

Journal Pre-proof

“Definitely Mixed Feelings:” The effect of COVID-19 on bereavement in parents of children who died from cancer

Gabrielle Helton, Joanne Wolfe, MD MPH, Jennifer M. Snaman, MD MS



PII: S0885-3924(20)30722-3

DOI: <https://doi.org/10.1016/j.jpainsymman.2020.08.035>

Reference: JPS 10624

To appear in: *Journal of Pain and Symptom Management*

Received Date: 26 August 2020

Revised Date: 27 August 2020

Accepted Date: 28 August 2020

Please cite this article as: Helton G, Wolfe J, Snaman JM, “Definitely Mixed Feelings:” The effect of COVID-19 on bereavement in parents of children who died from cancer, *Journal of Pain and Symptom Management* (2020), doi: <https://doi.org/10.1016/j.jpainsymman.2020.08.035>.

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

© 2020 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine

“Definitely Mixed Feelings:” The effect of COVID-19 on bereavement in parents of children who died from cancer

Gabrielle Helton,¹ Joanne Wolfe MD MPH,^{1,2} Jennifer M. Snaman MD MS^{1,2}

¹Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute,
Boston, Massachusetts

²Department of Pediatrics, Boston Children’s Hospital, Boston, Massachusetts

Corresponding Author:

Jennifer M. Snaman, MD, MS

Dana-Farber Cancer Institute

450 Brookline Ave

Boston, MA 02215

Phone: (617) 632-5548

Fax: (617) 582-7271

Email: Jennifer_Snaman@dfci.harvard.edu

Running Title: Parental Bereavement during COVID-19

Tables: 1

Figures: 1

References: 11

Word Count: 1496

Abstract

Context: COVID-19 has impacted most elements of daily life, including the provision of support following a child's death and the experience of parental bereavement.

Objectives: This study aims to examine ways in which COVID-19 has affected the bereavement experiences of parents whose children died from cancer prior to the pandemic.

Methods: Parents who participated in a survey-based study examining the early grief experience were invited to complete a semi-structured interview. During the interview, which focused on examining the current support for parents and other family members within the first several years following the child's death, participants were asked how COVID-19 has impacted their life and bereavement.

Results: Fifteen of thirty-three eligible parents completed the interview; 14 were White and non-Hispanic, 5 were male. Parents participated an average of 19 (range 12-34) months after their child's death. COVID-19 was addressed in 13 interviews. Eleven codes were used to describe interview segments; the most commonly used codes were 'change in support,' 'no effect,' 'familiarity with uncertainty/ability to cope' and 'change in contact with care/research team.'

Conclusion: Parents identified multiple and variable ways – both positive, negative and neutral – how COVID-19 has affected their bereavement. While many parents commented on feeling more isolated because of the inability to connect with family or attend in-person support groups, others acknowledged their experience has made them uniquely positioned to cope with the uncertainty of the current situation. Clinicians must find innovative ways to connect with and support bereaved parents during this unique time.

Key Message: This manuscript describes bereaved parents' perceptions of the mixed effects of COVID-19 on their bereavement. The variable parental responses to COVID-19 highlight the importance of continuing contact between the care team and family to assess coping and offer additional support as needed.

Key words: COVID-19; grief; bereavement; pediatric cancer; bereaved parents

Running title: Effects of COVID-19 on parental bereavement

Journal Pre-proof

"Honestly this epidemic is not even like a drop in the bucket of how hard things got for us...."

– Bereaved parent

Introduction

The global COVID-19 pandemic has affected most aspects of daily life, including the experience of death, grief and bereavement.¹ Forced changes in end-of-life care and rituals following death, physical distancing requirements, and changes to work and home life due to COVID-19 may affect individuals' bereavement. The current literature is focused on the adverse outcomes in adults bereaved due to the pandemic^{2,3} and ways to better support individuals who are grieving the death of loved ones killed by the virus.^{1,4} However, much less is known about the effect of the pandemic on the bereavement in individuals who experienced the death of a loved one prior to COVID-19.

Although parental grief decreases in intensity over time, the death of a child results in grief that is never-ending.^{5,6} Social support following the child's death may help parents to "work through" their grief.⁷ However, both formal mental health and informal social support has been dramatically altered by the pandemic. We sought to examine the unexplored effect of COVID-19 on the bereavement of parents of children who died from cancer prior to the pandemic. To our knowledge, this is the first study to explore the various ways in which COVID-19 has altered parental bereavement.

Methods

Parents of children who died from cancer and had participated in a survey-based study examining the early grief experience of parents were invited to participate in a semi-structured

interview. In a previous study, parents of children who died from cancer 6-24 months prior completed a comprehensive survey. At the end of the survey, parents indicated if they would be willing to be contacted for future studies. The aim of the current study was to explore the early grief experience of parents of children who died from cancer, with emphasis on the support received, barriers to adequate support, and exploration of possible additional supportive interventions. Parents who indicated their openness to be re-contacted were mailed a letter outlining the goals of the study. Parents could complete the interview alone or with a partner (if applicable). Phone interviews were audio-recorded and transcribed verbatim, excluding personal identifiers. All interviews were conducted by a female research assistant (GH) with a background in qualitative research. After the first four interviews were conducted, a specific question about the effect of COVID-19 was included. Parents were asked, “*Has COVID-19 or anything going on in the world right now impacted your experience at all and if so, how?*” This study was approved by the Dana-Farber Cancer Institute IRB.

Thematic analysis of interview transcripts was conducted utilizing both inductive and deductive approaches.⁸ Initial coding was inductive and then combined with prefigured codes from the interview guide. Each transcript was independently coded by two team members (GH, JS), and the coders engaged in reflective discussion to resolve differences and refine codes. Thematic analysis was used to identify key impressions, contexts, and patterns across interviews. Ethnographic software (NVivo 12) was used for data management and to facilitate analysis.

Results

Thirty-three parents were sent a prenotice letter outlining the goals of the study, 17 parents agreed to participate and 15 completed the interview (Figure 1). All interviews were conducted alone with a research assistant in a single sitting. Interviews lasted an average of 32 (range 12-

42) minutes. Eleven parents were asked directly about the impact of COVID-19, 2 parents brought up the topic on their own, and 2 parents did not mention COVID-19. Five fathers and ten mothers participated, including three married couples. Parents participated an average of 19 (range 12-34) months from their child's death. One parent identified as Hispanic, all other parents were White and non-Hispanic. No further demographic information was collected.

Eleven codes were identified relating to the effect of the COVID pandemic on bereavement. Derived codes, definitions and example quotations are presented in Table 1. The most commonly used codes were: 'change in support,' 'no effect,' 'familiarity with uncertainty/ability to cope' and 'change in contact with care/research team.' Most parents spoke about how the pandemic has led to a change in the support they were receiving – often referencing an inability to meet with others face-to-face, with individual supportive figures or a support group. Parents also described changes in how they were in contact with their child's care team, with most noting that they had not heard from or were unable to visit with staff and clinicians in person. In contrast, one parent mentioned the pandemic led to a new ability to participate in research meetings related to their child's diagnosis.

Parents remarked that the pandemic increased their sense of isolation because of the physical separation from others and additional stress caused by the many life changes. Some parents found the change in routine and forced isolation beneficial, providing time and presence of family members to "do the work" of grieving. In contrast, 2 parents noted the loss of routine and being homebound led to a constant reminder of their loss. Another parent expressed that while social isolation has provided time and space to reflect, it has also made it easier to withdraw from society.

While parents acknowledged the negative impacts of COVID-19, these parents and others

expressed feeling resilient and able to deal with the current uncertainty because of their experiences during their child's illness and death. Two parents expressed being thankful that their child did not have to experience the pandemic and that their child's end of life was not impacted. Two others spoke about how the elements of the pandemic (face masks, hand sanitizer) triggered negative emotions or traumatic stress in them or their family members.

Lastly, 3 parents expressed that the pandemic has not influenced their bereavement, noting they have maintained their routine (work) or familial support. Two of these parents went on to explain one or more ways in which their bereavement has changed.

Discussion

Overall, parents expressed mixed effects of COVID-19 on their bereavement. The parents who participated in this study were early in the bereavement, with an average time since their child's death of 19 months. Given their proximity to their child's death, these parents may be more vulnerable to the more negative effects of the pandemic, particularly the loss of a support system, mental health or support group, or physical presence of a supportive figure or care team member. This is consistent with prior literature indicating that multiple losses or compounded isolation may worsen or exacerbate parental grief.⁶

Continued contact between bereaved families and members of the care team after the child's death is important in parental bereavement⁹ and has been identified as standard of care in pediatric oncology.¹⁰ Given the absence of structured activities, hospital visits, or memorials that allow families a chance to connect with their child's care team, parents may feel less supported now. Several parents shared ways in which clinicians and mental health providers had attempted to maintain supportive contact, including sending cards or notes or shifting support groups to

virtual meetings. Clinicians must continue to adapt and innovate to develop new ways to provide ongoing support to parents of children who died and their family members throughout the pandemic and beyond.

Just as the experience of grief and bereavement is highly individual and likely differs from person to person,¹¹ the effect of COVID-19 on each bereaved individual is variable. Some parents may be able to find strength or recognize their resiliency during this time, while other parents may be more affected by compounded isolation and require additional support from the care team, hospital, and local community. Clinicians should refrain from making assumptions about the impact of the pandemic on a person's or family's grief and instead proactively reach out to parents to let them know that their child and family are remembered and that additional supports are available.

There are several limitations to this study. Thirteen parents did not respond to invitations to participate in this study; the impact of COVID on these individuals may have been different. All participants were parents of children who were treated at a single, tertiary care institute in a large metropolitan city. Very limited demographic information was collected but available data indicates minimal ethnic/racial diversity. Concurrent with the COVID-19 pandemic and associated economic consequences, calls and protests for racial justice and societal upheaval may disproportionately impact bereaved parents of color, which are not represented in this current study. Despite these limitations, we believe these findings are important as the first examination of the effect of the current pandemic on parental bereavement.

Conclusion

The COVID-19 pandemic has had mixed effects on parental bereavement. The social distancing requirements and other methods for slowing the spread has resulted in increased feelings of isolation and disruption of sometimes fragile support systems. Despite the many challenges imposed, many parents found some benefit in the current situation, including allowing more time to grieve and recognition of their coping skills and resiliency. Providers and hospitals should proactively contact bereaved parents to assess for the need of additional support and find innovative ways to connect and provide ongoing support for parents and families.

Disclosures: The authors have no disclosures to report

Acknowledgments: The authors would like to thank the amazing parent participants in this study and who shared the stories of their children, families, and themselves.

Figure Legend

Figure 1. Study eligibility and enrollment pathway. Shaded box indicates the number of parents that participated in the survey-based study examining the early psychosocial and health outcomes of parents of children who died from cancer. Parents that agreed to be contacted for further studies were approached to participated in semi-structured interviews (dashed box)

References

1. Mayland CR, Harding AJE, Preston N, Payne S. Supporting Adults Bereaved Through COVID-19: A Rapid Review of the Impact of Previous Pandemics on Grief and Bereavement. *J Pain Symptom Manage*. 2020;60(2):e33-e39.
2. Kokou-Kpolou CK, Fernandez-Alcantara M, Cenat JM. Prolonged grief related to COVID-19 deaths: Do we have to fear a steep rise in traumatic and disenfranchised griefs? *Psychol Trauma*. 2020;12(S1):S94-S95.
3. Goveas JS, Shear MK. Grief and the COVID-19 Pandemic in Older Adults. *Am J Geriatr Psychiatry*. 2020.
4. Wallace CL, Wladkowski SP, Gibson A, White P. Grief During the COVID-19 Pandemic: Considerations for Palliative Care Providers. *J Pain Symptom Manage*. 2020;60(1):e70-e76.
5. Morris S, Fletcher K, Goldstein R. The Grief of Parents After the Death of a Young Child. *Journal of clinical psychology in medical settings*. 2019;26(3):321-338.
6. Snaman JM, Kaye EC, Torres C, Gibson D, Baker JN. Parental Grief Following the Death of a Child from Cancer: The Ongoing Odyssey. *Pediatric blood & cancer*. 2016;63(9):1594-1602.
7. Kricbergs UC, Lannen P, Onelov E, Wolfe J. Parental grief after losing a child to cancer: impact of professional and social support on long-term outcomes. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2007;25(22):3307-3312.
8. Green J, Thorogood, N. *Qualitative Methods for Health Research*. 4th Edition ed. United Kingdom: SAGE Publications; 2018.

9. Snaman JM, Kaye EC, Torres C, Gibson DV, Baker JN. Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys. *Cancer*. 2016;122(17):2757-2765.
10. Lichtenthal WG, Sweeney CR, Roberts KE, et al. Bereavement Follow-Up After the Death of a Child as a Standard of Care in Pediatric Oncology. *Pediatric blood & cancer*. 2015;62 Suppl 5:S834-869.
11. Thompson AL, Miller KS, Barrera M, et al. A qualitative study of advice from bereaved parents and siblings. *Journal of social work in end-of-life & palliative care*. 2011;7(2-3):153-172.

Table 1. Bereaved parents' (N=13) responses to the question, "Has COVID-19 or anything going on in the world right now impacted your experience at all and if so, how?"

Code (Number of parents using code)	Definition	Example Quotation(s)	
Change in Support (8)	Difference (real or perceived) in the type or level of support felt prior; new/different ways to connect	"I mean I guess it's – yeah, it definitely has, especially with so many anniversaries and his birthday and we couldn't be around friends or family. That was tough, since obviously we're trying to stay safe and everything. That was really hard." – Parent 581A	[Our therapist] keeps trying to fire us but we keep insisting, it's pretty funny. I think that's – I think she's the one who's been affected in COVID. I think people who work in that field are just overwhelmed. - Parent 550A
No effect (5)	No perceived change in bereavement or support	"Well, actually, it really hasn't affected me, except for one way. But I'm home most of the time, anyways, and I don't really see anybody." – Parent 553A	
Familiarity with uncertainty/Ability to cope (4)	Resiliency, adaptability, perspective, preparation for grief/uncertainty; pandemic making grief more universal	"But I think the flip side or the good side of that...that I feel like there's also like a resiliency that we've got that I see other people not having quite as much because we kind of got used to just accepting things for what they were and then trying to move through it. And so I think that there's definitely a good side to it, too, and I think we have a way of coping that we've been able to extend into this time, so I think it's helped us as a family." – Parent 573A	"It's not the fear of a pandemic. Because if any group of people are prepared to have their world turned upside down overnight and not really not know the future, those are familiar places." -Parent 505B
Change in contact with care/research team (4)	Shift in ways families communicate with their child's care team or research team; can be new/different ways	"His care team – we've been visiting them before the COVID-19, and we usually just talk on [about] their lives and told them what was happening with us. So, they've been a very, very big support. But with this COVID-19, we have not been able to do that. But they have sent little notes and stuff." –	"So we are in some ways trying to help get some more research in [my child's cancer diagnosis]...So we have checked with them in that sense just trying to understand what's going on and how are we making any sort of progress and with a cure ...we've been like participating in ...workshops

		Parent 582A	through Zoom and other forms of communication that we'd be able to take part... And it has just helped us – keeps us informed, and I think we still want to be a part of that and that you somehow do care." – Parent 520B
Compounded isolation (3)	Physical distancing adding to already present sense of isolation or separation/feeling separate from others	"For me, I kind of wanted to withdraw from the world and so COVID, the pandemic sort of played into that. I didn't really want to go out and have much social interaction... I think it's been a mixed bag. I think it's been helpful and what I needed to do at the same time might have slowed things down a little bit." – Parent 590B	
Thankfulness (2)	Parents expressing gratitude that child did not experience and/or they could experience EOL care before pandemic	"It honestly makes me very – I feel – I'm so happy that [my child] didn't have to go through her sickness during this time. I keep saying .. that she was able to receive care without masks and wasn't frightening... she was able to say good bye with the family. She was able to give everybody hugs...I'm glad she didn't have to suffer through this." – Parent 503A	
Trigger (2)	Pandemic and associated factors causing increased anxiety or triggering disturbing memories	"For a long time I didn't know that was happening and I was having essentially panic episodes and could not link it to anything until I realized oh wait the smell of hand sanitizer is triggering this... There's just a whole array of physical symptoms that I wasn't necessarily connecting to the grieving process... And even our youngest who witnessed everything as a 2 and 3-year-old, all the sudden seeing everyone in masks has that same reaction." – Parent 505B	
Forced pause/Time to grieve (2)	Time and space to "do the work" of grieving	"Well, it's definitely mixed feelings. Like there's moments where I think it's good to be – if everybody could just stop and take – stop with their lives. And that's kind of like how I've been feeling for the past year and a half or two years, really, since my daughter's diagnosis that my life kind of stopped and I haven't really been out in the world so much. So I think right now is a time when everybody's experiencing some of that. And in ways it's good, like for me it has been good to just have the time to grieve	For me, I kind of wanted to withdraw from the world and so COVID, the pandemic sort of played into that. I didn't really want to go out and have much social interaction. And I think that's still here even though it's been just over a year now since my daughter died... I think it's been a mixed bag. I think it's been helpful and what I needed to do at the same time might have slowed things down a little bit." – Parent 590B

		more and really all those feelings kind of come back because it really resembles a lot of how I was feeling right after her passing or even just after her diagnosis..." – Parent 520B	
Loss of routine or personal time (2)	Change in regular activities; less time to be alone	"You don't realize your commute in the morning and getting out of your house and the movement and routine how, much of a help those are getting through everything." – Parent 505B	
Additional Stress (1)	More strain or pressure	"I said, you know – we tried to, met up, and we met up a couple of times and after COVID like we're dealing with all this extra stress and trying to do another Zoom thing, we were just like we just can't handle that. It was just hard to organize and motivate to do anything else. We're all pretty kind of stressed and dealing with a lot." – Parent 520B	
Constant reminders/no break from grief (1)	Surrounded by items, memories, feelings of grief	"And when you take away your routine and now you're stuck in your house where there are the arts and craft pictures and the toys and the stuffed animals. And instead of having breaks from that you're in it all day – that can exacerbate a lot of the recovery stuff. " – Parent 505B	

