

## RESEARCH ARTICLE

## Educational and Psychological Aspects

# Psychological and self care outcomes for children and adolescents living with type 1 diabetes and their caregivers attending diabetes camp: A mixed methods study

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## Abstract

**Aim:** Diabetes camps for children and adolescents living with Type 1 Diabetes (T1D) offer an important opportunity to foster self-efficacy and 'common humanity', a sense that they are not alone in their challenges. The current study primarily aimed to assess whether psychological wellbeing, diabetes self care behaviours and HbA1c improved amongst campers and their caregivers, and whether these would be sustained at 3- and 6-months.

**Methods:** Children and adolescents aged 7–13 years who attended the 2023 diabetes camp in Auckland, Aotearoa New Zealand and one of their caregivers were invited to participate. Campers and caregivers were assessed at camp enrolment and then at 1-week, 3-months and 6-months post-camp. Guided by the Theoretical Framework of Acceptability, optional qualitative interviews were also used to explore campers' experiences of camp.

**Results:** Of the 31 children and adolescents who attended the 2023 camp, 27 (87%) participated in the study with a caregiver. Campers showed reduced feelings of isolation ( $p = 0.036$ ) and overidentification ( $p = 0.036$ ) 6 months. Caregivers demonstrated overall improvements in self-efficacy ( $p = 0.034$ ), caregiver distress and burden ( $p = 0.006$ ) and caregiver quality of life ( $p = 0.039$ ). Qualitative findings confirmed high acceptability, with participants reporting positive camp experiences.

**Conclusions:** Diabetes camps can improve caregivers' self-efficacy, diabetes distress and quality of life, and reduce feelings of isolation and overidentification among campers. Future work is needed to promote cultural inclusivity within camps and improve their accessibility, to be able to optimise the wellbeing of all children and adolescents living with T1D and their families.

## KEYWORDS

adolescent, child, diabetes camp, psychosocial aspects, type 1 diabetes

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## 1 | INTRODUCTION

Children and adolescents living with Type 1 Diabetes (T1D) face a constant balancing act to manage their diabetes care including continuously monitoring blood glucose levels and adjusting insulin doses in response to a multitude of factors such as physical activity, dietary intake, hormonal fluctuations and emotional and physical well-being. Unsurprisingly, the frequency of these decisions and the level of self care behaviours place demands on children and adolescents living with T1D as well as their families. Research has shown that children and adolescents living with T1D experience heightened levels of psychological distress compared to their peers,<sup>1</sup> often feeling socially isolated in their challenges.<sup>2</sup> Similarly, caregivers of youth living with T1D report elevated levels of depression, stress, anxiety and isolation compared to caregivers of children without a chronic health condition.<sup>3</sup> The well-being of caregivers and their children living with T1D is closely intertwined, with indices of caregiver wellbeing showing associations with psychological wellbeing<sup>4</sup> and diabetes-related outcomes.<sup>5,6</sup>

Diabetes camps are widely recognised as an important resource for providing education and emotional support for children and adolescents living with T1D.<sup>7</sup> These camps offer a unique environment to connect with peers facing similar challenges, often for the first time, whilst supported by a multi-disciplinary medical team. Central to the camp experience is the cultivation of a sense of ‘common humanity’, a sense that we are not alone in our challenges and we all as humans make mistakes and face setbacks. In addition to peer support, diabetes camps also focus on developing self care skills and diabetes management knowledge, potentially enhancing psychological wellbeing through increased self-efficacy and confidence.<sup>8</sup>

Despite the potential benefits, a recent systematic review and meta-analysis illustrated that while short-term benefits of camps for youth living with T1D are evident for glycaemic outcomes and diabetes knowledge, the impact on psychological outcomes such as anxiety and quality of life has been less conclusive.<sup>9</sup> The review highlights a need for future studies to use validated psychological outcome measures and include long-term follow-ups. In addition, the possible benefits of camps for caregivers have been relatively understudied to date and shown mixed results.<sup>10</sup> Whilst some studies have observed no significant changes,<sup>10</sup> others have shown significant improvements in parental diabetes distress<sup>11,12</sup> and perceptions of resilience,<sup>13</sup> independence<sup>12,14</sup> and self care<sup>11</sup> in their child immediately following camp. In Aotearoa New Zealand, despite over 40 years of diabetes camps facilitated by Diabetes New Zealand and regional groups, such as

### What's new?

- Camps for children and adolescents living with diabetes, while providing opportunities to promote self-efficacy and ‘common humanity’, have shown mixed evidence of changes to psychological outcomes and often lack long-term follow-ups or the inclusion of caregivers.
- Our findings show high acceptability and psychological benefits from camp for children and adolescents living with Type 1 Diabetes as well as their caregivers, extending up to 6 months following camp.
- Future research should prioritise including caregiver assessments and long-term measurements, whilst prioritising cultural inclusivity and accessibility in camp development and delivery.

Diabetes Youth Auckland, the formal evaluation of their impact remains unexplored.

The present study aimed to fill these gaps by assessing whether psychological wellbeing, diabetes self care behaviours, and HbA1c improved amongst campers and one of their caregivers. By evaluating these outcomes up to 6 months post-camp and including caregivers as study participants, this study seeks to explore the sustainability of any observed improvements and expand upon existing literature. Our primary hypothesis was that an increase in common humanity, or a decrease in isolation as its opposite concept, would be observed amongst campers and their caregivers. Additional outcomes included diabetes distress to measure changes to emotional burden amongst campers and caregivers, quality of life to capture the overall impact on holistic wellbeing and camper HbA1c. Camper diabetes self care behaviours and both camper and parental self-efficacy were also measured to assess the suitability of these measures for future studies investigating potential mechanisms underlying camp benefits. With the study being the first formal evaluation of diabetes camps within Aotearoa New Zealand, a qualitative component was added to explore the camps acceptability and prioritise areas for future improvement.

## 2 | METHODS

### 2.1 | Study design

The current study utilised a mixed methods pre-post study design, incorporating focus groups to gain insight

into campers' perspectives on camp, and assessing outcomes at baseline, 1-week, 3-months and 6-months post-camp. Ethical approval was granted by the Auckland Health Research Ethics Committee (AHREC Reference AH24109) and all participants provided informed consent/assent. Recruitment started on 29 December 2022 and was completed by 9 January 2023. Focus groups were conducted between April 15th and 17th 2023. The following methods are reported following both the Consolidated Criteria for Reporting Qualitative studies (COREQ)<sup>15</sup> and Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement<sup>16</sup>; see [Tables S1](#) and [S2](#) for checklists.

## 2.2 | Participants and recruitment

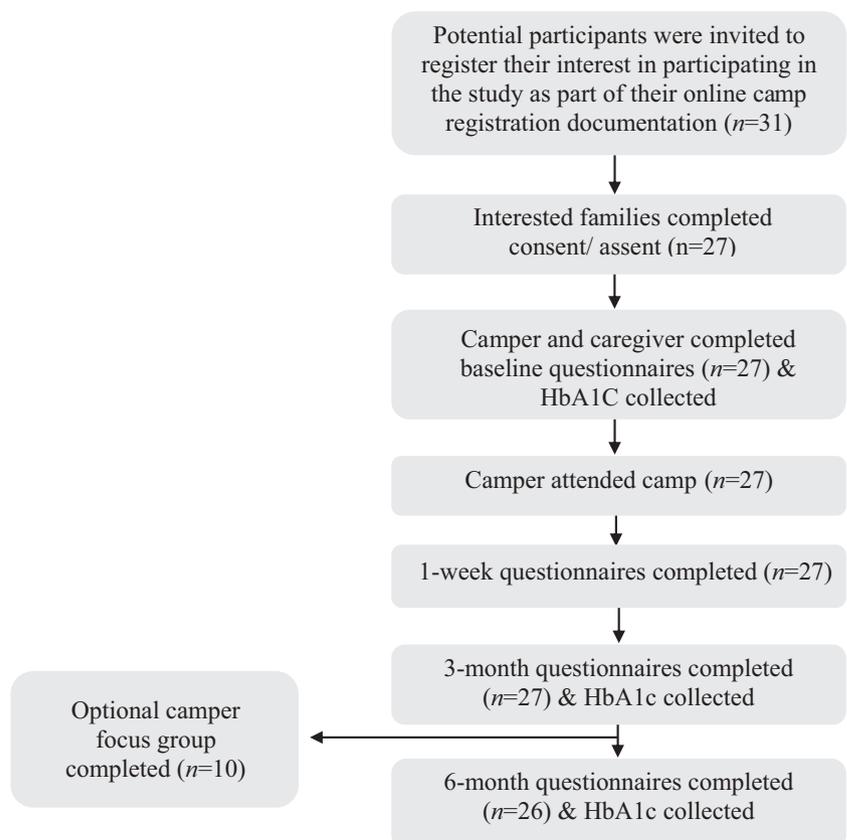
Children and adolescents (aged 7 to 13 years of age) living with T1D attending the 2023 Auckland Diabetes camp were invited to participate in the study by Diabetes Youth Auckland as part of the camp registration paperwork. A caregiver or parent of a child or adolescent who agreed to participate was also invited to participate. With an average of 70 attendees attending across two camps in previous years, we aimed to recruit approximately 50 children and adolescents. For an overview of the flow of participation throughout the study, see [Figure 1](#).

Participants who were non-English speaking or diagnosed with severe developmental disorders (e.g., Autism Spectrum Disorder) were excluded to ensure that participants could independently understand and complete the informed consent process and questionnaires, without the need for a caregiver's influence. Children diagnosed with a serious mental health disorder requiring ongoing treatment (e.g., psychosis or eating disorders) were also excluded to avoid possible conflating bias due to ongoing mental health treatment. Research Electronic Data Capture (REDCap)<sup>17</sup> was used to check self-reported eligibility criteria, obtain informed consent/ assent and collect questionnaires across the four time points. Participants were offered an NZD\$20 voucher on completion of the 3-month questionnaires, another NZD\$20 voucher on the completion of the 6-month questionnaires, and a third NZD\$20 voucher for those who participated in the optional focus group.

## 2.3 | Procedure

### 2.3.1 | Diabetes camp

The Auckland Diabetes Camp is a three-day and two-night event facilitated by volunteers, healthcare professionals and youth leaders as part of a collaboration between



**FIGURE 1** An overview of participant flow throughout the study. Potential participants were invited to register their interest in participating in the study as part of their online camp registration documentation ( $n = 31$ ).

Diabetes Youth Auckland and the Starship Diabetes medical team. The camp is located within Shakespeare Regional Park, located 40 minutes north of Auckland, and was once home to Ngāti Kahu before European settlement. Today, the park is a wildlife sanctuary featuring beaches, walking trails, picnic areas and native bush, offering opportunities for swimming, hiking and birdwatching. The park also includes a site specifically designed for children's camps, focusing on building confidence, teamwork and outdoor skills through engaging activities. These activities include mountain boarding, archery, a climbing wall, high ropes, fire making, orienteering, surfing, kayaking, safe boating, coastal walks and sandcastle competitions. Campers are supported with skills such as carbohydrate counting, insulin adjustment, injection technique, continuous glucose monitoring and other technologies, site changing, insulin adjustment for physical activity, glucose monitoring frequency and managing hypoglycaemia and hyperglycaemia, as opportunities arise. In terms of cost, the camp is subsidised with a reduced required caregiver contribution of NZD\$165.

### 2.3.2 | Optional focus groups

Children and adolescents who indicated on their assent/consent form that they would like to participate in the optional post-camp focus groups were invited to participate in online Zoom focus groups. Focus groups were conducted by study authors AB, a female Intern Psychologist at the time, and RS, a female Diabetes Nurse Specialist, with both authors having experience in facilitating group sessions with children and adolescents living with T1D. Being a Diabetes Nurse Specialist within the Auckland region, RS attended the camp and had existing relationships with some of the participants. To mitigate the expectation to provide positive feedback, participants were explicitly assured that their feedback would not affect the care they received and were encouraged to be as honest as possible for the aim of improving future camps. Anonymous open-ended questions were also included separately in the 1-week post-camp questionnaire to offer an additional opportunity for feedback that youths did not feel comfortable sharing in a focus group format.

Three 90-minute focus groups were to be conducted, with one focus group reserved solely for Māori and Pacific participants to ensure their feedback is prioritised for future camp improvements. Following the Theoretical Framework of Acceptability,<sup>18</sup> a semi-structured interview schedule was devised by AB and RS. Examples of questions included: “how would you describe the feel of camp?”, “what worried you about going to camp?”, and “how do you think we could make camp more inclusive

of people from different cultures?”. Data saturation was discussed after each focus group.

## 2.4 | Quantitative Measures

### 2.4.1 | Campers

Demographic data, including age, gender, ethnicity, duration of diabetes, insulin treatment, BMI, deprivation and number of camps attended previously, were collected from participants via REDCap at baseline. Psychological wellbeing measures detailed below were also collected via REDCap at baseline, 1-week post-camp, 3-months and 6-months. HbA1c (average blood glucose over the past 2 to 3 months) closest to these time points was also collected from the participants' clinical records.

1. Self-compassion was measured by the Self-Compassion Scale, Youth Version (SCS-Youth).<sup>19</sup> The 17 items are measured on a 5-point Likert scale (1=almost never to 5=almost always) and contain six subscales reflecting the three components of self-compassion – self-kindness versus self-judgement, common humanity versus isolation and mindfulness versus overidentification. The scale has shown strong construct validity and good reliability in adolescent samples,<sup>19</sup> with the current study demonstrating adequate internal consistency ( $\alpha=0.68$ ).
2. Diabetes distress was measured by the Problem Areas in Diabetes Survey, Paediatric Version PAID-Peds.<sup>20</sup> PAID-Peds contains 20 items on a 5-point Likert scale (0=agree to 4=disagree), with higher scores indicating higher distress. Similar to the good reliability shown in the literature,<sup>21</sup> the current study showed good internal reliability ( $\alpha=0.88$ ).
3. Self care behaviours were measured by the 15-item Self Care Inventory-Revised Version (SCI-R).<sup>22</sup> Items reflect the main components of the T1D regimen and ask participants to rate how often they perform the behaviour from never<sup>1</sup> to always.<sup>5</sup> The current study demonstrated acceptable internal reliability ( $\alpha=0.72$ ), similar to the paediatric diabetes literature.<sup>23</sup>
4. Self-efficacy was measured by the 10-item self-efficacy for Diabetes Self-Management questionnaire for youth (SEDSM).<sup>24</sup> The SEDSM assesses youth's perceived self-efficacy to complete diabetes self care behaviours on a 1 (“not sure at all I could do that behaviour”) to 10 (“completely sure I could do that behaviour”). The scale shows good internal consistency ( $\alpha=0.90$ ) and test-retest reliability ( $\alpha=0.89$ ) in the literature,<sup>24</sup> with the current study showing an acceptable level of internal consistency ( $\alpha=0.76$ ).

5. Quality of life was measured by the Paediatric Quality of Life Inventory (PedsQL) 3.2 Diabetes Module,<sup>25</sup> which is a measure of diabetes-specific quality of life. The PedsQL 3.2 Diabetes Module contains five subscales: diabetes symptoms, treatment barriers, treatment adherence, worry and communication. The following age-specific forms were utilised for age 7 (young child), 8–12 (child) and 13 (adolescent). The current study revealed an acceptable level of internal consistency ( $\alpha=0.79$ ), similar to levels of reliability and validity in the existing literature.<sup>26</sup>

## 2.4.2 | Caregivers

Similarly, demographic data, including gender and caregiver type, were collected from participants who were caregivers via REDCap at baseline. Caregivers also completed psychological wellbeing measures at the same time points of baseline, 1-week post-camp, 3-months and 6-months:

1. Caregiver diabetes-specific self-compassion was measured by Diabetes-Specific Self-Compassion for Parents of Youth with T1D (SCS-Dp).<sup>27</sup> Similar to the youth version, items are measured on a 5-point Likert scale (0=almost never to 5=almost always) and the scale contains six subscales of self-kindness, self-judgement, common humanity, isolation, mindfulness and over-identification. The scale has shown good reliability and construct validity,<sup>27</sup> however, the current study yielded poor internal reliability ( $\alpha=0.59$ ).
2. Caregiver diabetes distress and burden was measured using the Problem Areas in Diabetes Survey – Parent Revised Version (PAID-PR).<sup>28</sup> Similar to the PAID-Peds questionnaire, the questionnaire uses a 5-point Likert scale (0 = “agree” to 4 = “disagree”), with a higher total score indicating more stress. The PAID-PR has shown high internal consistencies ( $\alpha=0.86$ ),<sup>28</sup> with the current study showing excellent internal consistency ( $\alpha=0.90$ ).
3. Self-efficacy was measured by the Maternal Self-Efficacy for Diabetes Management Scale (MSED),<sup>29</sup> which asks the primary caregivers to rate their confidence in managing diabetes-related tasks on a 5-point Likert scale (1 = “not at all confident” to 5 = “very confident to help”). The scale has demonstrated good internal consistency and convergent and discriminate validity,<sup>29</sup> with the current study demonstrated good internal reliability ( $\alpha=0.86$ ).
4. Quality of life was measured by the age-specific parent proxy versions of the Paediatric Quality of Life Inventory (PedsQ).<sup>25</sup> Similar to the youth versions, the

parent versions contain the same five subscales: diabetes symptoms, treatment barriers, treatment adherence, worry and communication. Consistent with the literature, the current study showed good internal reliability ( $\alpha=0.84$ ).

## 2.5 | Data analysis

### 2.5.1 | Quantitative analysis

Demographics are reported in frequencies and percentages for categorical variables and means and standard deviations for continuous variables. As outcome measures were repeated over four time points (baseline, 1-week, 3-months and 6-months post-camp), the GENMOD procedure with the REPEATED statement in SAS was used to fit a generalised estimating equations (GEE) model. Participants' ID was used as the clustering variable.

### 2.5.2 | Qualitative analysis

Focus groups were digitally recorded (with participant consent) and transcribed. Open-ended camp feedback questions were also included. Guided by the Theoretical Framework of Acceptability, AB and RS used direct content analysis to independently code the data into the principal codes dictated by the framework categories of affective attitude, burden, intervention coherence, opportunity costs, ethicality, perceived effectiveness and self-efficacy. A deductive approach was chosen in which directed content analysis was used to systematically organise the data to find key themes and patterns amongst the data.<sup>30</sup> Such approach is recommended in the evaluation of interventions within healthcare settings to explore acceptability and prioritise areas for improvement.<sup>18</sup> Data continued to be examined to the point of thematic saturation and any discrepancies in coding were resolved by consensus. The framework's category of ethicality was not included as quotes were found to be better conceptualised in the other categories and a principal category of ‘cultural inclusivity’ was added to encapsulate a prominent theme.

## 3 | RESULTS

### 3.1 | Participants

Of the 31 children and adolescents who attended the 2023 camp, 27 children and adolescents (87%) participated

	All youth campers ( <i>n</i> = 27)	Focus group participants ( <i>n</i> = 10)
Age	11.5 (1.3)	11.72 (1.3)
Gender (% female)	12 (44%)	4 (10%)
Ethnicity		
NZ European	18 (67%)	5 (50%)
Māori	2 (7%)	1 (10%)
Pacific	2 (7%)	1 (10%)
Other	5 (19%)	3 (30%)
Duration of diabetes (years)	4.8 (3.6)	5.1 (3.4)
Insulin treatment		
Pump	17 (63%)	6 (60%)
MDI	10 (37%)	4 (40%)
BMI	19.5 (3.8)	19.4 (4.74)
Baseline HbA1c		
mmol/mol	59.7 (11.5)	60.2 (8.1)
%	7.61 (1.09)	7.66 (0.74)
Deprivation score	4.4 (2.9)	4.4 (3.6)
Number of camps attended previously	0.70 (1.23)	1.10 (1.45)

TABLE 1 An overview of youth camper demographics.

in the study with a key caregiver. See Table 1 for an overview of the camper's demographic variables. Of note, two Māori youth participated in the study (7% of the sample), which is under-representative of the wider population of youth living with T1D in Aotearoa New Zealand.<sup>31</sup> Caregivers who chose to participate were all women. In terms of retention, 96% of campers and caregivers were retained at the final 6-month follow-up. Ten participants partook across three focus groups and were generally representative of the larger sample (refer to Table 1). See Figure 1 for an overview of participant flow throughout the study.

## 3.2 | Quantitative results

### 3.2.1 | Campers

Between baseline and the post-camp time points of 1-week, 3-months and 6-months, no significant changes were observed in common humanity nor the total scores of any psychological measures for campers (refer to Table 2). However, within the self-compassion subscales, reductions were noted in feelings of isolation between baseline and 6 months post-camp ( $p=0.036$ ) (see Table S3 for an overview of sub-scale measures of self-compassion for campers across baseline, 1-week, 3-months and 6-months). Overidentification of feelings also decreased significantly between baseline and

1-week post-camp ( $p=0.004$ ) and baseline and 6-months post-camp ( $p=0.035$ ). HbA1c did not change following camp (as shown in Table 3).

### 3.2.2 | Caregivers

Following camp, there were overall improvements in caregiver self-efficacy, distress and burden and quality of life (Table 4). Self-efficacy showed significant improvement at 1-week and 6-month post-camp. Caregiver distress and burden significantly improved at all time points. Caregiver's quality of life significantly improved at 1-week post-camp, particularly in communication ( $p=0.005$ ), treatment adherence ( $p=0.009$ ) and treatment barriers ( $p=0.012$ ) subscales (see Table S4 for an overview of sub-scale measures of quality of life for caregivers across baseline, 1-week post-camp, 3-months and 6-months). While changes in caregiver diabetes-specific self-compassion across all time points did not reach overall significance, there was a significant improvement between baseline and 6 months post-camp ( $p=0.030$ ). Notably, subscales identified significant improvements in self-judgement at 3 months ( $p=0.001$ ) and 6 months ( $p=0.031$ ) post-camp, reduced feelings of isolation at 6 months post-camp ( $p=0.018$ ), and improved mindfulness at 1 week ( $p=0.049$ ) and 3 months ( $p=0.041$ ) post-camp (see Table S5 for an overview of sub-scale measures of self-compassion for

**TABLE 2** An overview of psychological measures for campers across baseline, 1-week post-camp, 3-months and 6-months.

Measure	Time-point	n	Mean (SD)	Estimate (SE)	95% CI	p-value	Overall p-value
Self-compassion	Baseline	27	2.9 (0.4)	0	-		0.532
	1-week	27	3.0 (0.6)	0.13 (0.08)	-0.04 to 0.30	0.123	
	3-months	27	3.0 (0.6)	0.10 (0.12)	-0.13 to 0.32	0.408	
	6-months	27	3.0 (0.8)	0.11 (0.13)	-0.14 to 0.36	0.397	
Diabetes distress	Baseline	27	49.0 (15.7)	0	-		0.419
	1-week	27	44.8 (20.8)	-4.17 (2.80)	-9.66 to 1.33	0.137	
	3-months	27	46.4 (18.8)	-2.59 (3.35)	-9.15 to 3.97	0.439	
	6-months	27	43.8 (20.7)	-5.14 (4.27)	-13.5 to 3.23	0.229	
Self care behaviours	Baseline	27	3.4 (0.5)	0	-		0.319
	1-week	27	3.5 (0.4)	0.13 (0.08)	-0.02 to 0.28	0.097	
	3-months	27	3.5 (0.5)	0.10 (0.07)	-0.04 to 0.25	0.165	
	6-months	27	3.4 (0.6)	0.01 (0.07)	-0.13 to 0.16	0.855	
Self-efficacy	Baseline	27	5.5 (1.4)	0	-		0.561
	1-week	27	5.7 (1.5)	0.24 (0.23)	-0.22 to 0.70	0.302	
	3-months	27	5.9 (1.6)	0.40 (0.27)	-0.13 to 0.93	0.137	
	6-months	27	5.8 (1.7)	0.35 (0.27)	-0.19 to 0.88	0.200	
Quality of life	Baseline	27	33.5 (10.2)	0	-		0.972
	1-week	27	33.3 (10.9)	-0.27 (1.58)	-3.37 to 2.83	0.866	
	3-months	26	33.3 (12.3)	-0.22 (1.86)	-3.86 to 3.42	0.905	
	6-months	26	34.3 (11.8)	0.73 (1.91)	-3.02 to 4.48	0.704	

**TABLE 3** An overview of HbA1c across pre-camp, 3 months and 6 months.

Time-point	n	Mean (SD)	95% CI	Estimate (SE)	p-value	Overall p-value
Baseline						
mmol/mol	27	59.7 (11.9)	55.0–64.4	0		0.242
%		7.61 (1.09)	7.18–8.04	0		0.295
3-months						
mmol/mol	27	56.2 (10.6)	52.0–60.4	-9.61 (2.57)	0.258	
%		7.29 (0.97)	6.91–7.57	-0.31 (0.30)	0.285	
6-months						
mmol/mol	24	58.8 (9.6)	54.7–62.8	-5.95 (4.13)	0.723	
%		7.53 (0.88)	7.16–7.90	-0.08 (0.25)	0.740	

caregivers across baseline, 1-week post-camp, 3-months and 6-months). However, no significant changes to common humanity were observed.

### 3.2.3 | Qualitative results

Overall, participants expressed high levels of acceptance toward the camp and unanimously stated that they would recommend attending the camp to others living with T1D.

See [Table 5](#) for an overview of the qualitative themes identified across camper responses within the focus groups as well as open-ended questions included alongside the 1-week post-camp questionnaires.

Following the Theoretical Framework of Acceptability, affective attitude (defined as how the participants felt about their camp experience) was the most prevalent principal code. Participants described positive experiences at camp, with outdoor activities at camp commonly being mentioned as a highlight. For example, “*camp made me*

TABLE 4 An overview of psychological measures for caregivers across baseline, 1-week post-camp, 3 months and 6 months.

Measure	Time-point	n	Mean (SD)	Estimate (SE)	95% CI	p-value	Overall p-value
Self-compassion	Baseline	27	3.5 (0.8)	0	-		0.223
	1-week	27	3.6 (0.6)	0.12 (0.09)	-0.05 to 0.30	0.170	
	3-months	27	3.7 (0.6)	0.23 (0.12)	0.0-0.46	0.052	
	6-months	27	3.7 (0.8)	0.26 (0.12)	0.02-0.49	0.030	
Diabetes distress	Baseline	27	53.5 (17.3)	0	-		0.006
	1-week	27	48.0 (19.0)	-5.45 (2.21)	-9.79 to -1.11	0.014	
	3-months	27	46.2 (19.1)	-7.25 (2.25)	-11.7 to -2.84	0.001	
	6-months	27	37.9 (23.8)	-15.6 (3.32)	-22.1 to -9.08	<0.0001	
Self-efficacy	Baseline	27	4.1 (0.5)	0	-		0.034
	1-week	27	4.3 (0.4)	0.21 (0.07)	0.08-0.34	0.001	
	3-months	27	4.3 (0.4)	0.13 (0.08)	-0.03 to 0.29	0.099	
	6-months	27	4.3 (0.4)	0.21 (0.09)	0.04-0.38	0.015	
Quality of life	Baseline	27	34.2 (11.3)	0	-		0.039
	1-week	27	28.2 (10.0)	-6.07 (1.98)	-9.95 to -2.20	0.002	
	3-months	27	31.5 (11.2)	-2.69 (2.48)	-7.55 to 2.17	0.278	
	6-months	26	29.9 (12.1)	-4.28 (2.66)	-9.50 to 0.93	0.107	

feel happy... just doing all the activities gave me a lot of adrenaline” [11-year-old Chinese male, first camp experience]. A sense of connection among fellow campers, peer leaders and healthcare professionals who attended was also commonly highlighted, with many reporting having stayed in touch in the months following camp. A sense of psychological safety was also highlighted here, with participants commonly appreciating the unique environment of camp where “diabetes was just normal” [10-year-old Māori female, first camp experience].

Regarding intervention coherence (defined as the extent to which the campers understood the purpose of camp and how it could be of benefit), participants demonstrated a clear understanding of the camp’s purpose, emphasising its educational value while also acknowledging its enjoyable aspects. For example, “we learn more about diabetes... like new stuff... but it’s fun for all of us too and get to make new friends” [13-year-old NZ-European female, fifth camp experience]. Campers highlighted that they thought it would be especially helpful for those newly diagnosed. However, campers who had been diagnosed for longer amounts of time expressed surprise at the new skills and information they gained, particularly surrounding diabetes technologies.

Cultural inclusivity was the code, which contained the most suggestions for how camps could be improved in the future, with all participants in the Māori and Pacific group suggesting the incorporation of more culturally relevant activities. For example, “more cultural activities to let people feel more welcome. Maybe like find out which culture

people are from and then we could do activities based off that... like more karakia [prayer], waka ama [outrigger canoes], learning about the area, like where we are, natives and stuff like their connection” [13-year-old Māori male, second camp experience].

Additional minor themes included an increase in their self-efficacy and confidence in being able to manage their T1D independently, as well as heightened interest in utilising diabetes technology. Similarly, participants also reported themes of effectiveness in noticing increased blood glucose stability while at camp. While some amount of interventional burden was mentioned, such as homesickness and difficulties with sleeping and weather conditions, participants overwhelmingly perceived the benefits of camp as outweighing these challenges.

## 4 | DISCUSSION

Diabetes camps serve as crucial environments where children and adolescents living with T1D can find support, develop self care skills and form lasting peer connections. Incorporating caregiver perspectives, extended follow-up periods and a qualitative component, this study provides a comprehensive understanding of the impacts of diabetes camps as well as the first evaluation within the context of Aotearoa New Zealand. While camp attendance was lower than expected, reducing statistical power, almost all campers participated in the study and were retained at the 6-month follow-up.

**TABLE 5** An overview of qualitative themes throughout focus groups and open-feedback responses, ordered by frequency.

Acceptability concept	Definition	Frequency	Example quotes
Affective attitude	How the participants felt about their camp experience	Referenced in 137 question answers or responses	I felt really supported, I felt included a lot. I was just happy that everyone included me in [13-year-old Māori male, second camp experience] It was really cool to see other people with the stuff that we've got and it doesn't make you feel alone [11-year-old Chinese male, first camp experience]
Intervention coherence	The extent to which the campers understood the purpose of camp and how it could be of benefit	Referenced in 30 question answers or responses	It would be pretty helpful to the people who just got diagnosed with diabetes. Cause they'd be really lost with what to do, with what to start with. But with people that also have diabetes and also people who know how to manage them, it'd be easier for them to also know how to manage so they feel really comfortable [11-year-old Pacific Island male, fourth camp experience] It could help you through your journey through diabetes, it can really make you learn things through it [11-year-old NZ-European male, first camp experience]
Burden	The perceived amount of effort that is required to participate in camp	Referenced in 23 question answers or responses	It was kind of pretty far away from my, where I normally live and I've never been to a camp without my parental guardian [10-year-old Māori female, first camp experience] I couldn't get to sleep because it was too noisy [10-year-old NZ European female, first camp experience]
Perceived effectiveness	The extent to which the camp was perceived to achieve its purpose or benefit	Referenced in 13 question answers or responses	My diabetes was definitely on point [while on camp]. I didn't have lots of highs or lows, it was best it had been in months [13-year-old NZ European female, fifth camp experience]
Cultural inclusivity	The extent to which their camp experience felt inclusive of their culture	Referenced in 12 question answers or responses	More karakia [prayer] would be cool... not just diabetes learning activities but cultural activities as well [13-year-old Māori male, second camp experience] All the coaches were from different cultures which was good... [11-year-old Pacific Island male, fourth camp experience]
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate at camp and in their long-term diabetes self-management	Referenced in 7 question answers or responses	Well, to be honest, I felt a little uneasy [about managing my diabetes at camp] at first, but then over like the course of the camp, I felt better. I felt more confident and stuff [11-year-old NZ-European male, first camp experience] A break from parents always on at me about doing my diabetes. Proves I can do it myself [13-year-old NZ-European female, fifth camp experience]
Opportunity cost	The extent to which benefits or values must be given up to engage in diabetes camp	Referenced in 2 question answers or responses	Well, this isn't a problem for me. But if like some people got like homesick or something, that would like put them off coming [10-year-old NZ-European female, first camp experience] If we were allowed our phones before bed to text our parents I'm sure it would make a lot more kids comfortable at camp [11-year-old NZ-European male, first camp experience]

While quantitative findings showed no significant overall changes in camper's self-compassion, diabetes distress, self care behaviours, self-efficacy, or quality of life, a notable reduction in feelings of isolation was observed at 6 months, meeting the primary hypothesis of the study. This reduction likely reflects the camp's impact, especially in terms of the camp's aim of fostering meaningful connections with peers, healthcare professionals and camp leaders. Many participants described the camp as a place where diabetes was "normal" and a place where they felt a strong sense of belonging, mirroring the literature.<sup>12</sup> The lasting nature of these connections beyond camp, as described throughout the focus groups, likely explains the reduction in isolation at 6 months.

The lack of significant changes in other measures among campers, particularly for HbA1c, self-efficacy and self care behaviours, may be due to several factors like the small sample size and optimal baseline HbA1c. Focus group participants emphasised that while they gained new knowledge surrounding diabetes technology, the educational aspects of camp may be more beneficial for those newly diagnosed. Camps may see larger improvements for those newly diagnosed. Equally, the self-efficacy and self care behaviour measures<sup>22,24</sup> used in the study do not specifically include items surrounding confidence, perceptions, or knowledge related to the use of diabetes technology, which was highlighted as a benefit of camp. With growing consensus surrounding the selection and development of new measures,<sup>32,33</sup> future studies can leverage the availability of reliable and valid youth- and diabetes-specific tools to assess these possible mechanisms more directly.

The qualitative findings also suggest that the diabetes camp experience could benefit from a stronger focus on cultural inclusivity, an area particularly emphasised by our Māori and Pacific participants. Suggestions included incorporating more culturally relevant activities, such as connecting to the local land and nature, prayer (*karakia*), and sharing favourite foods to enhance inclusivity. This feedback aligns with calls within the literature to ensure initiatives are culturally responsive to diverse populations.<sup>34–36</sup> By embedding culturally meaningful practices into the camp experience, camps could foster a greater sense of inclusion and appeal to a more diverse audience.

Importantly, benefits were observed for caregivers with improvements in self-efficacy, distress and burden and quality of life, particularly evident at 1-week post-camp. Improvements in self-compassion were also noted at the 6-month follow-up, particularly in self-judgement, feelings of isolation and mindfulness. These findings mirror studies which have shown improvements in distress<sup>11,12</sup> and extend the literature by demonstrating improvements

in self-efficacy and quality of life for caregivers. These benefits to caregivers emphasise the importance of including assessments of caregiver and family perspectives. Qualitative investigations into the contributors to these benefits would be valuable to further understand the broader impacts of diabetes camps. For instance, understanding whether increased connections for youth also extended to connections among other family members, or whether there were benefits associated with their child's increased connectedness or possible ability to take care of their diabetes more independently.

Although the study provides valuable insights, there are several limitations to consider. Coupled with reduced statistical power, the pre-and post-camp study design prevents us from definitively attributing changes solely to the camp experience. Most participating families were also of New Zealand European descent, emphasising the need for future camps to actively welcome families from diverse backgrounds. Financial barriers to camp participation also exist, with additional costs like equipment and travel potentially preventing families from accessing these programmes. Given the benefits illustrated in this study, efforts should be made to increase accessibility and prevent exacerbating inequities in outcomes for youth living with T1D.

In conclusion, the study offers valuable insights into the benefits of diabetes camps for youth living with T1D and their caregivers. Both campers and their caregivers experienced reductions in isolation, with caregivers also showing improvements in psychological outcomes. These findings extend the literature, demonstrating that diabetes camps can have multifaceted impacts beyond the campers immediate experience. Importantly, the study highlights the need for diabetes camps to include more culturally inclusive activities and to be accessible to all families, regardless of their socio-economic status. Looking ahead, future research should explore the mechanisms driving these outcomes in a fully powered sample, evaluate the sustainability of camp effects and continue to include caregiver assessments. By enhancing the cultural relevance, accessibility and measurement of camp interventions, we can strive to optimise the wellbeing of youth living with T1D and their families.

## AUTHOR CONTRIBUTIONS

RS, AB and CJ came up with the concept and design of the study. RS recruited participants, collected data and conducted the focus group sessions with the assistance of AB. BA and CJ provided clinical insight and overview. AB assisted RS with the coding of qualitative data. DYH conducted the statistical analyses. AB wrote the manuscript with RS, BA and CJ. All authors edited and approved final versions of the manuscript.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

Due to the nature of a small sample, which is potentially identifiable, data is not available.

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## SUPPORTING INFORMATION

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