A Specialized Multi-Disciplinary Clinic for Children with Esophageal Atresia/Tracheoesophageal Fistula (EA/TEF)

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Background

Innovations and improvements in neonatal resuscitation and management have improved survival. We have developed a multi-disciplinary team approach to managing these patients in the ambulatory setting. Our team involves pediatric surgery, gastroenterology, neonatology, respiratory, otolaryngology, cardiology, dietitian, occupational therapy, nursing & a nurse practitioner. Our clinic was initiated April 2013 and is held monthly. We follow patients from infancy to adolescence (18 years) and formally transition them to adult health care.

Aim

To evaluate patient and family satisfaction with a new centrally coordinated multi-disciplinary for EA/TEF clinic.

Methods

Ambulatory patient satisfaction surveys were used to collect information anonymously from April-July 2014. The response rate was 83% (29/35). We focused on:

- Education
- Coordination of Care
- Family Feedback
- Net Promoter Score (NPS)

Results

Education

We focused on patient and family education regarding diagnosis and plan of care.

Statements included:

- The staff explained the next steps for care in a way that made sense
- The staff gave me relevant information about my child's experience that was easy to understand
- My child and I were included in the decision about the care
- The staff explained the outcome of the surgery, clinic visit or discharge in a caring manner

Family Feedback

- "Please have more staff to answer the phone. Messages left on voicemail should be attended and a call back would be greatly appreciated."
- "Call to confirm patient appointment."
- "Instead of sending a letter about the new app it would be better to discuss it in person or on the phone with the parents. We always have to change the app because we have to go to different doctors and have other appointments as well."

Coordination of Care

In this category, we looked at how well the visit was coordinated with a multi-disciplinary team.

Statements included:

- Tests and procedures required before my visits were arranged and ordered
- The scheduling process to arrange today's visit was easy
- During my visit, my appointment started on time
- During my visit, I experienced short or no waits

Net Promoter Score (NPS)

The "Net Promoter Score (NPS)" - a standard net promotor question is "How likely it is that you would recommend our company to a friend or colleague?" and respondents indicate this likelihood on a 10-point rating scale. Those scoring services with a 9 or 10 are promoters, those scoring 0-6 are detractors and those between 7-8 are passively satisfied or neutral.

The NPS is the difference between the percentage of users who would recommend your services minus the percentage of those who would not. A score of 75% or above is considered quite high.

Conclusion

After 16 months of our new EA/TEF clinic, we are receiving positive feedback from families. We continue to focus on education for families regarding diagnosis and long term quality of life for EA/TEF patients. We must consider what the families' needs are and how we can provide this care, in our diverse population from being culturally sensitive into integration in a normal life for these patients.