

Assessing the Need for a Multi-Disciplinary Patient and Family Education Initiative for the Medically Fragile Pediatric Patient in an Inpatient Pediatric Rehabilitation Setting

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Background

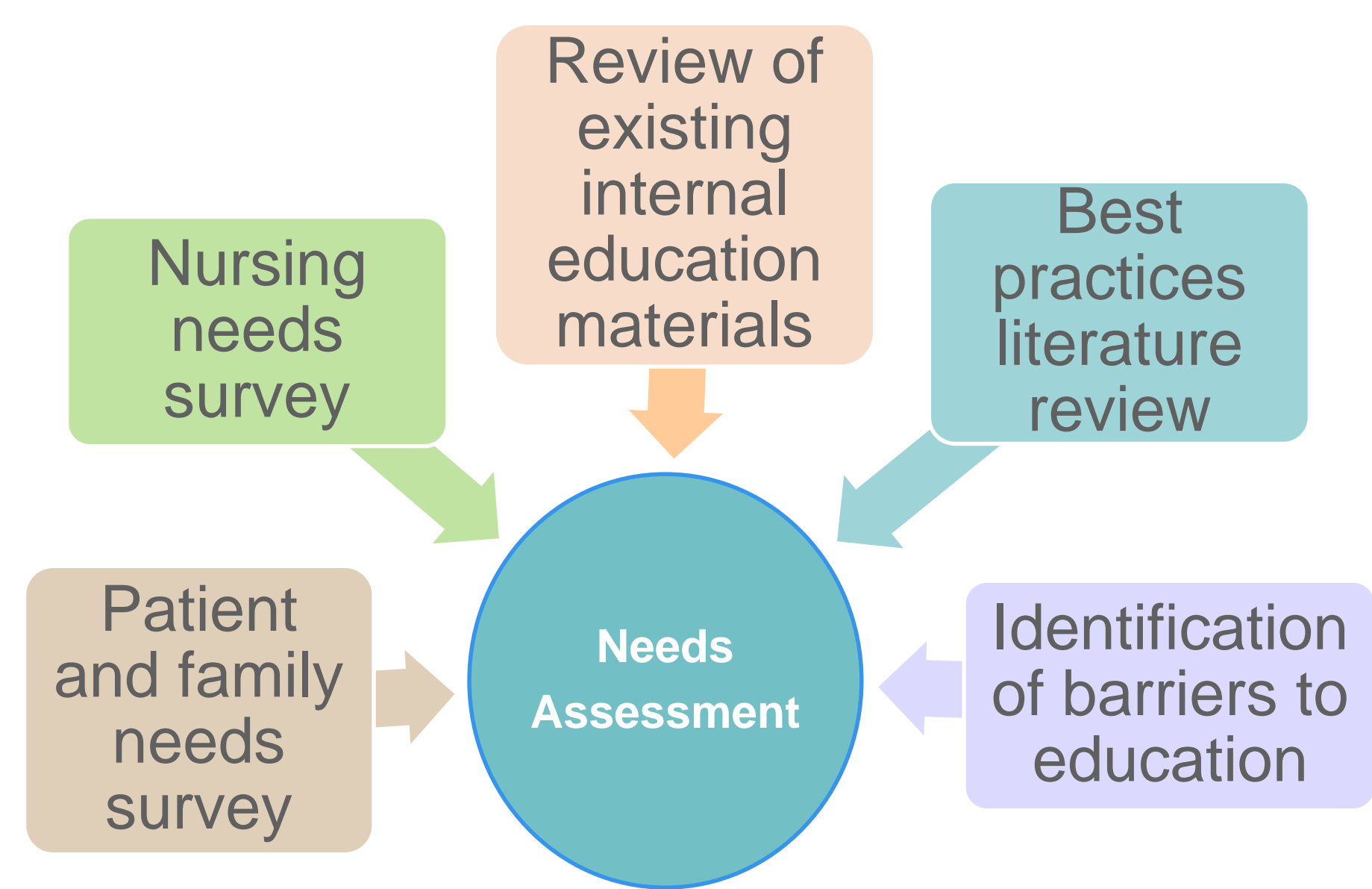
Patient and family education is a critical component of successfully managing the complex pediatric patient in preparation for self-care after discharge. Providing early access to multi-modal education and emotional support decreases the anxiety of parents at the time of discharge when they find themselves thrust into the new role of medical caregiver.

Despite the tremendous need for research and best-practice models in this area, there is a gap in the literature describing comprehensive education programs implemented prior to discharge for medically fragile children living with complex disorders.

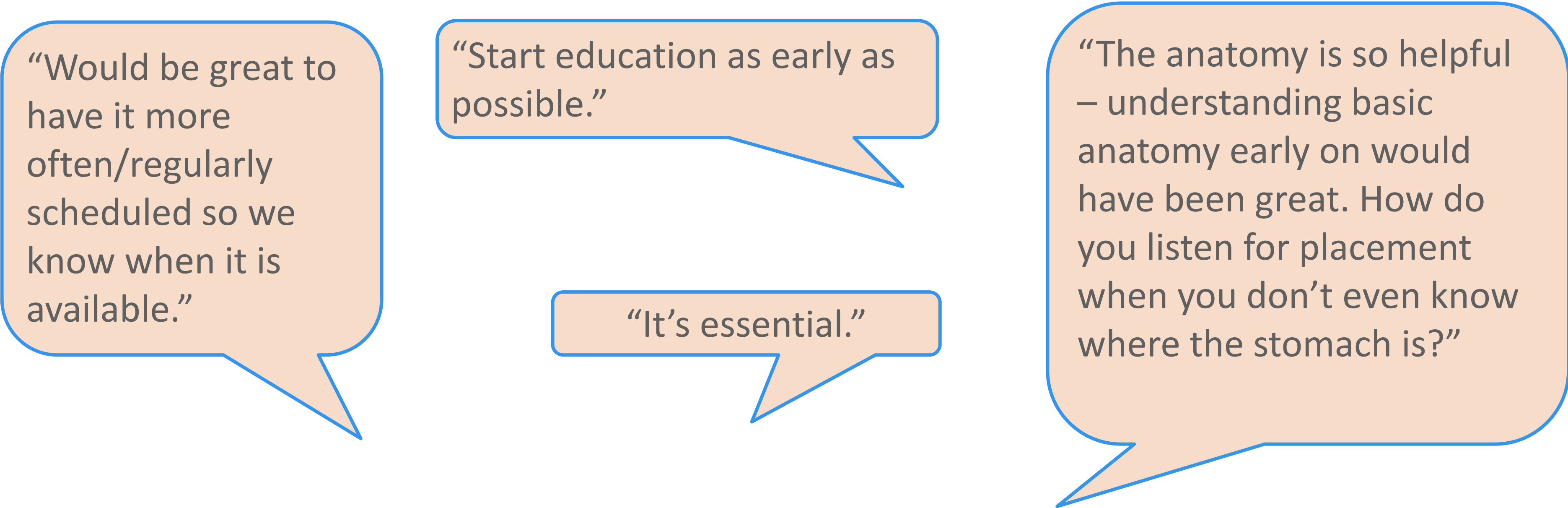
Due to several converging factors (including improving the standard of care, patient/family satisfaction, monitoring best practices, and transforming bedside care) our facility recognized the need to explore a formal multi-disciplinary education program.

Methods

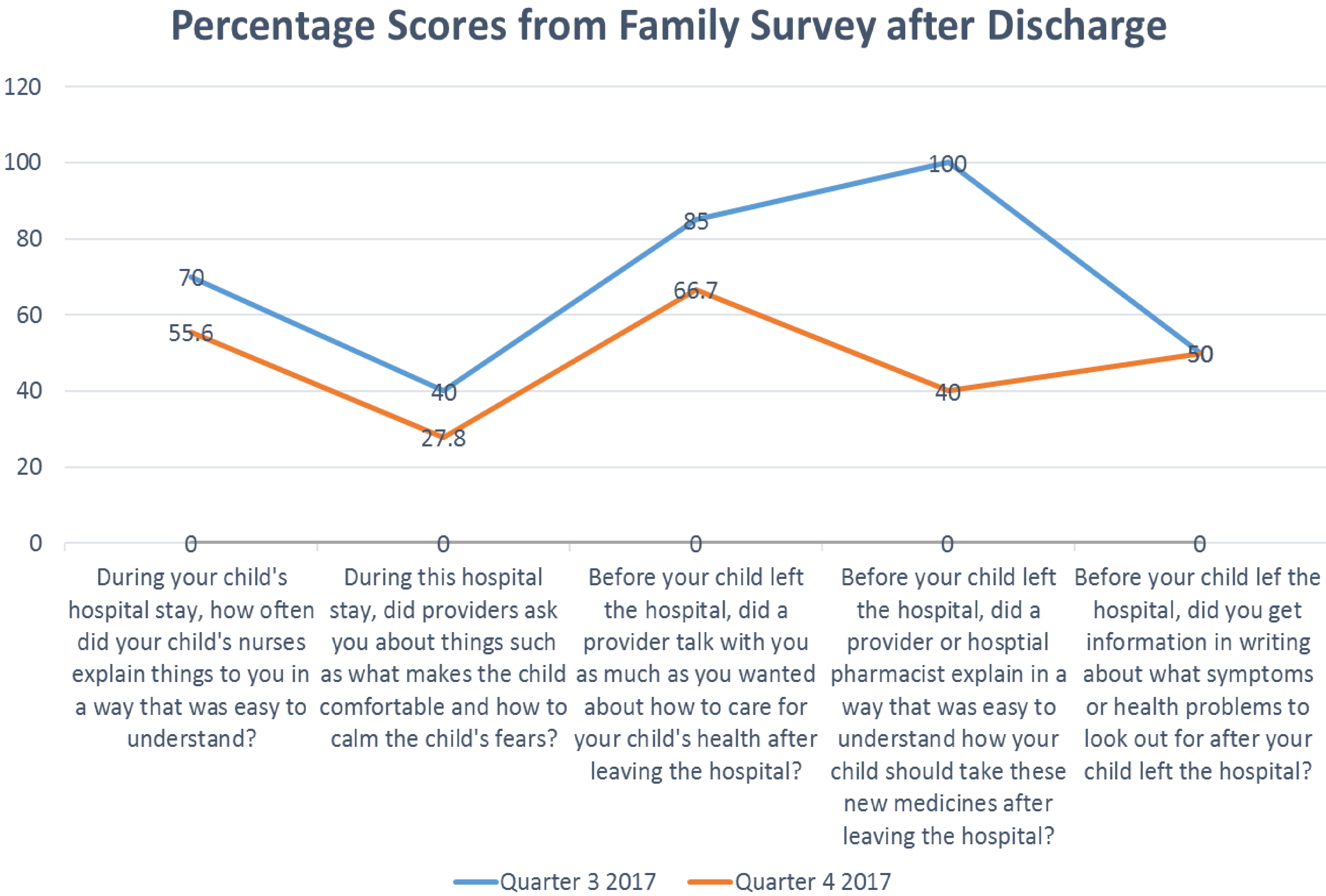
To better identify specific and quantifiable needs, an ad hoc multi-disciplinary committee (nursing, child life, respiratory therapy, social work), with the support of nursing leadership, implemented a qualitative and quantitative assessment of education and support. This assessment had multiple components.



Results: Qualitative Feedback from Families



Results: Quantitative Feedback from Survey



1. Results across all stakeholders overwhelmingly favored early access to multi-disciplinary, multi-modal education for patients and parents.
2. Nurses revealed that additional time to teach patients/families and a variety of resources and teaching materials are critical components of care
3. A comprehensive literature review demonstrated a significant gap of best education practices for this population
4. Review of existing educational materials revealed an area of significant need of revamping and consideration

Goals

1. Develop formal process for education beginning at admission
2. Prioritize initial topics for patient/family education
 - Nasogastric tube/GT
 - Medication administration
 - Tracheotomy care
3. Review best practices in the literature for each topic
4. Review of internal education policies
5. Creation of teaching materials

Future Direction

- The PF has identified five long term goals for the education project:
1. Collection and measurement of outcomes data including:
 - Length of time for education
 - Objective criteria for Independent skill sign off
 - Patient/family satisfaction
 2. Expand educational offerings to include:
 - Additional topics
 - Self-care in an older population
 - Enduring materials (videos) on an education portal
 3. Outreach to community-based visiting nurses, school nurses, and EMTs to share respiratory (trach care and emergency procedures) training
 4. Thought leader peer-reviewed publications
 5. Determine appropriate sources for grants/project funding

