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Feasibility of Web-based Technology to Assess Adherence to Clinic Appointments in Youth with Sickle Cell Disease

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Abstract

Web-based tools to improve clinic attendance have been effectively used in pediatric conditions but have not been tested in pediatric sickle cell disease (SCD). The goal of this pilot study was to assess barriers to clinic attendance and the feasibility of a web-based assessment tool to promote problem-solving around clinic appointments. Study participants included 30 youth with SCD ($M=11.7\pm3.5$ years; 57% male; 60% HbSS; 20% HbSC; 17% HB+Thal) and their primary caregivers. Medical chart review indicated that 61% of participants attended at least two SCD clinic appointments in the past year. The primary barrier to clinic attendance was inability to take off from work/school (33%). Regarding feasibility and acceptability, the computerized program was well-received by patients and caregivers, with youth and caregivers reporting a high degree of usefulness and preference for computerized assessment. Results suggest that this innovative approach shows promise and should be tested on a larger sample of youth with SCD.

Keywords

innovation; compliance; disease management; technology; pediatric

Introduction

Practice guidelines for the management of sickle cell disease (SCD) recommend that patients attend routine clinic appointments every 6 months, and more frequently if the patient has frequent pain episodes, hospitalizations, or recurrent complications (e.g., acute chest syndrome) [1]. In addition, flu shots and other immunizations, which occur at routine appointments, are given as standard of care to prevent infections [2]. Thus, to effectively manage sickle cell disease, patients must attend routine follow-up visits with physicians who prescribe and refill medications (e.g., hydroxyurea) and monitor symptoms and medication side-effects. "Nonadherence with regularly scheduled clinic appointments represents one of the most costly problems in outpatient care, both in terms of economical and human resources spent" [3].

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Research examining nonadherence to clinic appointments for youth with SCD is sparse. A meta-analytic review regarding adherence to pediatric healthcare appointments suggested rates of approximately 60% [4]. However, adherence rates for routine clinic appointments in SCD ranged from 46-77% [5, 6]. Parent and adolescent-perceived barriers to clinical appointments include competing activities, health status, patient-provider relationships, adverse clinical experiences, and forgetting [7]. Interventions to improve adherence to clinic appointments or even treatment in pediatric SCD have been limited [8], with only two studies focused on improving adherence to penicillin with educational interventions [9, 10].

Systematic assessment and intervention approaches to improve treatment adherence and clinic attendance using newer technologies (e.g., computer-based, text messaging) have been effectively used in many diseases, including diabetes [11, 12], asthma (Stop Asthma Clinical System [13]) and adults with hypertension [14]. Use of new web-based technologies may provide a vehicle for delivering effective, standardized, and cost-effective assessment and intervention. These types of interventions may also appeal to this generation of patients (e.g., adolescents and young adults) who are highly engaged in media-based social networking and seeking health information [15] through technological mediums. Furthermore, despite disparities in access, African American youth are increasingly accessing information through a multitude of technologies, including computers, internet, and personal electronic devices [16]. These data suggest that web-based assessment and interventions may be promising for youth with SCD.

In light of the gaps in the SCD literature related to treatment adherence to clinic appointments, and the web-based interventions emerging in other pediatric populations, the goal of this pilot study was to assess: 1) clinic attendance, barriers to clinic attendance, and possible solutions to improve clinic attendance, and 2) the feasibility of a web-based, voice-automated computerized assessment tool to identify barriers and to promote problem-solving for adherence to clinic appointments in youth with SCD and their caregivers. We anticipated that a majority of participants would know the recommendations regarding clinic appointments and that barriers would include forgetting, competing activities, and the health of the child/teen. It was also hypothesized that the computer-based tool would be rated as feasible, user-friendly, and beneficial by patients with SCD and their families.

Materials and Method

Participants and procedure

All youth with SCD (6-21 years) and their caregivers seen in an urban, Midwestern comprehensive sickle cell clinic at a pediatric hospital were invited to participate in a research and education event [17]. Of the 150 youth seen in the sickle cell clinic that were eligible and able to be contacted for the event, approximately 69 youth attended the event. Notably, patients could participate in one of three studies: one focused on child/adolescent self-concept and coping style (n=14), one focused on adolescent spirituality (n=30) and/or the current study (n=30). Of the 41 youth and caregivers eligible for this study, 30 (73%) agreed to participate. Reasons for study declines included lack of time, both the child and/or caregiver dyad were not present, or participation in the other study. Dyads completed a module of the web-based Disease Management Interview- SCD (WDMI) and then a subset of dyads (n=14), based on a convenience sample, answered questions about the module's user-friendliness, format, and potential for use in clinic. The WDMI module began with the introduction of the web-based avatar, "ROGER," which is an acronym for Remembering appointments and Being On time; Getting medication and taking it Everyday equals Responsibility (Figure 1). The WDMI module included 28 questions regarding patient's clinic attendance, barriers to clinic attendance and possible solutions to improve clinic

attendance. Medical chart review was also conducted to ascertain clinic attendance in the past year.

To assess feasibility and usability, participants were asked to complete a 5-item survey (see Table 1) about the module. Items were either on a 10-point Likert scale, with 0 being low (e.g., not useful/honest at all) and 10 being high (e.g. very useful/honest) or yes or no responses. Patients and caregivers viewed the program together but were instructed to complete the survey individually. For child participants, trained research staff were available to assist with completion of the questions, as needed. The study was approved by the Institutional Review Board. Descriptive data was analyzed using SPSS version 19.0.

Results

Participants

Study participants included 30 youth with SCD ($M=11.7\pm3.5$ years; 57% male; 60% HbSS; 20% HbSC; 17% HB+Thal) and their primary caregivers. This sample is similar to our larger SCD clinic population ($M=10.6$ years; 48% male; 50% HbSS; 28% HbSC).

WDMI module data

The module took approximately 15-20 minutes to complete. Medical chart review indicated that 60.7% of participants attended at least two SCD clinic appointments in the past year. Based on dyad report, approximately 75% of patients and their caregivers understood that their SCD providers recommend clinic appointments at least twice a year. Eighty-three percent of patients indicated their mother schedules and keeps track of their appointments. Forty percent of participants indicated no barriers to clinic attendance while some participants chose multiple barriers. Of those participants (60%) who identified barriers to clinic attendance, the following were identified: forgetting (7%), inability to take off from work/school (33%), competing activities (e.g., sports; 3%), transportation difficulties (13%), feeling sick (3%), feeling well (3%), feel it is unnecessary (3%). Participants were asked to rate potential solutions on a 4-point Likert scale from "Wouldn't work at all" to "Would work very well." When the "would work well" and "would work very well" categories were aggregated, 70% reported that having the child/teen use a calendar was beneficial. Eighty-nine percent felt that having a cell phone reminder would work well, while 94% felt that having the parent take over appointment-making/tracking would be beneficial.

Module Format

Ninety-two percent of youth and 100% of caregivers indicated that they would prefer the computer format versus paper/pencil. They also reported they would be more honest using a computer relative to a paper/pencil format.

Clinic Utility

Overall, clinical utility was rated favorably (See Table 1). The majority of participants and caregivers felt the module would be useful in clinic and 92% indicated that the information collected would be useful for clinic staff.

User-Friendliness

Top-rated characteristics participants felt would increase the user-friendliness of the module were: using a touch screen instead of a mouse, being able to log-on from home and see a graph, and using a relatable avatar for youth.

Domains

Patients and caregivers agreed that a number of domains should be addressed in the module: Physical Health/Challenges (92% youth, 92% caregivers); Medications/Associated Challenges (84% youth, 100% caregivers); Emotions and Coping (92% youth and caregivers); Friends/Social Life (85% youth, 100% caregivers); School/Grades (84% youth, 92% caregivers); Family/Home Life (92% youth and caregivers).

Discussion

This pilot study examined the potential for using web-based technology to provide a standardized assessment of adherence to clinic appointments for youth with SCD. Initial chart review findings indicated that 61% of participants attended at least two routine clinic visits in the past year. However, a larger percentage of families (75%) indicated that they understood that their SCD providers recommended clinic appointments at least twice a year. Barriers to clinic attendance were similar to those reported in our prior work [7], with inability to take off from work or school (e.g., competing activities) being the primary barrier for this cohort. Interestingly, participants felt that several suggested strategies would work well/very well to improve clinic attendance, including text reminders and parents taking over the scheduling/tracking. These data are consistent with recent research indicating that caregivers with SCD are primarily responsible for remembering/tracking clinic appointments [18]. While these approaches are likely useful for younger children with SCD, shifting responsibility to caregivers is counter to the pediatric chronic illness transition literature suggesting that adolescents should be assessed for transition readiness and guided into taking more responsibility for their own disease management [19]. As such, SCD providers may need to work closely with families regarding when to transition SCD management from the caregiver to the patient, with the knowledge that supervision is critical during this time period [20].

Regarding feasibility and acceptability, the computerized ROGER program was well-received by patients and caregivers, with youth and caregivers reporting a high degree of usefulness and preference for computerized assessment. In addition, participants reported that touch screen technology, completion of surveys with their parent/child, completion of the assessment at home, use of an Avatar, and feedback on their progress would be useful. Based on data from the current study, we have improved upon the ROGER program by adding touch screen technology, audio-recordings that read the screen information to patients, and use of both a male and female Avatar. The improved ROGER program is currently being tested to improve clinic attendance during routine clinic visits with youth with SCD. The initial cost to develop the ROGER program was \$8000, with a yearly maintenance cost of approximately \$2000.

Participants also indicated that the module should focus on assessing challenges related to physical health and medications and that a report would be useful to them and to clinic staff. This is consistent with the larger literature indicating that good patient-provider communication positively correlates with adherence to treatment and clinic appointments [21-24]. If youth with SCD and their caregivers feel supported by their healthcare team as a result of discussing and problem-solving ways to improve clinic attendance, this may potentially improve adherence to other aspects of the SCD regimen and the ROGER program could be beneficial on multiple levels.

To our knowledge, this is the first study to test the feasibility of a web-based program to assess and problem-solve around barriers to attending clinic appointments. However, several limitations are noted. First, participants represent a small convenience sample of patients with SCD and their families attending a sickle cell research event; thus, results may not be

generalizable to all youth with SCD. However, barriers reported in the current study were similar to those reported in prior studies of youth with SCD [7]. Second, the study relied solely on questionnaires rather than a combination of other qualitative research methods (e.g. focus groups), which may have provided additional insights into module format or content. Finally, the data presented is descriptive in nature and further work needs to be conducted to prospectively assess the relations between module utility, clinic attendance, and health outcomes (e.g. health utilization, quality of life).

Overall, this study represents an important first step in integrating technology in clinical care, improving parent-child-staff communication, and optimizing adherence to appointments and treatments. It also has implications for clinical practice. The use of web-based programs, such as ROGER, could improve the treatment adherence of eligible patients thereby increasing the likelihood that they will be offered these types of treatment. We are currently testing the efficacy of the ROGER program to improve both clinic attendance and adherence to oral medications, including hydroxyurea, deferasirox, and/or penicillin.

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Figure 1.
ROGER Avatar

Table I**Ratings of Feasibility, Acceptability, and Usability**

Question	Youth	Caregivers
	M ± SD	M ± SD
1. How useful would it be to have computerized surveys in clinic?	9.0 ± 1.5	8.9 ± 1.4
2. Overall, how honest do you think you could be in answering questions about your health using:		
☐ Face to face	9.1 ± 1.5	9.3 ± 1.5
☐ Paper and pencil survey	8.0 ± 3.1	8.8 ± 1.7
☐ Computer survey	9.6 ± 1.0	9.3 ± 1.5
	% endorsed	% endorsed
3. Do you think the information that you complete on a computer survey would be helpful to clinic staff and to your care?		
☐ No	8%	8%
☐ Yes	92%	92%
4. Do you prefer a computerized survey or paper/pencil format?		
☐ Computerized format	92%	100%
☐ Paper/Pencil format	8%	0%
5. What would make the computer survey more user-friendly?		
☐ Being able to use a touch screen instead of a mouse	100%	100%
☐ Talking with someone about the questions/answers	3%	31%
☐ More privacy/confidentiality	67%	46%
☐ Having parents/children complete the surveys together	73%	85%
☐ Have parents/children complete the surveys separately	70%	18%
☐ Having a report that you can take home	70%	82%
☐ Having a report that you can show clinic staff	55%	75%
☐ Being able to log-on and complete the survey at home	100%	83%
☐ Being able to log-on and see a graph that shows how I am doing	100%	83%
☐ Use ROGER or a similar character that kids can relate to	80%	82%

Note. Items were on a 10-point Likert scale, with 0 being low (e.g., not useful/honest at all) and 10 being high (e.g. very useful/honest)