Life with type 1 diabetes (T1D) outside clinic: Connecting online, in person, and through diabetes organizations

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ABSTRACT

Objective: As most T1D management occurs outside of formal healthcare settings, opportunities for people with T1D and their parents/partners to connect with one another online, in-person, and through diabetes organizations may supplement care. Provider awareness of these activities may support comprehensive care, yet little is known about these experiences and their impact on quality of life with T1D. Methods: As part of a larger qualitative study, 43 youth and adults with T1D and 36 parents and partners participated in semi-structured interviews about diabetes health-related quality of life, including experiences with diabetes organizations and online or in-person interactions with others with T1D. Interview transcripts were coded and analyzed to derive themes about positive and negative aspects of these connections. Results: Positive aspects included feeling less isolated and more empowered through receiving social/emotional support, helping others with T1D, having enhanced access to information/resources, and participating in T1D-related advocacy. Barriers to engagement included having limited time to explore opportunities to become involved, having had previous negative experiences, and wanting a “break” from T1D. While participants in all groups commented, parents tended to share the most perspectives about involvement with other families with T1D and diabetes organizations, and several described it as a source of meaning in the context of the challenges of T1D. Conclusions: Many people with T1D and their parents/partners derive a variety of benefits from engaging with others with T1D online, in-person, or through diabetes organizations. Yet for some, the positives do not outweigh the negatives. Understanding individuals’ and families’ experiences with diabetes community involvement may help providers connect their patients with the most appropriate sources of support for the challenges of living with T1D outside of clinic.

METHODS & PARTICIPANTS

• As part of a large qualitative study on diabetes-related quality of life, 43 people with T1D (age 12-89 yrs.), 23 parents, and 13 partners were interviewed about health-related quality of life.
• This analysis focuses on responses related to the diabetes community, including responses to questions about sources of T1D-related support and participation in online or in-person activities.
• Interviews were recorded and transcribed verbatim before coding.
• Three psychologists and three research staff reviewed transcripts to develop thematic codes, which were applied using NVivo software (25% double-coded).

RESULTS

• Participant described both positive experiences and challenges to interacting with other people with T1D online, in-person, and through diabetes organizations.
• Participants in all groups (youth and adults with diabetes, parents, and partners) commented about this topic. Parents tended to share the most about interactions with the diabetes community.

Benefits to Engagement

Social/emotional support decreases isolation, increases sense of empowerment

“When I’m having a diabetes emotional crisis I call one of the moms who has children with diabetes and get it. It frustrates me when doctors are like, “I understand what this is like for you.” And I’m like, “No, you really don’t….” Nobody really understands. And it’s nobody’s fault… if I really want support, I have to get it from people that are living the same reality that I am.” – Parent

“I felt lonely because I thought no one else had type 1 diabetes, until I went to camp” – Child

Increased access to resources and information about T1D

“There’s a Facebook group… and people are putting stuff in there all the time. Asking questions, sharing articles, sharing experiences which I never had really done before… it’s kind of cool to be able to read about and interact with people that I’m probably never going to meet in person but just hearing their stories, just being able to share that way.” – Adult

“… I think it’s nice having that network of people… if they need help finding something, getting something just having a piece of information brought to them… If they’re going through complications for the first time, they don’t know anybody else to talk to.” – Adult

Giving back and participating in T1D-related advocacy

“I think it is the silver lining… My daughter’s had the opportunity to meet girls close to her age that are very newly diagnosed… They might not necessarily talk about diabetes, but sometimes they do. Or they might check their blood sugar at the same time. It’s mainly to help a newly diagnosed realize that you’re not alone… it’s been me, in particular, I think, a way to deal with the sadness… It’s given me an opportunity to kind of do something good with that…” – Parent

“We’ve gone to visit different congressmen, senators, things like that to talk about their diabetes to hopefully get more funding. Pretty much anything that we can get involved with, we do.” – Partner

BACKGROUND & AIDS

• Most T1D management takes place outside the healthcare setting: at home, school, work, and in day to day activities.
• Across chronic conditions, increasing access to peer support and interactions with others with the same condition may help supplement self-care and improve quality of life1.
• Peer coaching interventions for parents of youth with T1D and adults with type 2 diabetes suggest promising impact on behavioral and clinical outcomes2–5.
• However, little is known about experiences of people with T1D and family members around obtaining peer support and connecting with others in the diabetes community.
• Understanding sources of support can inform clinical approaches to support self-management and promote optimal quality of life and health outcomes.
• The goal of this study was to characterize the experiences of youth and adults with T1D and their family members with other people with T1D outside of the healthcare setting.

REFERENCES

3. Fang, et al. Research support from: The Leona M. and Harry B. Helmsley Charitable Trust (2015SG-P1D084 (Pis: M. Hilliard & B. Anderson) & NIDDK K12DK098769 (Pis: B. Anderson) Questions or inquiries may be directed to Marisa Hilliard, PhD at marisa.hilliard@bcm.edu or 832-824-7209.