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Understanding Social Support Programs for Individuals Living with Type 1 Diabetes: The Perspectives of Support Program Leaders

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UNDERSTANDING SOCIAL SUPPORT PROGRAMS FOR INDIVIDUALS LIVING WITH TYPE 1 DIABETES:

The Perspectives of Support Program Leaders

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People Living with And Inspired by Diabetes

ABSTRACT

Objective: Limited research is available examining community-based social support programs (SSPs) for individuals with type 1 diabetes (T1D). The purpose of this study was to describe SSPs characteristics and the perceived benefits and barriers to attendance from the perspective of SSPs leaders.

Research Design and Method: This study used a qualitative study design. In-depth interviews were conducted with SSP leaders (n = 9) in the Washington D.C. metro area. Individuals were recruited from community- and college-based programs. Using content analysis, interviews were analyzed for key themes.

Results: The programs served different populations, which led to different group discussions. For example, college-based groups discussed alcohol use, while community-based groups discussed issues related to the management of their child's diabetes. Informational support, emotional support, and peer networking were described by SSP leaders as benefits of program attendance, whereas logistics, stigma, and avoidance of diabetes were described as barriers to program attendance.

Conclusions: Exploring the characteristics of SSPs is essential to understanding their utilization and role in self-management and empowering individuals with T1D. SSPs offer many benefits, and SSP attendance should be encouraged.



INTRODUCTION

Type 1 diabetes (T1D) is an incurable disease affecting over one million individuals in the United States. The incidence of T1D is increasing, leading to a growing need to understand effective treatments and strategies to aid individuals living with T1D [1]. Individuals living with diabetes engage in lifelong self-management activities including medication taking, self-monitoring of glucose level, adherence to dietary recommendations, and other lifestyle modifications [2, 3]. Diabetes distress, in part caused by the burden of self-management activities and the emotional toll of living with diabetes, has been identified as a major detriment to the lives of individuals living with diabetes and is associated with numerous psychosocial, emotional, and behavioral difficulties [4-9]. Further, given that many individuals living with T1D are diagnosed as children, they will face a unique set of challenges when they transition to independent living [10-12]. To overcome these difficulties and barriers, providing appropriate support is crucial for young adults living with diabetes.

Social support, defined as “support accessible to an individual through social ties to other individuals, groups and larger community,” has long been studied as a theoretical construct with an important role in improving health outcomes [13, 14]. Social support has been reported to improve patient engagement with healthy behaviors and adherence to medical treatments through multiple pathways [13-17].

Social support interventions can be beneficial for individuals living with diabetes. Meta-analyses examining peer support interventions for individuals living with diabetes found significant reductions in Hemoglobin A1C (A1C), a measure of glycemic control [18, 19]. Classic support structures, such as a family member or friends, can offer practical help and aid in stress management but lack insight that other individuals living with diabetes may have with regard to the daily management of diabetes [20]. Many different models of SSPs for type 2 diabetes (T2D) have been extensively described, and include a variety of approaches such as in-person and group interactions, use of peer coaches and community health workers, and telephone- or internet-based SSPs [21]. Furthermore, the American Diabetes Association (ADA) recommends monitoring psychosocial factors in patients living with diabetes, and accounting for the psychosocial impacts of diabetes into care plans for all individuals living with diabetes [22].

Compared to T2D, however, relatively little research has been conducted to understand the key aspects of SSPs for individuals with T1D. While there is less literature available on SSPs for individuals living with T1D, a 5-month SSP with weekly group meetings and guidance from a trained clinical psychologist decreased A1C and increased self-care activities among participants [23]. Additionally, a less formal community-based SSP for adults was evaluated and was well-received by attendees [24]. Outcomes from this SSP include building a community, forming connections due to the experience of living with T1D, and being an enjoyable environment to share resources [24]. Social support may play a key role in T1D management by influencing underlying psychosocial variables such as self-efficacy and stress, or by influencing health behaviors related to diet and exercise [17]. Social support has been shown to be an important factor in T1D self-management activities, with program attendees varying on preferences of whom they receive support from and level of social support desired [25].

There are little empirical studies describing the current state of community-based SSPs for individuals living with T1D and their characteristics. In response, this study examines the characteristics, perceived benefits and barriers to SSPs, and their utilization from the perspective of those who have organized, lead, or managed SSPs for individuals living with T1D.

METHODS

Study Design and Subjects Recruitment

For the present study, in-depth interviews with SSP leaders (n=9) in the metropolitan Washington D.C. area were conducted to examine the characteristics of programs and program participants, and the perceived benefits and barriers to attendance. A qualitative approach was selected in order to capture the full experience and perceptions of support program leaders [26]. For the purposes of this study, SSPs were defined as any group serving individuals with T1D for the purpose of providing social support and not clinical recommendations to attendees. Two national organizations, the Juvenile Diabetes Research Foundations (JDRF) and the College Diabetes Network (CDN) were identified as sources to find local SSPs. The CDN was selected to purposively target groups serving young adults in a transition stage. Because this was a preliminary investigation, convenience and snowball sampling were used to identify potential inter-

viewees. Contact information for potential interviewees was found on the Local Support Groups webpage of the Greater Chesapeake and Potomac chapter of JDRF (<http://www.jdrf.org/greatercp/>) as well as local CDN groups' webpages (<https://www.collegediabetesnetwork.org/>). Additional contact information was provided by individual referrals from a JDRF employee and program leaders who had agreed to be interviewed. Twenty-six individuals were contacted and asked to participate in interviews between December 2014 and May 2015. Out of the 26 individuals contacted, nine agreed to be interviewed. Each individual interviewed lead or had previous experience leading a SSP, with all interviews representing the experiences from a total of 9 distinct SSPs. One individual who was contacted was not willing to meet for an interview, and sixteen individuals did not reply after the first or second interview request.

In-depth Interview Procedure

In-depth interviews were conducted by the first author. After written informed consent was obtained, the interviewer then proceeded to ask a predetermined set of questions. These questions covered a variety of topics related to SSPs and were largely open-ended. Sample interview questions included: "Describe your involvement in social support groups or programs for T1D," and "What do you see the role of social support groups or programs being in T1D management?" Also, in determining the characteristics of the SSP, the interviewees were asked about their personal relationship with T1D, how they organized and promoted their SSP, how the program was managed, and what topics were discussed at the meetings. Interviewees were also encouraged to provide suggestions on how to improve current programs.

Each interview lasted between 45 and 60 minutes. Throughout the interview, the interviewer took field notes to summarize responses based upon the in-depth interview protocol. Additionally, all discussions were audio recorded with the permission of interviewees. This research was approved by the Institutional Review Board of the University of Maryland-College Park.

Data Analysis

Using content analysis [27], key factors were identified, summarized, and sorted into several categories: characteristics of SSPs and program participants, barriers to program attendance, or benefits of program attendance. Based on

the thematic framework, codes were applied to both the questions and answers. The interviewees' answers to each question were summarized and compiled into a spreadsheet based on the field notes and the audio recording. These were further refined based on subsequent review of the field notes and audio recordings. For two interviews that did not have audio recordings due to technical error, the extensive field notes were reviewed. Based on these data, common themes and key ideas emerged.

RESULTS

Interviewee Description

Of the nine interviews conducted, six of these were of either current or former leaders and/or coordinators of SSPs welcoming any individuals with T1D or their families. Of these six, one was living with T1D, another was a certified diabetes educator working in a diabetes clinic, and the remaining four were parents of children living with T1D. Of the six interviewees, four were Caucasian females, one was a Caucasian male, and one was an African American male. The additional three interviewees were founders of CDN chapters. All three interviewees from CDN groups were undergraduate students at their respective universities, were Caucasian females with T1D, and were based in Maryland and Virginia. Table 1 summarizes the interviewee demographics.

<i>Variables</i>	<i>n (%)</i>
Gender, Female	7 (77.8)
Race/Ethnicity, Caucasian	8 (88.7)
<i>Recruited from type of program</i>	
Community-based	6 (66.7)
College-based	3 (33.3)
<i>Relationship with T1D</i>	
Living with T1D	4 (44.4)
Parent of child living with T1D	4 (44.4)
Certified Diabetes Educator	1 (11.1)

Types of Social Support Programs: Community-and College-based

Out of the nine interviews conducted, two types of SSPs were identified (Table 2). Community-based SSPs often met monthly at a community location, typically a church, clinic, or library, and consisted of alternating meeting style between unstructured discussions and invited speakers on relevant diabetes topics. These programs welcomed all individuals with or affected by T1D, but often served parents of individuals living with T1D and adolescents living with T1D. For programs that mainly served parents and their children, interviewees noted that often both a parent and their child would attend. One program served adult insulin pump users, and another was specifically for older adults (aged 45-65) living with T1D, all of whom were typically older than college-aged adults. College-based social SSPs organized exclusively for students of that institution met monthly or bimonthly on campus. These programs either consisted solely of unstructured discussions, or alternated between unstructured discussions and invited speakers. All program leaders were highly motivated individuals who had a strong interest in T1D management and the issues faced by individuals living with diabetes. One quote summarized many of the program leaders' attitudes towards managing a

group and their role in providing resources: "People don't know there are resources out there, and I am willing to go out and get those things, so if you are not like that I can share them with people to make life easier."

Characteristics of Social Support Programs

Both types of programs met one or two times per month, and seven out of nine programs regularly invited experts to speak on diabetes-related topics. Six of the program leaders stated that their program was associated with a clinic, either formally or through individual clinicians who knew of the program, or with JDRE. The major recruitment strategy for both types of program was word-of-mouth referrals, and both reported that advertisements either through flyers, online presence, or campus presence were less effective at finding new members. Recruitment of new members was not a major priority for eight of nine program leaders; instead, efforts focused on program maintenance and the demonstration of value to current members. Attendance, especially regular attendance, and participant engagement, appreciation, and perceived benefits by participants, such as increased quality of life, sharing of resources, and having emergency support systems, were the major indicators of success among program leaders. For example, one SSP

<i>Type of Group</i>	<i>Community-based (n=6)</i>	<i>College-based (n=3)</i>
Venue	<ul style="list-style-type: none"> • Church • Library • Community center • Clinic 	<ul style="list-style-type: none"> • On campus
Meetings per Year	<ul style="list-style-type: none"> • 7-12 	<ul style="list-style-type: none"> • Informal meetings (about 24)
Target Audiences	<ul style="list-style-type: none"> • Parents of children with T1D and their children • Adult insulin pump users • Older adults 	<ul style="list-style-type: none"> • Undergraduate • Graduate students
Recruitment	<ul style="list-style-type: none"> • Word of mouth • Clinical connection • Juvenile Research Diabetes Foundation • Advertisements 	<ul style="list-style-type: none"> • Word of mouth advertising • Connections to on and off campus clinics
Definition of Success	<ul style="list-style-type: none"> • Members reporting benefits • Attendance • Support given • Questions being asked • Participant thanks 	<ul style="list-style-type: none"> • Members reporting benefits • Increase in quality of life perceived by the program leader • Increasing instrumental support • Interest in joining the group by potential members

leader stated, “They keep coming back. The fact that we have people return on a regular basis means some people are at least getting something out of it.”

Both program types had a similar focus – to provide a venue for individuals with similar experiences and to share their experiences, both positive and negative, with a group who empathize and provide comradery. The major difference between the programs was the demographics of its members, and thus the resulting focus of discussions. For example, community programs were attended by parents discussing problems encountered by their child at school, while the discussion topics of college-based programs centered on other topics such as alcohol use.

Perceived Benefits for Attending Social Support Programs

The perceived benefits of attending SSPs were described and grouped into three categories: 1) informational support, 2) emotional support, and 3) building a peer network. Informational support included the sharing of practical skills and personal experiences. The sharing of information, experiences, and techniques were mentioned by most interviewees as benefits of SSP attendance, and the concept of learning from other participants was present in all interviews. For example, one interviewee said, “I feel like I am well educated and involved in the diabetes community, but every time I went to a meeting I learned something new.”

Another major benefit of SSP attendance perceived by many SSP leaders was the opportunity to get different perspectives from other attendees. One interviewee stated, “Sometimes you’ve been doing something for years and you think it’s the right thing, but it’s not.”

Emotional support was mentioned in some way in all interviews. A common comment was that attending SSPs let members “know they are not alone” in having T1D -- with 5 interviewees using the exact phrase and all of the others echoing similar sentiments. The burden of living with T1D was reflected in two leaders’ responses: “Seeing people that are going through the same thing is helpful because diabetes isn’t like other chronic conditions, its constant care,” and “Diabetes is something you have to stay on constantly, it’s the nature of the game, and that’s hard as a young adult.”

Related to these responses, making connections to other individuals living with T1D was stated as a benefit of attending SSPs. In particular, meeting other individuals living specifically with T1D, rather than T2D, was noted as important. One interviewee stated, “Meeting and talking to people, just knowing you aren’t alone, because you meet a lot of people and it’s type 2.”

The SSP provides a place to share emotions and vent frustrations and give the opportunity to address the emotional side of diabetes with individuals who will understand the experience. Recalling a meeting with an invited speaker on the topic, one program leader stated, “One of the most popular topics was having someone come in to talk about the emotional side of diabetes.”

Finally, establishing a peer network was identified as a major benefit of attending SSPs. The role of the SSP was often suggested as being a place to find empathy from other individuals living with T1D. Attending a SSP also builds comradery among individuals, which can lead to positive motivation to self-manage their diabetes. In addition to motivation, some leaders noted the empowering nature of SSP attendance. For example, an interviewee stated, “If you are meeting on a regular basis, even just to talk, even just the idea of spending time around other people with diabetes, I think can be very empowering and very motivating.”

The program leaders stated that the psychosocial aspects most improved from attending SSPs were reducing negative perception of T1D, increasing both motivation and engagement in self-management activities, dealing with challenges associated with self-management, reinforcement of good behaviors, and accepting T1D as a part of life.

Perceived Barriers to Attending Social Support Programs

Program leaders described a number of perceived barriers to SSP attendance. The barriers were categorized into: preconceived notions regarding SSPs, practical issues with program attendance, stigma regarding living with T1D, and avoidance of T1D.

Prior notions and thoughts about the SSPs were described as barriers to program attendance. An interviewee stated that individuals perceive the attendance of SSPs to imply that an individual is “weak,” and therefore, may choose not to attend SSPs. The program leaders felt that this mentality is utilized by individuals who cannot handle the stresses

of their condition, have poor control, or may not recognize SSPs as an outlet for individuals to share experiences regardless of their status.

Practical issues related to a number of aspects of SSPs were often mentioned among interviewees as a barrier. Despite poor attendance, most group leaders did not actively recruit new members and relied on word of mouth to recruit new participants. According to group leaders, this was mainly due to lack of funding and time, and privacy issues associated with seeking out new members through clinics.

Logistical issues were also mentioned as a reason for poor attendance. Without regular meeting times and current locations, individuals may find it difficult to plan and allot time in their schedules to attend SSPs. Additionally, long travel time to a SSP was perceived as a barrier, which suggests a need for more localized SSPs. Related to the time commitment, competing life priorities, i.e. school, work, or employment, were also perceived as barriers to attendance.

Finally, difficulties in developing an engaging and productive meeting agenda led to poor attendance. Interviewees felt that this barrier was reduced somewhat by inviting guest speakers and facilitating unstructured group discussions; however, due to the limited number of speakers available and topics to be addressed, poor attendance continued to be an issue.

Interviewees suggested that one reason individuals do not attend a SSP is the concern of being identified as a “diabetic” and perceived stigma. Group leaders indicated this might be due to poor public knowledge of T1D, privacy concerns, or a reluctance to accept T1D as a major factor in one’s life. Attending a SSP identifies the individual as living with T1D -- information they may not want to make public. One leader stated, “I think there’s still a stigma as diabetes as a disability, maybe you’re limited and can’t do certain things, some people do not want to reveal they are diabetic because of that stigma.”

A common impression was the societal stigma accompanying living with type 2 diabetes. The perceived poor public knowledge of T1D was a major contributor towards stigma and reluctance to engage in SSPs for individuals living with T1D. For example, one participant stated, “People don’t like the association with type two, and the questions.”

Avoidance, or the purposeful neglect of self-management activities and/or recognition of one’s diagnosis, was also mentioned as a program barrier. Avoidance of diabetes is common among individuals living with T1D, it and was stated as a major reason that individuals do not attend SSPs.

The avoidance of diabetes is commonly referred to as disease burnout, which is accompanied by the lessening or lack of self-management due to the stress of disease management. Program leaders stated that complete denial of the condition and almost no self-management may occur among newly diagnosed individuals, while disease burnout is an issue for all individuals diagnosed with diabetes. One program leader noted that young adults may be particularly vulnerable to avoidance. For example, SSP leaders commented that, “Young people aren’t ready to talk about diabetes yet” and that “[Diabetes] is a lifestyle interference, so the blood glucose testing and insulin taking is inconsistent.”

DISCUSSION

While various organizations, such as the American Diabetes Association (ADA), CDN, JDRF, and health clinics offer SSPs for individuals living with T1D, limited information is available on the characteristics or utilization of these programs as reported by individuals who organize and lead these programs. Gathering this information is critical for improving current programs and increasing participation.

SSPs provide a venue where techniques and strategies for successful self-management of T1D can be shared. They also serve as an outlet where the numerous stresses and frustrations can be vented to an empathetic peer group, and provide opportunities to form peer support networks. These results are consistent with other studies examining the perspective of a community-based SSP [24]. Attending SSPs have been shown to provide numerous benefits for individuals living with diabetes, including improved glycemic control and psychosocial functioning [23]. In addition, this research underpins that SSPs may provide the needed emotional, informational, and perceived social support for individuals such as adolescents and young adults who are going through life transitions that can negatively affect diabetes management [10-12, 28-30]. College-based SSPs such as the ones described, though limited to individuals who are attending college and thus are not able to serve a significant proportion of young adults living with T1D, may be an important avenue for addressing poor glycemic

control and lapses in care seen in young adults who are going through a significant change in their life [10-12, 29-30].

The demographics of SSP members tended to shape the topics discussed during meetings. SSPs in general have been shown to have numerous benefits, and diabetes care teams should be encouraging their patients to seek out a program that matches their demographics [19-21, 23]. This will improve the program by bringing in additional peers to share experiences and management strategies, and be more beneficial for the individual as the discussions would more likely be relevant to their experiences. As mentioned by interviewees, logistical problems can act as a major barrier to program attendance, so there is a need for SSPs serving numerous demographic groups, including parents of children, adolescents, younger adults, and older adults living with T1D.

LIMITATIONS

While these interviews provided insight into SSPs, there were limitations to this study. Due to a lack of response from program leaders, particularly college SSPs, and the fact that there are a limited number of SSPs for individuals with T1D in our target areas, the sample size was small and all interviews took place in the Washington D.C. metro area. Despite these limitations, the answers of the interviewees were similar, and themes were recurring throughout SSP leaders, indicating that these individuals shared similar experiences. Due to the small sample size, it is not believed that this data collection reached saturation, and further data collections should be conducted to capture the full experience of SSP leaders.

Additionally, this study did not examine online support communities, which have become more prominent in recent years [31-33]. Online SSPs have the potential to address many of the barriers to program attendance mentioned by interviewees, and should be viewed as another resource for individuals living with T1D in conjunction with or as an alternate to in-person SSPs. Future studies should examine the characteristics of these communities in order to improve utilization and understand their role in T1D self-management.

CONCLUSION

Despite these limitations, the research presented here identified the characteristics of nine SSPs and provided insight into their characteristics, functions, and needs. The interviews suggested that SSP leaders identified providing information support, emotional support, and building a peer network with other individuals living with T1D to be important roles of SSPs for individuals living with T1D. Furthermore, this study used social media and publically available information to recruit individuals who may have been difficult to reach and enroll in a research study. Moving forward, researchers should view SSPs as a potential venue to recruit individuals living with T1D as well as individuals living without T1D who are still affected by the disease, while avoiding concerns around privacy and patient confidentiality associated with recruitment. Future work should examine these insights from the perspective of SSP participants as well as expanding on the preliminary work with SSP leaders presented here.

Because referrals and word of mouth were the foremost recruitment strategy for SSPs, health professionals working with individuals living with T1D should actively encourage attendance to SSPs and connect individuals living with T1D to community organizations, such as the JDRE, CDN, ADA, and other community-based organizations providing this type of program. Referrals should be made to programs that include individuals who share similar concerns and are within the same demographic group. This would improve satisfaction and increase the odds of sustained attendance. Numerous benefits have been associated with SSP attendance, but lack of active recruitment and poor attendance may limit the effectiveness and sustainability of SSPs. Further efforts to promote and encourage SSP attendance should be implemented, especially for individuals experiencing increase diabetes-related distress and poor care outcomes.

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CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. The authors report no potential conflicts of interest relevant to this article.

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