An Ecosystem of Digital-Health Solutions is Needed for Teens with Chronic Conditions Transitioning to Self-management and Independence

Abstract

Background
Chronic disease management is critical to the quality of life for both teen patients with chronic conditions and their caregivers. However, current literature is largely limited to a specific digital-health tool, method, or approach to manage a specific disease. Guiding principles on how to use digital tools to support the transition to independence are rare. Considering the physiological, psychological and environmental changes that teens experience, the issues surrounding the transition to independence are worth investigating to develop a deeper understanding to inform future strategies for digital interventions.

Objective
The purpose of this study is to inform the design of digital-health solutions by systematically identifying common challenges among teens and caregivers living with chronic disease(s).

Method
Chronically ill teens (n=13) and their caregivers (n=13) were interviewed individually and together as a team. Verbal and projective techniques were used to examine teens’ and caregivers’ concerns in-depth. Recorded and transcribed responses were analyzed thematically to identify and organize emerging patterns.

Results
Teens and their caregivers identified ten challenges and suggested technological solutions. Recognized needs for social support, access to medical education, symptom monitoring, access to healthcare providers, and medical supply management were the predominant issues. The envisioned ideal transition included a five-component solution ecosystem in the transition to independence for teens.

Conclusion
This novel study systematically summarizes the challenges, barriers, and technological solutions for teens with chronic conditions and their caregivers as teens transition to independence. A new solution ecosystem based on the ten identified challenges will guide the design of future implementations to test and validate the effectiveness of the proposed five-component ecosystem.

Keywords: Adolescent Health; Chronic Disease; Self-management; teen health; Transition to Adult care; Qualitative Research; Chronic Disease Management; Digital-health; Technology-based Solutions

Introduction
Self-management for those with chronic diseases is a significant component for maintaining wellbeing. Nationally, chronic diseases are causing 7 in 10 deaths of US citizens every year, and the large portion of national health care costs were generated by chronic disease patients [1]. Hence, self-management sustainability greatly impacts national healthcare cost reductions while increasing the individual’s wellbeing and financial independence. Digital solutions developed in recent years assist patients in self-management. Youth especially use healthcare management technologies (e.g., telehealth and mobile health) enabling greater self-management [2].

Digital solutions in chronic disease management
Digital solutions and mobile health (mHealth) applications regarding chronic disease management and behavioral change for teens have been widely discussed with new solutions proposed in the literature. Hamine et al.’s [3] review on self-management of diabetes, cardiovascular disease, and chronic lung diseases concluded mHealth can potentially facilitate adherence to chronic disease management. Fedele et al. [4] argued mHealth interventions are also a “viable” approach in behavioral change interventions in young population (< 18 years). However, adopting technology to assist teens in transition is a work-in-progress. Huang et al. [5], tested a web-based and text-delivery disease management
application and reported that technology can be a useful and cost-effective solution as a transition intervention. They also discussed that use of communication technologies (i.e., mobile phone calls, SMS, email, and VoIP) promoted engagement, relationship, and trust between teens and healthcare providers [6]. These studies support the use of digital solutions and demonstrate a promising next step in chronic disease management technology. In another case, Holtz et al. [7] developed and tested a patient-centered mobile application using focus group interviews with teens having Type-1 Diabetes and their parents. Participants reported that they thought that the mobile application would help to improve communication among family members. Many of these studies focused on a specific delivery modality of digital interventions. Our study, in contrast, started with a broader inquiry of patient-centered needs, and then explored relevant technological solutions.

However, given the physiological, psychological and environmental changes that teens experience in chronic disease management, digital solutions may fail to keep up with expectations. Slater et al. [2] underlined that mHealth interventions have failed to integrate into real-world settings and adoption practices. The impact of using self-management digital communication tools on relationships among parents, teens, and HCP was unclear [8]. Furthermore, the evidence in the literature is limited on caregiver and teens in transition to independence, with no identified studies on digital communication between caregivers and teens in transition [8].

To improve the delivery of healthcare among teens transitioning to independence with chronic illnesses, Nationwide Children’s Hospital (NCH) undertook a quality improvement project. We employed a patient-centered approach to identify and better understand the core problems of chronic disease management and to seek solutions to permit the teen to transition to independence. Our specific aim was to generate a roadmap for chronically-ill teens to gain independence.

Methods

Data collection methodology, included generative tools utilizing verbal and projective techniques to collect rich data from participants regarding their needs and expectations [9,10]. Our study questions focused on “What common challenges do teens and their caregivers face in preparation for the transition to independent health management?” and “What digital solutions and opportunities would help to overcome the challenges and barriers?” To address these questions, we first identified the challenges, barriers and gaps during the life journey, and then envisioned digital solutions and opportunities to facilitate a successful transition to independence and self-management. Thematic analysis was employed to identify challenges, opportunities, and barriers teens and caregivers faced and the desired solutions at strategic times on their journey [11]. Thematic analysis is a commonly used methodology to identify and analyze patterns within qualitative data, and report the findings [12]. As defined by Braun and Clarke [12], thematic analysis includes the following progression: 1) familiarizing with the data, 2) generating
initial codes, 3) searching for themes, 4) reviewing/refining themes, 5) defining and naming themes, and 6) reporting the findings.

**Participants**
An independent recruiting agency selected participants based on the following inclusion criteria: (1) age 13-18, (2) a minimum of one chronic condition for more than 6 months, and (3) medication taken multiple times a day. The NCH patient network also supported this recruitment process. During a telephone invitation patients and caregivers were informed on voluntary participation, study goals, and financial compensations for their time. Subsequent interviews were held on NCH’s main campus. The study was approved by NCH as a quality improvement project and was not subject to the Institutional Review Board (IRB).

The study enrolled 13 teens with chronic conditions and their caregivers (n=13). Patient ages ranged from 13 to 18 years. Chronic conditions included at least one of the following diseases: type 1 diabetes, cystic fibrosis, epilepsy, and attention deficit hyperactivity disorder (ADHD). Most participants lived with the chronic condition for more than 5 years (Table 1).

<table>
<thead>
<tr>
<th>Demographics</th>
<th># of patients</th>
<th>% of patients</th>
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<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11-13</td>
<td>2</td>
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<tr>
<td>14-15</td>
<td>4</td>
<td>31%</td>
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<tr>
<td>16-18</td>
<td>7</td>
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<tr>
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</tr>
<tr>
<td>Female</td>
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<tr>
<td>Chronic condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 1 Diabetes (T1D)</td>
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</tr>
<tr>
<td>Cystic Fibrosis (CF)</td>
<td>2</td>
<td>15%</td>
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<tr>
<td>Epilepsy</td>
<td>3</td>
<td>23%</td>
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<tr>
<td>ADHD</td>
<td>4</td>
<td>31%</td>
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### Data collection and analysis

The aim was to develop an in-depth understanding of each participant’s experience starting from pre-diagnosis. Each interview commenced with a brief introduction of the study, including goals, agenda, and roles.

The first activity began with the review of the homework assignment (short reflective exercises completed prior to the interviews). To encourage free expression, concurrent sessions were scheduled for this first activity, separating teens and their parents (Figure 1). Next, the teen and caregiver worked together to envision an ideal journey that depicts the teen’s successful transition to independent management of their therapy. To promote their participation, a canvas outlining the stages and tools was used, which participants were able to follow the process as well as to type, draw and elaborate their opinions (Multimedia Appendix 1).

The second activity was a joint session with the teen and caregiver. Together, each pair shared their current experience and ideal state, identified overlapping experiences and differences, technology adoptions, challenges, opportunities, and expectations in line with the transitioning. An additional canvas was presented to be used for outlining ideal transition journey (Multimedia Appendix 1). The second session, which focused on technological solutions, discussed the following: the use of technology applications (apps) in care, how they are used, the benefits and drawbacks, what are the apps they wished for, what is needed, why they are not using the technology. The interview session ended with a closure talk and soliciting final thoughts from participants.

**Figure 1. Interview process**

At least 2 researchers attended each session, which was recorded. Researchers served as moderator and assistant/note taker. All recordings were transcribed, and aggregated with memos and observational notes. Information on the canvases, recordings and notes were analyzed by thematic analysis. The combination of information sources from both teens and caregivers increased the richness of the data acquired. Figure 2 summarizes data collection, analysis and creation of themes and ecosystem process in this study.

<table>
<thead>
<tr>
<th>Length of time since diagnosis</th>
<th>Count</th>
<th>Proportion</th>
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<tbody>
<tr>
<td>6 months - 2 years</td>
<td>1</td>
<td>8%</td>
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<tr>
<td>2 - 5 years</td>
<td>1</td>
<td>8%</td>
</tr>
<tr>
<td>5 - 10 years</td>
<td>9</td>
<td>69%</td>
</tr>
<tr>
<td>+ 10 years</td>
<td>2</td>
<td>15%</td>
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</table>
Findings and Discussions

Themes - Challenges and Opportunities

Thematic analysis applied to information collected from teens and caregivers resulted in 10 themes that identify challenges and opportunities during the transition to independent disease management. All patients and caregivers were frequent smartphone users, using at least 2 apps weekly. When talking about challenges, participants also spontaneously suggested some digital opportunities. Thus, we also include self-reported technology solutions here.

1. Lack of social support and communication

**Key challenges and barriers.** Teens and caregivers reported that in a crisis, they cannot manage their condition without the understanding and help of others, (e.g., teachers, school nurses, classmates, coaches, and extended family). However, others frequently are not informed on or misunderstand their condition or are ignorant of how to offer relevant assistance. Some parents realize the core issue.

“Educating her [the teen’s] core group of friends was the best thing we could do for her because they know what she needs when mom isn’t around.”
(Epilepsy Caregiver)

Caregivers also reported that they often have contentious relationships with school nurses and administration. Some parents perceive that schools resist providing equal opportunity to children with chronic conditions.

“When we got into the school district that we’re in now, like, 3rd Grade, they wanted to diagnose [my child] with ADHD ...one of the teachers said, ‘You need to medicate your child.’ And I said, ‘You need to learn how to teach my child.’” (ADHD caregiver)

In addition, tools are needed that facilitate communication between Healthcare providers (HCPs), caregivers, and school nurses to assist all healthcare givers in managing updates in a teen’s care. Support in rural areas can be even more challenging. Families who live in rural areas have fewer support groups and resources available. Traveling nurses in rural schools are frequently not available. Thus, school nurses who may only be available one day a week, are not a sufficient support system.
**Digital Opportunities.** Participants identified several technologies that could help fill in for their lack of support, which include

- An audio, video, or text tutorial sent to caregiver (e.g., mom/school/nurse/coach) on how to manage a health crisis.
- A real-time instructional video to educate witnesses/friends about how to help in a crisis (when the crisis is happening).
- Prescription updates sent digitally to the school nurse.
- Tools that simplify coordination between caregiver and school nurse.
- A tool that will give coaches or teachers real-time alerts or symptom reading skills so they will know to pull the teenager out of the game or class, and ensure that they get help.

### 2. Managing social stigma

**Key challenges and barriers.** Teens did not want to be labeled as a sick person nor draw too much attention at school, which may lead to feeling isolated, ostracized, or depressed. Depression may also induce them to skip their therapy at school, no matter how urgently needed, to defend against being seen as different. Labels like “sick person” may cause peers to misconstrue a teen’s abilities and limitations and also lead to hurtful comments, judgements, and unwanted advice. These misconceptions disrupt developing trusting friendships that could provide needed support.

“The first grand mal seizure happened in school in front a lot of her classmates, since then she feels awkward and ashamed of the condition because no one there gets what she has.”

**Digital Opportunities.** Teens and caregivers suggested that education and communication technologies could develop or enhance peer awareness:

- Educational tools: To alleviate the social stigma teens with chronic disease may face with peers, some teens suggested having a short video ready on a phone app to inform peers in simple language
  - What the chronic diagnosis is and means.
  - How it affects the diagnosed teen.
  - How peers can be respectful of the teens’ struggles with the disease.
- Encouraging Communications: A digital platform that facilitates sharing with younger teen patients’ positive stories of older patients overcoming hurdles to help overcome depression and anxiety.

### 3. Access to education

**Key challenges and barriers.** Following diagnosis, caregivers are frequently frantic to understand the disease and its short- and long-term implications. The most common question asked is, “How will my child’s diagnosis and treatment impact
their lifestyle and the family’s?” Caregivers are looking for the right information at the right time in the right dose. For instance, soon after their child’s T1D diagnosis, a caregiver joined a Facebook group hoping to find tips and support. They were devastated when other caregivers were discussing the potential long-term effects and worst-case scenarios. The group didn’t realize someone new was present in the conversation. During the diagnostic and initial adjustment phases, caregivers are uncertain where to find trustworthy, authoritative sources of information and frequently get misguided or insufficient information.

“You know, you turn to the Internet, parents of kids with diabetes, which is helpful in some ways with some practical questions but, in other ways, frightening because a lot of...I finally had to like exit because it was a lot of moms that were really just really scared.” (T1D caregiver)

“No one was telling me anything...I mean I knew I had stuff wrong with me but no one was telling me what it was or what it meant or what that means for the rest of my life.” (ADHD Teen)

**Digital Opportunities.** In their quest of knowledge, caregivers reported technological solutions that would help to facilitate the access to education they are looking for:

- **Pre-categorized discussion groups:** Allows the caregiver to match what they are looking for before they get caught up in topics that are not helpful.
- **Pre-approved, credible information sources (e.g., reputable clinics, local hospitals, their doctor):** Provides access to reliable information when they need it the most (e.g. when symptoms don’t make sense and caregivers want access to tips). They don’t want to browse through thousands of sites to find key information.
- **A tool that helps compare efficacy in competing manufacturers (e.g., in the case of diabetes, commercial options in medications or food brands).**

## 4. Symptom monitoring and support

**Key challenges and barriers.** The initial adjustment period is rife with triggers, which frequently catch caregivers and teens off guard and can lead to full on symptoms. Without timely support, symptom onset causes significant distress of being overwhelmed or unprepared. Teens are looking for ways to get immediate help with their symptoms without having to call their caregiver or an HCP. Avoiding hospitalization is certainly another key goal for the family.

Caregivers and teens struggle with how to deal with the sudden symptom onset, especially at night, or when the teen is away from home or the caregiver. Both teens and caregivers are diligently seeking pre-emptive alerts of a healthcare crisis. For instance, one participant caregiver reported that she constantly wakes up in the middle of the night to double-check her teen’s blood sugar. A mother of another teen
fears a Sudden Unexpected Death in Epilepsy (SUDEP) crisis known to occur overnight with people who live with epilepsy.

In addition to unmet needs regarding symptom monitoring, teens also desire actual symptom relief or advice when away from their caregiver or other support. Like this caregiver who had a son with ADHD and anxiety:

“I [caregiver] said, 'Are you really anxious about this?' And he [teen] said, 'Yeah. Why?' And I said, "Because you have scratches." So, having an app or some sort of technology that could be like, "Hey, you're kind of, digging your...a hole in your arm. Can't you stop doing that?" Like, it would be awesome. So, if he was able to be like, "Oh, I'm scratching. I should put that in. That's happening." And so now he knows when it happens, and we can talk about what was going on when it happened. “

**Digital Opportunities.** Participants outlined the technologies that would support them in symptom monitoring:

- A symptom trigger tracker which gives advance notice to the caregiver when symptoms may be developing.
- Voice activated tools (like Alexa, Siri, or Google assistant) to orally report and record symptoms (e.g., “begin timing of seizure”) or have a technology to automatically begin video-recording the episode for future reporting to the HCP.
- Tools that capture potential triggers or patterns over time that are unique to each teen to prompt early responses or preemptive actions.
- Families dealing with diabetes, cystic fibrosis, and epilepsy especially desire night monitoring in the form of a Smartwatch or clothing/wearable scanner. These devices could sound an alarm when vitals suggest a crisis is imminent or send automatic phone or text messages that warn and/or report to teen, doctor, and/or caregiver, simultaneously.

**5. Safety during driving**

**Key challenges and barriers.** Caregivers have a constant fear that their teen may have a dramatic, medical event while driving. Caregivers mistrust their teen's judgement if they are driving when an emergency occurs.

“So, if something could alarm her to sit down and be safe, you know. And or appear where she’s driving, and to stop. Stop the car, pull over. Don’t go any further. And I wouldn’t care what form it would be in, if it would be a piece of clothing, if it would be the watch, if it would be, you know, a kind of, like, an earpiece, like those things that people use, a...not a GPS, Bluetooth. That’s it. Something to make her stop what she’s doing.” (Epilepsy caregiver)
Digital Opportunities. Caregivers shared several technological solutions that may help to reduce risk when driving:

- Technology to prevent teens from driving if they’re at risk of a medical event because symptoms aren’t under control, e.g., similar to a breathalyzer that stops someone from driving under the influence.
- Tools that help avoid the event that cause the teen to lose control when driving such as extreme low blood sugar, seizures, and difficulty staying attentive.
- Wearable technology in jewelry, clothing, or a watch similar to an emergency button in the car. When pressed, the device transfers key health information to first responders or other passengers.
- Technology that records the teens driving activity. Records can be used to differentiate if an accident was due to their condition or poor judgement.

6. Access to HCPs

Key challenges and barriers. Issues accessing HCPs are numerous and varied. Key barriers include distance to hospital, scheduling problems (cancellation, wrong scheduling), responsiveness to requests and questions, lack of integration and consistency among multiple providers, and communication issues with/among HCPs.

“[Doctors] don’t listen to me. I called, I paged them that night because she still couldn’t walk after two and a half hours. She had hit her head on the wall and then the floor, and I paged neurology after the first one and they were like, “Oh, well just increase her meds.” They don’t want to see her, they don’t want to do anything else. They just want to increase her meds. I was livid.”
(Epilepsy caregiver)

Patients and caregivers that need to travel long distances, or frequent visitors with scheduling issues suffer the most, which leads to delayed healthcare services. Currently, communication with doctors is based on what the caregiver or teen can recall without written instructions. Further, no significant communication usually occurs between visits to the HCP. However, teens are willing to text/communicate directly with their HCP to bridge that gap.

Digital Opportunities. Technological solutions suggested were as follows:

- A 24-hr text line to healthcare providers - not necessarily their own HCP - but an HCP they can trust and ask general questions.
- A real-time decision-making tool to answer questions like, “I am going to work-out for 2 hours. What snack may be good?”
- A channel where teen and caregiver can contact an HCP expert and get general advice for non-critical situations without waiting until the next HCP’s appointment.
• Caregivers need a pre-appointment tool so teens can prepare questions before going to the appointment.
• Telemedicine to improve the access to care.

7. Relationship between caregiver and patient

Key challenges and barriers. The caregiver has a potential to be the “bad guy” since they take on the responsibility to remind the teen regarding proper management of their diagnosis. Because teens struggle with medication compliance, caregivers constantly remind teens to take medications. Conflicts over compliance may cause relationship problems. Some teens who feel overwhelmed with the therapy may lie to their caregivers. This situation, besides being detrimental to their therapy management, may cause the caregiver to mistrust the teen.

“Just when you think you got it...Everybody was really trying their hardest, and that’s when I’m finding the meds being hid. And it’s like, ‘I thought we had finally had a breakthrough and now defeated again,’ back to square one.” (ADHD Caregiver)

Digital Opportunities. Communication technologies, which assume the reminder-police role may help to increase the strength of the relationship between teen and caregiver:

• Caregivers wish that technology could deliver news, reminders, and directions so they didn’t have to be the “nagger.”
• Teens want improved and remote communication between caregiver and themselves when they first move out of the home (e.g., college).
• A tool to allow caregiver and teen to collaborate on a daily checklist that will help with reminders but also provide a way for caregivers to check in instead of verbally asking multiple times a day. Teens believe this tool will help improve their relationship with the caregiver.
• A tool that offers caregivers objective proof that the teen has done their therapy (e.g., a vitals readout, video footage of the teen completing therapy related activities).
• A “Virtual mom”. When the patient desires, they can give caregiver a real-time readout of vitals or other statistics that will help double-check decision making and make check-ins easy.

8. Long-term perspective

Key challenges and barriers. Caregivers perceived that their teen tends to think in the moment without perceiving how their actions and choices can have a negative impact on their therapy path. In addition to gaining life skills and understanding as
any normal teen, teens with a chronic medical condition have the extra challenge of learning about different circumstances caused by their condition.

“I worry if my son understands that how the choices he makes now will affect his long-term health. He has his typical teen attitude of resisting our instructions, but it will have a big impact on his future.” (CF caregiver)

**Digital Opportunities.** Technology to help develop a right mindset for better decision making was requested.

- Decision assistance tools: to help teens understand how choices today affect long-term health.
- Technology to visually demonstrate how good choices today add up long term.
- Scenario tools that help teens think through situations specifically related to their condition and prompt them to be proactive about proper management.

9. Supply management

**Key challenges and barriers.** Teens don’t want to be burdened with keeping track of their supplies (e.g., ordering, and maintaining an emergency stash), especially when at college. Some teens didn’t have access to school nurses as these nurses serve more than one school on any given day. Thus, when an emergency supply is needed, a backup is not available (e.g., students with T1D at rural schools).

Parents expressed feeling overwhelmed managing the medication supply aspect of care. In addition to managing their own busy schedules, they also carry the burden of keeping an inventory of supplies and medications. Families with several children or with a teen with multiple conditions, face greater challenges in managing supplies.

“I have a hard-enough time keeping up with all their school activities and appointments. It’s overwhelming to keep up with all the medications and making sure we have all the refills at the right time for each of my children.” (Epilepsy Caregiver)

**Digital Opportunities.** Teens and caregivers shared their ideas about technology that could help.

- Inventory tools: to assist in tracking and to alert caregivers when supplies are low.
- Smart ordering, delivery, and storage for a seamless ongoing supply. This tool could ease the transition to college or away from home.
10. Financial struggles

Key challenges and barriers. Caregivers are commonly overwhelmed with complex insurance policies and health care coverages. While they suspect they may not have the optimal coverage, they lack time or expertise to compare or assess options. For example, despite long-term use, they may experience sudden loss of access to a drug or an important medical supply. Solving this problem can be time-consuming and anxiety-provoking. Finances are not a teen stresser at this stage.

“Insurance, we had to adapt to the Ohio systems. Well, it’s the secondary insurance that was really the problem...I’ll just say, secondary state-assisted insurance, essentially, changed. This is very stressful.” (CF caregiver)

Further, caregivers are aware that some medical technologies are limited by insurance’s willingness to pay and because demand exceeds supply. They also wish to tap into the insurance navigation expertise they believe exists among the professionals at the hospital. In that regard, caregivers would like to rely on the hospital to give advice on getting the best out of their insurance or choosing the best insurance considering the chronic conditions they have.

Digital Opportunities. Caregivers expressed their expectations on technology-based financial decision support.

- A digital concierge-type service to better compare options and maximize coverage.
- Digital tools to improve the price transparency in care.

An ecosystem of technology solutions is needed to facilitate an ideal transition

In this study, once we identified with teens with chronic conditions and their caregiver the characteristics of their specific challenges in their healthcare managements, we used the participant’s inputs to suggest technological solutions and opportunities that could facilitate the transition to independence. Our patient-centered approach helped to identify some digital opportunities that could assist teens and caregivers achieving an ideal transition. The following five solutions are synthesized from the ideal experience activity that the patient and caregiver collectively envisioned. To support each proposed solution, we also include examples from the current literature.

1. The Teen-Caregiver Communication. A new platform (e.g., device, app, software) that would provide several times a day support and cushioning in communication between caregiver and teen during early transition. This platform would act as a bridge by providing a collaborative, task-sharing platform with a built-in reward system. However, the platform should also evolve to help the teen expand their support network while keeping the caregivers in the loop through weekly or monthly reporting.
Current Implementations: Researchers from Michigan State University proposed a mobile app, MyT1D Hero, to create a communication platform among teens with type-1 diabetes and their parents to support self-management [7].

2. Education and Tracking. This integrated platform would provide a channel of daily dose of age-appropriate education and information tracking for the teen and support the caregivers in their daily decision making. The focus at this early stage is helping the teen understand their body, their disease, symptoms, and triggers. Later in the transition when teens start making therapy decision on their own, the platform needs to evolve into becoming a coach.

Current Implementations: The gamification concept has been used to educate kids and parents for managing diabetes [13], and for tracking the teen’s condition [14,15].

3. Teen/ Caregiver and HCP Communication Bridge. This platform needs to provide seamless communication between HCP, caregivers, and school to lessen the additional burden on caregivers and keep everyone on the same page. The teen begins to communicate more with their HCP early on to help build trust, while the caregiver continues to be the main point-of-contact and influence in the early stage.

Current Implementations: A communication platform among caregiver, HCP, school administration, and teen has not been observed. However, use of social media was found to be effective in creating a communication network, but not without several limitations and privacy concerns [16].

4. Emergency Support System. This platform would provide emergency support and cautionary alerts for caregiver and teen, and external networks (e.g., HCP, school nurses, and first responders). The system needs to be designed to prevent serious consequences from sudden onset of medical events from occurring, while also training the teen and peers to know how to act/respond during an emergency. This system would be connected to a mobile device (phone, wearable device) for the teen that is similar to a medical alert button.

Current Implementations: Emergency support systems at the individual level for teens have not been observed in chronic disease management literature. However, emergency apps on the market can be leveraged in chronic disease related emergencies, such as Medical ID app [17].

5. Supply Management System. This platform aims to reduce the burden of supply management and organization for the caregiver and teen by providing
a fully integrated system of alerts, reminders, and automated supply replenishment/management. Additionally, the platform could provide assistance with and education regarding insurance, financial and legal support.

**Current Implementations:** An integrated supply management has not been observed in literature, but Mango Health app [18] enables caregiver and teen to track their medications. Retail pharmacies like CVS and Walgreens are also starting to have integrated systems for patient’s medical supply management.

The five technology opportunities above are interrelated and form a technological ecosystem, enabling information flow and communication between the solution systems to create an integrated approach to chronic disease management. The proposed solution ecosystem (Figure 3) is designed for seamless communication and information flow among parties and technology solutions to assist a teen managing a chronic disease to transition to independence. In the figure, the circles represent the 5 digital opportunities identified to enhance the teen-to-independence transition while managing a chronic diagnosis. Lines in between the concepts indicate integrated lines of communications between other digital solutions. These connections are hypothesized based on study observations. The boxes present examples for each solution. Each of these solutions can evolve with the changing needs of the teen throughout their transition. For instance, the teen and caregiver bridge may promote medication compliance in early transition, logging therapy tasks and sending reports to HCP in mid-transition, and using time management tools for managing therapy in late transition. Further interview notes on technology opportunities in transition to independence are provided in Multimedia Appendix 2.

**Figure 3.** Proposed ecosystem of digital-health solutions.

**Discussions**

**Transition Challenges require a multifaceted solution approach**

The ten themes identified in our study are well supported by the literature. #1) *Lack of support* and #2) *managing social stigma* revealed that support from the social environment is a fundamental need, necessitating a deeper understanding of teens’ social state [19]. Koetsenruijter et al. [20] also argued that individuals with chronic conditions need social support for health management. #3) To support their teens, caregivers desire *access to educational material* to learn as much as possible regarding the disease’s symptoms, management, and treatment options. Despite the importance of education to support self-management in chronic disease management (CDM) [5,19], the literature suggested that barriers to having quality education and information included unreliable web resources and limited health and computer literacy of users [21]. #4) In addition to managing symptoms, families want a preemptive advantage through continuous *symptom monitoring*. If an impending medical crisis could be identified through early alerts, their teens could receive aid quickly, possibly mitigating more severe consequences. Several digital
solutions have been offered for symptom monitoring and support [22], yet adoption is not widespread. #5) Safety of teens while driving is another major concern. Since commuting is a significant part of the daily routine, caregivers are rightfully concerned about medical emergencies which may occur while teens are driving. The severity of driving accidents among young drivers with a chronic condition has been argued in the literature. Comparing young drivers with and without ADHD, a study demonstrated teens with the chronic condition had higher driving risks [23]. Thus, CDM initiatives should incorporate “commuting safety”. #6) Access to HCPs is problematic in regards to open communication and information sharing. CDM technologies, which are available to access health care, are highly efficient and help reduce clinic visits [5], but our findings suggest that practical use of these technologies has not yet reached maturity. #7) Likewise, technology use in families revealed that communication technologies would enhance a reciprocal relationship between the caregiver and teen. This would be a promising aspect of technology use, to further extend the benefits of technology, e.g. mobile health interventions, in healthcare management and communication for teens among caregiver and HCP [4]. #8) Communication technologies can also be used to support teens making healthy decision from a long-term perspective. Clinical decision-making systems have proven successful in chronic disease management in a clinical environment [24]. Yet, our findings suggest that the focus for decision support needs to be individualized for teens to assist them in transitioning. #9) Similarly, individualized technologies for controlling medicine inventories and enhancing personal supply management would assist teens in transitioning to independence. #10) Above all, caregivers report financial struggles as a major barrier to accessing current assistive technologies in chronic disease management. Thus, financial issues may have a mediating effect on other challenges. Likewise, the families interviewed wished to receive medical support using low cost communication and information technologies.

Guidance and empowerment through an ecosystem of digital solutions
A single technology solution was insufficient to meet the many challenges patients and caregivers face in launching to independence a teen with a chronic condition. Rather, our study derived an ecosystem of digital-health solutions. The five proposed technology opportunities for ideal transitioning were derived from self-reported technological expectations of teens and caregivers. Fundamentally, these opportunities reflect their expectations and need for a communication system that links the core stakeholders (patient, caregiver, and HCP stakeholders). Measuring the patient’s quality-of-life and quality of communication among caregivers, teens, and HCPs is problematic [5,19]. Therefore, to overcome the major communication issues, we propose developing a communication platform. Similarly, enhancing medical education and health literacy would also be beneficial during the transition and for the long-term CDM for teens [5]. The identified opportunities align well with Miller et al.’s [25] findings regarding the technology preferences of young people in transition for access to healthcare and communication needs, and Ranade-Kharkar et al.’s [26] information goal types among HCPs and caregivers for kids with special health needs.
From a broader perspective, teens may benefit from using technology in the long term, starting with early introduction of technology tools and successfully engaging with technologies through adulthood for CDM [27,28]. The technology use for communication and self-management would facilitate the treatment and consulting process, assist teens for condition-specific needs, and make digital CDM more sustainable [19,5]. Yet, per the suggestions in this study, sustainability and long-term engagement need focus and familiarization to reduce teen frustration and reluctance with technology [29,30]. In that regard, Griffiths et al. [6] suggested using technology-based healthcare services with an existing, trusted HCP team for conveying services to identified needs. The HCP team also needs to work on effective information resource use for timely access. To maximize efficacy, collaborative co-design with patients and continuous improvement of solutions should be considered [2]. Within this context, gamifying the CDM concept to promote engagement, sustainable self-management, and communication is another possible approach for digital-health development.

**Limitations**

As a quality improvement study to improve digital-health delivery at Nationwide Children’s Hospital, we recognize important limitations on generalizability. Our study only covered three out of the top nine chronic conditions among children in the United States [31]. Also, the sample size may be insufficient to derive generalizable results. Since the study lacks quantifiable input, power and other statistical analyses are precluded to test our findings. As is frequently the nature of qualitative methods, analyst bias could have affected this study to some extent in both data collection and interpretation. These limitations can be addressed by future implementations to validate the findings from this study.

**Conclusion**

In this study, challenges and barriers for teens with chronic diseases and their caregivers were identified, discussed, and matched with technological opportunities and solutions. Technological solutions and digital-health mechanisms were suggested as mediating tools for better communication among patient, caregiver, healthcare provider, and authorities. These findings would help to extend current efforts using mobile health management and intervention methods [32]. We suggest future studies to create a virtual bridge among individuals and institutions, and to disseminate the technology and its use.

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Conflicts of Interest
None declared.

Abbreviations
ADHD: Attention deficit hyperactivity disorder
CF: Cystic Fibrosis
CDM: Chronic disease management
HCP: Health care provider
mHealth: Mobile health
NCH: Nationwide Children’s Hospital
T1D: Type 1 Diabetes
SMS: Short Message Service
VoIP: Voice over Internet Protocol

Multimedia Appendix 1

Multimedia Appendix 2

References


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