Psychological Well-Being of Carers of Children with Type 1 Diabetes: A Comparison with Carers of Children without a Chronic Condition

Francesca E. Thomson¹  Philip B. Bergman²,³  Margaret Hay⁴

¹Department of Clinical Psychology, School of Psychological Sciences, Monash University, Clayton, Victoria, Australia  ²Department of Pediatric Endocrinology and Diabetes, Monash Children's Hospital, Clayton, Victoria, Australia  ³Department of Pediatrics, Monash University Clayton, Victoria, Australia  ⁴Faculty of Medicine, Nursing and Health Sciences, Monash Institute for Health and Clinical Education, Monash University, Clayton, Victoria, Australia

Address for correspondence  Francesca E. Thomson, DPsych(clinical), Department of Clinical Psychology, School of Psychological Sciences, Monash University, Office 107, 27 Rainforest Walk, Clayton Campus, Wellington Road, Clayton, Vic 3800, Australia (e-mail: dacs.carer.wellbeing@gmail.com).

Abstract

Context  Caring for a child with a chronic illness requires additional responsibilities and burdens.

Aims  This research examined psychological well-being of carers of children with type 1 diabetes mellitus (T1DM). A comparison group of carers of children without a chronic condition was included to determine the specific influence T1DM has on carer well-being.

Methods  This cross-sectional correlational study included a sample of 93 carers of children with T1DM, and 84 comparison carers. Participants were administered the 21-item Depression, Anxiety, and Stress Scale (DASS21), and the Parenting Stress Index Short Form 4th edition via an online questionnaire.

Results  Multivariate analysis revealed no significant differences between carer groups; additional univariate analyses, however, indicated that carers of children with T1DM scored significantly higher on depression and stress subscales on the DASS21, and recorded elevated anxiety scores.

Conclusions  Carers of children with T1DM appear to manage parenting stress; however, they may be at increased risk of depression, general stress, and anxiety.

Introduction

A child’s type 1 diabetes mellitus (T1DM) diagnosis has found to be a particularly distressing time for carers.¹ Carers have reported experiences of initial shock and grief, with associated feelings of depression and anxiety.²⁻⁴ While this distress may diminish in intensity as carers adjust to and gain confidence in their new responsibilities and roles,⁵ research suggests that it does not disappear entirely.⁶ Parents report a state of “constant vigilance” required to maintain their child’s blood sugar levels within the safe range.⁷⁻⁹ Anxiety experienced when T1DM management is outside of the control of carers was also reported by parents of both young children¹⁰ and adolescents¹¹ with T1DM.

Carers also report the disruption T1DM can have on the family, and stress associated with adapting T1DM roles and responsibilities into family routines.¹,¹² Loss of spontaneity due to T1DM has also been highlighted by carers, with associated feelings of social isolation.³ One qualitative study highlighted what the authors termed “chronic sorrow” experienced by carers.¹³ Interviews with 17 parents who had managed their child’s T1DM for up to a decade discussed that...
Despite adapting to management responsibilities over time, they continued to experience episodes of grief precipitated by key developmental milestones.

A recent mixed-method systematic review investigated distress of carers of children with T1DM. The definition of “distress” included stress (both life stress and parenting stress) and symptoms of anxiety, depression, and/or post-traumatic stress. Their literature search generated 34 studies (20 quantitative and 14 qualitative) published between 1994 and 2011. The average age of children included in the studies ranged from 4.4 to 14.4 years; and duration of T1DM ranged from first diagnosis to an average of 4.4 years.

Of the 20 quantitative studies, only nine included prevalence of rates of carer distress ranging from 10% to 74% across studies, with higher levels of distress experienced at diagnosis (mean of 33.5%) compared with distress experienced 1 to 4 years after diagnosis (mean of 19%). Importantly, only three studies included a control group of carers of children without a chronic illness to enable between group comparisons. Of these, two studies reported increased parenting stress in carers of children with T1DM, and decreased parenting competence, self-efficacy, and parenting satisfaction in this group. The remaining study reported no significant differences in parenting stress between groups.

Notably, these three studies, all published at least over a decade ago, included relatively small sample sizes, ranging from 25 to 53 carers of children with T1DM, and 25 to 40 comparison carers. In addition, all three samples were limited to carers of predominantly younger children with T1DM.

Addressing the sample size limitation was study conducted in the Netherlands by Maas-van Schaaijk et al who compared parenting stress between 229 carers of adolescents with T1DM (126 mothers and 103 fathers) and 161 comparison carers (106 mothers and 55 fathers). Results indicated that fathers of adolescents with T1DM reported significantly more parenting stress than comparison fathers, while no significant difference was found between mothers. Parenting stress was also explored with reference to illness information (in the form of blood glucose levels); however, this was between T1DM carers, not including the comparison group. Results indicated that mothers of adolescents with poorly controlled T1DM reported significantly more parenting stress than mothers of adolescents with suboptimally or optimally controlled diabetes. No significant difference was reported among fathers. Differing from the current study, this study focused on carers of older adolescents aged between 12 and 18 years, who had been diagnosed with T1DM for a minimum of 6 months.

The current study, therefore, aimed to explore the prevalence of depression, anxiety, and stress (both general stress and parenting stress) among carers of children with T1DM compared with carers of children without a chronic condition. Diagnosis of T1DM was limited to a minimum of 12 months to allow for carer adjustment following initial diagnosis.

To address limitations of previous research, this study included a comparison group, and recruited nearly double the sample size of comparative studies included in the Whitemore et al. review. In addition, this study assessed illness and T1DM management variables in between group comparisons, two variables that have been found to impact on levels of T1DM carer well-being.

While previous comparative research has produced mixed results, it was expected that, given the demands associated with T1DM, carers of children with T1DM would report greater distress levels relative to the comparison group. It was also expected that within the carers of children with T1DM, optimal blood glucose levels and use of a continuous subcutaneous insulin infusion (CSII) pump would report decreased distress levels.

Methods

Participants

Two groups of participants were recruited for this cross-sectional correlational study. Group one comprised of carers of children who were attending two outpatient diabetes clinics of a tertiary metropolitan pediatric hospital, and one diabetes outpatient clinic of an outer suburban hospital. Group two consisted of carers of children who had no diagnosis of a chronic illness. Participants were part of a doctoral research study exploring prevalence and predictors of psychological well-being of carers of children with T1DM.

Only carers of children aged 16 and under were eligible to participate in this study. This age limit was set, as these children would most likely still be living at home, and have a higher level of dependence on their carer(s) for support. English proficiency and access to an Internet connection to complete the online survey were further inclusion criteria.

Carers of children with T1DM qualified for inclusion if their child had received a diagnosis of T1DM for at least 12 months prior to recruitment time. This timeframe was based on research who deemed this the minimum time to allow for psychological adjustment to a diabetes diagnosis.

Participants in the comparison group were excluded from participating if they were currently caring for a child diagnosed with a chronic illness, disability, or cognitive disorder that would require regular consultation and/or treatment.

Carers of children with T1DM who met the inclusion criteria were approached by members of the research team during their child’s appointment. Medical staff also promoted the study during their consultations. Carers of children without a chronic condition were approached via three main sources: (1) invited by carers of children of T1DM who were involved in the study, (2) advertisements listed on an internal online university bulletin, and (3) advertisements listed on public internet forums. This study was approved by the Monash University Human Research Ethics Committee, and Health Human Research Ethics Committees of recruitment outpatient clinics.

A total of 93 carers of children with T1DM and 84 comparison carers were recruited. Of the comparison group, 14 (17%) were recruited by carers of children with T1DM, 60 (71%) were recruited via the online university bulletin, and 10 (12%) via public internet forums. Given the nature of recruitment, a final response rate could not be calculated.
Materials
Demographic information was collected before participants completed the following scales. The 21-item Depression, Anxiety and Stress Scale (DASS21) was used to measure carer psychological well-being. It consists of three 7-item scales, which measure common depression, anxiety, and stress-related symptoms, as they have occurred over the previous week. Each response is associated with a score ranging from 0 to 3, from which a scale score was taken; with higher scores indicating higher severity of symptoms. The Cronbach’s coefficients in this study for the entire sample included depression $\alpha = 0.87$, anxiety $\alpha = 0.81$, and stress $\alpha = 0.84$.

Participants were also administered the Parenting Stress Index Short Form 4th edition (PSI-4-SF). The PSI-4-SF is a 36-item self-report questionnaire that measures stress within the parent–child system. Carers reported the degree to which they agreed with each item on a 4-point Likert scale ranging from strongly disagree to strongly agree. A Total Stress Score was then derived, with higher scores indicating higher parental stress. This measure is distinct from more general assessment of stress, as scores reflect stresses solely related to the carer’s experience of parenting, including interaction with their child, and stresses that result from the child’s behavioral characteristics. Indeed, in the current study, the relationship between the PSI total score and the general stress subscale of the DASS21 was $r = 0.57$. Strong reliability was also reported with a Cronbach’s coefficients in this study for the entire sample was $\alpha = 0.94$.

Diabetic information, including a 12-month average glycosylated hemoglobin A1c (HbA1c) level, and mode of insulin administration were collected from medical records.

Results
Approach to Statistical Analysis
Comparisons between carer groups were investigated using both univariate and multivariate analyses. A one-way multivariate analysis of variance (MANOVA) was conducted, similar to the protocol of Powers et al. This technique allowed the comparison between a categorical independent variable among two or more continuous dependent variables. In the current study, the DASS21 subscale and PSI-4-SF Total Parenting Stress scores were entered as the continuous dependent variables. Carer group was the categorical independent variable.

An additional four chi-square tests of independence for DASS21 subscale scores and the PSI-4-SF Total Parenting Stress were conducted, following the statistical protocol conducted in previous pediatric illness carer research by Cochrane et al. DASS21 subscale scores were dichotomized into “normal” versus “mild to extremely severe” scores based on original scale scoring by Lovibond and Lovibond. PSI-4-SF Total Parenting Stress scores were dichotomized into “normal” versus “borderline clinical and clinical” scores following original scoring instructions by Abidin.

To further explore illness and T1DM management variables, two Kruskal–Wallis tests were performed. This nonparametric statistic was utilized given the unequal sample sizes among carer groups. The first Kruskal–Wallis test compared parenting stress among comparison carers, and carers of children with optimal (HbA1c < 7.5%), suboptimal (HbA1c 7.5–9%), and high-risk (HbA1c >9%) HbA1c levels, as per the guidelines stipulated by International Society for Pediatric and Adolescent Diabetes. The second Kruskal–Wallis test compared parenting stress among comparison carers and carers of children who were administered insulin via twice-daily injections, multiple injections, or CSII pump.

The sample met minimum required sample size for all proposed analyses.

The demographic data are presented in Table 1. The majority of participants were female (82.5%), Australian and married. Carers of children with T1DM were found to be significantly older; however, mean difference in years was relatively small, and significance may have been reached due to a larger sample size. Carers of children without a chronic condition had higher educational qualifications; however, this might have been expected given many were recruited via a university bulletin.

The mean age of children under participant care was significantly older for carers of children with T1DM, and gender split was similar. Medical data indicated that the mean duration of T1DM diagnosis was 51.72 months (standard deviation (SD) = 38.23 months). Insulin was administered via CSII pump for 29% of children with T1DM, twice daily injections for 30%, and multiple daily injections for 40%. The mean glycosylated HbA1c level, a typical measure of glycemic control, was 8.48% (as measured in Diabetes Control and Complications Trial units), which also can be reported as 69 mmol/mol (as measured in International Federation of Clinical Chemistry units).

Table 2 presents how the sample fell within each glycemic control category as stipulated in the clinical guidelines recently published by the International Society for Pediatric and Adolescent Diabetes. For the four carers who had more than one child diagnosed with T1DM, sibling mean HbA1c levels were included in analysis. Four couples completed the survey independently; child HbA1c levels were recorded only once.

Although information was not collected from those who declined participation, to gauge representativeness of T1DM sample, these illness and T1DM management data were compared with clinic data sourced from the two metropolitan outpatient clinics taken at time of recruitment. Data from these clinics indicated that the 257 patients (aged 16 or under, with T1DM diagnosis for minimum 12 months) attending clinics over a 12-month period had a mean HbA1c level of 8.58%. In addition, 35% were receiving multiple daily injections, 24% were receiving twice daily injections, and 41% were utilizing a CSII pump.

Preliminary Analysis
Exploration of demographic data indicated that 15 carers of children with T1DM and 16 comparison carers had received a previous diagnosis of a mental health disorder. Of the 15 T1DM carers, three had received their diagnosis.
following their child’s T1DM diagnosis. Preliminary analysis revealed three extreme scores (at least three SDs above the mean) across measures from the comparison carer group, and one extreme score from the T1DM carer group. As recommended by Tabachnick and Fidell, these raw scores were changed on the offending variables to one unit larger than the next most extreme score in the distribution. No multivariate outliers were identified at $p < 0.001$, and there were no missing data.

Sample data were compared with normative data reported in respective test manuals. As with the full-length PSI-4, the PSI-SF-4 provides percentiles as normative metrics, based on the normative sample of 1,056 parents across America. With respect to the current sample, the mean Total Parenting

### Table 1 Sample characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Carers of children with T1DM (N = 93)</th>
<th>Carers of children without a chronic condition (N = 84)</th>
<th>p–Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
<td>15</td>
<td>0.91\textsuperscript{d}</td>
</tr>
<tr>
<td>Female</td>
<td>77</td>
<td>69</td>
<td></td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>5</td>
<td>3</td>
<td>0.90\textsuperscript{d}</td>
</tr>
<tr>
<td>Defacto/Living with partner</td>
<td>12</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>71</td>
<td>63</td>
<td></td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Household income\textsuperscript{a}</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$&lt; 60,000$</td>
<td>19</td>
<td>16</td>
<td>0.13\textsuperscript{d}</td>
</tr>
<tr>
<td>$60,001–100,000$</td>
<td>36</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>$&gt; 100,000$</td>
<td>38</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td><strong>Educational background</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year 10 or less</td>
<td>6</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Secondary/TAFE</td>
<td>40</td>
<td>6</td>
<td>&lt;0.0001\textsuperscript{d}</td>
</tr>
<tr>
<td>Tertiary</td>
<td>47</td>
<td>78</td>
<td></td>
</tr>
<tr>
<td><strong>Place of birth</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>71</td>
<td>63</td>
<td></td>
</tr>
<tr>
<td>Great Britain</td>
<td>6</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Malaysia</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td></td>
<td>4</td>
<td>0.41\textsuperscript{d}</td>
</tr>
<tr>
<td>Singapore</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Ukraine</td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>13\textsuperscript{b}</td>
<td>8\textsuperscript{c}</td>
<td></td>
</tr>
<tr>
<td><strong>Age of carer (mean/standard deviation in years)</strong></td>
<td>42.92 (6.28)</td>
<td>40.76 (6.90)</td>
<td>0.03\textsuperscript{c}</td>
</tr>
<tr>
<td><strong>Number of children under care (mean)</strong></td>
<td>2.64</td>
<td>2.25</td>
<td>0.62\textsuperscript{c}</td>
</tr>
<tr>
<td><strong>Age of children under care (mean/standard deviation in years)</strong></td>
<td>10.78 (3.24)</td>
<td>8.51 (4.13)</td>
<td>&lt;0.0001\textsuperscript{c}</td>
</tr>
<tr>
<td><strong>Gender of child</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>45</td>
<td>43</td>
<td>0.71\textsuperscript{d}</td>
</tr>
<tr>
<td>Female</td>
<td>49</td>
<td>41</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: T1DM, type 1 diabetes mellitus; TAFE, Technical and Further Education.

Note: Four carers had more than one child diagnosed with T1DM, gender for each of these children, and mean age of siblings were included in calculations. Four couples completed the survey independently child gender and age of each couple were recorded only once.

\textsuperscript{a}Income measured in Australian dollars.

\textsuperscript{b} Remainder of T1DM group consisted of single responses from Canada, China, Colombia, Croatia, Germany, Greece, India, Indonesia, New Zealand, South Africa, Switzerland, United States of America, and Zimbabwe.

\textsuperscript{c} Remainder of Comparison group consisted of single responses from Canada, China, Fiji, Holland, Pakistan, Saudi Arabia, Taiwan, and Vietnam.

\textsuperscript{d}p–Value for chi–square test of independence.

\textsuperscript{e}p–Value for independent t–test.
Stress scores for T1DM carers and comparison carers converted to 56th and 46th percentiles, respectively. As noted in the test manual, scores that fall within the 16th and 84th percentiles are considered to be within the normal range.\textsuperscript{25} This would suggest that the current sample was experiencing typical levels of stress associated with parenting. Scores in relation to the DASS21\textsuperscript{19} are detailed in \textit{Table 3}.

As presented in \textit{Table 3}, though T1DM carers reported higher DASS21 subscale scores compared with the comparison group, only stress scores were elevated compared with the normative sample.

\textbf{Multivariate Analysis of Variance}

Testing for normality, linearity, homogeneity of variance–covariance, and multicollinearity was conducted, with no serious violations noted. The MANOVA revealed no statistical significance between carers of children with T1DM and comparison carers on DASS21 subscale and PSI-4-SF Total Parenting Stress scores, $F(4,172) = 0.97$, $p = 0.33$; Wilks’ $\lambda = 0.97$. This suggests there was no difference found on a composite-dependent variable comprising both DASS21 and PSI-4-SF scores between carers of children with T1DM and carers of children without a chronic illness.

\textbf{Chi-Square Test for Independence}

Additional chi-square tests for independence (\textit{Table 4}) indicated that carers of children with T1DM were more likely to report higher DASS21 depression subscale scores ($\chi^2[1, n = 177] = 4.01, p = 0.05, \phi = 0.15$), and DASS21 stress subscale scores ($\chi^2[1, n = 177] = 6.32, p = 0.01, \phi = 0.19$). As seen in \textit{Table 4}, approximately twice the amount of carers of children with T1DM scored DASS21 depression and stress subscale scores above normal cut-off range. Though carers of children with T1DM were more likely to report higher DASS21 Anxiety Subscale and PSI-4-SF Total Parenting Stress scores, these differences were not statistically significant.

\textbf{Kruskal–Wallis Test}

The first Kruskal–Wallis test conducted found no statistically significant differences in DASS21 depression ($\chi^2[3, n = 177] = 1.18, p = 0.76$), anxiety ($\chi^2[3, n = 177] = 1.82, p = 0.61$), and stress ($\chi^2[3, n = 177] = 3.38, p = 0.34$) subscale scores, and PSI-4-SF total scores ($\chi^2[3, n = 177] = 2.34, p = 0.50$) among comparisons carers, and carers of children with optimal suboptimal and high-risk HbA1c levels. Similarly, the second Kruskal–Wallis test reported no statistically significant differences in DASS21 depression ($\chi^2[3, n = 177] = 1.21, p = 0.75$), anxiety ($\chi^2[3, n = 177] = 5.49, p = 0.14$), and stress ($\chi^2[3, n = 177] = 3.13, p = 0.37$) subscale scores, and PSI-4-SF total scores ($\chi^2[3, n = 177] = 3.22, p = 0.36$) among comparisons carers, and carers of children utilizing a CSII pump, twice daily insulin injections, and multiple daily insulin injections.

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|}
\hline
\textbf{HbA1c levels} & <7.5\% (Optimal) & 7.5–9\% (Suboptimal) \add\% (high risk) \\
\hline
\textbf{N (%)} & 16 (18\%) & 47 (52.8\%) & 26 (29.2\%) \\
\hline
\end{tabular}
\caption{HbA1c levels}
\end{table}

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|c|c|c|c|c|}
\hline
\textbf{} & \textbf{Depression} & \textbf{Anxiety} & \textbf{Stress} \\
\hline
\textbf{T1DM carers} & 5.78 & 3.63 & 11.63 \\
\textbf{Comparison carers} & 4.22 & 2.67 & 9.46 \\
\textbf{Normative sample}\textsuperscript{a} & 6.34 & 4.70 & 10.11 \\
\hline
\textbf{Mean} & 6.06 & 4.61 & 7.13 \\
\textbf{SD} & 3.86 & 3.19 & 4.89 \\
\hline
\end{tabular}
\caption{DASS21 means and SDs of current and normative sample}
\end{table}

\begin{table}[h]
\centering
\begin{tabular}{|c|c|c|c|}
\hline
\textbf{Carers of children with T1DM, \%} & \textbf{Carers of children without a chronic illness, \%} & \textbf{Chi-square} & \textbf{p–Value} \\
\hline
\textbf{DASS21 depression subscale scores mild–extremely severe range} & 28 & 15.5 & 0.05 \\
\textbf{DASS21 anxiety subscale scores mild–extremely severe range} & 19 & 11.9 & 0.18 \\
\textbf{DASS21 stress subscale scores mild–extremely severe range} & 30.1 & 14.3 & 0.01 \\
\textbf{PSI–4–SF Total Parenting Stress scores borderline clinical and clinical range} & 8.6 & 6 & 0.50 \\
\hline
\end{tabular}
\caption{Prevalence (\%) of DASS21 and PSI–4–SF Total Parenting Stress scores outside normal range}
\end{table}

Abbreviations: DASS21, 21–item Depression, Anxiety and Stress Scale; T1DM, type 1 diabetes mellitus; SD, standard deviation.

Abbreviation: HbA1c, hemoglobin A1c.

\textsuperscript{a}$n = 2,914$. 

Abbreviations: DASS21, 21–item Depression, Anxiety and Stress Scale; T1DM, type 1 diabetes mellitus; SD, standard deviation.
Discussion

Prevalence of T1DM continues to rise both in Australia and internationally. With many of the management responsibilities of this chronic pediatric condition falling to carers, the current study aimed to explore the impact of T1DM on carer psychological well-being. The current study’s design included carers of children without chronic condition to allow for between group comparisons; it also assessed the impact of illness severity and T1DM management on carer well-being.

Univariate analyses revealed that carers of children with T1DM were significantly more likely to score higher DASS21 subscale scores. No statistically significant differences between the two groups were found for DASS21 Anxiety subscale and PSI-4-SF Total Parenting Stress scores. This pattern was not evident in multivariate analysis, where no differences between carer groups were found.

As discussed in the introduction, previous studies exploring between group comparisons have produced mixed findings. For example, current findings differ from those of Powers et al., Maas-van Schaaijk et al., and Sullivan-Bolyai et al., who reported significantly higher PSI scores of T1DM carers than matched controls; however, they support findings from Sullivan-Bolyai et al., who found no significant differences in PSI scores. One might argue that sample characteristics could account for discrepancy in findings, such as ages of children, or duration of T1DM diagnosis. For example, differences in parenting stress between T1DM and comparison carers might be strongest for carers of younger children who have more recently been diagnosed. This could be understood as younger children relying on carers more heavily for support, as parents come to terms with their new roles and responsibilities. This interpretation is consistent with the findings of Stallwood, that families caring for younger children with T1DM reported high levels of distress.

In saying this, however, differing findings have been reported among demographically similar samples. For example, Powers et al., Maas-van Schaaijk et al., and Sullivan-Bolyai et al., explored carers of younger children with a more recent diagnosis, and Maas-van Schaaijk et al. and the current study included older children with a longer T1DM diagnosis duration. Differences in findings, therefore, might reflect other carer-child-related factors yet to be discovered, such as support from extended family or school. This type of exploration was beyond the scope of the current study; however, it is recommended for future research.

Findings from this study also indicated no differences in psychological well-being among carers of children without a chronic illness and T1DM carers categorized based on illness (HbA1c levels) and management (mode of insulin) variables. These differ from those reported by Maas-van Schaaijk et al., who found increased HbA1c levels to be related to increased maternal stress, and those by Müller-Godeffroy et al., who reported CSII therapy to significantly reduce parental pediatric stress. Nonsignificant findings of the current study could be related to smaller and less equal sample sizes entered into analysis. Importantly, research incorporating these variables is scarce, and further exploration may uncover more consistent findings.

Interestingly, the current study found no difference in parenting stress scores, yet T1DM carers were significantly more likely to score greater general stress scores. To the authors’ knowledge, this is one of the very few to compare groups of carers using measures of distress beyond those associated with the specific role of parenting. Therefore, with respect to DASS21 results, there is limited comparative research. Nonsignificant parenting stress scores indicate carers of children with T1DM are managing parenting roles and responsibilities just as well as carers of children without a chronic condition. The incongruity between parenting stress and more general stress could suggest that carer’s efforts to manage the challenges of caring for a child with T1DM may impede their ability to manage stress outside their caregiving role. Balancing the needs of a child with a chronic illness with other roles and responsibilities has been associated with practical, social, and financial strains and. Several studies have investigated the negative impact childhood chronic illness has on carer employment, marital relationships, and engagement in recreational activities and. It is also important to mention that the PSI-4-SF may not be sensitive to particular stress associated with caring for a child with a chronic illness, which may also have contributed to nonsignificant results.

In the current study, carers of children with T1DM reported higher anxiety than comparison carers. While this difference was not statistically significant, the discrepancy in scores does hold clinical significance and highlight an important area for clinicians working with T1DM carers to be aware of. Previous research on carers of children with T1DM has highlighted ongoing experiences of anxiety and fears related to both short- and long-term medical complications associated with the condition. Current results do suggest carers of children with T1DM experience greater levels of anxiety, and future research with larger sample sizes may see this relationship approach statistical significance. A statistically significant difference in depressive scores was found between carer groups. Previous research has discussed ongoing sorrow and emotional turmoil experienced by carers at diagnosis and beyond. Exhaustion and fatigue associated with T1DM management responsibilities, as well as feelings of guilt and powerlessness, have also been reported. With the duration of T1DM diagnosis of the current study in mind, higher reports of depression could suggest that while anxiety and parenting stress may be more episodic in nature, depressive symptoms, such as grief and sadness, may be durable. This chronicity of depression has also been argued in other pediatric carer populations.

The present study is one of few to compare psychological well-being between carers of children with T1DM with carers of children without a chronic condition. While the voluntary nature of recruitment resulted in lack of data on those participants who declined participation, medical sample data were compared with broader clinic data, supporting sample representativeness of the target carer population. Nonetheless, the findings need to be considered within the context of the following limitations. First, discussed findings have been taken from univariate analyses, which are more susceptible to type 1 error. It is important to recognize that
though this statistical approach has been utilized in previous carer research\(^\text{[21]}\); our multivariate analysis, carrying greater statistical power, produced nonsignificant results. Furthermore, the carer sample was predominantly educated, middle to upper socioeconomic status, married, Australian females. While this demographic profile is common in much carer research,\(^\text{[4]}\) the lack of diversity may limit generalizability of findings. The outcome variables used in analysis were measured indirectly via self-report. Although measures in this study were psychometrically sound, they, as with all self-report measures, remain vulnerable to subject bias. Finally, being a cross-sectional design, it is difficult to determine the cause–effect impact of T1DM on carer psychological well-being.

Despite these limitations, from a clinical standpoint, important implications can be drawn from the current findings. Perhaps most notably is that carers are handling the challenges of caring for a child with T1DM relatively well. This could be attributed to experience and confidence gained in T1DM management over time. In saying this, however, psychological support may still be required. In particular, it is important for psychologists and social workers working with T1DM carers, to understand stress as multifaceted, and be sensitive to and aware of stress experienced by carers that is not necessarily directly related to their caregiving role. Furthermore, depressive symptoms, regardless of T1DM diagnosis duration, may be more enduring than parenting stress. Continual encouragement of parents to discuss the emotional toll of T1DM is important in order for health professionals to provide ongoing support.

The present study provided a unique opportunity to investigate the impact of T1DM on carer psychological well-being. The findings suggest that while parenting stress may be well managed by carers of children with T1DM, the condition may have more lasting effects on depressive anxiety, and general stress symptoms. Findings taken from this study advocate the continual need for carer psychological support and highlight areas for psychological intervention. The study also hopes to provide valuable information in this important research area and to inspire future research and investigation to help further enhance the understanding of the psychological well-being of carers of not just children with T1DM, but other pediatric chronic illness conditions.

**Key Messages**

Findings highlight the importance of professionals working with carers to appreciate that distress is multifaceted, and that carers may also need support for psychological difficulties that are not directly related to their caregiving role.

**Presentation at a Conference**

The paper was presented at the VIII Ibero American Congress of Clinical and Health Psychology at Old San Juan in October 2016.

**Funding**

None.

**Conflict of Interest**

None.

**Acknowledgments**

Authors wish to thank the carers involved in the study, as well as staff of Department of Pediatric Endocrinology and Diabetes, Monash Children’s Hospital, and Department of Pediatrics, Peninsula Health. In particular, the authors extend thanks and appreciation of assistance from Dr. Justin Brown, Dr. Cecelia Garcia-Rudaz, Dr. Peter Sims, and Dr. Mary White.

**References**

Well-Being of Carers of Children with Type 1 Diabetes


Abidin RR. Manual for the Parenting Stress Index. Odessa, FL: Psychological Assessment Resources; 1995


