UNIVERSITY of WASHINGTON
SCHOOL OF PUBLIC HEALTH

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 **fails 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 point 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

> Conduced parent individual **interviews** to learn from families of tube-fed children their perceived gaps and needs in the discharge process

RESULTS

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

NEXT STEPS

> Create a family-centered discharge education protocol

-Partner with families

-Address caregiver's confidence and skills

-Tailor the format and content of education

> Improve interdisciplinary care coordination and communication between in-patient and community providers

-Describe the division of responsibilities

-Ensure consistency of education

-Facilitate communication between providers

-Make pertinent referrals

-Explore reimbursement for care managers

-Schedule follow-up appointments

> Provide social and emotional support to families

-Screen patients and caregivers for psychological distress

-Provide support and follow-up

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PPC PEDIATRIC PULMONARY CENTERS

References available upon request.

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