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## Supporting children with complex needs in the community: Challenges for Advanced Community Nurses

Cora O'Leary Clinical Practice Specialist



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## Introduction

Breakthroughs in medicine and technology mean that children are surviving longer with complex medical needs

Numbers of children with complex medical are increasing.

Following a review of policy and practice in the provision of home care for children with complex medical needs in Ireland (2014), a service framework was devised to guide commissioning and delivery these services.

## Literature Review

- Search terms – medically complex, medically fragile, special healthcare needs, technology dependence / dependency / dependent, knowledge, home care community nurses
- 32 articles initially sourced and 7 secondary
- 14 articles fit the criteria
- 2 articles were in relation to the nurse

CINAHL®  
Advanced Searching Tutorial

Available via EBSCOhost

PubMed

MEDLINE®  
on Ovid®

## Technology Dependent

A person dependent on medical technology is defined as 'one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability (OTA 1987)

1. Dependent on ventilation for part of the day
2. Prolonged administration of nutrition or medications
3. Daily dependence on respiratory or nutritional support
4. Prolonged dependence for a vital body function & substantial nursing care

## Literature Review

Main themes found were:

- Hospital discharge / transitioning home
- Family centred care
- Home care
- Home care nursing / home as the work place
- Education and knowledge

## Objectives

To explore nurses' knowledge in enteral feeding

To explore nurses' knowledge in tracheostomy care

To identify challenges nurses' encounter caring for children who are technology dependent

## Sampling

- Population 100
  - Convenience sampling
  - $n = 100$
  - Response 67%
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- Ethical approval was granted by Cork Clinical Research Ethics Committee (May 2017)

## Methodology

- Sequential mixed method approach
- 1. Self administered questionnaire
  - Demographic section
  - 5 questions of knowledge on tracheostomy care
  - 5 questions of knowledge on enteral feeding
  - 10 free test questions on challenges identified through the literature review



## Methodology

### 2. Focus groups

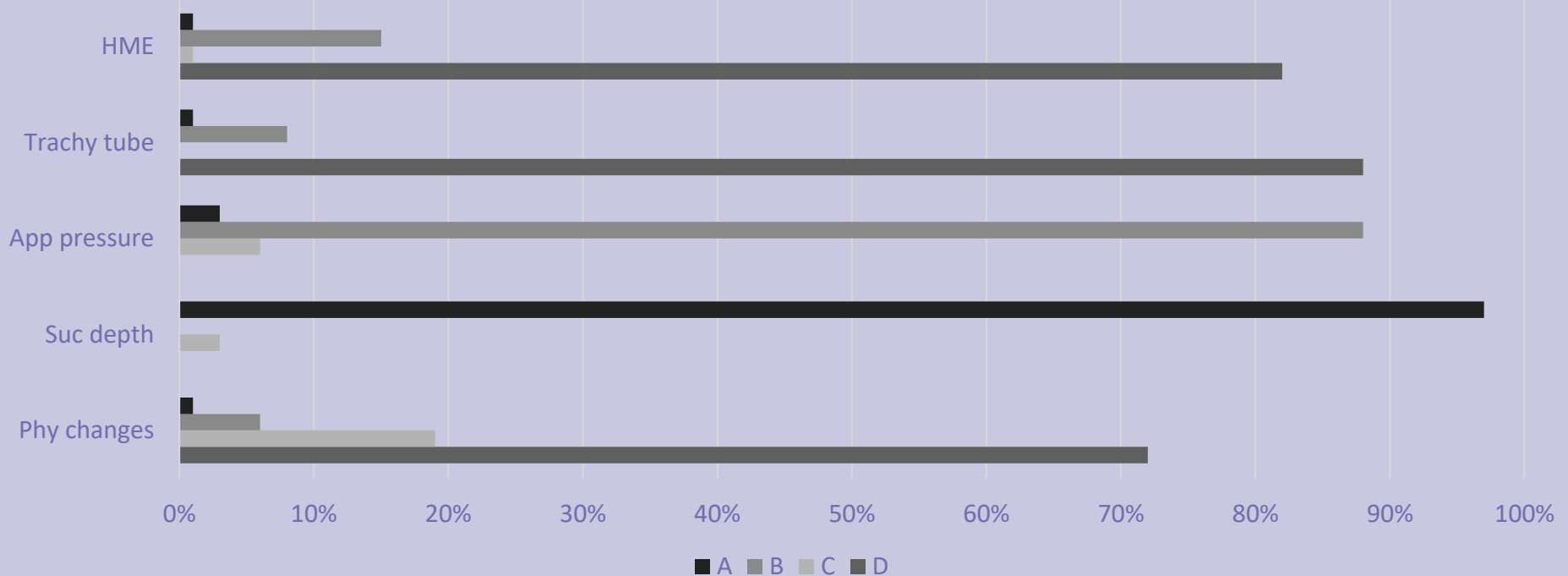
- Based on answers from free text questions in the questionnaire
- Self selected
- 3 focus groups (n = 13)
- Held in informal venues
- Note taker / concept maps

## Findings

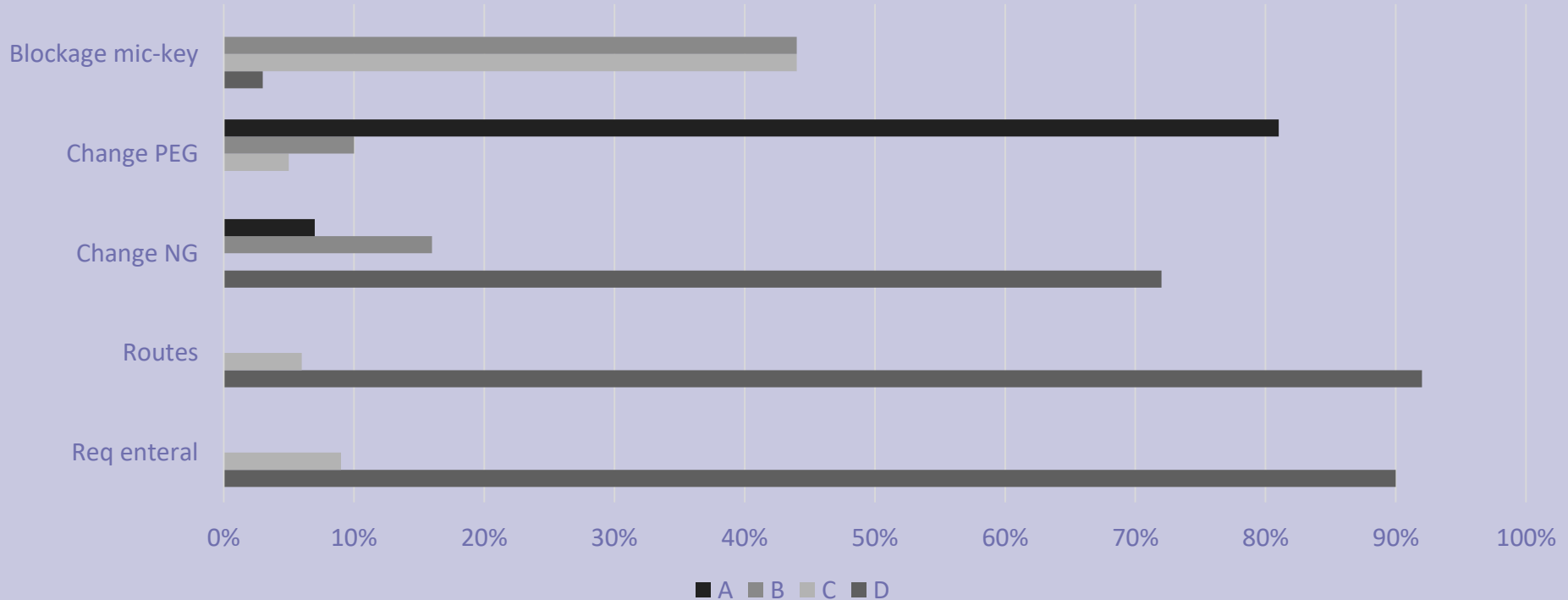
### Demographics

- 99% were female
- Over half (54.7%, n= 36) degree qualification
- Almost half the participants worked in the community for 3-4 years (44%, n = 29)

## Knowledge on Tracheostomy Care



## Knowledge on Enteral Care



## Findings

- Themes identified
  - Family dependency
  - Care planning and competency
  - The nurse parent relationship

'I think bridging the gap between us (ACC nurses)... tertiary centre and the family is needed' (P5)

'No one to run things by' (P1)

'I think we just need to show them (families) that we care. Show them empathy for the situation that they are in' (P10)

'No one to share your successes with' (P3)

'We need to trust them (parents), and they need to trust us...it's a two-way thing' (P6)

'my concern is, who protects us?' P7

'We do get invested in the family and their lives, but you can still maintain that professionalism' (P12)

## Recommendation

- National Conference
- Greater emphasis on the team – workplace, support
- Role of Clinical Practice Specialist
- Education & training
- NMBI accredited training
- Placements for student nurses
- Schwartz Rounds
- Policies & guidelines

## Conclusion

- Nurses working in the community find it both rewarding and challenging in equal measures.
- Education and training is vital to ensure nurses are competent
- Identifying challenges enables us to support nurses
- Better support for nurses means better services for families by retaining well trained, competent staff



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## Thank you.



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## References

- \* HSE 2014 (a) Review of current policy and practice in the provision of home care to children with complex medical conditions. Retrieved from <http://www.lenus.ie/hse/handle/10147/620918> on 10.03.2018.
- \* Kaziny B.D. (2014). The Prehospital care of children with special health care needs. *Clinical Pediatric Emergency Medicine*, 15 (1) 89 – 95.
- \* Larcher et al. (2014) Making decisions to limit treatment in life-limiting and life threatening conditions in children: a framework for practice. *British Medical Journal*. Retrieved from [http://adc.bmj.com/content/archdischild/100/Suppl\\_2/s1.full.pdf](http://adc.bmj.com/content/archdischild/100/Suppl_2/s1.full.pdf) on 04.06.2018.
- \* U.S. Congress, Office of Technology Assessment (1987) *Technology-Dependent Children: Hospital v. Home Care—A Technical Memorandum OTA-TM-H-38*. U.S. Government Printing Office, Washington DC