Technology Access and Preferences for Smartphone App Intervention to Optimize Iron Chelation Adherence among Adolescents, Young Adults, and Parents of Individuals Receiving Chronic Transfusions: Cross-sectional survey

Paavani Reddy, Margaret Locke, Sherif Badawy

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Paavani Reddy[1, 2, 3*] MD; Margaret Locke[4*] MD; Sherif Badawy[1, 5*] MD, MS, MBA

[1]Lurie Children's Hospital Division of Hematology, Oncology, and Stem Cell Transplant Chicago US
[2]Massachusetts General Hospital Department of Psychiatry Boston US
[3]McLean Hospital Department of Psychiatry Belmont US
[4]Donald & Barbara Zucker School of Medicine at Hofstra/Northwell Department of Internal Medicine Hempstead US
[5]Northwestern University Feinberg School of Medicine Department of Pediatrics Chicago US
[*]these authors contributed equally

Corresponding Author:
Sherif Badawy MD, MS, MBA
Lurie Children's Hospital
Division of Hematology, Oncology, and Stem Cell Transplant
225 E Chicago Ave., Box # 30
Chicago
US

Abstract

Background: Iron chelation therapy (ICT) is an essential medication for people with hematological disorders requiring chronic transfusions to minimize the risk of iron overload, yet suboptimal adherence is prevalent. Widespread use of personal technology makes mobile health (mHealth) an attractive platform to promote adherence.

Objective: To examine access to mobile technology and preferences for an mHealth intervention to improve adherence to ICT.

Methods: A cross-sectional survey was administered through REDCap during packed red blood cell (pRBC) transfusion visits. Parents of children receiving chronic transfusions, as well as adolescents and young adults (AYAs) receiving chronic transfusions were enrolled between August 2018 and June 2019. Patients had to have a hematologic diagnosis requiring chronic transfusions, be on ICT, and be 12 years or older to complete the survey. Parents were required to have a child older than 24 months who met these criteria.

Results: A total of 60 participants were included (median age [IQR] 31.5 [20-39]; female, 66.7% [40/60]), with 29 parents and 31 patients. The most endorsed mHealth app features among all participants included laboratory monitoring (91.7%, 55/60), reminders to take ICT (83.3%, 50/60), and education about ICT (81.7%, 49/60). Parents' most endorsed features included laboratory monitoring (93.1%, 27/29), and education about ICT (86.2%, 25/29). Patients' most endorsed features included laboratory monitoring (90.3%, 28/31) and reminders to take iron chelation medication (90.3%, 28/31). There were no significant differences between parents and patients in their preferences, although there was a greater proportion of patients compared to parents who preferred positive feedback when taking medications as an app feature (87.1% vs. 68.96%, p =0.09).

Conclusions: Parents and AYAs reported a strong interest in multiple mHealth app features. Participants provided valuable insight into optimal strategies and preferred app features for developing a multifunctional technology-based behavioral intervention to promote ICT adherence.

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Authors: Paavani S Reddy, MD[1,2,3], Margaret Locke, MD[4], Sherif M Badawy, MD, MS, MBA[5,6]

Authors' Affiliations:
[1]Department of Medical Education, Northwestern University Feinberg School of Medicine, Chicago, IL, USA; [2]Department of Psychiatry, Massachusetts General Hospital Department of Psychiatry, Massachusetts General Hospital, Boston, MA, USA; [3]Department of Psychiatry, McLean Hospital, Belmont, MA, USA; [4]Department of Internal Medicine, Zucker School of Medicine at Hofstra/Northwell, Hempstead, NY, USA; [5]Division of Hematology, Oncology, and Stem Cell Transplant, Ann & Robert H. Lurie Children's Hospital of Chicago, IL, USA; [6]Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, IL, USA

Corresponding author: Sherif M. Badawy, MD, MS, MBA; Ann & Robert H. Lurie Children's Hospital of Chicago; 225 E Chicago Ave., Box # 30, Chicago, IL, USA; Email: sbadawy@luriechildrens.org; Phone number: 312-227-4836; Fax number: 312-227-9376

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Abstract

Background: Iron chelation therapy (ICT) is an essential medication for people with hematological disorders requiring chronic transfusions to minimize the risk of iron overload, yet suboptimal adherence is prevalent. Widespread use of personal technology makes mobile health (mHealth) an attractive platform to promote adherence.
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Keywords: thalassemia, sickle cell disease, medication adherence, iron chelation therapy, behavior change, technology access, mHealth

Introduction

Iron overload is the major cause of morbidity and mortality in transfusion dependent hematological disorders, such as thalassemia[1]. One of the cornerstones of treatment for refractory anemia is packed red blood cell (pRBC) transfusions. Over time, transfusions can lead to excess iron accumulation in the heart, liver, and spleen, among other tissues, leading to a wide array of complications, including endocrinopathies, cardiomyopathies, and hepatic failure.

Iron chelation therapy (ICT) is an essential medication for people with thalassemia and other hematological disorders requiring long-term red blood cell transfusion to minimize the risk of iron overload. Previous work has shown that adherence varies widely and is often suboptimal[2-5]. Suboptimal adherence to iron chelation medication is prevalent and has been associated with an increased risk of iron overload, resulting in increased morbidity, mortality, and healthcare utilization. Thus, interventions to improve ICT adherence are important to investigate and essential to improving morbidity and mortality.

Medication adherence is complex and multifaceted[6]. Studies of adherence among patients taking iron chelation medication often report multiple factors contributing to low adherence, and it is difficult to compare and establish rates of adherence among patients taking iron chelation medication[2-3]. One potential avenue to address and improve adherence to medications would be through the development of mobile health (mHealth) tools– the use of mobile and wireless applications (SMS text messaging, apps, wearable devices, remote sensing, social media etc.) in delivery of health-related services[7-8]. The most recent (2021) Pew Research Institute survey found that 97% of adult US residents owned a mobile phone, with 85% owning a smart phone[9]. Similarly, the vast majority of adolescents have access to digital devices, including smartphones (95%), and 97% of all adolescents reported using the internet daily[10]. However, while the Pew Research Institute surveys are designed to sample a population that reflects the demographics of the United States, it does not necessarily reflect the demographics of individuals and families of those with chronic medical conditions, such as thalassemia. It is important to ensure that pediatric patients, parents, adolescents, and young adults receiving chronic transfusions have access to technology when considering mHealth interventions.

Moreover, there are a variety of potential avenues and tools that can be integrated in mHealth interventions. Observational studies have shown that sharing healthcare experiences online can lead to decreased isolation, support, an exchange of coping strategies, and healthcare learning from shared experience[11]. There is also some evidence that adolescents who develop skills to monitor their symptoms and self-manage their health may experience improved outcomes in disease knowledge and adherence, specifically through text messaging and mobile phone applications in both healthy adolescents, as well as those with chronic health conditions[12-14]. A pilot study of a medication reminder app demonstrated the feasibility and potential usefulness of using mHealth in adolescents and young adults (AYAs) with chronic transfusions[15]. In addition to access to mHealth and efficacy of these features, it is important that mHealth interventions have high engagement as well. While adolescents in general are avid smartphone users, only 2% of teens report frequent usage of an mHealth app[16]. Thus, it is crucial that mHealth interventions are designed with accessibility and engagement in mind.

Involving users in the early development process has been shown to promote engagement[17-18]. User-centered app design is a method of designing mobile apps that begins with a needs assessment, followed by iterative cycles involving the intended end user. Apps involving end-user input

throughout the development, testing, and dissemination process are more likely to be perceived by users as useful, as well as easy to use[19].

Thus, this study is a needs assessment for an mHealth adherence app as the first step in a user-centered design process. First, we aimed to evaluate patients' and parents' access in technology-based (mHealth) interventions. Second, we aimed to assess interest and preferences for an mHealth intervention to promote ICT adherence. We hypothesized that AYAs and parents of children receiving chronic transfusion would have high interest in an mHealth app, and that AYAs and parents may have different preferences and priorities for mHealth. Ultimately, this study is the first step in developing an mHealth tool to promote medication adherence and optimize health outcomes among patients receiving chronic transfusions.

Methods

Recruitment

This is a cross-sectional single institution study. Participants completed a cross-sectional survey that was administered through RedCap using tablet computers during pRBC transfusion visits at a single institution. Eligibility criteria for patients included (1) having a hematologic diagnosis requiring chronic transfusions, (2) being on ICT, and (3) being at age 12 or older to complete the survey. Parents were required to have a child older than 24 months who met these criteria. Potential study participants (parents of children receiving chronic transfusions, as well as adolescents and young adults receiving chronic transfusions) were approached during transfusion appointments between August 2018 and June 2019. The Institutional Review Board at the Ann and Robert H. Lurie Children's Hospital of Chicago approved the study and all procedures were conducted in accordance with the current version of the Helsinki Declaration. Data were collected on electronic tablets through REDCap supported by the Northwestern University Clinical and Translational Sciences (NUCATS) Institute.

Study Measures

Our study instrument included 63 items assessing technology access, mHealth preferences, and demographics. These surveys were based on current literature investigating technology-based interventions and medication adherence among patients with chronic conditions for adult and pediatric populations, from previous studies conducted at our institution[20-24].

The technology access portion of the survey included 7 questions about access to electronic devices, as well as 8 questions about SMS text message and call limits, and home or school internet signal strength. The mHealth portion of the survey included 8 yes/no questions, 1 rank order question, and 6 multiple choice questions that evaluated interest in general mHealth features and notification preferences, which have been previously reported by studies at our institution[22,24].

Statistical Analysis

Descriptive statistics for categorical data were reported in frequencies and percentages. Chi square

tests were run to determine the significant associations among variables and different sub-groups. All tests were two-sided and a *P*-value <0.05 was considered statistically significant. Statistical analysis was conducted using Excel.

Results

Demographics and Technology Access

A total of 60 participants were included, with 29 parents and 31 patients (Table 1). The median age of participants was 31.5 (IQR 20-39 years), and 66.7% were female (40/60). The most common diagnoses included thalassemia (51.7% [31/60]), and sickle cell (18.6% [21/60]). Reported ICT treatments varied, with 65% taking deferasirox, oral formulation (39/60), 26.7% taking deferasirox, tablet-form (16/60), 8.3% taking deferiprone (5/60), and 5% taking deferoxamine (3/60). All participants' characteristics are summarized in Table 1. All parents and patients owned an electronic tablet, a smartphone, or both. Most parents and patients owned cell phones (96.6% [28/29] and 90.3% [28/31]), but tablet ownership was less pervasive (65.5% [19/29] and 32.3% [10/31]). Most parents and patients had unlimited plans for text messaging (93.1% [27/29] and 80.6% [25/31]) and data (72.4% [31/29] and 67.7% [21/31]), as well as fast home internet connection (82.8% [24/29] and 74.2% [23/31]).

Table 1. Participants' characteristics

	All (N=60)
Age (years), median [IQR]	31.5 [20-39]
Age group (years), n (%)	
Parents	29 (48.3%)
Patients	31 (51.6%)
Adolescents (12-17)	10 (16.7%)
Young adults (≥18)	21 (35%)
Female, n (%)	40 (36.7%)
Race/Ethnicity	
Black	16 (26.7%)
Asian	23 (38.3%)
Hispanic	4 (6.7%)
White	17 (28.3%)
Diagnosis, n (%)	
Thalassemia	31 (51.7%)
Sickle Cell	21 (18.6%)
Other hematology disorder [a]	8 (13.3%)
Iron chelation, n (%)	
Exjade (Deferasirox)	16 (26.7%)
Jadenu (Deferasirox)	39 (65%)
Ferriprox (Deferiprone)	5 (8.3%)
Desferal (Deferoxamine)	3 (5%)
Other medications	
Hydroxyurea (%)	1 (1.7%)
Penicillin (fl)	13 (21.7%)

Folic Acid (10^3/ml)	3 (5%)
Insulin	3 (5%)
Multivitamins	4 (6.7%)
Amiloride	3 (5%)
Others [b]	16 (26.7%)
Insurance, n (%)	
Private	34 (56.7%)
Public/Medicaid	18 (30%)
Unsure	3 (5%)
None	5 (8.3%)

[a]Other hematological disorders among participants included Sideroblastic Anemia (n=1, 1.7 %), Diamond-Blackfan Anemia (n=3, 5%), Congenital Dyserythropoietic Anemia (n=2, 3.3%), Fanconi Anemia (n=1, 1.7%), and Pyruvate Kinase Deficiency (n=1, 1.7%)

[b]Other medications included ibuprofen (n=1), betamethasone ointment (n=1), risedronate (n=1), levothyroxine (n=1), hormonal replacement therapy (n=1), medroxyprogesterone (n=1), wellbutrin (n=1), venlafaxine (n=1), enalapril (n=1), hydrocortisone (n=1), hydroxychloroquine (n=1), oral contraceptive pills (n=1), aspirin (n=1), unspecified medications (n=3)

Interest in mHealth Features

All 8 proposed mHealth features were endorsed by over 50% of participants [30/60], including parents [15/29] and patients [16/31] (Table 2). The median number of features endorsed by both parents and patients was 7 (IQR 6-8). The most endorsed mHealth app features among parents and patients included laboratory monitoring (91.7%, 55/60), reminders to take ICT (83.3%, 50/60), and education about ICT (81.7%, 49/60). In particular, parents' most endorsed features included laboratory monitoring (93.1%, 27/29), and education about ICT (86.2%, 25/29). Patients' most endorsed features included laboratory monitoring (90.3%, 28/31) and reminders to take iron chelation medication (90.3%, 28/31). There were no significant differences between parents and patients in their preferences, although a greater proportion of patients compared to parents preferred positive feedback in the form of encouraging messages when taking medications as an app feature (87.1% vs. 68.96%, p =0.09) (Table 2).

Table 2. Frequency of participants' reported interest in general mHealth features.

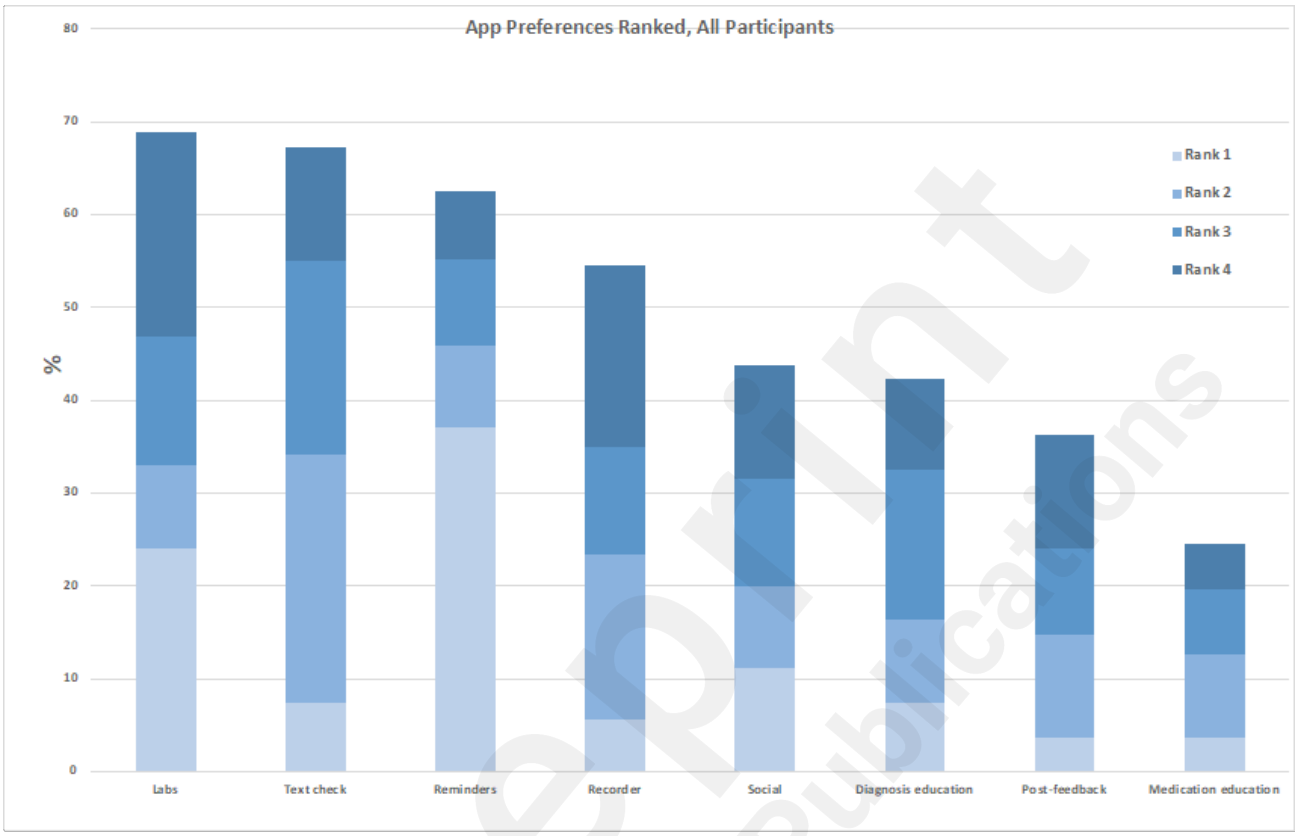
App Features	**All Participants** (n= 60)	***Parent*** *(n= 29)*	***Patient*** *(n=31)*	***P*-value**
Medication reminders, n (%)	50 (83.3%)	22 (75.9)	28 (90.3%)	0.13
Medication log, n (%)	45 (75%)	23 (79.3%)	22 (70.96%)	0.46
Positive feedback, n (%)	47 (78.3%)	20 (68.96%)	27 (87.1%)	0.09
Adherence text prompt, n (%)	48 (80%)	21 (73.4%)	27 (87.1%)	0.16
Social media, n (%)	39 (65%)	20 (68.96%)	19 (61.3%)	0.53
Diagnosis education, n (%)	45 (75%)	23 (79.3%)	22 (70.96%)	0.46
Medication education, n (%)	49 (81.7%)	25 (86.2%)	24 (77.4%)	0.38
Laboratory monitoring, n (%)	55 (91.7%)	27 (93.1%)	28 (90.3%)	0.70

The cumulative ranking of the proposed smartphone app features among parents and AYAs are summarized in Figure 1. Medication reminders (32% [8/29]) were most frequently ranked most important among parents, followed by the ability to review laboratory results (28% [7/29]), and social media features (12% [3/29]). Patients also most prioritized medication reminders (41.3%,

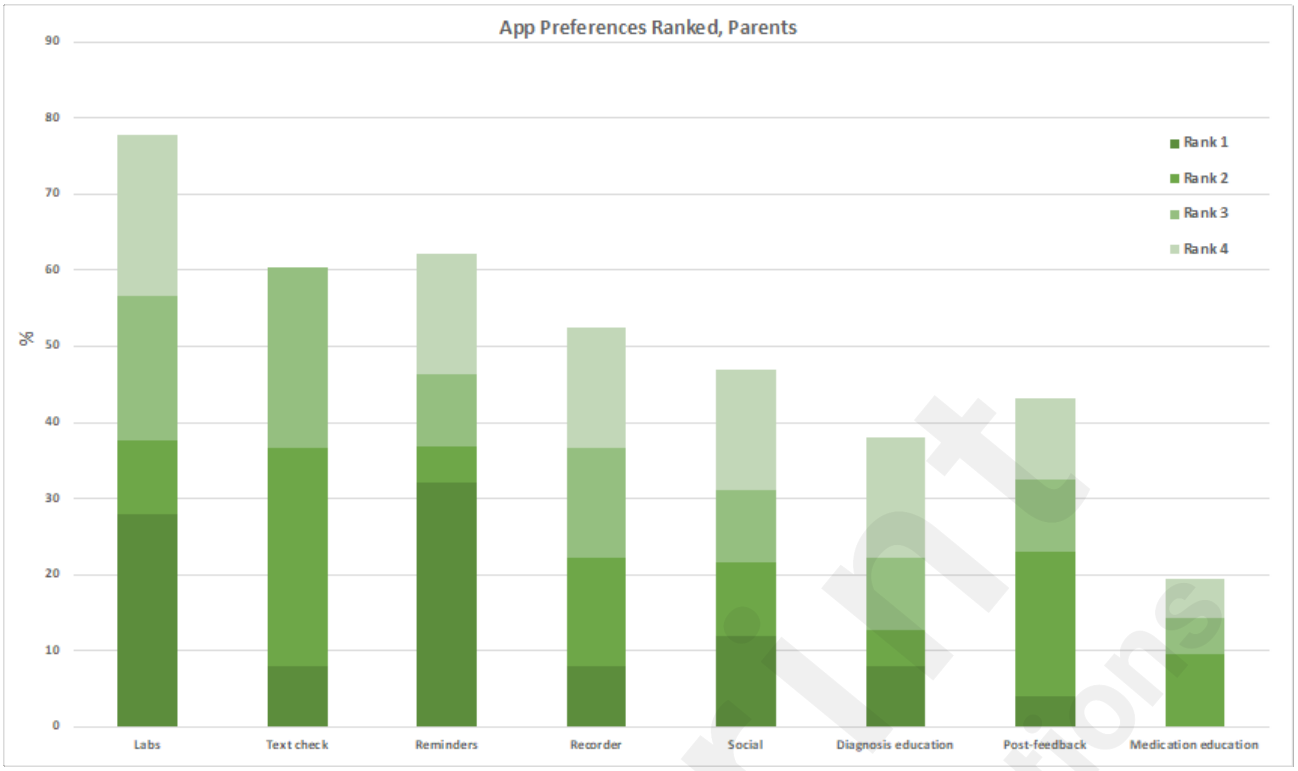
[12/31]), followed by laboratory results (20.7% [6/31]), and social media features (10.3% [3/31]).

Figure 1. Participants cumulative ranked preferences for a thalassemia smartphone application (app)

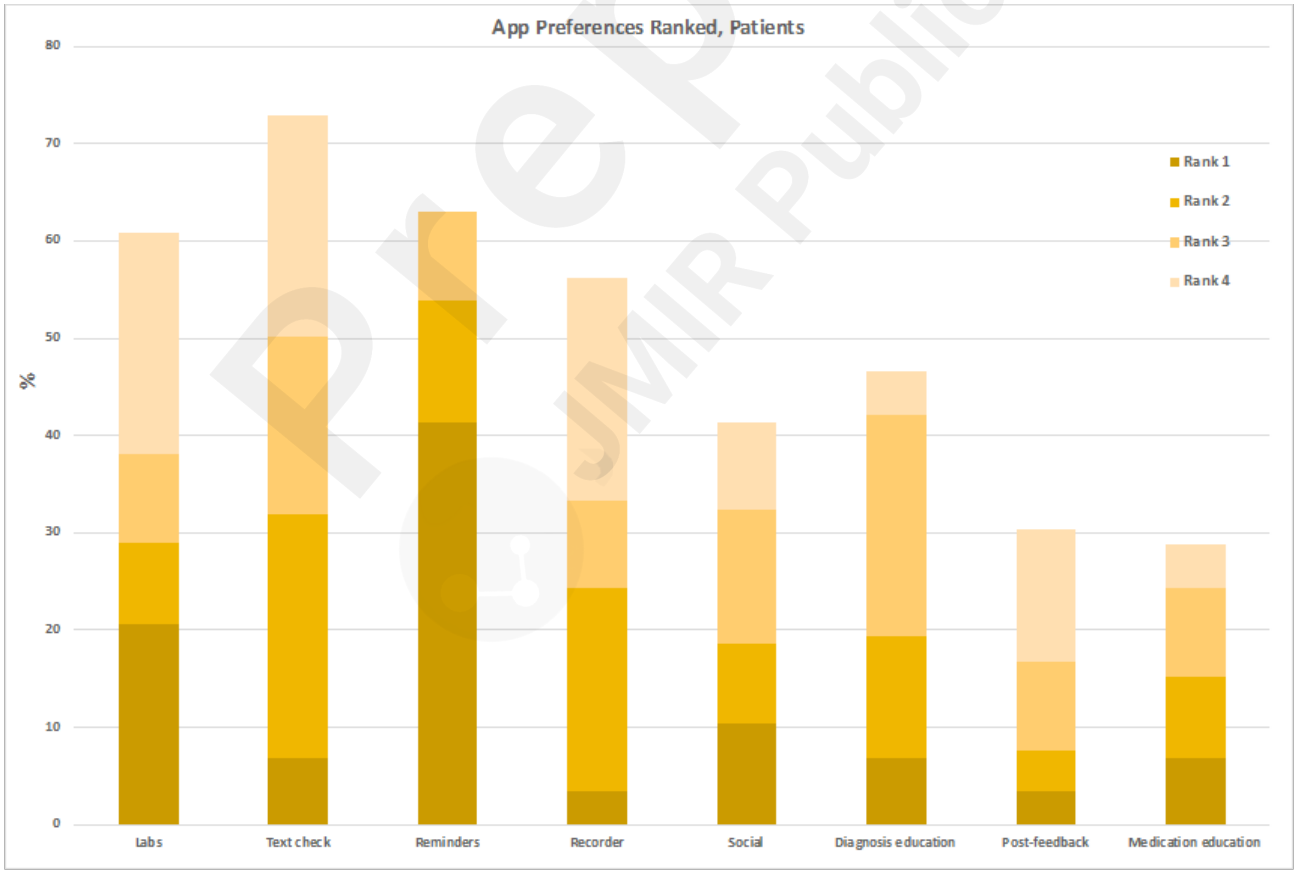
1a. All Participants



1b. Parents



1c. Patients



Discussion

Principal Results

Our participants' high rate of technology access is comparable to reports of the general population, and supports that mHealth interventions may be an accessible, useful tool to promote adherence[9-10]. Our study adds to the existing literature by demonstrating a strong interest in multiple mHealth app features by patients receiving chronic transfusions. Participants provided important insight into preferred app features for developing a technology-based behavioral intervention (mHealth app). These findings can help guide the development of an effective mHealth tool to promote ICT adherence for AYA with thalassemia or other chronic-transfusion-dependent conditions.

While there are some limited mHealth applications currently available, the strong interest from both patients and parents in mHealth features in our study suggests that there may be some features and tools that would be more beneficial and engaging to users than those that currently exist. This further highlights the importance of user-centered development in ensuring that these applications prioritize features that are of interest to the populations that are intended to use them. One international study in 2018 found that although there are currently many mHealth applications available for use, they often do not match patients' expectations due to lack of user-centered development[25]. Our study represents the starting point of user-centered design, assessment of patients' and parents' interest in mHealth interventions and features among patients taking ICT. User-centered design should continue throughout the phases of development, including creation, deployment, testing, implementation and dissemination[19].

Of the application features highlighted in our study, there was particularly strong interest in laboratory monitoring, medication reminders, and social media/virtual connections to other patients with transfusion-dependent illness. Of note, there was no statistically significant difference between the mHealth preferences of parents and patients surveyed, with a nonsignificant but slightly greater proportion of patients preferring positive feedback when taking medications compared to parents. Prior literature has often highlighted the ways in which barriers to adherence may vary from adolescence to adulthood, and the ways in which adolescents may have unique preferences for mHealth interventions due to their relative usage of technology compared to other age groups[26-28]. One possible explanation for the lack of discrepancy between the preferences of parents and patients could be that most participants had interest in multiple mHealth features with a median number of features endorsed as 7 out of 8. An mHealth tool with multiple features may be beneficial to both patients taking ICT and parents.

Our study had several strengths. We were able to provide a thorough evaluation of access to technology, assessing both access to multiple modes of technology, as well as barriers to technology usage, such as data plans and Wi-Fi access. Moreover, this study examined both patients' and parents' preferences for an ICT mHealth app, allowing us to effectively examine a group of all potential users of this mHealth intervention, while also comparing preferences. Lastly, our patient population was diverse, both racially/ethnically, and in terms of ICT therapy used, as well as in insurance status.

Limitations

There are several limitations worth noting in this study. Of note, this is a single institution study with a relatively small sample size. While our survey items have not been validated, they have been used in other published studies[22-23]. Additionally, since we adapted existing survey items, we did not provide an exhaustive list of potential mHealth interventions and application features. Lastly, we did not survey our participants about prior experience with mHealth applications, which may have been

helpful to note in participants' perceptions of mHealth and preferences for mHealth features.

Comparison with Prior Work

This study builds upon previous literature examining adherence interventions for patients taking ICT[2-4,15]. In particular, a 2017 study highlighted a pilot intervention utilizing a medication reminder app, and demonstrated the feasibility and potential usefulness of using mHealth in AYAs with chronic transfusions. Our study is focused more on the development stages of an mHealth intervention, particularly around getting user-centered feedback on which features might be preferred and promote adherence. Moreover, our study examined not only AYA's, but also parents, who are also a potential user-group of an mHealth intervention.

The results of this study are consistent with the literature on technology access and preferences among patients with other complex chronic conditions, including cystic fibrosis, diabetes, sickle cell, and acute lymphoblastic leukemia [22,24,29-31]. This further supports that an mHealth application with multiple features could be a promising tool to promote ICT adherence in patients receiving chronic transfusions.

Conclusions

In conclusion, parents and patients reported high accessibility to mobile technology. Overall, there was a high level of interest in mHealth interventions, as well as features specifically intended to promote medication adherence. These findings support an interest and need for the development of a user-centered mHealth intervention as a tool to promote medication adherence among patients with thalassemia and other conditions requiring chronic transfusions, as well as their parents. Parents and patients reported similar preferences for mHealth features, centered on medication adherence, education, and connection with the broader community of individuals requiring chronic transfusions and their families. In the future, continuing to center user experiences and feedback will be important in maximizing engagement and utility of an app as an intervention to improve adherence and healthcare outcomes among patients taking ICT.

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Conflicts of Interest

The authors have no relevant conflict or competing interests

Abbreviations

ICT: Iron chelation therapy
pRBC: packed red blood cell
AYA: adolescents and young adults
mHealth: mobile health

References

1. Cao A, Galanello R. Beta-thalassemia. Genet Med. 2010;12(2):61-76.
2. Reddy PS, Locke M, Badawy SM. A systematic review of adherence to iron chelation therapy among children and adolescents with thalassemia. Ann Med. 2022 Dec;54(1):326-342. doi: 10.1080/07853890.2022.2028894. PMID: 35103514; PMCID: PMC8812788.
3. Locke M, Reddy PS, Badawy SM. Adherence to Iron Chelation Therapy among Adults with Thalassemia: A Systematic Review. Hemoglobin. 2022 Jul;46(4):201-213. doi: 10.1080/03630269.2022.2072320. Epub 2022 Aug 5. PMID: 35930250.
4. Rofail D, Abetz L, Viala M, Gait C, Baladi JF, Payne K. Satisfaction and adherence in patients with iron overload receiving iron chelation therapy as assessed by a newly developed patient instrument. Value Health. 2009;12(1):109-117.
5. Porter J, Bowden DK, Economou M, et al. Health-Related Quality of Life, Treatment Satisfaction, Adherence and Persistence in β-Thalassemia and Myelodysplastic Syndrome Patients with Iron Overload Receiving Deferasirox: Results from the EPIC Clinical Trial. Anemia. 2012;2012:297641.
6. Peipert JD, Badawy SM, Baik SH, Oswald LB, Efficace F, Garcia SF, Mroczek DK, Wolf M, Kaiser K, Yanez B, Cella D. Development of the NIH Patient-Reported Outcomes Measurement Information System (PROMIS) Medication Adherence Scale (PMAS) PPA. 2020 Jun;Volume 14:971–983. doi: 10.2147/ppa.s249079
7. Borrelli B, Ritterband LM. Special issue on eHealth and mHealth: Challenges and future directions for assessment, treatment, and dissemination. Health Psychol. 2015 Dec;34S:1205–8. doi: 10.1037/hea0000323.
8. Radovic A, Badawy SM. Technology Use for Adolescent Health and Wellness. Pediatrics. 2020 May;145(Suppl 2):S186–S194. doi: 10.1542/peds.2019-2056G.
9. Pew Research Center Mobile Fact Sheet. 2021. Accessed January 3, 2023
10. Pew Research Center. Teens, Social media & technology 2022. Accessed January 3, 2023.
11. Naslund JA, Grande SW, Aschbrenner KA, Elwyn G. Naturally occurring peer support through social media: the experiences of individuals with severe mental illness using YouTube. PLoS One. 2014; 9 (10):e110171
12. Bal MI, Sattoe JN, Roelofs PD, Bal R, van Staa A, Miedema HS. Exploring effectiveness and effective components of self-management interventions for young people with chronic physical conditions: a systematic review.
13. Badawy SM, Kuhns LM. Texting and Mobile Phone App Interventions for Improving Adherence to Preventive Behavior in Adolescents: A Systematic Review. JMIR Mhealth Uhealth. 2017 Apr 19;5(4):e50. doi: 10.2196/mhealth.6837. PMID: 28428157; PMCID: PMC5415660.
14. Badawy SM, Barrera L, Sinno MG, Kaviany S, O'Dwyer LC, Kuhns LM. Text Messaging and Mobile Phone Apps as Interventions to Improve Adherence in Adolescents With Chronic Health Conditions: A Systematic Review. JMIR Mhealth Uhealth. 2017 May 15;5(5):e66. doi: 10.2196/mhealth.7798. PMID: 28506955; PMCID: PMC5447825.
15. Leonard S, Anderson LM, Jonassaint J, et al.. Utilizing a novel mobile health "'selfie' application to improve compliance to iron chelation in pediatric patients receiving chronic transfusions. J Pediatr Hematol Oncol. 2017;39(3):223–229
16. Wartella E, Rideout V, Montague H, Beaudoin-Ryan L, Lauricella A. Teens, Health and Technology: A National Survey. MaC. 2016 Jun 16;4(3):13–23. doi: 10.17645/mac.v4i3.515
17. Perski O, Blandford A, West R, Michie S. Conceptualising engagement with digital

behaviour change interventions: a systematic review using principles from critical interpretive synthesis. Transl Behav Med. 2017 Jun;7(2):254–267. doi: 10.1007/s13142-016-0453-1

18. Blandford A, Gibbs J, Newhouse N, Perski O, Singh A, Murray E. Seven lessons for interdisciplinary research on interactive digital health interventions. Digit Health. 2018;4:2055207618770325. doi: 10.1177/2055207618770325.
19. Schnall R, Rojas M, Bakken S, Brown W, Carballo-Dieguez A, Carry M, Gelaude D, Mosley JP, Travers J. A user-centered model for designing consumer mobile health (mHealth) applications (apps) J Biomed Inform. 2016 Apr;60:243–51.
20. Badawy SM, Kuhns LM. Texting and Mobile Phone App Interventions for Improving Adherence to Preventive Behavior in Adolescents: A Systematic Review. JMIR Mhealth Uhealth. 2017 Apr 19;5(4):e50. doi: 10.2196/mhealth.6837.
21. Badawy SM, Barrera L, Sinno MG, Kaviany S, O'Dwyer LC, Kuhns LM. Text Messaging and Mobile Phone Apps as Interventions to Improve Adherence in Adolescents With Chronic Health Conditions: A Systematic Review. JMIR Mhealth Uhealth. 2017 May 15;5(5):e66. doi: 10.2196/mhealth.7798.
22. Badawy SM, Thompson AA, Liem RI. Technology Access and Smartphone App Preferences for Medication Adherence in Adolescents and Young Adults With Sickle Cell Disease. Pediatr Blood Cancer. 2016 May 04;63(5):848–52. doi: 10.1002/pbc.25905.
23. Badawy SM, Cronin RM, Hankins J, Crosby L, DeBaun M, Thompson AA, Shah N. Patient-Centered eHealth Interventions for Children, Adolescents, and Adults With Sickle Cell Disease: Systematic Review. J Med Internet Res. 2018 Jul 19;20(7):e10940. doi: 10.2196/10940.
24. Heneghan MB, Hussain T, Barrera L, Cai SW, Haugen M, Morgan E, Rossoff J, Weinstein J, Hijiya N, Cella D, Badawy SM. Access to Technology and Preferences for an mHealth Intervention to Promote Medication Adherence in Pediatric Acute Lymphoblastic Leukemia: Approach Leveraging Behavior Change Techniques. J Med Internet Res. 2021 Feb 18;23(2):e24893. doi: 10.2196/24893.
25. Tarricone R, Cucciniello M, Armeni P, Petracca F, Desouza KC, Hall LK, Keefe D. Mobile Health Divide Between Clinicians and Patients in Cancer Care: Results From a Cross-Sectional International Survey. JMIR Mhealth Uhealth. 2019 Sep 06;7(9):e13584
26. Webb TL, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res 2010 Feb 17;12(1):e4 [FREE Full text] [doi: 10.2196/jmir.1376] [Medline: 20164043]
27. Badawy S, Thompson AA, Kuhns LM. Medication Adherence and Technology-Based Interventions for Adolescents With Chronic Health Conditions: A Few Key Considerations. JMIR Mhealth Uhealth 2017 Dec 22;5(12):e202 [FREE Full text] [doi: 10.2196/mhealth.8310] [Medline: 29273573]
28. Hanghøj S, Boisen KA. Self-reported barriers to medication adherence among chronically ill adolescents: a systematic review. J Adolesc Health 2014 Feb;54(2):121-138. [doi: 10.1016/j.jadohealth.2013.08.009] [Medline: 24182940]
29. Hilliard ME, Hahn A, Ridge AK, Eakin MN, Riekert KA. User Preferences and Design Recommendations for an mHealth App to Promote Cystic Fibrosis Self-Management. JMIR Mhealth Uhealth. 2014 Oct 24;2(4):e44. doi: 10.2196/mhealth.3599.
30. Cafazzo JA, Casselman M, Hamming N, Katzman DK, Palmert MR. Design of an mHealth app for the self-management of adolescent type 1 diabetes: a pilot study. J Med Internet Res. 2012 May 08;14(3):e70. doi: 10.2196/jmir.2058.
31. Frøisland DH, Arsand E, Skårderud F. Improving diabetes care for young people with type 1 diabetes through visual learning on mobile phones: mixed-methods study. J Med

Internet Res. 2012 Aug 06;14(4):e111. doi: 10.2196/jmir.2155.

Supplementary Files

Figures

Participants cumulative ranked preferences for a thalassemia smartphone application (app).