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ORIGINAL ARTICLE

Telehealth survey of providers and caregivers of children on peritoneal dialysis during the COVID-19 pandemic

Stephanie L. Clark[1] · Brandy Begin[2] · Heidi G. De Souza[3] · Kathleen Mallett[4] · Melisha G. Hanna[5] · Troy Richardson[3] · Megan Esporas[3] · Ariana Bowie[6] · Karri Taylor[2] · Laura Castellanos Reyes[7] · Monica Hughey[8] · Alicia Neu[9] · Bradley A. Warady[4]

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Abstract

Background There has been growing support for the adoption of telehealth (TH) services in pediatric populations. Children on chronic peritoneal dialysis (PD) represent a vulnerable population that could benefit from increased use of TH. The COVID-19 pandemic prompted rapid adoption of TH services in the population among pediatric centers participating in The Children's Hospital Association's Standardizing Care to Improve Outcomes in Pediatric ESKD (SCOPE) Collaborative.

Methods We developed a survey to explore the experience of both pediatric PD providers and caregivers of patients receiving PD care at home and using TH services during the COVID-19 pandemic.

Results We obtained responses from 27 out of 53 (50.9%) SCOPE centers that included 175 completed surveys from providers and caregivers. Major challenges identified by providers included inadequate/lack of physical exam, inability to visit with the patient/family in-person, and inadequate/lack of PD catheter exit site exam. Only 51% of caregivers desired future TH visits; however, major benefits of TH for caregivers included no travel, visit takes less time, easier to care for other children, more comfortable for patient, and no time off from work. Providers and caregivers agreed that PD TH visits are family centered ($p = 0.296$), with the lack of a physical exam ($p < 0.001$) and the inability to meet in-person ($p = 0.002$) deemed particularly important to caregivers and providers, respectively.

Conclusions TH is a productive and viable visit option for children on PD; however, making this a successful, permanent part of routine care will require an individualized approach with standardization of core elements.

Keywords Pediatric · Peritoneal dialysis · Telehealth · COVID-19

Introduction

Over the past 10–15 years, there has been growing support for telehealth (TH) services in pediatric populations with proposed benefits including improved access to care, subspecialty provider outreach, and resource utilization [1–3]. Despite these proposed benefits, improved reimbursement, and government support, adoption of TH services into routine practice has been slow due to technological barriers, provider and patient/caregiver concerns, financial barriers,

✉ Stephanie L. Clark
clarks@chop.edu

1 Department of Pediatrics, Division of Nephrology, The Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA, USA

2 Doernbecher Children's Hospital, Oregon Health & Science University, Portland, OR, USA

3 Children's Hospital Association, Washington D.C. and Lenexa, KS, USA

4 Children's Mercy Kansas City, Kansas City, MO, USA

5 Children's Hospital Colorado, Department of Pediatrics, Division of Nephrology, University of Colorado, Aurora, CO, USA

6 Phoenix Children's Hospital, Phoenix, AZ, USA

7 Cohen Children's Medical Center, Queens, NY, USA

8 St. Louis Children's Hospital, St. Louis, MO, USA

9 Department of Pediatrics, Division of Nephrology, Johns Hopkins University School of Medicine, Baltimore, MD, USA

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credentialing and licensing barriers, legal concerns, and a lack of uniformity in the TH policies of individual states and countries [1–5]. A paucity of rigorous studies showing the effectiveness and safety of TH for children has likely also influenced the limited penetrance of TH into pediatric care prior to the COVID pandemic [4].

Pediatric patients on maintenance home peritoneal dialysis (PD) represent a vulnerable population that could potentially benefit from increased use of TH services, in part as a means by which children who live at a distance from their home dialysis center could receive more readily available access to care [5, 6]. In March 2020, the COVID-19 pandemic necessitated a shift from mostly in-person visits to mostly TH visits for children receiving home PD with rapid implementation of the technology and infrastructure that previously had been difficult to adopt [6]. The Children's Hospital Association's Standardizing Care to Improve Outcomes in Pediatric End-Stage Kidney Disease (ESKD) (SCOPE) Collaborative is a multicenter quality transformation effort to reduce infectious complications through implementation of standardized care practices among children receiving maintenance dialysis that currently includes 53 centers [7]. Prior to the COVID-19 pandemic, only one of 42 pediatric centers participating in SCOPE at that time and completing the collaborative's Practice Inventory reported using TH in the care of their PD patients. With the onset of the pandemic, 35 out of those 42 pediatric centers reported using TH for the management of these patients.

There has been published success regarding teleconsultation in pediatric nephrology [8] and a recent publication by Raina et al. [9] based on a survey of pediatric nephrologists and their patients reported that telemedicine was feasible and acceptable in this population. In addition, Rohatgi et al. reported outcomes for adult telenephrology care in Australia that were at least equivalent to in-person care [10]. However, to date, there have not been any published experiences with TH in the pediatric dialysis population. In turn, we sought to leverage the multicenter nature of the SCOPE collaborative to explore the experience of both pediatric PD providers and caregivers of patients receiving PD care at home and using TH services during the COVID-19 pandemic.

Methods

We developed a survey for providers (Appendix 1), as well as caregivers (Appendix 2), based on the Iowa telehealth survey (Appendix 3), specifically pertaining to the care of children who were receiving maintenance PD. The provider survey included 20 questions, with several questions specific for a particular discipline as follows: 2 questions for dietitians, 3 questions for social workers, 3 questions for pharmacists and nurses, 1 question for PD nurses, and 2 questions for pediatric nephrology fellows. The caregiver survey included 17 questions. Caregivers of children on hemodialysis were not included in this survey. The surveys were distributed to providers and caregivers at centers participating in the SCOPE collaborative between October 2020 and March 2021. Institutional Review Board approval was obtained by each center as per the requirements at each institution.

Providers surveyed encompassed members of the PD multidisciplinary team including attending physicians, pediatric nephrology fellows, heretofore referred to as fellow physicians, nurse practitioners (NPs) or advanced practice nurses (APNs), nurse managers, PD nurses, social workers, dietitians, and pharmacists. All providers in a center were given the opportunity to participate in the survey. Surveys were distributed electronically via Qualtrics and each institution determined the best way to contact caregivers of their patients regarding the survey. Most institutions distributed the surveys via email. Reminder emails were sent out as per each institution's preference. We did not track the distribution of surveys from each site, precluding us from determining a survey response rate. Caregivers had the opportunity to proceed with the survey if they had not completed a TH visit in the past 6 months; however, analysis for questions pertaining specifically to TH visits only included data from those respondents who indicated they had completed a TH visit in the past 6 months. Incomplete surveys are included in the data and missing responses are noted for all questions.

Telehealth was defined as the use of telecommunication and information technology to provide access to health assessment, diagnosis, intervention, consultation, supervision, and information across distance (https://www.medicaid.gov/medicaid/benefits/telemedicine/index.html). TH devices include such technologies as computers, telephones, cloud-based platforms for video conferencing (i.e. Zoom, BlueJeans, EPIC), facsimile machines, electronic mail systems, and remote patient monitoring devices which are used to collect and transmit data for monitoring and interpretation (https://www.medicaid.gov/medicaid/benefits/telemedicine/index.html).

Descriptive statistics were reported as frequencies and percentages. Several questions allowed respondents to choose all that apply. Three similar survey questions were included in both the provider and caregiver surveys. The content of these questions included desired frequency of TH visits, benefits of TH, and challenges to TH. These three questions and responses were mapped to a common response scale and the equivalent responses between providers and caregivers were assessed using chi square tests. Comparisons of provider responses by provider type were also assessed with chi square tests. All analyses were completed using SAS, version 9.4 (Cary, NC, USA) and p values < 0.05 were considered statistically significant.

Results

Demographic information

We obtained responses from 27 out of 53 total SCOPE centers for a center response rate of 50.9%. Response characteristics can be found in Table 1. In all, the centers provided 175 completed surveys including 130 surveys from providers and 45 caregiver surveys. Provider respondents included attending physicians, fellow physicians, nurse managers, NP/APNs, PD nurses, dietitians, and social workers (Fig. 1). Of the caregiver respondents, the greatest percentage lived in a suburban setting and traveled less than 1 h to attend in-person PD visits (Fig. 2). The majority of caregiver respondents had access to both the internet (n = 43, 95.6%) and email (n = 44, 97.8%). The most common devices used for TH visits were a smart phone with internet access (n = 44, 97.8%) and a tablet with internet access (n = 43, 95.6%).

Provider responses (Table 2)

The majority of providers (64%) felt that time efficiency with TH was better or much better compared to in-person visits. There was no difference in this response by provider discipline (p = 0.732). The greatest percentage of providers (47%) felt that the ideal frequency of TH visits was alternating monthly TH visits with in-person visits. When asked about the benefits of TH visits, the top responses included the ability to observe the home, family centered, ability for all team members to meet with the family together, and the ability to review medications with access to the medication bottles. When asked about the challenges of TH, the top 3 responses consisted of inadequate/lack of physical exam, inability to visit with the patient/family in-person, and inadequate/lack of PD catheter exit site exam. The majority of providers including doctors (90.9%), nurses (83.3%), and others (87.9%) felt that their therapeutic relationship with the patient/family was not adversely affected by conducting TH visits and there was no difference between providers in this response (p = 0.832). In addition, the majority of doctors (67.3%), nurses (59.5%), and others (75.8%) also felt that PD education was not affected by conducting TH visits, with no difference between providers (p = 0.837).

Approximately 45% of social workers felt that social concerns were addressed during TH visits to about the same degree as during an in-person visit. Just over half (54%) of nurse respondents stated that they were able to visualize their patient's medication bottles during the TH visit, and 51% thought the medication reconciliation process was able to be carried

Table 1 Demographic information and characteristics of survey responses

	n	%
Number of surveys	175	100
Completed surveys	166	95.0
Number of centers	53	
Center response rate	27	50.9
Respondents		
Providers	130	74.3
Attending physician	48	27.4
Fellow physician	7	4
Nurse Manager	8	4.6
NP or APN	4	2.3
PD Nurse	30	17.1
Dietician	21	12
Social Worker	12	6.9
Caregiver/Guardian	45	25.7
Caregiver responses	45	
Patient home location		
Rural	16	35.6
Suburban	19	42.2
Urban	10	22.2
How far do you need to travel?		
Less than 1 h	17	37.8
1–2 h	12	26.7
2–3 h	8	17.8
3–4 h	5	11.1
Greater than 4 h	2	4.4
Missing	1	2.2
Internet access?		
Yes	43	95.6
No	1	2.2
Missing	1	2.2
Email access?		
Yes	44	97.8
No	1	2.2
Currently have access to (check all that apply)		
Desktop computer	11	24.4
Laptop computer	30	66.7
Tablet with internet access	43	95.6
Tablet without internet access	1	2.2
Smart phone with internet access	44	97.8
Smart phone without internet access	1	2.2
Cell phone (without a video option)	4	8.9
Landline	3	6.7
Telehealth visit in last 6 months		
Yes	38	84.4
No	7	15.6
Of those that had a visit, how was the telehealth visit completed?		
Audio only	7	18.4
Video and audio	30	78.9
Missing	1	2.6

out "very well" during a TH visit. Of fellow respondents, the majority (85.7%) felt that their PD education was not adversely affected by conducting PD visits via TH.

Caregiver responses

Out of the 45 caregivers who responded to the survey, 38 participated in a TH visit. The majority (58%) of caregivers who participated in TH visits felt that their child's needs were addressed in a manner that was similar to an in-person visit. However, only 51% (n = 21) of 41 respondents to this question desired additional TH visits in the future. All those who did not want more TH visits felt that the care provided by TH was the same or worse than what was provided during an in-person visit. Of those who wanted additional TH visits, the greatest percentage (43%) felt that the ideal frequency of PD TH visits was alternating monthly TH visits with in-person visits (Table 3). In contrast, 42% of respondents felt that TH visits should not be conducted for pediatric PD patients.

In terms of the relationship between geography and TH, there was no statistically significant relationship between how often families wished to have TH visits and the location of their home (rural, suburban, or urban) or how far they needed to travel to have an in-person visit (Table 3). When asked about the benefits of TH, the top responses consisted of no travel, visit takes less time, easier to take care of other children, more comfortable for the patient, and do not need to take time off from work. When asked about the challenges of TH, the most frequent responses were the absence of a hands-on physical exam, inability to visit with the dialysis team members in-person, and hard to focus on the visit when there are competing needs of other children in the home.

Provider and caregiver agreement (Table 4)

There was no difference between providers and parents/caregivers in the percentage who identified a major benefit

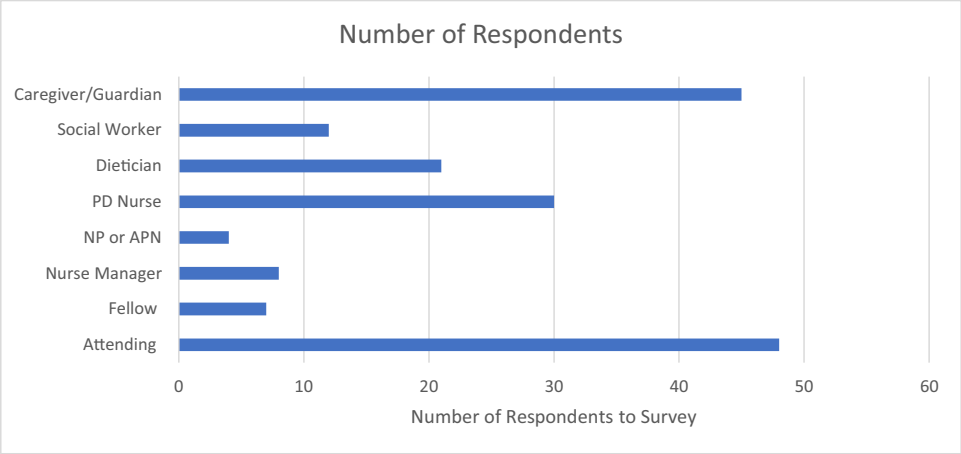

Fig. 1 Provider respondents

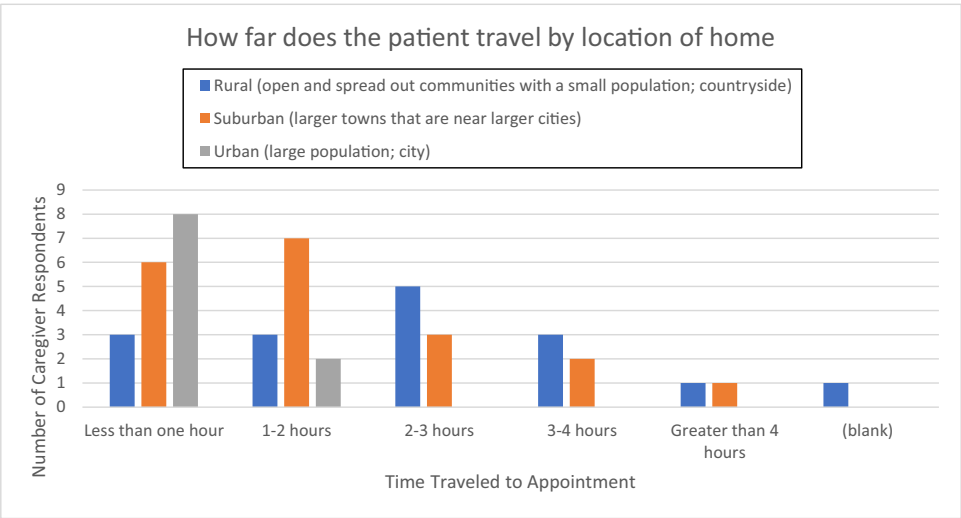

Fig. 2 Number of caregiver respondents and how far they traveled to appointments by location of patient's home

Table 2 Responses by provider type including count and percentage of total respondents. The "Other" category includes dieticians and social workers. Questions with N/A were only offered to certain providers based on their discipline. Note: Q49 and Q50 were only for fellow physicians

Question	Doctors	Nurses	Other	p-value
Q33. In general, how would you rate the time efficiency of telehealth visits for PD patients vs. in-person visits?				0.723
Better	25 (45.5)	19 (45.2)	11 (33.3)	
Much Better	10 (18.2)	6 (14.3)	10 (30.3)	
Same	17 (30.9)	12 (28.6)	8 (24.2)	
Worse	2 (3.6)	4 (9.5)	3 (9.1)	
Missing/no response	1 (1.8)	1 (2.4)	1 (3.0)	
Q36. How do you think that your therapeutic relationship with your patient and their family (trust, interpersonal dynamic, openness, etc.) has been affected by conducting PD visits via telehealth?				0.832
Negatively affected	3 (5.5)	4 (9.5)	3 (9.1)	
Not affected at all	35 (63.6)	24 (57.1)	17 (51.5)	
Positively affected	15 (27.3)	11 (26.2)	12 (36.4)	
Missing/no response	2 (3.6)	3 (7.1)	1 (3.0)	
Q37. What percentage of your PD patients were unable or unwilling to participate in a telehealth visit over the past 6 months?				0.101
0%	32 (58.2)	16 (38.1)	15 (45.5)	
10–25%	5 (9.1)	8 (19.0)	2 (6.1)	
25–50%	3 (5.5)	0.0	2 (6.1)	
50–75%	1 (1.8)	2 (4.8)	0.0	
75–90%	0.0	3 (7.1)	0.0	
< 10%	10 (18.2)	9 (21.4)	12 (36.4)	
> 90%	0.0	1 (2.4)	0.0	
Missing/no response	4 (7.3)	3 (7.1)	2 (6.1)	
Q38. Do you think that the peritoneal dialysis education of the patient and family has been affected by conducting PD visits via telehealth?				0.837
Negatively affected	14 (25.5)	14 (33.3)	6 (18.2)	
Not affected at all	33 (60.0)	21 (50.0)	22 (66.7)	
Positively affected	4 (7.3)	4 (9.5)	3 (9.1)	
Missing/no response	4 (7.3)	3 (7.1)	2 (6.1)	
Q42. To what extent do you feel that the social concerns (e.g. financial, insurance, education, behavior issues, etc.) of your patients and their families have been adequately addressed via telehealth?				
About the same as in person	N/A	N/A	5 (15.2)	
Much better than in person	N/A	N/A	2 (6.1)	
Somewhat worse than in person	N/A	N/A	4 (12.1)	
Missing/no response	N/A	N/A	22 (66.7)	
Q43. Do you have concerns regarding privacy when discussing social issues on a telehealth visit?				
No	N/A	N/A	2 (6.1)	
Yes	N/A	N/A	2 (6.1)	
Missing/no response	N/A	N/A	29 (87.9)	
Q46. Are you usually able to visualize the patient's medication bottles during the telehealth visit if applicable?				
No	N/A	17 (40.5)	N/A	
Yes	N/A	20 (47.6)	N/A	
Missing/no response	N/A	5 (11.9)	N/A	
Q47. How appropriately do you feel that medication reconciliation is able to be carried out during telehealth visits?				
Moderately well	N/A	11 (26.2)	N/A	
Slightly well	N/A	7 (16.7)	N/A	
Very well	N/A	19 (45.2)	N/A	
Missing/no response	N/A	5 (11.9)	N/A	
Q49. Do you think that your education regarding peritoneal dialysis is affected by conducting PD visits via telehealth?				
Negatively affected	1 (1.8)	N/A	N/A	

Table 2 (continued)

Question	Doctors	Nurses	Other	p-value
Not affected at all	5 (9.1)	N/A	N/A	
Positively affected	1 (1.8)	N/A	N/A	
Missing/no response	48 (87.3)	N/A	N/A	
Q50. To what extent does conducting PD visits via telehealth affect your therapeutic relationship with the patient and their family (trust, interpersonal dynamic, openness, etc.)?				
Not affected at all	4 (7.3)	N/A	N/A	
Positively affected	3 (5.5)	N/A	N/A	
Missing/no response	48 (87.3)	N/A	N/A	

Table 3 Desired frequency of TH visits by caregivers in relation to home location and travel time to dialysis clinic including count and percentage of total respondents

	How often should there be PD Telehealth visits ?					
	Every 3 months	Every other month	Every visit	Never	When in-person is not an option	p
Home is located						0.915
Rural (open and spread-out communities with a small population; countryside)	1 (25.0)	3 (33.3)	2 (33.3)	9 (45.0)	0 (0.0)	
Suburban (larger towns that are near larger cities)	2 (50.0)	4 (44.4)	3 (50.0)	8 (40.0)	1 (50.0)	
Urban (large population; city)	1 (25.0)	2 (22.2)	1 (16.7)	3 (15.0)	1 (50.0)	
How far do you need to travel						0.429
Less than 1 h	1 (25.0)	3 (33.3)	2 (33.3)	10 (50.0)	0 (0.0)	
1–2 h	2 (50.0)	3 (33.3)	2 (33.3)	3 (15.0)	1 (50.0)	
2–3 h	1 (25.0)	2 (22.2)	1 (16.7)	3 (15.0)	1 (50.0)	
3–4 h	0 (0.0)	0 (0.0)	0 (0.0)	4 (20.0)	0 (0.0)	
Greater than 4 h	0 (0.0)	1 (11.1)	1 (16.7)	0 (0.0)	0 (0.0)	

of PD TH visits being family centered ($p = 0.296$). However, while providers felt that the ability to observe the home ($p < 0.001$) and have the entire team meet with the patient and caregiver at one time ($p < 0.001$) were significant benefits of TH visits, those factors were less important for caregivers. The lack of a physical exam was deemed a significant negative aspect of a TH visit by both providers and caregivers, although more so for caregivers ($p < 0.001$). The inability to visit in-person was also seen as a major challenge associated with PD TH visits for both providers and caregivers, although more so for providers ($p = 0.002$). Finally, providers felt that the lack of private time with the patient was a major challenge associated with PD TH visits, while this was not a challenge for many caregivers ($p < 0.001$).

Discussion

The experience of the SCOPE centers highlights the rapid expansion of TH to accommodate patient care in a pandemic and is reflective of the expansion of this technology throughout pediatric medicine during COVID-19 [6, 9, 11]. This expansion has also been highlighted across a variety of pediatric subspecialties, as published by Williams et al. [12]. While our survey showed that many patients and caregivers in the pediatric PD community do not necessarily desire expansion of TH services, there is an emphasis by some to make TH a permanent part of how we care for patients as evidenced by the CONNECT for Health Act of 2021 [13]. This Act would remove many of the provider barriers to TH in the USA on a permanent basis, many of which were temporarily removed during the COVID-19 pandemic. This Act has wide support and has been endorsed by more than 170 organizations, including the American Academy of Pediatrics, Renal Physicians Association, and the National Association of Pediatric Nurse Practitioners.

The findings from this survey build upon the earlier published experiences of TH in both adult and pediatric nephrology. Rosner et al. discussed the promise of TH in home kidney replacement therapies as it pertains to improved access, and potentially better outcomes and increased patient satisfaction [14]. Raina et al. and Brophy identified that TH

Table 4 Ratings of telehealth visits by caregivers (among caregivers who have had a TH visit in the last 6 months) and providers including count and percentage of total respondents

Q	Results (n = 168)	Caregiver (n = 3 8)	Provider (n = 130)	Chi square p-value
How often should there be PD Telehealth visits?				< 0.001
Every 3 months	38 (22.6)	4 (10.5)	34 (26.2)	
Every other month	68 (40.5)	8 (21.1)	60 (46.2)	
Every visit	12 (7.1)	5 (13.2)	7 (5.4)	
Never	16 (9.5)	16 (42.1)	0 (0.0)	
Whatever is requested by family	6 (3.6)	0 (0.0)	6 (4.6)	
When in-person is not an option	23 (13.7)	2 (5.3)	21 (16.2)	
Missing	5 (3.0)	3 (7.9)	2 (1.5)	
What do you like about PD Telehealth visits?				
Family centered	102 (60.7)	20 (52.6)	82 (63.1)	0.296
Observation of home	103 (61.3)	7 (18.4)	96 (73.8)	< 0.001
Team meets all at the same time	88 (52.4)	9 (23.7)	79 (60.8)	< 0.001
What do you NOT like about PD Telehealth visits?				
No physical exam	78 (46.4)	25 (65.8)	53 (40.8)	< 0.001
Inability to visit in person	77 (45.8)	14 (36.8)	63 (48.5)	0.002
Lack of private time with patient	45 (26.8)	5 (13.2)	40 (30.8)	< 0.001

is accessible and favorable for both providers and patients, but providers must have education and training to optimize patient care when using TH [5, 11]. Our survey questions were similar to that of Raina et al. in capturing responses on the mode of TH services, satisfaction, and benefits/challenges [11]. While our survey did not ask about TH education, it did address perspectives on the potential for more TH in future visits and the ideal timeframe between TH visits. Most importantly, our results complement the work of Brophy, Raina, and others and provide important information upon which to develop a more permanent infrastructure for a center's TH resources if the CONNECT for Health Act is signed into law. The variability of survey results suggests that consideration of a personalized approach is likely most desirable, with the frequency of TH visits an important component of care that should be individualized. The finding that greater distance from the dialysis center was not associated with a preference for TH visits emphasizes the importance of shared decision-making between providers and caregivers in PD care. While it appears that a team approach to TH with all members of the multidisciplinary team present on the TH platform during a patient's visit is desirable, the absence of the capacity to conduct a physical exam, and the lack of a standardized approach to assess the status of the PD catheter exit site during a TH visit are important clinical issues that need to be successfully addressed if TH is to remain a viable and productive visit option.

The data we collected with our survey is unique in that we were able to assess perspectives regarding TH from both pediatric PD providers and caregivers of children on PD, and to determine similarities and differences in the results. The findings provide preliminary data that can inform future work. Additional research from SCOPE and other pediatric and adult home PD programs is needed to determine differences in outcomes and costs between in-person and TH visits in the pediatric PD population in the USA and around the globe.

There were several limitations to our study. The surveys were limited by a somewhat low center response rate (50.9%) among SCOPE centers; thus, the responses may not reflect the attitudes of providers and caregivers in all areas of the USA. The distribution of responses across centers is not known so it is possible that responses from providers and caregivers at a few centers are driving the results. There was also a low response rate from specific provider disciplines, such as social workers, dieticians, and fellow physicians. While the survey was offered to all providers at every location, very few providers in certain disciplines completed the survey. Given this low response rate, the descriptive analysis for these groups should be interpreted with caution. In addition, there were only 3 questions that were able to be mapped between providers and caregivers. Given that the majority of patients across centers were young in age, the decision was made not to directly survey adolescent patients. The direct evaluation of adolescent patient's experience with TH services remains an important area for future study and would provide an opportunity to compare patient and caregiver responses. Despite the limitations noted above, these data pertaining to TH usage in the pediatric PD population generated by the SCOPE collaborative are uniquely informative and along with prior and future published experiences, will ideally facilitate the development of uniform

recommendations regarding the performance of high-quality TH visits for the pediatric dialysis population.

In conclusion, there are significant potential benefits associated with the provision of care via TH for pediatric PD patients from both the provider and caregiver perspectives, along with many challenges. Based on the results of this preliminary study, the approach needs to be individualized with a focus on shared decision-making and should include standardization of core elements to improve the experience and delivery of care. The process of creating these workflows can be informed by future research that includes a larger sample of providers and caregivers from diverse institutions along with inclusion of patients' perspectives.

Supplementary Information The online version contains supplementary material including a graphical abstract available at https://doi.org/10.1007/s00467-022-05543-z.

Declarations

Conflict of interest The authors declare no competing interests.

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