

SURVIVORS' PERSPECTIVE OF A SUCCESSFUL
TRANSITION TO ADULT CARE

by

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ABSTRACT

Many young adult cancer survivors are not receiving regular follow-up care after they leave pediatrics due to lack of education about their need for cancer surveillance and communication between pediatric and adult providers. This study aimed to identify the gaps in defining a successful transition from oncology specialty care to adult primary care, the view of young adult (YA) cancer survivors. The findings presented here are part of a larger study exploring the successful transition in all YA cancer survivors. The specific clinical question being answered is as follows: How do YA childhood cancer survivors of acute leukemia (AL) define a successful transition to adult care? The inclusion criterion of this study was that the YA survivor had to be at least 18 years of age at the time of the study and did not attend the general oncology or survivorship program in the past two years. The researchers conducted this qualitative descriptive study using audio-taped focus groups and individual interviews exploring themes that have salience for YA leukemia survivors during their transition to adult care. Investigators used a qualitative descriptive approach to analyze the transcripts of the focus groups and interviews. To allow for optimal data saturation, investigators conducted both focus groups and individual interviews. Nine of 30 (30%) YA leukemia survivors participated in this study and were a mean age of 29.67 years at the time of the study and a mean age of 9.13 years at the time of their diagnosis. The survivors were a mean of 17 years from completion of their cancer treatment. The majority were males (n = 7). The survivors identified three major themes representative of their perceptions of a successful transition to adult care: Dialogue about cancer history (Communication), Provider handoff (Continuity of Care), and Teaching on long-term expectations, limitations, and necessary cancer surveillance (Education).

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Survivors' Perspective of Successful Transition to Adult Care

More than 80% of children diagnosed with childhood cancer will survive to adulthood and require transition to adult-oriented care for life-long disease management and surveillance (St. Jude's Research Hospital, 2018). The increase in pediatric cancer survivorship rates highlights the need for appropriately transitioned childhood cancer survivors to adult care in order to optimize their health-related quality of life, help them independently manage their healthcare, and allow adult healthcare providers to maintain surveillance of the survivor's status. However, most of adolescent and young adult (AYA) survivors are not receiving risk-based survivorship care to evaluate for physical and psychosocial late effects (Sadak, DiNofia, & Reaman, 2013). Pediatric healthcare facilities often lack age and developmentally appropriate settings for the delivery of survivorship care to young adults, so they need to transition to adult care (Sadak et al., 2013). Poor transition processes may result in negative medical, psychological, and financial consequences, including declines in adherence to follow-up care and increased rates of hospitalization (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

To improve patient outcomes and follow-up care investigators need to further study and address the AYA cancer survivors' definition of a successful transition to adult care. Potosky et al. (2011) completed a study discussing transition from the provider perspective, but few studies have examined this issue from the perspective of the young adult childhood cancer survivor. This paucity of research is especially true regarding childhood cancer survivors (Sadak, DiNofia, & Reaman, 2013). This study aimed to identify the gaps in defining a successful transition from the perspective of young adult (YA) cancer survivors. The specific clinical question researched was: How do young adult childhood cancer survivors of acute leukemia (AL) define a successful transition from pediatric to adult care?

Theoretical Framework

The theoretical framework used as the foundation of this research was the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART). The SMART model identifies patient readiness for transition to adult care beyond such typical markers as patient age, patient knowledge, and patient skills. Additional components of SMART include socio-demographics/culture and healthcare access, patient characteristics (disease, neurocognitive and developmental status), and the inter-related components of knowledge, skills/self-efficacy, beliefs/expectations, goals, relationships, and psychosocial functioning of patients, parents, and providers (Schwartz et al., 2011). By addressing these additional factors, the SMART broadened conceptualization of transition readiness and created a social-ecological framework used to advance and optimize the transition process. This model assumes that transition readiness involves patients, parents, and providers, is measurable, is influenced by actions taken to enhance transition, and is a precursor to engagement in adult care (Schwartz et al., 2011).

The SMART model emphasizes (1) individual transition-relevant aspects of the patient, (2) the inter-related constructs of the patient, parent, and provider, and (3) components amenable to intervention in medical settings (Schwartz et al., 2011). The SMART model can serve as both a framework from which to develop appropriate measures of transition readiness while facilitating a successful transition to adult care for survivors of childhood cancers. Using the SMART model and data from previous investigative work on this population, the student investigator explored what a successful transition means to an acute leukemia (AL) survivor.

Theoretical and Operational Definitions

Addressing the dynamic and complex issues relating to the transition process from pediatric to adult care poses a challenge in creating a universal successful transition plan. Investigators created a new theoretical model in an attempt to establish evidence-based programs to smooth this transition for use with YAs with chronic health conditions. Schwartz et al. (2011), developed the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) as a conceptual framework for pediatric cancer survivors. The SMART model acknowledges the roles of family, peers, and health-care providers in defining transition readiness. By gauging readiness, the SMART model aims to promote a successful transition in childhood cancer survivors; however, defining and measuring success is a challenge in itself. Current literature fails to present a consistent use of transition-related language, with authors using “transition readiness,” “transfer to adult care,” and other transition-related terms interchangeably.

The SMART model clearly articulates the goals of transition readiness and how it relates to the broader transition process in order to operationalize the process. The *transition process* is the purposeful, planned movement of AYAs with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems (Blum, 1995.) The goal of a successful transition is adequate engagement by the adult health care system in order to receive medically appropriate care based on each patient’s unique medical history. Schwartz, Hobbie, and Ginsberg (2011) define *transition readiness* as the capacity of the adolescent and those in his or her primary medical system of support (family and medical providers) to prepare for, begin, continue, and finish the transition process successfully. Participants in the current study consisted of childhood cancer survivors (AL) who participated in a recently completed survey study

examining the successful transition of young adult AL survivors. Investigators in this study wanted to learn more about how YA survivors defined a successful transition to adult care.

Review of the Literature

Past literature demonstrates that YA childhood cancer survivors are not receiving necessary survivor-focused care as they transition to adulthood (Nathan et al., 2009). The survivorship literature also demonstrates that the transition from cancer patient to cancer survivor can also pose a challenge to AYAs (Casillas et al., 2010). A search of CINAHL Complete, MEDLINE, EMBASE, and Cochrane Library identified studies reporting barriers that prevented successful transitioning of childhood cancer to adult care. Search terms included “*successful*” “*young adult*” AND “*AYA*” AND “*YA*” AND “*childhood cancer survivor*” AND “*transition.*” The student investigators included other search terms such as “*barriers*” and “*facilitators*” to further lay the foundation of knowledge about transition in the young adult survivor, and as well to attempt to fill the gaps in the knowledge about successful transitions.

Barriers to Successful Transition

In a qualitative descriptive study, 507 members of the Children’s Oncology Group completed electronic surveys in order to describe the barriers of transition practices (Kenney et al., 2016). The results of Kenny et al.’s (2016) research noted that barriers related to a successful transition included emotional attachment to pediatric oncologist, lack of adult-oriented providers, survivors’ cognitive/emotional delay, patient noncompliance, instability of the survivors’ medical condition, and health insurance issues. Four themes emerged from the open-ended response questions regarding barriers to transition and transfer practices: (1) the need for flexible transfer criteria; (2) the view of providers as barriers to transfer; (3) the demand for help/support with process; and (4) the need for teamwork.

Casillas et al. (2010) hosted a qualitative focus group using a comparative analytic approach to explore the parents' view of their child's perceptions of their transition experience. The parents claimed that cancer carries a stigma; people commonly view cancer as an incurable contagious illness and this idea becomes a barrier to moving forward and transferring to adult care. Additionally, this study confirmed that survivors often avoided talking about the potential late effects of cancer out of fear that voicing such risks might make them more vulnerable to developing late effects. The emotional distress associated with recalling their cancer experience inhibited survivors from initiating conversations about their cancer history to address the need for survivorship care with adult healthcare providers.

Kenny et al. (2016) revealed that several pediatric oncologists viewed themselves as barriers to a successful transition for YA survivors transferring to adult care. Many pediatric providers considered themselves experts in the care of YA childhood cancer survivors, but believed they lacked confidence in the adult providers' knowledge of survivorship care and ability to facilitate the successful transition of these survivors to adult care. Similarly, Riley, Hough, and Whelan (2010) found that the transition from the pediatric oncologist into adult care was a source of anxiety for patients and families due to the emotional bonds among the patient and family with the pediatric healthcare team. The emotional bonds and personal relationships the YA survivors share with their pediatric oncologists is an inevitable loss when the survivor transitions to adult care, but a successful transition will bridge this gap and smooth the transition to a new, unfamiliar adult care provider. The communication between YA survivors, pediatric oncologist, and adult health care providers is insufficient in the current transition methods (Dulko et al., 2013). Many survivors suggested the need for innovative programs that include collaboration with adult providers and institutional support for these programs in order to smooth

survivors' actual transfer to adult care (Kenny et al., 2016).

Facilitators of Successful Transition

A myriad of research studies sought to identify aspects of a successful transition by childhood cancer survivors to adult care. Szalda et al. (2017) completed a qualitative study that used purposeful sampling to obtain data. This study identified being diagnosed at an earlier age, having insurance, having assistance in health care decision-making, achieving higher internal motivation, and increasing comfort speaking to providers as specific aspects that promote a successful transition. Each of these factors is associated with attendance at adult-oriented follow-up care visits. The Johns Hopkins Nursing Evidence-Based Practice tool is an evaluation system that identifies quality of research. This study is level three criterion based on the Johns Hopkins Scale, found in Appendix A (Johns Hopkins University School, n.d.). Health care providers must recognize that many of these variables are modifiable, and necessitate interventions.

By focusing on improving the modifiable aspects of the transition process, health care providers can increase survivor engagement and the success of transitioning to adult care. Research completed by Casillas et al. (2010) found that involving the nuclear family in the transition process acts as an important facilitator to promote the success in transfer to adult care. In a similar descriptive, cross-sectional study completed by Sadak, DiNofia, and Reaman (2013), survivors rated flexibility in scheduling of transition care important when considering participating in follow-up care. Riley, Hough, and Whelan (2010) identified several key elements of effective transitioning to adult care, including gradually preparing patient and family for transition, formalizing the transition plan, communicating between health-care teams, and verbally and non-verbally supporting the patient. Additionally, Freyer (2010) reported the need

for a standardized approach to the transition of care for cancer survivors to identify the best ways to enhance compliance with recommended follow-up.

The American Academy of Pediatrics (AAP) has established guidelines for clinicians to begin transition as early as age 12 years to allow for acquisition of skills necessary for the independence of children when they become adults (AAP, 2002; 2011). The timing of transition to adult services may vary depending upon the health care center and the disease, and no consensus exists as to the best time to begin this process. However, the key is to begin the conversations and education early so that the eventual transfer of care is a natural expectation of children. The age range may vary from 16-21 years of age. Healthcare providers should consider not only the chronological age of the adolescents, but also their developmental age (Tuchman et al., 2010). The transition of young adult cancer survivors to adult services also requires a consideration of the YA survivors' developmental stage.

Survivors' Definition of Successful Transition

Few studies have examined survivors' transition care from the perspective of the young adult childhood cancer survivor (Casillas et al. 2010; Sawicki, Kelemen, & Weitzman, 2014). This gap warrants the need for further research, which would inform a well-developed transition plan for adolescent and young adults (AYAs) with chronic health problems from pediatric to adult provider services. Sawicki, Kelemen, and Weitzman (2014) completed a descriptive, cross sectional study that described the preferences of young adult survivors of childhood cancer regarding the transition of their survivorship care. The researchers developed a questionnaire to collect survivors' responses on the most important program components of a clinical survivorship transition program. Based on the results from this study, survivors reported they preferred a multidisciplinary care team that offers care across multiple specialties and

subspecialties as an important factor in defining a successful transition.

Casillas et al. (2010) completed a similar study consisting of 27 informant interviews with Latino AYA survivors. This study emphasized the role healthcare providers have in promoting a successful transition. The AYA survivors identified emotional support and trustworthiness of their adult care provider as an important facet in a successful transition. Survivors viewed their adult healthcare providers as trustworthy and competent if the providers directly addressed the AYA survivors' concerns regarding specific symptoms caused by previous cancer treatment.

In summary, limited evidence exists examining and defining what a successful transition is and how YA childhood cancer survivors define a successful transition. The current study aimed to explore the definition of a successful transition from the YA survivors' point of view.

Methods

Design

This was a qualitative descriptive study using focus groups and individual interviews.

Procedure

The student investigator obtained Institutional Review Board (IRB) approval for human subject research through Cook Children's Health Care System (CCHCS) and through Texas Christian University and the Nursing Review Board for nursing Honors student engagement in this project. The investigators contacted the young adult childhood cancer survivors treated at CCHCS who participated in the telephone surveys in *Successful Transitions or Opportunities for Improved Care* (IRB-2015-054) as part of a larger transition study conducted within the CCHCS. The student investigator recruited 30 eligible participants who reported either a successful or

non-successful transition to adult services from pediatric oncology to explore their perspectives of their transition, investigate their current experiences in adult services, and to learn more about how healthcare providers can better support them. Nine of the 30 eligible participants agreed to participate in the current study.

The student investigator recruited participants by sending an informational cover letter by postal mail to the 30 respondents of the previous survey questionnaire, inviting them to participate in the current project. The cover letter is found in Appendix B. If interested, the letter asked eligible participants to call the investigator if they wished to participate in the focus groups or individual interviews. As a follow-up to the mailed postal letter, the student investigator made telephone calls one to two weeks after sending the postal mail introduction letters and invited participants to attend one of two planned focus groups or individual interviews in the event they could not attend a planned focus groups. (See Appendix C to view the phone call script).

The student investigator then assigned participants who chose to take part in the study to one of the focus groups agreed upon by both the survivors and the investigators. The investigators intended on having a purposeful sample of 30 total participants divided into two groups of 15 for the focus groups with additional individual interviews for participants who could not attend the focus groups. The student investigator called one week prior to each focus group's assigned meeting time to remind participants who had agreed to partake in the study.

Sample and Setting

The student and faculty investigators conducted two separate focus groups, and they made all efforts to have the focus groups on days and times convenient to both the investigators and the participants. Because the student investigator was unable to schedule four of the young

adults in one of two focus groups, the faculty investigator hosted four individual interviews. The student investigator and faculty investigator conducted two audio-taped focus group interviews for five participants at a time that was convenient to both the investigators and the participants. Because the goal of this study is to define a successful transition from the perspective of the patient, we attempted to recruit sufficient participants to have two focus groups. The student and faculty investigator obtained informed consent from the participants when they arrived at the focus groups.

Young adult cancer survivors who had already transitioned to adult care, who had not been seen in the Hematology and Oncology Center in at least two years, and who completed the telephone transition survey on the previous study (IRB-2015-054) were eligible to participate in the current study. Survivors who did not complete the survey by telephone in the previous study (2015-054) were not eligible to participate in this study because they did not provide contact information. The previous study was anonymous; therefore, any participant that did not complete the telephone survey could not be contacted.

The focus groups and the individual interviews took place at the CCHCS Hematology and Oncology Center on a day and time that was convenient and agreed upon by the participants and investigators. The student and faculty investigator obtained informed consent from the participants when they arrived at the focus groups. Participants received \$15 for participating in the focus group as a compensation for their time.

Data Collection

The qualitative method aimed to elicit cancer survivors' perception of successful transitioning to adult care and possible supportive interventions including better transition

practices. The student investigator chose focus groups in addition to individual interviews as an effective means of collecting in-depth data from a number of patients in one setting. In addition, the interactions and dynamics between the group members were an integral part of the process and were a key factor in selecting this methodology (Fain, 2017). Four survivors who wanted to participate in the study either could not attend the focus groups or preferred to discuss their transition experience individually. As a result, the student and faculty investigator arranged individual interviews at a day and time that was convenient for both investigators and the survivor.

At the time of the focus groups, the student investigator explained the study thoroughly with the participants and answered any questions they had. After obtaining signed informed consent from the participants, the student investigator asked the participants a series of open-ended questions addressing their perceptions of a successful transition (see Appendix D). Other data collected included a demographic data sheet (see Appendix E). To ensure the investigators did not miss key points or observations during the focus groups, the student and faculty investigators took field notes while the student investigator facilitated questions. The faculty investigator conducted the individual interviews without the student investigator. Additionally, the focus groups and individual interviews were audiotaped. A professional transcription service transcribed the audiotaped focus groups and individual interviews verbatim.

Data Analysis

Following professional transcription, the investigators individually analyzed the transcripts of the focus groups and individual interviews. The student and faculty investigator used qualitative descriptive analysis procedures to analyze transcription line by line, in an

attempts to capture the events the participants discussed in everyday terms (Sandelowski, 2000). After completion of the individual data analyses, the student and faculty investigators came together to discuss their individual analyses and to assure dependability in the findings. If the investigators found a discrepancy in conclusions gleaned from the focus group analysis, the third research assistant would have reviewed the discrepant piece. No discrepancies emerged; however, a research assistant with years of experience in qualitative investigation in the Hematology and Oncology Department reviewed the transcripts to ensure further dependability in the findings. The goal of the analysis was to identify themes in the responses based on the words of the participants. Investigators analyzed participant responses by identifying ongoing and repeated words, ideas, or phrases by the participants in order to capture the overarching themes of the focus groups.

Investigators analyzed the participants' demographic characteristics using descriptive statistics with IBM SPSS Statistics for Windows, Version 23.0.

Results

Quantitative

Nine YA acute leukemia survivors participated in this study. The mean age of participants at the time of the study was 29.67 years (range, 21-35), and a mean age at the time of their cancer diagnosis was 9.13 years (range, 3-17). Participants were 77.8% male. Four participants completed individual interviews and 5 participants attended focus groups. The majority of YA AL cancer survivors surveyed were non-Hispanic White or Caucasian (88.9%), and married (44.4%). All participants had health insurance. The survivors who participated

completed their cancer treatment a mean of 17 years prior to this study. Table 1 (see Appendix G) displays the characteristics of participants.

Qualitative

This study aimed to discover YA AL cancer survivors' definition of a successful transition to adult care. The participants responded to open-ended questions, which elicited their own definition and perspective of a successful transition. The open-ended questions allowed participants to articulate their transition experience and expand upon improvements for future YA AL cancer survivors' transition to adult care. The themes that emerged as participants discussed their transition experience fell into three main constructs: *communication*, *continuity of care*, and *education*.

Communication. Overall participants expressed positive opinions and gratitude for their care at Cook Children's Medical Center and their pediatric oncologists throughout the course of their treatment. A thirty-five-year-old, African American male participant stated, "I can't think of nothing you all could have done better to help me than what you all did." Despite the quality of care participants' receive at Cook Children's, there is a gap in the communication after transitioning to adult care facilities. One reason this gap in communication occurs is because many survivors do not feel informed or educated on how to discuss their cancer history or experience with their adult care providers. This same participant went on to say, "I had a hard time trying to find a doctor to talk to me about cancer, because they wanted histories I couldn't give them, that Cook [pediatric hospital] couldn't give me."

The majority of the participants reported attending annual physician visits; however, the participants stated that their adult care providers did not initiate conversation or follow-up on their cancer history. When asked if his adult care provider addresses his cancer history, one

participant responded, “No. None of that.” Another participant added, “Yeah. I wouldn’t say mine does either.... I just go for a physical every year.” Another male participant agreed, saying, “my provider just kind of brushes it off.” The need for successful transition and communication is vitally important to maintain health in YA cancer survivors.

The majority of the participants in this current study were male. Based on the responses to the open-ended questions, the male participants in this study often mentioned that it took their mothers or wives to get them to go to the doctor and/or recognize their need for follow-up care. Though reminders and physician encouragement is extremely important, survivors must also commit to investing in long-term care in order to maintain a successful transition and continuation of health.

Healthy People 2020 identified increasing transition planning from pediatric to adult care for youths as one of the primary goals for youths with special health care needs. (U.S. Department of Health and Human Services, 2018). The results of this study revealed a break in the continuity of care after transitioning due to the lack of communication between the adult care providers and the YA survivors about their cancer history. One male participant who underwent total body radiation said, “I feel like I need to go with someone that is aware of my situation, so that if I come in with something, they’ll know, this isn’t just your normal guy on the street.”

Survivors stated that this failure to discuss their history caused them to doubt their adult care providers; “I told them [adult provider] I had leukemia back in 2003, but they never bring it up. These doctors never bring it up. Maybe because they’re not hematology doctors or whatever. They’re just regular doctors, I guess. I don’t know.” Participants of this study included effective communication between the pediatric oncology provider, the YA survivor, and the adult care provider obtaining the care of the YA survivor in their definition of a successful transition to

adult care. Effective communication between the pediatric oncologist, YA survivor, and adult provider is an imperative factor in defining a successful transition to adult care.

Continuity of care. Another theme that emerged from the focus groups and individual interviews was continuity of care. A gap in the communication between providers and the survivors led to a break in the continuity of care. Participants articulated that having a doctor who is familiar with their case is important to them in defining successful transition. One participant reported, “I didn’t have a doctor to go to that was familiar with my case or anything, so that would’ve been nice.” Another participant added, “Having a doctor that knows the red flags to look for is really important.” However, participants reported that they did not know where to go after leaving their pediatric providers. One participant who is seventeen years out of treatment reported, “I wish they would have told me where to go. I had no idea where to go once I left there [pediatric provider.] So I was like a chicken with no head. I didn’t know where to go.”

In addition to receiving referrals to recommended providers, these participants identified that follow-up reminders would have been helpful to ensure continuity of care when asked about recommendations for future improvement on successful transition. One male patient stated, “Some sort of annual or semi-annual follow-up, whether it’s automated or from a real person, would be helpful.”

Finally, participants revealed that they were not aware of what to expect and what to avoid doing. An older male participant stated, “Just having the information to know what you can and can’t do within a certain time frame would have been the most beneficial for me.” Another male participant added that it would have been helpful if his providers had told him “you need to do this...” Continuity of care ensures that providers follow-up and maintain the

progress the YA survivor achieved throughout their transition to adult care. Safety is key in transitioning and survivorship which demands effective continuity of care.

Education. Participants also acknowledged the density of information during transition due to the complexity of treatment, the difficult timing of transition, and various members of the team involved in the transition process. The recurrent theme noted in the participants' responses was the need for education. Despite receiving binders or packets of information, participants reported not feeling adequately prepared for the transition to adult care.

Several participants admitted that although they may have learned about long-term expectations and necessary follow-up appointments at the time they were being discharged, they were not emotionally ready or focused on that teaching. One participant said that "...at the time, my focus was getting out of being treated, not thinking about what treatment I should get in the future. But now that I'm 15 years out of it, I realize that making sure that you stay up on your maintenance and that kind of stuff is really important." Another added, "I'm sure I was given all the information, and I'm sure it went immediately onto a shelf somewhere that's probably still at my mother's house."

Despite participants' receiving education at the time of transition, responses to the question regarding transition education revealed that providers did not present the information in a way that positively aided the participants' shift to adult care providers. One participant said: "You all gave me a packet and it had a book, and stuff to help me transition. And I completely forgot about it until now." A male participant reported not receiving any discharge instructions or material: "I was told I was going to get a binder with all my medical history. I guess my doctor has it, but I never received that. And that was it. That's all I was told. And I went on my merry way and lived my life till now."

Other participants remembered receiving discharge material; however, they admitted never reviewing the material and did not know where it was today. One patient stated, “I think my mom has it. It’s on the shelf somewhere.” Another participant stated, “She [participant’s mother] has the packet somewhere.” Educating YA survivors on anticipated follow-up, future expectations, and self-advocacy skills is an imperative component in successful transitioning. Surviving pediatric cancer is not just a single life event; this is a continuous process throughout the course of one’s life. The need for continuous education and follow-up care is vitally important in order to achieve a successful transition.

Discussion

The open-ended questions addressing the participants’ definition of a successful transition from pediatric to adult care provided information in areas necessitating improvement within the transition process. Harris, Freeman, and Duke (2010) claim that the recognition of issues and problems regarding transition has increased during the past decade, but meaningful systematic changes have not occurred. The current study revealed that communication is an area of needed improvement in the transition process. According to Rooney (2016), “more effective communication between oncologists and primary care providers must exist to enhance the quality of care for young adult survivors of cancer” (p. 12). A survivor in the current study reported that receiving a list of recommended providers where he lives would have been beneficial in his transition to adult care. Though this issue is an insurance-driven topic, several other participants also mentioned the challenge of knowing where to go after transitioning from their pediatric facility and oncologist.

In addition to the communication between the pediatric provider and the YA survivor, communication between the pediatric provider and the adult care provider assuming control of

the YA survivor is equally as important in continuing care. White and Ardoin (2016) completed a literature review examining the transition to adult care for youth with rheumatic conditions. Their conclusions emphasized the importance of communication between pediatric and adult providers as well as timely exchange of current medical conditions. Among the various childhood life-long health conditions, the demand for improving transition is unmistakable. In 2015, a report from the Institute of Medicine (IOM) addressing the health and wellbeing of young adults prioritized the transition from pediatric to adult health care as a key issue to improve, focusing primarily on young adults with special health conditions. (IOM, 2015).

One can compare the idea of provider communication regarding specific patient care to the nurse handoff report that occurs at each shift, on every floor of every hospital. Friesen, White, and Byers (2008) stated, “An effective handoff supports the transition of critical information and continuity of care and treatment” (p. 2). This transfer of essential information and responsibility of care from one provider to another is recognized as an integral component of communication in health care among each unit (Friesen et al., 2008). Patterson et al. (2004) added, “The primary objective of any patient handoff is the accurate transfer of information about a patient’s state and care plan” (p. 125). Additionally, when the acuity of an individual patient and diagnosis increases, the importance of the handoff report proportionally increases. Though this fundamental practice is a recognized principal in the acute care setting, providers are not applying the handoff concept within the transition process from the pediatric oncologist to the adult care provider.

In this study, the majority of participants reported that their adult health care provider does not address their cancer history. Survivors and providers must facilitate discussion of a patient’s history, individual diagnosis and treatment, and future care plans in order to achieve a

successful transition. This lack of communication leads to neglecting imperative follow-up care. Follow-up care is an important aspect in successful transition. Participants in this study stated that they remember addressing future late effects when transitioning out of pediatric care; however, there was a gap in the commitment to proper follow-up care. One participant stated that receiving automated text reminders would have been helpful in attaining a successful transition. He stated that he would have been more consistent in seeking follow-up care had he received text-reminders instructing him on the type of follow-up care he was due to receive.

Lockhart, Gillespie, and Grant (2017) conducted an integrative review analyzing nine separate clinical trials that examined the impact text message reminders (TMR) had on compliance and attendance at follow-up appointments. Each study reviewed showed an increase in appointment compliance through the use of TMRs. Additional benefits measured in this review included cost-effectiveness, acceptability, satisfaction, usefulness, and usability. By applying this method to important follow-up reminders for transitioned survivors, providers could more effectively and efficiently promote continuity of care. Other participants in this discussion and throughout this study agreed. Though automated reminders may increase awareness of the need for follow-up care that alone is not enough to ensure future care.

In a previous study, Jupina (2017) found that knowledge about the importance of follow-up care does not equal readiness to transition from the pediatric to adult-care setting. When young adult cancer survivors transition, it affects more than just the location of treatment; they lose respected and revered health care providers and must trust new and unfamiliar providers (Viner, 2001). Providers must properly equip and educate young adult survivors on personal advocacy in order for these survivors to recognize their potential risk factors for developing late health problems as a result of their cancer treatment and when to seek medical attention. Patients

must be empowered by health care professionals to become knowledgeable about their medical history and to become effective self-advocates of their care in the future (Quillen et al., 2016). Once YA survivors know how to advocate for themselves, they can take more control of their health care and feel more prepared to seek adult care. McNally, Unwin, and Cruickshank (2012) added, "It is important to empower young people to make their decisions, particularly as they assume more responsibility for their own healthcare" (p. 4). When YA survivors feel informed, they can take control of their own health care and become more prepared for adult services, creating a smooth transition from pediatric to adult care.

This research study supports that progress has been made in educating patients about their specific risks and the importance of follow-up. Though researchers have conducted a plethora of studies regarding the transition of care from pediatric to adult care from the view of the providers, this study aimed to identify the definition of a successful transition from the survivors' perspective. Analysis of all participants' open-ended responses revealed that there is progress toward a successful transition. Further research and assessment are needed in order to reach saturation and generalize results to the greater population.

Limitations

A limitation of this study is the relatively small sample size, inclusion of only AL survivors, and subjectively reported data. To qualify for this research study, participants had to have partaken in a previous study (IRB-2015-054) and completed the phone survey, further narrowing the pool of eligible participants. The previous study was completed one year ago. Therefore, several eligible participants' provided outdated phone numbers. Due to potential harassment, the student investigator only called the eligible participant three times before making no further attempts to recruit participants for the study. Many people no longer answer their

phones if they are unfamiliar with the number, and in order to protect patient privacy, investigators could not leave voicemails. In addition to the difficult recruitment of participants, this study also required the participant to attend a focus group or individual interview at Cook Children's Medical Center. Therefore, investigators had difficulty coordinating a mutual time multiple eligible participants were available. Finally, many eligible participants were YAs several years out of treatment and no longer lived in proximity to the hospital, making commuting to focus groups inconvenient.

Further Research

To gather further data about survivors' definition of a successful transition to adult care, researchers should expand the inclusion criteria to all pediatric cancer and/or chronic, life-long disease diagnosis. Expanding the eligible inclusion criteria would provide a larger sample size and an opportunity to reach saturation in the themes pertaining to participants' perception of successful transition. In addition, it would be beneficial to examine a comparison between the various diagnoses in order to further identify areas demanding improvement and attention. Future research creating a deeper and more comprehensive understanding of successful transition will benefit not only the YA survivors, but families and providers as well.

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Appendix A

Levels of Evidence and Grading of the Literature Review

| Authors | Type of Study | Strength of Evidence | Quality of Article |
|----------------------|----------------------------------|-----------------------------|---------------------------|
| Szalda et al. 2011 | Qualitative Study | Level III | Good |
| Kenney et al. 2016 | Qualitative Study | Level III | Good |
| Casillas et al. 2010 | Qualitative Comparative Analysis | Level III | High |
| Sadak et al. 2013 | Cross-Sectional Study | Level III | High |
| Riley et al. 2010 | Qualitative Study | Level III | Good |
| Dulko et al. 2013 | Descriptive Pilot Study | Level III | Good |
| Potosky et al, 2011 | Stratified Sample Study | Level III | High |

Appendix B

Cover Letter



April 3, 2017

To: Young Adult Survivor of Acute Leukemia and Other Cancers

Re: Opportunity to share your transition to adult care story

Hello,

We are writing on behalf of the Adolescent and Young Adult Oncology (AYAO) program and the Life After Cancer Program (LACP). We would like to ask you more about your perceptions and beliefs about what is a successful transition. We would like to invite you to come to Cook Children's Medical Center to share your story with us and other young adult survivors about your transition experience.

We would like to ask you and other young adults several questions in the group setting (focus groups) about how you were transitioned and if you feel you are receiving good cancer follow-up care in the adult clinic. You provided information to Dr. Lisa Bashore and or Lauren Jupina as part of another study, but we want to learn more about your transition experience in person so we can improve how we transition other young adults to adult care.

If you are interesting in coming to Cook Children's Medical Center and talking in a group with other young adult survivors about what is a successful transition, please contact Lisa Bashore at 817-257-4248 or at lisa.bashore@cookchildrens.org or Joyce Bender at 682 885-2164. Otherwise, we will contact you by phone in the next week to see if you are interested in being part of this study.

Respectfully,

Lisa Bashore, Ph.D
Faculty Investigator, AYAO Program

Kenzi Dannelly, SN
Student Investigator

Appendix C

Phone script



Hello, my name is _____ and I am calling from Cook Children's Medical Center and am interested in talking to _____.

- a. *If the survivor is not there but the number and home of the survivor is validated, then ask them to return the call to either Lisa Bashore at 817 257-4248 or Joyce Bender 682 885-2164.*
- b. *If it is the wrong number, please apologize for the wrong number and hang up*
- c. *If no one answers the phone and a message machine does not indicate the home is that of the survivor than there will NOT be a message left. If the machine indicates it is the home of the survivor leave a message:*
- d. This is _____ from CCMC and I would be very interested in talking to you about your health care. Please call Lisa Bashore at 817 257 4248 or Joyce Bender 682 885-2164.

. Thanks

If the survivor answers the phone, proceed with the following script;

I am calling on behalf of the Adolescent and Young Adult Oncology (AYAO) program and the Life After Cancer Program (LACP). We are inviting you to share your story of transition in person with us at Cook Children's Medical Center. We appreciated your completion of the medical survey in a recent survey, but we want to learn more about your transition experience. Would you be interested in coming to Cook Children's to attend a focus group (talking with other cancer survivors)?

- a. *If the survivor answers, Yes, the student investigator will proceed to schedule the survivor in one of the two focus groups.*
- b. *If the survivor answers No, the student investigator will thank them for their time.*

Name of person making the call (investigator)

Appendix D

Demographic Data Form

| | | |
|---|---|--|
| Age Currently _____ | Age at Diagnosis _____ | Diagnosis: -ALL |
| Gender: -Male (0) -Female (1) | Treatment: -Chemotherapy (1) -Surgery (2) -Radiation (3) -Combination Chemo/Radiation (4) | Radiation to Brain: -Yes (0) -No (1) |
| Health problems you have (diagnosed before or after you were transitioned from Cook): -Yes (0) -No (1) List them: | Income: -< 20,000 (1) 20,001-40,000 (2) 40,001-60,000 (3) 60,001-80,000 (4) 80,001-100,000 (5) >100,000 (6) | Education: -Less than high school (1) -Some high school (2) -High school graduate (3) -GED (4) -Some College (5) -College graduate (6) -Graduate school (7) -Post Graduate school (8) -Doctorate (9) -Professional (MD, DO, JD) (10) |
| Marital status: -Single (1) -Married (2) -Divorced (3) -Separated (4) -Living with significant other (5) -Widowed or Widower (6) | Employment: -Student (1) -Part time & Student (2) -Part time only (3) -Full time (4) -Disabled (5) | Insurance: Yes (0) No (1) |
| Living Arrangement: -Alone (1) -With friend (2) -With significant other (3) -With Parents (4) | Race: -American Indian or Alaskan Native (1) -Asian (2) -Black or African American (3) -Native Hawaiian or Other Pacific Islander (4) -White or Caucasian (5) | Ethnicity -Hispanic or Latino (1) -Not Hispanic or Latino (2) |

Appendix E

Focus Group Introduction Script

“Hello. My name is Kenzi Dannelly I am the student investigator from TCU Harris College of Nursing hosting this research focus group with Dr. Lisa Bashore on this study. Today we would like to have a conversation with you about your transition from pediatric care to adult care. What we are trying to accomplish before we leave here today is to get a better understanding of how you defined your successful transition and your perspective on the transition process you received”

“Let’s go over some rules. First, let’s all turn off our cell phones so we are not interrupted. So that we can keep track of what people are saying, remember that we will only have one person talking at a time. Please do not interrupt someone when they are talking. Also, everything you tell us today will be kept completely confidential. We will summarize the things you tell us and will not share any personal names as part of this study. We will plan to combine the information we collect in this focus group with the other focus group. One of my jobs today as the moderator is to make sure we discuss all of the issues we plan to discuss. If I ask you questions while you are talking, I’m not being rude; I’m just making sure everyone has a chance to talk and that we discuss all of the issues. Just to get us started, let’s have everyone tell us your name and when you were transitioned from Cook’s care to your adult provider.

Appendix F

Interview Questions

1. Talk about your current health.
 - a. Medical or other problems you are experiencing.
2. Tell us about the medical or health care you are receiving.
 - a. What type(s) of medical doctors or other health providers do you see regularly?
 - b. Talk about how well are your health care needs being met.
3. What information do you and your health care provider talk about during your visits?
4. Talk about the conversations you have with your current adult care provider about your cancer history
5. Tell us what your Cook pediatric oncologist and or other health care providers did to help you get ready to transfer to adult care.
 - a. What information or education did you receive?
 - b. How helpful was the information or education you received?
6. Tell us exactly what other information or education would have been helpful to you as you were asked to leave Cook.
 - a. What specifically could we have done to better prepare you to leave Cook? Think about how you are doing now, and your current situation and not just at the time you left Cook.
7. Are there are final questions? Thank you for your time with us today.

Appendix G

Demographic Data

| Characteristic | <i>n</i> | % |
|------------------------------------|----------|-------|
| Current Age | | |
| 18 – 25 years old | 1 | 11.1% |
| 26 – 35 years old | 8 | 88.9% |
| > 35 years old | 0 | 0.0% |
| Age at Diagnosis | | |
| 0 – 5 years old | 5 | 55.6% |
| 5 – 10 years old | 0 | 0.0% |
| 10 – 15 years old | 2 | 22.2% |
| 15 – 20 years old | 2 | 22.2% |
| Time Since End of Treatment | | |
| 0 – 5 years | 0 | 0.0% |
| 5 – 10 years | 0 | 0.0% |
| 10 – 15 years | 5 | 55.6% |
| 15 – 20 years | 2 | 22.2% |
| 20 – 25 years | 2 | 22.2% |
| Gender | | |
| Male | 7 | 77.8% |
| Female | 2 | 22.2% |
| Treatment | | |
| Chemotherapy | 6 | 66.7% |
| Radiation | 0 | 0.0% |
| Combination | 3 | 33.3% |
| Radiation to Brain | | |
| Yes | 4 | 44.4% |
| No | 5 | 55.6% |
| Income | | |
| < 20,000 | 2 | 22.2% |
| 20,001 – 40,000 | 1 | 11.1% |
| 40,001 – 60,000 | 1 | 11.1% |
| 60,001 – 80,000 | 3 | 11.1% |
| 80,001 – 100,000 | 1 | 33.3% |
| >100,000 | 1 | 11.1% |
| Education | | |
| Less than high school | 0 | 0.0% |
| Some high school | 0 | 0.0% |

| | | |
|---|---|--------|
| High school graduate | 1 | 11.1% |
| GED | 1 | 11.1% |
| Some College | 2 | 22.2% |
| College graduate | 2 | 22.2% |
| Graduate school | 0 | 0.0% |
| Post Graduate school | 1 | 11.1% |
| Doctorate | 0 | 0.0% |
| Professional | 2 | 22.2% |
| Marital Status | | |
| Single | 3 | 33.3% |
| Married | 4 | 44.4% |
| Divorced | 1 | 11.1% |
| Separated | 0 | 0.0% |
| Living with significant other | 1 | 11.1% |
| Widowed or Widower | 0 | 0.0% |
| Employment | | |
| Student | 0 | 0.0% |
| Part time & Student | 1 | 11.1% |
| Part time only | 0 | 0.0% |
| Full time | 7 | 77.8% |
| Disabled | 1 | 11.1% |
| Insurance | | |
| Yes | 9 | 100.0% |
| No | 0 | 0.0% |
| Living Arrangement | | |
| Alone | 0 | 0.0% |
| With Friend | 1 | 11.1% |
| With significant other | 6 | 66.7% |
| With Parents | 2 | 22.2% |
| Race | | |
| American Indian or Alaskan Native | 0 | 0.0% |
| Asian | 0 | 0.0% |
| Black or African American | 1 | 11.1% |
| Native Hawaiian or Other Pacific Islander | 0 | 0.0% |
| White or Caucasian | 8 | 88.9% |
| Ethnicity | | |
| Hispanic | 0 | 0.0% |
| Non-Hispanic | 9 | 100.0% |
