

# Psychological State of Camp Counselors with Type 1 Diabetes who Have Attended Diabetes Camp

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## ABSTRACT

**Introduction.** By 2050, more than 580,000 children in the United States will be diagnosed with type 1 diabetes (T1D). Management of T1D requires careful and continuous intervention, and children with T1D experience unique challenges in disease management compared to their adult counterparts. Diabetes camps are designed to help those with T1D learn diabetes management skills while experiencing summer camp. Psychological aspects are not addressed explicitly in diabetes camps located in Kansas. The purpose of this study was to evaluate the psychological state of past campers and camp counselors from one diabetes camp in Kansas.

**Methods.** Campers and counselors, all of whom had T1D, and attended diabetes camp from 2015 to 2019 in Kansas were recruited to complete a survey about diabetes-related stress, diabetes management self-efficacy, and symptoms of depression. A link to the online survey was distributed to previous campers and counselors by email and through Facebook.

**Results.** A total of 24 camp counselors and 10 campers were surveyed, 100% of whom reported having T1D and attending camp at least once. One-third of respondents (n = 8) reported having severe diabetes-related stress, and 100% (n = 34) reported high levels of diabetes management self-efficacy. Most participants reported moderate levels of depression, and 9% (n = 3) reported a past suicide attempt. These results suggested a relatively high prevalence in signs of psychological distress from former campers and camp counselors with T1D.

**Conclusions.** This study suggested that campers and counselors with T1D have high levels of diabetes-related stress, high diabetes management self-efficacy, and many signs of depression.

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## INTRODUCTION

Every year in the United States, approximately 18,200 children are diagnosed with type 1 diabetes (T1D).<sup>1</sup> In 2018, 187,000 children had T1D, and by 2050, more than 580,000 children are expected to be diagnosed.<sup>2,3</sup> Annually, healthcare costs and lost income associated with T1D exceeds \$16 billion.<sup>4</sup> Despite modern interventions and advances in medicine, there is a strong association between T1D and premature mortality, partially due to complications from poor blood glucose control.<sup>5</sup>

Management of T1D requires careful and continuous intervention, and children with T1D experience unique challenges in disease management than their adult counterparts. Constant changes in growth, puberty, and hormonal development are all factors unique to children

that have major impacts on blood sugar control.<sup>6</sup> Additionally, counting carbohydrates, calculating insulin doses, and factoring in blood glucose corrections require math and logic too advanced for some children.<sup>7</sup> Accordingly, children often rely on their parents, caretakers, doctors, nurses, or school supervisors for help.<sup>8</sup> This can be problematic as many of these adults are not trained in proper T1D care, and changing between different caretakers can mean changes in the way a child's T1D is managed.

Adolescents and young adults with diabetes experience higher levels of stress from having a serious medical condition than their peers without diabetes.<sup>9</sup> This diabetes-related stress can occur as a result of multiple factors (e.g., the challenges of management, isolation, fear of adverse reactions) and can lead to poorer outcomes in diabetes management. This can manifest as increased levels of depression and anxiety when compared to their peers without diabetes, which can lead to suboptimal blood sugar control.<sup>10</sup>

Depression is a serious concern among those with T1D. Adolescents and young adults with T1D have a higher prevalence of both depression and anxiety, between 14% and 32%, which is almost double the prevalence of their adolescent counterparts without T1D.<sup>11,12</sup> Increased levels of depression are known to be related directly to poorer diabetes management, leading to higher HbA1c levels and a decreased frequency of blood glucose monitoring.<sup>11</sup>

Self-efficacy is a factor that can play a role in diabetes management. As a principle, self-efficacy encompasses one's belief in oneself to perform necessary tasks to attain a goal. Adolescents and young adults with T1D are in a transition period of gaining more freedom and having less help from parents or caregivers in their diabetes management. This can correlate with changes in self-efficacy.<sup>13</sup> Self-efficacy levels impact young adults' management strategies and their blood glucose control overall, as well as playing a role in mediating the stress levels associated with T1D.<sup>14</sup> All of these factors have a role in a young adult's ability to maintain good diabetes control in order to minimize diabetic complications.

Diabetes camps are designed to help those with T1D experience traditional summer camp, learn diabetes management techniques, and meet others with diabetes.<sup>15</sup> Camps are effective in helping children better manage their T1D. One study suggested that mean HbA1c levels decreased from 10.0 before camp to 8.2 after camp.<sup>16</sup> For this reason, participating in diabetes camp can play an important role for children with T1D. By 2011, more than 30,000 people had attended a diabetes camp in North America.<sup>17</sup> However, there is limited research regarding the psychological state of campers and camp counselors who have T1D and attended diabetes camp, including diabetes-related stress, diabetes management self-efficacy, and symptoms of depression. The purpose of this study was to assess former campers and camp counselors with T1D regarding diabetes-related stress, diabetes management self-efficacy, and signs of depression.

## METHODS

**Participants.** Eligible participants attended at least one, week-long diabetes camp in Kansas, Camp Discovery, as a camper or camp counselor anytime from 2015 to 2019. Camp Discovery hosts approximately 100 kids with T1D in 4th through 10th grades each summer at Rock Springs 4-H Center in northeast Kansas. All eligible participants had a diagnosis of T1D. Parents of children campers were emailed links for their children to complete, and previous camp counselors were emailed directly. Participants were asked to complete a survey, and if needed, the child's parent/guardian could assist them in completing the survey. No incentive was provided to study participants.

**Instrument.** A novel survey was developed for this study and included demographics (e.g., age, gender), self-reported health-related variables (e.g., HbA1c levels, duration of disease), and diabetes management strategies (e.g., type of insulin therapy, glucose monitoring). In this study, a HbA1c level of less than or equal to 7 was used as "normal," whereas greater than 7 was considered elevated or "poor control," as established by the American Diabetes Association (ADA) criteria for adolescents with T1D.<sup>18</sup> In addition, standardized assessments were used to measure diabetes-related stress, diabetes management self-efficacy, and signs of depression.

The Problem Areas in Diabetes (PAID) scale was used to measure diabetes-related stress.<sup>19</sup> A total score of 40 or greater indicated high stress levels from diabetes. The Self-Efficacy for Diabetes (SED) scale was used to assess for self-efficacy in: diabetes management (SED-D), medicine (SED-M), and general self-efficacy (SED-G).<sup>20</sup> Respondents' scores for each category were added for a total score. Maximum scores on SED-D, SED-M, and SED-G are 120, 25, and 30, respectively. Scores of 40% or greater of the maximum per category indicated increased self-efficacy in that scale. The Patient Health Questionnaire-9 Modified (PHQ-9M) was used to assess for signs of depression. PHQ-9M scores of 10 or greater had high sensitivity and specificity for major depressive disorder.<sup>21</sup>

**Procedures.** This project was approved by the Institutional Review Board at the University of Kansas Medical Center. Eligible participants were identified through three channels. On June 23, 2020, the Director of Youth and Family Initiatives for the Central Territory of the American Diabetes Association, which hosted the camp, e-mailed the online survey link to former campers' parents from the summers of 2018 and 2019. The ADA sent a second e-mail on July 5, 2020 to campers' parents from 2015 through 2019. On July 2, 2020, a research team member e-mailed the survey link to former camp counselors from the summers of 2015 through 2019 (the list of which was provided by ADA), and the camp's private Facebook page displayed a request for former campers or counselors to complete the survey.

Surveys were electronically administered in Research Electronic Data Capture (REDCap®).<sup>22</sup> Depending on the age of the potential participant, the survey was accompanied by parent/guardian consent and child assent forms, or just an adult consent form. These forms

described that the survey was voluntary and parental assistance was allowed, and potentially complex terms were defined, especially for those younger than 18 years. Participants were given two weeks to complete the survey once open.

**Statistical Analysis.** SAS 9.4 (SAS/STAT Inst., Cary NC) was used for data analysis. The socio-demographic characteristics were summarized using descriptive statistics. Means and standard deviations, or medians and interquartile ranges, were reported for continuous variables; counts and percentages were reported for categorical variables. Likelihood ratio chi-square and Fisher's exact tests were used for 2\*2 and r\*c contingency tables to test the association between the categorical and nominal variables. Phi coefficient was used to quantify the strength of association between categorical variables. Further, the Cochran-Mantel-Haenszel test was used to reveal associations between categorical/nominal variables after controlling for the strata variables in a multiway table. Prior to the analyses, continuous outcomes were tested for normal distribution using the Shapiro-Wilk test. For normally distributed variables, an independent t-test with Welch corrected t-test was used to compare the mean difference between groups. In the case of non-normal distribution with appropriate transformation operations on the response variables in group lists, Mann-Whitney U test was conducted to test differences between groups. The test results of Mann-Whitney U were justified with the Savage Two-Sample Test. All statistical tests at  $p \leq 0.05$  were considered significant.

## RESULTS

A total of 34 surveys were completed. Most respondents (79%,  $n = 27$ ) reported being female, and 71% ( $n = 24$ ) reported having been a camp counselor (Table 1). Ages of respondents ranged from 13 to 48 years, with an average of 31 years. The reported average time since their diabetes diagnosis was 23 years ( $SD = 11$ ). Their mean (self-reported) current HbA1c level was 7.25 ( $SD = 0.96$ ), with 55% (18) reporting a HbA1c of greater than 7.0. Most (82%,  $n = 28$ ) respondents reported using a continuous glucose monitor, and 18% ( $n = 6$ ) reported using a traditional glucose meter. Most participants (79%,  $n = 27$ ) reported they were more likely to have an insulin pump for infusion therapy, and 21% ( $n = 7$ ) reported using multiple daily injections.

Among the 34 respondents, 91% ( $n = 31$ ) self-reported feeling that they had their diabetes "under control". However, 55% ( $n = 18$ ) of all respondents reported HbA1c levels greater than 7.0. PAID scores ranged from 19 to 87, with an average of 39.8 ( $SD = 17.8$ ). One third (33%,  $n = 8$ ) reported severe diabetes-related stress. Respondents' SED-D scores ranged from 76 to 120, with an average score of 109 ( $SD = 10$ ). SED-M scores ranged from 15 to 25, with a mean score of 23 ( $SD = 3$ ). SED-G scores ranged from 10 to 30, with a mean of 26 ( $SD = 5$ ). Overall, 100% ( $n = 34$ ) reported high levels of self-efficacy in every category: SED-D, SED-M, SED-G. The PHQ-9M scores ranged from 9 to 35, and the mean score was 15 ( $SD = 6.2$ ). In total, 95% ( $n = 21$ ) of participants completing the PHQ-9M had scores of 10 or greater, indicating a high risk of major depressive disorder. Three respondents (8.8%) indicated a history of suicide attempts. Amongst these three, two had high HbA1c levels (greater than 7.0), and all three had PHQ-9M scores that indicated risk of depression. Two of the three had been counselors at the camp. Regardless of age, gender, counselor

status, or years of attending diabetes camp, these results for HbA1c, PAID score, SED score, and PHQ-9M were not different.

**Table 1. Participant characteristics.**

	Percent	Total
<b>Gender</b>		
Female	79%	27
Male	21%	7
<b>Age in years</b>		
13 to 18	6%	2
19 to 25	27%	9
26 to 35	38%	13
> 35	29%	10
<b>Years with diabetes</b>		
< 10	9%	3
10 to 15	9%	3
16 to 25	41%	14
> 25	41%	14
<b>Years of camp attendance</b>		
1 to 5	29%	10
6 to 10	35%	12
11 to 15	18%	6
> 15	18%	6
<b>Participation status</b>		
Previous camp counselor	71%	24
Previous camper only	29%	10
<b>Insulin therapy</b>		
Insulin pump	79%	27
Injections	21%	7
<b>Blood glucose monitoring</b>		
Continuous glucose monitor	82%	28
Glucometer	18%	6
<b>HbA1c</b>		
< 7.0	38%	13
7.0 to 7.9	35%	12
8.0 to 8.9	21%	7
> 8.9	6%	2

## DISCUSSION

The current study suggested poor diabetes control, regardless of age, among more than half of respondents with T1D (n = 18). This was consistent with past research on people with T1D, although not studied on past diabetes camp attendants.<sup>23</sup> Approximately 25% of young adults (18 to 25 years) with T1D and 50% of those older than 25 years with T1D have a HbA1c of less than 7.0 for optimal diabetes control.<sup>24</sup> The current study's average age was 31 years, and typically there is an increase in HbA1c levels after adolescence, which potentially is attributed to less help from parents or caretakers than when they were younger.<sup>13,25</sup>

The current study suggested that the number of years attending diabetes camp was unrelated to depression, stress, and self-efficacy levels

among those with T1D. Few studies have discussed these outcomes specifically; nonetheless, of the available literature, these findings were concerning, especially because diabetes camps can build self-efficacy through educational activities.<sup>15,26</sup> Through our results of poor diabetes control, yet high levels of self-efficacy, we also saw this inconsistency. This may be due to a variety of factors including, but not limited to, a misunderstanding of diabetes control, limitation of resources, or even extenuating circumstances not elicited in this study. Additionally, previous studies have associated lower stress levels with camp, as participants demonstrate improved attitudes toward their chronic disease due to friendships made at camp.<sup>27,28</sup> Therefore, attending camp more often should help to improve stress levels, which may be inconsistent with our study results. This finding was surprising given the past research of diabetes camps and their effects on participants; however, with little historical data on camp counselors, this could be one reason why we see different results among our study participants specifically.

The current study suggested that children and young adults with T1D who have attended or worked at a diabetes camp reported high levels of diabetes-related stress, which was consistent with research on adults with T1D who have not attended camp.<sup>24</sup> As diabetes camp should improve diabetes-related stress levels, this may suggest an inconsistency; however, many other factors contributed to one's diabetes-related stress levels.<sup>28</sup> Research in this field is important as diabetes-specific stress and depression were associated with higher HbA1c levels and poor self-management strategies.<sup>9,29</sup> Our study suggested that one-third (33%, n = 8) of respondents scored high enough to indicate severe diabetes distress. This was in line with another study that suggested that 36% of participants with T1D who had not attended camp scored in the high diabetes stress range on PAID;<sup>30</sup> whereas another study suggested that 14% of those with T1D scored high enough to indicate diabetes-related stress.<sup>31</sup> In one study of Korean children with T1D from a diabetes camp consistently reported high stress and depression levels.<sup>32</sup> These inconsistencies in the literature lead to a need for further studies evaluating the diabetes-related stress levels among this vulnerable population.

All study respondents reported high scores of self-efficacies across all three categories of the SED scale. As our study did not include young children, this was consistent with previous research stating self-efficacy improves during adolescence.<sup>33</sup> This is thought to be due to an increase in autonomy during adolescence when patients become more responsible for their diabetes care. Additionally, one study documented improvements in self-efficacy after attending a diabetes camp; this was likely a factor associated with the high levels of diabetes self-efficacy reported amongst respondents.<sup>26</sup> In the study of Korean children from a T1D camp, participants consistently reported low levels of T1D self-efficacy which further suggested that younger age groups may have lower levels of self-efficacy in their diabetes management.<sup>32</sup>

The current study suggested that 9% had previously attempted suicide, and all participants reported some level of depression.



This was consistent with research that young adults with T1D are at higher risk for depression and suicide when compared to their same-age counterpart without diabetes.<sup>34</sup> This unique population is known to be at high risk for psychological problems. In fact, a meta-analysis suggested that suicide is an increased cause of mortality amongst those with T1D, with approximately 16% having a previous suicide attempt.<sup>35</sup> This is much greater than adolescent populations without diabetes, where approximately 9% have attempted suicide.<sup>36</sup> With such elevated prevalence of depression and suicide, research with this high-risk population is warranted, especially to identify how to best support these young adults in coping with their chronic disease.

**Future Research.** Further research is needed to understand the impact diabetes camp has on people with T1D. The current study has been a preliminary look into the psychological traits of both campers and camp counselors alike. Many factors must be considered when evaluating the psychological state of adolescents and young adults. Diabetes camp may be one factor that could be associated with varying levels of stress, depression, and self-efficacy. However, socioeconomic status, race, and family dynamics have a large and consistent impact on mental health and need to be considered in further studies.<sup>37,38</sup>

A pre- and post-camp study could provide insight as to the impact of such a camp on diabetes-related stress, management self-efficacy, and signs of depression. A prospective study comparing a diabetes camp control group to a group that offers a psychological counselor at camp could provide new information to the field of psychology and diabetes camps. By evaluating the effect of psychological support at diabetes camp, we may uncover if the psychological state of campers and camp counselors truly is affected by the activities of diabetes camp.

Due to the high amount of stress, depression, and suicidal attempts among this small sample size, it warrants further investigation into how we can serve this vulnerable population. This gives a steppingstone to improve the psychological supports offered to improve the lives of those with T1D. Diabetes camp is just one part of a larger life for people with T1D but offering some type of psychological support at camp may be one way to increase quality of life for these individuals.

**Limitations.** There were multiple limitations to the study. First, this was a small study including 34 respondents with T1D. Due to the barrier of parents needing to act as a liaison between our survey and their children, the average age of participants was high, as most participants were of age to access the survey themselves. Future work must include larger sample sizes to illustrate more accurately the uniqueness of this group. Additionally, this study was cross-sectional, which only allowed for a baseline look at this population. In the future, studies with a longitudinal design may enumerate relationships between variables better, such as HbA1c and depression. Moreover, due to the nature of self-reported data, the current study may suffer from both recall and non-response bias.

The SED scale for measuring self-efficacy, especially among people with T1D, has been controversial. Although it is used widely, it does

not have sufficient data to prove its reliability; in fact, there was limited support for its validity.<sup>20</sup> Future research would benefit from a more reliable scale to measure self-efficacy among persons with diabetes.

This research was conducted during the COVID-19 pandemic, and psychological states may not have reflected accurately non-pandemic psychological states. However, due to the lack of research on this population, we proceeded with this study. Of particular note, no research with T1D camp counselors has been conducted prior to this study, and there appeared to be a clear need to provide support and interventions to camp counselors with T1D in addition to the campers.

## CONCLUSIONS

Campers and counselors with T1D have high levels of diabetes-related stress, high diabetes management self-efficacy, and many signs of depression. Future research must evaluate the psychological distress experienced by people with T1D further, and how interventions are needed to decrease diabetes-related stress, improve diabetes management self-efficacy, and prevent and treat depression.

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