



Citation for published version:

Loecher, N, Jordan, A, Spunt, SL, Simon, P, Simons, LE, Dahl, G, Kosyluk, K & Heathcote, L 2024, "“You don't accept he's completely ok”": A reflexive thematic analysis of parents' roles in monitoring their child's health and symptoms after finishing childhood cancer treatment', *Journal of Cancer Survivorship*, vol. 18, pp. 950-959. <https://doi.org/10.1007/s11764-023-01353-w>

DOI:

[10.1007/s11764-023-01353-w](https://doi.org/10.1007/s11764-023-01353-w)

Publication date:

2024

Document Version

Peer reviewed version

[Link to publication](#)

This is a post-peer-review, pre-copyedit version of an article published in *Journal of Cancer Survivorship*. The final authenticated version is available online at: <https://doi.org/10.1007/s11764-023-01353-w>

University of Bath

Alternative formats

If you require this document in an alternative format, please contact:
openaccess@bath.ac.uk

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

“You don’t accept he’s completely ok”: A reflexive thematic analysis of parents’ roles in monitoring their child’s health and symptoms after finishing childhood cancer treatment

Nele Loecher¹, Abbie Jordan², Sheri L. Spunt³, Pamela Simon⁴, Laura E. Simons⁵, Gary Dahl^{3,4}, Kristin Kosyluk¹
& Lauren C. Heathcote⁶

1 Department of Mental Health Law and Policy, University of South Florida, Florida, USA

2 Health Psychology Section, Institute of Psychiatry Psychology and Neuroscience, King’s College London, London, UK

3 Department of Pediatrics, Stanford University School of Medicine, Stanford, CA, USA

4 Lucile Packard Children’s Hospital at Stanford, Palo Alto, CA, USA

5 Department of Anesthesiology, Perioperative, and Pain Medicine, Stanford University School of Medicine, Stanford, CA, USA

6 Department of Psychology & Centre for Pain Research, University of Bath, Bath, UK

*Corresponding author information: Nele Loecher, 13301 Bruce B Downs Blvd, Tampa, FL 33613, USA.

Email: nloecher@usf.edu. Tel: 717-894-9454

Authors Nele Loecher, Sheri L. Spunt, Laura E. Simons, Abbie Jordan, and Lauren C. Heathcote contributed to the study conception and design. Material preparation, data collection and analysis were performed by Nele Loecher, Lauren C. Heathcote, Pamela Simon and Gary Dahl. The first draft of the manuscript was written by Nele Loecher and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

ABSTRACT

Objectives/purpose: Childhood cancer survival brings continued mental and physical health challenges both for the child and for the family. In this study, we investigated how parents viewed their roles in their child's health and symptom monitoring during the survivorship period.

Methods: 21 parents of childhood cancer survivors (n = 18 mothers; Parent Mage = 49.78 years, Child Mage = 18.50 years; Range = 12-25 years), whose children were at least one year off-treatment (m = 3.67 years; SD = 2.25; various diagnoses), completed semi-structured interviews. Interviews were recorded, transcribed, and analyzed using reflexive thematic analysis.

Results: Analyses generated three themes which reflect roles that parents may adopt in the context of monitoring symptoms in their childhood cancer survivor. 'Vigilant Mama and Papa' (theme 1) described parents who expressed a strong sense of responsibility for protecting their child's health during survivorship resulting in careful monitoring of their child's symptoms and health. 'Pragmatic Mamas and Papas' (theme 2) described parents who adopted an approach to symptom and health monitoring that emphasized moving past cancer and focusing on the future. Finally, 'Encouraging Mamas and Papas' (theme 3) described parents who focused on educating and preparing their child to develop an autonomous approach to health and symptom self-monitoring as they transitioned to survivorship and adulthood.

Conclusion: Parents take on varying roles in monitoring their child's symptoms and health after finishing childhood cancer treatment.

Implications for Cancer Survivors: Understanding the ways in which parents continue to be involved in their child's cancer journey, helps researchers develop interventions to support dyadic coping in survivorship.

Keywords: parent perspectives, adolescents and young adult, survivorship, childhood cancer

INTRODUCTION

While survivorship rates for childhood cancer are increasing, surviving childhood cancer remains a stressful experience for the child, the parent(s), and the larger family system. A recent meta-analysis in childhood cancer survivor (CCS) populations found that the child's global distress was correlated with parents' post-traumatic stress symptoms, global distress, depression, and anxiety, with medium to large effect sizes [1]. One particular challenge for parents is illness uncertainty, which is always an issue after cancer treatment but may be particularly pronounced when the child describes new or ambiguous symptoms during the survivorship phase [2], [3]. Parents may feel uncertain about their child's long-term prognosis, the potential for late effects of treatment, and the likelihood of disease recurrence. Research evidence shows that illness uncertainty is correlated with increased depression, anxiety, and post-traumatic stress in parents of children with chronic illness, including cancer [4], [5]. Addressing illness uncertainty was identified as key for improving parent psychosocial health in parents of CCS [6].

For parents of CCS, one salient source of uncertainty is knowing how to support the child's new and ongoing health concerns, including how to respond to new or ambiguous symptoms that their child reports or displays. Symptom monitoring, that is attending to bodily sensations as possible symptoms of illness, is often viewed as an intrapersonal process. These intrapersonal aspects of symptom monitoring within the context of cancer survivorship are well described in the Cancer Threat Interpretation (CTI) model, which offers a cognitive-affective explanation of how cancer survivors can appraise and make sense of pain [7]. Yet, *interpersonal* factors also likely contribute to symptom monitoring and appraisal during cancer survivorship, especially in CCS. In a qualitative interview study, Tutelman and colleagues [8] found that parents of CCS report worrying about their child's bodily sensations, such as everyday headaches, as potentially indicating a cancer recurrence or late effect of treatment [8]. In turn, parental worry about symptoms may shape the child's worry about and response to their own symptoms, including their health-related behaviors such as help-seeking [8], [9]. Beyond this qualitative study, little is known about how parents view their roles in helping their child to manage the challenge of symptom monitoring after completing cancer treatment.

Continued parental participation in symptom monitoring can also extend to parents wishing to stay involved in their child's healthcare into adulthood, with one study indicating that two thirds of parents continued to accompany their child to follow-up appointments after they became adults [10]. Continued parental involvement in the child's healthcare, while providing emotional and practical support, can also hinder the child's ability to develop self-management skills. Providers identify these parental behaviors as a barrier to independent

self-management, and CCS describe parents as gatekeepers to health information [11], [12]. The balance between providing support and preparing the child to become more independent in their survivorship care is a particularly salient challenge for parents of CCS transitioning through adolescence and early adulthood.

There is a need to better understand how parents view their roles in monitoring their child's health and symptoms after finishing childhood cancer treatment. This can guide future research into how adoption of these different roles relates to parental perception of risks, how adopting these roles influences both the child and parental mental health and wellbeing, and intervention approaches to support parents in navigating this salient source of uncertainty after their child has finished cancer treatment. In this study, we used a qualitative semi-structured interview methodology and reflexive thematic analysis approach to begin to investigate and describe these perceived roles in parents of CCS.

MATERIALS & METHODS

Study Design

The current study used semi-structured interviews to investigate how parents viewed their roles in helping their CCS monitor their symptoms and their health during the off-treatment, survivorship stage. Interviews were conducted either in-person or via Zoom video calls, which are a commonly used alternative when in-person interviewing is not possible [13]. Video calls were offered to all participants as alternative if there were time or transportation constraints. Our research design was guided by the 'Big Q' approach to qualitative analysis [14], [15], which acknowledges and values the subjectivity of the context in which data is gathered and the researcher's disciplinary knowledge.

Parents were recruited alongside their CCS, but interviews were conducted separately for the parent and child. Analysis of the child data examining their responses to bodily sensations is published elsewhere [9]. One parent chose to participate even though their child did not complete the child focused interview. As we were particularly interested in understanding the role of parents in symptom and health monitoring, we purposively oversampled survivors of sarcoma and leukemia as these populations report more symptom burden than survivors of other pediatric cancers (e.g. pain and fatigue [16]–[18]).

Participants

Parents were recruited from a cancer center at a large children's hospital on the West Coast of the United States. Eligible parents were identified through clinician referrals and by reviewing electronic health records of

patients with appointments for off-treatment follow-up. Parents were eligible to participate if their child 1) was between the ages of 12 -25 years, as this is a typical adolescent and young adult age range, 2) was previously diagnosed with any cancer and 3) had finished curative cancer treatment more than one year previously. Parents were not eligible to participate if they 1) were unable to read, write, or speak in English. We contacted 27 parents; 21 parents agreed to participate (see Table 1). Parents whose children had multiple diagnoses are represented more than once in the table. Reasons for nonparticipation included: lack of response to contact (n = 3), concerns about English fluency (n = 1), concern that the interview may be too distressing (n = 1), and declining to participate without stated reason (n = 1). The study protocol was approved by the Stanford School of Medicine Institutional Review Board and the Stanford Cancer Institute's Scientific Review Committee.

Procedure

Prior to participating in the interviews, informed consent was obtained from all participants via digital signature for virtual interviews and hand-written signature for in-person interviews. Participants took part in individual semi-structured interviews with members of the research team (NL and/or LCH). Interview schedules (see supplemental materials) were developed by LCH and NL and revised based on feedback from an experienced qualitative pediatric health researcher (AJ). Interview questions focused broadly on how parents had and were experiencing their CCS's symptoms and cancer trajectory, including how they perceived their CCS's symptoms and bodily sensations, and how and if these caused concern (see supplementary materials for full interview schedule). Consistent with best practice, the interview schedule allowed flexibility in the content and order of topics discussed [19]. Parents were compensated for their time with a \$30 gift card. Duration of interviews ranged from 18 to 69 minutes ($M = 48$ minutes; $Mdn = 47$ minutes). The audio was recorded on two separate digital recording devices and stored on HIPAA compliant servers until they were transcribed verbatim by undergraduate research assistants, who removed all identifiable information. The data that support the findings of this study are available from author LCH, upon reasonable request.

Analysis

Analysis followed Braun and Clarke's [20]–[23] reflexive thematic analysis method. This qualitative analysis method, contrasted with other theming approaches emphasizes flexibility in identification and interpretation of patterns within the data [22]. Reflexive thematic analysis allows for an approach removed from theory, without being atheoretical [22]. Our analysis focused on both semantic and latent features of the data,

considering both what the participants said (i.e., content and meaning) and how they said it (i.e., language use). We used an inductive analytic approach, generating initial codes from the data. Following the 6 steps outlined by Braun and Clarke[20], the primary coder (NL) first familiarized herself with the data through reading and re-reading transcripts while noting items of potential interest (step 1). Codes were then developed and revised based on iterative discussion with LCH and AJ (step 2). Transcripts were coded using NVivo version 12 (QSR International Pty Ltd., 2020) and clustered into candidate themes by NL and LCH. Three initial candidate themes were generated (step 3) that were then reviewed to avoid substantial overlap (step 4), refined, finalized (step 5), and written up (step 6). The reflexive thematic analysis method [20]–[23] advises against the use of inter-rater reliability as a measure of quality, as these methods are inconsistent with the postpositivist epistemological and ontological assumptions of the reflexive thematic analysis approach [20]. Excerpts of transcripts are used as examples of each theme and were selected to illustrate both the central components of each of the 3 themes and the breadth and diversity of perspectives. Each quotation includes information and underneath each quotation is the participant ID, nature of parental relationship to child (mother/father), and their child’s diagnosis and age to provide further context for the reader.

Analysis was guided by Braun and Clarke’s criteria for quality control in thematic analysis [21] including: inspecting transcripts against audio recordings for accuracy, paying equal attention to each data item in the coding process, and balancing data and analytic narrative. Additionally, to ensure that all participant accounts were represented, we included quotations across the sample to yield a broad representation of experiences, by quoting most participants once and no participants more than once. Moreover, the researcher was positioned as an active member in the research process [14]. The research team was primarily female and consisted of five psychologists, two pediatric oncologists, and an oncology nurse practitioner. The majority of the research team had been involved in psycho-oncology work before, all clinicians had extensive experience caring for CCSs, and at least one member of the research team had personal experience with childhood cancer.

RESULTS

Our sample consisted of 86% mothers (n = 18), who were mostly White/Caucasian (n = 11) and non-Latino (n = 17). Parents were 49.78 years old on average. Their children were on average 13.56 years old when they were diagnosed and averaged 3.67 years since treatment completion. A variety of cancer diagnoses was represented, including osteosarcoma (n = 9), leukemia (n = 5), Ewing sarcoma (n = 2), and brain tumor (n = 2).

<insert Table 1 about here>

Analyses generated three themes which illustrate the different ways in which parents described their dynamic and complex roles in the monitoring and appraisal of their child's health and symptoms during cancer survivorship. These themes do not reflect entirely distinct roles, but instead, describe different roles which parents inhabit at different times and in different settings, and sometimes even simultaneously. Themes are presented in turn below alongside illustrative anonymized quotations from participants to support our interpretation.

Theme 1: Vigilant Mamas and Papas

The role of Vigilant Mama and Papa was centrally characterized by parents who described a motivation or tendency to actively monitor the symptoms and overall health of their child during the survivorship period. A few parents described that they had not fully internalized that their child is now well, causing them to continue to monitor for threats to their child's health. Parent 7 described that he could perceive any sensation as a potential symptom of his child's cancer having recurred. He described worrying about various symptoms being an indication of a recurrence, ranging from the same type of sensation in the same area as the initial cancer diagnosis (the leg) to a cough. Parent 7 described this worry as becoming the focus of attention for his family, who discovered a genetic predisposition towards cancer after their child's diagnosis. He perceives his child's cancer as a defining event in his (the parent's) life after which the "new normal" included constant vigilance about bodily sensations.

So even now, him being completely finished – knock on wood – given his clean bill of health [...] you don't accept like he's completely ok even though he is. It's the focus of our life now, and I don't think you ever get off that fence. [...] Any pain in his leg, any bone pain, that he says, you know, 'hey, my shoulder hurts now' [...] you just go to the worst, what's going on with his shoulder? Cough? Anything.

- Parent 7, Father of a 16-year-old osteosarcoma survivor

For one parent, the motivation for monitoring their child's symptoms was driven by a recognition that cancer can appear in the absence of noticeable bodily changes. The lack of objective or physical symptoms increased some parents' need to check in with their child's subjective sensations, as a way to potentially identify a recurrence or late effect.

I always ask him, you know, how he's feeling, you know. And he says I'm fine. And I ask him about his leg, he says it's fine [...]. He doesn't tell me too much when I talk to him. He says he feels fine. I mean it's like you can't see [cancer].

- Parent 18, Mother of a 21-year-old osteosarcoma survivor

Much like Parent 18, parents often described that their child would typically report no symptoms of concern in response to their questioning. While for some parents these negative responses were reassuring, other parents described worrying that their child might hide their symptoms, motivating a need to further monitor and probe their child. Even in the absence of reported sensations, some parents did not feel suitably reassured that there was no recurrence of their child's cancer, with some stating that only testing could conclusively demonstrate a lack of cancer. Like Parent 4, below, parents sometimes described attending to visual cues as a clue to whether their child was experiencing symptoms, despite what the child said about the sensation. Such parental assumptions reinforce a need to visually monitor their CCS in addition to checking in with them. It also indicates that there is very little that ultimately reassures such parents that their child is free of cancer.

A lot of time, because she [daughter] try [sic] so hard, she try to hide her pain. And sometimes I say 'why are you – why are you sweating, are you in pain?' and she say [sic], 'No I'm fine' and she keep doing what she's doing, try to work harder to cover it.

- Parent 4, Mother of a 23-year-old brain tumor survivor

A few participants described that the way they respond to their child's symptoms has been shaped by their child's initial diagnosis experience. Parent 13, below, described how he believed the course of his child's cancer could have differed had the diagnosis been identified earlier in his child's cancer journey, indicating that his continued vigilance is driven by a concern that lacking vigilance in his child's initial diagnosis may have resulted in more intense treatment. Thus, this parent's vigilance was driven by a desire to catch a recurrence early. He explained that this vigilance has also influenced how he thinks about and reacts to his other children's symptoms now and that his experience with his son caused him to request further tests when his daughter started showing symptoms of unclear origin.

Maybe our experience with [our son] caused us to be a little bit alerted with [ambiguous symptoms] and [...] caused us to really escalate it quickly and really take to the next level cause... with [our son] he complained about knee pains for few months, right? That by the way was hard for me to deal with the beginning and during treatment that, we kind of didn't pay attention to that, that we could've maybe caught it earlier, [...] what could have been done better, could've been caught sooner and then maybe we shouldn't have been – shouldn't need to go under chemotherapy.

- Parent 13, Father of a 16-year-old osteosarcoma survivor

Some parents described responding to their child's symptoms with questioning and probing of those symptoms. For one parent, this repeated questioning appeared to comprise searching for (or ruling out) other signs

and clues that could indicate that the symptom was a cancer-related concern. Parent 6 describes this questioning as a “*drill*”, implying intense and serious vigilance.

I drill him with questions, for sure, I just go over everything. I mean if he tells me he has anything, then it's like 'ok, how about that? How about this? How about that?', you know, and I just keep kinda questioning him and yeah, probably, drives him crazy- so he tells me something in the morning and in the afternoon I'll follow up with him or in the evening.

- Parent 6, Mother of a 16-year-old osteosarcoma survivor

Like for Parent 6, several parents recognized that monitoring and asking about their child's symptoms may negatively influence the child's emotional state. For one mother, this negative consequence was perceived as necessary to ensure that her child was fully aware of possible symptoms of concern. Yet, the mother also described tailoring her language so as not to directly probe for symptoms of recurrence, which could be distressing for her child, but rather to ask more generally about how her daughter was feeling. Like Parent 11, several parents expressed that they had reflected on their degree of worry and some of those identified their worry as excessive. However, parents simultaneously expressed the sentiment that their child “*needs to know*” (Parent 11) about symptom and health monitoring during survivorship and they therefore continued to inform and ask their child about their health, albeit softening their language. Parent 11 displays similar vigilance to Parent 6 but adjusts her language to ask about her daughter's sensations without explicitly mentioning fears of recurrence. Parents tailor the directness of their questioning to what they perceive their children's needs and responses to be.

I knew when I was saying these things, I was gonna affect [my child] too, but I was like 'Oh she needs to know' [...] I have to be careful how I go about asking, so I go like 'Hey, how's it going?' stuff like that you know, I can't be like 'Hey, do you still feel like the cancer's coming back?'. {laughter} I don't know if other parents are this bad, but I am also one of those parents that [...] maybe I dwell on things too much, I guess.

- Parent 11, Mother of a 24-year-old Wilms tumor survivor

To several parents, vigilance provided a means for continued involvement in their child's survivorship care. For some parents, this was a recognition that their caregiver role continued despite a transition to adult care given that parents held much of the child's medical history information. One mother described the transition to more independent survivorship care as difficult for herself and her child, as she wished she could help her child but felt that the clinicians were no longer interested in speaking with her.

As parent, we cannot, say, call the doctor and say what can I do for my [daughter]? They don't want to talk to us anymore [...] [Daughter] needs to talk to different doctor and [...] she forgot a lot of details [...] they

even ask her [...] radiation regimen and how does that look like. She was 15 and she was sick, how could she know? [...] and I say that was mom's job. {laughter}

- Parent 4, Mother of a 23-year-old brain tumor survivor

Additionally, most parents adopting the Vigilant Mama and Papa role described remaining involved in their child's follow-up care, both attending and setting up appointments, regardless of their child's age. Occasionally, parents described this being requested by their child rather than initiated by the parent. Other parents described their continued involvement in their child's survivorship care as necessary, either because the child explicitly requested parental support or they felt that the child's continued care is a "*family thing*" in which family members mutually supported one another, as they had during treatment. This experience of universal ownership over the cancer experience may be one reason underlying parents' wish to continue to stay closely involved during their child's survivorship in symptom monitoring and beyond.

[Child] doesn't know when exactly the appointment is. Usually maybe a week before or maybe a few days before I would just say, 'Hey we have this appointment coming up [...] I think I'll probably go to all of his appointments {laughs} I think he – you know it's really a family thing, that we do this together. Like I wanna be there for him. My husband will always go to all the appointments because I needed him to be there for me, yeah {laughs}

- Parent 17, Mother of a 19-year-old osteosarcoma survivor

The Vigilant Mama and Papa role reflects a parental style of actively probing the child for symptoms and remaining actively involved in the child's symptom and health monitoring, sometimes long into the survivorship phase. Some parents inhabiting this role described an understandable sense of worry about new and ambiguous symptoms in their child, with the tendency towards vigilance sometimes related to the perception of having missed or been late with identifying the child's initial cancer symptoms.

Theme 2: Pragmatic Mamas and Papas

The role of Pragmatic Mama and Papa is characterized by a more hands-off approach to monitoring the health and symptoms of their child, and by expressing generally low levels of fear and worry about cancer recurrence and late effects of their child's cancer treatment.

For the father below, while he recognized that he *could* interpret his child's minor symptoms as indicating cancer, he stated that worrying about them would be futile until a doctor examined them. This particular father's

rationale for not worrying about minor symptoms was the outlook that the child's cancer was in the past and that living in a state of concern was not helpful, suggesting that new symptoms or health issues going forward did not need to be framed within the context of cancer. Instead, this father (Parent 19), emphasized that there was nothing their concern would do, so it would be best not to worry.

- *Recently [my daughter] said oh her arm, you know she feeling [sic] a pain. And then she say she has concern, okay, but I say 'concern for what?' I mean you can always think to the worst, this is something wrong with that or is this second coming [sic] of the cancer [...] instead of living in that kind of mode I just say 'cope with that' and if it get to the point that we'll go see a doctor, and they do all the tests for you, and they come back, and say 'yeah, sorry it's in comeback [sic]' or whatever. But even if that happened, okay, what we do [sic], not much we can do in order to avoid that.* Parent 3, Father of a 23-year-old brain tumor survivor

Another parent (Parent 21) described that while appraising new symptoms as possibly indicating cancer crossed her mind, she attempted not to dwell on this thought, as it was out of her control. Like Parent 13, this mother referred to the child's cancer as being in the past. For Parent 21, her faith was an important aspect of coping during and after treatment. When her child was diagnosed with cancer, she comforted her by saying *"just the way God got Grandpa through cancer, and God got your stepdad through cancer, and He's going to get you through cancer too"* (Parent 21) and she refers to her faith when discussing post-treatment concerns as well. As with Parent 13, Parent 21 is motivated to continue moving away from cancer instead of viewing it as a continued part of their lives.

There's a part of that in the back of your mind like 'it's cancer' you know, you do think it, just crossed your mind but I tried my best not to even go there you know what I mean? I don't want to go there again, that was then, that's over, God got us through that we're going to go forward from here. We're not gonna dwell on the past so that's the way I kinda look at it.

- Parent 21, Mother of a 16-year-old acute lymphoblastic leukemia survivor

Other parents describing a pragmatic approach drew their confidence from a trust in their child's cancer care team. As for Parent 21, she used trust in an entity other than themselves to reassure themselves and their children. Parent 5 described how she drew confidence from the oncology team's expertise and the hospital's reputation. This reassured her that a recurrence or late effect of the child's cancer would be detected through regular surveillance and that any such late effects could be treated.

- *I also think that, you know being able to get treated [here] made a difference. [...] I'll give you an example, I was questioning his radiation oncologist [...] about this newest technology and she said 'T-cell, we invented the linear accelerator I think we know what we're doing'.* Parent 5, Mother of a 17-year-old Ewing sarcoma survivor

A few parents described their sense of calm in the face of their child's health-related uncertainty as a response to their child's reliance on them for emotional support. For example, one father described the perceived importance of him and his wife showing their child that they were "mentally being strong" (Parent 13). For other parents, the choice to adopt a calm demeanor was in response to others' distress in the family unit. Highlighting a possible lack of agency, one mother emphasized that between a nervous husband and an anxious child, "somebody" (Parent 12) had to stay calm. In these situations, she described stepping in and reassuring her family members that there was no need to worry.

I think [my son] sometimes he gets very nervous, and my husband is very anxious all the time [...]. So he gets really anxious, and he gets really anxious as well, so I have to – somebody have [sic] to keep calm. Stop. Nothing's gonna happen, everything is gonna be fine.

- Parent 12, Mother of a 21-year-old acute myeloid leukemia survivor

In contrast to the first theme, parents embodying the role of Pragmatic Mama and Papa typically did not describe proactively asking about their child's symptoms but rather responding in a pragmatic way if symptom-related concerns arose. Parent 1 described managing her child's symptoms in stages, first with over the counter remedies and investigating its cause before worrying and approaching a physician about the symptom only as a last resort.

He never mentioned it again and kinda, for me if you never mention it, it's not there anymore so I never ask. [...] I'm that kind of mom so like I always kid with my little ones, they say 'Oh my arm hurts' 'Okay do we need to take it off' or you know I always take it lightly. [...] When they tell me they're in pain, what is the cause of the pain? Why are you in pain? So, should we give you some ibuprofen to pi- [sic] make you feel better? And if that takes care of the problem then okay.

- Parent 1, Mother of an 18-year-old Ewing sarcoma survivor

This second theme captures a style of parenting characterized by a recognition that while they might understandably respond to their child's symptom reports with fear and anxiety, instead they aimed for generally calm, reassuring responses to minor symptoms. For several Pragmatic Mamas and Papas, this approach was

matched by an intention to see the child's cancer as an experience in the past and, instead, to focus on the present and moving forward.

Theme 3: Encouraging Mamas and Papas

The role of Encouraging Mama and Papa was characterized by parents educating and preparing the child to engage in symptom self-monitoring and increasing self-management of survivorship care. Parents often described encouraging their child learn how to be responsible for and independent in managing their health care. One mother described it feeling “*sudden*” (Parent 14) that she was asking her child to independently undertake tasks that she previously did collaboratively with her child but emphasized that her child was approaching an age where she would be solely responsible for her own care.

It's very challenging because I have monitored her care with her up to this point and all of a sudden I'm like {sighs} [Child], you need to do this. [...] Okay [Child], why won't we try this? Let's send the doctor an email, I'll help you compose it, right? So just like pushing her just a little bit towards adulthood because she's going to be 18 next year. [...] It's not that far away and so just like giving her that support but in a different way, that's been my goal the past six months to a year.

- Parent 14, Mother of a 17-year-old Ewing sarcoma and rhabdomyosarcoma survivor

Several parents described that part of preparing their child for monitoring their own health and symptoms was still being supportive and involved in healthcare decisions when the child needed them to be. For many, this is a difficult balance, knowing when to intervene and when to stand back with both information and support. Parent 8 described engaging in a delicate balance of supporting her child while also respecting her independence. Instead of actively questioning her child, she waited to be approached for support requests.

[Child] wants to be independent but still contacts us. Like [Child] got burned with something and sent us a picture and said, you know 'What should I do?' [...] again [Child] wants to be on their own, doesn't want us hovering around but, yes, when [Child] sprained their ankle, wanted to know 'how do I deal with this?'

- Parent 8, Mother of a 20-year-old osteosarcoma survivor

Other parents adopting the Encouraging Mamas and Papas role described trying to prepare their child for independence through modeling as well as guiding their children on what they considered to be appropriate health behaviors to reduce cancer risk, such as abstaining from substance use and eating healthily. One mother described the inability to watch over her child's actions now that he is a young adult. She emphasized that when he was a

child she could “*stay behind*” him whereas now she must trust his decision-making regarding his health behavior choices.

I always try to, to tell him, ‘Sweetie, please eat healthy stuff’ [...] we have to do our best with the food because food is very important but he always say ‘Yes mommy no worries, I will do that.’ {laughs} We teach him, my husband and I, we don’t [drink or smoke] [...]. I hope [pause] he take a good decisions on his life because when they little kids I can stay behind them but now, the life is on his hands, he has to take a good choices on his life.

- Parent 15, Mother of a 16-year-old acute lymphoblastic leukemia survivor

Whereas Parent 15 described an uncertain but hopeful understanding of her child’s health behaviors, other parents appeared to feel more certain that their child was adhering to appropriate health behavior guidelines. When asked if she actively encouraged her son’s adaptive health behaviors, Parent 20 described her son’s adherence to and knowledge of adaptive health behaviors as a reason to not be concerned.

There’s things that you, [the parent], have to watch out for. Like, because he had this treatment, he is more at risk of skin cancer if he bakes out in the sun. He doesn’t do that, he’s very careful. [...] And he knows the importance if he does – if he did go somewhere that it’s important because his risk is higher.

- Parent 20, Mother of 17-year-old acute lymphoblastic leukemia survivor

Many parents in the Encouraging Mamas and Papas role expressed that they wanted their children to live a normal life and did not want fear or worry interfering with this. Parent 16 expressed having accepted her own worry as part of her maternal role, while wanting her child to not experience this same concern. While these parents wanted their child to be responsible for their own health behaviors and symptom monitoring, they also want them to live free of some of the burden of their disease. Part of setting their child up for success was alleviating the psychological ramifications of cancer, while teaching them to continue making healthy decisions.

I was worried about [late effects] with him. Is he gonna always feel, like, inferior? [...] Or is this gonna, like, bother him psychologically? I mean I’m fine with it bothering me a little bit, I think that’s kind of like my job a little bit as a mom, but I never want him to worry about it, you know? I just want him to live his life.

- Parent 16, Mother of a 17-year-old non-Hodgkin’s lymphoma survivor

Parents acting in the role of Encouraging Mamas and Papas use a variety of techniques to help prepare their children for independent symptom and health monitoring, including planning for concrete challenges such as obtaining health insurance. They also employed a variety of techniques to aid their children in self-management

of their own symptom monitoring and survivorship care, such as modeling behaviors or advising on health scares directly.

DISCUSSION

Parents' involvement in their child's symptom and health appraisals in the cancer survivorship period can be a challenge. Parents may be motivated to support their child's ongoing health needs and risks, while encouraging self-management behaviors as the child transitions to survivorship and young adulthood [24]. Using a reflexive thematic analysis of semi-structured interview data, we generated novel insights into how parents view their roles in helping their child appraise and monitor their symptoms and health concerns after completing cancer treatment. Our analysis yielded three themes. These themes demonstrated that parents could feel a strong sense of responsibility for monitoring their child's symptoms and intervening in them, as well as managing health concerns during survivorship (theme 1), could take a more pragmatic approach to symptom and health monitoring that reflected a focus on the future rather than dwelling on the past (theme 2), or could focus on educating and preparing their child to in self-management of symptom monitoring and survivorship care (theme 3).

Our findings build on previous research in cancer survivors and other health populations. A recent study identified receiving family support as the most commonly stated self-management strategy among CCSs, emphasizing the importance of the family unit in pediatric cancer survivorship care [25]. Our data corroborate this need, with several parents describing that their child would seek support as symptom concerns arose. Other studies have also found that it is common for parents of CCSs to stay actively involved in their child's healthcare as the child reaches early adulthood. One study found that 60% of parents continued to accompany their adult children to cancer follow-up appointments [10]. Reasons for parents attending appointments were concern for their child's health and well-being, the unique bond between parent and child, and logistical reasons, such as not having a driver's license or being unable to travel the distance alone [10], [26]. Our data show that some of these concerns were also primary reasons for parents to remain engaged in other aspects of their child's health and symptom monitoring during survivorship. Doshi et al. (2014) noted that general support and companionship was a driver of continued parental involvement, which was also reflected in the Vigilant Mama and Papa role. Our third theme, Encouraging Mamas and Papas, offers an additional nuance to this supportive role, suggesting that one way in which parents support their children following cancer treatment is to become gradually less involved in their child's healthcare in order to promote self-management.

In a previous paper presenting the child data from this cohort [9], we described that CCSs sometimes seek guidance from their parents when uncertain about symptoms. In the current analyses of the parents' data, we have identified a range of ways that parents interpret their role in responding to these symptoms, thus revealing a dynamic, dyadic process of symptom meaning-making and responding. In a qualitative study including both CCSs and their parents, Tutelman and colleagues [8] found that parents often adopted a more negative recollection of the cancer experience compared to their children, which led to more fearful appraisal of symptoms in survivorship. Although our analyses did not provide a direct comparison of parent and child data, our findings support Tutelman and colleagues' [8] description that parents had continued involvement in their child's symptom monitoring and appraisal long into the survivorship phase. Of note, Tutelman and colleagues [8] also found that parents reported a continued perception of health-related and bodily-related threat for their child, which contributed to their felt need to be vigilant for new and emerging symptoms. In the current study, several parents described a continued sense of health risk, which for some was shrouded in a concern of having missed the initial warning signs of cancer. Yet, in the second theme (Pragmatic Mamas and Papas), we also described parents who reported a felt need to shift focus away from threat and towards a new or continued life going forward.

Our findings described in the third theme, Encouraging Mamas and Papas, may be particularly relevant to consider within the existing literature on transitions in childhood cancer survivorship care. While parental support in survivorship care is largely adaptive, studies have found that parents can act as gatekeepers of information for their children even after the child becomes an adult [11]. This gatekeeping may become a barrier to CCSs' ability to grow independent in their symptom and health monitoring as they transition both to survivorship care and to early adulthood. Previous studies have found that parental perceptions of their child's self-management skills directly impact their child's success in transitioning to adult care [27], indicating the importance of parental perspectives and influence when preparing CCS for independent adult care. This also has implications for interventions to aid in the transition of CCSs to adult care. Transition models such as that presented by Schwartz and colleagues [28] include parental readiness to transition as an important component of successful transition. Our data provide additional insights into the nuanced reasons for continued parental engagement or disengagement from symptom and health monitoring. These insights could help to guide interventions in survivorship care transition programs aimed at addressing concerns parents have about their children being independently responsible for self-management of their health and medical care.

There are limitations to this study. Firstly, we oversampled certain diagnostic groups. Our sample suggested that there is some parental awareness of their child's diagnosis-specific risk and symptoms. Future

research would, therefore, benefit from targeting other groups and examining how symptom and health appraisals differ between groups. Secondly, certain minority groups (both racial/ethnic and sociodemographic) were underrepresented or not represented at all. However, we had a good representation of Hispanic and Asian parents in our sample. Additionally, given our recruitment approach we likely over-sampled for parents and families who are still actively involved in survivorship care, thus missing both parents and families who have fallen out of their survivorship care pathways. This at-risk group may indeed provide different perspectives on the role of parents in their child's ongoing health needs.

Despite these limitations, our findings provide direct insights from parents of CCSs into how they view their roles in managing their child's health and symptom concerns during the survivorship stage. These findings can guide further research to understand how adoption of these different roles relates to parental perception of risks, and how adopting these roles influences both the child's and parents' mental health and wellbeing. Our findings may be useful for guiding family-centered approaches to childhood cancer survivorship care.

References

- [1] D. Bakula *et al.*, “The Relationship Between Parent and Child Distress in Pediatric Cancer: A Meta-Analysis,” *J. Pediatr. Psychol.*, vol. 44, Jul. 2019, doi: 10.1093/jpepsy/jsz051.
- [2] J. M. Chaney *et al.*, “Parent Perceptions of Illness Uncertainty and Child Depressive Symptoms in Juvenile Rheumatic Diseases: Examining Caregiver Demand and Parent Distress as Mediators,” *J. Pediatr. Psychol.*, vol. 41, no. 9, pp. 941–951, Oct. 2016, doi: 10.1093/jpepsy/jsw004.
- [3] U. Pöder, G. Ljungman, and L. von Essen, “Parents’ perceptions of their children’s cancer-related symptoms during treatment: a prospective, longitudinal study,” *J. Pain Symptom Manage.*, vol. 40, no. 5, pp. 661–670, Nov. 2010, doi: 10.1016/j.jpainsymman.2010.02.012.
- [4] B. F. Fuemmeler, L. L. Mullins, and B. P. Marx, “Posttraumatic Stress and General Distress Among Parents of Children Surviving a Brain Tumor,” *Child. Health Care*, vol. 30, no. 3, pp. 169–182, Sep. 2001, doi: 10.1207/S15326888CHC3003_1.
- [5] J. L. Stewart and M. H. Mishel, “Uncertainty in childhood illness: a synthesis of the parent and child literature,” *Sch. Inq. Nurs. Pract.*, vol. 14, no. 4, pp. 299–319; discussion 321–326, 2000.
- [6] L. L. Mullins *et al.*, “A clinic-based interdisciplinary intervention for mothers of children newly diagnosed with cancer: a pilot study,” *J. Pediatr. Psychol.*, vol. 37, no. 10, pp. 1104–1115, Dec. 2012, doi: 10.1093/jpepsy/jss093.
- [7] L. C. Heathcote and C. Eccleston, “Pain and cancer survival: a cognitive-affective model of symptom appraisal and the uncertain threat of disease recurrence,” *Pain*, vol. 158, no. 7, pp. 1187–1191, 2017, doi: 10.1097/j.pain.0000000000000872.
- [8] P. R. Tutelman *et al.*, “When ‘a headache is not just a headache’: A qualitative examination of parent and child experiences of pain after childhood cancer,” *Psychooncology.*, vol. 28, no. 9, pp. 1901–1909, 2019, doi: 10.1002/pon.5170.
- [9] L. C. Heathcote *et al.*, “Symptom appraisal in uncertainty: a theory-driven thematic analysis with survivors of childhood cancer,” *Psychol. Health*, vol. 0, no. 0, pp. 1–18, Oct. 2020, doi: 10.1080/08870446.2020.1836180.
- [10] I. B. B. Ressler, J. R. Cash, D. McNeill, S. Joy, and P. M. Rosoff, “Continued Parental Attendance at a Clinic for Adult Survivors of Childhood Cancer,” *J. Pediatr. Hematol.*, vol. 25, no. 11, pp. 868–873, Nov. 2003.
- [11] C. J. Berg, E. Stratton, N. Esiashvili, and A. Mertens, “Young Adult Cancer Survivors’ Experience with Cancer Treatment and Follow-Up Care and Perceptions of Barriers to Engaging in Recommended Care,” *J. Cancer Educ. N. Y.*, vol. 31, no. 3, pp. 430–442, Sep. 2016, doi: <http://dx.doi.org/10.1007/s13187-015-0853-9>.
- [12] L. B. Kenney *et al.*, “Transition and transfer of childhood cancer survivors to adult care: A national survey of pediatric oncologists,” *Pediatr. Blood Cancer*, vol. 64, no. 2, pp. 346–352, 2017, doi: 10.1002/pbc.26156.
- [13] V. Lo Iacono, P. Symonds, and D. H. K. Brown, “Skype as a Tool for Qualitative Research Interviews,” *Sociol. Res. Online*, vol. 21, no. 2, pp. 103–117, May 2016, doi: 10.5153/sro.3952.
- [14] V. Braun and V. Clarke, *Successful qualitative research: a practical guide for beginners*. Los Angeles: SAGE, 2013.
- [15] L. H. Kidder and M. Fine, “Qualitative and quantitative methods: When stories converge,” *New Dir. Program Eval.*, vol. 1987, no. 35, pp. 57–75, 1987, doi: 10.1002/ev.1459.
- [16] Q. Lu *et al.*, “Pain in Long-Term Adult Survivors of Childhood Cancers and Their Siblings: A Report from the Childhood Cancer Survivor Study,” *Pain*, vol. 152, no. 11, pp. 2616–2624, Nov. 2011, doi: 10.1016/j.pain.2011.08.006.
- [17] K. A. Meeske, S. E. Siegel, D. R. Globe, W. J. Mack, and L. Bernstein, “Prevalence and correlates of fatigue in long-term survivors of childhood leukemia,” *J. Clin. Oncol. Off. J. Am. Soc. Clin. Oncol.*, vol. 23, no. 24, pp. 5501–5510, Aug. 2005, doi: 10.1200/JCO.2005.03.210.
- [18] D. A. Mulrooney *et al.*, “Fatigue and Sleep Disturbance in Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS),” *Sleep*, vol. 31, no. 2, pp. 271–281, Feb. 2008.
- [19] J. Mason, “Semistructured Interview,” in *The SAGE Encyclopedia of Social Science Research Methods*, 3 vols., Thousand Oaks: SAGE Publications, Inc., 2004, pp. 1021–1021. doi: 10.4135/9781412950589.
- [20] V. Braun and V. Clarke, “Using thematic analysis in psychology,” *Qual. Res. Psychol.*, vol. 3, no. 2, pp. 77–101, 2006, doi: 10.1191/1478088706qp063oa.
- [21] V. Braun and V. Clarke, “Reflecting on reflexive thematic analysis,” *Qual. Res. Sport Exerc. Health*, vol. 11, no. 4, pp. 589–597, Aug. 2019, doi: 10.1080/2159676X.2019.1628806.
- [22] G. Terry and N. Hayfield, “Reflexive thematic analysis,” *Handb. Qual. Res. Educ.*, pp. 430–441, Aug. 2020.

- [23] K. A. Campbell *et al.*, “Reflexive Thematic Analysis for Applied Qualitative Health Research,” *Qual. Rep.*, vol. 26, no. 6, pp. 2011–2028, Jun. 2021, doi: 10.46743/2160-3715/2021.5010.
- [24] A. M. Psihogios *et al.*, “Preferences for cancer survivorship care among adolescents and young adults who experienced healthcare transitions and their parents,” *J. Cancer Surviv. Res. Pract.*, vol. 13, no. 4, pp. 620–631, Aug. 2019, doi: 10.1007/s11764-019-00781-x.
- [25] M. Brown, A. Higgins, and J. MacArthur, “Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities,” *J. Clin. Nurs.*, vol. 29, no. 1–2, pp. 195–207, Jan. 2020, doi: 10.1111/jocn.15077.
- [26] K. Doshi *et al.*, “Why mothers accompany adolescent and young adult childhood cancer survivors to follow-up clinic visits.,” *J. Pediatr. Oncol. Nurs. Off. J. Assoc. Pediatr. Oncol. Nurses*, vol. 31, no. 1, pp. 51–57, Feb. 2014, doi: <http://dx.doi.org/10.1177/1043454213518111>.
- [27] G. Heath, A. Farre, and K. Shaw, “Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents’ experiences,” *Patient Educ. Couns.*, vol. 100, no. 1, pp. 76–92, Jan. 2017, doi: 10.1016/j.pec.2016.08.011.
- [28] L. A. Schwartz, L. K. Tuchman, W. L. Hobbie, and J. P. Ginsberg, “A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions,” *Child Care Health Dev.*, vol. 37, no. 6, pp. 883–895, 2011, doi: 10.1111/j.1365-2214.2011.01282.x.

Statements and Declarations

The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.

The authors have no relevant financial or non-financial interests to disclose.

Table 1 Demographic characteristics of participants

Parent Characteristics	<i>M</i>	<i>SD</i>	<i>Range</i>	<i>n</i>	<i>%</i>
Gender					
Male				3	14
Female				18	86
Race					
White/Caucasian				11	52
Asian				4	19
Hawaiian Native/Pacific Islander				2	10
Mixed race				1	5
Other				3	14
Ethnicity					
Latino or Hispanic				4	19
Not Latino or Hispanic				17	81
Age at interview, y	49.78	6.79	41 - 69		
Child Cancer Characteristics					
Diagnosis					
Leukemia				5	23
Osteosarcoma				9	42
Ewing Sarcoma				2	9
Rhabdomyosarcoma				1	4
Synovial Sarcoma				1	4
Lymphoma				1	4
Wilms Tumor				1	54
Brain Tumor				2	9
Gender					
Female				5	23
Male				14	67
Non-Binary				2	10

Current Age	18.50	2.87	12 – 24
Age at diagnosis, y	13.56	3.48	9 – 22
Time since treatment completion, y	3.67	2.25	1 – 8
Interview length, min	47.97	11.67	18 - 69

Study Title: Living amidst symptom uncertainty: capturing the meaning of bodily sensations after childhood cancer

Interview Schedule - Parent

First of all, we would like to thank you for taking the time to participate in this study and to help with our research. As you know we are interested in understanding yours and your child's experience of life after childhood cancer, especially how your child experiences his/her body and cope with bodily symptoms like pain, fatigue, breathlessness, or any other bodily sensations that s/he might experience. We are interviewing around 20 other young people and their parents. We hope that by doing this study we help other young people to cope well with life after cancer and to have a good quality of life.

All the information that you provide today will be anonymized, meaning that no one outside of our research group will know that this information came from you. There are no right or wrong answers as we are most interested in your experience and your thoughts about life after your child's cancer. You do not have to answer the questions and if you want to stop at any time you can do so.

Section A. Cancer history & rapport building

1. To start off, can you tell me about the type of cancer your child had and how s/he was first diagnosed?

2. Can you tell me about the treatments that your child had?

Section B. Finishing treatment and entering remission

3. Can you tell me about how you felt when your child finished treatment?

Possible Prompts/Follow-up Questions

- What kinds of emotions did you feel?
- What kinds of positive/negative emotions did you feel?
- What did you think was going to happen in the future?
- How did you think yours and your child's life would change?

4. Can you tell me about what you talked about with your child's doctor after finishing treatment?

- What types of things did s/he tell you about life after cancer?
- How did you feel about the amount of information you were given?
-

Section C. Fear of recurrence & symptoms

5. Some people tell us that they worry a lot about their child's cancer returning. Can you tell me about how that has been for you?

Possible Prompts/Follow-up Questions

- Can you tell me about what things make you particularly worried?
- How does this worry affect your day-to-day life?
- How do you cope with this worry?
- Who do you talk to about this worry?

6. Sometimes people say that their child having physical sensations like aches and pains, feeling sleepy, or feeling dizzy, can make them particularly worried that their child's cancer might be coming back. Can you tell me about how this is for you?

Possible Prompts/Follow-up Questions

- What kinds of physical sensations make you worry?
- Are these sensations similar to anything you felt when you had cancer?
- How frequently do you find yourself worrying about these things?
- How do you think this worrying affects your everyday life?
- What sorts of things do you do if you find yourself worrying about this?

7. Can you please tell me about a time that comes to mind after finishing treatment when your child had a physical symptom that you were worried about?

Possible Prompts/Follow-up Questions

- What was this symptom?
- What did you think this symptom meant?
- Can you tell me what you were thinking about the chances of your child's cancer returning at this point?
- Who did you talk to about it?
- What did you do about it?

8. Some people tell us that one of the hardest things about life after their child's cancer is living with uncertainty; not knowing what is going to happen in the future. Can you tell me how this has been for you?

Possible Prompts/Follow-up Questions

- How does it feel to not know whether or not your child might get sick again?
- How does it feel to not be sure what is going to happen in the future with your child's health?

Section D. Additional concerns

9. Is there anything else that you would feel it would be helpful for me to know that we have not yet spoken about?

Thank you so much for doing this interview with me and helping out with our research. I really enjoyed talking with you and hearing about your experiences today.