated that intensive treatment and leaving school or work to receive care were negatively associated with educational and/or employment plans (Smith et al., 2018). Further, AYAs discussed the inability to integrate cancer care with daily life activities, including work and school. The data obtained with this study relating to work and school posed implications on the AYAs success.

### **Survivorship Experience**

AYAs also describe difficulties with unaddressed concerns as they transition from active cancer treatment to survivorship. The survivorship phase is defined with both early and late survivorship (Janssen et al., 2021). The early survivorship phase is composed of the first five years since the termination of initial treatment, while late survivorship is defined as the time greater than five years since termination of initial treatment. Throughout survivorship, AYAs are in between age-centered follow up for childhood cancer survival as well as disease-centered follow-up appointments for adult cancer survival. The needs of AYAs differ from those of other patients due to the unique needs that they require. Such needs are influenced by factors that include but are not limited to their age, developmental stage, and time lost due to their disability, poor health, and wellbeing (Janssen et al., 2021). AYAs are at an elevated risk of developing cancer and/or treatment-related late effects (Adams et al., 2020). These late effects that AYAs may experience include secondary cancers, cardiovascular disease, impaired cardiorespiratory fitness, endocrine dysfunction, fatigue, cognitive impairments, and psychological distress (Adams et al., 2020). These factors all play a key part in survivorship and post-cancer care and can affect survivors for decades (Janssen et al., 2021).

Researchers have concluded that the end of medical treatment is accompanied with diminished support due to the healthcare team and the patient parting ways (Janssen et al., 2021). Survivors feeling seen and heard throughout their post-treatment life is important, but many

health care providers and general practitioners may only see a limited number of AYA patients in their practices. Thus, these health providers are unfamiliar with the AYA-specific needs and lack AYA experience and expertise regarding their care. For providers, services for their AYA patients should be centered on education about cancer treatment and related effects; surveillance, screening, and treatment for medical, long-term, and late effects; psychosocial support for reintegration in relation to the developmental stage of the AYA; peer support; and access to legal and/or financial support (Janssen et al., 2021). Researchers discussed the urgent need for late effects screenings for management of post-treatment complications for AYA survivors (Adams et al., 2020). The published literature acknowledges that AYA survivorship knowledge is becoming increasingly more recognized throughout Canada and the US as a priority subject for further research (Adams et al., 2020). Researchers suggest that there is a critical need for research to challenge pre-conceived assumptions to improve the overall rigor of the evidence regarding AYA survivors' late effects and their impact on survivors' overall wellbeing (Adams et al., 2020).

The student researcher has found consistent gaps in the literature focused on both the individual needs of AYA long-term survivors and with long-term trajectory of survivorship care for the entire AYA population. The literature reviews that AYA survivorship care needs to be established long-term for both individualized patient and overall population care and focus on the overall needs of the population as well as the individualized needs of each survivor. For AYA survivors, school reintegration is an important way to form social interactions with peers, and this can be disrupted by serious illness (Broholm-Jorgensen et al., 2022). Qualitative research conducted with Danish AYAs resulted in a variety of themes, one of which being “thoughts about and/or experiences of returning to school/education following treatment” (Broholm-Jorgensen et al., 2022). The data collected indicates that AYAs in secondary school

are left “in limbo” when balancing their education and cancer treatment (Broholm-Jorgensen et al., 2022). The AYAs who missed school more than 10% of the time were not able to have their cancer-related absenteeism approved or credited by the educational institution to receive the life-saving medication required by their disease progression. There were discrepancies noted in how AYA students were treated, with some students receiving flexibility and consideration from teachers, while others had teachers who were inflexible and did not approve extra time on exams or an absentee rate above 10%. These researchers suggested the establishment of a multidisciplinary team and/or professional support group to tailor to the specific needs of AYAs that are between completing cancer treatment and survivorship (Broholm-Jorgensen et al., 2022).

### **Readiness to Return to School**

Rennick and Lee (2016) conducted a qualitative study using interviews with an interpretive description approach to identify the significance of returning to the academic setting for adolescent survivors who have completed their treatments. The researchers interviewed 11 adolescents aged 13-17 years. Participants responded to open-ended interview questions regarding their feelings and specific school experiences both before their diagnosis and after returning to school. Three main themes were identified based on the responses during the interviews: (1) being on the right track to recovery; (2) bridging two worlds; and (3) establishing a new life at school. Students addressed difficulties with adjusting to a new life, struggling to rebuild friendships, and feeling different. The researchers acknowledged that both the diagnosis and treatment of cancer presented a deviation from a more certain and anticipated “normal” life at school, and the idea of returning to something familiar was possibly stressful for the survivors and could affect their readiness (Rennick & Lee, 2016). The researchers indicated that the care



team's effectiveness can be enhanced by acknowledging and understanding the importance of returning to school post-treatment from the adolescent survivors' perspectives.

Cancer diagnoses and treatments delay necessary developmental milestones in adolescents (Vetsch et al., 2018). Interviews conducted with adolescent survivors revealed their experiences with reintroduction into the academic or workplace setting as well as the changes the adolescent faced regarding their educational or vocational pursuits. AYA survivors (N=442) aged 15-26 were interviewed, and the survivors had all completed treatment at least 24 months prior to the start of the study. The interviews revealed that the extended absences from school combined with the physical implications of treatment, such as decreased energy and impaired cognition, poses difficulties for adolescent survivors achieving educational ambitions. Survivors discussed the difficulties that they faced when returning to school, alluding to their struggles with concentration and fatigue. The adolescents and young adults also revealed that their goals were the same or greater in importance, but they have more difficulties achieving them. An 16-year-old male #2 survivor mentioned that his plans pre-diagnosis involved going to university and working upon completion of high school but that these goals were interrupted due to his diagnosis. He further stated that his health at that time needed to be his priority resulting in his goals to be set back (Vetsch et al., 2018). If adolescent cancer survivors are unable to properly reintegrate into the education system, they will face more long-term ramifications in their course of life. The researchers suggested that more support could be used to assist adolescent and young adult survivors in readjusting to educational and vocational settings. Adolescent and young adult survivors may benefit from early and regular screening for educational and/or vocational difficulties in accordance with the psychosocial standard of care guidelines.

A mixed methods qualitative analysis addressed the varying experiences of adolescent cancer survivors (Wong et al., 2017). Among the 13 themes identified, three were relevant to this student investigator's project: (1) social interaction; (2) normalcy; and (3) school concerns. The researchers identified patterns throughout the interviews with the adolescent survivors, which represented common unmet needs. Adolescent survivors revealed their school performance was behind that of their peers. Survivors also fell behind in their educational progress, and participants reported that they felt stuck in high school while watching their peers and siblings graduate and go to college. Adolescents felt that they had lost connections with friends once they were diagnosed with cancer, needed to restart their life, and build new relationships at school. One participant reported that the only true difficulty they had when returning to high school was companionship since they felt like they lost all their friends when they were diagnosed. The survivor reported this experience as like a restart, requiring them to build new relationships with others. Subthemes of "back to school adjustment" and "support environment" were created based on such responses. The adolescents also expressed distress regarding the unknown outcomes of their transition back into school and if it would work out for the survivors. One survivor reported that they are looking forward to returning to school, but they are scared about the transition process and how it will work out for them. The researchers suggested that the information reported can be used to create more personalized tools to meet the unmet needs of individual adolescent survivors.

### **Barriers to Returning to School**

Yi et al. (2016) addressed the adolescent school reintegration experience using in-depth qualitative interviews of 31 childhood cancer survivors aged 15-39 years. All participants had completed their cancer therapy at the time of the study participation. Survivors stated that they

were excited about their school re-entry but also expressed feelings of fear and concern regarding their academic performance and peer relationships. The researchers reported that the most influential factor impacting the survivors' return to school was their relationships with their peers and teachers. The survivors expressed psychosocial problems and concerns regarding school re-acclimation and felt they had a lack of social skills. Common themes that emerged throughout the interviews were (1) fear of re-entry; (2) peer relationships; (3) teachers; and (4) psychosocial experience. Within these themes were subthemes related to the experiences. The researchers discussed that teachers who had the knowledge and ability to work with adolescent cancer survivors increased significantly when they had undergone proper training to work specifically with these students (Yi et al., 2016). A teacher training program was proposed and enforced, and the study participants reported that it was both effective and feasible. The researchers suggested that further programs need to be developed to provide specific services for these students since there are few qualitative studies that identify the educational progression and experiences of these students' following re-entry to the academic setting.

A national survey conducted in Canada focused on the experiences and unmet needs of post-treatment adolescent and young adult cancer survivors (Jones et al., 2020). A total of 575 surveys were completed and returned by the survivors, and most survivors were able to return to work or school. Most participants reported that they were satisfied with the resources with which they were provided. Amidst going back to school, the survivors stated that they needed to adapt and reduce their tasks and time of work. The majority of respondents (83%) reported at least one physical concern post-treatment, with 49% of these respondents reporting changes with their concentration or memory. Many participants (62%) reported practical concerns in regard to returning to school or work, and this was a "big" concern for the survivors (Jones et al., 2020).

The delays and breaks in school had long-term implications regarding career opportunities and school readjustment. The researchers concluded that the medical, psychosocial, and AYA teams should advocate for school accommodations for the survivors and stated that programs focusing on the return to school and work could be effective in assisting with re-entry and deciding on individualized accommodations for the students. Creating programs that support this population with their academic work while promoting peer relationships could also be helpful, according to the researchers. The study authors suggest conducting further research should be done to create informed, developmentally targeted, and individualized care for this specific group of students.

A literature review of the evidence demonstrated a cancer diagnosis and treatment negatively affect cancer survivors' educational plans and goals (Filler et al., 2019). A variety of studies including randomized control trials, longitudinal studies, and non-randomized comparisons were assessed, with the majority being randomized control trials. Sample sizes in the studies ranged from 13-374 participants. The authors revealed that the ability of adolescent and young adult survivors to return to school is difficult post-treatment. The survivors experienced difficulties returning to school and the workforce, such as needing to work fewer hours and days due to experiencing higher levels of fatigue. The literature review findings suggested that individualized care plans be made for adolescent and young adult survivors. Survivor cohorts should be created, inclusive of the full AYA age range, to acknowledge any questions that the survivors may have. The authors concluded that there is a gap in the current literature regarding barriers to school re-acclimation post-treatment (Filler et al., 2019).

### **Returning to a Sense of Normalcy**

A survey of the effect of cancer on the success of returning to school for adolescent cancer survivors was completed with a focus on the transition to school (Parsons et al., 2012). A

total of 388 participants were surveyed at 6-16 months post cancer diagnosis followed up after 15-35 months after the initial cancer diagnosis. The purpose of the study was to analyze any changes regarding the psychosocial, work, and quality-of-life outcomes that patients were experiencing throughout their cancer treatment trajectory. Researchers assessed returning to school, plans for school, and problems with school post-diagnosis. Of the 388 participants, 72% reported they had returned to school or work full-time 15-35 months post-diagnosis. The results revealed that cancer therapies and treatments negatively impacted the educational pursuits of the patients, as indicated by 50% of the participants. The research showed that while many adolescents and young adults are able to return to school, the intensity of the cancer therapies, lack of insurance, and leaving school (non-physical attendance) altogether negatively influenced the survivors' educational outcomes (Parsons et al., 2012). Furthermore, the ability to return to school and pursue educational goals improves the overall quality of life in survivors by diminishing social isolation and improving self-esteem. The researchers suggest that future research should focus on promoting best practices for more effective school and workplace re-entry for adolescent and young adult survivors after the end of treatment (Parsons et al., 2012).

### **Literature Review Summary**

A literature review of published articles, research studies, and position statements was conducted to analyze the late effects of cancer on adolescents and young adults, as well as effective care planning and transition back to "normal" life to better understand the concepts of survivorship (Patterson et al., 2015). The authors reported that these survivors must simultaneously manage their transition back to life as independent adolescents or young adults while also transitioning from cancer patients to survivors. Physical and cognitive changes pose difficulties regarding concentration, studying, and returning to the rigorous environment

provided by academics or work. Many of the survivors left their education and/or work setting to undergo cancer treatment, which poses a challenge for trying to re-integrate back into the system. The survivors also reported feeling marginalized in their social relationships, further generating worries and concerns when returning to school or work. Gaps exist regarding how to best support survivors when they are ready for school re-entry. Based on the findings analyzed in the literature, the authors suggested that understanding the impact that a cancer diagnosis has on adolescents and young adults and their ability to return to “normal” life is important to providing care and support (Patterson et al., 2015). Multidisciplinary teams can work together to provide this care and support based on the individualized needs of the survivors.

## **Methods**

### **Design**

This was a qualitative descriptive study using focus groups and individual interviews to gain insight into the perceived and recognized support and resources that adolescent survivors of adolescent cancer report to facilitate their successful transition and reintegration into school. The aim of this study is to identify how the interprofessional team can work with and alongside the education system to best support adolescent survivors’ return to school.

### **Sample and Setting**

The research population consisted of adolescent cancer survivors aged 15-18 years old at least six months off cancer treatment. Focus groups were planned with up to 8 adolescent survivors per focus group, and individual interviews would be conducted for adolescents who would prefer to remain anonymous to other survivors and/or those who cannot accommodate the focus group schedule. All interviews were held over a secure videoconference platform, Zoom, and were conducted at Cook Children’s Medical Center with secure, password encrypted computers and Wi-Fi.

**Procedure**

Following Institutional Review Board (IRB) approval from Cook Children's Health Care System to work with the Cook Children's Adolescent and Young Adult (AYA) Oncology Program staff, the student researcher engaged collaboratively and under the supervision of the Cook Children's Medical Center (CCMC) AYA Oncology Program team.

**Recruitment for Individual Participant Interviews and Focus Groups**

In collaboration with the AYA Oncology program investigative team, the student reached out to adolescents from both the control and intervention groups for the student honors project. The criteria for inclusion in the current honors project and the Cook Children's AYA Oncology team is to recruit participants based on the following inclusion criteria: (1) individuals currently aged 15-18 years (AYAs) at the time of enrollment, diagnosed with malignant cancer, and their parent/caregiver if present at the time of study enrollment; (2) AYAs treated with any combination of surgery, chemotherapy, and radiation for initial presentation of cancer; (3) AYAs must have completed all planned cancer therapy within the last 6 months; and (4) ability to understand study procedures and to comply with them for the entire length of the study. Exclusion criteria is as follows: (1) AYAs whose cancer is not in remission at end of therapy; (2) AYAs who completed therapy for relapsed cancer; (3) AYAs who completed therapy for a secondary cancer; and (4) inability or unwillingness of patient or parent/legally authorized representative to complete survey or give written informed consent. Formal informed consent for the honors project was waived, and the agreement to participate in the student honors project was sufficient and met the CCMC IRB guidelines.

The AYA study staff approached or communicated with potentially eligible participants during clinic visits to introduce the study and explain the purpose of the honors project study.

The AYA survivors who agreed to participate in the study were compensated for participation with a \$10 Amazon gift card after completion of the focus group or individual interview.

This student researcher's project focused on the school re-entry experiences with both focus groups and individual interviews. The agreement to participate in the study was completed prior to any data collection. The hospital patient database, EPIC, was used to identify any other potential participants that fit the study criteria for both age and time off treatment. Interested and/or qualifying participants were also contacted via a secure phone number separate from the student researcher's cell phone number via Google Voice. This student investigator communicated with willing participants' parents via Google Voice as well as through secure, encrypted email via the student investigator's Cook Children's email platform.

### **Data Collection**

The focus group and individual participant interviews were conducted by the student investigator and the AYA Oncology team. The interviews were held via Zoom at Cook Children's Medical Center. The participants were asked five focused questions regarding their school re-entry experience as well as any follow-up questions that arose throughout the interview process that this student researcher requested that participants could expand or elaborate upon. These interview questions focused on the adolescents' return to school, perception of re-entry, feelings throughout the process, and how both the treatment team and school supported the transition. The responses were transcribed by a professional transcription site, transcribeme.com, and then the investigative team analyzed the transcripts. Key phrases were identified, and thematic analysis was assessed to determine data saturation. Participants were given a \$10 Amazon eGift Card for their participation in this study as a stipend for their time and commitment to this project's success. Funding for this study for both participant stipends and for



the costs of transcription were provided by the Texas Christian University, Elizabeth Brackin Allen Endowed Scholarship, Harris College.

### **Data Confidentiality**

All focus groups and individual participant interviews were conducted at Cook Children's Medical Center at a time and day that is convenient for both the participants and investigators. All efforts were made to ensure participant confidentiality, and participants were asked to not use formal names or identify themselves throughout the interview discussions. All audio-recorded transcribed interview transcripts were maintained electronically in password-protected Microsoft software within the Cook Children's Health Care System (CCHCS), and the recordings of the focus group and individual interviews were deleted after confirmation and accuracy of the transcripts,

The transcripts of the focus groups and individual participant interviews were kept confidential. No transcripts contained focus group and individual participants' names and any formal names identified on the transcripts were removed. The transcribed interview documents were also retained in the password protected Redcap database within the CCHCS. Only Cook Children's investigators will have access to this data.

This student researcher asked participants 4-5 interview-based open-ended questions (Appendix A) during the focus group and individual interviews regarding the transition to school reintegration. Prompts were used to gain more insight into the responses of the participants and learn more about their perspectives on the transition back to school. The focus group and individual participant interview questions addressed the students' experiences with going back to school, addressing concepts such as their feelings and preparedness with the process. The participants were asked to identify the most difficult part of returning to school as well as what can be done to further support the survivors.

**Data Analysis**

This student researcher utilized thematic analysis and qualitative research as the method of data analysis for this project. Throughout the process of data collection, this student researcher utilized data collection through individualized patient interviews and focus groups.

**Field Notes**

Throughout the interviews and focus groups, this student researcher took field notes as necessary to follow up on key phrases or sentiments as shared by the participants. This student researcher found it beneficial to utilize field notes to continue discussing the key ideas shared from the participants. Field notes allowed this student researcher to maintain the structure of the pre-meditated protocol questions as well as allow the participants to expound upon their experiences. They also used field notes to capture key information participants shared during the interviews to ensure most accurate coding and the themes of the information.

**Coding and Thematic Development**

Throughout this project, this student researcher and the research team coded, sorted, and identified themes as the method of data analysis. Thematic analysis was crucial to identifying recurrent themes throughout the data collected (Terry et al., 2012). The investigators (AH, LB, DE) analyzed the participant focus group and individual transcripts and the associated themes and subthemes in the responses. Analyses of the interviews were conducted individually to mitigate and reduce biases. After establishing secure codes through open coding, the analyses were then discussed with the group to compare findings and achieve thematic saturation. The investigative team met regularly to establish a consensus on the emerging thematic patterns throughout the interview and coding process. Discussions were held to ensure adequate communication regarding the codes, and any discrepancies were acknowledged. Individual interviews and focus group interviews continued until thematic saturation regarding common

difficulties with school transition were identified across the dataset. The study team (AH, LB, DE), with AH as the primary investigator, reviewed the individual interview and focus group transcripts throughout the data collection time to determine whether thematic saturation had been achieved. This information was used by the student investigator and the AYA team to assess the needs of the participants and other survivors.

### **Validity and Reliability with Thematic Development**

Throughout the course of the focus group and individual interviews, common themes and statements arose throughout discussion. These findings accurately reflect the data demonstrated throughout the review of the literature. The thematic analysis also achieved validity due to each member of the investigative team reviewing the transcript and deciphering codes based on ideas presented throughout the interviews. Individual coding of the interviews was performed to strengthen the validity of the study. The codes created by individual investigators (AH, LB, DE) clearly and accurately represent the perspectives of the participants in an unbiased manner.

The investigators also ensured that the data collected was reliable. The data obtained throughout the interviews remained consistent, with each participant stating similar experiences and sentiments as the other participants. Our decisions to pursue this project were intentionally expressed to the willing participants, and all participants were aware of the aim of the project. Throughout the research, the student researcher and primary investigator (AH) were able to achieve findings that were consistent between both the interviews and the literature. The data attained throughout this project also achieved neutrality or confirmability. Truth value, consistency, and applicability were all addressed throughout the interview data analysis. The participants engaged in interviews that were between 18-30 minutes long, and all participants were aware that their interview could last up to 90 minutes if necessary. The interview questions were complex, so all participants were aware of the engagement necessary for the interviews.

The research team (AH, LB, and DE) completed individual review and analyses of each interview and set aside personal intrinsic biases to holistically understand the perspectives of the participants.

## **Results**

There was one focus group containing two participants and two individual interviews were also conducted. A total of four participants were interviewed throughout the duration of the project. Of the 4 participants, 25% of them identified as female, and 75% identified as male, with one male participant identifying as a transgender male. For race and ethnicity, 25% of participants identified as African American, and 75% identified as Caucasian.

### **Major Themes**

Eight major themes emerging from the focus group and individual interviews included: (1) preparedness; (2) coursework challenges; (3) change and adjustment; (4) consistency and help with adjustment; (5) emotional and social impact; (6) physical impact; (7) normalcy; and (8) positive outlook. They are further elucidated below.

#### **Theme 1. Preparedness**

Across the focus group and individual interviews, participants described their experience of transition from end of treatment care back to school as difficult due to the students' lack of preparedness. Participants discussed the suddenness of returning to school and how this impacted their preparedness to return to school. Further, participants discussed how teachers were supportive of the students' return but were not as communicative with the student about their needs as time passed and students progressed into higher grade levels. Two participants stated:

*"Well, the way it worked was like, "Okay. I want to go back to school." "And then my social worker talked to the school about it, and I was ready to go back. And I just kind of went back. ... wasn't really any guidance through it. It was just, "One day I was homebound. The next,*

*I'm back in public school with everyone else." "And so, I just kind of figured it out myself, I guess. So yeah, I wouldn't really say there was much of a preparedness... I mean, I knew it would be a little bit harder. And I guess I did know. I just wasn't ready for it." (16-year-old female)*

*"You had to do a little more reaching out and emailing and kind of hold your teachers accountable, stuff like that. So that was a little tough." (18-year-old male)*

However, one participant noted that they did feel prepared to return to school.

*"I felt pretty prepared since I didn't have anything other than the chemo treatment and radiation going on. So, I was ready." (16-year-old male #2)*

One participant stated that they wish they had waited longer to return to school due to the timing of their end of treatment care and the need for more rest. Another participant noted that they had no idea they were returning to school until their parents had called the school the day before.

Their quotes are presented here:

*"Well, I finished proton radiation. And then I think within five days of me finishing it, I went back to school... the doctors were okay with it... I do wish I had waited sooner to go back and just given myself more time to recover." (16-year-old female)*

*"Oh. Literally, my mom called the, the, the, the, the school and stuff, and the next day I knew, I was at school, and I had nowhere to go." (16-year-old male #2)*

Participants also revealed that they were unaware of any possible changes to their schedule or academic progression prior to returning to school, and some participants found out about their academic schedules the day they returned. As one participant stated,

*“So, I didn't know if, like, the classes changed or not.” (16-year-old male #2)*

The preparedness for these students to return to school was compounded with a lack of communication between both students and the educational institution, as well as miscommunication between the teachers and administrators on how to provide for these students. One participant described a lack of communication and substantial support between the student and the student's teachers.

*“They definitely could have checked in more. Maybe stopped by in person because I know the teachers were allowed to do that. At max, I would get an email a week, or with my AP chemistry teacher, she would email me with assignments I needed to finish. And a lot of times, she wouldn't respond to my emails. That was really the only way me and my teachers communicated. A lot of times, I didn't see them until I had actually come back to school and met them.” (16-year-old female)*

This same participant expressed that the teachers did provide support in terms of lenience with school assignments and meeting assignment deadlines, but there wasn't substantial communication outside of that.

*“The way it went was like, “Hey, guys, I'm having to do chemo or I'm really sick, so don't expect a lot of assignments this week.” And then they'd be like, “Okay, hope you feel better soon.” And other than that, they would just post the assignment in Google Classroom... And there wasn't really any sort of talking about the lesson or how to do it... And I wasn't always the first thing they were worrying about. I was kind of put on the back burner for a lot of these teachers.” (16-year-old female)*

One participant also reported that they were not required or recommended to participate in summer school courses to prepare for their return to in-person education.

*“No. They were like, “You know what? Don't go to that summer school. You're, you're perfectly fine.” (16-year-old male #1)*

When asked if completing work outside of school during treatment was necessary for preparation to return to school, one participant stated that they did not complete any work during their treatment to prepare or stay on track for school. This was due in part to the beginning of the COVID-19 pandemic and the new onset diagnosis of cancer.

*“I wasn't doing anything when I was being-- when I was literally being diagnosed to prepare for school, but...” (18-year-old male)*

A consistent sentiment expressed throughout the topic of preparedness, both for the participants and the teachers, was that the participants felt as though the school did everything possible to prepare these students to return to school. Participants stated,

*“So, with school-- with school, I felt like I had the support that they could provide. Like, whatever they could provide, I felt like I had that.” (16-year-old male #2)*

*“But I mean, I'm sure my school doesn't deal with cancer kids very often, so I don't blame them for not knowing or anything. It's okay, I guess.” (16-year-old female)*

*“I mean, I guess I was well-prepared for going back to school. I mean, I don't think that there's anything necessarily they can do because it wasn't health or anything like that that was stopping me.” (18-year-old male)*

Homebound learning was a topic discussed by one of the participants as well. This participant engaged in homebound learning throughout the course of treatment so they could be prepared to return to in-person school after the end of their treatment. Throughout the interview, all participants discussed the difficulties in preparedness and transition from homebound to in-person learning, mentioning that the teachers were unequipped to provide successful homebound learning. Two participants stated,

*“So, a lot of the teachers had never had a homebound student before, so they didn't understand how to do it. It was their first time.” (16-year-old female)*

*“Oh yeah, and school is tough because everything was online, everybody was trying to get used to the new programs and everything like that.” (18-year-old male)*

When asked how homebound learning impacted this student's success with the return to in-person learning, the participant stated,

*“I do think they could have been prepared better because I mean, for them, it was just like, “Okay, we just don't deal with the homebound anymore. You're just in person now. So, I'm going to treat you like all of my other students.” (16-year-old female)*

The participant also discussed how the transition was difficult between homebound learning and returning to in-person school. The participant furthered their statement, saying,

*“So, I think the week before I went back to school, I got that week assignments done. And then I emailed them. I was like, “I'll see you in person.” And then I got there. And then it was*



*pretty-- I don't know what word to use. Pretty basic, I guess. It was just, "Okay, now, you're going to do the assignments everyone else does." (16-year-old female)*

## **Theme 2. Coursework Challenges**

The participants discussed difficulties that they faced regarding coursework when returning to in-person classes at their schools. Many of the participants discussed the feeling of playing “catch-up” to stay on track for their classes and with standardized testing amidst the new transition and continuing to balance follow up appointments with school. Participants stated,

*“Yeah. There-- and, like, especially the-- like, the STAR test. It was-- that, that was hard. That was extremely hard for me. Like, I had to, like, start remembering everything for, like, the STAR test, try to, like, study, like, with the other students, and, like, try-- just try to focus. (16-year-old male #1)*

*“Yeah. It's just like you got to figure out where [the classes] are, and it's like you have to catch up or you're going to, like, have to fail or something like that...and anything I had to make up from last year, I caught up in this year. So, I mean, yep, I'm caught up.” (16-year-old male #2 #1)*

*“It was a little tough because I was going to the hospital every week, so just tough to keep up with all my work... It was pretty difficult because I would have to-- I'd miss out every day, so that put me behind. So, then I'd have to spend the whole week catching up. Once I caught up finally, I had to do it again, keep doing it again. So, I'd keep pushing me back behind then I'd have to keep catching up.” (18-year-old male)*

Discrepancies between online and in-person learning negatively affected the participants and their success in school. One participant discussed how they felt like they were falling behind

due to the lack of proper teaching for the curriculum coursework and had to cheat on exams to maintain their grades. Another participant discussed how the COVID-19 pandemic put a hold on academic learning, and once the patient was diagnosed, they were not held accountable for continuing their work. This caused this particular participant to fall behind in math and catch up on their own in order to continue on with their academic grade. The participants stated,

*“And then, in math class, because although I did the online assignments, I didn't get the actual teaching. So, there were things that I didn't know how to do, and everyone else, it was super easy for them. And I had just kind of fallen behind... And because I was at home, I could cheat on all the tests. And so, if I didn't get it, I would just look it up, which I shouldn't have done, but I did.” (16-year-old female)*

*“So, while I was playing catch-up, I was also trying to connect from going from half a year of algebra into geometry. And so, once you miss that, you're just trying to catch up in geometry. Then you go next year, and you're doing algebra II. I mean, it was tough to try and figure that stuff out. So, I kind of fell behind in math.” (18-year-old male)*

Further impacts on retaining the information being learned in school were influenced by the participants' need to stay on time and ahead in their classes. One participant described doing almost anything they could to complete assignments on time, but not to truly learn and absorb the information beyond the scope of completing an assignment. Further, reaching out to the teachers for extra help felt burdensome. The participant stated,

*“I just kind of figured it out to get these assignments done, not enough to really understand the material...The teachers were always like, “Yeah, I can come over if you really*

*need help." But a part of me was like, "No, I got it." And I would understand it enough for the assignment." (16-year-old female)*

This same participant discussed how the pressure from completing assignments but not being able to retain the information was due to self-inflicted pressure to succeed. This created emotional difficulties for this participant, making it even more difficult to stay ahead with schoolwork. The participant mentioned,

*"I've always been a straight A's, honors kid, super smart. And I didn't want to let that go." (16-year-old female)*

Participants also described cognitive difficulties related to their cancer and cancer treatment and how this negatively impacted their ability to succeed in their courses. Participants stated,

*"Focusing [was the most difficult part]." (16-year-old male #1)*

*"Chemotherapy has a large effect on your cognitive abilities. And chemo brain is known- or it causes fogginess, memory loss. Overall, it's just harder to understand and absorb things...And I struggle with it still. And it's really hard for me to absorb material sometimes and remember what I was going to say. And a lot of times, I'll forget what I'm saying in the middle of speaking. And it can be very hard to learn in school when something like that happens." (16-year-old female)*

### **Theme 3. Change and Adjustment**

Across the focus groups and individual interviews, all participants discussed elements of change that occurred as the students were transitioning from end of treatment care back to in-

person schooling. One element of change discussed by the participants was the initial awkwardness of returning to school. Participants stated,

*“The first time I went back to school was kind of-- kind of weird, you know. It was like most things changed in-- but it was also, like, the same... It was like new groups, uh, like new people, I guess, and it's just like people are, like, kind of, like, staring at you. It's like-- it's like, oh, like, you're the new kid, almost, but you're not the new kid.” (16-year-old male #1)*

*“I wasn't who I was before. And I think it was a thing both I and the people I knew had to understand and figure out.” (16-year-old female)*

Appearance was also a factor in one participant's feelings about returning to school. The initial change of needing to wear a hat or beanie in public was discussed by this participant. The participants discussed how they had to get special permission from the principals and administration of their school to wear a beanie, and how wearing a beanie when returning to school posed insecurities. The statements given by this participant highlighted both positive and negative aspects of adjustment and preparedness, and the overall element of change regarding the initial return to school. The participant stated,

*“The, um-- my counselor, he knew about the situation... And I don't think, like, any of the other principals did. So, they usually tell us to take our hats off in the hallway... And on the first day, uh, after treatment, I believe, um, I had on my beanie, and they asked me to take off the hat. And I went to go tell them, and they just let me wear it all throughout the year. And other than that, it was cool.” (16-year-old male #2)*

Participants also discussed how they felt as though their initial return to school was scary and that the students did not know what to expect. One participant noted that,

*“It's just scary... It was-- it's just like when you go in, it's like you don't know what to do anymore. It's like, "Do I still continue what I've been doing since I was a kid? Or will things be different? How will people treat me now?" (16-year-old male #1)*

The aftermath of cancer and cancer treatment also took a physical toll on the participants. One participant discussed how although they were cancer-free, the effects of their treatment often left them feeling unhealthy and tired at the end of the school day. One participant noted,

*“And my health still wasn't good. I would get very winded at the end of the day. I was very stressed out. I had to deal with work and school. And it was really overwhelming a lot of times.” (16-year-old female)*

Along with the post-treatment effects, the participants also had to manage follow up appointments with their treatment team as necessary to ensure remission. One participant discussed the difficulties of time management in relation to prioritizing appointments with the treatment team and completing schoolwork on time. Furthermore, this participant had to stop any other extracurricular activities to manage the appointments and schoolwork, which caused a substantial change and adjustment in this student's daily life. The participant shared,

*“I think the most difficult part returning to school was probably just having to manage my time of getting better and having to play catch-up. Yeah, probably having to play catch up with going to the doctor, missing that day, and then having to play catch up through the week*

*and then continuing that.... I was either going to the doctor or focused on school, so I never really did a whole lot other than that.” (18-year-old male)*

#### **Theme 4. Consistency and Help with Adjustment**

Peer-connectedness and friendships are critical aspects of adolescent development. Throughout the course of cancer diagnosis and treatment, the participants in this study had to isolate themselves from their peers. Upon returning to school, some of the participants were met with openness from peers that helped them throughout the process of returning to school. Amidst the change that had occurred around the participants throughout the course of their treatment, the consistency of their friendships had stayed constant. Two of the participants mentioned,

*“Uh, it was just like same, same friends, you know, same classes, classrooms, seats, I guess. [crosstalk] chairs.” (16-year-old male #2)*

*“I always had my friends to help me because a lot of times we're in the same advanced placement classes. So, I had people to help me even if it wasn't the way someone would normally go about it.” (16-year-old female)*

The teachers at the schools also provided extra lenience with assignments and help to keep the students on track. Study participants discussed the extent of lenience they were provided to juggle schoolwork and medical appointments, and how the teachers demonstrated empathy when the student was prepared to return to in-person instruction. The participants stated,

*“And everyone or the teachers...gave me lenience. They still gave me extra time to get assignments done as they did during chemo, and they understood it would be a hard transition back.” (16-year-old female)*

*“Well, I got extra time on stuff like that, so they were good about that. They were good about letting me-- sometimes you have to remind them. But I mean, for the most part, they were good about letting me have my extra time and assignments and explaining stuff well.” (18-year-old male)*

When asked what can be done to better improve the transition of going back to school for adolescent survivors, one participant stated that it is important for the teachers to be aware of the students' situations and provide help as needed to allow the student to succeed. The participant mentioned,

*“I think really pushing for the 504 plan that allows them to get extra time and whatever they need necessary. And hopefully, that other schools keep up with that and notice that they're going through a lot more than it looks like. And so just being easier on them and letting them have the time that they need and maybe provide an extra help whenever they need it.” (18-year-old male)*

A key part in the adjustment process for one participant was the ability to have time to rest throughout the course of the school day. The physical implications of the cancer treatment had impacted this student and their ability to complete the school day. The participant discusses the help that the school's nursing office tries to accommodate the student and help with their transition to in-person school. The participant stated,

*“When I'm having a really hard day, I am able to just lay in the nurse's [cot]. At one point, I did it for nearly the entire last half of the day. And they understand that it's still hard. And they give me lenience. And I haven't had a problem with any teachers and that sort of thing... So, they've been very helpful.” (16-year-old female)*

### **Theme 5. Emotional and Social Impact**

One participant elaborated on their feelings about wearing a beanie at school, mentioning that the biggest concern they had with returning to school was the fact that they no longer had hair. This participant's description of needing to wear a beanie illustrates the psychological, social, and emotional distress because of their changed appearance. This participant stated,

*“Um, I would say-- uh, it's not about people looking at me different, but I was really big on my hair... So just, like, having to wear a hat or a beanie every day... Um, not taking it off, or having to pull out a pass, and I was able to wear it every time somebody asked. So yeah, it was really my hair.” (16-year-old male #2)*

Another participant discussed the difficulties of appearance in relation to emotional status. The patient discussed the idea that others assumed they were “fine” because they had hair, but that it was assumed that the person was not doing well when they were bald. The participant discussed how regardless of hair, the person may still be struggling with the effects of the cancer. The participant stated,

*“I guess, I mean, the only way to put it is when you see someone with hair, you think, “Oh, they're fine,” when actually they're still going through all the same stuff that they went through whenever they're fresh off diagnosis.” (18-year-old male)*



The emotional impact and pressure to perform well in school after diving back into in-person coursework was apparent. One participant noted,

*“Trying to catch up on [grades] while, while in and out of school. And um-- it was really just my grades. That's it.” (16-year-old male #2)*

The social impact of peer relationships was also noted throughout the studies.

Participants discussed the difficulties of communicating their whereabouts and/or diagnosis with their peers, as their peers were reaching out to them. One participant stated,

*“Until I was done with radiation, I went back [to school]. But I think some of the appointments-- I didn't have much, but I think if I did, it'd probably be a little bit difficult for me, because then I'll have to ask around and then be, like, difficult because people will probably be like, "Oh, where have you been?" you know, and it's, like, hard to, like, tell them...I, I got, like, most-- like, a lot of calls, almost, be like, "Hey, where are you? Are, are you-- are, are, are you, like, homeschooled now? Did you move?" It was just-- it was, like, weird, almost.” (16-year-old male #1)*

One participant discussed that they were excited to see their friends again and that returning to school was beneficial for their social relationships. However, this participant also had difficulties with a peer who passed judgement regarding the participant's cancer story. The participant stated,

*“Most of my friends were really happy I was back. They were all happy to see me... But there were some kids, like I remember in one instance, this girl told me I spoke too much about my cancer. I brought it up too much.” (16-year-old female)*

Social interaction is something that the participants lacked throughout the course of their cancer treatment. Social interaction is necessary for the adolescent population, and one of the primary methods that promote social interaction is school attendance. One participant discussed missing the aspect and significance of social interaction, and another discussed that they could not see their peers or play sports because of their new diagnosis. The participants mentioned,

*“I still didn't really hang around people too much just because, I mean, I was still fresh off diagnosis and everything, and COVID was still around and everything...Once I was diagnosed, I had to stop playing basketball.” (18-year-old male)*

*“I was excited. I was a little nervous, but I wanted to see everyone and have that social interaction I had missed during cancer treatment.” (16-year-old female)*

When asked if social interaction was a benefit to the participant's initial return to school, the participant stated,

*“Definitely. Yeah. I pretty much isolated myself during cancer treatment and talking to people and interacting with them more brought me out of the sort of depression cancer treatment put me in. And it helped me get kind of a more positive outlook on how things were going.” (16-year-old female)*

The physical effects of cancer and treatment impacted participants' emotional state due to the need to balance follow-up appointments with academic work. One participant stated.

*“So around after summer, I believe, close to the end of the year, I went back. Um, after chemo, I was having leg pain, so I don't know if that affected, like, my school. But I don't-- I had*

*to take some days off, I believe, to go. But other than that, I think that was it.” (16-year-old male #2)*

The impact of cancer diagnosis and treatment negatively impacted participants’ emotional states upon returning to school and beginning to resume in-person coursework. One participant stated that,

*“-- I remember, a lot of times, I just wasn't understanding it, and I would cry, and I would just not be able to get anything done because I was getting so overwhelmed.” (16-year-old female)*

### **Theme 6. Physical Impact**

Chronic health problems because of the cancer and cancer treatment impacted the daily school life of one participant interviewed. Having to walk from class to class, give presentations, and participate in activities all impacted this participant’s overall success while at school post-treatment. The participants further expressed that they experienced feelings of joint pain because of walking to classes and needing to take time to recharge in the nurse’s office. Throughout the next three statements, the participant noted,

*“So, my high school campus is pretty big. And I've noticed that walking from one end to the other - I've had to do that before - I get really tired and oftentimes I have a lot of hip pain or joint pain...And I get out of breath very easily... I don't have the stamina or endurance to keep up with school.” (16-year-old female)*

*“So, it's hard to give presentations and speak loudly and for extended periods of time. And it's just what an average person could do easily five days in a row.” (16-year-old female)*

*“When I'm having a harder health day like that, I try to just do what I can at school. And then once I've recuperated and I had time to rest, I do get the work done.” (16-year-old female)*

One participant discussed the effects of treatment on school attendance. This participant was receiving chemotherapy outside of school, and the student would be expected to return to school the next day but would have to miss school due to the physical effects of the chemotherapy treatments. The participant discussed,

*“So, since I was going to school weekly, after the appointment, I would not feel well because I was getting chemo, so I'd miss the whole day of school.” (18-year-old male)*

Cancer is a complex disease process that poses a multitude of implications on patients enduring the course of treatment to hopefully achieve a cure. An example of such implications are the physical limitations that cancer, cancer treatment, and post-treatment pose on patients and survivors. One participant discussed how they had to learn to live not only with cancer, but with the effects that arise from post-treatment that affect the patient's health and what they consider to be normal. This participant explained,

*“It's still hard, but I just have to adjust to how it is going to be because I've realized now that cancer isn't a single thing, and then you move past it. It sticks with you. Even if you don't have that label of having cancer and you're free of it, it's still there in a sense. You still have to deal with all the chronic problems and the side effects from all the chemo.” (16-year-old female)*

### **Theme 7. Normalcy**

The idea of returning to in-person school was appealing to one participant because of the idea of returning to a state of normalcy. Since this participant had not interacted with their

classmates or peers since beginning cancer treatment, this participant was excited to return to a sense of feeling normal now that their treatment course had ended. The participant even discussed with her parents about returning to school earlier than planned to feel this sense of normalcy again. However, the participant was met with difficulties when trying to return to a normal life at school. The participant states,

*“So, I think I went back too soon, but I really wanted to go back to normal as soon as I could... And I just had a really hard time even though I was back to normal, I wasn't normal. I did kind of butt heads with my parents a little. They thought I should have waited.” (16-year-old female)*

Although homebound learning was utilized to keep the participants up to date with their schoolwork, the online learning style did not provide these students opportunities to interact with their peers or have the same face-to-face learning experience as the other students. One of the participants discussed their feelings of thinking that their experience with school would return to normal once they went back to in-person instruction versus homebound learning. The participant explained,

*“I guess I kind of thought that not doing homebound school anymore and going back to school, everything would kind of-- it would be kind of like the domino effect. Once that happened, then everything would be how it was before cancer. And then really, none of it was.” (16-year-old female)*

Throughout the course of the school year, participants missed out on many experiences because of their active cancer treatment, and life at school had continued as planned, despite the

patients' inability to be there. The relationships formed and built between peers while these participants were isolated and unable to attend school impacted the participants' perceptions of peer relationships and returning to school, and how they felt left behind in terms of social relationships. One of the participants discussed,

*“Everyone had these memories they had made and sort of like things they had planned out in advance. And the kids that had, I don't know, for example, joined debate and did debate in the summer, and I'd missed all of that. And I was just trying to play catch up with something I couldn't really catch up on. I couldn't go back and know everything they were talking about.”*  
(16-year-old female)

Cancer left a lasting impact on the participants interviewed in nearly all aspects of their lives. One of the biggest impacts that cancer had on the participants that was noticed by this student researcher throughout the interviews was the effect on normalcy and the participants' pre-cancer normal life. Throughout the interview, one participant discussed at length their wish to return to normalcy once cancer treatment had ended, but this participant quickly realized that normalcy was unattainable after such a large life event. When asked if the participant had achieved a sense of normalcy now that they had returned to school, the participant stated,

*“I kind of don't think I will go back to the of normalcy because I thought it would just be back to how things were before. But I don't think things can go back to how they were before after something as big and impactful as cancer. I think I'm trying.”* (16-year-old female)

### **Theme 8. Positive Outlook**

Despite all the changes that had occurred for the participants, beginning with their cancer diagnosis, and extending into their current daily lives, the participants expressed gratitude for

their experiences and ability to return to school. Amidst the differences in experiences that these participants had in comparison to their peers, the participants emphasized that they are proud of who they are and had a positive outlook on returning to school. When asked what can be done to better support survivors in their transition back to in-person school, two of the participants noted,

*“Just stick your head up and don't be ashamed of who you-- like, who you are.” (16-year-old male #1)*

*“Be yourself. Just because you went through something doesn't change who you are and how people should see you.” (16-year-old male #2)*

*“I think every year, I was excited to go back to school. Just another school year... I feel like it all worked out.” (18-year-old male)*

### **Discussion**

The participants in the current study revealed important information about their experiences during the transition from active therapy to school engagement. In accordance with the interviews, eight major themes were developed: (1) preparedness; (2) coursework challenges; (3) change and adjustment; (4) consistency and help with adjustment; (5) emotional and social impact; (6) physical impact; (7) normalcy; and (8) positive outlook.

The impact of preparedness was demonstrated through the survivors' descriptions of their return to school. A consistent finding throughout the interviews was a lack of and/or an inconsistency of communication between the participants and their schools and/or the participants' parents and the schools. The participants mentioned that they were unaware of the classes they were going to be taking until they had arrived for their first day back for in-person instruction. Further, the participants suggested that the schools were ill-equipped for them to return to school. One participant discussed their experience with communicating to school

administrators their need to wear a hat while at school, and other participants discussed how they were expected to keep up with their classmates after a sudden transition from homebound online learning to in-person learning. Though prior research did not address preparedness to return to school, AYA survivors feel unprepared for their transition to survivorship (Jones et al., 2020). The participants stated that they did not feel prepared for survivorship and had a difficult time explaining to others that while they weren't sick, they didn't feel healthy (Jones et al., 2020).

Coursework challenges also posed a detriment to the participants and their success with school reintegration. The participants stated that they struggled to get their work done at the same pace as their classmates, often requiring breaks or extra time to finish their assignments. The participants also explained that they struggled with retaining and truly learning the information they were being taught via the homebound program. These participants discussed that they were doing everything they could to absorb the information just for the sake of completing assignments, but they had difficulties with applying and retaining the information long-term. One participant discussed cheating on assignments while doing homebound learning at home just for the sake of completing the assignments on time. Teenagers post-treatment had a higher likelihood of repeating a school year, and 43% of adolescent survivors were not on track with their previous educational progression plans (Magrath et al., 2021). In the current study, a participant talked about the support they received from their art teacher, and that the art teacher was helping this student learn concepts from other classes. Participants described that their teachers were as helpful as they could have been during this process, but the participants also discussed how they were reluctant to seek help when struggling with assignments, resulting in psychosocial detriments and the students feeling overwhelmed.



Change and adjustment was a constant theme throughout the participants' transition and reintegration back into the education system. The participants shared sentiments of feeling as though they had joined a new "club" that everyone else had been a part of while they were away for treatment, causing psychological distress and nervousness when returning to school and attempting to fit in. The AYA survivors have described both positive and negative effects of returning to school, with negative effects such as time spent away from school attributing to peer relationships, but more positive impacts were reported, such as increased social interaction and continuing education (Smith et al., 2019). The participants in the current study also discussed the physical appearance changes that they dealt with when returning to school such as the need to wear a hat. The participants also discussed how they felt as though people would stare at them once they had returned to school and treated them like "the new kid." In contrast, the literature did not focus as heavily on the change and adjustment back to school for AYA survivors but focused instead on the holistic impact of change on AYA survivors (Smith et al., 2019). Such impacts included dating, sexual intimacy, body image, and control over life (Smith et al., 2019).

While there was considerable change with returning to school, participants revealed a sense of consistency and help with adjustment. The participants all explained that their teachers were willing to accommodate and help them to succeed by giving them lenience with assignments. This finding is congruent with current literature focusing on the support of teachers helping survivors' transitions back to school. Research has shown that survivors have described a need for control on their ability to return to school and discussed with educators the need to accommodate their needs (Magrath et al., 2021). One participant in the current study explained that the teachers understood that the transition back to school would be difficult. The participants also revealed how the nurse's office was willing to allow them to rest and recuperate throughout

the school day because of the enduring post-treatment effects the survivors were experiencing. The participants also mentioned that their friends were excited to have them back at school and were willing to help them with school assignments and readjustment. A major component of the overall adjustment for these participants was the realization that although they were cured of their cancer, they still had to endure all the chronic long-term effects of treatment. One participant described this as something that will stick with them forever despite being cured of their disease.

The emotional and social impact of returning to school was apparent throughout the participant interviews. Participants described the emotional impact of feeling and looking different because of needing to wear a hat at school. One participant talked about the emotional difficulties of not having hair and the need to show a special pass to anyone who requested that they remove their beanie. Another participant talked about their academic record, stating that they are a straight-A student. This participant struggled with not being able to retain information being taught in school, and they would frequently become overwhelmed with the material they were learning and expected to absorb. The development of self-image and identity, formulating relationships with peers, achieving a sense of self, and appreciating privacy and peer support are all key psychosocial care factors that influence AYA care (Ferrari et al., 2021). Researchers also discussed how AYAs form their identities due to their psychological development, and this process is impacted greatly by school attendance (Magrath et al., 2021). Similarly to the coursework struggles, the participants in this current study felt as though they were struggling to play catch up to stay ahead on assignments and move forward in school with their peers. While peers were excited to have the participants back in school, the participants described the difficulty of explaining why they had been gone. They stated that their peers would reach out to

them when they were not at school, inquiring where they had gone, and that it was difficult to explain their situation to others. While many peers were welcoming and friends were excited that the survivors had returned, one participant had difficulties with peers stating that they spoke about their cancer experience “too much,” causing increased psychological distress and insecurity for this participant.

The physical impact of cancer treatment greatly impacted the participants’ ability to return to school. The participants revealed that they had to take time throughout their school day to allow their bodies to rest. The findings presented in the interviews were similar to those of other studies that focused on the impact of late effects on survivors. Researchers found that throughout the process of returning to school, survivors experience a multitude of late effects that impact their success with school reintegration (Magrath et al., 2021). The participants interviewed for this project described feeling fatigued, winded, and in pain after participating in school activities, which is like the late effects findings discussed previously in the research completed by Magrath et al. (2021). One participant described their walk across school as tiring due to the size of their school and the distance they had to walk to classes. These physical impacts played a role in the success in coursework as well, since the survivors also described difficulties with cognitive functioning, memory, and brain fog, as well as persistent fatigue. One participant explained these chronic health problems as their new normal and something they were learning to cope with while returning to school. Research indicates that such late effects these survivors endure include cognitive impairments and extreme fatigue, resulting in survivors “drip feeding” their way back into school, meaning they often miss part of school days to rest (Magrath et al., 2021).

The pursuit of normalcy and a normal life was a substantial factor motivating the participants to return to school. Furthermore, participants felt rushed to return to school to achieve a sense of normalcy, despite feeling unprepared to return to school. Throughout the interviews, participants stated that they were ready to return to school to see their peers and resume their former “normal” life. Congruent with previous research returning to school post-treatment helps AYA survivors to achieve a sense of normality, but that an unsuccessful return to school can accumulate into psychological distress and poorer school achievement or school regression (Magrath et al., 2021). In our study, one participant described going back to school before the date that they and their parents had initially discussed because this participant was ready to resume their life outside of treatment. This sentiment was parallel to the findings found in other research, and researchers stating that the fear of missing out on events and day-to-day life with peers was a significant stressor for these survivors, often influencing their premature return to school (Magrath et al., 2021). Another study discussed how AYA survivors returned to school as quickly as possible as to keep up with their peers and have that sense of normalcy back (Altherr et al., 2023). The participants described this need for normalcy, but they also discussed how the return to school was not as normal as they thought it would be. One participant described the experience, stating that it is difficult to return to normalcy after enduring such a life-altering diagnosis and treatment. This participant described their current life as their new normal and stated that going back to the way things were before is essentially impossible due to their experience and story with cancer. Despite returning to school and interacting with the same friends and peers, having the same classmates, and learning the same material as others, the experiences endured by the participants when returning to school appear individualized and cannot be categorized in the subjective sense of “normal.”

Despite the experiences that these participants had with cancer, treatment, and survivorship, all the participants had a positive outlook on returning to school. The participants also described a sense of increased self-worth and acceptance, stating that it is important to appreciate who you are and to be yourself – no matter the circumstances and irrespective of cancer. These positive sentiments are consistent with statements survivors had reported in other studies. Survivors have a positive approach to how cancer impacted and transformed their lives and made them the person they are today (Steinberg et al., 2020). The researchers also discussed how survivors were able to find silver linings throughout their course of post-cancer life, and having a strong social support system is important for a positive mindset (Steinberg et al., 2020). The participants expressed gratitude for the support they had received from others throughout their diagnosis, treatment, and return to school, stating that they felt as though everyone had done all that they could to support their transition and reintegration into the education system.

### **Strengths and Limitations**

Strengths of this study were that the participants were similar in age and time since completion of cancer therapy. Participants shared important insights into the complexity of cancer treatment during adolescence and their struggles in the transition and integration back into the academic environment. The study was limited by solely interviewing participants from one medical center, and the participants shared some of the same treatment team members. In addition, the student researcher was only able to recruit four participants who agreed to participate in this study. Further, most of the participants studied (75%) were Caucasian, with 50% of the participants being Caucasian males.

### **Implications for Future**

By recognizing and acknowledging the themes found and information the survivors shared throughout this study, stakeholders can facilitate the transition of adolescent cancer survivors as they return to school. The survivors discussed that they did not feel as though their treatment team assisted them with returning to school; however, the survivors also stated that they did not feel as though it was the treatment team's job to help them with readjustment, but rather to focus only on cancer treatment. Furthermore, the participants disclosed that the schools and teachers can be more aware of the specific needs of the survivors and have a greater understanding for the long-term health problems and cognitive issues that the survivors will endure while at school. With enhanced support and understanding from schools and individual teachers, survivors reintegrating back into the education system will be able to catch up and learn at a pace specifically for them. From a standpoint of interprofessional coordination, the health care team and the education system can work hand in hand to help survivors transition back to school. The participants in the study all stated that they felt as though it was not the health care treatment team's job to assist them with the school reintegration process. This, however, is an important component of the health care team's role since preparation for life after treatment begins with the treatment team. The research conducted with these participants highlights a need for communication between the treatment team and schools to best support the survivors' transition and reintegration back to in-person education.

### **Conclusion**

The student researcher and research team aimed to identify the gaps in school reintegration support for adolescent cancer survivors within the treatment team and education system to identify how the two systems can work together to best support survivors when

returning to school. To achieve success with assisting adolescent cancer survivors and their return to in-person school instruction, the specific personal needs of the survivors need to be addressed and expressed. Our qualitative study utilized individual and focus group interviews with thematic content analysis to identify eight specific themes relevant to the school reintegration experience. These themes included: (1) preparedness; (2) coursework challenges; (3) change and adjustment; (4) consistency and help with adjustment; (5) emotional and social impact; (6) physical impact; (7) normalcy; and (8) positive outlook. By acknowledging and supporting the recommendations made in this study, specific support for adolescent and AYA cancer survivors can be prioritized and the reintegration process for survivors returning to school will be comprehensive and structured. Perhaps a qualitative study conducted by health providers and school administrators to design best practices to help survivors could be beneficial for the future. Furthermore, the themes and research identified here can be utilized to develop AYA-specific interventions for the treatment team and school administration and allow these two entities to work together to help the adolescent survivors transition back into the education system as seamlessly as possible.

## **Appendix A**

### Interview Questions

1. Tell me about your experience going back to school.
2. What were your feelings about returning to school?
3. How prepared were you to return to school?
4. What was the most difficult part for you about returning to school?
5. What can be done to better support survivors going back to school?



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