Trajectory of parental hope when a child has difficult-to-treat cancer: a prospective qualitative study

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‡Our esteemed colleague and friend Dr. Beverley Antle died during the early stages of data collection for this study in 2008.

Abstract

Objective: This prospective and longitudinal study was designed to further our understanding of parental hope when a child is being treated for a malignancy resistant to treatment over three time points during the first year after diagnosis using a qualitative approach to inquiry.

Methods: We prospectively recruited parents of pediatric cancer patients with a poor prognosis who were treated in the Hematology/Oncology Program at a large children’s hospital for this longitudinal grounded theory study. Parents were interviewed at three time points: within 3 months of the initial diagnosis, at 6 months, and at 9 months. Data collection and analysis took place concurrently using line-by-line coding. Constant comparison was used to examine relationships within and across codes and categories.

Results: Two overarching categories defining hope as a positive inner source were found across time, but their frequency varied depending on how well the child was doing and disease progression: future-oriented hope and present-oriented hope. Under future-oriented hope, we identified the following: hope for a cure and treatment success, hope for the child’s future, hope for a miracle, and hope for more quality time with child. Under present-oriented hope, we identified hope for day-to-day/moment-to-moment, hope for no pain and suffering, and hope for no complications.

Conclusions: For parents of children with a diagnosis of cancer with a poor prognosis, hope is an internal resource that can be present and future focused. These views fluctuated over time in response to changes in the child’s well-being and disease progression.

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Introduction

The concept of hope has been widely studied and acknowledged to be an important construct in cancer care, in particular with adults experiencing their own adversity, terminal illness, and end of life [1–8]. Individuals with advanced cancer have described dealing with pain and suffering by maintaining hope, defining this hope as an ‘inner resource and coping mechanism essential for their quality of life’ [1; 2, p. 248]. Hope has been described as integral to a cancer patient’s quality of life [9] and as essential to their coping and well-being [10–13]. Hope as an inner resource refers to a positive mental construct, an internal source (as opposed to external resources such as medications and social support), that people going through adversity can draw on in times of crisis or stress.

Hope has also been defined as a transformative process by which individuals acknowledge the reality of their circumstances, search for meaning, and reappraise their life, which in turn, transforms their hope [2,3]. Moreover, hope in other illness populations has been associated with improved coping strategies and has been essential to recovery from illness [14]. Studies that have looked at caregivers for mentally ill patients have found that hope in the caregiver was an essential part of the coping process of the family members [15–17] and that family caregivers often served as ‘hope carriers’ for the patient [18].

Despite the importance of hope for cancer patients and their families, few studies have explored parental hope in the context of caring for children with cancer. Within this context, parental hope has been defined as a multidimensional construct, an orientation towards life and the future, and has
been associated with a child’s disease progression (cancer that continues to grow and/or not responding to treatment), health status, and prognosis [19–24]. A few studies looking at parents of children with cancer found that hope helped them cope with their child’s disease even if the prognosis was poor or their child was dying from the illness [22–25]. Moreover, with two exceptions, the majority of qualitative studies on parental hope in the context of cancer were retrospective [20–23]. In one of the only prospective studies on the topic, Salmon and colleagues [25] interviewed parents of children with cancer regarding their fears and hopes about treatment and the cancer journey at 2, 6, and 12 months post-diagnosis. The authors reported that parental hope across time seemed to be related to meeting short-term goals for the child’s treatment. The authors noted,

Psychologically, the defining feature of parents’ hope was short-term focus. Most parents described a time frame constrained by events associated with treatment, typically the next consultation or the next results; avoiding information about the longer term was critical. Hope is, therefore, an ambiguous term; hope meant not hoping for, or thinking about, the long-term outcomes that mattered most. [25, p. 403]

In the other prospective study, our team investigated the nature of parental hope 3 months after the child was diagnosed with cancer that had a poor prognosis [19]. We found two predominant types of hope: hope for cure of the disease and hope for a future [19]. In this current study, we further examined the nature of hope longitudinally at 3, 6, and 9 months post-diagnosis when a child has a poor prognosis in order to better understand changes in parental hope as they follow their child’s cancer treatment. To our knowledge, no other studies have prospectively and longitudinally examined the type of hopes experienced by parents whose children have a poor prognosis at the time of diagnosis. This population of patients and caregivers is particularly rare because the vast majority of childhood cancers (more than 80%) are curable and have good treatment outcomes [26].

Methods

Participants and procedure

We prospectively recruited parents of pediatric cancer patients who were treated in the Hematology/Oncology Program at a large children’s hospital for this longitudinal grounded theory study. We used the grounded theory method in our study design. As such, the sampling of participants was purposeful and theoretically guided. As data collection and analysis proceeded, we sought out participants who were able to help inform the developing theory and elaborate and refine the categories that were part of the developing findings [27]. Additionally, data collection procedures were designed to develop the richest base of data possible, while being sensitive to the particular burdens that parents of children with a poor cancer prognosis face. This approach directed the researchers and interviewer to seek participants who had an in-depth appreciation of the issues at play. To achieve the greatest amount of variation within the sample population, we approached parents whose children initially had poor prognosis from all the cancer clinics within hematology/oncology. Parents were interviewed at three time points: Time 1 occurred within 3 months of the initial diagnosis; Time 2 occurred at 6 months; and Time 3 occurred at 9 months. The inclusion criteria were as follows: (a) parents of children diagnosed with a known poor prognosis of cancer who were told this information (10% expected survival; the disease was known to be resistant to treatment; standard treatment protocol cannot cure the disease; high risk disease; stage IV; and/or the child was at high risk for mortality in the opinion of the responsible physician); this included children who were diagnosed with leukemia or lymphoma (38%), brain tumor (23%), neuroblastoma (23%), germinoma (8%), and Wilms’ tumor (8%); and (b) parents of a child who had stopped receiving curative treatment for cancer and/or who had entered Phase I clinical trials. Exclusion criteria included the following: parents whose child’s physician or social worker deemed to be too upset or having difficulty coping with the challenges and demands of the child’s treatment and hence parental participation in the study may cause additional undue hardship, or the parent’s inability to speak English.

The characteristics of the sample, recruitment, and general procedure of the study have been described previously [19]. Briefly, after obtaining ethics approval, 44 eligible parents were contacted; 35 agreed to participate and were interviewed between May 2006 and October 2009. Nine parents refused participation because of feelings of being overwhelmed with the demands of their child’s treatment. The average child’s age was 6 years, and the children ranged in age from 3 months to 16 years; 55% of the children were female. Of the 35 parents participating at Time 1, 26 were mothers and 9 were fathers. Nine were couples, but each parent was interviewed individually. Thirty participants were married or in a long-term partnership, four participants were single or divorced, and one was widowed. Sixty-two percent of the parents were White, 17% were South Asian, 11% were Black, and 9% reported other ethnicities (Aboriginal, Hispanic). At Time 2, 30 parents participated; at Time 3, 27 parents participated. The main reasons for attrition at Times 2 and 3 were parent’s lack of interest in the research and/or feeling overwhelmed with the child’s condition and demands of treatment. One child died during the Time 2–Time 3 interval and, therefore, dropped out of the study and was not interviewed at Time 3.
Parents at all three time points were interviewed at a convenient time for them in the hospital using a semi-structured guide. Questions focused on what hope meant to them, how it changed over time (for Time 2 and Time 3 interviews) and the circumstances that helped maintain and/or challenge their hope in the face of their child’s diagnosis and treatment (see Table 1 for sample questions asked). Interviews ranged from 30 to 60 min and were audio-recorded and transcribed.

Data analysis
Data collection and analysis took place concurrently using line-by-line coding. Initially, one researcher organized and labeled codes using participants’ words and meanings, which were further distilled into domains to assist in the development of categories, and ultimately themes and subthemes. Two other investigators reviewed data and the emergent codes, categories, and themes. Other team members examined a portion of the data to achieve consensus regarding categories, themes, and subthemes, and to compare and contrast codes to assist in the analysis and organization of findings. Data collection continued until saturation was achieved, whereby no new codes were identified in the data. After analysis of Time 1 transcripts was completed, the core categories and themes for Time 1 were used as the basis for analysis of Time 2 and Time 3 transcripts, identifying any changes over time and documenting any additional emerging themes and sub-themes. Data management and analysis was supported by the use of qualitative data management software (Nvivo).

Findings
Although all the children of these parents were considered to have poor prognosis from the beginning of the study, it became evident from Time 1 on that in spite of the poor prognosis, some children were responding well to treatment and that this had a major impact on parents’ views of hope at each interview. On the basis of information from the child’s medical chart and parental reports of the child’s well-being at Time 1, we organized participants into two groups. The first group (N=22 at Time 1, 18 at Time 2, and 17 at Time 3) included parents of children who were doing well (defined by the child being in remission, or having reduction of lesions or reduction of tumor size, and the child being able to engage in some normal routines such as resuming school). The second group (N=13 at Time 1, 12 at Time 2, and 11 at Time 3) included parents of children who were not doing well (defined by child with progressive disease, the child receiving only palliative care—pain management and comfort to maintain good quality of life). It is important to note that even the children who were responding relatively well to treatment were undergoing aggressive treatment with an uncertain outcome. In addition, the children who were doing well at Time 1 continued to do well at Times 2 and 3.

Two overarching categories defining hope as a positive inner source were found across time: future-oriented hope and present-oriented hope. Under these categories, specific themes were identified. Under future-oriented hope, the following themes were identified: hope for a cure and treatment success, hope for the child’s future, hope for a miracle, and hope for more quality time with child. Under present-oriented hope, the following themes were identified: hope for day-to-day/moment-to-moment, hope for no pain and suffering, and hope for no complications. These categories and themes represent different types of hopes and were found at the three time periods but varied greatly depending on how the child was responding to treatment. Importantly, we note that there was no linear or straightforward progression for these hopes and that they fluctuated over the course of the study. To convey these changes across the three time points, we indicate whether a theme remained consistent, increased, decreased, or fluctuated over time. This is described for parents whose child was doing well separately from parents whose child was not doing well. Table 2 summarizes these findings. As we show in Table 2, the only hope that remained consisted for all parents throughout the entire study period was hope for a cure and hope for a recovery. This hope, however, co-existed with other future-oriented and present-oriented hopes that parents held on to throughout the cancer journey with their child. As will be shortly reported, for example, hope for no suffering co-existed with hope for a cure. Parents at each interview at each time period spoke about which hope was most salient to them at the moment (and this often depended on how their child was doing with treatment), without implying that hopes held earlier on in the cancer journey no longer existed in their thoughts.

Table 1. Sample questions from the interview guide

<table>
<thead>
<tr>
<th>Question</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you tell me a little bit about what is going on now with [name of child with cancer] and what is important to you right now?</td>
<td>Can you tell me what your focus is right now as it relates to your child’s treatment?</td>
<td>Can you tell me what your focus is right now as it relates to your child’s treatment?</td>
<td>Can you tell me what your focus is right now as it relates to your child’s treatment?</td>
</tr>
<tr>
<td>• What do you expect from treatment?</td>
<td>• How does hope relate to your child’s treatment?</td>
<td>• How does hope relate to your child’s treatment?</td>
<td>• How does hope relate to your child’s treatment?</td>
</tr>
<tr>
<td>When you think about hope, what things come to mind?</td>
<td>If you had to define hope, how would you describe it?</td>
<td>How is your notion of hope different or similar to your husband or wife?</td>
<td>How is your notion of hope different or similar to your husband or wife?</td>
</tr>
<tr>
<td>• What are the perspectives of your family’s or other close friends’ concepts of hope?</td>
<td>• If you had to define hope, how would you describe it?</td>
<td>• If you had to define hope, how would you describe it?</td>
<td>• If you had to define hope, how would you describe it?</td>
</tr>
<tr>
<td>Do you feel that you share the same perspectives?</td>
<td>• How is your notion of hope different or similar to your husband or wife?</td>
<td>• How is your notion of hope different or similar to your husband or wife?</td>
<td>• How is your notion of hope different or similar to your husband or wife?</td>
</tr>
<tr>
<td>• What role does hope play relationship to and her health?</td>
<td>• Are there some things that make it easier to be hopeful?</td>
<td>• Are there some things that make it harder to be hopeful?</td>
<td>• Are there some things that make it easier to be hopeful?</td>
</tr>
<tr>
<td>What helps you to maintain hope?</td>
<td>• Some people look to their faith or to a higher power to find hope, can you talk about the role faith plays in your life right now? Has faith always existed as a source of hope for you prior to the diagnosis or?</td>
<td>• Some people look to their faith or to a higher power to find hope, can you talk about the role faith plays in your life right now? Has faith always existed as a source of hope for you prior to the diagnosis or?</td>
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</tr>
<tr>
<td>• Have there been other sources of support?</td>
<td>• Some people look to their faith or to a higher power to find hope, can you talk about the role faith plays in your life right now? Has faith always existed as a source of hope for you prior to the diagnosis or?</td>
<td>• Some people look to their faith or to a higher power to find hope, can you talk about the role faith plays in your life right now? Has faith always existed as a source of hope for you prior to the diagnosis or?</td>
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</tr>
</tbody>
</table>
Table 2. Fluctuation of parental hopes for their children at 3, 6, and 9 months post-diagnosis

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
<th>Well child</th>
<th>Not well child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Future-oriented hope</td>
<td>Hope for a cure/recovery and treatment success</td>
<td>Consistent</td>
<td>Consistent</td>
</tr>
<tr>
<td></td>
<td>Hope for future</td>
<td>Increases</td>
<td>Decreases</td>
</tr>
<tr>
<td></td>
<td>Hope for a miracle</td>
<td>Decreases</td>
<td>Increases</td>
</tr>
<tr>
<td></td>
<td>Hope for more time with dying child</td>
<td>Not applicable</td>
<td>Increases</td>
</tr>
<tr>
<td>Present-oriented hope</td>
<td>Hope for day-to-day/moment-to-moment</td>
<td>Fluctuates</td>
<td>Fluctuates</td>
</tr>
<tr>
<td></td>
<td>Hope for no pain and suffering</td>
<td>Consistent</td>
<td>Increases</td>
</tr>
<tr>
<td></td>
<td>Hope for no complications</td>
<td>Decreases</td>
<td>Fluctuates</td>
</tr>
</tbody>
</table>

Consistent, Hope remains consistent over three time periods; Increases, Hope increases across time periods; Decreases, Hope decreases across time periods; Fluctuates, Hope fluctuates (increases and decreases) across time period.

Future-oriented hope

Hope for a cure and treatment success

The predominant theme across the three interviews was hope that the treatment would work, that the child would be cured, defined as making a full recovery. Even though all parents knew that their child had a poor prognosis and thus an unlikely chance of cure, this type of future-oriented hope served as an inner force and motivating factor that helped parents in their daily caregiving responsibilities. Hope functioned as a motivator to keep going through the tremendous affective and physical work associated with caregiving for a child with cancer (e.g., keeping the sick child’s spirits up, administering medications, taking the child to appointments, and taking care of other children in the family). More than three quarters of the parents of children doing well reported this hope consistently at 3, 6, and 9 months. Understandably, for parents of children who were not doing well, the hope for a cure was strongest at Time 1 and became increasingly precarious over the course of the study during which the child’s health had deteriorated and the possibility of the child’s death became more apparent. In fact, in the last interview, this hope was rarely expressed by parents whose child was not doing well. On the other hand, with one exception, none of the parents openly spoke about their child’s imminent death. The following quotes illustrate these changes in hope for some parents and, conversely, the consistency in hope over time for other parents.

At Time 1, a mother of an adolescent who was not doing well noted, ‘Of course we are expecting to see him healthy six months or maybe five years.’ At Time 2, this mother similarly remarked, ‘My expectation is (for) the illness to completely be removed.’ At Time 3, however, this mother did not speak about hope for a cure in her interview but spoke more abstractly about hope. She stated,

Without hope we can’t believe. If you think it will not be good or he’s not making it then we can’t plan for the future we can’t do anything. When we have hope, we know that they will get there, if you try to push him to get there actually I mean spiritually not physically, because we don’t know anything about the medications things like that. But...hope gives us the motivation to go forward.

Another mother of a 5-month-old child diagnosed with acute lymphoblastic leukemia who was doing well was consistently hopeful for cure across all three interviews. At Time 1, she noted that she ‘Hope[d] of having a full recovery.’ At Time 2, she stated, ‘The doctors say hope of remission but, I want to use a stronger word, my hope is that she is healed. You know? Cured. That is the ultimate. I believe she is cured...that is my ultimate hope.’ At Time 3, she similarly identified, ‘[hope] to have complete recovery...like, she’s healed completely.’ Thus, it appears that while parents seem to be aware of the child’s poor prognosis, they continued to have hopes for the child’s cure, and this hope may serve as a motivator to continue to care for a very sick child.

Hope for the child’s future

Hope for the future was embedded in the hope for a cure, but it was also a consistent, clear, and robust independent theme over time for parents whose children were responding well to treatment. For the parents whose children’s disease was not responding to treatment, however, this theme decreased over time. Like hope for a cure, hope for the future seemed to serve as motivation to keep parents going through some of the rougher patches of their child’s treatment. At Time 1, this hope took the shape of hoping for a long and healthy life, returning as much as possible to a normal or a ‘new normal’. At Times 2 and 3, this hope changed to focus on future goals and developmental milestones such as the children being able to go to school regularly, get married, and have children. For instance, at Time 1, one mother of an 11 year old with acute lymphoblastic leukemia who was doing well explained, ‘Well thinking very positive. Thinking of the future. Planning the future. It gives us, hope gives us a reason to plan.’ Although this parent did not speak about the future at Time 2, at Time 3, she began looking forward towards her child’s life, including thinking about insurance and education. She noted,

You have to start planning for not only his education funds but for other funds for him, just in case he ever has problems ever getting a mortgage...but you have to try to see the bigger picture for him and make sure that his life is as normal as possible.

On the other hand, for those parents whose children were not doing well, talk of the future came up only at Time 1. One mother of a 3 year old with a brain tumor
who was not doing well spoke about focusing on future goals for her child as illustrated in the following.

Time 1: My hope for him (is) that he’s going have girl-friends, get married, hopefully have children. . . We’re hoping that this is just a blip on the radar . . . That this is just a period in his life that we’re going to get through, that we’re going to get over and that we’re going to move on.

Of note, this mother did not make any further reference to these goals in either Time 2 or Time 3 interviews.

**Hope for a miracle**

A few parents spoke about hoping for a miracle for their child’s well-being and recovery. Hope for a miracle was usually, but not always, related to spiritual beliefs and praying for a cure for the child. Like hope for a cure, and for a future, hope for a miracle gave parents the motivation to continue through this difficult journey of caring for a very sick child. For parents whose children were doing well over time, hope for a miracle was not a theme that came up at Times 2 and 3. For parents whose children were not doing well, however, hope for a miracle emerged across the three time points. For example, at Time 1, the father of a 6-year-old child with a brain tumor who was not doing well explained that he wanted ‘to cure him, miracles have happened before.’ At Time 2, the mother of this child similarly noted, ‘What do I expect? I don’t know. . . Like I’m hoping that things will continue to be good. I believe in miracles, but as far as expecting? I don’t, I hope.’ And at Time 3, this father noted, ‘Maybe there’s a miracle. Maybe things will be, you know, like I say you gotta’ hope. If you don’t hope for something it’s just not worthwhile.’

**Hope for more quality time with child**

For parents whose children were not doing well, they spoke of hope for extending time with the child that eventually morphed into hope for more time with the child if they had a good quality of life. This was not a relevant category for the parents whose child was doing well, because they were not at a point where their child’s disease was not responding to treatment. At Time 1, a father of a 6-year-old child with a brain tumor who was not doing well remarked,

> Without treatment, they were suggesting about 6 months. With radiation treatment, up to 8 months to a year. With (this) addition, . . . the hope is to lengthen that honeymoon period; the term they use for the radiation treatment can slow down the tumour growth and potentially stop it, but it can’t finish it. So once the treatment is over at the end of the 6 weeks, it will eventually start to metastasize again and then we’re into trouble. So, the hope is to just extend it as long as we can and fight.

At Time 2, when the treatment had failed and the child had been through several painful complications from treatment and was nearing death, hope fluctuated from time extending life to for extending quality of life specifically. Her father remarked,

> We’re trying to balance quantity, I guess, of life, versus the quality. We’ve decided to stop the chemotherapy. . . I guess the internal pressure there is, you just feel as a parent, you’re giving up on her. . . We could continue to try to aggressively fight this, to try to buy her some more time, but the odds of it giving her a second or third stroke and reducing the quality of life even farther, is just too, too scary. So, we’ve decided to just try to make her happy, and get her off the pills and let’s have some fun.

This child died peacefully a few weeks later.

**Present-oriented hope**

Unlike future-oriented hope, present-oriented hope was based on the day-to-day quality of life for the child or parents’ short-term and moment-to-moment hopes for their child’s well-being; the hope that the child would not suffer or be in pain; and the hope for minimal complications and side effects from the treatment the child was currently receiving. For some parents, this type of hope was related to spiritual beliefs and praying.

**Hope for day-to-day/moment-to-moment**

While many parents hoped their child would have a future, they also spoke about hoping for moments of grace and peace in day-to-day life with their child. For both sets of parents, this hope fluctuated widely between Time 1 and Time 3; however, parents whose children were not doing well at each time point spoke about this hope as being particularly important to them. One father whose child was not doing well and eventually died from the disease shortly after Time 3 remarked at Time 1,

> We’re 4 weeks into it. She’s as happy as the day she started it. The only hope is that you just live day to day and hold off that change. You just do your best. You pray you wake up and she jumps in your bed and she’s smiling again. And that’s it.

At Time 2, this father noted that over time, hope was becoming more about the small moments with his child—a smile, a laugh, or a joke. He explained,

But, in terms of hope, what hope means to me is, you know, is waiting and it’s a positive feeling for a positive future, or something that you’re looking forward to. That just doesn’t exist anymore. . . Now when you can see her smile, you can see her laugh, you’re hoping to have
Hope for no pain and suffering
Although parents in general hoped that their child would not suffer nor be in pain, understandably, the parents whose children were not doing well were more likely to bring this up as a hope over the three time periods. For example, one mother of an 8-year child diagnosed with neuroblastoma and who eventually died from the disease explained at Time 1 that ‘(the) first thing is just hoping that we can get her feeling better. She can’t even walk. So, I want her to be pain free.’

Hope for no complications
At each interview, parents expressed a hope for their child to have minimal complications and side effects from treatment. For parents of children who were doing well, this hope increased over time, particularly if the side effects had long-term consequences. One mother of a 5-year-old girl who was doing well remarked at Time 1,

She’s started a new chemo this time…one of the side effects is, it could cause an entirely different kind of cancer in her body… And it, it says that if your child takes this, she may not be able to have children in the future. …And I started crying and crying in the playroom, and the nurse comes in and she’s like oh my God, are you okay? And I’m like, this one’s gonna make her sterile? She’s like, they can all make her sterile.

At Time 2, this mother spoke again about hoping for minimal complications in desiring ‘no long-term side effects and I would really, really, like for her sterility to be intact…’ I don’t want her sterile, I want her fertility to be intact.’

For parents whose child was not doing well, this hope varied over the three time periods, depending on whether treatment complications resulted in discomfort for the child. These parents were spending more time in the hospital, and they were becoming aware of the potential side effects of chemotherapy treatment. Consequently, the hope for no complications increased. One of these parents, the mother of a boy, remarked, ‘[I’m hoping] just that he doesn’t get any complications… I wanted [him] not to get really, really sick [from treatment].’ Another mother similarly explained at Time 2, ‘[I’m hoping] there’ll be little or minimal complications.’

Discussion
In a previous report, we found that 3 months after the child was diagnosed with cancer and given a poor prognosis, parental hope was primarily linked to the child’s cure and future. Being hopeful, however, oscillated between tenacious and tenuous, depending on how the child was responding to treatment, with little reference to the child’s poor prognosis and the possibility of death [19]. In this report, we examined longitudinally how the trajectory of parental hope changes over the first year post-diagnosis. Several important findings emerged from this study. Even though all the children were given a poor prognosis at the time of diagnosis, hope appeared as a positive inner source and motivator that was both future and present oriented to life. Within these categories, themes emerged and varied over time. More importantly, they varied depending on how well the child’s disease was responding to treatment, if the child was still receiving treatment for curative purpose, or how the child was coping with the disease progression and the effects of the treatment such as the impact of chemotherapy, pain tolerance, and general quality of life. Thus, for parents whose children were doing
well, hope for the future increased over time as hope for a miracle decreased. The opposite was true for parents whose children were not doing well.

Within the present-oriented hope category, for parents whose child was doing well, hope for no pain and suffering was consistent across time, and hope for no complications generally decreased over time or was more focused on long-term complications such as infertility. In contrast, for parents of children who were not doing well, hope for no pain and suffering increased over time, but hope for no complications and for good moment-to-moment quality of life fluctuated over time, depending on how the child was coping with the disease progression.

The present-focused hope found in this study is similar to the short-term focused hope reported by Salmon and colleagues [25]. Surprisingly, however, Salmon and colleagues did not find future-focused hope. Because the focus of Salmon’s study was not exclusively on hope, their results may be constrained by the timing of the interviews when parents came to the clinic for follow-up visits with the child’s treating oncologist. Perhaps the focus on the clinic visit prevented parents from considering the child’s future openly. The future-focused hope was also reported in previous studies [20–22]; however, present-focused hope was not reported in those papers. Previous studies examined parental hope by interviewing parents retrospectively, after the child had died or when the child was dying, which may have limited parental reflection on present-focused hope.

Remarkably, although parents in this study had a child with a poor prognosis, and some of the children were in the process of dying by the second interview, when given the opportunity to reflect freely and openly about their views on hope, they were able to present multiple perspectives of hope and place those views within a time trajectory. This interpretation does not assume that parents were unaware of their children’s poor prognosis and, in some cases, imminent death. Indeed, although some observers might assume that parental hope in the face of such a dim prognosis is a form of denial, hope in this case differs from rejection of reality. Denial has been defined in the literature as a disavowal or a defense against a threatening external reality [28]. The parents in our study were told of the poor prognosis and were only too aware of the reality of caring for a very sick child who may die. Yet, they appeared to have learned to focus on diverse types of hope that helped them carry on with their difficult task of caring for their child and help the child to live fully while still alive. For example, when hope for a cure was no longer accessible (e.g., the child being close to death), hope for different aspects emerged (e.g., hope for no suffering). Parents, in this case, were holding on to a more general hopefulness that was fluid and fluctuated throughout the process of the child’s treatment. In this sense, parents were more aligned with Dufault and Martoccio’s definition of hope that distinguished between general hopefulness and hope for specific outcomes [29]. To our knowledge, although this finding that hope remains present even when the child is dying is innovative in the context of parental caregivers for a child with cancer, this finding is consistent with reports of adult patients at end of life whose hope remains high even when close to end of life [30–32].

Within stress and coping theory [33], hope, like stress, is considered to be contextual, involving the transaction between the person and the environment that may change over time. Moreover, hope is viewed as resulting from appraisal of the circumstances and personal resources, a dynamic process that ‘waxes and wanes’, and is considered to have a reciprocal relationship with coping. Folkman’s view of the concept of hope seems to concur with the findings of this study regarding parental hope [33].

The findings from this study suggest several clinical implications for healthcare professionals (HCPs). First, HCPs can recognize that there are different types of hope that emerge for parents over the course of caring for their child with cancer, and all are valid and important to the parents coping with these difficult times in their lives. These hopes are not necessarily linear or happen in a straightforward progression but may emerge and recede over the course of the cancer treatment. HCPs can respect these fluctuations in hope by acknowledging and validating them in conversations with parents and, when necessary, redirecting or helping parents refocus on more accessible hope when in times of despair (e.g., helping a despairing parent whose child is dying redirect their hope for a peaceful death or for no suffering for their child).

Most pertinent, HCPs can assist parents whose child has a poor prognosis in maintaining different types of hope that focus on the moment-to-moment and living, as well as on the future throughout the first cancer treatment, while recognizing the fact that hope for a cure can be tenuous or tenacious [19] and that it is not the only hope that parents experience. Most practically, HCPs can directly intervene and ensure that the child does not suffer from uncontrolled symptoms or pain. Although HCPs will naturally monitor the child suffering and do everything in their power to ameliorate pain, continually communicating this intent and practice to parents will help them maintain their hope.

To summarize, our study represents the first in-depth, qualitative, prospective, and longitudinal study that focused exclusively on a comprehensive analysis of the nature of parental hopes and their fluctuations during the first year after childhood cancer diagnosis with a poor prognosis. Parents reflected on their hopes, considering both the child’s present and future life and the quality of such life in light of the disease and its treatment. Moreover, our findings speak of the positive, inner resource, and dynamic nature of parental hope as a motivator for life, and the various types of hope that helps parents cope with the daily demands of caring for a very sick child who may be in the process of dying. Thus,
parents can ‘transform’ their hope or inner resource in a similar way as do elderly patients with advanced cancer [1,2]. Whether hope, as an inner resource, is future focused or present focused, it seems to provide the motivation to move forward and to readjust their coping, as conceptualized by Folkman [33].

The findings of this study need to be considered in light of some limitations. First, although we had a relatively small participant attrition rate from Time 1 to Time 3, it is possible that those parents who dropped out of the study did so because they felt overwhelmed with the demands of caring for a very sick child. It is also possible that those parents also felt a loss of hope for the future, which might have led them to decline further participation in this study. As such, it is plausible that there were parents who had different views of hope (or loss of hope) who were not represented in this sample. Second, using purposive sampling, the sample was composed of parents whose children all had a poor prognosis at the start of the study. Although this demographic provides a tremendous illumination into the various types of hope that parents hold on to in spite of very negative circumstances, it is possible that parents of children who have a better prognosis from diagnosis (more than 80% of children with cancer survive their initial disease [26]) will also have different views of hope.

Despite these limitations, this study uniquely offers a prospective and longitudinal in-depth examination of the nature of hope for parents whose children have a poor prognosis as a result of childhood cancer. Although parents of children who were doing well had slightly different hopes than those whose children were not doing well, all parents had expressed various types of hope for their child as they went through the cancer treatment and all hoped for a cure. Regardless of the child’s poor prognosis, or response to treatment as long as their child was alive, the parents chose to hope for life for their child. The various types of hope—future oriented and present oriented—shifted, transformed, sometimes increased, sometimes decreased, and sometimes remained consistent over time, depending on how well the child was doing over the course of treatment when facing poor prognosis. Future research needs to further investigate what factors (other than the disease/treatment and how the child copes with it) may contribute to different types of parental hope and how these types of hope relate to HCPs and parental social support. Finally, these findings cumulatively speak to the value of education both for the family and HCPs in understanding these complex processes, and continue clinic-based support for families as they navigate this complex and shifting terrain of childhood cancer and its treatment.

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Conflict of interest

The authors have no conflict of interest to declare.

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