GOING HOME WITH A FEEDING TUBE: A NEEDS ASSESSMENT

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BACKGROUND

- Bringing home a child with a feeding tube is an overwhelming experience for families
- Pre-discharge education and training is offered to families to support the continuation of enteral nutrition support at home
- Lack of a comprehensive education provided may result in preventable complications, family dynamic disruption and increased healthcare costs
- Education and support offered often fail to address the needs of the families

RESEARCH OBJECTIVES

Family-centered standardized discharge education protocols for pediatric patients going home with a feeding tube are lacking.

- To identify the needs and opportunities related to the discharge process of children that require enteral nutrition support
- To develop recommendations that can serve as starting points towards a family-centered discharge process for tube-fed children

METHODS

- Conducted a literature search to assess what guidelines or protocols exist for effective parental education practices at discharge
- Issued a survey to registered dietitians in the Washington Nutrition Network to evaluate the current landscape, gaps and needs
- Conducted parent individual interviews to learn from families of tube-fed children their perceived gaps and needs in the discharge process

SURVEY FINDINGS

Throughout the survey there were four themes that resonated with respondents:

1. Care coordination and communication
   - "Kids who don’t have a specialty RD seem to be discharged with a feeding tube with no clear plan on who will be managing the tube feeding going forward."

2. Education and training
   - "There is definitely a gap here, especially for families who primarily communicate with a different language than English."

3. Assessment of confidence
   - "The feeding plan and caregivers’ expertise on this part of their child’s care should not be something thrown together at the 11th hour when a child is being discharged."

4. Support and resources
   - "I don’t think parents are given much social/emotional care for this disappointment or transition. We generally don’t see the involvement of a social worker or therapist."

FAMILY FEEDBACK

- All interviewed families expressed that they did not feel fully confident or competent in managing the feeding tube when they left the hospital
- Parents feel they are not receiving enough social and emotional support throughout this transition
- Education and training is rushed and strategies to improve caregiver’s confidence are not implemented
- Segregation between in-patient and community providers affects continuation of care
- The burden of coordinating care often lies on the families
- Navigating the system is challenging, especially for families whose primary language is not English or those living in the rural communities

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