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Working with hope: Learning from bereaved parents

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Abstract

Objectives. The complexity of hope in serious childhood illness can be underestimated in clinical practice. We sought to explore the lived experience of hope among bereaved parents to help clinicians interpret and engage with parents' varied and changing expressions of hope over the course of their child's illness.

Methods. Semi-structured interviews were conducted with bereaved parents of children known to a statewide pediatric palliative care service who died aged 16 years or younger from any medical condition. A phenomenological framework underpinned the study, and reflexive thematic analysis was employed. Institutional ethics approval was obtained.

Results. Twenty bereaved parents, including 6 fathers, participated. Their children ranged in age from 1 day to 16 years. Overall, parents' hopes were personal, multidimensional, and changed over time. Four main themes emerged: (1) Objects of hope, including survival, experiences in life, day-to-day normality, memory-making, and experiences at end-of-life; (2) patterns of hope, including hope's dynamic nature, alignment between parents, and hope and prognostic awareness; (3) factors that influence hope, including hope's intrinsic nature, clinical information, and clinician communication; and (4) the value of hope, both positive and negative.

Significance of results. The study's findings support existing research describing hope as multidimensional, dynamic, and potentially coexisting with prognostic awareness. We share new insights into how clinicians can work with parental hope in ways that can be both beneficial and detrimental. Additionally, we describe how some parents may perceive hope as potentially harmful.

Background

Parents of children with serious or life-limiting illnesses are tasked with being caregivers, advocates, and decision-makers, all while confronting their own grief. Hope can be central to this experience. Despite literature demonstrating that hope and prognostic awareness are not mutually exclusive (Mack et al. 2007; Kaye et al. 2020; Katz et al. 2025), our experience suggests that clinicians can struggle to engage with parental hope. Clinicians may mistakenly interpret hope as a misunderstanding or denial of prognosis, and worry that parents will be unprepared when their child dies. Furthermore, clinicians might be concerned that maintaining hope enables parents to delay important decisions, continue aggressive treatments, and potentially extend a child's suffering (Hasan et al. 2021; Katz et al. 2025).

The literature describes hope in the face of serious childhood illness as dynamic and multidimensional, extending well beyond hope for cure or survival (Feudtner 2009; Reder and Serwint 2009; Rosenberg and Feudtner 2016; Hill et al. 2018, 2023; Sisk et al. 2018; Kaye et al. 2020). Barrera et al. (2013) described oscillations between "tenacious and robust" and "tenuous and elusive" hopes as parents became aware of their child's inevitable death. Some, but not all, parents may shift their priorities as previously held goals become less achievable (Hill et al. 2014, 2019). Importantly, parents can remain aware of their child's mortality while continuing to hold hope, challenging dichotomous assumptions that equate hope with denial (Mack et al. 2007; Kaye et al. 2020). Parents themselves might even express a tension between hoping for survival and hoping to avoid suffering for their child (Reder and Serwint 2009).

The dynamic nature of parental hope can be understood through theories of grief. The Dual Process Model explains healthy grieving as oscillating between engaging with loss and engaging in everyday life (Stroebe and Schut 1999), while the Dual Framework approach proposes that the aim is for individuals to hold the possibility of dying alongside a focus on living well

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(Jacobsen et al. 2018). These frameworks help us understand how hope may fluctuate or coexist with awareness of loss.

Studies have shown that hope can enhance parental coping (Reder and Serwint 2009; Sisk et al. 2018; Liu et al. 2024), and, in fact, that some parents fear losing hope (Bally et al. 2014). More recent studies have therefore focused on the clinician's role in recognizing and supporting hope, offering broad communication strategies (Mack et al. 2007; Rosenberg and Feudtner 2016; Hill Dl and Feudtner 2018; Christianson and Kaye 2025) and tools to foster hope (Bally et al. 2014, 2021; Fonseca et al. 2021; Hammer et al. 2023).

Clinician discomfort with interpreting and engaging with parents' expressions of hope can create a gap between parents and clinicians, which, in turn, can negatively affect children, parents, and clinicians (Katz et al. 2021). This study aimed to address this gap by examining parental hope through lived experiences, focusing on the various objects and patterns of hope, and how hope is demonstrated and engaged with during interactions between parents and clinicians.

Methods

Study setting and team

The study team included 2 palliative care physicians and a bioethicist.

Recruitment

Eligibility criteria included parents of a child known to a statewide pediatric palliative care service, who were aged 16 years or younger at death, and died at least 6 months prior to, but within 10 years of, recruitment. Parents of the same child were invited to participate in separate or joint interviews. Twenty parents participated, with 10 participants comprising 5 parental couples. Of these, 2 couples participated in separate individual interviews, while 3 couples participated together in a single interview (Table 1). Funding limitations precluded the use of interpreting services; therefore, participating parents were required to speak conversational English.

Data collection

A semi-structured interview schedule was developed and refined iteratively. Interviews were conversational, with the interviewer following participants' lead to elaborate on their lived experiences. All interviews were conducted via Zoom, and audio files were saved, transcribed verbatim, and anonymized.

Data analysis

Transcripts were managed and coded using NVivo and Word software. A selection of transcripts was co-coded by all authors, with discussions at regular intervals to compare and consider interpretations of the data. Data were analyzed using Braun and Clarke's 6-step reflexive thematic analysis, offering a flexible yet rigorous approach to theme generation (Braun and Clarke 2021). A phenomenological framework underpinned the study, with the analysis grounded in parents' lived experience (Ayton et al. 2023). Analysis was iterative and inductive. Broad expressions of hope, such as "want" and "wish," were included as they mirror what clinicians may observe in clinical practice.

Table 1. Parent and child details (M denotes mother, F denotes father)

Parent	Time since bereavement (months)	Child age	Cancer
M1	29	8 years	Yes
M2	19	5 years	No
M3	47	8 months	No
F4			
M5	15	9 years	Yes
M6	22	5 years	No
M7	23	1 day (antenatal diagnosis)	No
M8	22	13 months	No
F9			
M10	39	4 years	No
F11	40		
M12	11	1 year	Yes
M13	23	2 years	No
M14	77	16 years	Yes
M15	56	4 years	Yes
F16			
M17	16	12 years	Yes
F18			
F19	65	9 years	Yes
M20	49	9 years	No

Results

Study population

Twenty parents of 15 children participated in the study; 6 (30%) were fathers. Seven (47%) children had a cancer diagnosis (Table 1).

Parents gave rich and complex accounts of the nature of their hopes, how these played out over time, and how interactions with clinicians influenced their hopes. Four main themes, with subthemes, emerged. A summary table including illustrative quotes is presented (Table 2). Not all parents shared the same hopes, and some appeared to hold multiple, seemingly contradictory hopes simultaneously. Differences in the child's diagnosis or likelihood of death did not appear to produce different themes.

Objects of hope

Survival

Several parents described their hopes as being focused on survival.

> *…we hear all that… but we're also gonna focus on this and the possibility, and the chance, and the hope.* (M12, cancer)

Conversely, several other parents described an early understanding of their child's prognosis, and therefore not having hope for a miracle or cure.

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Table 2. Themes, subthemes, and illustrative quotes

Theme	Subtheme	Illustrative quote
1. Objects of hope	1.1 Survival	*…in the hospital, you see happy results, you see the ones that beat it… You live it, you see it, and you think we can be one of them… So, you hold onto that."* (F18, cancer)
	1.2 Child's experience in life	*And I think because [oncologist] was matter of fact at the beginning… made us focus on the present moment with [child]… I guess it was the hope for his experience, because we always knew what the outcome would be.* (M15, cancer)
	1.3 Day-to-day normality	*…even though [child] couldn't stand or walk or she wasn't really eating, I'd still pack her lunch box… sometimes she'd just dip her finger in the hummus and I just wanted her to experience something normal.* (M2, non-cancer) *Every time I come here it's just bad news and I just wanna be in this bubble and really just enjoy being pregnant.* (M7, non-cancer)
	1.4 Memory-making	*…just because you're not going to take the child home, it doesn't mean you can't have a lived experience with the child right here, right now. And I think that's one of the key things that the palliative care team taught me about creating memories because ultimately, we are all going to be just memories.* (M7, non-cancer)
	1.5 Child's experience at end-of-life	*… I had a really big fear of him dying in PICU, intubated in sterile environment…. So I really wanted a clear plan of, when I was at work or not with him, so people knew where I wanted that endpoint to be.* (M6, non-cancer)
2. Patterns of hope	2.1 Dynamic nature of hope	*I had to switch, [when] there wasn't necessarily a hope of taking him home… then having that hope of being able to see his face, hold his hand, thought of what the weight of his body feels like… I just wanted that hope.* (M7, non-cancer)
	2.2 Alignment between parents	*F16: …we discussed everything, but it wasn't like any one of us had opposing views, that the other one had to debate…* (F16, cancer) *M15: …or compromise on. I think we both kind of agreed.* (M15, cancer) *I know [child's] dad was definitely in denial… I had hope, but I don't think I was in denial. Like he kept saying things like, have you done your exercises today? My son was a paraplegic, like he had no, his legs were gone.* (M14, cancer)
	2.3 Hope and prognostic awareness	*Hope and the idea that things might not go well, I think they're almost always coexistent. If it's not in your own case you see in NICU so many other families going through your worst nightmare.* (M3, non-cancer) *I was hoping for a higher power and divine intervention right up until the last minute… even when she did take her last breath, I was like… she's going to come back to us, the cancer is going to go because when you die, the cancer goes and then she'll come back alive and she'll just say, okay it's gone, now let's go to school…* (M17, cancer)
3. Factors that influence hope	3.1 Intrinsic nature of hope	*So for me, there was always hope, 100%, I didn't doubt, I just kept believing that it's going to be okay… I kept believing and hoping.* (F18, cancer)
	3.2 Clinical information	*And that's what you hope… especially because she clinically looked so well… She wasn't one of these cancer kids where they're constantly sick or victimised in their beds. (M17, cancer)*
	3.3 Clinician communication	*I think that it will definitely be helpful if someone can channel us, what is the thing to hope for, or to help us to find the hope that we can get… better quality of life, look at how happy the kid is and the bonding between siblings… create a good memory. That will be the hope that parents need.* (M10, non-cancer)
4. Value of hope	4.1 Positive value of hope	*…you try to hold on to only hope… because that will keep you moving, that will take you through those sleepless nights, that will get you through all the hours that are very critical… the thought of him passing away would only put me down.* (M3, non-cancer) *Without hope you've got nothing… otherwise you're just a depressed wreck the whole time waiting for a disastrous outcome.* (M7, non-cancer)
	4.2 Negative value of hope	*I see hope so often now as something that is manipulated to keep certain things rolling along, to stop certain questions, to send people off on certain directions while other things can happen, usually not good things.* (F19, cancer)

I wasn't full of hope of a miracle or a cure or… I know medical science, well for me, it's not perfect… I saw it… [child]'s not going to make it through this. (F19, cancer)

Child's experience in life

Several parents shared their hopes of maximizing their child's experiences throughout their lives.

…we wanted to let him experience whatever he could in whatever time he had because we had no idea if he was going to live for a month, ten years, we just didn't know. (F9, non-cancer)

Some parents shared hopes for their child's quality of life.

…it was always about quality of life for us, not more time. If he was hanging on in a vegetative state just for our benefit, that was no good… (F16, cancer)

The desire to tailor interventions to quality of life and comfort was expressed.

…we spent so much of our time fighting for less interventions, less appointments, but then trying to get hip surgery done, we had to fight really hard… everyone kept saying oh no, but she's never going to walk… her legs were so stuck together, you couldn't open them to clean her nappy… (ID13, non-cancer)

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Day-to-day normality

Some parents expressed hope for normality in the face of illness.

> *I wanted to have a, for lack of a better word, normal pregnancy, not one filled with fear and worry…* (M7, non-cancer)

One parent expanded on this by describing how such hope for normality was disrupted by frequent clinical visits.

> *And for instance, we knew [child] was dying, but we wanted to have a normal life as much as possible, right till the very end. Having medical staff coming regularly every day and different people coming stopped us from living that normal life.* (M14, cancer)

Memory-making

Making memories in the face of diminishing time was a conscious focus for some parents.

> *I just could see where we were going… and we'd started to talk about making memories and making them fast and doing the things that we wanted to do 'cause we didn't have time up our sleeve. (M6, non-cancer)*

Child's experience at end-of-life

In addition to hopes for their child's experience during life, some parents shared hopes for their child's experience at the end of life.

> *I guess our hope was that it would be quick and that it would be relatively painless.* (M13, non-cancer)

Patterns of hope

Dynamic nature of hope

Parents described how their hopes evolved over time across various clinical stages.

> *I didn't have much hope at the start when he didn't open his eyes for a month and then when he did… a little bit of hope just increased as time goes on."* (M8, non-cancer)

Vitally, parents explained that finding new objects of hope in the face of changing clinical information takes time, *"…people need time to process and find hope maybe in a different way…"* (M3, non-cancer)

Alignment between parents

Some parents described sharing similar priorities and hopes as they navigated treatment decisions.

> *We also were not going to be parents who would say, he must come home at any cost, because it's not like that…* (F4, non-cancer)

Conversely, differing hopes for parents of the same child were also observed.

> *So one of us became very invested in hope, and one of us didn't. I didn't have, and that's partly how I am, but I didn't, I wasn't full of hope of a miracle or a cure.* (F19, cancer)

Hope and prognostic awareness

Some parents described simultaneously experiencing hope and being aware of the potential for a bad outcome. One parent described a connection between hope and denial, but pointed out that they are not the same.

> *I think there's a distinct difference between hope and denial, I think hope is what keeps you going and they are maybe, brothers and sisters, siblings, but they're not the same.* (F4, non-cancer)

Another parent illustrated this further by drawing a distinction between uncertainty and denial, "*I think we've never been in denial. We might occasionally have been not completely certain about where we were.*" (F4, non-cancer)

Parents who demonstrated an awareness of their child's impending death, for example, by having conversations about death or having palliative and end-of-life care supports in place, still had moments of hoping for survival or more time.

> *I remember sitting there thinking before he died, I wonder if he'll make it to his 10th birthday, that would be really cool…* (M5, cancer)

While some parents described hope and reality-based thinking as existing simultaneously, others described them as alternating states, highlighting that holding hope did not mean denying reality.

> *I think we did… swing from one to the other… but I think a lot of the time throughout the journey we did have an underlying approach of being hopeful… but in saying that it wasn't being naïve..*" (M12, cancer)

Another father described having hope for a cure throughout his daughter's illness, only relinquishing this when death was imminent.

> *I still thought there was hope… and that's when I gave in… knowing that it was going to take our daughter.* (F18, cancer)

Factors that influence hope

Intrinsic nature of hope

Some parents described hope as arising from within, independent of interactions with clinicians.

> *I don't think you have to give it [hope] to them because I think it's an intrinsic, almost a survival thing.* (M3, non-cancer)

A few parents said that, on some level, all parents hope their child will survive, but not necessarily at all costs.

> *…as a parent, you always have that little hope somewhere hidden, saying I hope for a miracle… it's difficult because you hope for a chance, but not the way she was.*" (M1, cancer)

Clinical information

Parents' expressions of hope were influenced by their child's clinical picture. Some parents sought or found hope for survival by observing the positive elements of their child's clinical condition.

> *It was just his lungs, right?.. They can grow out of it… everything worked, other than the lungs.* (M3, non-cancer)

Other parents found hope in statistics, even if the odds were against them.

> *We used to say that someone had to be in that 30%, that 30% survival.* (M5, cancer)

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Uncertainty about the clinical trajectory left room for parents to hold hope that their child would respond to disease-targeted treatment.

> *But because it was untested and no one, no child had been, undertaken this treatment… we went… we have to give him the best chance of success.* (F9, non-cancer)

Clinician communication

Interactions with clinicians influenced and tapped into parental hope. For example, one parent's desire to be a parent to her unborn and unwell child was highlighted by the hope she found when clinicians used her unborn baby's name and validated her love and role as a mother.

> *…she [palliative care nurse] said, 'it's so beautiful, I can see the love you have for your child…' and that just hit me… it just made him real to me.* (M7, non-cancer)

Another mother described how clinician language about individual differences and uncertainty can provide hope, "*…and I guess the doctors give you hope as well because they say that every person's cancer is different.*" (M17, cancer)

Value of hope

Positive value of hope

Parents shared how hope allowed day-to-day survival in the face of their child's condition. A parent (who described that for her hope did not equate to denial) emphasized the importance of hope by suggesting that forcing a family to face reality, even if they are in denial, can make getting through each day even more challenging.

> *And even if that family is in denial, what is wrong with supporting that, because at the end, that child is still going to die. So then why knock them down even further if that's what they want or need to be able to get through every day without falling to shit and rocking in the corner, which is what you want to do.* (M14, cancer)

Parents conveyed the value of hope by sharing the negative impact of its absence.

> *…I almost wish he had cancer because at least then we would have had some hope, because there is a chance for a cure where his diagnosis, there really at this stage with the current technology, there was only one end point, and that was him passing before his time.*" (M6, non-cancer)

Negative value of hope

Some parents shared concerns about potential negative outcomes from both hope itself and from clinicians' attempts to maintain hope.

One parent described how hope can distract from important conversations or difficult treatment decisions in the face of death. This parent expressed how hope can be potentially harmful by allowing burdensome procedures that are unlikely to provide clinical benefit and preventing honest conversations about death.

> *…hope… I'm a bit suspicious of it to be honest… it's like there's a bear about to eat you in the room, and you're saying, I'm pretty hopeful this will go okay.*" (F19, cancer)

Additionally, clinicians' expressions of hope were not always viewed positively. Parents shared how clinicians sharing low-probability anecdotes to offer hope could make it harder to understand their child's prognosis.

> *… he (oncologist) kind of spoke in terms of, 'we're going to do things to minimise the long-term impact', like the prognosis was different…* (M15, cancer)

> *…I can definitely see how it could be confusing to, I guess more hopeful, or parents that allow themselves to look for miracles…* (F16, cancer)

Discussion

The results of this study build on existing literature and provide new insights into how parents experience hope when their child is facing a life-limiting condition and how clinicians can influence and work with parents' expressions of hope. Particularly striking were the findings that: (1) clinicians can affect parents' hopes in ways that may be beneficial or detrimental, and (2) although most parents consider hope to be positive and helpful, some perceive it as negative or potentially even harmful.

As described in previous studies, our findings support the idea that hope and prognostic awareness can coexist (Kamihara et al. 2015; Kaye et al. 2020). Some parents described holding both hope and prognostic awareness simultaneously, while others reported oscillating between the 2. Importantly, for many parents, hope did not equate to denial. One parent highlighted a distinction between clinical uncertainty and denial. This is important because, in the face of clinical uncertainty, clinicians may focus on potential threats and losses and seek to ensure that parents understand the risk that things may not go well. In contrast, parents may focus on the hope and possibility that things will go in the desired direction, even if the probability of this occurring is low (Ruddick 1999; Reder and Serwint 2009). Clinicians may therefore witness parents' hopes fluctuating with changes in their child's condition, including improvement, deterioration, and uncertainty.

This study, in keeping with the existing literature, showed the "breadths of hopes" experienced by parents of children with serious illness (Feudtner 2009; Kamihara et al. 2015; Hill et al. 2018). It is notable that some of the hopes identified in our study, such as hope for survival or for a response to treatment, may not be within a parent's control, whereas others may be, such as hope for their child's experiences in life and at the end of life, day-to-day normality, and memory-making. Parents described packing lunchboxes even when their child had limited oral intake, wanting to experience pregnancy rituals even when the likely outcome was limited survival after birth, and making memories in the face of a limited life expectancy. Importantly, parents explained that these were not features of denial, but rather expressions of hope.

The various types of hope observed in this study offer insights into how clinicians can interact with parental hopes. A parent in our study reflected that it would have been helpful for clinicians to have guided them towards achievable hopes. This reflects Snyder's conceptualization of hope as "the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways" (Snyder 2002; Snyder et al. 2018). This supports the value of clinicians guiding parents to actively engage in hopes for goals they can influence.

The hope for normality, free from constant reminders of their child's illness and inevitable death, suggests that for some families, grouping or minimizing clinical encounters where possible may be

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helpful. This needs to be carefully balanced against the risk of families feeling abandoned. Importantly, in this study, seeking a break from clinical encounters and conversations did not necessarily mean parents were unaware of or unable to engage with the seriousness of their child's condition. Rather, the extent to which they could engage in any given moment might have varied. For example, a parent hoping for day-to-day normality might decline a palliative care visit, which may lead clinicians to mistakenly assume that they are not engaging with the idea of death. Clinicians may then impose more conversations about prognosis and death when these are not needed or helpful, risking fractured therapeutic relationships and negative outcomes for the child and parents. Knowing this, clinicians should ask themselves whether focusing any given conversation on a child's prognosis is for their own benefit or truly for the parent's or child's benefit (Katz et al. 2021).

To our knowledge, while studies have described clinicians' concerns about parental hope (Reder and Serwint 2009), ours is the first to describe parents' own concerns. Some parents worried about the potential for well-meaning clinicians to inadvertently manipulate or bolster hope, for example, by sharing accounts of rare positive outcomes. Concern was also expressed that hope, even if intrinsically generated, may enable treatments that were unlikely to be effective and distract from important tasks, such as conversations about death and dying. This is important because it highlights that not all parents want clinicians to focus conversations only on hope for survival, as they may risk missing opportunities to prepare for death. Additionally, parents highlighted how inconsistent messaging from different clinicians about prognosis, including information about low likelihood but positive outcomes, can be confusing for parents.

The distinction in our findings between intrinsic hope and clinician-influenced hope highlights the importance of clinicians recognizing their role in shaping and supporting parents' hopes, while not overestimating their influence on fundamental parental hopes. At the same time, clinicians should consider the many other factors that influence hope, such as a child's response to treatment, spirituality, social support, and emotional coping (Barrera et al. 2013). Exploring these domains may offer additional avenues for support and improve parents' experiences as they navigate some of the most difficult moments in their lives. In doing so, clinicians might work with parents' hopes to support treatment decision-making, potentially influencing outcomes for the child during their life, and the parents in bereavement.

Finally, while most parents of the same child shared similar hopes, priorities, and concerns, this was not always the case. The potential for parents of the same child to have different hopes over the course of their child's illness has been previously described (Hill et al. 2017; Milville et al. 2024). While this discordance adds complexity for clinicians, making time and space to explore each parent's hopes and fears is important to ensure both parents' voices are heard. This can also facilitate parents' understanding of each other's perspectives, even if they do not share the same decision-making approaches.

Strengths and limitations

A strength of the study was the inclusion of parents of children with both cancer and non-cancer conditions. While bereaved parents may have different perceptions from when their child was alive, their voices offer long-term insights, including whether hope was protective, helpful, or potentially misleading and harmful. Limitations include recruiting from a single statewide pediatric palliative care service, requiring parents to speak conversational English, and the potential for additional reflections from parents who declined to participate.

Conclusion

This study explored the complexity of hope through bereaved parents' experiences. Some of the results reported in this paper confirm features of hope recognized in previous research: that hope is multidimensional, changes over time and can coexist with prognostic awareness. Beyond this, however, other results of this study offer new insights into how hope can be both generated intrinsically and shaped by clinical events and interactions with clinicians. Importantly, in the face of serious and life-limiting illness, not all parents find it helpful when clinicians focus on hope for survival, and some may even perceive hope for survival as misleading or harmful. Our findings highlight the individual and distinctive nature of hope, including among parents of the same child. This underscores the need for clinicians to avoid assumptions and approach each clinical encounter anew to best consider how to work with parental hope in every interaction.

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