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Stakeholder Validation of a Model of Readiness for Transition to Adult Care

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Abstract

IMPORTANCE—That too few youth with special health care needs make the transition to adult-oriented health care successfully may be due, in part, to lack of readiness to transfer care. There is a lack of theoretical models to guide development and implementation of evidence-based guidelines, assessments, and interventions to improve transition readiness.

OBJECTIVE—To further validate the Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) via feedback from stakeholders (patients, parents, and providers) from a medically diverse population in need of life-long follow-up care, survivors of childhood cancer.

DESIGN—Mixed-methods participatory research design.

SETTING—A large Mid-Atlantic children's hospital.

PARTICIPANTS—Adolescent and young adult survivors of childhood cancer (n = 14), parents (n = 18), and pediatric providers (n = 10).

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MAIN EXPOSURES—Patients and parents participated in focus groups; providers participated in individual semi-structured interviews.

MAIN OUTCOMES AND MEASURES—Validity of SMART was assessed 3 ways: (1) ratings on importance of SMART components for transition readiness using a 5-point scale (0-4; ratings >2 support validity), (2) nominations of 3 “most important” components, and (3) directed content analysis of focus group/interview transcripts.

RESULTS—Qualitative data supported the validity of SMART, with minor modifications to definitions of components. Quantitative ratings met criteria for validity; stakeholders endorsed all components of SMART as important for transition. No additional SMART variables were suggested by stakeholders and the “most important” components varied by stakeholders, thus supporting the comprehensiveness of SMART and need to involve multiple perspectives.

CONCLUSIONS AND RELEVANCE—SMART represents a comprehensive and empirically validated framework for transition research and program planning, supported by survivors of childhood cancer, parents, and pediatric providers. Future research should validate SMART among other populations with special health care needs.

The dramatic increase in youth with special health care needs surviving to adulthood in recent decades has prompted attention to transition from pediatric to adult-oriented care and how best to facilitate it. To address the need to improve transition care, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians jointly authored a clinical report in 2011 that provides an algorithm for providers to implement best practices for transition of patients both with and without special health care needs.¹ The report and prior consensus statements emphasize that transition is a multifactorial process requiring the engagement of not only the patient, but also the family and health care providers.¹⁻⁴ While this effort based on expert consensus was extremely timely and critical for advancing transition care, the algorithm and guidelines were developed in the absence of theoretical models and evidence-based assessment tools and interventions and a paucity of longitudinal data on transition planning and posttransfer outcomes. A valid multifactorial model of transition readiness for youth with special health care needs that addresses the role of multiple stakeholders in the process is needed to inform the implementation of the transition planning algorithm and the development of related evidence-based assessment and intervention.⁵ The present study fills this gap in transition research and care by using a mixed-methods participatory approach with patient, parent, and provider (PPP) stakeholders to further validate a newly developed model of transition readiness: the Social-ecological Model of Adolescent and Young Adult Readiness to Transition⁵ (SMART) (Figure 1).

SMART applies a social-ecological framework to transition readiness, emphasizing multiple factors, stakeholders, and systems and their reciprocal relationships in influencing the readiness for and likelihood of success in transfer to adult-oriented care. Transition readiness is defined as indicators that patients and those in their support system (eg, parents and providers) can begin, continue, and finish the transition process from child-centered to adult-oriented health care, through the event of transfer.^{6,7} SMART purports 4 preexisting objective factors that are not or are less amenable to change and may influence processes

among PPP (sociodemographics/culture, access/insurance, medical status/risk, and neurocognitive functioning/IQ), 6 more modifiable subjective factors of PPP (knowledge, beliefs/expectations, goals/motivations, skills/ self-efficacy, relationships/communication, and psychosocial functioning/emotions), and 1 additional factor specific to the patient, developmental maturity. The broader systems issues and disease status (ie, the objective factors) are considered critical for influencing the subjective factors, which are believed to be more modifiable in a clinic setting. While most research on transition focuses on patient disease knowledge and skills, SMART considers additional indicators of transition readiness, attends to multiple stakeholder (ie, PPP) perspectives, and distinguishes between variables more and less amenable to change within the context of clinical settings and multidisciplinary teams. The comprehensive process of developing SMART following the methods of Jaccard and Jacoby⁸ was the first step of its validation. In particular, SMART was informed by relevant research on transition, disease management, and adjustment to pediatric chronic illness; related theoretical models⁹⁻¹³; and expert clinical opinion on transition readiness from providers in adolescent medicine and oncology (including physicians, nurses, and psychologists).⁵

Data collection to further support its validity has been conducted in childhood cancer survivorship. While SMART is intended to be generalizable to all adolescents and young adults with compromised health and will be tested in multiple chronic illness populations in future research, childhood cancer is a broad diagnosis with applicability to many different health conditions. Survivors of childhood cancer represent a variety of cancer diagnoses and treatments, subsequent treatment-related medical issues (ie, late effects that affect every organ system such as cardiac, renal, pulmonary, and endocrine) that often emerge in young adulthood, and an increased risk for future cancers.^{14,15} Thus, survivors of childhood cancers are a heterogeneous population ranging from those experiencing good health but requiring surveillance for future problems to those with significant life-threatening problems and/or disabilities. Guidelines recommend, at minimum, annual lifelong follow-up care,^{14,16} yet only about 40% of young adult survivors access appropriate medical care related to their prior cancer or treatment,¹⁷ highlighting the need for improved transition care for this population.¹⁸

Preliminary findings with providers in a pediatric cancer survivorship clinic indicated that SMART variables were related to the providers' assessments of the level of transition readiness of all 100 patients.⁵ The findings supported initial validity from the providers' perspectives, thus warranting data collection with multiple stakeholders to further test the validity of SMART. The current article extends this work by further validating SMART using mixed-methods (quantitative and qualitative) data collection with PPP in the context of pediatric cancer survivorship and provides a framework by which to test SMART in other chronic health conditions.

Methods

The study was approved by the institutional review board at the hospital where the study took place. Patients older than 18 years, parents, and providers provided written informed consent, and patients younger than 18 years provided written assent. A mixed-methods

participatory approach with patients (adolescent and young adult survivors of childhood cancer aged 16-28 years), parents, and pediatric providers was used. The validation process was strengthened by using a participatory approach that assures the model is consistent with stake-holder experiences¹⁹⁻²¹ and mixed methods that allow for complementary types of data to evaluate SMART.^{20,22-24} Qualitative data collection occurred with patients and parents via focus groups and with pediatric providers via semi-structured interviews, a method that better accommodated their work schedules. Qualitative data were intended to inform modifications to SMART and definitions of its components. The quantitative data—assessment of PPP perceived importance of each SMART component—were used to further validate inclusion of each of the SMART components. Attention was paid to the consistency across reporters and the 2 data collection modalities.^{23,24}

Participants

Patients, parents, and providers participated. Patient participants (n = 14) were required to be (1) at least 5 years from diagnosis of a childhood malignancy, (2) at least 2 years since end of treatment, (3) at least 16 years old, (4) able to speak and read English, and (5) cognitively capable of participating in a focus group and answering questions, as determined by their oncology provider or parent. Parents (n = 18) were eligible if they had a child who met the patient participation criteria and could speak and read English. Sample sizes were based on the number of participants needed (at least 25 across participant groups) to reach redundancy and data saturation during qualitative analysis.^{25,26} Purposeful sampling²⁷ was used to identify a maximally diverse sample of patients and parents in terms of demographics (age, sex, and race/ethnicity) and cancer-specific variables (type of cancer, treatment modalities received, and severity of late effects). Forty-seven patients and their parents who were potentially eligible were identified by clinical providers on the study team and other pediatric oncology providers. Of those, 30 patients and 29 parents were reached. Of those, 12 patients and 14 of their parents (12 mothers and 2 fathers, including 2 married couples) agreed to participate. An additional 2 patients and 4 parents participated without their parent/child. See the Table for demographics, disease-related information, and type of provider seen for follow-up care. Only 1 patient had transferred all care (oncology and primary care) to adult providers. Reasons for decline were unavailable on days focus groups were offered (n = 9), patient relapsed (n = 2), too busy (n = 2), too far to travel (n = 3), not interested (n = 1), or no reason given (n = 10).

For providers, efforts were made to establish a sample unfamiliar with SMART and with variability in terms of years in practice, transition practices (ie, providers ranging from frequently transferring patients to those known to keep patients long term), and medical specialties and interests (eg, nurse practitioner/physician, types of cancers treated, and experience/expertise with adolescents and young adults). Providers (n = 10) with expertise in childhood cancer or transition care who practice at the children's hospital where the study took place (n = 9) or at the affiliated, adjacent adult hospital (n = 1) were invited to participate and all agreed. Six pediatric oncologists, 2 pediatric oncology nurse practitioners, and 2 pediatricians with expertise in transition care participated. Clinical foci of the participants included leukemia and lymphoma (n = 3), neuro-oncology (n = 3), hematopoietic transplant (n = 1), solid tumors (n = 1), and medicine/pediatrics (n = 2). All

providers interviewed were non-Hispanic white, and most were female (n = 8). Number of years in practice ranged from 1 to 31 years (median = 15.00 years).

Procedures

Patients and parents and providers were invited to participate in a focus group or interview, respectively, to discuss long-term cancer-related follow-up care. Focus groups and interviews followed parallel procedures using scripts guided by L.A.S. or J.A.D. In addition to a team member taking notes, all sessions were audio-recorded and professionally transcribed.²⁸ To minimize response bias, the focus group leaders called for alternative explanations and possibilities from the participants and performed techniques such as round-robins to assure systematic input of all group members.²⁸ Finally, questionnaires on demographics and ratings of SMART components were completed individually to gather data privately from participants.

Focus Groups—Two patient and 2 parent focus groups were held with 5 to 10 participants each,²⁸ lasting approximately 60 to 90 minutes. Facilitators presented a definition of transition readiness and a visual presentation of SMART to facilitate discussion (Figure 1). Focus group scripts were used to guide inquiry on 3 topics: (1) long-term follow-up care (eg, “How important is [follow-up care, health care appointments] to you/your child?”); (2) transition readiness (eg, “Do you think you/your child are ready to transition to an adult health care provider?”); and (3) introduction to the SMART model and its individual components (eg, “What are your thoughts on this component of the model?”).

Provider Interviews—The in-person, semi-structured interviews lasted 40 to 60 minutes using a script that paralleled that used in focus groups. Additional questions probing for assessment of transition readiness were asked such as, “How do you advise your patients, if at all, with regards to long-term follow-up care?”

Measures

Demographics and Disease/Treatment Information—Patients and parents provided demographic information on age, sex, race/ethnicity, education level, marital status, income, employment status, and cancer-specific information including diagnosis, date of diagnosis, relapse(s) (if applicable), treatment length, type of treatments, and type of follow-up care they attend (if applicable).

SMART Component Importance—Participants completed a brief questionnaire after the focus groups/interviews that assessed perceived importance of the 11 SMART components (see the eTable in Supplement for list of components) in 2 ways: (1) ratings on a 5-point scale (0 = not at all to 4 = extremely) and (2) nominations of the 3 “most important” components.

Data Analysis

Qualitative Content Coding—Transcripts were uploaded into Atlas.ti software (ATLAS.ti Scientific Software Development GmbH). Using the principles of a directed content analysis, prior definitions of SMART components⁵ (eTable in Supplement) were

used to deductively guide coding, allowing for the application of multiple codes throughout.²⁹ A data auditing system was implemented to ensure rigor of analysis; thus, coding was conducted by a primary coder (L.D.B.), a secondary coder (L.A.S.), and a final reviewer (J.A.D.). Only discussion of survivorship care, transition readiness and planning, and transfer to adult-oriented care were included in coding. Coders wrote field notes as they assigned codes.²⁰ The team discussed the application of codes and reached a consensus on the final assignment of codes. Inductive methods were then employed to use the qualitative data to enrich and modify definitions of SMART components.

Quantitative Analysis—Descriptive statistics were performed on demographic and disease/treatment data, ratings of SMART component importance, and nominations of “most important” SMART components. Criterion for content validity of each SMART component was defined as an average stakeholder group rating of greater than 2 (on a scale from 0-4).³⁰ To rank the “most important” SMART components and assess potential variability among groups, the percentage of each group that nominated each component as “most important” was calculated. The presence of variability among PPP on nominations of the most important components was examined to assess whether transition readiness is a process that involves multiple, and presumably differing, perspectives—something that is implied by SMART.

Data Integration—Qualitative and quantitative data from PPP regarding SMART components were compared to evaluate the data for consistency and complementarity.^{23,24} Definitions of components deemed valid (as determined by an average importance rating >2) were modified, as needed, based on qualitative data.

Results

Qualitative Results

The original definitions of SMART components, additions from the current content analysis, and representative quotes are presented in the eTable in Supplement (additions are underlined). The qualitative data provided support for all SMART components and the full model. The PPP endorsed SMART as comprehensive and applicable to their experiences with transition. Very few suggestions were made for changes to the definitions of the objective, pre existing factors. Additions were made to the descriptions of the subjective, modifiable indicators of SMART. There were no recommendations for additional components.

Quantitative Results

The PPP each reported a mean more than 2 for all SMART components on importance (mean = 2.95-3.60; SD = 0.54-0.93) (Figure 2), meeting criteria for validity. Of patients, 100% rated health, development, and relationships as more than 2 on importance; 100% of parents rated relationships more than 2; and 100% of providers rated developmental maturity more than 2 on importance. The highest-rated components by PPP were medical status/risk (mean = 3.71), skills/self-efficacy and neurocognition/IQ (both with mean = 3.72), and developmental maturity (mean = 3.55), respectively. The components endorsed by

more than 40% of the stakeholder groups as “most important” were access/insurance and knowledge for patients, skills/self-efficacy and relationships/communication for parents, and relationships/communication for providers (Figure 3).

Data Integration

High quantitative ratings on importance of SMART components (>2) were consistent with qualitative results endorsing SMART components. The consistency between data collection modalities supported the use of qualitative data to modify and enhance existing definitions of SMART components.

Discussion

To our knowledge, SMART is the only model of transition readiness that has followed multiple steps to establish its validity, including the process of theory development⁵ and testing it via mixed methods that incorporate the input of stakeholders. Mixed-methods results indicated strong support for SMART and its components. Only minimal additions and some examples were added to component definitions; no information was removed from definitions, and no additional components were suggested. The variability among PPP on nominations of the “most important” SMART components supported the importance of considering multiple stakeholder perspectives. For example, that “relationships” were deemed “most important” by the parents and providers is especially validating of SMART's focus on interactions of multiple stake-holders as an important part of the transition process. It further reinforces the need for transition services to address relationships and needs of parents and providers in addition to patients.¹⁹ Furthermore, that no provider endorsed “knowledge” as one of the “most important” components is contrary to the emphasis placed on patient knowledge in the transition literature and related assessment tools, thus further emphasizing the importance of the many SMART constructs.^{5,31,32} This may indicate that knowledge is an important precursor to transition readiness but may not be sufficient to translate to appropriate skills and motivations that are necessary for transition readiness. Taken together, results support conceptualizing transition readiness as a multi-factorial, dynamic process involving multiple stakeholders and psychosocial variables.

A valid model fills a critical gap in the literature by providing a framework to guide implementation of the transition algorithm, development of evidence-based assessments and interventions, and theoretically informed research on transition. SMART represents targets of intervention identified and corroborated by PPP and should be used to inform development of valid, evidence-based assessment tools and interventions that target all aspects of transition readiness already shown to be important to stakeholders. When implementing the transition algorithm in clinical practice, SMART can help to operationalize the process by identifying specific variables for providers to target in assessment, discussions, and planning.

The findings support the need for multidisciplinary teams to facilitate the transition process for youth with special health care needs. For example, promoting autonomous disease management skills, managing family conflict and traumatic memories related to illness experiences, and changing negative beliefs and expectations about adult health care may

require efforts by nurses, psychologists, social workers, and transition coordinators beyond what can be accomplished in a time-limited medical visit with a physician. Addressing these transition-related concerns and barriers with the aid of a multidisciplinary team may ultimately reduce costs by enhancing the likelihood of a successful transfer of care and reducing poor transition outcomes (eg, increased morbidities and use of emergent medical care).^{33,34}

There are several limitations of this study. The majority of participants were middle to high income; thus, future research should elicit perspectives on transition readiness from low-income families to examine if additional or conflicting themes emerge in content analyses. Almost all providers interviewed practiced in the same pediatric setting. Thus, future research may benefit from including adult providers and providers from multiple institutions. Despite these limitations, participants presented diverse perspectives while also supporting the model. Also, the content analysis necessitated an informed coder who may be biased to find more supportive than nonsupportive evidence.²⁹ However, we addressed this limitation by having a 3-fold audit trail of coders and self-report questionnaire data, which supported findings from content analysis. Additionally, results from questionnaires administered after the interview or focus group were relatively reflective of the discussions; future studies may want to administer a more general questionnaire before and after discussion. Finally, the focus on pediatric oncology may limit the generalizability of the findings. However, given the heterogeneity of health status and organ systems affected in childhood cancer survivors, results are expected to generalize to other youth with special health care needs.

In conclusion, SMART is an empirically validated model of transition readiness that lends support to and expands on the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians joint clinical report, consensus statements, and guidelines that were developed without established models of transition readiness.¹⁻⁴ Advancements in transition care are hindered by the lack of valid measures and interventions that could identify outcomes and best practices. Thus, SMART fills a gap in the burgeoning literature on transition by providing an evidence-based framework to inform research and the development of assessment tools and interventions. Future research is needed to test SMART with other disease populations, further test and confirm the components of SMART via larger samples and quantitative analysis, and understand the criterion level (eg, extent of disease knowledge and management skills, beliefs, emotions) of each component that indicates optimal transition readiness.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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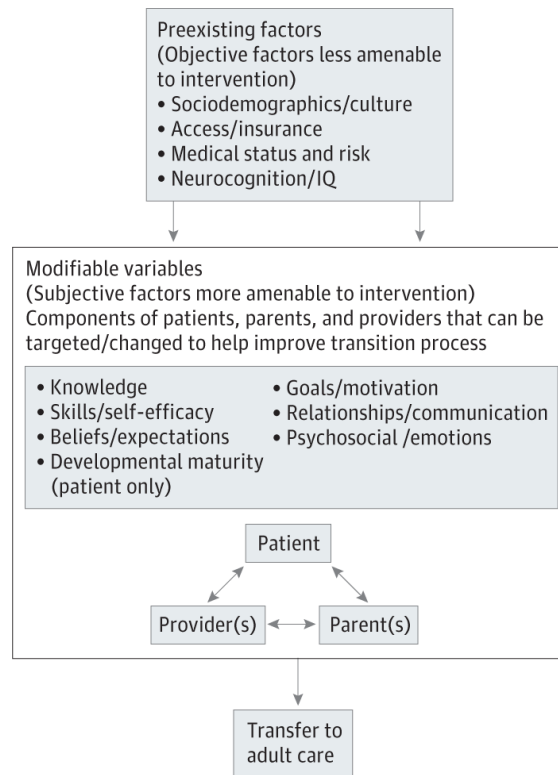


Figure 1.
Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) Model

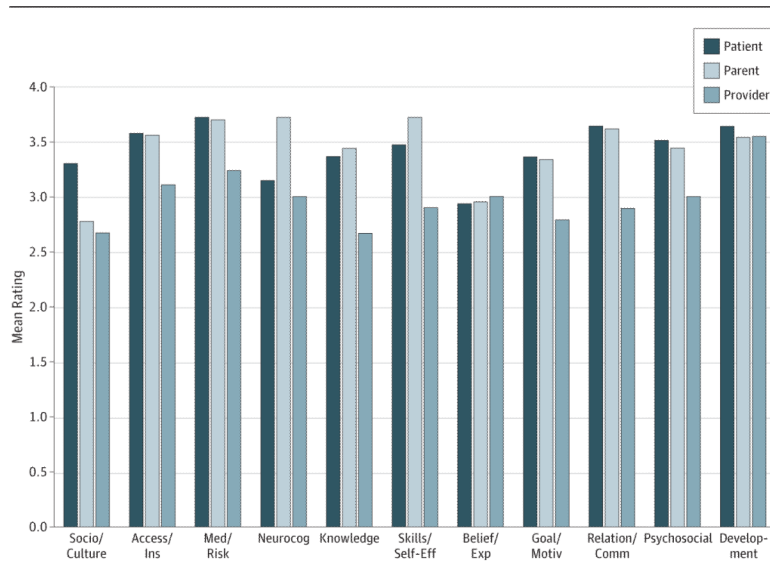


Figure 2. Ratings of Importance of Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) Components by Stakeholder Group

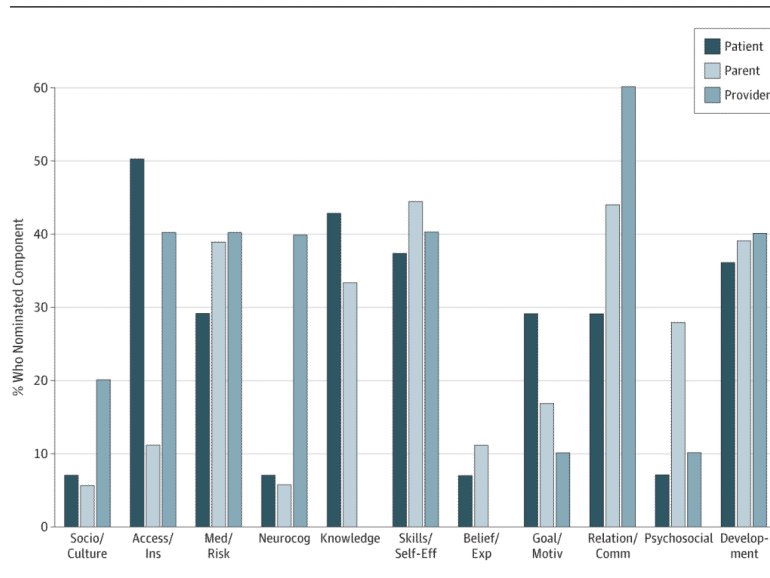


Figure 3. Comparison Between Patient, Parent, and Provider Nominations of Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) Components as a “Most Important” Component

Table**Demographics and Disease/Treatment Information of Patients and Parents^a**

	No. (%)	
	Patients (n = 14)	Parents (n = 18)
Demographics		
Age, y, mean (SD) [range]	21.93 (3.45) [16-28]	52.60 (7.41) [36-66]
Race/ethnicity		
White	8 (57)	12 (67)
Asian	4 (29)	4 (22)
African American/black	2 (14)	2 (11)
Female	8 (57)	16 (89)
Education		
High school	5 (36)	1 (6)
Some college or completed 2-y degree	2 (14)	4 (22)
4-y College degree	7 (50)	9 (50)
Graduate school	0	4 (22)
Marital status		
Single	9 (64)	1 (6)
Committed relationship	5 (36)	2 (11)
Married	0	15 (83)
Family income, \$ ^b		
<25 000	1 (7)	1 (6)
25 000-49 999	1 (7)	0
50 000-74 999	2 (14)	3 (17)
75 000-99 999	1 (7)	3 (17)
100 000	6 (43)	9 (50)
Personal income of patient, \$		
No personal income	6 (43)	...
<25 000	1 (7)	...
25 000-49 999	1 (7)	...
50 000-74 999	3 (21)	...
Employment status		
Not working	7 (50)	5 (28)
Part time	3 (21)	5 (28)
Full time	4 (29)	8 (44)
Disease/treatment ^c		
Diagnosis		
Leukemia	3 (21)	1 (25)
Lymphoma	3 (21)	1 (25)
Brain tumor	4 (29)	1 (25)
Other solid tumor	4 (29)	1 (25)

	No. (%)	
	Patients (n = 14)	Parents (n = 18)
Years since diagnosis, mean (SD) [range]	14.35 (5.30) [7-23]	13.83 (5.47) [7-24]
Treatment		
Major surgery	10 (71)	2 (50)
Chemotherapy	13 (93)	4 (100)
Irradiation	5 (36)	3 (75)
Bone marrow transplant	0	1 (25)
Years not receiving treatment, mean (SD) [range]	12.50 (5.92) [4-22]	12.35 (6.06) [3-22]
Relapse (yes)	3 (21)	1 (25)
Second cancer (yes)	2 (14)	0
Follow-up care		
Pediatric oncology provider	13 (93)	2 (50)
Adult oncology provider	1 (7)	0
Adult primary care provider	1 (7)	1 (25)
Pediatric primary care provider	0	0
No follow-up care	0	1 (25)

^aPercentages in each category may not add up to 100% because of missing data or participants who selected multiple options.

^bParent-reported family income was only reported once for married couples who participated together.

^cData in the Parent column for disease/treatment information represents the children of the parents who participated without their children (n = 4). Patient disease characteristics were reported by the parent unless a parent did not participate (n = 2).