Parents' Experiences After the Death of a Child from Cancer: A Qualitative

Examination of Perceptions of Bereavement Care Services and Support

███████

This thesis is submitted in partial fulfilment of the degree of Masters of Psychology (Health)

School of Psychology

University of Adelaide

September 2021

Word Count: 7138 words

Table of Contents

Declaration

This dissertation contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, contains no materials previously published except where due reference is made.

I give permission for the digital version of my dissertation to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the School to restrict access for a period of time.

██████

September 2021

Statement of Contribution

The research supervisors conceived the initial idea and design for this project. I then contributed to the design of the research, including in developing the interview questions. The ethics application was completed by myself and one of my research supervisors with assistance from my other research supervisor. I scheduled and conducted all interviews; one of my research supervisors assisting with a pilot interview before I conducted the remainder of the interviews alone. I transcribed the interviews and analyzed the data with discussion with my research supervisors about emerging and final themes as is typical of qualitative research. I refined the results after discussion and review by my research supervisors and I wrote up the thesis.

Conference Presentation

XXXX., XXXX., & XXXX. (2021). Parents' Views about Peer Support Following

Bereavement from Childhood Cancer. The Australian Psychological Society National Health

Psychology Conference 2021. November 2021.

Parents' Experiences After the Death of a Child from Cancer: A Qualitative

Examination of Perceptions of Bereavement Care Services and Support

██████

*School of Psychology, The University of Adelaide, Adelaide, South Australia, Australia

Corresponding Author: ████████

School of Psychology, The University of Adelaide

Adelaide, South Australia 5000

Email: [removed for blind review]

Please note that all spelling in the manuscript is American English as it is a requirement of the selected journal.

Paarents' Experiences After the Death of a Child from Cancer: A Qualitative

Examination of Perceptions of Bereavement Care Services and Support

Abstract

The present study sought to qualitatively explore the experiences of parents bereaved by childhood cancer. Semi-structured interviews with 12 Australian parents bereaved by childhood cancer were examined using reflexive thematic analysis. Five themes relating to parents' experiences of, and preferences for, bereavement support were generated. The current findings highlight the need for early and ongoing support; care, and empathy from close health professionals especially in communicating with parents; greater inclusivity of men in supports; increased accessibility for those outside of metropolitan areas; and the value of peer support when managed well.

Key Words: pediatric cancer; bereavement; grief; support; peer support

Introduction

Cancer is the leading cause of disease-related death in children aged one to 14 in Australia, with an average of 101 cancer-related deaths per year for children under 15 (Australian Childhood Cancer Registry, 2017). The death of a child can affect family members' physical, emotional, and mental wellbeing (Stroebe et al., 2006), with an increased risk of anxiety, depression, and complicated grief compared to other losses (Lichtenthal et al., 2015; Ljungman, et al., 2014; Reilley-Smorawski, 2002). Persistent grief can adversely impact marriages and occupational, financial, and social wellbeing (Barrera et al., 2009; Goodenough et al., 2004), further compounding the loss (Snaman et al., 2017).

One way to encapsulate the ever-shifting and pervasive experience of parents' grief that may be helpful when supporting bereaved parents is Stroebe's (1999) 'dual-process model of grief'. It suggests that individuals oscillate between confrontation and avoidance of grief and that this oscillation is healthy and integral to coping. Further, it illustrates a waxing

and waning of grief, rather than clear stages, while individuals adjust to additional losses coinciding with the loss of their loved one (i.e., feelings of loneliness, the adjustment of 'parent of a child' to 'parent of a deceased child') (Stroebe, 1999).

Formal and informal supports (Dyregrov, 2004) are necessary throughout treatment, palliation, and following a child's death (Kowalczyk et al., 2014; Wiener et al., 2015). Guidelines to inform quality bereavement care practices exist but vary in their implementation in hospitals (deCinque et al., 2006). Within hospital settings, health professionals may effectively deliver psychosocial support, in conjunction with regular medical intervention, due to the close nature of the relationships they often form with families (Giorgali, 2020; Rando, 1983).

After a child's death, it is suggested that bereavement follow-up meetings occur between families and the physician(s) so parents can gain additional information, emotional support, and provide feedback on their experience if they wish (Borasinoa et al., 2008; Cook et al., 2002; Eggly et al., 2011). Various supports are usually offered, including information packages (i.e., pamphlets, newsletters), professional support, outreach programs (i.e., camps and getaway experiences), hospital-based bereavement services, and group and peer support programs (within hospitals or external support organizations) (Cook et al., 2002; Creed et al., 2001; Vega et al., 2014).

Support preferences and needs may vary according to gender. For example, while bereaved mothers have reported emotional support from peers and health professionals to be helpful (Nikkola et al., 2013) less is known about fathers' preferences and needs (Nicholas et al., 2016 and 2020). Prior literature has demonstrated that mothers adopt help-seeking behaviours and utilise peer support, while some fathers report a need to be the 'strong parent' (Donovan et al., 2021) or are more task-oriented (Alam et al., 2009), thus hindering themselves from accessing support and deterring others from offering (Stroebe et al., 2013).

The wider literature suggests parents receive insufficient emotional support after their child's death (i.e., Gijzen et al., 2016) and there is little evidence to confirm the effects of interventions on parents after their child's death (Endo et al., 2015). Moreover, negative perceptions of social support have been linked to poor outcomes and parental identity disintegration after the death of a child from cancer (O'Connor & Barrera, 2012). Barriers to successful bereavement care include health professionals' lack of knowledge and possible lack of communication skills (Liisa et al., 2011; Helton et al., 2020). Despite positive endorsements by parents, many hospitals work from a limited theoretical basis, and do not always screen for complicated grief risk, nor formally evaluate their programs. As a consequence, unmet needs exist. Therefore, future research should explore bereaved families' needs to guide bereavement services (deCinque et al., 2006).

While there is abundant emerging research solidifying the necessity of support for parents bereaved from childhood cancer, parents continue to report mixed experiences of support (Gijzen et al., 2016). To bridge the gap between supports offered and the perceived helpfulness of such support, the present study aimed to explore the support preferences and needs of parents bereaved by childhood cancer. Asking parents to share thoughts on bereavement services allows us to gain unique and valuable insights into their grief, which may be intrinsic to adapting existing or developing and implementing future bereavement services.

Materials and Methods

Participants

People were eligible to participate if they were: parents, fluent in English, who had experienced the death of a child to cancer (diagnosed under 18 years of age) between six months and ten years prior. This time frame was chosen to minimize participant distress. Participants comprised 12 Australian parents: two males and ten females, aged 38 to 60 years

(M = 48, SD = 6.7) at the time of interview. Nine participants were married, with three separated or in a relationship. One couple were interviewed together.

Participants' children were diagnosed with cancer from one year and six months through to 18 years (M = 10.9, SD = 5.6). Children's diagnoses included acute lymphoblastic leukemia (n = 2), angiosarcoma (n = 1), diffuse intrinsic pontine glioma (n = 1), glioblastoma multiforme (n = 1), leukaemia (n = 1), medulloblastoma (n = 1), optic glioma (n = 1), osteosarcoma (n = 1), and rhabdomyosarcoma (n = 1). At death, participants' children were aged from two years and three months to 21 years (M = 13.7, SD = 6.4), and the time since death ranged from nine months to 10 years (M = 4.6, SD = 3.1).

Procedure

The University of [removed for blind review] Human Research Ethics Committee approved this study. Australian support organizations that provide services for families affected by childhood cancer shared information about the research with their consumers. Potential participants were invited to contact the researchers to express their interest. Recruitment also occurred via passive snowballing.

A qualitative design using semi-structured interviews with open-ended questions from a realist ontological position, where participants' accounts were taken to directly reflect their experiences, was employed. Questions were developed based on prior studies in the area (i.e., Alam et al., 2012; Barrera et al., 2009; deCinque et al., 2006; Helton et al., 2020) and the clinical experience of two of the researchers. Example questions from the interview schedule included: 'Can you tell me about your experiences with the death of your child?', 'Can you tell me about the supports you received, if any, at the time of your child's death?' and 'What would you say your main needs for support were/are?' Participants could refuse to answer any question, pause or end the interview, or could speak with a psychologist after their interview. None did so. Prior literature suggests it may be therapeutic for parents to have the

opportunity to openly share their stories and provide feedback (Donovan et al., 2018;

Dyregrove, 2004; Tager, 2019).

After emailing participants, the author, a provisional psychologist, conducted the

interviews via Zoom and telephone (due to COVID) between November 2020 and June 2021.

Together with a research supervisor, the author conducted a pilot interview in November of

2020 to assess the proposed interview schedule's suitability. The interview schedule was

deemed appropriate, and the pilot interview was included in the final analysis. Interview

lengths ranged from one hour and three minutes to two hours and 45 minutes (M = 66

minutes). While data saturation was achieved, consistent with reflexive thematic analysis

(Braun & Clarke, 2021), the focus was on continuing data collection until sufficient meaning

could be generated. With consent, the interviews were audio-recorded and transcribed

verbatim. Participants were assigned a pseudonym, and all identifying information was

removed from the transcripts to protect confidentiality.

This study followed the Consolidated Criteria for Reporting Qualitative Research

(COREQ) guidelines (Tong, 2007), a 32-item checklist for interviews and focus groups (see

Appendix A: Supplementary Table 1). Following Tracy's (2010) criteria for excellence in

qualitative research, the author maintained an audit trail to enhance methodological rigor and

facilitate analysis. Furthermore, participants could review their transcripts as part of 'member

reflections'; four participants did so, and two added a reflection. As researchers may

influence data collection and interpretation, self-reflexivity (Braun & Clarke, 2013; Tracy,

2010) was used throughout the research process. The author is a young woman without

children and does not have experience of bereavement to childhood cancer. Given

participants' engagement, it appears that the author's circumstances did not adversely affect

participants' willingness to share; participants stated it was a welcomed opportunity to talk

freely, and rapport was quickly established.

Data Analysis

Braun and Clarke's (2006, 2019) six-step reflexive thematic analysis was employed to analyze the data. The approach involves: (1) familiarization with the data through transcription and repeated reading; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining themes; and (6) writing the results, including using illustrative extracts (Braun & Clarke, 2006). Initially, a deductive approach was taken, where the data was examined according to the research questions. Then, an inductive approach explored any additional themes. The author and the researcher supervisors discussed the analysis throughout, refining themes, and all agreeing on the final themes.

Results

Five themes, each with subthemes, were generated: 1) Care, empathy, and connection assist with bereavement; 2) Communication makes a difference; 3) Supports must be offered early and be available ongoing if desired; 4) Gender matters when grieving the loss of a child; and 5) The pull of peer support.

Care, empathy, and connection assist with bereavement

Care and empathy from health professionals after death

Most participants spent significant time in hospital settings and expressed that health professionals' understanding, support, and empathy comforted them during their bereavement. Care from this close network of professionals marked the significance of the relationships between child, family, and health professionals. Though parents acknowledged that professionals may have many such relationships, to them these relationships were momentous:

> "It's impossible to explain that it was like having the closest relationship you could
>
> with an auntie or a grandparent or something, and they ended up being pallbearers,
>
> you know. I said to them that I know that [the daughter's name] was just one of their

patients, you know, that they might have lots of relationships with patients like that.

But I just said in terms of for [daughter's name] herself, they were her world."

(Phoebe)

Many parents shared how health professionals whom they had formed close relationships with acknowledging their child's death assisted with their grief. Health professionals were described to hold space for families in the immediate aftermath, coming in to say goodbye, and attending funeral services:

"And everyone, you know, took the time and the care, considering they are clearly under-resourced and probably overworked. A lot of staff came to the funeral as well, the staff from the hospital. So, that was a pretty nice touch." (Rhys)

In contrast, some parents described adverse emotional impacts when post-death care lacked empathy. For instance, Nora discussed pain and shock when without forewarning, immediately after her death, her daughter was removed from a hospital app the family had used throughout treatment. She stated, "I clicked on this app and it's just this person no longer exists." Nora further discussed fainting from distress when a doctor insensitively asked questions about her daughter's autopsy:

"So, I'm signing this form and this doctor goes: oh, and by the way, when we're finished with her lungs, would you like me to just get rid of them or replace them back in? And that's when I passed out."

The importance of health professionals' care and empathy for parents after their child's death was evident. Empathetic care can be beneficial, while lack of compassion and sensitivity can contribute to heightened distress.

Missing hospital staff and longing to reconnect

Parents had relied on health professionals for support and suddenly losing relationships with people they had shared intense experiences and memories with when their child died was difficult:

> "The nurses and the doctors and hospital staff were my absolute lifeline for nine months like I didn't really see friends or family, or anyone except for staff. And then as soon as your child dies, you never see them again. It is honestly just like you have, you share this whole thing and then you get a divorce, and you can never talk to or see anyone again. And all these memories involve these people, but you can't kind of share them with anybody that was part of it." (Phoebe)

Most participants spoke of no longer having a reason to see close health professionals. The severing of these relationships was challenging and contributed to feelings of not fitting in:

> "You're not allowed to have contact with any of the people that you've met because we don't fit into that good box as in… You don't fit in with the ones that are still fighting, you don't fit in with the ones who survived, and you don't fit in at home because people just don't know how to deal with you." (Nora)

The sudden end of relationships with health professionals after their child's death was experienced as another loss to bereaved families, and a longing to reconnect was clear. This sub-theme again demonstrates that care, empathy, and ongoing connection are beneficial in bereavement.

Communication makes a difference

Communication from health professionals potentially leads to distress

Communication with health professionals, particularly regarding palliation and post-death interactions, sometimes induced distress. Zoe said, "Sometimes the approach of the medical professionals was the worst part really of the whole experience." A few participants

discussed moments of lacking empathy or sensitivity from health professionals, showing the importance of 'people skills' and careful communication to avoid undue distress:

> "It wasn't the best experience, actually it was horrible. Horrible in the fact of what was happening around me in the hospital. The doctor – he had absolutely no people skills; not the right skills to be dealing with that situation." (Maya)

Some participants referred to the significance of their child having long hospital stays and consequently needing empathetic communication in this context, particularly after their child's death. For example, Phoebe highlighted a hurtful moment that signified what was essentially an erasure of her child by the hospital:

> "I think she lived almost a third of her life in that hospital. She lived longer in that hospital than she lived in our house that we've got here… And I just couldn't believe that they were like they basically had someone cleaning out our room while we were gone and just telling us to get out."

While participants had experienced positive interactions with health professionals, they were surprised and distressed when communication lacked compassion.

Communication between organizations with consent could positively benefit families

Families may benefit if, with consent, communication about their family between health and support organizations increased. Sharing information could be conducive to better care provision and avoid upsetting interactions (i.e., contacting the family not knowing their child has died). For example, one participant described several interactions she had with support organizations or medical facilities after her daughter's death where she was incorrectly fined for pathology testing and then questioned about her child accessing supports. Nora said, "We lost her a month ago, but they don't communicate." Several participants described disappointing interactions with support organizations after their child's

death. Many had expected support which was not forthcoming and desired for organizations to initiate contact:

> "I thought they would have reached out. 'We're just seeing how you're going.' That's all... I was disappointed that didn't happen. For me it was more around, I was going to them, and they didn't reach out to me if I needed them." (Maya)

When participants had to actively seek support, rather than have organizations offer it, they described feeling disappointed, with some expressing that they had fallen "through the cracks" (Phoebe). Sharing information between support organizations would minimize accidental insensitive interactions after children die.

Supports must be offered early and be available ongoing if desired

Peace of mind that the door is always open: ongoing connections or the ability to reconnect with supports is important

Parents explained that early and ongoing contact with organizations was essential and aided in managing grief and learning coping strategies:

> "As early as possible. And by that, I mean… the preparation we had, as I said we had five years to prepare, and it was not enough. You know, so it's never going to be long enough. So, starting early. Starting somewhere." (Miles)

Most participants desired ongoing connections or the ability to reconnect with support organizations. Some participants spoke of a mind 'fog' in early bereavement and a need to be 'brave' that adversely impacted their ability to seek support. Some participants suggested that follow-up by support organizations at this time was essential for them to access support later:

> "I guess it then fogs out. So, it was definitely something that had to be reiterated to me again… Then it was that remember the like, yeah, oh, I can tap into that. Are you brave enough? Because you don't feel very brave in a lot of it. But you want to be brave." (Julie)

When follow-up was absent, participants described being less likely to seek supports. Ongoing contact from support organizations provided participants with comfort that services remained accessible to them as required:

> "They're [support organization] always there. So, that's really good – it gives us peace of mind that they're always there and that door is always open." (Rhys)

Participants expressed comfort in knowing that they could tap into and out of supports as needed. The continued offer of support, and thus continued relationships, made it easier for participants to reignite supports:

> "So, last year, he stopped… But then during this year, he said, 'oh mom I'm just not having a great time, I'm not feeling good, I'm missing [his sister], I think I'd like to go speak to someone.' So, he went to a psychologist [someone new] that we found and then after a few weeks he said, actually I think I'd like to speak to [cancer psychologist that assisted family previously], so he reconnected." (Ivy)

The "door remaining open" (Rhys) allowed participants to reconnect months or years later with someone who already knew their story and appeared to facilitate greater immediacy of relevant support.

Psychological support is beneficial

All participants highlighted formal psychological support as beneficial to their families. For example, Zoe described that grief seeped "out into other aspects of life" and psychotherapy enabled her to "make that connection and sort of deal with that." In addition, several participants explained that while they could speak to non-formal supports, formal psychological supports conferred added benefits, including the ability to speak freely:

> "It was fine to have a chat, to talk to someone who was totally not a friend or family that didn't really know anyone, and I could just feel free to say you know whatever." (Maya)

Being able to speak in formal therapeutic settings allowed for deeper sharing to occur:

> "Because professionals, I guess I feel safe in that space that I don't cross any line or put too much on a friendship. And friends want to fix it too. I think that's the biggest thing there, friends and even though they know they can't help themselves. I've noticed 90 percent of people are sympathetic, but only 10 percent are actually empathetic. So, then there's this whole guilty, just messy awkwardness in it. So, the professional support is easier because that's the dynamic of it. I don't have to worry about, I'm not offending them. That's what they're there for." (Julie)

Most participants explained that psychological support was beneficial, and the connections formed with psychologists or counsellors were appreciated.

Distance as a barrier to support

A significant barrier to accessing bereavement support was distance caused by transitioning between states (from where treatment occurred back to home) or living remotely from supports. A need for localized support services was highlighted:

> "I was actually going to go to [a different city] last week and see [her psychologist] in person... I ended up saying 'can we just get online because I just don't think I can actually drive to [a different city] today'. I didn't think I'd concentrate. So, that is an area that I go, 'where's the person just up the road?'" (Julie)

The absence of local support for participants who did not reside in major cities meant a struggle to access support:

> "But to actually put you in contact with people that you need… whether because we live in a country town. The hospital said they have great support groups. Yeah. But do you want to drive hours for it?" (Nora)

Participants who resided outside of a metropolitan area repeatedly indicated that distance was the primary barrier to accessing often longed-for support services.

Gender matters when grieving the loss of a child

Gendered experiences of support – men not discussing openly or accessing supports as readily

Men and women alike described a range of difficulties relating to gendered experiences of support. Participants indicated potentially gendered differences in emotional openness and communication in their grief response, coupled with gender itself as a possible barrier to support for men. One father reflected that perhaps men experienced greater difficulty in being open with their emotional experiences, stating they "just don't have or want to show or let their guard down, or show their emotions" (Rhys). This perspective was shared by most participants, highlighting differences between how men and women expressed their grief. Participants also suggested men may be less likely to seek formal support, which was a double-edged sword, in that their absence from support groups then made such groups less welcoming for other men to attend:

> "I think men deal with grief differently. I just think men don't cry, don't show their emotions as much, dealing with other men and they don't like talking about it, so at a bit of a disadvantage, less likely to talk about it themselves and they have other men who are also less likely… He [her son] didn't want to join groups that were mostly women." (Kate)

Some participants felt men were disadvantaged by being less likely to discuss their grief openly, and similarly less likely to have others approach them to discuss their grief:

> "So just in terms of day-to-day people like no one ever mentions her to my husband and people always mention her to me. My husband… he can't even tell who knows and who doesn't because, yeah, because no one mentioned it. But then a couple of times we've gone out to dinner or something, and everyone will be there, and I haven't even met these people and within a couple of minutes they will talk to me and

ask about her, and they'll ask questions. And once people were even asking to see

photos of her. And my husband was really upset. And he was really upset in the car.

And he just said, you know, I would like to show people photos." (Phoebe)

Gendered patterns in how men, and others around them, approach men's grief may inhibit

access to supports. It was expressed that men's needs may be overlooked due to gendered

assumptions about grief expression.

Focus on the mother's grief to the detriment of the father/male caregiver

Many participants noted that gender-specific stereotypes may dictate male support

needs as different to or less than those of females (in a heterosexual relationship). Participants

spoke of men missing out or being treated differently than their female partner; Chloe stated,

"He [her husband] always felt he was treated differently." Regarding supports offered,

Charlotte said, "There was probably more there for moms", a perspective many participants

shared. Even within support organizations there appeared to be a focus on mothers' grief,

with little focus on fathers' experience or needs:

> "But the difference between what my husband got at [support organization] and what
>
> I got was massive. So, after [daughter's name] died… there was a masseuse that came
>
> in, but she would only massage the females. And there was a mother's meditation that
>
> they did, which was sort of a grief meditation, and it was just for the moms. And I'm
>
> pretty sure there was a hairdresser that came in and just cut the women's hair as well.
>
> But there was so much stuff that was for me and there was nothing for him." (Phoebe)

Participants noted that gendered assumptions about support needs were prevalent throughout

support services and could lead to men not receiving adequate support. For example, one

participant described an instance of online peer support where users tried to dismiss father's

grief as being less-than that of mother's, a statement that distressed one of the male online

support users and the participant:

"There was a lot of mothers, and they were saying stuff about mothers feel the grief more than fathers because they've carried the child. And this man comes out and said he was a dad who lost a child… and he said it's not a competition and we all grieve equally. So, they gave it to him. So, then I added, hang on a minute – my husband may not have given birth to our daughter, but he was there when she was born, he taught her to ride a bike, he has been as important to her as I have. So, they kicked me out. They said I wasn't for the women. I said, this isn't a women's group, this is a grieving parent's group." (Nora)

There was a frequent pattern of men not feeling appropriately welcomed or acknowledged within support settings resulting in unmet needs. Most participants strongly discussed a necessity for greater inclusivity.

The pull of peer support

Mutual understanding, shared experience, guidance from someone further along

The mutual understanding gained only through shared experience was frequently discussed by participants as being of enormous benefit and great importance:

"I like the fact when I know the other person understands where I'm coming from, that means a lot to me. It's not this empty kind of, I don't know. It's like they think they can understand but they can't because they haven't been through it. So, I find to have that connection with someone who actually understands is really important to me… That's the sort of support that I really liked - that peer support. That level of understanding." (Maya)

Participants acknowledged the value of group settings and peer support as being reciprocal – they gained benefits from others' stories and from sharing their own:

"I saw value in it for myself in terms of actually just being able to speak candidly amongst other people who were not going to be shocked by the things that I would

say, just by virtue of that they had the same thoughts or behaviors themselves. And then I felt, and I also had sort of feedback from the facilitators and one of the participants as well, that there was value in my having been there because of the distance I had." (Zoe)

Helpful information gained from group experiences included acknowledging difficult periods ahead and suggestions on how to handle them. For example, Chloe noted, "It was just lovely to be able to speak to those different people and talk about how you can handle [those firsts like birthdays and Christmas]." Additionally, there was value in normalizing experiences:

"I guess, you become wanting to share your story because it's important to you now in a really different way. It's unique, but it's common. It has commonalities to others. And the commonalities start to make you feel normal because you feel so not normal." (Julie)

Hearing peers discuss their experiences normalized parents' grief. Peer support was comforting to participants and allowed them to benefit from strategies that others have successfully employed.

Peer support is beneficial but can present difficulties

While beneficial, difficulties also arose from peer support. One such difficulty emphasized by some participants was the desire to continue connecting with peers met through support services outside of the service setting and an inability to do so:

"It's all privacy laws. You can't necessarily find out 'oh hey, what's their phone number because I want to contact them.' So, unless people are sort of willing to pass out their information on the day then you might… you hear about someone's story and wonder how they're going but can't ever sort of get into contact with them." (Eloise)

Other participants illustrated difficulties in seeking peer support despite a desire for it due to lack of regular group meetings or time constraints:

"It's the mother perspective I want. So, I wonder how other moms manage their other kids. How do you navigate your marriage? How do you do you some days? So, for me, a group would definitely have to be in that way… if there was one that ran more regularly that I had access to… if it was fortnightly." (Julie)

Though not frequently expressed, some participants indicated that peer support was emotionally draining and that this may act as a barrier to access. Maya expressed, "By the time it got to me I was going oh my god like I am so sad, so drained." In addition, some participants expressed not relating to the specific emotional experience of their peers. For instance, Phoebe said she did not return to the group due to being unable to relate to other parents' shared experience of anxiety:

"I'm personally not somebody that has taken massive comfort from other bereaved parents… I don't know that listening to other people's struggles with fitting back into life has made me feel any better. In general, bereaved mom's just talk so much about how they're overly anxious, and anxiety is such a big thing. And I personally have not struggled with anxiety since [daughter's name] died." (Phoebe)

Content of peer support groups can be overwhelming and/or draining to hear. Some participants suggested this might be overcome by offering activity-related peer support to share stories more organically rather than one at a time in a circular setting.

Discussion

This study explored parents' experiences of bereavement care services following the death of their child from childhood cancer. Consistent with previous research, participants expressed that bereavement adversely impacted their physical, emotional, and mental wellbeing (Lichtenthal et al., 2015; Wender, 2012), including their relationships, occupation,

financial and/or social wellbeing (Reilley-Smorawski, 2002). All participants accessed a range of formal or informal supports. As in deCinque et al.'s study (2006), large variability existed in the supports offered and utilized by participants.

Participants emphasized the importance of follow-up care from hospital staff due to the nature of these relationships (Borasino et al., 2008; Cook, 2002; Van der Geest et al., 2018). Demonstrations of care and empathy from hospital staff were well-received and appreciated by participants and appeared to assist with bereavement. Participants expressed missing hospital staff and longing to reconnect with them. Follow-up care from hospital staff could aid in the challenging transition from existing within the supportive hospital environment to finding longer-term supports post-death, a shift in care that some participants emphasized as traumatizing.

The current findings suggest that health professionals' communication can potentially lead to parental distress. Consistent with prior research, parents reported receiving insufficient emotional support or shortcomings in informational support from health professionals (Gijzen et al., 2016; O'Connor & Barrera, 2012). When health professionals' communication with parents was perceived as lacking empathy or insensitive, parents reported distress. Families may benefit, with consent, from increased information sharing between health and support organizations to ensure that appropriate supports can be seamlessly provided.

The wider literature recommends both formal and informal support (Dyregrov, 2004), and parents in this study oscillated between the two, involving themselves in supports ranging from groups, private counselling/psychotherapy, general bereavement support or special event days, peer support, and hospital-organized activities (consistent with Creed et al., 2001; Di Marco et al., 2001). Supports offered early and ongoing were voiced as needed so families can tap into and out of supports as required. Findings suggest a continuation of offered

support by organizations enabled families to reconnect later with the comfort that someone who knows their story will be available to them, thus facilitating relevant support. The primary barrier to support for participants living outside of metropolitan areas was distance. Such participants spoke of unmet support needs and a longing to connect with organizations. Therefore, ways to provide supports to parents living outside of metropolitan cities is required. Online support options may be one way to service these needs.

Participants identified limitations in support for fathers. As demonstrated in previous literature (i.e., Donovan et al., 2012; Stroebe et al., 2013), the current study found that men may be overlooked due to stereotyped gendered expressions of grief. Participants identified the essential need for support to cater to both genders equally. Efforts to validate fathers' grief and encouragement of discussions about grief and psychological distress with fathers may increase their engagement with services. Services could benefit bereaved men by being inclusive (i.e., inclusive language and activities), offering male-specific support options, and training facilitators to be aware of potential gender differences in grief needs and expression.

Consistent with Nikkola et al.'s (2013) findings, the current study confirmed that bereaved mothers often experienced the most helpful support from peers and health professionals. Fathers also appreciated support from peers and health professionals when it was received. The reciprocal nature of peer support was acknowledged, with participants experiencing benefits from hearing others' stories and sharing their own. Peer support normalized grief experiences, enabling parents to feel less alone, and provided strategies to navigate difficult times ahead. Barriers to peer support revolved around accessibility (i.e., when, where, and how often groups ran) and being overwhelmed from the sequential sharing of traumatic experiences. Participants suggested peer support could be improved by engaging in activity-based peer support, thus facilitating a more organic sharing of information. Other suggestions for service providers included considering the frequency and time of group

sessions to increase attendance. Also, the facilitation of sharing contact information between parents who wished to stay in touch was welcomed by participants.

While the current findings offer valuable insights, the sample contained predominately educated, married, Caucasian women, with only two male participants. Further research exploring the bereavement experiences of under-represented populations, including fathers, parents from different socioeconomic status, culturally and linguistically diverse backgrounds, parents identifying as lesbian, gay, bisexual, transgender, queer, or otherwise in non-heterosexual relationships, and single parents, is needed. Also, research into the experiences of parents bereaved by childhood cancer living in rural and remote areas is warranted to adequately understand the experiences of all parents.

The present study contributes to the literature about parents' preferences for, and experiences of, support following bereavement by childhood cancer. Findings highlight the need for care, empathy and connection from health professionals and service providers, especially in communicating with parents. The current findings point to the need for supports to be offered early and to remain available ongoing if desired. Furthermore, support services should be accessible to those living outside metropolitan areas, and gender should be considered as it can impact whether support needs are met. Finally, peer support can be valuable for parents bereaved by childhood cancer when managed well; peer support would benefit from activity-based interactions and seeking to encourage greater participation from fathers.

Acknowledgements

References

Alam, R., Barrera, M., D'Agostino, N., Nicholas, D., & Schneiderman, G. (2012).
Bereavement experiences of mothers and fathers over time after the death of a child due to cancer, *Death Studies, 36*(1), 1-2. https://doi.org/10.1080/07481187.2011.553312

Australian Childhood Cancer Registry, (2017). *A summary of childhood cancer statistics in Australia, 1983-2017.* Cancer Council, Queensland. (pp.1-3). Australia:
https://cancerqld.org.au/research/viertel-cancer-research-centre/childhood-cancer/australian-childhood-cancer-registry/.

Barrera, M., O'Connor, K., D'Agostino, N. M., Spencer, L., Nicholas, D., Jovcevska, V., Tallet, S., & Schneiderman, G. (2009). Early parental adjustment and bereavement after childhood cancer death. *Death Studies*, *33*(6), 497–520.
https://doi.org/10.1080/07481180902961153

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589-597.
https://doi.org/10.1080/2159676X.2019.1628806

Braun, V., & Clakre, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health, 13*(2), 201-216.
https://doi.org/10.1080/2159676X.2019.1704846

Borasino, S., Morrison, W., Silberman, J., Nelson, R. M., & Feudtner, C. (2008). Physicians' contact with families after the death of pediatric patients: a survey of pediatric critical care practitioners' beliefs and self-reported practices. *Pediatrics*, *122*(6), e1174–e1178.
https://doi.org/10.1542/peds.2008-0952

Cook, P., White, D., & Ross Russell, R. (2002). Bereavement support following sudden and unexpected death: guidelines for care. *Archives of Disease in Childhood, 87*(1), 36-8. https://doi.org/10.1136/adc.87.1.36

Creed, J., Ruffin, J., & Ward, M. (2001). A weekend camp for bereaved siblings. *Cancer Practice*, *9*(4), 176-182. https://doi.org/10.1046/j.1523-5394.2001.94005.x

deCinque, N., Monterosso, L., Dadd, G., Sidhu, R., Macpherson, R., & Aoun, S. (2006). Bereavement support for families following the death of a child from cancer: experience of bereaved parents. *Journal of Psychosocial Oncology*, *24*(2), 65–83. https://doi.org/10.1300/J077v24n02_05

Donovan, L. A., Wakefield, C. E., Russell, V., Fardell, J., Mallitt, K. A., Hetherington, K., & Cohn, R. (2021). Variables associated with grief and personal growth following the death of a child from cancer: A mixed method analysis. *Death Studies*, *45*(9), 702–713. https://doi.org/10.1080/07481187.2019.1682087

Donovan, L. A., Wakefield, C. E., Russell, V., Hetherington, K., & Cohn, R. J. (2019). Brief report: Bereaved parents informing research design: The place of a pilot study. *Death Studies*, *43*(1), 62–69. https://doi.org/10.1080/07481187.2018.1436616

Dyregrov K. (2004). Bereaved parents' experience of research participation. *Social Science & Medicine*, *58*(2), 391–400. https://doi.org/10.1016/s0277-9536(03)00205-3

Eggly, S., Meert, K. L., Berger, J., Zimmerman, J., Anand, K. J., Newth, C. J., Harrison, R., Carcillo, J., Dean, J. M., Willson, D. F., Nicholson, C., & Eunice Kennedy Shriver (2011). A framework for conducting follow-up meetings with parents after a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine*, *12*(2), 147–152. https://doi.org/10.1097/PCC.0b013e3181e8b40c

Endo, K., Yonemoto, N., & Yamada, M. (2015). Interventions for bereaved parents following a child's death: A systematic review. *Palliative Medicine*, *29*(7), 590–604. https://doi.org/10.1177/0269216315576674

Giorgali, S. (2020). Bereaved parents' needs regarding hospital based bereavement care after the death of a child to cancer, *Death Studies*, 1-9. https://doi.org/10.1080/07481187.2020.1824202

Gijzen, S., L'Hoir, M. P., Boere-Boonekamp, M. M., & Need, A. (2016). How do parents experience support after the death of their child? *BMC Pediatrics*, *16*(1), 204. https://doi.org/10.1186/s12887-016-0749-9

Goodenough, B., Drew, D., Higgins, S., & Trethewie, S. (2004). Bereavement outcomes for parents who lose a child to cancer: are place of death and sex of parent associated with differences in psychological functioning? *Psycho-oncology*, *13*(11), 779–791. https://doi.org/10.1002/pon.795

Helton, G., Morris, P., Dole, O., Wolfe, W., & Snaman, J. (2020). Parental perceptions of hospital-based bereavement support following a child's death from cancer: room for improvement. *Journal of Pain and Symptom Management, 61*(6), 1254-1260. https://doi.org/10.1016/j.jpainsymman.2020.11.012

Kowalczyk, J., Samardakiewicz, M., Fitzgerald, E., Essiaf, S., Ladenstein, R., Vassal, G., Kienesberger, A., & Pritchard-Jones, K. (2014). Towards reducing inequalities: European standards of care for children with cancer. *European journal of cancer, 50*(3), 481-485. https://doi.org/10.1016/j.ejca.2013.11.004

Lichtenthal, W.G., Sweeney, C.R., Roberts, K.E., Corner, G.W., Donovan, L.A., Prigerson, H.G., & Wiener, L. (2015). Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. *Pediatric Blood Cancer, 62,* 834-869. https://doi.org/10.1002/pbc25700

Liisa, AL., Paavilainen, E., & Jaunonen, M. (2011). Mothers' experiences of peer support via

    an Internet discussion forum after the death of a child. *Scandinavian Journal of Caring*

    Sciences, 26(3), 417-426. https://doi.org/10.1111/j.1471-6712.2011.00929.x

Nicholas, D. B., Beaune, L., Barrera, M., Blumberg, J., & Belletrutti, M. (2016). Examining

    the experiences of fathers of children with a life-limiting illness. *Journal of Social Work in*

    End-of-Life & Palliative Care, *12*(1-2), 126–144.

    https://doi.org/10.1080/15524256.2016.1156601

Nicholas, D., Beaune, L., Belletrutti, M., Blumberg, J., Ing, S., Rapoport, A., & Barrera, M.

    (2020). Engaging fathers in pediatric palliative care research. *Journal of Social Work in*

    End-of-Life & Palliative Care, *16*(1), 42–56.

    https://doi.org/10.1080/15524256.2019.1703877

Nikkola, I., Jaunonen, M., Liisa, AA. (2013). Mother's experience of the support from a

    bereavement follow-up intervention after the death of a child. *Journal of Clinical Nursing,*

    22(7-8), 1151-1162. https://doi.org/10.1111/j.1365-2702.2012.04247.x

Reilly-Smorawski, B., Armstrong, A. V., & Catlin, E. A. (2002). Bereavement support for

    couples following death of a baby: program development and 14-year exit analysis. *Death*

    Studies, *26*(1), 21–37. https://doi.org/10.1080/07481180210145

Snaman, J. M., Kaye, E. C., Levine, D. R., Cochran, B., Wilcox, R., Sparrow, C. K., Noyes,

    N., Clark, L., Avery, W., & Baker, J. N. (2017). Empowering bereaved parents through

    the development of a comprehensive bereavement program. *Journal of Pain and Symptom*

    Management, *53*(4), 767–775. https://doi.org/10.1016/j.jpainsymman.2016.10.359

Stroebe, M. S., Folkman, S., Hansson, R. O., & Schut, H. (2006). The prediction of

    bereavement outcome: development of an integrative risk factor framework. *Social*

    Science & Medicine, *63*(9), 2440–2451. https://doi.org/10.1016/j.socscimed.2006.06.012

Stroebe, M., Finkenauer, C., Wijngaards-de Meij, L., Schut, H., van den Bout, J., & Stroebe, W. (2013). Partner-oriented self-regulation among bereaved parents: The costs of holding in grief for the partner's sake. *Psychological Science, 24*(4), 395-402. https://doi.org/10.1177/0956797612457383

Tager, J., Battles, H., Bedoya, S. Z., Gerhardt, C. A., Young-Saleme, T., & Wiener, L. (2019). Participation in Online Research Examining End-of-Life Experiences: Is It Beneficial, Burdensome, or Both for Parents Bereaved by Childhood Cancer? *Journal of Pediatric Oncology Nursing*, *36*(3), 170–177. https://doi.org/10.1177/1043454219836963

Tracy, S.J. & Hinrichs, M.M. (2017). Big Tent Criteria for Qualitative Quality. In the international encyclopedia of communication research methods (eds J. Matthes, C.S. Davis and R.F. Potter). https://doi.org/10.1002/9781118901731.iecrm0016

Tong, A., (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

van der Geest, I. M., Darlington, A. S., Streng, I. C., Michiels, E. M., Pieters, R., & van den Heuvel-Eibrink, M. M. (2014). Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *Journal of Pain and Symptom Management*, *47*(6), 1043–1053. https://doi.org/10.1016/j.jpainsymman.2013.07.007

Vega, P., Rivera, M. S., & Gonzalez, R. (2014). When grief turns into love: Understanding the experience of parents who have revived after losing a child due to cancer. *Journal of Pediatric Oncology Nursing, 31*(3), 166–176. doi:10.1177/1043454213515547

Wiener, L., Kazak, A.E., Noll, R.B., Patenaude, A.F., Kupst, M.J. (2015). Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatric Blood Cancer, 62*, 419-424. https://doi.org/10.1002/pbc.25675

Appendix A – Supplementary Table 1: COREQ Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	12
Credentials	2	What were the researcher's credentials? e.g., PhD, MD	12
Occupation	3	What was their occupation at the time of the study?	12
Gender	4	Was the researcher male or female?	12
Experience and training	5	What experience or training did the researcher have?	12
Relationships with participants			
Relationship established	6	Was a relationship established prior to study commencement?	12
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g., personal goals, reasons for doing the research	12
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g., bias, assumptions, reasons and interests about the research topic	12
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g., grounded theory, discourse analysis, ethnography, phenomenology, content analysis	11
Participant selection			

Sampling	10	How were participants selected? e.g., purposive, convenience, consecutive, snowball	11
Method of approach	11	How were participants approached? e.g., face-to-face, telephone, mail, email	11
Sample size	12	How many participants were in the study?	10
Non-participation	13	How many people refused to participate or dropped out? Reasons?	11
Setting			
Setting of data collection	14	Where was the data collected? e.g., home, clinic, workplace	12
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	12
Description of sample	16	What are the important characteristics of the sample? e.g., demographic data, date	10-11
Data collection12			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	12
Repeat interviews	18	Were repeated interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	12
Field notes	20	Were field notes made during and/or after the interview or focus group?	12
Duration	21	What was the duration of the interviews or focus group?	12
Data saturation	22	Was data saturation discussed?	13
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	13
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	13

Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	13
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	12
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number	13-24
Data and findings consistent	30	Was there consistency between the data presented and the findings?	13-24
Clarity of major themes	31	Were major themes clearly presented in the findings?	13
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	24

Developed from: Tong, A., Sainsbury, P., Craig, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349-357.

About the Journal

Death Studies is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Death Studies accepts the following types of article:

- Full-length research articles or reviews of the literature and brief reports

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 32% more citations* and over 6 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal.

Please visit our Author Services website or contact openaccess@tandf.co.uk if you would like more information about our Open Select Program.

*Citations received up to Jan 31st 2020 for articles published in 2015-2019 in journals listed in Web of Science®.

**Usage in 2017-2019 for articles published in 2015-2019.

Peer Review and Ethics

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing Your Paper

Full-length research articles or reviews of the literature and brief reports

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should contain an unstructured abstract of 100 words.
- Full-length research articles or reviews of the literature and brief reports Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as

appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list) Should contain an unstructured abstract of 100 words. Should contain between 3 and 5 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use American spelling style consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word or LaTeX formats. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact us here.

Though exceptions can be made for methodologically complex studies, it is suggested that full-length articles not exceed 25 pages, including abstract, references, tables, and figures. Brief reports are encouraged and should be no longer than 15 pages

References

Please use this <u>reference guide</u> when preparing your paper.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, <u>visit this website</u>.

Checklist: What to Include

1. **Author details.** All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. <u>Read more on authorship</u>.

2. You can opt to include a **video abstract** with your article. <u>Find out how these can help your work reach a wider audience, and what to think about when filming</u>.

3. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:

   For single agency grants

This work was supported by the [Funding Agency] under Grant [number xxxx].

For multiple agency grants

This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

4. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. <u>Further guidance on what is a conflict of interest and how to disclose it</u>.

5. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). <u>Templates</u> are also available to support authors.

6. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a <u>recognized data repository</u> prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.

7. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about <u>supplemental material and how to submit it with your article</u>.

8. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for color, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PDF, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For

information relating to other file types, please consult our [Submission of electronic artwork](#) document.

9. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

10. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about [mathematical symbols and equations](#).

11. **Units.** Please use [SI units](#) (non-italicized).

Using Third-Party Material in your Paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on [requesting permission to reproduce work(s) under copyright](#).

Submitting Your Paper

This journal uses ScholarOne Manuscripts to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in ScholarOne. Please read the guidelines above and then submit your paper in [the relevant Author Center](#), where you will find user guides and a helpdesk.

If you are submitting in LaTeX, please convert the files to PDF beforehand (you will also need to upload your LaTeX source files with the PDF).

Please note that *Death Studies* uses [Crossref™](#) to screen papers for unoriginal material. By submitting your paper to *Death Studies* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about [sharing your work](#).

Data Sharing Policy

This journal applies the Taylor & Francis [Basic Data Sharing Policy](#). Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see [this information](#) regarding repositories.

Authors are further encouraged to [cite any data sets referenced](#) in the article and provide a [Data Availability Statement](#).

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a

pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication Charges

There are no submission fees, publication fees or page charges for this journal.

Color figures will be reproduced in color in your online article free of charge. If it is necessary for the figures to be reproduced in color in the print version, a charge will apply.

Charges for color figures in print are $400 per figure (£300; $500 Australian Dollars; €350). For more than 4 color figures, figures 5 and above will be charged at $75 per figure (£50; $100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open

access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates here. Find out more about sharing your work.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Article Reprints

You will be sent a link to order article reprints via your account in our production system. For enquiries about reprints, please contact Taylor & Francis at reprints@taylorandfrancis.com. You can also order print copies of the journal issue in which your article appears.

Queries

Should you have any queries, please visit our Author Services website or contact us here.

Updated 27-04-2020