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Title:
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Date:
2021-09-01

Citation:
Katz, N. T., Hynson, J. L. & Gillam, L. (2021). Dissonance in views between parents and clinicians of children with serious illness: How can we bridge the gap?. Journal of Paediatrics and Child Health, 57 (9), pp.1370-1375. https://doi.org/10.1111/jpc.15612.

Persistent Link:
https://hdl.handle.net/11343/298650

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Dissonance in views between parents and clinicians of children with serious illness: How can we bridge the gap?

Viewpoint

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Acknowledgements

Naomi T Katz is a PhD Candidate, in receipt of Research Training Program and Murdoch Children's Research Institute PhD Top Up scholarships. The authors wish to thank Dr Michelle Gold and Dr Bronwyn Sacks for their manuscript review and feedback. Finally, and most importantly, we wish to acknowledge the parents and young people we look after. You motivate us to conduct research, so that we can care for you in the best way possible.

Conflicts of interest

None to declare.

Abstract

Parents of children with serious illness must find a tolerable way of living each day, while caring for their child and making decisions about their treatments. Sometimes clinicians worry that parents don't understand the seriousness of their child's illness, including possible death. This can lead to tension, disagreement, and even conflict. Such situations continue to occur despite expanding literature to help clinicians understand drivers of parental behaviour and decision-making. Some of this literature relates to the role of hope and how parents characterise being a 'good parent'. This article will summarise some of the applications and limitations of the hope and 'good parent' literature, as well as frameworks to understand grief and loss. We propose however, that there is at least one missing link in understanding potential dissonance in views between parents and clinicians. We will make a case for the importance of a richer understanding about if, and how, parents ‘visit’ the ‘reality’ that clinicians wish to convey about their child’s diagnosis and prognosis. We propose that clinician understanding about the benefits and burdens of ‘visiting’ this ‘reality’ for an individual family may help guide conversations and rapport, which in turn may influence decision-making with benefits for the child, family and clinicians.

Key words

Palliative care, child, serious illness, reality, conflict

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Through unimaginable grief, parents of children with serious illness must find a tolerable way of living. Although the circumstances (e.g., congenital versus acquired) and nature (e.g., malignant versus non-malignant) of the illness may vary, parents find themselves 'members of a club' they never wished to join. The stakes are high; how parents process their situation has significant implications for their child, and entire family. Crucially, it influences decisions about what clinical interventions the sick child will undergo, and aspects of family life such as schooling, finances and employment. Clinicians are tasked, often in a brief window of time, with understanding how individual parents get through each day, and how they think about their child's illness in the context of their broader values, culture and psychosocial background. The relationship between clinicians and families is paramount and is at risk of being fractured when parents and/or clinicians feel misunderstood or unheard.

The purpose of this article is to review some of the applications and limitations of existing literature that may be helpful when there is a dissonance in understanding, wishes, or plans between parents and clinicians of children with serious illness. We will outline practice implications, and conclude with a call for the importance of further empirical work to understand how parents 'visit' the 'reality' that clinicians wish to convey about their child's illness. Suggested communication strategies will be outlined throughout the article, and are summarised in Table 1.

The importance of 'bridging the gap' between parents and clinicians

The 2017 Charlie Gard case illustrates what conflict can look like at the extreme with media and community involvement, legal proceedings and opinions expressed by world leaders such as the Pope and the President of the United States.(1) While this represents very severe and entrenched conflict, the potential for lesser forms of tension or disagreement between clinicians and parents exists at any point in the course of an illness.(2) Contributing factors may include communication breakdown, conflicting information from different clinicians, disagreements over treatment, and unrealistic parental expectations.(2, 3) Medical advancements and ready access to online information about unproven treatments can add fuel to fire.(4)

We suspect that we are not alone in seeing families who are trying to take a 'positive' approach to their child's illness feel disappointed or angry because clinicians:

1. Repeatedly engage in efforts to convince them of the 'reality' of their child's situation;
2. Do not join in their pursuit of any or every possible investigation or intervention; or,
3. Do not seem to join in their unwavering hope for a cure or miracle.

These phenomena, which we will refer to in this article as a dissonance in understanding, wishes or plans between clinicians and parents, or simply as dissonance, may occur together, or in isolation. In our experience, dissonance may result in families feeling uncared for, clinicians feeling helpless or frustrated, and children being exposed to conflict or burdensome interventions. In response, there is expanding literature to try to understand the worlds of parents of children with serious illness like cystic fibrosis, cancer, and neurodegenerative diseases.(5-12) This includes conceptual and empirical work around hope(13-24) and the concept of what it means to be a ‘good parent’.(16, 25-31)

US ethicist, Abram Brummet differentiates between metaphysical and moral claims as they relate to clinical processing and decision-making.(32) Metaphysical claims focus on how individuals see the world, and cover phenomena such as religion, identity, causation and free will, while moral claims focus on the ‘right’ or ‘good’ path forward.(32) We see examples where parents’ views are seen as metaphysical and even emotionally driven, while clinicians’ views are seen as grounded in evidence and correct. However, this is flawed thinking as clinicians are not immune to cognitive biases or ‘rules of thumb’ that may be subconsciously adopted and result in medical or processing error.(33) In this article, we will focus on situations where there is dissonance in views between clinicians and parents of children with serious illness as this can be a source of distress. We acknowledge that neither clinicians nor parents universally hold ‘the truth’, and we will therefore use inverted commas when referring to ‘reality’.

Why might parents not see things as the clinician does? What factors might contribute to an apparent dissonance or disconnect? While many factors contribute to parental behaviour, in this article we will focus on the role of hope, the importance of being a ‘good parent’ and models of grief and adjustment to illness. We will use existing literature and anecdotal experience to highlight how these concepts may help clinicians avoid assumptions about how parents make decisions, which can help bridge gaps, build trust and enhance the parent-clinician relationship. This has potential benefits for the child, family and clinicians but unfortunately, in our experience, is not always enough to resolve disagreement or conflict when parents feel misunderstood or unsupported in their processing and decision-making.

We believe there is at least one missing piece to this puzzle and suggest that it relates to the extent to which parents can ‘visit’ what clinicians wish to convey about their child’s serious illness, for example, a life of daily blood glucose monitoring, a life of never walking or talking, or a life that will end prematurely. If, and how, parents ‘visit’ this ‘reality’ is important because it affects decision-making, with significant implications for:

1. The child and the experiences to which they are exposed;
2. The parents, while the child is living, and in bereavement if that is the outcome; and,
3. The clinicians caring for the child and family.

Parental hope in the face of a child’s serious illness

Hope in the setting of living and coping with serious illness features prominently in the literature.(11, 13, 14, 16, 19, 21, 30, 34-44) Hope can be used in different contexts, and mean different things to different people. We have seen parents hope for a possible but exceedingly unlikely outcome, such as cure in the setting of an incurable illness. We have also seen parents hope for an outcome that has some small possibility of occurring, but is highly unlikely to occur such as response to chemotherapy for a relapsed solid organ cancer.

Hope may carry less "inaccuracy of belief about the desired outcome" than denial or unrealistic optimism, which is considered important because inaccurate beliefs have potential to compromise informed decision making.(45) However, it can be difficult to distinguish between hope, denial and unrealistic optimism, and furthermore, unrealistic beliefs may not always be harmful.(45)

We now know that hope is dynamic, helpful, associated with improved quality of life and a means to allow individuals to live in the present.(46, 47) Individuals can hope simultaneously for more than one thing … "from the miraculous to the mundane".(13) Prognostic awareness refers to awareness or understanding of the incurable nature of a disease or limited life expectancy,(48, 49) and this can co-exist with hope for a cure.(22, 50-52) For the purpose of this article, prognostic awareness refers to parents being able to see the possible or likely 'reality' of their child's illness in the same way that their treating clinician does. This 'duality' is possible for some parents who may hope until the end for their child to beat the odds and survive, and at the same time, hope for a comfortable and dignified death.(13, 17, 22)

We read with interest recent work by Kaye et al. about bereaved parents' reflections on their experiences of hope and realistic thinking across their child's cancer illness.(53) They challenge the idea that parents swing like a pendulum between hoping for the best and preparing for the worst.(53) Kaye et al. argue that the pendulum model risks clinicians not appreciating that hope and prognostic awareness can co-exist; that is that parents may hope for a cure, and at the same time be able to 'visit' the 'reality' of the child's prognosis. By understanding this, clinicians may avoid feeling compelled to repeatedly attempt to convince already-aware parents of the 'reality' of their child's illness. This is particularly relevant as clinician misunderstanding or assumptions about how parents navigate hope and realism can contribute to conflict between families and clinicians. We have seen examples of this in our practice where, albeit with the best of intentions, clinicians (mis)diagnose hope for cure as a pervasive inability to acknowledge a serious illness or possibility of death. As a result, repeated conversations about the 'reality' of the situation may then be imposed on an already understanding family.(53) This may also cause harm to clinicians who can worry that they are failing in their responsibility to ensure families 'get it' and feel bad for the distress they may cause by repeatedly trying to achieve this. Clinicians and parents can both feel frustration and suffering, but for different reasons. Improved understanding of parental hope and 'realism' could avoid unnecessary and unproductive tension or conflict.

Exploring the breadth of parental hopes can be very helpful.(13, 17) Asking (potentially a few times), 'what else do you hope for?' may help families articulate and reflect upon co-existing hopes that traverse various potential future realities. Clinicians can also help parents to re-frame or broaden hopes by asking: 'in the face of everything your child is up against, what are you hoping for now?' This may help families to 'get off the train' of hoping for cure or seeking experimental therapies. However, this approach has some limitations. It will not work for all families. Not all parents are able to re-frame or hold multiple hopes, and some may struggle to 'get off the train' despite sensitive conversations. This approach also leaves unanswered the practical question of how to tell whether parents who express hope for cure also have accurate prognostic awareness, and what to do if they don't. These conversations may be complicated by the existence of experimental therapies. Even raising the possibility of an unproven therapy may imply to parents that they should pursue it, so the discussion must be carefully handled. Balanced and transparent communication about the goals and intent of any therapy is vital.(54)

A more fundamental question about hope concerns the implicit idea that allowing one's mind to go to the undesired outcome (i.e., 'visiting reality'), and hope for the desired outcome, are in opposition to each other. A quote from a parent in Kaye et al.'s study speaks to this: "hope is the antithesis of despair, not reality".(53) Seneca, the Roman Stoic philosopher, wrote: "fear follows hope… each alike belongs to a mind that is in suspense, a mind that is fretted by looking forward to the future." This ties in with Feudtner's suggestion that "to be a master of hope, one has to become well acquainted with the fear of darkness that hope helps us surmount, to become comfortable and capable of confronting this darkness directly".(14) Exploring fears may actually be equally or more important than exploring hopes. And so, the hope literature may be helpful but also has its limitations.

Being a 'good parent' to a child with a serious illness

Studies show that parents of seriously ill children are often thinking about how to be a 'good parent'.(25-27, 29, 55) How parents characterise a 'good parent' varies, and may shift over time; for example, from "making informed decisions" to "ensuring my child feels loved".(26, 29). Parents are comforted and receive strength from striving to achieve their personal definition of what it is to be a 'good parent', and bereavement outcomes are affected by the extent to which parents feel this was achieved.(29) Parents must live with their decisions for the rest of their lives. In bereavement, regret (for example, about treatment decisions) and unfinished business (for example, about not having conversations with their child about death) can be associated with distress related to caregiving while the child was alive, and prolonged grief symptoms.(56) Clinicians can support parents to feel like they are being good parents, for example, by helping them feel that "all that can be done is being done", supporting them to seek additional opinions and allowing them to feel respected and supported in advocating for their child.(29)

Insights from the 'good parent' literature can be applied in a number of ways. One is to use language and themes to explore, support and affirm parents in their quest to navigate heart-wrenching decisions for their child. Naming the predicament can normalise the impossible decisions families face. A clinician may say: 'Many parents tell me they feel caught on the horns of a dilemma: how do I leave no stone unturned in the search for a cure and also protect my child from treatments that might be harmful? Do you ever have thoughts like this?'. Responses such as 'I can't just sit back and wait for the cancer to get us', can provide openings to important and rich conversations. For example, a response such as 'I imagine that so much of your child's experience must feel out of your control' may open an 'emotional' space with an opportunity for expression of grief and helplessness. For parents to feel safe and supported, it is important that clinicians are equipped to respond to such emotions. Alternatively, clinicians may involve disciplines such as social work or palliative care to support a space for grief and loss.

Another application of the ‘good parent’ literature, is to provide validation and affirmation, for example, ‘I can see how [child’s name] is at the centre of every decision you make’. This may help foster the parent-clinician relationship as a parent feels that they are viewed by their child’s clinician to be a ‘good parent’. Again, however, in our experience, these approaches will not be effective for all families and are not always enough to shift parents away from potentially harmful decisions such as burdensome and physiologically futile treatments. While the ‘good parent’ literature can help clinicians better understand the lived experience of parents, it too has its limitations.

A potential gap: understanding how a parent ‘visits’ the ‘reality’ of their child’s illness

The hope and ‘good parent’ literature offer helpful frameworks to assist clinicians in bridging gaps with parents of children with serious illness, but is not always sufficient. In our experience, a missing piece of the puzzle may be the extent to which parents contemplate what clinicians perceive to be the ‘reality’ of their child’s illness, including the potential or likely death of their child. Some parents seem to spend a lot of time thinking about these concepts, some can only ‘visit’ them from time to time, and others cannot think about them at all. Clinicians’ motivation for parents to ‘visit’ such ‘reality’ stems from the desire to emotionally and intellectually prepare them for the future, and facilitate informed decision-making. However, this may be at odds with some families’ avoidance of ‘reality’ as a protective measure. Clinicians may find themselves talking at cross purposes with parents who are not able to contemplate ‘reality’ in that moment but on another day, the conversation may be very different. A challenge in these situations is to consider and assess whether parents have co-existing hope for a cure **and** prognostic awareness as suggested by Kaye et al, even if prognostic awareness is not apparent at the time.

As clinicians, we may impose our view of how much time parents should spend ‘visiting reality’, without appreciating the contextual needs of each unique family. How do clinicians establish the processing style and needs of a family? Is it always appropriate for clinicians to impose ‘reality’ on parents? There may be situations where the benefits for a family of not ‘visiting reality’ outweigh the burdens.

Frameworks for understanding adjustment to a potential or actual unwanted 'reality'

Looking to the adult literature, the *Dual Framework to Focus on Living Well and Tolerate the Possibility of Dying* and *Dual Process Model of Coping with Bereavement* may be helpful.(57, 58)

We have discussed literature that describes how hope and prognostic awareness can co-exist. This notion of two things being held simultaneously is articulated in a different way by Jacobsen et al. as an existential developmental process of integrating two seemingly contradictory ideas of "living well" with "the possibility of dying".(57) Jacobsen et al. describe that for many people with advanced illness, contemplation about the future, let alone the possibility of dying, is overwhelming. They suggest therefore, that some individuals instead focus exclusively on hope and cure, and others maintain "an emotional equilibrium… by swinging, like a pendulum, between moments of realism… and moments of optimistic hope…".(57) In order to help individuals achieve this 'dual framework', clinicians should start by holding hope with the patient, while acknowledging the seriousness of their disease, and then expand conversations to living well. Jacobsen et al. explain their experience that the ability to focus on living well enhances patients' ability to tolerate the possibility of dying, which allows rich and important conversations about the future, including planning for possible deterioration and death. While this framework may be helpful in some situations, in our experience, some individuals may never be able to think beyond cure and living, while those who can, may not always be able to stay in this space. And so, hoping to live well while **simultaneously** tolerating the possibility of dying, which is the goal of the *Dual Framework*, may not work for everyone and therefore has limitations.

In 1999, Stroebe and Schut revolutionised understanding of grief and bereavement, with the *Dual Process Model of Coping with Bereavement.* They capture the dynamic nature of processing and suggest that adaptive grieving occurs in 'doses', through oscillation between loss and restoration-oriented coping.(58) This oscillation may actually be very important for adjustment and function, providing there are not unhealthy or unhelpful behaviours such as extreme or persistent denial. Loss-focused coping can be viewed as 'grief-work', while restoration-focused coping can be seen as 'life-work' that provides a break from grieving or a way to participate in activities that allow 'getting on with it'. While clinicians must be ready to respond to or discuss challenging topics such as clinical deterioration, an important communication strategy may be to ensure some consultations focus on positive aspects of a child's progress or experience. This may allow families to feel that clinicians are not simply focused on potentially painful or difficult outcomes, and that there is a space to focus on 'living'.

While grief, fear and sadness related to a child's illness is embedded in a family's existence, parents must still get up each morning and attend to the practicalities of life, such as taking the rubbish out, buying groceries, working, and taking other children to school. We suggest that if in bereavement individuals need to grieve in doses, perhaps this is the same when the sick person is still alive. And so, attempts by clinicians to impose 'reality' on parents may not actually achieve the desired outcome, or may even be harmful.

If this is the case, clinicians have the task of assessing whether an expression of hope for cure represents healthy and temporary grief-avoidance, or a more pervasive inability to contemplate the possibility of death. This area needs to be further explored.

Where to from here?

We suggest that there is a need to better understand how, or if, parents can manage and want to 'visit' the potential 'reality' of their child's serious illness or prognosis, and how this may influence coping and decision-making. This is likely not a linear or binary process and parents are likely to 'visit reality' to varying degrees, for variable amounts of time, and perhaps not on-demand. These patterns may change over the course of a child's illness, and both parents of the same child are likely to have individual needs and patterns. We suggest that attempts to force a parent to 'visit reality' may be harmful. In addition, there are dangers in making an assessment about whether parents ever 'visit reality' based on what is ascertained from a single consultation. We propose that the next step is to explore parental perspectives about this concept. A richer understanding of how parents 'visit reality' may facilitate sensitive and productive conversations between clinicians and parents, and enhance outcomes and well-being for the child, parents and clinicians.

We propose a series of questions that may help clinicians when faced with dissonance in views between parents and clinicians, and suggest it may be helpful to solicit parental reflections on these concepts. Our intention in articulating these questions is to provide a framework for clinicians to evaluate the value, benefits, and burdens of progressing conversations about 'reality'. This is a starting point, as more research needs to be done in this area, and these questions may need refining.

Textbox:

1. Does this family ever 'visit reality' with me?
2. If not, do they 'visit reality' with other members of their child's care team (e.g., occupational therapist or social worker)?
3. If this family spends little or no time 'visiting reality', what are the benefits for them, and their child (e.g., able to live in the day to day from a practical and emotional perspective)?
4. If this family spends little or no time 'visiting reality', what are the actual or potential burdens of avoiding 'reality':
    a. For the child (e.g., exposure to burdensome interventions)?
    b. For the parents (e.g., lack of preparation for the future, regret in bereavement)?
5. Is my desire to have a conversation about 'reality' for my benefit (e.g., so that I do not feel like I am colluding with an avoidance of 'reality') or the family's benefit?

Conclusion

Conceptual frameworks about hope and ‘good parent’ beliefs can help clinicians think and speak with families when their child is seriously ill, providing ways to avoid misunderstanding, disagreement or conflict. An example of this is when parents appear to not comprehend that their child is going to die. However, these frameworks do not explain and provide a way forward in all circumstances. A much richer understanding of parental perspectives about if and how they ‘visit’ what clinicians believe to be the ‘reality’ of their child’s serious illness is needed, including the benefits and burdens of ‘visiting’ or avoiding this ‘reality’ for a family. This in turn will further guide clinicians in their conversations with parents, influencing decision-making and the child’s experience. There is a need to better understand these ideas, primarily by obtaining parents’ views in future studies.

References

1. Boseley S. Children's healthcare: new advice aims to avoid breakdown of parents' trust
Guidelines for doctors hope to prevent the sort of conflict that took place in cases such as Charlie Gard and Ashya King. The Guardian. 2019 April 18, 2019.
2. Linney M, Hain RDW, Wilkinson D, Fortune P-M, Barclay S, Larcher V, et al. Achieving consensus advice for paediatricians and other health professionals: on prevention, recognition and management of conflict in paediatric practice. Archives of Disease in Childhood. 2019;104(5):413-6.
3. Forbat L, Teuten B, Barclay S. Conflict escalation in paediatric services: findings from a qualitative study. Archives of Disease in Childhood. 2015;100(8):769-73.
4. Larcher V, Turnham H, Brierley J. Medical Innovation in a Children's Hospital: ‘Diseases desperate grown by desperate appliance are relieved, or not at all’. Bioethics. 2018;32(1):36-42.
5. Carpenter DR, Narsavage GL. One breath at a time: living with cystic fibrosis. Journal of pediatric nursing. 2004;19(1):25-32.
6. Clarke JN. Mother’s home healthcare: emotion work when a child has cancer. Cancer Nursing. 2006;29(1):58-65.
7. Collins A, Hennessy-Anderson N, Hosking S, Hynson J, Remedios C, Thomas K. Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study. Palliative Medicine. 2016;30(10):950-9.
8. Muscara F, Burke K, McCarthy MC, Anderson VA, Hearps SJ, Hearps SJ, et al. Parent distress reactions following a serious illness or injury in their child: a protocol paper for the take a Breath Cohort Study. BMC psychiatry. 2015;15(1):153.
9. Rallison LB, Raffin-Bouchal S. Living in the in-between: families caring for a child with a progressive neurodegenerative illness. Qualitative Health Research. 2013;23(2):194–206.
10. Samson A, Tomiak E, Dimillo J, Lavigne R, Miles S, Choquette M, et al. The lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness. Chronic Illness. 2009;5(2):103-14.
11. Wong MG, Heriot SA. Parents of children with cystic fibrosis: how they hope, cope and despair. Child: Care, Health & Development. 2008;34(3):344-54.
12. Young B, Dixon-Woods M, Findlay M, Heney D. Parenting in a crisis: conceptualizing mothers of children with cancer. Social Science and Medicine. 2002;55(10):1835-47.
13. Feudtner C. The Breadth of Hopes. New England Journal of Medicine. 2009;361(24):2306-7.
14. Feudtner C. Responses from Palliative Care: Hope Is Like Water. Perspectives in biology and medicine. 2014;57(4):555-7.
15. Feudtner C, Santucci G, Feinstein JA, Snyder CR, Rourke MT, Kang TI. Hopeful thinking and level of comfort regarding providing pediatric palliative care: a survey of hospital nurses. Pediatrics. 2007;119(1):e186-92.
16. Hill DL, Feudtner C. Hope, hopefulness, and pediatric palliative care. Perinatal and pediatric bereavement in nursing and other health professions. New York, NY: Springer Publishing Co; US; 2016. p. 223-47.
17. Rosenberg AR, Feudtner C. What else are you hoping for? Fostering hope in paediatric serious illness. Acta Paediatrica. 2016;105:1004-5.
18. Alidina K, Tettero I. Exploring the therapeutic value of hope in palliative nursing. Palliative & supportive care. 2010;8(3):353-8.

19. Bally JM, Duggleby W, Holtslander L, Mpofu C, Spurr S, Thomas R, et al. Keeping hope possible: a grounded theory study of the hope experience of parental caregivers who have children in treatment for cancer. Cancer Nurs. 2014;37(5):363-72.
20. Baru J. Hope. Journal of hospital medicine. 2010;5(4):255-6.
21. Isaacs D. Hope and despair. Journal of Paediatrics & Child Health. 2016;52(10):917-8.
22. Kamihara J, Nyborn JA, Olcese ME, Nickerson T, Mack JW. Parental hope for children with advanced cancer. Pediatrics. 2015;135(5):868-74.
23. Nafratilova M, Allenidekania A, Wanda D. Still Hoping for a Miracle: Parents' Experiences in Caring for their Child with Cancer Under Palliative Care. Indian J Palliat Care. 2018;24(2):127-30.
24. Wong NW. The Role of Hope, Compassion, and Uncertainty in Physicians' Reluctance to Initiate Palliative Care. AMA journal of ethics. 2018;20(8):E782-6.
25. Feudtner C, Walter JK, Faerber JA, Hill DL, Carroll KW, Mollen CJ, et al. Good-Parent Beliefs of Parents of Seriously Ill Children. JAMA Pediatrics. 2015;169(1):39-47.
26. Hill DL, Faerber JA, Li Y, Miller VA, Carroll KW, Morrison W, et al. Changes Over Time in Good-Parent Beliefs Among Parents of Children With Serious Illness: A Two-Year Cohort Study. Journal of Pain and Symptom Management. 2019;58(2):190-7.
27. Hinds PS, Oakes LL, Hicks J, Powell B, Kumar Srivastava D, Spunt SL, et al. “Trying to Be a Good Parent” As Defined by Interviews With Parents Who Made Phase I, Terminal Care, and Resuscitation Decisions for Their Children. Journal of Clinical Oncology. 2009;27(35):5979-85.
28. October TW, Fisher KR, Feudnter C, Hinds PS. The Parent Perspective: "Being a Good Parent" When Making Critical Decisions in the PICU. Pediatric Critical Care Medicine. 2014;15(4):291-8.
29. Weaver MS, October TW, Feudnter C, Hinds PS. “Good-Parent Beliefs”: Research, Concept, and Clinical Practice. Pediatrics. 2020;145(6):e20194018.
30. Mack J, Wolfe J, Cook E, Grier H, Cleary P, Weeks J. Hope and prognostic disclosure. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2007;25(35):5636-42.
31. Meert KL, Eggly S, Pollack M, Anand KJ, Zimmerman J, Carcillo J, et al. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. Pediatric Critical Care Medicine. 2008;9(1):2-7.
32. Brummett A. Whose harm? Which metaphysic? Theoretical Medicine and Bioethics. 2019;40(1):43-61.
33. O’Sullivan ED, Schofield S. Cognitive Bias in Clinical Medicine. Journal of the Royal College of Physicians of Edinburgh. 2018;48(3):225-31.
34. Arzuaga BH. Clinical challenges in parental expression of hope and miracles. Pediatrics. 2015;135(6):e1374-6.
35. Barrera M, Granek L, Shaheed J, Nicholas D, Beaune L, D’Agostino NM, et al. The tenacity and tenuousness of hope: parental experiences of hope when their child has a poor cancer prognosis. Cancer Nursing. 2013;36(5):408-16.
36. De Graves S, Aranda S. Living with hope and fear - the uncertainty of childhood cancer after relapse. Cancer Nursing. 2008;31(4):292-301.
37. Feudnter C, Carroll KW, Hexem KR, Silberman J, Kang T, Kazak AE. Parental Hopeful Patterns of Thinking, Emotions, and Pediatric Palliative Care Decision Making. Archives of Pediatrics and Adolescent Medicine. 2010;164(9):831-9.

38. Gengler AM. "He's doing fine": Hope work and emotional threat management among families of seriously ill children. Symbolic Interaction. 2015;38(4):611-30.
39. Janvier A, Farlow B, Barrington KJ. Parental hopes, interventions, and survival of neonates with trisomy 13 and trisomy 18. Am J Med Genet C Semin Med Genet. 2016;172(3):279-87.
40. Kamihara J, Nyborn J, Olcese M, Nickerson T, Mack J. Parental hope for children with advanced cancer. Pediatrics. 2015;135(5):868-74.
41. Lotz JD, Daxer M, Jox RJ, Borasio GD, Fuhrer M. "Hope for the best, prepare for the worst": A qualitative interview study on parents' needs and fears in pediatric advance care planning. Palliat Med. 2017;31(8):764-71.
42. Mednick L, Cogen F, Henderson C, Rohrbeck CA, Kitessa D, Streisand R. Hope more, worry less: hope as a potential resilience factor in mothers of very young children with type 1 diabetes. Children's Health Care. 2007;36(4):385-96.
43. Stafford CO. A Case Study of Trisomy 13: Balancing Hope and Reality. Advances in neonatal care : official journal of the National Association of Neonatal Nurses. 2015;15(4):285-9.
44. Venning AJ, Eliott J, Whitford H, Honnor J. The impact of a child's chronic illness on hopeful thinking in children and parents. Journal of Social and Clinical Psychology. 2007;26(6):708-27.
45. Blumenthal-Barby JS, Ubel PA. In Defense of "Denial": Difficulty Knowing When Beliefs Are Unrealistic and Whether Unrealistic Beliefs Are Bad. The American journal of bioethics : AJOB. 2018;18(9):4-15.
46. Post-White J, Ceronsky C, Kreitzer MJ, Nickelson K, Drew D, Watrud Mackey K, et al. Hope, spirituality, sense of coherence and quality of life in patients with cancer. Oncology Nursing Forum. 1996;23(10):1572-9.
47. Benzein EG, Berg AC. The level of and relation between hope, hopelessness and fatigue in patients and family members in palliative care. Palliat Med. 2005;19(3):234-40.
48. Gelfman LP, Sudore RL, Mather H, McKendrick K, Hutchinson MD, Lampert RJ, et al. Prognostic Awareness and Goals of Care Discussions Among Patients With Advanced Heart Failure. Circulation: Heart Failure. 2020;13(9):e006502.
49. Diamond EL, Prigerson HG, Correa DC, Reiner A, Panageas K, Kryza-Lacombe M, et al. Prognostic awareness, prognostic communication, and cognitive function in patients with malignant glioma. Neuro-Oncology. 2017;19(11):1532-41.
50. Reder EA, Serwint JR. Until the last breath: exploring the concept of hope for parents and health professionals during a child's serious illness. Archives of Pediatric and Adolescent Medicine. 2009;163(7):653-7.
51. Mack JW, Wolfe J, Grier HE, Cleary PD, Weeks JC. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2006;24(33):5265-70.
52. Nierop-van Baalen C, Grypdonck M, van Hecke A, Verhaeghe S. Hope dies last ... A qualitative study into the meaning of hope for people with cancer in the palliative phase. European journal of cancer care. 2016;25(4):570-9.
53. Kaye EC, Kiefer A, Blazin L, Spraker-Perlman H, Clark L, Baker JN. Bereaved Parents, Hope, and Realism. Pediatrics. 2020;145(5):e20192771.
54. Bond MC, Pritchard S. Understanding clinical trials in childhood cancer. Paediatrics & child health. 2006;11(3):148-50.

55. October TW, Fisher KR, Feudnter C, Hinds PS. The Parent Perspective: "Being a Good Parent" When Making Critical Decisions in the PICU Pediatr Crit Care Med. 2014;15(4):291-8.

56. Lichtenthal WG, Roberts KE, Catarozoli C, Schofield E, Holland JM, Fogarty JJ, et al. Regret and unfinished business in parents bereaved by cancer: A mixed methods study. Palliative Medicine. 2020;23(3):367-77.

57. Jacobsen J, Brenner K, Greer JA, Jacobo M, Rosenberg L, Nipp RD, et al. When a Patient Is Reluctant To Talk About It: A Dual Framework To Focus on Living Well and Tolerate the Possibility of Dying. J Palliat Med. 2018;21(3):322-7.

58. Stroebe M, Schut H. The dual process model of coping with bereavement: Rationale and Description. Death Studies. 1999;23(3):197-224.