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IDENTIFYING FACTORS ASSOCIATED WITH PARTICIPATION IN T1D SUPPORT PROGRAM FOR YOUNG ADULTS

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People Living with And Inspired by Diabetes

ABSTRACT

Objective: Type 1 diabetes (T1D) has been shown to have a significant and stressful impact on an individual's transition into young adulthood. Young adults are often experiencing new levels of independence and decision-making at this time. Insufficient research has been conducted on the use and impact of T1D support programs tailored to young adults in relation to the emotional impacts of the disease, access to programming, and desired outcomes of programs. This study assesses awareness, utilization, and emotional needs of T1D support programs tailored to young adults.

Research Design and Methods: A cross-sectional analysis was performed on surveys collected through specific groups on Facebook (n=529). Logistic regression was used to assess factors associated with participation in T1D support programs.

Results: Approximately 41% of participants had been involved in a program or activity for young adults. The average age was 24 (range 18-30) with females being overrepresented (85%). Individuals who attended a T1D support program for young adults were more likely to disagree that: 1) their T1D keeps them from having a normal life; 2) they feel their T1D controls their life; 3) they feel their T1D takes up too much mental/physical energy; or 4) they need more peer-to-peer support with T1D.

Conclusion: The findings highlight the importance for T1D support programs for young adults and the unique needs of a population with T1D. T1D support programs should be considered in combination with clinical support to better prepare individuals as they transition into young adulthood.



INTRODUCTION

Individuals with type 1 diabetes (T1D) require multiple daily injections of insulin and monitoring of blood glucose levels to maintain a constant level of control of the glucose levels in their body. This has proven to be a very stressful lifelong demand on the individual and their families. People with T1D need to monitor their daily activity levels, nutrition, and stressors, along with their blood sugar levels in order to prevent complications from the disease such as kidney failure, neuropathy, or blindness [1, 2]. Today in the United States one out of every 400 individuals, under the age of 20, has type 1 diabetes [3]. According to the Centers for Disease Control and Prevention, there is a projected annual increase of 18,000 people being diagnosed with type 1 diabetes in the United States [4]. Thus, the number of individuals in need of solutions for this complex and all-encompassing disease is increasing.

When being diagnosed with type 1 diabetes, there are many kinds of emotions that may run through the mind of patients and their family members such as fear, worry, and helplessness. Those individuals burdened with coping for their type 1 diabetes including the emotional distress, hormonal changes, and young adulthood life transitions have been shown to lead to a poorer quality of daily glycemic control if not addressed properly [5]. These distresses are often difficult to address by the medical providers and family members of individuals living with type 1 diabetes, making it even more complicated to address the needs for further support [6]. If these distresses go unaddressed in a patient, glycemic control is believed to decline quickly along with their self-care and quality-of-life, which can be associated with a higher incidence rate of clinical depression [7].

Young adulthood may be one of the most challenging times in a person's life with T1D because of various complex changes occurring, such as moving away from their major support systems, attending college, and hormonal changes [8]. Young adulthood is a period in life commonly marked as one for decreased motivation and a lapse in proper glycemic control among individuals with T1D because of other overwhelming stressors such as: college, stigma, parental involvement, and medical provider interactions [6, 5]. Young adulthood, also called emerging adulthood, is a time of life when transitions and personal development occur, generally between the ages of 18-25 or 18-30 [5]. While young adults may correlate this time period as being unstable, even more so because of their diabetes, they still do not consider their diabetes to limit their opportunities in

life [9]. However, this population has been shown to have poor recorded glycemic control and limited awareness of their actions towards potential medical complications [1].

As mentioned, chronic diseases alone may be associated with multiple complications and stressors, yet the addition of life transitions (i.e., to young adulthood) can heighten these issues. If left unattended, these issues may lead to worsening health and poor overall glycemic management. However, there are strategies to help these young adults cope during this time period [10]. Rasmussen et al. found that there was an established benefit for the young adults who attended T1D support programs (e.g., a camp for children with T1D), because it provided them with a sense of togetherness and not feeling alone when dealing with their disease [11]. This suggests that peer support in the form of peer-to-peer interactions or participation in T1D support programs can be effective solutions to manage transitions into young adulthood.

METHODS

A convenience sample of young adults aged 18-30 with T1D (n=529) were recruited to participate in this study. Participants were asked to answer online surveys assessing what they look for in T1D support programs, what barriers may prevent them from attending the events, and what distresses they experience in relation to their chronic disease. An electronic survey, developed by the researchers, consisted of 12 questions and included forced-choice and open-ended response options. Survey participation was completely voluntary and anonymous. The Institutional Review Board at Boise State University approved this study. The inclusion criteria for participation in the study was being within the desired age range of 18-30 and having type 1 diabetes. There were no incentives provided to the participants of this study.

Surveys were distributed through young adult and college diabetes programs called D'Treat and College Diabetes Network. Along with these programs, the survey was promoted in 50 various groups pertaining to peer-to-peer interactions with people dealing with T1D on the social media platform Facebook.

Variables

Survey participants were asked to complete demographic variables such as age (continuous), gender (male, female), race (White/Caucasian, other), and education (high school/GED, some college, 2-year college degree, 4-year college degree, graduate degree). Factors associated with participation in a T1D support program were also collected. These included whether one was involved in support programs as a minor, under 18, (yes/no), and whether one was currently involved in support programs for young adults, specifically programs aimed at people 18-30. Further, Hemoglobin A1C range (A1C ranges: 4.5-5.5; 5.6-6.5; 6.6-7.5; 7.6-8.5; 8.6-9.5; 9.6-10.5; 10.6-11.5; 11.6-12.5; 12.5 and above) was also included to assess severity and level of control of diabetes. The major independent variable was past attendance in a T1D support program for young adults. Events (e.g., graduating high school, having a child) that individuals encountered during their young adulthood were also identified. Further, barriers to participation in T1D support programs were also identified (e.g., program availability, cost of programs). Major outcomes of interest included several items pertaining to one's agreement/disagreement with how diabetes affects their life and peer support.

Statistical Analyses

Analysis was conducted using the SAS (version 9.3, SAS Institute, Inc., Cary, NC). Descriptive analyses of demographic variables, attendance patterns, perceived benefits of participations, and barriers to attendance were performed. The relationships between selected variables were explored using logistic regression models predicting disagreement (versus agreement) with our outcomes of interest.

RESULTS

Descriptive Analysis

The 529 participants who met the eligibility requirements of being 18-30 years old and having type 1 diabetes were predominantly of White/Caucasian descent (91%) with the majority (85.20%) identifying as female (see Table 1). The mean age of participants was 24.29. Hemoglobin A1C distribution varied, with the largest segment between 6.6-7.5 (29.33%), followed by 7.6-8.5 (23.24%). The largest proportion of individuals reported completing some college (38.83%) followed by those reporting completing a 4 year degree (26.14%).

Table 1: Participant Characteristics
Age (mean= 24.287 median =24; range = 18 – 30)

Characteristic		n	Percent
Gender	Male	78	14.8%
	Female	451	85.20%
Race	White/Caucasian	476	90.15%
	Other	52	9.85%
Education	High School/GED	81	15.34%
	Some College	205	38.83%
	2-year College Degree	64	12.12%
	4-year College Degree	138	26.14%
	Graduate Degree	40	7.58%
Involved in Support Programs as a minor	Yes	246	50.72%
	No	239	49.28%
Currently Involved in Support Programs for Young Adults	Yes	121	24.95%
	No	284	58.56%
	No, but have in the past	80	16.49%
A1C Range	4.5-5.5	17	3.24%
	5.6-6.5	90	17.14%
	6.6-7.5	154	29.33%
	7.6-8.5	122	23.24%
	8.6-9.5	54	10.29%
	9.6-10.5	39	7.43%
	10.6-11.5	18	3.34%
	11.6-12.5	11	2.10%
12.5 and above	20	3.81%	

While a little over half of the individuals reported participating in T1D-related programs as a minor (50.72%), such as JDRF event/walks, diabetes camps, or American Diabetes Association events, the percentage of individuals involved in programs for young adults was lower (24.95%). Of these individuals, a majority have experienced transitions in young adulthood that can be considered as a stressor while dealing with T1D such as: graduating high school (84.87%), enrolling in higher education (81.09%), having a significant relationship (67.48%), moving out of their parent/guardian's home (64.65%), and joining the workforce (62.94%) as seen in Table 2.

Table 2: Events That Subjects Have Encountered During Their Young Adulthood

<i>Event</i>	<i>n</i>	<i>Percent</i>
Graduated High School	449	84.87%
Enrolled in higher education	429	81.09%
Had a significant relationship	357	67.48%
Moved out of parent/guardians' home	342	64.65%
Joined the workforce	333	62.94%
Had a major change in support/friend groups	319	60.30%
Completed some college	309	58.41%
Had a significant move	309	58.41%
Transitioned in adult medical care	236	44.61%
Had a child	96	18.14%

Barriers and Desired Opportunities of T1D Young Adult Programming

Participants reported that some of their greatest barriers in attending T1D support programs included being unaware that programs existed specifically for young adults (38.75%), no programs held in a location near the participant (29.86%), and not being involved in a program previously (26.65). However, barriers that were the least reported included not enjoying a program they attended in the past (3.21%), feeling out-of-place at an event (8.50%), and the cost of the programs available (9.64%) as presented in Table 3. When attending programs, these young adults desire educational opportunities on topics such as: new technology (77.78%), motivation for managing their T1D (76.33%), and peer-to-peer support (72.38%).

In Table 4 there is the distribution of these desired opportunities: T1D support programs. Educational topics with the lowest rates of being identified as 'very important' relative to other items included: college support (25.11%), complications of T1D (15.37%), and insurance (14.80%). This was in contrast to education on new technology (77.78%), motivation for managing my diabetes (76.33%), and peer-to-peer support (72.38%), which were noted as being 'very important' by more than 70% of respondents.

Adjusted Analysis

Adjusted analyses were reported for our main outcomes of interest in both Tables 5 and 6.

Table 3: Perceived Barriers by Subjects of Being Involved in Programs for Young Adults with T1D

<i>Barrier</i>	<i>n</i>	<i>Percent</i>
Unaware of programs specific to young adults	205	38.75%
No programs are available where I am located	158	29.86%
Have not been involved in a program before	141	26.65%
Programs I've attended weren't specific towards young adults	55	10.39%
I don't feel the need to participate in a program for young adults with T1D	53	10.01%
Cost of program limited my participation	51	9.64%
I felt out of place at programs I've attended	45	8.50%
I did not enjoy the program(s) I've attended	17	3.21%

T1D and Peer Relationships

After controlling for all other variables in the model, results indicated that individuals attending diabetes support programs have more peer interactions that positively affect the way that they manage their diabetes. For example, having attended a T1D support program for young adults (vs never attended) was associated with a lower likelihood (OR 0.272; 95% CI 0.107-0.693) of disagreeing that knowing a friend with T1D makes it easier to manage. Males were more likely than females to disagree that knowing a friend with T1D makes it easier to manage (OR 3.517; 95% CI 1.534-8.064). Those individuals that attended a T1D support program for young adults (versus never attended) were less likely to disagree that: they have a large group of peers with T1D (OR 0.164; 95% CI 0.102-0.263); that their peers that also have diabetes are their main form of support for my diabetes (OR 0.390; 95% CI 0.248-0.611); and that they feel that their family is their main form of support for my diabetes (OR 0.648; 95% CI 0.423-0.994). Program attendance (versus never attending) was found to be associated with a greater likelihood of disagreeing with the following items: feeling like they need more peer-to-peer support with their diabetes (OR 2.577; 95% CI 1.568-4.237); and that they wish they knew more people their age that deal with T1D like they do (OR 1.928; 95%

Table 4: Opportunities Subjects Desire from a Program for Young Adults with T1D

<i>Opportunity</i>	<i>Very Important</i>	<i>Percent</i>	<i>Somewhat Important</i>	<i>Percent</i>	<i>Not Important</i>	<i>Percent</i>
Education on new technology	350	77.78%	90	20.00%	10	2.22%
Motivation for managing my diabetes	345	76.33%	84	18.58%	23	5.09%
Peer-to-peer support	325	72.38%	106	23.61%	18	4.01%
Education on living healthier	298	65.63%	138	30.60%	17	3.77%
Help on managing my diabetes	279	61.86%	141	31.26%	31	6.87%
Friendship	269	59.51%	158	34.96%	25	5.53%
Education on starting a family	261	57.87%	134	29.71%	56	12.42%
Education on research for a cure	255	56.67%	155	34.44%	40	8.89%
Education on insurance	221	49.55%	159	35.65%	66	14.80%
Education on complications of T1D	216	48.11%	164	36.53%	69	15.37%
Education on college support	196	43.65%	141	31.33%	113	25.11%

TABLE 5A: Adjusted analyses for Disagreement the following statements in regards to the subjects T1D and peer relationships

<i>Variables</i>		<i>Knowing a friend with diabetes makes it easier to manage</i>			<i>I have a large group of peers that have diabetes</i>			<i>I feel that peers that also have diabetes are my main form of support for my diabetes</i>		
		<i>OR</i>	<i>95% Confidence Intervals</i>		<i>OR</i>	<i>95% Confidence Intervals</i>		<i>OR</i>	<i>95% Confidence Intervals</i>	
YA Program Attendance	Attended vs Never Attended	0.272*	0.107	0.693	0.164*	0.102	0.263	0.390*	0.248	0.611
Gender	Male vs Female	3.517*	1.534	8.063	0.795	0.416	1.517	1.491	0.774	2.872
Education	High School vs Graduate Level Degree	2.095	0.504	8.705	1.369	0.458	4.091	0.955	0.350	2.607
	Some College vs Graduate Level Degree	0.461	0.108	1.977	1.023	0.394	2.655	1.052	0.435	2.547
	2 Year Degree vs Graduate Level Degree	0.609	0.108	3.435	0.940	0.316	2.801	1.775	0.615	5.123
	4 Year Degree vs Graduate Level Degree	0.822	0.194	3.480	1.556	0.576	4.203	1.797	0.713	4.527

* significant at alpha 0.05 using 95 % confidence intervals

CI 1.036-3.587). Males were more likely to disagree with feeling like they need more peer-to-peer support with their diabetes (OR 2.404; 95% CI 1.298-4.451).

T1D Management

After controlling for the variables in the model, results indicated that individuals attending support programs feel as though they have greater control over their diabetes management. For example, having attended a T1D support program for young adults (versus never attending) was associated with a greater likelihood of disagreeing that: they feel that their diabetes keeps them from having a normal life (OR 1.584; 95% CI 1.047-2.397); they feel that their diabetes controls their life (OR 1.646; 95% CI 1.076-2.517); and they feel that their diabetes takes up too much mental and physical energy everyday (OR 1.919; 95% CI 1.187-3.104). While program attendance was associated with a

lower likelihood of disagreeing that they feel that they do the best that they can with their diabetes management (OR 0.514; 95% CI 0.309-0.853).

DISCUSSION

This research study evaluated factors associated with young adults with T1D and their perspectives towards young adult diabetes support programs. Further correlations between program attendance and various outcomes related to T1D were identified. With the use of an online survey, this research was able to reach a unique and emerging population while still remaining anonymous and conducting the study at a relatively low cost. Findings indicate that there is a strong association between young adult program attendance and feelings toward T1D management and influences from family and peers.

TABLE 5B: Adjusted analyses for Disagreement the following statements in regards to the subjects T1D and peer relationships

Variables		<i>I feel that my family is my main form of support for my diabetes</i>			<i>I feel like I need more peer to peer support with my diabetes</i>			<i>I wish I knew more people my age that deal with diabetes like I do</i>		
		OR	95% Confidence Intervals		OR	95% Confidence Intervals		OR	95% Confidence Intervals	
YA Program Attendance	Attended vs Never Attended	0.648*	0.423	0.994	2.577*	1.568	4.237	1.928*	1.036	3.587
Gender	Male vs Female	0.988	0.546	1.787	2.404*	1.298	4.451	1.929	0.899	4.139
Education	High School vs Graduate Level Degree	1.072	0.454	2.532	1.054	0.352	3.153	0.756	0.188	3.037
	Some College vs Graduate Level Degree	0.883	0.412	1.891	0.708	0.267	1.875	0.729	0.221	2.405
	2 Year Degree vs Graduate Level Degree	0.585	0.229	1.495	0.958	0.320	2.871	1.165	0.301	4.505
	4 Year Degree vs Graduate Level Degree	0.726	0.325	1.619	0.958	0.358	2.562	0.793	0.234	2.689

* significant at alpha 0.05 using 95 % confidence intervals

TABLE 6A: Adjusted analyses for Disagreement the following statements in regards to the subjects T1D management

Variables		<i>I try to avoid things that remind me of my diabetes</i>			<i>I feel that I am failing with maintaining a good diabetes routine</i>			<i>I feel that my diabetes keeps me from having a normal life</i>		
		OR	95% Confidence Intervals		OR	95% Confidence Intervals		OR	95% Confidence Intervals	
YA Program Attendance	Attended vs Never Attended	1.402	0.848	2.317	1.177	0.780	1.774	1.584*	1.047	2.397
Gender	Male vs Female	0.989	0.504	1.938	1.440	0.809	2.563	1.646	0.918	2.953
Education	High School vs Graduate Level Degree	0.288	0.075	1.115	0.579	0.227	1.477	0.842	0.331	2.141
	Some College vs Graduate Level Degree	0.307	0.086	1.098	0.829	0.368	1.870	0.682	0.305	1.525
	2 Year Degree vs Graduate Level Degree	0.209*	0.053	0.820	0.955	0.371	2.464	0.912	0.350	2.375
	4 Year Degree vs Graduate Level Degree	0.451	0.122	1.675	1.709	0.736	3.969	1.029	0.448	2.360

* significant at alpha 0.05 using 95 % confidence intervals

Results from the survey demonstrated that only about a quarter of individuals participate in T1D support programs for young adults, which may be in part due to lack of awareness, limited availability of T1D support programs for young adults near the participants, and not being previously involved in T1D support programs for young adults. While looking at the transitions individuals have encountered in young adulthood, the findings are similar to those found by others in the field with transitions such as: moving from home, attending college, having a child, transitioning to adult medical care, and graduating high school [5, 8]. Interestingly, cost was not found to be a barrier of attendance by this young adult population.

Finally, results identified in the adjusted analysis indicated that several factors associated with peer support may be influenced by participation in T1D support programs for young adults. In many instances results indicated that individuals who attended a T1D support program for young adults were more likely to feel they have control of their diabetes.

Thus, T1D support programs for young adults may improve the emotional complications seen to emerge in young adulthood [1, 8, 12].

STRENGTHS AND LIMITATIONS

Using social media for survey dissemination can be both a quick and effective way to reach one’s target population. However, social media may not be able to control who participates in the survey. While we targeted Facebook groups for individuals with T1D, we could not restrict participation to a select target group as one might in a more clinical setting. Given the seeming ubiquity of social media as a platform that can be used to collect information, further research into using this platform in research studies should be conducted to assess its feasibility in broader populations.

TABLE 6B: Adjusted analyses for Disagreement the following statements in regards to the subjects T1D management

Variables		<i>I feel that my diabetes controls my life</i>			<i>I feel that my diabetes takes up too much of my mental and physical energy every day</i>			<i>I feel that I do the best that I can with my diabetes management</i>		
		OR	95% Confidence Intervals		OR	95% Confidence Intervals		OR	95% Confidence Intervals	
YA Program Attendance	Attended vs Never Attended	1.646*	1.076	2.517	1.919*	1.187	3.104	0.514*	0.309	0.853
Gender	Male vs Female	1.107	0.628	1.953	2.289*	1.227	4.270	0.626(0.307	1.278
Education	High School vs Graduate Level Degree	0.866	0.324	2.312	1.036	0.314	3.421	2.107	0.766	5.793
	Some College vs Graduate Level Degree	1.033	0.441	2.421	1.130	0.386	3.311	1.213	0.481	3.057
	2 Year Degree vs Graduate Level Degree	1.423	0.541	3.743	2.579	0.800	8.310	1.411	0.491	4.049
	4 Year Degree vs Graduate Level Degree	1.875	0.782	4.496	1.584	0.532	4.716	0.704	0.260	1.910

* significant at alpha 0.05 using 95 % confidence intervals

Further, this study was cross-sectional in nature and as such causality is not implied. In addition, recall bias may be a limiting factor, given participants were reporting on past events in their youth. The survey was also limited in terms of generalizability, especially given limited racial and ethnic diversity and the relatively larger percent with some college or more. This sample may also be limited by inherent bias due to the nature of self-selecting to participate in the survey. Those who are more accepting of their disease may be more open to participating in the study while those who may need the most amount of support may have forgone participating in the study. While around half of the population noted having their HbA1c close to the recommended goals, this is a factor that future research should explore due to the nature of this population. There are many factors that impact glycemic control and HbA1c that could not be addressed in this study. Future studies should focus on finding more diversity within the sample. Further, additional qualitative aspects such as focus groups with open-ended study questions may add a more depth to the findings and are recommended for future research.

FUTURE PRACTICES

Program directors, camps, and any organization looking to hold programs for young adults with type 1 diabetes can utilize this data moving forward. By utilizing these results one can see the importance of T1D support programs for young adults while also having a better understanding of specific topics to address in future offerings of these programs. Further, identifying any life transitions their participants might be experiencing and how to aid them can be critical to strengthening their confidence in managing their diabetes.

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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