

What are the perceptions of nurses on caring for children with life-limiting conditions, who have complex and/or palliative healthcare needs in one of the acute settings in the Republic of Ireland? – A Qualitative Research Study

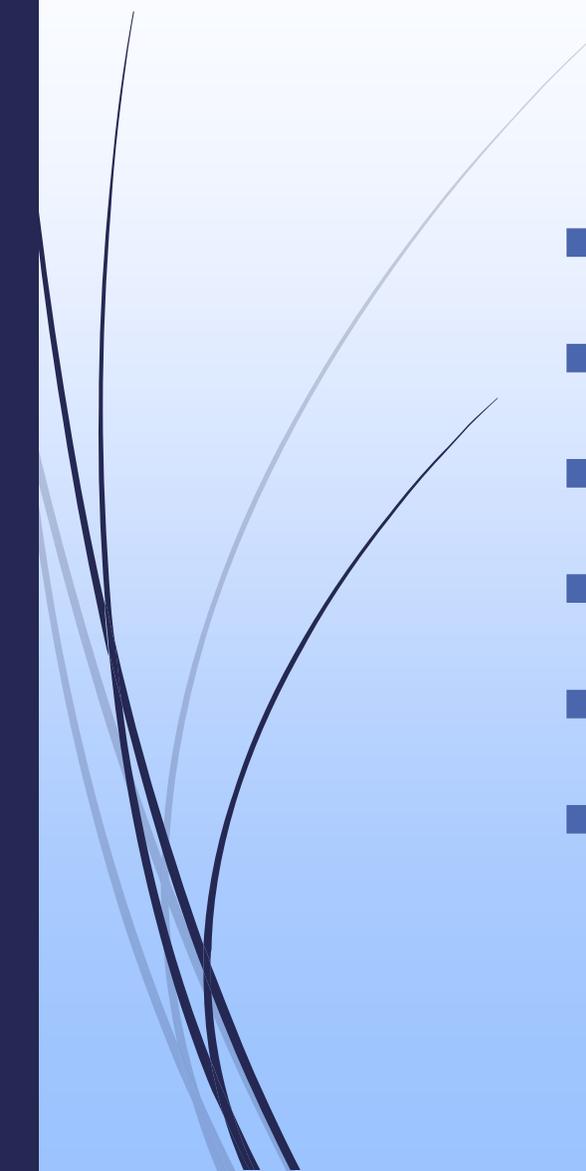
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# Outline

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- Introduction
  - Literature Review
  - Research Design
  - Research Findings
  - Discussion and Recommendations
  - Conclusion

# Introduction

- ▶ The purpose of this study was to explore the perceptions of Irish nurses in caring for children who have life-limiting conditions which results in them having complex and often, palliative health care needs.
- ▶ The objectives were;
  - ▶ To explore nurses' experiences of meeting the complex healthcare needs of children with life-limiting conditions and providing palliative care to children.
  - ▶ To ascertain what is involved in providing paediatric complex and palliative care from the nurses' perspective and
  - ▶ To identify the barriers and facilitators to providing this care and ascertain what can be done to better assist nurses in caring for children with life-limiting conditions.

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- ▶ Life-limiting conditions that affect children and young people are those for which there is no realistic hope for a cure and from which the child will inevitably die prematurely.
  - ▶ Paediatric palliative care is an active aspect of care which encompasses the child as a whole, attending to their physical, psychological and spiritual needs and also caring for their family. This requires input from a wide range of healthcare professionals in order to optimise quality of life of the child and family (WHO 1998)

# Some facts and figures

- ▶ It is estimated that there are 3840 children living in Ireland with a LLC (Ling et al., 2016)
- ▶ Figures show that an average of 423 children die in Ireland each year, 322 of whom as a result of having a LLC (The Irish Hospice Foundation and LauraLynn, Ireland's Children's Hospice (2013))
- ▶ The Development of Paediatric Palliative Care in Ireland
  - ▶ 2009 - National Policy for PC for Children with LLCs (DOHC)
  - ▶ 2011 - Ireland's First PPC Consultant in 2011
  - ▶ 2011 - Opening of Laura Lynn Children's Hospice
  - ▶ 2012 - Appointment of 8 Children's Outreach Nurses – Now 11 Clinical Nurse Coordinators for Children with Life Limiting Conditions

# Literature Review

- Conventional literature review was carried out using various databases
- Literature was critically analysed and discussed under three main headings;
  - Education and Training in Paediatric Complex and Palliative Care
  - The emotional toll endured by nurses in caring for children with life limiting conditions and providing palliative / end of life care to children
  - The important role of communication when caring for children with Life Limiting Conditions
- Implications of literature review
  - Scarcity in the research done from an Irish perspective in caring for children with LLCs and PC needs
  - Did not come across any study carried out in the acute general paediatric setting in Ireland
  - Knowledge provided a solid foundation upon which the research questions for this study were based



# Research Design

- ▶ Sampling strategy
- ▶ Recruitment of participants (N = 14)
- ▶ Data collection method – Semi structured interviews
- ▶ Ethical considerations
  - ▶ Upholding participants right to dignity and respect throughout
  - ▶ Non-maleficence and beneficence
  - ▶ Anonymity and confidentiality
  - ▶ Informed consent
  - ▶ Rigour and bias
- ▶ Data analysis – Braun and Clark's Thematic Analysis

# Research Findings

- ▶ Thematic analysis identified five key themes;
  - ▶ Nurses' emotive journey when caring for children with LLCs
  - ▶ The barriers faced in caring for children with life-limiting conditions in the acute setting
  - ▶ The facilitators to caring for children with life limiting conditions in the acute setting
  - ▶ Education and Training
  - ▶ The emotional toll endured in caring for children with life-limiting conditions



# Nurses' emotive journey when caring for children with LLCs

- ▶ Subjective feeling of managing complex healthcare needs

“I find it really difficult to be honest, like I'm no more confident I don't think than when I first started because they're all so different” – Orla.

“I suppose its hugely satisfying, I think. It's just, it's such a special relationship, you know the family so *well* you know the children so *well*, emm, the families are just awesome and I suppose I feel that you know they need your help so much and it really is honestly that word a privilege to mind them” – Mary.

“I suppose it's just **the overall sense of like, can I do what I'm supposed to do, to go in and help them to the best of my ability**, so it's like that kind of, stepping up and feeling more competent to go in and say like, I can manage this today kind of thing.. it's a situation that you don't want to be humming and hawing in” – Lucy.



## ► Interpretations of caring for a child at end of life

“but you're very much on your own, even though you have all the nursing support, you're still on your own you know...” – Sally

“A peaceful death. It's all you ask for, a comfortable peaceful death, that they're not struggling... you just have to change your way of nursing like, you're not going to fix this child you just have to know that you have to do the most for this child that you can and make their last time comfortable” – Kate

“but you might go to a situation where like, you might have a constipated child and she is five or six and she is all chit chat you know, and she is mad to talk to you, but your head is in the other room you know, and then obviously if you don't answer her, or if you're rude to her, you have six parents in a room kind of going, what's wrong with that one, she shouldn't be here like. **It's like you shouldn't be on a paediatric ward unless you have a smile on your face...**” – Molly

# The barriers faced in caring for children with life-limiting conditions in the acute setting

- Understanding the nuances of family dynamics and adapting communication skills

“so you obviously have the issue where the two parents don't agree on what they want for their child and you have to deal with marital tensions, and you're in the room, and you know, what do you say... its intense like, it's an intense family environment to have a sick child. It's not the same, **it's not getting up for breakfast and having coco pops, its suctioning, nebbing, all these medications, venting, making sure they don't vomit, the whole routine is all medicalised**” – Sarah

“They can get very angry, they feel guilty, depressed, we have moms that haven't been able to deal with it, or dads, so like it's hard, the family definitely does break down as well like there is probably conflict between the parents as well because one blames the other, one can't deal with it, one obviously has to work as well... **like you can understand why like, it's a huge diagnosis, it's devastating like so there would be a huge conflict... conflict like within the family unit as well**” - Orla



► Perception of the acute setting environment;

“... when you are inside the room and you can hear all the activity of an acute ward, and you can hear the hustle and bustle and the plates and meals being delivered, and **children running up and down and children laughing, like that is all very normal, but what is happening inside the room isn't normal.** It is difficult and you know you are going out and you're meant to be having your breaks and you just don't feel like eating and it's just a really difficult time”. - Mary

“I think maybe the facilities we have on the unit aren't great ... **for washing, bathing, that kind of thing** ... there's no baths for them, there's no like they could be there for weeks and there's no facilities ...” – Sally



## ► Everyone singing off the same hymn sheet

“then you’ve everybody singing different hymns from different hymn sheets, so what “Mary” says, “Patricia” might not agree with, and everybody’s telling the parents different things ... but even from handover, to handover ... the important things are getting lost along the way and it depends who gives you the handover, as to the amount of info you’re given” – Claire.

“lots of the children can have more than one problem so **they can have lots of different consultants looking after them, and I definitely see in situations that I find quite difficult that some of the MDT, you feel that not everybody is on the same page...** and ehm, I think that is really rather difficult, you know I think that poses a lot of problems, particularly when it comes to end of life care with some of the children” - Mary

“sometimes they were given hopeful information, as in he is not palliative, he is for seizure control, and then other times it was kind of, well he is probably shutting down now ... **I think families are obviously going to grasp onto any bit of hope but like, I don’t know, it needs to be a lot clearer, as clear as possible**” – Jennifer.



➤ Powerlessness to dedicate the required commitment ;

“on a particular day, I could have 2 babies for theatre that are day patients, I could have a long term complex child ... so you're trying to give a very high level of care to that particular family because there is so much going on with that child, and yet you're still trying to give the same amount of good care to the child that's only coming in for a day procedure and going home, and sometimes that can be very challenging” – Louise.

“it is really busy you never know when they might have a seizure, or the PEG will leak or someone will vomit or this and that, ya massive difficulty or obstacle is definitely trying to manage your day ... **trivial things, the phone going and it's just like aaagh, you know, I'm not an octopus with 8 hands that I can do all this at once.**” – Lucy.



# The facilitators to caring for children with life limiting conditions in the acute setting

- ▶ How nurses continue to provide this demanding level of care;

**“you’re allowing this family and that child a quality of life and giving the family and siblings memories... I think if I see a child responding to music or to the sound of the parents voice or laughing, I just think that allows us to know as nurses and parents to know that we are doing a good job and this child has a quality of life ... So, I think that knowing that the parents are happy, and the child is happy and us being able to recognise that is really rewarding and allows us to keep going.”** – Noelle

“Ya twas really nursing colleagues was my crux of support really especially the more experienced nurses that were here longer than me I found them a huge help to me” – Tara



➤ The supportive role of the Clinical Nurse Coordinator for Children with Life Limiting Conditions (CNCLLC);

“it was [The CNCLLC] that was my link person ... it was just difficult then, only for [The CNCLLC] you know ... [The CNCLLC] was fantastic that day, a massive support like, without [The CNCLLC] it would probably have been awful like... like [The CNCLLC] is so good like, [The CNCLLC] puts in the drivers and things like that, **at a time where [The CNCLLC] is off you would feel totally overwhelmed like...** [The CNCLLC] knew he would have an uncomfortable night if we didn't do something about it” – Lucy

“I think the outreach nurse that we have is completely over worked ... I don't know, [The CNCLLC] is very much based out in the community, I think there needs to be someone on the ward as well, like I know [The CNCLLC] comes in as well but I think **he is just too run thin from it and its definitely affecting [The CNCLLC] too I think emm, ya complete burnout for people**” - Sally

# Education and Training

- ▶ The scarcity of education in this area of nursing;

“Like I wouldn’t say that any of my college days would have yielded a whole lot – like I know we did ‘death and dying’... **there’s definitely been a lack of paediatric education and study days** and that like so I have been kind of like there’s no point in going to adults because it’s so completely different” – Alice.

“you see with students now even the some of the paedics students we have coming in, I think it should be taught from first year. From the beginning, because this is something that is going to be more and more all the time now. You know. **A lot of the students you would have on [the ward] they’re in the early years, first year, second year, they are scared of their lives like**” – Sally.



► The necessity for further education and training prospects;

“we do have these kiddies on an ongoing basis, and we need to have the education to be able to support everybody and not look on each other as ooh, we don't know, we can't know everything” – Claire.

“I think everyone on the ward needs that day, like needs a refresher or like even just how to deal with things like these situations I think it would be great even to have a couple of hours or a half a day to learn a bit more to learn about PC or to learn about caring for children with LLCs... **I think is there one in Crumlin, but like it's in Crumlin, so it would be great if there was one [here]**” – Orla.



► You learn something new every day;

“I suppose you learn, like even this weekend. I was looking after a child with complex needs, and he was deteriorating, and it is heading in a palliative direction, I’ve learned *SO* much just this weekend **so I think every time I meet a child it’s not going to get easier but it’s going to get a bit clearer in some ways**”  
– Jennifer.

“To be honest I’m still learning all the time because like, we come across different things ... **it’s just a huge learning curve for everybody so that’s the hardest part, we are always learning so I can’t say I’m confident to be honest**”  
- Orla

# The emotional toll endured by nurses caring for children at end of life:

- Coping strategies and support services following the death of a child;

“when **you have been through that then you feel like you’ve been actually run over by a truck, like your whole emotions**, everything after it and it’s so difficult to recover from it. You could be, like that child could pass away at 4pm and you’re still meant to be on for a couple more hours and you come out and you’re not normal, you can’t be normal, you could be working the next day and it’s just so difficult to put that behind you and start fresh. You go home that night and you are thinking about them, you can’t sleep, you wake up and you’re thinking of them, they are always in your mind, every milestone, every date that passes, it is really difficult (UPSET, CRYING PAUSE .. )” – Mary

“I think sometimes children die and then there’s nothing more about it you know, I find that kind of hard ... **I think it’s a side we could do with more support on too like. I think definitely we are left to fend for ourselves with that...**” -Tara



➤ "No one else gets it";

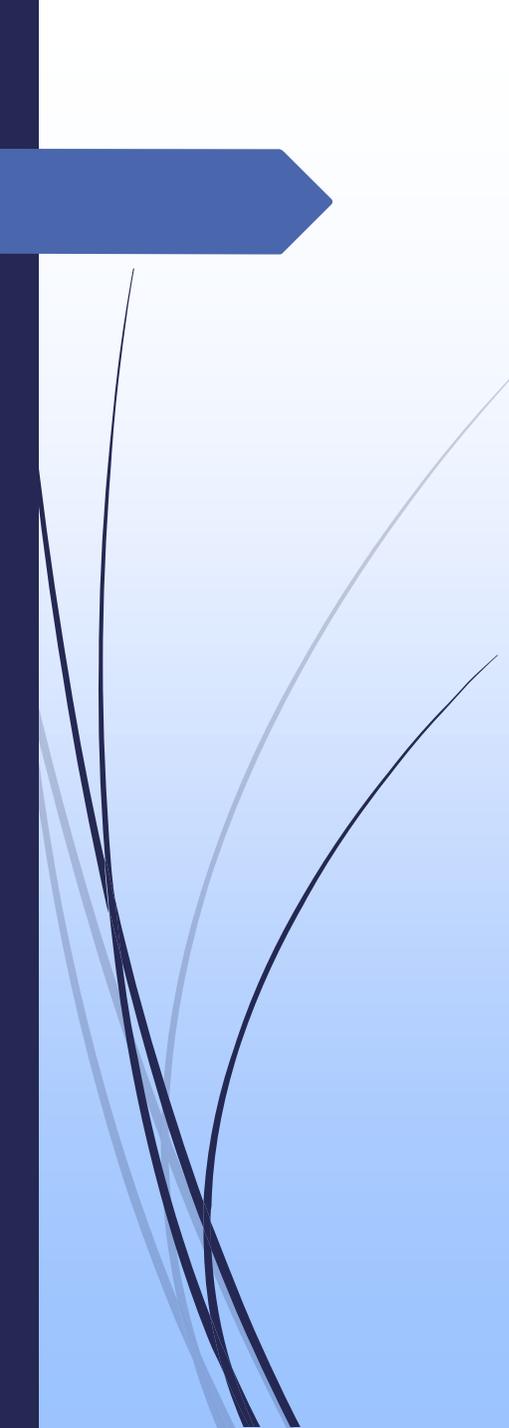
"I do find when you go home or whatever and you're on the phone to somebody and you're like a child died and they're like WHAT you know... **but then the conversation changes 2 minutes later**" – Alice.

"I said to [my colleague] I can't cope with this, I just said why, what's happening, and I know, sure her quality of life isn't great she must be uncomfortable all the time, she is getting so heavy now we can't even do anything with her, when you think of it matter of fact like, but then you just think, this is so crap" – Sarah



# Discussion and Recommendations

- ▶ The implications of my research;
- ▶ New insights into the central concept of caring in nursing this growing population of children
- ▶ Suggestion of creating the role of a key worker for children with LLCs
- ▶ Further research needs to be carried out in the acute setting to better understand how communication breaks down. I suggest the use of focus groups to encourage group discussion and debate and some solutions to this concern may be reached that would be acceptable across all components of the multi-disciplinary team.
- ▶ My findings emphasize the necessity to advocate for improved support networks for nurses to sustain their abilities in caring for this vulnerable population of children and improve staff retention, **but also to support nurses as individuals in their own right.**

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- ▶ There is a need within the Irish Health System to examine nurse: patient ratios
  - ▶ Due consideration needs to be given in future developments of care facilities to create an environment which is ergonomic, child and family friendly and fosters an atmosphere which is more appropriate to facilitate the needs of these families during the most harrowing time of their lives.
  - ▶ There is an imperative need for improved education in this area, increased access to learning opportunities and it could be argued there is a requirement for undergraduate and postgraduate education syllabi to be improved to address this issue as this population continues to grow in number and complexity
  - ▶ Learning opportunities need to be tailored to meet the specific needs of healthcare professionals in the different settings where these children are encountered as their needs constantly change

# Conclusion

