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Building Bridges Through Collaboration and Consensus: Expanding Awareness and Use of Peer Support and Peer Support Communities Among People With Diabetes, Caregivers, and Health Care Providers

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Abstract

Diabetes, regardless of type, is a complex disease. Successful management to achieve both short- and long-term health goals and outcomes is highly dependent on learning, mastery, and regular implementation and execution of self-care behaviors. The importance of a positive mental outlook and minimization of psychosocial barriers to care is increasingly identified as important in managing the whole person with diabetes and, as appropriate, the caregivers. Ongoing support from HCP and increasingly ongoing support from peers are critical elements of quality diabetes care. With the availability of virtually accessible technologies for social media and networking, the volume of peer support among people with diabetes and their caregivers has increased exponentially and will likely continue to do so. With the value of ongoing peer support recognized as an important element in diabetes health, a growing number of peer support communities and increasing engagement in these communities among some diabetes educators, the American Association of Diabetes Educators (AADE) embarked on an initiative to more formally work with diabetes peer support communities and their leaders. To initiate this effort AADE held and supported a consensus meeting in 2017. This article reviews the history and goals of this effort and details the meeting outcomes. It also discusses the collaborations completed since the initial meeting along with plans for the near future. This collaboration is unique and presents a model for similar endeavors in diabetes or other chronic diseases.

Keywords

diabetes online community, diabetes self-management education and support (DSMES), peer support, peer support communities, people with diabetes and their caregivers

The criticality of self-care in diabetes management to achieve positive short- and long-term outcomes is well documented.[1,2] Research demonstrates that education on and implementation of positive self-care behaviors, such as the AADE7 Self-Care Behaviors™,[3] supplemented with ongoing support delivery by clinicians and/or peers using an array of models can improve clinical[1,2] and psychosocial parameters.[4] Technology has enabled the availability and use of virtual diabetes peer support. Social media and social networking have given rise to a number of virtual diabetes-focused communities referred to as diabetes online communities (DOC).[5-7] As a collective these peer support communities (PSC) have broad objectives and audiences. A relatively scant, but growing, body of research demonstrates the value of virtual diabetes peer support for a limited, but growing, population of people with diabetes and their care givers.[8-10] In 2017, after working informally and with individual PSC from 2011 to 2015, the American Association of Diabetes Educators (AADE) embarked on an initiative to formalize the association's relationships with PSC. This article reviews the history and goals of this effort. It details the outcomes from an initial consensus meeting and the ongoing collaboration focused on mutually agreed to goals and efforts. The aim of sharing this unique collaboration between a professional

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association, representing a constituency of health care professionals, and a diverse group of people with diabetes and caregivers, is to present a model for similar endeavors in diabetes or other chronic diseases.

Historical Development of Diabetes Peer Support Communities

Successful management of diabetes, regardless of type, is greatly dependent on the abilities of the PWD to manage this increasingly complex disease, for the most part, on their own.[1] Even with optimal health care and skilled health care providers (HCP) most PWD interact with their HCP for minimal time.[11] It is well accepted that ongoing diabetes self-management education and support (DSMES) is a critical component of quality care.[1,2] Peer support, whether delivered one to one or within an ongoing in-person support group, has been an important element of achieving successful diabetes outcomes. Of late the importance and recognition of the mental health and mental health providers in the care of people with diabetes has been identified and substantiated.[4]

The global reach of the internet and the growth of social media and social networking has facilitated the availability and use of peer support among PWD[5] and has given rise to an evolving array of PSC, personal blogs, Twitter chats, discussion boards, and more.[5,6,8] Virtual peer support has helped more people with this demanding chronic disease feel less alone, have an avenue to reach out for practical guidance 24/7, share victories, move through life's setbacks and to give and receive emotional support more readily and regularly. Two recent publications offer in-depth history of the growth of the DOC.[6,7] As a collective, these communities have a broad array of objectives and audiences and will continue to evolve.

Defining Peer Support

Peers for Progress, a program initiated by the American Academy of Family Physicians Foundation in 2006 and currently based at University of North Carolina, is an international network of peer support researchers, experts, and advocates.[9] This entity defines peer support as linking people with a chronic condition, such as diabetes, to share knowledge and experiences. Peers for Progress defines peer support as being frequent, ongoing, accessible, and flexible and can take many forms, from phone calls to group meetings, home visits, and text messaging.[12,13] Peer support complements and enhances other health care services and has four core functions: assistance in daily management, social and emotional support, linkages to clinical care and community resources, and ongoing support delivered over time.[12,13] Litchman uses the term "peer health" and defines it as the interaction, education, and support offered by peers with the same condition to promote health-enhancing change.[9] The related terms "peer health advice" and "peer to peer health care" are also used.[14] This article uses the term "peer support."

Research Evidence

Research has demonstrated both clinical and psychosocial benefits of peer support. Much of the work of Peers for Progress has focused on diabetes.[13] A 2017 systematic review by Fisher et al showed that in an extended review of diabetes, 26 of all 30 studies (86.7%) reported significant positive impacts of peer support, with 17 studies (56.7%) reporting between-group differences and another 9 studies (30.0%) reporting significant within-group changes. Nineteen of the 30 studies reported A1c data and showed an average reduction of 0.76%.[15] A 2012 systematic review by Dale et al found the use of peer support was associated with statistically significant improvements in glycemic management, blood pressure, and cholesterol; however, there was no consistent pattern of effect related to any one model of peer support.[16] The data were too limited and inconsistent to offer clear recommendations for the delivery of peer support.

For about a decade, the availability of social media and networking has enabled a new form of and forum for peer support among people with diabetes and their caregivers. To date there is limited research on the value of peer support obtained from virtual peer support that is peer-driven and occurs with minimal or no HCP interaction or oversight. Litchman has published two studies.[8,9] In an online survey completed by 183 adults who used at least one of 4 different DOCs, participation reduced the odds of an A1c $\geqslant$ 7% by 33.8% for every point increase in DOC engagement. Survey participants noted that they did not inform their HCP about their DOC engagement (67.2%). Survey participants were more likely to have high health-related quality of life and diabetes self-care levels.[8] It's difficult, however, to determine whether their DOC involvement was the reason for their use of peer support or instrumental in their improved diabetes care. Litchman et al conducted telephone qualitative interviews (N = 20) among older US adults who used the DOC. Several themes emerged about how people participated in peer support to obtain information including to improve their self-care, for giving and receiving emotional support and to belong to a community.[9] A scoping review on the value of virtual support for people with diabetes has been conducted by Litchman et al and is under review.

Netnography is an emerging methodology that uses an ethnographic research approach to study internet-based social activity.[17] A netnographic analysis of the social activity of people with diabetes identified six themes regarding life with diabetes, including humor, diabetes pride, personal relationship with diabetes technology, tips and tricks, building community, and venting about life with diabetes.[15] A more detailed analysis of this work is under review.

Research on the value of virtual diabetes peer support remains minimal but as the use of these media increases the research base will expand. A primary limitation to this research is that the data are generally derived from individuals who choose to engage. It appears at this point to be skewed toward people with type 1 diabetes and their caregivers, people from higher socioeconomic strata, and those more actively engaged in their health, health care, and quality of life.

Concerns about Recommending Peer Support

Research shows HCP may not encourage people to use and engage with blogs, PSC, and related social media due to concerns including the spread of misinformation,[10] lack of review or moderation of content by a trained clinician, and the fear of an imbalance of power between the HCP and PWD.[8] These concerns and an unsupportive attitude about these resources can cause people to either not utilize peer support or not share their use of these resources with their HCP.[8] Oser et al used an inductive thematic qualitative study design to conduct reviews by two physicians of the type of quality of information shared on type 1 diabetes caregiver blogs. They concluded that misinformation was very rare and of minimal clinical impact when it was provided.[10]

To maximize open communication and increase the use of peer support and related resources among PWD, HCP should raise their awareness of peer support resources,[5] ask PWD about their interest in accessing peer support, refer PWD to potentially beneficial resources, and follow up on the use and value of these resources during clinical encounters.

History of AADE and Diabetes Peer Support Communities Collaboration

Over the years diabetes educators have been engaged with promoting the value and use of ongoing support,[1] including peer support. As the DOC evolved and more people with diabetes and diabetes educators engaged in social media, the avenues for collaborations expanded and flourished. From about 2010 to 2015 a small number of diabetes educators and AADE volunteer leaders championed initiatives between AADE, the professional association representing the interests and advancement of diabetes educators, and PSC leaders. AADE began to collaborate with several PSC on projects and sent volunteer leaders and staff to key meetings/programs.

Since 2010 several efforts have centered on active participation at AADE's annual conferences as detailed in Table 1. The value of this engagement has been bidirectionally advantageous. To demonstrate the value of this type of engagement between HCPs and patients, Utengen et al analyzed the value of inviting engaged patients to nearly 1700 physician-based health care conferences between 2014 and 2016.[18] Their results showed that when engaged patients were integrated

Table 1. Initiatives at AADE Annual Conferences, 2010 to 2018.

Year	Initiative
2010	• Introduce use of social media with promotion of conference hashtag+
2011	• Members of the PSC host small invitation-only event
	Annual Conference Session*
	• *The DOC: What the Heck Is Going On?*
2012	Annual Conference Session*
	• *Power Your Practice in Our Socially Networked World From Chaos to Connections and Inspirations: Using Social Media to Build Your Visibility and Practice*
2013	• Accept session submissions from members of PSC+
	Annual Conference Session*
	• *Social Media for Diabetes: Step Up to the Genius Bar* (3-hour preconference workshop)
2014	Annual Conference Sessions*
	• *Social Media-Technology Tools for Online Communication*
	• *The DOC Rx: The Role of Social Media in Managing Type 1 and Type 2 Diabetes*
2015	Annual Conference Sessions*
	• *The "e" Is for Engagement* (general session)
	• *The Diabetes Online Community: A Social Medi(c)a(l) Approach to #DiabetesCare*
	• *Social Media: Why Should I Bother*
	• *Social Media: All "Hands-On" Deck*
2016	• Introduce Live Twitter chat^ conducted by Diabetes Social Media Advocacy (DSMA), a nonprofit organization, to provide an avenue of interface between PSC members and attendees+
	• PSC members invited to serve on the annual conference planning committee+
	• AADE and AstraZeneca host a reception for members of PSC
	Annual Conference Sessions*
	• *The e-Community: How eHealth Can Engage People and Providers*
	• *Working From a New Mindset: Flourishing*
	• *The Potent Power of Patient Leadership*
2017	• Introduce AADE Twitter Lounge# with the goal of helping attendees increase and improve engagement in social media+#
	Annual Conference Sessions*
	• *The Power of "Me Too": An Analysis of Peer Health in the Diabetes Online Community*
	• *Success Beyond A1C: How Social Support Networks Help Improve Diabetes Outcomes*
2018	Annual Conference Sessions*
	• *Peer Support Communities Improving Mental Health for People with Diabetes—Let's Talk About It!* (general session)
	• *Listen and Learn: The Perspectives of a Panel of People With Diabetes*
	• *The Educator's Role in Advocating Peer Support: Why, When, and How?* (presentation and panel)
	• *Transition to Independence: Understanding and Addressing the Emotional and Lifestyle Barriers to Teens and Young Adults With Type 1 Diabetes*

+Initiative has occurred at all AADE annual conferences since this year.
*Sessions on peer support and/or on increasing the social media expertise of attendees presented by or in conjunction with members of peer support communities at AADE annual conferences. Unless noted these programs were presented as concurrent sessions.
^Sponsored by Roche Diabetes Care.
#Sponsored by the Johnson & Johnson Diabetes Institute.

Table 2. Collaborative Initiatives Between AADE and Individual Peer Support Communities and Members, 2015 to 2018.

Year	Initiative
2015	• AADE signs letter for support for initial PCORI pipeline proposal award for iDOCr (Intercultural Diabetes Online Community Research Council)—a collaborative group of peer support, health care, and industry representatives supporting research co-created between HCP and the DOC. • AADE invites members of PSC to participate in the newly launched AADE Diabetes Technology Workgroup.+
2016	• AADE partners with the College Diabetes Network to offer a mentor/mentee program. This program pairs students with diabetes pursuing a career to become a diabetes educator with an AADE member with the role of cofacilitators of the Member Affiliates Council (MAC). • AADE works with Children with Diabetes to offer an annual scholarship award given to an AADE member working in pediatric diabetes care to attend the annual Children with Diabetes Friends for Life conference.+ • AADE invites members of PSC to participate in the development of the AADE and ADA consensus statement *The Use of Language in Diabetes Care and Education*.[19]
2017	• AADE supports and coordinates a meeting between AADE, diabetes educators, and PSC leaders: *Educators and Peer Support Communities: Working Together for the Good of People with Diabetes*.*
2018	• AADE collaborates with Diabetes Daily to create a series of articles for their website based on the 4 key times people with diabetes should see a diabetes educator.^ • AADE collaborates with DiabetesSisters to promote diabetes education and educators through webinars and articles. • AADE offers financial support for librarian assistance for a scoping review on the evidence for the value of online peer support.

+Initiative has occurred annually since 2016.
*Detailed in this publication.
^Based on the joint position statement developed by AADE and the American Diabetes Association in 2015.[20]

into conferences, they increased the flow of information spread via Twitter and deepened engagement in the conversation more than physician attendees. The authors stated that health care conferences that fail to engage patients may risk limiting their engagement with the public and disseminating conference-based information.[18] AADE has also developed collaborations with several PSC and active leaders since 2015, as detailed in Table 2.

In 2015, AADE drafted their 2016 to 2018 strategic plan.[21] The association intentionally placed people with, affected by, and at risk for diabetes at the center of the graphical representation of their strategic plan and has become increasingly committed to raising the awareness of and referral to PSC by their members to improve diabetes self-care and outcomes.

In 2017, AADE formalized their collaboration with PSC. The initial action was to convene an invitation-only in-person facilitated meeting supported by AADE and held in Chicago at AADE headquarters in October 2017. Two conveners, one a diabetes educator and past president of AADE (2016) and the other a PSC leader, this article's coauthors, were selected to work with AADE to convene this meeting and assist in coordination.

Formalizing the AADE-PSC Collaboration

Meeting Preparation

In preparation for the meeting, AADE staff held a series of planning conference calls with the co-conveners and invited a small group of stakeholders to give input at a meeting held at the AADE annual conference in August 2017 (participants hereafter referred to as meeting organizers). The group recognized several overlapping interests between AADE, diabetes educators, and PSC leaders. These included the need to cross-promote the value of ongoing peer support and DSMES delivered by diabetes educators with recognition that both services are currently underutilized. There was also general recognition that ongoing collaboration between the two previously siloed entities had the potential to lead to new and innovative avenues to support each other's goals.

The meeting organizers reached consensus that the main objective of the formal meeting was to identify concrete ways for the two groups to work more strategically together and identified these goals.

1. Determine the current status, needs, and wants of PSCs with reference to AADE and diabetes educators
2. Determine the current status, needs, and wants of AADE and diabetes educators-at-large from the PSCs
3. Determine opportunities for synergistic efforts to support each other's goals
4. Identify short-term tactical opportunities for improvement and long-term expansion of these relationships to foster dialogue and actions for better support of those affected by or at risk for diabetes and their caregivers

The meeting organizers also determined that a professional facilitator should be utilized for this two-day meeting. Thus AADE contracted with Terrance Barkan, CAE for these services.

The list of invitees was assembled to represent various interests including PSC, AADE, and diabetes educators-at-large. AADE included representatives from their current board of directors, diabetes educators with strong connections to PSC

Table 3. Questions Posed by Meeting Facilitator to Attendees.

1. What are the opportunities you see in the near and distance future that diabetes educators and/or AADE can play for people with/affected by diabetes?
2. What do you see as the role of diabetes educators and/or AADE in a person's practical management of their diabetes and life with diabetes?
3. How could the DOC help dramatically more people with diabetes, particularly with help from diabetes educators?
4. What obstacles do you feel are preventing DOCs and diabetes educators and/or AADE from working together more effectively?

and several not engaged with PSC. On the PSC side, leaders of several large PSC, people with whom AADE had existing working relationships with and active members of PSC were invited. The attendees list is in the meeting report.[22]

To prepare for the meeting, the facilitator spoke with the AADE staff and co-conveners to understand the meeting goals, background on each attendee, desired outcomes, and potential areas of disagreement. He then held one-on-one telephone interviews with most participants and gathered insights based on the questions in Table 3.

To achieve level setting and meeting efficiency, the meeting organizers circulated background reading materials that focused on the existing research on the value of peer support, the DOC, and PSC.

The Meeting

The 2017 meeting, titled Educators and Peer Support Communities: Working Together for the Good of People with Diabetes, is summarized here. A comprehensive meeting report is available.[22]

Day 1

Visioning the ideal collaboration. Attendees were asked by the facilitator to ignore restraints and visualize what an ideal collaboration between AADE, diabetes educators, people with diabetes and their caregivers, and PSC might look like. The consensus was:

- A shared view of the role of diabetes educators and peer support, and the value it provides
- Complete awareness between and among PWDs, PSCs, and DEs
- Complete and free flow of information comparing formal practices vs reality between DEs and PSCs
- True, deep, and meaningful collaboration

Exploring shared principles. Developing shared principles were identified as an essential element of any sustainable collaboration. As a group attendees identified these principles:

- The best interests of the PWD is our highest priority.
- We will maintain a culture of empathy, compassion, and understanding.
- We will maintain a culture of respect and trust and remain nonjudgmental.
- Each party will own its actions and responsibilities.
- Each party will diligently and consistently follow the guidelines and principles.
- We will consistently work with, and share, best practices. We will not suppress information.
- Medical advice shall not be provided by unqualified persons nor in inappropriate settings.

Identifying barriers to achieving productive and successful collaboration. Attendees brainstormed 13 barriers preventing the ability of both groups to achieve a shared vision and are listed in the meeting report.[21]

Strengthening interpersonal relationships through informal interactions. To conclude the first day attendees were invited to an intentionally informal dinner to enable unstructured conversations, an opportunity to break down barriers and build relationships.

An important discussion that took place early on day one was about the use of the term "DOC" to describe participants in this collaboration. The attendees concluded that DOC was not a completely accurate or inclusive term. It doesn't include, for example, support delivered in person by diabetes educators and some PSC. The group chose to transition to use the term "peer support communities." However, it was not the intent of the participants to, in any manner, disallow, exclude, or remove use of the DOC term from the community's lexicon.

Day 2

Brainstorm actions to address identified barriers. The group brainstormed 63 actions that each stakeholder could take to address the identified barriers. Following the meeting, the facilitator organized and condensed this list into a formal set of actions for AADE and PSC which are both detailed in the comprehensive meeting report.[22]

Meeting Follow-Up

The meeting report was distributed to the attendees for their review and input. After all input was integrated by AADE the report was sent to a wider group of PSC stakeholders and published on AADE's website.[21] Several PSC attendees published blogs about the meeting.[23-25] Several key actions have to date been accomplished as detailed in Table 4.

To continue this collaboration, AADE organized a follow-up meeting at their 2018 annual conference (August 17-20). The list of invitees was expanded to include additional representatives of PSC. The goal was to continue to make progress

Table 4. Key Accomplishments of Collaboration Since Initial Meeting.

- Launch Peer Support Resources section of AADE website. Blog introducing: https://www.diabeteseducator.org/news/aade-blog/aade-blog-details/aade/2018/02/21/unveiling-new-peer-support-resources-for-you, Resource section: https://www.diabeteseducator.org/living-with-diabetes/tip-sheets-and-handouts/peer-support[5]
- Revise, host, promote, and distribute an online and print handout *Learn-Connect-Engage* for health care provider and PSC use to promote peer support https://www.diabeteseducator.org/living-with-diabetes/tip-sheets-and-handouts/peer-support.[5]
- Financial support for scoping review on value of online diabetes peer support
- Publication detailing the AADE-PSC collaboration
- Initiate development of AADE practice paper on value of peer support for 2019 publication
- Integrate content about peer support into AADE's *Core Concepts* course which educates entry level diabetes educators and others
- Promote *Share your Story* #peersupport advice in peer support resources section of AADE website
- Programs at AADE18 on peer support, importance of mental health (see Table 1)

on the formal set of actions AADE and PSC identified at the initial meeting[22] and expand the footprint of this collaboration by engaging a larger and diverse set of voices.

Conclusion

As the use of social media continues to expand and as people far more attuned to the use of virtual resources age, the reach, and impact of PSC will expand. Given this reality, it will be critical for AADE and PSC to continue collaborating to achieve the aim of increasing the use of peer support, PSC, and services delivered by diabetes educators. There is value in reaching out to some PSC with less reach than some of the communities engaged in this effort that may have been inadvertently not included. There is also value in reaching out to other professional organizations who have interest in this collaboration. This effort will be maximally effective if it includes the breadth of both communities.

This effort supports the goals of improving the self-care, clinical care and mental health of people with diabetes and their caregivers. It is critical for positive short- and long-term diabetes clinical outcomes and mental health to more effectively integrate these services into health care delivery to make them integral components in the diabetes care continuum. Due to the limited availability of research in this area and the increasing utilization of peer support and PSC it will be important to continue to support research in this area. AADE has and will continue to collect, support, and publish evidence and recommendations for practice about the value of all types of HCP and peer support.

Today health care entities and systems are piloting and deploying a host of virtual communication and digital health therapeutics to more efficiently and effectively improve outcomes. More care will be delivered virtually. Time-pressured and resource-constrained health care settings and HCP can provide care, education, and ongoing support while PSC can offer a 24/7 community of ready, willing, and able peer supporters who are people with or affected by diabetes. The unique collaboration of a professional organization, like AADE, and a dedicated group of PSC leaders can serve as a means to improve diabetes outcomes and to serve as a model for other chronic diseases.

Abbreviations

AADE, American Association of Diabetes Educators; DOC, diabetes online community; DSMES, diabetes self-management education and support; HCP, health care provider/professional; A1c, hemoglobin A1c; PSC, peer support communities; PWD, people with diabetes and their caregivers.

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