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Parental decision making and gastrostomy: professionals' awareness of conflict and strategies for support

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Introduction

- Children with Cerebral Palsy experience difficulties eating and drinking[1] with implications for their health, growth and development.
- A gastrostomy feeding tube (GFT) is usually recommended but can meet with parental opposition[2,3].
- A recent systematic qualitative synthesis of the research on parental experiences of decision making described a 'conceptual framework of decisional conflict'[4] whereby Health Care Professionals (HCPs) are deemed to operate within a biomedical sphere.
- This framework highlights three domains where conflict may arise:
  Values e.g. meaning of food
  Context e.g. family culture
  Process e.g. information sharing and support.
- Few studies have explored HCPs views or practices in relation to this framework.

Aims: To

- Explore the experience, perceptions and practices of community HCPs in supporting families to decide about a GFT for their child.
- Determine whether HCPs have an awareness of the values that parents hold and the strategies they use to support families.
- Determine whether Mahant et al.'s framework reflects HCP practice in a community sample.

Participants

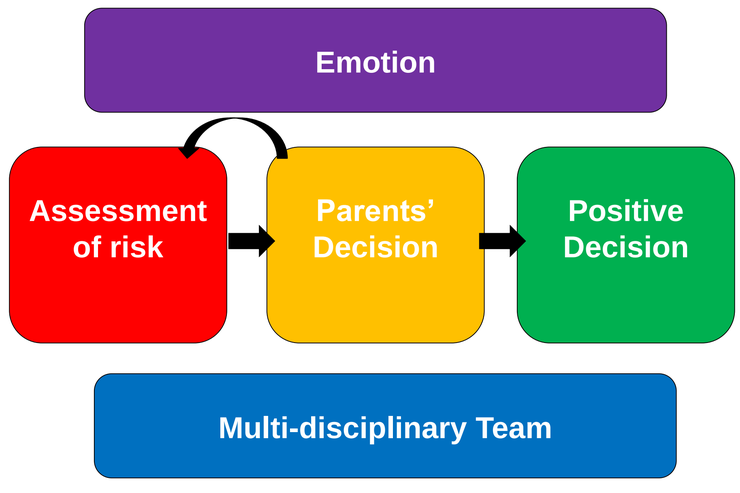
- 10 community HCPs recruited from a special schools service in one London NHS trust. Recruitment was through multi-disciplinary team meetings and individual follow-up emails with written information.
- The catchment area of the service was characterised by high levels of social diversity.
- Participants of 3 professional groups were recruited. Dieticians (2), Speech and Language Therapists (5), Specialist School Nurses (3) with a range of clinical experience ranging from 1 to 15 years.

Methods

- Qualitative interviews lasting between 24 and 54 minutes were audio-recorded, transcribed and analysed.
- Inductive thematic[5] (bottom-up) and deductive directed content analysis[6] (top-down) were used drawing on Mahant et al.'s framework of decisional conflict.

Results

A. How do HCPs support gastrostomy decision making?



Five main themes were found. A three step process with two overarching themes.

- **Assessment of risk** – Followed clinical assessment e.g. weight monitoring, oral supplement use which led to a recommendation of GFT when the risk to safety of the child was sufficiently high.

> **..that risk to the child's health and safety. And we have a duty to ensure the child is kept as safe as possible**

- **Parents' Decision** – HCPs described 'decisional conflict' following the recommendation of GFT. Re-assessment of risk continued providing supporting evidence of a child's need for GFT.

> **They will have said no at first. I think everyone initially, that's the initial reaction**

> **There isn't an alternative anyway, they haven't got a choice**

- **Positive Decision** – When parents accepted the GFT this was viewed as a positive decision by HCPs compared to the risk of oral or naso-gastric tube feeding.

> **I would happily have a hundred tubes in my stomach rather than one on my nose if it was my option**

Two other themes impacted on the three step timeline.

- **Emotion** - Typically negative emotions dominated the decision making process for HCPs and families. Emotions were more 'positive' once the decision was made to accept GTF.

> **That's when I find it really hard….it's hard for us and the families**

- **Multi-disciplinary Team** - Integral to all three steps with general agreement of roles and responsibilities of the different HCPs.

> **but I don't ever do it in isolation anyway, 'cause we work in a…. multi-disciplinary team**

B. HCPs awareness of decisional conflict

- HCPs experienced the decisional conflict described in Mahant et al.'s model.
- The most frequently discussed area of decisional conflict revolved around the values of normalcy, food as nurture, feeding as a social process, concerns about surgery and fears about the loss of oral feeding.
- Although aware of the range of values that were important to families HCPs regarded the child's physical health and wellbeing as paramount thereby subordinating parental values.
- HCPs used a range of support strategies commonly recommended in the literature[4,7] but still experienced the decision making process as difficult and characterised by conflict.
- HCPs approach to support was one of persuading families to make the 'right' decision which was to have a GFT[8].

Conclusions

- This sample of HCPs viewed gastrostomy positively and as inevitable once recommended.
- That HCPs were using many of the current recommended strategies to support families and yet still described frequent decisional conflict requires further examination.
- Formal evidence based guidance on how best to support families is an area for development .

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Ethics

- Ethical approval was granted by City University London Psychology Department Research & Ethics Committee .
- Research & Development approval was granted by the local NHS Trust.

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