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## Transitional care practices, services, and delivery in childhood cancer survivor programs: A survey study of U.S. survivorship providers

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### Abstract

**Purpose**—There are limited reports describing transition of young adult childhood cancer survivors (CCS) from pediatric to adult-focused survivorship care. The purpose of this study was to characterize current transitional care practices in the United States.

**Project Description**—An online survey was sent to one preselected respondent at 163 Children's Oncology Group member institutions in the United States. Data were collected about (i) the availability and type of long-term follow-up services for adult CCS and (ii) policies and

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#### CONFLICTS OF INTEREST

There are no conflicts of interest for any of the authors.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

procedures for transitioning. Logistic regression was used to evaluate factors related to care for CCS.

**Results**—The response rate was 60% (97/163). Eighty-one respondents (84%) represented centers with specialized pediatric-focused CCS programs. Thirty-nine percent (38/97) of programs delivered specialized transitional care for adult CCS. Adult-centered care was delivered in both pediatric (39%, 15/38) and adult oncology clinics (39%, 15/38). The most common perceived transition barriers were lack of available partnering adult providers and adult providers' lack of knowledge regarding CCS. The larger the program in terms of new diagnoses, the more likely they were to offer formal transitional care (<50 vs >200: odds ratios [OR] 20.0; 95% CI 3.2, 100.0,  $P=0.004$ ).

**Conclusions**—A variety of models are utilized for delivering care to adult CCS. Our results suggest that interventions to establish effective partnerships with adult providers on appropriate care of CCS may facilitate expanded availability of these services.

### Keywords

transition; childhood; cancer; survivor; survey

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## 1 | INTRODUCTION

Although nearly 85% of pediatric cancer patients become long-term survivors, many manifest an accumulating burden of physical and psychosocial late effects of cancer treatment in the years after therapy completion.<sup>1,2</sup> For this reason, the National Academy of Medicine recommends life-long, risk-based survivorship care for the growing population of adult survivors of childhood cancer (CCS).<sup>3–5</sup> A major challenge in accomplishing delivery of age-appropriate care across the lifespan is providing an effective transition of care, defined as transfer of the patient from pediatric-centered to adult-centered providers and facilities.<sup>5,6</sup> In pediatric-centered care, several aspects of the provider–patient relationship, including communication, decision-making, and healthcare responsibility, are shared between the patient and the parent/caregiver. Adult-centered care addresses these aspects of care primarily with the patient. Optimal transitional care provides longitudinal survivor-focused care that seamlessly follows adolescents into young adulthood so health promotion and surveillance via established screening guidelines can be continued and appropriate psychosocial support can be delivered.

Best clinical practices and models of survivorship care transition have not been established. To create an optimal model of transition care to adult providers, there is a need to first understand the existing models of care in use, as current survivor-focused program evaluation data are neither contemporary nor complete.<sup>7</sup> The knowledge of predominant models in use will lead to the identification of factors that facilitate successful transition.

To address this need for more current and complete information, we conducted this study to characterize current transitional care practices for young adult CCS at U.S. institutions, including the availability of care for young adult survivors, personnel, clinical setting,

program funding, and research activities. For this survey, particular attention was paid to assessing the practices for transition and transfer from pediatric to adult care for CCS.

## 2 | METHODS

### 2.1 | Study population

We identified children's hospitals, cancer centers, and community medical centers that treat childhood cancer in the United States using the Children's Oncology Group (COG) public domain website (<https://childrensoncologygroup.org/locations>). Military medical centers and institutions outside the United States were excluded due to fundamental differences in their clinical infrastructure, models of care, and insurance mechanisms. One survey contact was identified per institution through use of online resources and telephone inquiry, if necessary. A total of 163 eligible participants were identified. This study was approved by the University of Minnesota's institutional review board before initiation.

### 2.2 | Survey distribution

An email was sent to all eligible participants with an invitation to complete an online survey through REDCap. The email contained a direct link with the survey's URL and included a \$5 gift card to incentivize survey completion. Email invitations were resent to nonresponders a total of four times at two-week intervals between May 2015 and August 2015. For nonresponses, two months after the original distribution of the survey invitation, a study team member contacted the institution by telephone to confirm the availability of the targeted respondent and, if necessary, identify a replacement.

### 2.3 | Survey instrument

The online survey was created by a study team with significant combined survivorship expertise through an iterative process until convergence on all items was reached (Supporting Information Figure S1). The survey assessed (1) the availability and type of long-term follow-up services for adult CCS and (2) specific policies and procedures related to transitional survivorship care. The survey contained 48 multiple-choice questions and three open-ended questions. Use of conditional branching (skip logic) for some questions resulted in as few as 12 or as many as 51 questions being asked. When applicable, questions had an "Other" answer choice with opportunities for free-text entry. Questions were categorized as follows: program demographics and characteristics, pediatric-centered care services, adult-centered care services, and transitional care services. In comparison with our previous 2007 survey,<sup>7</sup> current survey items captured detailed descriptions of clinical and research team composition and personnel, clinical setting, program funding, research activities, and specific components of transitional care. Specialized survivorship care was defined as the delivery of services that include targeted screening for late effects based on therapeutic exposures, management of complications related to cancer treatment, health education, and psychosocial support. A survivor care plan (SCP) was defined as a "care plan or medical summary that summarizes previous cancer treatments and outlines necessary surveillance."

## 2.4 | Statistical analysis

Survey responses were analyzed using descriptive statistics. Logistic regression was used to identify factors associated with provision of adult care for CCS and report of barriers to providing care. Results were reported as odds ratios (OR) with their 95% confidence intervals (95% CI). Two-sided *P* values less than 0.05 were considered statistically significant. All analyses were conducted using SAS version 9.3 (SAS Institute Inc., Cary NC).

## 3 | RESULTS

### 3.1 | Participating institutions

The survey completion rate was 60% (97/163). Program demographics and practice characteristics of respondents and nonrespondents are summarized in Table 1. Most respondents were either physicians or nurse practitioners (80/97, 82%), with responses rates of 52% (44/85) and 92% (36/39), respectively. About half (59%, 57/97) of the participating centers reported having fewer than 100 new diagnoses of childhood cancer per year. Sixty-nine percent (67/97) were located on the same campus as an adult medical center. Most respondents (56%, 54/97) were from centers on the East Coast. Almost all of the Upper Midwest centers invited to participate completed the survey (92%, 11/12 centers).

Nonrespondents (66/163) were classified as either small-, medium-, or large-size institutions based on 2018 COG enrollment data for front-line therapeutic trials. Using this classification as a surrogate for program size, respondents, and nonrespondents were compared using a  $\chi^2$  test ( $P=0.028$ ), with nonresponders tending to have smaller programs.

### 3.2 | Pediatric-centered survivorship care services

Most institutions (84%, 81/97) reported having a clinical program comprising providers that specifically cared for CCS. The reported numbers of yearly survivorship visits (new and returning patients) per institution were 100 for 19% (15/81) of programs, 101 to 300 for 44% (36/81) of programs, 301 to 500 for 22% (18/81) of programs, and > 500 visits for 10% (8/81) of programs. Table 1 summarizes the disciplines routinely represented on the clinical team. The most frequently consulted subspecialists were cardiology (86%, 70/81), endocrinology (86%, 70/81), pulmonology (75%, 61/81), nutrition (68%, 55/81), physical therapy (67%, 54/81), social work (59%, 48/81), and psychology (59%, 48/81). When respondents were asked who submitted a bill for their services, 90% (73/81) reported the MD/DO, 43% (35/81) the nurse practitioner, 43% (35/81) the psychologist, and 25% (20/81) the nutritionist. Sixty-two percent (60/97) of pediatric-centered programs reported having designated personnel to support research, such as a clinical research associate (CRA).

### 3.3 | Transitional care services

When participants were asked, "Through your program or elsewhere, is specialized survivorship care available to transfer adult survivors from the pediatric model of care to the adult model of care," 39% (38/97) endorsed they did. The wording of this question may have led programs that provide life-long follow-up care in a single program, but without formal transition mechanisms, to respond negatively. Only respondents who answered affirmatively

were then asked: “If clinically indicated, may adult survivors receive life-long care through this program?” Almost all (95%, 36/38) answered “yes.” The typical age of transition to an adult-centered model was 18 to 21 years for 42% (14/33) of programs, 22 to 25 years for 30% (10/33) of programs, and >25 years for 27% (9/33) of programs (5 programs did not report age).

**3.3.1 | Introduction to transition**—For the remaining survey questions on this topic, respondents were able to select more than one answer. Thirty-nine percent (15/38) of programs “always” introduced survivors and families to the idea of transitioning to adult-centered care greater than one year prior to the actual transfer of care. About the same number of programs (37%, 14/38) “sometimes” introduced the transition greater than one year prior to the transfer, whereas 24% (9/38) did not. Most of the time, either physicians (63%, 24/38) and/or nurse practitioners (55%, 21/38) were involved with introducing the idea of transitioning to adult-centered survivorship care.

**3.3.2 | Care coordination related to transition**—Thirty-seven percent (14/38) of programs had a patient navigator (PN) or transition coordinator. Of the 14 programs with a PN, 10 reported that the financial support for this role came from the institution, three programs reported philanthropy, and one program used grants. Eleven (32%, 11/34) programs assessed if survivors were developmental and logistically ready for transition and, of those, nine programs used provider opinion while three used an internally developed scale (four programs did not respond to the questions regarding transition readiness). A standardized scale to assess transition readiness was not used by any program. When asked if insurance reimbursement prevented the transition to adult-centered survivorship care, 47% (18/38) said “yes” and 53% (20/38) responded “no.”

**3.3.3 | Education and communication**—During the transition, patients were given an SCP by 94% (32/34) of programs (four did not answer the question). In most cases, the SCP was provided to survivors multiple times. This included during pediatric-centered care (82%, 28/34 programs), at the time of transfer from pediatric- to adult-centered care (59%, 20/34), and during adult-centered care (35%, 12/34). At the time of transition, insurance topics were also reported to be part of the educational message delivered to survivors by 22 of the 38 programs (58%). In most cases, this insurance education was delivered by the social worker (73%, 16/22) or nurse practitioner (32%, 7/22). Vocational counseling was part of the education delivered at the time of transition by 21 programs (55%, 21/38). Again, in most cases, vocational counseling was delivered by social workers (76%, 16/21) or nurse practitioners (29%, 6/21). When a survivor was transitioned from pediatric-centered to adult-centered survivorship care, the accepting adult care provider was notified of the transition by email (29%, 11/38), by receipt of medical summary (29%, 11/38), and by telephone (18%, 7/38). However, eight programs reported that at least one provider was in both settings and six programs reported that this communication occurred in person via a joint visit with both the pediatric- and adult-centered providers.

### 3.4 | Adult-centered survivorship care services

Programmatic feature centers offering specialized care for adult CCS are summarized in Table 2. Almost all programs (95%, 36/38) with specialized care for adult CCS reported offering adult-centered care that was life-long with no upper age-limit.

**3.4.1 | Team composition**—Programs were queried about the specialty area of the clinical providers who deliver care to adult CCS. Participating specialties included pediatric oncology (34%, 13/38), internal medicine/family practice (29%, 11/38), adult oncology (18%, 7/38), pediatric oncology combined with internal medicine/family practice (21%, 8/38), pediatric oncology combined with adult oncology (18%, 7/38), and adult oncology combined with internal medicine/family practice (11%, 4/38). Two programs reported having a radiation oncology provider involved and one had an adolescent medicine provider involved in the adult-centered care.

**3.4.2 | Education and communication**—All 38 institutions (100%, 38/38) gave survivors an SCP in the context of adult-centered care, after the transfer of care was completed. Participants were then asked to describe an SCP by checking all the definitions that applied from a list of multiple choices. In most cases, the SCP was described as being a summary with diagnoses and treatments received (95%, 36/38), a paper document (92%, 35/38), plan of care for screening tests needed (84%, 32/38), and a part of the electronic medical record (58%, 22/38). Eight (21%) of programs reported that the SCP was also available as a transportable electronic document. At most institutions with adult-centered care, either the nurse practitioner (66%, 25/38) or physician (53%, 20/38) prepared the SCP. Thirty-two of 35 (91%) programs provided patients with education about their disease, previous treatments, and follow-up care (three programs did not respond). Most programs reported that this education was delivered through discussion during clinic times (97%, 31/32) and/or through educational handouts from the COG (72%, 23/32). Many programs delivered this education through the use of electronic resources (56%, 18/32), but the specifics of these were not described in the data captured. In general, this education was delivered by nurse practitioners 78%, 25/32), physicians (69%, 22/32), or nurses (41%, 13/32). Sixteen (42%, 16/38) programs with specialized care for adult CCS reported having a designated CRA to support research.

### 3.5 | Perceived barriers

Reported barriers to providing survivorship care to adult CCS are summarized in Table 3. Smaller programs were less likely to report lacking available partners in the adult-centered medical system (<100 vs >300: OR 0.37; 95% CI, 0.10–1.44;  $P=0.089$ ) and larger programs were more likely to offer formal transitional care (<50 vs >200: OR 20.0; 95% CI, 3.2–100.0;  $P=0.004$ ). After controlling for the program size, having adult-centered providers on the same campus as pediatric providers was not associated with offering formal transitional care (OR 0.81; 95% CI, 0.29–2.25;  $P=0.687$ ). For the 59 institutions that did not offer specialized adult-centered survivorship care, 58 (98%) thought they should. Only one institution reported that they should not offer specialized adult-centered care and then they were subsequently prompted to enter free text as to why not. The response read, “If pediatric patients transitioning to adult care have received good information and

recommendations on their potential for late effects and surveillance recommendations, a good internist can provide the necessary care for adults.” Of these 59 institutions that did not offer specialized adult-centered survivorship care, 90% (53/59) believed that survivorship care for adult-age survivors should be adult-centered.

## 4 | DISCUSSION

The objective of this study was to describe the current U.S. practices for the transition and transfer of survivorship care from pediatric to adult-centered models. Our data revealed that a minority of childhood cancer programs transition care to adult-centered providers and settings, resulting in most childhood cancer survivorship programs not facilitating or delivering adult-centered care to adult CCS. Of those that did, most transferred care between the ages of 18 and 25 years and delivered care in oncology clinics, either pediatric or adult. The most common perceived barriers were a lack of available partnering adult providers and adult providers’ lack of knowledge regarding CCS. The identification of these perceived barriers may assist in directing resources to improve this transition. In conjunction with previously published research, new and improved models of communication between pediatric and adult providers will be necessary to ensure that these transitions are successful and valuable to adult-centered providers.<sup>8</sup> This includes streamlined transfer of critical survivor medical history as well as formal transition readiness assessments to standardize the transfer.<sup>8</sup> To our knowledge, these findings represent the largest and most current study of transitional care practices for CCS in the United States.

As the adult CCS population continues to expand and mature, there is heightened awareness of how and where to deliver survivor-focused care to these young adults. These questions are highlighted by examining the role of risk stratification and the primary care provider in delivering care to CCS as well as the perspective of the CCS and their family. Both at the provider level and the healthcare system level, there is minimal information describing current transitional care practices for young adult CCS at U.S. institutions.<sup>7,9,10</sup> This includes a paucity of contemporary published literature describing the specific details of such care as well as programmatic information such as team personnel, risk stratification, clinical setting, program funding, and research activities. A lack of data on prospective outcomes has resulted in limited benchmarks of best practice that differentiate various transitional care models. The concept of risk stratification provides a potential benchmark that has widespread implications including on systems-based practices such as resource utilization and establishing the medical home.

Among the 97 participating centers that treated childhood cancer throughout the United States, clinical practices were not uniform as only 39% of responding institutions offered specialized care for adult CCS. The majority (73%, 24/33) of sites that delivered transitional care did so for survivors between ages 18 and 25 years. The lack of qualified, available adult-centered providers was the most commonly reported transition barrier and was associated with larger-sized survivorship programs. The findings of this study highlight the need for models of care that establish an effective collaboration between pediatric-and adult-centered providers. As most CCS receive adult care in the community,<sup>11</sup> it is imperative to

identify approaches that efficiently and effectively communicate survivor-focused care recommendations to the adult providers who deliver this care.

In 2011, the COG reported on the models of care that were in use in 2007 for adult CCS through a survey study with an 81% response rate.<sup>7</sup> In this 2007 study, 87% of respondents did report providing some form of late effects services to survivors, just not through a specialized program. Compared with that study, the number of institutions with a specialized childhood cancer survivorship program increased from 59% to 84%. However, during the same time period, the composition of survivorship teams evolved such that fewer survivorship programs now include nutritionists (35% vs 49%), psychologists (41% vs 74%), and social workers (67% vs 87%). The 10-year trend, which is somewhat surprising and concerning, can be interpreted several ways. Although it could reflect a reduced emphasis on or limited resources for multidisciplinary clinic teams for childhood cancer survivorship care, this trend could be explained by having multidisciplinary care delivered in new ways. For example, one possible explanation may be more supportive care being delivered outside of survivor-focused clinics, such as medical homes where primary care providers partner with personnel to address psychosocial concerns. However, it must be noted that other studies suggest that only a minority of all adult CCS are receiving care in survivor-focused settings, as most are accessing healthcare in community settings as opposed to cancer centers and survivor-focused clinical programs.<sup>11</sup>

Transition readiness of the survivor is an important component of transitional care for CCS. Formal assessments of transition readiness were rarely used by the study's respondents. Given that fewer than 20% of young adult CCS report getting survivor-focused care with surveillance and screening recommendations, optimizing the transition to adult-centered care may provide a critical opportunity to ensure the continuation of care when the risks of being lost to follow-up are greatest.<sup>11</sup> Additionally, even those survivors engaged in LTFU care experience decreased adherence to recommended care as they age into young adulthood.<sup>14</sup> This suggests a clear need for validated and predictive readiness assessment tools that facilitate the transfer of CCS to adult-centered care. One promising such tool is the Transition Readiness Inventory (TRI) item pool based on the Social–Ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) that provides a comprehensive and empirically validated framework for CCS and their transition care.<sup>12,13</sup> This tool was created and validated using input from all key stakeholders (CCS, parents, and providers) supporting the most comprehensive approach to readiness assessment. The TRI is currently undergoing further validation and refinement using the SMART model and leads the way in transition readiness assessment tools for CCS.

This study has limitations common to surveys. Bias from self-selection of participating centers may have resulted in potential overestimates of how many offer adult-centered care for CCS. Responders and nonresponders differed based on profession, geographic location, and program size. To mitigate self-selection bias based on the survey's topic, the invitation to participate was general and did not specify the topic as being related to transitional care. Moreover, the invitation to participate was more focused on adding to the knowledge base of how and where adult-aged CCS received care. Another attempt to avoid self-selection bias was the diligent effort to engage specific survivorship-focused providers as survey



respondents because of their knowledge about the program. Although potential participants were from all U.S. geographic locations, the data presented here mostly came from the eastern half of the country, possibly resulting in findings less generalizable to other parts of the United States. Lastly, respondents may have claimed program components that were in development but not fully operational in an adult-centered context. Similarly, the survey instrument did not collect information on longitudinal follow-up occurring in the community through primary care providers.

Nevertheless, our results indicate that during the past 10 years, more clinical programs have begun to provide care for adult-aged CCS; and that, there are still great variations in the models of care used to deliver care to this population. Given that most CCS receive care in the community outside of survivor-focused programs,<sup>11</sup> our findings regarding barriers and facilitators could be applied to general practitioners in a community setting by establishing effective collaborative relationships with the survivorship center. Our data suggest a striking lack of availability and use of transition readiness assessment tools. This is an area of great opportunity for the development and implementation of readiness assessment measures that are both simple, yet also validated, and could apply to the transfer from pediatric to adult providers in community settings. Over time, the potential interventions through health services research will become more clearly defined and ultimately inform the creation and evolution of models that care for adult CCS in a variety of clinical settings within the United States, including both community and survivor-focused providers.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Abbreviations

<b>CCS</b>	childhood cancer survivors
<b>COG</b>	Children's Oncology Group
<b>CRA</b>	clinical research associate
<b>OR</b>	odds ratios
<b>PN</b>	patient navigator
<b>SCP</b>	survivor care plan
<b>SMART</b>	Social–Ecological Model of Adolescent and Young Adult Readiness to Transition
<b>TRI</b>	Transition Readiness Inventory

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TABLE 1

Demographics and practice characteristics of respondents and nonrespondents

Characteristic	Respondents (n = 97) <sup>a</sup>	Nonrespondents (n = 66) <sup>a</sup>
Profession of the respondent		
Physician	44 (45)	41 (62)
Nurse practitioner	36 (37)	3 (5)
Nurse	16 (16)	19 (29)
Social worker	1 (1)	1 (2)
Coordinator (not a nurse)	0 (0)	2 (3)
Newly diagnosed patients/year		
<50	25 (26)	
50–100	32 (33)	
101–150	13 (13)	
151–200	12 (12)	
201–250	4 (4)	
>250	8 (8)	
Not known	3 (3)	
Survivorship patients seen/year		
<50	5 (6)	
50–100	10 (12)	
101–300	36 (44)	
301–500	18 (22)	
501–800	3 (4)	
>800	5 (6)	
I do not know	4 (5)	
Have specialized survivorship program		
Yes	81 (84)	
No	16 (16)	
Survivorship team members by discipline (n = 81)		
Physician	73 (90)	
Nurse practitioner	59 (73)	
Physician assistant	2 (3)	
Nurse	46 (57)	
Nutritionist	28 (35)	
Social worker	54 (67)	
Psychologist	33 (41)	
Trainee (fellow/resident/medical student)	22 (27)	
Other	34 (42)	
Location of adult providers		
Same medical campus	67 (69)	
Separate medical campus/ different location	12 (12)	

Characteristic	Respondents	Nonrespondents
	( <i>n</i> = 97) <sup>a</sup>	( <i>n</i> = 66) <sup>a</sup>
No adult providers at institution	16 (16)	
Other	2 (2)	
Offer SDecialized care for adult CCS <sup>b</sup>	38 (39)	
Region of practice in the united States		
New England	5	7
Middle Atlantic	14	9
SouthAtlantic	20	13
East NorthCentral	20	8
East SouthCentral	3	5
West NorthCentral	11	1
West SouthCentral	6	10
Mountain	7	3
Pacific	11	10

<sup>a</sup>Values are reported as numbers (percentages). Missing values are excluded from percentage calculations. Respondent sample size is *n* = 97 for all variables unless otherwise noted above.

<sup>b</sup>CCS: childhood cancer survivors.

**TABLE 2**Practice characteristics of centers offering specialized care for adult CCS ( $n = 38$ )

Characteristic	Respondents
	$n$ (%) <sup>a</sup>
Offer life-long adult-centered care	37 (97)
Typical age at transfer	
<16years	0 (0)
16–17 years	0 (0)
18–21 years	14 (42)
22–25 years	10 (30)
>25years	9 (27)
Location of adult-centered care	
Pediatric cancer clinic	15 (39)
Adult cancer clinic	15 (39)
Adolescent and young adult cancer clinic	1 (3)
Pediatric non-cancer clinic	1 (3)
Adult non-cancer clinic	9 (24)
Pediatric and adult non-cancer clinic	3 (8)
Not known	1 (3)
Adult-centered team members by discipline	
Physician (MD/DO)	32 (84)
Nurse practitioner	20 (53)
Physician assistant	0 (0)
Nurse	13 (34)
Nutritionist	8 (21)
Social worker	17 (45)
Psychologist	12 (32)
Trainee (fellow/resident/medical student)	5 (13)
Other	6 (16)

<sup>a</sup>Missing values are excluded from percentage calculations.

**TABLE 3**Top three perceived barriers to providing survivorship care to adults of childhood cancers ( $n = 97$ )

<b>Barriers</b>	<b>Count (%)</b>
Lack of available adult providers to partner with	53 (55)
Available adult providers lack knowledge in childhood cancer survivorship	56 (58)
Survivors desire to continue pediatric-centered care	37 (38)
Parent/caregiver desires to continue pediatric-centered care	33 (34)
Limitations due to survivor insurance coverage	30 (31)
Survivors no longer come to appointments	29 (30)
Survivors not ready for adult-centered care from a psychosocial standpoint	18 (19)
Lack of the necessary adult subspecialty providers	17 (18)
Pediatric survivorship provider not willing to "let go" of survivor	11 (11)
Adult models of care cannot accommodate influx of new patients	11 (11)
Survivors not ready for adult-centered care from a medical standpoint	5 (5)
Other	12 (12)

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