Parent participation in the context of diagnosing shunt malfunction in children

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This presentation will:

- Describe study methods
- Provide an exemplar of the data
- Hydrocephalus - long-term condition identified in childhood
- Main treatment - shunt diverts excess fluid from the brain
- Shunts - prone to malfunction which can be life threatening
- Symptoms of shunt malfunction (vomiting, drowsiness, headache) are same as childhood illnesses
- Parents are responsible for recognising and responding to possible shunt malfunction in their child
- Healthcare professional have a duty to identify possible shunt malfunction in children with hydrocephalus
First stage of research, interview-based study exploring parents’ experiences of living with child with hydrocephalus, suggests:

- Parents develop considerable expertise in managing their child’s condition
- Can differentiate between signs of potential shunt malfunction and common childhood illnesses

But

- Parents felt their experiences were not valued and they were not involved in treatment decisions when seeking advice for their child about suspected shunt malfunction
United Kingdom health policy drivers:

- Services must be patient, or in the case of children, child and family-centred
- People with long-term conditions wish active involvement in managing their condition, and their expertise valued
- Working in partnership with parents when making decisions about a child’s healthcare is fundamental to the provision of family-centred care

Research suggests:

- Parents feel interactions with healthcare professionals are not child and family-centred
- Professional/parent communication are aimed at information giving and establishing good rapport
- Decision-making processes are based primarily on ensuring consent/assent for treatment

Study aim and objectives

- **Aim:**
  - Explore parent’s involvement in care decisions when establishing a diagnosis of shunt malfunction

- **Specific objectives:**
  - Explore how parents engage with healthcare professionals
  - Explore how health professionals respond to and evaluate information from parents when making judgement about a child’s shunt
  - Describe parents’ perceptions and experiences of their encounters with professionals when they suspect their child has a shunt malfunction
  - Describe healthcare professionals’ perceptions and experiences of their encounters with parents when making decisions about the child care
Study setting/sample

- Children with hydrocephalus acute care based at regional children’s neurosurgical services:
  - Recruitment of parents/ healthcare professionals from NHS hospital regional children’s neurosciences ward

- Prospective study, participants purposefully selected:
  - All parents seeking advice about suspected shunt malfunction in their child will be eligible to participate
  - Healthcare professionals (children’s nurses, paediatric house officers, paediatric neurologists, neurosurgical registrars and paediatric neurosurgeons) assessing the child will be invited to participate
Study Design

- Mixed design - primarily qualitative methodologies
- Qualitative methods:
  - Conversation analysis (CA) applied to audio recordings of consultations between parents/child and healthcare professionals
  - Semi-structured follow-up interviews, parents and healthcare professionals
- Modified version of OPTION scale, validated tool relating to decision-making tasks (Elwyn et al 2005)
- Review ward audit data (clinical presentation and admission outcomes)
Recruitment and ethical challenges

- Unpredictability of shunt malfunction, children admitted any time during 24 hour period

- Recruitment challenges
  - Reliant on the senior nurses identifying participants/ providing information/ gaining consent
  - Maintaining effective communication

- Ethical challenges
  - Ensuring participants’ rights are maintained
  - Ensuring consent is an informed choice
  - Ensuring participants are respected and treated sensitively
  - Ensuring participants’ information remains confidential
Data analysis: recorded consultations

- CA will focus on how healthcare professionals engage with parents, how parents describe their child’s symptoms and how treatment decisions are made.

- Four main stages to CA:
  - Transcribe interaction - highly detailed
  - Locate discrete phenomena relating to study focus - involving parents
  - Describe discrete phenomenon in depth - patterns in sequencing and organisation of interactions
  - Return to original corpus to identify other instances of the phenomenon

(Hutchby and Woofftet 1998)
Data analysis: follow-up interviews

- Framework approach, based on thematic analysis, used to analyse data from individual interviews

- Three stages of the framework approach:
  - Data management (verbatim transcription of interviews/ identify initial themes / sort coded data)
  - Descriptive accounts (map diversity within themes / refining themes until ‘whole picture’ emerges)
  - Explanatory accounts (interpretation themes and categories / reflecting back on the original transcriptions)

  (Spencer et al 2003)

- NVivo software will be used to assist data management
Data analysis: quantitative data

- OPTIONs scale will be used to identify congruence between parents and professionals perceptions of the interaction.

- Audit data will be used to identify similarities/differences between parents and professionals judgements in diagnosing shunt malfunction.

- Analysis of OPTION scale and audit data will use descriptive statistics such as frequencies, means and percentages.
Data collected to date

- 14 families (13 mothers) and 14 healthcare professionals (2 senior nurses/ 2 staff nurses/ 7 junior doctors/ 3 specialists neurosurgical registrars) have participated to date resulting in:
  - 21 recorded interactions
  - 31 follow up interviews including OPTIONS scale (3 participants decline follow up-interview invitation)
- 5 audit data obtained
Interaction Mum₁ / SHO₁:

1 SHO: That ear does look sore↑ (. ) it might be that’s all due to the
2   ear (. ) I mean has he ever reacted like that with an ear
3   infection [before
4 Mum: [No not really
5 SHO: (. ) Has he got a perforated ear drum

CA transcription symbols:
(. ) pause, __word emphasis, [ overlap, ↑ high pitch
Mum 1
‘…they thought it was an ear infection and I had to keep saying this was nothing like when he had an ear infection…I suppose at first they did not really listen’

Senior Nurse 1
‘You have to listen to them and include them in care. It is really about working in partnership with parents’

SHO 1
‘…the first and most obvious thing is you to listen to what they are telling you. They know him better than anybody…so whatever was going on something wasn’t right with him so you listen from that point of view’
### OPTIONS

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<td>✓</td>
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<td>SHO</td>
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<td>Senior Nurse</td>
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<td>Satisfaction involving parents/ being involving</td>
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<td>Senior Nurse</td>
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**Outcome:** CT scan shunt blocked, shunt revised, discharged 2 days post surgery
Preliminary review of interactions identified two main sequences where there is potential for active participation:

- Identifying parents concerns
- Formulating a plan of action

Initial themes (forming coding index) developed from follow-up interview:

- Establishing a diagnosis
- Involving parents
- Care delivery
- Beliefs about involvement
Conclusion

- Mixed methods will assist in achieving study aims
- Study outcomes:
  - Describe and understand interactions between parents/healthcare professionals in context of shunt malfunction
  - Identify facilitators/barriers within the interactions in relation to parent’s involvement in their child’s care
- Potential benefits to participants:
  - Parents sharing their views may have a therapeutic effect
  - Professionals may develop greater understanding of factors that support or hinder parents’ contribution to care decisions
Where next?

- Continue data collection and analysis

- Integrate findings from complementary data collection methods

- Contextualise findings by comparing with theoretical perspectives and established literature
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Thank you for listening