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The Diabetes Mixer: Fostering a Diabetes Community to Support Peer Health

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THE DIABETES MIXER:

Fostering a Diabetes Community to Support Peer Health

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People Living with And Inspired by Diabetes

ABSTRACT

Objective: Opportunities for individuals affected by type 1 diabetes (T1D) to engage in peer health activities are limited. The Diabetes Mixer is a community-based, non-clinical, face-to-face, peer health event for adults with T1D and their support person. The purpose of this paper is to 1) provide a program description of the Diabetes Mixer, and 2) analyze attendee perceptions of the Diabetes Mixer.

Research Design and Method: An analysis was conducted with Diabetes Mixer attendees to understand their perceptions of the event. Attendees included individuals with T1D and their support person. Surveys included quantitative and qualitative questions and were completed by attendees at the conclusion of the Diabetes Mixer. A descriptive analysis was conducted.

Results: Both individuals with T1D and support persons valued the Diabetes Mixer as a peer health event. All attendees stated they would attend a future Diabetes Mixer. Attendees planned to continue their relationship with the individuals they met at the Diabetes Mixer beyond the event, in-person, and through social media. Three themes were identified: building a community, connection through common experiences, and a fun venue to gain resources.

Conclusions: The Diabetes Mixer is a feasible, successful peer health event that provides education and support to individuals with T1D and their support person in a judgment-free atmosphere. Diabetes stakeholders should work together to develop peer-support resources for adults with T1D in non-clinical settings. Further research is needed to identify how interactions with peers can support diabetes management.



INTRODUCTION

Type 1 diabetes (T1D) is becoming more prevalent in adulthood as life expectancy increases [1]. Despite this shift, a lack of resources tailored for adults with T1D often leads to feelings of isolation and frustration. Diabetes support groups are uncommon, but when they are available, they are conducted in clinical settings, typically structured and facilitated by a healthcare provider in small groups.

Since individuals with T1D often have useful experiential knowledge [2], maximizing this knowledge to support others with T1D may facilitate a community of support. Peer health is an important factor in the management of diabetes, especially in terms of knowledge enhancement and psychosocial support. In this study, peer health is defined as the interaction, education, and support offered by peers with the same condition to promote health-enhancing change. Mental health can be enhanced when peer health is present. For example, peer health can improve coping [3], increase psychosocial support [4-11], and decrease diabetes distress [12] by means of shared experiences [7, 8, 10, 13, 14]. Peer health can also increase patient knowledge [4, 15, 16], confidence in diabetes management [17], self-efficacy [12, 18, 19], and improve glycosylated hemoglobin (A1C) [12, 16, 20-26].

Opportunities for children and adolescents with T1D to engage in peer health activities (e.g., diabetes camps) exist; however, programs for adults with T1D are limited. Historically, peer health has occurred in 1) face-to-face group visits in the clinical setting (e.g., diabetes classes, shared medical visits), 2) small patient-led “meet-up” groups outside of the clinical setting, or 3) patient-led online activity via the Diabetes Online Community. In 2011, a new concept emerged, the Diabetes Mixer. The Diabetes Mixer is a community-based, non-clinical, face-to-face, peer health event for adults with T1D in Salt Lake City, Utah.

In January 2011, the authors, who are also the Diabetes Mixer co-founders, were employed at a private endocrinology practice in Salt Lake City, UT, overseeing a patient population with T1D. While providing care management for these patients, it became immediately evident that there were patients with T1D who were struggling with their condition. In particular, two female patients, both aged 19 at the time, struggled immensely with their diabetes management, leading to frequent hospitalizations for hyperglycemia with and without diabetic ketoacidosis, isolation, vulnerability, depression, and other risk-altering behaviors. When asked

what their biggest trials were from this chronic condition, they both stated on separate occasions that, “No one gets what I’m going through,” and “I don’t know anyone else with type 1.”

A search for local community resources to assist these two patients in an outpatient setting yielded no results for this age bracket. Due to the rarity of T1D, the founders began discussing ideas on how to connect these two female patients together without violating the health privacy law, Health Insurance Portability and Accountability Act (HIPAA). Similar to the concept of diabetes camps offered to children and adolescents with T1D, the authors decided to host a peer health event for adults with T1D called the Diabetes Mixer, in hopes that these two individuals would attend, network, and establish a connection with one another. The initial development of the Diabetes Mixer was organized by clinicians; however, the planning of subsequent events included several stakeholders in diabetes care such as patients and community members. The purpose of this paper is to provide a program description of the Diabetes Mixer, along with an analysis of attendee perceptions of the Diabetes Mixer.

METHODS

Sample and Recruitment

At the end of each Diabetes Mixer event, attendees were asked to complete a one-page survey evaluating the event. Survey questions included basic demographic information, eight 5-point Likert scales ranging from 1-5 (1=poor, 2=fair, 3=neutral, 4=good, 5=excellent) regarding how participants felt about certain aspects of the event (i.e., food, speaker, venue), and open-ended questions (e.g., Why did you decide to attend the Diabetes Mixer? What was the best part of the Diabetes Mixer? What would have made the Diabetes Mixer better?). The authors analyzed participant surveys from three of the five Diabetes Mixers.

Analysis

Survey data were entered into Research Electronic Data Capture (REDCap). REDCap is a secure, web-based study management system [27]. Quantitative data were analyzed using SPSS 22 [28]. Open-ended questions were analyzed using qualitative content analysis, a methodology that uses a consistent set of codes to organize similar data [29].

The qualitative data on the first 20 surveys were read and re-read to generate the initial coding template by one of the investigators. The codes were then systematically applied to the remaining surveys with an option for open coding to capture any additional codes that may have been missed with the initial development of the codebook [29, 30]. To ensure credibility, all of the coded data were reviewed separately by the co-authors. Corresponding themes were then developed from the codes [31].

RESULTS

Program Description

Non-Clinical Setting

The Diabetes Mixer was hosted in Salt Lake City, UT in non-clinical settings, such as restaurants or community centers. Direct to patient advertisements were written with the intent to avoid clinical jargon, and instead, focused on the peer health and entertainment aspect of the event. Diabetes Mixer attendees were encouraged to bring one support person (spouse, paramour, family member, friend, etc.) to the event. The fun, relaxing, non-clinical setting promoted a judgment-free atmosphere, allowing attendees to feel at ease and interact with one another.

Entertainment

In order to cater to a diverse range of adults with T1D of all ages, the event provided a variety of activities consisting of live music performed by local musicians, live painting provided by a local artist, a photo booth, a live auction facilitated by an auctioneer, and an opportunity drawing. All items from the live auction and opportunity drawing were donated by various community members supporting the cause. At the conclusion of the event, attendees were provided with a “swag bag.” The swag bag included diabetes-specific items, such as low carbohydrate snacks, no carbohydrate beverages, and glucose tablets; and items not specific to diabetes, such as clothing, water bottles, and coupons for local businesses. All swag bag items were donated by stakeholders and local businesses.

Food

A certified diabetes educator collaborated with the Diabetes Mixer restaurant/catering chef to identify all ingredients for each menu recipe to allow for accurate carbohydrate

count calculation. All carbohydrate counts were displayed in front of each menu item (e.g., appetizers, entrée, dessert, and beverages) to decrease the speculation related to taking an insulin bolus for food.

Education

Attendees received education focused on T1D in two forms: exhibitor booths and motivational talks. The exhibitor booths provided attendees with information on diabetes-related products such as glucometers, insulin, insulin pumps, and continuous glucose monitoring systems. Guest speakers provided motivational talks in a variety of forms, using elements of standard presentation style, comedy, or poetry. Guest speaker topics varied and focused on self-care, mental health, advocacy, and research.

Community Stakeholders

To eliminate financial burden, individuals with T1D and their support person attend Diabetes Mixers free of charge. This was made possible through sponsorship and associated fees generated from exhibitor booths. Sponsorship opportunities were offered to diabetes stakeholders such as local health departments, hospitals, clinics, and ancillary healthcare companies. Pharmaceutical and diabetes device companies, durable medical equipment companies, and pharmacies were offered the opportunity to purchase an exhibitor booth to provide education as noted above.

Community Volunteers

The Diabetes Mixer was made possible due to numerous community volunteers, including healthcare providers and students, industry employees, governmental workers, and individuals living with or affected by diabetes.

Data Analysis

The average age of attendees was 33 years (SD 10.4). There was no significant difference in age between those with type 1 diabetes and the support person ($p=.737$). Individuals with T1D varied in duration of diabetes diagnosis from 0-55 years, with an average of 16.3 years (SD 11.5). Females with T1D were more likely to be in attendance than males ($p=.006$), with no difference in gender among support persons. Support persons were more likely to be a romantic partner. The Diabetes Mixer included attendees from a 90,000 square-mile radius across Utah and Idaho. Additional demographic information can be found in Table 1.

| Table 1. Demographics | | |
|----------------------------------------|--------------------------------|------------------------------|
| | <i>Type 1 Diabetes (N=118)</i> | <i>Support Person (N=67)</i> |
| Age Mean (SD) | 33.5 years (10.4) | 33 years (10.6) |
| Diabetes Duration Mean (SD) | 16.3 years (11.5) | - |
| <i>Gender</i> | | |
| Male | 31 | 29 |
| Female | 84 | 32 |
| <i>Marital Status</i> | | |
| Single | 34 | 6 |
| Married | 76 | 18 |
| Divorced | 5 | 1 |
| Widowed | 0 | 1 |
| <i>Living With</i> | | |
| Spouse/Partner | 82 | 38 |
| Parents | 14 | 2 |
| Other Family | 5 | 3 |
| Roommate | 8 | 1 |
| Alone | 8 | 2 |
| <i>Relationship to person with T1D</i> | | |
| Parent | | 4 |
| Spouse/Partner | - | 31 |
| Friend | - | 10 |
| Other | - | 5 |
| <i>Employment</i> | | |
| Student | 12 | 7 |
| Working Part-Time | 15 | 2 |
| Working Full Time | 78 | 7 |
| Unemployed | 18 | 2 |
| <i>Diabetes Provider Type</i> | | |
| Physician | 63 | - |
| Nurse Practitioner | 45 | - |
| Physician Assistant | 8 | - |
| Diabetes Educator | 10 | - |
| <i>Diabetes Management</i> | | |
| Exercise | 57 | - |
| Carbohydrate Counting | 82 | - |
| Insulin Injections | 34 | - |
| Insulin Pump | 83 | - |
| Pramlintide | 2 | - |
| CGMS | 35 | - |
| Other | 2 | - |

Attendees positively evaluated the Diabetes Mixer (Table 2). Seventy-four percent of attendees had a plan to continue relationships beyond the event with those whom they met at the Diabetes Mixer. Of those, 52% planned to meet in-person, 35% planned to connect via Facebook, 4% planned to connect via Twitter, and 7% planned to connect via Instagram. Attendees were unanimous in stating that they planned to attend another Diabetes Mixer in the future, and 98% said they would recommend the Diabetes Mixer to others with T1D. Concerns about the Diabetes Mixer were related to minimal seating and loud music.

Table 2. Diabetes Mixer Evaluation

| <i>How would you rate the...</i> | <i>Mean(SD)</i> |
|----------------------------------|-----------------|
| Service | 4.7 (.56) |
| Food | 4.5 (.78) |
| Location | 4.5 (.79) |
| Exhibitors | 4.6 (.68) |
| Speakers/Host | 4.6 (.74) |
| Entertainment | 4.9 (.40) |
| Overall | 4.8 (.48) |

Note. N=184. Scores were based on a Likert scale from 1-5 (1=poor, 2=fair, 3=neutral, 4=good, 5 = excellent)

Qualitative Analysis

The results of the study provided insight about the benefits for providing a non-clinical peer health event for adults with type 1 diabetes. The analysis resulted in three themes: 1) building a community, 2) connection through common experiences, and 3) a fun venue to gain resources. Codes corresponding with each theme are noted in Table 3.

Building a Community

The majority of individuals attended the Diabetes Mixer in order to meet other people with T1D. Attendees noted that the Diabetes Mixer allowed them to not feel so isolated with their T1D diagnosis. The ability to see so many adults with T1D in one place was encouraging. One attendee noted, “People are like me,” while another stated, “Seeing others with type 1, you don’t feel so alone.” Diabetes Mixer attendees were also able to find support from other attendees. One attendee stated, “I always end up coming [to the Diabetes Mixer] to network and build my support group.”

Table 3. Themes with Corresponding Codes

| <i>Theme</i> | <i>Codes</i> | <i>Frequencies</i> |
|---------------------------------------|--------------------------------------------|--------------------|
| Building a Community | Meeting or Networking with Others with T1D | 65 |
| | Creating or Further Developing Friendships | 21 |
| | Support Person | 16 |
| | Past Diabetes Mixers | 10 |
| Connection through Common Experiences | Experiential Knowledge | 8 |
| | Ability to Relate | 6 |
| | Speaker | 12 |
| A Fun Venue to Gain Resources | Atmosphere | 25 |
| | Exhibitors | 12 |
| | Entertainment | 11 |
| | Prizes | 15 |
| | Food | 16 |

Connections made at the Diabetes Mixer often times resulted in friendships beyond the event. Repeat Diabetes Mixer attendees noted that they look forward to the Diabetes Mixer and return each year to connect with the friends they had made at previous events. One attendee noted, “It’s always fun [to] see friends I have made, make new friends, talk ‘betes!” Another stated, “My husband and I look forward to [the Diabetes Mixer] all year. We love the opportunity to meet other diabetics.”

Support persons identified the importance in accompanying the individuals in their lives with T1D not only to support them, but to also find support for themselves. Individuals who were married specifically acknowledged that they valued meeting other spouses of individuals with T1D. Overall, attendees viewed the Diabetes Mixer as a way to expand their network and build a community of individuals affected by diabetes.

Connection through Common Experiences

Attendees were inspired by and connected with others through stories and experiences. Inspirational emphasis was placed on those who had overcome challenges or who had lived with diabetes successfully for decades. For example, an attendee stated, “[the best part of the Diabetes Mixer was] hearing inspiring stories from diabetics who had diabetes for over 40 years.” Others were encouraged by those with

T1D who had successful pregnancies. “I met a woman with 2 children and it gave me hope,” stated another attendee.

Hearing other people’s stories allowed attendees to gain an instant connection with a complete stranger, identifying with each other through the shared experience of being affected by T1D. Individuals shared many aspects of T1D, ranging from struggles and accomplishments to diabetes treatment options and emerging research. Attendees felt validated by “talking with other people who have diabetes and can relate.”

Fun Atmosphere to Gain Resources

Attendees noted the value of being in a non-clinical, laid back social setting in order to connect with others who understood what they were going through. Individuals also expressed that they gained up to date information about T1D in a variety of ways. One attendee noted the Diabetes Mixer allowed him to “hear about the new advancement in medical care,” while a support person stated he was appreciative of the helpful information the Diabetes Mixer gave his wife.

Valuing several aspects of the event, attendees commented positively about the music, food, guest speakers, exhibitors, and prizes. Each component set the mood for the event, allowing participants to enjoy themselves. One attendee noted that the Diabetes Mixer allowed him to “hang out with some friends, have a fun date night with my wife,” while another said, “Awesome! This event was amazing.” Several past Diabetes Mixer attendees stated they, “look forward to it every year,” now having become an annual tradition in their lives.

DISCUSSION

It is important for stakeholders in diabetes care to identify ways to support adults with T1D. Overall, Diabetes Mixer attendees enjoyed the event because it created a means to build a diabetes community, they were inspired and felt connected by the experiences of others, and the event occurred in a fun, relaxing atmosphere where they could gain knowledge and resources about T1D. The Diabetes Mixer provided individuals affected by T1D a different means of support outside of the clinical setting that did not previously exist.

The Diabetes Mixer was a feasible peer health event that addressed an identified gap in resources for individuals with T1D. The Diabetes Mixer supplied educational opportunities and psychosocial support through networking with peers and sharing common experiences. The Diabetes Mixer also provided an avenue to foster lasting relationships with others affected by T1D, encourage unity within a community, support peer health activities, and promote social support. Social support among family members and close friends can lead to positive diabetes outcomes [32], but it is not clear how social support from a peer, as seen in this research, might impact diabetes outcomes.

When exchanging information with individuals at the Diabetes Mixer, attendees may be seeking peers with optimal heterophily [33]. Optimal heterophily occurs when individuals have contact with others who have similar interests and a shared perspective, but one of the individuals in the group has experience in a certain area [34]. For example, this individual may have more experience with exercise training and living with T1D than other individuals in the group. This type of experiential knowledge may support a peer-based anticipatory guidance. Anticipatory guidance is a proactive counseling technique routinely used by health-care providers in the pediatric setting in which guidance is provided to parents in order to anticipate the developmental changes of children [35]. Anticipatory guidance, as it relates to this research, indicates that those with more diabetes management experience in a certain area are well positioned to help those who lack experience with diabetes management.

The success of the Diabetes Mixer is multifactorial. However, one critical element is the judgment-free, non-clinical setting. Feelings of inferiority, short appointment times, and interruptions in a fast-paced setting may hinder an environment where patients may not feel like they can share certain aspects of their diabetes openly. Even in scenarios where patients feel positive about their healthcare team, “good” or “bad” numbers (e.g., A1C, glucose levels) can create feelings of apprehension and judgment. Peers can interact with each other in the clinical setting through shared medical appointments, although it is currently recommended that clinicians either facilitate or moderate these peer health discussions [36]. Creating the right environment for patients places them in the driver’s seat and allows them to steer in the direction they feel is most valuable to them. The Diabetes Mixer offers T1D patients opportunities to advocate for their own health while being supported by their peers.

Support persons were an integral component of the Diabetes Mixer. The management of diabetes has been referred to as a family condition [37]. Support persons attending the Diabetes Mixer were most often romantic partners. There is increasing evidence that romantic partners of those with T1D require support independent of their loved one [38] and need education focused on the psychosocial impacts of diabetes to ease the emotional strains that can occur [39]. Overall, the Diabetes Mixer provides both support and education to the support person, who may then be able to better advocate for the person living with T1D.

There are policy implications related to this research. While there are examples of community outreach to support diabetes management (e.g., health fairs), very few are tailored to specific communities, such as adults with T1D, or offer a fun atmosphere to gain resources. Peer health events, such as the Diabetes Mixer, could be replicated in other communities, including diverse groups. Further, peer health is a low-cost solution that may help to enhance population health efforts, and may be especially beneficial for those with low socioeconomic status or decreased access to healthcare. While the Diabetes Mixer did start with two individuals, it would not have grown to what it is today without support from community stakeholders in diabetes care. Individuals and organizations vested in diabetes care should identify ways to create non-clinical, judgment-free environments specific to the individuals in their community to encourage peer health support activities.

This study does have limitations. Participants self-selected to attend the event and participate in the survey, so they may not reflect the views of all adults with T1D. The majority of participants resided in Utah and results cannot be generalized to other parts of the country. In addition, data was obtained through a satisfaction survey at the end of the Diabetes Mixer. Because all of the satisfaction scores were so high, it could be inferred that the scale did not capture variation within the sample. A more well-rounded scale would demonstrate variation within the sample. Additionally, since the data was collected on a one-page survey, only short quotes were obtained from the participants.

Finally, this study did not evaluate the effect of peer health on diabetes management strategies or outcomes, nor did it detail how relationships were managed beyond the Diabetes Mixer, if at all. Future research is needed to 1) examine how peer health provided in a non-clinical setting impacts health outcomes, and 2) identify how relationships initiated at the Diabetes Mixer continue between events to support a diabetes community.

In conclusion, the findings in this study suggest that the Diabetes Mixer can support attendees through the attainment of knowledge and the critically important psychosocial aspect of T1D through peer health. The Diabetes Mixer is a feasible solution to support peer health successfully in a non-clinical setting. Diabetes stakeholders in other communities should work together to develop resources for adults with T1D to obtain support from peers in non-clinical settings.

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CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Dr. Litchman reports other from Dexcom, Inc., outside the submitted work. No other disclosures were reported.

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