

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

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#### 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.

## **Keywords**

- ► type 1 diabetes mellitus
- carer psychological well-being
- ► comparison group

#### 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.<sup>2-4</sup> While this distress may diminish in intensity as carers adjust to and gain confidence in their new responsibilities and roles<sup>4,5</sup>, research suggests that it does not disappear entirely.<sup>6</sup> 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.<sup>13</sup> Interviews with 17 parents who had managed their child's T1DM for up to a decade discussed that

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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.<sup>14</sup> 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. 15,16 The remaining study reported no significant differences in parenting stress between groups. 9

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<sup>17</sup> 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

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 Whittemore et al,<sup>14</sup> 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.<sup>17,18</sup>

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.<sup>6</sup>

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)<sup>19</sup> 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  $\alpha$  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).<sup>20</sup> 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  $\alpha$  coefficients in this study for the entire sample was  $\alpha = 0.94$ .

Diabetic information, including a 12-month average gly-cosylated 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.<sup>21</sup> DASS21 subscale scores were dichotomized into "normal" versus "mild to extremely severe" scores based on original scale scoring by Lovibond and Lovibond.<sup>19</sup> PSI-4-SF Total Parenting Stress scores were dichotomized into "normal" versus "borderline clinical and clinical" scores following original scoring instructions by Abidin.<sup>20</sup>

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.<sup>22</sup> 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.<sup>23</sup>

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.<sup>23</sup> 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.<sup>22</sup> 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.

Alhough 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

**Table 1** Sample characteristics

Characteristics	Carers of children with T1DM (N = 93)	Carers of children without a chronic condition (N = 84)	p-Value	
Gender				
Male	16	15	0.01d	
Female	77	69	0.91 <sup>d</sup>	
Relationship status		<u>'</u>		
Single	5	3		
Defacto/Living with partner	12	13	0.90 <sup>d</sup>	
Married	71	63	0.90	
Separated/divorced	5	5		
Household income <sup>a</sup>		·		
< 60,000	19	16		
60,001-100,000	36	22	0.13 <sup>d</sup>	
> 100,000	38	46		
Educational background				
Year 10 or less	6	0		
Secondary/TAFE	40	6	<0.0001 <sup>d</sup>	
Tertiary	47	78		
Place of birth				
Australia	71	63		
Great Britain	6	5		
Malaysia	3			
Germany		4	0.41 <sup>d</sup>	
Singapore		2		
Ukraine		2		
Other	13 <sup>b</sup>	8°		
Age of carer (mean/standard deviation in years)	42.92 (6.28)	40.76 (6.90)	0.03e	
Number of children under care (mean)	2.64	2.25	0.62e	
Age of children under care	10.78 (3.24)	8.51 (4.13)	<0.0001e	
(mean/standard deviation in years)				
Gender of child	1	- 1		
Male	45	43	0.71d	
Female	49	41	0.71 <sup>d</sup>	

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.

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,<sup>24</sup> 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.<sup>20</sup> With respect to the current sample, the mean Total Parenting

alncome measured in Australian dollars.
bRemainder 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.

<sup>&</sup>lt;sup>c</sup>Remainder of Comparison group consisted of single responses from Canada, China, Fiji, Holland, Pakistan, Saudi Arabia, Taiwan, and Vietnam. <sup>d</sup>p–Value for chi–square test of independence.

<sup>&</sup>lt;sup>e</sup>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.<sup>20</sup> This would suggest that the current sample was experiencing typical levels of stress associated with parenting. Scores in relation to the DASS21<sup>19</sup> are detailed in **Table 3**.

As presented in **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.

#### **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.

#### **Chi-Square Test for Independence**

Additional chi-square tests for independence (>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 **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.

#### 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.

**Table 2** HbA1c levels

	<7.5% (Optimal)	7.5–9% (Suboptimal)	>9% (high risk)
N (%)	16 (18%)	47 (52.8%)	26 (29.2%)

Abbreviation: HbA1c, hemoglobin A1c.

**Table 3** DASS21 means and SDs of current and normative sample

	Depression		Anxiety		Stress	
	Mean	SD	Mean	SD	Mean	SD
T1DM carers	5.78	6.06	3.63	4.61	11.63	7.13
Comparison carers	4.22	3.86	2.67	3.19	9.46	4.89
Normative sample <sup>a</sup>	6.34	6.97	4.70	4.91	10.11	7.91

Abbreviations: DASS21, 21–item Depression, Anxiety and Stress Scale; T1DM, type 1 diabetes mellitus; SD, standard deviation.  $^{a}N = 2,914$ .

Table 4 Prevalence (%) of DASS21 and PSI-4-SF Total Parenting Stress scores outside normal range

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	Carers of children with T1DM, %	Carers of children without a chronic Illness, %	Chi-square p-Value
DASS21 depression subscale scores mild-ex- tremely severe range	28	15.5	0.05
DASS21 anxiety subscale scores mild-extremely severe range	19	11.9	0.18
DASS21 stress subscale scores mild-extremely severe range	30.1	14.3	0.01
PSI–4–SF Total Parenting Stress scores borderline clinical and clinical range	8.6	6	0.50

Abbreviations: DASS21, 21-item Depression, Anxiety and Stress Scale; PSI-4-SF, Parenting Stress Index Short Form 4th edition; T1DM, type 1 diabetes mellitus.

### 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,15 and Maas-van Schaaijk et al,17 who reported significantly higher PSI scores of T1DM carers than matched controls; however, they support findings from Sullivan-Bolyai et al9 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<sup>25</sup> 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,<sup>15</sup> and Sullivan-Bolyai et al<sup>9</sup> explored carers of younger children with a more recent diagnosis, and Maasvan Schaaijk et al<sup>17</sup> 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, <sup>17</sup> who found increased HbA1c levels to be related to increased maternal stress, and those by Müller-Godeffroy et al <sup>18</sup> 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<sup>26</sup> and.<sup>27</sup> Several studies have investigated the negative impact childhood chronic illness has on carer employment, marital relationships, and engagement in recreational activities28 and.29 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.<sup>30</sup>

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.<sup>2,31-34</sup> 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.13 Exhaustion and fatigue associated with T1DM management responsibilities, as well as feelings of guilt and powerlessness, have also been reported.35 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.<sup>36</sup>

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<sup>21</sup>; 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,<sup>14</sup> 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.

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None.

#### **Conflict of Interest**

None.

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#### References

- 1 Wennick A, Hallström I. Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus: an ongoing learning process. J Fam Nurs 2006;12(4):368–389
- 2 Buckloh LM, Lochrie AS, Antal H, et al. Diabetes complications in youth: qualitative analysis of parents' perspectives of family learning and knowledge. Diabetes Care 2008;31(8):1516–1520
- 3 Lowes L, Lyne P, Gregory JW. Childhood diabetes: parents' experience of home management and the first year following diagnosis. Diabet Med 2004;21(6):531–538
- 4 Sullivan-Bolyai S, Rosenberg R, Bayard M. Fathers' reflections on parenting young children with type 1 diabetes. MCN Am J Matern Child Nurs 2006;31(1):24–31
- 5 Lowes L, Gregory JW, Lyne P. Newly diagnosed childhood diabetes: a psychosocial transition for parents? J Adv Nurs 2005;50(3):253–261
- 6 Northam E, Anderson P, Adler R, Werther G, Warne G. Psychosocial and family functioning in children with insulin-dependent diabetes at diagnosis and one year later. J Pediatr Psychol 1996;21(5):699–717
- 7 Clarke WL, Gonder-Frederick A, Snyder AL, Cox DJ. Maternal fear of hypoglycemia in their children with insulin dependent diabetes mellitus. J Pediatr Endocrinol Metab 1998;11(Suppl 1): 189–194
- 8 Marrero DG, Guare JC, Vandagriff JL, Fineberg NS. Fear of hypoglycemia in the parents of children and adolescents with diabetes: maladaptive or healthy response? Diabetes Educ 1997;23(3):281–286
- 9 Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M. Constant vigilance: mothers' work parenting young children with type 1 diabetes. J Pediatr Nurs 2003;18(1):21–29
- 10 Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M. Mothers' experiences raising young children with type 1 diabetes. J Spec Pediatr Nurs 2002;7(3):93–103
- 11 Mellin AE, Neumark-Sztainer D, Patterson JM. Parenting adolescent girls with type 1 diabetes: parents' perspectives. J Pediatr Psychol 2004;29(3):221–230
- Marshall M, Carter B, Rose K, Brotherton A. Living with type 1 diabetes: perceptions of children and their parents. J Clin Nurs 2009;18(12):1703–1710
- 13 Bowes S, Lowes L, Warner J, Gregory JW. Chronic sorrow in parents of children with type 1 diabetes. J Adv Nurs 2009;65(5):992–1000
- 14 Whittemore R, Jaser S, Chao A, Jang M, Grey M. Psychological experience of parents of children with type 1 diabetes: a systematic mixed-studies review. Diabetes Educ 2012;38(4):562–579
- 15 Powers SW, Byars KC, Mitchell MJ, Patton SR, Standiford DA, Dolan LM. Parent report of mealtime behavior and parenting stress in young children with type 1 diabetes and in healthy control subjects. Diabetes Care 2002;25(2):313–318

- 16 Rodrigue JR, Geffken GR, Clark JE, Hunt F, Fishel P. Parenting satisfaction and efficacy among caregivers of children with diabetes. Child Health Care 1994;23(3):181–191
- 17 Maas-van Schaaijk NM, Roeleveld-Versteegh AB, van Baar AL. The interrelationships among paternal and maternal parenting stress, metabolic control, and depressive symptoms in adolescents with type 1 diabetes mellitus. J Pediatr Psychol 2013;38(1):30–40
- 18 Müller-Godeffroy E, Treichel S, Wagner VM; German Working Group for Paediatric Pump Therapy. Investigation of quality of life and family burden issues during insulin pump therapy in children with type 1 diabetes mellitus—a large-scale multicentre pilot study. Diabet Med 2009;26(5):493–501
- 19 Lovibond SH, Lovibond PF. Manual for the Depression Anxiety Stress Scales. 2nd edition. Sydney: Psychology Foundation; 1995
- 20 Abidin RR. Manual for the Parenting Stress Index. Odessa, FL: Psychological Assessment Resources; 1995
- 21 Cochrane JJ, Goering PN, Rogers JM. The mental health of informal caregivers in Ontario: an epidemiological survey. Am J Public Health 1997;87(12):2002–2007
- 22 Rewers MJ, Pillay K, de Beaufort C, et al; International Society for Pediatric and Adolescent Diabetes. ISPAD Clinical Practice Consensus Guidelines 2014. Assessment and monitoring of glycemic control in children and adolescents with diabetes. Pediatr Diabetes 2014;15(Suppl 20):102–114
- 23 Pallant J. A Step by Step Guide to Data Analysis Using the SPSS Program. SPSS Survival Manual, 4th edition. New South Wales, Australia: Allen and Unwin Books; 2010
- 24 Tabachnick BG, Fidell LS. Using Multivariate Statistics, 5th edition. Needham Height, MA: Allyn & Bacon; 2007
- 25 Stallwood L. Influence of caregiver stress and coping on glycemic control of young children with diabetes. J Pediatr Health Care 2005;19(5):293–300
- 26 Duis SS, Summer M, Summers CR. Parent versus child stress in diverse family types an ecological approach. Top Early Child Spec Educ 1997;17:53–73

- 27 Turner-Henson A, Holaday B, Swan JH. When parenting becomes caregiving: caring for the chronically ill child. Fam Community Health 1992;15:19–30
- 28 Kuhlthau KA, Perrin JM. Child health status and parental employment. Arch Pediatr Adolesc Med 2001;155(12): 1346–1350
- 29 Quittner AL, Opipari LC, Espelage DL, Carter B, Eid N, Eigen H. Role strain in couples with and without a child with a chronic illness: associations with marital satisfaction, intimacy, and daily mood. Health Psychol 1998;17(2):112–124
- 30 Streisand R, Braniecki S, Tercyak KP, Kazak AE. Childhood illness-related parenting stress: the pediatric inventory for parents. J Pediatr Psychol 2001;26(3):155–162
- 31 Hatton DL, Canam C, Thorne S, Hughes AM. Parents' perceptions of caring for an infant or toddler with diabetes. J Adv Nurs 1995;22(3):569–577
- 32 Hilliard ME, Monaghan M, Cogen FR, Streisand R. Parent stress and child behaviour among young children with type 1 diabetes. Child Care Health Dev 2011;37(2):224–232
- 33 Grey M, Whittemore R, Ambrosino JM, Lindemann E, Grey M. Coping and psychosocial adjustment in mothers of young children with type 1 diabetes. Child Health Care 2009;38(2):91–106
- 34 Streisand R, Mackey ER, Elliot BM, et al. Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: opportunities for education and counseling. Patient Educ Couns 2008;73(2):333–338
- 35 Lowes L, Eddy D, Channon S, McNamara R, Robling M, Gregory JW; DEPICTED study team. The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study. J Pediatr Nurs 2015;30(1):54–62
- 36 Ones K, Yilmaz E, Cetinkaya B, Caglar N. Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). Neurorehabil Neural Repair 2005;19(3):232–237