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Text Messaging for Disease Monitoring in Childhood Nephrotic Syndrome

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Introduction: There is limited information on effective disease monitoring for prompt interventions in childhood nephrotic syndrome. We examined the feasibility and effectiveness of a novel text messaging system (SMS) for disease monitoring in a multicenter, prospective study.

Methods: A total of 127 patients <19 years with incident nephrotic syndrome were enrolled in the ongoing Nephrotic Syndrome Study Network between June 2015 and March 2018. Text messages soliciting home urine protein results, symptoms, and medication adherence were sent to a designated caregiver ($n = 116$) or adolescent patient ($n = 3$). Participants responded by texting. Feasibility of SMS was assessed by SMS adoption, retention, and engagement, and concordance between participant-reported results and laboratory/clinician assessments. The number of disease relapses and time-to-remission data captured by SMS were compared with data collected by conventional visits.

Results: A total of 119 of 127 (94%) patients agreed to SMS monitoring. Retention rate was 94%, with a median follow-up of 360 days (interquartile range [IQR] 353–362). Overall engagement was high, with a median response rate of 87% (IQR, 68–97). Concordance between SMS-captured home urine protein results and edema status with same-day in-person study visit was excellent (kappa values 0.88 and 0.92, respectively). SMS detected a total of 108 relapse events compared with 41 events captured by scheduled visits. Median time to remission after enrollment was 22 days as captured by SMS versus 50 days as captured by scheduled visits.

Conclusion: SMS was well accepted by caregivers and adolescent patients and reliably captured nephrotic syndrome disease activity between clinic visits. Additional studies are needed to explore the impact of SMS on disease outcomes.

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Idiopathic nephrotic syndrome is one of the most common chronic glomerular diseases in children, characterized by heavy proteinuria leading to hypoalbuminemia, edema, and hypercholesterolemia.[1] The vast majority of children are treated empirically with corticosteroids on initial presentation, and most respond to treatment with resolution of proteinuria and correction of biochemical disturbances. However, 80% to 90% of the children initially sensitive to corticosteroids will experience disease relapse, with half relapsing frequently or becoming dependent on corticosteroids to maintain remission.[2–5] During relapses or

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active disease, patients can suffer from edema, acute kidney injury, serious infections, and thromboembolic events.[1]

Management of children with nephrotic syndrome thus entails long-term outpatient surveillance and adherence to treatment. Home care is a key component of disease management and includes the important task of checking urine for protein with test strips. Timely detection of proteinuria is important, as it signifies disease relapse and allows physicians to initiate or adjust corticosteroid therapy before the development of edema and disease-related complications. Tracking the urine for resolution of proteinuria also is important so that treatments can be adjusted promptly once remission is achieved. Currently, physicians rely on patients and caregivers to report home urine testing results between clinic visits; yet poor adherence with urine testing, inaccurate documentation, and delayed communication with providers are frequent barriers for effective monitoring and timely medication adjustment.[6] There are currently no proven efficacious interventions to improve disease monitoring in childhood nephrotic syndrome.

Mobile health (mHealth) is a rapidly growing field in disease monitoring and management. Currently, 95% of all US adults own cellphones, and 77% own smartphones.[7] In addition, 95% of adolescents report either owning a smartphone or having access to one.[8] The ubiquitous presence of mobile phones with advanced computing and communication capabilities make them excellent tools in helping patients manage chronic medical conditions.[9] Most cellphones provide SMS, also known as text messaging, which is an inexpensive method of asynchronous communication that is less intrusive than phone calls.[10] We examined the feasibility and effectiveness of using SMS for disease monitoring in childhood nephrotic syndrome in a study conducted through the Nephrotic Syndrome Study Network (NEPTUNE), part of the National Institutes of Health Rare Disease Clinical Research Network. We hypothesized that SMS would enable better characterization of nephrotic syndrome disease activity as compared with conventional in-person visits due to rapid and nonintrusive symptom tracking in-between visits.

MATERIALS AND METHODS

Data Sources and Study Population

The NEPTUNE study (NCT01209000) is a multicenter, longitudinal cohort study conducted in the United States and Canada that prospectively collects demographic and clinical information, as well as biospecimens, on patients with nephrotic syndrome. The NEPTUNE study protocol does not dictate disease treatment. Full details of the study design have been published elsewhere.[11] The SMS patient surveillance procedure was implemented among all NEPTUNE pediatric participants younger than 19 years with incident nephrotic syndrome who did not receive a biopsy for diagnosis. Eligibility criteria included individuals with clinical diagnosis of nephrotic syndrome, less than 30 days of immunosuppressive therapy for nephrotic syndrome, and documentation of nephrotic range proteinuria (urinalysis $>2+$ protein or random urine protein: creatinine ratio >2 g/g) and edema or serum albumin <3 g/dl. Exclusion criteria included prior solid organ or bone marrow transplant, end-stage kidney disease, secondary nephrotic syndrome (e.g., nephrotic syndrome resulting from systemic lupus erythematosus), clinical or histologic evidence of other renal disease (e.g., Alport syndrome, Nail Patella syndrome, diabetic nephropathy), or genitourinary malformations with vesicoureteral reflux or renal dysplasia, unwillingness or inability to give informed consent, or institutionalization. Urine protein dipsticks (ProAdvantage Urine Reagents Strips, Model P080012, Nashville, TN) were provided to all participants for home urine protein monitoring. For the small number of NEPTUNE participants without a working mobile phone or for those with a preference to use a study-specific phone, the study provided a phone to enable participation (participants who received a study phone = 2). Participants opting to use their own phone were provided a monthly stipend of $15 to offset the cost of the study-related text messages. Participants were enrolled from June 2015 through March 2018, with follow-up for the current analysis through May 2018. The study was approved by the institutional review boards at all participating sites and conducted in accordance with the Declaration of Helsinki. Consent from legal guardians and minor assent (where appropriate) were obtained from all study participants.

SMS Monitoring and Study Protocol

Text messages were sent to either the parent/guardian ($n = 116$) or participant $\geq$12 years old ($n = 3$) depending on participant preference to more closely reflect how a mobile health tool would be adopted by families living with nephrotic syndrome. The messages were automatically delivered to the participants via a central system for 1 year after enrollment into NEPTUNE. Messages were delivered in the language preferred by the participants (English, 116 participants; Spanish, 3 participants) and at the time of day and days of the week preferred by the participants. Questions on urine test results and symptoms of swelling were sent daily for the first 90 days, followed

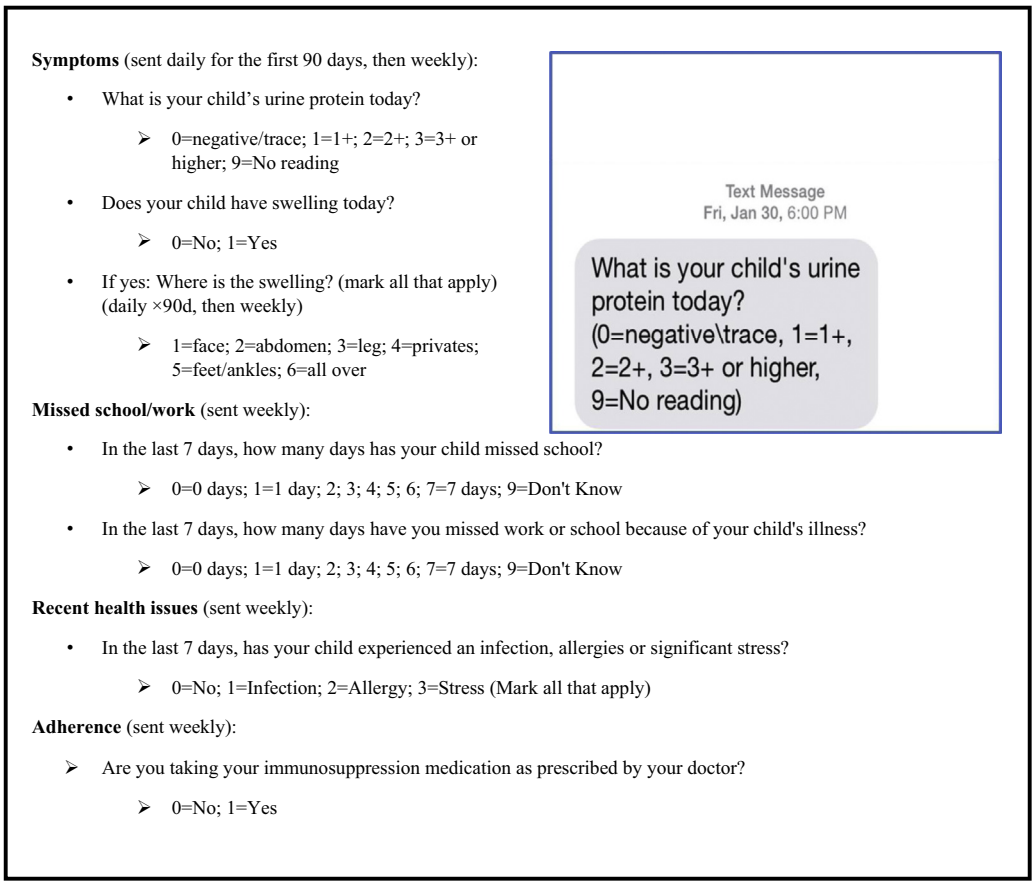

Figure 1. Study text messages and sample screen shot.

by weekly for the rest of the year. Questions on missed work/school, issues with infections/allergies/stressors, and adherence with medications were sent weekly. Participants responded to the texts by texting back a numeric answer. Figure 1 displays the messages sent to participants with a sample screen shot. The SMS system could be paused for planned vacations or during hospitalizations by the study coordinator. The participant-reported urine protein results were stored centrally in the NEPTUNE electronic data management system (NEPTUNE-LINK) and analyzed. The back-end managing system generated e-mail alerts to the study staff for recurrence of proteinuria $\geq$2+ for 3 days in a row indicating new disease relapse, if participants reported new edema, or if the participant reported not taking medications. The alert message included a recommendation for the study team to follow up with participants, but treatment and additional actions were left to the discretion of the study site investigators. The SMS system also generated alerts to the study staff if no responses were received from the participants for $>$1 week. Study site investigators were instructed to contact participants to make sure there were no logistic or technical barriers for SMS response (e.g., lost Internet access, planned vacation, unplanned hospitalization). Other than responding to the text messages and receiving study-provided urine dipsticks, participants were instructed to follow their treating physician's instructions for disease monitoring and communication. In particular, the NEPTUNE study did not specifically instruct participants on when to contact their treating physician.

In-person study visits in the first year included screening, baseline, and quarterly visits that captured the following information: demographic characteristics; medical, family, and social history; disease relapses and hospitalizations; physical examination; past and current medications; patient-reported outcomes; and results of clinical laboratory testing. Disease relapse events were recorded by direct participant inquiry and review of provider documentation, with start and end dates, if available.

Outcomes and Variables

The primary aims of this study were to determine the feasibility of SMS for childhood nephrotic syndrome monitoring and its ability to increase detection of relapse/remission as compared with in-person visits. We examined the acceptability of the SMS system among caregivers/participants as defined by the adoption, engagement, and retention of SMS, as well as the concordance of SMS information with laboratory results

and physician assessment. We compared the detection of disease relapses/remissions by SMS versus conventional scheduled in-person visits. Variables included the following: proportion of caregivers/patients who refused to participant in the SMS procedure (adoption), proportion of caregivers who dropped out of the SMS study (retention), response rate to texts as defined by the percentage of texts answered on a daily or weekly basis (engagement), change in response rate over time (engagement over time), concordance of participant-reported urine protein results via the SMS system with same-day in-clinic urinalysis results, concordance of participant-reported edema status with same-day clinic physical examination findings, number of disease relapses captured by SMS or by history collected during in-person study visits, and time to disease remission after study enrollment captured by SMS or by history collected during in-person study visits.

Time to remission after study enrollment as collected by SMS was defined as 3 consecutive reports of negative/trace urine protein during the first 90 days of daily SMS prompts or 1 report of negative/trace urine protein following prior positive findings during weekly SMS prompts. Disease relapse as collected by SMS was defined as 3 consecutive reports of ≥2+ urine protein or a single report of 3+ urine protein with edema following a period of negative/trace urine protein results during the first 90 days of daily SMS prompts; or 1 report of ≥2+ urine protein following a period of negative/trace urine protein during weekly SMS prompts. Disease relapse events were captured with start and end dates (indicating time to remission) during scheduled in-person visits by participant recall and review of physician documentation (if available). Estimated glomerular filtration rate was calculated from serum creatinine at enrollment using the bedside Schwartz equation.[12]

The secondary aim was to determine predictors of SMS acceptance by examining changes in responsiveness over time as related to patient demographic and baseline clinical characteristics: age, sex, race, ethnicity, primary language, urine protein-to-creatinine ratio, estimated glomerular filtration rate, and serum albumin.

Statistical Analysis

Patients' clinical and demographic characteristics were described as frequencies and percentages and medians and IQRs. Overall SMS response rate was calculated as the proportion of days in which an SMS query was sent to which the patient responded. To examine response rate over time, we examined weekly response graphically for the overall cohort and stratified by clinical and demographic characteristics. A participant was considered to have "responded" for a given week if he or she answered at least 1 text during that week.

Changes in response rates over time were assessed by generalized linear mixed models. The association between text responses and patients' clinical and demographic characteristics was analyzed using univariate generalized linear mixed models for the first 90 days (daily SMS) and from day 91 to 365 (weekly SMS). P values <0.05 were considered to be statistically significant. Patients who had not yet had 1 year of follow-up were censored on the day of the last text message delivered, date of study withdrawal, or the date of withdrawal from the SMS data collection. Administrative censoring occurred on the date of the data extraction: May 23, 2018.

Agreement between participant-reported urine protein results and the same-day urinalysis was determined by concordance, kappa, and weighted kappa. These were first calculated for exact agreement in values. A sensitivity analysis considered differences of 1 level between patient- and clinician-reported values as concordant (e.g., 1+ from the SMS report, 2+ from the clinic urinalysis).

Number of disease relapses per patient were calculated for relapses captured by the SMS system and clinical report forms from in-person visits, and compared using a Poisson regression. Time to disease remission after initial enrollment was estimated by Kaplan-Meier plots for both SMS-captured data versus clinical report form data from in-person visits, and compared using log-rank tests.

Statistical analyses were performed using SAS version 9.4 (SAS Institute, Inc., Cary, NC).

RESULTS

Patient Characteristics

Between June 2015 and March 2018, 127 pediatric patients were enrolled in the NEPTUNE incident children's cohort at the time of disease onset but before kidney biopsy. On average, patients were enrolled into the NEPTUNE incident children's cohort 23 days after onset of disease (IQR, 11–35). Figure 2 shows participant flow: 8 (6%) patients declined participation in the SMS study, and 7 subsequently withdrew after enrolling.

Baseline characteristics of the participants at the time of enrollment are summarized in Table 1. The median age was 4 years with 60% of patients 0 to 4 years old. The cohort was 43% female, 23% black/African American, and 17% Hispanic. At the time of enrollment, the median urine protein-to-creatinine ratio was 9.9 g/g (IQR, 6.5–20.2), the median estimated glomerular filtration rate was 110 ml/min per 1.73 m^2 (IQR, 94–152), and the median serum albumin was 1.5 g/dl

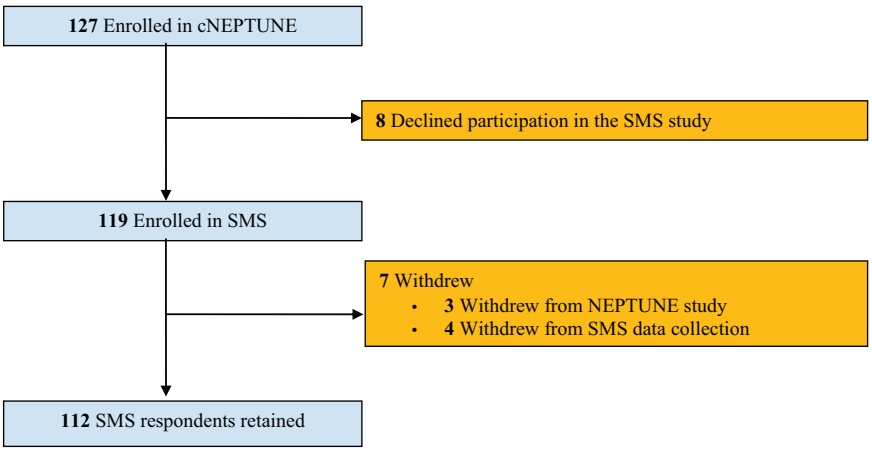

Figure 2. Participant flow in Nephrotic Syndrome Study Network (NEPTUNE) short message service (SMS) study. cNEPTUNE, children's nonbiopsy incident cohort.

Table 1. Characteristics of NEPTUNE pediatric nonbiopsy incident cohort (cNEPTUNE) within the SMS study

Participant characteristics	SMS study participants (n = 119)
Age (yr), median (IQR)	4 (2–6)
Age (yr), *n* (%)	
0–4	72 (61)
5–9	31 (26)
10–18	16 (13)
Female, *n* (%)	51 (43)
Race, *n* (%)	
Multiracial	8 (7)
Asian/Asian American	9 (8)
Black/African American	27 (23)
Native Hawaiian/other Pacific Islander	1 (1)
White/Caucasian	59 (50)
Unknown	15 (13)
Hispanic, n (%)	20 (17)
Primary English speaker, *n* (%)	107 (90)
UP:C (g/g), median (IQR)	9.9 (6.5–20.2)
UP:C (g/g), *n* (%)	
1–2	4 (3)
2–3	2 (2)
≥3.0	97 (82)
Unknown	16 (13)
eGFR[a] (ml/min per 1.73 m^2), median (IQR)	110 (94–152)
eGFR[a] (ml/min per 1.73 m^2), *n* (%)	
>90	94 (79)
60–90	21 (18)
30–60	4 (3)
<30	0 (0)
Serum albumin (g/dl), median (IQR)	1.5 (1.2–2.0)
Serum albumin (g/dl), *n* (%)	
≥3.0	2 (2)
<3.0	110 (92)
Unknown	7 (6)

eGFR, estimated glomerular filtration rate; IQR, interquartile range; NEPTUNE, the Nephrotic Syndrome Study Network; SMS, short messaging service; UP:C, urine protein-to-creatinine ratio.
[a]Estimated GFR is calculated from serum creatinine at enrollment using the Beside Schwartz formula.[12]

(IQR, 1.2–2.0). All participants were treated with corticosteroids on presentation per local standard of care. Comparisons of the characteristics of those who declined SMS study participation (n = 8) or withdrew from NEPTUNE (n = 3) or SMS participation (n = 4) after initial consent to the participants who remained in the SMS study (n = 112) are included in Supplementary Appendix S1. There were no statistically significant differences in baseline characteristics between participants who remained in the SMS study and those who declined or withdrew from the study.

SMS System Acceptance

Patient/caregiver adoption of the technology in cNEPTUNE was high, with 119 of 127 (94%) patients agreeing to participate in the SMS portion of the study. Median duration of SMS study follow-up was 360 days (IQR, 353–362), and respondents provided a median of 100 responses (IQR, 78–121). Seven of 119 participants (6%) subsequently withdrew from NEPTUNE/SMS study. Thus, overall, the retention was 96% with a median follow-up of 1 year.

Median patient-level responsiveness was high (i.e., 87%; IQR, 68%–97%). Response frequency over time is shown in Figure 3. There was no change in response rate during the daily SMS period from day 1 to day 90 (odds ratio [OR] per 30 days: 1.4; 95% confidence interval [CI]: 0.9–1.9; P = 0.07), and response rates were >90% in each week. However, there was a significant decrease in the proportion responding after day 90 when participants transitioned from daily to weekly SMS messages. Thus, 94% of participants responded to SMS assessment in week 10 compared with 80% in week 20, 59% in week 30, 61% in week 40, and 52% in week 50. There was a statistically significant decline in the likelihood of

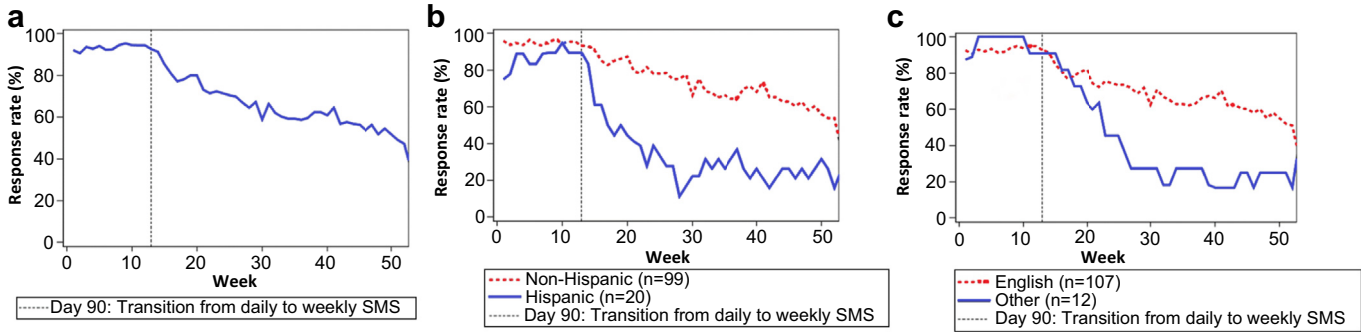

Figure 3. Weekly short message service (SMS) response rate over time ($n = 119$) among the (a) entire cohort, (b) Hispanic versus non-Hispanic participants, and (c) primary English speakers versus nonprimary English speakers. Participants were considered "responders" in a given week if they responded to at least 1 SMS message.

response over time in the day 91 to 365 period (OR per 30 days: 0.7; 95% CI: 0.6–0.7; $P < 0.001$).

Concordance of Participant-Reported Data and Same-Day In-Clinic Laboratory Testing and Physician Examination

Urine protein levels reported by the participants via SMS exactly agreed with urinalyses on the same day in 105 of 135 (77%) instances (Table 2), with a weighted kappa of 0.76, indicating good agreement. Although SMS-reported urine protein levels are deemed to be "in agreement" with urinalyses if they are only 1 level off, the concordance and kappa increased to 94% and 0.88, respectively, indicating excellent agreement. In a sensitivity analysis limited to 48 same-day SMS-urinalysis results performed after day 60 of the study, there was 100% concordance (kappa = 1.0), suggesting the concordance improved over time.

Edema status (yes or no) reported via SMS was confirmed by same-day physical examination in 27 of 28 (96%) of visits, with kappa of 0.92, indicating excellent agreement (Table 2).

Table 2. Concordance of participant-reported home urine protein test results and edema via SMS with same-day in-clinic assessments

SMS-captured home urine protein results	Same-day clinic urinalysis protein results			
	Negative/Trace	1+	2+	≥3+
Negative/trace	67[a]	2[b]	1[c]	4[c]
1+	4[b]	6[a]	4[b]	2[c]
2+	2[c]	0[b]	5[a]	10[b]
≥3+	0[c]	1[c]	0[b]	27[a]
SMS-captured edema self-assessment	Same-day physician edema assessment			
	Edema	No edema		
Edema	8	0		
No edema	1	19		

SMS, short message service.
[a]Exact agreement between the SMS-captured home urine protein result and the same-day clinic urinalysis protein result.
[b]SMS-captured home urine protein result and the same-day clinic urinalysis protein result differed by 1 level.
[c]Discrepancy of 2 or more levels.

Disease Relapse and Remission Detection by SMS Compared With In-Person Clinic Visits

Figure 4 displays the percentage of patients with nephrotic range protein (2+ or higher by dipstick) at a given follow-up time-point as captured by SMS reporting versus conventional in-person clinic follow-up. The SMS system captured more disease relapse events compared with relapses identified by study visits: total number of relapse events was 108 versus 41, total number of patients with relapse was 55 versus 41, and number of relapse events per patient with at least 1 relapse was 2 (1, 4) versus 1 (1, 1; $P < 0.01$). In addition, without SMS data capture, the median estimated time to disease remission following study enrollment was 50 days (IQR, 21–150). However, the more frequent proteinuria data captured by SMS enabled the generation of an improved time-to-remission estimate of 22 days (IQR, 13–64; Figure 5).

Predictors of Responsiveness Over Time

Results of unadjusted models examining the relationship between patient clinical/demographic characteristics and SMS response are shown in Table 3. During the

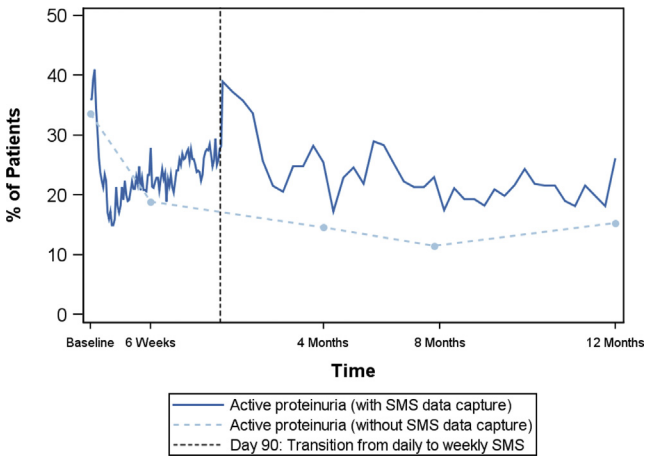

Figure 4. Percentage of patients with nephrotic range proteinuria as captured by short message service (SMS) reporting versus in-person clinic visits.

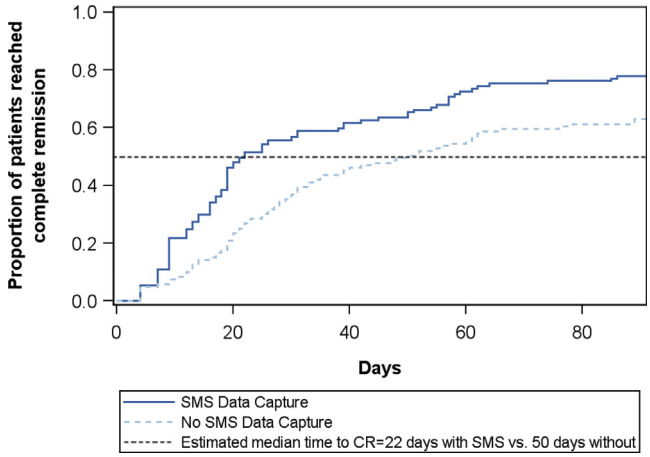

Figure 5. Time to remission after study enrollment by short message service (SMS)–captured urine protein results versus participant reporting during in-person study visits. CR, complete remission.

daily SMS period, responsiveness was high in all participants and there were no statistically significant differences in response rate by age, sex, race, ethnicity, primary language, proteinuria, estimated glomerular filtration rate, or albumin at enrollment (all $P \geq 0.05$). However, during the weekly SMS period between day 91 and 365, Hispanic ethnicity and non-English primary language were negative predictors of responsiveness (Table 3). OR of response in Hispanic versus non-Hispanic individuals was 0.1 (95% CI: 0.1–0.2; $P < 0.001$) and OR of response in non-English primary speakers versus English primary speakers was 0.1 (95% CI: 0.1–0.6; $P < 0.01$), even though messages were sent in the recipient's preferred language.

Figure 3 shows the responsiveness over time among those of Hispanic versus non-Hispanic ethnicity (Figure 3b) and English versus non-English primary speakers (Figure 3c). In our cohort, 8 of 20 (40%) Hispanic individuals were non-English primary speakers, compared with 4 of 99 (4%) of non-Hispanic individuals. Because these 2 variables have a high degree of overlap, we examined the relationship between Hispanic ethnicity and response rate after adjusting for primary language. A multivariable generalized linear mixed model with both ethnicity and language found ethnicity (OR: 0.2; 95% CI: 0.1–0.3; $P < 0.01$), but not non-English language (OR: 0.5; 95% CI: 0.1–3.4; $P = 0.45$) to be a significant predictor of response rate.

Table 3. Univariate analysis of patient characteristics and SMS response over time ($n = 119$)

	First 90 days		Days 91–365	
Patient characteristics	OR (95% CI)	*P*	OR (95% CI)	*P*
Age (per 5 yr)	1.0 (0.4–2.2)	0.92	1.0 (0.5–2.3)	0.93
Female	0.8 (0.2–2.5)	0.67	1.5 (0.5–5.2)	0.49
Race		0.15		0.44
Black/African American	0.3 (0.1–1.1)	0.06	0.4 (0.1–1.9)	0.25
White/Caucasian	REF	REF	REF	REF
Other	0.4 (0.1–1.8)	0.23	1.1 (0.3–4.7)	0.89
Hispanic	0.4 (0.1–1.5)	0.15	0.1 (0.1–0.2)	<0.001
Non-English primary[a]	1.6 (0.2–12.2)	0.67	0.1 (0.1–0.6)	0.01
UP:C (per 1 g/g)	1.0 (1.0–1.0)	0.53	1.0 (1.0–1.0)	0.98
eGFR[b] (per 30 ml/min per 1.73 m^2)	1.0 (0.7–1.4)	0.92	0.9 (0.6–1.1)	0.28
Serum albumin (per 1 g/dl)	0.9 (0.3–2.3)	0.77	1.5 (0.4–3.0)	0.94

CI, confidence interval; eGFR, estimated glomerular filtration rate; OR, odds ratio; REF, reference; SMS, short messaging service; UP:C, urine protein-to-creatinine ratio.
[a]SMS respondent characteristic.
[b]Estimated GFR is calculated from serum creatinine at enrollment using the Beside Schwartz formula.[12]

DISCUSSION

In this prospective, multicenter study, we demonstrated that text messaging is a feasible tool for home disease monitoring in childhood nephrotic syndrome. Patient/caregiver adoption of the technology was high, with most patients agreeing to participate, and excellent retention on follow-up at 1 year. In addition, we found that participating subjects were very engaged with the SMS system over the entire period of observation. Concordance between SMS-captured home urine protein testing results with same-day urinalyses was high and improved over time, supporting the validity of patient-reported information via SMS. We acknowledge that there is no validated tool to enable standardized assessment of edema; however, our findings suggest there is good concordance between caregiver and physician evaluation of this physical finding in children with nephrotic syndrome. Furthermore, the SMS system captured more disease relapse events and more precise information on time to remission as compared with conventional in-person visits, offering a more accurate account of nephrotic syndrome disease activity.

Although overall engagement with the SMS system was high in our cohort, we did find that engagement over time decreased after the initial 90 days. A notable change from the first 90 days of follow-up to the period between 90 days and 12 months was text message frequency. Texts were sent daily during the first 90 days but weekly thereafter. As a result, it is unclear whether the drop off in responsiveness was due to time trends or the change in frequency of messaging during later periods. A limitation of our study is that adequate engagement was defined as at least 1 response per week. After the first 90 days, texts were sent only once a week, reducing the opportunities for the participant to respond, which may have affected their engagement as defined. Further study is needed to determine the optimal text message frequency to sustain user engagement and align with informational requirements. We found that Hispanic individuals and

non-English primary speakers showed significantly reduced response rate over time after 90 days, despite the availability of a Spanish version of the SMS system. A review by Chesser *et al*.[13] found that eHealth literacy, pertaining to operational and navigational skills and the ability to choose and critically evaluate available electronic information, is lower in underserved populations, including Hispanic individuals and those with limited English language. It is possible that factors reducing eHealth literacy have negatively affected SMS engagement in our patients; however, there were several unexamined factors in our study that may also affect engagement, including educational level, perceived utility and value, motivation, and privacy concerns.[14] We attempted to remove technical and logistic issues by providing free phones as needed and stipends for text message–related fees and periodically reaching out to families who were not responding to texts. These measures likely improved SMS adoption, retention, and engagement, but it is unlikely that all technical/logistic barriers were removed. More in-depth evaluations are needed to fully explore the influences and strategies to promote mHealth engagement and acceptance in childhood nephrotic syndrome.

Our analysis comparing the ability of SMS to capture disease relapse/remission compared with standard in-person visits was likely biased by the uncontrolled study design. The SMS system triggered alerts to the study staff of new disease relapses and edema, and the study staff in turn reached out to participants to follow up on their disease status. These actions likely increased caregiver and provider awareness of new disease relapses and medical chart documentation, such that more events will be captured by our definition of conventional, in-person study visits (where relapse/remission history is obtained from participant inquiry and medical chart documentations). The differences in the number of disease relapses and times to remission captured by SMS versus in-person visits were likely underestimated by this study. Our study was also limited by the small patient numbers, including very few adolescent self-respondents ($n = 3$), which precluded our ability to perform adjusted analyses of predictors of SMS engagement.

In summary, we found that SMS was well accepted by caregivers and adolescent patients and reliably captured nephrotic syndrome disease activity between clinic visits. There is very limited published experience on strategies and tools to improve childhood nephrotic syndrome monitoring, although this disease is one of the most common chronic kidney diseases with significant negative impacts on financial and psychosocial status and quality of life.[15–17] The relapsing-remitting pattern among most children necessitates home urine monitoring, the results of which are critical to support timely treatment decisions and avert progression of nephrotic syndrome symptoms and complications with high morbidity due to delayed relapse therapy. With the current encouraging findings of feasibility of SMS use in childhood nephrotic syndrome, ongoing research is needed to determine whether mHealth solutions can promote home monitoring and improve nephrotic syndrome outcomes.

DISCLOSURE

All authors declared no competing interests.

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SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Appendix S1. Comparison of the characteristics of NEPTUNE pediatric nonbiopsy incident patients retained in the SMS study versus not retained.

Appendix S2. Members of the Nephrotic Syndrome Network.

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