PARENTING AND TYPE ONE DIABETES

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SCHOOL OF PSYCHOLOGICAL SCIENCES
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WORD COUNT: 23401
Abstract

Parenting and Type One Diabetes
Doctor of Clinical Psychology, The University of Manchester.

This thesis considers parental psychological well-being and the acceptability of parenting support for those who have an adolescent with type one diabetes (T1D). Within the literature it is acknowledged that T1D diagnosis and management can have an effect on all family members. Furthermore poor parental well-being can impact negatively on adolescent well-being. It is therefore important to understand parental well-being in the context of adolescent T1D. Paper one presents a literature review of the psychological status of parents of adolescents with T1D. The review highlighted that adolescent T1D diagnosis impacts on parental psychological well-being, with some parents experiencing clinically concerning symptoms of anxiety, depression or psychological distress at different time points during their adolescent’s chronic illness.

Over recent years it has increasingly been recognised that psychosocial variables can impact on physical well-being and illness management. It is important that individuals who experience distress are offered appropriate support. With regard to families and parents, psychological support may be offered through parenting interventions. Paper two aimed to explore whether Teen Triple P Positive Parenting Programme resources were acceptable to parents of adolescents with T1D and whether they would be interested in undertaking a parenting intervention. It also explored whether adolescent behaviour difficulties, parental psychological distress or diabetes-related family conflict were related to parents’ acceptability ratings and intentions to participate. Diabetes factors, such as time since diagnosis and levels of blood glucose control were also considered. The results indicated that the Teen Triple P resources were acceptable to parents and that they would be interested in participating in a parenting intervention.

The critical reflection considers both the literature review and the scientific study. Within this paper the approaches used, the challenges encountered, and the implications for clinical practice, and future research, are considered.
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Acknowledgements

I would like to thank my supervisor Professor Rachel Calam for her guidance, support, feedback and positive approach throughout all stages of this thesis. Thanks also to Professor Matt Sanders for his advice and for the use of the Triple P parenting resources.

In addition, I am grateful to Francesca Doherty for her role in organising the feasibility exercise and for facilitating recruitment. Further gratitude goes to Austin Lockwood for his technical expertise and patience whilst developing the website, and to Julie Morris for her statistical advice.

This thesis would not have been possible without the parents who took part in the research and the organisations that supported recruitment. I would like to express my gratitude to all of those involved.

Finally heartfelt thanks to my family and friends for their understanding and support throughout this whole process.
The Psychological Status of Parents of Adolescents with Type One Diabetes: A Systematic Literature Review

Prepared in accordance with the author guidelines for

The Journal of Pediatric Psychology

(Appendix 1)

Word Count: 7786
Abstract

**Objective:** To identify and extend knowledge regarding the psychological status of parents of adolescents with type one diabetes (T1D), by considering levels of anxiety, depression or psychological distress within this population.

**Methods:** A systematic search of PsychINFO, Medline and CINAHL was conducted and reference lists of selected articles reviewed. In total, 19 papers reporting on anxiety, depression or psychological distress in parents who had an adolescent with T1D were identified.

**Results:** Parents, particularly mothers, are likely to experience increased, but subclinical emotional responses in the context of their adolescent’s T1D. Some parents experience clinically significant symptoms of anxiety, depression or psychological distress.

**Conclusions:** T1D amongst adolescents has the potential to impact upon the psychological status of parents. It is important for paediatric diabetes care teams to monitor parental anxiety, depression or psychological distress and to offer direction to appropriate support.

**Key words:** parents, anxiety, depression, psychological distress, adolescents, type one diabetes
Introduction

Type one diabetes (T1D) is a health condition whereby the body does not produce sufficient insulin and if left untreated can lead to potentially life threatening blood glucose levels (World Health Organisation [WHO], 2011). T1D is one of the most common childhood chronic illnesses affecting the endocrine system (Soltesz, Patterson, & Dahlquist, 2009) and has a rising worldwide incidence rate in adolescents aged less than 16 years (The Diamond Project Group, 2006; Patterson et al., 2009). Effective management of T1D requires an intensive and life-long treatment regime.

Published literature acknowledges that a diagnosis of T1D results in many challenges for the adolescent and their family (Liberman, Buckingham, & Phillip, 2012; Striesand, Mackey, & Herge, 2010; Whittemore, Jaser, Guo, & Grey, 2010). In response to T1D diagnosis, parents may exhibit emotional reactions such as increased levels of either or both anxiety and depression (Streisand et al., 2010; Whittemore et al., 2010). Although some parents experience a reduction in emotional distress over time (Kovacs et al., 1985) for others this may not be the case (Hoff et al., 2005). These emotional responses may impact upon a parent’s ability, and in turn, their adolescent’s ability to cope with T1D.

Parental emotional reactions to family stressors are of particular interest due to the link between parent and child psychological well-being in general (Colletti et al., 2010; Goodman et al., 2011) and in the context of childhood chronic illnesses (Drotar, 1997). Barlow and Ellard (2006) reviewed the literature relating to the psychosocial well-being of all family members in the context of a child’s chronic illness, by considering previously conducted systematic reviews. Despite using a wide array of search terms, including diabetes, they only identified two review papers relating to parental well-being in the context of childhood cancer and sickle cell disease (Barlow & Ellard, 2006). Consistent
with these findings, the current authors failed to identify any systematic reviews considering parental psychological well-being in the context of T1D.

The studies included in Barlow and Ellard’s (2006) review indicated that different patterns of parental emotional distress are likely depending on the child’s health condition. Parents of children with cancer were reported to experience elevated levels of emotional distress at diagnosis and throughout treatment, whilst parents of children with sickle cell disease demonstrated no differences in their mental health in comparison to a control group (Barlow & Ellard, 2006). Although research findings relating to other childhood chronic health conditions provide a useful framework for understanding parental psychological reactions, in the absence of a systematic review, the type and extent of emotional responses experienced by parents in the context of T1D are as yet unclear.

In the field of adolescent T1D several studies have observed associations between parental psychological well-being and the diabetic and psychological status of their adolescent. It has, for example, been demonstrated that caregiver psychological distress is related to poor adolescent glycaemic control (Cunningham, Vesco, Dolan, & Hood, 2011). In addition, the presence of maternal clinical depression over the first year of T1D has been demonstrated to increase the risk of depressive disorder development in the adolescent (Kovacs, Goldston, Obrosky, & Bonar, 1997). Furthermore, overall maternal psychological distress elevates the risk of an adolescent with T1D developing a psychiatric disorder (Kovacs et al., 1997). In view of the highlighted research findings, it is important that parental levels of anxiety, depression or psychological distress are understood in the context of an adolescent’s T1D so that appropriate support can be provided.

On the basis of the literature, a conceptual model (Fig. 1) would need to consider the links that exist between parent and adolescent psychological well-being alongside T1D. Parent
and adolescent psychological well-being are linked in the general population (Colletti et al., 2010; Goodman et al., 2011) and therefore the pre-diagnosis level of functioning is likely to impact on how the adolescent and their parents cope with T1D diagnosis and management. T1D presents many challenges for families (Liberman et al., 2012; Striesand et al., 2010) and parents may experience emotional responses (Striesand et al., 2010), such as feelings of anxiety, depression or psychological distress. Such parental emotional responses can impact on adolescent well-being (Kovacs et al., 1997) and in turn can influence diabetes management (Cunningham et al., 2011).

**Figure 1: A conceptual model of T1D and psychological well-being**

![Figure 1: A conceptual model of T1D and psychological well-being](image)

**The current review**

Within T1D research, measures of parental mental health are often collected however these are only occasionally the focus of the research studies. Recent T1D treatment and management guidelines (International Diabetes Federation [IDF], 2011; National Institute for Health & Clinical Excellence [NICE], 2004) recommend monitoring family psychosocial functioning and the provision of support through mental health services where necessary. An understanding of the level and potential patterns of emotional distress experienced by parents of adolescents with T1D would assist paediatric diabetes teams in
identifying and responding to the psychological needs of parents and set an agenda for future research.

The objective of the current paper is to provide a systematic review of the psychological status of parents of adolescents with T1D by considering papers which measured parental anxiety, depression or psychological distress. Anxiety or depression were chosen as they represent distinct clinical concepts which have been highlighted as potentially impacting on an adolescent’s physical and psychological health in the context of T1D (Cunningham et al., 2011; Kovacs et al., 1997). Psychological distress was also included as it refers to “the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person” (Ridner, 2004, p. 539). Furthermore, many self-report measures used in research explore this concept, for example, the Symptom Checklist 90-Revised (Derogatis, 1983).

Method

Relevant papers were identified through searches of PsychINFO, Medline and CINAHL. Studies were limited to those written in English language and human subjects. A range of search terms were selected in relation to ‘parents’, ‘type one diabetes’, ‘adolescents’, ‘anxiety’, ‘depression’ and ‘distress’ (see supplemental material for full search terms; Appendix 2). Blocks of search terms relating to parents (seven terms), type one diabetes (six terms) and adolescents (eight terms) were created and these terms were combine using the OR feature. The search results of each block were then combined using the AND feature to identify papers which reported on parents in the context of adolescent type one diabetes. The search results from this process were then combined with fifteen different search terms relating to anxiety, depression and psychological distress using the AND function. The search strategy involved searching titles and abstracts for the selected terms.
The following criteria had to be met for inclusion: a) published between 1980 and 2011, b) sample of parents of adolescents with T1D, c) adolescent mean age of 11 years or more, or groups of adolescents aged 11 or more d) standardised measure of parental anxiety, depression or psychological distress and descriptive statistics or clinical cut offs reported. When adolescent sample mean age was not provided, this was inferred from the reported age range. Papers were excluded if they: a) used qualitative methodology, b) if the T1D parents could not be isolated out from other participants, d) and if they were dissertation abstracts, conference proceedings or measure development papers.

In the first instance all abstracts were read and the content checked next to the inclusion criteria to ensure that papers related to parents of adolescents with T1D and to establish whether parental anxiety, depression or psychological distress had been measured. Abstracts which met the inclusion criteria were identified and the full articles obtained, whilst those that did not were disregarded. On several occasions abstracts made reference to the collection of parental measures, but it was unclear what these were. In such cases, the full paper was obtained and read to clarify what measures parents had completed and whether the paper met the inclusion criteria. The reference sections of each included article were reviewed to identify further papers which may meet the inclusion criteria. The reference review involved the screening of paper titles and seeking the abstracts of those which had the potential to meet the inclusion criteria based on the terms used. Once abstracts were obtained the same process described above was followed. An independent reviewer assisted when it was unclear whether papers met the inclusion criteria. Several papers shared participants; all were included and the shared sample acknowledged. When standardised measures descriptive statistics were reported but not individually discussed, the reported means were interpreted using the articles measure description or published norms, where possible.
Results

The PsychINFO, Medline and CINHAL database searches and reference screens led to a total of 19 studies published between 1985 (Kovacs et al., 1985) and 2011 (Cunningham et al., 2011; Wiebe et al., 2011) being selected for inclusion. A summary of the included studies can be seen in Table I. Of the 19 papers, two sets of papers utilised the same sample; Hood (2009) and Williams, Laffel, & Hood, (2009); Herzer and Hood (2010) and Ingerski, Laffel, Drotar, Repaske and Hood (2010). Cohorts of the same sample were reported by Kovacs et al., 1985, Kovacs et al., 1990 and Kovacs, Goldston, Obrosky, and Bonar (1997) and also by Berg et al. (2007) and Wiebe et al. (2011).

Studies were conducted predominantly in the United States of America (n=17). The remaining two were conducted in Australia (Northam, Anderson, Adler, Werther, & Warne, 1996) and Lebanon (Azar & Kanann, 1999). Four research papers considered parental well-being in the context of newly diagnosed T1D (Kovacs et al., 1985; Kovacs et al., 1990; Kovacs et al., 1997; Northam et al., 1996). A further 13 considered parents in the context of T1D diagnosis of at least one year (Azar & Kanann, 1999; Walker, Ortiz-Valdes, & Newbrough, 1989) through to a mean length of diagnosis of 7.03 years (Gonder-Frederick et al., 2006). One study had a mixed sample of adolescents including those newly diagnosed and those one year post T1D diagnosis (Chaney et al., 1997) and one did not report the mean time since diagnosis (Butler et al., 2009).

Primary focus and aims of the studies

Parents were the primary research focus for seven studies (Azar & Kanann, 1999; Cunningham et al., 2011; Hood 2009; Kovacs et al., 1985; Kovacs et al., 1990; Walker et al., 1989; Wiebe et al., 2011). Nine papers focused on the adolescent and their parents (Berg et
Five papers aimed to explore parental psychological distress (Chaney et al., 1997; Kovacs et al., 1985; Kovacs et al., 1990; Northam et al., 1996; Williams et al., 2009). One further study aimed to explore maternal factors over the first year of diagnosis in relation to rates and risk factors for psychiatric disorders in youths with T1D (Kovacs et al., 1997). Two studies examined blood glucose monitoring, glycaemic control and quality of life in the adolescent with T1D whilst considering parental well-being (Herzer & Hood, 2010, Ingerski et al., 2010). Eight studies aimed to explore the relationships between parental, adolescent and illness factors (Azar & Kannan, 1999; Berg et al., 2007; Butler et al., 2009; Butner et al., 2009; Jaser & Grey, 2010; Lopez et al., 2008; Walker et al., 1989; Wiebe et al., 2011). Three remaining papers aimed to develop a mediation model (Cunningham et al., 2011), to test the depression-distortion hypothesis (Hood, 2009) and to identify factors which would predict hypoglycaemia (Gonder-Fredrick et al., 2006).
Sample characteristics

The number of parents of adolescents with T1D included in studies ranged from n= 24 (Walker et al., 1989) to n= 330 (Butner et al., 2009) at baseline. Twelve studies included mothers and fathers, six reported on mothers and one provided no details regarding recruited parents (Lopez et al., 2008). The psychological well-being of mothers’ and fathers’ was considered separately in five papers (Butler et al., 2009; Butner et al., 2009; Chaney et al., 1997; Kovacs et al., 1985; Northam et al., 1996) with the number of participating fathers ranging from n=24 (Northam et al., 1996) to n= 177 (Butler et al., 2009). Seven papers considered parental psychological well-being collectively (Azar & Kannan, 1999; Cunningham et al., 2011; Gonder-Frederick et al., 2006; Herzer & Hood, 2010; Hood, 2009; Ingerski et al., 2010; Williams et al., 2009). One study had a greater number of fathers than mothers in their sample (Azar & Kannan, 1999); this may have been due to cultural differences. Two study samples included parents of children with other health difficulties and children who were well as comparison groups (Lopez et al., 2008; Walker et al., 1989).

Parents were predominately White, of non-Hispanic origin (minimum 47%, maximum 87.4% of participants), Caucasian (minimum 83.5%, maximum 100% of participants) or European-American (99%; Wiebe et al., 2011). Four papers did not report ethnicity data (Azar & Kannan, 1999; Butler et al., 2009; Northam et al., 1996; Walker et al., 1989). Study samples were broadly representative of the middle class population. Five studies did not report socioeconomic status (SES) in relation to household income, but commented on health insurance or welfare status (Cunningham et al., 2011; Herzer & Hood, 2010; Hood, 2009; Ingerski et al., 2010; Williams et al., 2009). One study did not report SES details (Gonder-Frederick et al., 2006), whilst one referred to SES only in the analysis (Azar & Kannan, 1999).
Table I: Included studies

<table>
<thead>
<tr>
<th>Study &amp; Country</th>
<th>Sample (baseline n)</th>
<th>Baseline adolescent age (mean, SD in years)</th>
<th>Length of adolescents’ T1D (mean, SD in years)</th>
<th>Study design</th>
<th>Parental psychological well-being measure</th>
<th>Psychological status of parents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Papers measuring anxiety</strong></td>
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<tr>
<td>Gonder-Frederick et al., 2006. USA</td>
<td>39; 38 mothers &amp; 1 father.</td>
<td>15.36, 1.53.</td>
<td>7.03, 4.0.</td>
<td>Cross-sectional, questionnaires.</td>
<td>State-Trait Personality Inventory, trait anxiety subscale.</td>
<td>Mean scores not interpreted due to inaccessible references.</td>
</tr>
<tr>
<td>Herzer &amp; Hood, 2010***. USA</td>
<td>276 primary caregivers. 82.6% mothers.</td>
<td>15.63, 1.39.</td>
<td>6.6, 4.0.</td>
<td>Cross-sectional, questionnaires.</td>
<td>State Trait Anxiety Inventory – trait anxiety subscale (STAI-T).</td>
<td>Mean scores in line with general population norms.</td>
</tr>
<tr>
<td><strong>Papers measuring depression</strong></td>
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<tr>
<td>Walker et al., 1989. USA</td>
<td>24 mothers.</td>
<td>3 groups: 8-10, 11-14 &amp; 15-19 years.</td>
<td>At least one year.</td>
<td>Cross-sectional, questionnaires verbally administered.</td>
<td>Center for Epidemiologic Studies-Depression Scale (CES-D).</td>
<td>Mean CES-D score below clinical cut off.</td>
</tr>
<tr>
<td>Study &amp; Country</td>
<td>Sample (baseline n)</td>
<td>Baseline adolescent age (mean, SD in years)</td>
<td>Length of adolescents’ T1D (mean, SD in years)</td>
<td>Study design</td>
<td>Parental psychological well-being measure</td>
<td>Psychological status of parents</td>
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<tr>
<td>Hood, 2009**. USA.</td>
<td>187 caregivers; 153 mothers, 27 fathers &amp; 7 other.</td>
<td>14.4, 2.4.</td>
<td>6.5, 3.9.</td>
<td>Cross-sectional, questionnaires.</td>
<td>CES-D.</td>
<td>22% of caregivers met clinical cut off for depressive symptoms. No differences between mothers, fathers &amp; other group observed.</td>
</tr>
<tr>
<td>Ingerski et al., 2010***. USA.</td>
<td>261 primary caregivers. 82% mothers.</td>
<td>15.7, 1.4.</td>
<td>7.0, 3.9.</td>
<td>Cross-sectional, questionnaires.</td>
<td>CES-D.</td>
<td>Mean depression scores below clinical cut off.</td>
</tr>
<tr>
<td>Berg et al., 2007****. USA.</td>
<td>127 mothers.</td>
<td>12.85, 1.71.</td>
<td>4.52, 2.86.</td>
<td>Cross sectional, mixed methods; interview &amp; questionnaires</td>
<td>CES-D. Positive &amp; Negative Affect Schedule (PANAS).</td>
<td>Negative emotional adjustment generally low amongst mothers. Mean CES-D scores below clinical cut-off. 17% of mothers met CES-D clinical cut-off.</td>
</tr>
<tr>
<td>Butner et al., 2009. USA.</td>
<td>330; 185 mothers &amp; 145 fathers</td>
<td>12.5, 1.3.</td>
<td>4.78, 3.0.</td>
<td>Cross-sectional, mixed methods; interviews &amp; questionnaires</td>
<td>CES-D.</td>
<td>Mean mother &amp; father CES-D scores below clinical cut-off for depression.</td>
</tr>
<tr>
<td>Wiebe et al., 2011*****. USA.</td>
<td>82 mothers.</td>
<td>12.79, 1.70.</td>
<td>5.4, not reported.</td>
<td>Longitudinal; baseline and 16 month follow-up, questionnaires.</td>
<td>CES-D.</td>
<td>28% of mothers at baseline &amp; follow up met the CES-D clinical cut-off. 9 mothers above clinical cut-off at both time points.</td>
</tr>
<tr>
<td>Study &amp; Country</td>
<td>Sample (baseline n)</td>
<td>Baseline adolescent age (mean, SD in years)</td>
<td>Length of adolescents’ T1D (mean, SD in years)</td>
<td>Study design</td>
<td>Parental psychological well-being measure</td>
<td>Psychological status of parents</td>
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<tr>
<td>Northam et al., 1996. <em>Australia.</em></td>
<td>48 mothers &amp; fathers.</td>
<td>3 groups: &lt;4, 4-11 &amp; &gt;11 (only &gt;11 included in results).</td>
<td>Baseline: Newly diagnosed.</td>
<td>Longitudinal, mixed methods; interview &amp; questionnaires. Baseline &amp; 1 year follow-up.</td>
<td>The General Health Questionnaire (GHQ-28).</td>
<td>Baseline: mothers mean scores 2 points higher than normative sample. Fathers scores similar to norms. <strong>Follow-up:</strong> mothers’ scores decreased to below normative mean. Father’s scores increased &amp; were 2 points higher than norms.</td>
</tr>
<tr>
<td>Chaney et al., 1997. <em>USA.</em></td>
<td>48 families; both mothers &amp; fathers.</td>
<td>11.4, 2.4.</td>
<td>2.94, 3.16. (Two groups: newly diagnosed &amp; T1D &gt; 1 year)</td>
<td>Longitudinal, mixed methods; interview &amp; questionnaires. Baseline &amp; 1 year follow-up.</td>
<td>Symptom Checklist-90-Revised (SCL-90-R), Global Symptom Index.</td>
<td>Mean scores at baseline &amp; follow-up below cut-off for significant distress for all parents. No significant differences between distress levels at baseline &amp; follow-up for all parents. <strong>Baseline:</strong> 27% of mothers &amp; 31% of fathers’ met clinical cut-off. <strong>Follow-up:</strong> 21% of mothers &amp; 32% of fathers met clinical cut-off. 13% of mothers &amp; 19% of fathers met clinical cut-off at both baseline &amp; follow-up.</td>
</tr>
<tr>
<td>Lopez et al., 2008. <em>USA.</em></td>
<td>68 adolescents and their parents.</td>
<td>14.71, 1.61.</td>
<td>6.7 years, 4.6.</td>
<td>Cross sectional, questionnaires.</td>
<td>Brief Symptom Inventory (BSI), Global Severity Index.</td>
<td>Mean distress scores below clinical cut-off.</td>
</tr>
<tr>
<td>Study &amp; Country</td>
<td>Sample (baseline n)</td>
<td>Baseline adolescent age (mean, SD in years)</td>
<td>Length of adolescents’ T1D (mean, SD in years)</td>
<td>Study design</td>
<td>Parental psychological well-being measure</td>
<td>Psychological status of parents</td>
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<tr>
<td>Williams et al., 2009*</td>
<td>187 parents; 153 mothers, 27 fathers &amp; 7 others.</td>
<td>14.4, 2.4.</td>
<td>6.5 years, 3.9.</td>
<td>Cross-sectional, questionnaire.</td>
<td>CES-D. State Trait Anxiety Inventory (STAI).</td>
<td>23% met the CES-D clinical cut-off. 15% &amp; 18% respectively met cut-off for significant state &amp; trait anxiety. 24% of parents met clinical cut-off for anxiety. Higher than normative rates.</td>
</tr>
<tr>
<td>Butler et al., 2009*</td>
<td>177 families; mothers &amp; fathers.</td>
<td>12.53, not reported.</td>
<td>Not reported.</td>
<td>Cross-sectional, questionnaire.</td>
<td>CES-D. STAI- Trait anxiety subscale.</td>
<td>Mean mother &amp; father depression scores below clinical cut-offs. Unable to interpret STAI- trait means due to lack of manual.</td>
</tr>
<tr>
<td>Jaser &amp; Grey, 2010*</td>
<td>30 mothers.</td>
<td>12.6, 1.6.</td>
<td>5.76, 4.68.</td>
<td>Cross-sectional, mixed methods; questionnaire &amp; video interaction.</td>
<td>CES-D. State Trait Anxiety Inventory (STAI) – state anxiety subscale.</td>
<td>Mean state anxiety &amp; depression scores below clinical cut-offs. 23% met the CES-D clinical cut-off. 13% met cut-off score for anxiety symptoms.</td>
</tr>
<tr>
<td>Cunningham et al., 2011</td>
<td>147 primary caregivers; 130 mothers, 13 fathers &amp; 4 other.</td>
<td>15.5, 1.40.</td>
<td>Baseline: 6.0 years, SD 3.8.</td>
<td>Longitudinal, questionnaire. Baseline,T2 7 months later, T3 3.4 months post T2.</td>
<td>STAI- Trait anxiety subscale. CES-D (collected at baseline only).</td>
<td>Mean trait anxiety &amp; depression scores in line with general population norms.</td>
</tr>
<tr>
<td>Study &amp; Country</td>
<td>Sample (baseline n)</td>
<td>Baseline adolescent age (mean, SD in years)</td>
<td>Length of adolescents’ T1D (mean, SD in years)</td>
<td>Study design</td>
<td>Parental psychological well-being measure</td>
<td>Psychological status of parents</td>
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<td>Papers measuring anxiety, depression and psychological distress</td>
<td>Kovacs et al., 1985****. USA.</td>
<td>74 parents; mothers &amp; fathers.</td>
<td>11, 1.6.</td>
<td>Baseline: Newly diagnosed (2-3 weeks post hospital discharge).</td>
<td>Longitudinal, mixed methods; questionnaire &amp; interview. Baseline &amp; 3-4 assessments over the 1st year.</td>
<td><strong>Self report:</strong> BDI. Hopkins Symptoms Checklist-90 (SCL-90). <strong>Clinician Rated:</strong> Hamilton Rating Scale – Depression (HRS-D). Hamilton Rating Scale – Anxiety (HRS-A).</td>
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<td>Study &amp; Country</td>
<td>Sample (baseline n)</td>
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<td>Kovacs et al., 1997****, USA.</td>
<td>92 mothers.</td>
<td>11, 1.5.</td>
<td>Baseline: Newly diagnosed (2-3 weeks post hospital discharge).</td>
<td>Longitudinal, mixed methods; questionnaire &amp; interview. Median follow-up 8.9 years. (Maternal measures 1st year only).</td>
<td>Self-report: SCL-90. BDI. Clinician rated: HRS-D. HRS-A.</td>
<td>First year of T1D diagnosis: 37% mothers experienced for clinical depression. 37.9% mothers had elevated anxiety levels. 22.5% mothers experienced significant psychological distress.</td>
</tr>
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</table>

**Papers measuring depression and psychological distress**

| Kovacs et al., 1990****, USA. | 95 children and their parents. Mother’s data only reported. | 11.1, not reported. | Baseline: Newly diagnosed (2-3 weeks post hospital discharge). | Longitudinal, mixed methods, questionnaire & interview. Baseline, 3-4 assessments over the 1st year & annual follow-up for 6 years. | BDI. SCL-90. | Mean depression & distress scores consistently below clinical cut-off. Mean depression scores increased slightly between year 2 & 5 follow-up, but remained subclinical. Levels of psychological distress increased following the 1st year of diagnosis. **2-3 weeks post-diagnosis:** 17% of mothers moderately to severely depressed. **Follow up years:** levels of clinical depression in line with norms. |

** Same sample reporting the same CES-D data. *** Same sample reporting on different outcome measures. ****/***** Cohorts of the same sample.
**Measures of parental psychological well-being**

A range of self-report measures (Table I), with generally sound psychometric properties, were used to assess parental psychological well-being across studies. Two studies supplemented this with clinician measures of anxiety and depression (Kovacs et al., 1985; Kovacs et al., 1997). Seven studies collected parent measures longitudinally, whilst the remaining 12 used a cross-sectional design (see Table I).

**Parental Anxiety**

Eight papers considered anxiety amongst parents of adolescents with T1D. At the time of diagnosis parents in general experienced anxiety symptoms to a lesser extent than clinical populations (Kovacs et al., 1985). Mothers experienced anxiety symptoms to a greater extent than fathers at diagnosis; this difference was maintained one year later (Kovacs et al., 1985). Over the first year of diagnosis parents typically demonstrated a reduction in their anxious feelings (Kovacs et al., 1985). However throughout the first year of diagnosis, 37.9% of mothers experienced noteworthy anxiety symptoms (Kovacs et al., 1997).

Five papers considered parental anxiety at different stages of adolescent T1D, with a mean length of diagnosis between 5.76 (Jaser & Grey, 2010) and 7.03 years (Gonder-Frederick et al., 2006). Parental state (Jaser & Grey, 2010) and trait anxiety (Cunningham et al., 2011; Herzer & Hood., 2010) mean scores were found to be consistent with general population levels across several studies. In direct contrast, elevated reports of overall levels of parental anxiety were found in comparison to normative samples (Williams et al., 2009). Increased likelihood of elevated trait anxiety scores among ethnic minority groups was also reported (Cunningham et al., 2011). Within these samples, 13% of mothers (Jaser & Grey, 2010) and 15% of all primary caregivers (Williams et al., 2009) were identified as experiencing significant symptoms of state anxiety. In addition, 18% of parents were found to experience significant symptoms of trait anxiety (Williams et al., 2009). In some studies,
within data analysis, all caregivers were grouped together and therefore it was not possible to ascertain if there were differences between mothers and fathers anxiety levels.

In summary, the literature indicates that when parents experience anxiety around the time of their adolescent’s T1D diagnosis, this is generally sub-clinical, however mothers appear more likely to experience increased anxiety symptoms. As time since T1D diagnosis increased levels of parental anxiety commonly reduced. However, there is evidence suggesting that significant symptoms of anxiety are experienced by some parents at different points during their adolescent’s T1D.

**Parental Depression**

Fourteen studies measured depression amongst parents of adolescents with T1D. At the time of their adolescent’s T1D diagnosis mothers were found to experience symptoms of depression at a higher rate than community samples but to a lesser extent than clinical samples (Kovacs et al., 1985). Within the same sample, fathers’ depression levels were consistent with the general population (Kovacs et al., 1985). During the first year of diagnosis in general there was a reduction in parental depressive symptoms; mothers continued to experience depressive symptoms to a greater extent than fathers (Kovacs et al., 1985). Clinically significant depression was found amongst 17% of mothers at time of T1D diagnosis (Kovacs et al., 1990), and in between 11% (Kovacs et al., 1985) and 37% (Kovacs et al., 1997) of mothers over the first year of diagnosis. Data relating to the number of fathers experiencing clinically significant depression was not reported (Kovacs et al., 1985).

For parents of adolescents with longer time since T1D diagnosis mean depression scores below clinical cut-offs have been described (Berg et al., 2007; Butler et al., 2009; Butner et al., 2009; Cunningham et al., 2011; Ingerski et al., 2010; Jaser & Grey, 2010; Walker et al., 2010).
In contrast elevated depressive symptoms amongst parents of adolescents with T1D have also been reported (Azar & Kannan, 1999; Williams et al., 2009). Within these studies between 17% (Berg et al., 2007), 23% (Jaser & Grey, 2010) and 28% (Wiebe et al., 2011) of mothers demonstrated clinically significant depressive symptoms. When caregivers were considered collectively between 22% (Hood, 2009) and 23% (Williams et al., 2009) reported clinically significant depressive symptoms. No differences in depressive symptoms across caregivers were reported by some (Hood, 2009). A six year longitudinal study found that between two and five years post-diagnosis, mean levels of maternal depressive symptoms slightly increased, but remained subclinical, with different patterns relating to SES observed (Kovacs et al., 1990).

In summary, at the time of T1D diagnosis, it appears that mothers in particular may experience some depressive symptoms. Although for many parents, depression symptoms decrease over time, for some mothers clinical depression may occur. As length of time since T1D diagnosis increases levels of depressive symptoms across parents are generally subclinical. However a group of parents who experience clinically significant depressive symptoms have been consistently identified.

Parental Psychological Distress

In total, six studies measured psychological distress among parents of adolescents with T1D. At the time of diagnosis mean levels of psychological distress below clinical cut-offs (Chaney et al., 1996; Kovacs et al., 1985) have been reported. However, slightly elevated levels of psychological distress, in comparison to the general population, at time of diagnosis have been found amongst mothers (Northam et al., 1996; Kovacs et al., 1985). Levels of psychological distress experienced by mothers and fathers have been found to differ by some (Kovacs et al., 1985), but to be similar by others (Chaney et al., 1997).
Over the first year of diagnosis, mothers were found to experience reducing levels of psychological distress (Chaney et al., 1997; Kovacs et al., 1985; Northam et al., 1996). For fathers a slight increase in mean level of psychological distress has been observed by some (Northam et al., 1996), and a decrease reported by others (Chaney et al., 1997). In general parental levels of psychological distress during the first year of their adolescent’s T1D diagnosis remain below the clinical threshold. However, 22.5% of mothers have been reported to experience significant distress during this period (Kovacs et al., 1997).

With increasing time since T1D diagnosis levels of parental psychological distress below clinical cut-offs have been reported (Chaney et al., 1997; Kovacs et al., 1990; Lopez et al., 2008). Interestingly, within one sample fathers’ mean levels of distress were two to three points higher than mothers, at baseline and one year follow-up (Chaney et al., 1997). Levels of distress among parents have been reported to remain relatively constant over a one year period (Chaney et al., 1997), but have also been shown to increase slightly between two and five years post T1D diagnosis (Kovacs et al., 1990).

When parents of an adolescent with T1D are considered collectively regardless of time since diagnosis, changes in the number who demonstrated clinically significant symptoms of psychological distress over a one year period have been observed. Significant distress was reported by 27% of mothers and 31% of fathers at baseline and by 21% of mothers and 32% of fathers one year later (Chaney et al., 1997). Six mothers and nine fathers demonstrated significant distress at both baseline and follow-up (Chaney et al., 1997). These results indicate that for some parents clinically significant levels of distress may be constant, whereas for others, increased distress levels may occur at different time points.

In summary, it appears likely that parents, particularly mothers, will experience increased but sub-clinical levels of psychological distress at the time of their adolescent’s T1D
diagnosis. There are contrasting findings as to whether levels of psychological distress among parents increase or decrease with a greater length of time since diagnosis. However, evidence indicates that some parents experience clinically significant levels of psychological distress across different time points in their adolescent’s illness.

**Discussion**

This paper aimed to identify the psychological status of parents of adolescents with T1D through reviewing the literature. Only 19 studies were included, several of which considered different cohorts of the same sample, indicating that parental psychological well-being has not been widely explored in the context of adolescent T1D. The lack of research is surprising as it has long been established that parental psychological status can impact upon adolescent psychological well-being in the context of a chronic illness (Drotar, 1997; Kovacs et al., 1997). The review findings present a mixed picture of parental psychological well-being and highlight an area which warrants further research. It is important to note that although the reviewed literature suggests parents of adolescents with T1D can and do experience elevated symptoms of anxiety, depression and psychological distress it is unclear whether this is due to their adolescent’s T1D specifically. In addition, due to the cross-sectional nature of many studies and the lack of control groups, it is unclear whether the psychological well-being of parents of adolescents with T1D differs from that of other parents whose children have different or no medical conditions. In view of this the results of this review should be interpreted cautiously.

 Mothers of adolescents at time of T1D diagnosis were often reported to experience more symptoms of anxiety, depression or psychological distress than fathers and normative samples. This may be as a consequence of mothers taking on the role of primary care giver (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005) and therefore being responsible for the management of their adolescent’s condition. This finding may also be reflective of the
often small numbers of fathers who participated in the reviewed research. It was positive that many study samples included fathers, as within the field of paediatric psychology they are somewhat understudied (Phares et al., 2005). However, many studies created a primary caregiver group for analysis thus limiting the conclusions that can be drawn in relation to the psychological well-being of fathers.

From the literature it appears that over the first year of T1D, mothers and fathers typically experience a decrease in levels of anxiety, depression or psychological distress. However, there were often some parents, mainly mothers, who met the clinical threshold for symptoms of anxiety, depression or psychological distress. As time since T1D diagnosis increases mixed results relating to levels of parental state and trait anxiety, depression or psychological distress have been described. However consistently, a group of parents who demonstrated clinically significant symptoms has been identified. Interestingly a greater number of significantly distressed fathers were reported by some (Chaney et al., 1997).

The number of parents found to experience clinically significant psychological symptoms indicates that paediatric diabetes teams have a role to play in monitoring parental mental health in general at all stages of an adolescent’s care. This would enable those experiencing symptoms to be identified and provided with direction to appropriate support. There is a need for clinicians to remain mindful of parental emotional responses in the context of an adolescent’s T1D as qualitative research has highlighted that parents often felt assumptions were made regarding their level of coping and subsequently experienced a lack of support (Bowes, Lowes, Warner, & Gregory, 2009). It should not be assumed that a parent who has not previously demonstrated symptoms of anxiety, depression or psychological distress will not do so at a later date. It appears important that paediatric teams are mindful of the parent’s emotional reactions when their adolescent is diagnosed as there is evidence to suggest that parental emotional reaction at this time is a predictor of future distress.
Monitoring of parental psychological well-being should be an ongoing process as the adolescent’s length of time since T1D diagnosis increases as parents may have varying psychological needs at different times.

*Methodological limitations of the included studies*

The methodologies used in the included studies limit the conclusions that can be drawn in relation to the psychological status of parents of adolescents with T1D. Firstly many studies were cross-sectional thus only giving an indication of parental anxiety, depression and psychological distress at one time point. Without data collected at different time points, it is difficult to draw conclusions on whether levels of parental anxiety, depression or psychological distress have increased or decreased in comparison to previous levels.

Amongst the reviewed studies, some collected data at time of diagnosis, whilst others collected data from those with a longer length of time since diagnosis. Those which measured parental psychological well-being at time of diagnosis are able to draw relatively sound conclusions relating to the impact that T1D diagnosis has on parental well-being as diagnosis is a discrete event. The length of time since diagnosis in the sample means and standard deviations for the remaining studies highlights the diversity of their samples and therefore the conclusions drawn relating to parental well-being at different stages of an adolescent’s T1D must be interpreted with caution.

A further methodological issue is the use of normative data as a means to interpreting and concluding on the levels of parental anxiety, depression and psychological distress experienced by parents of adolescents with T1D. Researchers cannot assume that the normative data is representative of their sample; for example, it is not possible to know how many individuals amongst normative groups are parents. Furthermore, it is often the case that the normative data is collected within one country or cultural population, e.g. the
USA, and at only one time point. Such factors limit the use of norms as comparison groups.

A variety of measures were used in the research to explore anxiety, depression or psychological distress and therefore conclusion and comparisons relating to levels of parental psychological well-being should be interpreted with caution. Every study used parental self-report measures. These are easy to use and do not require clinician involvement. However, they are also susceptible to under or over reporting of symptoms due to factors such as lack of understanding, shame and perceived secondary gain. Kovacs and colleagues (1985; 1997) were the only group to use clinician-rated measures of anxiety and depression, thus strengthening their conclusions.

The majority of studies which explored depression used the Centre for Epidemiological Studies Depression Scale (CES-D) therefore the conclusions which can be drawn in relation to this domain are strengthened. However, the CES-D scale indicates the level of depressive symptoms, rather than a diagnosis of clinical depression (Sharp & Lipsky, 2002). Therefore it is difficult to conclude on the number of parents who may be experiencing a depressive disorder. With regard to anxiety, many researchers used the State Trait Anxiety Inventory (STAI). Subscale use was often inconsistent and there are limitations to using this measure. Firstly, trait anxiety scores are considered stable (Cameron, Young, & Wiebe, 2007) and therefore may not be influenced by the presence of an adolescent’s T1D. Secondly, state anxiety scores assess situational stressors, one of which may be an adolescent’s T1D, but they may also reflect other systemic factors such as marital stress. Results in relation to parental anxiety should be interpreted with this in mind. Finally, the levels of psychological distress described amongst parents must also be interpreted with caution as it is not a well-defined concept (Ridner, 2004).
It is particularly important to note that of the studies included, only one reported the number of parents taking psychotropic medication (Kovacs et al., 1985) and only three excluded parents if they had a major psychiatric disorder (Cunningham et al., 2011; Herzer & Hood, 2010; Ingerski et al., 2010). The remaining 15 studies did not report information relating to pre-existing psychological difficulties amongst parents. The research conclusions are therefore limited as it is possible that the reported psychological status of parents may not necessarily be directly related to their adolescent’s T1D.

The studies in this review reported on parental psychological well-being over a 31 year period. During this time, knowledge, understanding and awareness of psychological well-being are likely to have changed within professional and public forums. Alongside this societal events, such as economic decline, have also occurred. Such events have the potential to impact upon the psychological well-being of parents alongside their adolescent’s illness. Consequently, conclusions and comparisons between the different findings relating to parental psychological well-being must be made with the passage of time in mind.

As the majority of the studies included took place in USA, cultural differences must be borne in mind when applying findings to parents in Europe and the rest of the world. The study samples were also predominately middle class and of White or Caucasian ethnic background making it difficult to draw conclusions in relation to parents from ethnic minority groups and lower SES.

**Future research**

Future research should aim to explore parental anxiety, depression or psychological distress whilst controlling for other factors, such as existing parental mental health difficulties, to establish whether emotional responses are specific to their adolescent’s T1D. The current
literature only enables suggestions to be made that parents psychological well-being can be impacted on by the presence of an adolescents T1D as opposed to firm conclusions that offspring T1D leads to the potential elevation of anxiety, depression and psychological distress levels. Ideally, future research should be conducted using longitudinal methodology to establish patterns of causality. Efforts should be made be to explore differences in psychological status across SES and ethnic groups. This is important as research has highlighted that SES (Kovacs et al., 1990) and ethnicity (Cunningham et al., 2011) may mediate parental experiences of symptoms. Researchers should also aim to consider fathers as an independent group. A review of the relationship between parental psychological well-being and the physical and psychological well-being of the adolescent would also be useful.

Limitations of the current review

The review findings must be considered in light of several limitations. The search strategy was limited to English language papers; therefore studies involving parents from different cultures may have been missed. Furthermore, a formal quality assessment was not used to assess the methodological rigour of the included studies.

Conclusions

The findings of this review suggest that the diagnosis and management of T1D in adolescents has the potential to impact on the psychological well-being of mothers and fathers. The literature consistently indicated that a group of parents experience clinically significant symptoms of anxiety, depression, or psychological distress. However, it is unclear if such levels of clinically significant symptoms are elevated in comparison to other groups of parents and whether this is related specifically to adolescent T1D. Nonetheless, paediatric diabetes care teams must be mindful of these findings and ensure that they monitor parental psychological well-being.
References


Triple P Positive Parenting Programme for Type One Diabetes: An Exploratory Study of Consumer Acceptability

Prepared in accordance with the author guidelines for The Journal of Pediatric Psychology

(Appendix 1)

Word Count: 7119
Abstract

Objective: To explore the consumer acceptability of the Triple P Positive Parenting Programme amongst parents of adolescents with type one diabetes (T1D).

Methods: Ninety-eight parents of adolescents with T1D registered for an online survey. Parents completed measures of adolescent behaviour, parental psychological well-being, diabetes-related family conflict and provided T1D information. The acceptability of Triple P resources, intention to participate in a parenting intervention and barriers to participation were explored. There were high rates of sample attrition.

Results: Triple P resources were acceptable to parents and relatively strong intentions to participate were demonstrated. Correlational analyses indicated some significant relationships between ratings of acceptability and measures of adolescent behaviour, diabetes-related family conflict and time since diagnosis. Intention to participate was significantly related to acceptability ratings and measures of adolescent behaviour and diabetes-related family conflict.

Conclusions: These findings support the development and adaptation of Triple P for parents of adolescents with T1D.

Keywords: parenting, adolescents, type one diabetes, consumer acceptability, Triple P
Introduction

Type one diabetes (T1D) is a chronic endocrine condition which is commonly seen in adolescents (Soltesz, Patterson & Dahlquist, 2009). Following the findings of the Diabetes Complications and Control Trial ([DCCT]; 1993) current treatment guidelines recommend intensive medical management (International Diabetes Federation [IDF], 2011; National Institute for Health & Clinical Excellence [NICE], 2004). T1D management has been shown to impact upon children and parents across a range of psychosocial variables (Jaser, Whittemore, Ambrosino, Lindermann & Grey, 2008).

Parenting an adolescent with T1D is likely to present additional challenges which can impact upon parental psychological well-being (Lowes, 2010). A recent meta-synthesis found that parents of children with chronic illnesses often experience worry and emotional distress (Coffey, 2006). In relation to adolescent T1D, a considerable number of parents demonstrate elevated levels of anxiety and depression (Williams, Laffel, & Hood, 2009). Such emotional responses can impact on parenting style (Jaser & Grey, 2010), diabetes-related family conflict (Williams et al., 2009) and glycaemic control (Cunningham, Vesco, Dolan, & Hood, 2011).

Parenting style, including the level of involvement and affection provided to adolescents, is important in the context of T1D (Harris, Mertlich & Rothweiler, 2001). Child-centred relationships are linked to better child outcomes (Harris et al., 2001) and supportive parent-adolescent relationships impact positively on adolescent behaviour and self-efficacy which moderate diabetes management (Berg et al., 2011). Greater levels of psychological distress reduce parental ability to provide child-centred parenting (Jaser & Grey, 2010).

Adolescent externalising behaviour, which is overt and disruptive (Keil & Price, 2006) may also impact upon T1D management. Research has found that levels of adolescent
Externalising behaviours are related to poor glycaemic control over four (Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004) and eight year follow-ups (Bryden et al., 2001). Externalising behaviour amongst adolescents may also lead to family conflict which can impact upon T1D management. Indeed, higher rates of diabetes-specific family conflict have been found to impact negatively on adolescent glycaemic control (Anderson et al., 2002).

Despite the parenting challenges which may be faced in the context of an adolescent’s T1D, relatively few parent-orientated psychological interventions have been designed for use with this population. A number of interventions including behaviour family systems therapy (Wysocki et al., 2006), community-based support programmes (Ireys, Chernoff, DeVet, & Kim, 2001) and multi-systemic therapy (Ellis et al., 2005) have been used and evaluated. These interventions have demonstrated positive effects on parent-adolescent relationships and diabetes family conflict (Wysocki et al., 2006), adolescent diabetes factors (Ellis et al., 2005; Wysocki et al., 2006) and levels of parental psychological distress (Ireys et al., 2001). However, the evidence-base supporting their use is currently in its infancy and the focus of such interventions are very specific with the parenting support offered targeting families in which the young person has chronically poor metabolic control (Ellis et al., 2005), parental risk for mental health difficulties (Ireys et al., 2001) and diabetes specific problems (Wysocki et al., 2006). In addition such interventions are costly to run and require a considerable amount of clinical time to support implementation.

The Triple P Positive Parenting Programme (Sanders, 2012) is a widely utilised evidence-based parenting programme which to date has not been used with parents of adolescents with T1D. In contrast to the abovementioned parent interventions Triple P offers an approach which strives to build on the existing skills of parents to prevent the development of adolescent behavioural or emotional problems (Sanders, Markie-Dadds, & Turner, 2003).
through addressing general family functioning, as well as specific parenting challenges. It is based on five core principles including assertive discipline and parental self-care and its multilevel design ensures it can be responsive to the specific needs of different groups of parents (Sanders, 2008). Triple P has the potential to offer parenting support which is applicable to all parents who have an adolescent with T1D, including those who would like general support as well as those who may be experiencing more specific challenges. Furthermore Triple P has been designed to minimise costs whilst maximising efficiency thus making it attractive to service providers.

The development of the Triple P model over time, and for use with different populations, has led researchers to draw on Participatory Action Research (PAR) principles (McTaggart, 1991) and a consumer perspective approach. The consumer approach has been successfully implemented to enable the elicitation of parental views regarding parenting interventions, and to support the identification of factors which facilitate and prevent participation (Metzler, Sanders, Rusby, & Corwley., 2012; Sanders, Haslam, Calam, Southwell, & Stallman, 2011). A consumer approach supports the development of interventions which are responsive to patient needs and is consistent with patient-centred healthcare models (Santucci, McHugh & Barlow, 2012). Despite policy recommendations for patient involvement (Department of Health [DOH], 2011; 2012), it is unclear how this is incorporated into the evidence-base. The use of a consumer perspective approach may facilitate the synthesis of policy recommendations and the development of the evidence-base which demonstrates patient involvement.

Research has indicated that parents of adolescents with T1D are interested in receiving psychological support and suggests they should be involved in intervention design (Christie, Ramano, Thompson, Viner, & Hindmarch, 2008). The value of consumer input for enhancing the development of Triple P programmes which are responsive to parents
needs has been highlighted in several studies (Metzler et al., 2012; Sanders et al., 2011). Specifically, consumer information relating to acceptability is important and facilitates the development of parenting resources which are attractive to parents (Metzler et al., 2012). Furthermore, an important element of programme development required prior to the intervention adaptation process is an exploration of the acceptability of existing resources for the target population (Sanders & Kirby, 2012). The flexibility of Triple P indicates that it has the potential to be adapted for use with parents of adolescents with T1D.

The current study

To support the adaptation of Triple P for parents of adolescents with T1D this research adopted a consumer perspective approach. Parental perspectives were explored to build knowledge and understanding as to whether Teen Triple P resources were acceptable to this population and to identify psychosocial factors which may influence this.

A cross-sectional online survey was used to gather information. Initially, the study aimed to establish the consumer acceptability of the Teen Triple P resources in terms of usefulness, interest, realism and familiarity, and intention to participate in a parenting intervention. Secondly the study aimed to explore whether acceptability ratings and intention to participate were related to demographic factors, adolescent behaviour difficulties, parent psychological well-being, diabetes-specific family conflict or T1D factors. A further aim was to develop an understanding of the barriers to parenting intervention participation. The conversion from intention to participate to action was also explored. This was achieved by recording whether parents accepted the offer of taking part in a trial of Triple P for T1D which was recruiting at the same time.
Method

Participants

Parents were eligible to participate if they could; i) read a newspaper unassisted, ii) had no co-morbid mental health difficulties and iii) if their adolescent had no co-morbid physical or mental-health difficulties, with the exception of coeliac disease, asthma, eczema and dyslexia. Parents were excluded if they had previously undertaken a Triple P intervention. Ninety eight parents commenced the online study; forty completed the full survey whilst fifty eight did not finish. No significant differences between parents who did not finish the survey and those who completed it were found in relation to their adolescent’s diabetes factors; length of diagnosis in years, (Mdn completers 6.00, Mdn non completers 5.50; U=636.5, z=-1.06, p>.05, r = -.12), or recent measures of blood glucose control (HbA1c%), (Mdn completers 7.70, Mdn non completers 7.85; U=631.5, z=-.164, p>.05, r = -.02). The study design meant it was not possible to ascertain the number of potential participants accessed or reasons for survey attrition.

Feasibility exercise and study procedure

Initially, sixteen families with a child or adolescent with T1D were consulted to explore whether they would be interested in receiving parenting support and to inform the development and design of the survey. Study recruitment took place nationally (across the UK) and locally (in Greater Manchester). All parents were recruited through adverts (Appendix 3) which provided a summary of the study, a website link and a contact e-mail address. Nationally, parents self-selected to take part through responding to adverts which were distributed to diabetes charities, parent support groups and online parent communities between October 2011 and May 2012. Locally, potential participants were identified by outpatient diabetes teams and adverts distributed at outpatient clinics between March 2012 and May 2012. Occasionally, in-clinic parents received letters of invitation
(Appendix 4). An opt-in sheet (Appendix 5), which collected parents’ permission to be contacted about the research, was used in one outpatient clinic to facilitate staff recruiting. With online recruitment parents were responsible for assessing themselves against eligibility criteria in the participant information sheet (Appendix 6), whilst locally the research team undertook this responsibility. Both mothers and fathers were eligible to take part and a paper-based survey was available if desired. Parents did not receive any incentive for taking part.

Upon accessing the survey website parents were initially asked to complete screening questions to ensure that they met the inclusion criteria and a consent form (the time and date of completion was recorded electronically). If a parent did not meet the inclusion criteria they were unable to progress to the survey questions. Within the survey, parents were presented alternatively with standardised questionnaires and the sample Triple P material, for example, the diabetes questionnaire, followed by the ECBI and then the Triple P chronic illness tip sheet, then the DASS-21 etc. All questionnaires were presented electronically on one page and parents selected their response. The Triple P information was presented in a written format on one page, with the exception of the Triple P video which played in a window on the website, and was followed by the consumer acceptability questions. Following the last sample Triple P material, the questions relating to intention to participate and barriers to participation were presented. At the end of the survey parents were thanked for taking part.

The study received ethical approval from the University of Manchester Ethics Committee, the National Research Ethics Service as well as the relevant boards of the involved institutions. Informed consent (Appendix 7), including the date and time of provision, was obtained online. Parents were directed to appropriate support services in the event that they became distressed.
Instruments

Diabetes Questionnaire

The diabetes questionnaire (Appendix 8) was designed to gather information about diabetes factors including diagnosis date, measures of blood glucose control (as measured by glycoslated haemoglobin (HbA1c; % and mmol/mol)) and treatment regime.

Family Background Questionnaire-Brief (FBQ-B)

The FBQ-B (Sanders, Markie-Dadds, & Turner, 1999; Appendix 9) was used to collect demographic information including socio-economic status (SES), ethnicity and level of parent education.

Eyberg Child Behaviour Inventory (ECBI)

The ECBI (Eyberg & Pincus, 1999; Appendix 10) was used to measure adolescent behaviour difficulties and has been standardised for use with children aged 2-16 years and chronic illness populations. It consists of 36 items rated on two scales: a 7 point intensity scale, and a yes/no problem scale. Scores of 131 (intensity scale) and 15 (problem scale) are used as the clinical cut-off. The ECBI has good psychometric properties and high internal consistency ($\alpha=0.98$ for both scales). Good internal consistency was observed in the current sample (intensity and problem scales $\alpha=0.93$).

Depression-Anxiety-Stress-Scale-21 (DASS-21)

The DASS-21 (Lovibond & Lovibond, 1995; Appendix 11) was used to measure parental psychological well-being. It consists of 21 questions and provides three subscale scores; depression, anxiety and stress. It has good reliabilities amongst UK populations; depression scale $\alpha=0.88$, anxiety scale $\alpha=0.82$, stress scale $\alpha=0.90$ (Henry & Crawford, 2005).
Adequate internal consistency was observed for this sample; depression scale \( \alpha = 0.87 \), anxiety scale \( \alpha = 0.76 \) and stress scale \( \alpha = 0.85 \).

**Revised Diabetes Family Conflict Scale – parent version (RDFCS)**

The RDFCS (Hood, Anderson, Butler, & Laffel 2007; Appendix 12) was used to explore diabetes-related family conflict. It has 19 items rated on a three point scale resulting in a score of between 19 and 57. The questionnaire has strong psychometric properties in terms of reliability and validity (Hood et al., 2007). Acceptable internal consistency for caregiver report of diabetes-related conflict have been described, \( \alpha = 0.81 \) (Hood et al., 2007). The sample in this study demonstrated the same Cronbach’s alpha.

**Triple P Materials**

Three sources of sample Teen Triple P material (Appendix 13) were used; a video extract from the Every Parent’s Guide to Teenagers, a chronic illness tip sheet (Morawska & Sanders, 2010) and workbook captions from the group Teen Triple P facilitators manual (Sanders & Ralph, 2002). Triple P resources were used with the permission of the Triple P group at the University of Queensland, Australia. The chronic illness tip sheet provided parents with information around managing anxiety and treatment routines. The video was a seven minute introduction the key aspects of the programme. The workbook captions provided parenting strategy examples for encouraging appropriate behaviour, developing positive relationships and managing problem behaviour.

**Acceptability and participation questions**

The acceptability and participation questions (Appendix 14) were adapted, with permission, from those used by Metzler et al. (2012). The usefulness, interest, realism and familiarity of the Triple P resources and intention to participate were rated on a five point scale, with higher scores indicating greater acceptability and intention. The acceptability questions
demonstrated acceptable internal consistency within the sample; video $\alpha=0.87$, tip sheet $\alpha=0.80$ and workbook captions $\alpha=0.85$. Parents completed a single question relating to intention to participate and barriers to participation in a parenting intervention.

**Overview of the analysis**

Statistical analysis was conducted using SPSS (v. 16.0, Chicago, IL, USA). Tests of normality indicated variability in the extent to which measures met this assumption. As the consumer acceptability measures were not normally distributed non-parametric analysis was used throughout for consistency. Mann-Whitney U tests were conducted to establish if significant differences in diabetes factors existed based on adolescent gender. Correlational analyses between the Triple P acceptability responses adolescent behaviour difficulties, parent psychological well-being, diabetes-related family conflict and diabetes factors were conducted. Intention to participate was also correlated with these variables. Due to multiple testing, the significance value was adjusted to $p<0.01$ as suggested in the literature (Carley & Lecky, 2003; Teo & Chong, 2006).

**Results**

Of the parents who dropped out ($n=58$), 38 completed some, but not all measures and there were no data for 20. Figure 1 demonstrates the sample attrition based on the number of questionnaires completed by parents who dropped out of the survey. Due to only a small number of parents completing the Triple P acceptability questions, these partial data sets were excluded from the analysis.
Figure 1. Questionnaires completed by parents who dropped out of the survey

Of the 40 parents who fully completed the survey, two were excluded because one adolescent had a neuropsychiatric disorder and one parent had already completed a Triple P intervention. The remaining 38 full datasets were included in the analysis.

**Parent and adolescent characteristics**

The parent and adolescent demographic characteristics and the descriptive statistics for all variables can be seen in Table I. In relation to SES, 26% (n=10) reported being unable to meet their essential monthly expenses over the last year. Parents were in general married (79%, n=30) and the majority of adolescents resided with their original family (87%, n=33). The median level of diabetic control, as measured by HbA1c % values was slightly higher than the clinical recommendation of 7.5% or below (NICE, 2004). No significant differences between male and female adolescents were found in relation to length of time since diagnosis in years (Mdn male 6.3, Mdn female 6.0; U=157.5, z = -.66, p >.05, r = -.11) and measures of blood glucose control (HbA1c % Mdn male 7.6, Mdn female 7.8; U = 128.5, z = -1.05, p>.05, r = -.17).
Within the current sample, 13% (n=5) and 16% (n=6) of parents reported ECBI intensity and problem scores in the clinical range respectively. On the DASS-21, the median anxiety and stress scores of parents fell within the normal range, whilst their depression scores fell within the mild range. Based on severity categories, 42% of stress scores, 29% of anxiety scores and 66% of depression scores fell above the normal range indicating that levels of parental psychological distress were elevated compared to the general population. Higher scores on the RDFCS indicated greater levels of diabetes-related family conflict.

Table I. Demographic characteristics of the sample

<table>
<thead>
<tr>
<th></th>
<th>Median</th>
<th>IQR (25-75)</th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent age (years)</td>
<td>45</td>
<td>42-46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent relationship to adolescent (mother)</td>
<td>92</td>
<td>(35)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent highest level of education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed high school</td>
<td>16</td>
<td>(6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College qualification</td>
<td>34</td>
<td>(13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>University degree</td>
<td>26</td>
<td>(10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>24</td>
<td>(9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescent gender (female)</td>
<td>53</td>
<td>(20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescent age</td>
<td>14</td>
<td>12-16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of diagnosis (years)</td>
<td>6.1</td>
<td>4.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recent HbA1c (%)</td>
<td>7.6</td>
<td>7.1-8.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recent HbA1c (mmol/mol)</td>
<td>60</td>
<td>54-69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment regime</td>
<td></td>
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<tr>
<td>Injections</td>
<td>50</td>
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</tr>
<tr>
<td>Pump therapy</td>
<td>50</td>
<td>(19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity (White British)</td>
<td>55</td>
<td>(21)</td>
<td></td>
<td></td>
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<tr>
<td>ECBI Intensity</td>
<td>91</td>
<td>75-119</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ECBI Problem</td>
<td>4</td>
<td>0-12</td>
<td></td>
<td></td>
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<tr>
<td>DASS-21 Depression</td>
<td>12</td>
<td>6-15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DASS-21 Anxiety</td>
<td>4</td>
<td>0-9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DASS-21 Stress</td>
<td>14</td>
<td>8-21</td>
<td></td>
<td></td>
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<tr>
<td>RDFCS</td>
<td>26</td>
<td>23-30</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(1) Inter-quartile range

Triple P Ratings of Acceptability

A summary of the Triple P resources median acceptability scores can be seen in Table II.

In general, the median acceptability scores for the sample Triple P information indicated
that parents found the information reasonably useful, interesting, relevant and familiar. The median realism scores for the chronic illness tip sheet and the workbook captions were slightly higher, demonstrating that parents found the content of these resources realistic to a greater extent than the video. The greatest proportion of parents rated the tip sheet as ‘quite’ useful and realistic, whilst an equal number rated it as ‘somewhat’ and ‘quite’ interesting. In terms of familiarity of the situations presented most parents ratings were in the ‘somewhat’ acceptable category for the tip sheet. With regard to the video the greatest proportion of parents found it ‘somewhat’ useful, realistic and familiar and an equal number rated it as ‘somewhat’ and ‘quite’ interesting. The workbook captions were generally found to be ‘somewhat’ acceptable with the exception of ratings for realism which were mainly considered ‘quite’ acceptable. The acceptability ratings for the tip sheet were slightly stronger than those for the video and workbook. Across all of the Triple P resources only, 3% (n=1) to 8% (n=3) of parents rated them “not at all” useful, interesting, realistic and familiar.

**Table II. Acceptability ratings for the Triple P tip sheet, video and workbook**

<table>
<thead>
<tr>
<th></th>
<th>Median</th>
<th>IQR(1)</th>
<th>Resources rated ‘somewhat’ acceptable %</th>
<th>Resources rated ‘quite’ acceptable %</th>
<th>Resources rated ‘very’ acceptable %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(n)</td>
<td>(n)</td>
</tr>
<tr>
<td><strong>Tip Sheet</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Useful</td>
<td>3</td>
<td>3-4</td>
<td>32 (12)</td>
<td>37 (14)</td>
<td>11 (4)</td>
</tr>
<tr>
<td>Interesting</td>
<td>3</td>
<td>3-4</td>
<td>32 (12)</td>
<td>32 (12)</td>
<td>13 (5)</td>
</tr>
<tr>
<td>Realistic</td>
<td>4</td>
<td>3-4</td>
<td>26 (10)</td>
<td>40 (15)</td>
<td>18 (7)</td>
</tr>
<tr>
<td>Familiar</td>
<td>3</td>
<td>3-4</td>
<td>37 (14)</td>
<td>32 (12)</td>
<td>13 (5)</td>
</tr>
<tr>
<td><strong>Video</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Useful</td>
<td>3</td>
<td>2-4</td>
<td>32 (12)</td>
<td>29 (11)</td>
<td>8 (3)</td>
</tr>
<tr>
<td>Interesting</td>
<td>3</td>
<td>3-4</td>
<td>32 (12)</td>
<td>32 (12)</td>
<td>13 (5)</td>
</tr>
<tr>
<td>Realistic</td>
<td>3</td>
<td>3-4</td>
<td>50 (19)</td>
<td>21 (8)</td>
<td>16 (6)</td>
</tr>
<tr>
<td>Familiar</td>
<td>3</td>
<td>3-4</td>
<td>50 (19)</td>
<td>21 (8)</td>
<td>13 (5)</td>
</tr>
<tr>
<td><strong>Workbook</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Useful</td>
<td>3</td>
<td>2-4</td>
<td>42 (16)</td>
<td>21 (8)</td>
<td>11 (4)</td>
</tr>
<tr>
<td>Interesting</td>
<td>3</td>
<td>3-4</td>
<td>42 (16)</td>
<td>32 (12)</td>
<td>8 (3)</td>
</tr>
<tr>
<td>Realistic</td>
<td>4</td>
<td>3-4</td>
<td>37 (14)</td>
<td>40 (15)</td>
<td>16 (6)</td>
</tr>
<tr>
<td>Familiar</td>
<td>3</td>
<td>3-4</td>
<td>34 (13)</td>
<td>29 (11)</td>
<td>16 (6)</td>
</tr>
</tbody>
</table>

(1) Inter-quartile range
Correlates of acceptability

Table III shows correlations for all Triple P acceptability ratings and the adolescent behaviour difficulties, parent psychological distress, diabetes-related family conflict and diabetes measures. A significant relationship was found between the usefulness of the tip sheet and the adolescent’s length of time since T1D diagnosis ($r_s = -.419, p = 0.009$). The relationship between ratings of usefulness and diabetes-related family conflict ($r_s = .399, p = 0.013$) was also approaching significance. No significant relationships were found between the interest, usefulness, realism and familiarity of the Triple P video and parent, adolescent and diabetes factors. Ratings of usefulness of the Triple P workbook were significantly related to diabetes-related family conflict ($r_s = .419, p = 0.009$). The relationships between workbook caption ratings of interest ($r_s = .378, p = 0.019$) and familiarity ($r_s = .350, p = 0.031$) and diabetes-related family conflict were also approaching significance. Parental interest in the workbook captions was also found to be related to frequency of difficult adolescent behaviour ($r_s = .414, p = 0.010$).

Intention to participate in a parenting intervention

Parents demonstrated relatively strong intentions to participate in a parenting intervention (Mdn 4, IQR (25-75) 3-4). If offered a parenting intervention, 21% ($n=8$) of parents indicated they would definitely take part, 32% ($n=12$) indicated they would probably take part and 34% ($n=13$) said they would maybe take part. Only 3% ($n=1$) said they would definitely not take part. The offer of participating in a trial of Triple P for T1D was accepted by 18% ($n=7$) of parents indicating conversion of intention to participate to action. Due to the small number of parents who accepted the offer to participate in the trial further analysis on conversion of intention to action was not possible.
Correlates of intention to participate

The only significant correlates of intention to participate in a parenting intervention were frequency of adolescent behaviour difficulties ($r_s = .441$, $p = .006$) and level of diabetes-related family conflict ($r_s = .437$, $p = .006$). No other significant relationships between intention to participate and parent, adolescent or diabetes measures were observed.
Table III. Triple P resources acceptability rating correlations

<table>
<thead>
<tr>
<th>Measure</th>
<th>Tip sheet</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>1. Usefulness</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2. Interest</td>
<td>.60**</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.75**</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>.66**</td>
</tr>
<tr>
<td>3. Realism</td>
<td>.38*</td>
<td>.63**</td>
<td>-</td>
<td>-</td>
<td>.60**</td>
<td>.71**</td>
<td>-</td>
<td>-</td>
<td>.49**</td>
</tr>
<tr>
<td>4. Familiarity</td>
<td>.59**</td>
<td>.40*</td>
<td>.63**</td>
<td>-</td>
<td>.50**</td>
<td>.43**</td>
<td>.61**</td>
<td>-</td>
<td>.52**</td>
</tr>
<tr>
<td>5. ECBI Intensity</td>
<td>.17</td>
<td>.19</td>
<td>.32</td>
<td>.08</td>
<td>.05</td>
<td>.15</td>
<td>.04</td>
<td>.01</td>
<td>.26</td>
</tr>
<tr>
<td>6. ECBI Problem</td>
<td>.19</td>
<td>.27</td>
<td>.17</td>
<td>.09</td>
<td>-.02</td>
<td>.09</td>
<td>-.11</td>
<td>-.16</td>
<td>.28</td>
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<tr>
<td>7. DASS Depression</td>
<td>-.12</td>
<td>-.08</td>
<td>.02</td>
<td>.08</td>
<td>.07</td>
<td>.00</td>
<td>.10</td>
<td>-.07</td>
<td>.01</td>
</tr>
<tr>
<td>8. DASS Anxiety</td>
<td>.16</td>
<td>.05</td>
<td>.06</td>
<td>.24</td>
<td>.15</td>
<td>.02</td>
<td>.16</td>
<td>.19</td>
<td>.01</td>
</tr>
<tr>
<td>9. DASS Stress</td>
<td>-.04</td>
<td>-.04</td>
<td>.16</td>
<td>.17</td>
<td>.10</td>
<td>-.11</td>
<td>-.02</td>
<td>.00</td>
<td>.07</td>
</tr>
<tr>
<td>10. RDFCS</td>
<td>.40*</td>
<td>.28</td>
<td>.17</td>
<td>.29</td>
<td>.18</td>
<td>.18</td>
<td>-.01</td>
<td>.07</td>
<td>.42**</td>
</tr>
<tr>
<td>11. Length of diagnosis</td>
<td>-.42**</td>
<td>-.29</td>
<td>-.19</td>
<td>-.18</td>
<td>-.20</td>
<td>-.33*</td>
<td>-.02</td>
<td>-.14</td>
<td>-.33*</td>
</tr>
<tr>
<td>12. Recent HbA1c (%)</td>
<td>-.09</td>
<td>-.00</td>
<td>-.04</td>
<td>.12</td>
<td>.02</td>
<td>-.11</td>
<td>-.07</td>
<td>.10</td>
<td>-.07</td>
</tr>
</tbody>
</table>

*p<.05, **p<.01
With regard to the acceptability of the Triple P information, ratings of interest ($r_s = .543$, $p = .000$) and realism ($r_s = .441$, $p = .006$) for the chronic illness tip sheet were significantly related to parents intention to participate. Significant relationships between intention to participate in a parenting programme and ratings of interest ($r_s = .585$, $p = .000$) and realism ($r_s = .498$, $p = .001$) were also observed for the Triple P video. The relationship between intention to participate and the usefulness ratings of the video clip were also almost significant ($r_s = .400$, $p = .013$). For the workbook captions, significant relationships between all acceptability measures and intention to participate were found; usefulness ($r_s = .567$, $p = .000$), interest ($r_s = .648$, $p = .000$), realism ($r_s = .471$, $p = .003$) and familiarity ($r_s = .432$, $p = .007$).

**Barriers to participation in a parenting intervention**

Table IV shows the percentage of parents who selected each barrier to participation. Descriptive comments were provided by some parents and highlighted additional barriers. These included a lack of adolescent willingness to be involved, the daily impact on the family and childcare difficulties if absence from home was required to attend parenting sessions.

**Table IV. Percentage of parents who reported each barrier**

<table>
<thead>
<tr>
<th>Barrier</th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No barriers</td>
<td>37</td>
<td>(14)</td>
</tr>
<tr>
<td>Not enough information about parenting strategies</td>
<td>8</td>
<td>(3 )</td>
</tr>
<tr>
<td>Not enough time</td>
<td>26</td>
<td>(10)</td>
</tr>
<tr>
<td>Don’t agree with ideas presented</td>
<td>0</td>
<td>(0 )</td>
</tr>
<tr>
<td>Wouldn’t be able to do strategies</td>
<td>0</td>
<td>(0 )</td>
</tr>
<tr>
<td>Strategies wouldn’t work for us</td>
<td>5</td>
<td>(2 )</td>
</tr>
<tr>
<td>Too upset and stressed to try anything different</td>
<td>3</td>
<td>(1 )</td>
</tr>
<tr>
<td>Parenting improvements not needed</td>
<td>13</td>
<td>(5 )</td>
</tr>
<tr>
<td>Not enough support</td>
<td>16</td>
<td>(6 )</td>
</tr>
<tr>
<td>Other barriers</td>
<td>21</td>
<td>(8 )</td>
</tr>
</tbody>
</table>
Discussion

The purpose of this study was to use a consumer perspective approach to explore the acceptability of Teen Triple P parenting resources, in terms of usefulness, interest, realism and familiarity among parents of adolescents with T1D. The acceptability ratings indicated that Teen Triple P materials relating to general parenting strategies and those specifically for chronic illness were reasonably well suited and applicable to parents of adolescents with T1D. Reasonably strong intentions to participate were also demonstrated by parents. These findings provide support in favour of adapting Teen Triple P for chronic physical illness populations and specifically T1D.

The acceptability ratings for the different sources of Triple P information provide useful information with regard to the types of parenting resources parents are likely to find most appealing. The usefulness and realism ratings for the chronic illness specific tip sheet indicate that parents of adolescents with T1D are likely to find tip sheets an acceptable format in which to receive parenting support. For the Triple P video and the workbook captions, the acceptability ratings indicate that parenting advice in this format does have the potential to be acceptable to parents of adolescents with T1D. Taken together it seems that the Triple P resources could provide parenting support to those who have an adolescent with T1D in an acceptable manner. It is important to be mindful that the presented resources only provided a limited amount of example Triple P information and this may have impacted upon the acceptability ratings. Furthermore, the ratings are likely to have been impacted upon by personal preferences, for example, some parents may prefer to sit down and watch a video whilst others may prefer to read the information.

A further aim of this research was to explore the relationships between the acceptability of the parenting resources and adolescent behaviour difficulties, parent psychological well-being, diabetes-related family conflict and diabetes factors. In general, there were few
significant relationships between parental ratings of acceptability and adolescent behaviour difficulties. This may be explained by the levels of adolescent behaviour difficulties reported in this sample generally falling below the clinical range recommended by Eyberg & Pincus (1999). These findings are consistent with research which describes relatively low levels of behaviour difficulties amongst T1D adolescent populations (Cohen et al., 2004). However, in this study a small number of parents reported clinically significant behaviour difficulties. Taken together these findings may suggest that in general adolescents with T1D do not demonstrate behaviour difficulties which are of clinical concern. However, it seems plausible that for those who do, this may be reflective of factors other than their chronic illness. A significant relationship between ratings of interest for the workbook captions and the frequency of adolescent behaviour difficulties was found with stronger acceptability ratings associated with increased levels of behaviour difficulties. This relationship may be accounted for by the managing challenging behaviour example provided in the sample workbook captions.

Parents within this sample demonstrated elevated scores across all DASS-21 subscales in comparison to UK norms (Henry & Crawford, 2005) and had particularly raised depression and stress scores. Given that parents may face additional challenges in the context of an adolescent’s T1D (Lowes, 2010) and the intensive medical management of the condition, it is not surprising that parents stress levels were raised in comparison to the general UK population and fell at the top of the normal range. Consistent with other literature within this field (Kovacs et al., 1985; Williams et al., 2009), this sample of parents was found to demonstrate elevated depression scores, with 42% of parents scores falling in or above the moderate range. This is concerning and highlights the importance of identifying parents who may be demonstrating depressive symptoms as these can impact on parenting approach, adolescent mood and quality of life and ultimately T1D management (Jaser et al, 2008).
Despite the observed levels of parental psychological distress, no significant relationships were found between ratings of acceptability and their levels of depression, anxiety and stress. This may be due to the Teen Triple P resources providing parenting strategies for managing adolescent behaviour and distress as opposed to strategies directly aimed at parental emotional distress. It is possible that parents may consider factors external to themselves, such as their relationship with their adolescent, when deciding if parenting information is acceptable. However, one area Triple P aims to address is the emotional well-being of parents (Sanders, Markie-Dadds & Turner, 2003). Parents need to be made aware of the breadth of Triple P and this could be achieved through the adoption of a public health approach (Sanders, 2012) to increase knowledge of parenting interventions.

Levels of diabetes-related family conflict found in this study were slightly higher than those described by Hood et al. (2007). Nevertheless, these still fell at the lower end of the scale indicating that for most families there is only a small amount of conflict associated with diabetes management tasks. Despite this, diabetes-related family conflict was found to be significantly related to the usefulness of the workbook captions. In addition the relationship between the usefulness ratings of the chronic illness tip sheet and interest ratings for the workbook captions and diabetes-related family conflict scores were approaching significance. As levels of diabetes-related family conflict increased, ratings of acceptability became stronger. These findings may be due to the workbook captions and the chronic illness tip sheet providing examples of how to manage situations which could potentially lead to family conflict.

Diabetes factors, such as length of time since T1D diagnosis and measures of blood glucose control were in general not significantly related to acceptability ratings. This may indicate that parents do not necessarily view these factors as impacting upon their parenting. However, a significant relationship between the usefulness of the chronic illness
A tip sheet was found, with those whose adolescents had a shorter length of T1D diagnosis finding the information more useful. These findings are not surprising given the impact that T1D diagnosis has on parents (Streisand et al., 2010; Whittemore et al., 2010) and indicate that parents value supportive resources which are easily accessible. Such resources may be particularly helpful at time of diagnosis or shortly after.

A lack of significant relationships were found between the Triple P video acceptability ratings and adolescent behaviour difficulties, parental psychological well-being, diabetes-related family conflict or diabetes factors. This may be due to the video introducing the principles of Triple P and providing parent testimonials rather than examples of parenting strategies.

A considerable number of parents demonstrated an intention to participate in a parenting intervention. These findings are consistent with research which has reported that parents are open to receiving psychological support (Christie et al., 2008) and indicates that parents would welcome a Triple P intervention in the context of T1D. Despite many parents demonstrating reasonably strong intentions to participate, only a small proportion converted this to action by accepting the offer of taking part in a Triple P trial. Further exploration of intention to participate ratings amongst parents who demonstrated action revealed that it was not necessarily those with the strongest intentions who accepted the offer. This may be reflective of individuals who are keen to take part in research or those who felt they had sufficient time to engage in an intervention, as opposed to those who wish to receive a parenting intervention.

It is important that researchers strive to understand the potential barriers to participation in parenting interventions and that these are addressed during programme development (Sanders & Kirby, 2012). A selection of parents within this study indicated that they did not
see any barriers, whilst the most commonly identified barrier was time. Triple P is able to respond to such barriers through its range of delivery formats (Sanders, 2012), some of which can be used by parents in their own homes at their convenience, for example, the self-directed workbooks. Development of Triple P for parents of adolescents with T1D must carefully consider potential barriers and incorporate easily accessible and convenient parenting resources such as the chronic illness tip sheet.

Adopting a consumer approach has many advantages as it facilitates the development of meaningful interventions. When parents are involved in the development of a parenting intervention it is more likely that they will demonstrate intention to participate (Sanders & Kirby, 2012). Whilst the consumer approach taken in this work has considered only parents, there are a number of alternative consumers who must also be considered including the teenagers themselves and healthcare providers (Sanders & Kirby, 2012). Given that adolescent preferences may differ considerably from those of their parents (Christie et al., 2008), it is vital that their views are considered to promote their involvement and engagement with parenting strategies that may be introduced within the home. Furthermore, if parenting interventions are to become available in the context of an adolescent’s T1D, service providers need to understand what effective assistance can be offered. However, to date the consumer views of adolescents and healthcare providers is relatively unexplored (Sanders & Kirby, 2012). Further research using both quantitative and qualitative methodology must be conducted to support the development of parenting resources which address the needs of all those involved. An additional focus of this work must be building awareness of Teen Triple P, with a view to impacting on the demand for this form of psychological support in the context of adolescent T1D.

The results of this study must be considered in light of several limitations. The cross-sectional nature of the research and the small sample size limits the conclusions which can
be drawn. Furthermore, the sample broadly represented mothers, of White British background and with high levels of education. Therefore the findings cannot be generalised to ethnic minority groups and fathers or other caregivers. Despite these limitations, this research contributes new knowledge and understanding in relation to parents in the context of an adolescent’s T1D. The Triple P intervention may facilitate healthcare professionals in meeting clinical practice guidelines for the provision of psychological support. However validation studies must be undertaken first. Diabetes-related family conflict specifically may be one factor which can be used to guide the identification of families who require additional support. These research findings also highlight the importance of paediatric diabetes teams monitoring and responding to parental psychological distress.

This study indicates that parents of adolescents with T1D are open to receiving parenting support and that the Teen Triple P resources are acceptable to them. Parents demonstrated reasonably strong intentions to participate and a small number of significant relationships between ratings of acceptability and adolescent behaviour, parental psychological distress, diabetes-related family conflict and diabetes factors were found. Taken together these results indicate that parenting support would be welcomed by the majority of parents. The findings demonstrate that further research to support the development and validation of interventions which address the specific needs of parents in the context of their adolescent’s T1D would be of value.

References


PAPER THREE

Critical Evaluation

Word Count: 8496
Introduction

The presented papers aimed to consider and develop an understanding of the psychological status of parents and the acceptability of parenting support in the context of adolescent type one diabetes (T1D). It has been widely acknowledged within the literature that the management of an adolescent’s T1D can lead to challenges for the whole family and in particular parents (Hoff et al., 2005; Liberman, Buckingham & Phillip, 2012; Striesand, Mackey & Herve, 2010; Whittemore, Jaser, Guo & Grey, 2010). Evidence-based parenting interventions, such as Triple P (Sanders, 2012) and The Incredible Years (Webster-Stratton & Herman, 2010), offer a form of psychological support that is applicable to a range of parents. Such interventions are increasingly being recognised within policy documents, for example, those written by the National Institute for Health and Clinical Excellence (NICE). Parenting interventions could offer healthcare professionals a means of supporting mothers and fathers in negotiating the parenting challenges they may face in the context of an adolescent’s T1D.

Parents play an important role in supporting their adolescent to manage their T1D (Anderson, Auslander, Jung, Miller, & Santiago, 1990) and parental psychological well-being has been shown to impact upon parenting styles (Jaser & Grey, 2010). For these reason, a systematic review of the literature considering levels of parental anxiety, depression or psychological distress was undertaken. The literature presented mixed findings relating to levels of parental anxiety, depression or psychological distress in the context of their adolescent’s T1D. However, it was concluded that a group of parents are likely to experience significant symptoms of anxiety, depression or psychological distress for which they may require additional support. Importantly increased levels of parental distress were found to occur at different times throughout an adolescent’s T1D. At point of diagnosis elevated levels of distress in comparison to normative samples have been
reported (Kovacs et al., 1985; Northam, Anderson, Adler, Werther, & Warne, 1996), whilst several years following diagnosis a proportion of parents have been found to experience clinically significant depressive symptoms (Berg et al., 2007; Hood, 2009). A considerable methodological limitation of the papers reviewed was the lack of control for pre-existing parental mental health difficulties and other life stressors. This made it difficult to conclude that the reported levels of parental anxiety, depression or psychological distress were specifically related to their adolescent’s T1D.

The Triple P Positive Parenting Programme is an evidence-based parenting intervention which is widely used and was of particular interest due to its range of delivery formats (Sanders, 2012). Triple P is versatile and flexible thus enabling its strategies to be adapted for different parent populations and for parenting resources which address specific parenting challenges to be developed, for example, tip sheets. To date Triple P has not been tailored for use with parents of adolescents with T1D. To support the development of ecologically valid parenting interventions, the views of parents must be considered (Sanders & Kirby, 2012). The second paper presented is a study which aimed to explore the acceptability of Teen Triple P resources and to develop an understanding of additional factors which might influence parental ratings of acceptability in the context of adolescent T1D. Parents’ intention to participate in a parenting intervention, barriers to participation and conversion of their intention to action were also considered. It was hoped that this paper would provide evidence to determine the value of pursuing the development and validation of a Triple P intervention specifically for T1D populations. Over recent years, there has been a movement towards consumer involvement within health research (Boote, Telford & Cooper, 2002). The study described in paper two was to the author’s knowledge the first which has used a consumer acceptability approach in relation to a parenting intervention in the context of adolescent T1D.
This present paper aims to critically appraise both the literature review and the empirical paper giving consideration to their strengths and weaknesses. In addition implications for future research and clinical practice are discussed.

**Literature review**

Policy guidelines on the treatment of youth T1D emphasise the provision of psychological support for the adolescent and their family (International Society for Pediatric and Adolescent Diabetes [ISPAD], 2011; National Institute for Health and Clinical Excellence [NICE], 2004). Given this recommendation, and in view of the literature indicating that T1D diagnosis in an adolescent has an emotional impact on parents (Kovacs et al., 1985), it seemed appropriate and necessary to gain an understanding of the psychological status of parents of adolescents with T1D.

Adolescence was selected as the age group for consideration within the current review, as it is a period of developmental transition, which leads to a change in role for parents and the young person. One specific change that occurs is the transference of increasing responsibility to the adolescent for the management of their T1D (Anderson et al., 1990). The impact of this change is important to consider as levels of parental involvement in T1D management tasks have been highlighted as potentially impacting upon family conflict and T1D treatment adherence (Anderson et al., 2002). In addition, this age group has the greatest number of young people with T1D in the UK, with 76.8% of children with T1D falling between the ages of 10 and 17 years (Diabetes UK, 2011), thus increasing the relevance of the review.

Prior to undertaking the systematic review a search was conducted to find out whether any previous literature reviews on the psychological well-being of parents of adolescents with T1D had been conducted. None were identified and therefore the review undertaken fills a
gap within the literature. It was noted that a considerable number of research papers had explored parental anxiety, depression or psychological distress in the context of an adolescent’s T1D, thus highlighting that these factors were considered important within this field of research. Of the papers that had considered parental psychological status, it was frequently noted that parents were not the primary focus of the research. This presented challenges when selecting search terms and conducting the literature search, as it was possible that the studies may have collected parent data, but may not have reported this within the abstract or keywords.

The systematic review search strategy used a large array of search terms, which led to significant challenges. The over inclusive approach to search terms was adopted following advice from the faculty librarian and due to a number of different terms noted to be used within the literature when reading around the subject area. Furthermore, abstracts were very variable in the relation to the level of detail they provided regarding the parental measures collected. It was felt that using a wide range of search terms would minimise the chance of relevant papers being missed and would ensure that the review was thorough. However, this approach was not without problems, as it resulted in a considerable number of irrelevant papers amongst search results which indicates that the search terms selected were too broad. Indeed, it has been highlighted within the literature that search terms need to be balanced in breadth and focus to ensure relevant papers are not overlooked, whilst ensuring a minimal number of irrelevant papers are identified (Smith, Devane, Begley & Clarke, 2011). The search strategy used meant that the process of selecting appropriate articles was time consuming, however it ensured confidence that no relevant literature had been missed.

On reflection the search terms used in the systematic review were too broad. If conducting the review again, it would be beneficial to refine the key words selected to maximise the
number of relevant studies accessed and to reduce the number of irrelevant studies identified, for example, using terms type one diabetes, adolescents and parents alone and exploding these when conducting the searches as opposed to searching for a wide range of different variations. It would also be useful to streamline the number of terms used in relation to parental psychological well-being to anxiety, depression and psychological distress as opposed to the wide range used in the presented review. This would have the added benefit of enabling the reviewer to successfully track the article selection process without feeling overwhelmed by the search results. This could be achieved through more testing of the search terms prior to conducting the systematic review.

One potential limitation of the literature review was the decision not to conduct a formal quality assessment of the included studies. Although it is widely acknowledged that quality assessment is valuable, the use of tools which provide quality scores is not advocated (The Cochrane Collaboration, 2011; Centre for Dissemination York, 2008). Furthermore, a systematic review of critical appraisal assessments highlighted the limitations of such tools specifically within the field of allied health research (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004). In view of the lack of quality assessment tools that can be successfully applied across research designs, and their limited use in relation to health research, a formal quality assessment was not undertaken (Katrak et al., 2004). As an alternative, the author commented on some of the methodological limitations of the included studies in the discussion section. However, due to the journal guidelines being followed there was insufficient space for detailed discussion of these.

The literature review enabled an over-arching picture of parental psychological well-being at the time of an adolescent’s T1D diagnosis, and with increasing time since diagnosis to be established. The review indicated that the parental emotional response to adolescent T1D was variable. Unsurprisingly, at diagnosis parents were often reported to experience
increased levels of anxiety, depression or psychological distress, however the common trend was for this to decrease over time. Elevated levels of parental anxiety, depression or psychological distress were also reported amongst parents whose adolescents had had T1D for longer periods of time. Interestingly, for some parents increases in levels of distress were observed over time.

In general, the literature review indicated that parents coped successfully with the emotional impact of their adolescent’s diagnosis. However, it was also found that a group of parents experienced clinically significant symptoms of anxiety, depression or psychological distress at different stages of their adolescent’s T1D. This is particularly important when considering the impact that parental psychological well-being can have on their offspring’s psychological functioning (Kovacs, Goldston, Obrosky & Bonar, 1997; Mullins et al., 1995), and ultimately T1D management (Cunningham, Dolan, Vesco, & Hood, 2011). The review highlighted that parental psychological status is not an area which should be overlooked by paediatric diabetes teams. Indeed teams are well placed to monitor, identify and offer support to parents who may be experiencing symptoms of anxiety, depression or psychological distress.

The findings of the literature review must be carefully considered in the context of the methodologies used by the studies included. The lack of controlling for pre-existing mental health difficulties amongst parents and the cross-sectional nature of many of the studies make it difficult to confidently conclude that the levels of anxiety, depression and psychological distress reported are related specifically to the presence of adolescent T1D. It must be acknowledged that there are many additional factors which could impact on parental psychological well-being, such as, financial concerns and marital discord. In addition the limitations of comparing parental measures with normative data must be borne in mind. The use of published norms has many advantages as the measures have
often undergone psychometric testing in terms of validity and reliability and they are also a financially viable option (Kendal, Marrs-Garcia, Nath, & Sheldrick, 1999). However, the samples used for normative data collection may not be representative of those in research studies, particularly if the norms have been developed some time ago and in a different country from which the research is taking place in. Indeed Kendal and colleagues (1999) highlight that “it is not always clear which population is to be considered normative.” This is particularly important when considering parents as there is no guarantee that the normative sample individuals are parents.

Future research exploring parental psychological status should carefully consider methodology during the planning stage to ensure that the impact of T1D on parental well-being specifically is being explored. Studies should collect data on and control for pre-existing parental mental health difficulties and/or already raised levels of anxiety, depression or psychological distress. Such factors should be considered during the data analysis stage. Furthermore researchers should strive to use a longitudinal approach, preferably starting at time of T1D diagnosis and regularly monitoring parental well-being over time. It would also be advantageous for control groups to be used, for example, parents of adolescents with another chronic health condition and parents of adolescents who have no health conditions. Careful attention should be paid to the selection of control groups to ensure that they are as representative as possible. The use of such control groups would enable researchers to establish if there are different patterns of parental distress depending upon the adolescent’s health condition. The use of the abovementioned methodological approaches would enable a clearer picture of parental psychological well-being in the context of adolescent T1D to be established.

Undertaking a systematic literature review provided many learning opportunities and supported the development of new research skills. Time management was a considerable
challenge as completion of the empirical paper and clinical work was being undertaken at the same time. Furthermore, the systematic review undertaken was thorough and required additional work in identifying papers for inclusion as the abstracts often did not include sufficient information. The challenges faced were managed by carefully planning research time and by seeking out resources which offered guidance on conducting systematic literature reviews (Jesson, Matheson, & Lacey, 2011). Despite the challenges, the literature review offers research and clinical communities an insight into the psychological well-being of parents in the context of adolescents T1D and has implications for clinical practice and future research.

**Empirical paper**

Alongside the diabetes and parenting survey of consumer acceptability, a trial of self-directed Triple P for parents of adolescents with T1D was being undertaken by a fellow trainee clinical psychologist. The projects were independent. However, during the development stages of the research projects, much work was done collaboratively including the feasibility exercise and the website development. A joint website was set up for recruitment as they were both using online methodology. One advantage of the trial running concurrently was the ability to assess conversion of intention to participate through to action by recording which individuals went on to take part in the trial after completing the survey.

**Feasibility Exercise**

Prior to obtaining ethical approval, a feasibility exercise was carried out at a Diabetes Northern Ireland family weekend. This was arranged by the chief investigator of the Triple P trial who had volunteered with Diabetes Northern Ireland for a number of years. Sixteen families who had a child or adolescent with T1D were involved. This exercise was part of the programme for the family weekend and primarily aimed to explore if parenting support was of interest to parents of young people with T1D. During the session a brief
introduction to Triple P was provided followed by an exercise which involved parents writing down on post it notes the challenges that they faced as parents of young people with T1D and the areas that caused them the most concern. Parents were also asked if they would be interested in taking part in a parenting intervention, their preferences for receiving this information (i.e. paper based or web based) and the barriers and facilitators to taking part in research.

Parents were receptive to the idea of parenting support, and indicated that they would consider both paper-based and web-based interventions. Parents identified a number of areas that would be important to them when deciding whether they could benefit from a parenting programme. These included the provision of relevant and non-judgemental content, clear and concise information, empathy, parent testimonials and seeing progress for the child and the family. Parents expressed particular concerns relating to T1D including emotional responses, the impact on siblings, diabetes management responsibilities, challenges in relation to school and managing the ‘teenage years’ in general. This feasibility exercise indicated that amongst parents of adolescents with T1D, there was considerable interest in parenting interventions. However, the importance of adapting parenting support to meet this population’s specific needs was also highlighted. This exercise provided support in favour of research which explored the acceptability of Triple P parenting resources within this population.

Conducting the feasibility exercise highlighted that parent’s views provide a rich source of data in relation to the specific challenges they face in the context of their child’s T1D. Although the empirical study took a quantitative approach on reflection, a qualitative approach alongside this would have been very useful. Qualitative focus groups or interviews with individual parents would have provided detailed information regarding the specific parenting challenges they face in the context of their young person’s T1D and the areas with which they would like additional support. Such information would have enabled
the development of Triple P resources which are responsive to the specific needs of parents.

**Design**

In recent decades, society has become increasingly focused and centred on the use of technology. The internet has revolutionised the way in which people communicate and interact, and it provides researchers with a new tool to support study recruitment and involvement. Riva, Teruzzi, and Anolli (2003) highlighted the advantages of utilising a web-based approach, including increased access to potential participants and reduced financial research costs. Additionally, they found no differences in the completion of online questionnaires or paper based assessments. Indeed, the internet has been increasingly used within psychological research on parenting (Sanders, Haslam, Calam, Southwell, & Stallman, 2011; Metzler, Sanders, Rusby, & Crowley, 2012).

The study reported in this thesis used an anonymous web-based survey design, as a means of increasing access to parents of adolescents with T1D across the United Kingdom (UK). It is possible that the use of such an approach may reduce the representativeness of the sample as the participants recruited are often of higher socio-economic and education status (Riva et al., 2003). Furthermore, differences across cultures have been highlighted in relation to the health topics searched for on the internet and the frequency with which these are undertaken (Morahan-Martin, 2004). This could have potentially impacted on study recruitment as individuals belonging to different cultural groups may have not accessed the health related websites which were supporting study recruitment. However, recent statistics have indicated that within the last five years, there has been a considerable increase in the number of UK households who have internet access at home. In 2007 61% of households had internet access by 2011 this figure had increased to 77%. Importantly, data collected from households without internet access reported that for the majority of
people, the lack of internet access was because they felt they did not need it (Office for National Statistics, 2011). In an attempt to address this concern, a paper-based version of the survey was also made available. Of significant note, throughout recruitment only one request for a paper-based survey was made, however, due to exclusionary criteria, this individual was unable to take part. The lack of requests for a paper-based version of the survey provides further support in favour of using the internet to recruit research participants.

In designing the shared website for recruitment to the survey of consumer acceptability and the Triple P trial, a host web address “www.diabetesandparenting.org.uk” was purchased. This was selected as it was memorable and easy to type into a web-browser. The home page provided a brief introduction to each study, with a link to further details. The presentation order of the studies was randomised, with the survey presented first in some cases and the trial in others. It was hoped that this approach would encourage recruitment for both studies. Designing the website was a complicated progress which was facilitated by the web technician in the Division of Clinical Psychology at the University of Manchester.

In relation to the study of consumer acceptability presented in paper two, one element of the research design had to be adapted during recruitment. The initial questionnaire sequence required parents to complete the diabetes and demographic information, followed by measures of adolescent behaviour difficulties, parental psychological well-being and diabetes-related family conflict. After completing these questionnaires, parents were presented with the Teen Triple P parenting resources and rated them for acceptability. Due to the length of the survey, it was noted that many parents were dropping out before accessing the Triple P resources. Furthermore, the Triple P video, which was shown first, presented technical difficulties for several parents, potentially impacting on drop out from
the survey. In order to overcome these challenges, the questionnaire order was changed so that parents were presented with Triple P information and other questionnaires in an alternating fashion. The Triple P video was presented last in an attempt to minimise drop out due to technical difficulties. It was hoped that this would improve motivation and retention in the survey. Despite these efforts, this approach did not appear to impact considerably on the number of parents who fully completed the survey. On reflection, it would have been beneficial for the survey to have been shorter in length.

The survey design meant that parents were anonymous to the research team throughout their participation. It was thought this may have been advantageous as it provided parents with an extra level of confidentiality and may have enabled them to be more forthcoming in their questionnaire responses. However, it may have been beneficial to ask for a contact e-mail address. It is likely this would have facilitated study retention as parents could have been contacted with gentle reminders encouraging study completion.

Drop out was a considerable problem with 59% of those who commenced the survey not finishing. It could be suggested that this high rate of drop out implies that parents of adolescents with T1D were not interested in the Triple P parenting resources and that the likelihood of receiving favourable consumer acceptability ratings was increased as only interested parents completed the whole survey. However, very few parents accessed the Triple P resources prior to dropping out (as demonstrated by the graph on page 52 of the empirical paper). It therefore seems reasonable to speculate that there were other reasons for drop out. For example, one of the first questionnaires parents were presented with was the Eyberg Child Behaviour Inventory. This is a relatively long questionnaire to complete and it is possible that parents did not feel the questions were applicable to them and their adolescent. The initial questionnaires presented must be carefully considered as research has reported that most participants go through an orientation stage following completion.
of the consent form before making a final decision regarding participation (Reips, 2002). As the survey design did not enable reasons for drop out to be collected the conclusions drawn in the empirical paper must be considered with the rates of drop out in mind and the acceptability ratings tentatively interpreted.

**Consumer Perspective Approach**

The benefits of adopting a consumer perspective approach, particularly when developing interventions for new populations, have been document in several studies (Metzler et al., 2012; Sanders et al., 2011). Within this study and consistent with other research teams, parents were identified as the consumers of the parenting intervention. However, the breadth of consumer research needs to be extended (Sanders & Kirby, 2012). Although it is parents who directly engage in the parenting intervention, it is important to gather information about the teenagers’ perceptions of the strategies discussed in Triple P. Indeed, within the empirical research, one parent identified teenager agreement to adopting the approach as a barrier to participation. Research teams and programme developers should carefully consider the views of parents and their offspring, with a view to strengthening the acceptability of the parenting approach. Other potential consumers are the members of healthcare teams (Sanders & Kirby, 2012) who provide support to families of an adolescent with T1D. The views of clinicians and healthcare teams must also be considered and incorporated into the developing programmes to support implementation.

The consumer acceptability element of the empirical research involved a quantitative approach. One benefit of this was the ability to conduct statistical analysis on the data collected. It was hoped that a statistical approach would have enabled predictors of acceptability to be identified through regression analysis. Unfortunately this was not possible due to the small sample size (see recruitment and statistical analysis sections for
further details). On reflection and given that the research was exploratory in nature, it may have been beneficial to utilise a mixed methodology approach, so as to also incorporate qualitative data from parents. This would have enabled more detail to be gathered relating to parental views of the Triple P resources and the unique parenting challenges that are faced in the context of T1D.

The consumer acceptability ratings provided by parents were collected using a five point scale (Appendix 14). The chronic illness tip sheet received the greatest proportion of ‘quite’ acceptable ratings when compared to the video and workbook captions. This may have been due to the tip sheet providing a greater level of details than the other resources therefore enabling parents to form stronger opinions on the acceptability. Alternatively it may have been due to the tip sheet focus on chronic illness as opposed to the general parenting principles presented in the video and workbook. The ratings indicate that all of the Triple P resources presented have the potential to be well received by parents of adolescents with T1D. However it appears likely that the Triple P resources may need adapting slightly for this population to ensure that the parenting support offered is relevant to their situation. It might have been useful to have had free text response boxes alongside the consumer acceptability response scale so that parents could have provided more information regarding their rating selection and/or any changes they would suggest. This would have further supported the development of the Triple P resources for parents of adolescents with T1D.

**Recruitment**

Initially it was intended that individuals would be recruited to take part in the research through national diabetes charities and organisations, along with parent support groups and online parent communities. It was hoped that this would increase the reach of the research and facilitate access to a sample that was broadly representative of parents across the UK.
In addition, careful consideration of the national statistics published by Diabetes UK (2011) indicated that a greater number of parents of adolescents aged 11-17 years could be accessed through using a national as opposed to local recruitment approach (for example, through local Primary Care Trusts (PCTs). Despite successfully building links with a range of organisations including Diabetes UK and the online community for parents of children and adolescents with T1D, recruitment and more specifically retention of parents in the survey was problematic. It may have been advantageous to offer some form of incentive to encourage survey completion, such as, entry into a prize draw for gift vouchers. This was not considered during the planning stages of the research and therefore had not received ethical approval. Time limitations meant it was not possible to pursue this option. Furthermore, it may have introduced bias into the sample, and the research team would have had no way of entering those who had already completed the survey into the prize drawn.

Following two months of slow recruitment, a decision was made to apply for National Research Ethics Service (NRES) approval, to enable access to parents through local National Health Service (NHS) diabetes outpatient clinics. Networks were established with two local diabetic outpatient clinics by making contact with clinical psychologists who worked in the teams. Meetings with the multi-disciplinary team (MDT) took place during which the research project was presented and the recruitment approach discussed. Paediatric clinical staff had little knowledge of Triple P and seemed interested in the potential provision of parenting support for the families they cared for and were willing to support the research. To support the clinicians in recruiting participants and to remind the team about the study, the lead researcher attended clinic regularly.

Although this approach enabled access to a considerable number of parents, there was limited recruitment success. It was felt that this was due to the survey having been
primarily designed for completion online. Parents were provided with information about the survey, but had to demonstrate high levels of motivation to access the survey at home. Every effort was made to facilitate parents taking part, including the provision of aesthetically pleasing postcards which took the same format as the adverts (Appendix 3). One considerable limitation to this recruitment strategy was that the diabetes and parenting website could not be used to recruit parents from hospital-based sites, as the Triple P trial had not obtained NRES ethical approval. Subsequently, an alternative website was set up which was hosted on the University internet. However, this website address was predetermined and was lengthy, presenting a further barrier to recruitment. The Chief Investigator attempted to manage this limitation by inviting parents to make contact via e-mail, so that they could be sent a link to the website thus increasing accessibility for parents.

On reflection, the survey design would have been different had recruitment occurred primarily through outpatient diabetic clinics. If this approach had been pursued from the start, the survey would have used paper-based questionnaires which could have been completed in clinic, and may have focused on the acceptability of one specific parenting resource such as the chronic illness tip sheet. Another possibility would have been to provide copies of the Triple P chronic illness tip sheet for parents to take away, thus providing an incentive for taking part in the research project. Had this approach been adopted, a greater number of participants may have been retained which would have strengthened the statistical power of the research. Working with the paediatric diabetes teams highlighted the busy nature of the outpatient environment and indicated that ideally a dedicated researcher is required in clinic to facilitate study recruitment.
Sample Characteristics

A considerable challenge was accessing a population of caregivers who were representative of those who may be involved in an adolescents T1D management. Consistent with other research undertaken within this field (Gonder-Frederick et al, 2006; Ingerski, Laffel, Drotar, Repaske, & Hood, 2010), the sample of the participants recruited to the empirical study were found to be representative of mothers. It may be that mothers are highly represented in research due to the assumptions that they undertake the role of main caregiver role with the home (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005), and therefore in turn the management of T1D. Some fathers (n=3) had completed the survey, but due to the small number, it was not possible to treat them as a separate group for analysis.

Although many researchers recruit both mothers and fathers within the field of paediatric psychology research it has been noted that samples often report on “parents” as a whole (Phares et al., 2005). Researchers should strive to identify factors which encourage and facilitate fathers’ involvement thus leading to sufficient numbers for them to be considered separately from mothers. This is particularly important given that some research has indicated that paternal reports of psychological distress and child behaviour difficulties are greater than those reported by mothers (Sanders et al., 2011). During recruitment through the diabetes clinics, it was noted that fathers often attended with their adolescent and/or partner. Therefore, recruiting parents through diabetes clinics may lead to greater uptake of fathers within research. Indeed, some research teams have successfully recruited fathers using this approach (Butner et al., 2009).

Additionally, the study sample was representative of parents who had high levels of education; 26% of the sample had university degrees and a further 24% had post graduate degrees. These post-graduate rates of education are considerably higher than those
reported amongst the general UK population (Higher Education Statistics Agency, 2007). Within the UK workforce, 7.3% of individuals of a similar age to the parents in this study (45-49 years) identified themselves as having postgraduate qualifications in 2006 (Higher Education Statistics Agency, 2007). It is possible that those who have undertaken postgraduate qualifications are likely to have been involved in research previously and are therefore more likely to value its contribution and take part.

Ethnicity data were collected via a free text box for individuals to complete. A wide range of responses were provided, including variations on British, White British and different religions. Determining the best way to group people was difficult and led to discussions within the research team and with third parties to explore potential options. A decision was made to group people as British, or other. It may have been advantageous to have used an ethnicity question which provided pre-identified groups, for example, those used by the UK census (Office for National Statistics, 2005a). This would have enabled a clearer understanding of the ethnicity of the sample to be obtained. Despite these challenges, it was possible to identify that over 50% of the sample was British. A small number of alternative ethnic groups were also identified, including, Pakistani and White South African.

On reflection, it may also have been useful to collect SES information using, pre-identified categories, such as those used by the Office of National Statistics (Office for National Statistics, 2005b) as opposed to using a question relating to whether essential monthly expenses had been met in the family background questionnaire-brief (Appendix 9). Considering SES is particularly important as it has been linked to health status, including depression (Adler et al., 1994), and levels of externalising behaviour in adolescents, with those who demonstrate higher levels of externalising behaviour more likely to have a father from manual social class (Coleman et al., 2009).
Taken together, the parent characteristics limit the generalisability of the empirical paper’s findings. It is possible that differing levels of adolescent behaviour difficulties, parental psychological distress and diabetes-related family conflict, all of which can impact on T1D management, would be present amongst families of different ethnic backgrounds and educational status. However, it was not possible to explore this within the empirical paper.

The adolescents’ characteristics appeared more representative. The gender balance of the adolescents was relatively equal, with 53% female and 47% male. Furthermore, an equal number were receiving treatment through injections and pump therapy. No significant differences between males and females were found in relation to diabetes factors. A selection of the adolescents had additional conditions, some of which were not used as exclusion criteria, including coeliac disease, dyslexia, eczema and asthma. There were several factors which influenced this decision, including the small sample size, the exploratory nature of the research and the extent to which these conditions would impact on parenting. It was felt that parents whose adolescent had co-morbid physical and mental health conditions, such as learning disabilities or neuropsychiatric disorders, in addition to their T1D would require a greater level of support and therefore they were not included in the research. Greater consideration and attention should be paid to co-morbid conditions reported among adolescents with T1D in future research.

**Statistics**

Statistical advice and guidance was obtained throughout all stages of study. Due to the lack of previous work conducted within the field of parenting an adolescent with T1D and utilising a consumer perspective approach, there was no data on which to conduct a power calculation. The planned statistical analysis involved conducting a regression analysis to explore whether the consumer acceptability ratings of the Triple P information could be predicted by responses on measures of adolescent behaviour difficulties, parental
psychological well-being and diabetes-related family conflict. As an alternative to a formal power calculation, following statistical advice and the widely accepted convention (Field, 2009), the desired number of participants was identified through allocating ten participants per predictor variable to be entered into the regression equation. This led to a required sample size of 90.

Due to the aforementioned recruitment and retention difficulties, the planned statistical analysis had to be adapted following recruitment closure. At this stage it was hoped that a regression analysis using a maximum of four predictor variables could be conducted. To achieve this, a backwards stepwise approach was to be used, with variables which were found to be significantly related in correlational analyses to be entered into each model. Unfortunately, this was not possible due to the sample size and the small number of significant relationships observed.

As an alternative, correlational analyses were conducted to explore which factors were significantly related to parents’ ratings of acceptability and intention to participate.

Traditionally, correlation analysis involves the testing of hypotheses, with the measures being correlated selected based upon the existing literature within the field. Due to the exploratory nature of the empirical paper and given that no previous research had been conducted in relation to the consumer acceptability of parenting resources for those who had an adolescent with T1D it was not deemed appropriate to create hypotheses for testing as there was no basis for these. As an alternative the core measures used by the Triple P research group at the University of Queensland (ECBI and DASS-21) were used to support the research being comparable with other consumer acceptability work. The measure of diabetes family conflict was included as this is a factor which has been shown to be related to glycaemia control (Williams, Laffel, & Hood., 2009). The standardised measures used led to a total of six factors which were correlated with 12 acceptability ratings (4 per Triple P
resource). The large number of correlations being conducted led to concerns relating to multiple testing and Type I error. Following the statistician’s advice and given the literature regarding multiple testing (Carley & Lecky, 2003; Teo & Chong, 2006), the alpha level of significance was adjusted to \( p < 0.01 \). Despite this adjustment, due to the large number of correlations conducted the likelihood of a significant result being found by chance remained present.

Prior to data analysis, a variety of options were considered relating to the use of the consumer acceptability responses, with a view to reducing the risks of multiple testing and the likelihood of type 1 error. One option was to dichotomise the consumer acceptability responses into high and low acceptability groups. However, the five-point response scale led to difficulties regarding the management of the responses which fell at the midpoint. Ideally, when using this approach, cases in the middle group are excluded, however due to the small sample size this was not a viable option. An alternative option was to create composite scores of engagement, incorporating ratings of usefulness and interest, and realism, incorporating ratings of realism and familiarity, in line with Metzler, Sanders, Rusby and Crowley (2012). However, in doing so, detailed information regarding how useful, interesting, realistic and familiar the Triple P material was to parents would be lost. In view of the exploratory nature of the empirical paper, it was felt that keeping acceptability scores separate would provide a more interesting level of detail. On reflection and given the strong correlations that were found between the acceptability questions it would have been beneficial to use composite scores which would have reduced the number of correlations conducted and the risk of type one error.

There was considerable variability in the extent to which the data collected met the assumption of normality, as assessed through measures of skewness and kurtosis and the Kolmogorov-Smirnov test. Based on the statistician’s advice and given that the consumer
acceptability responses were not normally distributed, a decision was made to conduct non-parametric analysis throughout the results section to maintain consistency.

Consistently throughout recruitment the diabetes questionnaire was presented first, therefore a considerable number of the parents who had dropped out of the survey had completed this. Further analysis, to explore whether there were significant differences in relation to time since T1D diagnosis and measures of blood glucose control, amongst those who dropped out and those who completed the survey was therefore incorporated into the results section.

**Implications for clinical practice**

The literature review indicated that for a number of parents, significant symptoms of anxiety, depression or psychological distress are experienced. Particularly noteworthy was that these symptoms occurred at time of diagnosis, but also with increasingly length of time since diagnosis. Given the literature which highlights the impact that parental psychological well-being can have upon family relationships, parenting style and ultimately the medical management of T1D, it is important that paediatric care teams are aware of and monitor parental psychological status. Clinicians may be able to achieve this through asking parents to complete brief screening measures when they attend clinic with their adolescent.

The flexibility of the Triple P programme and its different levels and formats for intervention place it in a strong position to facilitate paediatric teams in offering psychological support to families who have an adolescent with T1D, as recommended in policy guidelines (ISPAD 2011; NICE, 2004). If clinicians adopt parenting approaches, such as the Triple P self-directed workbooks, it is likely that parents will feel supported and that their parenting needs might be met. Indeed one of the aims of Triple P is to address the emotional reactions of parents, including feelings of anxiety and low mood (Sanders,
Markie-Dadds, & Turner, 2003). However, it is important for Triple P to be empirically tested with parents of adolescents with T1D prior to clinicians advocating this approach.

**Implications for future research**

The literature review and the empirical paper indicate that further exploration of parental psychological status and the acceptability of Triple P are relevant and required. However, due to the small sample size, the results of the research should be considered preliminary. One significant challenge encountered during this work was retaining parents in the research. The number of participants who commenced the survey demonstrated that parents of adolescents with T1D are interested in web-based research and in parenting support. Thus the opportunity for initial engagement is present and successful when utilising a web based approach. However, retaining parents was a problem. Future research should carefully plan and consider ways of maintaining project engagement, potentially through gathering information from parents themselves regarding what facilitates retention. Alternatively, engagement could be maintained through the provision of incentives and careful study design, particularly with consideration being paid to the length of the survey or intervention. Hopefully, such an approach would lead to greater sample sizes, thus enabling stronger conclusions regarding the acceptability of parenting resources within this population to be made. In addition, a large sample would enable a greater understanding of the factors that may influence parenting intervention uptake.

Future research may also want to consider adopting a qualitative approach to explore the consumer acceptability of Triple P resources. This may be particularly important in relation to the adaptation of examples and the provision of support strategies that are specific to the needs of parents of adolescents with T1D. A randomised control trial of different levels of Triple P intervention would also be beneficial in building the evidence base for T1D.
Summary

This paper aimed to critically evaluate the literature review and empirical research undertaken, through the consideration of strengths and weaknesses. The challenges encountered were reflected upon and alternative methodologies discussed. The clinical implications and avenues for future research following on from this research were also identified.

References


Appendix 1: Author Guidelines for the Journal of Pediatric Psychology
MANUSCRIPT PREPARATION

Instructions to Authors

The *Journal of Pediatric Psychology* is an official publication of the Society of Pediatric Psychology, Division 54 of the American Psychological Association. JPP publishes articles related to theory, research, and professional practice in pediatric psychology.

Types of Manuscripts:

- Original research, including case studies
- Review articles
- Commentaries

Manuscript preparation: General Instructions

Full instructions for uploading data and files etc. are given on Manuscript Central at the website under Instructions for online submission: [http://www.oxfordjournals.org/our_journals/jpepsy/for_authors/submission_online.htm](http://www.oxfordjournals.org/our_journals/jpepsy/for_authors/submission_online.htm)

Organization of manuscripts

Manuscript Central will guide authors through the submission steps, including: Abstract, Keyword selection, and the Manuscript. The manuscript must contain an Introduction, Methods, Results, Discussion, Acknowledgements and Reference List.

Length of manuscript: Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter. Case reports should not exceed 20 pages. Review articles should not exceed 30 pages. Commentaries should not exceed 4 pages. The Journal of Pediatric Psychology no longer accepts brief reports but will accept manuscripts that are shorter in length than the 25 page manuscripts.

Manuscripts (text, references, tables, figures, etc.) should be prepared in detailed accord with the Publication Manual of the American Psychological Association (6th ed.). There are two exceptions:

(a) The academic degrees of authors should be placed on the title page following their names, and

(b) a structured abstract of not more than 150 words should be included. The abstract should include the following parts:

(1) Objective (brief statement of the purpose of the study);
(2) Methods (summary of the participants, design, measures, procedure);
(3) Results (the primary findings of this work); and
(4) Conclusions (statement of implications of these data).

Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch). Authors should remove all identifying information
from the body of the manuscript so that peer reviewers will be unable to recognize the authors and their affiliations. E-mail addresses, whenever possible, should be included in the author note.

**Informed consent and ethical treatment of study participants.** Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.

**Clinical relevance** of the research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

**Terminology** should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

**Special instructions for types of manuscripts**

(1) **Treatment studies/Randomized controlled trials:** If you are submitting a manuscript of a randomized clinical trial to JPP, you are required to submit a flowchart of your research showing the steps found in the Consort E-Flowchart. This should be submitted as a figure. The Consort E-Flowchart and a checklist of items to be included when reporting a randomized trial can both be found on http://www.consort-statement.org

(2) Case reports should not exceed 20 pages. Case reports are appropriate to document the efficacy of new treatment applications; to describe new clinical phenomena; to develop hypotheses; to illustrate methodological issues, difficult diagnoses, and novel treatment approaches; and to identify unmet clinical or research needs. Guidelines for case study submissions can be found in Drotar, D. (2009). Editorial: Case Studies and Series: A Call for Action and Invitation for Submissions, *Journal of Pediatric Psychology*, 34, 795-802.


(3) **Measurement development and validation articles:** For additional guidance please read, Holmbeck, G. & Devine, K. (2009) Editorial: An Author’s Checklist for Measure Development and Validation Manuscripts.

(4) **Review articles:** Please consult Checklist for Preparing and Evaluating Review Articles Scholarly reviews should not exceed 30 pages.

(5) **Commentaries:** Commentaries are invited on all topics of interest in pediatric psychology, and should not exceed 4 pages, including references.

**Additional Guidance:**

The following links provide additional guidance for authors and reviewers. Editorial Policy, Authors' Checklist, Guidelines for Reviews, Mentoring Policy, Suggestions for Mentored
Reviews, "People First," NIH policy, Replication of research, Duplicate and redundant policies Conflict of interest

See the following articles for detailed guidance concerning preparation of manuscripts: Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the Journal of Pediatric Psychology; How to Write a Convincing Introduction, ; Methods: Editorial: How to Report Methods in the Journal of Pediatric Psychology; Results and Discussion: Editorial: How to Write an Effective Results and Discussion Section for the Journal of Pediatric Psychology.

Funding

Details of all funding sources for the work in question should be given in a separate section entitled 'Funding'. This should appear before the 'Acknowledgements' section.

The following rules should be followed:
• The sentence should begin: 'This work was supported by …'
• The full official funding agency name should be given, i.e. ‘the National Cancer Institute at the National Institutes of Health’ or simply 'National Institutes of Health', not 'NCI' (one of the 27 subinstitutions) or ‘NCI at NIH’ (full RIN-approved list of UK funding agencies)
• Grant numbers should be complete and accurate and provided in parentheses as follows: ‘(grant number xxxx)’
• Multiple grant numbers should be separated by a comma as follows: ‘(grant numbers xxxx, yyyy)’
• Agencies should be separated by a semi-colon (plus ‘and’ before the last funding agency)
• Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number 'to [author initials]'.

Oxford Journals will deposit all NIH-funded articles in PubMed Central. See http://www.oxfordjournals.org/for authors/repositories.html for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above

Permission for Illustrations and Figures

Permission to reproduce copyright material, for print and online publication in perpetuity, must be cleared and if necessary paid for by the author; this includes applications and payments to DACS, ARS, and similar licensing agencies where appropriate. Evidence in writing that such permissions have been secured from the rights-holder must be made available to the editors. It is also the author’s responsibility to include acknowledgements as stipulated by the particular institutions. Oxford Journals can offer information and documentation to assist authors in securing print and online permissions; please see the Guidelines for Authors section. Information on permissions contacts for a number of main galleries and museums can also be provided. Should you require copies of this, please contact the editorial office of the journal in question or the Oxford Journals Rights department.

Updated April 2012
Appendix 2: Literature review search terms
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<tr>
<th>Systematic review search terms used</th>
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<tr>
<td>Parent</td>
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<td>Parents</td>
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<td>Mother</td>
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<td>Maternal</td>
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<td>Father</td>
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<td>Paternal</td>
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<td>Caregivers</td>
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<td>Diabetes mellitus</td>
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<td>Diabetes mellitus, type 1</td>
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<td>Diabetes</td>
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<td>Type one diabetes</td>
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<td>Metabolic diseases</td>
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<td>Chronic disease</td>
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<td>Adolescent</td>
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<td>Adolescents</td>
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<td>Teenager</td>
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<td>Youngster</td>
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<td>Psychosocial factors</td>
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<td>Stress, psychological</td>
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<td>Stress</td>
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<td>Distress</td>
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<td>Anxiety</td>
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<td>Caregiver Burden</td>
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<td>Emotions</td>
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<td>Emotional states</td>
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<td>Worry</td>
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<td>Agitation</td>
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<td>Panic</td>
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<td>Sadness</td>
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<td>Depression</td>
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<td>Major depression</td>
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<td>Depressive disorder</td>
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Appendix 3: Recruitment adverts
Advert used with diabetes charities, organisations and online parenting communities:

Are you a parent?
Does your child have type one diabetes?
Are they aged 11–17 years?
If yes, please read on, we could use your help...

Chronic illness like diabetes can impact on families in many ways. For example, following complex diabetes management plans to maintain health. Families have to find ways to adapt, and to help their child be well and develop independence. Our research team is running two research projects based on the Triple P Positive Parenting Program.

Triple P is used worldwide to help families build on their own knowledge and skills. It offers positive parenting advice and focuses on making small changes to achieve big differences. We want to see if this can be a helpful tool for diabetic families. The aim is to promote happy and healthy family life.

If you would like to know more please visit our website:
www.diabetesandparenting.org.uk
Or contact Sarah Woodhead and Francesca Doherty at:
DAP@manchester.ac.uk

NHS recruitment advert (Trust logos were added as appropriate):

Are you a parent?
Does your child have type one diabetes?
Are they aged 11–17 years?
If yes, please read on, we could use your help...

Chronic illness like diabetes can impact on families in many ways. For example, following complex diabetes management plans to maintain health. Families have to find ways to adapt, and to help their child be well and develop independence. Our research team is currently running a parenting survey based on the Triple P Positive Parenting Program.

Triple P is used worldwide to help families build on their own knowledge and skills. It offers positive parenting advice and focuses on making small changes to achieve big differences. We want to see if this can be a helpful tool for diabetic families. The aim is to promote happy and healthy family life.

If you would like to know more please visit the website:
https://www.psych-ssl.manchester.ac.uk/questionnaires/participantinformation.aspx?study_id=585
Or contact Sarah Woodhead at:
sarahlouise.woodhead@postgrad.manchester.ac.uk
(Version 1 - 29/11/2011)
Appendix 4: Letter of invitation – NHS recruitment only

(Logos were added as appropriate)
Dear Parent,

I am writing to invite you, as the parent of an adolescent, aged 11-17 years, with Type One Diabetes Mellitus, to take part in a parenting survey. This survey is being conducted as part of a Doctorate in Clinical Psychology qualification.

The aim of this research is to explore whether a Triple P parenting programme is acceptable to parents of adolescents with type one diabetes mellitus. The research also aims to look at the barriers to involvement in a parenting programme. The Triple P – Positive Parenting Program is a support strategy which aims to enhance the knowledge, skills and confidence of parents. Research has shown that a diagnosis of type one diabetes mellitus can lead to complex demands being placed upon the adolescent and their family. It is therefore important to develop means of supporting both the adolescents and their parents. Involvement of parents in exploratory research enables the developing support programmes to respond to their needs.

Enclosed with this letter a participant information sheet which provides more details about the survey and how to contact me if you have any questions.

If you are interested in completing the survey you can find it at the following web address: https://www.psych-ssl.manchester.ac.uk/questionnaires/participantinformation.aspx?study_id=585.

A paper based version is also available if required.

If you have any questions please do not hesitate in contacting me. Many thanks for your help.

Yours Sincerely,

Sarah Woodhead
Trainee Clinical Psychologist
The University of Manchester
Appendix 5: Opt-in sheet – NHS recruitment only

(Logos were added as appropriate)
**Diabetes and Parenting Survey: OPT IN SHEET**

Researchers at the University of Manchester are currently running a parenting survey about the Triple P Positive Parenting Program. Triple P is used worldwide to help families build on their own knowledge and skills. It offers positive parenting advice and focuses on making small changes to achieve big differences. We want to see if this can be a helpful tool for diabetic families. The aim is to promote happy and healthy family life.

If you are interested in taking part in this survey and would be happy to be contacted by the research team please complete the information below:

<table>
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<th>Please initial box</th>
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<tr>
<td>I confirm that I am interested in taking part in the diabetes and parenting survey</td>
</tr>
</tbody>
</table>

| I confirm that I am happy for the research team to contact me about the survey | ☐ |

The research team can contact me in the following way:

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<tr>
<th>By telephone</th>
<th>Yes</th>
<th>No</th>
<th>If yes, please provide your telephone number: (please circle one)</th>
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</thead>
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<tr>
<th>By e-mail</th>
<th>Yes</th>
<th>No</th>
<th>If yes, please provide your e-mail address: (please circle one)</th>
</tr>
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</table>

______________________  ______________  ____________________
Name of participant    Date                Signature

Thank you for taking the time to read this information. If you are interested in the Diabetes and Parenting Survey and are happy to be contacted you will hear from the research team shortly.

If you do not wish to be contacted by the research team but are still interested in taking part in our survey you can do so by visiting our website:

www.psych-ssl.manchester.ac.uk/questionnaires/participantinformation.aspx?study_id=585
Appendix 6: Participant information sheets.
Participant information sheet for recruitment through diabetes charities and organisations and online parenting communities:

**Triple P (Positive Parenting Program) for Type One Diabetes Mellitus:**
An exploratory study of consumer acceptability and intention to participate.

**PARTICIPANT INFORMATION SHEET**

You are being invited to take part in a research study to explore the acceptability of a Triple P - Positive Parenting Program for parents of adolescents with Type 1 Diabetes Mellitus. This study is being conducted as part of a Doctorate in Clinical Psychology qualification.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

**Who will conduct the research?**

Sarah Woodhead, Trainee Clinical Psychologist. Division of Clinical Psychology, 2nd Floor Zochonis Building, The University of Manchester, Brunswick Street, Manchester, M13 9PL.

**What is the aim of the research?**

The aim of this research is to explore whether a Triple P parenting programme is acceptable to parents of adolescents with type one diabetes mellitus. The research also aims to look at the barriers to involvement in a parenting programme. The Triple P – Positive Parenting Program is a support strategy which aims to enhance the knowledge, skills and confidence of parents. Research has shown that a diagnosis of type one diabetes mellitus can lead to complex demands being placed upon the adolescent and their family. It is therefore important to develop means of supporting both the adolescents and their parents. Involvement of parents in exploratory research enables the developing support programmes to respond to their needs.

**Why have I been chosen?**

You have been chosen to take part in this study because you have identified yourself as a parent or primary caregiver of an adolescent aged 11-17 years with type one diabetes mellitus. It is anticipated that approximately 100-120 parents or primary caregivers will take part.

**Are there any reasons why I wouldn’t be able to take part?**

Unfortunately you cannot take part if, you are unable to read without assistance, if your adolescent has additional health difficulties as well as Type 1 diabetes or if you have a mental health diagnosis. In addition if you have already completed the second set of questionnaires for the sister research project titled diabetes and parenting support, after following the self directed Triple P workbook for ten weeks, you are unable to complete this survey.

**What would I be asked to do if I took part?**
If you decide to take part you will be asked to complete an online survey, or a paper based survey if you prefer. This survey will involve you completing some questionnaires about your family, your adolescent’s behaviour and your mood. You will also be shown example Triple P material and be asked to rate how relevant, useful and interesting you find it. If you have more than one adolescent with type one diabetes we ask you to complete the questionnaires in relation to one adolescent only. It is not anticipated that completing the questionnaires will have any adverse consequences for you. There is a small possibility that some of the questions may cause distress. If this is the case for you, you are advised to contact the researcher, your GP or the Diabetes UK Careline (details below) who can offer confidential assistance.

What happens to the data collected?

The data collected will be statistically analysed on a group basis. The results of the research will be submitted to The University of Manchester, Division of Clinical Psychology as a thesis. The research will also be submitted for publication in a scientific journal.

How is confidentiality maintained?

All data will remain strictly confidential and anonymous in line with the Data Protection Act. You will be assigned a unique code upon entering the study and information provided will be stored using this code. You are not required to provide your name, address, telephone number or e-mail address and therefore you will not be identifiable to the research team. You may choose to provide some information if you wish to contact the researcher. The data will only be accessible to the Triple P research team and will be securely stored at The University of Manchester.

Technical Information

It is important that you have ‘cookies’ enabled on your computer, as this is how your unique code is generated to maintain confidentiality. Most computers have 'cookies' switched on to enable websites to function properly. If you want to check whether your ‘cookies’ are switched on you need to go to your Internet options, privacy, advanced, accept first party cookies. It is important that you complete the survey on only one computer.

Can both parents take part in the survey?

Both parents can complete the online survey using the same computer. However, it is important that each parent fully completes the survey before the other begins the survey.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be able to print off this information sheet to keep. You will also be asked to complete a consent form prior to taking part in the survey. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself or your adolescent.
Will I be paid for participating in the research?

No formal payment will be made for participating in this research. At the end of the survey there will be the opportunity to take part in the sister research project diabetes and parenting support (see research home page). You may benefit in the future through involvement in a Triple P programme.

What is the duration of the research?

The web based survey should take between 30 and 45 minutes to complete. You can take a comfort break whilst completing the survey and return to the same point as long as you use the same computer.

Where will the research be conducted?

The Division of Clinical Psychology, The University of Manchester, Manchester.

Will the outcomes of the research be published?

It is anticipated that the results of the research will submitted for publication in a scientific journal. The results will also be shared with the organisations that supported recruitment.

Contact for further information

Sarah Woodhead, Trainee Clinical Psychologist:

E-mail: sarahlouise.woodhead@postgrad.manchester.ac.uk

What if something goes wrong?

If you have any questions or concerns regarding the online survey and the research you should contact Sarah Woodhead, Trainee Clinical Psychologist and chief investigator on the above e-mail address. If the survey highlights any areas of concern specifically related to the health of yourself or your adolescent’s health please contact your GP, the NHS direct or alternatively Diabetes UK Careline on 0845 120 2960 or via e-mail careline@diabetes.org.uk.

If you wish to make a formal complaint about the conduct of the research you should contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.
Participant information sheet for recruitment through NHS clinics:

**Triple P (Positive Parenting Program) for Type One Diabetes Mellitus:**
An exploratory study of consumer acceptability and intention to participate.

**PARTICIPANT INFORMATION SHEET**

You are being invited to take part in a research study to explore the acceptability of a Triple P - Positive Parenting Program for parents of adolescents with Type 1 Diabetes Mellitus. This study is being conducted as part of a Doctorate in Clinical Psychology qualification.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

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Sarah Woodhead, Trainee Clinical Psychologist. Division of Clinical Psychology, 2nd Floor Zochonis Building, The University of Manchester, Brunswick Street, Manchester, M13 9PL.

**What is the aim of the research?**

The aim of this research is to explore whether a Triple P parenting programme is acceptable to parents of adolescents with type one diabetes mellitus. The research also aims to look at the barriers to involvement in a parenting programme. The Triple P – Positive Parenting Program is a support strategy which aims to enhance the knowledge, skills and confidence of parents. Research has shown that a diagnosis of type one diabetes mellitus can lead to complex demands being placed upon the adolescent and their family. It is therefore important to develop means of supporting both the adolescents and their parents. Involvement of parents in exploratory research enables the developing support programmes to respond to their needs.

**Why have I been chosen? (Inclusion criteria)**

You have been chosen to take part in this study because you are a parent or primary caregiver of an adolescent aged 11-17 years with type one diabetes mellitus. It is anticipated that approximately 100 parents or primary caregivers will take part.

**What would I be asked to do if I took part?**

If you decide to take part you will be asked to complete an online or paper based survey if you prefer. This survey will involve you completing some questionnaires about your family, your adolescent’s behaviour and your mood. You will also be shown example Triple P material and be asked to rate how relevant, useful and interesting you find it. If you have more than one adolescent with type one diabetes we ask you to complete the questionnaires in relation to one adolescent only. It is not anticipated that completing the questionnaires will have any adverse consequences for you. There is a small possibility that some of the questions may cause distress. If this is the case for you, you are advised to contact the researcher, your Diabetes Care Team, your GP or the Diabetes UK Careline (details below) who can offer confidential assistance.
How is confidentiality maintained?

All data will remain strictly confidential and anonymous in line with the Data Protection Act. You will be assigned a unique code upon entering the study and information provided will be stored using this code. You may be asked to provide your e-mail address so the chief investigator can contact you if necessary. Your e-mail address will be held in a secure location which is different to where your survey responses are stored. The data will only be accessible to the Triple P research team and will be securely stored at The University of Manchester.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Manchester, the NHS or regulatory authorities to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

What do I do if I have technical difficulties when completing the online survey, or if the online survey isn’t working?

This information is for anybody experiencing technical difficulties with the online survey. For the survey to work it is important that you have ‘cookies’ enabled on your computer, as this is how your unique code is generated to maintain confidentiality. Most computers have ‘cookies’ switched on to enable websites to function properly. If you want to check whether your ‘cookies’ are switched on you need to go to your Internet options, privacy, advanced, accept first party cookies. It is important that you complete the survey on only one computer. If you have any further problems please contact Sarah Woodhead on the e-mail address below.

Can both parents take part in the survey?

Both parents can complete the online or paper based survey. If you are using the same computer, it is important that each parent fully completes the survey before the other begins the survey.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be able to print off this information sheet to keep. You will also be asked to complete a consent form prior to taking part in the survey. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself or your adolescent.

Will I be paid for participating in the research?

No formal payment will be made for participating in this research.

What is the duration of the research?

The survey should take approximately 50 minutes to complete. When completing the online survey you can take a break and return to the same point using the ‘save now’ button at the bottom of each page. When you return to complete the survey you must use the same computer. To ensure that your data is saved correctly please complete the survey within one week. If you return after one week your data will not be remembered and you will have to start the survey again. If you complete the paper based survey, you will be
provided with a pre paid envelope to enable you to complete and return the questionnaires at your own convenience.

**Where will the research be conducted?**

The Division of Clinical Psychology, The University of Manchester, Manchester.

**Will the outcomes of the research be published?**

It is anticipated that the results of the research will submitted for publication in a scientific journal. The results will also be shared with the organisations that supported recruitment.

**Where can I find the survey?**

The online survey can be found at the following web address: https://www.psych-ssl.manchester.ac.uk/questionnaires/participantinformation.aspx?study_id=585

If you require a paper based survey please contact the chief investigator.

**Contact for further information**

Sarah Woodhead, Trainee Clinical Psychologist:

E-mail: sarahlouise.woodhead@postgrad.manchester.ac.uk

**What if something goes wrong?**

If you have any questions or concerns regarding the online survey and the research you should contact Sarah Woodhead, Trainee Clinical Psychologist and chief investigator on the above e-mail address. If the survey highlights any areas of concern specifically related to the health of yourself or your adolescent’s health please contact your GP, the NHS direct or alternatively Diabetes UK Careline on 0845 120 2960 or via e-mail careline@diabetes.org.uk.

If you wish to make a formal complaint about the conduct of the research you should contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.

In the event that something does go wrong and you are harmed during the research you may have grounds for legal action for compensation against the University of Manchester or the NHS but you may have to pay your legal costs. The normal NHS Service complaints mechanisms will still be available to you.

**THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET.**
Appendix 7: Consent forms
Consent form for recruitment through diabetes charities and organisations and online parenting communities:

**Triple P for Type One Diabetes**
An exploratory study of consumer acceptability and intention to participate

**CONSENT FORM**
If you are happy to participate please complete the consent form below.
By clicking on the submit button you are consenting to take part in this research project.

1. I confirm that I have read the participant information sheet provided on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.
   Yes
   No

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to any treatment/service.
   Yes
   No

3. I understand that all my personal information will be kept confidential and that the results of the study will be used for scientific objectives.
   Yes
   No

4. I understand that there is no guarantee that this study will provide any benefits to my child.
   Yes
   No

Thank you for agreeing to take part in this research project. To continue please click the button below.
Consent form for recruitment through NHS clinics:

CONSENT FORM

Title of project: Triple P (Positive Parenting Program) for Type One Diabetes Mellitus: An exploratory study of consumer acceptability and intention to participate.

Name of researcher: Sarah Woodhead

By clicking on the submit button you are consenting to take part in this research project.

Please tick box

1. I confirm that I have read and understand the information sheet dated 19/01/2012 (Version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected.

3. I understand that all my personal information will be kept confidential and that the results of the study will be used for scientific objectives.

4. I understand that there is no guarantee that this study will provide any benefits to my child.

5. I understand that relevant data collected during the study, may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

6. I agree to take part in this study.

Thank you for agreeing to take part in this research project. To continue please click the button below.
Appendix 8: Diabetes questionnaire
Diabetes Information

1. Date of child’s diagnosis of diabetes (dd/mm/yy): ____________________________

2. Value of child’s most recent HbA1c/HbA1c (hospital measure of diabetes control):
   % or mmol/mol

3. Date of child’s most recent HbA1c (dd/mm/yy): ____________________________

4. Which insulin regime does your child use: injections ☐
Pump therapy ☐

5. Normal Insulin Regimen

<table>
<thead>
<tr>
<th>Time</th>
<th>Name of insulin(s)</th>
<th>Dosage (units)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before Breakfast</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before Lunch (if applicable)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before evening meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before Supper (if applicable)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 9: Family background questionnaire brief
This questionnaire collects information about your family. Please read and answer every question.

1. Date: _____/_____/_____
   (Day) (Month) (Year)

2. Your age today: ______ (years)

3. Child's gender: Male □ Female □

4. Child's age today: ______ (years)

5. Your relationship to this child:
   - Mother (biological or adoptive) □
   - Father (biological or adoptive) □
   - Step-mother □
   - Step-father □
   - Foster mother □
   - Foster father □
   - Other (please describe) ________________________________

6. Your current marital status:
   - Married □
   - Divorced/separated □
   - Single □
   - Cohabiting □
   - Widow/er □
   - Other (please describe) __________________________________________

7. Which best describes the household in which your child is presently living?
   - Original family (both biological or adoptive parents present) □
   - Step family (two parents, one being a step parent) □
   - Sole parent family □
   - Other (please describe) __________________________________________

8. At present who lives at home with your child (e.g. parents, siblings, grandparents), including yourself?

<table>
<thead>
<tr>
<th>Relationship to child</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
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<tr>
<td>2.</td>
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<td>3.</td>
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<td>4.</td>
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<td>9.</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td></td>
</tr>
</tbody>
</table>
9. Which ethnic or cultural group do you most strongly identify with? (please write your response in the space) ____________________

10. Your highest level of education:
    - □ primary school or less
    - □ some high school
    - □ completed high school
    - □ trade/technical college qualification
    - □ university degree
    - □ post-graduate degree

11. Your partner's highest level of education (if applicable):
    - □ primary school or less
    - □ some high school
    - □ completed high school
    - □ trade/technical college qualification
    - □ university degree
    - □ post-graduate degree

12. Are you working outside the home right now?
    - □ yes, full time
    - □ yes, part time
    - □ not working, but looking for a job
    - □ home based paid work (child care, sewing, internet or phone-based work, etc)
    - □ not working (includes stay at home parents, retired)

13. Is your partner working outside the home right now? (if applicable)
    - □ yes, full time
    - □ yes, part time
    - □ not working, but looking for a job
    - □ home based paid work (child care, sewing, internet or phone-based work, etc)
    - □ not working (includes stay at home parents, retired)

14. During the past 12 months, has there been a time when your household could not meet its essential expenses? By essential expenses, we mean things like food, the mortgage or rent payment, utility bills, child care, or important medical care.
    - □ yes
    - □ no
    - □ don’t know

15. After you have paid for your essential expenses like food, housing, utilities, child care, and medical care, how much money is left over?
    - □ enough that we can comfortably purchase most of the things we really want
    - □ enough that we can purchase only some of the things we really want
    - □ not enough to purchase much of anything we really want

16. Does your child experience any of the following problems:
    - A chronic illness e.g., asthma, eczema?
      - Yes □ No □
    - A physical disability?
      - Yes □ No □
    - An intellectual disability?
      - Yes □ No □
    - A developmental delay?
      - Yes □ No □
    - If Yes to any of the above, please provide details____________________________
Appendix 10: Eyberg child behaviour inventory

Due to copyright restriction an electronic version of this measure is not included. For examination purposes a hard copy is enclosed in the pocket at the back of the thesis.
Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:
0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1 I found it hard to wind down
2 I was aware of dryness of my mouth
3 I couldn't seem to experience any positive feeling at all
4 I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)
5 I found it difficult to work up the initiative to do things
6 I tended to overreact to situations
7 I experienced trembling (e.g., in the hands)
8 I felt that I was using a lot of nervous energy
9 I was worried about situations in which I might panic and make a fool of myself
10 I felt that I had nothing to look forward to
11 I found myself getting agitated
12 I found it difficult to relax
13 I felt down-hearted and blue
14 I was intolerant of anything that kept me from getting on with what I was doing
15 I felt I was close to panic
16 I was unable to become enthusiastic about anything
17 I felt I wasn't worth much as a person
18 I felt that I was rather touchy
19 I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)
20 I felt scared without any good reason
21 I felt that life was meaningless
Appendix 12: Revised diabetes family conflict scale

Due to having author permission to use this measure only in the research project an electronic version is not included. For examination purposes a hard copy is enclosed in the pocket at the back of the thesis.
Appendix 13: Triple P parenting resources

Due to copyright restriction an electronic versions of these resources are not included. For examination purposes hard copies are enclosed in the pocket at the back of the thesis.
Appendix 14: Consumer acceptability and participation questions
Same questions used for each type of Triple P information presented:

Overall, how useful did you find this Triple P information?
1. Not at all useful
2. Only slightly useful
3. Somewhat useful
4. Quite useful
5. Very useful

Do you think you could learn practical parenting skills from this type of information?
1. Learn nothing
2. Learn only a little
3. Learn some
4. Learn quite a bit
5. Learn a lot

Do you think you would make use of the parenting strategies discussed in this example?
1. Definitely not
2. Probably not
3. Maybe/unsure
4. Probably
5. Definitely

How interesting did you find the information presented?
1. Not at all
2. Only slightly
3. Somewhat
4. Quite
5. Very

If Triple P videos/ a self-directed workbook/ tip sheets (or other parenting related resources) were available to you would you access them?
1. Definitely not
2. Probably not
3. Maybe/unsure
4. Probably
5. Definitely

How realistic did the sample Triple P material seem to you?
1. Not at all
2. Only slightly
3. Somewhat
4. Quite a bit
5. Very much

How much did the families’ situation/s presented seem familiar to you?
1. Not at all
2. Only slightly
3. Somewhat
4. Quite a bit
5. Very much
**Intention to participate question:**
If a parenting program is offered to you would you participate?

1. Definitely not
2. Probably not
3. Maybe/unsure
4. Probably
5. Definitely

**Barriers to participation question:**
What barriers do you see, if any, that would get in the way of you taking part in a Triple P parenting intervention? (check all that apply)

- I don’t see any barriers
- I don’t have enough information about strategies
- I don’t have enough time
- I don’t agree with the ideas presented
- I don’t think I would be able to do the strategies
- I don’t think the strategies would work for us
- I get too upset and stressed out to try anything different
- Parenting improvements not needed
- Not enough support
- Other barriers