Experiences of caring for a technologically dependent child at home with an emphasis on home ventilation

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Overview

- Research aim
- Background
- Literature to date
- Method
- Work to date
- Work plan
- Expected outcome
The aim of the study is to describe, interpret and understand parents experiences of ventilation at home
Where possible the children themselves and their siblings will be included

Objectives:

- Describe extent of home ventilation in NI
- Does the way the ventilator was introduced make a difference
- Do families feel services are adequate
- What do professionals think of home ventilation
Background

- Population of children unable to ‘wean’
- Population of children with neuromuscular disease
- Population of children with a congenital condition
- Population of children with trauma
- Development of ventilators has meant that the number of children able to go home (or stay out of hospital) is increasing
Background

• Policy driver: health services designed to meet children’s needs (Every Child Matters)
• Not much is known about
  • What the primary care givers think about this
  • What the children think
  • What effect this has on families
• Opportunity to produce knowledge
Literature review

• Review ongoing
• Empirical studies concerned with
  • Discharge planning and management
  • Adequacy of provision of services
  • Parental roles
  • Experiences of ventilation
• Policy documents concerned with
  • Designing and delivering needs based services
Ethical approvals

- Favourable ethical opinions obtained with minimal changes required
- Process took one year
- UU ethics approved (RG1, RG2 & RG3 + statement of joint indemnity)
- ORECNI approved (with minimal change)
- BHSCT approved
  - Similar to UU RGFC
  - Required honorary contract
  - Required Access NI disclosure
Research Design: Mixed methods

Phase 1: Survey extent

Phase 2: Interview staff

Phase 3: Interview parents

Phase 3: Interview children

Retrospective review of medical notes

Interview: Content analysis

Interview: IPA
Phase 1

- Phase 1: Survey the extent of home ventilation in N.I.
- Identification of population and sample
  - How many children have had home ventilation?
    - N = 27 (M = 10, F = 14, 3 unrecorded)
    - 5 children have stopped using ventilation
    - No post code pattern
    - LD? N=14, Y=4, Not recorded=9
Phase 1

- Mode of ventilation
  - Invasive ventilation (IV) vs. non invasive (NIV)
    - IV = 7, NIV = 19, Not recorded = 1
- Length of time from ventilation to discharge
  - Range from 0 days to 392 days
- Length of time on ventilation
  - Range: 0.58-8.64 years
  - Avg: 4.02 yrs
  - SD: 2.59yrs
Phase 1

- Charts being revisited to complete missing values
- PAS being queried to calculate number of readmissions following start of ventilation
Phase 2: Interview staff

- Paediatrician (15/01/09) [Transcribed]
- Discharge Coordinator RBHSC (28/01/09)
- ICU Technician (TBC)
- Physiotherapist
- Social Worker
- Community nurses

Analyse data to ensure that important issues are included

Pilot phase 3 interview will take place at this time to fine tune interview topic guide
Research Design

• Phase 3:
  • Recruit parents to study
    • Aim to recruit total of Nine families (IPA recommended recruitment = 5-10)
  • Interview parents
    • Option to be interviewed separately or together will be offered first
  • This contact will also demonstrate if it is possible to:
    • Interview siblings (where consent is obtained)
    • Interview the children (where consent is obtained and communication is not a barrier)
Analysis of data in IPA

Case by case analysis
- Reading, examination, annotation and making initial comments
- Themes identified. Connections forged and a thematic account produced

Connecting cases
- Identifying the unifying features of the accounts; producing superordinate themes
- Superordinate themes connected to themes, notes and case text

Producing an account
- Writing an account that outlines the themes with support from case text
- Present as analysis and discussion or both combined
### Work plan 2009-2012

<table>
<thead>
<tr>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
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</thead>
<tbody>
<tr>
<td>Analysis complete Easter 09</td>
<td>Interviews complete September 09</td>
<td>Family interviews begin</td>
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<tr>
<td>Analysis complete March 2010</td>
<td>Interviews complete April 10</td>
<td>Analysis complete April 2011</td>
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<td>Submit May 2012</td>
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Outcome

- To generate insights that will affect how practitioners interact with this group which will facilitate the delivery of family centred care
- To deepen our knowledge of what is involved in care in this arena
- To produce information suitable for training packages for both parents, professionals
Dissemination strategy

- Publication:
  - Clinical literature
  - Use of IPA
  - Findings (research report)
- Presentation at conferences
  - RCN research annual conference
  - CYP annual conference
  - EANS conference
- Presentation of findings (and implications) to home ventilation group