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ORIGINAL RESEARCH

Parenteral nutrition weaning in pediatric intestinal failure patients enrolled in remote patient monitoring: A descriptive study

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Abstract

Background: Remote patient monitoring (RPM) enhances patient surveillance. This study describes our initial experience with RPM in pediatric intestinal failure patients and its preliminary impact on parenteral nutrition (PN) reduction in an outpatient setting.

Methods: We performed a descriptive cohort study on pediatric patients with intestinal failure receiving home PN and enrolled in an RPM program managed by our intestinal rehabilitation team. Initiated in March 2021, the study compared PN energy and volume reduction rates before and after RPM implementation. We calculated the rate of PN decrease per day and the time to achieve a 20% reduction in PN volume. Paired *t* tests were used for comparisons. Statistical significance was set at $P < 0.05$. The study received institutional review board approval.

Results: Seventeen patients were included (52% male; mean age: 44 months). The most common etiology of short bowel syndrome was necrotizing enterocolitis (NEC), with a mean residual small bowel length of 15.5% ± 12.5%. Post-RPM, there was a greater reduction in PN energy and volume (0.22 ± 0.28 and 0.17 ± 0.24) compared with pre-RPM (0.08 ± 0.10 and 0.07 ± 0.08), though not statistically significant ($P = 0.11$ and $P = 0.17$). Time to achieve a 20% reduction in PN was shorter post RPM but not statistically significant ($P = 0.06$ and $P = 0.20$ for energy and volume, respectively).

Conclusion: Remote patient monitoring appears safe for pediatric intestinal failure patients, with potential for higher PN reduction and shorter time to achieve it. Further research is needed to fully assess RPM's impact on this population.

KEYWORDS
home parenteral nutrition, intestinal failure, intestinal rehabilitation, pediatrics

INTRODUCTION

Intestinal failure is defined as the reduction of functional intestinal mass below that which can sustain life, resulting in dependence on supplemental parenteral support for a minimum of 60 days within a 74 consecutive day interval.[1] Conditions leading to intestinal failure include short bowel syndrome, mucosal enteropathies, and intestinal dysmotility.[2] In pediatrics, short bowel syndrome accounts for 85% of cases of intestinal failure.[1]

Nutrition management for IF patients is complex, requiring methodical advancement of enteral nutrition with careful weaning of parenteral nutrition (PN) and fluid management to optimize adaptive potential and ensure adequate growth and hydration. Rapid PN reductions may harm patients, leading to dehydration, electrolyte abnormalities, and inadequate growth. Prolonged PN support is associated with complications such as intestinal failure-associated liver disease (IFALD), sepsis, and loss of central venous access. Achieving enteral autonomy is the ultimate therapeutic goal. When this is not possible, mitigation of comorbidities is paramount and in appropriate cases referral for intestinal transplantation may be the best longterm strategy.[3,4]

Management of pediatric patients with intestinal failure has evolved over the past two decades such that most are followed closely by their multidisciplinary intestinal rehabilitation program with frequent ambulatory visits. In our program, home PN patients are seen every 4–6 weeks in the clinic because of the need to assess overall growth, fluid, and electrolyte balance.

Remote patient monitoring (RPM) is a technology that enhances the close monitoring of patients by allowing caregivers to enter clinically relevant data in an application on their smartphone, having the data transferred and accessible to the clinical team in real time. The parameters that are monitored can be tailored to different patient populations.[5] In our population, we decided that data pertaining to intake and output would be monitored daily, and weights would be obtained weekly because those are relevant parameters to guide the nutrition plan.

The objective of this study was to describe our pilot experience with RPM technology in the pediatric population with intestinal failure and determine the preliminary impact on PN reduction in an outpatient setting.

METHODS

This study is a descriptive cohort study evaluating our experience with RPM technology. The RPM program at our institution was initiated in March 2021. To be included in the study, patients had to have intestinal failure and be receiving home PN. They had to be primarily managed by our multidisciplinary intestinal rehabilitation program and they needed to be proficient in English because the app is only available in English presently. When the RPM program began, enrollment first occurred in the ambulatory setting for patients already established on home PN. Subsequently, patients were enrolled in the hospital before their first discharge home receiving PN.

RPM nurses educate the families, allocate an age-appropriate home scale and activate a mobile application (app) on a caregiver's smartphone before discharge from the hospital on PN. Once home, the app prompts caregivers to enter intake and output data daily and weights every week. Specific values include volume of parenteral nutrition, volume and type of oral intake and feeding tube intake, urine and stool occurrences, or specific volume. RPM data are sent electronically to the RPM nurses in real-time, on a daily basis, who then create reports in the electronic medical record and send them to the Intestinal Rehabilitation team weekly for review.

Data for this study were obtained retrospectively from the patient's electronic medical record. Abstracted data included demographics, diagnosis, residual intestinal anatomy, and nutrition support, including both enteral and parenteral volume and energy.

The data management plan included descriptive analysis using the appropriate summary statistics (means with standard deviation for continuous variables and frequencies with proportions for categorical variables). We included patients who had home PN support data in the time period before and after RPM implementation. For all patients, we compared PN energy and volume reduction in the pre-initiation and post-initiation of the program periods. Our primary outcome was the rate of PN weaning (energy and volume). Our secondary outcome was time to achieve a 20% reduction in PN (energy and volume). This was performed in two ways. First, to account for different duration of follow-up per patient, we determined the rate of PN decrease per day by calculating the percentage of PN support before introduction of RPM (percentage of PN at RPM initiation minus PN support at first outpatient visit divided by the number of days) vs the percentage of PN received after RPM (percentage of PN at end of follow-up period post RPM initiation minus the percentage of PN at RPM start divided by the number of days). The second analysis included the determination of time (days) to achieve a 20% reduction in PN volume and energy in the time period before and after RPM initiation. We performed a paired *t* test to compare both groups. An alpha value <0.05 was considered statistically significant.

This project was approved by the Cincinnati Children's Hospital Institutional Review Board.

RESULTS

When the RPM program was instituted in March 2021, we had 49 patients who qualified to be enrolled in the program as they had a diagnosis of intestinal failure and were PN dependent. Of those, 31 (63%) were enrolled. Reasons for no enrollment included non-English speaking caregivers, family not interested in changing their system of tracking those variables at home, or patients who were primarily managed elsewhere. Of those 31, 17 (54%) had both “pre-RPM”. and “post-RPM” data available for comparison and were compliant with data entry over the analysis time period (March 1, 2021, to May 31,

TABLE 1 Patient characteristics ($n = 17$).

Characteristic	Value
Sex, male, *n* (%)	9 (52.9)
Age, mean (SD), mo	44.0 (37.0)
White race, *n* (%)	14 (82.4)
Hispanic ethnicity, *n* (%)	2 (11.8)
Etiology, *n* (%)	
Necrotizing enterocolitis	8 (47.1)
Intestinal atresia	2 (11.8)
Gastroschisis	4 (23.5)
Volvulus	5 (29.4)
Hirschsprung disease	1 (5.9)
Other	1 (5.9)
Intestinal failure category, *n* (%)	
Short bowel syndrome	16 (94.1)
Dysmotility	0 (0.0)
Mucosal enteropathy	1 (5.9)
Percent small bowel remaining, mean (SD)	15.5 (12.5)
Percent large bowel remaining, mean (SD)	70.2 (28.9)
Ileocecal valve resected, *n* (%)	12 (70.6)
Receiving teduglutide, *n* (%)	4 (23.5)
Days enrolled in remote patient monitoring, mean (SD)	343.2 (260.0)
Distance from medical center, mean (SD), miles	161.0 (163.0)

2022). Patient characteristics are shown in Table 1. There were 9 (52%) men, with a mean age at enrollment of 44 months. The most common diagnosis was short bowel syndrome, with necrotizing enterocolitis (NEC) being the predominant etiology. The mean residual small bowel percent expected for age was 15.5% ± 12.5%. The mean days of enrollment in RPM was 343.2 days. Overall, compliance with data entry was 74% (number of times caregiver entered data divided by number of times data entry was required).

Patients who only had post-RPM data were born or started to be followed by our team after the implementation of RPM. In those 17 patients, there was a higher PN energy (Kcal/kg) and volume (ml/kg) percentage reduction in the post-RPM period (0.22 ± 0.28 and 0.17 ± 0.24, respectively) compared with the pre-RPM period (0.08 ± 0.1 and 0.07 ± 0.08, respectively). However, the difference was not statistically significant ($P = 0.11$ and $P = 0.17$, respectively). The time in days to achieve a 20% reduction of PN was shorter in the post-RPM period for both energy (276 ± 181.8) and volume (240.5 ± 206) compared with the pre-RPM period (535.71 ± 293.5 and 363.6 ± 140.5, respectively) but without statistical significance. ($P = 0.06$ and $P = 0.2$; Figure 1).

DISCUSSION

Enteral autonomy is the ultimate goal for children with intestinal failure receiving PN. Predictors of enteral autonomy include underlying NEC, the presence of an ileocecal valve, and longer residual small bowel length, all characteristics of the patients that cannot be modified.[6] Our study suggests that close monitoring of patients is a potentially modifiable factor that can expedite the path to enteral autonomy and can be done safely as the data allowed for appropriate adjustments in PN composition and did not result in adverse events.

The care of children with intestinal failure can burden caregivers and significantly impact the child's quality of life, as well as, that of the broader family members.[7] With remote patient monitoring, our team has been able to more purposefully adjust PN composition between clinic visits based on reliable data provided by the family. The potential to decrease the number of trips to the hospital, especially in a population that typically has to travel long distances to be seen in a referral center (in our cohort of patients, the mean distance from the medical center was 131.3 miles) is another positive factor that can improve quality of life.

Through the Health Insurance Portability and Accountability Act of 1996 (HIPAA) compliant text messaging and video connection capabilities, RPM allows patients to communicate with a member of the nursing care team on-demand in a novel way. This increase in the frequency of evaluations allows for timely identification of changes in patient status and permits adaptation to the plan of care. As an example, we identified an increase in ostomy output in one of our patients, which prompted a phone call from the nurse to check on his status. During that phone call, we discovered that the patient was not taking one of his medications to control stool output. After being informed of this error, the patient promptly resumed that medication, and the stool output returned to baseline. If not identified promptly, the increase in ostomy output could have led to dehydration, requiring an emergency room visit and possible admission to the hospital.

We have had several opportunities to make changes in the nutrition plan of patients based on RPM data prior to clinic visits. We have decreased both PN energy and volume in patients who have demonstrated appropriate weight gain and fluid balance in RPM data when in the past, changes were only made at the clinic visit because it was the only setting where we could obtain accurate and reliable data.

In adult care, RPM has been utilized in several settings such as postoperative care of patients who underwent knee surgery, resulting in reduced readmissions in the patients who received RPM.[8,9] RPM in adult patients with implantable cardiac devices has been associated with fewer emergency department visits, lower healthcare expenditures for in-office visits, and lower healthcare expenditures for inpatient stays.[10]

The American Heart Association recommends RPM for single ventricle pediatric populations for oxygen saturation and weight biometric submissions, noting that morbidity and mortality rates are improved.[11] The pediatric asthma population has also noted

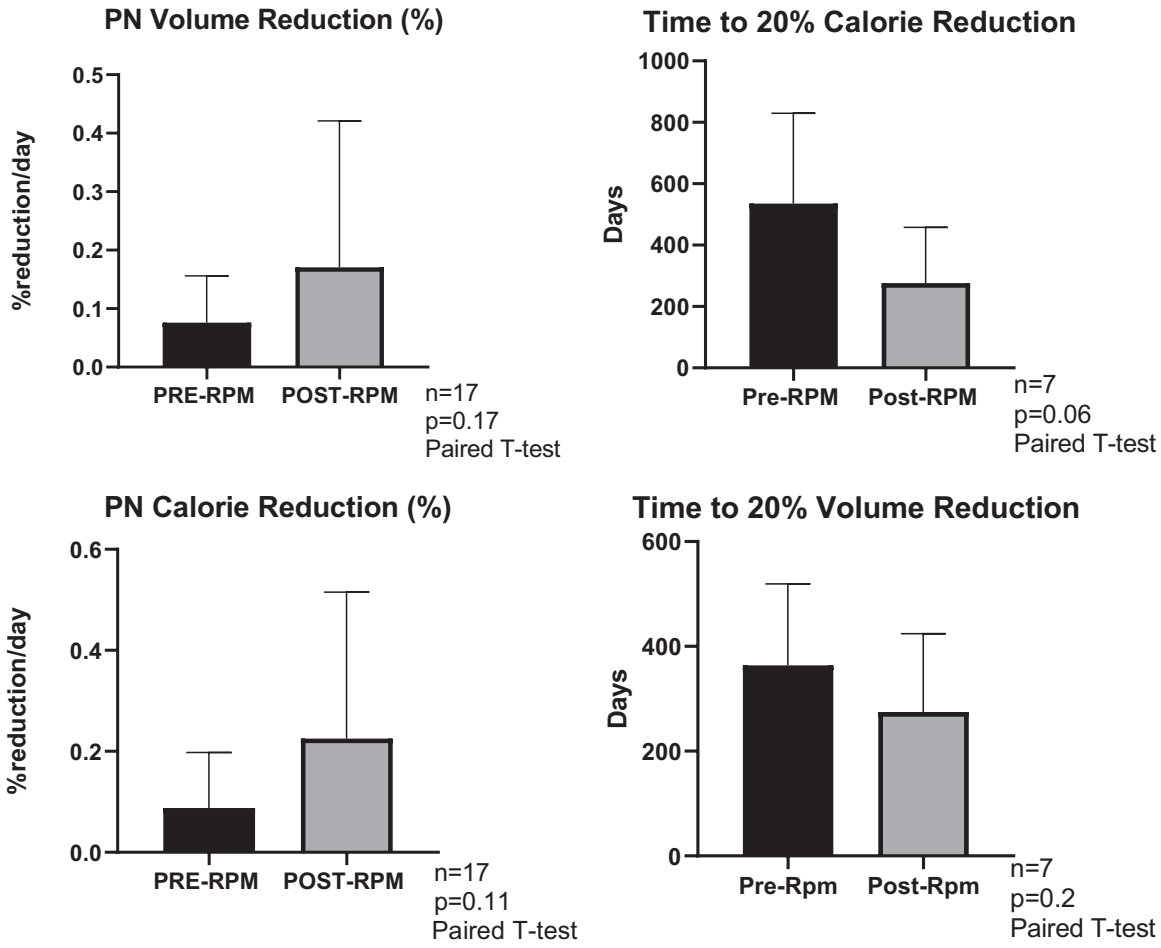

FIGURE 1 PN reduction pre and post-enrollment in the RPM program. The time to achieve a 20% reduction in energy and volume of PN was shorter in the post-RPM period compared with the pre-RPM period but failed to achieve statistical significance likely due to small sample size. The percentage rate of PN reduction tended to increase after RPM for both volume (ml/kg) and energy (kcal/kg), although it failed to achieve statistical significance. PN, parenteral nutrition; RPM, remote patient monitoring.

improvement in chronic disease management, showing an increase in asthma control test scores and improvement in medication adherence through RPM strategies.[12] RPM has also revolutionized the care of diabetes. In conjunction with the technological advancements of insulin pumps and continuous glucose monitors, endocrinologists can have access to the patient's blood glucose pattern and insulin requirement at any given time by looking at the RPM data.[13,14]

Limitations of this study include a small sample size of patients who had both pre and post RPM data; therefore, we were likely under-powered for our outcomes. The app we currently use has yet to have an interface in a language other than English, limiting the participation of non-English fluent patients. We now enroll all our patients in RPM, so we will not have a larger sample size of patients with "pre-RPM" data to increase the power of our data.

A total of four individuals were on teduglutide during the observation period. One of the patients in RPM for 14 months began teduglutide therapy 2 months after enrollment, so the degree of PN weaning could be confounded by impact of teduglutide. In the other three patients, two began teduglutide in the last 1–2 months of RPM follow-up and one initiated GLP-2 analogues several months before initiating RPM, so we believe the drug had reduced influence in these patients.

We will continue to offer enrollment to all our patients receiving PN. With a larger cohort, we can assess outcome at a population level. We also aim to evaluate the impact of RPM on PN-associated morbidity including IFALD, sepsis, and vascular complications. We hope to ascertain the impact on healthcare utilization such as hospital readmissions and emergency room visits. Future qualitative assessments include family satisfaction, barriers to participation, and compliance and economic impact on spillover costs related to travel, time away from work, and out-of-pocket expenses.

CONCLUSION

In this study, remote patient monitoring was a safe tool for patients with intestinal failure and can expedite the weaning of parenteral nutrition. There was a higher PN reduction in the post-RPM period

and a shorter amount of time to achieve 20% reduction; however, the differences were non statistically significant likely due to the small sample size. Further work needs to be performed as we integrate this tool into our family-centered and multidisciplinary approach to this population.

AUTHOR CONTRIBUTIONS

Stephanie B. Oliveira contributed to conceptualization, investigation, writing of the original draft, methodology, review and editing, and formal analysis; Julia D. Thomas contributed to writing of the original draft, review and editing, and formal analysis; Conrad Cole, Michael Helmrath, and Samuel Kocoshis contributed to conceptualization, supervision, and review and editing; Paul W. Wales contributed to conceptualization, writing of the original draft, review and editing, methodology, formal analysis, and supervision.

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CONFLICT OF INTEREST STATEMENT

None declared.

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