



Published in final edited form as:

*Pediatr Blood Cancer*. 2017 November ; 64(11): . doi:10.1002/pbc.26587.

## Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative study of survivorship providers

Karim Thomas Sadak<sup>1</sup>, Joseph P. Neglia<sup>1</sup>, David R. Freyer<sup>2,3</sup>, Eileen Harwood<sup>4</sup>

<sup>1</sup>University of Minnesota Masonic Children's Hospital, University of Minnesota Masonic Cancer Center, Minneapolis, Minnesota

<sup>2</sup>Children's Center for Cancer and Blood Diseases, Children's Hospital Los Angeles, Los Angeles, California

<sup>3</sup>Division of Hematology, Oncology and Blood and Marrow Transplantation, Department of Pediatrics, Keck School of Medicine, University of Southern California, Los Angeles, California

<sup>4</sup>Division of Epidemiology & Community Health, University of Minnesota School of Public Health, Minneapolis, Minnesota

### Abstract

**Background**—Long-term survival in childhood cancer is excellent. Most survivors will have a therapy-related chronic condition, yet very few receive survivor-focused care as they transition from adolescence to young adulthood. The purpose of this study is to identify indicators of success in current transitional care practices for young adult survivors of childhood cancer as defined by all members of survivorship care teams.

**Procedure**—An exploratory, phenomenologic qualitative study was conducted with key informants from medical teams involved in transitional care of childhood cancer survivors. Data were collected through phone interviews with providers from both pediatric and adult care settings.

**Results**—A multidisciplinary study sample of 29 participants from three institutions identified two major themes with multiple subthemes. The first major theme was that providers must be good communicators, and it emphasized the importance of having good relationships throughout the transition of care to optimize effective communication. The second major theme was that models of care must include well-established partners throughout the healthcare system that promote accessible subspecialty care with streamlined referrals and patient navigation services.

**Conclusions**—From the perspective of experienced pediatric- and adult-centered providers at three different institutions delivering life-long transitional care for childhood cancer survivors, the

---

**Correspondence** Karim Thomas Sadak, University of Minnesota Masonic Children's Hospital, University of Minnesota Masonic Cancer Center, 420 Delaware St., SE Mayo MMC 484, Minneapolis, MN 55455. ktsadak@umn.edu.

#### CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

#### SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

optimal model of care must be built around facilitating communication among all key stakeholders and emphasizing patient-friendly services that minimize patient stressors.

### Keywords

qualitative; survivor; transition

## 1 | INTRODUCTION

The 5-year survival rate for childhood cancer in the United States is 84.7%, with an estimated 388,501 survivors of childhood cancer alive in the United States.<sup>1,2</sup> More than 60% of the survivors will have a therapy-related chronic condition (late effect) and almost 30% will suffer from a severe and life-threatening late effect.<sup>3</sup> As young adults, 87% of childhood cancer survivors report general contact with medical care, but only 41.9% report a cancer-related visit and 19.2% a visit at a cancer center.<sup>4</sup> This suggests that most survivors are receiving care outside of childhood cancer survivor programs (CSPs). This poses a significant public health challenge, as only 31.5% of childhood cancer survivors report receiving care that focuses on their prior cancer and only 17.5% report receiving survivor-focused care that includes advice about risk reduction or discussion or ordering of screening tests.<sup>5</sup> This challenge is further amplified by the fact that this high-risk population is aging and growing.<sup>2</sup>

Health services research has begun to examine the models of care for childhood cancer survivors, particularly models that ensure the continuation of survivor-focused care as patients age out of the pediatric healthcare system.<sup>6–8</sup> This continuity of care is critical, as the risk of developing late effects increases with age, warranting the need for life-long survivor-focused care, including the transition of such care from pediatric to adult models.<sup>2,9</sup> However, little is known on how to best deliver survivorship care for the transition from pediatric- to adult-centered care (transitional care). This is especially true, as the success and delivery of survivor-focused care across the age continuum is highly variable across centers.<sup>10–14</sup>

Transitional care of childhood cancer survivors has been generally defined as an “active, planned, coordinated, comprehensive, multidisciplinary process to enable childhood and adolescent cancer survivors to effectively and harmoniously transfer from child-centered to adult-oriented healthcare systems.”<sup>15</sup> This definition highlights several potential obstacles to a successful transition. Many of these challenges relate to the stakeholders most intimately involved in the transition process.<sup>6</sup> For example, adult healthcare providers are often unfamiliar with the problems of adult survivors of childhood cancer and survivors are unaware of their potential risks.<sup>16</sup> There are also problems at the level of the healthcare system that may obstruct a successful transition of care such as institutional and insurance-related age restrictions for delivery and receipt of care.<sup>17</sup>

As additional research is needed in this area, a comprehensive, empirically validated socioecologic framework for cancer survivorship transition research and clinical care is in development and offers great promise.<sup>18,19</sup> Ultimately, the ideal model of transitional care for childhood cancer survivors will address the needs of survivors, parents, and providers,

but very little is known about the care preferences of these key stakeholders.<sup>20–23</sup> The purpose of this exploratory study is to identify indicators of success in current transitional care practices for young adult survivors of childhood cancer as reported by interdisciplinary members of survivorship care teams.

## 2 | METHODS

### 2.1 | Study design

A phenomenologic qualitative study was conducted with key informants from medical teams involved in the transitional care of childhood cancer survivors. Phenomenologic studies are characterized by particular experiences or events serving as the “phenomenon” of interest. In phenomenologic qualitative research, people serve as informants who subjectively describe an experience or event. Participants for such studies are selected because they are uniquely positioned to describe the events, which in this case is the transition of childhood cancer survivor care from the pediatric to adult care settings.<sup>24–26</sup>

### 2.2 | Sampling design

Purposeful sampling began with the identification of eligible US institutions meeting particular criteria: (1) having a long-standing childhood CSP and (2) a clear protocol for transitioning patients from pediatric to adult-focused care. The study team identified nine such institutions after reviewing a comprehensive list of medical centers on the Children’s Oncology Group Web site and excluding the centers represented by the authors. All were large urban academic healthcare institutions with National Cancer Institute (NCI) designated cancer centers. Using direct recruitment through communication with program directors, we invited three institutions to participate, which collectively represented the most broad and multidisciplinary sample. All the three institutions accepted and participated in the study.

Key informants were selected purposefully within each participating institution’s childhood CSP. Any member of the care team who had direct or indirect contact with survivors and/or their family before, during or after the transition to adult-centered care was eligible. Eligible team members included physicians, nurse practitioners, nurse coordinators, research nurses/assistants, schedulers, social workers, and psychologists. Program leaders at each institution provided contact information for a total of 29 individuals who were contacted by the study team to recruit and set up individual phone interviews. The desired sample size was 25 per standard phenomenologic requirements to achieve informational redundancy and theoretical saturation of the desired content.<sup>27</sup> The final sample size reached 29 providers within 9 weeks, which represented all eligible participants.

### 2.3 | Measures

A priori, transition was defined as the change over time from a pediatric model of care to an adult model of care where survivors are transferred outside the pediatric-centered program or setting for their cancer-related follow-up care. The interview script (Supplementary Table S1) was designed to elicit spontaneous narrative that considered various perspectives when assessing transition success. For example, a nurse educator may feel the transition is most successful when a survivor meets particular educational milestones, while a social worker

may prioritize components of psychosocial self-efficacy skill development. Varying perspectives were expected to overlap and differ while ultimately yielding a more detailed and comprehensive understanding of the process of a successful transition.

## 2.4 | Data collection

Narrative and short-answer data were collected through semistructured phone interviews. Participants were informed that the interview was being recorded and all data would be presented anonymously and in aggregate. An experienced health sciences qualitative interviewer conducted all interviews that ranged from 30 to 60 min. The interview schedule (Supplementary Table S1) was created to elicit information from participants on how they define a successful transition of survivorship care from the perspective of (1) the medical team, (2) the survivor, and (3) the survivor's parent. An example of how topics and perspectives were introduced in the interview is as follows: "Thinking about your experience working with adolescent and young adult (AYA) survivors of childhood cancer, how would you describe what someone from the medical team sees as a successful transition?" Prompts were included in the script to help the interviewer ensure that all pertinent perspectives and topics were covered.

De-identified interviews were digitally recorded and professionally transcribed to provide the data source for the analysis. Demographic information, aside from profession, was not collected from participants to help ensure anonymity due to the small sample size of participating centers.

## 2.5 | Analysis

Principles of directed content analysis (DCA) were used to identify major themes.<sup>28</sup> A DCA approach was selected because the goal was to extend the existing knowledge and conceptual theories on this topic.<sup>28</sup> Initial codes were drawn from an exhaustive review of relevant published literature and informal discussions with clinician researchers with content expertise and relevant clinical experience. This process ultimately influenced the initial coding scheme through a deductive category application.<sup>29</sup> Transcripts were reviewed on a rolling basis to adjust the interview script, as needed, to delve deeper into emerging themes and new directions to explore. The first author read and coded each key informant transcript and met periodically with the study team to discuss expected and evolving themes, codes, interpretations, and quotes to come to an agreement about theme labels, concepts, and relationships as the analysis moved forward and concluded. In addition, we evaluated thematic patterns for similarities and differences between participants that further refined coding and the development of themes.

We used NVivo 9.0 software to organize transcribed data for analysis. The University of Minnesota Institutional Review Board: Human Subjects Committee approved this study.

## 3 | RESULTS

### 3.1 | Informants

The study sample included 29 key informants from three medical centers located in large urban cities within the Mid-Atlantic, North-east, and Midwest regions of the United States. All were part of large academic institutions with NCI designated cancer centers where pediatric and adult facilities were located on the same campus. At these centers, childhood cancer survivors receive care from pediatric- and adult-centered survivorship providers in age-appropriate care settings. Participants represented a convenience sample selected by each program director of physicians (n = 10), nurse practitioners (n = 8), nurses (n = 6), psychologists (n = 2), a social worker, a dietician, and an appointment scheduler. Fifty-five percent (19/29) of the 29 providers interviewed were from pediatric teams; 41% (12/29) were from adult teams; and 2 informants represented both teams. These two participants (a physician and a dietician) provided care to survivors through both pediatric- and adult-centered programs.

### 3.2 | Themes

Informants offered their opinions on how a successful transition from pediatric- to adult-centered care might be defined from three perspectives: the provider, the survivor, and the parent of a survivor. Data analysis resulted in two major themes as described in Table 1.

**Theme 1: Providers must be good communicators**—From all three perspectives, informants described sound relationships as important in ensuring successful transitions of survivorship care that extends to obvious communications between survivors, their parents, and providers (Subtheme 1) and less obvious communications between pediatric- and adult-centered providers and their care teams (Subtheme 2). This was highlighted by repeated examples of the importance of (1) clear and developmentally appropriate communication between provider and survivor and its impact on the delivery of critical educational messages and (2) high-quality communication between the pediatric- and adult-centered survivorship providers when transferring records and making nonsurvivorship referrals. Provider informants perceived that, when communication is optimal, all involved parties obtain a comfort level with shared confidence that the transition of care will be both successful and a positive healthcare encounter for all.

#### **Subtheme 1: Providers must communicate effectively with both survivors and parents**

**1.a. Good communication builds confidence:** Informants from both the pediatric and adult teams felt that all providers involved in the transition of survivorship care need to possess a “comfort” and “familiarity” with this specific patient population. Pediatric providers reported that parents likely feel the same way and “worry because they feel like everyone in pediatrics knows exactly what happened [to their child]” and may wonder if adult-centered survivorship teams “really know” and “understand the consequences of having received the treatments that these kids have received.” Informants felt that, for parents, it is important to know that “their child is transitioning to a team of specialists who specifically focus on caring for the adult survivor [of childhood cancer].” Adult providers

further elaborated on this by emphasizing the need for and benefit from the pediatric team offering continued “reassurance” that the adult team members have the necessary expertise.

Many informants described from their own experience that “often, it’s really the parents who are the barrier to the transition.” An informant with over 20 years of experience caring for this population could not “ever remember a parent requesting the transition.” Identified parental barriers include issues related to attachment, anxiety, loss of control, and fear of the unknown. This was endorsed by an informant who “always” encourages parents to “express their concerns, express their feelings of loss about leaving the team that they have [in the pediatric world], or express their anger about whatever it is, their feelings about the relationship, giving them time to process it so they could move on.” Others anticipate this resistance by starting the conversation well before the transition. A pediatric care informant described this approach as a way to make the move more measured and thus to promote gradual parent preparation. Another informant described the transition conversation with parents as “a process that doesn’t necessarily happen at one fixed point in time but is an ongoing conversation that takes into consideration their developmental needs and their clinical needs. From a caregiver’s perspective, it’s an ongoing conversation.”

Participating providers had strong feelings about addressing this parental lack of confidence. One informant uses an approach of “validating [and acknowledging] what they experienced while their child was going through treatment.” Another commented that a parent may feel like the transition is successful “if they could see that their child could be more active in taking care of themselves.” Ultimately, informants felt that many parents are “used to being in full control of their kids: health care management and everything” and that it is not easy to overcome this common challenge of “letting go,” especially when it is heightened in the transition setting. Thus, one informant commented that the goal with parents should be to make them “feel confident that someone is going to be looking after their child carefully” to be sure that, “if something slips through the crack, there’s a safety net, that the medical team is there to make sure that what needs to be done gets done.”

### **1.b. Good communication delivers education and promotes**

**understanding:** Informants felt that strong relationships with both survivors and parents lead to more effective delivery of health education, patient engagement, and ultimately a smoother transition. One pediatric provider said that “educating the families about the idea of transition and why that’s beneficial is critical” and that the ultimate goal is to educate the survivor “to be an advocate for their own health care, so they are able to express what some of the issues have been and what they will be in the future.” An adult-centered provider added that patients and parents want to “understand the reason for the transition” because they are “confused...as to why” and “what it means” to be transferred.

Several informants reported that, when survivors “understand the value in seeing” a survivorship-focused care team, they then “see the need” and “understand the value of the [survivorship] visit,” especially in the adult-centered programs. However, it is challenging because “it’s not only transmission of information, but their [realistic] understanding of what they’re at risk for...so that they value the need for follow-up even when they’re not feeling poorly.”

As with survivor engagement, providers must cater to the specific needs and concerns of individual parents as well. One adult-care nurse practitioner noted that “you have parents who are very happy to work with us [through] the next step” and those who “come in with preconceived ideas that nothing’s going to be good enough because they don’t want to leave [the pediatric-centered team]... It’s all about meeting their expectations, or at least, ... addressing them.”

**Subtheme 2: Pediatric and adult providers must communicate effectively with each other**—The relationship between pediatric- and adult-centered teams was echoed repeatedly in the study interviews as a critical component of a successful transition.

Informants felt that the most seamless transfers happen when there is a “close connection between the programs,” and all pertinent medical information is transferred efficiently from one team to the next. Repeatedly, study participants commented either “I’m not sure how they do it in the adult world but here we...” or “I’m not sure how they do it in the pediatric world but here we...”

However, open communication between teams also includes sharing perspectives about the family. One informant said, “I would [make] sure that the new provider has...not just the medical nitty-gritty, but also the historical perspective” so that “the team that’s taking [on the new patient] understand[s] and that the patient and family really [feel] like they’re a part of the process.”

**Theme 2: The model of care must include well-established provider partners throughout the healthcare system**—Most informants highlighted a key facilitator to successful transitions as the existence of a multidisciplinary network of subspecialists both in the pediatric and adult care settings as a structural feature of the model of care at that institution. One example was the importance of multidisciplinary survivorship care that includes a psychosocial component ensuring that survivors “had their psychological and emotional needs met” and “episodic stressors or ongoing post-traumatic stress issues” were addressed.

Many informants spoke at length about the challenges and importance of having an accessible and willing network of subspecialists, particularly in the areas of adult medicine for childhood cancer survivors. When available, this model network was said to bring improved communication and increased scheduling accessibility around the time of referral. One informant offered an institutional example: “We have developed relationships with other subspecialists who have in turn put aside spaces in their schedules to see these [childhood cancer survivors] patients” and added a caveat that “not everyone’s interested in seeing these patients, depending upon the problems they’re presenting with.” In an effort to create awareness of this particularly complex patient population, the healthcare team overcame this barrier by “developing relationships with cardiology, endocrine, and all the subspecialties.” Another adult-centered provider informant said, “developing the relationships has been critical because we can get patients in quickly, and the patients are happier and the families are happier; so I think that’s somewhat [the] key to a successful transition from our perspective and I also think from the patient’s perspective.”



Taking a survivor point of view, informants imagined a great advantage to “being able to go to a center where they can see multiple specialists, so having one-stop shopping, not having to go to multiple institutions.” Several informants from across multiple centers reported a routine practice of trying “as much as possible to schedule all...[survivor] exams and scans, x-rays and blood work on the same day” as their survivorship appointment. Their implicit assumption was that the practice “helps a lot too if, instead of having to come back multiple times, they just think about it as that’s their follow-up day. It’s a whole day but they do it once a year and get everything out of the way all at once.” This model of care practice is “streamlined” as well as “comprehensive.” In this model, it is critical to plan and communicate well ahead for the annual visit. One informant said “doing things quick on the fly doesn’t always work” in survivorship care; but others felt that the “one-stop shopping” model of care isn’t as realistic for adult-settings because “adult medicine isn’t conducive to that.” This dissenter went on to say that “we’ve done everything in our power to get as close as we can to the pediatric model and still be reasonable in the adult world in terms of trying to do some of those things that make the patients feel like it’s not all that different.”

Informants also acknowledged that it is unique to practice in large urban academic medical centers with excellent access to both pediatric and adult subspecialty care. This greatly helps the “ability [of survivors] to access the resources we have with the specialists we have.” It “really made a difference that we’ve been able to establish these relationships with other non-oncology subspecialists in both the pediatric and adult care-settings.” To clarify, this informant added, “We don’t have to have a multidisciplinary day, but we have a multidisciplinary team that we can tap into and get folks in and expedite some of their appointments.”

Another facilitator in this team approach to survivor transition is the patient navigator (PN) who was described by many as “someone who the patients [feel] like they could call...to field [a question] and run it by [the provider]” or take care of appointment questions and various other issues that come up, a person who survivors and parents can turn to for care coordination. At the same time, the navigator helps bridge the gaps in expectations for responsible health care within and between pediatric- and adult-centered models.

A system barrier identified in these interviews was described as the perceived lack of primary care involvement in the general care of childhood cancer survivors around the time of transition. Informants talked about the lack of a “medical home” or “primary care provider” as a “huge barrier” to successful transitions. In an “ideal world, we [survivorship providers] should have lots of communication with a primary care provider.” The primary care provider can maintain healthcare continuity with the patient during the survivorship care transition. For some informants, this would create an additional potential partner for survivorship providers to help promote successful transitions.

### 3.3 | Summary of themes

Both pediatric and adult providers of survivor-focused care reported that the transition was most successful when everyone was “on the same page,” including survivors, parents, pediatric- and adult-focused providers. According to providers, when communication was optimal, relationships were strong and this seemed to result in successful transitions of



survivor-focused care to adult care settings. The second theme emphasized the importance of providers building models of care that specifically facilitated the delivery of survivor-focused care by making communication with other partnering providers easier. This included streamlined access to other subspecialty providers as well as the benefits of an identified contact, such as a PN, to handle all patient communications around and during the time of transition.

## 4 | DISCUSSION

In this study, informants represent a heterogeneous group of providers that directly or indirectly participate in survivor transitional care in either the pediatric or adult care setting. Thus, the unique perspectives of key informants of a little known phenomenon provide diverse insight into identifying indicators of success when transitioning patients from pediatric-centered to adult-centered survivor-focused care. Themes suggest that two hallmarks of success are (1) optimal communication between all involved parties and (2) adherence to models of care that promote accessible subspecialty care with streamlined referrals and patient navigation services. These hallmarks of success inform program development and may ultimately serve as the foundation for additional health services research aimed at measuring the value and efficacy of continuing survivor-focused care across the age continuum.

Previous research in transitional care for childhood cancer survivors has emphasized the need for multilevel interventions to eliminate barriers to successful transitions.<sup>22,23</sup> Within this context of existing literature, our findings are in agreement with previous research and additionally suggest several specific system- and provider-level recommendations for program development. One recommendation includes regular meetings between both the pre- and posttransition care teams to optimize communication between pediatric and adult providers, which may result in improved understanding of how each team functions in its respective pediatric- or adult-centered environment. If such meetings are not possible, mechanisms need to be in place so that pediatric survivor-focused teams are aware of these differences and can then deliver anticipatory guidance to survivors, thus preparing them for the upcoming changes. Similarly, if adult providers have a good understanding of how the pediatric team functions, they can provide great insight into survivor and family expectations for their survivor-focused care. This transfer of information between teams could help reduce variation in the attitudes, infrastructure, and capabilities of adult-centered care as compared to pediatric-centered models. For centers where pediatric and adult care are delivered on separate campuses, regular meetings with both teams may also help mimic the advantageous presence of a shared campus between pediatric- and adult-centered providers, which, in this study, was a reported facilitator to a successful transition of care. This may also create an environment that is advantageous from the perspectives of research collaboration and professional networking.

Our findings would also recommend the presence of a PN around the time of transition and beyond. A PN could represent the bridge that provides the continuity of care between the pediatric and adult care settings as well as assistance to maneuver a potentially complex healthcare system that bridges both the pediatric and adult worlds of medicine. The benefits

of this role have also been echoed in the general, nononcologic, transition literature.<sup>30</sup> Outside of childhood cancer survivorship, it is still unclear how pediatric healthcare professionals should support young people with chronic care needs to optimize their transfer of care to an adult medical home or subspecialists.<sup>31</sup> In this era of high-value care, cost-effectiveness has also become a major issue for individuals, families, payers, public policy, and society in general. Subsequently, this challenge has become an important area in children's health and resulted in the publication of a consensus statement (2002) and clinical report (2011) coauthored by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine.<sup>32,33</sup> These publications also emphasized the importance of facilitating the transition. Despite these efforts, transition support for children with chronic conditions continues to suffer from lack of an identified person on the care team responsible for facilitating the transition.<sup>30</sup>

While informative, our study has limitations. First, we included informants from only three institutions nationwide. Our decision to focus on three geographically dispersed clinics was justified by our desire to conduct an in-depth, multidisciplinary study in a limited number of sites, rather than a broad, more superficial survey of many sites. Our approach also limits the variability that might be introduced by including more sites with markedly different transition approaches while still including a diverse group of providers from each institution. We successfully interviewed 100% of those invited to participate, resulting in a large dataset of candid and rich narratives from 29 individuals.

Second, our study does not include perspectives of young adult survivors and their parents; yet, our long-term research goal was intentionally phased to begin with providers, a strategy others have recently taken to learn more about pediatric survivor transitional care.<sup>19,20</sup> Provider perspectives are informed by long experience of serving a wide variety of survivors and families, a characteristic of these informants that we saw as beneficial to achieving our research goals, and we have already begun the second phase of our research by interviewing young adult survivors and their families. Third, all narratives were coded by one member of the study team (KTS), potentially introducing a research bias such as confirmation bias. Owing to clinical experience at multiple institutions, he possesses personal knowledge of the many facilitators and barriers to successful transitional care in childhood cancer survivors. This experience was augmented by a priori knowledge of the existing literature on this topic. To prevent this bias, all prevailing themes were continually re-evaluated by a second member of the study team (EH) with expertise in qualitative research methodologies but no experience delivering clinical care. This allowed for a continual and unbiased review of anticipated and emerging themes.

A final limitation to our study findings, like those from other qualitative research studies, is that they do not statistically generalize to other institutions and providers. The data are not gathered or analyzed for statistical estimations of a population; instead, they describe experiential themes in enough detail that others in similar settings with similar responsibilities can relate to and learn from. This initial phenomenologic qualitative study provides valuable insight into the provider perspective and lays the groundwork for sequential studies that will expand on the understanding of transitional care in childhood

cancer survivors as a direct result of deep exploration into the perceptions of providers, survivors, and parents.

From the perspective of both pediatric- and adult-centered providers at three different institutions, transitional care for childhood cancer survivors benefits from optimal communication between all key stakeholders and models of care that are patient-friendly with available subspecialty care and navigation services. Emphasizing these findings when developing a childhood CSP may support enhanced continuation of survivor-focused care as survivors progress through adolescence to young adulthood and increase the numbers of AYA-aged survivors receiving survivor-focused care.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## ACKNOWLEDGMENTS

The authors would like to thank Constance L. Spear from the University of Minnesota for her outstanding work as the health interviewer for this study.

## Abbreviations

<b>AYA</b>	adolescent and young adult
<b>CSP</b>	cancer survivor program
<b>DCA</b>	directed content analysis
<b>NCI</b>	National Cancer Institute
<b>PN</b>	patient navigator

## REFERENCES

1. Howlader N, Noone AM, Krapcho M, et al., eds. SEER Cancer Statistics Review, 1975–2013. Bethesda, MD: National Cancer Institute; 2016 [http://seer.cancer.gov/csr/1975\\_2013/](http://seer.cancer.gov/csr/1975_2013/).
2. Phillips SM, Padgett LS, Leisenring WM, et al. Survivors of childhood cancer in the United States: prevalence and burden of morbidity. *Cancer Epidemiol Biomarkers Prev.* 2015;24(4):653–663. [PubMed: 25834148]
3. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med.* 2006;355(15):1572–1582. [PubMed: 17035650]
4. Oeffinger KC, Mertens AC, Hudson MM, et al. Health care of young adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Ann Fam Med.* 2004;2(1):61–70. [PubMed: 15053285]
5. Nathan PC, Greenberg ML, Ness KK, et al. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol.* 2008;26(27):4401–4409. [PubMed: 18802152]
6. Ginsberg JP, Hobbie WL, Carlson CA, Meadows AT. Delivering long-term follow-up care to pediatric cancer survivors: transitional care issues. *Pediatr Blood Cancer.* 2006;46:169–173. [PubMed: 16320315]
7. Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. *J Clin Oncol.* 2010;28(32):4810–4818. [PubMed: 20351333]

8. Henderson TO, Friedman DL, Meadows AT. Childhood cancer survivors: transition to adult-focused risk-based care. *Pediatrics*. 2010;126(1):129–136 [PubMed: 20547645]
9. Hudson MM, Oeffinger KC, Jones K, et al. Age-dependent changes in health status in the Childhood Cancer Survivor cohort. *J Clin Oncol*. 2015;33(5):479–491. [PubMed: 25547510]
10. Eshelman-Kent D, Kinahan KE, Hobbie W, et al. Cancer survivorship practices, services, and delivery: a report from the Children’s Oncology Group (COG) nursing discipline, adolescent/young adult, and late effects committees. *J Cancer Surviv*. 2011;5(4):345–357. [PubMed: 21894490]
11. McClellan W, Fulbright JM, Doolittle GC, et al. A collaborative stepwise process to implementing an innovative clinic for adult survivors of childhood cancer. *J Pediatr Nurs*. 2015;30(5):e147–e155. [PubMed: 26202467]
12. Overholser LS, Moss KM, Kilbourn K et al. Development of a primary care-based clinic to support adults with a history of childhood cancer: the tactic clinic. *J Pediatr Nurs*. 2015;30(5):724–731. [PubMed: 26278341]
13. Szalda D, Pierce L, Hobbie W, et al. Engagement and experience with cancer-related follow-up care among young adult survivors of childhood cancer after transfer to adult care. *J Cancer Surviv*. 2016;10(2):342–350. [PubMed: 26303367]
14. Kenney LB, Melvin P, Fishman LN et al. Transition and transfer of childhood cancer survivors to adult care: a national survey of pediatric oncologists. *Pediatr Blood Cancer*. 2016 [Epub ahead of print].
15. Mulder RL, van der Pal HJ, Levitt GA et al. Transition guidelines: an important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork. *Eur J Cancer*. 2016;54:64–68. [PubMed: 26735352]
16. Mertens AC, Cotter KL, Foster BM, et al. Improving health care for adult survivors of childhood cancer: recommendations from a delphi panel of health policy experts. *Health Policy*. 2004;69:169–178. [PubMed: 15212864]
17. Hilgers MA, Slater M, Sadak KT et al. Location, location, location: does it matter for childhood cancer survivors considering pediatric vs. adult care settings? *Pediatr Blood Cancer*. 2017 10.1002/pbc.26426. [Epub ahead of print].
18. Schwartz LA, Brumley LD, Tuchman LK et al. Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatr*. 2013;167(10):939–946. [PubMed: 23959392]
19. Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care Health Dev*. 2011;37(6):883–895. [PubMed: 22007989]
20. Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatr Blood Cancer*. 2013;60(8):1365–1368. [PubMed: 23441065]
21. Quillen J, Bradley H, Calamaro C. Identifying barriers among childhood cancer survivors transitioning to adult health care. *J Pediatr Oncol Nurs*. 2016 [Epub ahead of print].
22. Berg C, Stratton E, Esiashvili N, Mertens A, Vanderpool RC. Providers’ perspectives of survivorship care for young adult survivors of childhood cancer. *J Cancer Educ*. 2016;31(1):31–38. [PubMed: 25943901]
23. Mouw MS, Wertman EA, Barrington C, Earp JA. Care transitions in childhood cancer survivorship: providers’ perspectives. *J Adolesc Young Adult Oncol*. 2016 [Epub ahead of print].
24. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology and discourse analysis and grounded theory. *Qual Health Res*. 2007;17(10):1372–1380. [PubMed: 18000076]
25. Sandelowski M, Baroso J. Classifying the findings in qualitative studies. *Qual Health Res*. 2003;13(7):905–923. [PubMed: 14502957]
26. Sandelowski M Focus on research methods: whatever happened to qualitative description? *Res Nurs Health*. 2000;23(4):334–340. [PubMed: 10940958]
27. Sandelowski M Sample size in qualitative research. *Res Nurs Health*. 1995;18:179–183. [PubMed: 7899572]
28. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–1288. [PubMed: 16204405]

29. Mayring P Qualitative content analysis [28 paragraphs]. Forum Qual Soc Res. 2000;1(2):Art. 20 <http://nbn-resolving.de/urn:nbn:de:0114-fqs0002204>.
30. McManus M, Fox H, O'Connor K, Chapman T, MacKinnon J. Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care. Fact Sheet No. 6. Washington, DC: National Alliance to Advance Adolescent Health; 2008 <http://www.thenationalalliance.org/pdfs/FS6.%20Pediatric%20Perspectives%20and%20Practices%20on%20Transitioning.pdf>
31. American Academy of Pediatrics, Department of Research. Survey: transition services lacking for teens with special needs. AAP News. 2009;30(11):12.
32. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics. 2002; 110(6 pt 2):1304–1306. [PubMed: 12456949]
33. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. Clinical report-supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011;128:182–200. [PubMed: 21708806]

An outline introducing the organizing structure of the study findings as orientation to the collective narrative of the key informants' voices

**Table 1**

---

Theme 1: Providers must be good communicators

Subtheme 1: Providers must communicate effectively with both survivors and parents

- 1. a. Good communication builds confidence
- 1. b. Good communication delivers educational messages that promote understanding

Subtheme 2: Pediatric and adult providers must communicate effectively with each other

Theme 2: Model of care must include well-established provider partners throughout the healthcare system

---