



Family-centered care and pediatric death in the emergency department: A qualitative study using framework analysis

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ABSTRACT

Background: Family-centered care is an important concept underpinning care of children. Although much researched in some settings, little research has explored specialist settings, or areas where both children and adults are cared for, such as the emergency department.

Methods: This study sought to explore how nurses employ family-centered care in delivering care to children and families when a child dies in the emergency department. Using a descriptive, qualitative approach, semi-structured interviews were conducted with 24 emergency nurses from six Australian states. Interviews were audio-recorded and transcribed verbatim. Framework analysis was applied to examine alignment with family-centered care principles.

Findings: Nurses described providing support and education, and encouraged families to engage in care decisions, including about ceasing resuscitation efforts. Commonly, senior staff members were allocated during emergencies to support parents.

Discussion: Emergency nurses should be offered education on family-centered care, and research undertaken to explore families' experiences of their child dying in the emergency department.

Practice Implication: Family-centered care should be a focus for the care of children and their families in the emergency department, regardless of the pressure from rapidly occurring events.

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Whenever a child is admitted to a health care service, families are inevitably impacted. The concept of 'family-centered care' (FCC) has been recognized as an approach that considers and plans care around the whole family, rather than the individual child (Smith, 2018). In FCC, care providers work in partnership with families (Rawson & Moretz, 2016), recognizing that families are a constant in the child's life (Coynne et al., 2018), and that the result will be delivery of higher quality care (Christian, 2016; Coynne et al., 2018). FCC is widely regarded as the optimum model of nursing care delivery in both hospital (Hengeveld et al., 2020; Smith, 2018) and non-hospital settings (Ridgway et al., 2020).

However, a number of tensions and challenges have been reported to affect the delivery of FCC. These include a lack of clarity or understanding of the concept (Alabdulaziz et al., 2017), entrenched practices and power imbalances between families and health professionals (Smith et al., 2015), along with lack of recognition of parents' knowledge and experience (Smith et al., 2015). Other studies have identified

racial and ethnic (Boztepe & Yildiz, 2017; Guerrero et al., 2010), as well as geographical (Feeg et al., 2016) differences in how FCC is interpreted and practiced. In a study of nurses working with children in Ireland, Coyne et al. (2013) found that nurses supported FCC but had difficulty implementing it in their clinical practice due to organizational constraints. In another study, Mirlashari et al. (2020) explored physicians' and nurses' views on implementing FCC in neonatal intensive care in Iran. They found challenges relating to power imbalances between parents and physicians, psychosocial issues and organizational limitations that challenged its application. However, a grounded theory study of parents in a pediatric intensive care unit (PICU) in the US found that nurses were challenged in providing FCC as they sought to enforce explicit and implicit hospital rules that hindered parental input in decision making (Baird et al., 2015).

While FCC is widely applied in dedicated pediatric areas, it is recognized that children are not only patients in pediatric units but in more general hospital settings. In a study of adult-trained perioperative nurses' application of family-centered care, Hamilton et al. (2014) found that nurses generally supported the idea of parents being involved in the care of children in the perioperative environment. However, this support was not based specifically on FCC principles, rather on perceptions that caring for children was stressful and challenging,

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and that parents could help with allaying a child's distress. Study participants reported a lack of training and experience in caring for children. Similarly, in a study of nurses in a mixed adult and pediatric intensive care unit, working with children's families was found to be particularly challenging with physical, cultural and institutional factors impacting on nurses' abilities to provide appropriate care (Butler, Willetts, & Copnell, 2015).

The care of children in the emergency department requires care providers to effectively manage acute health crises, quickly develop therapeutic relationships with families and work effectively as a team (American Academy of Pediatrics et al., 2014a). It has been suggested that the application of FCC in the emergency department can improve parents' satisfaction and involvement in decision making, as well as family presence during procedures (Brown et al., 2008; Piskosz, 2007). A qualitative study with 68 parents of children accompanying their children to the emergency department of a large US pediatric health service sought to explore dimensions of FCC valued by parents (Byczowski et al., 2016). The findings revealed eight key dimensions that could be used to measure it, namely: (i) emotional support, (ii) coordination, (iii) elicit and respect preferences and involve the patient and family in care decisions, (iv) timely and attentive care, (v) information, communication and education, (vi) pain management, (vii) safe and child-focused environment, and (viii) continuity and transition.

The death of a child in the hospital has been described as disempowering for parents due to the environment and equipment (Butler, Hall, et al., 2015b). A child's death in the emergency department is most often sudden, and particularly traumatic for parents and the team providing care but is also complex. The American Academy of Pediatrics et al. (2014b) state that 'the death of a child in the emergency department (ED) is an event with emotional, cultural, procedural and legal challenges' (p.198). Amidst arising emotional trauma, such situations commonly require conversations about termination of resuscitation, organ donation, and coronial investigation (American Academy of Pediatrics et al., 2014a). Studies have been conducted into parents' experiences and needs when their child dies in PICUs and general wards (Butler et al., 2018; Butler, Hall, et al., 2015c). In these settings, Butler et al. (2018) describe how the relationship between parents and healthcare providers evolves according to parental needs at different points in a dying child's care. However, in the emergency department context, there is little time for such processes to occur. To date, there has been no literature on nurses' implementation of FCC in the emergency department involving the death of a child. Hence, as part of a larger study exploring pediatric death in the emergency department (Shimoinaba et al., 2021), this study sought to explore how and whether FCC is implemented in the context of pediatric death in the emergency department.

Method

Research design

A qualitative descriptive methodology was used employing semi-structured interviews. Eligible participants were nurses working in any Australian emergency department. The peak professional body for emergency nurses in Australia, the College of Emergency Nursing Australasia (CENA), forwarded an email to its members inviting participation and asking for the email to be forwarded to colleagues who may be interested in participating. Nurses were asked to contact the research team by email if they wished to participate.

Individual semi-structured interviews were conducted with 24 emergency nurses across remote, regional and urban settings in six Australian states, guided by an interview schedule. Questions covered frequency/number of deaths experienced, the individual's role, how equipped they felt, availability of support, counseling and debriefing systems, and family inclusion. All had at least one experience of caring for a child in the emergency department who had died or was declared

dead on arrival. Each participant was interviewed once, in a location of their choosing; one interview was conducted by phone. Interviews, lasting between 45 and 60 min, were conducted by an experienced post-doctoral nurse researcher and audio-recorded. Recordings were transcribed verbatim by a professional transcribing service. Data saturation was achieved by interview 20 whereby there was sufficient data for elements of the framework; however, given the nature of the research we proceeded with interviews for an additional four people who expressed interest in participating.

Data analysis

A framework analysis approach was employed to analyze interview data. Framework analysis is an approach to qualitative research whereby a structured framework is applied to the process of analysis. It has been identified as particularly beneficial to process transparency and enabling understanding of social and policy issues (Goldsmith, 2021; Smith & Firth, 2011). In order to understand how family-centered care was applied in care of children dying in the emergency department, the chosen framework utilized the eight dimensions of family-centered pediatric emergency care formulated by Byczowski et al. (2016) in their study exploring what was important for parents with children receiving emergency care, as described above.

Ethical considerations

This study received approval by the relevant university human research ethics committee. To be eligible to participate, individuals needed to have experienced the death of a child whilst working in an ED. Written participant information about the study and participation was provided before individuals agreed to participate. Verbal explanations and written informed consent were obtained prior to commencement of each interview. Given the sensitive nature of the interviews, participants were provided with contact details of support organizations should the interview process initiate distress about their experiences. No participant or organization is named in reporting the findings. Pseudonyms have been used to protect participants' identities.

Findings

Of the 24 nurses participating in interviews, 18 were female, the majority worked in urban hospitals and in mixed EDs. None were under 25 years old, and half were 46 years or over, hence presenting significant nursing experience (Table 1). Overall ED experience ranged from 15 months to 38 years and 17 were also parents. Nineteen worked in mixed EDs, while five worked in specific pediatric EDs.

From the analyzed interviews, seven of the eight categories described by Byczowski et al. (2016) were described, with all participants describing at least one category. Pain management was not raised by participants, which could be expected given the focus of the study.

Table 1
Participant demographic characteristics.

Characteristic	N = 24
Gender	
Male	6
Female	18
Age	
<25 years	0
26–35 years	6
36–45 years	5
>46 years	12
Unknown	1
Location of work	
Rural/remote	1
Regional	9
Urban	14

Emotional support

As would be expected for practicing nurses, many participants described how they provided emotional support for families experiencing death of a child. This was seen as the nurse's role, or that of a social worker if one was available:

...talking to patients is assumed that we're nurses and we should know how to do that or it's a social worker's role.

[(Susie)]

Usually the team leader of the emergency department or the social worker or there's someone allocated to a role to deal with the parents...so the parents do get, um, supported, usually with a social worker and a nurse, and that nurse is usually someone that's supernumerary on the floor, at that point.

[(Joy)]

Participants described times when nurses' provision of support often became an overt expression of their own emotions and a strategy for providing support:

I will often let them see that I am upset, like, I never cry to the point that I need looking after and I never cry while there's still a job to do, but I don't have a problem letting some tears out and have had that positively received from parents, that they can see that I'm moved by the death of their child.

[(Anastasia)]

Well you support them. You hug them, you cry with them, you give them a cup of tea and you support them. You ask them what else they need.

[(Daisy)]

Coordination

Coordination of emergency situations is a common occurrence for emergency nurses and this included involving families:

We usually try, if we can get the parent at the, to the head of the bed. If we can actually get them in there, so they can actually talk to their child while things are happening.

[(Kim)]

In the case of resuscitation situations, coordination of parental or family involvement was an important aspect, along with key support such as pastoral care, social work and nurse managers:

Where possible, we facilitate parental involvement in a resuscitation and that there should be a staff member allocated to, supporting them and it's true that when the child first comes in and ambulance are trying to hand over and all sorts of things, we do usually put the parents in the parent room. We immediately call social work, we immediately call pastoral [care].

[(Anastasia)]

However, given speed of activity in these situations, this was not always possible, was of lower priority or became overlooked:

But in traumas for example, when I've been nursing team leading the resus, and we haven't, and the child's come in quite quickly, we haven't had a chance to get social work, or we've had to start managing things very quickly, I've had to – or a child's been running from triage to the resus area, I've had to find a minute to stop, and when I've seen this parent either falling to pieces or looking shell shocked, say to them, this is what we're doing, and this is what we're going to do from here. One of

the doctors will come and explain things from a clinical perspective well.

[(Ann)]

I find that it's very much with the child itself, it's very much...auto-pilot. There are certain protocols, certain procedures that get done at certain times and you just do that.

[(Scott)]

Elicit and respect preferences and involve the patient and family in care decisions

Most participants were conscious of the need for families to be involved in decision making, particularly in relation to continuing resuscitation and ensuring they saw that everything that could have been done was done:

...you'll often have parents begging for longer and you'll often go on longer despite what you know is the outcome and then, at some point you can see that the parents understand it... that everything has been done...you'll go on because parents are wanting, you'll go on 'til...it feels like the parents are ready for you to call it too.

[(Christie)]

...we will continue for 20 more minutes so that that mother can see that we did everything we needed to. And so we, I advocated on her behalf... Mum arrived and she was able to see 15 people in a room doing everything they could and was, you know, part of the conversation with dad when we withdrew our care and things like that.

[(Anastasia)]

I talked to the mother and tried to keep her informed what was going on, and so did our doctors...But we kept trying to involve her, we'd be doing something and she'd move out of the way. We'd say no, no, come and stay, come and stay. She was singing to her. I remember that. It was... she was sitting with her and singing to her.

[(Bronwyn)]

I think it's just instinctive, but I've always liked the family to be present when we're doing resuscitations and I always would advocate for that in our ED even though we don't have a formal policy about that. I just think it helps for them to see that everything's being done in what can possibly be a hopeless situation.

[(Matthew)]

Culturally, there were often necessary rituals and these were facilitated by advocating staff:

We put the child in a side room and the elder came in and the family was there and there was a whole group. And everybody else was going oh there's so many people in there, and I'm going no, no, that's their culture, that's okay. Let's just let them do it this way. And yes, finally, eventually after they'd done what they needed to do they left.

[(AliceLouise)]

Timely and attentive care

Even though pediatric resuscitation and/or death was not an everyday occurrence, participants all described how they sought to provide timely and attentive care, including after the child had died:

We are going to help and also this is your child and I am invested in caring for them even though we've stopped doing CPR and things like that...and very gentle, and I use the child's name and I continue to talk to them and, it's often me that has to pick them up the first time and give them to the [parent], I always make sure that ... I treat that child the way as, I would if it was still alive, for them, as much as possible.

[(Anastasia)]

Furthermore, the nature of care for children was seen to be more complex in how it related to the age of the child:

In pediatrics you have the stress of trying to extend your scope and trying to provide really high-quality care which you might not have done for multiple months, coupled with the fact...that's a tiny baby, that's a three-year-old, you know, things like that.... Oh, here are some acutely grieving people right in front of me, and we're much better at having family presence in pediatrics than we are in adults, so it's much less common in adults for there to be someone sobbing in the room with you, you sort of have that barrier from them emotionally as well.

[(Anastasia)]

Information

All participants described the importance of provision of focused information for parents and families. This was a primary role for senior nurses and doctors both during and after emergencies:

Whoever is on call...they come in and sit with the families and things like that. But as far as for when they're in the room, we just try and find a staff member to be with them...so they can explain and also ensure that they don't...encroach on our resuscitation.

[(Anastasia)]

They will always take a Senior Nurse in with them to have that conversation and usually the person allocated to the family ideally would be the most senior person in the room who's not needed clinically.

[(Christie)]

...that's often explained several times... "we'll do this but if it's not successful...we're going to try this, we're going to do that, we're going to do this", and then eventually they'll understand. If they're trusting the resus they'll understand that everything was tried.

[(Christie)]

Social workers also played an important role in many settings, particularly after death had occurred and where a coroner's investigation was required:

The social worker's involved with...the counseling of the parents and giving them the information on how the coroner works and all of that sort of stuff and the coroner's come and collect them and they go off. But our social workers tend to follow them up afterwards as well.

[(Kim)]

Ewan described the balance between providing emotional support and information:

We said we've tried this...a balance between giving emotional support but also some ... data on like clinical things of why this is stopping to there, and...I know you might be upset but we're going to stop this because there's no you know, blood left, or you know she's not responding to those, heart's not pumping, there's no activity.

[(Ewan)]

Communication and education

While information provision was important, there was a need for more detailed information and education for families about many clinical aspects, such as presence of monitors or tubes:

We're starting to get some family involvement...to have the staff there to explain what's going on...Because you can imagine that if somebody's being intubated or if we are having six or seven attempts to cannulate or we are having to put in the intraosseous, it can look quite barbaric and if you don't have a staff member to say "This is routine practice, this is why we're doing this", it would almost look torturous.

[(Susie)]

So, say the child's died, then we still bring the families in, or even after we've revived them and they're just waiting for ICU or something like that, we get them in and we explain what the breathing tube is, what's all the monitoring and what's running in the pumps and why and things like that and that comes, usually from the resus team leader. So, they do need to learn that skill of being able to tell the family what's going on.

[(Amy)]

We make sure that we have someone designated to touch base with the family either in the room...or out of the room as well...to say, "This is what we're doing now. This is what this medication is. This is what we're trying to do."...just to have that constant support they know that someone's talking to them in a way that they can understand.

[(Patrick)]

Safe and child-focused environment

Family presence was not always limited to parents. On some occasions, siblings were present during emergencies. Hence, while the focus was on the patient, there was a need to provide a safe and child-focused environment to support siblings.

We got the phone call saying we've got a two-year-old found floating in the dam. CPR in progress. The mother was there, the social worker was there. She brought her boys in. She had three older boys... Brought her older boys in to see her. She was there most of the time.

[(Bronwyn)]

And there were times when the dad had to go and do paperwork and stuff, and we would just sit with the sister, or take out and sit with her, or make her a sandwich or a Milo or something and chat to her, or just let her sit on a lap and give her a hug, and just let her sob, just support like you would being an auntie or a friend or something.

[(Gwen)]

Kim and Mary described the importance of siblings being able to be in the room and opportunities to say goodbyes:

...we have no issues with bringing siblings in to say goodbye..., because...cause kids have really good, imaginations. And what they imagine is far worse than what is generally, reality. So, if they're allowed to come and say their goodbyes and see, their brother or sister before they go, it makes it easier for them to tuck it away and move on and grieve properly as well, without imagining what things were like.

[(Kim)]

...when the resus stopped and he was declared deceased, I said to mum and dad, do you want to come and just sit with him and give him a

cuddle and everything because, as you know, it will be a coroner's and we can't take tubes out... His sisters all wanted to give him a cuddle and all the fluids coming out of the tubes, so putting cotton wool in the tubes and making sure there was a nappy on. They all sat and cuddled and took some photos with him wrapped up. We wrapped him up in a nice, bright, in his bunny rug blanket and stuff.

[(Mary)]

Continuity and transition

Participants described the challenge in being able to assist families to transition from the emergency department, including leaving their deceased child behind. They outlined the need to build trusting relationships with parents to facilitate this:

...they can't take their child home and so, at the end the vast majority are like, thank you, I feel so comfortable to leave my child with you, thank you for the quality care that you've given. Like I take it as my point of pride to show them how much I am looking after, because they obviously have to step out while the coronial police come and so I've always made sure that I've built enough rapport to say I'm going to stay with your child, you know, I'm going to stay, I'm going to watch over them while the police are here. When you are ready and they've finished to come back, I will have your child ready for you to hug and hold and you'll be able to do many more, you know, because they've obviously always got tubes and mess and things like that.

[(Anastasia)]

I always make sure that they know I'm on their...team, I'm invested in caring for their child, which means that they're much more comfortable to leave the room for the coronial enquiries and then also to go home to their house without their child for that first time, usually unexpectedly, that they feel comfortable to leave their child with me through showing them that I am just as invested in this process as they are.

[(Anastasia)]

I always tried to make sure that they spent as much time with the baby as they needed, um, and that that was ah, my role once that patient died was to give them the best, them and the family the best care they could have at that time because this was the last time they were going to have that.

[(Emily)]

Discussion

Emergency departments are busy and unpredictable settings where cases appearing are acute and sudden, and requiring triage. While not commonly occurring, emergency nurses occasionally face the death of a child. This study sought to explore how emergency nurses enacted FCC when caring for a child who died, using a framework developed by Byczowski et al. (2016) around what parents want and value in pediatric emergency care. We chose this framework as it was particularly designed for emergency settings. Findings indicated that participants worked to provide emotional support, including through showing their own emotions, coordinated the emergency management, demonstrated respect for families' involvement and decision making, including siblings, and provided communication and education. Following the child's death, they also provided support through families' transitions to leaving their child at the hospital and coronial and other investigations. The care provided during this time is fundamental to parents' experiences and the memories they hold of their child's death (Butler, Hall, et al., 2015c).

In this study, elements of FCC were evident in the experiences of nurses, but sometimes ad hoc rather than planned. We found that

there was variation in how, and the degree to which, participants described interactions with families. Some settings provided a staff member, usually senior, to stay with parents at the back of the resuscitation room or positioned the parent at the child's head where they were able to talk with, or even sing to, the child. Having a specific staff member allocated to parents enables provision of emotional support and explanations throughout resuscitation (Piskosz, 2007). Notably, staff also described encouraging sibling presence, particularly after the death of a child. Gill (2020) argues that this is important to avoid potential adverse psychological or developmental outcomes for siblings, and reinforces the need for focus on sibling inclusion, need for emotional and social support as well as education.

Despite elements of FCC being present in nurses' accounts, there is need for greater consideration of FCC in the emergency department particularly in cases involving death of a child. While this study demonstrated that nurses enacted elements of FCC in their work with families these were not necessarily intentionally or overtly applied here. Smith (2018) asserts that there is a lack of education for nurses in operationalizing FCC, and our findings suggest that education for emergency nurses around its application is recommended. In a study of neonatal nurses and parents, there was strong support for FCC; however ongoing education and organizational support were identified as necessary in enabling its implementation (Trajkovski et al., 2016). According to October et al. (2018), after the death of a child, parental care should incorporate immediate support, a follow-up plan, screening for complicated grief or other serious reaction, a subsequent bereavement meeting, and support for the healthcare team in providing aftercare for families, such as through dissemination of information about memorial services, and support of extended staff in the hospital.

To date, there has been scant research attention paid to the complex area of pediatric death in the emergency department and the provision of optimal care for families during these deeply traumatic experiences. Hence, there is a clear need for more research to explore best practice family-centered care models in these situations in order to develop appropriate practice guidelines. Given this study only explored the issue from nurses' perspectives, studies exploring parents' experiences would be invaluable. Furthermore, the majority of our participants were experienced/senior nurses. Hence, the experiences of junior or less experienced nurses may be different.

There are limitations associated with this study. While there were participants from six states in Australia, emergency department care may be different in other countries. It is also possible that those nurses who volunteered to participate had particular experiences and an overwhelming need to discuss or debrief them and saw participation as a mechanism for doing that. Hence, the nature of their experiences might be different to others who did not participate.

Conclusion

Death of a child is difficult for care providers regardless of the context. In the emergency department, this poses additional challenges through emotional interactions with families, coronial and other investigations. Using framework analysis, this study examined emergency nurses' perspectives on the death of a child in the emergency department. It demonstrated how family-centered care is enacted in these settings along with its unique challenges. Further research is needed to explore families' experiences of the death of a child in the emergency department, while education for health professionals around facilitating FCC in the setting is needed.

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CRediT authorship contribution statement

Lisa McKenna: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing – original draft, Visualization. **Kaori Shimoinaba:** Conceptualization, Methodology, Writing – review & editing, Supervision. **Beverley Copnell:** Conceptualization, Methodology, Writing – review & editing, Supervision.

Declaration of Competing Interest

None.

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