EVIDENCE-BASED GUIDELINES DEVELOPMENT FOR THE SUCCESSFUL TRANSITION OF YOUNG ADULT CHILDHOOD CANCER SURVIVORS TO ADULT CARE PROVIDERS

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Abstract

Currently, there is a lack of support for pediatric cancer survivors as they transition to adult care. The student researcher outlined this discovery through an extensive review and synthesis of the literature. The major areas of concern for both survivors and care providers (pediatric and adult) are lack of communication between providers and survivors, support for survivors, and education of the survivors. The student researcher used the findings from the review of pertinent literature to create the transition guidelines of survivors based on the American Academy of Pediatric Got Transition Model (AAP, 2014). To facilitate implementation of these guidelines, the student researcher created a workbook for the Life After Cancer Program at Cook Children’s Health Care System in Fort Worth. Such guidelines are important because they will help to facilitate a successful transition rate of pediatric oncology survivors to adult care providers.
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Evidence-Based Guidelines Development for the Successful Transition of Young Adult Childhood Cancer Survivors to Adult Care Providers

According to the American Cancer Society (ACS), over 80% of children diagnosed with cancer survive at least five years after treatment (ACS, 2018). McClellan (2013) stated that 62% of survivors of childhood cancer will experience some type of late effect from their treatment. Due to the improved survival rates, childhood cancer survivors have an increased need for long-term follow-up care due to the chronic conditions they may develop because of their cancer treatment (Kenney et al., 2017). Adolescent survivors of cancer experience both a psychological and physical disconnect in the transition from pediatric to adult care (Frederick, Bober, Berwick, Tower, & Kenney, 2017). The survivors need a formal, intentional, and systematic approach to aid in their successful transition from pediatric to adult follow-up care (Kenney et al., 2017). To address these crucial needs, the student researcher addressed the following question: How can we intentionally direct education and transition practices to adolescent cancer survivors to facilitate a successful transfer to adult care?

Theoretical Framework

During his national conference in 1984, US Surgeon General C. Everett Koop, MD, brought attention to the issue of transitioning American adolescents to adult health care. The conference focused on adolescents with chronic, disabling health conditions who previously were not living into their adult years (Blum, Hirsch, Kastner, & Quint, 2002). Five years later in 1989, the Surgeon General’s Conference continued this emphasis: Growing Up and Getting Medical Care: Youth with Special Health Care Needs. The conference attendees strived to create a national model to guide health care providers to facilitate adolescent transition to adult care (Magrab & Millar, 1989).
In 2002, the American Academy of Pediatrics (AAP), along with the American Academy of Family Physicians, the American College of Physicians, and the American Society of Internal Medicine issued a statement on the need for a well-defined model for the transition of children with special medical conditions (Cooley & Sagerman, 2011). Their collaboration and research led to the creation of the Got Transition Model in 2009 using an algorithm focused on best practices for optimal transition care (AAP, 2014; Cooley & Sagerman, 2011). The model has three different transition applications, which are 1) youth to adult health care providers, 2) an adult approach to health care without changing providers, and 3) integrating young adults into adult health care (AAP, 2014, p. 2). Each of these models has six different steps that lay out a framework for health care institutions to address to successfully transition youth to adult care.

The student researcher used the first application, which is “youth to adult health care providers” (AAP, 2014, p. 2).

In step 1 of the Got Transition Model, the AAP identified the need for institutions to create a policy outlining the appropriate time to perform and complete transition care. The AAP also suggested that the process of transitioning should begin when the adolescents are between ages 12 and 14 and inform the adolescents, families, and providers about the policy in place. In addition, the AAP outlined the importance of going over each person’s role during the transition period to enable a smooth process (AAP, 2014).

The Got Transition Model’s step 2 recommends that institutions have clear documentation of the education provided to patients and family. Also, the model called for providers to record what educational documents and/or resources related to transitioning to the adult health care providers they discussed and shared with patients and families at each visit. This step emphasizes the importance of documentation in the electronic health record (EHR) to
show evidence of what the providers have done in relation to transition education. High quality documentation allows providers to evaluate adolescents’ transition readiness over time.

Step 3 of the Got Transition Model states that health care providers should begin to assess transition readiness in adolescents at ages 12 to 14. The providers complete this process by having adolescents demonstrate knowledge of their personal health history. Following this, the providers set expectations for the adolescents on what skills and information they will need to acquire as part of their transition. Providers should consider an individual approach for each adolescent to successfully meet these goals prior to the final transfer of care to an adult provider. The AAP recommends that adolescents transfer to an adult care provider by 22 years old.

In Step 4, the Got Transition Model states that adolescents must understand their roles and responsibilities in managing their own health and health care. Two of these critical responsibilities include being able to identify an adult provider and how to effectively communicate with him or her (AAP, 2014). Steps 3 and 4 may take several months to years to complete depending upon the development state of the adolescent and the timing of transfer from pediatric to adult care. Once the young adults finish the transition phases, they should be ready to transfer their care from pediatric to adult providers.

Step 5 of the Got Transition Model outlines the physical transfer of care and emphasizes that the young adults have an appointment scheduled with their new providers. In addition, the young adults should have completed and submitted all of the paperwork required by the new provider’s office.

The final step, Step 6, outlined in the Got Transition Model is to have follow-up appointments with the young adults to ensure they visited with, and talked to, their new providers to confirm they do not need any other further information (AAP, 2014).
**Modifications of the American Academy of Pediatrics’ Got Transition Model to Childhood, Adolescent, and Young Adult Cancer Survivors**

The student researcher created transition program guidelines based on the AAP Got Transition Model (AAP, 2014). The student researcher acknowledges that the AAP created this model for the use of chronically ill children, but perceives it as applicable to the childhood cancer survivor population even though the majority of survivors do not have complex chronic health problems as they age. The model applies to this population because many childhood cancer survivors are at risk for developing long-term chronic health problems from their cancer treatment. The student researcher applied the section of the AAP model called “youth to adult health care providers” which focuses on the transition of an adolescent to an adult provider following the six steps for best practices in transition (AAP, 2014, p.2) as outlined in Appendix A.

Using Step 1 of the Got Transition Model timeline, the student researcher developed transition guidelines for the Life After Cancer Childhood Cancer Survivorship Clinic (LACP). The student researcher deliberately did not use the work policy in this project due to the restrictive nature of policy development and the inability to hold providers accountable to such a policy. Instead, based on Step 2 of the Got Transition Model, the student researcher encouraged Cook Children Hospital Life After Cancer Team to use a documentation system that allows providers to articulate how they educated survivors, and enhance survivors’ readiness for transition to adult care (AAP, 2014).

The Cook Children Hospital Life After Cancer Team sees most childhood and adolescent cancer survivors annually after completion of cancer treatment. The transition process should
occur over a minimum of five to six years, and providers and staff will provide reinforcement of
the materials covered at each visit either every three to six months by phone or email.

In addition, the student researcher worked closely with the Life After Cancer Program
(LACP) staff to develop a tracking/documentation registry of survivors who have entered the
program. As suggested by the AAP, the education necessary for an improved transition will
probably need to occur at both the annual visit and in additional appointments. The student
researcher followed the AAP model (Steps 3-4) and created guidelines for what should be
included in the packet that allows the new adult care provider to gain a comprehensive
understanding of the cancer treatments and the risks the a specific survivor faces due to his or her
treatment (AAP, 2014). The last steps of the model (Steps 5-6) requires a follow-up that the
survivor has made the first appointment with the adult provider and communication with the
adult health provider to ensure a successful transfer of care. These steps will facilitate post-
transition follow-up appointments with patients and their providers to ensure they are receiving
the best quality care (AAP, 2014).

**Review of Literature**

The student researcher examined numerous databases in order to learn more about
improving the transition of care for pediatric oncology survivors to adult follow-up care. The
student used CINAHL, Medline, Ovid, ProQuest, Embase, Cochrane, Joan Briggs Institute, and
PubMed. The student researcher utilized the following search terms: *childhood cancer, child*,
*adult, provid*, *transition*, *surviv*, *cancer, neoplasm, program, coordin*, and *educ*. The
student researcher applied a combination of these search terms to identify the best evidence on
the transition of this population. For CINAHL, the student researcher used the search terms
*child* and *surviv* and *transition*, yielding 488 results; after restricting the search to published
material after 2013, the final yield was 237 results. For Medline Complete, the student researcher used the search terms *child* and *surviv* and *transition and adult*, which yielded 81 results. For Embase, the student researcher used the search terms *childhoods and cancer and surviv* and *transition*, resulting in 463 articles. For ProQuest, using the search terms *child* *cancer and surviv* and *transition* and *adult* yielded 13,944 results. In total, the student researcher’s initial search included 14,976 articles, while her supervising professor provided with additional articles. At the end of the search process, the student researcher used 20 articles to help create the evidence-based guidelines for young adult childhood cancer survivor’s transition to adult care providers.

Berg et al. (2016) conducted a qualitative descriptive study using phone interviews with pediatric oncology care providers in the southeast United States of America. In order to participate in the study, the providers had to have experience caring for childhood cancer survivors, ages 18 to 21, and had to work with childhood cancer survivors during their treatment or post treatment. The investigators recruited participants by emailing a description of the study to 30 providers in the university hospital system; 21 providers agreed to participate. The researchers categorized the data into primary codes (major ideas) and secondary (ideas within the big concepts) codes. The major themes identified by this group of survivors were “taking care of the whole survivor, education about late term effects, and helping survivors transition” (Berg et al., 2016). The researchers identified some structural issues, including the need to give survivors adequate education about their cancer history and the transition process, clear role identification for providers on the team, a system to communicate the transition progress, and the need for better insurance coverage for the survivors. The researchers also identified that there is a lack of time and resources to dedicate to transitioning survivors. Berg et al. (2016) stated a limitation of
the study was the small sample size since there were only 21 participants from the same facility, resulting in the lack of generalizability of the findings to all environments.

Coyne, Hallowell and Thompson (2016) completed an integrative review of the literature on patient outcomes following their formal transfer to adult care. The investigators facilitated the review of the literature in two segments. In the first segment, they searched CINAHL and OVID, which yielded 42 results. The second segment, which included a closer review of the literature identified, ensured the articles met the authors’ strict inclusion and exclusion requirements. Following these segments, the investigators had 19 articles. The authors also added three additional articles during the second part of the review. In total, the researchers used 22 articles for their integrative review of the literature (Coyne et al., 2016).

The articles were appraised with the Johns Hopkins Nursing Evidence-Based Practice Rating Scale (Dang & Dearholt, 2017). After appraising the articles, Coyne et al. (2016) pointed to a lack of research on the transition of care for survivors of childhood cancer. Many of the articles used non-disease-specific measures such as attendance at adult care provider appointments, satisfaction with the transition services provided, and young adults’ overall health related outcomes, including hospitalizations and their ability to independently care for themselves, to gauge the success of the transition to adult care. Several of the articles included in the integrative review of the literature evaluated the transition process one month following the formal transfer of care, and continued to follow up with the survivor every year for ten years after the transition.

Based on the review, Coyne et al. (2016) identified that studies have been void of adequate, standardized measurement of successful transition to adult care. Furthermore, they identified much variability in the health-related outcomes used to measure a successful transition...
of care from pediatric to adult care in both disease-specific transition and non-disease specific transition. Based on these findings, Coyne et al. (2016) suggested the need for a standardized, disease-specific transition model as well as an effective non-disease specific transition model.

Fredrick et al. (2017) published a qualitative research study using focus groups to elicit survivors’ suggestions on how to improve the transition process from pediatric to adult follow-up care. Participating survivors came from the Dana-Farber Institute of Cancer and The Next Step Childhood Cancer Survivor Clinics. All of the participants were under the age of 18 years when they were diagnosed with cancer and were between the ages of 21 and 39 years old at the time of the study. They also had to be cancer-free for at least a year prior to the study and able to speak English. The sample included 16 survivors with a mean age of 27.5 years and a mean age at diagnosis of 8.6. Of the 16 survivors, 8 were still receiving follow-up care from a pediatric provider and from their adult doctor. These investigators used semi-structured focus groups that followed the consolidated criteria for reporting qualitative research to assess survivors’ opinions and understanding of their late effects of cancer, access to follow-up care, transition to an adult provider and potential barriers, and the role of family and providers in the transition process.

The themes identified were, “education preferences, family role in transition, survivors expectations of providers, and knowledge deficits” (Frederick et al., 2017, p. 2). The childhood cancer survivors emphasized that their pediatric providers should begin the transition education early and educate them using several different methods. The survivors suggested that the pediatric care providers should help facilitate a connection between the survivor and the adult care provider to whom they will transition. The survivors stressed the importance that they needed to take the lead in their transition process instead of their parents. Lastly, survivors highlighted their lack of knowledge of their risk for long-term effects of their cancer treatment.
and overall knowledge of their cancer treatment. The primary limitation of the study was its small sample size (Frederick et al., 2017). The investigators also identified the need for additional research with pediatric cancer survivors in order to create the most successful transition program possible.

Survivors (≥ 18 years of age) who were diagnosed with cancer before the age of 21 and followed in the Young Adult Transition Clinic at Emory’s Winship Cancer Institute completed a survey on their survivorship care (Ganju et al., 2016). In order to participate, survivors must have been in the survivorship program and able to independently complete the survey. Of the 110 eligible participants, 93 (85%) completed the survey. All survivors completed a demographic questionnaire and a survey of questions assessing their involvement in long-term follow-up care and awareness of their risk for developing long-term effects as a result of their treatment history. The survivors also completed the Childhood Cancer Survivors Study Neurocognitive Questionnaire (NCQ) to assess how their cancer treatment affected their cognitive abilities (Krull et al., 2008). The authors created and tested the validity of the original version this questionnaire with 7,121 participants who had undergone cancer treatment. The updated version of the NCQ was used by Ganju et al. (2016). The investigators noted that survivors who had previously received survivorship care versus those who had not received survivorship care had an increased knowledge of their radiation history and the late effects of their cancer treatment (Ganju et al., 2016). Most of the survivors in the study struggled with remembering the specific chemotherapy agents used in their treatment; of the 89 participants who answered this question, only 22.5% knew the type of chemotherapy agents used during their treatment (Ganju et al., 2016). The limitations of the study include the small sample size and use of a single institution, so the findings cannot be generalized to other survivor centers.
Another study completed by Granek et al. (2012) examined the transition practices in two separate facilitates that had pediatric cancer survivorship programs. The researchers conducted qualitative interviews of survivors of childhood cancer aged 15 to 26 from the two pediatric cancer survivorship programs (Granek et al., 2012). One of the pediatric hospitals cares for survivors throughout the survivors’ adult life, while the other hospital transfers survivors to adult-focused care at age 18. The survivors in the study were either in the process of being transitioned, failed to be transitioned, or did not need to transition in the case of the hospital where their adult follow-up cancer care continued to be provided. All of the survivors transitioned to an adult follow-up cancer clinic instead of a primary care provider who covers cancer follow-up care.

Granek et al. (2012) conducted the interviews with 38 survivors and asked them about their cancer treatment experience and then used this as a way to discuss the barriers survivors faced when they left their pediatric care provider. The authors coded the interview data using an inductive approach, and the researchers continued to interview survivors until they reached thematic saturation.

The survivors stated one key barrier to them receiving follow-up care was their lack of knowledge concerning their cancer treatment history (Granek et al., 2012). The survivors’ emotional response when talking about their cancer history affected their successful transition to adult care. Furthermore, survivors who viewed their cancer experience as a dynamic part of their lives were more likely to be involved in the transition to adult care providers than were survivors who viewed cancer as not part of their lives. Survivors revealed that the fear of their cancer returning and being grateful that they survived motivated them to attend survivorship appointments, but for some survivors these fears resulted in non-attendance of follow-up
appointments. Granek et al. (2012) suggested that during the transition process, the pediatric oncology team should consider the psychological impact of leaving pediatrics to make the transition successful. The limitations of the study were that participants of the study were all formally transferred to cancer-focused follow-up programs rather than to primary care providers, and these findings may not be expanded to survivors who transferred to non-oncology-focused adult providers.

Pediatric oncologists completed a mailed survey intended to assess how they conduct transition care in their survivor programs and the challenges they face with transition of care for pediatric cancer survivors (Kenney et al., 2016). The researchers mailed surveys to 1,586 pediatric oncologists who work in oncology programs within the Children’s Oncology Group. After eliminating responses from providers who did not provide care to adolescent patients and surveys unsuccessfully delivered through email, only 347 participants remained. Researchers based the 23-item survey on the Boston Children’s Hospital cardiology transition model. The survey addressed the demographics of the providers, current transition practices, and barriers to transition; in addition, open-ended questions allowed for more in-depth information.

The researchers used content analysis to address the open-ended questions, and four themes emerged: “providers desired to have flexibility in the timeline of transferring a patient, survivor’s financial situation needs to be taken into account, provider’s lack of trust in adult care provider can make it difficult to transfer, the need for a system policy to transfer patients, and the need for more education on the difference between transfer and transition”. Many of the pediatric oncologists did not begin the transition program until the survivors were older than 16 years. The greatest barrier to transition was the emotional attachment between the survivors and their providers. The providers also reported the need for collaboration between the pediatric and adult
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providers during the transition process. The limitations noted by Kenney et al. (2016) were the low response rate to the survey and only targeting Children’s Oncology Group providers.

Childhood cancer survivors who are part of the tumor registry at Children’s Mercy Hospital and Clinics and the University of Kansas Cancer Center participated in a descriptive, mixed-methods study via mail distribution (McClellan et al., 2013). The researchers chose a mixed-method approach in order to encompass a more comprehensive picture of the survivors’ overall health and emotions toward the transition process. A total of 571 surveys were mailed, and the response rate was 48% (274/571). The survey consisted of 26 questions that focused on the long-term effects of cancer treatment and survivors’ general wellbeing related to their cancer history. Data analysis revealed the need for survivors to have increased access to their treatment summaries. Only 28% of participants received a treatment summary, and 32% of the participants could not remember if they were given a treatment summary. The investigators also stated the importance of recognizing that no two survivors are the same and that individual needs of each survivor should be considered during the transitions process. Two limitations of this study were that survivors did not complete all survey items and that response rate was only 50%.

Nandakumar et al. (2018) used a cross-sectional design to conduct semi-structured interviews of long-term cancer survivors from the 11 children’s hospitals in the Children’s Hematology/Oncology Group Survivorship Study in New Zealand and Australia. Mailed surveys were sent to 822 survivors/parents eliciting participant interest. To be eligible for the study, survivors had to be diagnosed with cancer at least five years prior, received treatment at one of the participating hospitals, speak English, and be in remission. For patients under the age of 16, the parent answered the interview questions, while children over the age of 16 answered the questions on their own. The researchers received 485 (59%) responses to the survey, and of
the 485 that responded to the survey 83 (17%) of the survivors/parents were willing to be interviewed. The researchers interviewed 15 parents of childhood cancer survivors and 18 survivors who were in the process of transition or who had already undergone formal transfer of care to an adult provider. Of the 33 survivors and parents interviewed, 18 survivors and parents rated their transition process as positive. Some survivors’ positive attitudes stemmed from being allowed to begin transition when they felt ready. Being empowered and confident in managing their own long-term follow-up were also reasons for survivors’ positive attitudes. The participants (24%) highlighted that effective communication between the previous health care provider and the new health care provider resulted in a successful transition. In addition, participants reported that receiving education about their treatment history at a younger age was important. The participants (18%) suggested a book or website to facilitate the transition. Following the formal transition of care, the participants reported that a follow-up phone call with the provider was beneficial in making the transition process smoother.

Communication and reliance on pediatric health care providers are challenges to a successful transition (Nandakumar et al., 2018). Participants (21%) in this study reported that lack of communication between the survivors’ pediatric care providers and adult care providers made it harder for them to feel comfortable leaving their pediatric providers. The survivors specified that they wanted to have a connection with their new provider and assurance that this provider would know their health history. The investigators discovered that several survivors and parents did not believe that adult care providers had enough knowledge in pediatric oncology to feel confident in managing the care of childhood cancer survivors. Also, the researchers recognized another challenge to transition was that survivors have always been viewed as special, and survivor’s fear they will not be treated the same after they are transferred to adult
care. Another challenge for 4 (24%) of survivors in this study were the cognitive deficits reported by the survivors due to their cancer treatment. The survivors with cognitive deficits suggested that a slow and long transition process would be helpful to allow them ample time for them to gain confidence and independence in their own health care. Limitations of the study were that participants self-reported their transition status. Nandakumar et al. (2018) stated more research needs to be conducted to validate these findings and to understand how survivors’ cognitive levels affect the success of their transition.

A descriptive survey study was conducted using online technology to examine the perceptions of transition services for childhood cancer survivors within a pediatric institution (Quillen, Bradley, & Calamaro, 2017). The validated online survey consisted of 17 questions (15 multiple choice; 2 open-ended questions) addressing the transition to adult care services provided by the institution. The inclusion criteria for this study were that survivors had to be between the ages of 20 to 25 years, able to speak English, already transferred to an adult care provider, with a history of cancer and access to a computer or smart phone, and able to independently complete the survey. Of the 79 eligible participants, 48 (61%) returned the survey. One theme that emerged from the study was the need for increased education of adult care providers about risks that survivors face due to their cancer history. Also, Quillen, Bradley, & Calamaro (2017) emphasized the importance of each survivor receiving a document about treatment history and late effects. The researchers suggested that the use of an App containing all of an individual survivor’s information would be helpful because most survivors are inclined to use technology. Some limitations of the study include a small sample size that was from one hospital and lack of racial/ethnic diversity in the sample.
Schwartz, Tuchman, Hobbie, and Ginsberg (2011) evaluated providers’ use of the Social-Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) model in order to further the research on how to successfully transition a childhood cancer survivor. The SMART model focuses on demographics, a survivor’s medical history and the interrelated aspects of a survivor’s life. The investigators noted that many survivors do not participate in follow-up care because they do not see the purpose when they are not experiencing any symptoms from their cancer treatment. The researchers also acknowledge the fact that survivors may also suffer from mental health problems, such as anxiety or depression, that make it difficult for them to engage in follow-up care. Schwartz et al. (2011) emphasized the need for providers and survivors to work together throughout the transition process. One of the key points of the article was the importance of a holistic transition program for survivors.

Svedlberg et al. (2016) performed a mixed-method cohort study with a convergent parallel design that focused on the impact of the support cancer survivors received during their transition process and the successful transfer to adult care. The authors sent out a questionnaire to all acute lymphoblastic leukemia survivors diagnosed from 1985 to 1997 in Sweden. The questionnaire had a Cronbach’s alpha of 0.864. Of 374 eligible survivors, 224 (60%) returned the questionnaire. The survivors had a mean age of 30 years and a mean age at diagnosis of 7 years. An almost even number of men and women participated in the study. The 13-item questionnaire had three parts. The first part focused on the survivors’ happiness with the care they received after they completed their cancer treatment, and the second part examined the health care providers’ role in their transition. The last part of the questionnaire asked open-ended questions for the survivors to describe their interactions with health care providers from treatment through survivorship follow-up care. Through the qualitative portion of the questionnaire, survivors
revealed that their knowledge of treatment history affected their successful communication with a primary care doctor.

Two studies reported that there is a need to educate adolescents about survivorship in the most developmentally appropriate method (Frederick et al., 2017; Svendlberg et al., 2016). Svendlberg et al. (2016) highlighted the mental health needs of childhood cancer survivors because many survivors reported that they suffered from mental health issues. A major theme identified by participants in this study was the need for an individualized holistic approach to the care of childhood cancer survivors when preparing them to transition.

Szalda et al. (2015) conducted a study among childhood cancer survivors treated at Children’s Hospital of Philadelphia. The inclusion criteria for this study included survivors who had transitioned to adult follow-up care in the last one to five years, who were over the age of 18, spoke English, and were able to independently complete the survey. The investigators identified 180 eligible participants, and 80 agreed to participate. The participants received a link via email to complete the survey. The survey included demographic items, questions about the participants’ post-transition care follow-up, attendance at other health care providers’ clinics (primary care), how frequently they discussed their cancer history with their primary care provider, and whether their cancer follow-up care needs were being met. A third party confirmed the cancer diagnoses and treatment of the participants’ cancer. The participants were aged 23 to 36 years, and 90% were Caucasian. Of the 80 participants, 44 received cancer-specific follow-up care in the last 12 months. Of the survivors who received cancer-specific follow-up in the past 12 months, 50% of them received follow-up care from primary care providers.

There were no reported differences between participants who attended primary care providers or cancer-specific adult providers on whether cancer-related topics were discussed.
The cancer-specific adult providers offered more education over the late effects and risks of cancer treatments. Also, there was not a significant difference in survivors’ views of providers’ competence with cancer follow-up care. Szalda et al. (2015) found that survivors believed that a formal transfer from pediatric follow-up care to an adult primary care provider might lead to a more successful transition. The limitation of the study was that the patients self-reported the data.

**Synthesis of the Literature**

Fredrick et al. (2017) and Svedberg et al. (2016) concluded that proper education is needed to successfully transition childhood cancer survivors from pediatric to adult care providers. Fredrick et al. (2017) stated that survivors should be the driving force of the transition, a viewpoint similarly reported by Svendlberg et al. (2016). These authors reported that transition education should be focused on the survivor instead of the parents. McClellan et al. (2013) reported that there needs to be increased education about the late effects of cancer treatment, which was also supported by Ganju et al. (2016); survivors who had received education about their risk of late effects from their cancer treatments and who received a copy of their treatment history had increased knowledge of their risks once they transferred to adult care.

McClellan et al. (2013) and Svendlberg et al. (2016) stated that the transition process should be individualized to the survivor, which aligns with reports by Schwartz, Tuchman, Hobbie, and Ginsberg (2011), Berg et al. (2016), and Granek et al. (2012), all of whom agree that it is important to include the psychosocial aspects of survivors’ previous cancer diagnosis in the transition process. Granek et al. (2012) further reported that survivors’ negative emotions or indifference toward their cancer experience could influence whether survivors are able to transition successfully. Schwartz et al. (2011) confirmed that survivors with a lack of emotions toward the transition of care to adult providers have less motivation to move on. Nandakumar et
al. (2018) and Kenney et al. (2016) reported that survivors want to feel special and that they have built bonds with their pediatric care team. Kenney et al. (2016) and Quillen, Bradley, & Calamaro (2017) also stated that it is important for the pediatric providers to communicate effectively with the new adult care provider about the survivor’s history, which might help with the patient still feeling important. Coyne, Hallowell and Thompson (2016) found that it helps to have a transition policy in place, which is not feasible for this project, but it is possible to use the concept proposed by Szalda et al. (2015) of having a formal date to transfer to adult care.

Following an extensive review and synthesis of the research results, the student researcher has identified critical components that need to be included in the guidelines. These components include effective communication from pediatric provider to the survivor and then to the new health care provider and the entire transition team. Effective communication may be met through appropriate education for all parties and should include the psychosocial concerns and emotional impact of the cancer experience of the survivors.

Several gaps addressed in the review of the literature were the challenges of applying the evidence to a wide spectrum of survivors with varying diagnoses and those experiencing significant neurocognitive deficits. The student researcher used the information collected from the review of the literature to help facilitate the creation of the guidelines. The literature evaluated as part of this evidence review was completed using the Johns Hopkins Evidence-Based Practice Appraisal Tool (Dang & Dearholt, 2017), as outlined in Appendix B.

**Methods**

**Design**

This project represents guidelines development to improve the transition of young adult childhood cancer survivors to adult care.
Guidelines Development

The student researcher used the AAP transition algorithm as a model with modifications in order to guide the formation of department-specific transition guidelines for the Cook Children’s Health Care System (CCHCS), Hematology / Oncology Program, Life After Cancer Program (See Appendix C).

The following steps represent an outline of transition guidelines:

- Steps 1-2 of the guidelines represent the transition policy (guideline) within the Hematology and Oncology Department to assure all providers, staff, and survivors are aware of the guidelines, the transition process flow, and the need to assess the survivor transition readiness.

- Step 2 includes the development of a registry to document the transition process and keep records of survivors following their actual transfer of care to assure follow-up. Currently, the CCHCS has a hospital-wide transition committee that is developing a transition readiness flow sheet and mechanism to maintain a registry of patients who have undergone transition services.

As part of the guidelines, the student researcher revised and improved a transition workbook that had been used in a pilot study to facilitate the successful completion of steps 3 through 5 of the modified AAP model. The transition workbook will be implemented starting at age 14 as recommended by the AAP, or two years following the end of the adolescent’s cancer treatment (Cooley & Sagerman, 2011). The workbook begins with a questionnaire that addresses what the survivors already know and what they need to learn (AAP, 2014; see Appendix D). The student researcher organized the workbook into several sections that are specific to Steps 3-5 of the AAP transition model.
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- Section 1 of the workbook (*My Health*) addresses knowledge of the survivor about the cancer diagnosis and treatment and the anticipated time for transition to adult care (Child Nephrology Foundation, 2017). Also, this section includes the survivor’s current medications and a summary of cancer treatment history. In addition, the section includes steps to take in case of an emergency (Cooley & Sagerman, 2011).

- Section 2 (*Taking Ownership*) of the workbook focuses on strategies for communication with an adult provider, responsibilities that come with adulthood, mental health information as suggested by Svendlberg et al. (2016), and information about insurance. The concepts include how to schedule an appointment, what to do on arrival, and how to advocate for oneself in the adult health care system. At this point in the workbook the survivor will identify a possible adult care provider.

- Section 3 (*Personal Life*) of the workbook includes information about requesting accommodations at school and/or work. Also, this section includes life planning and how to use community support.

**Transition Procedures**

After assessing the survivors at the onset of the transition process (age 12 years or at least two years from the end of cancer therapy), the LACP team will inform survivors and their families of the Cook Children’s Health Care System Hematology / Oncology Program transition guidelines and their child’s expected date of transfer of care. If the providers are not already addressing their questions to the survivors, they should begin to query adolescents about their readiness to transition. The providers should continue to remind the family about the transition
guidelines at subsequent visits until age 14 or two years of therapy when the formal transition process begins.

At the age of 14 or two years of therapy, the providers will begin the formal transition process by reminding the survivors and families of guidelines and goal transfer of care date and assessing survivors’ transition readiness by questionnaire. The providers will give survivors a workbook that is modified to their needs based on findings from the transition readiness questionnaire. This workbook will be completed by the survivors and their families with assistance by the LACP providers; ideally, completion of the workbook will facilitate the transition process.

From age 14 to 26 years old, LACP providers will continue to educate survivors about their cancer history and risks for late effects of their cancer treatment; in addition, providers will address questions survivors and their families may have related to survivorship. The education will include information about health, self-care and wellness, and communication with an adult care provider. Also, the provider should ensure that the survivors are leading the transition appointments, not the parent.

By age 28, the patient will be formally transferred to an adult care provider. The LACP team will assist survivors in finding a primary care provider (PCP) if appropriate. The LACP team will follow up with the survivor and their new PCP to make sure there are not additional questions or information needed. The transition guidelines’ effectiveness will also be evaluated by a member of the pediatric health care team who will communicate with survivors at six months and again at 12 months post-transfer of care to ensure the survivors have an adult care provider and are satisfied with the care they are receiving (AAP, 2014; see Appendix E). The
survivorship team will make every effort to ensure communication and consultation with the adult health care provider and survivors in an ongoing basis.

Conclusion

These guidelines for transitioning pediatric cancer survivors are timely and valuable; the student researcher found a gap in the literature related to the number of resources and support survivors receive as they transition to adult care and upon the final transfer of care to adult providers. The student researcher addressed the lack of communication between providers and the need for support and education for survivors through the guidelines. The evidence-based transition guidelines are expected to facilitate the successful transition and ultimate transfer of care to the adult health care system.
References


Retrieved from http://lup.lub.lu.se/record/8853034

Appendix A

**Figure 1. American Academy of Pediatrics 6-Step Transition Model**

**Side-by-Side Version**

### Six Core Elements of Health Care Transition 2.0

<table>
<thead>
<tr>
<th>Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)</th>
<th>Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)</th>
<th>Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Transition Policy</strong></td>
<td><strong>1. Transition Policy</strong></td>
<td><strong>1. Young Adult Transition and Care Policy</strong></td>
</tr>
<tr>
<td>• Develop a transition policy/statement with input from youth and families that describes the provider’s approach to transition, including privacy and consent information.</td>
<td>• Develop a transition policy/statement with input from youth/young adults and families that describes the provider’s approach to transition, including privacy and consent information.</td>
<td>• Develop a transition policy/statement with input from young adults that describes the provider’s approach to transition, including privacy and consent information.</td>
</tr>
<tr>
<td>• Educate all staff about the provider’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the youth, family, and pediatric and adult health care teams in the transition process, taking into account cultural preferences.</td>
<td>• Educate all staff about the provider’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences.</td>
<td>• Educate all staff about the provider’s approach to transition, the policy/statement, the Six Core Elements, and distinct roles of the youth, family, and pediatric and adult health care teams in the transition process, taking into account cultural preferences.</td>
</tr>
<tr>
<td>• Post policy and share/discuss with youth and families beginning at age 12 to 14, and regularly review as part of ongoing care.</td>
<td>• Post policy and share/discuss with youth and families beginning at age 12 to 14, and regularly review as part of ongoing care.</td>
<td>• Post policy and share/discuss with youth and families at first visit and regularly review as part of ongoing care.</td>
</tr>
<tr>
<td><strong>2. Transition Tracking and Monitoring</strong></td>
<td><strong>2. Transition Tracking and Monitoring</strong></td>
<td><strong>2. Young Adult Tracking and Monitoring</strong></td>
</tr>
<tr>
<td>• Establish criteria and processes for identifying transitioning youth and enter their data into a registry.</td>
<td>• Establish criteria and processes for identifying transitioning youth/young adults and enter their data into a registry.</td>
<td>• Establish criteria and processes for identifying transitioning young adults until age 26 and enter their data into a registry.</td>
</tr>
<tr>
<td>• Utilize individual flow sheet or registry to track youth/young adult’s transition progress with the Six Core Elements.</td>
<td>• Utilize individual flow sheet or registry to track youth/young adults’ transition progress with the Six Core Elements.</td>
<td>• Utilize individual flow sheet or registry to track young adults’ completion of the Six Core Elements.</td>
</tr>
<tr>
<td>• Incorporate the Six Core Elements into clinical care process, using EHR if possible.</td>
<td>• Incorporate the Six Core Elements into clinical care process, using EHR if possible.</td>
<td>• Incorporate the Six Core Elements into clinical care process, using EHR if possible.</td>
</tr>
<tr>
<td><strong>3. Transition Readiness</strong></td>
<td><strong>3. Transition Readiness</strong></td>
<td><strong>3. Transition Readiness/Orientation to Adult Practice</strong></td>
</tr>
<tr>
<td>• Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.</td>
<td>• Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.</td>
<td>• Identify and list adult providers within your practice interested in caring for young adults.</td>
</tr>
<tr>
<td>• Jointly develop and prioritize actions with youth and parent/caregiver, and document regularly in a plan of care.</td>
<td>• Jointly develop and prioritize actions with youth and parent/caregiver, and document regularly in a plan of care.</td>
<td>• Establish a process to welcome and orient new young adults into practice, including a description of available services.</td>
</tr>
<tr>
<td><strong>Notes:</strong></td>
<td><strong>Notes:</strong></td>
<td><strong>Notes:</strong></td>
</tr>
</tbody>
</table>
### Guidelines for a Successful Transition

#### Side-by-Side Version (continued)

<table>
<thead>
<tr>
<th>Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)</th>
<th>Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)</th>
<th>Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>4. Transition Planning</strong></td>
<td>Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan and, if needed, a condition fact sheet and legal documents.</td>
<td>Communicate with young adult’s primary pediatric provider(s) and arrange for consultation assistance, as needed.</td>
</tr>
<tr>
<td>• Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan.</td>
<td>• Prepare youth and parent/caregiver for optimal timing of transfer if both primary and subspecialty care are involved, discuss optimal timing for each.</td>
<td>• Prior to first visit, ensure receipt of transfer package (transition readiness assessment plan of care with transition goals and pending actions, medical summary and emergency care plan, and legal documents, condition fact sheet, and additional provider records).</td>
</tr>
<tr>
<td>• Prepare youth and parent/caregiver for optimal timing of transfer if both primary and subspecialty care are involved, discuss optimal timing for each.</td>
<td>• Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.</td>
<td>• Make pre-visit appointment reminder call/see how new young adult and identifying any special needs and preferences.</td>
</tr>
<tr>
<td>• Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.</td>
<td>• Plan with youth/parent/caregiver for optimal timing of transfer if both primary and subspecialty care are involved.</td>
<td>• Provide key to professional resources, self-care management information, and culturally appropriate community supports.</td>
</tr>
<tr>
<td>• Plan with youth/parent/caregiver for optimal timing of transfer if both primary and subspecialty care are involved.</td>
<td>• Obtain consent from youth/parent/caregiver for release of medical information.</td>
<td>• Provide linkage to insurance resources, self-care management information, and culturally appropriate community supports.</td>
</tr>
<tr>
<td>• Obtain consent from youth/parent/caregiver for release of medical information.</td>
<td>• Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.</td>
<td>• Provide linkage to insurance resources, self-care management information, and culturally appropriate community supports.</td>
</tr>
<tr>
<td>• Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.</td>
<td>• Provide information on insurance resources, self-care management information, and culturally appropriate community supports.</td>
<td><strong>5. Transfer of Care</strong></td>
</tr>
<tr>
<td><strong>5. Transfer of Care</strong></td>
<td><strong>6. Transfer Completion</strong></td>
<td><strong>6. Transfer Completion/Ongoing Care</strong></td>
</tr>
<tr>
<td>• Confirm date of first adult provider appointment.</td>
<td>• Contact young adult and parent/caregiver 1 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and seek feedback on experience with transition process.</td>
<td>• Communicate with pediatric practice confirming transfer and other consultation assistance, as needed.</td>
</tr>
<tr>
<td>• Transfer young adult when his/her condition is stable.</td>
<td>• Communicate with adult practice confirming completion of transfer and other consultation assistance, as needed.</td>
<td>• Continue with ongoing care management tailored to each young adult.</td>
</tr>
<tr>
<td>• Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan and, if needed, legal documents, condition fact sheet, and additional provider records.</td>
<td>• Build ongoing collaborative partnerships with pediatric primary and specialty care providers.</td>
<td>• Elect feedback from young adult to assess experience with adult health care.</td>
</tr>
<tr>
<td>• Prepare letter with transfer package, send to adult practice, and confirm adult practice’s receipt of transfer package.</td>
<td>• Confirm with adult provider the pediatric provider’s responsibility for care until young adult is seen in adult setting.</td>
<td>• Build ongoing collaborative partnerships with specialty care providers.</td>
</tr>
<tr>
<td>• Confirm with adult provider the pediatric provider’s responsibility for care until young adult is seen in adult setting.</td>
<td><strong>5. Transfer to Adult Approach to Care</strong></td>
<td><strong>5. Transfer to Adult Approach to Care</strong></td>
</tr>
<tr>
<td>• Address any concerns that young adult has about transferring to adult approach to care.</td>
<td><strong>6. Transfer Completion/Ongoing Care</strong></td>
<td>• Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed.</td>
</tr>
<tr>
<td>• Clarify adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.</td>
<td>• Assist young adult to connect with adult specialists and other support services, as needed.</td>
<td>• Assist young adult to connect with adult specialists and other support services, as needed.</td>
</tr>
<tr>
<td>• Conduct self-care assessment (transition readiness assessment); if not recently completed and discuss needed self-care skills.</td>
<td>• Review young adult’s health priorities as part of ongoing plan of care.</td>
<td>• Continue with ongoing care management tailored to each young adult.</td>
</tr>
<tr>
<td>• Review young adult’s health priorities as part of ongoing plan of care.</td>
<td>• Continue to update and share portable medical summary and emergency care plan.</td>
<td>• Elect feedback from young adult to assess experience with adult health care.</td>
</tr>
<tr>
<td>• Update and share portable medical summary and emergency care plan.</td>
<td><strong>6. Transfer Completion/Ongoing Care</strong></td>
<td>• Build ongoing collaborative partnerships with pediatric primary and specialty care providers.</td>
</tr>
</tbody>
</table>
### Appendix B

#### Table I

**Appraisal of the literature**

<table>
<thead>
<tr>
<th>Author and Year</th>
<th>Type of Evidence</th>
<th>Strength of Evidence</th>
<th>Quality of Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berg et al. (2016)</td>
<td>Qualitative, Descriptive</td>
<td>Level III</td>
<td>Good Quality</td>
</tr>
<tr>
<td>Coyne, Hallowell and Thompson (2016)</td>
<td>Integrative Review of Literature</td>
<td>Level V</td>
<td>Good Quality</td>
</tr>
<tr>
<td>Fredrick et al. (2017)</td>
<td>Qualitative</td>
<td>Level III</td>
<td>High Quality</td>
</tr>
<tr>
<td>Ganju et al. (2016)</td>
<td>Descriptive</td>
<td>Level III</td>
<td>High Quality</td>
</tr>
<tr>
<td>Granek et al. (2012)</td>
<td>Qualitative</td>
<td>Level III</td>
<td>Good Quality</td>
</tr>
<tr>
<td>Kenney et al. (2016)</td>
<td>Descriptive</td>
<td>Level III</td>
<td>Good Quality</td>
</tr>
<tr>
<td>McClellan et al. (2013)</td>
<td>Descriptive, mixed methods</td>
<td>Level III</td>
<td>Good Quality</td>
</tr>
<tr>
<td>Nandakumar et al. (2018)</td>
<td>Qualitative data</td>
<td>Level III</td>
<td>High Quality</td>
</tr>
<tr>
<td>Quillen, Bradley, &amp; Calamaro (2017)</td>
<td>Qualitative</td>
<td>Level III</td>
<td></td>
</tr>
<tr>
<td>Schwartz, Tuchman, Hobbie and Ginsberg (2011)</td>
<td>Descriptive</td>
<td>Level III</td>
<td>High Quality</td>
</tr>
<tr>
<td>Svedlberg et al. (2016)</td>
<td>Mixed Methods and Cohort Study</td>
<td>Level III</td>
<td>Good Quality</td>
</tr>
<tr>
<td>Szalda et al. (2015)</td>
<td>Qualitative</td>
<td>Level III</td>
<td>Good Quality</td>
</tr>
</tbody>
</table>
Algorithm for Hematology and Oncology Program transition policy

<table>
<thead>
<tr>
<th>Algorithm</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Begin the transition discussion at age 12 or two years off treatment</td>
<td>1) This is the step where the provider introduces the transition policy, but the actual transition does not begin until age 14.</td>
</tr>
<tr>
<td>At age 14 or two years of treatment the actual transition planning should begin.</td>
<td>2) This has been determined as the appropriate time by the AAP. The goal is to have all young adults transitioned by age 28.</td>
</tr>
<tr>
<td>Step 1: Tell the survivor and the guardian (if applicable) about the department transition policy.</td>
<td>3a) The department needs a policy that clearly states the expectations of the providers and of the survivors. This also includes the expected age of transition for the survivor.</td>
</tr>
<tr>
<td>Step 2: Requirement successful completion of step 1. The provider will create a transition plan modified to fit the survivor’s needs.</td>
<td>3b) This includes how the transition will be completed. The workbook will be the standardized tool used, but it will be adapted to fit survivor’s specific needs. Also, the provider will start the registry of the survivor’s transition progress at this step.</td>
</tr>
<tr>
<td>Step 3: Must complete steps 1 and 2. Provider reviews and modifies transition plan based on survivor’s progression.</td>
<td>3c) The provider constantly needs to be monitoring and tracking the survivors transition readiness through the use of documentation. If a survivor fails to complete a step, the provider will address and work on solving the problem.</td>
</tr>
<tr>
<td>Step 4: Need to complete all prior steps, then implementation of the adult health care model.</td>
<td>3d) The provider needs to give the adult primary care doctor and the survivor all the necessary medical records. Also, the provider will engage in a conversation with the adult care provider over any special medical needs if applicable.</td>
</tr>
</tbody>
</table>
## Appendix D

### Transition Readiness Tool

<table>
<thead>
<tr>
<th>My Health</th>
<th>Yes</th>
<th>No</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know your cancer history?</td>
<td>I always do this</td>
<td>I am learning how to do this</td>
<td>I don't need to do this</td>
</tr>
<tr>
<td>Do you have a copy of your cancer treatment summary?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can you EXPLAIN and have you SHARED your long term survivorship needs to your primary care provider?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can you identify symptoms that need medical attention?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can you list your medications, what they are for, when they need to be taken, and how to refill your medications?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you know that starting age of 18 we are not allowed to speak to your parents without your permission?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Taking Ownership

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a primary care provider?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you know how to make your own doctor appointments: PCP, Dental, Specialists?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you communicate your medical history, allergies, medications, and concerns (emotional/mental) to the doctor?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you know how to contact your insurance company; and are you aware of what your insurance covers?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a plan to keep health insurance after age 18</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Personal Life

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you request accommodation and support you need at school or work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a post graduation plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you know how to apply for a job</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you know how to get financial help with school or work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you use your community support services if you need them (such as emotional or mental health needs)?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Assessment answers provided by:
Appendix E

Guidelines for Transitioning to Adult Care

Step 1: Evaluation (age 12 or two years off therapy)

- Process begins at either 12 years of age or 2 years off therapy
- Evaluate the socioeconomic factors that might affect the ability for someone to transition to adult care. If applicable, involve social worker about possible options so that the survivor will still get health care after the age 18 or 26
- Evaluate the cognitive level of survivor and see if they are independent or if you will be focusing on educating the parents on how to transition.
- Document survivor in the transition registry

Step 2: Inform (age 12 or two years off therapy)

- Inform the family over the transition guidelines
- If not already doing, start asking questions directly to the survivor instead of the parents and encourage parents to allow survivor to answer the question
- Tell the family the expected date of transition to adult care
- For survivors that are 12 at every appointment until age 14 keep on reminding the survivor and their family about the policy and educate them that the actual transition program will not start until age 14

Step 3: Start the process (age 14 or two years off therapy at appointments)

- Remind the survivor of the guidelines and their goal transition date
- Give the survivor the transition workbook and go over briefly each section and the importance of bringing it to each meeting (*Make sure you are speaking to the survivor not the patient*)
- Modify transition workbook and guidelines to fit survivors needs
  - For example survivor is knowledgeable about cancer history may not need to complete that workbook section
- Activate text reminders in EPIC to be sent out to the survivor’s cell phone to bring the workbook the day before and the day off the visit
- Do the transition questionnaire with the survivor to find areas of weakness related to history of cancer.
- Educate survivor over area of weaknesses found through the questionnaire
- Inform the survivor the importance of taking control of their health care and the differences when they turn 18 years old
- Assess survivor’s emotions over the transition process and their expectations each visit
Between appointments: Survivors should be encouraged to attend transition workshops, provider should call survivor to go over information that they struggled with at the last appointment and assess the retention of information they learned at the last appointment.

- Possible educational videos sent if appropriate for situation

Step 4: Continue to educate (age 14 or two years off therapy to age 28)

- Assess survivors using the questionnaire in EPIC at each visit and continue to address areas of weakness.
- If the survivor continues to have a specific area of weakness give additional resources to help them retain the information
- Go through the assigned workbook section for the visit and address any questions or concerns the survivor has
- At age 16 or when provider deems appropriate: Provide education over how insurance works and if applicable help them understand how to get insurance for themselves
- Educate the survivor on how to talk to an adult care provider
- Make sure the survivors are leading the appointment not the parents

Step 5: The Transition (Age 26 to 28)

- Help survivor identify an adult care provider if they need help
- Make sure they have scheduled an appointment with the doctor
- Follow up after the scheduled appointment to see how it went and if they have any questions or concerns
- Call the adult care providers office to see if they need any additional information or support after the visit
- Step in EPIC for a reminder to pop up to call survivor 6 months after transition to assess if it was successful
- Text a short post transition questionnaire in order to evaluate the success of the program