JOURNAL OF ADOLESCENT AND YOUNG ADULT ONCOLOGY
Volume 00, Number 00, 2021
© Mary Ann Liebert, Inc.
DOI: 10.1089/jayao.2021.0070

Parents Caring for Children Diagnosed with a Blood Cancer from Infancy to Emerging Adulthood: A Life span Perspective

Amanda L. Kastrinos, PhD,[1,i] Carma L. Bylund, PhD,[2–4] Michaela D. Mullis, PhD,[2] Easton Wollney, PhD,[3]
Maria Sae-Hau, PhD,[5] Elisa Weiss, PhD,[5] and Carla L. Fisher, PhD[2,4]

Purpose: Pediatric blood cancer diagnosis is a stressful experience for families as it can involve urgent treatment that can be life-threatening and require extended hospital stays. Little is known about the experiences of parent caregivers of children with a blood cancer during the diagnosis period and how families' needs may differ in light of the patient's developmental phase in the life span.
Methods: We conducted semistructured in-depth interviews with 20 parent caregivers (aged 30–65) of children diagnosed with a blood cancer, recruited through The Leukemia & Lymphoma Society's (LLS) constituency. Interview transcripts were thematically analyzed using the constant comparative method. To elucidate similarities and differences in caregiving experiences, findings were compared across parents with children diagnosed in three developmental periods: infancy-early childhood, age 0–6 ($n=9$); pre-early adolescence, aged 9–14 ($n=5$); and late adolescence-emerging adulthood, aged 16–27 ($n=6$).
Results: Across all developmental periods, parents described three similar caregiving experiences during the diagnosis period: *being persistent to obtain a diagnosis*, *attending to the child's quality of life challenges*, and *attending to their other children's well-being.* Among caregivers of younger children, persistence was motivated by parental intuition and challenges included coping with traumatic physical and psychological impacts of treatment procedures. For caregivers of late adolescents-early adults, persistence was motivated by the child's self-assessment and fertility-related concerns emerged.
Conclusion: Results illustrate core issues for parent blood cancer caregivers and highlight ways to tailor supportive resources that facilitate good communication practices and shared decision-making to children's distinct developmental needs.

Keywords: life span, developmental differences, parent–child relationship, caregiving, leukemia, lymphoma, hematological malignancy

Introduction

Caregiving for a family member diagnosed with cancer is challenging physically, psychologically, socially, and financially.[1–4] Caring for a diagnosed child is uniquely stressful. Parents struggle to balance their child's needs with their own, while adapting to changing caregiving responsibilities across the disease trajectory.[3,5–8] Pediatric blood cancer may involve a diagnosis and treatment process that is urgent and intensive.[9–11] It can entail a complex diagnosis period that can require lengthy treatment immediately, even within hours of diagnosis, and a long hospital stay, which stresses and disrupts the entire family system.[12–16]

Caregivers' support needs are informed by life span factors. A life span lens recognizes that we constantly adapt to changes across the life span (some expected and some unexpected), and our communication is core to that adjustment.[17,18] Our experiences and needs during life changes, like a cancer diagnosis, will be informed by our developmental phase in life.[19,20] For instance, a cancer diagnosis

---

[1] Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, New York, USA.
[2] College of Journalism and Communications, University of Florida, Gainesville, Florida, USA.
[3] College of Medicine, University of Florida, Gainesville, Florida, USA.
[4] University of Florida Health Cancer Center, Gainesville, Florida, USA.
[5] The Leukemia & Lymphoma Society, Rye Brook, New York, USA.
[i] ORCID ID (https://orcid.org/0000-0001-8571-355X).

early in a child's life span is non-normative and, thus, unexpected and traumatic.[21,22] At the same time, the child's developmental maturity impacts their psychosocial needs and, as such, parents' caregiving experiences.[23] Although life span factors in parent–child bonds are critical to understanding families' unique needs after diagnosis, a life span lens is not widely utilized in cancer research or intervention development.[18,19,21,24]

Little is known about parents' blood cancer caregiving experiences or how it varies in relation to when the child was diagnosed in the life span. We sought to explore this further, using a life span lens to capture midlife parents' experiences caring for children diagnosed with a blood cancer in three developmental periods: (1) infancy through early childhood, (2) late childhood through early adolescence, and (3) late adolescence through emerging adulthood (EA). We aimed to identify parents' shared experiences and variations in relation to developmental differences.

Methods

Participants

In line with a life span approach, purposive sampling was used. Participant inclusion criteria were (1) being 30–65 years old, (2) self-identifying as a caregiver for one's living child with a blood cancer (acute myeloid leukemia, acute lymphoblastic leukemia, or lymphoma), and (3) having a child who completed treatment or maintenance therapy within the previous 1–18 months (Table 1). Data were collected as part of a larger study (IRB201800974) exploring the experiences of blood cancer caregivers for intervention development.

Procedure

Caregivers were recruited by email through The Leukemia & Lymphoma Society's (LLS) constituent database and using a recruitment posting to the LLS Community, an online community of patients and caregivers. Caregivers were given a link to an online screening survey with the option to provide contact information. They were then contacted through email to confirm eligibility and schedule an interview. A semistructured interview script was developed to identify caregivers' needs within the transitional experience of pediatric cancer, with special attention paid to identifying experiences contextually situated within developmental phases of life and multiple transitions experienced across the cancer continuum. The second author conducted 20 interviews over the course of 2 months and maintained investigator responsiveness, sampling adequacy, as well as thinking theoretically to ensure trustworthiness.[25] Interviews ranged from 33 to 63 minutes. Participants were compensated with a $50 Amazon gift card. The interviews were audio-recorded and transcribed resulting in 246 single-spaced pages.

Analysis

Transcripts were thematically analyzed using the constant comparative method.[26] Following Strauss and Corbin's[27] steps for analysis, one author conducted open coding using the following systematic steps: (1) identify concepts and assigning codes in transcripts and (2) collapsing concepts into categories to identify emergent themes. During open coding, analysis revealed differences in parents' reports based on children's developmental phase in the life span. Axial coding of the data was then conducted to identify thematic properties and isolate variant experiences based on life span factors. Finally, excerpts from data illustration rich description were identified for presentation of findings. Widely used thematic saturation criteria included repetition, reoccurrence, and forcefulness.[28] Two authors used the codebook to analyze different subsets of the data to validate the analysis and ensure rigor.[25] Exemplar quotes provide participants' relational role and child's age at diagnosis for context and to maintain confidentiality. Findings are presented as action statements in Table 2 using the ecological sentence synthesis approach.[29,30]

Results

Parents with children diagnosed across developmental periods encountered several shared experiences: (1) *being persistent to obtain a diagnosis,* (2) *attending to the diagnosed child's quality of life challenges,* and (3) *attending to other children's well-being.* However, parents' reports of each experience varied given the children's developmental phase. Summaries of themes show similarities in parents' experiences, with thematic properties illustrating variability given developmental differences.

Table 1. Participant Demographics

Demographics	
Caregiver gender	
Male	2 (10%)
Female	18 (90%)
Caregiver age, *M* (SD)	43 (8.26)
Patient gender	
Male	8 (40%)
Female	12 (60%)
Age at diagnosis	
Patients cared for by a parent	
Infancy and early childhood (<6)	9 (45%)
Pre- and early adolescence (9–14)	5 (25%)
Adolescence and young adulthood (16–27)	6 (30%)
Time since diagnosis	
Less than 1 year	6 (30%)
1–2 years	13 (65%)
3–5 years	1 (5%)
Race	
Black/African American	1 (5%)
Hispanic/Latino	1 (5%)
White	18 (90%)
Highest level of education completed	
Some high school	1 (5%)
High school	3 (15%)
Some college	3 (15%)
College graduate	8 (40%)
Post-graduate	5 (25%)
Patient disease type	
ALL	3 (15%)
AML	11 (55%)
Lymphoma	6 (30%)

ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; *M*, mean; SD, standard deviation.

Table 2. Variations in Parents' Blood Cancer Caregiving Experiences in Relation to Children's Developmental Phase in the Life Span

Caregivers described	*For their child*	*And the importance of*	*This finding informs this practical implication*
Being persistent to obtain a diagnosis	Diagnosed in infancy and early childhood and pre-early adolescence	Parental intuition motivating their pursuit of second opinions or additional testing.	Parents of young children need their concerns heard and practitioners hearing persistent concerns might consider diagnostics for cancer, an unexpected health issue this early in the life span.
	Diagnosed in adolescence and young adulthood	Relying on their children's self-assessment to intervene and be persistent. Managing patients' care upon diagnosis.	Parents of adolescent and emerging adult children may encounter their child seeking their help, which can be key to intervene for a diagnosis. While clinicians should encourage parents' ongoing involvement, patients' autonomy should also be protected.
Attending to quality of life challenges or well-being	Diagnosed in infancy and early childhood	Helping them cope with the traumatic physical and psychological impact of treatment procedures.	Parents of young children need help explaining the illness and procedures which is central to promoting a better quality of life.
	Diagnosed in adolescence and EA	Making decisions about their child's fertility.	Parents of adolescent and emerging adult children and clinicians need to engage in discussions about how treatment can impact fertility.
	Who were siblings of the patient (children in infancy-early childhood)	Preserving a sense of normalcy in the midst of multiple disruptions after diagnosis.	Parents with other young children need support to provide some consistency in their lives to promote their well-being.
	Who were siblings in late childhood through EA	Being able to balance attention for their diagnosed child with being there for their other children.	Parents with other children who are in late childhood-EA may benefit from a family-centered care approach that includes siblings

EA, emerging adulthood.

Being persistent to obtain a diagnosis

Parents reported a delay between symptom onset and diagnosis, ranging from weeks to years. They saw multiple providers, and children underwent (what were later deemed) unnecessary procedures. Parents shared how persistence was critical to receiving a diagnosis. What motivated their persistent communication differed by their diagnosed child's age.

Relying on parental intuition. Parents with children diagnosed in the two earliest age periods (infancy through early adolescence) described how their intuition motivated their pursuit of second opinions or additional testing, using phrases like, ''I just had this really weird feeling about this'' (Mother, daughter, 14), or ''I knew something was wrong'' (Mother, son, 11). Sometimes it was the parents' insistence that convinced physicians to take a second look or order more tests. This parent explained:

> Normally [daughter's] energetic, running around. … Now she's crying in the middle of the mall. She can't walk … I took her right back to the pediatrician. I'm like, ''Something is wrong with her. She can't even walk up the stairs at night.'' … He said, ''Well, while you're here, let me recheck her blood.'' (Mother, daughter, 5)

Relying on the child's self-assessment. Parents with children diagnosed in late adolescence through EA described how their children's communication motivated them to be persistent. Adolescent patients explicitly asked their parents to take them back to a physician. A mother recalled how her daughter (age 17) told her, ''You need to take me to the doctor. I want to go to Daddy's lung doctor.'' Parents were also motived by children's behavior during appointments. This mother shared:

> When he said, ''Take her home. Let her try Miralax for a couple of days. See if she gets better,'' she broke out into tears because she knows her body at this point. And she knows she's not constipated. So we pushed the doctor a little bit harder. He went ahead and ordered a CT of her stomach. (Mother, daughter, 16)

The experiences of parents of EAs differed somewhat because their children had recently transitioned to live independently outside of the home. Parents reported being persistent once EAs reached out for help with ailments that didn't resolve after seeking health care. A mother, whose son had prolonged cold symptoms, stated: ''He's a university student … He called me to say that he was having a difficult time breathing, and if I could come pick him up'' (Mother, son, 20). EAs ultimately relied on their parents to manage their care, as this mother stated: ''She moved home because she was too sick to take care of herself. And I took her to doctors here'' (Mother, daughter, 27). At times, parents assumed control of other aspects of their lives:

> We had to talk to her guidance counselor at school … to ask them if she could take her finals earlier because they wanted to start treatment fairly quickly. … She lived on campus, but I got a hotel room and we stayed there. We talked to everybody we needed to talk to. (Mother, daughter, 22)

Attending to the diagnosed child's quality of life challenges

Parents collectively described difficulties managing their diagnosed child's quality of life. Although all parents encountered issues, what they described varied in line with their child's age or developmental maturity.

Coping with physical and psychological effects of procedures. Parents of children in the youngest age group recalled traumatic reactions to procedures that impacted psychological and physical well-being. Parents witnessed children's extreme distress during painful procedures:

> They drew a bunch of blood, which is tough on a little kid. He already had blood drawn that day. They couldn't use the same arm, so they tried to use the other arm. And then that wasn't working … They tried to use his foot. It was just a long night of putting him through all this torture. Usually, he's a very good-natured kid, and he was not. It was one of the worst nights since the whole thing happened—was this first night. (Father, son, 2)

Parents explained how traumatic procedures or treatments impacted their child's behavior and temperament, becoming angry, emotional, and fearful. This parent shared how quickly this occurred after starting treatment:

> Within 24 hours her whole personality completely changed. She was so fearful of any and everyone who came into the room and didn't want to see anyone except for me or my husband really … even her grandparents who live down the street that she adores. She's like, ''Get them out of here. I don't want to see anybody.'' It was just very painful to see such a huge change in her personality. (Mother, daughter, 5)

As parents struggled to help their children cope, they noted how difficult it was to explain the traumatic procedures, treatments, and side effects to young children:

> At the beginning, he thought he was dying because of the chemo. … He had a fever and he wasn't—he was super, super lethargic, but the chemo was worse, right? He asked if he was dying. And I said, ''Well, actually, the medicine that's making you better is making you feel sicker, but it's making you better.'' (Mother, son, 10)

Identifying the long-term impact on fertility. In two cases, parents of daughters (a late adolescent child and an EA) encountered treatments affecting fertility. The mother of a teenaged daughter recalled having to decide between chemotherapy options with limited information. They didn't know that a risk was infertility until after treatment began, leaving them to manage this quality of life issue later:

> I don't know that we fully understood the side effects that she was going to get from the chemo. … We're discovering now not only is she most likely infertile, but she's got premature ovarian failure. Now at 18, she's menopausal. (Mother, daughter, 18)

In contrast, the mother of an EA said that they were informed about the infertility risk before treatment. Their oncologist recommended visiting a fertility specialist. The daughter had the option to delay her treatment and freeze her eggs: ''Of course we did it. She wanted to, and I wanted her to. That delayed the start of her chemo, by about three weeks because she had to go through that process. But that was well worth it'' (Mother, daughter, 22).

Attending to other children's well-being

Parents described attending to their other children's distress and behavioral changes (e.g., being angry, withdrawn), relating this to abrupt changes they faced as a family. Siblings' distress was tied to ''getting all the questions'' in schools, moving cities, or changing schools to be close to treatment. Older children (EAs) struggled to cope with their sibling's diagnosis while not living with the family. Parents described variant priorities in managing their other children's well-being given divergent developmental needs.

Needing normalcy. Parents of children diagnosed in infancy or early childhood typically also had other children in early childhood (8 or younger). They prioritized preserving a sense of normalcy to promote well-being in the midst of multiple disruptions after diagnosis. This mother shared: ''We didn't really want the kids there to watch their baby sister be hooked up to the machines and everything'' (Mother, daughter, 2). To maintain normalcy some parents had nearby family travel to help care for their other children so they could sleep at the hospital. Parents also split caregiving responsibilities: one parent stayed at the hospital and the other maintained the other children's routines—a difficult ''juggling'' act:

> I was sleeping at the hospital for the most part with my little one. My husband was coming to see her during the day and then going back to be with my older [daughter]. … We also didn't want her spending all her days at the hospital with us. … It was a lot of juggling, sleepless nights obviously, very stressful. (Mother, daughter, 5)

Parents were aware of their other children's need for normalcy, with some children expressing this. This mother recalled this after her diagnosed daughter spent a month in the hospital:

> [Other daughter said], ''I just want everyone to be home together so we can have a regular dinner like we used to … like chicken.'' … Obviously we were eating all take-out or at the hospital. … [I said] ''I know. We will. One day we will. We'll be home together.'' (Mother, daughter, 5)

Providing enough attention or being present. Parents of other children in late childhood through EA (ages 9–17) addressed challenges with being present and attentive. They made a conscious effort to help their other children feel included during treatment, which was challenging, as this mother explained:

> I was always very worried about my 17-year-old. … He would close himself down and not talk. … The first few weeks, [I tried] to give him as much of my attention as I could and [make] things about him also. … Everything was just worried about [diagnosed daughter] and that's all I could think about. (Mother, daughter, 14)

Because parents had to spend more time with their diagnosed child, it was hard to be present with other children. A mother explained the impact on her daughter, whose twin was diagnosed: ''My daughter has had more of a difficult time because I haven't been around, because she was pretty much seven months without me'' (Mother, son, 9). Similarly, a mother described the impact on her teenaged sons: ''[They] felt a bit neglected. … So much attention went to [diagnosed daughter], and it had to, especially those early days of her treatment. So maybe a little resentment came up'' (Mother, daughter, 5).

Discussion

Life span factors are not commonly used to tailor cancer coping resources and, yet, developmental variables play a role in caregivers', patients', and family members' variant needs.[31] Our findings offer insight on how to better meet the needs of parent caregivers and their children, identifying commonalities in caregivers' experiences in being persistent to attain a diagnosis, attending to the diagnosed child's well-being, and addressing their other children's quality of life challenges. Results also highlight divergent support needs in relation to children's age and maturity. We address these further with suggestions for tailoring interventions based on patients' developmental stage.[13]

Infancy–adolescence

For parents of children early in the life span, communication was especially challenging. Although parents collectively described how persistence was key to reaching a diagnosis, those with younger children had to rely on intuition and careful observation of behavioral cues, as opposed to parents with older children who could be explicit about their symptoms. Unfortunately, leukemia and lymphoma are often misdiagnosed by unsuspecting providers as infection.[32] Most symptoms of childhood cancer (e.g., headaches, fatigue, bruises) are not immediately indicative of cancer, and research shows that parents are typically the first to notice something is wrong.[33]

Parents of children diagnosed with cancer struggle with how much they are able to communicate with their child about their diagnosis, making it difficult to manage their child's quality of life and attend to their mental health needs.[34] Parents in our study observed their younger children's extreme distress and behavioral changes after undergoing traumatic procedures during initial treatment. They struggled to communicate what was happening to their children who were too young to understand or even voice their own mental health needs. This was true also of the diagnosed child's younger siblings.

Recent research has advocated for more attention to siblings' psychosocial coping, calling siblings the ''hidden patient'' and stressing the impact of sibling's developmental phase on their needs.[35–37] Parents in our study expressed concerns about the mental well-being of their other children, including younger children who are not yet able to voice their needs. Parents stressed maintaining some normalcy to promote a healthy adjustment for their youngest children. Our findings provide insight on how to promote a family-centered care approach and highlight the importance of listening to parents' concerns and soliciting feedback on their observations of their young children's behavior.[35]

Adolescence–EA

For adolescents and EAs, our findings illustrate how a critical developmental task—cultivating independence or self-differentiation—may be disrupted during the diagnosis period. Although parents are critical to getting a diagnosis and managing treatment, tensions regarding control and autonomy may emerge, and the child's independence is likely an important issue across the disease trajectory.[19,38–40] For EAs maintaining involvement in their health care and decision making is critical to developing the patient–provider communication and decision-making skills necessary to manage their health care as fully autonomous adults.[41]

Parents of diagnosed children in EA may need help facilitating decisions unique to this developmental period. Infertility is a known concern of childless women diagnosed in EA and young adulthood.[42–44] Yet, as is evident in our study, fertility may not be discussed before treatment decisions are made.[45,46] Given the inconsistency, it is imperative that parents know and learn to take the lead by engaging their children (and providers) in discussions of the long-term treatment risks while also involving adolescent and EA children in such decisions to cultivate independence and health care communication skills.

Conclusions and Limitations

Past research addresses the issues of pediatric cancer caregivers as a monolith. Our findings suggest that even within blood cancers diagnosed between infancy through EA, parents' experiences during the diagnosis period can vary given the age of the patient and their siblings. Future scholarship can explore these similarities and differences further with different cancer subtypes and by incorporating multiple relational perspectives, as well as deeper explorations of differences in diagnosis experiences among varying blood cancer types. Participants were mostly White, female, and mothers. Findings may not reflect diversity of family cancer caregiving experiences, which is important for future research.

Acknowledgment

We dedicate this article to the memory of Dr. Geraldine Fennell. Her work articulated the importance of effectively developing and delivering tailored information and support to caregivers, particularly to subgroups of caregivers with distinct needs.

Disclaimer

Parts of this article were presented at the National Communication Association conference in 2020.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

Funding for this project came from the Carolan Research Institute and The Leukemia & Lymphoma Society.

References

1. Biegel DE, Sales E, Schulz R. Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke. Newbury Park, Calif: Sage Publications; 1991.
2. Kim Y, Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. J Aging Health. 2008;20(5):483–503.
3. McLean S, Gomes B, Higginson IJ. The intensity of caregiving is a more important predictor of adverse bereavement outcomes for adult–child than spousal caregivers of patients who die of cancer. Psychooncology. 2017;26(3):316–22.
4. Pinquart M, SörensenS. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. Psychol Aging. 2007;18(2):250.
5. Higginson I, Wade A, McCarthy M. Palliative care: views of patients and their families. BMJ. 1990;301(6746):277–81.
6. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors. Cancer. 2008;112(11 Suppl):2556–68.
7. Kent EE, Rowland JH, Northouse L, et al. Caring for caregivers and patients: research and clinical priorities for informal cancer caregiving: informal cancer caregiving. Cancer. 2016;122(13):1987–95.
8. Fisher CL, Mullis MD, Kastrinos A, et al. ''Home wasn't really home anymore'': understanding caregivers' perspectives of the impact of blood cancer caregiving on the family system. Support Care Cancer. 2021;29(6):3069–76.
9. Kastrinos A, Fisher CL, Mullis MD, et al. A lifespan approach to understanding family caregiver experiences of a blood cancer diagnosis. Palliat Support Care. 2021. [Epub ahead of print]; DOI: 10.1017/S1478951521000389.
10. Bryant AL, Deal AM, Walton A, et al. Use of ED and hospital services for patients with acute leukemia after induction therapy: one year follow-up. Leuk Res. 2015;39(4):406–10.
11. Pailler ME, Johnson TM, Kuszczak S, et al. Adjustment to acute leukemia: the impact of social support and marital satisfaction on distress and quality of life among newly diagnosed patients and their caregivers. J Clin Psychol Med Settings. 2016;23(3):298–309.
12. Wang J, Shen N, Zhang X, et al. Care burden and its predictive factors in parents of newly diagnosed children with acute lymphoblastic leukemia in academic hospitals in China. Support Care Cancer. 2017;25(12):3703–13.
13. Fairfax A, Brehaut J, Colman I, et al. A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability. BMC Pediatr. 2019;19(1):215.
14. Klassen A, Raina P, Reineking S, et al. Developing a literature base to understand the caregiving experience of parents of children with cancer: a systematic review of factors related to parental health and well-being. Support Care Cancer. 2007;15(7):807–18.
15. Bergsträsser E. Childhood cancer—are there predictors of parental well-being? Support Care Cancer. 2007;15(7):799–800.
16. Edmond SN, Graves PE, Whiting SE, Karlson CW. Emotional distress and burden among caregivers of children with oncological/hematological disorders. Fam Syst Health. 2016;34(2):166–71.

17. Baltes PB. Theoretical propositions of life-span developmental psychology: on the dynamics between growth and decline. Dev Psychol. 1987;23(5):611–26.
18. Pecchioni LL, Wright KB, Nussbaum JF. Life-span communication. Mahwah, NJ: Lawrence Erlbaum; 2005.
19. Fisher CL. Coping together, side by side: enriching mother-daughter communication across the breast cancer journey. New York, NY: Hampton Press, Incoporated; 2014.
20. Fisher CL, Nussbaum JF. Maximizing wellness in successful aging and cancer coping: the importance of family communication from a socioemotional selectivity theoretical perspective. J Fam Commun. 2015;15(1):3–19.
21. Rolland JS. Cancer and the family: an integrative model. Cancer. 2005;104(11 Suppl):2584–95.
22. Segrin C, Flora J. Family communication. Mahwah, NJ: Lawrence Erlbaum; 2014.
23. Kazak AE, Baxt C. Families of infants and young children with cancer: a post-traumatic stress framework. Pediatr Blood Cancer. 2007;49(7 Suppl):1109–13.
24. Nussbaum, Jon F., eds. The Handbook of Lifespan Communication, (Bern, Switzerland: Peter Lang US, 2014) Accessed August 30, 2021 from: https://doi.org/10.3726/978-1-4539-1367-3
25. Morse JM, Barrett M, Mayan M, et al. Verification strategies for establishing reliability and validity in qualitative research. Int J Qual Methods. 2002;1:13–22.
26. Glaser BG, Strauss AL. Grounded theory: The discovery of grounded theory. Sociology. 1967;12(1):27–49.
27. Strauss A, Corbin J. Basics of qualitative research techniques. Thousand Oaks, CA: Sage; 1998.
28. Owen WF. Interpretive themes in relational communication. Q J Speech. 1984;70(3):274–87.
29. Barnett-Page E, Thomas J. Methods for the synthesis of qualitative research: a critical review. BMC Med Res Methodol. 2009;9(1):1–1.
30. Sandelowski M, Leeman J. Writing usable qualitative health research findings. Qual Health Res. 2012;22(10):1404–13.
31. Nussbaum JF, Worthington AK. Lifespan and developmental considerations in health and risk message design. Oxford Research Encyclopedia of Communication. 2017. Accessed July 30, 2021 from: https://oxfordre.com/communication/view/10.1093/acrefore/9780190228613.001.0001/acrefore-9780190228613-e-318
32. Chen J, Mullen CA. Patterns of diagnosis and misdiagnosis in pediatric cancer and relationship to survival. J Pediatr Hematol Oncol. 2017;39(3):e110–5.
33. Albritton K, Bleyer WA. The management of cancer in the older adolescent. Eur J Cancer. 2003;39(18):2584–99.
34. Son H, Haase J, Docherty SL. Parent-child communication in a childhood cancer context: a literature review. Pediatr Nurs. 2019;45(3):14.
35. Franklin M, Patterson P, Allison KR, et al. An invisible patient: healthcare professionals' perspectives on caring for adolescents and young adults who have a sibling with cancer. Eur J Cancer Care. 2018;27(6):e12970.
36. Hammond C. Against a singular message of distinctness: challenging dominant representations of adolescents and young adults in oncology. J Adolesc Young Adult Oncol. 2016;6(1):45–9.
37. Cheung CK, et al. The impact of a cancer diagnosis on sibling relationships from childhood through young adulthood: a systematic review. J Fam Soc Work. 2020;23(4):357–77.
38. Barnett M, McDonnell G, DeRosa A, et al. Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. J Cancer Surviv. 2016;10(5):814–31.
39. Fisher CL. Coping with breast cancer across adulthood: emotional support communication in the mother–daughter bond. J Appl Commun Res. 2010;38(4):386–411.
40. Stanley NB, Quinn G, Reed D, et al. Support for young adult cancer patients: perspectives of patients and their mothers. J Canc Educ. 2019;34(6):1097–102.
41. Young B. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. BMJ. 2003;326(7384):305.
42. Benedict C, Shuk E, Ford JS. Fertility issues in adolescent and young adult cancer survivors. J Adolesc Young Adult Oncol. 2015;5(1):48–57.
43. Canada AL, Schover LR. The psychosocial impact of interrupted childbearing in long-term female cancer survivors. Psychooncology. 2012;21(2):134–43.
44. Ellis SJ, Wakefield CE, McLoone JK, et al. Fertility concerns among child and adolescent cancer survivors and their parents: a qualitative analysis. J Psychosoc Oncol. 2016;34(5):347–62.
45. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. Cancer. 2011;117(10 Suppl):2329–34.
46. Canzona MR, Victorson DE, Murphy K, et al. A conceptual model of fertility concerns among adolescents and young adults with cancer. Psychooncology. 2021. [Epub ahead of print]; DOI: 10.1002/pon.5695.

Address correspondence to:
Amanda L. Kastrinos, PhD
Department of Psychiatry & Behavioral Sciences
Memorial Sloan Kettering Cancer Center
641 Lexington Avenue
New York, NY 10022
USA

Email: akastrinos@ufl.edu