DOI 10.1111/pedi.12499

# ORIGINAL ARTICLE



# Diabetes camp matters: Assessing families' views of their diabetes camp experience

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Jill Weissberg-Benchell, Child and Adolescent Psychiatry, Ann and Robert H. Lurie Children's Hospital of Chicago, 225 East Chicago Avenue, Box 10, Chicago, Illinois 60611. E-mail: jwbenchell@luriechildrens.org **BACKGROUND:** Camp offers a safe and fun environment for learning new information about diabetes care and for trying new self-care skills. It is a place where children and teens are able to meet with others who also have diabetes and who share their experiences.

**MATERIALS AND METHODS:** This study assessed self-reports before and after attending diabetes camp on diabetes-specific emotional distress, diabetes-specific quality of life, and self-care behaviors by surveying campers and their parents from over 42 diabetes-specific summer camps across the United States. Parents (N = 413), Teenagers (N = 154), and Children (N = 116) completed both pre- and post-camp surveys.

**RESULTS**: Parents reported higher levels of diabetes-specific emotional distress than their campers did. Both parents and children reported significant improvements in their own distress after camp. Teens reported improvements in distress but they were not statistically significant. Youth report higher levels of self-care skills than parents believe their children possess. Parents, Teens, and Children all reported significant improvements in the camper's self-care skills after camp. First time campers' and their parents' perspectives regarding self-care skills are consistent with veteran campers after attending camp. Self-reports post-camp reveals that campers and their parents see camp as a place where youth feel they are with others who really understand what it is like to live with diabetes. Respondents also report that camp is a place where youth are exposed to new technologies and where campers can try new self-care tasks.

#### KEYWORDS

adaptation, camping, pediatric psychology, psychological, type 1 diabetes

# 1 | INTRODUCTION

Among the many goals of diabetes camp, providing a safe environment where children and teens feel normal while having fun is key.<sup>1</sup> Camp offers a safe and fun environment for learning new information about diabetes care and for trying new self-care skills.<sup>1.2</sup> It is a place where children and teens are able to meet with others who also have diabetes and who share their experiences. Peer support during camp may decrease the emotional burden of diabetes by these shared experiences, decreasing a sense of isolation and providing psychosocial support. Camp is a place where children may have the opportunity to regard diabetes in a more positive, adaptive light.

While camp may offer a variety of psychosocial and self-care behavior benefits, the literature assessing the impact of camp is relatively sparse. One meta-analysis on the impact of camp on youth between 5 and 20 years of age, with a variety of chronic illnesses<sup>3</sup> showed small, but statistically significant improvements in youth's selfperceptions, but the studies of youth with diabetes were relatively old, with 1 from the 1970's, 2 each from the 1980s and 1990s, and 1 from the 2000's. Another study assessing the impact of camp with 90 youth between 6 and 16 years of age<sup>4</sup> with a variety of chronic illnesses (32 with diabetes) found that children's attitudes toward their illness became significantly more positive after attending camp.

A total of 3 published papers on the impact of camp for youth with diabetes shows similar benefits. One study assessed the impact of a diabetes self-management education program during camp in Thailand on glycemic control, knowledge, and psychosocial functioning.<sup>5</sup> Sixty individuals between the ages of 10 and 46 years were assessed. This age-range renders it difficult to make conclusions about the impact of camp. Moreover, while hemoglobin A1c



significantly decreased 3 months after camp, most participants (65%) were only taking 2 shots of insulin per day, and insulin regimens have changed significantly over the years.<sup>6</sup> Diabetes-specific knowledge improved and participants reported improved ability to cope with diabetes after attending camp. A second study assessing the impact of diabetes camp among youth ages 12-18 compared outcomes between 77 campers and 106 randomly selected youth from their diabetes clinic who did not attend camp. Results showed a decrease in hemoglobin A1c 3 months after camp for those who attended camp but an increase in hemoglobin A1c in those who did not attend camp. This study assessed parent reports on their child's camp experience, but not reports from the campers themselves. Parent reports suggest improved adherence behaviors and improved psychosocial adjustment.<sup>7</sup> The third study assessing the impact of diabetes camp among 131 youth between the ages of 8 and 16<sup>8</sup> assessed the impact of diabetes education during camp, collecting information about youth reports regarding what was learned at camp as well as parent-child agreement regarding what was learned during camp. Campers reported improved ability to manage diabetes and a higher sense of belonging and social support. Parent goals for their children while at camp did not match what children reported they learned. although children did report increased diabetes-specific skills after camp.

While promising, this literature on the impact of camp is relatively small, most were completed prior to current intensive insulin management protocols,<sup>3–5</sup> and the studies contain methodologic concerns, including relatively small sample size,<sup>4,5,7</sup> large ageranges,<sup>2–4</sup> and parent-only reports,<sup>7</sup> rendering it difficult to make conclusions about the impact of camp on diabetes outcomes. This study seeks to remedy these concerns by surveying campers and their parents from over 42 diabetes-specific summer programs from across the country, and assessing children separately from adolescents to assess respondent's perceptions regarding the potential benefits of attending camp.

Clinically, it is important to assess whether attending diabetes camp leads to improvements in diabetes-specific knowledge, as that is likely to lead to improved self-care and metabolic outcomes.<sup>1,2</sup> Moreover, it is important to assess whether attending diabetes camp leads to improvements in psychosocial functioning, as adaptation and coping with this chronic illness is key to improved medical outcomes.<sup>1,2</sup> Specifically, diabetes-specific emotional distress (experienced by both the patient and the parent) and diabetes-specific quality of life are psychosocial variables strongly associated with key diabetes outcomes such as adherence and metabolic control.9,10 Documenting the experience of attending camp from both the camper and parent perspectives will provide health care professionals with empirical support when they recommend camp to their patients and their families. The camp experience may change perceptions regarding independence in self-care behaviors (e.g., blood sugar checking) as well as diabetes specific psychosocial functioning. Therefore, we chose to focus on 3 key outcomes when assessing camper and parent reports of their camp experience: (1) improvements in independence regarding self-care skills; (ii) improvements in diabetes-specific emotional distress and (iii) improvements in diabetes-specific quality of life.

# 2 | METHODS

### 2.1 | Procedures

Campers and their parents were recruited from 42 diabetes camps throughout the United States, representing 106 separate camp sessions. All campers between the ages of 8 and 18 who had a parent able to consent to the study and able to complete the study questionnaires in English were eligible to participate. Camp directors sent e-mails and/or letters to families enrolled in camp, inviting them to learn more about participating in a study designed to assess their experiences of camp by going to the study website. Any families interested in learning more about the study went to the study website and reviewed the participant information sheet. Parents could then consent to participate and sign themselves and their children up for participation. Children reviewed their own study information sheet to assent to participation. Parents could choose to have both their surveys and their child's surveys sent to 1 e-mail address, or have each participant receive their surveys on their own e-mail address. Once parents consented, a link was sent to the e-mail address provided which contained the participant-specific questionnaires (child, ages 8-11; teen, ages 12-18; parent), 4 weeks prior to camp starting. Families were able to sign up for the study and complete the questionnaires as late as just prior to arriving on camp property. If parents signed up but did not complete the surveys within the first week, an e-mail reminder was sent, asking them to complete the surveys. Postcamp surveys were sent to families 2 weeks after camp, and a reminder to complete the surveys was e-mailed 1 week later for those who did not complete the surveys.

Parents were invited to participate in a study-based raffle. Families from each of the 42 camps were eligible to win a \$200 gift certificate if they complete the pre-camp questionnaires and again if they completed the post-camp questionnaires. Each camp had a winner selected for both the pre- and the post-camp questionnaires.

### 2.2 | Participants

Camp directors sent out a total of 7694 e-mails to potentially eligible families, inviting them to learn more about the study. After viewing the website, 1562 parents signed up to participate in the study. Prior to camp starting, 607 parents, 285 teenagers, and 213 children completed the pre-camp surveys. Of those who completed pre-camp surveys, 470 matched parent/camper pairs completed the pre-camp surveys. After camp ended, 413 parents, 154 teenagers, and 116 children completed the post-camp surveys. Of those who completed the post-camp surveys, 254 were parent/camper-matched pairs. Demographic information is in Table 1 for respondents who answered the pre-camp only and for respondents who completed both pre- and post-camp questionnaires (the matched pairs). The demographic distributions are very similar. The average age for children are 10 and the teen average is 14. There were more female than male campers. Most participants were Caucasian and the majority of campers lived with both parents. Mothers were more educated than fathers; however, the majority of parents were college educated. Most household income was greater than \$50 k and the pump was the most popular

#### **TABLE 1** Study sample characteristics

	-	otal 607¹)	Analyzed (n = 413 <sup>1</sup> )		
Age	Mea	ın (SD)	Mean (SD)		
Children	10.3	(1.4)	10.3 (	1.2)	
Teens	14.3	(1.6)	14.5 (	1.5)	
Gender	n	%	n	%	
Male	265	43.7	176	42.8	
Female	342	56.3	237	57.2	
Children live with					
Both biological parents	454	74.8	318	76.9	
Other living situation	153	25.2	95	23.1	
Mother's education					
Less than a college degree	168	27.7	104	25.3	
College degree	260	42.9	182	44.3	
Greater than a college degree	178	29.4	125	30.4	
Father's education					
Less than a college degree	267	45	170	48.2	
College degree	186	31.3	127	31.5	
Greater than a college degree	141	23.7	106	26.3	
Salary					
Less than \$50 000	116	21.3	71	19.1	
Greater than \$50 000	428	78.7	301	80.9	
Insulin delivery					
Pump	452	74.4	311	75.4	
Not pump	155	25.6	101	24.6	
Years camp attended					
First-time campers	191	31.5	141	34.1	
Veteran campers	416	68.5	272	65.9	

<sup>1</sup> Not all parents answered all characteristics questions.

form of insulin delivery. While a third of kids were first time campers, most had been to diabetes camp.

#### 2.3 | Measures

Measures assess 3 study outcomes: (i) improvements in diabetesspecific emotional distress, (ii) changes in independence regarding self-care skills, and (iii) improvements in diabetes-specific quality of life. Diabetes-specific emotional distress was assessed via the 26-item Problem-Areas in Diabetes for Parent of Teen measure, P-PAID-T,<sup>12</sup> the 26-item Problem-Areas in Diabetes for Teens measure, PAID-T,<sup>9</sup> the 26-item Problem-Areas in Diabetes for Parents of Children measure, P-PAID-C,<sup>13</sup> or the 26-item Problem-Areas in Diabetes for Children measure PAID-C.<sup>13</sup> These self-report measures assess the respondent's own distress in living with diabetes. Respondents report on how much distress they experience in a variety of areas (e.g., management being "off track," feeling like friends/family act like "diabetes police") on a 6-point scale, from "not a problem" to a "serious problem." Reliability for the child-report, teen-report, and parent-report measures are high (Cronbach alphas ranging from 0.91 to 0.96) and all show adequate construct validity.9,12,13 Self-care skills were assessed via the 23-item Self-Care Skills Checklist,<sup>11</sup> designed to evaluate an individual's perception regarding their ability to independently complete daily self-care skills tasks (in the areas of: insulin,



blood glucose management, hypoglycemia treatment, carbohydrate counting, exercise, and action plans to address out of range blood glucose). This measure is completed both as a self-report by the youth and as a parent-report on their child's self-care skills by the parent. Respondents report how much they agree they are (or their child is) completing these tasks independently on a 5-point scale, from strongly agree to strongly disagree. Higher scores indicate higher levels of independence in self-care skills. Cronbach alpha's for this measure are high (0.84 for teen report and 0.87 for parent report). Diabetes-specific quality of life was assessed via a 23-item version of the MIND Youth Questionnaire, MY-Q<sup>14</sup> completed by the youth. The body image and eating behavior subscales were not included as they had low item-to-total correlations in the paper describing the psychometric properties of the measure. Cronbach's alpha for the measure was 0.80. Finally, a family demographics questionnaire was completed by the parents, with information regarding child's age, ethnicity, family socio-economic status (SES) and basic diabetes variables (e.g., frequency of blood sugar checking, method of insulin delivery, method of blood sugar monitoring).

#### 2.4 | Data analysis

Camper demographics are reported in frequencies and percentages for categorical variables and means and standard deviations for continuous variables. Studies assessing both pre- and post-questionnaires may introduce biases when demographic characteristics are different between respondents that complete both sets of measures vs those that just complete pre-camp measures. Therefore,  $\chi^2$  analyses were run to determine if there were demographic differences between parents and campers who completed both pre- and post-camp instruments and those that just completed pre-camp.

A total of 3 primary outcomes were assessed: diabetes-specific emotional distress, diabetes-specific independence in self-care skills, and diabetes-specific quality of life. Parents, teens, and children answered pre-camp and post-camp surveys for diabetes-specific emotional distress and independent self-care skills. Teens and children also completed a pre- and post-camp survey on diabetes-specific quality of life. Paired t-tests were performed to assess the difference from pre-camp to post-camp for each measure for each respondent (parent, teen, and child). Analyses also included matched pairs of parents and their camper by a family ID. These matched pairs helped analyze whether parents and their campers were experiencing the same benefits of camp. The matched pairs were evaluated by linear mixed models with a random family effect that controlled for within family correlation. The mixed models include the random effect of family ID, fixed effects of time (pre, post), respondent (parent, teen, child), camp experience (first time, veteran) and the interaction of respondent and time. Additional secondary analyses explored demographic characteristics and their association with the primary outcomes. Analysis of improvements from pre-camp to post-camp included independent t-tests and one-way analysis of variance (ANOVA). Post hoc test of Tukey's honesty significant difference (HSD) were used for all significant ANOVAs. Seven demographic variables were used for demographic analysis: gender, who the camper lives with (either both parents or other living situation); education for



both mothers and fathers (less than a college degree [<CD], a college degree [CD], and a graduate or professional degree [>CD]; household income, less than \$50,000 [<\$50 k] and greater than \$50,000 [> \$50 k]); method of insulin delivery (either pump or not pump); and camper status (first-time camper or veteran camper).

Mean imputation was conducted for questionnaire items missing no more than 2-item responses. Ten percent of all scores were imputed. Statistical analyses were conducted using SAS 9.3 (SAS Institute Inc., Cary, North Carolina). All tests were 2-sided and significance was defined as P < .05.

# 3 | RESULTS

# 3.1 | Differences between respondents of pre-camp and respondents of both pre- and post-camp

Table 1 displays the demographic characteristics for all of the surveys submitted and for the number of paired sets that were analyzed. Demographic differences between respondents of pre-camp surveys (who did not complete post-camp) and respondents of both pre-camp and post-camp surveys were examined. There were 607 parentcompleted pre-camp surveys and 413 parent-completed pre- and post-camp surveys (68%). Over 88% of the respondents were Caucasian and 81% of parents were married, therefore, no race, or marital status comparisons were made. There were no demographic differences in parents that completed 1 survey or both surveys. Five hundred campers completed pre-camp surveys and 270 completed both pre- and post-camp (54%). Female campers (62.3%) were more likely than males (37.7%) to complete both surveys  $(X^2 (1) = 5.58)$ . P = .0181). Campers that lived with both parents (80.9%) were also more likely than campers that did not live with both parents (19.1%) to have completed both surveys ( $X^2$  (1) = 3.97, P = .0463).

# 3.2 | Changes in diabetes-specific emotional distress, independence in self-care skills, and quality of life

The 3 primary outcomes of the study are shown in Table 2. Paired *t*-tests determined changes in diabetes-specific emotional distress, self-care skills, and quality of life for each of the respondent groups (parents, teens, and children). Emotional distress shows statistically significant changes in parent and child reports. Although the teen scores showed less distress after camp, the change was not statistically significant. Independence in self-care skills for all 3 respondents showed statistically significant changes in the direction of increased independence. Quality of life for teens and children showed no changes.

# 3.3 | Matched pairs of parent and camper reports of changes pre- and post-camp

Further validating the paired t test for each respondent, linear mixed models were run for both emotional distress and independence in self-care skills. Quality of life were only answered by campers,

#### TABLE 2 Primary Outcomes Pre- and Post- Camp

Diabetes-specific emotional distress: pre-camp and post-camp-mean (SD)										
Respondents	Pre-camp	Post-camp	t (df)	Р						
Parents $n = 413$	75.9 (23.2)	69.2 (23.2)	8.83 (412)	<.0001						
Teens <i>n</i> = 154	70.3 (27.7)	69.2 (27.5)	0.84 (153)	.4						
Children n = 116	64.7 (21.4)	60.5 (21.4)	2.74 (115)	.0072						
Diabetes skills pre	-camp and pos	t-camp—mear	n (SD)							
Respondents	Precamp	Postcamp	t (df)	Р						
Parents $n = 391$	84.9 (13.7)	88.8 (12.3)	-9.20(390)	<.0001						
Teens <i>n</i> = 142	96.2 (12.3)	98.8 (12.4)	-3.72(141)	.0003						
Children n = 112	90.4 (13.9)	94.2 (14.8)	-3.52 (111)	.0006						
Quality of life pre-	camp and pos	t-camp—mean	(SD)							
Respondents	Precamp	Postcamp	t (df)	Р						
Teens <i>n</i> = 151	69.2 (12.8)	68.6 (14.5)	0.82 (150)	.4117						
Children n = 117	61.6 (10.9)	60.7 (11.1)	1.22 (116)	.2248						

therefore there are no matched pairs. Upon examining demographic characteristics, camp experience showed a trend toward decreased emotional distress (P = .10) and was significant for independence in self-care skills (P = .002). Thus, camp experience was controlled for in the final linear mixed models.

Table 3a reports the diabetes-specific emotional distress linear mixed model. Post-camp scores are lower than pre-camp indicating less emotional distress after camp. Overall, average scores for children and teens are significantly lower than their parents. The interaction term for respondents and time was not significant for modeling emotional distress. While there was a significant average drop in scores on emotional distress from pre- to post-camp, the rate of change did not differ among the respondents (children, teens,

 TABLE 3 (a) Linear mixed model for diabetes-specific emotional distress. (b) Linear mixed model for diabetes-specific self-care skills

Effect	Estimate	Standard error	df	t value	Р
(a)	Estimate		u.	t value	
Intercept	76,496	1.0254	606	74.6	<.0001
•	,, .	1.0254	000	74.0	<.0001
Time-pre-cam	•				
Post-camp	-5.3214	0.5839	2151	-9.11	<.0001
Role-parents					
Children	-9.3526	0.9338	2151	-10.02	<.0001
Teens	-4.6175	0.8396	2151	-5.5	<.0001
Camp experien	ce—veteran				
First camp	-3.8805	1.7703	2151	-2.19	0.0285
(b)					
Intercept	85.7363	0.6235	603	137.51	<.0001
Time-pre-cam	р				
Post-camp	3.8012	0.2875	2070	13.22	<.0001
Role-parents					
Children	8.7915	0.4578	2070	19.2	<.0001
Teens	7.6986	0.4156	2070	18.53	<.0001
Camp experien	ce—first cam	0			
Veteran	4.4659	1.0895	2070	4.1	<.0001

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parents). In addition, first time campers reported significantly less distress after camp than veteran campers.

Table 3b displays the linear mixed model results for independence in self-care skills. Results show that scores increase from precamp to post-camp suggesting that overall, perceptions regarding independence in self-care skills are higher after camp than before camp. Both children and teens report higher levels of perceived independence than their parents' report. As with diabetes-specific emotional distress, the interaction term for respondents and time was not significant for modeling independence in self-care skills. While there was a significant drop in scores on independence in self-care skills from pre- to post-camp, the rate of change did not differ among the respondents (children, teens, parents). Veteran campers report higher levels of perceived independence in self-care skills than first time campers.

## 3.4 | Demographic differences

Respondent characteristics include gender, who the camper lives with, mothers' education, fathers' education, family income, insulin delivery, and camp experience. Tables 4-6 show demographic differences in changes from pre-camp to post-camp for diabetes-specific emotional distress (Table 4), self-care skills (Table 5), and quality of life (Table 6). Exploratory analyses did not reveal improvements in

scores to be significantly different by demographic characteristics with the exception being camp experience. Parent-reported independence in self-care skills scores improved more with first time campers (mean = 5.8 [SD = 9.4]) than veterans of camp (mean = 2.8 [SD = 7.5]), (t = -3.21 (122) P = .002).

#### 3.5 | Self-reports about camp experience

We asked campers and parents to report on 3 topics post-camp, in an open-ended format: What were the best things about going to camp, what were some "firsts" they achieved while at camp, and what are they doing differently at home now that they have returned from camp. Not all individuals responded to these questions, some only gave 1 response per question, and some gave multiple responses to each question. We reviewed each response and organized them by major themes (e.g., self-care tasks included responses such as "checking blood sugars," "changing insertion sites," and "counting carbohydrates." With respect to what was "best" about camp, parents' responses (n = 641) clustered around 3 themes: (1) Shared Experience, for example: My child was with people "who were like them," "who shared the same experiences," and "who understand what they go through," (2) Emotional Experiences, for example: My child "had fun," "felt happy, and "made new friends," "felt normal," "felt safe away from home," and (3) Knowledge, for example: My child "learned

TABLE 4 Problem areas in diabetes-demographic associations in the difference from pre-camp to post-camp

	Parents				Teens			Children				
	Ν	Mean (SD)	Statistic	Р	Ν	Mean(SD)	Statistic	Р	Ν	Mean(SD)	Statistic	Р
Gender												
Male	175	-6.9 (16.3)	-0.29 (410) <sup>1</sup>	0.773	49	-0.6 (13.4)	0.43 (129) <sup>1</sup>	0.6654	47	-3.2 (13.2)	0.42 (113) <sup>1</sup>	0.676
Female	237	-6.44 (14.7)			91	-1.8 (19.1)			68	-4.5 (18.4)		
Lives with												
Both parents	316	7.0 (15.3)	-0.79 (409) <sup>1</sup>	0.433	114	-1.6 (16.8)	-0.50 (137) <sup>1</sup>	0.615	92	-5 (17.1)	-1.37 (113) <sup>1</sup>	0.174
Other	95	5.7 (15.5)			25	0.3 (19.8)			23	0.2 (13.2)		
Mother's educat	ion											
<cd< td=""><td>104</td><td>-8.23 (16.7)</td><td>0.72 (2,408)<sup>2</sup></td><td>0.482</td><td>35</td><td>1.4 (15.0)</td><td>0.86 (2,137)<sup>2</sup></td><td>0.406</td><td>26</td><td>-3.3 (14.2)</td><td>0.30 (2,111)<sup>2</sup></td><td>0.731</td></cd<>	104	-8.23 (16.7)	0.72 (2,408) <sup>2</sup>	0.482	35	1.4 (15.0)	0.86 (2,137) <sup>2</sup>	0.406	26	-3.3 (14.2)	0.30 (2,111) <sup>2</sup>	0.731
CD	182	-6.3 (14.8)			65	-3.3 (18.2)			52	-2.8 (14.9)		
>CD	125	6.0 (15.3)			40	-0.4 (17.8)			36	-5.5 (19.4)		
Father's education	on											
<cd< td=""><td>170</td><td>-7.3 (15.5)</td><td>0.16 (2,400)<sup>2</sup></td><td>0.845</td><td>55</td><td>0.7 (16.8)</td><td>-2.16 (2,133)<sup>2</sup></td><td>0.116</td><td>46</td><td>-5.1 (16.2)</td><td>0.38 (2,109)<sup>2</sup></td><td>0.666</td></cd<>	170	-7.3 (15.5)	0.16 (2,400) <sup>2</sup>	0.845	55	0.7 (16.8)	-2.16 (2,133) <sup>2</sup>	0.116	46	-5.1 (16.2)	0.38 (2,109) <sup>2</sup>	0.666
CD	127	-6.3 (14.6)			48	-5.7 (18.8)			34	-1.8 (18.4)		
>CD	106	-6.4 (14.9)			33	1 (15.5)			32	-4.6 (15.6)		
Family income												
<\$50 k	70	-6.2 (16.3)	0.10 (366) <sup>1</sup>	0.922	25	-2.4 (24.5)	-0.16 (28) <sup>1</sup>	0.871	16	-8 (21)	-1.02 (100) <sup>1</sup>	0.310
\$50 k+	298	-6.4 (14.9)			96	-1.6 (16.3)			86	-3.2 (16.5)		
Insulin delivery												
Pump	310	-7.3 (15.3)	-0.54 (409) <sup>1</sup>	0.589	105	-1.0 (15.0)	-0.37 (44) <sup>1</sup>	0.713	88	-3.6 (17.1)	-0.37 (113) <sup>1</sup>	0.714
Not pump	101	-6.4 (15.4)			35	-2.5 (23.1)			27	-5 (14.3)		
Camp experienc	e											
First camp	140	-8.4 (15.8)	1.65 (410) <sup>1</sup>	0.100	32	-3.1 (20.3)	0.65 (138) <sup>1</sup>	0.519	63	-5 (14.64)	0.74 (96) <sup>1</sup>	0.463
Veteran	272	-5.7 (15.1)			108	-0.8 (16.4)			52	-2.7 (18.4)		

Abbreviation: CD, college degree.

<sup>1</sup> T test.

<sup>2</sup> F test.

TABLE 5	Self-care skills—den	nographic assoc	ciations in the	difference from	n pre-camp to post-camp
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	Parents				Teens			Children				
	N	Mean (SD)	Statistic (df)	Р	N	Mean (SD)	Statistic (df)	Р	N	Mean (SD)	Statistic (df)	Р
Gender												
Male	162	3.9 (8.9)	0.04 (388) <sup>1</sup>	0.969	48	1.3 (7.3)	-1.53 (128) <sup>1</sup>	0.128	45	3.4 (11.9)	-0.39 (109) <sup>1</sup>	0.699
Female	228	3.9 (7.9)			82	3.5 (8.7)			66	4.2 (11.1)		
Lives with												
Both parents	300	3.9(8)	0.13 (127) <sup>1</sup>	0.900	106	2.4 (7.9)	-0.76 (127) <sup>1</sup>	0.449	89	3 (11.6)	-1.58 (109) <sup>1</sup>	0.117
Other	89	3.8 (9.5)			23	3.9 (9.8)			22	7.3(10)		
Mother's educat	ion											
<cd< td=""><td>101</td><td>3.3 (8.2)</td><td>-0.27 (2,385)<sup>2</sup></td><td>0.778</td><td>32</td><td>-0.1 (8.2)</td><td>2.63 (2,127)<sup>2</sup></td><td>0.076</td><td>26</td><td>4.4 (7.9)</td><td>0.27 (2,107)<sup>2</sup></td><td>0.781</td></cd<>	101	3.3 (8.2)	-0.27 (2,385) <sup>2</sup>	0.778	32	-0.1 (8.2)	2.63 (2,127) <sup>2</sup>	0.076	26	4.4 (7.9)	0.27 (2,107) <sup>2</sup>	0.781
CD	167	3.9 (8.5)			62	3.3(9)			50	3.1 (12.8)		
>CD	119	4.1 (8.4)			37	4.1 (6.5)			34	4.7 (11.8)		
Father's education	on											
<cd< td=""><td>158</td><td>3.6 (8.4)</td><td>0.13 (2,379)<sup>2</sup></td><td>0.870</td><td>49</td><td>2.1 (7.1)</td><td>0.60 (2,123)<sup>2</sup></td><td>0.564</td><td>43</td><td>3.8 (10.7)</td><td>0.03 (2,105)<sup>2</sup></td><td>0.964</td></cd<>	158	3.6 (8.4)	0.13 (2,379) <sup>2</sup>	0.870	49	2.1 (7.1)	0.60 (2,123) <sup>2</sup>	0.564	43	3.8 (10.7)	0.03 (2,105) <sup>2</sup>	0.964
CD	122	4 (7.7)			46	2.4 (10.1)			33	4.2 (11.4)		
>CD	101	4.1 (9.2)			32	4 (6.1)			32	3.5(15)		
Family income												
<\$50 k	63	2.4(8)	-1.56 (346) <sup>1</sup>	0.120	23	4.7 (10.5)	0.81 (27) <sup>1</sup>	0.425	16	3.3 (9.9)	-0.19 (97) <sup>1</sup>	0.853
\$50 k+	285	1.2 (8.3)			89	2.9 (6.9)			83	3.9 (12.2)		
Insulin delivery												
Pump	299	3.6 (8.3)	1.41 (387) <sup>1</sup>	0.159	97	2.6 (7.3)	0.10 (43) <sup>1</sup>	0.921	86	3.1 (11.9)	1.27 (109) <sup>1</sup>	0.206
Not pump	90	5 (8.1)			33	2.8 (10.7)			25	6.4 (8.9)		
Camp experience	е											
First camp	133	5.8 (9.4)	-3.21 (221) <sup>1</sup>	0.002	31	1.8 (6.8)	0.73 (128) <sup>1</sup>	0.469	60	4.5 (10.6)	-0.64 (109) <sup>1</sup>	0.521
Veteran	257	2.8 (7.5)			99	-3 (8.7)			51	3.1 (12.3)		

Abbreviation: CD, college degree.

<sup>1</sup> T test.

<sup>2</sup> F test.

new skills," "learned more information about diabetes," "is more independent in their self-care skills." Children's responses (n-144) clustered around Shared Experience, for example: "I was with people who are like me," and Emotional Experiences, for example: "I made new friends," "The camp activities were fun." Teenagers' responses (n = 177) clustered around Shared Experiences, for example: I was with people "who are like me," "who understand what I go through" and "who share the same experiences," and Emotional Experiences, for example: "I made new friends" more information and "The camp activities were fun."

With respect to *camp* "firsts", parents' (n = 1318), children (n = 280) and teenagers (n = 441) responses were consistent and clustered around 3 themes: (1) Self-care Tasks, for example: First time: "changing a pump site," "being responsible for my own diabetes care," "counting carbohydrates by themselves," (2) Exposure to Technology, for example: First time: "seeing an insulin pump," "seeing a CGM," and (3) Social Experience, for example: First time: "making a friend with diabetes," "being away from home." With respect to "doing things differently since going to camp," parents (n = 336), children (n = 66), and teenagers (n = 123) responses were consistent and clustered around 2 themes: (1) Self-Care Tasks, for example: "checking blood sugars more often," "counting carbohydrates more accurately," "rotating injection/pump sites," "taking more initiative," and (2) Social Experience, for example: "more willing to share diabetes in public settings." (Table 6).

# 4 | DISCUSSION

Diabetes camp is supposed to be a place for fun as well as a place where campers learn new skills and feel supported.<sup>1,2</sup> Our study is the first to assess a large number of camps across the United States, and assess both camper- and parent-reported perceptions. Our strengths include the large sample size, the inclusion of both children and adolescents (analyzed separately), and the inclusion of parents.

With respect to diabetes-specific emotional distress, parents reported higher levels of distress than their campers, both before and after camp, suggesting the emotional impact of diabetes may be greater on caregivers than on the youth themselves. Children and parents reported less distress after attending camp, suggesting that camp may have a role in improving perceptions of diabetes-specific emotional distress. These findings were statistically significant for children and for parents of both children and teens. Teens reported lower levels of emotional distress after camp; however, the reduction was not statistically significant. The open-ended feedback about camp experiences also suggests that campers and their parents see camp as a place where youth feel like they are with others who understand what it is really like to live with diabetes, which may be a key reason why distress improves after attending camp.

With respect to independence in self-care skills, campers perceived themselves as having more independence in their self-care

#### TABLE 6 Quality of life-demographic associations in the difference from pre-camp to post-camp



		٦	<b>Feens</b>				Children	
	N	Mean (SD)	Statistic (df)	Р	N	Mean (SD)	Statistic (df)	Р
Gender								
Male	47	-0.8 (7.9)	-0.36 (137) <sup>1</sup>	0.717	47	0.8 (8.5)	1.85 (114) <sup>1</sup>	0.067
Female	92	-0.3(9)			69	-2.0 (7.7)		
Lives with								
Both parents	112	-0.7 (9.1)	-0.82 (51) <sup>1</sup>	0.415	95	-0.8 (8.4)	0.26 (114) <sup>1</sup>	0.792
Other	26	0.5 (6.4)			21	-1.3 (6.9)		
Mother's education								
<cd< td=""><td>37</td><td>-0.5 (7.1)</td><td>0.57 (2,136)<sup>2</sup></td><td>0.567</td><td>26</td><td>-1.8 (7.7)</td><td>0.20 (2,112)<sup>2</sup></td><td>0.823</td></cd<>	37	-0.5 (7.1)	0.57 (2,136) <sup>2</sup>	0.567	26	-1.8 (7.7)	0.20 (2,112) <sup>2</sup>	0.823
CD	64	-1.3 (9.8)			53	-0.7 (7.3)		
>CD	38	0.002 (7.8)			36	-0.5 (9.6)		
Father's education								
<cd< td=""><td>56</td><td>-0.8 (9.5)</td><td>0.27 (2,132)<sup>2</sup></td><td>0.764</td><td>44</td><td>-0.4 (6.9)</td><td>0.25 (2,110)<sup>2</sup></td><td>0.778</td></cd<>	56	-0.8 (9.5)	0.27 (2,132) <sup>2</sup>	0.764	44	-0.4 (6.9)	0.25 (2,110) <sup>2</sup>	0.778
CD	48	0.3 (7.4)			34	0.9 (7.2)		
>CD	31	-1 (9.2)			35	-1.7 (10.2)		
Family income								
<\$50 k	25	1.5 (10.5)	0.79 (31) <sup>1</sup>	0.437	16	-3.1 (7.8)	-1.22 (101) <sup>1</sup>	0.226
\$50 k+	96	-0.2 (7.8)			87	-0.47(8)		
Insulin delivery								
Pump	106	-0.5(11)	-0.01 (42) <sup>1</sup>	0.995	88	-1.61 (8.6)	-0.56 (114) <sup>1</sup>	0.577
Not pump	33	-0.5 (7.8)			28	-0.62(8)		
Camp experience								
First camp	31	-0.7 (8.5)	-0.49 (137) <sup>1</sup>	0.623	63	-2.02 (8.4)	-1.42 (114) <sup>1</sup>	0.159
Veteran	108	0.2(9)			53	0.12 (7.8)		

Abbreviation: CD, college degree.

<sup>1</sup> T test.

<sup>2</sup> F test.

skills than their parents did, which is developmentally appropriate. Veteran campers and their parents believe that independence in selfcare skills increased after attending camp. Camp provides an opportunity for repeated, peer-group based practice of daily diabetes tasks, offering an opportunity to improve self-care skill independence. The open-ended feedback about camp experiences also suggests that campers and their parents see camp as a place where youth are exposed to more diabetes-specific technologies and where campers try a variety of new self-care tasks. Moreover, campers and parents report an increase in independence regarding daily self-care tasks after they return home from camp.

For all 3 outcomes (diabetes-specific emotional distress, independence in self-care skills, and quality of life), there were no significant demographic differences for parents and their campers with the exception of years of camp experience for parents' perceptions regarding their child's independence in self-care skills. Parents of first time campers felt their campers improved their independence in selfcare skills more than those with veteran campers. These findings suggest that all campers, regardless of their living situations and socioeconomic backgrounds, perceive improvements in self-reported diabetes-specific emotional distress and independence in self-care skills after attending diabetes camp.

Limitations of the current study include the fact that this was a pre- and post-camp study design that did not include a control group.

Moreover, in spite of recruiting from over 40 camps across the United States, and offering incentives for participation, the majority of families who chose to participate in the study were Caucasian, lived in a 2-parent home with parents who had a college degree, and who used insulin pumps. It is possible that this lack of diversity is a function of who attends camp (although all camps surveyed offer scholarships to families who cannot afford to attend camp), and it is also possible that this lack of diversity is a function of who chooses to sign up to participate in a survey research study. Future studies should focus on those campers who are more diverse to determine if these findings remain.

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How to cite this article: Weissberg-Benchell J, Rychlik K. Diabetes camp matters: Assessing families' views of their diabetes camp experience, *Pediatr Diabetes*, 2017. doi: 10.1111/ pedi.12499