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Health and social care professionals experiences of place of end-of-life decision making on the island of Ireland

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Health and Social Care Professionals' Experiences of Place of End-of-Life Decision-Making on the Island of Ireland

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



Rachel McCauley



*12th Annual Palliative Care Research
Network Symposium
7th Dec 2023*



Dr. Ashleen Crowe

Overview

Research overview

- All-island CO-DECIDE Study (Ireland)
- **Aim:** to co-produce, with parents and health and social care professionals, a decision-making framework for planning the place of end-of-life (EoL) care for children with life-limiting conditions and their families, on the island of Ireland.

Methodology

- 3 virtual multidisciplinary focus groups with health and social care professionals (HSCPs)
 - 2 Rol groups (n=6, n=3) & 1 NI group (n=8)
- Collaborative thematic analysis of anonymised data across DCU and QUB



Preliminary Findings: Themes

Assisting families in decision-making for place of end-of-life care requires:



Preliminary Findings: Themes

Establishment of Trust

“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

“Everyone has experience from a family saying we just want to go home. And it's a human desire, everybody to try and help them to achieve that. But it's not always a logical thing to proceed with that ... 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 at all times.”



Preliminary Findings: Themes

Clear Communication

“If you are not truly listening and connecting with the family if you are doing all the talking ... you should be “Where do you think we are?”, “What do you want for your child going forward right now?” “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

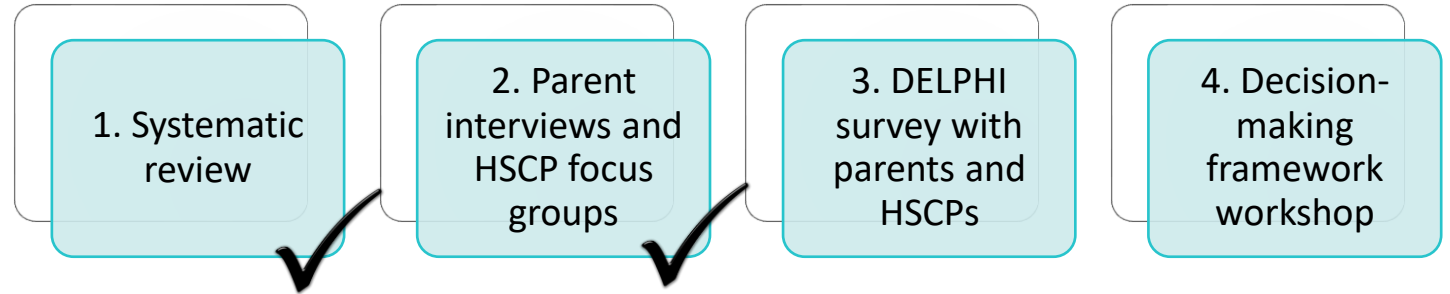
“What we could do more of is a bit more training for our staff. So then more people that feel comfortable and aren’t afraid ... I can see some situations where certain rooms might be avoided because “I don’t know what to say” or to hold that space.”

Collaboration between Teams

“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.”



Study Phases



Next Steps

Focus groups analysed in tandem with one-to-one interviews with bereaved parents (n=19)

Data from one-to-one interviews and focus groups combined to develop consensus statements for DELPHI survey

This data will inform the development of decision-making framework for place of EoL care for children.

Study Phases and Next Steps for CO-DECIDE Study

Thank you

rachel.mccauley@dcu.ie

a.crowe@qub.ac.uk

DCU

Ollscoil Chathair
Bhaile Átha Cliath
Dublin City University



Prof. Veronica Lambert (PI)

Dr. Yvonne Corcoran

Dr. Eileen Courtney

Dr. Gemma Kiernan

Rachel McCauley

International Advisor:

Prof. Jayne Price



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Dr. Patricia McNeilly

Prof. Joanne Reid

Dr. Tracey McConnell

Dr. Helen Kerr

Dr. Ashleen Crowe

Collaborators:

All-Ireland Institute of Hospice and Palliative Care

Irish Hospice Foundation

Children's Health Ireland

LauraLynn

Jack and Jill

Northern Ireland Children's Hospice

Royal Belfast Hospital for Sick Children

Belfast Health and Social Care Trust

Western Health and Social Care Trust

Parent Representatives (ROI and NI)