Background

Many children with neurodevelopmental disabilities struggle with oral feeding and benefit from non-oral feeding. Studies have shown improved growth when adequate nutrition can be provided (Sullivan et al., 2005). Despite this information, parents have a hard time making the decision for their child to have a gastrostomy tube placed (Craig et al., 2003, Mahant et al., 2011). Parents report that the decision to have the tube placed may be seen as giving up on their child or as “the easy way out”. They also may be fearful of the possibilities of complications from the tube and poor tolerance of feedings which they may have heard from other parents or from the internet. For some families it may seem that there is not enough support from the medical team to properly manage the gastrostomy tube and the feedings (Craig et al., 2003).

Through a quality improvement process at Nationwide Children’s Hospital (NCH) it was discovered that the management of gastrostomy tubes and gastrostomy tube feedings was fragmented and that there was parental dissatisfaction with this care. There was concern that because of this fragmentation there was increased morbidity for the children and an associated increased cost of care.

NCH has an accountable care organization, Partners for Kids (PKF), which is responsible for over 300,000 pediatric lives in central, eastern and southeastern Ohio. Many children who have neurodevelopmental disabilities and have gastrostomy tubes are covered under PKF. PKF was awarded a Center for Medicaid/Medicare Innovation Grant* to improve the overall quality and cost of care of complex patients. One of the aims of this grant was to develop and implement a standardized process for insertion, management and removal of gastrostomy tubes.

Objectives

1) Develop an insertion plan that included the reason for the gastrostomy tube, the goals of the family and the medical team related to feeding and the placement of the feeding tube, establish which physician is responsible for the placement of the tube, the management of tube complications, the feeding plan, and tube removal.

2) Develop a document of the child’s feeding plan for the electronic health record (EPIC) to facilitate coordination of the child’s care across settings including family, outpatient, inpatient and community members of the team.

3) Develop a common education tool for gastrostomy tube management to be used across the system: inpatient, outpatient, PICU and NICU, etc.

Process

Three subgroups were established to accomplish each of the stated objectives. Each subgroup was facilitated by a project coordinator from PKF. The insertion plan subgroup consisted of physicians from general surgery, interventional radiology, gastroenterology and complex care. There was input sought from the EPIC implementation team as well. The group established what studies were needed prior to the placement of the gastrostomy tube. The nutrition management team consisted of physicians from the complex care team, gastroenterology, NICU, dieticians on the outpatient and inpatient teams, occupational therapists, speech and language pathologists, and nurses. The EPIC team was engaged to help with the build out of the template after the team decided what information should be documented in the form. The education team consisted of nurses from all areas in the hospital, members from the family resource center, and parents. The subgroups had weekly meetings and then also had joint meetings to share progress with each other.

Results

The document in use is meant to be completed as part of the insertion process. The rest of the form is an ongoing journal of the child’s overall feeding plan. This is meant to be updated by the inpatient or outpatient team and a print off given to the family and faxed to their primary care physician.

Discussion

Gastrostomy tube feeding is a common method used to ensure adequate nutrition for children with neurodevelopmental disabilities and oral motor dysfunction. The placement of a gastrostomy tube is a major decision for families and their medical care team. There is evidence that these children’s lives can be improved with a gastrostomy, but parents need more support to manage the tube and the feedings (Sullivan et al., 2005, Craig et al., 2003, Mahant et al., 2011). Considerable effort went into the development of a plan to better manage feeding tube basic care, as well as complications of the tube, to develop a feeding plan document in the electronic health record, and keep in mind the families goals and when it may be possible to achieve oral feedings. The feeding plan document went live 10/7/2013. There will be several meetings to educate teams in the outpatient and inpatient setting about how to complete the form in EPIC and the expectations of who is to complete and update the form. The implementation of the insertion plan should follow shortly as well as the use of the new education program. Over the next 9 months the goal is to have 70% completion of a feeding plan for children with gastrostomy tubes. We hope to be able to show that families are better prepared to care for their child with a feeding tube and that there is an improvement in the quality of care and a decrease in the cost of care for these children.

References


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