

Educators and Peer Support Communities

Working Together for the Good of People with Diabetes

In AADE's 2016 to 2018 strategic plan people with, affected by and at risk for diabetes are at the center of our organizational work. AADE is increasingly aware through our work on revising the National Standards for Diabetes Self-management Education and Support and increasing collaborations with entities and members of peer support communities (also known as diabetes online communities), that peer support paired with DSMES, is an important tool to improve diabetes care outcomes.

In the fall of 2017, AADE worked with the technology workgroup to bring together a group of stakeholders from the online peer support communities and AADE/diabetes educator community to identify ways in which both groups can work together to better serve those affected by diabetes. Below is a summary report on that meeting.

Participants

Nancy D'Hondt – 2017 AADE President

Terrance Barkan – professional facilitator and founder/chief strategist of Global Strat. AADE staff and the co-conveners worked with Terrance to develop the objectives and agenda for the program. Prior to the program Terrance connected with each of the attendees to determine their goals for this gathering.
Co-chairs – Hope Warshaw (AADE) and David Edelman, CEO, Diabetes Daily (PSC)

Online Peer Support Community Members and Entities

Alice Morgan, diaTribe Foundation and DQ&A

Scott Johnson, Scotts Diabetes

Amy Tenderich, DiabetesMine

Ansley Dalbo, Diabetes What to Know

Manny Hernandez

Mila Ferrer, Beyond Type 1 and Children with Diabetes

Christel Aprigliano, Diabetes Patient Advocacy Coalition

Anna Norton, DiabetesSisters

Cherise Shockley, DSMA Live

AADE Members/Diabetes Educators

Molly McElwee-Malloy, AADE Technology Workforce Group Leader

Toby Smithson, Diabetes Educator, AADE Member (spokesperson)

Nicole Bereolos, Clinical Psychologist, AADE Board Member (2018 – 2020)

Chris Memering, AADE Board Member Affiliate Liaison (2016 – 2017)

Jasmine Gonzalvo, AADE Board Member (2015 – 2017)

Courtney Slater, Diabetes Educator, AADE Member

Laurie Schnorr, Diabetes Educator, AADE Member

Educators and Peer Support Communities: Working Together for the Good of People with Diabetes Report

On 20 – 21, October 2017, AADE hosted Educators and Peer Support Communities: Working Together for the Good of the People with Diabetes, held between invited representatives of peer support communities for people with diabetes - also referred to as the diabetes online communities (DOC) - and the diabetes educator community represented by AADE.

The objective of the meeting was to identify concrete ways for the two groups to work more effectively together and in tandem for the benefit of people with diabetes (PWDs) and the people that are impacted.

In just 8 hours of in-person meetings over two days, participants worked together to:

- a) describe what an ideal relationship might look like,
- b) define the principles and guidelines that would serve as the foundation for an ideal relationship,
- c) identify the benefits of an effective partnership for all of the key stakeholders,
- d) inventory the major barriers and constraints that stand in the way of a more effective collaboration, and
- e) consider concrete actions that can be taken to address, mitigate or eliminate the most important barriers and constraints in order to move closer to a more effective and successful future relationship.

This report captures the essential elements from the meeting with a focus on agreed observations, decisions and actions.

Preamble

One of the outcomes of the meeting was the realization that the term DOC (diabetes online community) was not an accurate descriptor for the groups represented. Each of the groups used a variety of methods to engage with their audiences, including in-person meetings. Therefore efforts will be made to transition to the name peer support communities (PSC)."

In addition, the group agreed that the term "people with diabetes" or PWDs refers not only to the individual that has diabetes but includes the immediate support group and family that are also impacted.

Another observation was made that not all diabetes educators (DEs) are Certified Diabetes Educators (CDEs) and that references to DEs collectively includes CDEs.

Designing the Future

The group was asked to look beyond current restrictions and constraints in order to visualize what an ideal relationship might look like between DEs, PWDs, and PSCs.

The result was a statement that clearly defined what that might look like. "In the future we will have:

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

Principles and Guidelines

In order to achieve and maintain a successful collaboration, it must be built on a bedrock of agreed values, principles and guidelines. These were also identified. The group identified the following principles to guide the future relationship. “This future relationship will be built on a bedrock of principles and guidelines:

- 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, trust and remain non-judgmental.
- 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.”

It cannot be overemphasized how important it will be for the partners to adhere to these principles. The advice provided is that when it is difficult to decide a particular course of action or to make a decision that it be measured against the above agreed principles.

Why are we doing this?

Another important outcome from the meeting was to recognize why the stakeholders should expend scarce time and energy in this joint effort? Every day we make choices on how we spend our time and other resources and it is important to know what we expect to gain as a result of our efforts. The group identified the following expected outcomes. “In the future we will have:

- Improved quality of life and outcomes for PWDs,
- Better coordination of care while increasing and improving the utilization of PSC and DE services,
- Empowered PWDs, DEs and PSCs,
- Creates a common understanding and a culture where collaboration is embraced and valued,
- Creates more effective DEs, including better and increased psychosocial skills.”

Barriers & Constraints

A significant portion of the meeting was devoted to understanding what stands between the current and future desired state of the relationship between DEs, PSCs and the PWDs we all serve.

In total, more than 30 items were identified and categorized so that they can be more efficiently addressed. The problems included those that were primarily “environmental” or systemic and outside the direct control of any of the stakeholders and others were issues like “perception” that can be directly addressed.

The participants then each individually scored what they felt were the most important and pressing problems to be addressed in order to move towards the ideal relationship.

The AADE generously offered to apply resources against those issues that were identified as “legal” in nature. AADE will commission a legal review and produce a report on the status of the following legal related issues:

- Defining the boundaries when a legal risk threshold has been crossed
- What constitutes “medical advice”
- Potential legal or brand liability based on the type of information provided
- Under which identity are you participating? (Personal, employer, other)
- Liability for a referral that results in a negative outcome
- Benefits / limitations of issuing a disclaimer
- HIPAA / Data Protection issues

This meant that the participants could then focus their attention on other issues not related to the legal aspects.

The individual scores were tallied and the result was a short list of 13 of the most important issues. These were then allocated to the participants to work on in small groups.

Note: Some of the problems identified will have the same or a similar solution. At the same time, some of the issues may be beyond the ability of the DEs and PSCs to change or influence attitudes and behaviors. Some of the problems will have relatively easy and short term solutions while others may require more time and resources.

Issues Addressed

The top 13 problems, obstacles and issues to be addressed by the group were:

1. Language and cultural barriers. This relates to the fact that not all stakeholders (especially PWDs in minority communities and not all DEs) are comfortable with engaging online. It also relates to the need of providing information and support to communities in the language of their choice.
2. Lack of awareness and perceived value from either community, there is a misunderstanding of what a DE is / does, lack of humility by PWDs and PSCs (we know best).
3. Degree of mistrust of some PSCs (formerly DOCs) by the DE community, primarily around concern about the quality of information and advice provided.
4. Some PSCs or PWD may not be viewed as credible by DEs because they do not have formal training, even when they are recognized by the community as experts.
5. DEs may fear being replaced or made redundant by the information provided by PSCs.
6. DEs do not have “street cred” in the eyes of PWDs or PSCs because many of them do not live with diabetes themselves every day.
7. A fear of being judged, especially in a public online forum, can prevent or stifle engagement. This issue applies to all three parties (PWDs, DE and PSCs).
8. There is an open conflict or animosity between some segments of the type 1 and type 2 PWD communities.
9. There is a mismatch of expectations between the DE and the PWD in the clinical setting (i.e. the DE wants to convey a maximum amount of information and the PWD is struggling to cope with information overload).
10. The evidence that does exist regarding the effectiveness and benefits of PSCs is primarily focused on type 1 and the remaining information is not conclusive.
11. There is a need for more and better data.
12. There can be a lack of “internet literacy” i.e. unfamiliarity with how to use online tools.
13. Shaming of participants (PSC/DE/PWD) in online forums. This relates to online group participants speaking with a lack of respect for other participants or shaming them publicly.

Suggested Solutions / Actions

The group spent a significant amount of time discussing and identifying potential concrete actions that could be taken to address each of the top 13 obstacles listed. This resulted in a list of no less than 65 potential actions.

Due to time constraints, this list of actions could not be refined down to next immediate steps. However the 13 problems to be addressed were coded and each of the 65 potential actions was mapped against one of the identified problems.

Conclusions

The first and most important item we want to acknowledge is that the group was extremely engaged, acted with a sense of purpose and was action oriented.

There were a number of clear accomplishments from the meeting including:

- Recognition that peer support communities are individual entities that take similar but different approaches to serving communities of PWDs and that the “DOC” label is not adequate to describe this group of entities.
- Recognition that the services and benefits provided by Diabetes Educators and PSCs alike are grossly underutilized by the PWDs community and that by working together they have the best chance to improve the utilization of these important services.
- Recognition that by working together we were able to design a more effective future relationship, that we have identified the core principles on which it will be built, that we enunciated the benefits of doing so and that we have recognized where we need to start the work.

Next Steps

The next actions to be taken include:

1. Distribute the report from the meeting to relevant stakeholders (including attachments).
2. That AADE will, in addition to the legal related issues, identify its next action steps from the list of potential actions (see attached excel sheet) and report back to the group with a list of actions to be taken and timelines.
3. That individual PSCs will identify steps from the list of potential actions and report back to the group with a list of actions to be taken and timelines.
4. The participants will agree a date and time for a follow-up meeting (potentially at the next ADA meeting June 22 - 26, 2018 in Orlando, Florida). At that meeting participants will:
 - a. Reaffirm the vision and principles
 - b. Report on actions taken since 21 October 2017
 - c. Report on their respective short term and long-term action plans
5. There will be an announcement regarding the collaboration and progress made in the general session at the AADE18 meeting on 17 – 20, August 2018 in Baltimore.
6. AADE will prepare and host a webinar in partnership with interested PSCs that is intended for other HCPs to review the work of the group and why it is important with emphasis on the peer support community website pages.

Thank you to each of the participants for your good faith engagement and contribution to what was one of the most productive meetings I have had the opportunity to facilitate.

T. Barkan, GLOBALSTRAT



ADDENDUM #1 - Actions to be taken by Peer Support Communities

This list was created from the pool of potential solutions to problems identified by meeting attendees.

- Initiate actions within your community to change from the term “diabetes online community” (DOC) to the term “peer support community” (PSC). Consider publication of blogs on this change. As a group we want to use the term “peer support communities.” We fully recognize that this terminology change will not take place quickly. It requires an evolution. However, we believe that if the well-known and key PSC and national diabetes organizations begin to use this term, then overtime the change will occur. (Timeline: late February)
- Pledge to support and post on your PSC or entity the *Seven Principles and Guidelines* and related content within, developed at Chicago October 2017 meeting (Timeline: late February 2018)
- Distribute AADE and PSC developed essential support materials to support this AADE-PSC collaboration. This includes:
 - A revision by AADE of the peer support communities’ resource. (Timeline: mid-January 2018)
 - Social media etiquette tip sheet for use by PSC and AADE.
 - Continue to share resources from the ADA/AADE joint language paper
 - Reviews of value of peer support for people with diabetes and/or chronic disease. Determine if/what currently exists: Peers for Progress, IDOCr (Timeline: by mid Jan)
 - AADE developed resource focused on the value proposition of diabetes educators for people affected by diabetes.
- Host facilitated discussions on the topic of “patient shaming” in one or more venues, such as Twitter chats, webinars and discussions forums.
- Build a speaker's bureau of people with and affected by diabetes who can engage with diabetes educators and speak to the value of peer support in quality of life with diabetes. Make an effort to engage and involve a more diverse group of individuals/leaders with, affected by diabetes at diabetes-related events and professional meetings/programs. Likewise encourage involvement of diabetes educators in events and programs hosted by PSCs.
- At AADE18 (and perhaps beyond) engage PSC members who will be attending the conference to work with diabetes educator attendees to build their social media skills. This could take place in the AADE Twitter Lounge (exhibit hall). This can build both trust and one-on-one relationships.
- Jointly promote the value of both diabetes self-management education and support and peer support (PSCs) for people with, affected by diabetes to additional communities of healthcare providers such as primary care physicians, nurse practitioners, endocrinologists.

ADDENDUM #2 - AADE Action Plan and Timeline

Below are items AADE has committed to completing within the proposed timeline

Complete Meeting Report and Action Plan (2017)

An overview report on the goals, activity and outcomes of the meeting will be sent to all participants for review and comment.

Develop/execute plan for informing the broader individuals and entities in the peer support communities (Early February)

Acknowledging that only a subset of the larger peer support community and a representation of AADE members participated in the meeting, a plan to share the outcomes with each group will be developed. Once revised with input from AADE and PSCs, the report and list of action items for AADE and PSCs will be shared.

Establish Peer Support Page on AADE website (February)

The first step in exposing AADE members to the broad group or organizations providing peer support. The page will include a list of communities as well as some of the articles in the pre-meeting reading, a video on the efficacy of peer support by Susannah Fox, and other resources. AADE will develop a communications plan to advance this work.

Initiate Legal Review (January 1 – March 31)

AADE will engage legal counsel in exploring the professional liability questions associated with recommendations that patients explore and engage in peer support communities.

Initiate Peer Support Practice Paper (February)

AADE will charge its Professional Practices Committee with establishing a practice paper on the value and educator's role in engaging patients in peer support communities.

Seek Board Approval for Practice Paper (April 30)

AADE Board review is a component of the practice paper approval process.

Convene Small or Larger Group to Discuss Progress (on a predetermined date during the ADA Scientific Sessions meeting 22-26 June)

The ADA meeting could provide a venue with which to convene a broader group of stakeholders within both the peer support community and the established diabetes community to gain buy-in and advance support for the use and engagement of peer support communities.

Develop Resources for Educators/People with Diabetes on PSC (April 30-August 1)

While mutual support at the organizational level is critical, tangible tools and resources that educators can use and provide to their patients are equally important. AADE will seek funding to develop tip sheets for key stakeholders.

AADE18 Session on Peer Support (August)

AADE's annual conference presents one important avenue for highlighting the role and value of peer support communities. Session captured from AADE18 will be made available to all AADE members (October).

ADDENDUM #3 - Potential Actions to be taken by AADE

This list was created from the pool of potential solutions to problems identified by meeting attendees that could be accomplished by AADE. AADE will do its best to accomplish these items as time and budget allow.

- Create track/online education on peer support that diabetes educators receive continuing education credits (CEs) to attend and likewise, inform PSCs of key educational opportunities offered by AADE
- Materials explaining what a diabetes educator does and doesn't do
- Patients (non-diabetes educators) to be on committees as stakeholders
- Promotion of PSC resources and stories, incorporate into healthy coping pages of AADE7 handouts, AADE Desk Reference and other content as appropriate.
- Make PSC handout part of core concepts handout and make sure content on PSC is included in the curriculum to draw attention to handout.
- Identify and publicize gaps in research on peer support: there's minimal research in type 2 diabetes.
- "Incentivization" to fill gaps, including potential funding but also "soft" benefits that reward people in terms of fame/career/reputation. Let's recognize the people who fill the gaps in some way.