



# HHS Public Access

Author manuscript

*J Pain Symptom Manage.* Author manuscript; available in PMC 2022 October 01.

Published in final edited form as:

*J Pain Symptom Manage.* 2021 October ; 62(4): 709–719. doi:10.1016/j.jpainsymman.2021.03.015.

## Stuck Moments and Silver-Linings: The Spectrum of Adaptation Among Non-Bereaved and Bereaved Parents of Adolescents and Young Adults with Advanced Cancer

**Jori Bogetz, MD [Acting Assistant Professor],**

Division of Bioethics and Palliative Care, Department of Pediatrics, University of Washington School of Medicine; Palliative Care and Resilience Lab, Center for Clinical and Translational Research, Seattle Children's Research Institute, 1900 Ninth Street, JMB-6, Seattle, WA 98101, United States

**Amy Trowbridge, MD [Assistant Professor],**

Divisions of Bioethics and Palliative Care/Hospital Medicine, Department of Pediatrics, University of Washington School of Medicine

Palliative Care and Resilience Lab, Center for Clinical and Translational Research, Seattle Children's Research Institute, 1900 Ninth Street, JMB-6, Seattle, WA 98101, United States

**Jenny Kingsley, MD [Assistant Professor],**

Division of Critical Care Medicine, Department of Anesthesiology and Critical Care Medicine, Keck School of Medicine at the University of Southern California; 4650 Sunset Blvd., MS #12, Los Angeles, CA 90027, United States

**Mallory Taylor, MD, MS [Acting Instructor],**

Division of Hematology/Oncology, Department of Pediatrics, University of Washington School of Medicine

Palliative Care and Resilience Lab, Center for Clinical and Translational Research, Seattle Children's Research Institute, 1920 Terry Ave, Seattle, WA 98101, United States

**Lori Wiener, PhD [Co-Director],**

Behavioral Health Core and Director, Psychosocial Support and Research Program, Pediatric Oncology Branch, Center for Cancer Research, National Cancer Institute, National Institutes of Health, 10 Center Drive, Room 1C247B-4, Bethesda, MD, 20892, United States

**Abby R. Rosenberg, MD, MA, MS [Associate Professor],**

Division of Hematology/Oncology, Department of Pediatrics, University of Washington School of Medicine

---

**Corresponding Author:** Jori F. Bogetz, MD; Seattle Children's Research Institute; 1900 Ninth Ave, M/S: JMB-6, Seattle, WA 98101, United States; Phone: 206-987-2000; jori.bogetz@seattlechildrens.org.

**Potential Conflicts of Interest:** The authors have no conflicts of interest relevant to this article to disclose.

**Financial Disclosure:** The authors have no financial relationships relevant to this article to disclose.

**Publisher's Disclaimer:** This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Director, Palliative Care and Resilience Lab, Center for Clinical and Translational Research, Seattle Children's Research Institute, 1920 Terry Ave, Seattle, WA 98101, United States

**Krysta S. Barton, PhD, MPH**

Director of Qualitative Methods, Palliative Care and Resilience Lab, Center for Clinical and Translational Research, Seattle Children's Research Institute, 1920 Terry Ave, Seattle, WA 98101, United States

## Abstract

**Context:** With advances in treatments that have resulted in children living longer with serious illness, it is essential to understand how parents adapt to changes during the final stages of their child's life or after their child's death.

**Objective:** To examine the process by which parents adapt to their child's serious illness and death among a group of non-bereaved and bereaved parents of adolescents and young adults (AYAs) with advanced cancer.

**Methods:** Qualitative study exploring the experiences of parents of AYAs who were being treated for recurrent or refractory advanced cancer (non-bereaved parents) or had died from their disease (bereaved parents) at one large academic center. Participants completed demographic surveys and semi-structured interviews to better understand parent adaptation. Data were analyzed using content and thematic approaches.

**Results:** Of the 37 participating parents; 22 (59%) were non-bereaved and 15 (41%) were bereaved. The AYAs predominantly had hematologic malignancies (n=18/34, 53%). Across both cohorts, parents described the process of adapting to their child's worsening health or death as moments of feeling stuck and moments of gratitude and meaning.

**Conclusion:** Adaptation to a child's serious illness and death likely occurs on a dynamic spectrum and parents may oscillate both cognitively and emotionally. This has important implications for how clinicians and communities support parents. Greater comfort with and normalization of the adaptation process may enable parents to more openly share both the unimaginable hardships and unexpected silver-linings that are part of their parenting experiences during their child's illness and death.

## Keywords

parents; grief and bereavement; pediatric; adolescents and young adults; cancer

---

## Introduction

Advances in medical care have resulted in children living longer with serious illness and dying after receiving intensive therapy for their disease.<sup>1</sup> Adolescents and young adults (AYAs) with advanced cancer often receive therapies such as stem cell transplant and immunotherapy, yet little is known about the lived experience of these patients and their families.<sup>2-5</sup> As families, and especially parents, provide the essential support, caregiving, and advocacy these children need during these intensive treatments, it is imperative to understand how they can be supported.<sup>6</sup> Parents also have to live with the events their child

experienced and the decisions that they made as parents after their child's death.<sup>7,8</sup> Even for children who survive, parents often question decisions made, especially if there are late effects of treatment.<sup>9</sup>

Important work has been conducted to understand the experiences of parents of seriously ill children during the final stages of their child's illness and in bereavement, yet our understanding is limited by the scope and constructs of these studies.<sup>10</sup> Historically, frameworks for parental emotional responses to their child's serious illness and death have focused on dualistic models, where parents are either in states of grief and distress or acceptance and resolution.<sup>11,12</sup> For example, studies on anticipatory grief among parents with children undergoing cancer treatment suggest sustained unease, helplessness, uncertainty, and lack of peace in parents during this process.<sup>13–15</sup> Similarly, studies in bereaved parents suggest that they struggle with grief-related separation distress after their child's death along with complicated/prolonged grief and regret.<sup>7,16</sup> In contrast, studies on parental acceptance and resolution suggest that parents' ability to focus on their roles as good parents, harness resilience resources, and be there for their child can bolster positive coping and post-traumatic growth after their child's death.<sup>17–20</sup>

Although this work has broadened our understanding of how parents respond to their child's serious illness and end of life, the binary model of grief and acceptance is limited, and there is a need to more deeply explore parent experiences. The aim of this study was to examine the process by which parents adapt to their child's serious illness and death among a group of non-bereaved and bereaved parents of AYAs with advanced cancer. In this study, we used the term adapt to represent the process by which changes occur over time and with new circumstances.

## Methods

The “*Exploring the Concept of ‘a Good Death’*” qualitative study was designed to gather perspectives about how to improve end of life care for AYAs with cancer and their families. It included four stakeholder cohorts: healthcare providers, AYAs, non-bereaved parents, and bereaved parents. Participants in this analysis included both non-bereaved and bereaved parents to explore the spectrum of experiences among these groups. Study methods have been detailed previously and are briefly described here.<sup>6</sup> Eligible participants were English-speaking parents or legal guardians of AYAs between the ages of 14–25 years treated at Seattle Children's Hospital who received treatment for advanced cancer (non-bereaved) or bereaved parents of AYAs who had died from advanced cancer 18 months prior. Advanced cancer was defined by the AYA meeting 1 of the following criteria: 1) relapsed or recurrent disease following initial treatment; 2) refractory disease; 3) eligibility for a phase 1 trial; 4) enrollment in hospice or receiving palliative care; or 5) patients with <50% likelihood of long-term survival as judged by the treating oncologist. Non-bereaved parents were enrolled between December 2017–July 2018 and bereaved parents were enrolled between September 2015–April 2017. Parents completed a brief demographic survey and a 60-minute (range 24–137 minutes) semi-structured interview in-person or by phone exploring their perspectives about decision-making, worries, and strengths/supports during their child's illness and/or in bereavement (see Interview Guide Supplement 1). Two sets of bereaved parents were

interviewed as a couple. Two additional bereaved parents completed separate interviews but were parents of the same child. Additional demographic information including the child's age, gender, advanced cancer type, and date of death (if applicable) were extracted from the child's health record. The Seattle Children's Hospital Institutional Review Board approved this study.

Following the Standards for Reporting Qualitative Research (SRQR) guidelines<sup>21</sup>, the study team included physician-researchers with training in palliative care (JFB, AT, ARR), critical care (JK), and pediatric oncology (MT, ARR) as well as a social worker and behavioral scientist with expertise in parental grief (LW) and a health services investigator with expertise in qualitative research (KSB). Interviews were conducted by two study team members (ARR, who may also have previously taken care of families in her role as a clinical oncologist, and KSB, who had no clinical contact with any of the families). Interviews were audio-recorded, transcribed verbatim, de-identified, and entered into Dedoose© software<sup>22</sup> for analysis. We used directed content analysis<sup>23</sup> for development of the initial codebook and coding structure. All primary and secondary coding was completed by one of three authors (JFB or AT for non-bereaved parents and JK, MT, or JFB for bereaved parents). Adjudication was led by a qualitative expert (KSB) during regular study discussions among the full coding team until agreement was reached.

After coding was complete, a combination of content and thematic analysis was used to analyze data.<sup>23,24</sup> Specifically, themes were derived both inductively and deductively from established constructs of experiences of parents of seriously ill children including grief and resilience scaffolds.<sup>25,26</sup> These scaffolds were then used to group excerpts from relevant codes by two study members (JFB and AT) for in-depth analysis. Themes were iteratively grouped and then re-grouped to form topics related to parental experiences. Data were also analyzed between non-bereaved and bereaved parent groups as well as across the responses from individual parent participants to more deeply explore topics. Additionally, data were analyzed based on whether parents were early (< 2 years) or late (> 2 years), since their child's diagnosis (for non-bereaved parents) or death (for bereaved parents). Subsequently, data were presented to the entire study team to iteratively review data analysis, areas of disagreement, and to come to consensus regarding data interpretation.

## Results

### Demographics

A total of 37 parents participated of which 22 (59%) were non-bereaved and 15 (41%) were bereaved at the time of interview. An additional 3 parents consented (2 non-bereaved and 1 bereaved) but did not subsequently complete interviews and 9 bereaved parents declined study participation. Parents were a median age of 47 years old [IQR 45–52] and the majority were female (n=29, 78%). Parents' AYA children (N=34) were a median of 17 years old [IQR 15–19] either at the time when their parent was interviewed (non-bereaved parents) or when they had died (bereaved parents). About half (n=18, 53%) were female and had primary hematologic malignancies (n=18, 53%). Four parents had children with central nervous system tumors (12%) and 12 with non-central nervous system solid tumors (35%). Additionally, non-bereaved parents were a median of 2.5 years from their child's diagnosis

[IQR 1–6] and bereaved parents were a median of 2 years from their child’s death [IQR 1.8–3.4]. Other parent and AYA demographics are shown in Table 1.

### Qualitative Findings

Parents described a spectrum of adaptation experiences as they navigated topics including control, meaning, acceptance, support, and hope. These topics are described in detail below, with additional representative excerpts shown in Table 2. There were no differences identified when data were grouped according to whether the parent was bereaved or non-bereaved and whether the parent was early or late in the time since their child’s diagnosis or death.

**Control: From guilt and feeling helpless to empowerment by recognizing their locus of control**—Regarding control, parents described a wide array of thoughts and perspectives. Some parents described feeling at fault for their child’s worsening health because they wondered if they could have prevented their child’s illness with different treatment choices. Similarly, many expressed a worry that they did ‘something wrong’ that contributed to the cancer returning.

Sometimes the hard thing is not knowing why it happened and why she relapsed. And we question why it was back and if we could avoid that, if there’s something we could have done. (Non-bereaved Parent 2)

Other parents discussed how relinquishing control enabled them to worry less about what would happen to their child or why their child did not survive. Many parents discussed focusing on the ‘moment’ and taking things ‘one hour at a time’ to ease worries.

Don’t worry about what happens next, don’t worry about how hard this might change things, because you are not in control, you may think you are in control, but you are not. (Non-bereaved Parent 3)

**Meaning: From senselessness to gratitude and meaning-making**—Many parents described the senselessness of their child’s illness and how far removed it felt from society’s conception of loss.

I think that when a child dies, there’s nothing that you’re looking at that feels like opportunity.... when an adult dies, there’s a lot of opportunity for learning and growth. And this is, you know, it’s growth but it’s forced growth and it’s growth that is isolating and it’s growth that is un-talked about and it’s secret and it’s dark, and it’s unrecognized in our society. (Bereaved Parent 27)

Some parents felt completely submerged in the senseless loss of their child such that nothing felt helpful to them. Other parents shared how the experience allowed them to find meaningful connection with other people, gratitude, and new appreciation for the ‘smallest things’ in life.

That kid was sent here to teach me love. Unconditional love. That’s what I’ve realized since he’s passed. He was here to teach me that and I didn’t have anybody to love me like that before that – unconditionally. (Bereaved Parent 26)

**Acceptance: From denial and questioning to acknowledging and moving forward**—Parents described diverse perspectives about accepting their child’s illness and death. Many parents described the push and pull of trying to accept the severity of their child’s illness or death in a ‘matter of fact’ way while also rallying against it with anger or sadness. Parents also described how they avoided thinking about their child’s illness and/or death to help them cope. Many parents described the importance of not looking too far ahead, particularly if they were concerned that time with their child was limited.

Today, what are you going to focus on? The answer is, you’re going to focus on today. Just today. And get through today. I try to practice what I preach. I do have concerns for her, but then again just going day-by-day. (Non-bereaved Parent 17)

Living in the moment helped parents to limit worries about the ‘what ifs’ while also bolstering feelings of acceptance. Many parents described focusing on quality time with their child or on the positive moments of their child’s life prior to their death.

Some parents also recalled repeatedly experiencing denial, questioning, and anger in regard to their child’s disease. Many wanted to know why their child was relapsing or why treatments weren’t working. Others wanted to accept their child’s death – but felt that they never would.

Some of us have strength in our minds and others don’t. Some accept the reality and others do not want to accept it. I mention this because in my case, I found it very difficult. For me, I didn’t want to accept that she was going to die. But just the same, I knew it was going to happen. And emotionally, I thought it was going to take me to a point where I was going to just give up. (Bereaved Parents 31+32)

**Support: From isolation to strength from connection**—The majority of parents described how important support was during the many difficult experiences they had as parents. Some parents recalled support from clinicians who acknowledged their struggle and encouraged them. Others gained support from other parents of children with cancer going through similar experiences, colleagues at work, or family and friends in their community.

[Another parent of a child with cancer] found out about [my child’s] relapse, so she was sending me encouragement which was pretty neat ‘cause... they’re the ones that really understand what this walk is like when they’re walking the same path. (Non-bereaved Parent 21)

Some parents also described times of wanting to be alone to process their feelings and experiences. Others experienced a sense of isolation during their child’s illness or after their child died.

I think it’s this huge ironman marathon and someone’s running this marathon. And if you’re running a marathon all by yourself and you have no one, there’s no one in sight and you’re running this marathon and you don’t even know where the end is. You don’t even know where the finish line is, you’re just running... I just don’t understand if you don’t have anyone helping you, what’s the point of running it and how is someone doing it all by themselves? I don’t think it’s possible. (Non-bereaved Parent 17)

**Hope: From feeling lost to trusting the outcome**—Although some parents described feelings of hopelessness when they realized their child would likely die, other parents expressed more consistent feelings of hopefulness regardless of their child’s prognosis. Parents often portrayed their faith and spirituality as a way to maintain and strengthen their hope. Sometimes this hope was focused on miracles or new treatments, while at other times, parents focused on things beyond their child’s remission or survival. Parents sometimes expressed simultaneous feelings of hopefulness that their child’s health would improve, while preparing themselves if their child’s health declined.

We’re always hopeful, we never lose hope. There’s always finding the silver-lining in anything. (Non-bereaved Parent 17)

### **Adaptation as a Process of Oscillation**

Within interviews, both non-bereaved and bereaved parents described oscillations in their adaptation. These included stuck moments and times of finding the silver-lining in their experiences. Specifically, when the content of excerpts was evaluated across individual participants, >80% (n=30/37) of parents described oscillations in their experiences (i.e., feeling lost to finding hope and trusting the outcome). This was exemplified by some parents who within the same interview, oscillated in their description of how they were adapting to their child’s illness or to their child’s death. For example, some parents described their lack of acceptance and also their appreciation for the “awesome” days. Other parents discussed having “ridiculously” hard days while also always having “a million good things to a few bad things.” Examples from the same parent demonstrating these scattered oscillations are shown in Table 3.

Parents also expressed the need to be able to openly show the full spectrum of their vacillating feelings, concerns, and experiences. Parents wanted to share this with their child’s clinicians, with other parents, and within their communities. Parents described the importance of shedding expectations about being strong and positive all the time. Rather, parents wanted to show ‘vulnerability’ to shift expectations about what is considered resilient and courageous during these experiences. Parents wanted to be supported and encouraged to share their feelings in an effort to foster transparency and awareness about their experiences.

You [need to have] the community support to be able to make things happen and stay present for [your child]. And I feel like that really ties into... community and support and all that comes with that... and vulnerability. Defining what is strong and what is courageous. And just, you know, shifting the paradigm... and that paradigm also being that the parents need to be taken care of. (Bereaved Parent 24)

I just really openly share about how painful things are and parents should be allowed to grieve. (Bereaved Parent 37)

### **Discussion**

In this qualitative study of both non-bereaved and bereaved parents of AYAs with advanced cancer, parents described the process of adapting to their child’s serious illness and



death. The majority of parents described experiences of devastation, denial, senselessness, and anger as well as meaning-making, growth, and gratitude. Parents also expressed the importance of being able to openly share the full range of their experiences and the need to shift expectations about how parents should feel and behave during these difficult experiences. Additionally, parents wanted to openly express moments of hardship and the need for support during their child's serious illness and after their child's death.

Recognizing and supporting parent well-being is an established standard of pediatric oncology psychosocial care.<sup>18,27–29</sup> Parent well-being is essential to the care of both the child and family – as distressed parents are less able to care for their children or themselves.<sup>18</sup> This is particularly important in the advanced cancer setting, where 1 of 7 parents have been found to be highly distressed.<sup>30</sup> To better support parents, it is imperative that we gain additional understanding about how parents navigate the process of adapting when their child has a serious illness or dies.<sup>31</sup>

This study suggests that parents can have perspectives and experiences that seem conflicting, sometimes simultaneously, in the process of adapting to their child's illness or death. This suggests that when parents exhibit signs that they are 'doing well,' they may also be struggling and vice versa. Indeed, these experiences are not a duality, but rather often consist of simultaneous and competing feelings and rational thoughts. Instead of considering parents' reactions to their child's illness and death as either 'positive' or 'negative', clinicians and communities might serve them better by considering these responses as multitudes of valid experiences and emotions. Similarly, rather than being defined by a single moment in time, clinicians and communities may need to consider parent experiences as a complex process where swings and cycles are expected and normalized.

This study has important implications for the care of parents during their child's serious illness and after their child's death. Specifically, these findings suggest that there are ways for clinicians to better understand and respond to parents' experiences. When clinicians hear parents expressing emotions of regret, denial, or anger – it is important to understand that for them, this is just one moment in time and may not represent the full picture of their understanding. Furthermore, these expressions may not represent understanding at all, but rather, may be the expression of regret, denial, or anger as grief coping mechanisms. Similarly, when clinicians hear gratitude, resilience, and meaning-making – they should not expect parents to remain in that constructive, positive mental space all the time. Understanding and expecting oscillations as parents adapt provides an opportunity to improve communication and enhance support for parents.<sup>32</sup> Recognizing that strong emotions will come up often, clinicians can respond to parents with empathy, using both silence and statements that acknowledge and normalize parents' emotion in that moment.<sup>33–35</sup> When parents appear angry or upset, clinicians can proceed non-defensively by validating parents' reactions and respecting their emotional response and advocacy for their child.<sup>36</sup> When parents are expressing denial, disbelief, or a seemingly disparate understanding of their child's prognosis, this is not always a sign that the parent needs more information. In fact, well-meaning attempts to help parents 'get it' by clarifying or repeating hard information can contribute to conflict or mistrust of the medical team.<sup>37</sup> Instead, clinicians can focus on assessing a parent's understanding of their child's illness



at a time when parents are feeling prepared for the discussion and by asking open-ended, non-judgmental questions. Although listening support is often helpful, at times, hearing expression of these emotions may call for further assessment of the parent, as clinicians need to be cognizant of issues with complex or prolonged grief. Similarly, when parents are expressing moments of acceptance, clinicians can be aware that their work is not done. Instead, clinicians can listen during moments of grief and sadness and bolster moments of resilience and meaning by looking for opportunities to normalize these experiences. Additionally, clinicians may benefit from communication training, bereavement education, and to have bereavement and psychosocial clinicians available to support parents and families.

Furthermore, these data present an opportunity for parents to hear honestly and openly from other parents about the process of adaptation. Anticipatory guidance from other parents and learning from parent experiences are important. As parents in this study suggest, there is a need to normalize oscillations as part of adaptation within our hospitals and communities. Parents and clinicians can help other parents by setting different expectations and underscoring that there is no need for parents to hide how hard the process is or to be 'perfect', optimistic parents who 'have it all together' and can 'do it alone.'<sup>38</sup> Furthermore, clinicians can allow parents opportunities to share what is bringing them peace, confidence, and gratitude while normalizing this as part of adaptation as well. These findings underscore the fact that parents recognize, manage, tolerate, and accept the breadth and change of their emotional and rational thoughts in variable ways. While established psycho-therapeutic techniques such as dialectical behavioral therapy and acceptance and commitment therapy may help, such formal intervention may also not be available to all parents. Instead, clinicians must learn to support parents, and scalable interventions to help are needed. Being a strong parent means having stuck moments and seeing silver-linings, and all of these oscillations may be necessary in the process of adapting as a parent to a child's serious illness or death.

This study has several limitations. The majority of parents in our study were white, educated, English-speaking mothers. This limits the generalizability of our study and our ability to better understand the unique needs of various parent populations. Additionally, this study is limited by selection bias, as parents included in this study were coping fairly enough to be interviewed. Due to the sensitive nature of this study, parents may not have felt comfortable sharing information about their experiences during interviews, although studies suggest that interviews may be better suited for collecting information on sensitive topics when compared with surveys.<sup>39</sup> Similarly, one of the interviewers (ARR) was known to some of the parent participants, and this may have enriched or restricted our data. Despite this, data were consistent in regard to themes with those completed by an interviewer unknown to families (KSB), suggesting that this may have had a limited impact. We also only interviewed parents at a single timepoint and did not follow parents from before to after their child's death, limiting our understanding of the longitudinal process of adaptation over time. We also included parents with varying lengths of time from their child's diagnosis (non-bereaved) or death (bereaved) to interviews, which may have introduced differing levels of recall bias. Furthermore, in spite of comprehensive analysis, some perspectives from parents may have been misunderstood. Nevertheless, we think these findings provide

a window into different points along parents' experiences and the ways clinicians and our communities might better respond to parents in caring and supportive ways.

## Conclusion

Parenting a child with life-threatening illness is extremely difficult. This is further complicated by advances in medical technology and the types of intensive treatments that AYAs may undergo throughout their illness trajectory. Understanding how parents adapt during the end of their child's life and thereafter is critically important to providing necessary supportive care. In this qualitative study, non-bereaved and bereaved parents alike described a process of adaptation that occurred on a spectrum. Parents described oscillating back and forth both cognitively and emotionally in their experiences. They also suggested that having a supportive space and opportunities to learn from other parents would be helpful as part of the normalization of the oscillation experience of adaptation. This study underscores the importance of clinicians being flexible, not over-reacting or over-assuming, and being present for families so that they can meet them where they are. Important work is needed within our hospitals and communities so that parents can more openly share the hardships and silver-linings that are part of their parenting experiences. Clinicians can support parents by witnessing, normalizing, and responding to oscillations with caring, understanding, and patience as these may be natural and necessary parts of the adaptation process.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgements:

We thank the parents who shared their stories and experience with us.

**Funding Source:** This study was supported in part by the Seattle Children's Guild Association Adolescent and Young Adult Cancer Fund. Funding for Dr. Jori Bogetz was supported by the Seattle Children's Research Institute, Center for Clinical and Translational Research, Clinical Research Scholars Program. For Dr. Lori Wiener, this work was supported (in part) by the Intramural Program of the National Cancer Institute, NIH.

## Abbreviations:

AYAs                      adolescents and young adults

## REFERENCES

1. National Vital Statistics System Centers for Disease Control and Prevention. [www.cdc.gov. http://www.cdc.gov/nchs/nvss/mortality\\_tables.htm](http://www.cdc.gov/nchs/nvss/mortality_tables.htm). Accessed December 28, 2020.
2. Maude SL, Laetsch TW, Buechner J, et al. Tisagenlecleucel in children and young adults with B-Cell lymphoblastic leukemia. *N Engl J Med*. 2018;378(5):439-448. doi:10.1056/NEJMoa1709866. [PubMed: 29385370]
3. Hucks G, Rheingold SR. The journey to CAR T cell therapy: the pediatric and young adult experience with relapsed or refractory B-ALL. *Blood Cancer J*. 2019;9(2):10-19. doi:10.1038/s41408-018-0164-6. [PubMed: 30670684]
4. Summers C, Annesley C, Bleakley M, Dahlberg A, Jensen MC, Gardner R. Long term follow-up after SCRI-CAR19v1 reveals late recurrences as well as a survival advantage to consolidation with

- HCT after CAR T cell induced remission. *Blood*. 2018;132(Supplement 1):967–967. doi:10.1182/blood-2018-99-115599.
5. Gardner RA, Finney O, Annesley C, et al. Intent-to-treat leukemia remission by CD19 CAR T cells of defined formulation and dose in children and young adults. *Blood*. 2017;129(25):3322–3331. doi:10.1182/blood-2017-02-769208. [PubMed: 28408462]
  6. Bogetz JF, Trowbridge A, Kingsley J, Taylor M, Rosenberg AR, Barton KS. “It’s my job to love him”: parenting adolescents and young adults with advanced cancer. *PEDIATRICS*. 2020;146(6):e2020006353. doi:10.1542/peds.2020-006353.
  7. Lichtenthal WG, Roberts KE, Catarozoli C, et al. Regret and unfinished business in parents bereaved by cancer: a mixed methods study. *Palliat Med*. 2020;34(3):367–377. doi:10.1177/0269216319900301. [PubMed: 32020837]
  8. Lichtenthal WG, Currier JM, Neimeyer RA, Keesee NJ. Sense and significance: a mixed methods examination of meaning making after the loss of one’s child. *J Clin Psychol*. 2010;66(7):791–812. doi:10.1002/jclp.20700. [PubMed: 20527057]
  9. Greenzang KA, Cronin AM, Mack JW. Parental preparedness for late effects and long-term quality of life in survivors of childhood cancer. *Cancer*. 2016;122(16):2587–2594. doi:10.1002/cncr.30092. [PubMed: 27219336]
  10. Morris S, Fletcher K, Goldstein R. The grief of parents after the death of a young child. *Journal of Clinical Psychology in Medical Settings*. 2019;26(3):321–338. doi:10.1007/s10880-018-9590-7. [PubMed: 30488260]
  11. Davies R. New understandings of parental grief: literature review. *J Adv Nurs*. 2004;46(5):506–513. doi:10.1111/j.1365-2648.2004.03024.x. [PubMed: 15139939]
  12. Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. *Death studies*. 1999;23(3):197–224. doi:10.1080/074811899201046. [PubMed: 10848151]
  13. Al-Gamal E, Long T. Anticipatory grieving among parents living with a child with cancer. *J Adv Nurs*. 2010;66(9):1980–1990. doi:10.1111/j.1365-2648.2010.05381.x. [PubMed: 20626475]
  14. Grootenhuis MA, Last BF. Predictors of parental emotional adjustment to childhood cancer. *Psycho-Oncology*. 1997;6(2):115–128. doi:10.1002/(SICI)10991611(199706)6:2<115::AID-PON252>3.0.CO;2-D. [PubMed: 9205969]
  15. James K, Keegan-Wells D, Hinds PS, et al. The care of my child with cancer: parents’ perceptions of caregiving demands. *J Pediatr Oncol Nurs*. 2002;19(6):218–228. doi:10.1177/104345420201900606. [PubMed: 12444574]
  16. McCarthy MC, Clarke NE, Ting CL, Conroy R, Anderson VA, Heath JA. Prevalence and predictors of parental grief and depression after the death of a child from cancer. *Journal of Palliative Medicine*. 2010;13(11):1321–1326. doi:10.1089/jpm.2010.0037. [PubMed: 20954828]
  17. Kars MC, Gryphonck MHF, van Delden JJM. Being a parent of a child with cancer throughout the end-of-life course. *Oncol Nurs Forum*. 2011;38(4):E260–E271. doi:10.1188/11.ONF.E260-E271. [PubMed: 21708521]
  18. Kearney JA, Salley CG, Muriel AC. Standards of psychosocial care for parents of children with cancer. *Pediatr Blood Cancer*. 2015; 62:S632–S683. doi:10.1002/pbc.25761. [PubMed: 26700921]
  19. Hinds PS, Oakes LL, Hicks J, et al. “Trying to be a good parent” as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*. 2009;27(35):5979–5985. doi:10.1200/JCO.2008.20.0204. [PubMed: 19805693]
  20. Picoraro JA, Womer JW, Kazak AE, Feudtner C. Posttraumatic growth in parents and pediatric patients. *Journal of Palliative Medicine*. 2014;17(2):209–218. doi:10.1089/jpm.2013.0280. [PubMed: 24443768]
  21. O’Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research. *Academic Medicine*. 2014;89(9):1245–1251. doi:10.1097/ACM.0000000000000388. [PubMed: 24979285]
  22. Dedoose Version 7.0.23, web application for managing, analyzing, and presenting qualitative and mixed method research data (2017). Los Angeles, CA: SocioCultural Research Consultants, LLC; [www.dedoose.com](http://www.dedoose.com).

23. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2016;15(9):1277–1288. doi:10.1177/1049732305276687.
24. Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. *Qualitative Research*. 2001;1(3):385–405.
25. Kübler-Ross E, Kessler D. *On Grief and Grieving*. Simon and Schuster; 2014.
26. Southwick SM, Bonanno GA, Masten AS, Panter-Brick C, Yehuda R. Resilience definitions, theory, and challenges: interdisciplinary perspectives. *European Journal of Psychotraumatology*. 2014;5(1):25338–14. doi:10.3402/ejpt.v5.25338.
27. Jones B, Currin-McCulloch J, Pelletier W, Sardi-Brown V, Brown P, Wiener L. Psychosocial standards of care for children with cancer and their families: a national survey of pediatric oncology social workers. *Social Work in Health Care*. 2018;57(4):221–249. doi:10.1080/00981389.2018.1441212. [PubMed: 29498614]
28. Steineck A, Wiener L, Mack JW, Shah NN, Summers C, Rosenberg AR. Psychosocial care for children receiving chimeric antigen receptor (CAR) T-cell therapy. *Pediatr Blood Cancer*. 2020;67(5):664–669. doi:10.1002/pbc.28249.
29. Wiener L, Kupst MJ, Pelletier W, Kazak AE, Thompson AL. Tools to guide the identification and implementation of care consistent with the psychosocial standards of care. *Pediatr Blood Cancer*. 2020;67(9):e28586. doi:10.1002/pbc.28586.
30. Rosenberg AR, Dussel V, Kang T, et al. Psychological distress in parents of children with advanced cancer. *JAMA Pediatr*. 2013;167(6):537–543. doi:10.1001/jamapediatrics.2013.628. [PubMed: 23545569]
31. Snaman J, Morris SE, Rosenberg AR, Holder R, Baker J, Wolfe J. Reconsidering early parental grief following the death of a child from cancer: a new framework for future research and bereavement support. *Supportive Care in Cancer*. 2019;28: 4131–4139. doi:10.1007/s00520-019-05249-3. [PubMed: 31872296]
32. Kaye EC, Cannone D, Snaman JM, Baker JN, Spraker Perlman H. The state of the science for communication training in pediatric oncology: a systematic review. *Pediatr Blood Cancer*. 2020;67(10):CD003751–10. doi:10.1002/pbc.28607.
33. Back AL, Arnold RM, Baile WF, Tulskey JA, Fryer-Edwards K. Approaching difficult communication tasks in oncology. *CA: A Cancer Journal for Clinicians*. 2005;55(3):164–177. doi:10.3322/canjclin.55.3.164. [PubMed: 15890639]
34. Boyle D, Dwinell B, Platt F. Invite, listen, and summarize: a patient-centered communication technique. *Academic Medicine*. 2005;80(1):29–32. [PubMed: 15618088]
35. October TW, Watson AC, Hinds PS. Characteristics of family conferences at the bedside versus the conference room in pediatric critical care. *Pediatric Critical Care Medicine*. 2013;14(3):e135–e142. [PubMed: 23392371]
36. Levetown M, American Academy of Pediatrics Committee on Bioethics. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *PEDIATRICS*. 2008;121(5):e1441–e1460. doi:10.1542/peds.2008-0565.
37. Feudtner C. Collaborative communication in pediatric palliative care: A foundation for problem-solving and decision-making. *Pediatric Clinics of North America*. 2007;54(5):583–607. doi:10.1016/j.pcl.2007.07.008. [PubMed: 17933613]
38. Woodgate RL. Living in a World without closure: reality for parents who have experienced the death of a child. *J Palliat Care*. 2019;22(2):75–82. doi:10.1177/082585970602200203.
39. Rosenberg AR, Dussel V, Orellana L, et al. What's missing in missing data? Omissions in survey responses among parents of children with advanced cancer. *Journal of Palliative Medicine*. 2014;17(8):953–956. doi:10.1089/jpm.2013.0663. [PubMed: 24865204]

**Table 1:**

## Parent and AYA Demographics

Variable	Results
<b>PARENTS</b>	<b>N=37</b>
Non-Bereaved, n (%)	22 (59)
Bereaved, n (%)	15 (41)
Age, median in years [IQR]	47 [45–52]
Gender Female, n (%)	29 (78)
Ethnicity Non-Hispanic or Latino, n (%)	28/32 (86)
Race, n (%) <sup>1</sup>	
White	26 (62)
Asian American	5 (12)
Black or African American	2 (5)
Native Hawaiian or Pacific Islander	2 (5)
American Indian or Alaskan Native	2 (5)
Unknown	5 (12)
Level of Education, n (%)	
Less than High School Diploma	1 (3)
High School Diploma	6 (16)
Associate or Trade School	11 (30)
Undergraduate Degree	8 (22)
Graduate Degree	7 (19)
Unknown	4 (11)
Annual Household Income, n (%)	
<\$50,000	6 (16)
\$51,000-\$100,000	6 (16)
\$101,000-\$150,000	5 (14)
>\$150,000	5 (14)
Unknown	15 (40)
Marital Status, n (%)	
Married	22 (59)
Divorced	9 (24)
Never Married	2 (5)
Unknown	4 (11)
Number of Children (including AYA with advanced cancer), n (%)	
1	4 (11)
2–3	22 (59)

Variable	Results
4-5	6 (16)
Unknown	5 (14)
Self-Described as Spiritual and/or Religious, n (%)	30/32 (94)
<b>AYAs</b>	<b>N=34</b>
Age at Time of Parent Interviews for Non-bereaved Parents or At Time of Death for Bereaved Parents, median in years [IQR]	17 [15-19]
Gender Female, n (%)	18 (53)
Ethnicity Non-Hispanic or Latino, n (%)	24/30 (80)
Race, n (%) <sup>1</sup>	
White	24 (65)
Asian American	3 (8)
Black or African American	2 (5)
Native Hawaiian or Pacific Islander	1 (3)
American Indian or Alaskan Native	1 (3)
Unknown	6 (16)
Primary Advanced Cancer Diagnosis, n (%)	
Hematologic	18 (53)
CNS Tumor	4 (12)
Non-CNS Solid Tumor	12 (35)
Years Since AYA's Diagnosis to Non-Bereaved Parent Interview, median in years [IQR]	2.5 [1-6]
Years Since AYA's Death to Bereaved Parent Interview, median in years [IQR]	2 [1.8-3.4]

<sup>1</sup>Parents and AYAs reported >1 race; IQR: interquartile range; AYAs: adolescents and young adult; CNS: central nervous system



**Table 2:**

Experiences of Parents of AYAs with Advanced Cancer Demonstrating the Spectrum of Adaptation

Experiences	Spectrum of Adaptation		
<b>CONTROL</b>	<i>Guilt and feeling helpless</i>		<i>Recognizing the locus of control</i>
	<ul style="list-style-type: none"> <li>• And sometimes, when treatment doesn't work, I feel like it's my fault, like I chose this route. These were the options given to us, and I made the decision to go this way. What if we would have gone the other way? (Non-bereaved Parent 19)</li> <li>• I just kind of play everything out in my head all the time. On when it started, when it ended. Is it me, did I do something wrong? Did he do something wrong? It's that whole religion thing, are you bad, so are you being punished? I don't know, I have no answers. (Bereaved Parent 28)</li> </ul>	<ul style="list-style-type: none"> <li>• You always question yourself, why didn't we do this, why didn't I do that, why didn't I say that? And sometimes I looked around [my son's] room wondering if he left something for us cause he knew, but, we did the best we could. And I think [my son] knew. (Bereaved Parent 34)</li> <li>• I don't know how I am going to deal with [my child's death]. Except to say that, it's going to be a day at a time and I can't worry about cancer coming... I can't let my head go that way... We will eventually have to, but [not now]... (Non-bereaved Parent 6)</li> </ul>	<ul style="list-style-type: none"> <li>• We try to really focus on what's most important right now... What do we need to worry about and what [we don't] need to worry about... That's something we've focused [on] as a family and try not to worry about the things that we just can't change. (Non-bereaved Parent 20)</li> <li>• You can't solve anything worrying. You really can't change the outcome of what is going to happen by worrying... just go the best way you can, just go one day at a time, one moment in time, one hour at a time. (Non-bereaved Parent 1)</li> </ul>
<b>MEANING</b>	<i>Senselessness Gratitude and meaning-making</i>		
	<ul style="list-style-type: none"> <li>• I remember hearing on the radio somebody saying 'what's the worst thing that could ever happen to you?' and the guy, the other talk show host was like 'oh, like a spouse dying.' And I was like, people think, when you think of the worst thing that [this is it] – [but] this is not... this is so bad that it doesn't even cross the human capacity that you might lose a child. (Bereaved Parent 27)</li> <li>• Not one thing [helps]... Yeah no, there really isn't anything. I just miss her every second. (Bereaved Parent 37)</li> </ul>	<ul style="list-style-type: none"> <li>• As much as you want to be out of this cancer circle and be normal - I think our new norm is you have to accept it for once. We do our best again and the thing is really you look at it whether it's the provider, whether the nurses, social worker and people who understand our situation and supporting us. I mean you are really so embraced and surrounded by very, very nice people. That's what I feel. It has been really quite an experience to see the benefit of the world as well. (Non-bereaved Parent 15)</li> </ul>	<ul style="list-style-type: none"> <li>• And literally you have to embrace each day and be thankful and have some gratitude in even the smallest things... I think that you do find a new sense of gratitude in life. (Non-bereaved Parent 11)</li> <li>• I just felt like I was gonna shrivel up. But I can honestly say that I enjoy my life and I have a measure of happiness more often than not. And I didn't think I was ever going to feel that way afterwards. (Bereaved Parent 23)</li> </ul>
<b>ACCEPTANCE</b>	<i>Denial and questioning Acknowledging and moving forward</i>		
	<ul style="list-style-type: none"> <li>• I sure would like to think I can get comfortable with it, but at the same time, it still pisses me off that she's not here, but I mean, I'm not accepting it still and I don't know if I ever will. (Bereaved Parents 29+30)</li> <li>• My family doesn't want to talk about it... Right now he's cancer-free and that's the thing I want to focus on. (Non-bereaved Parent 8)</li> </ul>	<ul style="list-style-type: none"> <li>• I wrestle with people[s] perspective of "it's god's will"... I don't think there is a given plan of what is going to happen to my child already... If I thought that his path was already set then why would I be putting him through the tortures of chemo? (Non-bereaved Parent 5)</li> <li>• I've thought about everything I could've done. But you know, at the time, I wasn't able to do it because I was seeing my son die. (Bereaved Parent 26)</li> </ul>	<p>I have to accept it. There's no other way around it. My faith gives me that I know she's in a good place, I know she's safe, and I'll be with her eternally one day. (Bereaved Parents 29+30)</p> <ul style="list-style-type: none"> <li>• There is a time that everybody has to pass away. And sometimes unfortunately that comes sooner for some people than later. And if we can humanly do anything to delay that for the right reasons, in this case, we would do that ... You don't want [death] to happen, but it happens. (Non-bereaved Parent 3)</li> </ul>
<b>SUPPORT</b>	<i>Isolation Strength from connection</i>		
	<ul style="list-style-type: none"> <li>• I was so mad at the funeral... I was just so overwhelmed I think. I just wanted to be by myself. (Bereaved Parents 29+30)</li> <li>• I think even in the context of being at Children's we felt very seen and then as soon as he died, we were cut off from the only place where we were understood... We were in</li> </ul>	<ul style="list-style-type: none"> <li>• Walking with another caregiver... sometimes [that was] hard too, because you know you're hearing their journey as well and your heart breaks for them and what they've been through, and that's been hard too. Because you're not only processing your own grief and what ifs, you're processing it with other people... So, I mean there's beauty in walking that road with other people, but it's also</li> </ul>	<ul style="list-style-type: none"> <li>• I work with a place with 700 employees and probably 40 or 50 people have donated me vacation hours to be here... And they say, "Take as long as you need. When you come back you, you have your job" (Non-bereaved Parent 16)</li> <li>• There was somebody always sleeping on the couch or sleeping on the floor and we'd be walking</li> </ul>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Experiences	Spectrum of Adaptation		
	<p>that world for months and that was our whole world. We sat there, we breathed there, we lived there, we ate there, we celebrated our holidays there. We had very weird experiences, very funny experiences, very horrible – everything. (Bereaved Parent 27)</p>	<p>heartbreaking. (Non-bereaved Parent 10)</p> <ul style="list-style-type: none"> <li>• The general public, they don't understand anything about what's really going on, but the healthcare team, they understand. So that empathy to say, "You are in an impossible situation and you are doing good. You're doing awesome. Keep going." From a healthcare team that means everything. (Non-bereaved Parent 17)</li> </ul>	<p>around them. And his friends are amazing, just amazing. And the support we still have with the friends – they come by, or they come over for football games. We've been so fortunate with that. (Bereaved Parent 26)</p>
<b>HOPE</b>	<i>Feeling lost Trusting the outcome</i>		
	<ul style="list-style-type: none"> <li>• It's hard to stay hopeful. Each time you have it, the more it takes out of you. (Non-bereaved Parent 8)</li> <li>• I was just hoping for some big miracle and it was going to change any day. I couldn't wrap my mind around 'he won't be here.' (Bereaved Parent 28)</li> </ul>	<ul style="list-style-type: none"> <li>• We're just people that can do both to where we have hope that she'll live and hope that she'll beat the odds - and we aren't afraid to be let down if that makes sense. We're very much optimist people and we fight for the optimal side of it with balancing a little bit of reality too... It's back and forth. You can fear death but then you're still an optimist. You still hope, hold onto that hope. (Non-bereaved Parent 17)</li> <li>• We just go push forward and make the best of it and hope for the best and it's not easy. This is the hardest thing he's ever had to do and this is the hardest thing I'll ever see him go through. We're scared but we want to try fighting than not try at all, and this is where we're at. And it's what we've got to do. (Non-bereaved Parent 8)</li> </ul>	<ul style="list-style-type: none"> <li>• I pray and I believe that God has got her here for as long as he does, and that it's my job to care for her and fight for her as long as I have her. And I'm hopeful that she'll live a long and happy healthy life and that this medical treatment will keep evolving, and getting better, and that someday there'll be some sort of a cure for her, and that she'll live a normal, fun, fulfilling life. (Non-bereaved Parent 12)</li> </ul>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 3:**

Representative Excerpts of Oscillations in Adaptation During Individual Parent Interviews

Parent	Oscillation in Adaptation		
<b>NON-BEREAVED</b>			
3	[W]hen it is your own child who has grown in front of you ideally, at least in our culture, you want to pass away before your kids. That is how we think and it is impossible to accept that. No matter what any person says, it is just impossible to accept that.	I stopped thinking a while back because there is no guarantees for anything, if it's positive or negative. Because I stopped believing in both— that there is a miracle treatment, that this is like an amazing thing, or oh boy this is it and it's gonna go bad either.	If it comes again, I don't know if it will or if won't come at all. I don't care. At this time, we just look at today and be like 'hey its good.' ... Today is an awesome day and you don't think about anything else.
17	There's that hard day or there's the emotional hard day where, 'This sucks and this is ridiculously, ridiculously hard.'	You just have to think of the good. There's always a million good things to a few bad things ... So then you just change your attitude and look at things with a different perspective.	I think for some reason we notice a lot more good that has come out of it, as far as just being able to see the good in people that I think a lot of people don't get to see. There's so many people that are just good people, and empathetic, and they care, and they love, and they serve, and they think outside of themselves. And I think the cancer for some reason a childhood cancer, it brings out the good.
<b>BEREAVED</b>			
27	And when [my son] died, all we could think of was this wasteland of potential. So I don't know how you can cut off potential from the world and think of it in a positive way.	It was very helpful to me to see trees growing and these weird things of like a dead tree and a live tree growing on that. It just meant a lot to me. It sort of gave me a sense of who I was and who [my child] was in the universe, or the world, and the context of time.	I was like we're feeling things very rawly and I think what comes out of that and what we've taken away from that is that there's something very beautiful with moving, and there's something worth fighting for, even when you're not who you thought you'd be.
33	In the beginning I did not accept any help at all. I didn't want to believe that it was that serious to need help and I didn't want to be a burden.	There's people that [say] things like, 'You never get better it never goes away, but you learn how to handle it and deal with it.' Which sounds almost weird and sort of depressing when people say that. And I would say now, having two years out I feel like I understand what they mean and at the same time know that that doesn't really describe it, but I don't have a better way to describe. Our language just doesn't, I don't think have the power to describe a lot of things that relate to emotions and feelings.	I really do think that does help me in my ... grief handling process that having that to look back and go, 'I did everything that I could. Everybody did everything that they could.' I don't know what it would be like if I had a bunch of regrets. I imagine that it would disastrous honestly. And so I am thankful that I don't have them.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript