

1-1-2019

Challenges to Family Management for Caregivers of Adolescent and Young Adult Survivors of Childhood Brain Tumors [Formula: see text].

Nicole SanGiacomo

Children's Hospital of Philadelphia, Philadelphia, PA

Jennifer Toth

Children's Hospital of Philadelphia, Philadelphia, PA

Wendy Hobbie

Children's Hospital of Philadelphia, Philadelphia, PA, hobbie@chop.edu

Elizabeth Broden

Elizabeth Ver Hoeve

See next page for additional authors

Follow this and additional works at: <https://digitalrepository.chop.edu/advpractice>



Part of the [Oncology Commons](#), [Pediatric Nursing Commons](#), and the [Pediatrics Commons](#)

Citation


SanGiacomo, N., Toth, J., Hobbie, W., Broden, E., Ver Hoeve, E., Knafl, K., Barakat, L., Ogle, S., & Deatrck, J. (2019). Challenges to Family Management for Caregivers of Adolescent and Young Adult Survivors of Childhood Brain Tumors [Formula: see text]. *Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses*, 36 (6), 402-412. <https://doi.org/10.1177/1043454219844229>


This Article is brought to you for free and open access by the Nursing & Clinical Care Services at CHOP Digital Repository. It has been accepted for inclusion in Center for Advanced Practice by an authorized administrator of CHOP Digital Repository.

Authors

Nicole SanGiacomo, Jennifer Toth, Wendy Hobbie, Elizabeth Broden, Elizabeth Ver Hoeve, Kathleen A Knaf, Lamia Barakat, Sue Ogle, and Janet A Deatrck

Challenges to Family Management for Caregivers of Adolescent and Young Adult Survivors of Childhood Brain Tumors

Journal of Pediatric Oncology Nursing
2019, Vol. 36(6) 402–412
© 2019 by Association of Pediatric
Hematology/Oncology Nurses
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1043454219844229
journals.sagepub.com/home/jpo


Nicole SanGiacomo, BSN, RN^{1,2}, Jennifer Toth, BSN, RN, CPHON^{1,2},
Wendy Hobbie, RN, MSN, CRNP, FAAN¹, Elizabeth Broden, BSN, RN²,
Elizabeth Ver Hoeve, MA^{2,3}, Kathleen A. Knafl, PhD, FAAN⁴,
Lamia Barakat, PhD^{1,2}, Sue Ogle, RN, MSN, CRNP¹,
and Janet A. Deatrck, PhD, RN, FAAN² 

Abstract

Due to the complexity of cancer late effects, the education required to provide anticipatory guidance and support to the caregivers of adolescent and young adult (AYA) survivors of childhood brain tumors can be difficult. Therefore, identifying challenges to family management (FM) could be helpful in anticipating complications with the integration of tumor and treatment late effects into family life. Building on previous research that described FM for children with chronic conditions, children who survived cancer, and the Family Management Styles Framework, the purpose of this study was to identify FM challenges for caregivers of AYA survivors of childhood brain tumors to guide clinical practice and research. Directed content analysis was used to identify FM challenges in data from semistructured interviews with 45 maternal caregivers for AYA survivors of childhood brain tumors living with them. Caregivers were largely White (89%) with an average age of 52 years, educated beyond the high school level (67%), and were partnered or married (53%). On average, caregivers had been caring for the AYA for 21 years since diagnosis, and 56% of their survivors had moderate functional restrictions. A primary and a secondary analyst were assigned to the data for each interview and completed a single summary matrix. A list of challenges was created by the research team based on Family Management Styles Framework, the literature, and clinical expertise. Seven core challenges to FM were identified: ensuring survivor well-being, supporting survivor independence, encouraging sibling well-being, planning family activities, sustaining parents as caregivers, attending to survivor late effects, and providing support and advocacy.

Keywords

adolescents and young adults, oncology, challenges, family functioning, family management

Introduction

Adolescent and young adult (AYA) survivors of childhood brain tumors are the most affected of all childhood cancer survivors according to critical indicators of long-term functioning and development (Bhakta et al., 2017). Physical, cognitive, and psychosocial late effects worsen over time and can affect developmental outcomes. These late effects have the potential to interfere with developmental milestones such as achieving vocational goals, living independently, seeking lasting friendships and relationships, and pursuing educational or career-related opportunities. AYAs' cognitive (e.g., impaired executive functions) and psychosocial late effects can also limit insight into their own functioning, capacity for independence, and self-management

capabilities (day-to-day management of their chronic conditions) (Brinkman et al., 2016). Families are tasked with managing the special needs of the AYA (Palma et al., 2015) at the same time they are hoping to maximize the AYA's self-management and health-related quality of life (HRQL) (Hobbie et al., 2016).

¹Children's Hospital of Philadelphia, Philadelphia, PA, USA

²University of Pennsylvania, Philadelphia, PA, USA

³University of Arizona, Tucson, AZ, USA

⁴University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

Corresponding Author:

Nicole SanGiacomo, BSN, RN, Children's Hospital of Philadelphia,
115 South 21st Street, Philadelphia, PA 19103, USA.
Email: sangiacomn@email.chop.edu

These AYA survivors and their family caregivers (usually their mothers) remain underserved and understudied. Through the identification of the core challenges to family management (FM), we hope to develop interventions that support these families in meeting and addressing these challenges. FM is based on the Family Management Styles Framework (FMSF) that conceptualizes how a family incorporates the care for their child's chronic condition or cancer into family life and addresses the interrelated nature of those responses among family members. Key components of FM are assessed by the Family Management Measure (FaMM) and relate to how the family views the survivor (AYA daily life), family (AYA' condition and future; family life; family working together), and caregiver (caregiver's confidence; caregiving effort) (Knafl, Deatrick, & Havill, 2012). The FaMM has been used to study both mothers and fathers in various populations of children with chronic conditions. (Fleming, Knafl, Knafl, & Van Riper, 2017; Van Riper, Knafl, Roscigno, & Knafl, 2017)) and cancer.

Patterns of family management for AYA survivors of childhood brain tumors were identified and validated using quantitative (caregiver/mother, child, and family measures), qualitative (interviews with mothers identified as caregivers), and mixed methods (Deatrick et al., 2018; Knafl et al., 2013) analyses. Quantitative validation measures included maternal, survivor, and professional assessments. Finally, the family management patterns were compared with those of children with data on family management patterns for children with chronic physical conditions (Knafl et al., 2013).

Four distinct family management patterns were identified (family-focused, somewhat family-focused, somewhat condition-focused, and condition-focused), which correlated significantly and meaningfully with the aforementioned caregiver, survivor, and professional data. Families either focus on incorporating the special needs of the AYA into the usual family routine (family-focused patterns) or organize family life around those needs (condition-focused patterns), with the latter linked to poorer child, caregiver, and family outcomes. Condition-focused families, by definition, report that symptom and condition management required considerable effort. These families often question their ability to manage their child's symptoms effectively. Alternatively, mothers in the family-focused patterns reported confidence in their abilities to manage their child's needs into their lives. AYA child adaptation and family functioning worsened from family-focused to condition-focused patterns. When these family management patterns were compared with those of children with chronic physical conditions, they were identified as being similar (Knafl et al., 2013; Van Riper, Knafl, Roscigno, & Knafl, 2018). Through the utilization of this information discovered from the parent

study, this systematic qualitative analysis intended to identify and describe the nature of the core family management challenges facing families of AYA of childhood brain tumors and to compare them within and across family management patterns.

Method

This institutional review board-approved study was a follow-up to a larger telephone survey collecting quantitative data regarding family management and HRQL from 189 mothers and 126 AYA who were willing and able to participate. The larger study of family management in brain tumor survivorship sought to describe a typology of family management patterns for AYA survivors of childhood brain tumors, validate the patterns using quantitative and qualitative data, and compare the patterns of family management patterns with those of children with chronic health conditions. For the larger study, potential participants were identified in the hospital cancer registry in the Mid-Atlantic area of the United States and then screened and recruited in telephone interviews. Inclusion criteria were maternal caregivers of survivors who were (a) diagnosed with brain tumors, (b) at least 5 years from diagnosis, (c) at least 2 years from discontinuation of treatment, (d) aged 14 to 40 years (National Cancer Institute, 2017), (e) living in the same household as the caregiver, and (f) legally related to the mother. For inclusion, the maternal caregivers also had to be acknowledged as the primary caregiver by herself and the survivor. Maternal caregivers were excluded if the survivors were (a) married or living in a partnered relationship, (b) diagnosed with genetic basis for brain tumor (e.g., neurofibromatosis 1), (c) diagnosed with mental retardation or developmental delay prior to cancer, or (d) not able to speak English or read independently at about fifth- to sixth-grade level. At the end of the larger study, all participants agreed to be recontacted for the follow-up qualitative home interview. A purposive, maximum variation subsample ($n = 56$ mothers) was then selected from 118 (87%) mothers from the parent study who lived within driving distance from the hospital (Patton, 2002). Participants were invited to participate in the home interview based on the nature and intensity of caregiver demands revealed during the telephone interviews. Fifty-two mothers could be contacted; 3 mothers were ineligible; 1 mother declined; and 3 interviews could not be scheduled resulting in 45 mothers consenting and completing home interviews (Knafl et al., 2013).

Qualitative Semistructured Interview

In the parent study, a semistructured interview guide was constructed by members of the research team with

Table 1. Sample Questions From the Maternal Interview Guide.

Rationale/Area of interest	Sample questions
Joining with the interviewee	<ul style="list-style-type: none"> • How has your life changed since your son/daughter was diagnosed with a brain tumor? • Tell me a recent story about what it means to you to be a mother/ caregiver for your son/daughter who survived a brain tumor.
Condition management effort	<ul style="list-style-type: none"> • How does your child's physical and/or cognitive functioning affect you and your role as mother and caregiver? • Has this changed? How does that affect your family? • How do you assist your adolescent or young adult with whatever is important to you or him/her? • Tell me a recent example of a particular struggle you faced as your child's caregiver? • What resources are you aware of and which have you used to assist you and your child? • How should health care providers help you with your caregiving?
Condition management ability	<ul style="list-style-type: none"> • What issues influence how you feel about yourself as a mother/caregiver to your son/daughter? Your family? • Tell me about your "ups and downs." • How do you feel about your abilities as a mother/caregiver? • How do the issues that you described in your story (and other issues) affect how you feel about yourself as a mother/caregiver to your son/daughter? Your family? Probe for beliefs, roles, processes, behaviors.
What other issues influence how your family functions, the effort you use to manage, or how you see yourself as a caregiver in terms of your ability?	<ul style="list-style-type: none"> • What about your son or daughter's quality of life? <ul style="list-style-type: none"> ◦ I noticed on the survey you completed about your son's or daughter's quality of life you said (XYZ). Does your assessment of his/her physical and psychological quality of life influence you as a caregiver? How? ◦ How do these issues influence the demands on you as a caregiver? ◦ How do these issues influence how you see your abilities as a caregiver?

expertise in qualitative interviewing, FMSF, pediatric oncology, and cancer survivorship. Following pilot testing with five mothers to strengthen content validity, the guide was modified to clarify wording and fully address topics respondents identified as important aspects of their family management. An interview structure was created to progress from a broad opening question, which was meant to encourage a conversation with the interviewer, to three questions pertaining to the various facets of family management. Each of the three questions had five to six probes that could be used based on mothers' responses to encourage further elaboration of their experiences. See Table 1 for sample questions from the interview guide (Hobbie et al., 2016; Palma et al., 2015).

The interviews were conducted face-to-face in a private setting in the maternal caregivers' home by the senior author (JD) after maternal caregivers provided written consent. Interviews, on average, were 46 minutes in duration. After the interview, the maternal caregivers received \$20 for their participation. Interviews were digitally recorded, shared with a professional transcription service by a secure file transfer drop box, transcribed verbatim by the transcription service, and stored on a secure server. In addition to the transcriptions, case summaries and field notes were included in the analyses.

Analysis

To identify and summarize key data concerning family management challenges, the two authors (KK and JD) who are two of the developers of the FMSF created a structured template for summarizing data from each participant related to the major dimensions of the framework. Using directed content analysis, data relevant to each dimension of the FMSF were transcribed into a summary matrix for each respondent (Table 2) (Hsieh & Shannon, 2005). The matrix summary process was pilot tested and refined by two of the authors (KAK and JAD). A primary and secondary analyst (JT, JAD, NS) completed the matrix summaries for the remaining interviews (Ayres, Kavanaugh, & Knafel, 2003). While the primary analyst completed the initial matrix summary, the second analyst reviewed the matrix to ensure accuracy and completeness.

After this matrix was completed for each of the 45 interviews, challenges to family management were identified within each family and within each family management pattern. Challenges were also compared across all four FM patterns (Table 3). The resulting list of challenges was then summarized by the research team. During preparation of the results, examples of each of these challenges were identified from the summarized materials.

Table 2. Example Data Matrix for Within-Case Analysis of One Family Management Scale—Mother of a 25-Year-Old Male Survivor of a Craniopharyngioma Diagnosed at Age 5 Years.

Scale	Evidence	Interpretation
Child's daily life-Child's daily life focuses on parents' perceptions of their child and the child's everyday life. More positive views indicate that a child has a more typical adolescent and adult life despite the condition.	"As far as in [name]'s world, food is 24/7. Everything and anything he does revolves around food. I can honestly say he's never been happy, because he doesn't allow himself to be happy, 'cause that would mean to stop thinking about food. He never enjoys anything, because everything is around, when's my next snack when my . . . you know, as you can see, I padlock everything."	Mother sees survivor as not like his peers. Daily life revolves around food. Survivor has limited insight. Challenges: Survivor late effects Survivor well-being

Rigor of the analysis was strengthened by using a team of analysts and documenting the analysis so the process could be audited (Whittemore, Chase, & Mandel, 2001; Wu, Thompson, Aroian, McQuaid, & Deatrck, 2016). Any inconsistencies between the primary and the secondary analyst were discussed by the team and resolved before further analyses were completed. The audit trail was documented in Excel to record how the analysis proceeded from specific case-related examples of challenges to broader conceptually consistent cross-case related challenges.

Results

Demographic Characteristics

The sample for this study ($n = 45$) is described in detail elsewhere (Deatrck et al., 2018). Caregivers were mostly White (89%), had some college education or higher (66%), were partnered or married (53%), and were employed full-time (56%). Their average age was 52 years, and they had been caregivers for an average of 21 years, and all were biologically related to the survivor. The average age of the survivors was 21 years; 62% were male; 56% had moderate restriction to daily activities; and 47% of their tumors were in the posterior fossa.

Challenges Across Family Management Patterns

Seven core challenges to FM were identified from these data and the FMSF: Ensuring Survivor Well-Being, Supporting Survivor Independence, Encouraging Sibling Well-Being, Planning Family Activities, Sustaining Parents as Caregivers, Attending to Survivor Late Effects, and Providing Support and Advocacy. These challenges are viewed as common problems that arise for caregivers and families in caring for or managing the late effects of their AYA survivor. These often include issues that also

affect balancing the needs of the AYA with the needs of the family. These challenges are defined, and examples are given in Table 3.

Three of these challenges focused on the survivor (Supporting Survivor Independence, Ensuring Survivor Well-Being, Attending to Survivor Late Effects). *Supporting Survivor Independence* incorporates encouraging the AYA to function independently and develop self-management skills to the degree thought possible by the family member(s). *Ensuring Survivor Well-Being* addresses issues encountered concerning the AYA physical, emotional, and social quality of life. *Attending to Survivor Late Effects* focuses on understanding and managing specific late effects of the brain tumor and its treatment.

Two challenges focused on the parent(s) (Sustaining Parents as Caregivers, Providing Support and Advocacy). *Sustaining Parents as Caregivers* describes the issues of incorporating the responsibilities for both roles over a sustained length of time. That is, due to the late effects the AYA experienced, they remained involved as both parents and caregivers well into the AYA phase of life. *Providing Support and Advocacy* addresses the helpfulness of others to the caregiver in the direct caregiving role, the issues encountered when advocating on behalf of the survivor, and the potential impact of that support and advocacy on the well-being of the survivor, caregiver, and family. Last, two of the challenges focused on family life (Planning Family Activities, Encouraging Sibling Well-Being). *Planning Family Activities* discusses negotiating activities that include the survivor and are considered usual for the family (AYA, parents, siblings). *Encouraging Sibling Well-Being* addresses balancing the needs and concerns of AYA with those of siblings.

Each of the families and mothers discussed in this study appeared to face similar challenges. These challenges, however, were addressed differently across the previously identified FM patterns as shown in Table 3. Mothers in condition-focused and somewhat condition-focused families expressed difficulty meeting the FM

Table 3. Challenges to Family Management for Adolescent and Young Adult (AYA) Survivors of Childhood Brain Tumors.

		Summary of implications for each family management pattern				
Family management challenge	Description	Examples of mother's perspectives	Family-focused	Somewhat family-focused	Somewhat condition-focused	Condition-focused
Supporting survivor independence	Encouraging the AYA to function independently and develop self-management skills to the degree thought possible by the family member(s) and optimally by the AYA	<ul style="list-style-type: none"> • Mother doubts if survivor will be able to live independently, sees no end to caregiving role • Survivor has lack of insight to be able to understand limitations regarding the ability to be independent • Survivor not being able to meet milestones (i.e., driving) highlights differences in his abilities from peers and siblings 	Voices satisfaction with the AYA ability to function as independently as possible and being able to help them develop self-management skills to the degree thought possible by the family member(s)	Voices some satisfaction with the AYA ability to function independently in terms of their self-management relative to his/her potential	Voices some dissatisfaction with the AYA ability to function in terms of their self-management skills relative to his/her potential	Voices dissatisfaction with the AYA ability to function independently in terms of their self-management skills relative to their potential
Sustaining parents as caregivers	Describes issues faced when incorporating the responsibilities for both roles over a sustained length of time. That is due to the AYA late effects, they remained involved as both parents and caregivers well into the AYA phase of life	<ul style="list-style-type: none"> • Mother views AYA's unhappiness as a reflection of her caregiving abilities • Mother feels powerless to manage AYA's emotional outbursts and behaviors • Mother relies on various support systems (extended family, faith community, etc.) • Mother finds meaning in volunteering/giving back to various cancer-related organizations and research • Mother is overwhelmed with multiple caregiving demands, including AYA, family, parents, and self • Mother feels competent in caring for the survivor, but it requires a lot of effort, which others many not see or recognize 	Voices that he/she is comfortable with the responsibilities of being both a caregiver and a parent	Voices that he/she is comfortable with some aspects of being a caregiver and a parent	Voices some discomfort with some aspects of being a caregiver and a parent	Voices discomfort with most aspects of being a caregiver and a parent

(continued)

Table 3. (continued)

Summary of implications for each family management pattern						
Family management challenge	Description	Examples of mother's perspectives	Family-focused	Somewhat family-focused	Somewhat condition-focused	Condition-focused
Providing support and advocacy	Addresses the helpfulness of others to the caregiver in the direct caregiving role, the issues encountered when advocating on behalf of the survivor, and the potential impact of that support and advocacy on the well-being of the survivor, caregiver, and family	<ul style="list-style-type: none"> Community resources are not a fit for AYA's needs and provides little support for mother Mother has to continually advocate for AYA in order to obtain services (school, insurance, employment, etc.) Mother finds value in advocating for other parents of brain tumor patients through web-based forums Mother feels uncertain about the future with regard to the survivor's health, quality of life, and ability to live independently AYA has difficulty meeting new people and making friends, which caregiver feels affects quality of life Mother has developed problem-solving skills to address AYA quality of life challenges 	Satisfied with the attempts of others to assist them regarding caregiving and advocacy; cites a somewhat positive impact of this support on the well-being of the survivor, caregiver, and family	Moderately satisfied with the attempts of others to assist them regarding caregiving and advocacy; cites a somewhat positive impact of this support on the well-being of the survivor, caregiver, and family	Moderately unsatisfied with the attempts of others to assist them regarding caregiving and advocacy; cites a somewhat negative impact of this lack of support on the well-being of the survivor, caregiver, and family	Unsatisfied with the attempts of others to assist them regarding caregiving and advocacy; cites a negative impact of this lack of support on the well-being of the survivor, caregiver, and family
Ensuring survivor well-being	Addresses issues encountered concerning the AYA physical, emotional, and social quality of life	<ul style="list-style-type: none"> Mother feels uncertain about the future with regard to the survivor's health, quality of life, and ability to live independently AYA has difficulty meeting new people and making friends, which caregiver feels affects quality of life Mother has developed problem-solving skills to address AYA quality of life challenges 	Feels confident with the ability to address issues regarding the AYA physical, emotional, and social quality of life; success with incorporating survivor functioning into everyday family life	Somewhat confident with the ability to address issues regarding the AYA physical, emotional, and social quality of life; some success with incorporating survivor functioning into everyday family life	Not confident with the ability to address some issues regarding the AYA physical, emotional, and social quality of life; feels moderately unsuccessful with incorporating survivor functioning into everyday family life	Not confident with the ability to address issues regarding the AYA physical, emotional, and social quality of life; feels unsuccessful with incorporating survivor functioning into everyday family life
Attending to survivor late effects	Understanding and managing specific late effects of the brain tumor and its treatment	<ul style="list-style-type: none"> Scheduling follow-up appointments is anxiety provoking for mother AYA with vision and hearing deficits that affect daily life AYA requires help managing appointments and care as well as medications and daily care tasks 	Describes an understanding of late effects and an ability to incorporate management of specific late effects of the brain tumor and its treatment into family life	Describes some understanding of late effects and an ability to incorporate management of specific late effects of the brain tumor and its treatment into family life	Describes moderate difficulty with understanding late effects and incorporating management of specific late effects of the brain tumor and its treatment into family life	Describes an inability to understand late effects and incorporate management of specific late effects of the brain tumor and its treatment into family life

(continued)

Table 3. (continued)

Summary of implications for each family management pattern						
Family management challenge	Description	Examples of mother's perspectives	Family-focused	Somewhat family-focused	Somewhat condition-focused	Condition-focused
Planning family activities	Negotiating activities that include the survivor and are considered usual for the family (AYA, parents, siblings)	<ul style="list-style-type: none"> Extended family members do not understand the challenges faced by mother and AYA when planning family activities Managing the survivor's condition is a major focus of family life and preclude family activities 	Able to negotiate the planning of activities that include the survivor and are considered usual for the family (AYA, parents, siblings)	Some difficulty in planning of activities that include the survivor and are considered usual for the family (AYA, parents, siblings)	Moderate difficulty in planning of activities that include the survivor and are considered usual for the family (AYA, parents, siblings)	Unable to plan activities that include the survivor and are considered usual for the family (AYA, parents, siblings)
Encouraging sibling well-being	Ability to balance the needs and concerns of AYA with those of the siblings and family	<ul style="list-style-type: none"> Siblings are protective but also resentful toward AYA Sibling with posttraumatic stress disorder from survivor's treatment Mother worries that the AYA will be a burden on siblings in the future when mother can no longer be a primary caregiver 	Able to balance the needs and concerns of AYA with those of the siblings and family	Some difficulty in balancing the needs and concerns of AYA with those of the siblings and family	Not able to consistently balance the needs and concerns of AYA with those of siblings and family	Unable to balance the needs and concerns of AYA with those of siblings and family

challenges and cited issues particularly related to problem-solving. Family-focused families used successful strategies for incorporating FM challenges into everyday family life. Somewhat family-focused families emphasized successful incorporation of condition management into everyday family life but to a lesser degree than those who were family-focused. Somewhat condition-focused families emphasized effort and difficulties with condition management and the impact of the condition on their child and family but to a lesser degree than those who were condition-focused. Condition-focused families were unable to incorporate changes in survivor functioning into family life and spent much effort attempting to manage the survivor's condition.

Discussion

These findings further support and inform FMSF theory, assessment, and application to future research and clinical care for this special population. Seven core challenges to FM for mothers of AYA of childhood brain tumors were identified across four patterns of FM based on FMSF. The challenges included Ensuring Survivor Well-Being, Supporting Survivor Independence, Encouraging Sibling Well-Being, Planning Family Activities, Sustaining Parents as Caregivers, Attending to Survivor Late Effects, and Providing Support and Advocacy. These core challenges were categorized as addressing and examining the impact on the survivor, parent/caregiver, and family. Explicating these theoretically based challenges can help understand practical and modifiable challenges and unmet needs of AYA and their families.

Understanding the challenges that are common across AYA is critical because they can be translated into actionable clinical and educational foci for clinicians, researchers, and policy makers. In fact, the consensus group that makes recommendations for patient/family education for newly diagnosed pediatric oncology patients identified the importance of developing such core informational content that can be individualized for application (Landier et al., 2016). This method has also been used as a standard for education in other pediatric chronic illnesses, such as type 1 diabetes (Silverstein et al., 2005), asthma (National Asthma Education Prevention Program, 2007), and sickle cell disease (Yawn et al., 2014). Because the larger FM study was theoretically based, the interdisciplinary research team was able to relate the data to a larger body of research about youth with other chronic health conditions and develop scientific knowledge related to the same. As such, this study illuminated that although families may differ in terms of their FM patterns, the challenges they face as they care for their AYA are remarkably similar. In addition, the qualitative evidence about the differences in the ability of maternal

caregivers to problem solve across FM patterns was important when interpreting study results.

Clinicians must be prepared with knowledge and skills to educate and support caregivers regarding how they integrate condition management into family life. A recent survey of oncology nurses reported a relatively low level of confidence, knowledge, and skills for supporting caregivers (Irwin et al., 2018). While the survey did not specify the percent of adult and pediatric respondents, the education of providers obviously needs to include family and caregiver issues throughout the life cycle. While other members of the interdisciplinary team are important in this work, most of the challenges identified in this study are issues that are central to that of the role of nurses. Explicating these theoretically based challenges is critical to the development of nursing skills because these challenges can guide professional's understanding of the issues confronting AYA survivors of childhood brain tumors, caregivers as they balance the roles of caregiver and parent, and families as they balance the needs of all family members (Deatrack et al., 2014).

Using these challenges as guidelines, members of the (multi) interdisciplinary team can provide targeted education, psychosocial support, and anticipatory guidance to assist with the decision making/intervention/advocacy that might be required as families face these challenges. Caregivers and families who are condition-focused, however, may be taught and advised about the survivor's late effects and other challenges only to have such guidance reinforcing the centrality of the late effects in family life instead of how they can integrate the management of the late effects into family life, so they are no longer the focus. Therefore, such education may better be reframed into how the caregiver and family can problem solve the issues that they systematically identify within the challenges identified in this study. For instance, using such an approach, the provider may find that the survivor has virtually no independent self-care skills (e.g., dressing, food preparation) and begin their work with the AYA and family based on them identifying how the AYAs' lack of self-care skills affects not only the survivor but also the caregiver and family. Then the provider can help them problem solve steps in developing basic self-care skills within ongoing family life and evaluate their success or results based not only on the survivors but also the caregiver and family.

The Children's Oncology Group seeks to address problem-solving concerns of the newly diagnosed pediatric oncology populations through workshops with nurses, social workers, counselors, clergy, and psychologists using an efficacious problem-solving curriculum, Bright IDEAS for Everyday Living. Participants are taught skills to work with parents of children with cancer to improve their problem-solving and to decrease their distress (Kirch et al., 2016).

This research indicated that condition-focused families face significant issues regarding problem-solving and condition management. Although support is provided to families and pediatric cancer patients through evidence-based problem-solving interventions such as Bright IDEAS for Everyday Living, there are no such efficacious interventions that target the needs of pediatric cancer survivors and their caregivers (Deatrack et al., 2014). The results of this project could prompt the development of an intervention that integrates FMSF with Bright IDEAS that targets these core challenges. Such an intervention could improve problem-solving, which in turn could potentially improve condition management. Qualitative and quantitative outcomes could include survivor (e.g., quality of life), caregiver (e.g., quality of life), and family (e.g., functioning) as well as important clinically related variables (Deatrack et al., 2014) using data from the survivor, caregiver, family, and health care professional.

In addition, our system of survivorship care needs to address the needs of these caregivers from a population perspective (Perez et al., 2018). These caregivers had little education or guidance on how to manage these unique issues save a visit once a year if they were fortunate enough to be engaged in a program that understands the unique needs of the AYA and their caregivers (Schubart, Kinzie, & Farace, 2008). Leadership in pediatric oncology and adult oncology settings need to ask themselves, "What kind of integrated services are being provided to AYA and their families?" "What kind of services are provided to AYA and their families like the ones included in this study who are were diagnosed more than two decades ago and whose AYA are living at home with them and have moderate functional difficulties?" Populations of AYA who survived childhood cancer or other serious childhood conditions provide compelling reasons to design evidence-based systems of accessible care.

In the interest of future research, certain limitations should be addressed. The primary limitations of this cross-sectional study are its lack of diversity. This study is most representative of White, married, non-Hispanic maternal caregivers who are educated and who have economic resources. Although the vast majority of caregivers investigated are mothers, there are other caregivers involved in the AYA life (i.e., fathers, grandparents, siblings) who should also be studied. Systematic investigation of other family members and how they might interpret these challenges would be beneficial. Furthermore, future research should address using participatory methods to develop an intervention focused around these seven FM challenges (Kazak et al., 2015) that integrates FM and problem solving.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: All phases of this study were supported by an NIH grant (RO1 NR009651) to Janet A. Deatrack (PI) and a grant from the Oncology Nursing Foundation to Janet A. Deatrack (PI).

ORCID iD

Janet A. Deatrack  <https://orcid.org/0000-0002-6447-3259>

References

- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research, 13*, 871-883. doi:10.1177/1049732303013006008
- Bhakta, N., Liu, Q., Ness, K., Baassiri, M., Eissa, H., Yeo, F., . . . Robison, L. L. (2017). The cumulative burden of surviving childhood cancer: An initial report from the St. Jude Lifetime Cohort Study (SJLIFE). *Lancet, 390*, 2569-2582. doi:10.1016/50140-6736(17)31610-0
- Brinkman, T. M., Krasin, M. J., Liu, W., Armstrong, G. T., Ojha, R. P., Sadighi, Z. S., . . . Krull, K. R. (2016). Long-term neurocognitive functioning and social attainment in adult survivors of pediatric CNS tumors: Results from the St. Jude lifetime cohort study. *Journal of Clinical Oncology, 34*, 1358-1367. doi:10.1200/JCO.2015.62.2589
- Deatrack, J. A., Barakat, L. P., Knafl, G. J., Hobbie, W., Ogle, S., Ginsberg, J. P., . . . Knafl, K. A. (2018). Patterns of family management for adolescent and young adult brain tumor survivors. *Journal of Family Psychology, 32*, 321-332. doi:10.1037/fam0000352
- Deatrack, J. A., Hobbie, W., Ogle, S., Fisher, M. J., Barakat, L., Hardie, T., . . . Ginsberg, J. P. (2014). Competence in caregivers of adolescent and young adult childhood brain tumor survivors. *Health Psychology, 33*, 1103-1112. doi:10.1037/a0033756
- Fleming, L., Knafl, K., Knafl, G., & Van Riper, M. (2017). Parental management of adrenal crisis in children with congenital adrenal hyperplasia. *Journal for Specialists in Pediatric Nursing, 22*, e12190. doi:10.1111/jspn.12190
- Hobbie, W. L., Ogle, S., Reilly, M., Barakat, L., Lucas, M. S., Ginsberg, J. P., . . . Deatrack, J. A. (2016). Adolescent and young adult survivors of childhood brain tumors: Life after treatment in their own words. *Cancer Nursing, 39*, 134-143. doi:10.1097/NCC.0000000000000266
- Hsieh, H.-F., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277-1288. doi:10.1177/1049732305276687
- Irwin, M. M., Dudley, W., Northouse, L., Berry, D. L., & Mallory, G. A. (2018). Oncology nurses' knowledge, confidence and practice in addressing caregiver strain

- and burden. *Oncology Nursing Forum*, 45, 187-196. doi:10.1188/18/ONF.187-196
- Kazak, A., Abrams, A., Banks, J., Christofferson, J., DiDonato, S., Grootenhuis, M., . . . Kupst, M. (2015). Psychosocial assessment as a standard of care in pediatric cancer. *Pediatric Blood & Cancer*, 62(Suppl. 5), S426-S459.
- Kirch, R., Reaman, G., Feudtner, C., Wiener, L., Schwartz, L., Sung, L., & Wolfe, J. (2016). Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine workshop highlights and next steps. *CA: A Cancer Journal for Clinicians*, 66, 398-407.
- Knafl, K. A., Deatrick, J. A., Knafl, G. J., Gallo, A. M., Grey, M., & Dixon, J. (2013). Patterns of family management of childhood chronic conditions and their relationship to child and family functioning. *Journal of Pediatric Nursing*, 28, 523-535. doi:10.1016/j.pedn.2013.03.006
- Knafl, K. A., Deatrick, J. A., & Havill, N. L. (2012). Continued development of the Family Management Style Framework. *Journal of Family Nursing*, 18, 11-34.
- Landier, W., Ahern, J., Barakat, L. P., Bhatia, S., Bingen, K. M., Bondurant, P. G., . . . Hockenberry, M. (2016). Patient/family education for newly diagnosed pediatric oncology patients: Consensus recommendations from a Children's Oncology Group Expert Panel. *Journal of Pediatric Oncology Nursing*, 33, 422-431. doi:10.1177/1043454216655983
- National Asthma Education Prevention Program. (2007). Expert panel report 3 (EPR-3): Guidelines for the diagnosis and management of asthma: Summary report 2007. *Journal of Allergy and Clinical Immunology*, 120(5 Suppl.), S94-S138. doi:10.1016/j.jaci.2007.09.043
- National Cancer Institute. (2017, April 23). Adolescents and young adults with cancer. Retrieved from <https://www.cancer.gov/types/aya>
- Palma, E., Deatrick, J. A., Hobbie, W. L., Ogle, S. K., Kobayashi, K., & Maldonado, L. (2015). Maternal caregiving demands for adolescent and young adult survivors of pediatric brain tumors. *Oncology Nursing Forum*, 42, 222-229. doi:10.1188/15.ONF.222-229
- Patton, M. Q. (2002). Designing qualitative studies. *Qualitative research and evaluation methods* (3rd ed., pp. 230-246). Thousand Oaks, CA: Sage.
- Perez, G., Rose, K. M., Spurlock, W., Bowers, B., Lutz, B., Arslanian-Engoren, C., . . . Reinhard, S. C. (2018). Position statement: Policies to support family caregivers. *Nursing Outlook*, 66, 337-340. doi:10.1016/j.outlook.2018.04.009
- Schubart, J. R., Kinzie, M. B., & Farace, E. (2008). Caring for the brain tumor patient: Family caregiver burden and unmet needs. *Neuro-Oncology*, 10, 61-72. doi:10.1215/15228517-2007-040
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., . . . Clark, N. (2005). Care of children and adolescents with type 1 diabetes: A statement of the American Diabetes Association. *Diabetes Care*, 28, 186-212. PMID: 156162541
- Van Riper, M., Knafl, G. J., Roscigno, C., & Knafl, K. A. (2018). Family management of childhood chronic conditions: Does it make a difference if the child has an intellectual disability. *American Journal of Medical Genetics Part A*, 176, 82-91. doi:10.1002/ajmg.a.38508
- Whittemore, R., Chase, S., & Mandle, C. (2001). Validity in qualitative research. *Qualitative Health Research*, 11(4), 522-537. doi:10.1177/104973201129119299
- Wu, Y. P., Thompson, D., Aroian, K. J., McQuaid, E. L., & Deatrick, J. A. (2016). Writing and evaluating qualitative research reports. *Journal of Pediatric Psychology*, 41(5), 493-505. doi:10.1093/jpepsy/jsw032
- Yawn, B. P., Buchanan, G. R., Afenvi-Annan, A. N., Ballas, S. K., Hassell, K. L., James, A. H., . . . John-Sowah, J. (2014). Management of sickle cell disease: Summary of the 2014 evidence-based report by expert panel members. *Journal of the American Medical Association*, 312(10), 1033-1048. <https://doi.org/10.1001/jama.2014.10517>.

Author Biographies

Nicole SanGiacomo, BSN, RN, is a clinical nurse at The Children's Hospital of Philadelphia in the department of pediatric oncology. She began her undergraduate studies at Cornell University with a degree in biology, but later found her passion at the bedside as a clinical nurse through the continuation of her education at the University of Pennsylvania, where she gained her bachelor's degree in nursing. She is currently continuing to pursue her education at the University of Pennsylvania to become an acute care pediatric nurse practitioner with a concentration in oncology. Her interests include clinical nursing, oncology treatment, survivorship and patient and family education.

Jennifer Toth, BSN, RN, CPHON, is a clinical nurse on the inpatient oncology unit at The Children's Hospital of Philadelphia. She began her nursing studies as an undergraduate student at The University of Pennsylvania and is continuing her studies at the university to become an acute care pediatric nurse practitioner with a concentration in oncology. She has a special interest in survivorship issues.

Wendy Hobbie, RN, MSN, CRNP, FAAN, is the Associate Director of the Cancer Survivorship Program at The Children's Hospital of Philadelphia. She has focused on improving the quality of life of survivors through research, education and clinical care. Ms. Hobbie has published extensively and is the co-editor/co-author of two books that educate survivors, families and health care providers.

Elizabeth Broden, BSN, RN, is a registered nurse in the PICU at The Children's Hospital of Philadelphia. She is continuing to pursue her research interests at the University of Pennsylvania as a doctoral student. Her research interests include pediatric end-of-life care, pediatric intensive care, nurse-family engagement and ethics.

Elizabeth Ver Hoeve, MA, is a second-year graduate student in the Clinical Psychology Doctoral Program at the University of Arizona. Elizabeth has worked as a clinical research coordinator at the University of California San Francisco Breast Care Center, where she coordinated cancer clinical trials for early and late stage breast cancer patients. She also coordinated psychosocial interventions for young adult cancer survivors at The Children's Hospital of Philadelphia. Elizabeth is continuing her studies and research interests by facilitating projects including

the development of an intervention to improve patient navigation throughout cancer diagnosis, treatment and survivorship.

Kathleen A. Knafl, PhD, FAAN, is the Frances Hill Fox Distinguished Professor at the University of North Carolina at Chapel Hill. Dr. Knafl is a sociologist who has spent her academic career in nursing. Her research addresses family response to childhood chronic illness. With colleagues Janet Deatrck and Agatha Gallo, she developed the Family Management Style Framework, and completed a series of studies describing distinct patterns of family response to the challenges presented by a child's chronic illness. Dr. Knafl lead the development of a valid, reliable measure of family management (Family Management Measure), which has been translated into 10 languages and is being used in multiple studies worldwide.

Lamia Barakat, PhD, is a professor of Clinical Psychology in Pediatrics and Psychiatry at the University of Pennsylvania Perelman School of Medicine. She also directs the Psychosocial

Services and Behavioral Oncology Research Programs for The Children's Hospital of Philadelphia Cancer Center. Her research focuses on applying risk and resilience models to understanding and promoting disease management and health-related quality of life among youth with chronic health conditions and their families.

Sue Ogle, RN, MSN, CRNP, is the Director of Oncology and Medical Subspecialty Nursing in the Cancer Center at the Children's Hospital of Philadelphia. Sue's current clinical, education and research is focused on fertility preservation and survivors of brain tumors.

Janet A. Deatrck, PhD, RN, FAAN, is a professor emerita at the University of Pennsylvania School of Nursing. Dr. Deatrck studies family management of children with chronic conditions and adolescent and young adult survivors of brain tumors. She contributes to research, research training, and research agendas in terms of parenting and caregiving within a family context.



Continuing Education Credit

The *Journal of Pediatric Oncology Nursing* is pleased to offer the opportunity to earn continuing nursing education contact hours for this article online in the APHON Continuing Education (ACE) Center available at www.aphon.org. Members may access this article in their free online product catalog and may earn CNE for free by deducting 1 point from their CNE credit bank available in the ACE Center. Nonmembers may purchase ACE Center access to this article, post-test and evaluation for \$19 on the APHON online store. 1 CNE contact hour will be awarded at the completion of the post-test and evaluation.

The Association of Pediatric Hematology/Oncology Nurses (APHON) is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.