

Health and Social Care Professionals' Experiences of Collaborative End-of-Life Decision-Making with Families

The All-Island CO-DECIDE study:

Co-production of a decision-making framework for planning the place of end-of-life (EoL) care for children, young people, and their families on the island of Ireland

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Background

- Pediatric palliative care delivery can be emotionally burdensome for HSCPs, with HSCPs reporting **distress**, a sense of **powerlessness** during a child's deterioration and **frustration** at often being unable to be stoic and **neutralise their emotional responses** (Judith Roach et al., 2023)
- Previous research has identified that HSCPs report hesitance around delivering pediatric palliative care due to **lack of perceived preparedness, both emotional and practical** (Yang et al., 2011).
- HSCPs continue to report feelings of **overwhelm, unpreparedness and anxiety** pertaining to the delivery of pediatric palliative care principles (Devitt & O'Hara, 2021), particularly in relation to **end-of-life decision making**, which often deviates from advanced care plans.



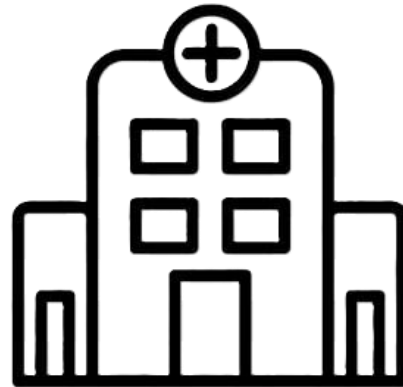
Background

- Despite these barriers, HSCPs are required to be **stoic, rational sources of information and advice** for parents and children attempting to make considered decisions at the end of a child's life.
- We know that **increased confidence** of HSCPs contributes to **improved end-of-life care** for children and families, including support in end-of-life decision-making (Bobillo-Perez et al., 2020).
- However, **HSCPs' experiences** in and perceptions of providing support in end-of-life decision-making have been **largely under-reported**.
- This study aims to investigate the factors which influence, inhibit and facilitate decision-making pertaining to a **child's place of end-of-life care** from the perspective of HSCPs.



Study Aim:

To describe and explain the factors which influence the decision-making process pertaining to the location of EoL care for a child, with respect to the experiences of EoL care in different settings (i.e., home, hospital, hospice).



Methodology

- Three virtual multidisciplinary focus groups with health and social care professionals (HSCPs)
 - Two groups from the Republic of Ireland (n=6, n=3) and one group from Northern Ireland (n=8)
 - Collaborative thematic analysis
 - Participants included: Pediatric Palliative Care Consultants, Social Workers, Play Therapists, Specialist Palliative Care Nurses,

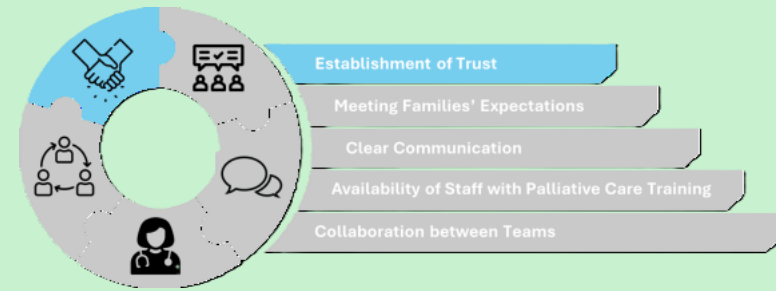


Preliminary Findings

Health and Social Care Professionals reported the following factors as intrinsic to being assistive in decision-making processes:



Establishment of Trust



- HSCPs believe fostering relationships with families to be of utmost importance to establish **true preferences** for care
- **Intuitive care** begins to occur when parents are known to HSCPs
- HSCPs act as a '**sounding board**' for parents to establish and gather information on all options
- HSCPs strive to **empower** parents to advocate for their preferences

"I would have a good relationship with the families, and I spend time building that up ... that is how you build trust, that is how you build a therapeutic relationship with a family and that is how they trust you. They will ask you the questions they are afraid to ask everybody else."

Meeting Families' Expectations



HSCPs perceive themselves to:

- **Meet** families' expectations – even when final decisions are not medically advised
- **Manage** expectations – what will caring for a child at home actually look like?
- Give families **all possible options** and as much **autonomy** as possible
- Regularly go **above and beyond** their formal duties to meet families' expectations
- Be **prepared to be unprepared** - plans respond to changes of mind or child's condition

"Everyone has experience from a family saying we just want to go home. And it's a human desire ... But it's not always a logical thing ... the goal is that we don't wrap the family up ... but that we empower them but do so safely so that they feel there's the scaffolding supporting the situation."

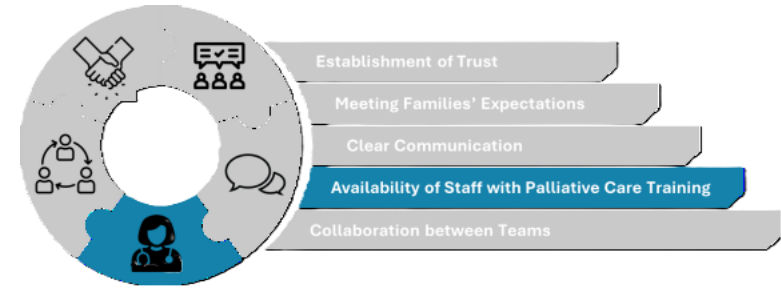
Clear Communication



- HSCPs report that **meticulousness and sensitivity** is required in all communications with families
- Managing **hope and expectations** in families with unrealistic optimism
- **Reiterating** potentially distressing information to ensure it is truly **'heard'**
- Having the **'courage' to introduce** the idea of end-of-life as early as possible

"If you are not truly listening and connecting with the family if you are doing all the talking ... you should be ... "What's the most important thing to you, is it an extra few weeks?" ... as professionals and in an acute setting you are an authority figure ... stop talking and listen far more."

Availability of Staff with Palliative Care Training



- Staff **overcapacity** results in distressing communications for parents
- Parents left in information '**blackouts**' with no specific point of contact
- **Reliance on HSCP 'goodwill'** to go outside of their formal responsibilities
- Need for increased degree of **palliative care principles** in all specialisations
- **Access to services** dependent on child's condition, age and geographical location

"What we could do more of is a bit more training for our staff. So then more people that feel comfortable and aren't afraid ... I can see some situations where certain rooms might be avoided because "I don't know what to say" or to hold that space."

Collaboration between Teams



- Need for sufficient and meticulous **collaboration and handover** particularly with regards to prognosis of child – **'no surprises'**
- Can be discordance in the aims of teams which can cause distress in parents - need for all teams to be on the **'same page'**
- Delivering **same message** to families to avoid false hope or overpromising
- **Coordinating visitation** of families so as not to overwhelm them

"One of the biggest challenges is the number of services involved. So it's coordinating all of those people and making sure there's good communication between all of the teams involved ... it can be overwhelming for families I think."

Key Learnings

- Despite their constraints and over-capacity, HSCPs state that they strive to meet the **high expectations of families**.
- In order to achieve this, communications between HSCPs and between HSCPs and families must be **meticulous, sensitive and recorded**.
- Families can lose trust in HSCPs when not receiving **consistent or sensitively delivered** information – further PC principles training needed.
- HSCPs aware that they must overcome their **own personal biases and fears** to ensure that each family is being treated with **autonomy and equity**.
- Open and honest communications, and the time in which to have them, are perceived by HSCPs as essential components **of rapport building and improved decision-making**.



Thank you

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References

- Bobillo-Perez, S., Segura, S., Girona-Alarcon, M., Felipe, A., Balaguer, M., Hernandez-Platero, L., ... & Cambra, F. J. (2020). End-of-life care in a pediatric intensive care unit: the impact of the development of a palliative care unit. *BMC Palliative Care*, 19, 1-8.
- Devitt, A., & O'Hara, M. (2021). Perceptions of nurses caring for children with life-limiting conditions in an acute setting in the Republic of Ireland. *International Journal of Palliative Nursing*, 27(6), 281-291.
- Judith Roach, E., Al Omari, O., Elizabeth John, S., Francis, F., Arulappan, J., Shakman, L., ... & Khalaf, A. (2023). Challenges experienced by nurses in providing pediatric palliative care: An interpretive phenomenological analysis. *Journal of Palliative Care*, 38(3), 355-363.
- Yang, C. P., Leung, J., Hunt, E. A., Serwint, J., Norvell, M., Keene, E. A., & Romer, L. H. (2011). Pediatric residents do not feel prepared for the most unsettling situations they face in the pediatric intensive care unit. *Journal of Palliative Medicine*, 14(1), 25-30.