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REVIEW

## **Telehealth interventions to reduce management complications in type 1 diabetes: A review**

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#### Abstract

Type 1 diabetes is a chronic illness with a high burden of care. While effective interventions and recommendations for diabetes care exist, the intensive nature of diabetes management makes compliance difficult. This is

especially true in children and adolescents as they have unique psychosocial and diabetes needs. Despite the development of effective in-person interventions targeting improving self-management and ameliorating psychosocial difficulties there are still a number of barriers to implementing these interventions, namely time, cost, and access. Telehealth interventions allow for the dissemination of these interventions to a broader audience. Self-management and psychosocial telehealth interventions are reviewed with a special emphasis on mobile phone and internet based technology use. While efficacy has been demonstrated in a number of telehealth interventions with improved cost effectiveness over inperson interventions, many challenges remain including high participant attrition and difficulties with receiving reimbursement for services rendered. These and other challenges are discussed with recommendations for researchers and telehealth providers provided.

Key words: Telehealth; Disease management; E-health interventions; Type 1 diabetes management; Type 1 diabetes

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**Core tip:** Type 1 diabetes is a chronic illness with a high burden of care. Despite the development of effective in-person interventions, telehealth interventions are necessary to improve access to and engagement in interventions to improve diabetes management. Mobile phone and internet based interventions appear to have the most potential to enact change. Challenges and recommendations for these telehealth interventions are provided.

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#### INTRODUCTION

The prevalence of chronic diseases, such as diabetes, cancer, cardiometabolic and respiratory conditions continues to pose a challenge for often overtaxed health care systems, requiring fundamental changes in the delivery and maintenance of patient care<sup>[1-4]</sup>. Telehealth (TH), defined as any medical activity involving an element of distance and use of a telecommunications strategy<sup>[5]</sup>, represents an approach which may enable patients with chronic medical conditions to seek disease specific information and support<sup>[6-9]</sup>, to be followed by clinicians more frequently and away from hospital settings<sup>[10-12]</sup>, reduce healthcare costs<sup>[13]</sup>, and to ultimately promote improved adherence to medical regimens resulting in improvement in health outcomes<sup>[14]</sup>.

#### **BRIEF HISTORY OF TH**

While TH interventions began more than 50 years ago with closed-circuit television, research into TH interventions did not truly begin to accelerate until the 1990s with a dramatic increase in TH publications through the 2000s<sup>[15,16]</sup>. Initial TH interventions primarily emphasized providing the same care that would be provided in-person through an intermediary such as a closed circuit television or telephone. A majority of interventions that subsequently developed relied on direct telephone contact by nurses or skilled health care professionals or transmission of simple self-management data via a modem<sup>[15]</sup>. The primary strength of these early TH interventions was in providing care coordination with more frequent feedback and without an in-person visit, which resulted in cost savings and improved patient health<sup>[14]</sup>. As technology advanced, TH interventions did as well, moving to material presented through video phones, home computers, pre-programmed interactive problem solving programs, and mobile phone and internet based interventions<sup>[17,18]</sup>. The flexibility and cost effectiveness of TH makes it well suited to be used in the treatment of chronic illnesses such as diabetes.

Previous interventions have shown efficacy implementing TH for a variety of chronic conditions, including cancer, transplant recipients, heart failure, and chronic pulmonary disease<sup>[3,7-10,12]</sup>. These interventions have shown support for TH in providing condition specific education, social support, and self management assistance. In addition, this previous work has demonstrated the wide acceptability of TH and the ability for TH interventions to reach previously underserved populations.

#### **NEED FOR TH IN TYPE 1 DIABETES**

Type 1 diabetes (T1D) is one of the most common chronic diseases in pediatrics in the United States and affects

more than 151000 youth under 20 years of age<sup>[19]</sup>. Poorly controlled diabetes poses many serious health complications thus optimal T1D management during childhood and adolescence is necessary to reduce negative health outcomes and improve life expectancy<sup>[19,20]</sup>. The management of T1D is a complex and challenging task that involves integration of daily medical tasks and lifestyle modifications. While demanding, the successful intensive management of T1D is associated with improved health outcomes and protections against complications that maintain for as many as 6-10 years following intensive management<sup>[21]</sup>.

Children and adolescents with T1D have unique needs that dictate different standards of care than adults<sup>[22]</sup>. Despite parental involvement in diabetes management being common, non-adherence is especially high in the transition to and within adolescence, increasing the risk of immediate and future microvascular complications<sup>[23-28]</sup>. T1D management is further complicated by the social, emotional, and psychological demands of the disease<sup>[23]</sup>. Poor psychosocial wellbeing (e.g., depression, anxiety, stress) is related to poorer short and long term health outcomes due to suboptimal disease management<sup>[29-34]</sup>. Family functioning, parent wellbeing, and family cohesion have also been identified as an important contributor to diabetes control<sup>[35-44]</sup>. Therefore, when evaluating T1D management interventions, assessing and addressing the impact of patient and parent psychosocial wellbeing while being flexible and developmentally sensitive to the needs of the patient is essential to ensure that the intervention has a lasting impact.

#### TH IN T1D

While previous in-person diabetes interventions have successfully targeted increasing patient knowledge<sup>[45-47]</sup>, improving illness perception<sup>[48,49]</sup>, fostering family communication and relationships<sup>[50,51]</sup>, and advancing technological accuracy and ease of management devices<sup>[52-54]</sup>, there are several remaining challenges to inperson interventions. Primary limitations of in-person interventions include poor ease of access for rural or underserved families, increased healthcare utilization costs, and poor attendance<sup>[55,56]</sup>. Additionally, individuals at greater risk for medical regimen nonadherence are likely to also be individuals who are at greater risk for not attending medical appointments<sup>[57]</sup>, making traditional clinic based recruitment and interventions potentially ineffective. TH addresses many of the limitations of previous T1D interventions by providing a unique avenue for improving the management of T1D that is engaging, cost effective, and accessible<sup>[58]</sup>.

# SELF MONITORING AND EDUCATION INTERVENTIONS

A hallmark of many TH interventions are to focus on providing education, improving self-monitoring through



electronic check ins, and establishing more frequent communication with health care providers. While traditional phone interventions have demonstrated positive improvements in glycemic control and selfefficacy<sup>[59,60]</sup>, the increased availability of smartphones and the internet facilitated further innovation and development. Deploying interventions on a mobile device, especially those compatible with text messaging, also proved effective in improving glycemic control in both adults and children<sup>[59,61-64]</sup>. These results suggest that text messaging and intervention through mobile phones are a substantial area for outreach and intervention. However, despite the increased ownership of mobile phones among adults (91%) and adolescents (78%), there is still a substantial portion of individuals without a mobile phone or texting ability, especially among younger adolescents<sup>[65,66]</sup>. Additionally, some interventions using text messaging or smartphone applications in children or adolescents have not shown an ability to improve glycemic control, although secondary benefits such as increased adherence, communication or knowledge are generally noted<sup>[41,67-69]</sup>. As such, while mobile based interventions are promising, continued research into maximizing desired outcomes and costeffectiveness is necessary.

Internet based interventions have the potential to overcome this limitation of mobile phone based interventions, because of the wide spread availability of the internet for adults (85%) and teens (95%) in the United States<sup>[66,70,71]</sup>. The internet may be especially appropriate for diabetes intervention, as one study suggests that 63.6% of parents of children with T1D use the internet to seek out diabetes information on their own<sup>[72]</sup>. For a child or adolescent with T1D, diabetes psychoeducation<sup>[73]</sup>, problem solving vignettes<sup>[74]</sup>, and physician monitoring of HbA1c and intervention<sup>[75-77]</sup>, have all recently shown moderate to strong evidence of successfully improving glycemic control when implemented in an online environment. Similar results have been found with adults; however, most studies rely on adults with T2D<sup>[78-80]</sup>. Despite their demonstrated efficacy and the wide spread availability of the internet, the primary challenge that continues to plague internet based interventions is the decreased engagement and participation of users over time, with participant attrition rates of 11.5%-37% reported<sup>[74,78]</sup>.

Notwithstanding the challenges in self-management interventions, these interventions have demonstrated effectiveness in multiple delivery modalities including voice calls, SMS/Text messaging, email, customized web portals, and video conferencing<sup>[61,81,82]</sup>. A systematic review revealed that telemedicine solutions for diabetes care are also feasible and acceptable to patients and providers<sup>[59]</sup>. Therefore, future research is necessary to integrate the previously proven delivery strategies with new technology that is engaging to users and cost-

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effective.

### PSYCHOSOCIAL AND SUPPORTIVE TH INTERVENTIONS

Other TH interventions have strived to improve adherence by providing psychosocial support and decreasing family conflict around T1D management. One such method of intervention developed by Grey et al<sup>[73]</sup> bundled effective psychoeducation intervention with Coping Skills Training which improved glycemic control, guality of life, social acceptance, and self-efficacy which maintained for a year after beginning the online program (which was only 5 wk in duration). Self-efficacy has also been targeted as a potential area of psychosocial intervention, with online interventions demonstrating a significant positive impact on self-care activities<sup>[83]</sup>. Individual wellbeing has also been successfully addressed with web-based Cognitive Behavioral Therapy and peer mentoring<sup>[84,85]</sup>. Taken together, the existing psychosocial interventions for patients with T1D have shown success in engaging patients and improving psychological wellbeing, but are mixed on their abilities to minimize attrition and improve objective measures of glycemic control (i.e., HbA1c).

TH interventions have also been utilized to support the family and environment of patients with T1D. These interventions have successfully improved communication, improved HbA1c levels, and quality of life suggesting that targeting those supporting the individual with T1D (i.e., nurses, physicians, and family) may also be an effective way to improve T1D health outcomes<sup>[81]</sup>. There also appears to be awareness from family members and service providers of their need to find information and support regarding T1D care and a preference for online interventions<sup>[86]</sup>. One way to reach supporting individuals and patients may be to extend interventions to build on pre-existing online networks and supports. Social networks and forums for T1D have been qualitatively examined; despite concerns regarding the quality of the information presented on these sources, it is clear that patients and family members actively use these online sources (such as Facebook and online message boards) for diabetes information and social support<sup>[6,87-90]</sup>. Most notably, in one study 84.3% of caregivers that used online forums reported that their child's care was impacted by information they encountered online<sup>[6]</sup>. Recent data also suggests that more than half of parents within a pediatric T1D clinic use the internet to seek out T1D information<sup>[72]</sup>. This identifies pre-existing internet sources as a potentially strong source for information dissemination but also as a potential venue for the unintended spread of misinformation. While prospective studies are needed to understand the association between parents' use of online forums and their child's glycemic control, these may be an appropriate area for

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future intervention.

#### **ONGOING CHALLENGES IN TH**

While research suggests that TH for patients with T1D can be a useful and effective method of improving glycemic control and overall adherence, there has been a significant delay in transitioning efficacious research interventions of T1D into community treatment settings. Chief among these issues are the financial feasibility and reimbursement for services delivered by skilled staff, creating and maintaining patient involvement in TH interventions while minimizing patient attrition, and ensuring patient safety, privacy, and legal accountability.

#### FINANCIAL CHALLENGES

A key challenge that permeates across the literature in TH is the difficulty in obtaining reimbursement for services. The literature suggests that providers' experience of receiving reimbursement varies significantly<sup>[91-93]</sup>. As of this publication only 15 states in the United States mandate coverage for TH services with 39 states providing at least some reimbursement for TH, although dramatically less so for behavioral TH despite behavioral TH's appropriateness<sup>[94,95]</sup>. Additionally, recent studies have suggested that private third party reimbursement is improving across the board, though the trajectory of these improvements continues to be slow<sup>[93]</sup>. For example in 2005, 58% of TH programs received reimbursement for their services while in 2012, 45% of TH programs sought reimbursement and 81% of those reported receiving it<sup>[92,93]</sup>. Obtaining grant funding to offset these costs increases the institution's ability to build a program<sup>[92]</sup>; however, if program personnel lack information about how to obtain reimbursement for their services from third party payers, the program may be discontinued after the grant funding has remitted<sup>[91,93]</sup>. This pattern of short term growth with long term discontinuation is concerning and hinders the growth of TH services.

The licensing and credentialing rules create another barrier to TH implementation. Similar to reimbursement regulations, there is a large discrepancy in state TH licensing laws. Current laws generally refer to the physical location of the patient as the place of service, regardless of the provider's location. Moreover, state laws generally require that providers be licensed and credentialed at the place of service, making state lines a finite barrier to service delivery<sup>[91]</sup>. In 2011, Children's Medical Services (CMS) began to allow institutions to accept the credentialing of the provider's home institution instead of requiring the outside institution to put the provider through their credentialing process<sup>[91]</sup>. The CMS regulations show promise for expanding the credentialing requirements and may facilitate providers' ability to reach patients who otherwise may not have been able to receive care. While efforts have been made to extend licensing adjustments by implementing

limited, federal, and reciprocal licenses, it is clear that the current system of licensure is hindering providers' ability to reach out to patients who live in other states and steps need to be made to resolve these concerns<sup>[95]</sup>.

#### PATIENT ENGAGEMENT AND ATTRITION

Attrition and noncompliance in TH interventions creates yet another barrier to successful establishment of TH interventions. As stated previously, attrition rates of 11.5%-37% among internet interventions have been reported [74,78]. However, patients who complete TH interventions may also not adhere adequately to the intervention, given the lack of in-person oversight. In a study conducted by Wangberg<sup>[83]</sup>, participants were requested to repeatedly view and engage with online modules targeting self-efficacy and diabetes self-care, yet only 34% logged in more than twice to interact with the modules. Similarly, a review of TH adherence found a recurring theme in suboptimal frequency of uploading and submitting blood glucose values<sup>[96]</sup>. Given these relatively high drop-out rates and problems with noncompliance, TH programs should incorporate measures to improve adherence and keep the patients engaged in treatment.

To this end, some studies have shown improved adherence when the TH interventions are tailored toward the patients unique needs by using customized messages, programs, or personalized functions within the program<sup>[97]</sup>. For instance, a program may allow patients to use a data base of pictures of foods that have predetermined carbohydrate amounts instead of requiring the patient to estimate the carbohydrates for food they consume. Including features that communicated with patient's preexisting diabetes technology (e.g., glucose monitors, insulin pumps) and automatically upload patients' blood glucose levels in order for parents or providers to review and provide feedback may also be helpful. Overall, these programs should be easy to access and provide immediate feedback<sup>[98]</sup>. Programs should also take demographics into account. For instance, older individuals<sup>[99]</sup>, women<sup>[100]</sup>, and patients with higher selfefficacy<sup>[101,102]</sup>, are more likely to adhere to internet interventions. Thus, providers who are developing or implementing TH interventions should work to determine which patients are going to be appropriate for the TH intervention and how to address those groups with a history of poor adherence to TH interventions<sup>[103]</sup>.

#### PRIVACY AND SECURITY

Possibly the most common TH concern relates to the ability for TH interventions to maintain patient privacy and security in a mobile or online environment. Appropriately managing personal health information (PHI) is an important piece to maintaining patients' confidentiality. The federal laws provide regulations for protecting PHI under the Health Information Portability and Accountability Act<sup>[104]</sup> (HIPAA). Each state also has



laws for managing PHI, which is not consistent from state to state and may be more or less stringent than HIPAA regulations<sup>[95]</sup>. When state privacy laws conflict with HIPAA, the general rule is that the provider follows the more stringent law<sup>[95]</sup>. TH providers who provide services across state lines must be aware of laws in both states and must work to resolve conflicts as they arise while being prepared for conflicting laws or regulations<sup>[105]</sup>. While managing these challenges across providers, technology technicians, nurses, medical assistants, and billing personnel in two states may be manageable with practice, negotiating differences among state and federal privacy laws is likely to be increasingly more difficult with each additional state, thereby deterring providers from expanding their services and possibly hindering patients' access to specialized mental health care[95]. In addition, though more recent technological advances and using secure or closed networks have improved security of online data transmission<sup>[91,95]</sup> regulations are not clear regarding where or how the data should be stored (e.g., online, at the providers' institution, or at the institution of the place of service). While providers should follow good safety procedures such as a personalized login, automatic time-out setting when not in use, encrypted data storage, and encrypted data transmission, they must also deliver informed consent and ensure a patient's understanding of the potential and ever-evolving risks of transmitting health information over the internet or mobile networks<sup>[95,105,106]</sup>. These challenges require that a provider maintain understanding not only of the HIPAA and PHI laws but also of technological capabilities and challenges to technological safety, which is a daunting task for even the most informed provider.

# CONCLUSION AND FUTURE DIRECTIONS

Taken together, research has shown the effectiveness and promise of TH in improving several primary (*i.e.*, glycemic control, adherence) and secondary (i.e., social support, comorbidity, and knowledge) outcomes in T1D patients. Although a previous review suggested that phone interventions appear to have more promise than internet interventions in improving targeted T1D outcomes, the reviewed literature above suggests promise in both web based and mobile interventions. Broadly, TH interventions must strive to be theory driven, integrate multiple platforms, be secure, and be userfriendly<sup>[87,107,108]</sup>. In doing so, TH interventions will expand to a broader audience and have an improved chance at reaching those most in need for TH, the underserved individuals who have difficulty accessing traditional services.

In order to improve current TH interventions, researchers and providers should invest in portability. As mobile computing and mobile phones reach a larger and larger share of the United States<sup>[65]</sup> TH interventions must be optimized to provide an efficient, appealing, and

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interactive environment on the smaller screen of mobile phones and tablets to reduce attrition and maintain participant engagement. This is especially true for adolescents and children, of whom a large portion (74%) access the internet from their phone and an increasing portion (25%) use their mobile phones as their primary device for navigating the web<sup>[109]</sup>. Researchers who do not adjust their TH interventions to take advantage of the increased computing power and accessibly of portable technology will continue to struggle with participant engagement and attrition as fewer and fewer young individuals use a traditional desktop computer.

Researchers and clinicians should also seek to integrate their TH interventions into existing technological infrastructure both to increase participant familiarity and ease of use. By intentionally creating interventions that integrate with diabetes technology (*i.e.*, blood glucose monitors, insulin pumps), providers improve their ability to obtain objective health information and increase participant engagement through ease in integration. Integration, especially automated or hands free integration, with these technologies also has the benefit of providing a method for providers to easily view and provide feedback without relying on patients to physically produce their blood glucose meters at appointments. This improves the quality of information that providers have to deliver care, as well as decreases the burden of appointment preparation on the patient and potentially improving compliance.

In addition to technological integration, effective TH interventions should seek to involve family members, providers, and other supporting members of the patient's T1D management team. An effective way to do this may be by building on the preexisting support networks targeting these individuals and developing ways to improve how individuals find, interoperate, and communicate the information they find online. Recent research has demonstrated that parents of children with T1D are especially likely to use these online sources and actively incorporate them into how they care for their child's T1D<sup>[6,72]</sup>. Providers may benefit from this predisposition of parents to search for information online by designing and implementing procedures to inform users of appropriate sources of information and increase awareness of effective TH interventions that may provide similar information. Building atop of pre-existing resources may also reduce the infrastructure cost that contributes to the short term growth and long term discontinuation of existing TH interventions.

Finally, clinical care providers are encouraged to advocate for improved legislation regarding TH. Notwithstanding substantial improvement over the last decade regarding TH reimbursement and rules, there continues to be a lack of guidelines regarding TH interventions delivered by the mental health profession and the associated technological, privacy, and security issues created by these interventions. In fact, many of the privacy and security concerns related to TH interventions may only be feasibly addressed by policy

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makers and technology manufacturers. The development and national recognition of TH guidelines in conjunction with improved licensure recognition across state lines may provide increased support to mental health professionals who wish to pursue TH interventions. As a part of these guidelines, providers and researchers are encouraged to pair with technology consultants whom are informed and educated both on technological advances and advances in privacy and security laws. With proper support and the development of structured guidelines, TH interventions can grow to fit within the evolving scope of health care policy, reimbursement, and technological advancement while reducing the number of individuals who are underserved.

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