Are We Providing Enough Psychosocial Support for Caregivers of T1 Diabetic Children?

Vivienne Howard
Student number: 103244554

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Supervisor: Dr. Chris Gibbons
Programme Leader: Dr. Rosie Reid

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Department of Psychology
Dublin Business School
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Abstract

This is a mixed methods, qualitative and quantitative study which aims to look at caregiving for juvenile type 1 diabetics from a biopsychosocial perspective. A sample of 89 caregivers responded to the survey, which was hosted on a closed internet-based support group. It used the biomarker HbA1c as a measure of metabolic control and has chosen to look at the psychosocial constructs; locus of control, social support and satisfaction with life in the caregiver. The study proposes that in times of constrained resources these psychological aspects of caregiver support are not adequately supported and that this may have implications for the health of their chronically-ill dependents. The study found significant relationships between locus of control, informational and practical support and health outcomes. It was found that locus of control, feeling understood and social supports have associations with wellbeing. The qualitative data supports this. A number of cost-effective interventions are proposed.
Introduction

Psychological wellbeing in caregivers has been shown to correlate positively with metabolic control in children with T1D (Liiakapoulou et al., 2001).

*Juvenile Type 1 Diabetes*

Type 1 Diabetes is an autoimmune disease, it occurs when the immune system attacks and gradually destroys the body’s insulin producing beta-cells, located in the pancreas. This causes the pancreas to stop producing insulin (a hormone which facilitates the absorption of glucose into the cells of the body to derive energy from food). The causes of this condition are not fully understood. It is thought that genetic factors predispose an individual and that environmental triggers are involved. Type 1 Diabetes (T1D) has nothing to do with lifestyle or diet. There is no cure, the condition is managed with a complicated and challenging protocol built around insulin therapy (multiple daily injections or pump), it involves round the clock care.

Insulin is injected or pumped multiple times daily to match carbohydrate intake. Insulin doses are worked out using algorithms that change constantly, in response to many factors including previous doses, present blood glucose, illness, stress and levels of activity. Also critical to this balancing act is an individual’s insulin sensitivity or tolerance. In some people this will vary, possibly many times a day (Tamborlane, Bonfig & Boland, 2001).

With insulin therapy the aim is to keep blood glucose within a relatively narrow range (4.5 – 7 mmol/L for a person with diabetes). Finger pricking blood tests are required, possibly 10-12 per day. When glucose levels drop below target (hypoglycemia) a person will experience dizziness, shaking, sweating, disorientation
and cognitive dysfunction. If recurrent or untreated, severe hypoglycemia will lead to brain damage. There is an immediate danger of collapse, coma and possibly death. Elevated glucose levels (hyperglycemia) will cause thirst, illness and clouded thinking. Over time this causes damage to body tissues, blood vessels and nerves. This results in complications that may include; kidney failure, loss of sight, nerve damage, heart attack, stroke and pregnancy complications (Davidson, 1981). A child with T1D may swing between both extremes, multiple times daily (De Fronzo, Ferrannini, Zimmet & Alberti. 2015). Another acute complication of T1D is ketoacidosis. This occurs when for some reason, i.e. a missed insulin injection, the body lacks insulin and metabolizes fat for energy. A byproduct of this process is keytones, an acid that is very toxic to the system and builds up quickly. This is an emergency situation where A and E intervention is needed because it can lead quickly to systemic collapse and possible death.

Other aspects of diabetes management include many scheduled diabetes care appointments in hospital for monitoring risks, consultations for treatment and screening for complications. Constant vigilance is required for proper care, this can feel overwhelming for parents (DeFonzo et al, 2015). Children and families living with diabetes live with a significant amount of extra stress (Northam, Anderson & Adler, 1996). As a result it is not surprising to find that children with diabetes have a significantly higher risk of developing depression and anxiety, with about 15-25% of T1 adolescents suffering from depression (Hood, Huestis & Maher, 2006; Grey, 2002) and 13-17% showing symptoms of anxiety (Herzer & Hood, 2010). Studies indicate that 10% of adolescent T1 diabetics suffer full-blown eating disorders and 14% reach sub-threshold levels of eating disturbance (Steel, Young, Lloyd & MacIntyre, 1989), possibly due to the focus on food. There have been many
significant advances in technological supports for T1D over the last 10 years, but ultimately it has been found that T1D still shortens life span, by 11 years in men and 13 in women (Wise, 2015).

Parents/guardians (to be referred to as caregivers) of juvenile T1D’s play a critical role in promoting positive management of the disease and related improved health outcomes. This may often be at the expense of the caregiver’s own wellbeing (Streisand, Swift, Wickmark, Chen & Holmes, 2005). Caregivers are routinely required to be highly involved in management of the condition and consistent parental involvement often results in better health outcomes (Anderson, Brackett & Ho, 1999). Findings suggest that difficulties in caregivers’ confidence in their ability to manage their child’s diabetes together with higher levels of hypoglycemia concern have a strong relationship with higher parenting stress. (Marrero, Guare & Vandagriff, 1997).

With about 500,000 children diagnosed worldwide, juvenile-onset Type 1 diabetes is one of the most common chronic autoimmune diseases in the western world, (Culliton, 2009). Currently, the incidence of T1D in Ireland is increasing by 6% year on year, with very little understanding of the reasons why (Patterson et al, 2009). Across Europe, prevalence in the under 15’s is predicted to rise from 94,000 in 2005 to 160,000 in 2020 (Patterson et al, 2009).

Overview of the Literature on Juvenile Type 1 Diabetes

The majority of psychological research around juvenile diabetes has focused on issues surrounding adjustment to the illness (Kovacs, Goldson, Obronsky & Bonar, 1997) and regimen adherence for health outcomes (Grey, 2000). Much of this research has focused on adolescents rather than children and tended to look at
behavioral disturbance, advocating interventions such as ‘triple-p, positive parenting program’ (Doherty, Calam & Sanders, 2013), rather than looking at ways to support all families in ways that might improve the caregiving experience and thus impact on management of disease. Other recent research has been looking at factors that may influence adherence to a medical treatment protocol in the individual and the familial context, for example, Grey, Boland, Davidson & Tamborlane (2000) looked at coping skills and problem solving. Improvements were demonstrated with skills training but again interventions were targeted primarily at adolescents, rather than parents, and as the interventions were short term there may be some issues with sustainability. Demographic predictors like social disadvantage and educational level have also been the subject of research, Berkowitz, Gao & Tucker (2014) showed that patients with poor SES profiles suffered disproportionate levels of diabetic morbidity. Recently, researchers have concluded that identifying and targeting psychosocial distress could be an important element of treatment in diabetes related care (Cameron, Northam, Ambler & Daneman, 2007). Although it is broadly recognized that childhood diabetes impacts on all members of the family (Wysoki, 2003), there have not been enough studies like that of Monaghan and Hilliard’s of 2009, which focused on caregivers and highlighted the issue of around the clock care (through-the-night blood glucose monitoring) leading to heightened parental anxiety, stress and sleep disruption with health repercussions for parent and child. They recommended further research and the need to address this in clinical practice.

Within the last ten years there have been a lot of major changes in treatment regimens, which have accompanied the huge leaps forward in technology; pump therapy, interstitial glucose monitoring and continuous glucose monitoring. Much of the current research in the area of juvenile T1D has focused on issues around
acceptance, attitudes and management of these new technologies. For example: Elleri’s, 2009 study on the role of closed-loop insulin therapy in managing hypoglycemic episodes through the night and the Kaufman et al. (1999) study on skills and attitudes to pump therapy, with few focusing on the psychosocial aspects. One study that did was Muller-Godeffroy’s 2009 research on psychosocial aspects of insulin pump therapy in juvenile T1D. Substantial psychosocial benefits were found but it is noticed that it was supported by a pump advocacy group. The present study would suggest that the area of caregiver support is getting lost in the rush to push forward with the technology and that while these advances are fantastic developments that many parents embrace (Plotnick 2003, showed that pump therapy has positive influence on HbA1c), what is not being discussed is the increased caregiver burden that accompanies all of them.

This Research

This study has chosen to look at caregivers for juvenile T1D’s from a biopsycosocial perspective. It has chosen to look at the psychosocial constructs of locus of control beliefs, support and wellbeing in the context of a biological indicator of medical regimen adherence, HbA1c.

Bio – HbA1c

The study will use the HbA1c measure as a biomarker for successful management of T1D and good medical regimen adherence. This test measures the amount of glucose in red blood cells, giving what equates to an average blood sugar reading over the last 2–3 months. It produces a scale measure and it is positively correlated with risk of diabetes related complications and thus serves as a good
indicator of level of metabolic control over a 3 month period. The recommended target HbA1c for a person with diabetes is 7.0% (De Fronzo et al., 2015). In a large study in 2001, Hoey et al. showed that lower HbA1c results were associated with lower diabetes impact, fewer worries and better health perception.

*Psychosocial*

*Locus of control beliefs*

This study is interested in looking at caregivers’ Locus of Control (LOC) beliefs in relation to their T1 child’s diabetic health. Locus of control refers to a construct of personality, which accounts for a person’s perceived control over his or her behavioral outcomes (control of reinforcement). This can be attributed to external or internal forces. Crucially, it doesn’t refer to reality but to the individual’s personal experience. It is measured along a continuous scale from high internal to high external. With internal control attributions, individuals will tend to view themselves as having control and responsibility over their own destinies, Wang, Bowling and Eschleman (2010) showed that internals have better problems solving skills and benefits to wellbeing. The opposite appears to be the case for external attributers who would see control as residing beyond themselves i.e., luck. They tend toward more health problems and a passive patient role (Maltby and McCaskill, 2010). This construct was proposed by Julian Rotter, a social learning theorist. He looked at locus of control in various goal domains, such as love or achievement, but concluded that a global conceptualization had greater validity. Other theorists have developed loci of control scales in particular domains, ie, Wallston and Wallston’s health locus of control (Lefcourt, 1992). This study will use Rotter’s global measure to see if
expectations about behaviors will determine actions in caregivers of juveniles with T1D.

In previous research greater internal control belief was associated with better self-management in adult T2 diabetics (Walker et al., 2012). As the T1D regime is more demanding, more T1 targeted research was called for. Peyrot and Rudin (1994) found that internal diabetes-specific LOC contributed significantly to the positive health outcomes in a general diabetic population (Type 1 and 2), though this was an adult population. In 1990, De Weerdt, Visser, Kok & Van der Veen linked internal health LOC beliefs together with a high knowledge base to achieve better outcomes for T1Ds, though the focus was on self-care rather than caregivers. Gillibrand (2006) showed that in adolescents, high LOC beliefs combined with high self-efficacy “predicted that the benefits of adhering to the self-care regime…as outweighing the costs of doing so”. That study though it claimed to be looking at adolescents, did in fact work with a population aged 16-25, with a mean age of 21, so they were in fact looking at young adults. They also used a self-report questionnaire and found they had only a 38% response rate, suggesting a bias in responding where it may be that the more motivated individuals engaged, calling representativeness into question.

There has been very little research done in the area of caregiving, juvenile T1D and LOC beliefs.

**Social support**

High levels of caregiver stress have been alluded to. Much research has looked at what’s called the ‘buffering effect’ of support in offering a protective mechanism in the face of potentially negative effects of stress (Cohen & Wills, 1985). Social support has been described as “the perception or experience that one is cared for, esteemed
and part of a mutually supportive network” (Taylor, 2011). It has been shown to moderate stress and related illness in response to negative life events (Sarason, Sarason, Potter & Antoni, 1985). Theoretical models of social support identify three functional dimensions of social support; emotional, instrumental (practical) and informational (Charney, 2004). As individuals may have a preference for a certain style of support, it’s been shown that when style experienced has closer correspondence with style desired there is increased stress resilience (Hyman, Gold & Cott, 2003). The effects of low social support on life expectancy are as powerful as the effects associated with obesity and smoking (Uchino, 1996). Equally, it has been shown that in certain cases ‘giving’ social support to others contributes significantly to our wellbeing (Brown, 2003). Barcroft (2015) illustrated this point with his study demonstrating the positive impact that offering and receiving peer support can have on carers of children with T1D.

Much research suggests that social support is a protective factor for stress in parents of children with chronic conditions (Horton & Wallander, 2001). Lewandowski & Drotar (2007) found quality of support within the marital relationship to be particularly helpful in parents of T1Ds. In another study, Arlene Smaldone (2011) found high levels of isolation among parents of T1Ds, reporting that family and friends has minimal understanding of their burden. She found that support groups lessened this effect. It should be noted that the study used a small sample (N = 11) sourced through a purposive snowball procedure, suggesting some homogeneity of sample, which may have had an influence on results. Elsewhere, socially supportive peer mentoring interventions, for parents of newly diagnosed T1Ds, were shown to be significantly helpful in qualitative studies by Sullivan-Boyai (2010, 2011), although, the peer mentors were given significant training and the support
included formal home visits, which might not be practical in real world settings. In 2016, when Sue Channon instigated a parent-to-parent support pilot program in a T1D community she found that the uptake was lower than expected. She suggested that “further study is required to ascertain parental preferences in relation to support”.

Clinical (informational) support has also been linked to health outcome, with higher levels of hospital contact correlating negatively with HbA1c results (Davies et al. 2013). This study will also look at educational achievement as high caregiver literacy had been linked to improved glycemic control (Pulgaron et al, 2014). Instrumental support has been shown to be critical also, a Spanish study in 2007 reported that only 34% of carers of T1Ds felt that school teachers would recognize symptoms of a mild hypoglycemic episode in their child and 17% had persistent problems in getting support for their child in the school setting. Almost 10% were forced to move school (Amillategui, Calle, Alvarez, Cardiel & Barrio, 2007). This study took place in Spain, the situation in Ireland is different as we have SNAs (special needs assistants) assigned to oversee the care of T1D’s in school, the issue here would be that inconsistencies in quality of care, according to anecdotal sources.

Wellbeing – Satisfaction with Life

The concept of wellbeing has it’s roots in Aristotle’s notion of ‘eudaimonia’ or ‘doing and living well’. It is a more multifaceted construct than happiness and was first highlighted by Bradburn (1969) who described it as “the ultimate goal of all human actions”. In the last two decades research in the area has flourished, with many theoretical perspectives and definitions.

Previous research has looked at many individual aspects of wellbeing and T1D in juveniles, for example Chimen et al., in a review of literature (2012), linked
physical activity and wellbeing in juvenile T1D. Much of this research focuses on adolescent patients. Hoey et al., (2001) found higher levels of wellbeing and QOL in adolescents with better metabolic control. De Wit et al., (2008) found therapeutic effect from monitoring and discussing wellbeing/QOL in adolescents with T1D. Although the samples were taken from 4 self-selected clinics and individuals were not randomized to conditions as interventions were at a clinic-wide level, what is interesting from an Irish perspective (the study is from the Netherlands) is that the intervention was structured in a way that would fit well with the Irish model of care, where clinic appointments happen 3 times annually and are structured very similarly. While some interventions would be hard to imagine in the Irish context, this model of psychosocial monitoring and discussion could be implemented relatively easily.

Research that looks at Wellbeing from the caregivers perspective tends to take a general approach, looking at caring for children with chronic diseases and exploring strategies to improve wellbeing and coping for a general population (Williams, 2012). This is very useful but there is little that recognizes the very particular stresses T1D places on a caregiver. This is a vulnerable population. Robin Whittemore (2012) completed a review of 34 articles that addressed the experiences of parents of T1D’s and found varied levels of parental distress to be present in 10-74% of cases, with corresponding negative health implications for children. This is a broad range which probably reflects a broad scope of the criteria for inclusion in the review, none the less, the authors have called for improved screening and intervention strategies.

This study is interested in looking at subjective wellbeing (SWB) a concept that has grown out of the theoretical perspective of positive psychology (Diener, 1999; Strathem, 2010, Seligman, 2011). Positive psychology suggests that wellbeing encompasses two aspects: affect (positive and negative) and cognitive (satisfaction
Life satisfaction refers to a judgmental process, in which individuals assess the quality of their lives on the basis of their own unique set of criteria (Shin & Johnson, 1978). Diener’s Satisfaction with Life Scale has been used in much of the research on the satisfaction with life element of SWB. It is commonly used to measure the subjective quality of life of people experiencing serious health difficulties, though it is non-domain specific (Pavot, 1993). There have also been studies looking at moderating factors in particular populations - in 2003, Ergh, Hanks, Rapport & Coleman showed how social support promotes caregivers satisfaction with life and in 1988 Hickson, Housley and Boyle showed that internal locus of control improves satisfaction with life in the elderly.

Demographic Factors

Social disadvantage has a negative impact on diabetes management with research suggesting that this group will benefit least from therapeutic advances (Brown et al., 2004), although it’s interesting to note that this study took place in the United States where significant inequalities in healthcare are the norm. A different perspective suggests that intelligence seems to predict positive health outcomes regardless of SES for adults with T1D (Gottfredson and Deary), 2004, possibly due to the high levels of knowledge, literacy and numeracy required. This is likely to be reflected in caregiver populations. Pulgaron et al., (2014) showed that higher maths literacy of caregivers resulted in improved health outcomes in younger juvenile T1Ds, though it’s notable that 30% of the sample group were pump users and some models of pump will do the necessary computations, rendering maths literacy redundant. Also, it may be the case that higher mathematical literacy has developed out of the necessity to engage with complicated mathematics daily.
**Rationale**

Researchers have suggested that identifying and targeting psychosocial
distress could be an important element of treatment in diabetes related care (Cameron
intervention research included tailoring interventions to meet individual families’
unique needs and strengths”. This study would like to contribute to that conversation.
This population is increasing its numbers significantly year on year. It may be
possible to help them towards being better equipped to manage the many challenges
they face in caring for their T1D children through a series of well targeted
interventions. The research is clear in showing that well supported carers are of
greater help to their children and their children’s lives depend on it.

This study is interested to see if LOC beliefs in caregivers will have an effect
on health outcome at a one step remove. It has chosen to look at support from a
qualitative and quantitative perspective, to see what style of support each participant
desires and measuring how much of each style they are in receipt of and combining
these scores for a deeper analysis. The study will look for relationships between
differing support styles and successful management of the condition by correlating
with the HbA1c biomarker. Researchers have chosen to look at wellbeing using
Diener’s Satisfaction with Life Scale as it reflects conscious values and goals, giving
a longer term perspective than affect, which tends to reflect the short term (Pavot,
1991). It will look to use educational achievement as a partial proxy for SES and
intelligence, while recognizing that there are many confounding factors at play.
Hypotheses

Hypothesis 1: There will be a significant difference between full use, partial use and no use technology groups in HbA1c results.

Hypothesis 2: There will be a significant difference between levels of educational achievement groups in HbA1c results.

Hypothesis 3: There will be a significant difference between levels of educational achievement groups in locus of control beliefs.

Hypothesis 4: There will be a significant relationship between locus of control beliefs and HbA1c results.

Hypothesis 5: There will be a significant relationship between desired plus experienced emotional, informational and practical support and HbA1c results.

Hypothesis 6: There will be a significant relationship between number of hospital contacts and HbA1c results.

Hypothesis 7: There will be a significant relationship between locus of control beliefs and satisfaction with life scores.

Hypothesis 8: There will be a significant relationship between perceived social support (emotional/practical/informational together) and satisfaction with life scores.

Hypothesis 9: There will be a significant relationship between feeling understood and satisfaction with life scores.
Methods

Participants

This study used purposive sampling, drawing self-selecting participants from the population of parents and caregivers for children aged 1 to 18 years who have been diagnosed with and are in treatment for Type 1 Diabetes. They were accessed through a post on a closed Facebook support group page, which linked to a survey. To achieve power to detect a medium effect at a .05 alpha, a sample size of 85 was required (Cohen, 1992). There were 96 respondents. A number were eliminated due to incomplete surveys and in one case where a number of identical surveys were completed. The final number was 89.

Of the 88 participants who identified their gender 11.4% (10) were male and 88.6% (78) were female. They ranged in age from 27 to 58, with a mean age of 42.59. On highest educational achievements, 18% (16) recorded as school leavers, 41% (36) recorded FETEC or ‘other’, 41% (36) indicated that they were graduates. Their children’s age on diagnosis ranged from 1 to 17 years, with a mean 6.94 years. Participants were given the opportunity to email their child’s name to enter a draw for a toy or sports shop voucher. 86.5% (77) participants availed of this offer.

Design

This was a mixed methods study, using both quantitative and qualitative approaches. Hypotheses 1-3 used a cross-sectional design with technology/levels of education as the predictor variables and HbA1c/locus of control beliefs as the criteria variables. Hypotheses 4-6 used a correlational design with locus of control beliefs/experienced plus desired social support/hospital contacts as the predictor
variables and HbA1c as the criterion variable. Hypotheses 7-9 used a correlational design with locus of control/feeling understood/perceived social support as predictor variables and satisfaction with life as the criterion variable. The qualitative piece used a self-report questionnaire.

Materials

An introductory and explanatory paragraph was posted on a Facebook support group page for parents of juvenile Type 1 diabetics, it included a link. Following the link led to a questionnaire that was hosted on Google drive. The questionnaire included six sections (Appendix I):

Section 1. Demographics.

This included some general demographic questions; gender, age and educational level as well as some other questions specific to the population; age when diagnosed, years since diagnosis, method of blood monitoring and method of insulin delivery, how much contact they have had with their diabetic care team in the hospital they attend and latest known HbA1c results.

Section 2. Support.

This comprised a series of 8 questions intended to measure perceptions of experienced and desired emotional, medical/informational and practical support. Questions 1, 3 and 5 asked respondents to indicate on a 7 point scale (from 1 = no support to 7 = extremely well supported) how well they felt supported for each kind of support. For example, question 1 asked “how much emotional support do you feel you have”. Questions 2, 4 and 6 asked how important emotional,
medical/informational and practical support were to them. A 7 point scale was used (from 1 = not important at all to 7 = extremely important). For example, “how important is practical support to you?”. Number 7 was short-answer qualitative question which asked what they felt was their biggest source of support. Finally, question 8 asked respondents to indicate on a 7 point scale the degree to which they feel their social supports understand what they are dealing with. This survey was created by the researchers so reliability was analysed after data was collected using Cronbach’s alpha. This was computed to be 0.56. An alpha of 0.7 or greater would be preferable.

Section 3. Rotter’s Locus of Control Scale (Rotter, 1966).

This scale is a measure of control beliefs (Appendix II). It is a 29 item scale. It was felt that in order to keep the time taken to fill out the questionnaire under ten minutes, reducing the scale down to 10 items was desirable. Irrelevant items (ie, pertaining to student life) were removed first and other items were categorized by theme (neutral, politics, luck, work related, social). Items were removed in equal numbers across the themes. Instructions were included which asked respondents to “select the one answer from a pair of alternatives labelled A. or B. which you more strongly believe to be the case as far as you’re concerned at this moment”. For example; A. Heredity plays the major role in determining one’s personality or B. It is one’s experiences in life which determine what they’re like. Scoring; neutral items were not scored and other items were scored 0 if they indicated an internal locus of control and scored 1 if they indicated an external locus of control. The scores were totaled with higher scored indicative of external control beliefs and lower scores indicative of internal control beliefs. Reliability: Retest reliability estimates for
Rotter’s Locus of Control Scale ranged between 0.49 and 0.83 (Rotter, 1966). Validity studies with the Marlowe-Crowne Social Desirability Scale ranged between $r = -0.41$ and $r = -0.12$ (Rotter, 1966). As this scale had been adapted by the researchers Cronbach’s alpha was calculated after data had been collected to establish reliability. The alpha was 0.59. This was deemed to be adequate, though an alpha of 0.7 or greater would be preferable.

Section 4. Satisfaction with Life Scale (Diener, 1985).

This scale measures satisfaction with life, which is a measure of the cognitive aspect of wellbeing (Appendix III), referring to the conscious judgements made by individuals reflecting their own values and goals (Diener, 2009). This measure has five items. Each item presents a statement i.e., “In most ways my life is close to my ideal”. Respondents are asked to indicate their level of agreement on a seven point scale where 1 = strongly disagree and 7 = strongly agree. Scoring involved summing the scaled scores. A neutral score is 20, higher scores indicate better levels of satisfaction with life and lower scores will indicate the opposite. With most groups, means will fall between 23 and 28 (Pavot and Diener, 1993). Reliability was established with an alpha of 0.87 (Deiner, 1985) and 0.85 (Pavot, 1991) and construct validity was shown through convergent scores with other similar measures such as the Fordyce Global Scale ($r = 0.82$). It was shown to have significant negative correlations with measures of distress, i.e., $r = -0.72$ with Beck Depression Inventory (Pavot and Diener, 1993).
Section 5: Qualitative Question 2.

This section presented an open-ended qualitative question: What do you think would be helpful to you in managing your child’s diabetes?

Section 6: Debrief and Thank You.

The debriefing page including contacts for aftercare both general, such as parentlink and specific to the population, such as the family support network at childrenwithdiabetes.com. (Appendix I)

Procedure

The study was approved by the Dublin Business School ethics committee. Participants were drawn from a closed internet support group for parents and caregivers for juveniles and adolescents with Type 1 diabetes. The researcher made contact with the administrator of the group and it was agreed that the researcher would post on the page. A message explaining the study was posted along with a link to the survey, which was hosted on google drive. The participants were a self-selecting group who followed that link. There was a brief introduction, introducing the researcher and explaining that the research is part of a thesis project for a Higher Diploma in Psychology at the Dublin Business School and was to be submitted for examination. It was made clear that anonymity was assured and that the data would be kept securely and destroyed after one year. It was explained that the anonymous nature of the process would make it impossible for a response to be withdrawn after the submit button had been pressed. As such, it was assumed that consent was implied by pressing the submit button. An email address was included for respondents to
make contact with the researcher if they would like to register their interest in receiving further information about the study.

The questionnaire included 33 items in total, taking between 7 and 10 minutes to complete. When the questionnaire was complete participants were asked to press the submit button and were then invited to email the researchers with the name of their Type 1 dependent to be entered into a draw for a toy/sports shop voucher. A thank you message and a debriefing sheet was included (Appendix I). The data was downloaded from google drive onto an excel spreadsheet. This was loaded into SPSS (version 24) where data analysis took place. The qualitative data was downloaded into a word document and thematic analysis was done by hand.
Results

*Descriptive Statistics.*

Research data are presented below. Table 1 contains descriptive statistics for the demographical information relevant to population.

Table 1. Descriptive Statistics on Demographical Information

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Minimum Possible</th>
<th>Maximum Possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years Since Diagnosis:</td>
<td>4.38</td>
<td>3.214</td>
<td>1</td>
<td>13</td>
</tr>
<tr>
<td>Age on Diagnosis:</td>
<td>6.94</td>
<td>4.375</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>Contacts with Hospital:</td>
<td>13.7</td>
<td>15.078</td>
<td>1</td>
<td>70</td>
</tr>
</tbody>
</table>

Table 2 contains descriptive statistics on the predictor variables and Table 3 contains descriptive statistics on criterion variables. The assumption of normality was checked using histograms and Lavene’s tests, it was met for all the data.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Minimum Possible</th>
<th>Maximum Possible</th>
</tr>
</thead>
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<td>Emotional Support:</td>
<td>3.4</td>
<td>1.887</td>
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<tr>
<td>Importance of Emotional Support:</td>
<td>6.01</td>
<td>1.133</td>
<td>2</td>
<td>7</td>
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<tr>
<td>Informational Support:</td>
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<td>1</td>
<td>7</td>
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<tr>
<td>Importance of Informational Support:</td>
<td>6.65</td>
<td>0.693</td>
<td>3</td>
<td>7</td>
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<td>Practical Support:</td>
<td>3.75</td>
<td>1.796</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Importance of Practical Support:</td>
<td>5.91</td>
<td>1.520</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Feeling Understood:</td>
<td>3.1</td>
<td>1.759</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Locus of Control:</td>
<td>4.2439</td>
<td>1.82593</td>
<td>1</td>
<td>8</td>
</tr>
</tbody>
</table>
Table 3. Descriptive Statistics on Criteria Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Minimum</th>
<th>Maximum Possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>HbA1c:</td>
<td>7.875</td>
<td>1.01</td>
<td>5.3</td>
<td>12.5</td>
</tr>
<tr>
<td>Satisfaction with Life:</td>
<td>23.45</td>
<td>6.18</td>
<td>10</td>
<td>35</td>
</tr>
</tbody>
</table>

Table 4 contains frequency statistics for technological and manual treatment options. Figure 1 illustrates how these group into all technology, no technology and mixed groups.

Table 4. Frequency Statistics for Treatment Regimen:

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Valid Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitor Blood Sugars</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continuous Monitor</td>
<td>6</td>
<td>6.7</td>
</tr>
<tr>
<td>Finger Prick</td>
<td>57</td>
<td>64</td>
</tr>
<tr>
<td>Sensor</td>
<td>26</td>
<td>29.2</td>
</tr>
<tr>
<td>Insulin Administration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pen</td>
<td>44</td>
<td>49.4</td>
</tr>
<tr>
<td>Pump</td>
<td>41</td>
<td>46.1</td>
</tr>
<tr>
<td>Syringe</td>
<td>4</td>
<td>4.5</td>
</tr>
</tbody>
</table>
Figure 1. Technology, non-technology and mixed technology users.

*Qualitative analysis*

*Inferential Statistics.*

**Hypothesis 1:** There will be a significant difference between all technology, no technology and mixed technology groups in HbA1c results. A one way between groups ANOVA was computed to look at HbA1c differences between those who use technology in their treatment regimen, those who do not and those who use a mixed approach. A one-way analysis of variance showed that the HbA1c results differed significantly between the three groups ($F(2, 84) = 5.09, p = .008$). A Bonferroni post hoc analysis highlighted that the significant difference lay between the all technology and the no technology groups (Mean difference = .95, $p = .006$, CI [95%] .22, 1.68).

Thus highlighting that the use of technological innovations for blood sugar testing and insulin delivery has a significantly positive effect on disease management in juvenile type 1 diabetics.

**Hypothesis 2.** There will be a significant difference between levels of educational achievement groups in HbA1c results. A one-way analysis of variance showed that the HbA1c results differed significantly between the three levels of
educational achievement groups (F(2, 84) = 5.41, p = .006). A Bonferroni post hoc analysis showed that the significant difference lay between the groups of highest and lowest educational achievement (Mean difference = .95, p = .006, CI [95%] .23, 1.67). Thus suggesting that higher levels of educational achievement have a significantly positive effect on disease management in caregivers for juvenile type 1 diabetics.

Hypothesis 3. There will be a significant difference between levels of educational achievement groups in locus of control beliefs. A one-way analysis of variance showed that the HbA1c results differed significantly between the three level of educational achievement groups (F(2, 86) = 4.45, p = 0.015). A Bonferroni post hoc analysis showed that the significant difference lay between the groups of middle and highest educational achievement (Mean difference = .11, p = .030, CI[95%] .01, .21). Thus suggesting that third levels educational achievement has a significantly positive effect on locus of control.
Table 5. Correlation matrix for predictor and criterion variables.

<table>
<thead>
<tr>
<th></th>
<th>HbA1c</th>
<th>Satisfaction with Life</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Locus of Control:</strong></td>
<td>.296*</td>
<td>-.413**</td>
</tr>
<tr>
<td><strong>Emotional Support:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plus Importance:</td>
<td>-.131</td>
<td>.067</td>
</tr>
<tr>
<td><strong>Informational:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support Plus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance:</td>
<td>-.288**</td>
<td>.203</td>
</tr>
<tr>
<td><strong>Practical Support:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plus Importance:</td>
<td>-.301**</td>
<td>.159</td>
</tr>
<tr>
<td><strong>Contacts with:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital:</td>
<td>-.038</td>
<td>.144</td>
</tr>
<tr>
<td><strong>Feeling:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understood:</td>
<td>-.135</td>
<td>.278**</td>
</tr>
<tr>
<td>Emotional, Informational and Practical Support:</td>
<td>-.135</td>
<td>.276**</td>
</tr>
</tbody>
</table>

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
Hypotheses 4, 5 and 6: There will be a significant relationship between locus of control beliefs/experienced plus desired emotional, practical and informational support/number of hospital contacts and HbA1c results. Significant relationships between locus of control, informational support (experienced plus desired) and practical support (experienced plus desired) with the biomarker for control, HbA1c are seen in Table 5. It was found that where LOC score increases, which indicates a externally perceived locus of control, that HbA1c values increase also, suggesting that an externally perceived locus of control has an association with reduced success in managing of blood sugars. Informational and practical support plus their perceived importance were found also to have a negatively significant relationship with HbA1c values. As need for and experience of informational and practical supports increase so does successful management of disease.

A Multiple regression was used, to test whether these three variables would predict HbA1c results. The results of the regression indicated that the predictors explained 20% of variance (R^2 = .20, R^2 adj. = .17, \(F(3,82) = 6.76, p < .001\)). It was found that locus of control significantly predicted better diabetes management (\(\beta = .24, p = .018\)) as did experienced plus need for practical support (\(\beta = -.24, p = .018\)).

Hypotheses 7, 8 and 9: There will be a significant relationship between locus of control beliefs/perceived social support/feeling understood and satisfaction with life scores. In a correlations matrix (Table 5) it is shown that a negative significant correlation was found between locus of control and satisfaction with life. As locus of control scores increase to indicate externally perceived control which is associated with lower satisfaction with life. Positive significant relationships were found between feeling understood and perceived social support (emotional, informational and practical together) and satisfaction with life.
Subsequently, a multiple regression was used to test whether these three variables would predict satisfaction with life scores. The results of the regression indicated that the predictors explained 23% of variance ($R^2 = .23$, $R^2_{adj} = .20$, $F(3, 81) = 8.14$, $p < .001$). It was found that locus of control significantly predicted satisfaction with life ($β = -.35$, $p = .001$).

**Qualitative Analysis**

Two qualitative questions were included. Question 1 elicited responses from 98.9% of respondents and Question 2 elicited responses from 95.5% of respondents.

**Qualitative question 1:** Who or what is your biggest source of support?

This resulted in responses of a categorical nature. From 88 respondents there were 113 responses in total. These were coded into 25 categories: ie, partner, husband, nurses. A word cloud was created to represent this data (Figure 2).

![Figure 2: Who or what is your biggest source of support?](image)
A number of categorical themes emerged from the analysis of these codes. Six thematic headings were chosen to fit the data (Figure 3):

1. **Peers**: Other people who are also caring for a child with T1D ie, family members with T1D and other parents caring for juveniles with T1 diabetes.

2. **Family**: Any relative excluding partners, i.e., sisters, grandparents and other children.

3. **Practical**: Responses that referred to tangible assistance with daily problems in managing the condition, i.e., school teacher, special needs assistant.

4. **Informational**: Responses that referred to medical assistance, i.e., clinic, nurses, doctors.

5. **Partner**: Includes ex partners.

6. **None**: Where participant felt they had no strong support at all.

Figure 3. Who or what is your biggest source of support?
Qualitative question 2: What do you think would be helpful to you in managing your child’s diabetes?

85 participants responded to the question, which yielded 144 descriptive responses. Taking an inductive approach, the responses were coded at semantic level, which resulted in 60 initial codes. The coding was repeated blindly a second time and it was found that the second instance tallied exactly with the first instance. The codes were further analyzed and four themes emerged with fourteen sub-themes. This model is illustrated in Figure 4 below.

Themes for model.

1. Access to technology: This theme accounts for all responses that indicated a desire for more access to some or all of the technological tools, that have become available recently, for used in the management of T1D. These would include insulin pumps, continuous glucose monitors and blood sugar sensors. An example would be respondent 12 “I feel like the libra sensor would aid immensely…I can’t afford to self-fund one.” Respondent 24 “availability of a pump and support for it locally”.

2. Improved hospital services: This theme corresponds to a large degree to informational support. It includes all responses that indicate a need for further support from medical and hospital services. An example would be respondent 50 who wants “more help from the hospital” and respondent 3 “more access to expert care” and respondent 75 says “more team members as nurses very busy”.

3. Need for practical help. This theme refers to those responses that singled out a need for practical and tangible assistance with the daily struggles involved. This would cover a broad range of issues from improved support in the classroom to information
on entitlements. Respondent 17 “the school care of type 1 children needs to be overhauled” and respondent 55 would like “time off work…put the time into helping her keep well”.

4. *Improved emotional supports:* This theme brings together all responses that indicated a need for more supports of an emotional and psychological nature. This includes, counselling, peer to peer support and understanding. Respondent 14 “somewhere that parents can go for maybe coping skills, counseling…hit me like a ton of bricks and I haven’t been able to lift myself back up since”, respondent 44 “support groups and access to a child psychologist”. Respondents 6, 21, 36 “emotional support”. 
Figure 4. Qualitative question 2: What do you think would be helpful to you in managing your child’s diabetes?*

*due to rounding up percentages do not add up to 100
Discussion

Aims: This object of this research was to look at caregivers for juvenile type 1 diabetics from a biopsycosocial perspective. Treatment protocols have changed significantly over the last 10 years, due to the arrival of some game-changing and very welcome technological advances. These new devices are complex and significant training is needed as well as ongoing medical and informational support. Hospital resources are necessarily being diverted towards helping people manage the significant challenges involved. This study asks if in the current climate of technological advances and cut backs in health funding, we are losing sight of the psychosocial aspects of caring for a juvenile with type 1 diabetes and perhaps not fully appreciating the increased caregiving burden these advances sometimes bring with them.

Quantitative Analysis.

Hypothesis 1. Result from the study confirmed that more use of technology was shown to have significantly positive effects on HbA1c test results. This is in line with much of the research, such as the Plotnick et al. study in 2003, showing the positive metabolic effects of pump therapy.

Hypotheses 2 and 3 were looking at respondents from the point of view of educational levels achieved. The participants were divided into three groups. Group 1 had school-based qualifications, group 2 had FETEC based and other qualifications, group 3 were university graduates. H2 was interested in whether educational level would influence disease management, as reflected in differences between HbA1c scores. The hypothesis was confirmed. Significant differences were found between
group 1 (school) and group 3 (university). This is consistent with the previous findings (Gottfredson et al., 2004) that have shown that higher levels of educational achievement influence managing of treatment. Interestingly, Pulgaron’s study in 2014, showed that maths achievement was the greatest relevant skill factor. This is important as it is the easiest area to address with intervention.

Hypothesis 3 was interested in whether there were differences between the educational groups in their locus of control belief scores. Significant differences were found between the university group and the FETEC/other group. This confirms the hypothesis but is a little surprising. Wang et al. (2010) found that high internal locus of control was a predictor for academic achievement and the reverse, as such it would have been more in line with the research if the significant difference was found between groups 1 and 3. Table 2 shows that the means of groups 1 and 2 were very close, it could be that the group 2 ‘other’ categorization was too vague a descriptor and possibly respondents with no qualifications selected that option.

Hypotheses 4 and 5 postulated that there would be an association between the variables; locus of control belief, support (perceived plus desired) and blood sugar control as measured by HbA1c. Correlations between these predictors and HbA1c revealed significant relationships with locus of control belief, informational and practical support and the HbA1c criterion. Both of the hypotheses were accepted. A multiple regression showed that the predictors were responsible for 20% of variance, with significant prediction of better HbA1c results with lower scores in locus of control which corresponds to a more internal locus of control belief. This ties in with research in adults with medical conditions (Walker et al, 2012) and in adult T1Ds (Peyrot et al, 1994) but is a new finding for caregivers of juvenile T1Ds. It is
interesting to note that locus of control is a factor in health management at a one step remove.

Practical support (experienced plus desired) also predicted better diabetes management but informational did not. Practical support included tangible help such as babysitting and SNA assistance. This is not surprising, given the relentless nature of the day to day requirements (Streisland et al., 2005). It is surprising that informational support is not a good predictor as suggested by De Weerdt et al, it could be that this links to the findings in H6, where hospital contacts did not show an association with metabolic control. It may be that once a certain amount of training and informational support has been received it is better for health outcome to have the confidence to manage a certain amount of care alone. It may be that this finding is linked to the findings on locus of control, where high internal control beliefs – i.e., more problem solving behaviours (Wang et al., 2010), link to better illness management. Suggesting that the more a respondent relies on medical support, beyond a certain point, the more external their locus of control.

There was no correlation found between emotional support (experienced plus desired) and HbA1c. This was another surprising finding. It is in conflict with the majority of research in the area (Horton et al., 2001) and with the qualitative data on respondent wishes from this study. It could be that the combining of data for experienced with the data for desired emotional support was a factor. Of the three styles of support the emotional data showed highest discrepancy between desire for and experienced (Table 2). This discrepancy is clear also from the qualitative piece and is discussed later.
Hypothesis 6. No significant relationship was found with hospital contact so the null hypothesis could not be rejected. This is an interesting result as much previous research has supported this assertion (Davies et al, 2013). The data set contained in this study did show a considerable skew to the right. A second analysis was run with the outliers removed but no significant relationship was found again. This would possibly suggest that there is an optimum number of contacts with hospital beyond which point the number of contacts is more reflective of crises in illness management. It could be that the Yerkes-Dodson curve is relevant here (Teigen, 1994). This is an area that would benefit from further investigation where hospital contacts could be qualitatively defined as well as quantitatively.

Hypotheses 7, 8 and 9 postulated that there would be an association between the variables; locus of control belief (H7), perceived emotional, practical and informational support (3 styles together – H8), feeling understood (H9) and satisfaction with life scores. Correlations found significant associations between these three predictors and the satisfaction with life criterion. The null hypotheses were rejected. These positive correlations with support correspond with much previous research (Sarason et al, 1985; Ergh et al., 2003) and speak to the clear need for these aspects of the caregiver experience to be protected as we see that caregiver wellbeing correlates positively with diabetic metabolic control in children (Liiakopoulou et al., 2001). The correlation with locus of control was moderately negative. This shows that internal control predicts better satisfaction with life scores, this tallies with research in the general population, ie, Hickson et al. (1988) who linked locus of control with satisfaction with life in the elderly. It is interesting to see that it has relevance to this population also.
A multiple regression showed that the variables accounted for 23% of variance in satisfaction with life scores but only locus of control was a significant predictor. With support and feeling understood so strongly represented in the qualitative data, and multicollinearity ruled out it is possible that the regression suffers from singularity between these variables, as it is conceivable that feeling understood is overlapping somewhat with feeling supported.

**Qualitative Analysis**

**Question 1**: Who or what is your biggest source of support? The greatest source of support was partner (33.6%). Family was next at 25.9%. Given the Lewandowski et al., (2007) findings that close family support is linked to more positive caregiving experience in parents of T1Ds, it is worth noting that 41% are getting their main source of support outside of family - peers, informational and practical support, which were all reported evenly totaling to 36.3%. With another 4.3% reporting that they had no support at all, it appears that there is a need for caregivers to gain skills in finding, asking for and accepting help.

**Question 2**: What do you think would be helpful to you in managing your child’s diabetes? In analyzing the qualitative data the researchers found it important that context was taken account of. The technological developments previously referred to are effective but are very expensive, out of reach for most families. In Ireland, funded Insulin pump therapy is available but not yet to everybody. From the caregiver’s point of view there are issues around clarity of criteria to qualify and consistency across hospitals as not all hospitals have the resources or the staff to provide and oversee pump therapy. The blood-sugar sensors are relatively new to the market. The HSE is in negotiations to have them included on the long-term illness
card (publicly funded). Some families are self-funding, but it is expensive. This has created an atmosphere where discussion on the topic dominates support group networks. For this reason the researchers were expecting technology to play a very strong role in the model that emerged.

Four themes emerged. Two themes dominated. Desire for ‘access to technology’ (37.8%) as expected but also, at 42% desire for ‘increased emotional support’. This was surprising given the context described above. The sub-themes for emotional support showed desire for increased availability of psychological services and more support groups; respondent 14 “somewhere parents can go for…counseling” respondent 35 “more active support groups” and respondent 16 “access to support groups of other families with diabetes”

Two thirds of the emotional support responses (over a quarter of total responses) expressed a need for emotional understanding. Many respondents expressed this as a desire for more public education about T1D so that the people in their lives would be more understanding. It is a common experience for caregivers to feel isolated (Smaldone et al., 2011) and this is clearly seen in the responses of this sample. Respondent 5; “more help from family instead of the dismissive attitude they have towards it”, respondent 37; “…very few realize the work behind keeping our child healthy” and respondent 59 “it’s not an illness that’s taken seriously”. Many of the responses categorized in this theme have been summed up in the words of respondent 79 “I’m not looking for pity just some understanding”.

The third theme represented almost 15% of responses, where people expressed a need for ‘improved hospital services’; respondent 35 “more frequent visits to the consultants” and respondent 86 “telephone contact with nurses to be easier”. Also, many felt a need for improved education and training. Respondent 54 “If the children
get more education on diabetes, so they can understand the risks of the highs and lows”. The fourth theme illustrates how 10% feel that they need tangible or ‘practical help’ such as improved special educational needs services; respondent 13 “my daughter has had a few awful experiences in school” or respondent 82 who needs “time off work”. This is indicative of the pressures that the system is under, given the cutbacks in educational supports over the last number of years as well as the large year on year increases in new diagnoses, services are strained and this is clearly having a psychological impact.

Interventions to address all these issues do not have to be complicated or expensive. This is discussed later.

Strengths and Weaknesses of this study

A primary strength of this study was that it provided some localized research. There are not many studies that look at this population in Ireland. Studies from other countries are of course valuable but each country’s health services take different approaches to delivering health care around T1D (i.e., many will provide care through primary care rather than hospital centers and in some countries private healthcare dominates). Secondly, this study joins in the conversation at a time when there are many changes afoot in care protocols, diverting resources to the support of technological advances. Thirdly, the study recognizes the increased, though welcome, caregiver burden the technology brings with it. Lastly, by using a mixed methods approach it uses strives to bring nomothetic and ideographic data together in a complementary way.

The study has a number of weaknesses, firstly, it uses self-report questionnaires, it is recognized that respondents may consciously distort their
responses if motivated to do so. Also, as the survey was posted on a Facebook support group page, the sample was self-selecting, the researchers were concerned that with this population it may present a particular problem. Caregivers for T1 are constantly under scrutiny, from doctors, nurses and others, the feeling that the day to day responsibility for the health of their child is completely dependent on themselves and the quality of their care, rests very heavily on a parent's shoulders. This invisible burden is why this is a very vulnerable population and why it was felt that there might be a response bias toward respondents who have achieved more positive results. The study by Gillibrand et al., in 2006 experienced a response rate of only 38% on a self-report questionnaire. For this study it was thought that offering an opportunity for each T1 child to participate in a draw for a voucher after completing the survey may dilute that effect, possibly acting as a distraction. It is also noted that the mean HbA1c for the sample was 7.8. This is considerably less than the mean of 8.4 reported in Hoey’s very large international study (2001). It could be that this reflects the use of more recent, improved insulin products and technology or it could be that the Facebook support group users are more actively engaged in managing the illness as evidenced by their use of the support network. So, while the findings are interesting, it is difficult to know if they are fully representative of the population as a whole. Lastly, the questionnaires were adapted and developed to keep the survey comfortably under 10 minutes. This resulted in weakened Cronbach’s alphas. On balance, it was probably better to have more information in less time, but the researchers are cognizant that this could have had an impact on data analysis.
Future Research

It would be interesting to repeat this survey with a larger population. Ideally, they would be accessed through diabetic clinics, throughout the country. With a larger population, stronger exclusion criteria could be applied, for example - years since diagnosis and age - giving stronger data. More emphasis could be put on technology users versus non-technology users in further research, this study has 65.5% (Fig. 1) using some technology, this number is only going to go up and that will have implications. This study suggests that support needs to be looked at further, using stronger instruments, perhaps to see if the Yerkes-Dodson curve is a helpful model and if this is the case, how best to determine the critical turning point in individuals.. It may be interesting to look at the kind of supports individuals would choose, many do not respond to internet-based networks (Channon, 2016). Other variables could be looked at also; depression, anxiety, health locus of control. Research of a quasi-experimental nature could be used to explore the usefulness of interventions. Lastly, more qualitative research of a consultative kind, asking what ideas caregivers might have for changes in practices or psychosocial supports that would benefit them and aid towards an improved health outcome for their children.

Interventions and Applications

There are a number or areas that could be looked at in terms of applying the information gleaned from this study and working towards addressing and providing some relief to the caregiver burden. Location of control came out reasonably strongly in the data, it’s linked to better disease management for the children, wellbeing in the caregiver and presents most strongly in the university educated group. Interventions here could be relatively easily implemented on a group and/or individual basis and
could begin on diagnosis. These might include, teaching problems solving skills and coping skills training, as well as education and training around caregiving and managing T1D. In order to boost confidence to manage the mathematics involved, the individuals could be invited to join math skill classes targeted at the problems they will encounter. Interventions to target emotional support could include facilitating face to face peer support groups, facilitating networking opportunities, organizing separate events on a regular basis for caregivers, teens and children. An example of this might be a monthly drop-in coffee morning, possibly in the diabetic unit with a diabetic nurse available for casual consultation. The researchers realize that these nurses are working to maximum capacity but suggest that more use might be made of caregiver volunteers, given that many have had to give up work to care for their child (Streisland et al., 2005).

Training and education could be improved with some directed toward the children themselves, in an age appropriate way. Practical support could be provided in many ways, such as instituting a call queuing system for nurse clinics, which would have a significant impact on day-to-day anxiety or providing some informational resources about entitlements. Training of special educational needs assistants could be addressed as inconsistencies in care, documented on the support webpages, clearly have significant impacts on wellbeing for the caregiver. In addition, it also impacts on the child’s ability to adapt to their circumstances (Kovacs et al., 1997). Lastly, a factor that feeds into wellbeing, which came across strongly in quantitative and qualitative data, was a strong need to be understood. Interventions targeting this could look to assertiveness training, teaching caregivers how to ask for and accept help, as well as teaching strategies to communicate their invisible daily struggles; respondent 15 “…never get a full nights sleep”, in such a way that they feel understood. As the
study (2001) by Liakopoulou et al. study showed, a happy parent correlates positively with a healthy child.

**Conclusion**

At a time when the population of juvenile T1Ds is growing at a fast rate and the children are being diagnosed younger, much work is being done in medical research to develop technologies, both biochemical and technological, that aid in the management of the illness and help towards better control, hopefully limiting the associated health implications for these children in later life. A big part of this picture is making sure that the children’s caregivers are supported in giving the kind of care that also supports a positive health outcome for the children. This study, following many others in the literature, has found that there are links between psychosocial aspects of caring and health outcome. It has asked the caregivers directly what kind of support would help them do their job best. The research has shown that caregivers feel that they could be better supported and quantitative and qualitative data analysis has shown where some of these supports could be targeted – locus of control, instrumental, informational and emotional support and feeling understood. Crucially, the application of psychosocial insights should be understood as cost-effective interventions that need to be considered against the costs involved in managing the medical complications that are associated with sub-optimal care.
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Appendices

Appendix 1. Survey for caregivers of juvenile type 1 diabetics

SURVEY OF CARERS FOR JUVENILE T1 DIABETICS

Thank you for following the link to this questionnaire.

I am studying towards a qualification in psychology (HDip) at DBS. As part of my course work I am doing a study around supporting parents of children with Type 1 Diabetes. This study will be submitted for examination.

I would like to assure you that absolute anonymity and confidentiality is assured. Once the link has been accessed there is no connection to any identifying information and responses cannot be attributed to any one individual. For this reason, it will not be possible to withdraw from the study after the questionnaire has been submitted. Direct quotes may be used in anonymity. All data will be kept securely and will be destroyed after one year.

If you would like any further information about the research please feel free to contact me at xxxxxx@mydbs.ie

Thank you very much for taking the time to complete this questionnaire, it should not take longer than 10 minutes.

Once I have reached 100 participants I will be turning off the questionnaire and holding a draw to pick two amazing T1 kids to each receive a voucher for €50 to use in Smyths toys, Lifestyle sports or Topshop. Just send your childs name to the email address at the end of the survey to enter, please remember to press SUBMIT first.

DEMOGRAPHIC INFORMATION

1. Gender of parent/guardian filling in questionnaire:

   Male/Female.

2. Age of parent/guardian

3. What is the highest level of education you have received to date:

   Junior Certificate
Leaving Certificate
FETEC Award
Primary Degree
Postgraduate Degree
Other

4. What was your child’s most recent HbA1c (approx.)?

5. What age was your child on diagnosis?

6. How many years is it since your child was diagnosed with T1 Diabetes?

7. Approximately how many contacts have you had with your hospital diabetic team over the last year (including phone contact and consultant’s appointments)?

8. How do you monitor blood sugar?
   Continuous Glucose Monitoring
   Finger Prick
   Sensor

9. How do you administer insulin?
   Insulin Pen
   Insulin Pump
   Syringe

**SURVEY 1**

Q. 1: How much emotional support do you feel that you have?

(Not supported at all) 1 - 7 (Extremely well supported)

Q. 2: How important is emotional support to you?

(Not important at all) 1 – 7 (Extremely important)

Q. 3: How much medical and informational support do you feel that you have?
Q. 4: How important is medical and informational support to you?
(Not important at all) 1 – 7 (Extremely important)

Q. 5: How much practical support do you feel that you get? (i.e. SNA, babysitting)
(Not supported at all) 1 – 7 (Extremely well supported)

Q. 6: How important is medical and informational support to you?
(Not important at all) 1 – 7 (Extremely important)

**SURVEY 2**

In this questionnaire each item consists of a pair of alternatives labeled a. or b. Please select the one statement of each pair which you more strongly believe to be the case as far as you’re concerned at this moment. There are no right or wrong answers. Don’t spend too much time on any one item but do find an answer for every choice.

Q. 1.
a. Many of the unhappy things in people’s lives are partly due to bad luck.
b. People’s misfortunes result from the mistakes they make.

Q. 2.
a. In the long run people get the respect they deserve in this world.
b. Unfortunately, an individual’s worth often passes unrecognized no matter how hard he tries.

Q. 3.
a. Without the right breaks one cannot be an effective leader.
b. Capable people who fail to become leaders have not taken advantage of their opportunities.

Q. 4.
a. Heredity plays the major role in determining one’s personality.
b. It is one’s experiences in life which determine what they’re like.

Q. 5.
a. When I make plans, I am almost certain that I can make them work.
b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.
Q. 6.
a. There are certain people who are just no good.
b. There is some good in everybody.

Q. 7.
a. In my case getting what I want has little or nothing to do with luck.
b. Many times we might just as well decide what to do by flipping a coin.

Q. 8.
a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
b. Getting people to do the right thing depends upon ability. Luck has little to do with it.

Q. 9.
a. It is hard to know whether or not a person really likes you.
b. How many friends you have depends upon how nice a person you are.

Q. 10.
a. With enough effort we can wipe out political corruption.
b. It is difficult for people to have much control over the things politicians do in office.

SURVEY 3

Below are five statements that you many agree or disagree with. Using the 1-7 scale please indicate your level of agreement. Please be open and honest in your responding.

Q. 1: In most ways my life is close to my ideal.
(Strongly disagree) 1 – 7 (Strongly agree)

Q. 2: The conditions of my life are excellent.
(Strongly disagree) 1 – 7 (Strongly agree)

Q. 3: I am satisfied with my life.
(Strongly disagree) 1 – 7 (Strongly agree)

Q. 4: So far I have gotten the important things I want in life.
(Strongly disagree) 1 – 7 (Strongly agree)

Q. 5: If I could live my life over, I would change almost nothing.
(Strongly disagree) 1 – 7 (Strongly agree)
...AND LASTLY:

Q. 1: What do you thing would be helpful to you in managing your child's diabetes?

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE.

I would be very happy to share the results of the study with you when it is complete. If you are interested please e-mail me with your contact details at: 10324454@mydbs.ie

If you find that the questionnaire has raised feelings, questions or issues for you, which you may want to discuss further, please use the following contacts:

Diabetes.ie Helpline: 1850 909 909
Parentline.ie Helpline: 1890 927 277
The Samaritans: 1850 60 90 60
www.dublinsamaritans.ie
Aware: 1890 303 302
www.aware.ie

Useful online resources include:
Childrenwithdiabetes.com – Family support network
Diabetesresearch.org – Parents empowering parents (PEP squad)
Joslin.org – Discussion portals, online diabetes classes, general information

As a small thank you I’d like to offer you a chance to win a prize for your T1. Please email your child’s name to: xxxxxx@mydbs.ie to enter your T1 in a draw for two €50 vouchers for Smyths Toyshop, Lifestyle Sports or Topshop.

Please remember to press the SUBMIT button.

Have a lovely day.
Appendix 2. Rotter's Locus of Control Scale

This is a questionnaire to find out the way in which certain important events in our society affect different people. Each item consists of a pair of alternatives lettered a or b. Please select the one statement of each pair (and only one) which you more strongly believe to be the case as far as you're concerned. Be sure to select the one you actually believe to be more true rather than the one you think you should choose or the one you would like to be true. This is a measure of personal belief: obviously there are no right or wrong answers.

Please answer these items carefully but do not spend too much time on any one item. Be sure to find an answer for every choice. In some instances you may discover that you believe both statements or neither one. In such cases, be sure to select the one you more strongly believe to be the case as far as you're concerned. Also try to respond to each item independently when making your choice; do not be influenced by your previous choices.

<table>
<thead>
<tr>
<th></th>
<th>a.</th>
<th>b.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>a. Children get into trouble because their parents punish them too much.</td>
<td>b. The trouble with most children nowadays is that their parents are too easy with them.</td>
</tr>
<tr>
<td>2.</td>
<td>a. Many of the unhappy things in people's lives are partly due to bad luck.</td>
<td>b. People's misfortunes result from the mistakes they make.</td>
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<tr>
<td>3.</td>
<td>a. One of the major reasons why we have wars is because people don't take enough interest in politics.</td>
<td>b. There will always be wars, no matter how hard people try to prevent them.</td>
</tr>
<tr>
<td>4.</td>
<td>a. In the long run people get the respect they deserve in this world.</td>
<td>b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.</td>
</tr>
<tr>
<td>5.</td>
<td>a. The idea that teachers are unfair to students is nonsense.</td>
<td>b. Most students don't realize the extent to which their grades are influenced by accidental happenings.</td>
</tr>
<tr>
<td>6.</td>
<td>a. Without the right breaks one cannot be an effective leader.</td>
<td>b. Capable people who fail to become leaders have not taken advantage of their opportunities.</td>
</tr>
<tr>
<td>7.</td>
<td>a. No matter how hard you try some people just don't like you.</td>
<td>b. People who can't get others to like them don't understand how to get along with others.</td>
</tr>
<tr>
<td>8.</td>
<td>a. Heredity plays the major role in determining one's personality.</td>
<td>b. It is one's experiences in life which determine what they're like.</td>
</tr>
<tr>
<td>9.</td>
<td>a. I have often found that what is going to happen will happen.</td>
<td>b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.</td>
</tr>
<tr>
<td>10.</td>
<td>a. In the case of the well prepared student there is rarely if ever such a thing as an unfair test.</td>
<td>b. Many times exam questions tend to be so unrelated to course work that studying in really useless.</td>
</tr>
<tr>
<td>11.</td>
<td>a. Becoming a success is a matter of hard work, luck has little or no effect.</td>
<td>b. Getting a good job depends mainly on being in the right place at the right time.</td>
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<tr>
<td>12. a. The average citizen can have an influence in government decisions.</td>
<td>b. This world is run by the few people in power, and there is not much the little guy can do about it.</td>
<td></td>
</tr>
<tr>
<td>13. a. When I make plans, I am almost certain that I can make them work.</td>
<td>b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.</td>
<td></td>
</tr>
<tr>
<td>14. a. There are certain people who are just no good.</td>
<td>b. There is some good in everybody.</td>
<td></td>
</tr>
<tr>
<td>15. a. In my case getting what I want has little or nothing to do with luck.</td>
<td>b. Many times we might just as well decide what to do by flipping a coin.</td>
<td></td>
</tr>
<tr>
<td>16. a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.</td>
<td>b. Getting people to do the right thing depends upon ability. Luck has little or nothing to do with it.</td>
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</tr>
<tr>
<td>17. a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.</td>
<td>b. By taking an active part in political and social affairs the people can control world events.</td>
<td></td>
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<tr>
<td>18. a. Most people don't realize the extent to which their lives are controlled by accidental happenings.</td>
<td>b. There really is no such thing as &quot;luck.&quot;</td>
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<tr>
<td>19. a. One should always be willing to admit mistakes.</td>
<td>b. It is usually best to cover up one's mistakes.</td>
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<tr>
<td>20. a. It is hard to know whether or not a person really likes you.</td>
<td>b. How many friends you have depends upon how nice a person you are.</td>
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</tr>
<tr>
<td>21. a. In the long run the bad things that happen to us are balanced by the good ones.</td>
<td>b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.</td>
<td></td>
</tr>
<tr>
<td>22. a. With enough effort we can wipe out political corruption.</td>
<td>b. It is difficult for people to have much control over the things politicians do in office.</td>
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<tr>
<td>23. a. Sometimes I can't understand how teachers arrive at the grades they give.</td>
<td>b. There is a direct connection between how hard I study and the grades I get.</td>
<td></td>
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<tr>
<td>24. a. A good leader expects people to decide for themselves what they should do.</td>
<td>b. A good leader makes it clear to everybody what their jobs are.</td>
<td></td>
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<tr>
<td>25. a. Many times I feel that I have little influence over the things that happen to me.</td>
<td>b. It is impossible for me to believe that chance or luck plays an important role in my life.</td>
<td></td>
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<tr>
<td>26. a. People are lonely because they don't try to be friendly.</td>
<td>b. There's not much use in trying too hard to please people, if they like you, they like you.</td>
<td></td>
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<tr>
<td>27. a. There is too much emphasis on athletics in high school.</td>
<td>b. Team sports are an excellent way to build character.</td>
<td></td>
</tr>
<tr>
<td>28. a. What happens to me is my time.</td>
<td>b. Sometimes I feel that I don't have...</td>
<td></td>
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</tbody>
</table>
own doing.  

<table>
<thead>
<tr>
<th>own doing.</th>
<th>enough control over the direction my life is taking.</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. a. Most of the time I can’t understand why politicians behave the way they do.</td>
<td>b. In the long run the people are responsible for bad government on a national as well as on a local level.</td>
</tr>
</tbody>
</table>

Appendix 3. Diener’s satisfaction with life scale

Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

- ____ In most ways my life is close to my ideal.
- ____ The conditions of my life are excellent.
- ____ I am satisfied with my life.
- ____ So far I have gotten the important things I want in life.
- ____ If I could live my life over, I would change almost nothing.

Scoring Diener’s satisfaction with life scale

- 31-35 Extremely satisfied
- 26 - 30 Satisfied
- 21-25 Slightly satisfied
- 20 Neutral

- 15-19 Slightly dissatisfied
- 10 - 14 Dissatisfied
- 5 - 9 Extremely dissatisfied
Understanding Scores on the Satisfaction with Life Scale Ed Diener

(Note: If we divide by the number of questions, rather than use the summed aggregate score, then the cutoffs below instead should be:
6-7
5-6
4-5 3-4 2-3 1-2

30 – 35 Very high score; highly satisfied

Respondents who score in this range love their lives and feel that things are going very well. Their lives are not perfect, but they feel that things are about as good as lives get. Furthermore, just because the person is satisfied does not mean she or he is complacent. In fact, growth and challenge might be part of the reason the respondent is satisfied. For most people in this high-scoring range, life is enjoyable, and the major domains of life are going well – work or school, family, friends, leisure, and personal development.

25- 29 High score

Individuals who score in this range like their lives and feel that things are going well. Of course their lives are not perfect, but they feel that things are mostly good. Furthermore, just because the person is satisfied does not mean she or he is complacent. In fact, growth and challenge might be part of the reason the respondent is satisfied. For most people in this high-scoring range, life is enjoyable, and the major domains of life are going well – work or school, family, friends, leisure, and personal development. The person may draw motivation from the areas of dissatisfaction.

20 – 24 Average score

The average of life satisfaction in economically developed nations is in this range – the majority of people are generally satisfied, but have some areas where they very much would like some improvement. Some individuals score in this range because they are mostly satisfied with most areas of their lives but see the need for some improvement in each area. Other respondents score in this range because they are satisfied with most domains of their lives, but have one or two areas where they would like to see large improvements. A person scoring in this range is normal in that they have areas of their lives that need improvement. However, an individual in this range would usually like to move to a higher level by making some life changes.

15 – 19 Slightly below average in life satisfaction

People who score in this range usually have small but significant problems in several areas of their lives, or have many areas that are doing fine but one area that represents a substantial problem for them. If a person has moved temporarily into this level of life satisfaction from a higher level because of some recent event, things will usually improve over time and satisfaction will generally move back up. On the other hand, if a person is chronically slightly dissatisfied with many areas of life, some changes
might be in order. Sometimes the person is simply expecting too much, and sometimes life changes are needed. Thus, although temporary dissatisfaction is common and normal, a chronic level of dissatisfaction across a number of areas of life calls for reflection. Some people can gain motivation from a small level of dissatisfaction, but often dissatisfaction across a number of life domains is a distraction, and unpleasant as well.

**10 – 14 Dissatisfied**

People who score in this range are substantially dissatisfied with their lives. People in this range may have a number of domains that are not going well, or one or two domains that are going very badly. If life dissatisfaction is a response to a recent event such as bereavement, divorce, or a significant problem at work, the person will probably return over time to his or her former level of higher satisfaction. However, if low levels of life satisfaction have been chronic for the person, some changes are in order – both in attitudes and patterns of thinking, and probably in life activities as well. Low levels of life satisfaction in this range, if they persist, can indicate that things are going badly and life alterations are needed. Furthermore, a person with low life satisfaction in this range is sometimes not functioning well because their unhappiness serves as a distraction. Talking to a friend, member of the clergy, counselor, or other specialist can often help the person get moving in the right direction, although positive change will be up the person.

**5 – 9 Extremely Dissatisfied**

Individuals who score in this range are usually extremely unhappy with their current life. In some cases this is in reaction to some recent bad event such as widowhood or unemployment. In other cases, it is a response to a chronic problem such as alcoholism or addiction. In yet other cases the extreme dissatisfaction is a reaction due to something bad in life such as recently having lost a loved one. However, dissatisfaction at this level is often due to dissatisfaction in multiple areas of life. Whatever the reason for the low level of life satisfaction, it may be that the help of others are needed – a friend or family member, counseling with a member of the clergy, or help from a psychologist or other counselor. If the dissatisfaction is chronic, the person needs to change, and often others can help.