

# Peer Support Through a Diabetes Social Media Community

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## Abstract

**Background:** Caregivers and individuals living with type 1 diabetes (T1D) who are members of CGM in the Cloud, a Facebook group associated with the Nightscout Project, were interviewed to assess how the online community impacted peer support.

**Methods:** Semistructured qualitative interviews were conducted with caregivers and patients who are part of CGM in the Cloud Facebook group. Interview transcripts were analyzed to identify various themes related to peer support in the online group.

**Results:** Members of the CGM in the Cloud Facebook group identified peer support through giving and receiving technical, emotional, and medical support, as well as giving back to the larger community by paying it forward. Peer support also extended beyond the online forum, connecting people in person, whether they were local or across the country.

**Conclusions:** An online community can provide many avenues for peer support through emotional and technical support, as well as serve as a tool of empowerment. The community as a whole also had a spirit of altruism that bolstered confidence in others as well as those who paid it forward.

## Keywords

type 1 diabetes, mobile technology, online community, social media, peer support

There are many reasons that individuals living with type 1 diabetes (T1D) and their caregivers seek out peer support, defined as support from a person who has “experiential knowledge of a specific behavior or stressor and similar characteristics as the target population.”<sup>1</sup> T1D is a complicated disease as patients and caregivers must perform blood sugar checks anywhere from 5 to 7 times a day, count carbohydrates at all snacks and meals, and administer insulin multiple times a day with continual adjustment of doses. Many patients and caregivers suffer mental exhaustion and report feelings of isolation<sup>2</sup> related to disease management, and report experiencing stigma associated with feelings of guilt, shame, and failure<sup>3</sup> when glycemic control proves to be difficult. While peer support has been documented in research extensively in other disease contexts<sup>4–6</sup> as well as diabetes,<sup>7–9</sup> few studies have looked at peer support in online forums.

There are a number of online patient communities in diabetes, but one community of particular interest began through the creation of the Nightscout Project.<sup>10</sup> The Nightscout Project is a do-it-yourself (DIY) mobile technology system, created by the father of a 4-year-old boy with T1D who wrote computer code that could pull glucose values from an FDA-approved

continuous glucose monitor (CGM) to the computing cloud via a mobile phone, and built corresponding mobile and web-based applications that allowed him to view the data. In collaboration with the broader diabetes community, he made the code open source and provided instructions on how to set up the system through a website and private Facebook group called CGM in the Cloud that has grown to over 27 000 members at the time of this publication. We recently conducted a quantitative survey study<sup>11</sup> that captured responses from over 1200 members of the CGM in the Cloud Facebook group and found that the majority of respondents indicated their primary use for the group were to learn more about Nightscout and to receive technological assistance while they contributed to the group by promoting it to

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others and offering technical assistance, support, or donation. We sought to expand on these findings by conducting individual interviews with members of this patient-driven online community to further examine the role of peer support using a qualitative approach.

## Methods

Participants were individuals with T1D and/or caregivers of individuals with T1D who took part in interviews with the study team. The semistructured interviews focused on their involvement with the Nightscout community and broader interest in diabetes-related research studies. Potential interviewees were recruited through a listserv of past participants in the Nightscout survey through email and social media advertising within the CGM in the Cloud Facebook group as well as other social media outlets such as Twitter. In total, 20 patient/caregiver interviews were conducted between 2016 and 2017. There were 12 males and 9 females interviewed; 15 were parents and 6 were individuals with T1D. The research study was approved by the Institutional Review Board at the University of Michigan, and informed consent was obtained prior to conducting the research interviews. Each interview lasted approximately one hour, and participants were compensated for their time.

All interviews were digitally recorded and transcribed into written text in a deidentified format. Interviews were thematically classified and analyzed by three research team members. A mutually compiled list and hierarchy of reoccurring themes was composed and agreed upon by research team members, and this shared codebook was used for analysis consistency across interviews.

## Results

We identified the following themes related to peer support that emerged from the interviews: patients/caregivers received and provided technical support related to the Nightscout system; patients/caregivers received and provided emotional support; patients/caregivers offered medical support; patients/caregivers felt compelled to give back to others in the community; patients/caregivers expanded connections from online to offline; and parents/caregivers experienced improvements in self-efficacy and empowerment. Interview questions were open-ended, which allowed participants to answer freely. With a total of 20 patient/caregiver interviews, we reached saturation in terms of qualitative analysis focus.

### *Patients and Caregivers Received Technical Support Related to the Nightscout System*

One of the original reasons the CGM in the Cloud Facebook group was created was to serve as community space for

individuals interested in building their own Nightscout setup. Setting up the Nightscout system involves a significant amount of work in terms of technical (using open-source code to pull data from the CGM, setting up a personal website for displaying data) and manual labor (soldering and assembling parts to create a “rig”). Numerous interviewees commented on how helpful the Facebook group was when they encountered a technical problem and required assistance to problem solve. Members typically requested technical assistance by posting in the group and received help via comments from other members, direct messaging, or even a phone call or FaceTime. One parent recalled reaching out to the CGM in the Cloud group and receiving technical help: “Everything was in mg/dL, and I’m in Canada and we use millimoles. So he helped me to convert it because it hadn’t been done.” Other interviewees reported positive experiences when resolving technical issues within the Facebook group, stating that “somebody’s always there to help you out, give you the answer.”

### *Patients and Caregivers Provided Technical Support Related to the Nightscout System*

Giving technical support varied from experts in the group giving very intricate technical support (eg, providing bug fixes for codes or troubleshooting specific user issues) to more basic technical support (eg, letting other members know where to purchase specific cords). Some of the interviewees were technical experts with some working full-time on programming and creating new features, or in one case, a full-time volunteer who answered technical questions in the CGM in the Cloud Facebook group in a similar format to what a help center would do. Experts were not the only ones answering questions though, as plenty of everyday members also answered technical questions to give support to others. Interviewees reported that they would respond to Facebook comment or post asking a question that they felt they could easily answer, although the frequency at which people reported doing so varied from only out of convenience to hours a week. In one case, technical help was even given in another language: “Because my husband is Portuguese . . . he even helped a family in Portugal set it up because he can communicate with them in their native language.” With a large global network of members, it is not surprising that many reported that technical help was always available and there was a wide range of skills that could be utilized by the community.

It is noteworthy to mention that since the creation of Nightscout and the formation of the CGM in the Cloud Facebook group, members continued tinkering and developing further technological advances including OpenAPS and Loop, DIY closed-loop systems that began with the Nightscout open-source code. The development of these innovative systems spurred conversation in the CGM in the Cloud Facebook

group related to the technology and how to set up the systems. In addition, as support and discussion around more general T1D topics grew in the community, a secondary, “off topic” Facebook group was formed, allowing members to continue these nontechnical conversations while keeping Nightscout-specific technical questions at the forefront of the main CGM in the Cloud group.

### ***Patients and Caregivers Received Emotional Support***

While this virtual community started as more of a technical collaboration and assistance forum, it quickly grew and became a place for members to provide emotional support and encouragement. For instance, one father explained his reasons for joining the online community: “I just kept reading the stories and I kept seeing how helpful they were and how kind they were and it really became a group that I really went to, not just for tech stuff, but just to see that supportive environment . . . so it really kind of built my confidence that you know, maybe I could do this.”

In addition to receiving encouragement that they could conquer the Nightscout setup, members also used the community to seek advice and support from others familiar with the complexity of T1D and self-management. In many parent interviews, parents remarked that when their child was first diagnosed, they had little in-person support aside from their medical team since there were few parents of a children living with T1D in their area, or no one at all who understood the anxiety and struggles a caregiver goes through to care for a child with diabetes. Despite the lack of local support, the CGM in the Cloud Facebook group offered a virtual network for these parents and families to turn to. One parent described that although they now have another family in their neighborhood with a child living with T1D, “I tend to still get most of my support from people on Facebook.” Through the expansion of technology and online community groups, emotional support can be provided virtually rather than relying on in-person relationships, especially when those relationships may not exist due to the sparse number of T1D parents in that area.

### ***Patients and Caregivers Provided Emotional Support***

As most members of the group benefited from receiving emotional support, many reciprocated and gave emotional support to others in the group. Emotional support ranged from assisting others in the group while setting up the Nightscout system to giving words of advice to other parents struggling with diabetes dilemmas such as bolusing or correcting high and/or low blood sugars. Fellow group members provided empathy to those struggling with bolusing or finding the right insulin adjustment. By sharing their common

experiences, concerns and frustrations were validated as members supported each other. Emotional support was also provided to those who were overwhelmed setting up the Nightscout rig and website, especially those who were not technology experts. As one interviewee described, “I’m not a technical person. That’s why I tell people on the page, if I can do it, then you can do it. Just sit down and take a deep breath and reach out for help if you get stuck.” Even though most group members did not personally know each other and their relationships may only exist in a virtual space, giving real-time support to one another through the shared experience of diabetes was an important aspect of belonging to this online community.

### ***Patients and Caregivers Offered Medical Support***

With an online community that largely focuses on disease management, it is not surprising that medical support was also a theme. While medical advice given by nonclinicians over the Internet may concern some, there was a general positive attitude by the interviewees as to receiving support for diabetes-related concerns. As most everyone in the community has the shared experience of dealing with the ups and downs of living with diabetes, many participants had advice to offer others in terms of disease management. In one example, a mother found a local family via the online community and met in person to watch a Dexcom sensor be placed on their child, which eased her and her daughter’s anxiety of placing a CGM sensor. As T1D management has many intricacies, peer medical support can help ease the burden of disease management.

### ***Patients and Caregivers Felt Compelled to Give Back to Others in the Community***

A common theme of altruism was also identified through the series of interview within this online community. There was a shared value of wanting to “pay it forward” to others because they benefited from others’ help at least one time, if not multiple times. This moral desire to help others compelled members to do things like stay on the phone for hours helping a complete stranger set up their equipment because someone previously did the same for them, or more tangible help such as shipping diabetes equipment (ie, CGM receivers) to anyone in need if they had a spare. Other interviewees reported they donated to the Nightscout Foundation as a way to give back, or gave by donating their data to research to hopefully contribute to meaningful research projects and outcomes for diabetes. Another interviewee is now officially involved with the Nightscout support team because of her experience receiving help setting up the system. Nearly everyone interviewed expressed gratitude for other members within CGM in the Cloud community and a desire to make a difference to someone else.

### *Patients and Caregivers Expanded Connections From Online to Offline*

While the majority of the peer support originated online in the Facebook group and members were virtually strangers to each other, there were some instances where online connections expanded to in-person meet-ups. For instance, one Nightscout expert invited people from the CGM in the Cloud Facebook group to have a “build party” in her home, which included soldering parts together and coding to set up their Nightscout system. Over 80 people attended the event which not only achieved the goal of building the Nightscout setup, but also fostered a collaborative environment where strangers came together to accomplish a common goal through peer support. Reflecting on this experience, the host shared: “I find that, for me, the most interesting part of getting that many people together is... you have 80 people that understand what you’re going through and get it, and, might have new ideas how to do something that you’ve never done before. So the community aspect has sort of been a really cool byproduct of a technical solution.” One attendee of the event shared that “this was the most exciting thing I’ve been invited to since my kid was diagnosed.”

Other instances of forming relationships through the online community were revealed by other interviewees which included meeting a family for dinner while out of state since the families had previously spent hours on the phone to get Nightscout setup. Not only did this community connect people via long distance, but also brought more awareness to local families who didn’t know each other until joining the online group. These connections may have started virtually within the online community, but became a bridge to connect people in person and further provide meaningful technical, emotional, or medical support.

### *Parents and Caregivers Experienced Improvements in Self-Efficacy and Empowerment*

Finally, members of the CGM in the Cloud Facebook group who shared their own knowledge in the online community reported an increase in their own self-efficacy and sense of empowerment. Interviewees reported that the experience of contributing in a meaningful way gave them a sense of empowerment to provide assistance to others, no matter how small the contribution was.

## **Discussion**

Members of the CGM in the Cloud Facebook group provided peer support through giving and receiving technical, emotional, and medical support, as well as giving back to the larger online community in meaningful ways. These findings are consistent with previous literature on the role online communities play as a resource for patients and caregivers to

receive peer support<sup>12,13</sup> as well as health information,<sup>14</sup> and further deepens our understanding of the nature of participation and contribution in the CGM in the Cloud community.

In our previous work surveying CGM in the Cloud members, 15% people in the community reported that they did something to “pay it forward.”<sup>11</sup> As a community initially focused on a DIY technology system, one would assume that only technically savvy individuals could make a meaningful contribution. However, in this qualitative analysis, we found that a majority of participants, regardless of their level of technological skill or ability, declared that they contributed to the group. The reciprocity of giving and receiving assistance makes this group unique as there is ample motivation from members to continue the spirit of altruism and contribution; to date the size of the group continues to grow.

This study provides additional evidence to support the link between peer support and self-efficacy. Previous literature<sup>15</sup> shows that participation in chronic disease online support communities by contributing information, sharing experiences, and helping others can empower patients by making them better informed, enhancing their self-esteem, and increasing their optimism. Peer interventions using social media may represent a cost-effective and scalable strategy for improving self-efficacy and achieving better diabetes outcomes in the long term.

We recognize that a limitation of our results could be that CGM in the Cloud members may be more motivated to search for and give health support on Facebook compared with individuals from the general diabetes population as they have already proactively built their own DIY remote monitoring system. We note that although negative responses were allowed, participants were nearly universally positive in their comments about the CGM in the Cloud community, which may be a reflection of the fact that the small sample of individuals who agreed to participate in our qualitative interviews may be different than those who chose not to participate.

In addition, the CGM in the Cloud Facebook group originated to help parents keep watch over their child at night and remotely with the Nightscout system, which is why there are more parents and fewer individuals with T1D who use this group today. Because the majority of our participants were parents who acted as caregivers for their child with T1D, we acknowledge that their perspective may be overrepresented in this interview population and may differ from those living with T1D. However, we note that this is indicative of the community, based on our previous study which revealed an overall proportion of approximately 80% caregivers and 20% individuals with diabetes.<sup>16</sup>

## **Conclusions**

Insights gleaned from this research can be applied to a wider network of online communities and chronic diseases as a way to foster peer support. People who understand the lived

experience, whether they are a caregiver or person living with the disease, are experts in their own disease management and often have valuable strategies of self-management to share with others. Some patients with chronic disease may feel isolated if they do not have others in their social circle who understand the nature of their condition on a deeper level, and online communities are a powerful tool to bridge the gap of peer support beyond their geographic confines.

### Abbreviations

CGM, continuous glucose monitor; DIY, do it yourself; T1D, type 1 diabetes.

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The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: JML is a consultant to T1D Exchange (formerly Unitio, Inc) and receives grant funding from Lenovo. She has no other relationships or activities that could appear to have influenced the submitted work. The other authors have no conflicts of interest to report.

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