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Parents' experience of extended viewing in a paediatric hospice: a qualitative study

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Abstract

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Key words: Paediatric palliative care, young person, cooled room, after death care, hospice, paediatric

Reflective questions:

What models of learning best support paediatric nurses end-of-life and after death care knowledge, practice and communications?

Are the bereavement needs of a new parent different from that of a parent of a child or young person who lived with a life limiting condition?

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Introduction

Globally, an estimated 21 million children live with a life limiting condition and require access to paediatric palliative and hospice care (Connor et al. 2017). In Australia, the epidemiology is largely unknown (Bowers et al. 2020) with one Australian state reporting the prevalence of life-limiting conditions in children and young people to be 43.2 per 10 000 population (Bowers et al. 2020). The rising prevalence of life-limiting conditions in children and young people warrant the evaluation of paediatric palliative care and hospice services (Australian Government Department of Health 2018; Bowers et al. 2020) that are offered to paediatric consumers and their families to ensure that care needs are met. The initiation of palliative care may commence at the point of diagnosis of a child's life-limiting condition, and continues throughout the trajectory of the condition and into the grief and bereavement phase. This study aims to develop a deeper understanding of how extended viewing is experienced by parents of a deceased child or young person who lived with a life limiting condition, and secondly to evaluate the bereavement care delivered during the first few days after death.

The lived experience of a child's death is traumatic and life-changing for those left behind (Gijzen et al. 2016; Albuquerque et al. 2017; Jonas et al. 2018). Palliative care literature and clinical care guidelines strongly encourage parental involvement in the after death care of a newborn or child to improve parent's ability to cope, good outcomes for the family (Riches and Dawson 2002; Forster and Windsor 2014; Norton 2018) and acceptance of death (Brown 2007; Wijngaards-de Meij et al. 2007, 2008). Advances in technology have expanded parental involvement in after death care (Norton 2018; Hackett and Beresford 2021). The introduction of extended viewing in a purpose-built cooled bedroom within a paediatric hospice in the United Kingdom commenced in 1982 (Hackett and Beresford 2021) and in Australia in 2001. Further development of temperature-controlled rooms, mattresses, blankets and cots enable parents to have extended time to be close to their deceased child for the first few days after death (Brown 2007; Forrester 2008; Price et al. 2011). An increasing number of studies suggest that the use of extended viewing of a child or newborn is beneficial to parents' bereavement (Davies R 2005; Norton 2018; Ainscough et al. 2019; Forrester 2008). Australian studies have explored new parents experience of extended viewing of their newborn within an obstetric facility (Norton

2018) or have focused on health care professionals' communication following a child's death in a paediatric hospital or at home (Forster and Windsor 2014). To date, no Australian studies have explored parents' experience of extended viewing of a deceased child or young person who lived with a life-limiting condition in the first few days after death. Focused research and evaluation are essential to drive continuous learning and delivery of high-quality palliative and bereavement care within hospice services (Australian Government Department of Health 2018). Developing a deeper understanding of how bereaved parents of children and young people experienced extended viewing informs paediatric palliative and bereavement nursing care and practice.

Methods

Design

A descriptive qualitative study using semi-structured in-depth interviews were undertaken in April to July 2018. Descriptive qualitative research, for this study, was selected to explore a focused area of health research under-researched in an Australian paediatric setting (Willis et al. 2016; Digerolamo and Davis 2017) and is considered an effective method used to evaluate health care needs (Neergaard et al. 2009).

Study site

The hospice, and study site for our research consists of eight beds and includes a purpose-built temperature controlled cooled room providing a bedroom-like environment for families and invited friends to spend a maximum of 72 hours with the deceased child.

Participants

Parents of children who had died from a life-limiting disease and had chosen to utilise the cooled bedroom for extended viewing from January 2012 to January 2016 were considered potential participants for the study. A multidisciplinary team of palliative care professionals developed an ethically sound study inclusion/exclusion criterion. Families considered at risk of significant emotional distress and harm based on the clinical experience and expertise of the multidisciplinary palliative care team were excluded. All families that fulfilled the inclusion criteria and English proficient were sent an expression of interest invitation and information letter outlining the purpose of the study. Potential participants were provided with an option to opt-out to avoid unwanted contact (Butler et al. 2018) or a contact number to participate in the study.

Ethics

Ethical approval was sought from the specialist paediatric hospital's Human Research Ethics Committee (HREC/17/ 158) and ratified at an academic institution. Willing participants were asked to sign a consent form to complete a short questionnaire (six questions about service use) and to participate in an audio recorded, in-depth interview. Interviewing bereaved parents is a sensitive issue with ethical challenges (Rosenbaltt 2001; Dyregrov 2004). A distress protocol was developed and approved for implementation (in the event a family member became upset) as required by the HREC. The interviewer (SSL) observed the body language and voice control of participants for emotional cues to pause or stop the interview. Participants were supported to stop the interview as needed (Rosenbaltt 2001). All participants were provided with a debriefing session post interview by a professionally trained palliative care counsellor.

Data collection

Interviews were conducted by an experienced qualitative nurse researcher independent from the hospice. The neutrality of the interviewer adds to the trustworthiness of the data by limiting the biases, motivations, interests, or perspectives of the inquirer (Seale 2002, 2004). An interview guideline, informed by palliative care and bereavement literature and concepts were developed by expert palliative care nursing and allied health staff. Questions were open-ended with the opportunity for participants to describe their experiences to enrich the interviewers understanding. In-depth interviews ranged in length between 42 and 77 minutes excluding appropriate interview pauses. Interviews were undertaken until no new experiences were described (Jackson et al. 2003; Fusch and Ness 2015) ensuring that data was rich and saturated.

Data management

Participant characteristics and hospice utilisation were collected and entered a Statistical Package for the Social Sciences (SPSS, Version 25) database. Digital audio files were transferred to a password-protected computer for storage. Interviews were transcribed verbatim, de-identified and transcripts double-checked for errors.

Data analysis

Qualitative data were analysed using Braun and Clarke's (2006) six phases of descriptive thematic analysis (Gifford 1998; Sandelowski 2000; Braun and Clarke 2006). The researchers' logical approach to the data was inductive, allowing for data to be analysed and classified without preconceived ideas (Rice and Ezzy 2000). To increase the trustworthiness of the data familiarisation and open coding of data were independently completed

by three researchers. Data immersion and familiarization occurred through listening to audio files and reading of interview transcripts numerous times. Polit and Beck (2010) suggest familiarization and data immersion allows for content reflection, identification of key points and potential meaning of the data (Polit and Beck 2010). Open coding of the transcribed interviews aimed to look at the data through a process of reflection and questioning, noting patterns that lie within and across the data (Rice and Ezzy 2000). Codes and themes were strongly linked to the data rather than a pre-existing framework (Rice and Ezzy 2000; Braun and Clarke 2006; Willis et al. 2016). The researchers manually sorted through data to identify repetitive words such as “peaceful” similar phrases and patterns of parent experiences and views. Identified concepts were grouped into coded data. Understanding how codes and developing concepts connect and relate to the research question is an essential component of inductive logic and descriptive qualitative research (Braun and Clarke 2006; Willis et al. 2016). The three researchers met to discuss documentation of data coding and to explore key concepts and the relationships that exist between them. An audit trail of data documentation, methods and written decisions making processes were kept. An audit trail was kept to increase data dependability (Rice and Ezzy 2000; Seale 2004). Consideration was given to the context of each evolving theme and how each theme category influenced parent and carer experience of extended viewing of their child in the ‘cooled bedroom’. Broad theme categories were explored and discussed by all researchers. Broad themes were refined via a consensus-building discussion until dominant themes were identified (Sandelowski 2000; Jackson et al. 2003).

Results

Seventeen bereaved parent/carer of thirteen children agreed to participate in the study. Mothers (n=7, 46%) Father-Mother parent pairs (n=4), and Fathers (n=2) utilised the cooled bedroom for an extended viewing mean time of 47 hours (SD 26, range 65). Participating parents reported that their family had attended the hospice for palliative and/or respite care intermittently for close to two years (mean 21months, SD 36) with a mean of three admissions (SD 2.6). Data analysis revealed four dominant themes; 1. The nature of the physical environment, 2. Seeing their child, 3. Time to say goodbye and 4. Supportive care

The nature of the physical environment

All parents/carers emphasized the “homely feel” to the cooled bedroom; the tranquil, comforting and safe space.

So yeah ... it's a beautiful room...peaceful room. Even though it's a sad, tragic time the room it takes all of that away. And you just feel relaxed in there. (Mother, Interview 6)

The privacy of extended viewing in the cooled room enabled personal grief to uniquely unfold. Parent’s shared stories of empowerment and intimacy being able to personalise the room with their deceased child’s belongings. The recall of life-long positive memories, during extended viewing, were described in detail as if no time had passed.

“Afterwards..., which was an absolute Godsend. He was in his pyjamas and it was just like he was in bed. Well, if you'd taken a photo, you'd think it was the kid's bedroom. And he was asleep. He was asleep” (Mother and Father pair, Interview 1)

Parents compared their extended viewing experience to the observed hospital viewing experience of other families. Hospital scenarios were described as rushed ‘noisy’, ‘busy’, ‘stressful’, ‘clinically white’ emotionally scarring, impersonal, having a ‘clinical hospital smell’ and lacking compassion.

“We reached a level of acceptance in the viewing room and I don't know if we would've been able to get it in a hospital. Because I mean, [Child's name] nearly died in ICU hospital a couple of times. And it was terrifying but, it wasn't the same experience we had when we arrived at [name of hospice]. You know, the stress, a lot of interaction with ICU staff and noise and machines. And when he passed away at [name of Hospice] it was not that at all... quite the opposite” (Mother, interview 9)

Seeing their child

The transformation and physical bodily changes that all parents observed during the extended viewing period were described as comforting. Access to an extended viewing enabled parents the benefit of time to recognise change and to formulate lasting impressions of their child's "relaxed", "asleep" and "pain-free" face.

"and her droopy face wasn't there, and she was just looking very, you know, normal and pretty, it was just gorgeous looking at her." (Mother, Interview 2)

"it was just like he had gone to sleep. No tubes, no suctioning, no machines and his colour actually came back, it was a surreal experience. He looked like... so good and his siblings just loved the experience." (Mother, Mother and Father pair, Interview 13,)

Time enabled parent's acceptance, the reality of their loss and facilitated an understanding of the permanence of death.

"what time in the room t really helped me with was to, believe that she ...was gone and that she wasn't in that body anymore" (Mother, Interview 5)

Time to Say Goodbye

Extending viewing enabled parents and other family members to say goodbye to their child in their way and in their own time. The time within the cooled bedroom was uninterrupted with no rules, no appointments, and no personal demands.

It was just, it was comforting to know that we had that time. That there was no rush to get anything done. That allowed all the arrangements to be done without any pressure. But that comfort of being able to go in and out, you know, still have the time with [child's name]...for family to come, travel from wherever they needed to travel. Um, too- to see [child's name]. Um, it was just, yeah, the whole thing gave us opportunity to build more memories and just to allow the reality of the situation to settle in, as well. Because as much as you mentally prepare for it, you're never emotionally prepared for it (Father, Mother & Father pair, Interview11).

Time permitted parents to be present with their deceased child and to 'finish things' that were shared and important to them.

"I had said to him, "I'll finish this book" so I sat there with him for the next two days and basically finished reading that book, which at the end of it, I completely collapsed into hysterics and burst into tears, but, but it was really important to me that I got to do that" (Father, Interview 4)

Supportive care

Parents appreciated the opportunity to 'share their stories' and acknowledged the supportive role that hospice staff play during and after the extending viewing time.

"...There was always somebody to talk to. It was made very clear that you could come and talk to staff, 24/7 if anything was wrong or you had any concerns, ... You were made to feel welcome and, treated very sympathetically, and also with a lot of empathy" (Father, Interview 4)

For most parents, difficult conversations and education prepared parents to view their child after death and to anticipate the physiological changes

"one of the things that I also wanted to say was that the nurse, had explained to us the process about rigor-mortis and all that stuff. I didn't really expect he was going to be that cold, but before we went in, they had explained all of that to us, which was really, really helpful. I always laugh. ... I remember being in there, saying goodbye and I touched him. Because of the rigor-mortis, everything kind of goes soft." (Father, Mother and Father pair, Interview 1)

However, some parents/carer's suggested that the timing of education and orientation to the notion of extended viewing in a cooled bedroom was inconsistent or poorly communicated. Although parents were unable

to recommend the most suitable orientation time, a lack of information perpetuated fear and negative perceptions of the cooled bedroom as the “dead room”, largely known about but not discussed.

Because I don't like things where I don't know about them. So, I wanted to see the room and I wanted to, um, you know, get that fear out of my head. About what was going on there. (Mother, Mother and Father pair, interview 11)

“So the first time we stayed, we stayed in the room next door and remember some of the parents ...they'd go “You are staying next the dead room”. We're like...What? And we saw people coming in and out of the room and we didn't really understand”
(Mother, Mother and Father pair, Interview 1).

Discussion

To the best of the authors' knowledge, this is the first Australian qualitative in-depth study exploring parents' experience of extended viewing within a temperature controlled cooled bedroom. Findings reinforce the therapeutic benefits of extended viewing and the importance of a skilled palliative care nursing workforce. Whilst we acknowledge the complexity and individual nature of grief, four dominant themes were identified from parent interviews; namely, the importance of the ‘physical environment’ being conducive to spending time with their child, ‘seeing their child’, ‘time to say goodbye’ and ‘supportive care’.

The surrounding physical environment influenced parents first days of bereavement and long-term memories of their deceased child. Despite the room temperature, the ambience of the cooled bedroom was warm, safe and peaceful enabling parents to create positive memories of the last place that they saw their child. Our findings are consistent with previous studies that highlight the important interaction between the physical environment and parents grieving needs within the first few days (Dunbar & Cater 2021, Hackett, J 2021).

Dunbar et al (2021) describes how a sense of belonging and attachment to a physical environment provide a tangible sense of safety for parents to stay. Creating a tranquil space that is inviting to all family members is a recognised stand-alone bereavement intervention (Jonas et al. 2018). The long-term impact that the type of viewing (extended and tranquil versus brief and clinical) has on parent's bereavement is well documented in the literature (Barrera et al. 2007; Meert et al. 2009; Cacciatore and Flint 2012; Jonas et al. 2018). Contrasting

hospital-based studies report parental distress attributable to feelings of being rushed, an acute awareness of environmental sounds, hectic space and a lack of privacy (Davies R 2005; Meert et al. 2009). Davies (2005) suggests that the acuity of hospital-based patient care and the pressures of patient bed flow serve as a time and space barrier however, measures to meet bereaved family's needs, in any setting, are imperative to support parental bereavement and recovery.

Extended viewing enabled parents to see their child in a peaceful, relaxed and pain-free state in contrast to seeing the distorted facial expressions of a child living the harrowing effects of illness or treatment and death. Previous studies highlight that spending time with a deceased child allows parental recognition and acceptance that their child has died as they observe the physiological changes and absence of life (Wijngaards-de Meij et al. 2008). Parent's involvement and need to be near their deceased child during the first few days after death reduces the risk of complicated grief (Lobb et al. 2010) and enables parents to construct new visual memories of their child at peace (Riches and Dawson 2002; Davies DE 2005; Brown 2007; Wijngaards-de Meij et al. 2007, 2008; Price et al. 2011; Forster and Windsor 2014).

Participating parents described stories of memory making, the formation of connections and acknowledged the benefits of time to achieve a sense of readiness to say goodbye. Although parents said that they were aware of their child's condition and life trajectory, the reality of death and sense of loss was paralysing. Extended viewing offered parents an opportunity to process their child's death and adjust to their loss slowly. The time that parents spent with their child after death, in this study, varied from hours to days. The optimal amount of time is largely unknown, and likely to be unique to the individual family and scenario. However, forming memories requires time as does the need for parents to be close to their deceased child, allowing a period of assimilation and acknowledgement of the situation (Brown 2007; Price et al. 2011). Price et al (2001) suggests that time enables parents to separate calmly and progress into the next stage of relationship with their child (Davies DE 2005; Price et al. 2011). Encouraging rituals and continuing bonds with a deceased child, encourages post-traumatic growth rather than trauma (Barrera et al. 2009; Cacciatore and Flint 2012) and a sense of connectedness (Jonas et al. 2018).

Hackett J and Beresford B, (2021) suggests that extended viewing in a supportive care environment activates the emotional and cognitive processes of grief. Parents acknowledged that support was just 'outside' the cooled

bedroom. Adequate support after the death of a child cannot be underestimated in its power to help people readjust (Meert et al. 2009; Martinez et al. 2019). The care provided at the time of death and immediately after can have a significant impact on later grief processes (Harrington and Sprowl 2011). The thoughtful and practical support offered by staff after the death of a child plays a critical role in helping families cope with the devastating impact of their child's death (Koopmans et al. 2013; O'Leary and Warland 2013). Cacciatore et al. (2007) suggest that a healing component of the grieving process is facilitated by adequate support and compassionate care.

Some parents raised concerns around the inconsistent timing of education regarding extended viewing, after death care and orientation to the cooled bedroom. Consistent with previous studies, an absence of information and or inconsiderate responses perpetuated parental fear or distress and long-term impressions (Davies R 2005; Hackett and Beresford 2021). Society as a whole view the concept of death and dying as taboo and a topic of distress (Kennedy et al. 2017) which challenges the normality of such conversations. However, supportive bereavement care encompasses communication and education to empower parents with the knowledge and readiness to accept the inevitable physiological changes and transitions that are expected to unfold after death and during extended viewing.

Limitations

Strengths of the study include rich meaningful data, use of an independent qualitative nurse interviewer to ensure that families were open and free to provide negative feedback about their experience of extended viewing. However, there are some study limitations given that some families were excluded from the study for ethical reasons and that participating families were more likely to have had a positive experience opting to participate rather than opt out of the study. Although of interest to staff, it was not within the scope of this study to explore cultural beliefs of extended viewing.

Conclusion

Ensuring that current practices of extended viewing and bereavement care are evidence-based is central to the delivery of high quality pediatric palliative care. Our findings build on the limited body of palliative care literature and evidence, particularly in Australia, that demonstrate the therapeutic benefits of extended viewing for parents of their deceased children and young people. Given the benefits to parents, measures to overcome the barriers that hinder parental access to extending viewing in paediatric acute care hospital settings should be explored and researched. Finally, findings serve as a reminder that a trained and competent palliative care

nursing workforce play a pivotal role in the delivery of high-quality care, communication and education and therefore continuing professional development is recommended.

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