



## Who really decides: Percutaneous endoscopic feeding decision-making and caregivers of children with cerebral palsy.

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### ABSTRACT (up to 300 words)

#### Abstract

**Background:** South Africa currently has no guidelines for clinical decisions for children with cerebral palsy (CP) requiring enteral feeds. Traditionally, enteral feeding decisions were made by medical doctors who were the most accountable health professional in this and all other similar clinical decisions. Situated as a doctors' scope of practice, patients were essentially treated passively within this paternalistic "doctor knows best" approach. Collaborative decision-making has been promoted as a favored model yet little is known about how these decisions are made currently in practical terms.

**Objectives:** This study aimed to identify the significant individuals, caregiver factors, and caregiver views involved in the enteral feeding decision-making process.

**Method:** A single-case research design was used in this qualitative explorative study. Data was collected using semi-structured interviews and analyzed using thematic analysis.

**Results:** Four primary individuals were identified in the decision-making process: doctors, speech therapists, caregivers' families, and God. Four factors were identified as extrinsically motivating for the caregivers: physiological factors, nutritional

factors, financial factors and environmental factors. Two views were identified as intrinsically motivating for the caregivers: personal beliefs regarding enteral feeding tubes and feelings of fear and isolation.

**Conclusion:** This study highlighted how enteral feeding decision-making within the South African public healthcare sector is dominated by a paternalistic approach supported by lack of caregiver knowledge, distinct patient-health provider power imbalances, and unilateral multidisciplinary healthcare dialogues. This study has implications for clinical practice, curriculum development at higher education training facilities, and institutional policy changes and development.

### BIOGRAPHY (up to 200 words)

Lavanya Naidoo is currently a lecturer at the University of the Witwatersrand, Johannesburg South Africa. She is currently working toward completing her Ph.D. degree at this institution, and was awarded her Masters in Speech-Language Therapy in 2018 (Overall mark > 75%). Ms. Naidoo has worked extensively as a public health Speech Therapist in South Africa (> 10 years) and has a special interest in research involving pediatric neurology and dysphagia cases, health communication, and 3<sup>rd</sup> party disability studies. Ms. Naidoo has thus far presented her research locally and internationally (conference).



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