



Peer Support Interventions on Digital Platforms for Children With Type 1 Diabetes and Their Caregivers

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Peer support for children with type 1 diabetes and their caregivers has been recognized as a key component in diabetes management and mental health. In this era of digitization, support programs delivered via technology are growing rapidly, particularly with increased access to technology and social media. Although the development of different digital modalities for this purpose is in its early stages, five different types of digital platforms have been recognized: voice, text, website, video, and social media. This article discusses the significance of peer support and explores various digital peer support interventions in pediatric patients with type 1 diabetes (0–18 years of age) and their caregivers.

The worldwide prevalence of type 1 diabetes (T1D) is 5.9 per 10,000 people, and the United States has observed a 21.1% rise in prevalence among youth aged 0–19 years (1,2). The intensive treatment regimen for T1D is complex and demanding, requiring multiple daily doses of insulin (by injections or insulin pump), frequent monitoring of blood glucose levels, carbohydrate counting, and insulin dose adjustments. Not surprisingly, the burden of chronic illness management rests largely on individuals with the illness and their caregivers.

Young children are diagnosed with T1D before they develop the skills to perform the complex tasks of managing diabetes independently. Thus, the involvement of parents as primary caregivers is essential. Parents must adapt emotionally to the chronic illness that will potentially affect their child's length and quality of life. Furthermore, they must gain an understanding of T1D childcare and also educate other family members. The constant fear of complications such as severe hypoglycemia, as well as daily struggles with managing their child's blood glucose, often leads to parental burnout. These burdens may also contribute to psychosocial distress, as they cause disruptions in caregivers' roles, family routines, and expectations for the future. Inevitably, parental psychological distress is associated with poor diabetes management, higher levels of child-reported stress and depressive symptoms, problematic child behavior, and poor quality of life (3).

The transition from adolescence to young adulthood presents another challenging developmental phase of life. In

addition to dealing with hormonal and physical changes, adolescents seek greater independence from parents and develop stronger ties with their peers. These normative development expectations, coupled with the burden of T1D, magnify stress around T1D management. Although teens and adolescents are concerned about glycemic control, other outcomes, including emotional and physical well-being, peer relationships, and academic performance, are equally, if not more, important. These relentless worries increase the psychological burden of living with T1D and can lead to poor treatment adherence and glycemic control.

Because controlling T1D in children and adolescents is significantly more challenging than in other age-groups, it is essential to develop interventions that are responsive to their unique needs and can be used across different settings, including home and school. The importance of social context and relationships is underscored by mounting evidence for the clinical and psychosocial benefits associated with peer support (4,5). Social support from peers has been rated important by adolescents with T1D, as peers can influence both psychosocial outcomes and diabetes self-management skills. As children grow to be teenagers and transition to adulthood, peers are more likely than family members to provide companionship and emotional support around diabetes care (4). Not only has peer support been related to decreased social isolation and decreased stress (6), but peer support programs for

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caregivers of children with T1D have been found to lead to reductions in stress and conflict within families. Such programs help parents develop better coping strategies, feel less apprehensive, and develop more confidence (7,8).

Most peer support models to date have been implemented through direct in-person programs. However, barriers to mobilizing peer support through such programs have limited the participation of both patients and caregivers. The main barriers identified are logistical challenges and lack of engagement. The logistical challenges include inconvenient meeting time, limited access to support groups, distance to the venue, and associated costs, including for travel and lost wages (9,10). The interpersonal barriers leading to lack of engagement and low motivation are related to differences in sociocultural background and linguistics, with discomfort in sharing personal experiences of living with T1D (10,11). Moreover, as the coronavirus disease 2019 (COVID-19) pandemic has forced a paradigm shift in the way we interact with patients and their families, innovative approaches to circumvent the traditional in-person peer support model are urgently needed (12). To overcome these barriers, we need to explore alternative solutions such as technology-based peer support.

In this article, we highlight approaches to extending conventional peer support programs to reach wider and more diverse communities via innovative use of technology. We provide a brief overview of different technology-based approaches to mobilizing peer support of children with T1D and their caregivers. These models often use platforms such as telephone, Web pages, social media platforms, and mobile applications (apps) to deliver peer support.

Understanding Peer Support

Peer support is defined as “support from a person who has experiential knowledge of a specific behavior or stressor and similar characteristics as the target population” (13). Peers who have similar experiences relate better, often have more valuable self-management strategies to share, and offer more empathy and validation than nonpeers. Although there has been a lack of standardization in the delivery and measurement of peer support services and opportunities, there has been a simultaneous increase in openness toward the value and importance of peer support. The success of peer support has been linked to the nonhierarchical and reciprocal relationships between peers and members of the target population that are shaped through sharing of similar experiential knowledge of a specific stressor and behaviors.

The American Diabetes Association identifies four critical time points during which people with diabetes should be provided diabetes self-management education: at diagnosis,

annually, when complications develop, and during the transition from adolescence to adulthood (14). Provision of multidimensional support during these stages and mileposts on the diabetes journey may foster psychosocial adaptation for children and families affected by chronic illnesses such as diabetes. There are four types of support offered by peers: 1) emotional support to encourage self-management and coping with negative emotions (i.e., care, empathy, and trust), 2) instrumental support encouraging linkages to clinical care and community resources (i.e., tangible aid or service), 3) informational support (i.e., the provision of knowledge relevant to problem-solving through the mechanisms of advice, suggestions, factual input, and feedback), and 4) appraisal support (i.e., ongoing help that reflects the lifelong nature of the disease and affirms the appropriateness of emotions, cognitions, and behaviors).

Peers are expected to share life experiences and lessons learned, but at the same time should not function as an extension of the medical diabetes team. According to Simmons et al. (15), support can be viewed on a continuum from directive to nondirective support, with unequivocal instruction through education and training on the former end and poorly informed advice that introduces confusion on the latter end. Figure 1 illustrates how peer support should lie at the intersection of two dimensions: the nature of support and that of relationship. This framework can be used to conceptualize potential peers as more than just illness companions (15).

Digitization of Peer Support Interventions

Technology-based (digital) peer support is defined as live or automated peer support services delivered through technology media, lowering the barriers to communication with peers (16) (Supplementary Table S1). Digitization offers the potential for improved accessibility, time flexibility, and the efficiency of resource use by eliminating geographical and scheduling barriers. Based on the social cognitive theory, it builds peer-to-peer networks and delivers peer interventions through synchronous and asynchronous technologies. Figure 2 depicts the hypothesized impact of peer support on improving T1D-related outcomes in patients and their caregivers.

In general, traditional peer support models include professional-led group visits, peer-led sessions, face-to-face self-management, peer coaches and mentors, community health worker-led programs, and support groups. Newer technology supplies novel forms of participatory communication and flexibility in implementation of these models that may render peer support programs more attractive to

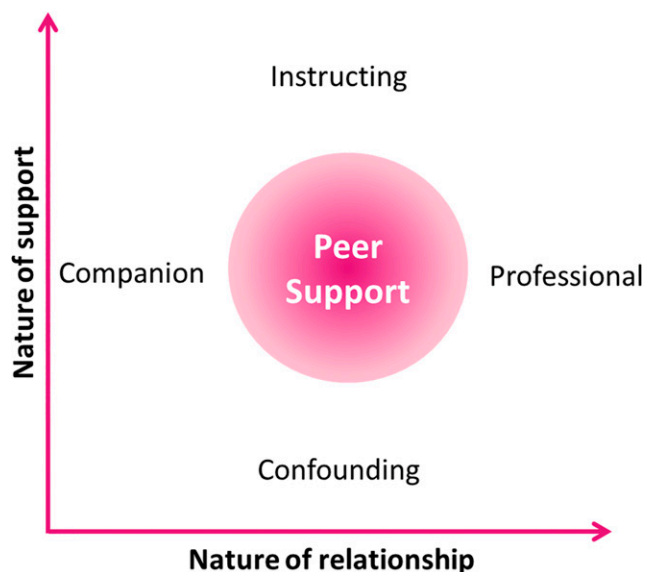


FIGURE 1 Locating peer support at the intersection of two dimensions (15).

children and their caregivers. A growing number of studies have evaluated the effectiveness of implementing such interventions in people with T1D and their caregivers to bring about better health outcomes. Digital peer support can be delivered by 1) telephone, 2) text messaging, 3) Web portals and mobile apps, 4) videoconferencing, and 5) social media platforms. However, these novel approaches are all still in their infancy. Supplementary Table S2 briefly describes these technology-based peer support interventions.

Telephone-Based Peer Support

Voice-based telephonic interventions are implemented as stand-alone programs or sometimes in conjunction with another intervention to provide support between scheduled visits with the diabetes clinic team. This approach is most frequently used to implement peer coach-based or peer mentor-based social support among parents of children with newly diagnosed T1D. Peers are connected

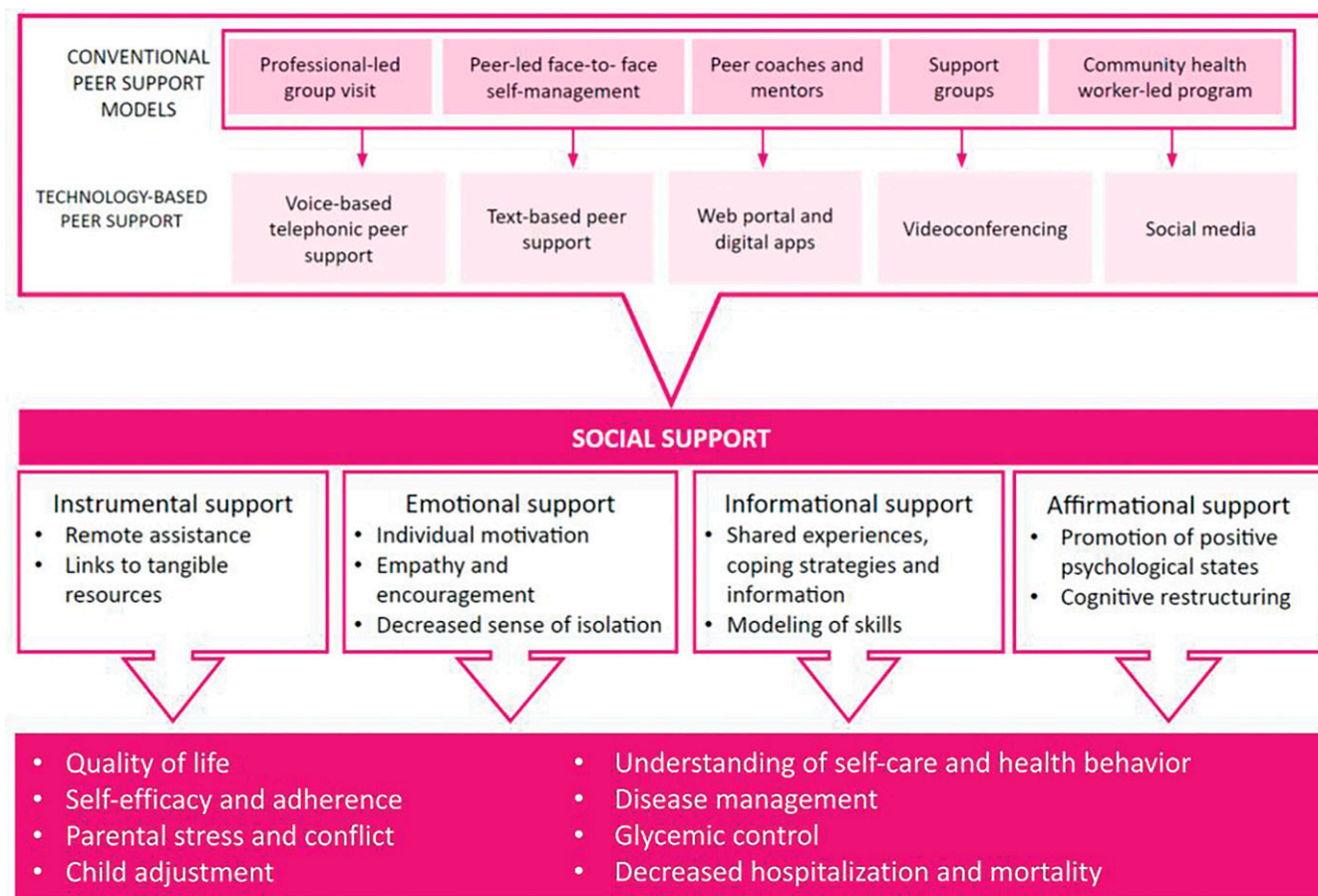


FIGURE 2 Hypothesized impact of peer support.

through a professional member of the diabetes care team. For example, Sullivan-Bolyai et al. (17) trained parent coaches to provide guidance and support through home visits and phone calls to parents of children with T1D. Parent mentors delivered practical, day-to-day management information, reassurance, and emotional support. After participation in this intervention, recipient parents reported fewer concerns, less perceived diabetes-related negative impact on the family, and greater confidence with regard to diabetes management (fathers only) (8,17).

Although this model addresses access barriers, some participants express apprehension regarding exchanging telephone numbers and are hesitant to participate because of associated cost and time constraints. Technology has generated a solution to overcome this barrier: the use of an interactive voice response (IVR) exchange platform, which ensures anonymity and privacy (18). IVR does not require the exchange of phone numbers, and calls between peers can be scheduled based on their availability and convenience. This is an internet-monitored system that does not require any additional service access besides possession of a telephone. Participants dial a designated toll-free IVR number to contact their peers using an identification code.

A trial using an IVR system to provide telephone-based peer support to young adults living with T1D found high levels of participation and satisfaction with the program (19). However, to the best of our knowledge, the efficacy of IVR in providing peer support in children living with T1D and their parents/caregivers has not been explored extensively.

Text-Based Peer Support

Text messaging via mobile phone not only provides an inexpensive portable mode of social communication, but also, with the potential to engage young people with diabetes, has been used to deliver health care information, reminders, lifestyle interventions, and, more recently, peer support. The traditional model of facilitating peer interaction via text messages faces barriers similar to those of voice-based telephone peer support programs. Hence, a system such as IVR is used to implement text-based support, which allows users to schedule, select, and define the frequency of messages.

In this format, peer support is provided via two distinct modes. The first is through individually tailored motivational text messages derived from peers. These messages are delivered based on user-set diabetes management goals. Messages focus on barriers such as burnout and stress; sports and exercise; communication; social support and

stigma; time pressure; and planning, reminders, diet, and autonomy support. The SuperEgo program, developed by Mulvaney et al. (20), provides affirmational support and motivates users to manage their diabetes through automated tailored messages. Although participants reported the program to be appealing, experienced encouragement around self-care, and felt less isolated and embarrassed, no significant impact on A1C was observed. The second mode centers on users nominating other peers as part of their support team, allowing these peers to contribute messages for the individual with diabetes. It is still in the nascent stage (21).

With little or no additional clinical effort, the text-based model is a socially acceptable low-cost peer support modality and has the potential to improve clinical outcomes for adolescents with T1D. A recent, multifaceted feasibility study of peer mentorship programs, including text messaging and social events, showed encouraging results (22). Designed to deliver a unique form of push support (i.e., favoring motivated participants), it garnered high reported levels of satisfaction and usability, and its most valued components were increased networking and social support. The program's mentors expressed improved glycemic control in themselves, and more mentees adhered to their routine endocrinology visits (22).

Web- and Mobile App-Based Peer Support

Web portals and mobile apps have been extensively used to improve adherence and glycemic control in patients with diabetes through reminders, tracking of blood glucose levels, and help in modulating insulin therapy. These two platforms are now being explored as a means of providing children with T1D and their parents/caregivers with access to information and peer support. Having the potential to do so in a timely and effective way allows easily accessible contact with peers and the diabetes care team. Availability of both synchronous and asynchronous mechanisms of seeking support has resulted in clinical and psychosocial improvement among users. Access to this form of digital technology is secured using two-factor authentication that includes a username-password combination and a personalized text-message code in the login procedure.

Web- and app-based interventions often consist of three different sub-interventions executed under the supervision of the diabetes care team (23,24). The foremost sub-intervention is social support, facilitated through a chat line, forum app, and blog app. The second sub-intervention is clinical support, and the third is informational support.

Sugarsquare is a chatline program that involves all three sub-interventions and was developed for Dutch parents and their children with T1D. This program is moderated by health care professionals (HCPs) and includes scheduled weekly group meetings to discuss predetermined topics. To maintain anonymity, each participant uses a nickname. Because of the anonymous nature of the chatline, this program delivers all five types of social support (25). Similarly, the forum and blog apps allow not only children with T1D, but also their parents to share their experiences. These apps are open to all users and monitored by HCPs. Post-intervention evaluations demonstrated that Sugarsquare has moderate acceptability and demand (23,26). Although clinical outcomes were not assessed, an improvement in quality of life was reported in children, with no increase in the stress levels of parents.

The remaining two sub-interventions focus on clinical support. In the context of Sugarsquare, clinical support takes the form of an app that provides an overview of treatment goals, tracks data from digital meters and insulin pumps, includes a diabetes diary, and allows for easily accessible private contact with HCPs. The app is used for nonurgent care and is often targeted to caregivers of children with T1D and used to discuss children's treatment and well-being. Moreover, information support (i.e., providing disease-related information) is presented through downloadable documents and Web links prepared by the diabetes care team. The app also allows users to add their own Web links after the diabetes care team confirms that these sites are reliable sources of information for other caregivers. Future studies should determine how such programs could improve clinical outcomes and affect parents' quality of life.

Videoconferencing-Based Peer Support

Traditionally, videoconferencing has been in use to facilitate communication between experts and remote health care teams. As more facilities are moving to telemedicine as a routine mode of providing outpatient care, there are new demands on health care systems to meet the needs of patients. Many facilities are now rapidly expanding telemedicine services to facilitate patient care, including support groups for youth with T1D and their caregivers. In addition to Web portal-based interventions, technology renders it possible to continue traditional supportive interactions with peers through videoconferencing.

As one example, a recent experiment conducted in Sweden used videoconferencing as a model for a peer support intervention for parents of children with T1D called

REDChiP (Reduce the Emotional Distress of Childhood Hypoglycemia in Parents) (27). The program consisted of 10 sessions lasting 30–60 minutes each and delivered via real-time videoconferencing facilitated by HCPs, with assigned time for peer discussion. These sessions focused on reviewing diabetes management skills, goal-setting, and problem-solving techniques, parenting strategies, and personal coping strategies to manage the fear of hypoglycemia. In addition to getting support from peers, parents also worked with HCPs to develop a T1D-related fear hierarchy and learned to identify and challenge cognitive distortion related to their fear of hypoglycemia. In this intervention, parents observed significant reductions in fear for hypoglycemia, the frequency of parenting stress, and perceived diabetes distress, along with a significant improvement in glycemic control for their children (28).

Another program used prerecorded videos from patients with T1D, parents of children with T1D, and medical experts. The target audience for these videos was children with T1D, and the aim was to improve their psychosocial outcomes. This project yielded a decrease in the yearly incidence of severe hypoglycemia, although a decrease in A1C was not observed (29).

The newer video-based telehealth interventions such as REDChiP have demonstrated initial feasibility and acceptability. There is some evidence supporting their efficacy in reducing fear of hypoglycemia and stress in parents of children with T1D. Thus, they may help parents of very young children with T1D to better achieve optimal glycemic control in their children. Key aspects of the intervention that helped parents to achieve self-perceived positive outcomes include increasing knowledge of diabetes management skills, parenting strategies, and coping strategies; building confidence with regard to handling fear-inducing situations; and being afforded opportunities to improve support systems (28). These will be important components to include in future interventions for parents of children with T1D. The next steps include determining the intervention's impact on objective parent and child outcomes, as well as large-scale efficacy testing.

Social Media-Based Peer Support

Often referred to as a two-way communication tool, social media enables social support and interaction in the online community. It provides opportunities for users to generate, share, receive, and comment on social content among the multiuser community. The platform can overlap among the various services that allow different communication channels such as social networking (Facebook), microblogging (Twitter), instant messaging (WhatsApp), video

sharing (YouTube), photo sharing (Instagram), and file sharing (Dropbox). Users are willing to share highly personal information on social media, including thoughts, feelings, and behaviors that they typically would not disclose because of stigma or embarrassment. The online community provides many avenues for peer support and also serves as a tool of empowerment.

Given its popularity among teenagers, this model comes with some limitations such as lack of reliability, quality concerns, lack of confidentiality and privacy, risks of disclosing personal information online, and risks of disseminating misinformation. Hence, these social media communities often are closed groups directed by HCPs, to which access is granted to prevent fake users and promote reliable information. For example, a feasibility trial developed and observed a high acceptance rate for a peer support community for adolescents with T1D on Instagram through which participants shared photos that represented their diabetes journey (30). Another study found that children with T1D using a social media community in everyday practice achieved better glycemic control (2). Various other organizations such as JDRC have developed peer support communities using virtual platforms and allowing use by caregivers as well. However, the impacts on clinical and psychosocial outcomes are mixed.

Future Implications

Peer support delivered by technology is a potentially flexible and low-cost approach to supplement formal health care support. Looking ahead, technology will play a greater role in diabetes treatment and management, particularly through advances in medical apps and devices linked to smartphone and digital tablet cameras. Although there is still much to learn about these modalities, carefully designed and implemented digital peer support interventions can be a powerful way to promote physical and mental health among children with T1D and their caregivers.

Discussions about remote telemedicine are rapidly increasing as a result of the COVID-19 pandemic. With the isolation and stay-in-place restrictions related to COVID-19, digital peer support platforms might reduce the depression and loneliness people could experience when forced to stay in the confines of their home for extended periods. Beyond the pandemic, these modalities may offer an alternative means to improve the efficiency and cost-effectiveness of care for people with diabetes.

Many current digital peer support interventions have not been explored and evaluated rigorously. This research area calls for a better understanding of which type of

digital peer support program is best for different age-groups within the pediatric T1D population and how to integrate different modes of peer support digitization into other health informatics systems and clinical diabetes care services. Further investigation exploring patterns of use in different age-groups and clinical subpopulations would be valuable, as would studies of the personal and contextual factors influencing the adoption of such technology. Additionally, future research examining other outcomes such as health care utilization and cost-effectiveness may be warranted to evaluate the effect of such interventions on health care usage and costs.

DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

AUTHOR CONTRIBUTIONS

R.T. researched literature and wrote the manuscript. S.A. and T.S.T. reviewed and edited the manuscript and contributed to discussion. All listed authors are the guarantors of this work and, as such, had full access to all the data reported and take responsibility for the integrity of the data and the accuracy of the review.

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