



“The place it puts us in emotionally and relationally with our child, it’s damaging”: understanding the real-world psychosocial needs of caregivers of childhood cancer survivors

Dori Beeler¹ · Vivian Christensen² · Kellee Parker³ · Erika Cottrell²

Received: 12 June 2023 / Accepted: 5 September 2023

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2023

Abstract

Purpose Understanding the lived experiences of childhood cancer caregivers can guide the development of effective psychosocial models of care. We conducted this qualitative study to understand triggers that impact the mental health, quality of life, and mental health supportive care needs of caregivers.

Methods A maximum variation sampling strategy was used to recruit study participants for semi-structured interviews. Using a grounded theory approach, transcripts were independently dual-coded using inductive thematic analysis. We conducted a secondary thematic analysis emphasizing the impact of pediatric oncology on caregiver mental health.

Results Our findings highlight caregiver experiences connected to their child’s appearance, quality of life, or change in behavior. Caregivers reported the need to transition between the role of nurturer and protector and simultaneously be part of the care team, which increased trauma for caregivers and their children. Caregivers noted that the hardest part of being a caregiver is witnessing, participating, and forcing the child to comply with cancer treatment. Caregivers were left wishing there had been more support for these situations.

Conclusion Our findings reveal real-world experiences that caregivers view as among the most stressful during their child’s cancer journey. These events provide insight into the nuanced and most difficult experiences from the caregiver perspective in which emotional support services would be most useful. These insights will inform a future model for mental healthcare.

Implications for Cancer Survivors Caregivers’ treatment-related stress is associated with the quality of life of pediatric cancer patients. Supporting the mental health, quality of life, and mental health supportive care needs of childhood cancer caregivers through supportive care guidelines may positively impact the caregiver–child relationship long into survivorship. Children’s and their caregivers’ treatment-related stress are indelibly connected to the quality of life concerns throughout the cancer journey. Supporting the mental health, quality of life, and mental health supportive care needs of childhood cancer caregivers through supportive care guidelines will positively impact the caregiver–child relationship long into survivorship.

Keywords Cancer · Caregivers · Family life · Health planning recommendations · Mental health · Oncology · Pediatric · Qualitative research

✉ Dori Beeler
dori.beeler@atriumhealth.org

Vivian Christensen
christev@ohsu.edu

Kellee Parker
kellee.parker@hsc.utah.edu

Erika Cottrell
cotrele@ohsu.edu

¹ Levine Cancer Atrium Health, Charlotte, NC, USA

² Oregon Health & Science University, Portland, OR, USA

³ University of Utah, Salt Lake City, UT, USA

Background

Childhood cancer has tremendous psychosocial impacts on caregivers, who must often assume responsibilities that are emotionally, physically, and psychologically demanding [1]. Caregivers are family members, friends, and others who most often help the cancer patient. For childhood cancer, caregivers include parent(s), grandparents, and legal guardians [2]. The complexity of caregiving is situated within the fluctuating levels of caregiver stress, including past and current mental and physical health experiences, family functioning, and marital distress [3].

Recently, researchers concluded that caregiver participation in shared decision-making is critical in mitigating the psychosocial impact of a childhood cancer diagnosis [4]. During the treatment phase, caregivers report waiting and longing for information and support that was not always forthcoming, resulting in reduced psychological well-being, described as “the hardest times we dealt with as a couple and a family” [5]. The treatment phase is described as an emotionally unstable situation for caregivers as their attention on caring for and protecting their child often means neglecting their own psychological needs [6]. It is only after curative treatment that many caregivers attempt to deal with the emotional trauma of childhood cancer [6].

Research suggests that caregivers who experience emotional support from attentive healthcare professionals during treatment may have more positive experiences with childhood cancer [7]. While the literature on caregiver well-being provides insight into their psychosocial needs, it does not provide a more nuanced understanding of the most difficult experiences from the caregiver perspective, which is necessary for successful implementation of caregiver support in the healthcare setting. Much of the qualitative research to date on the topic of caregiver mental health and childhood cancer has been done outside of the United States (US); thus, little is known about the experience of families living in the US, where mental healthcare is often not adequately covered by insurance [8] or is cost prohibitive [9].

In the US, patient guidelines highlight unique issues, identify available resources, and make evidence-based, supportive care recommendations [10] for patient management [11]. Apart from the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC), pediatric cancer guidelines do not include caregiver support. Furthermore, there is limited consensus in how these guidelines are applied across health systems [12]. While organizations draft guidelines to outline treatment recommendations based on existing evidence [13], the National Cancer Institute defines standards of care as treatment accepted by medical experts as a proper treatment for a certain type of disease and that is widely used by healthcare professionals [14]. Currently, there are no guidelines to support the implementation of standards of care for caregivers of children with cancer in the US [15]. Understanding caregivers lived experiences impacted by childhood cancer will provide valuable insight into the essential empirical guidance needed for psychosocial models of care to be effectively developed [16]. This study aims to better understand mental health supportive care needs and the impact of childhood cancer on caregiver mental health and quality of life.

Methods

Design

Using data from a comprehensive qualitative study examining family experiences with childhood cancer, we conducted a secondary thematic analysis of semi-structured interviews with caregivers of children who completed curative treatment. This inductive study design emphasizes narrative storytelling which provides caregivers an opportunity to highlight what matters most to them [17, 18]. We analyzed the mental health challenges experienced by caregivers during treatment and survivorship by highlighting especially stressful experiences that should be considered when designing and implementing caregiver support programs. A full description of the study’s methodology can be found in a previous publication [4].

Recruitment and data collection

A maximum variation sampling strategy was used to recruit study participants for interviews [17, 19, 20]. Any family member who participated in the child’s care was invited to participate. If the patient was 16 or older at the time of the interview, they were invited to participate. Families were eligible if they had a child diagnosed with cancer before the age of 15 and had completed curative treatment at least 1 year before their interview date.

Participants were recruited through a letter from an oncologist, outreach from a network of federally qualified health centers, community outreach, and national social media campaigns. All participants received additional information about the study by phone before scheduling their interview. Informed consent was obtained before the start of the interview. Participation was voluntary, and the Oregon Health & Science Institutional Review Board approved the study.

A semi-structured interview guide (Supplementary Material A) was developed based on information from a review of existing literature and consultation with an advisory group of clinicians, patient advocates, and caregivers of children who had experienced cancer. Interview questions focused on the process and perspectives of receiving the cancer diagnosis, experiences with treatment, information seeking, impact of cancer on the family, social support, and survivorship transitions. During the open-ended interviews in which participants were encouraged to focus on the issues most important to them, many brought up themes that were indicative of different types of trauma. In addition, interviewers asked about difficulties experienced during treatment as part of the a priori interview guide.

Interview guide refinements were made as the study progressed and new themes were identified.

Interviews were conducted between August 2018 and January 2020 by two interviewers with doctoral-level training in qualitative methodology (EK, VC). Interviews were audio and video recorded in either the participant's home, a location of their choosing, or remotely via a secure platform. If more than one family member was present,

interviews were conducted simultaneously. At the beginning of each interview, the participant was invited to tell the story of their family's cancer journey. Once the participant had provided their narrative, the interviewer probed topics that the participant(s) brought up and asked questions from the interview guide. Interviews lasted 90 min to 3 h. One fifty-dollar gift card was provided to each family for their participation.

Table 1 Patient demographics

Participant ID	Diagnosis	Age at diagnosis	Age at interview	Sex	Race/ethnicity
01	Leukemia	3 years	16 years	Male	White
02	Embryonal rhabdomyosarcoma	14 years	17 years	Male	White
03	Leukemia	14 years	22 years	Female	White
04	Leukemia	6 years	16 years	Female	White
05	Wilms tumor	4 years	11 years	Female	White
06	Leukemia	8 months	11 years	Female	White
07	Leukemia	2.5 years	11 years	Male	Multiracial
08	Leukemia	16 months	5 years	Male	Black
09	Leukemia	14 months	7 years	Female	Multiracial
10	Leukemia	5 years	10 years	Male	Multiracial/Hispanic
11	Hodgkin's lymphoma	8 years	11 years	Male	White
12	Leukemia	3 years	6 years	Male	White
13	Medulloepithelioma	9 years	11 years	Female	White
14	Ewing sarcoma	6 years	16 years	Female	White
15	Leukemia	4 years	9 years	Female	White/Hispanic
16	Leukemia	2.5 years	10 years	Male	White
17	Ovarian cancer	10 years	14 years	Female	White
18	Retinoblastoma	3 months	2 years	Male	White
19	Hodgkin's lymphoma	8 years	13.5 years	Male	White
20	Wilms tumor	2.5 years	11 years	Female	White
21	Wilms tumor	2 years	12 years	Male	White
22	Lymphoma (NHL)	4 years	8 years	Female	White
23	Retinoblastoma	18 months	12 years	Female	White
24	Rhabdomyosarcoma	4 years	7 years	Male	White
25	Leukemia	13 years	17 years	Female	White
26	Leukemia	4 years	10 years	Female	White
27	Wilms tumor	4.5 years	8 years	Male	White
28*	Hodgkin's lymphoma	13 years	27 years	Female	White/Hispanic
29	Neuroblastoma	4.5 years	13 years	Female	White
30	Ewing sarcoma	13 years	26 years	Female	White
31	Ewing sarcoma	6 years	10 years	Male	Multiracial
32	Leukemia	2.5 years	10 years	Male	White
33	Leukemia	3 years	10 years	Male	Other
34	Leukemia	4 months	6 years	Male	White
35	Rhabdomyosarcoma	13 years	19 years	Female	Not reported
36	Lymphoma	10 years	14 years	Male	White
37	Neuroblastoma	15 months	8 years	Female	Multiracial/Hispanic
38	Leukemia	5 years	15 years	Male	Multiracial/Hispanic
39	Chronic myeloid leukemia	11 years	16 years	Female	White

*Excluded from secondary analysis due to absence of caregiver present during interview

Data analysis

With this secondary analysis, we explored themes that emerged after initial analysis [21], to determine the impact of pediatric cancer on caregiver mental health. Coherence was maintained between the first and secondary analyses by utilizing the original data collection [22]. A Data Use Agreement was established, data were deidentified, and all interview data were used in our analysis.

Using a grounded-theory approach [23], three doctoral-level qualitative methodology trained research team members (DB, VC, EK) independently dual-coded the transcripts using inductive thematic analysis [24]. Identified themes were deliberated among study team members using an iterative process until consensus was reached. An initial codebook was developed using preliminary themes and subthemes. Codebook refinements were made as new themes and subthemes were identified. NVivo V.12 (QSR) was used to organize data for analysis. The unit of analysis for this study was the child who had been diagnosed with cancer.

Results

Fifty-five participants (33 mothers, 15 fathers, one grandparent, and six cancer survivors) representing 39 unique childhood cancer cases were interviewed (Table 1). A wide range of cancer types are represented in this group, and most caregivers are white and female. The following analysis focuses on 38 unique cases in which caregivers were interviewed and includes 49 caregivers (33 mothers, 15 fathers, and one grandparent). The original study included one patient who was interviewed without a caregiver present and is therefore excluded from this secondary analysis.

For this analysis, we take our cue from a mother who described her caregiving experiences as an “unexpected trauma” (#33). This informs our conceptual definition [25] of trauma and can be understood as a broad term

encompassing caregiver experiences that include high emotional distress described as “difficult” (#10; father), “horrible” (#27; mother), or feelings of helplessness (#20; mother). This is supported by the operational definition of trauma, which is, in brief, “any disturbing experience that results in significant fear, helplessness, dissociation, confusion, or other disruptive feelings intense enough to have a long-lasting negative effect [26].”

Based on our analysis, we start with a presentation of firsthand expressions of caregiver trauma connected to their child’s appearance, quality of life, or behavior. Next, we outline three categorical experiences that shape trauma: witnessing or participating in procedures; forcing their child to take medications; and the inability to comfort their child during a time of need. We demonstrate how these experiences have lasting impacts on caregiver mental health. Amplifying caregiver voices highlights the contextual experiences of impaired mental health. Figure 1 provides representation of the themes and subthemes of our analysis and Table 2 presents the full range of exemplary quotes from caregivers focusing on the identified themes.

Expressions of traumatic experiences

Caregivers recalled the most challenging experiences associated with their child’s cancer journey. The trajectory of trauma, and in some cases post-traumatic stress disorder, starts before the official diagnosis [4] and continues into survivorship. One caregiver (#38; mother) described her experience before the official diagnosis as “running from one place to the next with your child, who’s in agony. You know it’s an emergency, but you don’t know what’s happening...[w]e didn’t get...an official diagnosis for three days. It’s very frustrating, and it makes you feel very powerless as a parent because your number one job is to protect your child.” For another caregiver (#15; mother), her trauma emerged during treatment when she “would not leave the hospital room.” She added, “yes, I have really bad PTSD

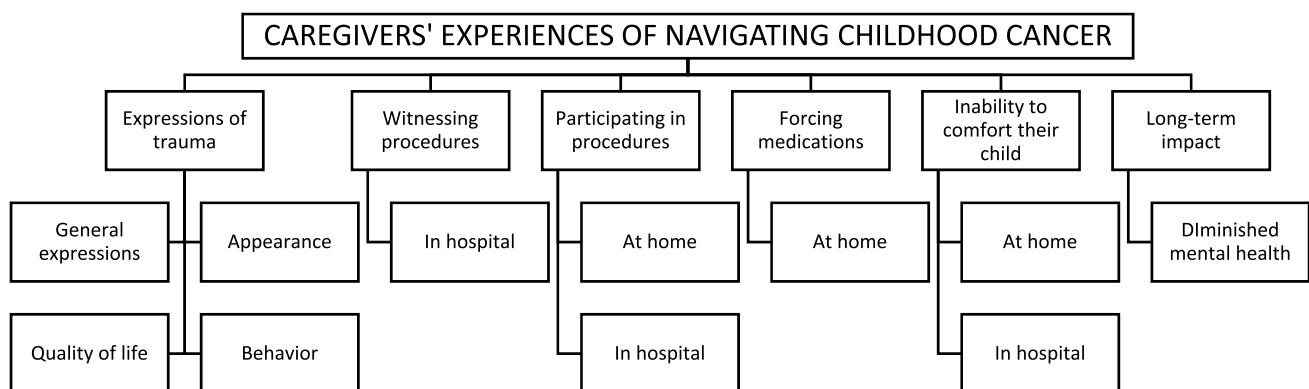


Fig. 1 Summary of the themes and subthemes based on secondary analysis of caregiver interviews

Table 2 Childhood cancer's impact on caregiver mental health. Exemplary quotes from themes identified in our analysis

Theme	Subthemes	Representative quotes
Expressions of trauma	General expressions	But like yeah, it's just like this—it's kind of like your heart's broken and it can't be unbroken. And you kind of hold it at bay. But I just notice how much more emotional I am than I ever was before, especially related to people, with children going through hard things. (#09; father)
		One thing I remember really well is so shocked. As we were being like hustled from one spot to the other throwing up.... I threw up in a trash bin. I threw up in some other thing; I couldn't even tell you now. But it was like my body's way of dealing with this unexpected trauma. (#33; mother)
	Appearance	Yeah, he dropped down to 22 pounds. So, he was 3 years old and 22 pounds, and he just looked like a bag of bones. He had no hair. His eyelashes were gone. His eyebrows were gone. Just a skull and big brown eyes and bony arms. (#01; mother)
		But they really didn't give us—they were like, "Oh, he's going to get a little like we call it pumpkin face or something like that," but they didn't say, like he's going to become unrecognizable, and he might—like even when he lost his ability to walk... (#07; mother)
	Quality of life	We came home. Patient was in a wheelchair when we got home, too weak to walk. When they took the tumor out, it had eaten basically her entire elbow. So, they put in an implant, a metal implant, a metal elbow. They tried; I do not know how many versions of this metal implant. Finally, it will be two years in March. Patient was just in so much pain. They had come up with a new implant to use, but the FDA did not approve it. So, they took her arm, right above the elbow, two years ago. (#14; mother)
		But with that, like there are the long-lasting side effects. He stopped walking, and so he was in physical therapy for three years. ...So, that was another surgery to clip his heel cords, to lengthen them out and cast it... and that was in kindergarten, so that was hard for him just to have to go to school in a cast, and... kids are rude, mean. And like he had not dealt with enough, he had to deal with that. ...even though treatment may not be all that long, but the lasting effects of all those treatments last years. (#21; mother)
B	You know, they put the stuff in her veins, and she slowly just starts. You know, you can see her energy level drop. You can see everything starting to happen. It was hard. Hair started falling out. She did pretty well for the first couple of treatments, and then it got harder and harder and harder as they went on. There was the vomiting, the diarrhea, the nausea, and the bone pain. (#35; father)	
	He was a different person on steroids. There was also the fact that he blew up physically. He didn't look like my child anymore. He didn't look like him, he didn't act like him. So, caring for him was so much harder. That was the hardest part. He was really irritable, really irritable, and demanding. And then on top of it, he was always hungry, and he just didn't look like my son because he was swollen. His face had swollen, his whole body was swollen, but his legs had atrophied. So, he could barely walk up the stairs. (#12; mother)	
	She went on food strikes in the hospital; she wouldn't eat or drink anything when she was physically admitted to the hospital—nothing. We brought Chick-fil-A milkshakes... nothing... brought her cups from the home, that was like once in a while, I could get her to drink half a cup of juice. (#26; mother)	
		The kids have reactions that which makes them angry and hostile and throwing things, trying to smash their upstairs window out with a fan. So, we're dealing with a four-year-old who we know is under treatment, who is uncontrollable. ... And then when he finally came off and those behaviors were continuing it was, "You know what? You're not taking those pills anymore. This is not -" So it almost became almost a learned type of a behavior where we had to turn around and go, "You're not on chemo anymore. This behavior is not okay. You can't do this." (#01; father)

Table 2 (continued)

Theme	Subthemes	Representative quotes		
Witnessing procedures	In hospital	<p>And then my daughter is just very challenging in a lot of ways, and when it came to them accessing her port, every single time it was a huge ordeal, and she would have to be held down. And she never really got used to that in all the months. So sometimes it would take 45 min just to access her port. So, you know, we were gone for several hours. And then we would get home and then we would both just be exhausted. (#05; mother)</p> <p>And all kinds of other complications and he ended up in ICU for two or – two, if not three nights recovering from the surgery. It was pretty bad, and they had him intubated. He became conscious while he was still intubated, which was really – I don't know if you've ever seen that look on somebody's face when they wake up to intubation, it's horrible. (#27; mother)</p> <p>So, that was the hardest part, and she doesn't remember any of it, and they said, "We give specific drugs so that they don't remember." I said, "Well, you need to give parents that drug too, seriously." I said, "You need to give parents the drug that makes them not remember that experience, because it was so scary there in the ICU, and then to have a breathing tube—and they have to have it. So, whether you want them to take it out or not, they're not going to take it out because I'm like, "Can't we just take it out, she'll be fine." "No, we don't know she will be." "Okay. Fine." And to see your child not be recognizable as your child at all, and to just see them suffering, and to hear the alarms, I think that was just... that was my scary, scary moment. And I was glad she doesn't remember any of that. (#30; mother)</p> <p>Putting him through physical suffering and pain that's unpleasant for him, watching him be sedated, watching him have biopsies, watching the tumor grow, and literally watching the lump over his eye get bigger. They had us taking photos every week and you could compare them and look and see that it was bigger. Early on, when I ran my hands through his hair and came away with a handful of hair and we shaved his head totally after that, but that's hard. All the emotions are just running high the whole time and you're supposed to be the adult. (#24; mother)</p>		
		Participating in procedures	At home	<p>Fortunately, my husband being a paramedic, knew the whole kit, right? But, you know, you have to hold her down and she can't move. So, it doesn't matter how much she's screaming. It doesn't matter how much she's screaming at you or just crying. I mean, she wasn't saying words because she was a little baby. But I mean, you know, you've got her kind of all laid out. And once you start you can't stop. (#23; mother)</p>
			Inpatient	<p>And then the PICC line was not fun either. It would be like weekly changes where we would have to hold him down and it was not—that was really bad, that was one of the worst parts of it all. (#18; mother)</p> <p>I think the hardest part was just having to tell my 4-year-old and my 5-year-old. First of all, that she had to get poked. We don't have a choice. She has to do it. There isn't a choice about it. Holding her down sometimes, too, where they could do it because there were some days where she just wasn't going to let it happen. You have to. You don't have a choice. (#15; mother)</p> <p>Thank god for Doc McStuffins, that cartoon doctor. Oh, my goodness, that was the saving grace of a life, because she wasn't afraid of doctors philosophically, just in general, because of her. So, we could take that, and she would... but she's a powerful kid, she's a control... she does not want to be restrained, and so needing to hold still for X or Y was the problem, and there was no negotiating with her; she didn't understand to negotiate. She didn't understand that "If you hold still for 30 s, I'll let go of you and never hold you again this afternoon." But the more she fought, the more I had to hold her still. And so, I became very much the bad guy. ... My husband's petrified of needles; he passes out—he doesn't mean to, he just really, legitimately... so, he's useless in some of those respects. So, he's there to pick me up off the floor after I've had to hold her down, so he's been wonderful in that respect, but there was no trade –I had nobody to trade with; I was always the one that had to hold her down. We've gone many battles, yeah. (#26; mother)</p> <p>So, the nurse would come in. I'd have to hold him down while they cleaned his PICC line, and he would just be screaming. There were other things that like seared in my brain. So [one] night I had to hold him, he lay against me, and I wrapped my arms around him so he couldn't move his arms. And it took of our nurses to hold him down while they tried to place the G tube in his nose. It was hard because he wasn't even four, and trying to explain that to a little boy is rough. He cried and cried and cried. And I sat behind him weeping so he couldn't see me. (#33; mother)</p>

Table 2 (continued)

Theme	Subthemes	Representative quotes
Forcing medications	At home	At one point his nausea got so bad, and we weren't being aggressive enough with the Zofran because again, we had to hold him down to chew the pill or squirt it into his mouth, that he ended up losing a lot of weight in a couple of weeks ... So, let's see; he has a lot of light sensitivities especially during radiation. That was really harsh. He was wearing sunglasses and a hat all of the time. He would press a wet cloth up against his eye when it hurt. When it itched—he ended up with an inflammation underneath his eyelid, so his eye radiation was basically giving him sunburn. He had sunburn around his eye, so we were trying to put cream on that, but he also had irritation under the eyelid, so his eye was puffy and swollen and it hurt. That was yet another time to hold him down, open his eye, and give him eye drops three times a day for a couple of months there in the middle. (#24; mother)
Inability to comfort their child	At home	Yeah, those were the hardest part with him; honestly, I think that it was very hard for well for us as well. I know that it was hard for me. It was difficult watching your kid go through so much pain and knowing that there's not a single thing you can do about it. (#10; father)

from it, from the whole experience, and everything like that.” These challenges spillover into survivorship, as explained by one caregiver (#09; father) that it “doesn't go away, ever...I don't think it will ever go away where you [can] just be like oh, remember that time where she had cancer back then?” Sharing the difficulty of their family's cancer journey this caregiver (#09; father) shared “your heart's broken and it can't be unbroken.”

Many caregivers described specific triggering events connected to their child's appearance, quality of life, or change in behavior. One caregiver (#21; mother) recalled her son changing from “a chubby, little happy two-year-old to this... gravely looking, sunken-cheek skeleton of my son;” no longer reflecting the child she knew. Another caregiver (#10; father) shared that “[d]uring the first two years of treatment, the only thing that I really noticed...he was just plunging deeper into this depression. He stopped caring about everything...most of the time he would just sit there crying, wanting to go home, because we were up [at the hospital] so much.” Caregivers also shared the challenges of dealing with new behaviors. One caregiver (#16; mother) described that their two-and-half year-old child was “throwing things, knocking over bookshelves... it was just rage. And that's hard to deal with...as a parent.” Most caregivers say they wished there had been more help for these situations. These descriptions of triggering events are a gateway for understanding the mental health supportive care needs of caregivers.

Witnessing procedures

For some caregivers, the trauma of caring for a child with cancer stemmed from witnessing the administration of treatment at the hospital. One caregiver (#22; father) reflected on seeing his daughter lying in her room and the overwhelming

“smell of death – that nasty dead smell when she was in the harsh treatment...[i]t was just like her whole room. I think we were sitting there going, is this right? We are poisoning our child.” Similarly, another caregiver (#35; father) recalls the first treatment when the nurse arrived “in a hazmat suit. I am thinking to myself; you are going to put that shit in my daughter's veins? Are you kidding me?” The sheer shock of the procedures led caregivers to question treatment decisions.

In another case, a caregiver (#06; mother) recalls “day 13, just after she had had her [bone marrow] transplant. She's bloated up to the 14.5 kilos. I wake up in the morning and they've got the (blow-by) on her face. She's not doing well. I'm getting concerned. And I am like borderline about to lose myself. [A]s a mother you want to take that pain away. You want to take her place. But what are you going to do?” The caregiver explained that this was particularly difficult because her child is “suffering; [a]nd that was the hardest thing to see.” Another caregiver (#10; mother) described how her child had to endure a monthly spinal tap procedure and cried every time it was discussed and conducted. For the caregiver, this was “upsetting. I could hear the pain in his voice...[i]t was hard to watch [and] to know that there was nothing we could do about it and that it had to be done.”

Participating in procedures

In many cases, caregivers were also participants in their child's procedures in the home and hospital. A caregiver (#23; mother) shares the traumatic memory of changing her daughters' dressings every 3 days at home and how it “was a three-person job. We had various people in town that would come over for the tear-inducing trauma of changing out a sterile dressing...you have to hold her down and she can't move...it doesn't matter how much she's screaming.”

One caregiver (#26; mother) described their hospital-based experience of drawing blood “[a]nd soon as she had spiked a fever, we had to go to the hospital, we had to get a blood draw, which was what I was—it was her worst part... she could not grasp or understand, ‘[h]old still for five seconds.’ She didn’t know how to count...[t]here was a nurse to hold her arm, there was a nurse to do the draw, and there was me holding the rest of her body. I literally laid on her stomach and just held her down.” This participation turned this caregiver into the “bad guy,” altering her relationship with her child.

In some cases, caregivers questioned the aftereffects of the caregiver role in their child’s treatment. One caregiver (#27; mother) shared that the hardest thing was “the day they had to put a mask on [her son’s] face, to put him under anesthesia...he was so adamant that he didn’t want to go under that I had to...pin all his limbs down so he wouldn’t tussle. We have to do that work. But the place it puts us in emotionally and relationally with our child, it’s damaging. [W]hat’s the alternative? I don’t know if there is one.” Experiences such as these were not limited to assisting in the treatment, and in some cases, caregivers had to administer medication without provider participation.

Forcing medications

Caregivers describe their experience of administering their child’s medication and the added stress it caused. One caregiver (#01; mother) remembered telling her son, “‘Patient do it or Daddy do it.’ And this was all going to happen one, two, three, and here it comes because it just all had to happen that quick or else it would just make our lives miserable.” She added “[s]ome of those days were really hard...he would take his pills, or I would...shove them down his throat, and then turn around and catch hi[s] puke in buckets.” Some children had an adverse reaction when caregivers were too passive regarding their child’s medication. Another caregiver (#24; mother) recalled that her son ended up losing a lot of weight because “[a]t one point his nausea got so bad and we weren’t being aggressive enough with the Zofran because again, we had to hold him down to chew the pill or squirt it into his mouth.” She added that she had difficulty with the radiation-induced eye irritation medication; she had to “hold him down, open his eye, and give him eye drops three times a day for a couple of months.” In these instances, caregivers turn from nurturers and protectors to their child’s primary source of distress and pain.

Inability to comfort their child

Caregivers also experienced the inability to actively comfort their child during cancer treatment. One caregiving couple (#20; mother and father) recalled wanting to hold their

2-year-old daughter when she had numerous tubes in her body. The child’s first caregiver (mother) recounts the moment when “I start[ed] to pick her up because I just couldn’t stand it anymore and...[e]verybody’s like, no you can’t touch her yet...[j]ust that helpless feeling like, I can’t even hold my baby?” The child’s second caregiver adds, “Yeah. That was really terrible...you can’t just pick her up...that was really hard.” Another caregiver (#08; mother) explained, “the hardest thing...is because he was 16-months, nonverbal, and [t]here were times when he would just scream and cry all night and the only thing I could do was hold him.” This inability for caregivers to comfort their child led to feelings of helplessness.

The long-term impact of childhood cancer on caregiver mental health

Caregivers described the lingering impact of childhood cancer on their mental health. One caregiver (#07; mother) recalled that 3 years after her son’s treatment, she felt like “we didn’t even have an excuse then. I didn’t even want to be like ‘oh my son had cancer three years ago’...[a]nd it’s like I’m really depressed now.” Another caregiver (#01; mother), whose child was diagnosed over 9 years before her interview, was explicit that it was “the PTSD, whatever you want to call it. And I don’t know if that will diminish or if that will ever go away, especially now because new things always come up.” This uncertainty was reflected on by another caregiver (#03; father) and his “disappoint[ment] that nothing [for mental health] was offered. I don’t think anybody, any parent on the ward talked about it, getting mental health for their problems...[i]t changed everything. It never went back to normal again.”

Discussion

This in-depth look into the mental health challenges experienced by caregivers during treatment and survivorship highlights the especially stressful experiences that should be considered when designing and implementing caregiver support programs. The trajectory of trauma for caregivers of children with cancer is genuine and often long lasting. These distinct challenges are a gateway for understanding the mental health supportive care needs of caregivers and the events that trigger trauma. Survivorship does not mean a return to normal. For many caregivers, the impact of their childhood cancer experience continues long after treatment has ended.

Given the structure of our in-depth interviews in which participants were encouraged to tell their story, focusing on the issues most important to them, the identified themes reflect the experiences that stand out to caregivers as the most challenging and thus require support. Caregiver experiences with trauma connected to their child’s appearance,

quality of life, or change in behavior left many wishing there had been more support for these situations. We found that caregivers must regularly transition between the role of nurturer and protector while simultaneously serving as part of the care team, which increases trauma for caregivers and the child. These traumatic events are experienced in varying degrees that necessitate mental health supportive care needs well into survivorship. In highlighting these events, we have identified key triggers of trauma.

For many caregivers, the challenging aspects of their child's cancer treatment entailed witnessing and participating in procedures, forcing the child to comply with their cancer treatment, and the emotional toll of not being able to comfort their child. Witnessing procedures left caregivers feeling that there was nothing they could do about their child's distress and pain. Participation in their child's treatment was often something caregivers dreaded. Some felt guilty for having to hold their child down knowing the procedure was scary or painful or having to administer medications that were unpleasant. It left caregivers feeling helpless to comfort their child. This helplessness associated with witnessing and participating in care was described as "traumatizing times" and "hard to experience as a parent," leading caregivers to question whether they were doing the right thing. These experiences were not limited to the hospital setting; for some caregivers, traumatic events occurred in the home, too, further blurring the boundary between roles. Actively participating in procedures, at home or in the hospital, puts caregivers in a difficult, and in some cases, impossible position with the potential to alter their relationship with their child. In some cases, participation in their child's care led them to reflect on how their actions turned them from caregiver to "bad guy," subsequently impacting a child/caregiver relationship centered on trust. These real-world experiences reveal the hidden and often overlooked nature of being the caregiver of a child with cancer.

The traumatic experiences of caring for a child with cancer can significantly impact caregiver mental health and caregiver/child relationships. Although the literature suggests that caregivers generally cope well [27], a recent longitudinal study reports that 28.7% of caregivers experience increased post-traumatic stress symptoms (PTSS) over time that necessitate targeted interventions [28]. Additional studies have outlined that caregivers experience clinically significant levels of anxiety, PTSS, poor health-related quality of life, or other mood symptoms [29–33] that may last well beyond the end of treatment [27]. Our real-world observations add to the literature by demonstrating the nature and extent of traumatic experiences. Furthermore, our data underscore that these traumatic experiences occur universally, across all cancer types, patient ages, types of residence (rural vs urban), and long after treatment has ended. Combined, these findings may help guide best practice for

delivering accessible and effective integrated medical and mental healthcare.

Trauma's pervasive nature is not limited to the hospital, and, in many cases, caregivers must continue to conduct a range of medical procedures of varying complexity in the home, further impacting caregiver burden. These findings are supported by existing literature on childhood cancer recognizing that caregivers are untrained to provide most medically related activities [1, 34]. Our findings are similar to that of other research which report that participating in medical procedures creates feelings of inadequacy and psychological trauma for the caregiver [35]. Furthermore, caregiver trauma is indelibly connected to the child and this idea is supported by the work of de Castro et al. [2], in which caregivers' PTSS is partially mediated by the relationship between the children's PTSS and caregivers' quality of life.

Understanding caregivers' traumatic experiences pre-diagnosis through survivorship can help establish and implement universal guidelines. In the US, guidelines focus on patient supportive care recommendations [10], and as stated above, with the exception of the PSCPCC, these guidelines do not include caregiver support. The PSCPCC recommends a standard of care (SOC) that includes early and ongoing assessments of caregivers' mental health needs with facilitated access to appropriate interventions [36]. However, a national pediatric oncology social worker survey suggests that improvement in the systematic implementation of PSCPCC SOC into daily practice is needed [15]. Models of psychosocial support could provide consistency to SOC implementation for caregivers of children completing treatment [34, 37] and enhance the effective and equitable use of existing guidelines across health systems. Considering that caregivers' PTSS mediates children's PTSS [2], the fact that published pediatric cancer guidelines [10, 12] do not encompass caregiver support is a significant oversight.

Educating caregivers at diagnosis on the importance of accessing psychosocial services is key to addressing uncertainties. Such services must also be broadly implemented across health systems, be readily accessible, and convenient for caregivers to access. Considering the traumatic experiences associated with turning from protector to the perpetrator of their child's primary source of distress and pain, psychosocial support from the onset of treatment is a vital aspect of caregiver support. An additional educational component should include caregiving resources during childhood cancer that allows caregivers to gain confidence in their treatment decisions and strategies for navigating changes in quality of life and behavioral challenges.

Clinical implications

Caregivers require guidance on the traumatizing aspects of pediatric oncology care to address feelings of helplessness

and to mitigate the risk of damaging the caregiver–child relationship. This includes reconsidering asking a caregiver to hold down their child for a procedure. For such situations, providers and caregivers could instead collaboratively create a resource plan to inform the medical team of caregiver expectations and preferences for procedural participation. In addition, hiring trained mental health professionals is key to forming a comprehensive care team. As such, a model for mental healthcare would include education on available support resources, implementation of a resource plan, and trained support staff. Pediatric oncologists do not receive mental health training and do not have the capacity to fulfill this need. With additional support for caregivers and providers, the inherent trauma of childhood cancer may be reduced throughout the cancer journey.

Study limitations

Allowing study participants to share their experiences with cancer and highlighting what they believe to be the most important aspect of their experience reveals the traumatic impacts directly associated with their child’s cancer journey from pre-diagnosis to survival. However, our study has several limitations, including potential recall bias. In some cases, caregivers were not interviewed separately, which may have led some participants to hold back experiences that could have been upsetting to others who were present during the interview. Furthermore, the study population does not allow for subgroup analysis. Further research is needed to evaluate caregivers’ experiences from diverse subgroups to determine if there are other traumatic experiences than those reported here. Additional research is needed to understand how best to implement these recommendations to inform guidelines aimed at reducing the negative impacts on caregiver mental health and quality of life in relation to childhood cancer.

Conclusion

This secondary analysis of qualitative data fosters a more in-depth understanding of the long-term impact that traumatic experiences of childhood cancer have on caregivers. Findings reveal firsthand expressions of caregiver trauma connected to their child’s appearance, quality of life, or behavior. These expressions are expanded across three categorical experiences that shape trauma: having to witness or participate in procedures; forcing their child to take medications; and not being able to comfort their child during a time of need. Increasing awareness of these challenges and developing effective and innovative ways to provide support to caregivers is essential. The experiences reported across this qualitative study provide important insight on the necessary

content for effectively designing and implementing caregiver support programs to reduce caregiver stress and burden.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s11764-023-01461-7>.

Author contribution All authors contributed to the study conception and design. V.C. and E.C. performed the data collection. V.C., E.C., and D.B. conducted the material preparation and analysis. D.B. and V.C. wrote the first draft of the manuscript and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Data Availability The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Declarations

Conflict of interest The authors declare no competing interests.

References

1. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology*. 2010;19(10):1013–25.
2. de Castro EK, et al. Assessing the relationship between PTSS in childhood cancer survivors and their caregivers and their quality of life. *Pediatr Hematol Oncol*. 2021;38(2):147–53.
3. Kearney JA, Salley CG, Muriel AC. Standards of psychosocial care for parents of children with cancer. *Pediatr Blood Cancer*. 2015;62 Suppl 5(Suppl 5):S632–83.
4. Christensen V, et al. ‘Never once was I thinking the c-word’: parent perspectives on the facilitators and barriers to getting a childhood cancer diagnosis. *J Clin Nurs*. 2022;32(13–14):3981–94.
5. Beddard N, et al. Childhood eye cancer from a parental perspective: the lived experience of parents with children who have had retinoblastoma. *Eur J Cancer Care (Engl)*. 2020;29(2): e13209.
6. Carlsson T, et al. Psychological distress in parents of children treated for cancer: an explorative study. *PLoS ONE*. 2019;14(6): e0218860.
7. Molinaro ML, Fletcher PC. “There is no before cancer... there is only cancer.” Perceived late effects of pediatric cancer on survivors. *Cancer Nurs*. 2020;43(6):468–477.
8. Fitzpatrick KM, Harris C, Drawve G. Fear of COVID-19 and the mental health consequences in America. *Psychol Trauma*. 2020;12(S1):S17–21.
9. Blunt EO, et al. Public insurance expansions and mental health care availability. *Health Serv Res*. 2020;55(4):615–25.
10. The Children’s Oncology Group. COG supportive care endorsed guidelines. Available from: <https://childrensoncologygroup.org/cog-supportive-care-endorsed-guidelines>. Accessed 15 July 2022
11. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Adolescent and Young Adult (AYA) Oncology Version 1.2023©. 2023 [cited 2022 September 15]; Available from: To view the most recent and complete version of the guideline, go online to NCCN.org.
12. Baum KT, et al. Implementing guidelines: proposed definitions of neuropsychology services in pediatric oncology. *Pediatr Blood Cancer*. 2017;64(8):e26446.
13. Lazor T, et al. Few guidelines offer recommendations on how to assess and manage anxiety and distress in children with cancer: a content analysis. *Support Care Cancer*. 2021;29(5):2279–88.

14. National Cancer Institute. Standard of care. NCI Dictionary of Cancer Terms 2023 [cited 2023 August 7]; Available from: <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/standard-of-care>. Accessed 15 July 2022
15. Jones B, et al. Psychosocial standards of care for children with cancer and their families: a national survey of pediatric oncology social workers. *Soc Work Health Care*. 2018;57(4):221–49.
16. Rabineau KM, Mabe PA, Vega RA. Parenting stress in pediatric oncology populations. *J Pediatr Hematol Oncol*. 2008;30(5):358–65.
17. Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Med Educ*. 2006;40(5):405–14.
18. Ziebland S, Grob R, Schlesinger M. Polyphonic perspectives on health and care: reflections from two decades of the DIPEX project. *J Health Serv Res Policy*. 2021;26(2):133–40.
19. Coyne IT. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *J Adv Nurs*. 1997;26(3):623–30.
20. Patton M. *Qualitative research and evaluation methods*. Los Angeles, London, New Delhi, Singapore, Washington DC: Sage Publications; 1990.
21. Heaton J. Secondary analysis of qualitative data: an overview. *Historical Social Research/Historische Sozialforschung*, 2008: p. 33–45.
22. Hinds PS, Vogel RJ, Clarke-Steffen L. The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qual Health Res*. 1997;7(3):408–24.
23. Corbin JM, Strauss A. Grounded theory research: procedures, canons, and evaluative criteria. *Qual Sociol*. 1990;13(1):3–21.
24. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
25. Bernard HR. *Research methods in anthropology : qualitative and quantitative approaches*. 5th ed. 2011, Lanham, Md.: AltaMira Press. xiii, 666 p.
26. American Psychological Association. trauma. APA Dictionary of Psychology 2023 [cited 2023 August 7]; Available from: <https://dictionary.apa.org/trauma>. Accessed 15 Jul 2022
27. Quast LF, et al. Psychosocial functioning among caregivers of childhood cancer survivors following treatment completion. *J Pediatr Psychol*. 2021;46(10):1238–48.
28. Sharp K, et al. Trajectories of resilience and posttraumatic stress in childhood cancer: consistency of child and parent outcomes. *Health Psychol*. 2022;41(4):256–67.
29. Koumariou A, et al. A review of psychosocial interventions targeting families of children with cancer. *Palliat Support Care*. 2021;19(1):103–18.
30. Ljungman L, et al. Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. *PLoS ONE*. 2014;9(7): e103340.
31. Wakefield CE, et al. Parental adjustment to the completion of their child’s cancer treatment. *Pediatr Blood Cancer*. 2011;56(4):524–31.
32. Wikman A, et al. Prevalence and predictors of symptoms of anxiety and depression, and comorbid symptoms of distress in parents of childhood cancer survivors and bereaved parents five years after end of treatment or a child’s death. *Acta Oncol*. 2018;57(7):950–7.
33. Wijnberg-Williams BJ, et al. Psychological adjustment of parents of pediatric cancer patients revisited: five years later. *Psychooncology*. 2006;15(1):1–8.
34. Cox T. Caregivers reflecting on the early days of childhood cancer. *Eur J Cancer Care (Engl)*. 2018;27(1):e12499.
35. Darcy L, et al. The everyday life of the young child shortly after receiving a cancer diagnosis, from both children’s and parent’s perspectives. *Cancer Nurs*. 2014;37(6):445–56.
36. Wiener L, et al. Pediatric psychosocial standards of care in action: research that bridges the gap from need to implementation. *Psychooncology*. 2020;29(12):2033–40.
37. Muskat B, et al. The experiences of parents of pediatric patients with acute lymphoblastic leukemia, 2 months after completion of treatment. *J Pediatr Oncol Nurs*. 2017;34(5):358–66.

Publisher’s note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.