

# Bereaved parents' experiences of paediatric end-of-life care: a multi-site qualitative study across the UK

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# Background

- In the UK >4,300 infants, children and young people die each year, ~50% in NICU, PICU and Cancer centres.
- Limited evidence on how care is experienced by parents and how this differs by setting.
- Bereaved parents at higher risk of poor mental and physical health outcomes.
- Published guidance must be underpinned by high-quality up-to-date evidence.
- Several frameworks and guidance, however draw on low quality empirical evidence.



# Methods

- **Aim:** To explore parents' experiences of receiving end-of-life care for their child.
- **Design:** Qualitative study, across all UK nations.
- **Setting:** Account for the place of death of more than 50% of the children who die in the UK each year: NICU, PICU, PTC-C, PTC-TYA.
- **Participants:** 55 bereaved parents of 44 children.
- **Recruitment:** Identified through NHS sites, hospices, charities and social media.
- **Data collection:** In-depth interviews.
- **Data analysis:** Thematic analysis.

NICU  
16



PICU  
11



C-PTC  
6



TYA-PTC  
11



# Parent and Public Involvement

- Collaboratively and in partnership.
- Study Parent Advisory Panel – 15 members, diverse experiences:
  - Study design, recruitment materials, topic guide, preliminary and final findings.
- Parent co-applicant:
  - Recruitment video, guided data collection, heavily embedded within analysis, findings, outputs.
- Family Advisory Board – 19 members:
  - Identifying, study design, findings.



# Results – 1. Building the foundations for high quality end-of-life care



## Ensuring parents are heard:

- Can lead to a lack of trust and a need to advocate for their child.
- Fathers not feeling included in care decisions.

## Keeping parents informed:

- Want to be fully informed, not “kept in the dark”.

## Professionals being human:

- Valued “humanness”, forming bonds, connections, and communicating inclusively.

*“We just felt disbelieved the wholetime, we were just arguing with them. We felt like we were battling to be listened to or believed, we didn’t trust anyone because they weren’t listening to us.” (NICU, Mother).*

*“If we had to make a decision, they’d listen to (mother’s name) and it was as if I was just there for moral support. I didn’t feel like a parent whatsoever.”(NICU, Father).*

*“It’s this whole thing of you have no control in these situations; there was nothing we could actively do to help (child’s name), but not to be told what’s going on...when you know (professionals) know...I always find it difficult that other people know more about my child than I’m allowed to know.” (Mother, PICU).*

*“The palliative care team knew her so well and had such a beautiful rapport with her, they would ask her what her wishes were. She had a voice and she had choice. It was important for us she was included.” (Mother, PICU).*

# Results – 2. Working together towards best decisions and care



Working with parents to develop conversations about EoL care:

- Professionals working alongside.
- Valued checking what information they'd like to be told, clear language and ensuring understanding.

Offering time and space to process information:

- Environment can bring challenges.
- Time to come to terms with decisions.

Tailoring care to the individual needs of families:

- Supporting choices limited by the system.
- Need to be prepared for final moments.

*“They’d explain in layman’s terms which is a massive help when you’re trying to take in information that you don’t understand.” (Mother, C-PTC).*

*“We were both a bit frazzled because they were doing that at her bedside. I would rather they had done that in a private room. There are other babies in the room, you can hear monitors, there’s lights flashing.” (Mother, NICU).*

*“And with that he (consultant) left us and we just sat there in a daze. We didn’t quite know what was going on. And then he came back and said, “Have you made your decision yet?” And I just thought, “I don’t know what decision they are expecting us to make, I don’t understand.” (Mother, C-PTC).*

*“Had we had the choice to have (child’s name) kept here at home and have people here, I would have preferred that, but there wasn’t that choice; we didn’t have nurses that could come.” (Father, C-PTC).*

# Results – 3. Continuing care after death and into bereavement



## Caring after death:

- Need to adapt care depending on preferences.
- Time with their child's body influenced by setting.

## Being proactive in offering bereavement support:

- Active referrals and proactive support important.
- Mostly provided by hospices and charities, more flexible and family-centred.

## Failures of the system, specific to bereavement:

- Poor coordination between services resulted in difficult experiences.
- Sudden withdrawal of financial support.

*"It was horrible, basically, they had to kick me out, "We're sorry but you're going to have to go shortly because we can't have (child's name) left in the room. You know, "We've got to wash her and get her ready". Well why couldn't I have washed her?"*  
(Father, TYA-PTC).

*"Even though I didn't want to see him, I just wanted him nearby so I knew he was safe."* (Mother, NICU).

*"You're referred to these organisations which take weeks, months, and that's a matter of going there, making that effort, which in the initial weeks you don't do, you're not interested."* (Mother, PICU).

*"I got a message from the health visitor, "congratulations on the birth of your baby, we're going to come out and see you". I can't tell you how painful it is to get something like that. It's like no one cares and no one cares you've had a baby and that baby has died because it doesn't mean anything to them."* (Mother, NICU).

*"Two days after (child's name) died I got a letter to say that my Child Disability Living Allowance stopped, how can they process it that quick but it took 18 weeks to set up?"* (Mother, C-PTC).

# Conclusions

- Largest UK-based study.
- Long way to go to optimise and individualise care.
- Policy and guidelines fall down in implementation and do not meet families' expectations.
- More proactive and family-focussed approach is needed.







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**Thank you, any questions?**

