

Learning through Lived Experience in Health Education and Training

Wednesday 5th March 2025 12.30hrs-13.30hrs

The webinar seeks to celebrate how students within undergraduate programmes are learning through stories of experience shared on Care Opinion and consider how we can further embed stories into our education and training programmes







Integrating patient experience across School of Nursing and Paramedic Science

Present by Linda Craig on behalf of the School of NPS



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"To deliver academic excellence in research and teaching that will encourage <u>innovation</u>, leadership and high quality care that will impact on health and wellbeing globally, through an <u>evidence-</u> <u>informed</u> and <u>person-centred approach</u>"



- A commitment across the school to voice of service users, families and carers
- Engaging with the Regional Patient Client Experience Programme as part of annual consolidation of learning for each year group
- Focus on the importance of experience to inform everyday practice and opportunity to reflect upon scenarios shared through Care Opinion





- Emphasise the importance of a positive patient experience
- Build relationships with service users/families and carers
- Understand what matters most to service users, families and carers
- Inform change to support a better experience
- Identify and celebrate good practice
- Inform Quality Improvement projects or research projects
- Contribute to professional development and revalidation
- Evaluate quality of care delivered and support individual reflection



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This is one of the realist things I've read...





An Interprofessional Education Approach to Learning from Patient Stories Through Care Opinions

Dr Jean Daly-Lynn Director of Interprofessional Education, FLHS Lecturer in Psychology, SoHS



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Interprofessional Provision

- Activity across 3 years
- Interprofessional module
- 900+ students
- 4 weeks (8 groups) (40 approx. per group)



Format of Workshops





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I loved the patient experience workshop



Learning from Interprofessional Workshops

- 8.29/10 enjoyment of workshop*
- Care Opinions enables students to see their profession within the stories
- Framework for staff responses
- Academic literature supported the use of Care Opinions (Baines et al. 2018; Hanna & Robert, 2021, Gillespie & Reader, 2021)

I found the patient experience session interesting, as it really made me think of things from a patient's perspective. Patient experience. You really got to see how your actions in the job impact on every single patient, positively or negatively



WEARFIEUK AND RELAND UNIVERSITY OF THE YEAR

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School Vision

The vision for the **School of Medicine** is to:

- Be a nationally and internationally excellent medical school competitively recruiting and retaining high quality staff and students.
- Produce graduates able to deliver whole person care with skill and compassion, as members and leaders of diverse clinical teams, in partnership with patient and clients.
- Produce graduates whose vision is community focused yet globally ambitious: academically capable change agents.
- Inspire and work in **partnership with our community** through high quality ambitious research, innovation and education.

How do we use Care Opinion as part of teaching? Student Selected Component (SSC)

- Opportunity to explore topic of interest, academically or career-related.
- Second year focus on developing research skills through secondary data analysis.
- Qualitative <u>or</u> quantitative
- Research poster
- Across first three cohorts, between ~66% 75% of students choosing qualitative projects.





Past project titles

- Supportive pillars of recovery: Insights from patients with alcohol use disorder
- A qualitative analysis of deaf patients' experience with communication and adapted services in the healthcare system
- Doctor-patient communication in emergency medicine in Northern Ireland: A qualitative analysis
- Navigating care: Perspectives of parents of children with autism spectrum disorder within hospitals in Northern Ireland
- Women's experience when seeking help with gynaecological conditions in the UK
- Voluntary blood donor experiences and motivations in Northern Ireland
- The impact of stoma care on service user experiences in Northern Ireland
- Patient experiences of smoking cessation services in Northern Ireland
- Psychosocial impact of skin conditions on patients in dermatology departments across NI
- Key factors negatively impacting women's experience of miscarriage in the NHS
- Factors impacting end-of-life care experiences of relatives in Northern Ireland
- Patient experience of "Phone First" service offered by HSC NI in Accident and Emergency

What did students learn from this project?

"How there can be a mismatch between patient experiences of consultations versus doctor experiences"

"How staff makes a patient and their family feel is one of the most, sometimes even the most, important aspects in a patient's healthcare journey." "It was great to get patients" insight and hear stories that they may not be comfortable sharing face-to-face."

"I was surprised to see so many positive comments so it was a pleasant experience. I felt patients were excellent at giving constructive criticism"

"It was really insightful to see the perspective of patients and what is important to them."





SCHOOL OF MEDICINE

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Ulster University

How a Neonatal Intensive Care Unit Helps to Lessen Common Stressors in Parents of Preterm Infants

Jennifer Durey, F year, MBBS Medicine, Ulster University





- Preterm birth is defined as <u>an infant born before 37 weeks gestation</u> (Gardner et al. 2016)
- 15 million preterm births worldwide every year (WHO, 2022).
- <u>1,740 preterm births in Northern Ireland in 2018 (Public Health Agency 2019).</u>
- <u>NICUs can be distressing</u>—intensive monitoring, alarms, unfamiliar medical teams, and parents' fear for infants' survival (Chifa et al., 2021).
- NICUs have <u>strategies in place</u> which can help to <u>lessen key stressors</u> parents experience in having a preterm infant in NICU.



Project Aim



To explore parents' experiences of NICU within Northern Ireland and how each NICU helped them.





- A qualitative approach with secondary data obtained from Care Opinion.
- Initial search using *common words relating to NICU* was used to extract 564 stories.
- These were filtered down via inclusion criteria:
- Stories were limited to Northern Ireland, only pre-term infants and any entries >8 lines.
- A <u>total of 26 stories</u> were imported into an excel spreadsheet for <u>thematic analysis</u> (Braun & Clarke, 2006).



Thematic Analysis

- When reading the stories, <u>initial</u> <u>thoughts and comments were</u> <u>annotated ('coding')</u> and collated on a mind-map to draw relationships and connections.
- This led to the development of the <u>key themes and subthemes</u> represented in the stories.
- The <u>three</u> main themes and subthemes emerged.



Theme 1: Supporting and caring pr parents

Quotes from stories relating to theme:

"Every member of staff- regardless of job title. Made myself and my partner feel relaxed, supported and reassured that our baby was progressing and being cared for by a staff whose work is undoubtedly a vocation..." (Parent 18)

"We were supported the whole way through... it is a unit that we never thought we would need and I will be forever grateful that it was there..." (Parent 24)

"We as a family endured a very traumatic journey... we cannot help but mention the fun and laughter we enjoyed with the team, that helped lighten the worries and anxieties endured..." (Parent 7)

Theme 1- Supporting and Caring for Parents University

- High levels of stress, anxiety and emotional distress experienced by parents in the NICUs.
- Descriptions of how *healthcare teams showed compassion & empathy* during times of need.
- Little acts of kindness had a huge impact on offering parents support, comfort and ٠ reassurance:
 - Notes left on incubators for parents on infants' progress
 - Nurses singing nursey rhymes to infants

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- Staff did their best to ensure that all loved ones could visit despite restrictions during COVID-19
- Staff took photos and set up FaceTime for a Covid-positive mother unable to hold her baby.
- Adma et al. (2021) details how many parents indicated the need for medical staff to have a level of *emotional intelligence* and that *parents appreciate staff who make them feel supported*, cared for and welcome.

Theme 2: Leaving Baby in Safe Hands

Quotes from stories relating to theme:

"We watched in awe at the way [staff] looked after and cared for our son and all other babies within the unit... Thank you so much for the way [staff] looked after and cared for him when we couldn't be there. We knew what safe hands he was in and it made a very emotional; and upsetting time so much easier on us." (Parent 20)

"...when you have to leave your own baby every evening in someone else's hands, it helps to know they are being treated with care and dignity, which I always felt there..." (Parent 4)

"...I would never have envisaged us finding ourselves being faced with prematurity... leaving my baby isn't something I thought I could do but... having witnessed the way my baby was being cared for... I knew she was in safe hands..." (Parent 18)





Theme 2- 'Leaving Baby in Safe Hands'

- Parents commenting on the comfort they found in having the same staff looking after their infant.
- *Parents feeling torn* as having other caring commitments young children at home.
- **Upsetting to leave their baby** as they returned to maternity wards or home.
- Adma et al. (2021) and Ferreira et al.(2021) detail that <u>continuity of care is a key factor</u> in helping to <u>establish trust between parents and the healthcare team</u>.
- Having the same medical team reassured parents that their infant was being well cared for and made them feel more comfortable in asking questions.

Theme 3: Co-operative Relationship between Parents and Healthcare Teamgster University

Quotes from stories relating to theme:

"...They were excellent at making you feel like the main carer, even though when your baby is in an incubator and being tube fed, there is very little you can actually do, but they were always fantastic at involving parents in as much as possible..." (Parent 4)

"...I cannot thank the staff in NNU enough and also to [Doctor] who always broke all information down properly so I could understand it..." (Parent 9)

"...At all times we felt respected and valued as part of the team, and therefore had an amazing experience with family integrated care and all plans of care were co-produced. We were thankful that during the current COVID-19 circumstances, that we were able to be with our baby every step of the way in order to facilitate this crucial integrated care..." (Parent 7)

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between Parents and Healthcare Teams

- Parents were delighted that medical staff <u>got them involved in bathing, feeding and</u> <u>changing nappies.</u>
- They were grateful to those medical professionals who took time to <u>explain their infant's</u> <u>health in a way that they could understand.</u>
- A key stressor for parents in a NICU is the <u>sudden loss of parental role</u>, as they feel that there is very little that they can do to help.
- <u>Navigating new medical terminology and adjusting to a new environment</u> (Obeidat et al. 2009; Govindaswamy et al. 2019; Adma et al. 2021).
- Parents who <u>are involved in the hands-on care</u> of their baby <u>feel more prepared</u> and comfortable for caring for their baby <u>once discharged from NICU</u> (Adma et al. 2021).



Conclusion + Reflections

- **Theme 1- Supporting & Caring**: Small things that can make the biggest difference
- Many parents recounted experiences of unexpected labours, emergency c-sections, traumatic births and separation of mother and baby straight after birth.
- On my placements I can see how taking 2 minutes out of your day to take a step back to engage with patients, taking stock of not just their physical medical needs but their psychological and emotional state makes a huge difference to their journey. I also like to have a good natter with a patient when I'm on the wards!
- This of course can be challenging given the current landscape of the NHS with the pressures; medical & surgical teams have a lot of patients to see during their days and time pressures are extremely evident with waiting lists and resource shortages.
- Hospitals can be very scary and isolating places for patients and their families But that doesn't mean we can't create a nurturing and supportive environment through kindness and empathy.

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- Theme 2 Leaving Baby in safe Hands: Continuity is key, establishes rapport between patients and health care staff
- Parents seeing their tiny, vulnerable infant hooked up to a ventilator and wires, enclosed within the bubble of an incubator, was not only visually upsetting but physically creates this separation from baby which can be distressing for both parents.
- However, parents were comforted knowing who was looking after their baby, having the same staff care for their baby helped to foster this trusting relationship between the parents and the NICU staff.
- Continuity really is key across all disciplines in medicine & surgery. Throughout my placements, I can see how patients feel comforted by having familiar faces throughout their healthcare journeys. Having even that one person they recognize from a previous encounter whether it be me, the medical student who they met on the ward, or pre-op room for theatre or in clinic, to their surgeon or nurse or doctor.
- Not only those this foster trust but also provides the important safe environment where patient's feel like they can ask questions about their own health or families can ask questions, because they feel like they can trust the people who are around them and that they are 'in safe hands'.
- We have all had those experiences where we can feel tension in a room, no one wants to make a sound or ask a question. Think in those situations how that made you feel, then think how a patient might feel given everything else they are dealing with on top of that. On the other hand, we have probably had 4x many experiences of being in a room where everyone knows everyone, there is trust, space for questions and is generally a nicer environment to be in.

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- Theme 3- Co-operative Relationship between Parents + Healthcare teams:
- Ensuring parents <u>do not</u> feel that they have lost their parental role- getting them involved, whether this through feeding, bathing, changing nappies or seeking their view on medical treatment or next steps.
- Parents recounted that they appreciated medical staff who explained their infants' treatment in a way that they could understand- providing them with the chance, now that they understood, to co-operate with staff and have an input with the teams looking after their baby.
- Throughout medical school and placements, the term 'person-centred care' is mentioned daily. As doctors/healthcare providers, it is important that we address our patients' health needs, but it is also important to ensure we include the patient in these decisions – What <u>do</u> they want? What do they <u>not</u> want?
- Patients not only need to navigate their own condition, but they are in unfamiliar environments with unfamiliar strange terminology thrown about.
- I feel through this project; I am more aware of how important it is to ensure that I can take the time to communicate with patients in a way they can understand, explaining complex medical concepts in a simple and easy manner. I am also learning that getting out a page and a pen to illustrate medical concepts can be an excellent way to do this.



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Thank you for listening







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