When a child dies in PICU: Practice recommendations from a qualitative study of bereaved parents

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Financial support:

This study was supported by the Australian College of Critical Care Nurses Novice Researcher Grant, and the Australian College of Children and Young People's Nurses Sister Mary Dorothea Sheehan Scholarship. A. Butler was also supported by an Australian Government Research Training Program Stipend (formerly Australian Postgraduate Award).

Copyright form disclosure:

Dr. Butler received support for article research from Australian College of Critical Care Nurses Novice Researcher Grant, Australian College of Children and Young People's Nurses Sister Mary Dorothea Sheehan Scholarship, and Australian Government Research Training Program Stipend. Dr. Copnell received funding from the Australian College of Critical Care Nurses. Dr. Hall disclosed that she does not have any potential conflicts of interest.

ABSTRACT

Objective: Around the world, the paediatric intensive care unit is one of the most common sites for hospitalised children to die. Although ensuring the best possible care experience for these children and their families is important, clear recommendations for end-of-life and bereavement care, arising from the parents themselves, remain limited within current literature. This report aims to describe bereaved parents' recommendations for improvements in end-of-life care and bereavement follow-up when a child dies in intensive care.

Design: Thematic analysis of incidental data from a larger grounded theory study.

Setting: Four Australian paediatric intensive care units

Participants: Twenty-six bereaved parents participated in audio-recorded, semi-structured interviews in 2015-2016. Interviews explored their experiences of having a child die in intensive care, and their experiences of end-of-life care and bereavement follow-up. Data pertaining to this report were analysed via thematic analysis.

Interventions: Nil

Measurements and main results: Bereaved parents identified several areas for care delivery and improvement across three time periods: during hospitalisation; during the dying phase; and during bereavement. During hospitalisation, parents' recommendations focused on improved communication, changes to the physical environment, better self-care resources, and provision of family support. During the dying phase, parents suggested private, de-medicalised rooms, familiar staff members, and support to leave the hospital. Recommendations for care after death focused mainly on the provision of ongoing support from the hospital or local bereavement services, as well as improved information delivery.

Conclusions: Findings from this study offer many concrete recommendations for improvements in care both during and after a child's death. These recommendations range from simple practice changes to larger organisational modifications, offering many potential avenues for change and improvement both on an individual healthcare provider level and within individual paediatric intensive care units.

Keywords: Bereavement; Child, hospitalised; Death; Health personnel; Intensive care unit, Pediatric; Parents.

INTRODUCTION

Each year, 2-10% of all children admitted to paediatric intensive care units (PICU) will die during their stay (1-4), making it one of the most common locations for children to die in hospital (5, 6). Almost universally, these children will be accompanied by a number of family members, such as their parents or guardians, their siblings, their grandparents, or other members of their extended family. It is well known that the family experiences of their time in hospital can have significant and long-lasting impacts on their memories of their dying child, and their subsequent bereavement journey (7 -10). Within the current literature, there are many recommendations for improvements in end-of-life care delivery from qualitative studies exploring parental experiences, most commonly focusing on elements such as communication, the provision of resources, or having ‘compassionate’ staff members (11-14). However, the recommendations made within research reports are often vague, with little discussion of how to translate these into actual, meaningful, clinical change. Many authors, for example, suggest ‘improvements in communication’, without articulating what this means for changes to current clinical practice. In order to begin to address this gap, this short report offers explicit recommendations for improvements in end-of-life care delivery and bereavement follow-up, as suggested by bereaved parents themselves.

MATERIALS AND METHODS

The Bereaved PICU Parent Study utilised a constructivist grounded theory methodology to explore 26 bereaved parents’ experiences of their child’s death in one of four Australian PICUs, and their interactions with healthcare providers during this time. A detailed description of our recruitment methods (15), and the main study findings (16-20), are available elsewhere. Briefly, bereaved parents were contacted via mailed letters or hospital-based social workers 6-48 months after their child’s death and were invited to take part in semi-structured, audio-recorded face-to-face or telephone interviews with the first author, a PICU nurse and qualitative researcher. Interviews with 18 mothers and 8 fathers of 18 deceased children were conducted during 2015 and 2016, focusing on parents’ experiences in PICU and their interactions with the healthcare staff.

During their interviews, many parents spontaneously offered suggestions for improvements in end-of-life care or bereavement follow-up. These comments were treated as supplementary data, with thematic analysis used to identify key themes within the parents' recommendations (21). All interviews were transcribed verbatim and entered into NVivo 10 for analysis by the first author. Line by line coding was undertaken, enabling familiarisation of the data. Further analysis and coding undertaken by the research team then enabled the collation of similar codes into concepts and categories. The use of diagrams enabled the identification of similar categories, which were then organized according to various timeframes within the parents' journey.

This study was reviewed and approved by the 4 Human Research Ethics Committees. Written informed consent was provided by all participants prior to their interviews.

RESULTS

Parents' recommendations pertained to three key time periods across their journey: during hospitalisation, during the dying phase, and during bereavement. A brief overview of the parents' key recommendations within each of these time periods is described below, and outlined in Table 1, with supporting illustrative quotes provided in Table 2.

During hospitalisation

Bereaved parents emphasised the need for honesty. They wanted to be clearly and directly told that their child's chances of survival were limited, as early as possible, using unambiguous language. Parents also suggested all information be both oral and written, including the use of pictures and diagrams, and reiterated multiple times to enhance recall and understanding. In addition, parents recommended the provision of a parents' respite room that included snacks, toiletries, facilities for showering or washing clothes, and phone charging access. The provision of meals and overnight accommodation was also commonly noted as important, as were improvements in car parking facilities and costs, easier access to the PICU, and bigger rooms with more natural lighting. Finally, though parents felt supported by the staff in the hospital, they recommended referral to appropriate community-based support services (such as counsellors, bereavement or disease-specific support groups, or pastoral care workers) earlier in their child's illness, as well as improved support and resources for the sick child's siblings.

During the dying phase

When their child was imminently dying, most parents preferred to be in a private room out of the main thoroughfare, which had natural light, was large enough for other family members to visit, and was de-medicalised as much as possible. Parents also recommended continuity of carer for all end-of-life discussions and life-support removal. Creation of mementos, particularly photos, was also commonly mentioned.

Parents also strongly recommended that staff members continue to stay with them after their child had died. They wanted assistance to wash their child, pack their belongings and walk out of the PICU and to their cars. A waiver of car parking fees was also commonly suggested. Additionally, many parents suggested improved information about visiting their child in the morgue, and an improved visiting room to spend time with their child's body after they had left the PICU.

During bereavement

All parents strongly recommended that follow-up care, such as phone calls, letters, meetings with staff, or staff presence at funerals, be routinely offered. Parents stressed the importance of including the whole family in follow-up care, not just the mother or the person who answers the phone each time, and recommended that follow-up begin a few days after the child's death and be gradually tapered off over 12 months.

In addition, parents wanted more information about what happened next: going home, planning a funeral for a child, the post-mortem examination, normal grief symptoms, and attending counselling or bereavement support groups. They also suggested they be given lists of local bereavement services as they were leaving the hospital, or a few days later during bereavement follow-up. Finally, some parents recommended connecting newly bereaved parents to others who have also had a child die, either through a hospital-based bereavement support group or via a parent buddy-system.

DISCUSSION AND CONCLUSION

The findings from this study offer many avenues for improvements in care delivery both during and after the time a child dies in the PICU, suggested by bereaved parents themselves. Generally, our findings reflect common themes identified in both PICU and general paediatric end-of-life care delivery over the past two decades, including the need for improved communication, better provision of resources for families of hospitalised children, the need to create mementos, and the strong need for provision of bereavement aftercare (9, 11, 22-25). Despite the relatively simple, low cost nature of many of the suggestions to improve care delivery made by bereaved parents across more than 20 years of research, our findings would suggest that the translation of these recommendations into clinical practice has not been well achieved, or has not been implemented in ways that are meaningful to the parents themselves. Whilst it is understandable that saving lives is prioritised in the allocation of resources, many of the recommendations made by bereaved parents are low cost and do not require significant allocation of either staff time or PICU or hospital funding. The reasons why it still remains challenging to implement these recommendations are unclear; further research is needed to pinpoint the barriers and identify ways to overcome them.

As such, we believe it is time to shift the focus of research away from exploring the experiences of bereaved families and move towards integrating recommendations of both researchers and families into clinical practice. Our findings offer many concrete suggestions that could be easily integrated into daily practice. Whilst we do not advocate for the standardisation of end of life or bereavement follow up care, the recommendations provided here may be helpful to staff when exploring the needs of individual families and the possible services or interventions that may be offered to them.

Some interventions, such as the provision of written information to supplement face-to-face discussions, are relatively simple but may help to improve parents' perceptions of communication and care. Other recommendations are more difficult to implement and may require longer term planning and institutional change, such as the development of dedicated bereavement follow-up services or the provision of continuity of carer during end of life discussions. Whilst it may not be feasible or even desirable for each PICU around the world to implement every suggestion made by the parents in this study, it is important to strive for the implementation of evidence-based care delivery despite the challenges it may pose. We need to begin to close the gap between research and practice by developing parental recommendations into achievable, realistic interventions, so that meaningful improvements to parents' end of life and bereavement care experiences can be achieved.

ACKNOWLEDGEMENTS: Nil

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Table 1. Bereaved parents' recommendations for end-of-life and bereavement care.

During hospitalisation	**During the dying phase**	**During bereavement**
Information and communication • Ensure open and honest communication • Clear, early discussions of the likelihood of or potential for death • Offer tacit 'permission' to withdraw life support • Provide verbal and written/visual information, including picture and diagrams • Maintain a photo board introducing the staff working on each shift *The provision of resources* • Provide a parent room with bathrooms, kitchens, a laundry, snacks, toiletries, phone chargers, internet access and comfortable seating • Organise/assist with ordered meals for parents/siblings • Provide parent accommodation within the hospital, close to the PICU • Improve parking facilities, with reduced cost for families of critically ill children *The environment* • Orientate parents to hospital and local community services (supermarkets, restaurants) • Improve environment: natural lighting, bigger rooms, more colour • Make PICU entrance processes simpler and easier • Place a window in PICU entrance doors • Give explanations when asking parents to wait outside *Support* • Refer/connect parents to external support services as early as possible • Provide a support worker for siblings • Offer assistance explaining the situation to siblings	*The hours before death* • A private room in an unobtrusive, quiet area of the PICU • De-medicalise the environment as much as possible • Provide space for extended family/friends • Allocate a familiar nurse and doctor • Offer professional photographs of the child *The hours after death* • Provide ongoing parent support from staff in the hours after death • Provide information on how to visit the child in the morgue • Improve the visitation room within the morgue • Walk parents out of PICU and to their car • Assist with transport home for parents • Waive parking fees for bereaved parents	*The delivery of follow-up care* • Ongoing contact with staff familiar to the family • Staff presence at funeral • Ensure whole family is followed up • Timing of follow-up: 1 week, 2-3 months, ongoing for 12 months • Specific attention to anniversaries or special dates (e.g. birthdays, mother's/father's day) *The provision of information* • Give a list of local funeral directors, counsellors, and grief groups, who specialise in children's deaths • Provide a "What happens next?" guideline, both for the post mortem examination process and for organising funerals/going home. • Be cautious with how much information is given • Clearly label all mail correspondence with sender and contents *Connecting to other bereaved parents* • Organise a parent support group for bereaved PICU parents from the hospital • Develop a 'buddy system' for parents in hospital before their child dies

Table 2. Illustrative quotes

Time period	Illustrative quotes
During hospitalisation	
Information and communication	“It would have been nice if there was some sort of board up to say such and such is on duty and this is this person, with maybe a picture” “I feel like they could have been a bit more straighter, just kind of said to us, you know, “Her chances of survival are very minimum”.” “Give us handouts to explain, you know, so, you know, they’d tell us and then they’d give us a handout ... You know, they had [condition], so they’d give us a handout on that.”
The provision of resources	“A few things like parents’ rooms where they can stay, I think that’s really, really important.” “A parents room or something where you could have a shower or do laundry and do whatever you needed to, have a cuppa.”
The environment	“Some rainbows and balloons and on the walls … got a blank wall, put a scene on it, you know, something fresh and colourful.” “A couple of lounges that where in [inside the PICU], so you could leave but easily get back to your child. There wasn't a door separating ... a locked door separating you.”
Support	“I definitely think that would be an avenue for consideration of having some key worker or someone allocated to support the siblings.” “I think we should have been put in contact with heart kids as soon as [the child] was diagnosed with a heart condition. I think we could have used their services more.”

During the dying phase	
The hours before death	“It would have been nice if you had a room with another room off it so that each member of the family can be privately with them, without sort of standing out on show” “It would have been a good idea, having the professional photos done.” “Get a proper old crib just to put him in, just a normal … not one with bars or anything, just a normal plastic one.”
The hours after death	“Even if the body needs to go and you need to do the bed and everything like that, maybe if there’s a room that you could say "Okay if you'd like to, we can gather your things and take you through to the family room or whatever, have a sit there for a couple of hours if you need to"” “Someone to maybe just even say, look we'll just come home and make sure you get home and everything is okay.” “The morgue could have been better set up. The room was quite stark, quite foreboding almost ….. Just to me it felt like there should have been a little bit more brighter or a little bit more warm, if you know what I mean? Whether it was curtains on the wall or furniture or whatever.”
During bereavement	
The delivery of follow-up care	“If the main nurse then goes to the funeral … I mean I think that’s wonderful and even if they made a phone call after a week just to check in and see how you're going and to say they're thinking of you” “It didn’t cross my mind at the time, but if they had of, offered, you know, “How’s your partner doing?” you know, “Does he need any help?” Because if that had of been, even though I didn’t think of it, if that had of been offered to me I would have said, “Absolutely…”” “So it’s like it's [follow up bereavement support] there if you need it. It might not be now, it might not even be tomorrow, 12 months, 2 years, but when you hit that wall, and you need it, it needs to be there.”

The provision of information	“That sort of stuff that came in the mail I found a little bit.....I dunno. It's like when you got the paperwork from the coroner, at least it was in an envelope that gave you warning, it was kind of double wrapped. Basically. And that was fine.” “Maybe if somebody had said to me, well this is what might happen and if she goes to the coroners court she might be there for so many weeks and yeah just having that information there of possibilities of what may have happened, if she hadn't have gone to the coroners court, how soon would she have been released from the morgue or how soon could I have organised for the [funeral directors] to pick her up.” “You almost need "Here are the top 10 numbers of the counsellors, here's the details of the funeral stuff, you know, look at it when you're ready"”
Connecting to other bereaved parents	“They could turn around and have a support group at the hospital for the parents who have lost children. They … you know, you could do it like once a month or something.” “It would have been nice to have some sort of bereavement there, even if it was just to meet another family or another parent who can turn around and say, “I’ve been where you are””