


Text messaging to improve connection between adolescents and their health care providers

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Abstract

Objective: Adolescence marks a time of transition where teenagers are learning to advocate for themselves. In those with underlying chronic conditions such as adolescent dysautonomia, improving communication between clinic visits may improve connection with their health care provider which may aide management. Our aims were as follows: (1) to implement a text message platform to increase communication between adolescent patients and health care provider (HCP); (2) to evaluate its effect on quality of life (QoL), symptom burden, and patient engagement; and (3) to determine patient satisfaction with the platform.

Methods: Participants (age 12–18) with access to a personal mobile phone were recruited from a pediatric dysautonomia clinic. A weekly automated text message asking “How are you?” was sent to participants (WelTel Inc.). Responses were triaged to HCP and responded to within 48 hours.

Results: Twenty-six participants with median (interquartile range) age of 16.8 (15.7–17.4) years completed the study. Duration of the text messaging intervention was 33 (26.8–37.3) weeks. A total of 896 automated weekly messages were sent, which resulted in 206 (23%) care conversations. Participants found texting useful (96%) and produced feelings of connection to their HCP (92%). There was no change in overall QoL or symptom burden ($p > 0.05$).

Conclusion: A text message platform was successfully implemented in adolescents seen in our Dysautonomia Clinic. Patients were engaged, satisfied with the platform, and felt connected to their HCP despite no changes in QoL or symptom burden.

Keywords

Teenager, POTS, implementation, m-health, pediatrics, digital health

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Introduction

Emerging mobile health (mHealth) technology is revolutionizing health care. Technologies such as SMS/text messaging may improve patient access and communication with health care providers (HCP) which in turn may improve health outcomes. Worldwide research has shown that the use of a health care-specific Short Message Service (SMS or text) messaging platform leads to significant health improvements in at-risk adult populations and improves the relationship between patients and their HCP.^{1–5} WelTel is a health care-specific text messaging platform that has been shown to increase engagement and treatment adherence and improve health outcomes for

HIV patients in both Kenya and Canada.^{2,3,6,7} Adolescents are a unique population who are transitioning from parent-led clinical interactions to self-care. They are adopters of technology and may be amenable to adopting mHealth technology. Approximately 94% of Canadian

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adolescents own a smartphone and send up to 100 text messages daily.^{8–10} Using text messaging with adolescent patients may promote engagement with the health care team, foster self-efficacy, promote behavior change, and improve treatment adherence by promoting independence and allowing communication to occur directly between adolescent and HCP.^{9,11–14}

Dysautonomia that occurs during adolescence is an umbrella term used to encompass conditions such as orthostatic intolerance, postural orthostatic tachycardia syndrome (POTS), and chronic fatigue. Dysautonomia of adolescence is more widely accepted in the literature as POTS.¹⁵ This is a complex and debilitating condition. Multiple organ systems can be involved. Patients may present with symptoms across any organ group most typically syncope, presyncope, palpitations, muscle/joint pain, gastrointestinal complaints, and fatigue. Fluctuations in symptom severity or onset of new symptoms are common, and quality of life (QoL) is severely affected.¹⁶ Many patients withdraw from school, sport, and recreational activities, resulting in social isolation and significant mental health challenges. This condition is similar to what is described in somatic symptom/somatoform disorder whereby the burden of symptoms, lack of timely diagnosis, repeated consults, and investigations has a negative impact on the patient.¹⁷ Galvin et al. have demonstrated that up to two-thirds of these with symptoms of autonomic dysfunction patients have significant mental health concerns.^{18,19}

Management of POTS patients in the pediatric setting is largely based around lifestyle changes, including increasing fluids and salt, lower-body strength training, and supporting mental well-being which were provided in an in-person clinic setting at time of diagnosis. There are often many months between clinic visits which can lead to a lack of consistency in sustaining these changes. As these pediatric patients are not routinely prescribed medication, adherence to the nonpharmacologic therapies is the mainstay of treatment. Supporting these lifestyle changes can be mediated by HCP without in-person clinic visits.^{16,20} We sought to implement WelTel to support POTS patients between clinic visits, to allow them to communicate with their HCP with regard to their treatment plan and to evaluate any change in their QoL and symptom burden. We also sought to assess participant engagement with the WelTel platform.

Methods

This was a prospective interventional cohort study. Eligible participants were between the ages of 12 and 18, English-speaking, and a patient in the Dysautonomia Clinic at British Columbia Children's Hospital (BCCH). Participants were excluded if they did not have access to a mobile phone. Forty-four eligible patients with POTS were approached for enrollment between 1 November

2018 and 31 December 2019. Data was collected until 30 June 2020. Each participant had received at least 6 months of standard of care treatment (T_0) which included lifestyle education on increasing fluid intake to 3–4 L per day, increasing salt intake to one-half teaspoon per day, participation in a lower-body strength training program, and support of their mental health with a clinical psychologist, if appropriate, prior to enrollment in the study.¹⁶ After this time, participants were added to the web-based WelTel platform (WelTel Inc, Vancouver, Canada) while continuing to follow the aforementioned standard of care recommendations. No other pharmacologic or medical interventions were prescribed during the intervention period. Participants immediately received their first weekly text message at enrollment (T_1) and received weekly messages for 6 months (T_2).

Written assent from all participants and written consent from their legally authorized representatives was obtained prior to study initiation. Ethical approval for this study was obtained from the University of British Columbia and Children's and Women's Health Centre Clinical Research Ethics Boards (Certificate H18-02193).

WelTel intervention

Every Monday, participants received an automated text message from WelTel to their personal mobile phone which asked "How are you?".³ Participant responses were triaged by a study team member to the appropriate HCP which included the participant's doctor, nurse, psychologist, or exercise physiologist. Participants were responded to via text message within 48 h by the appropriate HCP if follow-up was needed. If no response was received, an additional automated message was sent on Wednesday which asked "Haven't heard from you yet, how are you?." Messages were checked and responded to within clinic hours. Weekly text responses and number of care conversations (>2 text messages between participant and HCP) were recorded. Participant messages were categorized according to message themes.

Demographics

Age, sex, and mental health concerns noted in the medical chart were recorded for each participant. Mental health concerns documented included anxiety, depression, obsessive compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), learning disabilities, emerging personality disorders, suicidal ideation, and self-harm behaviors.

Self-report and parent-proxy PedsQL™

The PedsQL™ is a validated 23-item questionnaire used to measure health-related QoL in children and adolescents in various pediatric populations.^{21–25} The PedsQL™

comprises four domains (physical, social, emotional, and school functioning) with three summary scores (total, physical health summary, and psychosocial health summary). PedsQL™ measurements were taken at T₀, T₁, and T₂.

Symptom burden

The symptom burden questionnaire (Supplementary Material) was adapted form from the Dysautonomia Center of Excellence at UT Health and Memorial Hermann Hospital.²⁶ Symptom burden was categorized into the following: neurologic, cardiac, gastrointestinal, skin, joints/muscles, and energy/activity. A 5-point scale from 0 to 4 was used to determine symptom severity with no symptoms defined as a score of 0, occasional symptoms as a score of 1 or 2, and frequent symptoms as a score of 3 or 4. Measurements were taken at T₀, T₁, and T₂.

Surveys

Surveys were used to determine the utility of the text message platform along with participant experiences. The pre-survey was administered at T₁, and post-survey was administered at T₂. Surveys asked multiple choice and short answer questions related to participant opinions on treatment adherence, potential and experienced problems, effectiveness, use, outcomes, and overall experiences using the text messaging intervention (Supplementary material).

Statistical analysis

Frequency counts (%) were performed for all categorical variables and a univariate analysis performed on all continuous variables. Medians and interquartile ranges (IQRs) are reported. Nonparametric Friedman tests were used to determine differences in QoL scores over T₀, T₁, and T₂. A Wilcoxon signed-rank test was used to compare responses between paired time points. Pearson correlation coefficients were used to determine the association between self-report and parent-proxy PedsQL™ scores. All tests were two-sided and a $p < 0.05$ was considered statistically significant. IBM SPSS Statistical Software (IBM Corporation, Armonk, NY) was used to complete the analyses. Study data were collected and managed using REDCap electronic data capture tools hosted at the BCCH Research Institute.^{27,28}

Results

Thirty-five participants were consented and enrolled, representing an 80% recruitment rate. Three participants withdrew from the study; two cited responses as unhelpful and the reason for withdrawal was not reported by one.

Thirty-two participants were eligible to complete T₂ at the time of data collection, and six participants did not return their study measures and were excluded from analysis. Twenty-six participants completed the study (23 female, 88%) with a median (IQR) age of 16.8 years (15.7–17.4) at time of enrollment (Figure 1).

Intervention

Median duration of the intervention was 33 (26.8–37.3) weeks. A total of 896 automated weekly check-in messages were sent to participants. During the participant's intervention period, 96% asked their HCP at least one question, which were responded to by the most appropriate HCP. Seventy-one percent of all automated weekly check-in text messages received a response from participants. Response themes are shown in Table 1. Care conversations occurred in 23% of all weekly message check-ins.

PedsQL™

Figure 2 shows teen self-report PedsQL™ data across time points. There was no significant difference in Physical ($p = 0.458$), Emotional ($p = 0.666$), School ($p = 0.499$), Psychological ($p = 0.059$), and Total ($p = 0.259$) Functioning scores across time points. Post-hoc tests showed that Social Functioning worsened over the study time period, with scores decreasing between T₁ and T₂ ($p = 0.007$). Parent-proxy data was available for 18 participants. Parent-proxy and teen self-reports were highly correlated (eTable in the Supplement). There was no significant difference between teen and parent-proxy scores for Physical ($p = 0.946$), Emotional ($p = 0.871$), Social ($p = 0.731$), School ($p = 0.724$), Psychological ($p = 0.901$), and Total ($p = 0.411$) Functioning scores. Parent-report scores are shown in eFigure 1 in the supplement. Pearson correlation coefficients between parent and self-reports showed significance for all domains and data collection points. Twenty-seven percent of participants improved their school attendance from T₀ to T₂, and 15% of participants were able to secure part-time jobs since T₀. Twelve percent were accepted and went to college, and another 12% plan to attend college after graduating from high school.

Symptom burden

Complete data are presented for 22 participants. There was no difference between the median number of symptoms reported by participants across the study period, despite the ability to provide real time advice regarding fluid consumption and salt intake, along with exercise recommendations via the text messaging platform. Participants reported the number of occasionally present symptoms as 12.5 (8–

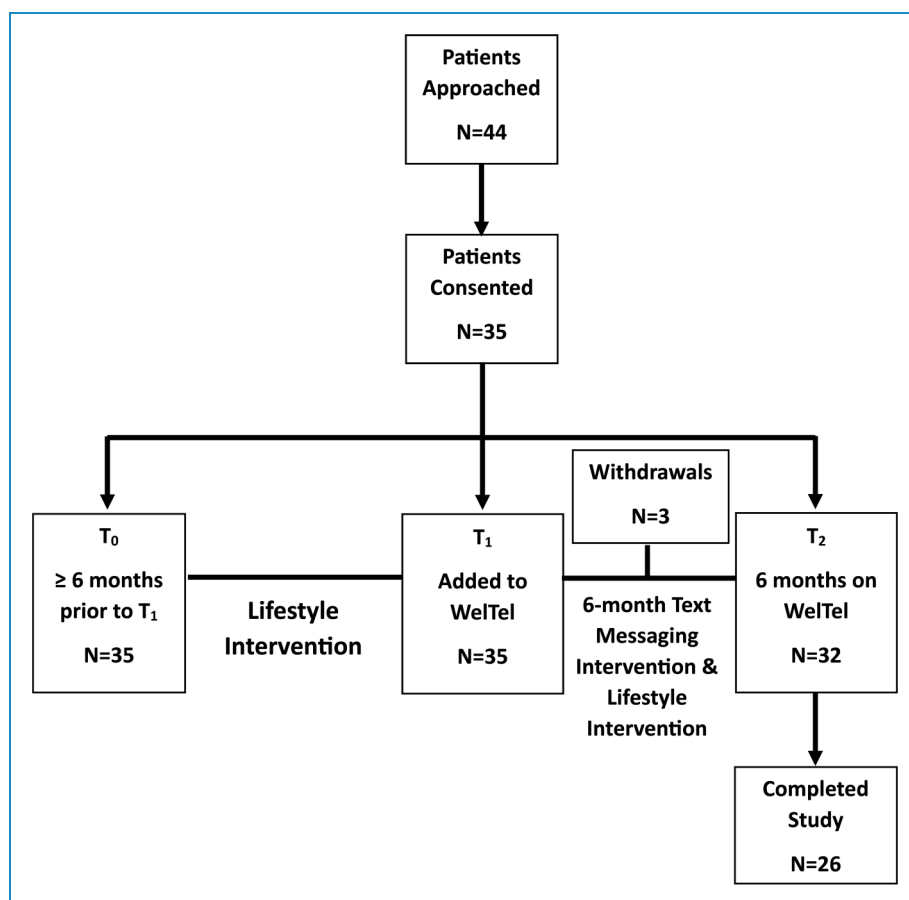


Figure 1. Participant flowchart.

19) vs 12.5 (9–17) vs 14 (9–16), ($p = 0.789$) over the study period and reported the number of frequently present symptoms as 13 (10–26) vs 14.5 (7–21) vs 17 (10–23), ($p = 0.258$) over the study period. Dizziness, nausea, feelings of weakness, and fatigue were rated as frequently present for more than 50% of the cohort across the study period.

Sixty-nine percent of participants with POTS had reports of a significant mental health challenge documented in their clinical chart. Those with a significant mental health challenge had anxiety ($n = 4$); anxiety and depression ($n = 4$); anxiety, depression, and a learning disorder ($n = 2$); anxiety and a learning disorder ($n = 3$); anxiety, emerging personality disorder traits, and learning disorder ($n = 1$); anxiety, depression, and OCD ($n = 1$); ADHD ($n = 2$); and depression ($n = 1$).

Surveys

Survey responses are shown in Table 2 along with participant feedback. Prior to intervention, five participants foresaw problems communicating via text message due to potential changes to their phone plan ($n = 1$) or forgetting to respond ($n = 4$). In the post-survey, 92% of participants reported that texting increased their feelings of connection

to their health care team. The majority felt comfortable reaching out for help. Feelings surrounding positive support were stated by 73% of the participants. Remembering to text back was cited as the most frequent obstacle (35%). Other critiques included not feeling comfortable enough to ask questions (15%) and the impersonal feeling of the automated weekly message (8%). Figure 3 shows participant responses to the impact of weekly text messaging on treatment adherence and outcomes after intervention.

Discussion

To our knowledge, this is the first study to evaluate the utility of a text messaging platform to support the care of adolescents with POTS. While QoL and symptom burden was largely unchanged in the majority of POTS patients, the text messaging platform gave these patients access to their HCP who could help them make lifestyle changes and support them in their difficult journey.

To date, there is no standardized treatment protocol for POTS patients and pharmacological interventions have shown modest effects, at best, with limited data available in pediatrics.^{29–31} An optimal management strategy of

Table 1. Themes of participant text messages responses.

Participant text message themes	Number of responses (n = 896)
No response	261 (29%)
OK	429 (48%)
Symptom concerns	118 (13%)
School concerns	14 (2%)
Exercise questions and advice	23 (3%)
Coping/mental health support	22 (3%)
Other (incl. appointment scheduling)	9 (1%)
Medication questions	10 (1%)
Sleep advice	4 (<1%)
COVID-19 concerns	4 (<1%)
Unknown	2 (<1%)

both pharmacologic and nonpharmacologic approaches may, in fact, improve QoL in our population but this will be only be possible as more evidence on the efficacy of pharmacologic treatments in pediatrics become available. In the meantime, a nonpharmacologic approach has been the mainstay of treatment at our institution and finding a way to connect with and support these patients has been our goal.

Communication is the cornerstone of interaction with people and is vital for maintaining human connection. It is arguably the most important component of the relationship between patients and their HCP. Finding novel ways to improve and personalize communication with adolescents may increase their engagement in their health care. Connecting with a patient and their story is one practice that has been shown to generate meaningful relationships with patients during clinical encounters that in turn can also reduce the number of consultations.³² In adolescent patients with chronic kidney disease improving communication between adolescents and their HCP has been thought to be a key component in improving medication adherence.³²

Campbell et al. used text messaging to communicate with surgical patients and reported that 90% of text messages were opened within 3 min and response rates to text messages (90%) were far higher than that of email (20%). They concluded that text messaging was an

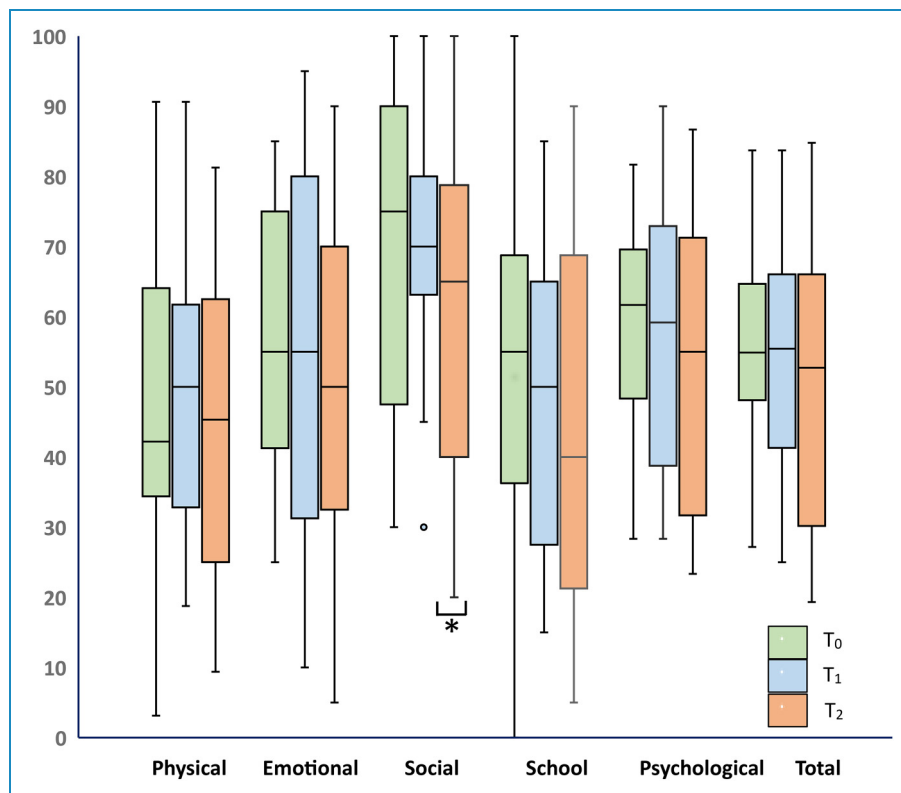
**Figure 2.** Teen self-report pedsQL™ scores across domains. Social functioning decreased from T1 to T2 (* $p=0.007$).

Table 2. Participant ($n = 26$) survey responses.

Question:	Yes	No	Unknown	No response
Presurvey				
Would CDM be beneficial?	25 (96%)	–	–	1 (4%)
Would you respond to a weekly message?	26 (100%)	–	–	–
Can you foresee problems?	5 (19%)	21 (81%)	–	–
Do you have any concerns communicating via text message with your HCP?	–	26 (100%)	–	–
Would receiving a weekly message help you to...				
Increase exercise?	23 (88%)	3 (12%)	–	–
Increase salt intake?	19 (73%)	–	5 (19%)	2 (8%)
Increase water intake?	21 (81%)	5 (19%)	–	–
Increase well-being?	24 (92%)	–	1 (4%)	1 (4%)
Postsurvey				
Did you find it useful to text message your health care team?	25 (96%)	1 (4%)	–	–
Would you like to continue to text message your health care team?	22 (85%)	4 (15%)	–	–
Would you recommend the platform to others with a health condition?	24 (92%)	2 (8%)	–	–
Did you feel comfortable reaching out for help via text message?	24 (92%)	2 (8%)	–	–
Did you experience problems sending and/or receiving text messages?	2 (8%)	24 (92%)	–	–
Participant feedback				
“The best thing from this for me was that it made me feel responsible for making sure I am doing what my body needs me to do and it encouraged me to connect with the health care team”				
“It was nice to have support from people who understand and can help me with what I’m going through.”				
“I think for me receiving a text every week was helpful to remind me to evaluate how my health was doing for that particular week and see what needed to be adapted or worked on.”				

acceptable and engaging communication platform.³³ Rathgeber et al. report that text messaging is a preferred method of communication for adolescent solid organ transplant patients.³⁴ In our study, 71% of all automated messages sent over the intervention period received a response from participants. Previous research using WelTel technology showed that the average response rate to the automated messages was 57%–76%.^{1,3,4,35} Our findings reflect a high level of engagement with the text messaging platform, such engagement has been shown in previous work to improve adherence to medical care.³

The WelTel technology allowed for the study coordinator to easily triage patients to the correct HCP based on the care conversation, all messages were responded to within 48 h as per study protocol. This text message platform allows the team to easily respond to multiple patients in a timely fashion without having to enter into each person’s electronic health record. Within a few minutes every week, multiple patient concerns were addressed. Previous work using WelTel has shown that 3% of messages from patients required follow-up from HCP.³ In our study cohort, 23% of messages required follow-up by a HCP. This may be an indication of the complex needs of

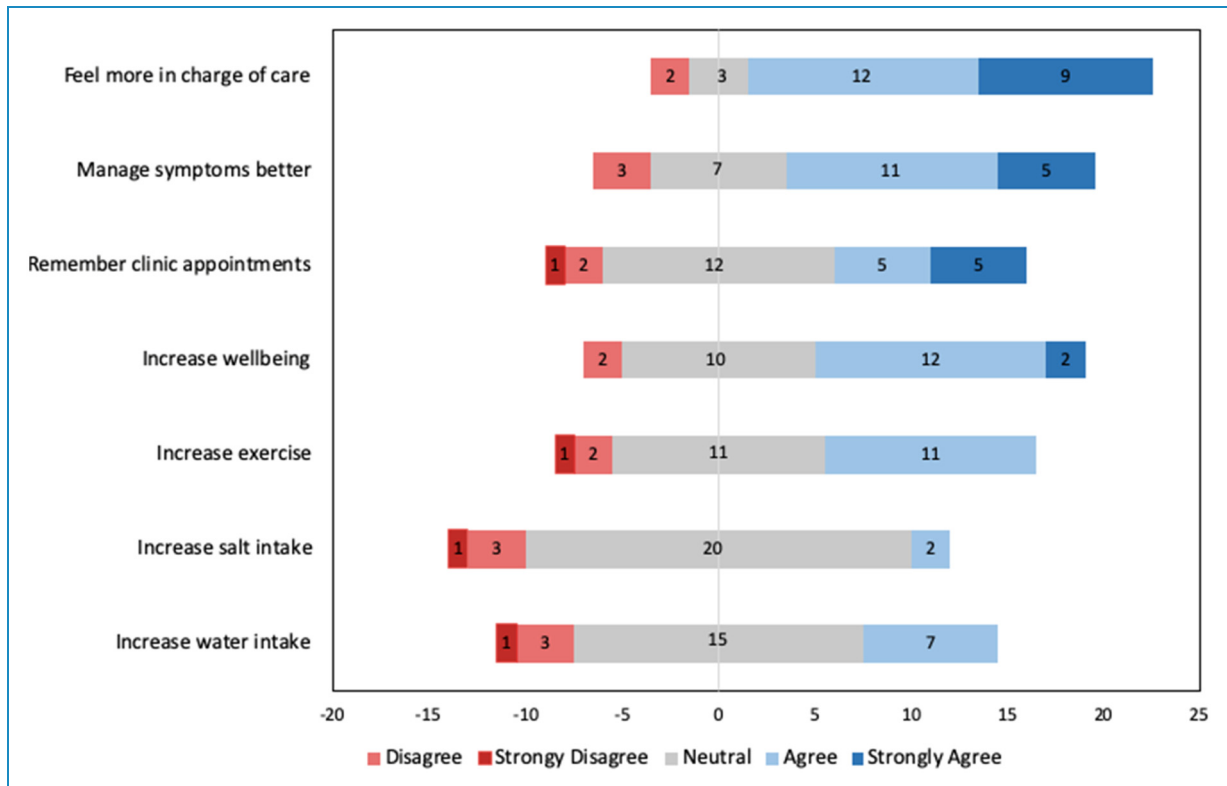


Figure 3. Participant ($n = 26$) agreement to treatment adherence and outcomes after participation in the text message intervention.

these patients and the high level of ongoing support needed by POTS patients in managing not only their symptoms but other facets of their life as shown by the variety of message themes. Adolescents, in general, may require more HCP support than adults as they learn to navigate life with their condition and the health care system. The use of “How are you?” open language for check-in allowed adolescents to direct the conversation to their own needs and acted as a way to reflect on symptoms.² Other studies aimed to be able to elicit behavior change and adherence to treatment recommendations.³⁶ While we did not specially target behavior change, our participants rated “neutral” on a Likert scale for helping them to increase exercise, fluid intake and salt intake, and treatment recommendations for POTS. The majority of participants did “agree” or “strongly agree” that text messaging their HCP helped them feel more in charge of their care, manage their symptoms better, and improve their well-being. It is unclear from this study what made participants feel that their symptoms were better.

Despite the positive responses of participants using the text message platform, QoL remained low and unchanged over the study period. Literature on QoL in youth with POTS is scarce; a more specific QoL measure may be needed in order to address the functional priorities and holistic well-being of these patients through pharmacological and nonpharmacological approaches.³⁷ At baseline, QoL

in our study cohort was lower than that of healthy children (83.0 ± 14.8) and children with other chronic illness (77.2 ± 15.5)²² including those with cerebral palsy (66.9 ± 16.7), cancer (72.2 ± 16.4), and diabetes (80.4 ± 12.9).^{21,24,25} QoL scores were similar to those with conditions with overlapping features of POTS such as chronic fatigue syndrome (49.0 ± 15.2) and Ehlers–Danlos and hypermobility (males 67.9 ± 15.5 , females 61.1 ± 19.2).^{38–42} Following the text message intervention, there was no significant improvement in QoL.

A recent review by Frye and Greenberg highlighted that QoL in POTS patients is multifaceted.³⁷ One such factor suggested, by Hutt et al., was abnormal functional capacity.⁴³ These findings are in alignment with our groups findings that showed improvements in QoL with strength training.¹⁶ Mental health challenges and fluctuating symptom burden may also contribute to the low QoL of our cohort throughout the study intervention period. More than half of the participants had a mental health challenge. Despite these challenges, only 3% of responses on the WellTel platform were related to “coping/mental health support.” Previous reports in adolescents with chronic pain, similar to symptoms experienced by POTS patients, report high levels of emotional distress and anxiety which may contribute to the low and unchanged QoL seen in our patient cohort.⁴⁴ In addition, the persistence of symptoms may also contribute to poor QoL. Symptom burden

remained high throughout the study period with 50% of the cohort reporting dizziness, nausea, feelings of weakness, and fatigue at all study time points. Despite high symptom burden, some participants improved their school attendance and went back to regular activities following the intervention.

Limitations

Due to the timing of our study, 15 participants (58%) completed study questionnaires during the COVID-19 pandemic. Participant ratings of QoL may have been negatively affected by the pandemic and may be a factor in decreased social functioning QoL scores with measures such as social distancing being put in place.

This was a small cohort study in POTS patients using pre-post data in which the participants acted as their own controls. A larger, randomized control trial should be completed as a future study to more effectively understand the clinical and health implications of using text messaging in the adolescent population. Future prospective studies should include measures of resilience, self-perception, and adolescent support systems as these may be factors in how well adolescents participate in, as well as give indication to, the levels of support individual patients need.

Conclusion

The use of a health care-specific SMS platform is a feasible way to improve communication and connection with adolescent patients. Adolescents in our study with POTS were receptive and supportive of the use of text messaging in their clinical care. The high level of engagement with HCP suggests a clinical need for continued support throughout their health care journey. Although there was no meaningful change in symptom burden, patients felt more engaged in their care with some patients having improved clinical functionality at the end of the study. Text messaging can be a useful tool in conjunction with regular clinical care to provide an outlet for adolescent patients to ask questions, manage their symptoms, and improve their connection with HCP.

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