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Patient Perspectives on Peer Mentoring: Type 1 Diabetes Management in Adolescents and Young Adults

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Abstract

Purpose—The purpose of the study was to identify attitudes and topics relevant to peer mentoring as an adherence-promoting intervention for adolescents and young adults (YAs) with type 1 diabetes (T1D).

Methods—Self-administered survey data were collected in two diabetes clinics from a convenience sample of adolescents as prospective mentees (ages 13–18) and YAs as prospective mentors (ages 19–25) with T1D. Survey topics included demographics, disease history, glycemic control, adherence, depression, barriers to disease management, social support, and interest in peer mentoring. Descriptive statistical analyses, thematic coding, and stepwise multivariate logistic regression were performed.

Results—A majority of the 54 adolescents and 46 YAs expressed interest in a peer mentoring program. Having supportive friends and living in a large household positively predicted adolescent interest in having a peer mentor. Approximately one third of all participants experienced social barriers to diabetes management. For adolescents, barriers included inflexible schedules, unfamiliar foods, and the embarrassment of checking blood glucose in front of others. Young adults reported barriers in tracking food consumption and remembering to check blood glucose. Various diabetes management skills were in high demand by adolescents, who especially desired to learn about managing T1D on their own and in college. Participants were open to multiple communication modes, including in-person meetings, phone, text messaging, and social media.

Conclusions—Many adolescents and young adults with T1D are interested in peer mentoring as a way to facilitate learning and sharing essential diabetes management skills and experiences.

Non-adherence is a significant contributor to poor glycemic control in type 1 diabetes (T1D).^{1,2} Poor glycemic control may result in severe comorbidities (e.g., nephropathy,

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retinopathy, neuropathy, and cardiovascular disease), higher healthcare costs, and shorter life expectancy.^{3–9} Non-adherence occurs among 30–67% of adolescents with T1D, a higher prevalence than for other age groups.¹⁰ Evidence suggests that non-adherence is related to anxiety or fears about being judged by peers, as well as adolescent development issues, which can compromise youth diabetes care.^{11,12} For example, adolescents feel pressured to “fit in” with peers and friends, while developing an identity independent from their parents.^{13–18} Thus, many adolescents skip blood glucose monitoring in social settings when they expect negative reactions from peers.^{19–21}

Recognizing the importance of peer influence, interventions targeting youth with T1D have been implemented on a peer basis. In some interventions, adolescents with diabetes received group medical appointments or group skill training, allowing interactions among patients.^{22,23} In another study, adolescents were paired with their best friend for learning problem-solving skills in diabetes management.²⁴

However, most studies focused on peer support from friends without diabetes, or group learning among patients of the same age. Little has been studied on the benefits of pairing youth with slightly older and more experienced peers with diabetes to help improve T1D management. This intervention strategy has been effective for alcohol and drug abuse prevention in youth, prolongation of breastfeeding period, and diabetes control in older adults.^{25–27} For example, Grossman and Tierney found that at-risk adolescents 10–16 years old were 27.4% less likely to start using alcohol and 45.8% less likely to start using illicit drugs when they were being mentored by a Big Brother or Big Sister 2–4 times per month for at least a year.²⁵ In a more recent study in Philadelphia, African American veterans with type 2 diabetes and a glycosylated hemoglobin (A1C) level of >8% at baseline were randomized into a mentoring program to be matched with a peer who had previously experienced but overcome poor glycemic control. The 6-month mentoring intervention was associated with a mean decrease of 1% in A1C (from 9.8% to 8.7%) among the mentees versus the controls.²⁷ In light of the potential effectiveness of peer mentoring on adolescents and diabetes self-care, the authors conducted a study among youth with T1D, to (1) assess patient interest in a peer mentoring program as a potential intervention to improve adherence, and (2) identify topics that patients would like to incorporate in a peer mentoring program.

Methods

Research Design

Given that little data exist on patient interest and preferences for a peer mentoring program among youth with T1D, this research was designed as a feasibility study to gather preliminary survey and clinical data and identify key details to consider for a future peer mentoring intervention for this patient population. Our aim was to describe patient attitudes and perspectives, associated patient demographics, and patient diabetes management behaviors and challenges.

Sample and Setting

Fifty-four adolescents as prospective mentees and 46 young adults (YAs) as prospective mentors with T1D were recruited from January–September, 2012 in two Los Angeles-based diabetes clinics. Clinic 1 is within a large tertiary children's hospital that serves patients of mixed socio-economic status and insurance types. Clinic 2 is within the Los Angeles county hospital system, which mainly provides medical care for underrepresented populations, often minorities and those with public or no insurance. The study recruited from both clinics in order to obtain a sample representative of the patient population. The institutional review boards of both clinics approved the study protocol.

Prospective mentees were 13–18 years old who had been clinically diagnosed with T1D. Prospective mentors were 19–25 years old who had been clinically diagnosed with T1D for at least 3 years. Exclusion criteria for both groups included pregnancy, blindness, or severe functional limitations due to cancer or other medical conditions. A total of 129 eligible patients were approached, 101 agreed to participate and gave informed consent, and 100 completed the survey, resulting in an overall response rate of 78%.

Data Collection Procedures

Patients scheduled for clinical appointments at the two participating diabetes clinics were pre-screened by the survey team. Those who fit our inclusion criteria in terms of age and T1D diagnosis were approached on the day of their appointment as they were waiting to be seen in the clinic. Participant eligibility was confirmed before the informed consent process started. After informed consent was obtained, participants were given a peer mentoring questionnaire on a laptop computer. Each participant received \$15 as a token of appreciation for their time. The questionnaire on average took 15–20 minutes to complete. The few participants who did not complete the survey in the clinic were given a web link to continue finishing the survey online at a later time of their choice. REDCap electronic data capture tools were used to administer the survey and store survey data.²⁸

Measures

Data collected included patient demographics, diabetes history and management, self-reported and laboratory A1C values, diabetes adherence measured by the Self Care Inventory-Revised (score range 1–5),²⁹ depression measured by the two 10-item versions of the Center for Epidemiologic Studies Depression Scale (CES-DC-10 for adolescents and CES-D-10 for YAs, score range 0–20),^{30,31} level of patient empowerment measured by the Diabetes Empowerment Scale-Short Form (score range 1–5),³² barriers to adherence related to school/work, vacation, social situations, and illness adapted from the Diabetes Control and Complications Trial,¹ social support questions including the Social Connectedness Scale (score range 1–48),³³ and patient interest and preferences in peer mentoring.

For all validated survey instruments mentioned above, higher scores indicate a higher level of the outcome intended to be measured. Barriers to adherence were asked in two steps. First, participants were asked whether they experienced any barriers in each of the categories (school or work, vacation, social situations, and illness), and if they answered positively, they were then asked open-ended questions to describe exactly what the barriers

were. Adolescents were asked about current barriers only and YAs were asked about both past and current barriers so that we could investigate any changes in barriers over the critical developmental period from adolescence to young adulthood.

In the last survey component, preferences in topics, delivery frequency, and delivery modes of peer mentoring were solicited. Preferences in peer mentoring topics were asked in open-ended questions. Preferred delivery frequency and modes were offered with multiple choices. Participants were asked to choose a delivery frequency ranging from “once a week” to “every six months” and indicate all delivery/communication modes they would prefer.

Data Analyses

Patient characteristics were summarized. Stepwise multivariate logistic regression was used to identify factors associated with patient interest in peer mentoring. All quantitative analyses were performed with Stata (version 13.0, STATA Corp LP, Texas, USA).

Thematic coding was conducted on qualitative data to gain a better understanding of barriers to diabetes management and of preferred topics in peer mentoring. Two investigators (YL and EAP) reviewed patient responses to open-ended questions on barriers and preferred mentoring topics and generated a list of themes for each question, for mentors and mentees respectively. Two trained research assistants independently assigned appropriate themes to each participant for each question. Any disagreements in theme assignments were reconciled by one investigator acting as the tie-breaker (YL). Frequency tabulations were performed on the various themes, to identify specific areas most desired for peer mentoring.

Results

The demographic characteristics of the sample are outlined in Table 1. Overall, demographics were similar across the adolescent and YA groups with the exception of age (15.8 vs. 20.5 years); proportion in a romantic relationship (11.1 vs. 43.5%), and insurance status (a greater proportion of adolescents than YAs had private insurance, 51.9 vs. 32.6%; and more YAs had “other” insurance, 26.1% vs. 3.7%). Participants came from diverse racial and ethnic backgrounds: among adolescents, there were 21 Caucasians, 18 Hispanics, 6 African Americans, 4 Asian Americans, and 5 reporting two or more race/ethnicities. Among YAs there were 22 Hispanics, 18 Caucasians, 4 Asian Americans, and 2 African Americans.

Diabetes Adherence

The adolescents and YAs reported medium diabetes adherence in terms of performing various diabetes management tasks, according to the self-care diabetes inventory score (Table 1). Adolescents reported higher scores than YAs (3.4 vs. 3.1 on the scale of 1–5, $p<0.004$). Adherence measures with low scores included recording glucose results, checking ketones when blood glucose is high, wearing a medical ID bracelet, and keeping food records. The YAs reported lower adherence than the adolescents in several measures: blood glucose checking ($p<0.01$) and recording ($p<0.004$), eating on time ($p<0.007$), taking medication or insulin at the right time ($p<0.04$), and checking ketones ($p<0.001$) (Figure 1).

Patient Empowerment

Both the adolescents and YAs reported high scores on the Diabetes Empowerment Scale (4.3 vs. 4.4 on the scale of 1–5), indicating self confidence in their diabetes control (Table 1). No statistically significant differences were observed between the two age groups on any of the items included in the Scale.

Glycemic Control

About 87% of the adolescents and 80% of the YAs were able to report their most recent A1C values, which were similar to the laboratory values with negligible differences (−0.14% vs. −0.34%). According to the laboratory values, 78% of the adolescents (n=42) and 89% of the YAs (n=41) did not reach the age-specific A1C targets recommended by the American Diabetes Association (<7.5% for ages 13–19 and <7.0% for ages ≥20).³⁴ The statistics were similar to those from national data.³⁵ Notably, among those who did not meet the targets, a large proportion had their glucose moderately controlled (A1C <9%), including 46% of all adolescents (n=25) and 41% of all YAs (n=19). Specifically, 32% of adolescents (n=17) and 48% of YAs (n=22) had an A1C <9%.

Barriers to Diabetes Control

School, work, vacation, and social situations all contributed to barriers to diabetes control, with social barriers being the most common among the participants (Table 1). About a third of the adolescents (n=14) and YAs (n=13) reported that they experienced current social barriers to diabetes control (Table 2). However, the underlying reasons were different by age: embarrassment about blood glucose monitoring or insulin injection in social situations was a major barrier for adolescents, but much less prevalent in YAs (50% vs. 15%, $p=0.054$). The adolescents also reported that they were more often “unable to be spontaneous” in social situations than the YAs (57% vs. 15%, $p=0.024$). Knowing the kinds of food consumed and the correct food portions was equally challenging for adolescents and YAs.

Interest in Peer Mentoring

Fifty-seven percent of the adolescents (n=31) and 87% of the YAs (n=40) expressed interest in participating in a peer mentoring program ($p<0.001$) (Table 1). Stepwise multivariate logistic regressions among the adolescents suggested that social factors, such as having supportive friends who know about their condition (OR=5.7, $p=0.02$) and living in a large (>5) household (OR=4.9, $p=0.02$), were positively associated with interest in having a peer mentor. Glycemic control, measured by either self-reported or laboratory A1C values, was not a predictor for interest in peer mentoring. Likewise, age at diabetes diagnosis, extent of diabetes self-care, level of depressive symptoms, and barriers to adherence did not predict interest in peer mentoring. Other factors analyzed included gender, race/ethnicity, parents' educational attainment, relationship status, total number of diabetes-related complications, the use of an insulin pump, and the frequency of blood glucose checking.

Stepwise multivariate logistic regression among the YAs yielded no results, due to the perfect prediction of outcomes by the included factors, a situation that arises when a very high proportion of a dichotomous outcome is either 1 or 0.

Among the 23 adolescents who did not want a peer mentor, 60% said they did not need help, 22% did not feel comfortable sharing personal T1D experiences with others, and 26% had no time. Among the 6 YAs who did not want to be a mentor, 4 stated that lack of time was the main reason (66%). The other 2 did not provide a reason for their lack of interest.

Preferred Topics of Peer Mentoring

Diabetes management skills was the one theme that both adolescents and YAs were highly interested in. “Diabetes management on one’s own and in college” was the most frequently mentioned (Table 3). Many adolescents stated that they wanted to learn as mentees about “everything,” without providing specific details. The YAs raised other topics on which they were interested in mentoring, such as how to effectively communicate with different people (friends, family, physicians, healthcare workers) about their diabetes and how to cultivate supportive friendships. They also stressed the importance of adhering to the treatment regimen and the importance of positive attitudes toward having diabetes.

Preferred Delivery Mode of Peer Mentoring

All survey participants expressed interest in phone, email, text messaging, and social media (such as Facebook and Twitter) as communication modes, as well as in-person meetings. Adolescents preferred phone (55%), text messages (58%), and social media (58%) over email (42%). The YAs preferred phone (88%), email (83%), and text messages (88%) over social media (65%).

Discussion and Conclusions

A majority of the adolescent and YA participants with T1D were interested in peer mentoring as a potential intervention to improve glycemic control. Patient responses regarding social barriers to diabetes control and preferred peer mentoring topics suggested that information on diabetes management is in fairly high demand. A peer mentoring program is especially suitable for helping to overcome social barriers to diabetes control, which were recognized by both adolescent and YA participants (30%), but approached differently. Specifically, non-adherence due to embarrassment in social settings (e.g., not checking blood glucose or performing insulin injections when one should) was prevalent among adolescents, but the issue was greatly diminished among YAs (50% vs. 15%, $p=0.054$). This suggests an opportunity for YAs who have overcome social embarrassment related to diabetes to share their experiences with adolescents. In addition, diabetes management on one’s own and in college were frequently listed as preferred peer mentoring topics by the adolescents. The YAs, who had the benefit of hindsight regarding managing diabetes in adolescence, also raised mentoring topics that the adolescents did not mention, including the importance of adherence based on personal experience, building positive attitudes toward having diabetes, and cultivating supportive relationships with friends and family. These topics are important for youth with T1D, as they learn to be independent and proactive in diabetes management.

The findings of the study also suggest that age is a not natural divider between prospective mentors and mentees. The transitional phase from adolescence to young adulthood, often

referred to as “emerging adulthood”,³⁶ can be challenging for both age groups. As shown in our data, overall glycemic control of adolescents and YAs were equally poor. This is supported by existing literature that adherence and good glycemic control is difficult to maintain in both age groups.^{10,34} Many factors unique to chronic condition management in emerging adulthood contribute to the issue, such as disrupted transitions from pediatric to adult care, changes in living environments, and heterogeneity in acquiring necessary self-care knowledge and skills to maintain good glycemic control independently.^{37,38} Like emerging adults without chronic conditions, emerging adults with T1D are also vulnerable to depression, low self-esteem, and eating disorders; however, these psychological and developmental issues could lead to more severe, longer-term adverse health effects and complications related to T1D.^{37–39} Thus, in addition to desirable mentor qualities such as great communication skills, non-judgmental attitudes, ease around younger peers, compassion and empathy, it is important to consider YA’s adherence and glycemic control when selecting YA mentors to pair with adolescent mentees. Our data suggest that many YAs have poorer self-care and glycemic control than adolescents. Screening and selecting those with at least adequate self-care and glycemic control to serve as mentors may be beneficial. In addition, young adults with poor glycemic control may be able to benefit from peer mentoring as well, though the mentoring themes may be personalized depending on their needs. For example, a 21-year-old with T1D and poor adherence may benefit from a peer mentoring relationship with a 24-year-old who has developed positive self-care strategies. Thus, the assignment of a mentee or mentor role should be need-based, instead of age-based. The need for a peer mentor can be assessed from an individual’s glycemic control, interest, and barriers to diabetes management.

Voluntary peer mentoring can only benefit those who opt to participate. In our study, few observable factors were shown to be statistically significantly associated with interest in peer mentoring, possibly due to the small sample size of our survey. Factors such as age, glycemic control, and adherence measures were thought to be logical predictors of patient interest, but these factors were found to not matter. Instead, social factors stood out. The adolescents who were interested in having a peer mentor were more likely to have “supportive friends who know about their condition” (OR=5.7, p=0.02) and to live in a large household (≥ 5 members, OR=4.9, p=0.02). It is possible that exposure to supportive friends facilitates adolescent communication about diabetes with peers, at an age when some may be reluctant to disclose for fear of not fitting in. Adolescents who lack positive experiences communicating about their diabetes with friends may not have a frame of reference for understanding how a peer mentoring program could be beneficial. However, they may benefit as much, or more, from a peer mentoring program. Innovative incentives may be needed to reach prospective mentees who are less willing to share their diabetes experiences. Alternatively, other interventions not involving direct social interactions may be more suitable to improve adherence in these individuals. Further research is needed to understand why living in a large household is associated with greater interest in peer mentoring participation. It is possible that adolescents from large households have multiple siblings and may not have sufficient one-to-one attention and diabetes support from their parents. If so, this subgroup of adolescents would especially benefit from having a dedicated peer mentor.

Limitations

Data collected in the study were mainly from patients residing in Los Angeles County. Although patient characteristics in our study were similar to those in national data in terms of glycemic control, the findings may not be directly generalizable to the broader U.S. population. However, many barriers to diabetes control are universal among young patients, regardless of their geographic locations. And preferred mentoring topics are indicative of patient needs during the transition from parental supervision to self-management. Another potential limitation is the use of a survey for soliciting patient interest. Even though the majority of the participants stated an interest, this may not directly translate into a high participation rate in an actual program. There is some evidence for great difficulty in recruiting youth for any type of diabetes-related intervention, especially among minorities.^{40,41}

In conclusion, our study suggests that peer mentoring has the potential to improve glucose control in youth with diabetes. In this way, slightly older youth with good glycemic control contribute to building positive attitudes, overcoming embarrassment, and sharing college-related experiences. A tailored program with high mentor availability may be achievable, because a very high percentage of YAs are interested in serving as mentors. Directions for future research include a clinical trial of peer mentoring in T1D that measures changes in adherence and glycemic control. It is important to use multiple communication modes in the trial, to ensure frequent contact between mentees and mentors, especially in large metropolitan areas where subjects may live far away from each other. A wide range of topics on diabetes management are of interest and should be included, to help adolescent patients prepare for optimal glycemic control in their adult years.

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Figure 1.

Diabetes self-care inventory measures, adolescents vs. young adults

Note. 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Usually, 5 = Always. The error bars represent the 95% confidence intervals for each item.

Table 1

Characteristics of survey participants, adolescents vs. young adults

	Adolescents (n=54)	Young adults (n=46)	P-value
Outcomes			
Interest in peer mentoring, %	57.4	87	<0.001
Glycemic control			
Laboratory A1C (%)	8.4 (7.5–9.3)	8.9 (7.5–10.1)	0.124
Demographics			
Age, y	15.8 ± 1.8	20.5 ± 1.5	<0.001
Female, %	46.2	54.3	0.427
Hispanic, %	37	47.8	0.281
In a romantic relationship, %	11.1	43.5	<0.001
Household size	4.4 ± 1.5	4.1 ± 1.4	0.429
Diabetes History			
Age at diabetes diagnosis	7.9 ± 4.4	8.4 ± 4.1	0.550
Duration of diabetes	7.9 ± 4.5	12.1 ± 4.3	<0.001
Wearing an insulin pump, %	48.1	39.1	0.370
Ever had diabetic ketoacidosis	33.3	32.6	0.648
Ever had severe hypoglycemia	37	37	0.708
Insurance Status			
Public insurance, %	35.2	21.7	0.143
Private insurance, %	51.9	32.6	0.053
Other insurance, %	3.7	26.1	0.001
No insurance/Don't know, %	9.3	19.6	0.142
Diabetes Management			
Self-Care Inventory score (1–5)	3.4 ± 0.5	3.1 ± 0.6	0.004
Diabetes Empowerment score (1–5)	4.3 (3.6–4.8)	4.4 (4.0–4.6)	0.686
Past barriers to glycemic control, %	n.a.	69.6	n.a.
Current barriers to glycemic control, %	46.3	43.5	0.780
School or work	16.7	26.1	0.253
Vacation	13	13	0.991
Social situations	29.6	30.4	0.931
Social factors			
CES depression score (0–20)	5 (3–9)	5 (2–8)	0.592
Social Connectedness score (1–48)	42 (38–48)	43 (39–47)	0.994
Know someone with type 1 diabetes, %	57.4	43.5	0.168
Have supportive friends, %	74.1	80.4	0.456

Note. Data are presented in percentages for dichotomous variables, in means ± SD for normally-distributed continuous variables, and in medians and interquartile ranges (IQR) otherwise. Public insurance included Medi-Cal, Medi-Cal managed care (e.g., LA Care, Healthnet), and California Children's Services. A higher CES depression score indicates a higher likelihood of depression. P-values are from two-sided t tests.

Table 2

Themes related to barriers, among those experiencing current social barriers to diabetes control, adolescents vs. young adults

	Adolescents (n=14)		Young adults (n=13)	
	n	%	n	%
Embarrassment due to diabetes management	7	50	2	15
Food-related issues				
Having different or inappropriate foods	1	7	1	8
Hard to control/keep track of food portions	3	21	3	23
Schedule-related issues				
Variable eating schedule	0	0	1	8
Unable to be spontaneous	8	57	2	15
Other issues				
Forgetting due to distractions and interferences	2	14	4	31
Lack of a quiet place to check blood glucose	1	7	2	15
Supplies	1	7	2	15

Table 3

Preferred topics of peer mentoring among those interested in a mentoring program, adolescents vs. young adults

	Adolescents (n=28)		Young adults (n=39)	
	n	%	n	%
Diabetes management skills				
Diabetes management on one's own and in college	11	39	9	23
Diabetes management regarding pump use	0	0	2	5
Diabetes management regarding sports/exercise	2	7	4	10
Diabetes management in social situations	4	14	3	8
Diabetes management regarding emergencies (such as high and low blood glucose)	2	7	3	8
Diabetes management with inflexible schedules (class, work, travel)	2	7	5	13
General diabetes management skills	3	11	0	0
Communication skills and social support development				
Importance of help and support from friends and family	0	0	5	13
How to cultivate supportive friends	0	0	4	10
How to communicate with doctors, friends, and family about diabetes	0	0	8	21
Acceptance of diabetes/positive attitude towards diabetes	0	0	16	41
Importance of adherence	0	0	14	36
Other topics				
General experiences as a teenager	0	0	5	13
Food choices and portions	1	4	5	13
Alcohol and drug use	0	0	1	3
Help with late diagnosis	0	0	1	3
How to cope with stress and emotions	2	7	0	0
Gaining different perspectives	10	36	0	0