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Title

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

Introduction

Parental decision making regarding children's need for a gastrostomy is described as one of 'decisional conflict' (Mahant et al. Pediatrics 2011; 127(6):1471-148). Studies investigating parents' experiences have made various recommendations to improve healthcare professionals' (HCPs) practice. There are few studies investigating HCPs' views and practice.

Participants and Methods

Interviews were conducted with 10 community HCPs from 3 professions: dietician (2), specialist school nurse (3) and speech and language therapist (5), between June-July 2013. Interviewees were part of a multidisciplinary team supporting children with neurodisability. Interviews were audio-recorded, transcribed and analysed using content and thematic analysis using Mahant et al.'s (2011) framework of 'decisional conflict' as an overarching guide.

Results

HCPs demonstrated good awareness and expectation of the 'decisional conflict' that arises for families. However they perceived the decision making process as one that inevitably leads to surgery, placing the child's physical health and wellbeing as paramount over parental values. They described gastrostomy risks as minimal in comparison to naso-gastric tube (NGT) feeding or maintaining 'unsafe' oral feeding regimens. HCPs find the role of supporting families challenging and experience strong responsibility for owning the assumed risk associated with oral or NGT feeding. HCPs adopt a range of strategies to support families to consent to a gastrostomy.

Conclusion

This sample of HCPs viewed gastrostomy positively and as inevitable for children with neurodisability. Formal guidance to support decision making is required to ensure consistency of practice including advice on how to support families.