



Review Article

## Telemedicine and mHealth Interventions for Children and Young People with Type One Diabetes (T1DM)

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### Introduction:

Type 1 Diabetes Mellitus (T1DM) is a complex illness involving many self-care activities including regular blood glucose monitoring (BGM), management of diet, regular exercise, insulin administration and adjustment, and management of hypoglycaemia. The responsibility of diabetes management falls largely to the patient and their family, presenting a considerable burden in day-to-day life. Children and young people with T1DM have referred to the “constant interruptions” to their daily life caused by diabetes and its treatment [1]. For children and adolescents with T1DM, this burden of self-care manifests in balancing the need to check blood glucose levels during school and whilst playing, having to carry equipment at all times, considering dietary restrictions and administering insulin injections, facing social pressures and not being considered ‘normal’ by peers, and dealing with changes in family dynamics or conflict with family members related to self-care behaviours [1-4]. Ensuring that young people are well equipped to manage their diabetes is of lifelong significance, since improved self-management of T1DM is associated with better health outcomes, fewer diabetes-related complications and improved quality of life [5].

Technology is increasingly integrated into everyday life and as such, provides a convenient platform for promoting health and supporting self-management of long-term conditions. Telemedicine and mHealth (mobile health) interventions may be particularly appealing to younger populations due to their familiarity with, and everyday usage of

technologies such as mobile phones, the internet and smart phone applications (apps) [6-8], including adolescents from low income, urban and minority backgrounds [9]. For those with chronic conditions, technology can be used to impart knowledge about self-management practices, and provide psychosocial support. A recent critical review assessed the benefit of electronic media technologies in supporting children and young people aged 0-19 years with a range of long-term conditions, including T1DM [10]. The review included 40 studies that focused on patient-reported psychosocial outcomes. Here, supportive intervention using electronic media technology was found to increase disease-related knowledge and improve aspects of psychosocial function, although the conclusion was tentative given the poor methodological quality of existing evidence and the lack of user input in product development. Technology-based interventions can target the individual, the family and systemic/healthcare system within the same intervention [5]. Naranjo and colleagues propose that for individuals with T1DM, technology-based intervention may support adjustment to the condition, provide practical and psychosocial support, and support individualised communications based on the patient’s blood glucose data. For the family, technology may assist with positive communication, lowering opportunities for parent-child conflict surrounding T1DM and supporting developmentally appropriate self-management behaviours for the young person. Within the healthcare system, technology may facilitate communication with healthcare professionals (HCPs), and reduce barriers to accessing care [5].

The aim of this scoping review was to describe the application of telemedicine and mHealth

interventions specifically amongst children and young people with T1DM and their families.

### **Search Methods:**

An electronic literature search was conducted using: Web of Science, PubMed, PsycINFO and Google Scholar. The following search terms were applied in various combinations: adolescent, children, paediatric, technology, type 1 diabetes, T1DM, diabetes, mobile health, mHealth, text messaging, mobile phone, self-management and interventions. Forward citation searching and backward searching of references of articles meeting search criteria was undertaken. Relevant manuscript titles, abstracts and full-articles were reviewed after applying the selection criteria detailed below.

Reviews and studies were included if they focused on children and young people primarily  $\leq 18$  years old with a diagnosis of T1DM, or parents/guardians of children and young people with T1DM. Restrictions were not applied in terms of research design or methods, however the focus of included studies/articles was restricted to the use of technology (e.g., mobile phones, video/multimedia resources, web/online resources, emailing, videoconferencing, gaming, handheld devices) for health promotion, health behaviour change and/or self-management for children with T1DM (and their parents where appropriate). Unpublished data were not sought from authors. Studies were conducted in any country and published in English in a peer-reviewed scientific journal.

### **Findings**

A scoping of the evidence identified a number of narrative and systematic reviews relating to the use of technology with children and adolescents with T1DM. Harris and colleagues [11] provide a narrative review of the use of technology in the management of T1DM in adolescence. Their review summarises the three successful uses of technology for adolescents with T1DM: (i) technology that can directly impact day-to-day management of diabetes (e.g., insulin pumps and continuous glucose monitors); (ii) technology that allows for interventions other than in-person (e.g., telehealth and texting); and (iii) web-based support for health behaviours. Dougherty and colleagues [12] provide a narrative review of telemedicine applications for adolescents with T1DM, which describes a variety of key studies in this field and highlights a lack of consistent and significant positive outcomes in this population.

This article focuses predominantly on approaches that use technology to provide support for self-care and health behaviours, or deliver interventions

other than in-person. The majority of telehealth and mHealth interventions for children and young people with T1DM have included the use of mobile phones, smartphone applications, web-based interventions, online patient web portals, emailing, videoconferencing and handheld personal digital assistants (PDAs) devices. This article overviews current literature for each of these technologies and describes how they have been used to support children with T1DM and their families.

### **Mobile Phones & Smartphone Applications**

Mobile phones and smartphones are currently commonplace amongst young people [6,8] and as such, they represent a convenient platform for health promotion and health communication between healthcare professionals and their patients.

A number of studies have utilised mobile phone interventions to promote diabetes self-management with children or adolescents with T1DM. The majority of the studies are summarised in two reviews [13,14], although additional studies describing intervention developments, parent-targeted interventions, or more recent research are included.

The two reviews previously conducted on mobile phone intervention studies for children and adolescents with T1DM, have some overlap in included studies. Herbert [13] conducted a systematic review specifically including text message interventions for adolescents with T1DM aged 8 - 25 years. The review included seven studies with sample sizes ranging from 11 to 92 participants and intervention durations of 11 weeks - 12 months. The aim of included interventions was varied, and included improving glycaemic control [15-18]; increasing blood glucose monitoring frequency [19] or physical activity [20], or to evaluate the use of text messages to provide T1DM information [21]. Study designs included three randomised controlled trials [18-20], one randomised crossover trial [15] or quasi-experimental designs without controls [17,21] or with matched controls [16]. Only one study in this review [13] referenced the use of behavioural theory in the development of the intervention [18]. Each of the included studies measured a unique set of outcome measures to evaluate program effectiveness and feasibility. The most common outcomes measured were HbA1c (as an indicator of glycaemic control), and participant satisfaction. Other outcomes included frequency and response rate to the program, number of text responses and participation in Website diaries, daily step count, body mass index, blood pressure, quality of life, social support and usability of the text message program.

This systematic review identified only a small number of text messaging intervention studies for the T1DM population, with wide variability in study design, intensity and duration of intervention and outcomes collected. Feasibility of delivering text messaging to children, adolescents and young people with T1DM was demonstrated by all of the included studies. However, retention rates varied across studies, and satisfaction with messaging was mixed (although most participants enjoyed receiving messages, some found them intrusive). From studies included in the systematic review, the influence of text messaging interventions on glycaemic control (HbA1c) and daily self-care behaviours is less clear, and the authors convey a need for larger, theoretically informed experimental studies to determine the impact of mobile phone text messaging on diabetes outcomes. The authors identified limitations with the included text messaging studies, which included high attrition rates, brevity of intervention, technological issues with text delivery, and for some, a lack of a control group. Some of the included studies were multimodal, where text messages were not a single element of the intervention, and so it is difficult to determine the influence of the messaging alone.

In a narrative review of mobile phone intervention studies for adolescents with T1DM [14], six studies including mobile phone interventions were identified, four of which were text-messaging interventions that were included in the previous review [13]. This narrative review included four pilot studies, one of which was randomised [17,19,22,23], one feasibility study [15], and one randomised controlled trial [18]. Included studies were targeted to children and adolescents aged 10-19 years, and had sample sizes ranging from 10 (adolescent-parent pairs) to 126. Findings for glycaemic control were mixed. In this review, only three of the included studies showed improvements in glycaemic control following the intervention [15,18,22], the remaining three studies found no significant reductions in HbA1c [17,19,23]. The authors inferred that there was not enough evidence to reliably conclude that mobile phone interventions can reduce HbA1c and improve glycaemic control. However, none of the studies showed increases in HbA1c, and as such, the authors tentatively concluded that these interventions may mitigate the increase in HbA1c that is commonly observed during adolescence.

Although the review was based on a small number of studies, it seems that interventions that are more 'engaging' for participants may confer more benefits. Barnaba and Burr [14] observed that there were greater reductions in HbA1c in those studies which adopted more interactive and supportive

interventions (e.g., those which involved participants directly sending their blood glucose readings to healthcare professionals who provided feedback via text messaging) [15,22] compared with studies that focused on simple reminders to self-monitor blood glucose levels. The less interactive studies showed no significant improvements in clinical indicators of diabetes control [17,19]. Additionally, the authors noted that the demographics of participants may be relevant, since positive outcomes were found in studies involving younger adolescents rather than studies involving older adolescents. Although self-management behaviours measured in included studies were varied, there was some indication from this review that self-care behaviours may improve with text messaging interventions, although self-care behaviours did not necessarily translate into improvement in glycaemic control.

Details of the nine studies are available in their respective reviews [13,14], although selected studies are described here to demonstrate the application of mobile phone interventions with this population group (Table 1).

Mobile phone technology has been used to improve self-monitoring behaviours for diabetes management. These studies have demonstrated that mobile phone interventions are acceptable to participants, although the influence of the intervention on blood glucose monitoring has been inconsistent. Cafazzo [23] interviewed adolescents and their families to inform the development of a mobile app 'bant', aimed at increasing self-monitoring of blood glucose. This app incorporated elements identified as being important to the adolescents. These included simple, automated transfer of glucometer readings, the use of a social community and the concept of gamification where routine behaviours were rewarded using gift vouchers. The app was piloted over a 12-week period with 20 adolescents aged between 12-16 years who were provided with the app running on an iPhone/iPod Touch device, a glucometer and Bluetooth adapter for automated transfers of blood glucose monitoring data to the app. After 12 weeks, the daily average frequency of blood glucose monitoring had increased by 50%; user satisfaction ratings were high with 88% of the adolescents indicating they would continue to use the system. The findings indicated that the intervention was feasible and acceptable to adolescents, and that blood glucose monitoring behaviour was improved following use of the app. However, the efficacy of the app in generating behavioural change and improving clinical indicators of diabetes control (HbA1c) needs to be tested in a sufficiently powered randomised controlled study.

In the Computerized Automated Reminder Diabetes System (CARDS) study, the authors [19] conducted a pilot randomised trial with 40 adolescents that compared text messaging with email reminders for encouraging change in their engagement in regular blood glucose monitoring. When compared, mobile phone messaging resulted in significantly more blood glucose monitoring than email messaging. The ubiquitous nature of mobile phones may increase the likelihood of adolescents being exposed to and engaging with messaging. However, despite an initial peak in responses, the authors observed attenuation in text messaging responses over the 3-month intervention period. As such, it was unclear from this study whether behaviour change was sustained but participants were non-responsive to follow-up messaging, or whether participants were disengaged with both the behaviour and the messaging response. Understanding how best to maintain behaviour changes over time, dealing with attrition and non-response to follow-up remain challenging problems in mobile phone and text messaging intervention studies.

To promote overall self-care behaviours in diabetes, Frøisland [17] pilot tested a mobile-phone app with 12 adolescents with T1DM aged 13-19 over a 3-month period. The app consisted of a picture-based diabetes diary to record physical activity and photographs of food eaten using the mobile phone's camera. The phone also used Bluetooth technology to communicate with a glucometer to record blood glucose levels. Findings from qualitative interviews with participants indicated that the app was perceived to be valuable by adolescents; the picture-based mobile phone diary enabled them to visualise important factors of diabetes self-care (e.g., diet, insulin dosage, physical activity, and pre- and post-prandial glucose measurements) into one picture and reflect on their behaviours to provide a better holistic understanding of their diabetes treatment. As found by Cafazzo [23] participants indicated they would like to continue using the app beyond the life of the study period. However, participant satisfaction was influenced by technical issues, such as poor battery-life and issues around glucometers not always effectively transmitting blood glucose data to the app. Although adolescents' attitudes towards the app were positive, the study did not demonstrate any changes in adolescents' knowledge about diabetes from pre-post intervention, and no changes were observed in HbA1c levels.

Franklin and colleagues developed and tested a text-messaging system 'Sweet Talk' designed to enhance self-efficacy, facilitate uptake of intensive insulin therapy and improve glycaemic control in

young people with T1DM aged 8-18 years [18]. This is one of the few studies utilising an intervention which is informed by behaviour change theory, and measuring psychological outcomes. In this randomised controlled trial, 92 patients were randomised to conventional insulin therapy (n=28), conventional therapy and 'Sweet Talk' (n=33) or intensive insulin therapy and 'Sweet Talk' (n=31). The 'Sweet Talk' software sent participants daily tailored text messages to reinforce goal setting at clinic visits. 'Sweet Talk' when used alone did not result in improvements in glycaemic control. However, there were improvements in HbA1c for those who received 'Sweet Talk' in combination with intensive insulin therapy, and participants self-reported that 'Sweet Talk' had improved their diabetes self-management. Importantly, use of 'Sweet Talk' was associated with improvement in diabetes self-efficacy and self-reported adherence compared with controls on conventional therapy (important for long-term behaviour change), although it remains unclear whether enhancing diabetes self-efficacy confers long-term improvement in glycaemic control [18].

Mulvaney [16] used the 'SuperEgo' system to deliver a combined mobile and web-based intervention to improve diabetes adherence. This aimed to motivate and remind adolescents about diabetes self-care tasks such as checking their blood glucose and carrying supplies. In this pilot study, 23 adolescents with T1DM received an average of 10 tailored text messages per week (range 8-12) over three months. The messages were aimed to address their individually-reported barriers to diabetes self-care. After three months, there were no changes in HbA1c in the intervention group although matched controls had significantly higher HbA1c.

Other studies have shown positive outcomes for improving glycaemic control. Rami's [15] study suggested that the use of mobile technology is acceptable to young people with T1DM and may have positive outcomes for the clinical management of diabetes. This six-month, randomised crossover trial evaluated a mobile phone support program for children and adolescents aged 10-19 years with T1DM. The intervention consisted of three months of a mobile phone support program, compared with three months of 'conventional' support and a paper diary. During the intervention phase, participants were required to use a mobile phone to send 'real-time' monitoring data directly to a server, including date, time, blood glucose level, carbohydrate intake and insulin dosage. Diabetologists sent back weekly text messages with their advice.

In this study, HbA1c levels were significantly improved during the intervention phase. Although participants in this study expressed positive opinions about the program, as found by [12] there were technical issues (in this case, with transmission of information) that negatively influenced participant satisfaction.

Further studies have been undertaken which were not included in the [13,14] reviews. Participant acceptability of mobile phone interventions has been assessed in a feasibility study conducted with 16 children and adolescents with T1DM aged 14-17 years [24]. The authors assessed the acceptability of using a sensor to monitor physical activity, which was integrated into a mobile phone and combined with a system for continuous blood glucose monitoring. The system was designed to allow for an accurate, real-time assessment of an individual's physical activity to be used for insulin-dose adjustment. The technology was highly accepted by all of the children who used the device and was perceived as a mechanism for reducing the burden of T1DM self-management.

A program of research has been undertaken by Carroll and colleagues [22,25-27] with the final intervention study [22] included in the review by [14]. Carroll [25] investigated the attitudes of children and young people with T1DM towards the use of mobile phones to support blood glucose monitoring in T1DM. The researchers conducted separate focus groups with young people aged 14-18 with T1DM and their parents, and found positive opinions from both towards mobile phone use for blood glucose monitoring. Parents and adolescents in their sample agreed that mobile phone use was prevalent in this age range and recognised the benefit of integrating a blood glucose tester into the mobile phone in reducing the need to carry multiple items around with them (e.g., testing equipment in addition to their mobile phone). Automatic uploading of blood glucose data to a website accessible to parents, HCPs and the adolescents was perceived positively. Parents reported that they would feel reassured by having access to accurate data that had not been altered by children; children felt this would reduce the need for constantly updating parents and reduce their perceptions of parental 'nagging'. Researchers then developed and evaluated a mobile-phone blood glucose monitoring (BGM) device called Glucophone™ [26] assessing user satisfaction and the ability of the device to transmit self-monitoring data to a website for review and analysis by HCPs, parents and patients. The intervention was perceived by the adolescents to be useful and acceptable for self-management. However, despite positive feelings expressed by participants towards

the technology and the service, when this device was tested in a feasibility cohort study there were no significant changes at follow-up (3 and 6 months) following use of Glucophone™ in quality of life of the adolescents, their level of conflict with parents, their reported self-management of diabetes or their average glycaemic control [27]. This intervention was adapted in a further study to include 'behavioural contracts' between the adolescents and their parents [22]. These contracts gave adolescents clear timings for monitoring their blood glucose, with parents agreeing to limit their reminders (or 'nagging'). The process involved the engagement of a third party whereby a nurse practitioner would intervene to encourage testing with adolescents who monitored less frequently than negotiated, and young people could notify their nurse practitioner should parents 'remind' to test more frequently than was agreed. In this pre-post cohort study, after three months, adolescents reported significantly improved self-management of diabetes and there was a significant reduction in HbA1c levels demonstrating potential for improved glycaemic control.

More recent studies have demonstrated positive clinical outcomes following mobile phone intervention, although these outcomes need to be tested in a large-scale controlled trial. In a feasibility study [28], Bin-Abbas and colleagues delivered a six-month intervention in which daily information messages, weekly interactive messages and multimedia video messages (on request) about procedures relating to diabetes care, were sent to parents of 200 children with T1DM. The messaging resulted in significant improvements in parents' knowledge about diabetes. Furthermore, the study indicated potential for improvement in clinical outcomes, since significant reductions in fasting blood glucose level, post-prandial glucose level, HbA1c levels and frequency of hypoglycaemic attacks were observed at the end of the intervention compared with baseline.

Telephone support interventions in paediatric diabetes management have presented inconsistent findings. Regular telephone support has been shown to be acceptable to children and adolescents, and beneficial for augmenting conventional care [29]; (23 youths aged 9-17 years, 12 week intervention). However, Nunn's [30] randomised controlled trial showed no positive effect of bimonthly supportive phone calls on glycaemic control, self-management, diabetes knowledge or hospital admissions [30]. Mobile phones have been used to provide telephone support in paediatric diabetes management. Farrell and Holmes-Walker [31] examined the relationship between the use of a mobile phone support system providing

'real-time' support on 'sick days', and hospital admissions due to diabetic ketoacidosis. Although frequency of use of the system was not associated with HbA1c, 94% of users avoided hospital admission irrespective of their glycaemic control [31].

Overall, the research on mobile phone interventions comes largely from feasibility or pilot studies in which interventions have been developed and tested for usability and satisfaction with a single cohort of children, adolescents and young people with T1DM. There are few studies that assessed outcomes using controlled designs and randomisation procedures.

Evaluation data is commonly collected using qualitative interviews with users and their families. Mobile phone interventions are generally perceived to be feasible and highly acceptable to participants and their families, although there can be technical challenges which hamper user satisfaction. Based on the descriptions provided by authors, few studies reported that the development of their intervention was informed by theories of behaviour change. Mobile phone interventions were mostly targeted towards encouraging participants to self-monitor their blood glucose, to support calculation of insulin dose, to instill diabetes knowledge or to motivate health behaviour change (e.g., physical activity). Outcome data is commonly collected using before and after measures with users. Many of the studies collect follow-up data relating to diabetes control (e.g., HbA1c), self-care behaviours (e.g., blood glucose monitoring) or diabetes knowledge, with some collecting data on psychosocial outcomes (e.g., quality of life, family conflict) but few collecting data on psychological outcomes known to be associated with long-term behaviour change (e.g., self-efficacy). There was great variation in the length and intensity of the delivered interventions, and the timeframes for follow-up assessment, although few studies measured outcomes over a longer time period. The majority of the studies were targeted to adolescents, although across the studies the age range was diverse, and participants have included children (from the age of 8 years), adolescents and young people (up to 25 years). Interventions often involved parents, through assessing their views and opinions at the outset to inform intervention design, through evaluating their experiences of using the technology-based interventions to support the management of their child's diabetes, through engaging them directly in the intervention (e.g., website access for blood glucose data, text messaging, setting behavioural contracts) and through measuring outcomes associated with the parents (e.g., conflict with parents, parenting stress,

parental diabetes knowledge). Interventions designed specifically for parents of children with T1DM were less common [28,32]. Sample sizes of identified studies ranged from 10 to 200 participants, although the majority of studies were based on small samples.

The research undoubtedly shows that mobile phone interventions are feasible and acceptable to young people with T1DM and their families, despite occasional technical challenges of delivery. The available studies suggest that there is promise for mobile phone-based interventions to improve aspects of diabetes management (e.g., blood glucose monitoring) and improve glycaemic control (especially in combination with support for behaviour change), although study findings can be mixed which may indicate uncertainty with regards to the benefits for clinical outcomes, or may simply reflect brevity of interventions or follow-up periods. Studies have diverse samples, varied types and durations of intervention, and inconsistency in outcome measures; as such, the clinical significance of mobile phone interventions remains unclear and there is a need for larger-scale randomised controlled trials assessing outcomes of theoretically-informed interventions. There are potential issues with usage and engagement with mobile phone interventions over time, and it has been suggested that mobile phone interventions requiring minimal effort (e.g., automatic information exchange compared to the adolescent actively sending information to a system/HCPs) may result in higher usage and participant engagement.

#### **Internet-delivered applications and online patient web portals**

The Internet now has a common role in everyday life and is frequently used by young people and adults in information searching, communication and social networking. As such, there has been a rise in the use of web-based interventions to promote self-management of paediatric chronic illness, including diabetes [11,33-36].

It has been proposed that there are clinical and cost benefits of telehealth applications using internet technology. For example, remote internet transmission of blood glucose data has been shown to reduce clinic visits without impacting on glycaemic control and satisfaction with care [37]. Studies conducted in recent years have indicated that internet transmission of blood glucose data is viewed positively by adolescents, and has benefits for communication between patients and diabetes healthcare providers [38]. However, adherence to such systems can be poor [38], which is consistent with findings from early studies using remote

transmission of data using fax sent from home or local pharmacies [39]. Ho and colleagues [49] conducted a review of websites and social media related to diabetes management which outlined five feature categories of online health communities (OHC) and their relationship with self-management: [1] social learning and networking, [2] information, [3] guidance, [4] engagement, and [5] personal health data sharing. Although the evidence is limited, web-based interventions have demonstrated potential for improvement in patient self-management behaviours and psychosocial outcomes [33-35]. Effects on glycaemic control are unclear [34-36], although it would seem that in some instances, interventions have potential to offset decreases in glycaemic control that are typical in adolescence [36]. For details on studies using Web-based interventions see Table 2.

Psychosocial benefits are evident in research by Nicholas and colleagues [33], who conducted a mixed-methods evaluation of an 8-week online education and support website intervention for adolescents aged 12-17 years with T1DM. This randomised study identified non-significant trends towards improved quality of relationships with those external to the family in intervention group adolescents (n=31) compared with controls (n=16). Qualitative interviews showed the potential of the website for generating psychosocial benefits, in that intervention participants experienced decreased isolation, knowledge gain, and normalization of experience after its use.

Similarly, Grey [34] observed improvements in psychosocial outcomes with greater improvements arising from combined education and behavioural intervention. In a multi-site, randomised clinical trial with 320 children aged 11-14 years, the authors [34] tested the efficacy of two Internet-based psycho-educational programs: [i] Internet Coping Skills Training (CST) program 'TeenCope' and, [ii] Internet diabetes health education program 'Managing Diabetes' designed to improve outcomes for youth with type 1 diabetes transitioning to adolescence. Glycaemic control (HbA1c), quality of life and psychosocial outcomes (social acceptance, self-efficacy, perceived stress and diabetes family conflict) had improved by 18 months in both groups, although in this crossover study, completion of both programs led to better outcomes than completion of one program suggesting that a combination of diabetes management education and behavioural intervention may be more effective than one element alone. However, as with many studies utilising internet-delivered interventions, attrition was high after 12 months (28%).

Mulvaney [36] randomised 72 adolescents aged 13-17 years to receive either usual care plus 'Your Way', an Internet-based self-management intervention for adolescents with T1DM, or usual care. The intervention was theoretically informed through learning, social-cognitive, and self-determination theories. Elements of self-management (problem solving, and self-management adherence) improved in those who received the intervention although findings were limited by as-treated analysis. Although A1C (indicator of glycaemic control) did not change in the intervention group, intervention participants did not experience the increase in A1C found in the control group.

Others have utilised the internet for delivery of health communications or health advice from the diabetes team. Iafusco [35] evaluated the impact of a weekly physician-moderated chat line involving 193 children and adolescents (aged 10-18 years) with T1DM. Quality of life and metabolic control were monitored and compared with age and sex-matched controls (n=203) one and two years after enrolment. Those patients who participated in the chat sessions showed significant improvements in quality of life. There were no significant differences in glycaemic control although the drop in HbA1c observed after the intervention was greater in intervention than control participants.

Patient web portals are created by healthcare organisations and used for a range of reasons but often to facilitate communication between patients, families and healthcare professionals, to enhance access to health data, or to provide information and peer support. Although commonly used in adult populations, there are limited evaluations of online patient web portals for children and young people with T1DM. Feasibility studies have indicated that patient web portals designed for children and adolescents with T1DM are well-received, and offer benefits for healthcare practitioners, patients and families [40-44]. However, a paediatric portal study that included T1DM participants highlighted some concerns about privacy with use of portals and noted racial and socioeconomic disparities in access [45].

Boogerd [40] developed and evaluated the feasibility of a secured web portal intervention called 'SugarSquare'. This incorporated four components: information, patient-professional interaction (via private messages between adolescents and health professionals), peer support (via chat and forum applications for communication between adolescents using the website), and a treatment overview.

In this study, sixty-two children and young people aged 11-21 years were randomly assigned to usual care (n=31) or usual care plus intervention (n=31) with outcomes assessed at baseline and nine months. This study demonstrated that the SugarSquare intervention was feasible and acceptable, since all 13 healthcare professionals accessed the portal, over two-thirds of the participants accessed the portal at least once (65%) and more than half of the participants repeatedly accessed it (52%). Usage of the portal's applications included 5795 page views, 3580 chat messages, 427 forum messages and 40 private interactions between 11 adolescents and healthcare professionals, demonstrating diversity in use and access. Adolescents who received the intervention reported more positive evaluations of care, improved quality of life and improved communication with healthcare professionals compared with control participants. Whilst the researchers did not demonstrate improvements in HbA1c, this small feasibility study was not appropriately powered to detect differences in clinical outcomes. A protocol has recently been published for a randomised controlled trial [46] in which the efficacy of SugarSquare will be tested for reducing self-reported parenting stress at six and 12 months, with secondary measures including psychosocial outcomes, satisfaction with care, diabetes knowledge and treatment adherence.

Studies have examined the views of healthcare professionals and parents towards online patient web portals. In these studies, the web portals have included discussion forums, blog tools, self-care and treatment information, research updates and news for local practitioners [41], or interactive pedagogic devices, social networking tools, locally produced self-care and treatment information [42]. These studies indicated that diabetes healthcare professionals view web portals positively where the information contained is accurate, evidence-based, and has been developed in collaboration with clinical professionals [41,42]. Healthcare practitioners perceived this online web portal to be a useful complement to traditional care, and a helpful source of scientifically sound information and advice that would provide practical and social support to patients and parents. An important element appeared to be the ability to read patients' dialogues online which enabled them to learn more about the patients' perspectives of T1DM and its management. This research emphasised the need to carefully consider *which* elements of advice can be delivered effectively using online web portals, and which elements are best delivered during face-to-face appointments.

The perspectives of patients and their families towards online patient web portals have also been examined. Qualitative studies have reported on the views of adolescents' and their parents' experiences of using online portals for T1DM. Key benefits that they report include being able to search for reliable information provided by local clinicians, having access to the answers to difficult-to-ask or sensitive questions (e.g., surrounding anxiety and fear), feelings of security and being in control of their diabetes management, and feeling reassured [43,44]. The presentation of online materials is perceived to be important; young people require online portals and websites to be straightforward, functional and comprehensible in terms of layout and content [47].

Adolescents and their parents indicated that web portals generated more information than they anticipated and this increased their use of the portal; similarly, the potential for peer-to-peer interaction through message boards and chat rooms were valued aspects of the web portal although the value of social contact varied between individuals and over time [48]. Users of the portal reported that they would be more encouraged to return to the portal if they viewed visible signs of change, site maintenance and updates (e.g., current events, recent happenings and new research in relation to T1DM), or signs of activity from other users [43,47]. As with the healthcare professionals, young people [47] and their parents [48] are also concerned with whether the website appears to be professional, reliable and trustworthy. The researchers found that password-enabled portals/websites could generate access issues which may result in discontinued use; participants proposed the use of a largely open portal which can be accessed by important people in the child's life (e.g., school personnel, relatives and friends for information about T1DM) which could lead to greater feelings of social support and understanding [43].

In summary, there is a wealth of online materials surrounding self-management in T1DM, although it has been emphasised that many of the publicly accessible online resources that are currently commercially available for T1DM are not informed by the needs of users, and are not based on evidence-based principles for diabetes care [49]. The current evidence shows that healthcare professionals, young people with T1DM and their parents have positive perceptions towards evidence-based web interventions and online patient web portals that have been developed by, or in collaboration with, healthcare teams. Internet-delivered applications have potential to enhance

self-management and provide psychosocial support. However, there is scope for further research to test the efficacy of online patient portals and other web-based interventions in improving patient behavioural and clinical outcomes.

#### **Email**

Very few studies to date have utilised email interventions with children and young people with T1DM. The randomised study by Hanauer and colleagues [19] described above, compared text messaging with email reminders for encouraging 40 adolescents and young adults aged 12-25 years to engage in regular blood glucose monitoring. The authors demonstrated that it is feasible to implement a fully automated system to engage youth with diabetes. However, in this study, the adolescents were more responsive to messaging delivered by mobile phone text than by email. This may be due to the ubiquitous nature of mobile technologies and 'texting' amongst young people; indeed the majority of those participants who did not engage with the intervention at all were those randomised to the email group.

More recently, email messaging has been used in an intervention that targeted parents of children with T1DM. Toscos [32] randomised 48 children aged less than 12 years (mean 8.8 years) with T1DM to a control group (conventional care without technology) or an experimental group. Participants in the experimental group received conventional care plus an 'Automated Diabetes Management System' (ADMS), which automatically collected blood glucose values and sent an email to parents each night with a 21-day blood glucose trending report for their child. After 12 months, children in the experimental group were more meticulous in self-care behaviours, and had significantly lower HbA1c levels compared to children in the control group, particularly amongst those families who used the ADMS more frequently. Although these findings are promising regarding the use of automated emails for communicating tailored blood glucose information to parents of children with T1DM, further research is required to assess whether there is value in pursuing the development of email interventions for messaging directly to adolescents, and to assess the perceptions of healthcare professionals towards the use of automated or healthcare practitioner-delivered email messaging.

#### **Videoconferencing / Skype**

Videoconferencing software (e.g., Skype) is recognised as a communication technology that could potentially be used to deliver healthcare consultations that do not necessarily need to be delivered in clinic. The clinical use of Skype is

most prevalent in the management of chronic diseases and has shown to be a feasible and pragmatic approach to providing telemedicine services [50], although the clinical and economic benefits are not well understood. There are few published evaluations of the emerging use of these technologies in healthcare environments and whether they help, or hinder advice giving, clinical outcomes or the therapeutic relationship. Freeman [51] conducted a randomised trial with seventy-one adolescents aged 12-19 years old with poorly controlled T1DM, and their caregivers. Adolescents paired with one family caregiver were randomised to an in-clinic or a Skype condition to receive up to 10 sessions of a family-based behavioural health intervention (previously shown to improve adherence to diabetes regimens and family functioning). At the end of treatment, no significant differences were found in therapeutic alliance between the two groups, which indicated that behavioural health care can be delivered to adolescents with T1DM via videoconferencing technology without compromising the therapeutic relationship between healthcare professionals and their patients. Freeman and colleagues [51] present an important finding since patient adherence to treatment regimens is associated with the patient-practitioner relationship and therapeutic alliance.

Regular phone and video communication by therapists (several times per week over a series of months) has been used to improve family functioning and diabetes management in adolescents with repeated hospitalisations for diabetic ketoacidosis or poor glycaemic control [52]. Adolescents participating in this study had improved glycaemic control and all avoided hospitalisation during the intervention period. Videoconferencing using Skype has been used to support exchange of diabetes-related information in monthly meetings between school nurses, students, diabetes professionals and parents, in combination with delivery of online diabetes education modules for completion by the school nurse and school educators [53]. Participants in the intervention group had fewer urgent school nurse visits and acute events such as hospitalisations and emergency department visits, and felt better equipped for aspects of self-care in the school setting.

This is an emerging area of research with a limited evidence-base (Table 3), although this study suggests that videoconferencing technologies may be useful for delivery of healthcare, particularly for families who may otherwise struggle to attend clinic-based interventions. Further research is needed to draw firm conclusions, and to investigate

the behavioural, clinical and cost-effectiveness outcomes of healthcare delivery via this method.

#### **Personal Digital Assistants (PDAs) / Handheld Wireless Devices**

The popularity of Personal Digital Assistants (PDAs) was relatively short-lived, and as such there are few current studies utilising PDAs or other handheld devices with children and young people with T1DM (Table 3).

In a randomised study with 40 children and adolescents aged 8-18 years, Kumar and colleagues [54] compared control participants (using only PDAs) with intervention participants (receiving PDAs plus a motivational game). The motivational game used in the intervention involved participants having to guess a blood glucose level, following the collection of three earlier blood glucose readings. Although the study did not have a true 'no intervention' control group, findings suggested that the motivational game was beneficial when added to the PDA. Those in the motivational game group had significantly less instances of hyperglycaemia, significant increases in diabetes-related knowledge and a non-significant trend towards improved HbA1c levels.

Researchers have examined the acceptability of a PDA intervention for promoting self-management in children and young people with T1DM [55]. In a one-month intervention, 40 participants aged 8-18 years were provided with a blood glucose meter enabled with an infrared port to upload their data to a PDA, which transmitted data directly to a central secure server. Children and their parents viewed the intervention positively. Families agreed that the automatic downloading of data to the PDA helped them to self-monitor their blood glucose. The majority of participants felt positively about their data being made available to their healthcare team. Although the researchers found that a high proportion of the sample self-reported 'beaming' their blood glucose results once per day, only a small proportion did this each time their blood glucose was checked, emphasising the need to maintain realistic expectations about the use of technology in T1DM self-management for busy families.

The interventions show that children and young people with T1DM are receptive to the use of technology and have indicated the potential value of handheld devices such as PDAs at the time the studies were conducted. However, the use of PDAs in the mass market has largely been replaced with newer technologies such as smartphones and tablet computers (e.g., iPads), which often have integrated email and mobile technology.

#### **Conclusions:**

Managing diabetes in childhood and adolescence is challenging and complex given the social and psychological demands of the condition. Telemedicine and mHealth is an exciting, but emerging field in paediatric diabetes. The evidence is limited, but suggests that young people with T1DM and their families are able to adapt to and implement new technologies to facilitate blood glucose monitoring and other aspects of diabetes self-management. Qualitative studies have demonstrated that technology is largely acceptable to young people and their families, when used to support or deliver health advice, promote self-care behaviours and support communication within the therapeutic relationship.

Much of the evidence is drawn from feasibility studies focusing on the design and implementation of interventions, and their delivery in single cohorts. As such, studies are predominantly based on small samples with children and adolescents of diverse age ranges (and/or their parents). However, they provide important information about the usability of technological interventions and user satisfaction, with some studies suggesting there may be potential for improved diabetes-related knowledge, self-care practices (e.g., blood glucose monitoring) and diabetes control (e.g., HbA1c). Existing interventions are heterogenous in nature in that they utilise diverse technologies, lack homogeneity in intervention type and duration, vary with regards target audiences and age range of participants. Some studies target young people and others involve parents or family members. It is therefore difficult to make direct comparisons between the findings of published studies.

Research designs are diverse, and only a small number of studies have experimental designs. There are relatively few randomised controlled trials assessing behavioural, clinical or cost-effectiveness outcomes of technology-based interventions for children and young people with T1DM and their families. Those available tend to measure clinical outcomes (e.g., HbA1c) with few assessing self-efficacy or other psychosocial outcomes that may be important in sustaining self-care behaviours. Importantly, few interventions are informed by behavioural change theory (or this has not been well-described in the published research). The lack of studies using rigorous and robust methodological designs means that it is difficult to assess whether there are significant and consistent outcomes for technology-based intervention in young people with T1DM.

As such, it is difficult to assess the true value of these technology-based interventions in improving diabetes self-management, or to determine which types of technologies may be most beneficial. Studies are needed with longer follow-up periods, that investigate the potential of technology-based interventions both in improving, and sustaining, self-care practices over time to engender longer-term diabetes control. Our conclusion parallels the findings of previous reviews in T1DM [11,12,56-58]. There is a need to improve both the quantity and quality of telemedicine and mHealth intervention research in T1DM to realise the full potential of technology-based interventions for this complex condition.

### **Recommendations**

Future research should strive to address the methodological issues reported above. That is, in order to establish the overall efficacy of technology-based interventions, more research is needed that uses larger samples, and random allocation of participants to experimental and control conditions. Outcome measures should be assessed over longer time periods to determine the longer-term implications for physical and psychosocial wellbeing. Since HbA1c levels can increase in adolescence, it may be important to randomise, or at least control for HbA1c in future studies, as suggested previously [36]. Technical issues such as battery life, software malfunctioning should be closely considered and improved on; whilst seemingly minor these issues can be impactful with regards user satisfaction. Lastly, we recommend that full consideration is given to level of interactivity and engagement within the intervention, since those interventions that are most 'engaging' appear to result in better intervention adherence. Based on the findings of this review, we would argue that technology-based interventions are commonly well-accepted by users, and have great potential for improving the health and wellbeing of target patient groups. However, more research efforts are required to fully determine the clinical efficacy of technology-based interventions, and to ascertain the nature of those interventions that have the greatest impact on clinical outcomes and psychosocial wellbeing in young people with T1DM and their families.

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