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Why Mothers Accompany Adolescent and Young Adult Childhood Cancer Survivors to Follow-up Clinic Visits

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Abstract

Purpose—Parents often accompany adolescent and young adult (AYA) pediatric cancer survivors to follow-up oncology clinic visits and remain involved in their care, although little is known about their reasons for doing so.

Method—This mixed methods (qualitative–quantitative) study of 76 mothers of AYA survivors of childhood cancer uses content analysis and logistic regression to identify and explore reasons mothers provided for coming to the visit. Demographic and treatment data are examined as potentially explanatory factors.

Results—Ten reasons (in decreasing order of frequency) were derived: Concern for Child's Health and Well-Being, Practical Support, Transportation, Familial Experience, General Support, Companionship, Personal Interest in Follow-up Care, Characteristics of their Child, Emotional Support, and Parental Duty. The reasons were not related to demographic or treatment factors.

Conclusion—Mothers accompany AYAs to survivorship clinic for both maternal/family-focused and survivor-focused reasons that can be incorporated in survivorship and transition care to reflect ongoing communications among survivors, parents, and health care teams.

Keywords

adolescent and young adult; follow-up care; parents; survivorship; childhood cancer

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Declaration of Conflicting Interests

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Background and Significance

Survivors of childhood cancer must continue follow-up care in adulthood to identify and treat current or potential medical, psychological, and social late effects of cancer treatment and to promote general health. Many factors may affect how adolescent and young adult (AYA) survivors transition care from pediatric to adult settings, including aspects of the disease and treatment, sociodemographic characteristics, and role of the family (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Pediatric cancer care is often family-centered whereby parents are expected to be actively involved (Dix et al., 2009). Parents tend to continue to play an active role in the AYA period, with more than 60% of AYAs accompanied to follow-up visits by a parent (Ressler, Cash, McNeill, Joy, & Rosoff, 2003). There are many potential reasons why parents come to clinic, including lack of knowledge, parental anxiety, and practical support. Parents also view themselves as advocates and continue to accompany their AYA to oncology visits (Kinahan et al., 2008), which may be important in promoting the continued engagement of AYA survivors in long-term follow-up care. Alternatively, parents' continued presence at follow-up clinic visits could impede the transition to adult-centered care and the survivor's ability to manage his or her own health (Ginsberg, Hobbie, Carlson, & Meadows, 2006).

Little research has been conducted to identify parents' reasons for continuing to accompany their AYA on their visits to the survivorship clinic. Understanding parents' decision to accompany their AYA to follow-up visits may inform best practices related to promoting AYA disease self-management and readiness to transition to adult-focused follow-up care (Henderson, Friedman, & Meadows, 2010). This study used mixed methods (Sandelowski, 2000) in order to identify and explore mothers' reasons for accompanying their AYA to follow-up clinic visits and factors that may be associated with their attendance.

Method

Participants and Procedure

From March 2006 through August 2009, parents accompanying their AYA long-term cancer survivor to an oncology follow-up clinic appointment in a pediatric oncology program at a large children's hospital were approached for participation in this institutional review board–approved study. Parents consented to the study in follow-up clinic after the AYA consented to a separate but related institutional review board–approved study of psychological outcomes in cancer survivorship (see Kazak et al., 2010 for details). Demographic and disease/treatment data on the survivors are presented in Table 1. Of the 174 survivors participating in the related study, 139 (79%) had at least one parent accompany them to their visit. Five were excluded because of a non-English-speaking parent, resulting in 134 eligible families with at least 1 consenting parent (mothers only $n = 101$, fathers only $n = 21$, both parents $n = 24$).

As a result of sample size considerations, only maternal data were analyzed and reported. Of the 113 mothers who consented to the study, 75 (66%) completed the questionnaire packet analyzed in this study. The majority of respondents (92%) were Caucasian (age $M = 50.88$ years, $SD = 5.21$), and 87% were currently married. The sample was generally well-

educated; all were high school graduates, and 54% had completed college. No information is available regarding the nonresponding mothers.

Measures

Reasons for Accompanying AYA to Follow-up Visit—Participants provided a written response to the following questionnaire item, “Please describe the reasons why you came with your child to this medical visit today,” which was used for the qualitative analysis.

AYA Demographic and Treatment Information—Data on patient age, diagnosis, and whether the visit to the survivorship clinic was a first appointment was recorded from the medical record. The Intensity of Treatment Rating Scale 2.0 (ITR-2; Werba et al., 2007) was used to classify AYA childhood cancer survivors’ cancer treatment intensity on a 4-point scale based on data abstracted from the medical record related to diagnosis, stage, and treatment modality. Interrater reliability of ITR ratings, based on 2 raters (physician/nurse practitioner), for the entire sample is $r_s = 0.96$. Because of the limited number of survivors whose treatments were classified at the lowest level, treatment intensity was collapsed into 2 levels (least/ moderate intensity and very/most intensity).

Analysis

Content Analysis Procedures—Responses to the open-ended question from 76 mothers were analyzed using content analysis (Hsieh & Shannon, 2005). Responses were transcribed verbatim from the questionnaire to a spreadsheet with identifiable information removed. Codes were inductively derived from the data. The investigators added new codes and collapsed codes into broader categories as indicated by the analysis process. Analysis involved line-by-line independent coding by a study psychologist and a psychology fellow. Codes with similar meanings were placed into the same category. The coders met to discuss and determine the final list of categories (the coders met on a separate occasion to discuss emerging categories). The rigor of the data analysis process was strengthened through use of the constant comparative process when data were simultaneously examined within and across coding contexts. Together with a definition and a relevant example, each code and category was compiled into a codebook (Ryan & Bernard, 2003).

Quantifying the Qualitative Data—In order to ascertain how the qualitative data were related to other factors, the qualitative data were quantified. Research assistants (EKS, MB) independently reviewed the transcripts using the codebook, and indicated “1” when *a particular category was present* and “0” when *that particular category was absent* in the response. Codes were applied in a manner such that an individual response could receive multiple codes depending on the context of the response. Cohen’s kappa (Cohen, 1960) was calculated to determine interrater reliability, and any discrepancies in the analysis (ie, one investigator detected a presence of a category where another recorded an absence of the code) were resolved with arbitration by the psychology fellow (MCH; Carey, Morgan, & Oxtoby, 1996).

Calculating the Frequency of Responses by Category—All calculations were performed at the categorical level. Each category of reason was dichotomized to indicate whether the mother's response indicated at least one code within the category or not in their written responses.

Predictors of Reasons—Those categories that represented at least 20% of the sample (number of responses = 15) were identified and included in subsequent analyses in order to verify the relative importance of the issue and to assure that adequate data were available to understand the issue. Logistic regression analyses were then used to identify predictors for each reason derived. One model was constructed for each categorical variable to determine whether reasons for attending were related to objective characteristics of the survivor and their treatment. Independent variables (ie, predictors) included demographic variables (eg, gender, age, age at diagnosis), the intensity of treatment rating, and type of visit. Logistic regression analyses were performed using SPSS version 20.

Results

Categories Derived for Reasons for Accompanying AYAs to Medical Visits

Mothers provided 10 reasons for accompanying their AYA on their visit to the survivorship clinic. Table 2 provides details of the categories, subcategories, frequencies, interrater reliabilities (kappa) and examples of items. These reasons can be grouped into survivor-focused and maternal- or family-focused reasons.

Survivor-focused reasons included concern for the health and well-being of the survivor, characteristics of the AYA, general support, emotional support, practical support, and transportation. The clinic visit afforded mothers the opportunity to ask questions and seek reassurance about the AYA's health and necessary medical care. In addition, mothers mentioned specific characteristics or factors, such as the AYA's current age that they considered when deciding whether to attend the visit. Finally, mothers' attendance was meant to offer several kinds of support. Clinic attendance was seen as a demonstration of general support that is either provided spontaneously by the parents or requested by the AYA. They saw themselves as offering emotional support by providing sympathetic and compassionate comfort through listening, encouragement, and counsel. Mothers reported that they gave their AYA practical support, such as assisting with gathering and providing information during the appointment. Mothers reported concern that their AYA would not be able to manage the appointment alone, including gathering information about where to obtain future follow-up care. Given the distance, many AYA travel to the clinic; facilitating transportation was also a reason provided.

Maternal/family-focused reasons included parental duty, personal interest, family experience, and companionship. Mothers cited that thus involvement in their child's care was their parental responsibility. In addition, mothers said that they had a personal interest in follow-up care and that their personal attendance models the importance of follow-up care to their child. Mothers also said that clinic attendance was a family experience and was a customary event for which family participation is considered routine. Finally, apart from

providing support, mothers see their attendance as providing the AYA with companionship, regardless of whether it has been requested.

Quantification of Qualitative Data

Table 2 shows the frequency of responses by category. Concern for health and well-being and practical support were the most frequently mentioned reasons that mothers cited for attending clinic with their AYA survivor. The investigators obtained good ($\kappa = .61-.80$) or very good interrater agreement ($\kappa = .81-1.00$) for most categories. Differences in rating were resolved by arbitration, and therefore, no codes were removed from the analyses.

Predicting Reasons

Current age, age at diagnosis, the intensity of their child's treatment, gender, and whether this was the first or subsequent visit were not associated with the reasons mothers provided for being present at the survivorship clinic visit.

Discussion

This study describes reasons for the widely observed but little understood phenomena of continued maternal attendance at survivorship clinics for AYA childhood cancer survivors. Although ongoing parental attendance at survivorship clinic visits has been observed (eg, Kinahan et al., 2008; Ressler et al., 2003), the reasons why mothers accompany their AYA child to follow-up visits are not well documented.

Mothers attend clinic, in large part, out of concern for their AYA's health and well-being and to provide practical support. These two most frequently cited reasons are highly consistent with the role that the mother played throughout their child's illness and treatment and represent logical reasons for continuing to accompany their AYA survivor.

These mothers recognize the importance of engaging in long-term follow-up care (Kinahan et al., 2008) and are committed to offering ongoing support to assure the survivors' physical well-being and to ensure their AYA's engagement in follow-up care (Young, Dixon-Woods, Findlay, & Heney, 2002). At the same time, mothers may remain apprehensive about their AYA child's health and well-being long after the successful treatment of cancer, reflecting uncertainty about current and future health (Ginsberg et al., 2006). Coming to clinic visits may serve to reassure them (Kinahan et al., 2008), independent of the survivor's objective health. It is, however, interesting that concerns about new health problems or changes in overall health being communicated during the visit were prominent as reasons for attending and that more objective characteristics of the disease/treatments were not associated with specific reasons for attending clinic.

One of the more intriguing aspects of the study is understanding reasons for attending clinic that are focused on the mother and characteristics associated with being the parent of a cancer survivor. Mothers of childhood cancer survivors have often developed a strong sense of social competence as they have served as an advocate for their child for many years (Doshi et al., 2011). At the same time, childhood cancer treatment can remain a traumatic experience for parents, which may strengthen the enduring bond between parents and

children (Rourke et al., 2007). Mothers' beliefs about their own health and vulnerabilities may be associated with concerns about their child's health and also prompt them to remain invested in their child's health care (Doshi et al., 2011).

Parent attendance in follow-up care may be addressed differently across settings. For patients who continue care in a pediatric oncology follow-up program, parents often have close working relationships with the treatment team, and these collaborations may encourage ongoing engagement in clinic visits (Klassen, Gulati, & Dix, 2012). When transitioning from a pediatric cancer program to other survivorship programs, parental skill in navigating the health care system and providing detailed treatment information may be an asset. Regardless of setting, determining developmentally appropriate plans for transferring responsibility for care to AYAs is important. Reasons for attending clinic visits may also differ when initial visits are examined separately from ongoing visits or when the age of the AYA is considered in more detail.

The current study represents an initial step in understanding the role of parents in survivorship care. There are a number of limitations that must be recognized. First, caregivers of brain tumor survivors were not included in this study, but report higher levels of stress and uncertainty due to the high incidence of late effects, including neurocognitive impairments and may be more likely to attend clinic visits (Hutchinson, Willard, Hardy, & Bonner, 2009). Given the associated risk for ongoing dependence of their offspring on parents, their reasons for attending and the role at visits is likely different from the current sample.

Second, the sample is from one center and was primarily Caucasian and highly educated, likely reflecting more motivated parents than might be seen in a more representative sample. It is essential that future research in this area include a more diverse representation of pediatric cancer survivor families, given risks for health and mental health disparities (Meeske et al., 2013). Third, although the majority of parents who accompany their child to follow-up clinic visits are mothers (Kinahan et al., 2008; Ressler et al., 2003) and up to 77% of mothers identify themselves as the primary caregiver (Bonner et al., 2006), fathers are important caregivers in pediatric cancer whose unique understanding of survivorship and transition care is not well-understood. Inclusion of fathers in future research in this area will be important. Survivors also likely play a role in whether their parents attend clinic and it is important to understand this more fully in order to appreciate the role of parent attendance in follow-up care.

This study provides information that can inform nursing practice. Mothers attend follow-up visits as interested, committed, and competent parties and can participate in the development of care plans and communications among the survivor, family, and health care team (Kinahan et al., 2008). The specific role of the parent in the visit is determined by developmental and health considerations and health care teams must balance the involvement of parents with the need to treat the survivor as an adult patient. It may be helpful to note parental behavior in formulating approaches; for example, a parent who is anxious may be focused on getting his or her own questions answered rather than those of the survivor.

As the number of childhood cancer survivors who require long-term follow-up care increases, it is important to ensure transition from a pediatric to an adult health care setting guided by creative and flexible models that are inclusive of all stakeholders, including parents (Schwartz et al., 2013). Being accompanied by their mother may provide scaffolding and support for encouraging the transition to adult care, or conversely, might impede AYA survivors' ability to manage their own health care. Mothers are likely to attend clinic visits for reasons that are reasonable and focused on both their child and themselves. Understanding these reasons and expanding work in this area to understand the broader context of ongoing care may help to facilitate optimal outcomes for AYA survivors and their families.

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Table 1Demographic and Health Information of Adolescent and Young Adult (AYA) Childhood Cancer Survivor.^a

	AYA Child (n = 75)
	Mean (Standard Deviation)
Current age in years	19.31 (3.00)
Age at diagnosis in years	6.71 (5.013)
Time since diagnosis in years	13.19 (4.61)
Time since ending treatment in years	11.00 (4.58)
Number of medical late effects	5.77 (4.25)

	n	Percentage
Gender		
Male	35	46.7
Female	40	52.6
Current educational status		
In high school	20	26.7
High school graduate	5	6.7
In college	32	42.6
College graduate	18	24.0
Diagnosis		
Leukemia	33	43.4
Lymphoma	14	18.4
Solid tumors ^b	28	36.8
Intensity of treatment rating		
Least/moderate intensity	33	43.4
Very/most intensity	42	55.3
Type of visit		
First visit to survivorship clinic	9	11.8
Subsequent visit to survivorship clinic	63	82.9

^aSurvivor ethnicity was consistent with mother-reported ethnicity. The majority of survivors live with their parents (73%) and either work part-time (44%) or full-time (25%).

^bIncludes rhabdomyosarcoma (n = 5), Wilms's tumor (n = 9), retinoblastoma (n = 1), hepatoblastoma (n = 2), osteosarcoma (n = 3), Ewing's sarcoma (n = 4), germ cell tumor (n = 2), and neuroblastoma (n = 2).

Table 2

List of Categories and Themes Identified in Responses to “Please describe the reasons you came with your child to this medical visit today?”

Categories/Subcategories	Frequency	κ	Example
Concern for their child’s health and well-being	23	.81	
Health concerns			I am concerned about her health and continuing well-being. I also feel it is best to have more than just the patient present at important health appointments so as to gain the best understanding of what is said and done and also insure that nothing has been overlooked
Desire to know current medical advice care status			To know the long-term effects of chemo plus to ask questions about some concerns I had to her health in the future
Reassurance			Concern regarding my child’s bloodwork and physical. I need or like reassurance that he is doing well
Practical support	21	.75	
Gather information			Good opportunity to ask his doctor questions.
Provide information			To provide information
Assist survivor			I also feel it is best to have more than just the patient present at important health appointments so as to gain the best understanding of what is said and done and also insure that nothing has been overlooked
Transportation	17	.96	
General			Drive her to her yearly appointment
Child unable to drive			He doesn’t have a driver’s license and the train takes a lot longer than driving
Child able to drive but does not want/like to drive			She is a timid driver and doesn’t like driving into city
Distance			The distance is too far from our home, she cannot drive long distances and has no experience driving in the congested city Live 600 miles away
Family experience	16	.82	
Tradition			Yearly survivorship appointment. I have been coming with her for every appointment since the beginning
Shared family experience			I always come to these visits with her. We are in this together
Togetherness			I feel it’s a good time to be together, so we can talk about anything
General support	13	.80	
Be supportive			I came with my child today to be supportive
If needed			I come for support and want to be there if needed
Demonstration			Support; demonstration of continuing support
Requested/preferred by child			She asked me to come with her to keep her company and give her some support
Companionship	9	.68	
Spend time with survivor			To keep her company and to be with her
Requested by child			We did talk about whether she’d want to come alone and she said she could, but prefers company
Not objected by child			She didn’t ask me to come but she didn’t tell me not to come. If she didn’t want me to come she would have told me
Personal interest in follow-up care	7	.75	
Facilitate transition of health care responsibility			Familiarize my son with the appointments so he can take over care of his health as he grows to an adult

Categories/Subcategories	Frequency	κ	Example
Learn about survivorship care			To get introduced to the survivor clinic and see what they have to offer my daughter
Wants to be included in survivorship care			This is a new step. I wanted to be included in what was taking place
Teach/model importance of follow-up care			I wanted a coordinated effort in looking at her health and I want to teach her to look at her health as a cancer survivor I also wanted to show my child that I think it is important to keep up these visits—if I take time out of a busy day to come here, she should too
Characteristics of their child	4	1.00	
Survivor demographic characteristics			My daughter is only 17 and needs a legal guardian to sign for her
Parental duty	4	.65	
Parental duty			Have committed to coming with him to every visit together as parents.
Parental logistics/availability			The timing worked with my day off and my husband is retired but working another full-time job but has less time off
Emotional support	5	.83	He needs moral support—it is difficult for him to come