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Recurrent gastrojejunostomy tube dislodgement/dysfunction in pediatric patients: an analysis of biologic and sociodemographic factors that predict frequent replacements

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Recurrent gastrojejunostomy tube dislodgement/dysfunction in pediatric patients: an analysis of biologic and sociodemographic factors that predict frequent replacements

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An abstract of
A thesis submitted to the Faculty of the Rollins School of Public Health of Emory University
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Abstract

Recurrent gastrojejunostomy tube dislodgement/dysfunction in pediatric patients: an analysis of biologic and sociodemographic factors that predict frequent replacements

By Meghann J Cantey

Objective: This study aims to determine whether certain biological and sociodemographic factors influence the frequency of gastrojejunostomy tube (GJT) dislodgements or dysfunction in children requiring GJT replacement in interventional radiology (IR) at Children's Healthcare of Atlanta (CHOA) in Atlanta, GA.

Design: Primary analysis of longitudinal GJT replacement data obtained from CHOA in Atlanta, Georgia from October 2018- October 2021.

Methods: Children were grouped by disease origin: congenital anomalies without known genetic component (reference group), chromosomal abnormalities, and postnatal injuries, and the incidence of replacements were compared according to several biological and sociodemographic characteristics using negative binomial regression.

Results: 430 children were included in the analysis. Incidence rate ratios (IRRs) for GJT replacements for children with chromosomal abnormalities (n= 132) was 0.83 [95% confidence interval (95% CI): 0.72- 0.96] times that of children with congenital anomalies. Children with postnatal injuries had an IRR 0.83 times that of children with congenital anomalies (95% CI: 0.70- 0.98). Female children had IRRs 0.87 times that of male children (95% CI: 0.76- 0.98). Black children had an IRR 1.15 times that of White children (95% CI: 1.00- 1.32), while the IRR comparing Asian and Other race children to White and to Black was not statistically significant. Race was found to confound the association. Home health care was strongly associated with the number of GJT replacements with our analysis showing that those without home care had an IRR 1.47 times that of children with (95% CI: 1.11- 1.96). Our analysis did not find any statistical significance related to parents' employment status, ethnicity, preferred language, or Gini Index.

Conclusion: Among children with congenital anomalies, Black children, and children without home health care, we observed an increased incidence of GJT replacements compared with White children, children with chromosomal abnormalities and postnatal injuries, and those with home health care. The strongest association was observed in those children without home health.

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Chapter 1: Background Literature Review

Introduction

Outcomes for children unable to take food by mouth have improved dramatically since the first pediatric gastrostomy was placed in an eight-year-old boy North Carolina in 1870 [1]. Advancements in insertion techniques, including image-guidance, and tube care and design mean that children dependent on this technology have fewer complications, can get their feeding tube earlier in life, and consequently spend more time home with their families and less time in the hospital [2].

The insertion of a gastrojejunal feeding tubes (GJT) in a child requires precision as the end of the feeding tube must be placed through the pyloric sphincter at the bottom of the stomach and into the jejunum. Nutrition can then be delivered directly into the small intestines. The tube is held in place by a balloon on the inside of the stomach. Because the small intestines cannot accommodate a large amount of food at once, most children are fed continuously. However, some feeding schedules call for nutrition to be delivered over 18 or 20 hours per day.

Smaller patients necessitate smaller tubes and also have more delicate tissues which can result in more frequent dislodgements and complications, and as a result, more frequent replacements[2-4]. Complications notwithstanding, a GJT should last approximately six months in most patients as smaller children and babies will require longer tubes as they grow, and balloons break or leak after extended exposure to gastric juices[5]. However, at Children's Healthcare of Atlanta we have noticed that dislodgement and breakage occur much more frequently in some children, with some patients' tubes repeatedly lasting fewer than 30 days.

We will investigate the current literature that examines the risks and complications, especially of repeated GJT exchange, and what interventions have been tested to mitigate these risks or reduce the frequency of exchange. And finally, we will discuss the information missing in the literature and how our research will help address this gap in knowledge.

Background

Pediatric GJT placement is a widely accepted and relatively safe method of providing enteral nutrition to children who cannot take any or enough food by mouth or tolerate gastric feedings [2, 5-9]. This frequently includes children with multiple complex comorbidities, severe neurological impairment, congenital heart disease, and pulmonary hypertension[2, 4-6, 8].

The most common indication for GJT placement is for the management of gastro-esophageal reflux (GER) in children with severe neurological impairment for whom other options are considered too risky[2]. Additional indications are failure to thrive (FTT), a history of aspiration, gastroparesis which is delayed gastric emptying, and microgastria in which the stomach is small and underdeveloped[4, 8].

Risks and Complications

GJT are associated with a significant risk of complication, though most are minor, and require revision and/or replacement frequently. Minor complications associated with GJT include peristomal complaints, such as granulation tissue, redness, cellulitis, or leaking, and mechanical complications, such as breakage or dislodgement[2-4]. Major complications do occur, but rarely, and include intestinal perforation, intussusception, and death[2, 4].

Several studies have shown that younger children and children with lower weight are at increased risk of these more severe complications[4, 6, 8]. Additionally, children are more sensitive to stochastic effects of radiation exposure than adults placing them at potentially high risk of cancer or other iatrogenic disease[6]. Radiation exposure results from imaging conducted to determine proper positioning of the GJT. In fact, one study found that younger children were more prone to GJT trauma and had higher rates of peristomal complications which resulted in more frequent and repeated tube replacements and exchanges which may greatly increase their cumulative radiation exposure[10].

Additionally, while GJT replacement is not particularly painful, it can be uncomfortable and scary for children. Such fear makes staying still for this somewhat precise procedure impossible. However, the risks of sedation and anesthesia are greater for younger and medically fragile children such as those requiring GJT feedings and must be considered carefully[4, 6, 8].

Exogenous risks and considerations

Since their GJT is often the only safe means to feed and hydrate them, most children with a dysfunctional or dislodged GJT initially present at a hospital emergency department (ED). During the week it may be possible for the tube to be replaced the same day in interventional radiology (IR) as an outpatient procedure, thus avoiding the ED. However, emergencies rarely adhere to normal business hours. GJT issues that arise on weekends or holidays still require a visit to the ED, and most likely, an inpatient hospital stay for intravenous (IV) hydration while they await their procedure.

Image-guided insertion as an outpatient procedure by interventional radiologists has reduced time spent waiting for a tube replacement, which in turn has reduced the need for

inpatient admission, in addition to reducing the inconvenience and expense for patients, families, and hospitals compared to replacement in an operating room[9]. Despite these improvements, pediatric GJT replacement is still a resource-intensive procedure that carries significant risks for the patient and costs for hospitals and families[11]. In fact, the cost billed to insurance for a single, uncomplicated GJT replacement without sedation or anesthesia in an interventional radiology (IR) suite is nearly $10,000 at Children's Healthcare of Atlanta as of October 2021.

Areas of development

Trips to the emergency room, expensive medical bills, time off work, and fear for the health and safety of a medically fragile child can result in significant emotional and financial disruption and distress for caregivers. Hospital-based quality improvement initiatives aimed at reducing the number of these ED visits and inpatient stays have shown to be beneficial at reducing hospital costs and inpatient admissions.

One such program from 2007 at The Hospital for Sick Children in Toronto, Ontario, Canada implemented a "weekend GJ-maintenance service"[12]. A member of the interventional radiology team would check with the hospital ED once per day on weekends and most holidays if any children requiring GJT replacements had presented overnight. If so, an on-call team would come in to do the procedure thus preventing the need for inpatient admission. They found that the program significantly reduced the number of admissions, the length of time a patient waited for the procedure, and the amount of time the procedure itself took.

Another program from The Children's Hospital of Wisconsin in 2016 studied the effect of including a patient-specific recommendations to the radiology post-operative note following a tube maintenance procedure[9]. The IR team, feeding service, and the patient's primary medical

provider discussed and determined what should be done for each patient in the event of the tube malfunction or dislodgement outside of regular IR department operating hours. This information was then shared with the family prior to discharge following the procedure. The goal of the program was to decrease the need for after-hours procedures, which came at great cost to the hospital, and a reduction in family anxiety. They concluded that this program did result in a cost-savings to the hospital but were unable to effectively determine patient/caregiver satisfaction or reduction in parental anxiety.

More and more, researchers are interested in exploring the effect of sociodemographic factors and barriers to care on chronic health conditions. These studies often exclude children with multiple concurrent comorbidities or if they do not exclude, they only focus on one health issue. A study from Baylor College of Medicine is an example of the latter and sought to examine the associations between sociodemographic factors and delays in epilepsy surgery for children with medically intractable seizures related to focal cortical dysplasia[13]. They found that race, distance to surgical center, and kind of insurance were correlated with patient age at the time of epilepsy surgery. Another study from Cincinnati Children's Hospital Medical Center in vulnerable children with asthma assessed barriers to care and primary care is an example of the former[14]. They used a questionnaire to assess barriers to care, such as pragmatics, life skills, acculturation and marginalization, and parental expectations of care, knowledge, and beliefs, and found that these factors explained excess variance in the sample's primary care characteristics that was not explained by access, demographic factors, and severity of disease. However, they excluded children with comorbid conditions that they believed might affect care or outcomes.

Evidence Gaps

Both the Sharafinski (2016, #9) and Jaskolka (2013, #12) GJT studies did show significant reduction in admissions exclusively for GJT replacement either by making patient-specific plans for GJT dislodgement easy to find in a patient's chart or by having an interventional radiologist check in with ED on weekends. However, limitations in this body of evidence include short study periods and small sample sizes making conclusions difficult to extrapolate[9, 12]. Additionally, they were not intended to address tube durability which, given the well-documented risks of repeated GJT replacements, arguably should be paramount in pediatric GJT research.

The studies of Crowley (2014, #6) and Shahi (2021, #11) have established evidence using patient-level demographics and disease processes and have resulted in improved tube design and insertion techniques which have subsequently led to a reduction in the occurrence of both major and minor complications[6, 11]. The focus of their research was on the mechanics of insertion and complications in general rather than on excessive dislodgement. Demehri (2016, #4) and Friedman's (2004, #8) studies identified an increased risk especially among smaller children and those with more fragile health[4, 8]. However, they did not offer suggestions or interventions for how to improve care and outcomes for pediatric patients with significant barriers to care and from vulnerable populations. Additionally, to the best of our knowledge, there have been no studies investigating the socio-behavioral and sociodemographic factors that contribute to pediatric GJT durability.

Since children with GJT almost always have multiple concurrent comorbidities, isolating and measuring the effect of one health issue on tube durability may be especially challenging, and in fact, these comorbidities may be related to tube durability. Moreover, the

interplay between these health issues and sociodemographic characteristics of the family may provide important information that can meaningfully improve outcomes for those patients at the intersection of this population who are both medically fragile and socially vulnerable[15].

Anticipating barriers to care, educational deficits, language discordance, and resource misalignment would allow healthcare professionals to preemptively ameliorate these factors and help guide efforts aimed at improving GJT durability and patient outcomes in this particularly vulnerable pediatric population. By examining what factors place a child at increased risk of premature GJT dislodgment, we hope to measurably improve tube duration and patient outcomes and reduce resource utilization and expense for families and hospitals.

Statement of problem

There is a need to identify the biological and sociodemographic factors that place a child at increased risk of early dislodgement of their gastrojejunostomy (GJ) tube. A better understanding of these factors may allow for identification of at-risk populations that may require more supports or follow up to prevent displacement /dysfunction or allow for development of population specific interventions based on increased risks.

Purpose of the Study

To investigate which biological and sociodemographic factors are associated with increased GJT dislodgement and dysfunction in pediatric patients.

Public Health Implications

Furthermore, a better understanding of who is at greater risk of GJT dislodgement will allow for earlier intervention and additional support for these children and their families that may improve the duration of tube placement and reduce the risks for the patient associated with repeated replacements, while also decreasing costs for families and hospitals within the Children's Healthcare of Atlanta network. The three-year study period will allow for a larger sample size which is needed to assess less common variables.

Chapter 2: Journal Article

Abstract

Objective: This study aims to determine whether certain biological and sociodemographic factors influence the frequency of gastrojejunostomy tube (GJT) dislodgements in children requiring GJT replacement in interventional radiology (IR) at Children's Healthcare of Atlanta (CHOA) in Atlanta, GA.

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number of GJT replacements with our analysis showing that those without home care had an IRR 1.47 times that of children with (95% CI: 1.11- 1.96). Our analysis did not find any statistical significance related to parents' employment status, ethnicity, preferred language, or Gini Index.

Conclusion: Among children with congenital anomalies, Black children, and children without home health care, we observed an increased incidence of GJT replacements compared with White children, children with chromosomal abnormalities and postnatal injuries, and those with home health care.

Introduction

Pediatric GJT placement is a widely accepted method of providing enteral nutrition to children who cannot take food by mouth[8]. Image-guided insertion as an outpatient procedure by interventional radiologists has reduced time spent waiting for tube replacement, which in turn has reduced the need for inpatient admission and reduced the inconvenience and expense for patients, families, and hospitals compared to replacement in an operating room[9]. Despite these improvements, pediatric GJT replacement remains a resource-intensive procedure that carries significant risks for the patient such as radiation exposure, intestinal perforation, infection, and bleeding and costs for hospitals and families[8, 11, 16]. Patients requiring GJ feeding are almost always medically fragile with multiple concurrent health issues that make the procedure and sedation or anesthesia particularly risky[8]. In addition, children are more sensitive to stochastic effects of radiation exposure than adults placing them at potentially higher risk of cancer and other iatrogenic disease later in life [11]. Although the risks of pediatric GJT replacement are well documented, and multiple studies have been done investigating the procedural components

of the GJT placement, to the best of our knowledge, there have been no studies exploring the influence of biological and sociodemographic factors together on pediatric GJT durability [2-4, 6, 8, 12].

Therefore, this study is indicated in order to identify at-risk populations that may require more supports or follow up to prevent displacement /dysfunction or allow for development of population specific interventions based on increased risks.

Methods

Using data obtained from Children's Healthcare of Atlanta Interventional Radiology department in Atlanta, Georgia, we performed a retrospective cohort study of 430 children ranging in age from just under two months to 21 years who had at least one gastrojejunostomy tube replacement within the study period. Interestingly, there were exactly 215 females and 215 males in the cohort. De novo GJT placements were excluded, as were replacements that took place before or after the study period. Replacements that took place in locations other than the interventional radiology suites were also excluded. Demographics of this cohort can be viewed in Table 1.

Covariates included date of birth, date of death (if applicable), dates of all GJT replacements, whether they had a GJT at the end of the study period, active diagnoses, race, ethnicity, parent's employment status, preferred language as documented in the patient's medical record, whether they had home health care, and zip code. Zip code was used to obtain Gini coefficient from the U.S. Census department ACS 1-year estimates 2020 to use a proxy for socioeconomic status as we did not have access to patient household income, education level, or other socioeconomic information. Whether a child has a primary care provider (PCP) was also

collected but ultimately not used in the analysis because only four children did not have a documented PCP. Dummy variables were created for the categorical variables disease origin, race, preferred language, and parental employment status. Referent groups were always set to zero in the class statement, and zero indicated the most populous group with the exception of patient sex as it contained an equal number of each sex. Since each GJT dislodgement/ dysfunction required a replacement, we use the terms "dislodgement" and "replacement" interchangeably. A frequency plot of the distribution of replacements can be found in Figure 1.

Differences in follow-up time were accounted for by taking the natural log of the difference between each child's study start date or date of birth, whichever was later, and study end date or date of death, whichever was sooner. This number was used as the model offset.

Children were placed in one of three diagnosis categories to differentiate between disease processes and origins. Children with a confirmed chromosomal abnormalities or diagnoses known to be almost exclusively associated with a genetic abnormality were placed in one group termed "genetic" (n= 132). Children whose disease process was present at birth but is not known to necessarily be genetic in cause were in another group called "congenital" (n=217). The last group was comprised of children whose difficulties arose as a result of some complication or injury after birth referred to as "postnatal injury" (n=81). This group includes children who were born prematurely but were otherwise healthy at birth and those who had catastrophic neurologic injuries such as Shaken Baby, motor vehicle accident, or near drowning. Since many of the diagnoses of this sample population are extremely rare, classifying them this way allowed us to group children with similar characteristics despite their actual diagnoses being different.

Using SAS 9.4, we performed descriptive analysis including frequency distribution, mean, median, variance and range on each covariate and then modeled each with only the

outcome to better understand its characteristics and its relationship to the outcome. Upon learning that the mean number of replacements was less than the variance at all levels of disease origin which indicated overdispersion, we opted to use a negative binomial distribution to obtain incidence rate ratios (IRR) for each covariate and level of covariate.

We then built a model with all covariates and systematically removed covariates with the highest (i.e., least significant) p-value and reassessed. We proceeded in this way until all remaining covariates had p-values less than 0.05 for at least one level. Using this model, we assessed for statistically significant interactions among clinically significant covariate combinations. We assessed for confounding effects of individual variables on our outcome by comparing the β estimates of our exposure in models with and without the variable we were assessing.

Results

We had 217 children with congenital anomalies, 132 children with chromosomal abnormalities, and 81 children with postnatal injuries. The lower mean compared to variance indicated overdispersion, which means that there is greater variability in a sample than would be expected in a Poisson distribution model, and in this *particular* case means that the observed number of GJT dislodgements over our three year and one month study period is greater than would be expected. The mean time between replacements was 106 days. Thirty-three children's GJTs lasted longer than 180 days (10.34%).

Our analysis indicates that the IRR for replacements among children with chromosomal anomalies is 0.83 times [95% confidence interval (95% CI:): 0.72- 0.96, p-value= 0.014] that of children with congenital abnormalities controlling for age at first replacement, patient sex, race,

and home health care (Table 3). Among children with postnatal injuries, the IRR is 0.83 times (95% CI: 0.70- 0.98, p-value= 0.031) that of children with congenital abnormalities also controlling for age at first replacement, patient sex, race, and home health care suggesting an increased risk of dislodgement for children with congenital anomalies compared to both other groups.

A child's age at their first GJT replacement was associated with an IRR for GJT dislodgement of 0.99 times (95% CI: 0.98-1.00, p-value= 0.011) for each increase in age of one year indicating that older children were at slightly and progressively lower risk of GJT dislodgement compared with younger children.

The IRR for female children was equal to 0.87 times (95% CI: 0.76- 0.98, p-value= 0.024) that of male children (referent) suggesting a fairly strong association between sex and GJT dislodgement.

Race was a confounder in the relationship between number of dislodgements and disease origin as evidenced by a change in the β estimate (i.e., IRR) of greater than 10% in models with and without the covariate for race. We controlled for this bias by including race in all our models. Black children had an IRR equal to 1.15 times (95% CI: 1.00- 1.32, p-value= 0.044) that of White children (referent) when controlling for age at first replacement, patient sex, and home health care. No association was observed comparing Asian children nor Other race to White or Black children.

The IRR for number of dislodgements for children who did not have home health care was 1.47 times (95% CI: 1.11- 1.96, p-value= 0.008) that of children with home health care when controlling for disease origin, age at first replacement, patient sex, and race indicating a

strong and statistically significant relationship between number of replacements and home health care.

We tested for effect modification of several interactions that were clinically meaningful to our research question on the relationship between disease origin and number of GJT replacements: race and Gini Index, ethnicity and Gini Index, disease origin and age at first replacement, disease origin and Gini Index, and parent employment status and Gini Index. However, none of these terms were statistically significant in our sample and were thus not included in the model. The deviance of our final model was 0.9712 indicating good fit of the data to the model.

Discussion

This study is the first study to data that assesses the effect of disease origin in the presence of several biological and sociodemographic covariates on the number of gastrojejunostomy tube dislodgements in pediatric patients ranging in age from just under two months to 21 years undergoing tube replacement in interventional radiology at Children's Healthcare of Atlanta in Atlanta, Georgia. Our findings indicate that GJT replacements were more frequent among children with congenital anomalies, Black children, males, those without home health care, and in younger children. The strongest predictor by far for GJT dislodgment was whether a child had home health care suggesting that additional effort should be made for these children to ensure that home health care is in place before leaving the hospital, and that it remains in place without interruption until no longer needed.

More troubling and more difficult to address though is the evidence of racial disparities among Black children. Race was only a significant predictor among Black children which

suggests that this group may require more supports or follow-up to prevent dislodgement and specific interventions based on their increased risk. Determining the reasons for this disparity was not only outside the scope of the research, but also outside the scope of Epic data. Improved data collection from patients and families would have allowed for much more robust investigation of these associations. Children are completely dependent on their parents, especially the children in this study, and yet, virtually no parent data such as employment, healthcare literacy, education, social supports are collected even though these factors have been shown to have significant influence on pediatric healthcare outcomes [17-21].

In regard to language, despite difficulties inherent in communicating medical education in the presence of language discordance, our research did not find preferred language to be a significant predictor of number of GJT replacements. This could be because although people may be fluent in one or multiple languages, they could still have difficulty even with the help of an interpreter with the higher register of medical terminology, meaning that all groups may have had similar difficulty or none at all. Interestingly, most of the children who identified as "Other" race also indicated Hispanic ethnicity or Spanish as their preferred language, and as no association was found between "other" race, language, or Hispanic ethnicity and number of replacements, this suggests that factors other than English fluency and healthcare literacy could be responsible for racial differences in this population. Testing this would require greater variability than this sample provided, and future studies should aim for more racial diversity.

The findings of this study suggest that while some factors that predict the frequency of GJT dislodgement are actionable, most are not directly. Future studies should attempt to have better representation of racial groups other than Black and White and better variation and validation of language preferences to dive much deeper to discover the association between race

and GJT replacement. Atlanta is the number one city in America for income inequality, with median household income for Black families in 2020 at $35,048 and White families at $102,693, though that difference is not as dramatic outside of city limits [21]. Economists, public health researchers, and sociologists have found causes for this disparity to be related to distance from work, pay, access to healthcare and insurance, and family structure. In other words, complicated [17-21]. A great deal of work needs to be done to address this inequity on a molecular level, but until then, finding ways to better support Black and brown children is an imperative to prevent GJT displacement and dysfunction in this extremely vulnerable population. Care or patient navigators have been shown to improve health related outcomes and reduce disparities in low-income and minority pediatric patients for chronic illness and disabilities such as asthma, hearing loss, and cancer [22-24]. The cost of implementing such a program at Children's Healthcare of Atlanta is beyond the scope of this discussion, but the knock-on cost saving to families and organizations as a result of improved access to healthcare and reductions in costs from more efficient resource utilization cannot be overlooked.

There are some limitations to this study. First, although we had sufficient sample size, our results may not be generalizable to other populations, hospitals, or geographic locations as this is a single-site study. However, this specificity can also be considered a benefit as it casts a powerful magnifying lens on racial and socioeconomic disparities in Georgia. The high-utilization, medically fragile, and diverse population in this study would be a great fit for implementation of pilot studies assessing the impact of healthcare navigator programs discussed above.

One final note is that although our research did not find parental employment status and/or Gini Index to be significant predictors of the number of replacements, these variables do

not account for changes in a child's circumstances related to foster care placement, those placed formally or informally under the care of a grandparent or other relative, or those in single parent homes with limited social safety nets. Beyond more accurate and detailed data regarding language proficiency and race, future research should seek to include information about family structure, income, and education levels to help better accommodate the unique needs of this population. This information is challenging to collect and subject to reporting bias. Incorporating Gini Index or other measures of income inequality in models along with individual-level socioeconomic data, access to reliable personal transportation, caregiver burden perception, and other barriers to healthcare accessibility may help identify the sociodemographic disparities within this population and associations that we were not able to capture in this research.

Healthcare is a human right as articulated in the 1946 Constitution of the World Health Organization, and as such, the findings of this study indicating that Black and brown children are falling behind White children in health and well-being in Georgia have great implications for public health [25]. Finding areas where disparities exist within our healthcare system is an important first step to achieving health equity for marginalized populations. Hospital-based programs that are already in use such as the Learning Needs Assessments may be underutilized but could also be made more robust to better ascertain healthcare literacy and language proficiency for native and non-native English speakers alike. We've only begun to appreciate the complex interconnectivity of socioeconomic, biologic, and sociodemographic factors on human health. In particular, financial stressors within families and caregiver burnout are common among parents of profoundly disabled, medically fragile children [27-29]. Identification of these stressors and a better understanding of a family's journey earlier in the process of care delivery could allow additional support networks to be put in place earlier.

Especially important is eliminating gaps in care related to home health which could be mitigated with case management and care navigators. Healthcare navigators are not currently utilized at Children's Healthcare of Atlanta, however, these finding suggest that implementing such a program could be beneficial for our patients, families, and the hospital system.

Tables and Figures

Table 1. Sample Characteristics (n= 430)

	Total
Age at first replacement– years, median (IQR)	5.9 (1.9 – 11.2)
# of GJT replacements- median (IQR)	3 (1– 5)
Male sex- n (%)	215 (50)
Race – n (%)	
Black or African American	165 (38.4)
White	253 (50.9)
Asian	12 (2.8)
Other	34 (7.9)
Ethnicity - n (%)	
Hispanic	70 (16.3)
Non-Hispanic	359 (83.5)
Disease origin - n (%)[a]	
Chromosomal abnormality	132 (30.7)
Postnatal injury	81 (18.8)
Congenital, not genetic	217 (50.5)
Parent employment – n (%)	
Yes	227 (52.8)
No	95 (22.1)
Unknown	108 (25.1)
Language preference – n (%)[b]	
English	394 (91.6)
Spanish	31 (7.2)
Other	5 (1.2)
Home health care – n (%)	412 (95.8)

Notes

[a]Disease origin refers to primary source of health issue that has resulted in requiring GJT feedings

[b]Arabic, Nepali, Portuguese, Swahili, and Vietnamese were collapsed into Other

Figure 1. Frequency plot of distribution of replacements

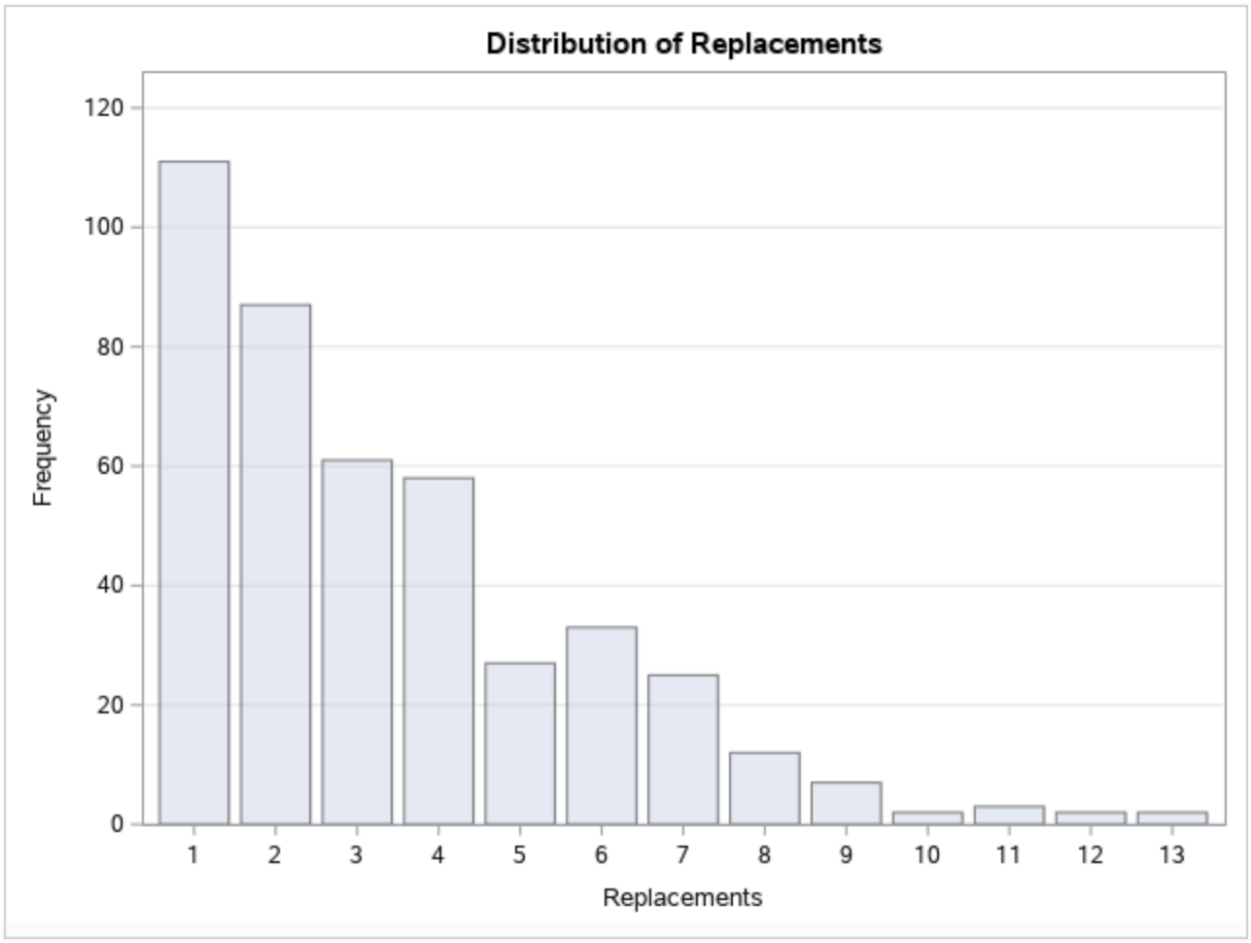

Table 2. Incidence Rate Ratio

	IRR	95% CI	p-value
Disease origin[a]			
Chromosomal abnormality	0.83	0.72, 0.96	0.014
Postnatal injury	0.83	0.70, 0.98	0.031
Age at 1st replacement[b]	0.99	0.98, 1.00	0.011
Female sex	0.87	0.76, 0.98	0.024
Race			
Black	1.15	1.00, 1.32	0.044
Asian	0.97	0.64, 1.47	0.890
Other	0.80	0.62, 1.03	0.080
Home health care (yes)	1.47	1.11, 1.96	0.008

Notes

[a]Congenital anomalies is reference group

[b]Replacement may also be indicated for patient growth rather than tube dysfunction

[c]White race is reference group

Chapter 3

Future Directions/ Public Health Implications

This study is the first study to data that assesses the effect of disease origin in the presence of several biological and sociodemographic covariates on the number of gastrojejunostomy tube dislodgements in pediatric patients ranging in age from just under two months to 21 years undergoing tube replacement in interventional radiology at Children's Healthcare of Atlanta in Atlanta, Georgia. Our findings indicate that GJT replacements were more frequent among children with congenital anomalies, Black children, males, those without home health care, and in younger children. The strongest predictor by far for GJT dislodgment was whether a child had home health care suggesting that additional effort should be made for these children to ensure that home health care is in place before leaving the hospital, and that it remains in place without interruption until no longer needed.

More troubling and more difficult to address though is the evidence of racial disparities among Black children. Race was only a significant predictor among Black children which suggests that this group may require more supports or follow-up to prevent dislodgement and specific interventions based on their increased risk. Determining the reasons for this disparity was not only outside the scope of the research, but also outside the scope of Epic data. Improved data collection from patients and families would have allowed for much more robust investigation of these associations. Children are completely dependent on their parents, especially the children in this study, and yet, virtually no parent data such as employment, healthcare literacy, education, and social supports are collected even though these factors have been shown to have significant influence on pediatric healthcare outcomes [17-20].

Despite difficulties inherent in communicating medical education in the presence of language discordance, our research did not find preferred language to be a significant predictor of number of GJT replacements. This could be because although people may be fluent in one or multiple languages, they could still have difficulty even with the help of an interpreter with the higher register of medical terminology. Interestingly, most of the children who identified as "Other" race also indicated Hispanic ethnicity or Spanish as their preferred language, and as no association was found between "other" race, language, or Hispanic ethnicity and number of replacements, this suggests that some difference other than English fluency and healthcare literacy could be responsible for racial differences in this population. Testing this would require greater variability that this sample provided, and future studies should aim for a more diverse sample population.

The findings of this study suggest that while some factors that predict the frequency of GJT dislodgement are actionable, most are not directly. Future studies should attempt to have better representation of racial groups other than Black and White and better variation and validation of language preferences to dive much deeper to discover the association between race and GJT replacement. Atlanta is the number one city in America for income inequality, with median household income for Black families in 2020 at $35,048 and White families at $102,693 in 2020, though that difference is not as dramatic outside of city limits [21]. Economists, public health researchers, and sociologists have found causes for this disparity to be related to distance from work, pay, access to healthcare and insurance, and family structure. In other words, complicated [17-21]. A great deal of work needs to be done to address this inequity on a molecular level, but until then, finding ways to better support Black and brown children is an imperative to prevent GJT displacement and dysfunction in this extremely vulnerable population.

Care or patient navigators have been shown to improve health related outcomes and reduce disparities in low-income and minority pediatric patients for chronic illness and disabilities such as asthma, hearing loss, and cancer [22-24, 26]. While the cost of implementing such a program at Children's Healthcare of Atlanta is beyond the scope of this discussion, the knock-on cost saving to patients, families, and organizations as a result of improved access to healthcare and reductions in costs from more efficient resource utilization cannot be overlooked [25].

There are some limitations to this study. First, although we had sufficient sample size, our results may not be generalizable to other populations, hospitals, or geographic locations as this is a single-site study. However, this specificity can also be considered a benefit as it casts a powerful magnifying lens on racial and socioeconomic disparities in Georgia. The high-utilization, medically fragile, and relatively diverse population in this study would be a great fit for implementation of pilot studies assessing the impact healthcare navigator programs.

One final note is that although our research did not find parental employment status and/or Gini Index to be significant predictors of the number of replacements, these variables do not account for changes in a child's circumstances related to foster care placement, those placed formally or informally under the care of a grandparent or other relative, or those in single parent homes with limited social safety nets. Beyond more accurate and detailed data regarding language proficiency and race, future research should seek to include information about family structure, income, and education levels to help better accommodate the unique needs of this population. This information is challenging to collect and subject to reporting bias. Incorporating Gini Index or other measures of income inequality in models along with individual-level socioeconomic data, access to reliable personal transportation, caregiver burden perception, and

other barriers to healthcare accessibility may help identify the sociodemographic disparities within this population and associations that we were not able to capture in this research.

Healthcare is a human right as articulated in the 1946 Constitution of the World Health Organization, and as such, the findings of this study indicating that Black and brown children are falling behind White children in health and well-being in Georgia have great implications for public health [25]. Finding areas where disparities exist within our healthcare system is an important first step to achieving health equity for marginalized populations. Hospital-based programs that are already in use such as the Learning Needs Assessments may be underutilized but could also be made more robust to better ascertain healthcare literacy and language proficiency for native and non-native English speakers alike. We've only begun to appreciate the complex interconnectivity of socioeconomic, biologic, and sociodemographic factors on human health. In particular, financial stressors within families and caregiver burnout are common among parents of profoundly disabled, medically fragile children [27-29]. Identification of these stressors and a better understanding of a family's journey earlier in the process of care delivery could allow additional support networks to be put in place earlier. Especially important is eliminating gaps in care related to home health which could be mitigated with case management and care navigators. Healthcare navigators are not currently utilized at Children's Healthcare of Atlanta, however, these finding suggest that implementing such a program could be beneficial for our patients, families, and the hospital system.

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