THE UNIVERSITY OF HULL

Children and adolescents with type 1 diabetes: Parents' psychological wellbeing, sibling empathy and the quality of the sibling relationship

being a Thesis submitted for the Degree of

Doctor of Clinical Psychology

in the University of Hull

by

Faye Louise Melbourne

BSc (Psychology)

July 2010

Acknowledgements

I am eternally grateful for the dedication and support Dr Annette Schlösser has given during the development of this portfolio thesis. I'd like to thank Dr Claudine Crane for her guidance in the initial stages of the project and my field supervisor Mary Raeburn-Binns for her support with recruitment. I would also like to thank Dr Eric Gardiner for his guidance with the statistics for the empirical paper.

I would like to thank the diabetes teams who offered a great deal of help in recruitment. A huge thank you also goes to all the families that took part in the research.

Finally, I would like to say a special thank you to my parents, my brother, Carl and my partner Jonathan who have all been incredibly supportive. Without their love and continuous encouragement this thesis would not have been possible.

Overview

This portfolio thesis comprises three parts: a systematic literature review, an empirical study and a set of appendixes.

Part one is a systematic literature review, in which the literature pertaining to factors that impact on the psychological wellbeing of parents of children with type 1 diabetes is reviewed. The review begins with an overview of the research relating to parents of diabetic children, which is followed by a rationale for why this review would be an interesting addition to the literature. The paper then describes the methods used to collect the relevant studies. The review synthesises the results in a way which makes it clear which factors impact on each measure of psychological wellbeing. An overview of the findings is then given. The paper closes with limitations of the review, suggestions for future research and conclusions.

Part two is a preliminary pilot study in which empathy and sibling relationships are the focus. This cross-sectional study explores empathy and the quality of the sibling relationship as perceived by diabetic children, their healthy siblings and siblings in which both children are physically healthy. Based on Furman and Burhmester's (1985) model of the determinants of the quality of sibling relationships, the study moves on to explore the predictive effect of empathy on children's perceptions of their sibling relationship. The paper presents the findings and conclusions before discussing the clinical implications and the pilot study's limitations.

Part three is a set of appendixes to support the work in the first two parts. It also contains a reflective account to explore the process of developing this portfolio thesis.

Contents

Ackno	owledgements	2	
Overv	view	3	
Part 2	1: Systematic Literature Review	8	
	Abstract	9	
	Introduction	10	0
Aims		13	3
	Method	13	3
	Inclusion criteria	13	3
	Exclusion criteria	14	4
	Quality assessment	1:	5
	Data extraction	1:	5
	Data synthesis	1:	5
	Details of included and excluded studies	1:	5
Resul	ts	10	б
	Participant samples and demographic information	10	б
	Overview of the quality of the included studies	1′	7
	Study design	1′	7
	Factors	1′	7
	Table of included studies	19	9
	Main outcomes	22	2

Discussion	26				
Ove	erview of the reviewed research	26			
Lim	itations of the research	29			
Lim	itations of the review	30			
Futu	are research and clinical implications	31			
Con	clusions	32			
References		33			
Part two: I	Empirical paper	41			
Abs	Abstract				
Intro	Introduction				
	Type 1 diabetes	43			
	Systems Theory and childhood illness	43			
	Positive Psychology and Empathy	44			
	Sibling Relationships	45			
	Sibling relationships and Type 1 Diabetes	46			
	Equity Theory	47			
	Aims and hypotheses	47			
Met	Method				
	Participants	49			
	Procedure	51			
	Measures	52			
	Statistical analyses	53			

Results

Empathy as a predictor of the quality of the sibling relationship	55		
Healthy siblings' empathy	57		
Empathy difference between siblings	57		
Discussion			
Clinical Implications	63		
Limitations of the study	64		
Areas for future research	67		
Conclusions	69		
References	69		

Part three: Appendixes

Appendix A: Guidelines for authors for the systematic literature review
Appendix B: Guidelines for authors for the empirical paper
Appendix C: Quality checklist for systematic literature review
Appendix D: Review data collection form
Appendix E: Information on excluded studies
Appendix F: Ethical approval letter
Appendix G: Trust research governance approvals
Appendix H: Cover letters (clinical and control group)
Appendix I: Parents information letters (clinical and control group)
Appendix J: Parent consent form (clinical and control group)
Appendix K: Demographic data form (clinical and control group)

Appendix L: Child information letters

Appendix M: Child assent form

Appendix N: Sibling Relationship Questionnaire

Appendix O: The Index of Empathy

Appendix P: Thank you letter

Appendix Q: GP letter

Appendix R: Selected SPSS output

Appendix S: Reflective statement

Appendix T: Glossary of medical terms

Table for systematic review

Table 1: Characteristics of included studies

Tables for empirical paper

Table 1: Demographic details of participants

Table 2: Means and Standard Deviations for empathy difference

between siblings

Figures:

Figure 1: Determinants of sibling relationship qualities (Furman and Buhrmester, 1985)

CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES: PARENTS' PSYCHOLOGICAL WELLBEING, SIBLING EMPATHY AND THE QUALITY OF THE SIBLING RELATIONSHIP

Part 1

Systematic Literature review

Factors that impact on the psychological wellbeing of parents of children with type 1 diabetes: A Systematic Literature Review

Faye L. Melbourne* & Dr Annette Schlösser

Department of Clinical Psychology, Hertford Building University of Hull, Hull, HU6 7RX, UK

*Corresponding author: Tel: +44 1482 464106; fax +44 1482 464093

Email address: f.melbourne@2004.hull.ac.uk

This paper is written in the format ready for submission to Psychology and Health Please see Appendix A for the Guidelines for Authors

Abstract

Diabetes Type 1 is a common chronic childhood illness. Parents of these children are at risk of developing psychological difficulties. This systematic literature review examines the empirical literature investigating factors that impact on the psychological wellbeing of parents of children with Type 1 Diabetes. PsycINFO, Web of Science, CINAL and the Cochrane library were searched to identify the relevant literature. Sixteen studies met the inclusion criteria. The review highlights that a number of factors including medical factors, intrapersonal factors and socio-ecological factors can impact on parents' psychological wellbeing. The measures used to assess wellbeing varied and participant samples were heterogeneous so that comprehensive conclusions could not be made. The review highlights that more consistency is needed across this area of the literature. Future research should focus on fathers' wellbeing and on positive aspects of psychological wellbeing such as happiness. The limitations of the review are discussed. **Key words: Parents, diabetes, psychological wellbeing wellbeing, factors.**

Factors that impact on the psychological wellbeing of parents of children with type 1 diabetes: A Systematic Literature Review

The number of children suffering with type 1 diabetes has increased over the years and it is now estimated that 20,488 children have this chronic illness in England alone (Department of Health, 2010). The management of the illness involves a complex treatment regime and therefore parental involvement is essential (Delamater, 2009).

Parents play a key role in the management of childhood chronic illnesses. In the case of type 1 diabetes, parents have to learn how to inject their child, check blood glucose levels and keep track of their child's exercise and dietary plan (Rodrigue, Geffken, Clark and Hunt and Fishel, 1994) to avoid negative consequences such as hypoglycaemia. In the most severe cases, poor management can result in seizures, limb amputations, and death (Williams and Pickup, 2007). Parents therefore have a crucial role in maintaining the physical wellbeing of their child. The management of this illness and the task parents face in trying to retain a normal lifestyle for their diabetic child can be highly challenging for parents (Sherifali and Ciliska, 2006).

Given that parental involvement is essential in the management of childhood illnesses, it is important that they are able to emotionally cope with the ongoing demands of the illness (Eiser, 1990). Parenting a healthy child can at times be difficult (Ostberg and Hagekull, 2000). Therefore, it is not surprising that parenting a child with health difficulties can present further challenges for parents (Sherifali and Ciliska, 2006).

Following a diagnosis of a chronic illness, the individual and indeed family members go through a process of adjustment (Bradford, 1997). The initial stages after diagnosis can be a very traumatic time for families (Thernlund, Dahlquist, Ivarsson and Ludvigsson, 1996) and thus it is not surprising that studies have identified that the individual and their family members may be vulnerable to psychological difficulties. Lowes, Gregory and Lyne (2004), for example, reported that parents displayed symptoms of grief. Moreover, it has been reported that following the diabetes diagnosis, a proportion of parents met the criteria for a diagnosis of Posttraumatic Stress Disorder (e.g. Landolt, Vollrath, Laimbacher, Ghehm and Sennhauser, 2005). It is reported that parents' initial reactions to the diagnosis may subside in the first year (Koizumi, 1992). However, it has also been suggested that parents may never fully adjust to their child's illness and accept the loss of their physically healthy child (Lowes, Gregory and Lyne, 2004).

Whilst it is necessary to understand the initial emotional impact of a diagnosis, an awareness of families' longer term psychological functioning is important (Delamater, 2009). Research examining parents' mental health years after the diagnosis of paediatric diabetes report negative findings. A study by Horsh, McManus, Kennedy and Edge (2007), for example, found that parents displayed high levels of anxiety and depression. Moreover, Cameron, Young and Wiebe (2007) reported that mothers' psychological difficulties had a negative impact on their child. More specifically, they found that mothers who displayed high anxiety, were more likely to be over protective of their child, which subsequently resulted in poorer glucose control and low mood in the child. Furthermore, Williams et al (1999) reported that mothers' positive mood had

a beneficial impact on siblings of diabetic children. This is important as siblings of children with chronic illnesses are also at risk in the development of psychological difficulties (Sharpe and Rossiter, 2002).

Although childhood chronic illnesses leave parents vulnerable to develop mental health difficulties, it is well documented that in the face of adversity, some individuals appear to show no such difficulties (Tugade and Fredrickson, 2004). Wallander, Varni, Babani, Banis and Wilcox (1989), for example, offer a conceptual framework to help explain maternal adaptation to chronic conditions. They stated that a number of factors may influence the psychological outcome of mothers. Such factors included socioecological factors (e.g. family support), intrapersonal factors (e.g. competence) and stress processing factors (e.g. coping strategies). Further to these, they reported that risk factors included factors relating to the disease (e.g. medical problems), parents' psychosocial stresses (e.g. daily hassles), and the child's level of independence. Indeed, a study examining parents of children with intellectual disabilities concluded that parents' wellbeing was "dependent upon the interplay of risk and protective factors" (Olsson and Hwang, 2008, p1102).

Paediatric services support families not just with the medical aspects of treatment but the psychological aspects too (Delamater, 2009). Given that parents of children with type 1 diabetes are likely to develop psychological difficulties, it seems crucial for paediatric services to be aware of the factors that may positively and negatively impact on parents' psychological wellbeing, in order for them to offer effective interventions. The importance of this awareness has been reported in other areas of the literature (e.g. Wang, Hsu, Lin, Cheng and Lee, 2010).

Aim

Although the psychological wellbeing of parents of children with chronic illnesses is essential and a number of factors can play a role in their wellbeing, thus far no reviews have been conducted to help provide a comprehensive overview of this area of the literature. The aim of this systematic literature review was therefore to review the empirical literature pertaining to factors that impact on the psychological wellbeing of parents of children or adolescents with type 1 diabetes. A further aim of this review was to highlight areas for future research.

Method

An electronic search was conducted on Web of Science, PsycINFO, Cochrane Review Library and Cumulative Index to Nursing and Allied Health Literature (CINAHL). Search terms were parent, mother, father, paternal, maternal, diabetes, children, adolescents and paediatric. Psychological terms were not used in the searches to prevent any psychological outcome from being missed. Keeping the search terms broad allowed the researcher to capture all the studies conducted on parents of children with type 1 diabetes, to then select the relevant studies.

Inclusion criteria

The inclusion criteria for this review were:

- 1. Quantitative or mixed design (only the quantitative outcomes would be reported)
- 2. Used at least one measure with reported reliability and/or validity data
- 3. Peer reviewed
- 4. Published in English

5. Factors included were any independent or predictor variable (Field, 2009)

6. Studies assessing any positive or negative aspect of psychological wellbeing as "positive and negative affect are distinct dimensions of well-being" (Ryff, 1989, p1070)7. Due to the paucity of research in this area of the literature both cross sectional and longitudinal research were included.

Exclusion criteria

Studies were excluded if any of the following criteria were met:

1. Published before 1980, due to an increase in interest in studying the family as well as the diabetic child since this time (Anderson and Auslander, 1980).

2. Case studies

3. Literature reviews

4. Discussion papers

5. Papers focusing on family functioning, with no specific reference to parents

6. Newly diagnosed diabetes and studies that examined parents in only the first year of the diagnosis (i.e. a mean diagnosis time of 1 year or less) as Koizumi (1992) reported parents displayed higher levels of psychological distress in the first year of the diabetes diagnosis.

7. Studies examining chronic illnesses, with no specific examination of diabetes.

8. Studies which used correlation analyses as this only shows a relationship between variables (Field, 2009).

9. Quality of life as an outcome variable as this includes other domains of wellbeing in addition to psychological wellbeing (Gill and Feinstein, 1994)

Quality

The quality assessment of papers included in a systematic literature review is essential in order to understand of the reliability of the evidence (NICE, 2007). A range of checklists have been devised for the purpose of quality assessment, however there is no one checklist that is suitable for all systematic reviews (NICE, 2007). Therefore, to assess the quality of the studies in this review a checklist was devised. The devised checklist was adapted from Downs and Black (1998) and STROBE (2007). To ensure the checklist was suitable, it was piloted on a small number of studies before it was applied to all the papers in the review. A copy of the checklist can be found in appendix C.

Data extraction

For each included paper, a protocol was followed to extract the necessary information. Such information included the study design, aim of the study, the participants, relevant demographic information, the factor(s) being investigated and the outcomes in relation to the factors and findings of each study.

Data synthesis

Due to the heterogeneity of the included studies, the results were synthesised qualitatively.

Details of included and excluded studies

A total of 6886 articles were produced during searching. A large proportion of the papers related to medical outcomes (5377). Within the remaining 1509 articles, 1471 were excluded because the title and abstract were not relevant to the review question. For the remaining 38 studies, the full papers were obtained. However, four were excluded as quality of life was the outcome variable, six examined chronic illness with no specific reference to diabetes, one studied family functioning, four used correlation analysis, six studied newly diagnosed diabetes and one compared diabetes to cancer (see appendix E for details of excluded studies). A total of 16 studies met all the inclusion criteria. The references of these papers were also checked to identify further studies. This yielded no further studies.

Results

Sixteen papers were included in the review, which were published between 1990 and 2010. Table 1 highlights the pertinent details of the included papers. Only the main findings of the papers are reported.

Participant samples and demographic information

Study sample sizes varied between 30 (Carpentier, Mullins, Chaney and Wagner, 2006) and 330 participants (Butner et al, 2009). Six studies focused on mothers (Kovacs, Iynergar, Goldston, Obrosky, Stewart and Marsh, 1990; Blankfield and Holahan, 1996; Jaser, Whittemore, Ambrosino, Lindermann and Grey, 2003; Mednick, Cogen, Henderwon, Rohrbeck, Kitessa and Streisand, 2007; Berg et al, 2007; Berg, Schindler and Maharajh, 2008 and Olsen, Berg and Wiebe, 2008), one focused on fathers (Mitchell, Hilliard, Mednick, Henderson, Cogen and Streisand, 2009) and nine studied both parents (Butner et al, 2009; Monaghan, Hilliard, Cogen and Streisand, 2009; Carpentier et al, 2006; Streisand, Swift, Wickmark, Chen and Holmes, 2005; Marrero, Guare, Vandagriff and Fineberg, 1997; Gonder-Frederick et al , 2006); Haugstvedt, Wentzel-Larsen, Graue, Sovik and Rokne, 2010; Chaney et al, 1997). The children's mean age ranged from 4.5 years (Monaghan et al, 2009 and Marrero et al, 1997) to

15.36 years (Berg et al, 2008). The mean years of diabetes diagnosis ranged from newly diagnosed (Kovacs et al, 1990) to 8.67 years (Carpentier et al, 2006).

Overview of the quality of the included studies

The quality of the studies ranged from 52.9% (Blankfield and Holahan, 1996) to 94.1% (Butner et al, 2009). Six studies were assessed by an independent researcher to check inter-rater reliability. Using a one way random effect model to calculate interclass correlation, a score of 0.83 was obtained. Field (2009) reported that a score of 0.8 or above demonstrates good reliability.

Study design

Of the 16 studies included in the review, three employed a longitudinal design (Kovacs et al, 1990; Carpentier et al, 2006 and Chaney et al, 1997). The remaining 13 were cross sectional in design.

Factors

A range of factors were investigated in the studies and, consistent with Wallander et al (1989), have been placed into the following categories; disease factors (Kovacs et al, 1990; Monaghan et al, 2009; Carpentier et al, 2006; Streisand et al, 2005; Marrero et al, 1997, Gonder-Frederick et al, 2006; Haugstvedt et al, 2010 and Chaney et al, 1997); parental psychosocial stressors (Kovacs et al, 1990; Streisand et al, 2005; Mitchell et al, 2009 and Gonder-Frederick et al, 2006); intrapersonal factors (Jaser et al, 2009; Mednick et al, 2007; Carpentier et al, 2006; Streisand et al, 2005 and Mitchell et al, 2009); social-ecological factors (Blankfield and Holahan, 1996; Butner et al, 2009; Mitchell et al, 2009; Haugstvedt et al, 2010; Chaney et al, 1997; Berg et al, 2007; Berg et al, 2008 and Olsen et al, 2008) and demographic factors (Kovacs et al, 1990 and Haugstvedt et al, 2010). It is important to highlight that factors (excluding demographic variables) in the studies were assessed using measures with reported psychometric properties (excluding Berg et al, 2007). Berg et al (2007) devised their own categories of mother-child coping based on recognised procedures.

Psychological outcome measured

Across the studies, seven psychological outcomes were investigated. As this review is concerned with parents' psychological wellbeing, the studies will be grouped together based on their outcome variable. Synthesising the results this way will highlight the factors that impact on each measure of psychological wellbeing and will allow possible trends to emerge across the psychological domains.

Table 1. Details of the included studies				
Authors	Design	Participants	Factor(s)	Outcome
Kovacs, Iyengar, Goldston, Obrosky,	Longitudinal	95 mothers	Illness duration*, initial symptoms*, SES*,	*Depression (BDI-II)
Stewart & Marsh (1990)			children's compliance with medical regime,	*Distress (SCL-90)
			metabolic control & rehospitalisation.	
Blankfield & Holahan (1996)	Cross-	52 mothers	Family support*	*Depression (Health and daily
	sectional			living form)
Butner et al (2009)	Cross-	185 mothers	Parent-adolescent discrepancies in adolescent	*Adjustment (Psychosocial
	sectional	145 fathers	competence*	Wellbeing Scale)
				*Depression (CED-S)
				*Marital satisfaction (L-
				WMAT)
Jaser, Whittemore, Ambrosino,	Cross-	67 mothers	Perceived coping with the diabetes*	*Depression (CED-S)
Lindemann & Grey (2009)	sectional			*Anxiety (STAI)
Mednick, Cogen, Henderwon, Rohrbeck,	Cross-	75 mothers	Hope*	*Anxiety (STAI)
Kitessa & Streisand (2007)	sectional			
Monaghan, Hilliard, Cogen & Streisand	Cross-	69 mothers	Nocturnal blood glucose monitoring*	Fear of hypoglycaemia (HFS)

(2009)	sectional	2 fathers		*Anxiety (STAI- state
				subscale)
				* Paediatric parenting stress
				(PIP-F)
Carpentier, Mullins, Chaney & Wagner	Longitudinal	26 mothers	Illness uncertainty*	*Distress (GSI)
(2006)		4 fathers	Attribution style	
Streisand, Swift, Wickmark, Chen &	Cross-	115 mothers	Self efficacy*, Responsibility for diabetes	*Paediatric parenting stress
Holmes (2005)	sectional	19 fathers	management*, Fear of hypoglycaemia*	(PIP-D* and PIP-F*)
Mitchell, Hilliard, Mednick, Henderson,	Cross-	43 fathers	Child behavioural problems*, hope, fear of	*Paediatric parenting stress
Cogen & Streisand (2009)	sectional		hypoglycaemia, self efficacy	(PIP-D)
Marrero, Guare, Vandagriff & Fineberg	Cross-	56 mothers	History of hypoglycaemia and loss of	*Fear of hypoglycaemia (HFS)
(1997)	sectional	5 fathers	consciousness*	
Gonder-Frederick et al (2006)	Cross-	38 mothers	Trait anxiety; history of hypoglycaemia	Fear of hypoglycaemia (HFS)
	sectional	1 father		

Haugstvedt, Wentzel-Larsen, Graue,	Cross-	103 mothers	Hypoglycaemia history*, intensive insulin	*Fear of hypoglycaemia (HFS)	
Sovik & Rokne (2010)	sectional	97 fathers	treatment, glucose monitoring, HBA _{1c} *, child		
			age, co-morbid physical or mental		
			disorder *		
Chaney et al (1997)	Longitudinal	27mothers	Illness duration, child, mother & father	*Adjustment (SCL-90-R)	
		21 fathers	adjustment*		
Berg et al (2007)	Cross-	127 mothers	Appraised support, collaboration in coping*,	Adjustment (CED-S & PANAS)	
	sectional		appraised control* & lack of child involvement*,		
			child age* and sex*		
Berg, Schindler & Maharajh (2008)	Cross-	84 mothers	Collaboration	Adjustment (CED-S & PANAS)	
	sectional				
Olsen, Berg & Wiebe (2008)	Cross-	84 mothers	Dissimilarity in mother and adolescents' illness	Adjustment (CED-S & PANAS)	
	sectional		representations*		
Note. * indicates that the factor was reported to have an impact on an outcome measure. The asterisk also highlights which outcome measures related to					

the studied factor. Abbreviations used: SES = Socioeconomic status, BDI-II = Beck Depression Inventory, SCL-90 = Hopkins Symptom Checklist – 90 item version, CES-D = Center of Epidemiological Studies of Depression Scale, L-WMAT = Locke-Wallace Marital Adjustment Test, STAI=State-Trait Anxiety Inventory, PIP-D = The Paediatric Inventory for Parents – difficulty, PIP –F = The Paediatric Inventory for Parents - frequency, HFS = Hypoglycaemia Fear Survey (worry subscale), GSI = Global Severity Index, PANAS = Positive Affect Negative Affect Schedule.

Depression

Four studies comprised depression as an outcome variable. Within these studies, three measures of depression were utilised. Kovacs et al (1990) reported that mothers who displayed high levels of depression when their child was diagnosed with diabetes demonstrated high levels of depression five years post diagnosis. However, mothers who displayed lower levels of depression initially and who had higher socio economic status (SES) displayed the highest levels of depression. With regard to time since diagnosis they reported that depression scores increased over time, particularly for mothers of lower SES. However, mothers of higher SES displayed higher levels of depression. They further reported that medical factors were not associated with mothers' depression.

Blankfield and Holahan (1996) reported that depression in mothers was lower when they had higher levels of family support (mediated by mothers' ability to cope). Further studies reported that when mothers agreed with their adolescent about the adolescents' competence and ability to manage their illness independently, they displayed lower levels of depression. However, this finding was not true for fathers (Butner et al, 2009). Lastly, it was reported that mothers displayed higher levels of depression if they perceived greater difficulty in coping with the illness and had lower family income (Jaser et al, 2009).

Anxiety

Three studies comprised anxiety as an outcome variable. It was reported that mothers with higher levels of hope, displayed lower levels of anxiety (Mednick et al, 2007). Further studies reported that parents who sometimes engaged in monitoring the

child's glucose levels during the night, displayed higher levels of anxiety compared to those who did not conduct nocturnal monitoring (Monaghan et al, 2009). Jaser et al (2009) reported that higher levels of difficulty in coping with the diabetes and lower family income predicted mothers' anxiety.

Distress

Two studies examined psychological distress using two different measures. Psychological distress was reported to increase following the first year of the diabetes diagnosis. Furthermore, the distress displayed when the child was diagnosed predicted the mothers' distress five years later (Kovasc et al, 1990). This study reported that medical factors or SES did not predict mothers' distress. In the second study, higher levels of parents' illness uncertainty were found to predict higher levels of distress 5 to 6 years later (Carpentier et al, 2006). However, they reported that parents' attribution style for the diabetes events did not predict parents' distress levels.

Stress

Three studies assessed parenting stress. The studies reported that parents with greater fear of hypoglycaemia, higher levels of responsibility and lower self efficacy, reported more frequent stress. Those with greater hypoglycaemia fear and more responsibility also reported greater magnitude of stress (Streisand et al, 2005). Monaghan et al (2009) reported that parents who completed nocturnal blood glucose monitoring reported more frequent stress. Lastly, study Mitchell et al (2009) reported that only child behavioural problems predicted the magnitude of stress. They found that fathers' hope, fear of hypoglycaemia and self efficacy did not predict the magnitude of fathers' stress.

Fear of hypoglycaemia

Four studies assessed fear of hypoglycaemia as an outcome variable. These studies reported that worry regarding hypoglycaemia was higher in parents if their child had previously lost consciousness due to their diabetes (Marrero et al, 1997). Haugstvedt et al (2010) also found that higher hypoglycaemia worry was found in parents whose children had experienced more frequent difficult hypoglycaemia events in the past year, had children with higher HBA1c and additional medical or psychological problems. Gonder-Frederick et al (2006) reported that hypoglycaemia frequency or trait anxiety did not predict hypoglycaemia worry scores. Other factors which were found not to have an impact on parents' fear were the age of the child, disease duration, frequency of insulin intake, blood glucose checks (Haugstvedt et al, 2010) and nocturnal blood glucose checks (Monaghan et al, 2009).

Adjustment

As shown in table 1, adjustment was assessed using four measures relating to differing outcomes such as depression, positive and negative effect, distress and psychosocial wellbeing (environmental mastery and purpose in life). The studies comprising 'adjustment' as the outcome variable will be reported here.

Chaney et al (1997) reported that mothers' and fathers' adjustment did not change significantly over a one year period. However, they reported that mothers displayed less distress if fathers' distress had increased over the year. A similar finding was reported for fathers, with fathers' distress decreasing if mothers' distress increased over the year. They reported that child adjustment only impacted on fathers' adjustment, with increases in child distress predicting increases in fathers' distress.

Berg et al (2007) reported that mothers, particularly of older children, displayed less positive emotion and higher levels of depression if they perceived their child to be uninvolved in coping with stress associated with diabetes. However, this finding was not true for a measure relating to maternal negative mood. With regard to support offered by the child in coping with diabetes, no predictive effect was reported on any of the outcome variables measuring adjustment. However, when mothers perceived the child working with her to cope with the stress of diabetes, it was reported that mothers displayed higher levels of positive emotion, specifically for mothers of females. Greater levels of collaboration in coping also predicted a less negative mood, regardless of sex. However, this factor did not impact on maternal depression. Lastly, when the mother perceived their child as controlling in coping with the stress, significantly less positive emotion was displayed. However, this factor did not impact on mothers' depression or negative emotion.

Berg et al (2008) reported that collaboration between mother and adolescents on problem solving in the management of diabetes did not predict better adjustment. Study 16 reported that when mothers had a better understanding of the illness compared to their adolescent, they displayed poorer adjustment. However, no other perception of illness representation predicted adjustment.

Lastly, Butner et al (2009) reported that when mothers and adolescents held similar views regarding the adolescents' competence, they displayed higher levels of environmental mastery and having a purpose in life. For fathers this finding was only significant when having a purpose in life was the outcome variable.

Marital satisfaction

One study assessed marital satisfaction. Butner et al (2009) reported that mothers who held similar views as their adolescent with regard to the adolescents' competences displayed higher levels of marital satisfaction. This finding was not reported for fathers.

Discussion

This review aimed to systematically gather and synthesise the literature pertaining to factors that impact on the psychological wellbeing of parents of diabetic children to a) provide paediatric services with a comprehensive understanding regarding parents that may be particularly vulnerable to the development of psychological difficulties and b) highlight areas for further research to build upon this area of the literature. Sixteen studies were included in the review. Within these studies, a range of psychological outcomes were addressed in relation to a number of differing factors. Fourteen studies reported the impact of at least one factor on a measure of psychological wellbeing. The findings will be discussed below.

Overview of the reviewed research

The review employed a broad search strategy to capture pertinent factors across a range of psychological domains. The review highlighted that a number of studies assessed the impact of medical factors on different domains of psychological wellbeing. Whilst this is important, it is encouraging that a number of other factors were studied such as hope, family support and mother – child interactions given that Wallander et al (1989) reported that a number of different factors can influence psychological adjustment.

Although all of the studies investigated the impact of a factor on a measure of psychological wellbeing, the studies were diverse, which complicated study cross comparison. However, some trends appeared to emerge across the psychological outcomes. With regard to the interpersonal factors, apart from one, they appeared to influence parents' anxiety, depression and parenting stress. More specifically, a greater level of the particular factor (e.g. hope) predicted lower levels of psychological difficulties. The impact of disease factors (e.g. hypoglycaemia history, illness duration and co-morbid illnesses) and social-ecological factors (e.g. family support) also appeared to demonstrate their influence across the range of psychological outcomes. However, there were inconsistencies in the findings. Factors relating to parents' psychosocial stressors were particularly inconsistent. Therefore, the highlighted trends are tentative. Nevertheless, the findings lend support to Wallander et al's (1989) model as various factors were found to influence psychological outcomes. The variations across the studies which complicated study cross comparison and may explain the inconsistent findings will now be discussed.

The review highlighted that seven psychological domains were studied, which highlights that psychological wellbeing is a multi-dimensional construct (Ryff, 1995). It may also suggest that there is a lack of agreement within the literature regarding the most important psychological outcomes to study for parents of diabetic children. Nevertheless, the range of outcomes complicates the comparison of studies.

There were also complications in the comparison of studies assessing the same psychological outcome. Adjustment was assessed using four different questionnaires. This may reflect the lack of an adjustment definition in the literature and clarity on how

this process is measured. Indeed, adjustment and its measurement has been criticised within the literature (Bradford, 1997). On the other hand, studies assessing depression and distress for example, also varied in their measurement which may be suggestive of a more generic problem in the literature. This, however, inhibited reliable cross comparisons of studies assessing the same outcome.

Characteristics of the samples also varied widely. The age of diabetic children ranged from 4.5 years to 15.4 years. It has been reported that there are unique challenges to parenting a child with a chronic illness at different developmental stages. Parents of younger children face challenges in helping their child gain an understanding of their illness and treatment. Adolescence, on the other hand, provides a unique set of challenges with the necessity for parents to balance their involvement in illness management, whilst allowing the adolescent independence to develop their own identity (Streisand and Tercyak, 2004).

Participant gender also differed across the studies, with one study comprising only fathers, others only mothers, while some studied both. It has been reported that mothers and fathers display different reactions to type 1 diabetes (Kovacs, Finkelstein, Feinberg, Crouse-Novak, Paulauskas and Pollack, 1985). Such findings highlight a further complication in comparing studies and may explain the inconsistencies within the results.

Parents were also studied at a relatively wide range of times since the child's diagnosis. Given that time since diagnosis can influence parents' emotional response (Kovacs et al, 1990), this variation may have impacted on the consistency of the findings. For example, studies Marrero et al (1997) and Haugstvedt et al (2010) reported

that a history of hypoglycaemia impacted on parents' fear of hypoglycaemia, whereas Gonder-Frederick et al (2006) reported that no such association was found. However, the parents' children in this study had been diagnosed with diabetes for approximately three years longer. This may represent that overtime parents feel more confident in dealing with these events as reported in a qualitative study by Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane and Grey (2003).

Limitations of the research

The quality assessment score of the studies ranged from 55.6 % to 94.1%, suggesting there was a wide variability in the reliability of the studies. Although there were a number of weaknesses which compromised quality scores, common limitations were found. A number of the studies' quality ratings were affected by the representativeness of the sample used. However, it is difficult to ascertain whether this was because a representative sample was not used or because studies failed to clarify the representativeness of the recruited sample. The external validity of the studies is therefore questionable (Barker, Pistrang and Elliot, 2002).

Type 1 diabetes can be controlled either with insulin injections or an insulin pump. Each of these treatment regimes comes with its own complications (Wilson, Buckingham, Kunselman, Sullivan, Paguntalan, Gitelman, 2005). It is therefore surprising that 37% of the included studies did not report the child's treatment regime.

A further weakness with some studies was the small sample size. Sample sizes varied from over 200 participants, in comparison to others in which the sample consisted of approximately 50 participants or less. However, there was a consistent lack of reported power calculations across the studies. Without these calculations, it is difficult

to ascertain whether enough participants were recruited to detect significant differences (Field, 2009).

The majority of the studies employed a cross-sectional design and whilst this provides insight at one time point (Barker, Pistrang and Elliot, 2002), it is argued that longitudinal research provides a more accurate estimate of the factors impacting on psychological wellbeing as they can be shown to precede the psychological outcome (Wille, Bettge and Ravens-Sieberer, 2008). However, interestingly one of the longitudinal studies obtained a particularly low quality assessment score (55.6%) in comparison to some of the cross sectional research.

Limitations of the review

This systematic literature review has provided insight into important factors to consider in the context of parents' psychological wellbeing. It has also allowed insight into both mothers' and fathers' psychological wellbeing. Whilst the aim was to provide a high quality review, there are some important limitations.

The first limitation may relate to the exclusion criteria applied to this review. The review may have provided more insight if correlation designed research was included, as relationships between psychological outcomes and other variables will have been highlighted. However, a direction between the variables could not have been implied (Barker, Pistrang and Elliot, 2002) and therefore these studies would have been limited in answering the review question. With regard to quality assessment, an independent researcher rated a sample of the papers to help ensure the quality scores were objective. However, the searching and exclusion of papers was primarily conducted by the researcher and thus the possibility of subjective judgements cannot be

ruled out. Lastly, the exclusion of 'gray literature' (e.g. unpublished dissertations) may have limited the review, such that publication bias was possible (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, and Figueira, 2009).

Future research and clinical implications

This review supports Wallander et al's model (1989) as it highlights that there are factors other than medical issues which have the potential to impact on parents' psychological wellbeing. It has been documented that psychologists within paediatric services should be available to support families and the team in effectively managing mental health difficulties that may arise when one child has type 1 diabetes (Delamater, 2009). As the review highlighted that intrapersonal and socio-ecological factors were also found to play a part in parents' psychological wellbeing, it supports the need for psychologists within paediatric teams. However, it needs to be borne in mind that only a limited number of studies were included and some of the research yielded inconsistent findings. However, the review was able to identify areas for future research which may help services to gain a clearer picture regarding parents that may be at particular risk for developing mental health difficulties.

One such area relates to the design of the studies. In particular, it would be useful to conduct more longitudinal research to examine the causal effect of the factors on psychological functioning (Gass, Jenkins and Dunn, 2007). This evidence would help paediatric teams to prevent the development of psychological difficulties in parents.

Importantly, the review highlighted that the study of fathers' psychological wellbeing was significantly overlooked compared to mothers' wellbeing. This appears to be a common finding across the childhood literature, particularly in paediatric

research (Phares, Lopez, Fields, Kamboukos and Duhig, 2005). This is striking given that when a child is chronically ill, the fathers' involvement in the management of the illness can have a positive impact on family functioning (Wysocki and Gavin, 2006). Further research on fathers is therefore warranted.

Given that Wallander et al (1989) reported that the parents' outcome was dependent on a number of different factors, it would also be invaluable for research to examine the effect of an interaction of factors to predict psychological wellbeing (Wille et al, 2004). On the whole studies examined one factor in isolation from other possible factors, rather than interactions between them. Unsurprisingly, Wille et al (2004) reported that when more than one risk factor was present, the participants' psychological outcomes were detrimental. Teams need to be aware of parents who are at particular risk (Delamater, 2009).

Interestingly, despite a growing body of literature which stresses the importance of the study of positive outcomes, such as happiness (Seligman and Csikszentmihalyi, 2000), the majority of the studies utilised a measure assessing psychopathology. This is surprising given that psychological wellbeing encompasses positive outcomes, in addition to a lack of mental health difficulties (Ryff, 1989). Future research should also focus on assessing positive outcomes.

Conclusions

The review provides an overview of the empirical research on factors that may impact on the psychological wellbeing of parents of children with type 1 diabetes. Although some trends were recognised, such as the impact of illness related factors, socio-ecological and intrapersonal factors on psychological wellbeing, the studies were wide ranging and inconsistencies were evident, therefore comprehensive conclusions could not be made. However, this review has enabled valuable insight into areas of future research. Further research may help paediatric teams to gain a clearer understanding regarding which parents are at particular risk of developing psychological difficulties. This would help paediatric teams to develop further interventions to effectively support parents of diabetic children and adolescents.

References

- Anderson, B. J., & Auslander, W. F. (1980). Research on diabetes management and the family: a critique. *Diabetes Care*, 3, 696-702.
- Barker, C., Pistrang, N., & Elliot, R. (2002). Research Methods in Clinical Psychology: An introduction for students and practitioners. Chichester: John Wiley & Sons Ltd.
- Berg, C. A., Schindler, I., & Shannon, M. (2008). Adolescents' and mothers' perceptions of the cognitive and relational functions of collaboration and adjustment in dealing with type 1 diabetes. *Journal of Family Psychology*, 22, 865-874.
- Berg, C. A., Wiebe, D. J., Beveridge, R. M., Palmer, D. L., Korbel, C. D., Upchurch, R., Swinyard, M. T., Lindsay, R., & Donaldson, D. L. (2007). Mother-child appraised involvement in coping with diabetes stressors and emotional adjustment. *Journal of Pediatric Psychology*, 32, 995-1005.

- Blankfeld, D. F., & Holahan, C. J. (1996). Family support, coping strategies, and depressive symptoms among mothers of children with diabetes. *Journal of Family Psychology*, 10, 173-179.
- Bradford, R. (1997). *Children, families and chronic disease: Psychological models and methods of care*. New York: Routledge.
- Butner, J., Berg, C. A., Osborn, P., Wiebe, D., Butler, J. M., Godri, C., Fortenberry, K.
 T., Barach, I., & Le, H. (2009). Parent-adolescent discrepancies in adolescents' and parent well-being in the context in type 1 diabetes. *Developmental Psychology*, 45, 835-849.
- Cabizuca, M., Marques-Portella, C., Mendlowicz, M. V., Coutinho, E. F. S., & Figueira,
 I. Posttraumatic Stress Disorder in Parents of Children With Chronic Illnesses: A
 Meta-Analysis. (2009). *Health Psychology*, 28, 379–388.
- Cameron, L. D., Young, M. J. & Wiebe, D. J. (2007). Maternal trait Anxiety and
 Diabetes Control in Adolescents with Type 1 Diabetes. *Journal of Pediatric Psycholgy*, 32 (7), 733-744
- Carpentier, M. Y., Mullins, L. L., Chaney, J. M., & Wagner, J. L. (2006). The relationship of illness uncertainty and attributional style to long-term psychological distress in parents of children with type 1 diabetes mellitus. *Children's Health Care*, 35, 141-154.
- Chaney, J. M., Mullins, L. L., Frank, R. G., Peterson, L., Mace, L. D., Kashani, J. H., & Goldstein, D. L. (1997). Transactional patterns of child, mother and father adjustment in insulin-dependent diabetes mellitus: A prospective study. *Journal* of pediatric psychology, 22, 229-244.

- Delamater, A. M. (2009). Psychological care of children and adolescents with diabetes. *Paediatric diabetes*, 10, 175-184.
- Department of Health (2010). Six Years On Delivering the Diabetes National Service Framework. Retrieved June 2010 from http://www.dh.gov.uk/en /Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_112
- Downs, S., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*, 52, 377-384.
- Eiser, C. (1993). *Growing up with a chronic disease: The impact on children and their families.* UK: Jessica Kingsley Publishers Ltd.

Field, A. (2009). Discovering Statistics Using SPSS. (3rd edition). London: SAGE

- Gass, K., Jenkins, J., & Dunn, J. (2007). Are sibling relationships protective? A longitudinal study. *Journal of Child Psychology and Psychiatry*, 48, 167-175
- Gill, T. M., & Feinstein, A. R (1994). A critical appraisal of the quality of quality of life measurements. *The Journal of the American Medical Association*, 272, 619-626.
- Gonder-Frederick, L. A., Fisher, C. D., Ritterband, L. M., Cox, D. J., Hou, L., DasGupta, A. A., & Clarke, W. L. (2006). Predictors of fear of hypoglycemia in adolescents with type 1 diabetes and their parents. *Pediatric Diabetes*, 7, 215-222.
- Haugstvedt, A., Wentzel-Larsen, T., Graue, M., Sovik, O., & Rokne, B. (2010). Fear of hypoglycaemia in mothers and fathers of children with type 1 diabetes is

associated with poor glycaemic control and parental emotional distress: a population based study. *Diabetic Medicene*, 27, 72-78.

- Horsch, A., McManus, F., Kennedy, P., & Edge, J. (2007). Anxiety, depressive and posttraumatic stress symptoms in mothers of children with type 1 diabetes. *Journal of Traumatic Stress*, 20, 881-891.
- Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindermann, E., & Grey, M. (2009). Coping and psychosocial adjustment in mothers of young children with type 1 diabetes. *Children's Health Care*, 38, 91-106.
- Koizumi, S. (1992). Japanese mothers' responses to the diagnosis of childhood diabetes. *The Journal of Pediatric Nursing*, 7, 154-160
- Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paulauskas., & Pollock.
 (1985). Initial psychologic responses of parents to the diagnosis of insulindependent diabetes mellitus in their children. *Diabetes Care*, 8, 568 -575.
- Kovacs, M., Iyengar, S., Goldston, D., Obrosky, D. S., Stewart, J., & Marsh, J. (1990).
 Psychological functioning among mothers of children with insulin-dependent diabetes mellitus: A longitudinal study. Journal *of Consulting and Clinical Psychology*, 58, 189-195.
- Landolt, M. A., Vollrath, M., Laimbacher, J., Ghehm, H. E., & Sennhauser, F. H.
 (2005). Prospective study of posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes. *Journal of the American Academy of Child Psychiatry*, 44, 682-689.
- Lowes, L., Gregory, J. W., & Lyne, P. Newly diagnosed childhood diabetes: a psychosocial transition for parents? *Journal of Advanced Nursing*, 50, 253-261.
- Marrero, D. G., Guare, J. C., Vandagriff, J. L., Fineberg, N. S. (1997). Fear of hypoglycemia in the parent of children and adolescents with diabetes:
 Maladaptive or healthy response? *The Diabetes Educator*, 23, 281-286.
- Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R.
 (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with Type 1 Diabetes. *Children's Health Care*, 36, 385-396.
- Mitchell, S. J., Hilliard, M. E., Mednick, L., Henderson, C., Cogen, F. R., & Streisand,
 R. (2009). Stress among fathers of young children with type 1 diabetes. *Families, Systems and Health*, 27, 314-324.
- Monaghan, M. C., Hilliard, M. E., Cogen, F. R., & Streisand, R. (2009). Nighttime caregiving behaviours among parents of young children with type 1 diabetes: Associations with illness characteristics and parent functioning. *Families, Systems and Health*, 27, 28-38.
- National Institute for Clinical Excellence (2007). *The Guidelines Manual*. Retrieved June 2010 from http://www.nice.org.uk/aboutnice/howwework/developing niceclinicalguidelines/clinicalguidelinedevelopmentmethods/theguidelines manual2007/the_guidelines_manual__all_chapters.jsp
- Olsen, B., Berg, C. A., & Wiebe, D. J. (2008). Dissimilarity in mother and adolescent illness representations of type 1 diabetes and negative emotional adjustment. *Psychology and Health*, 23, 113-129.

- Olsson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 52 ,1102– 1113
- Ostberg, M., & Hagekull, B. (2000). A Structural Modeling Approach to the Understanding of Parenting Stress. *Journal of Clinical Child & Adolescent Psychology*, 29, 615 – 625.
- Phares, V., Lopez, E., Fields, S., Kamboukos, D., & Duhig, A. M. (2005). Are Fathers Involved in Pediatric Psychology Research and Treatment? *Journal of Pediatric Psychology* 30, 631–643
- Rodrigue, J. R., Gekkken, G. R., Clark, J. E., & Hunt, F., & Fishel, P. (1994). Parenting satisfaction and efficacy among caregivers of children with diabetes. *Children's Health Care*, 23, 181-191.
- Ryff, C. D. (1989). Happiness Is Everything, or Is It? Explorations on the Meaning of Psychological Well-Being. *Journal of Personality and Social Psychology* 57, 1069-1081.
- Ryff, C. D. (1995). Psychological well-being in adult life. Current Directions in *Psychological Science*, 4, 99-104.
- Seligman, M., & Csikszentmihalyi, M. (2000). Positive Psychology: An introduction. American Psychologist, 55, 5-14.
- Sharpe, D., & Rosssiter, L. (2002). Siblings of children with a chronic illness: a metaanalysis. *Journal of Pediatric Psychology*, 27, 669-710.

- Sherifali, D., & Ciliska, D. (2006). Parenting children with diabetes and Belsky's Determinants of Parenting Model: literature review. *Journal of Advanced Nursing* 55, 636–642.
- Streisand, R., Swift, E., Wickmark, T., Chen, R., & Holmes, C. (2005). Pediatric parenting stress among parents of children with type 1 diabetes: The role of self efficacy, responsibility and fear. *Journal of Pediatric Psychology*, 6, 513-521.
- Streisand, R., & Tercyak, K. P. Parenting chronically ill children the scope and impact of pediatric parenting stress. In Hoghughi, M., & Long, M. (Eds.), *Handbook of parenting: Theory and research practice* (pp181 – 197). London: SAGE.
- STROBE (2007). *Checklist for cross sectional studies*. Retrieved April 2010 from http://www.strobe-statement.org/index.php?id=available-checklists
- Sullivan-Bolyai, S., Deatrick, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003).
 Constant Vigilance: Mothers' Work Parenting Young Children With Type 1
 Diabetes. *Journal of Pediatric Nursing*, 18, 21-29
- Thernlund, G., Dahlquist, G., Ivarsson, S. A., & Ludvigsson, J. (1996). The initial psychologic reactions of the parents at the onset of insulin-dependent diabetes mellitus in children and short-time adaptation. *Nordic Journal of Psychiatry*, 50, 199-206.
- Tugade, M. M., & Fredrickson, B. L. (2004). Resilient Individuals Use Positive Emotions to Bounce Back From Negative Emotional Experiences. *Journal of Personality and Social Psychology*, 86, 320–333.
- Wallander, J., Varni, J., Babani, L., Banis, H., & Wilcox, K, (1989). Family

resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. In Bradford, R. (1997). *Children, families and chronic disease: Psychological models and methods of care*. New York: Routledge.

- Wang, R. H., Hsu, H. Y., Lin, S. Y., Cheng, C. P., & Lee, S. L. (2010). Risk behaviours among early adolescents: risk and protective factors. *Journal of Advanced Nursing*, 66, 313-323.
- Wille, N., Bettge, S., & Ravens-Sieberer, U. (2008) Risk and protective factors for children's and adolescents' mental health: results of the BELLA study. *European Child & Adolescent Psychiatry*, 17, 133-147.
- Williams, G. & Pickup, J. (2007). *Handbook of Diabetes 3rd edition*, Blackwell Publishing.
- Williams, P. D., Williams, A. R., Hanson, S., Graff, S., Ridder, L., Curry, H., Liebergen,
 A., & Karlin-Setter, R. (1999). Maternal mood, family functioning, and
 perceptions of social support, self esteem, and mood among siblings of
 chronically ill children. *Children's Health Care*, 28, 297- 310.
- Wilson, D. M., Buckingham, B. A., . Kunselman, E. L., Sullivan, M. M., Paguntalan, H. U., & Gitelman, S. E. (2005). A Two-Center Randomized Controlled Feasibility Trial of Insulin Pump Therapy in Young Children With Diabetes. *Diabetes Care*, 28, 15-19.
- Wysocki, T., & Gavin, L. (2006). Paternal Involvement in the Management of Pediatric Chronic Diseases: Associations with Adherence, Quality of Life, and Health Status. *Journal of Pediatric Psychology*, 31, 501–511.

CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES: PARENTS' PSYCHOLOGICAL WELLBEING, SIBLING EMPATHY AND THE QUALITY OF THE SIBLING RELATIONSHIP

Part 2

Empirical paper

Children and adolescents with Type 1 Diabetes: Sibling Empathy and the Quality of the Sibling Relationship

Faye L. Melbourne*, Dr Annette Schlösser, Dr Claudine Bowyer-Crane & Dr Mary

Raeburn-Binns

Department of Clinical Psychology, Hertford Building University of Hull, Hull, HU6 7RX, UK

*Corresponding author: Tel: +44 1482 464106; fax +44 1482 464093

Email address: f.melbourne@2004.hull.ac.uk

This paper is written in the format ready for submission to The Journal of Family

Psychology

Please see Appendix B for the Guidelines for Authors

Abstract

Based on family systems theory this preliminary pilot investigation aimed to explore relationships between empathy and sibling relationship quality when one child has a diagnosis of type 1 diabetes to determine the feasibility of examining these concepts in a cross sectional study. Both siblings, in which one had a diagnosis of diabetes, were asked to complete questionnaires assessing their level of empathy and their perspective on the quality of the sibling relationship. A control group, in which both siblings were healthy, were also included as a comparison group. Results showed that healthy siblings did not display higher levels of empathy in comparison to the control group. The empathy difference between the healthy sibling and diabetic child did not significantly differ to that between two healthy siblings. Finally, results showed that empathy in the healthy sibling predicted warmth in the sibling relationship, regardless of whether both siblings were healthy or when one child was diabetic. Results are discussed in the context of methodological limitations and areas for future research are highlighted based on the findings from this pilot investigation.

Key words: Diabetes, sibling relationship, empathy, pilot study

Siblings of children with Type 1 Diabetes: Sibling empathy and the Quality of the Sibling Relationship

Type 1 diabetes

Type 1 diabetes is one of the most common chronic childhood illnesses (NICE, 2004). It is estimated that 20,488 children in England are affected by this illness (Department of Health, 2010). Type 1 diabetes is diagnosed when the pancreas makes little or no insulin. Treatment therefore involves daily insulin via injections or an insulin pump. A controlled dietary regime and regular blood glucose monitoring are also important aspects of the treatment plan (NICE, 2004). The management of this chronic illness can affect the entire family system. However, research examining the effect of this illness on siblings has previously been overlooked, with the focus mainly on the diabetic child and the mother (Hollidge, 2001).

Systems theory and childhood illness

A system has been defined as "an entity made up of interacting parts which communicate with and influence each other" (Dallos and Draper, 2005, p24). A change in any part of a family system, such as the diagnosis of a childhood illness, affects each family member (Cooper, 1999). There is a growing body of literature reporting the effect of a chronic illness on the healthy siblings' psychological functioning. Sharpe and Rossiter (2002) reported that the prevalence of depression and anxiety were higher in siblings of chronically ill children compared to siblings of healthy children. More specifically to siblings of diabetic children, it has been reported that they may develop a

lower self concept than their peers (Ferrari, 1987), display increased levels of stress (Hollidge, 2001) and sadness (Loos and Kelly, 2006).

Positive Psychology and Empathy

Whilst the study of psychopathology is important, there is a growing interest in the study of positive psychology, a framework encompassing positive emotion and positive individual traits (Seligman and Csikszentmihalyi, 2000). Research has reported that there are also positive effects for siblings living with a chronically ill child. Siblings of children with cancer, for example, have been found to show increased compassion (Sargent et al, 1995), patience and sensitivity (Tritt and Esses, 1988). These findings are not restricted to childhood cancer. Cuskelly and Gunn (2005) reported that siblings of children with Down's syndrome displayed more empathy than siblings of healthy children. With reference to type 1 diabetes, Loos and Kelly (2006) found that following a diagnosis of diabetes, siblings displayed more caring behaviour towards their diabetic sibling and offered them emotional support.

Prosocial behaviour, such as caring for another individual, may stem from empathic concern (Eisenberg and Strayer, 1987). Empathy has been defined as "an emotional response that stems from another's emotional state or condition and that is congruent with the other's emotional state or situation" (Eisenberg and Strayer, 1987, p5). As reported by Labay and Walco (2004), empathy may play an important role for siblings of children with a chronic illness. In their study of childhood cancer, they found that healthy siblings with higher levels of empathy demonstrated more positive adjustment to their sibling's diagnosis, as indicated by a lack of externalising and internalising difficulties. They suggested that empathy may help siblings to understand

the need for parents' attention to focus on the ill child.

More generally, empathy can promote the most positive displays of behaviour and a lack of it can relate to the most challenging behaviour problems (Dadds et al, 2008). Moreover, empathy plays an important role in the development of interpersonal relationships, such as the quality of sibling relationships (Dunn and Kendrick, 1982).

Sibling relationships

The sibling relationship plays a significant role in the development of social and emotional understanding in children (Sanders, 2004). Gass, Jenkins and Dunn (2007) also reported that close sibling relationships may also serve as a protective factor. More specifically, they found that during times of adversity, children with affectionate sibling relationships displayed significantly less emotional difficulties compared to children without such relationships.

Furman and Buhrmester (1985) devised a model to highlight the factors that influence the quality of sibling relationships (see figure 1). The model indicates that children's characteristics, such as their ability to empathise, can impact on the quality of the relationship. This is reported by Dunn and Kendrick (1982). Furthermore, the model indicates that the sibling relationship also impacts on the development of children's characteristics

Figure 1 Furman and Buhrmester's (1985) model of the primary determinants of

sibling relationship qualities



Sibling relationships and type 1 diabetes

Sibling relationships are affected by an illness in one child. Loos and Kelly (2006) in their qualitative study of diabetic children found that many siblings reported that their relationship had become closer. However, other siblings reported that their relationship had become strained. Other studies (e.g. Loman, 2001) have reported that the sibling relationship did not differ from healthy siblings. However, only the healthy siblings' view was obtained. Vogt (2001) included both siblings' perspective of their relationship and found that both siblings held a similar view of the relationship.

The study of sibling relationships when one child has diabetes is important. Hanson, Henggeler, Harris, Cigrang and Schinkel (1992), for example, found that the sibling relationship had a significant impact on the adaptation of the diabetic child to their illness, independent to the ill child's relationship with their mother. However, the way in which sibling relationships are affected by diabetes is not clear. It is surprising that given the number of variables that can impact on the quality of a sibling relationship (Furman and Buhrmester, 1985), no factors have been studied that may help to explain the differences found. Given that empathy may help healthy siblings to understand and feel more able to accept that the ill child may gain more parental attention (Labay and Walco, 2004), this factor may positively impact on the quality of the sibling relationship.

Equity theory

Equity theory poses that fairness and equity are important for individuals to feel satisfied and happy within a relationship. Inequities within an interpersonal relationship results in each individual within the relationship feeling distressed (Walster, Berscheid and Walster, 1973). Although it may be positive that healthy siblings have been found to display increased levels of empathy and compassion (e.g. Cuskelly and Gunn, 2003, Sargent et al, 1995), according to equity theory, if this is not reciprocated by the ill child, this would negatively impact on both the healthy sibling and the diabetic child. **Aims and hypotheses**

The primary aim of this pilot study was to identify if empathy predicted the quality of the sibling relationship differently when one child has diabetes compared to when both siblings are healthy. Exploring the relationship between empathy and the

quality of the relationship may help to gain an understanding of why following a diagnosis of diabetes some sibling relationships are more strained than others. Moreover, this would also allow further exploration of Furman and Buhrmester's (1985) model to understand if healthy siblings' characteristics (i.e. their empathy) also predict the quality of the sibling relationship when one child has a diagnosis of type 1 diabetes. Given that it has been reported that empathy is important in siblings of chronically ill children to help them understand the needs of the ill child and the need for additional parental attention (Labay and Walco, 2004), it was hypothesised that sibling empathy would be more important in predicting the quality of the sibling relationship when one child has diabetes compared to when both children are healthy. Two further exploratory questions were added to be investigated.

Following on from previous studies investigating positive traits, the second aim of the preliminary study was to investigate whether siblings of diabetic children displayed a difference in their level of empathy compared to siblings of healthy children. As it has been reported that siblings of chronically ill children display differences in their level of empathy (e.g. Cuskelly and Gunn, 2003 and Sargent et al, 1995) it was hypothesised that siblings of diabetic children would display differences in their level of empathy in comparison to siblings of healthy children.

In line with equity theory, the final aim of the pilot study aimed to explore whether there is a difference in the level of empathy between the healthy sibling and the diabetic child in comparison to a sibling group in which both children are healthy. Given that previous research has found that siblings of ill children display differences in their level of empathy compared to siblings of healthy children (e.g. Cuskelly and Gunn,

2003) and healthy siblings offer emotional support to the diabetic child (Loos and Kelly, 2006), it was hypothesised that there would be a difference in empathy inequities between siblings when one child has diabetes compared to when both children are healthy.

Method

Participants

Participants for the pilot study's clinical group were sibling dyads recruited from NHS paediatric diabetes clinics. Participants for the control group were sibling dyads recruited through schools and informal networks. In both groups both siblings (a) were aged between 8 to 13 years old; (b) were biological siblings; (c) lived together (d) spoke fluent English. The two siblings closest in age were chosen if more than two siblings met the inclusion criteria. Additional inclusion criteria for the clinical group were that (a) one sibling had a diagnosis of type 1 diabetes controlled with daily injections; (b) the diabetic child had no further chronic health conditions or developmental disabilities (excluding thyroid problems or celiac disease); (c) the non diabetic sibling had no chronic diseases or developmental disabilities. Additional inclusion criteria for the control group required both siblings to have no diagnoses of chronic illnesses or developmental disabilities.

Forty five families were identified who would potentially meet the inclusion criteria in the clinical group. Twenty eight families gave consent to take part in the preliminary research, with a further eight families not meeting the research criteria due to a child being under 8 or over 13 years old. A further nine families did not want to take part. Some families were included who did not perfectly meet the inclusion criteria for

reasons such as a child having mild asthma (n=3) or Mccune albright (n=1). The final clinical group consisted of 28 diabetic children (16 boys and 12 girls, mean age = 10.8, SD = 1.6) and their siblings (13 boys and 15 girls, mean age = 10.5, SD = 1.9). Fourteen diabetic children were older than the healthy siblings (50%). Diabetic children had been diagnosed for a mean of 4.9 years (SD = 3.04) and had a mean of 3.4 daily injections (SD = 0.8).

For the pilot's control group, a total of 750 research information packs were sent home to parents of children aged 8 to 13. A total of 10 parents returned forms consenting to take part (response rate = 1.3%), with three of these families being excluded due to a sibling being aged 17 (n=1), a child having epilepsy (n=1) and siblings being non biological related (n=1). A further 60 information packs were given to families through informal networks. A total of 25 packs were returned (response rate = 41.7%), with a further two families being excluded due to being non biological siblings. The final control group consisted of 31 sibling dyads (35 girls and 27 boys). The control sibling used as a comparison for the healthy sibling in the clinical group had a mean age range of 10.7 years (SD=1.6) and the sibling used as a comparison for the diabetic child had a mean age of 10.5 years, SD = 1.7).

Previously published research was not available to reliably estimate effect sizes that may be present in this preliminary pilot study. The planned sample size was therefore based on a pragmatic estimate of the recruitment rate for the study during the study period. The sample size calculation determined that 40 sibling dyads in each group (clinical and control) would give 80% power to detect an effect size of 0.10, using multiple regression to test for an R-squared increase in one variable after controlling for four other variables with a 5% significance level. It was estimated that 40 sibling dyads in each group would give 80% power to detect an effect size of 0.63 for the remaining research questions. The planned sample size for the pilot study was unfortunately not met.

Procedure

Ethical approval for this preliminary investigation was obtained from an NHS Research Ethics Committee and Trust approval was granted for each research site (see Appendix F and G for approval letters). For the clinical group, the Diabetes Specialist Nurses identified potential families and sent information letters home to parents two weeks before their child's clinic appointment (see appendix I). When families attended their appointment, the diabetes nurse asked the family if they wanted to take part in the research. If parents consented and children met the inclusion criteria (following the completion of the consent and demographic data form at the diabetes clinic by the researcher, see appendix J and K), a home visit was arranged to meet with the children. For the control group information letters, consent forms and demographic data forms were sent home to parents. Interested parents completed the forms and returned them to the researcher. The researcher then contacted the family to arrange a home visit. In both the clinical and control group, the researcher read through an information letter with each child (appendix L) and gave them the opportunity to ask questions. If the child was happy to take part, they completed the assent form (appendix M) and questionnaires.

Measures

Demographic questionnaire

One parent completed a demographic questionnaire to a) identify if the family met the pilot study's inclusion criteria and b) to gain demographic details. A separate questionnaire was devised for the control and clinical group (see appendix K for a copy of each questionnaire).

Index of Empathy for children and adolescents (Bryant, 1982)

Both siblings in each dyad completed this questionnaire to assess their level of empathy. This questionnaire can be used for 6 to 13 year olds. Bryant (1982) reported high test-retest reliability ($\alpha = .81$) and convergent validity (r = .68) for a sample of children aged 9 and 10. Children and adolescents are required to answer 22 statements by circling either 'Yes' or 'No'. Questions are either worded positively e.g. 'It makes me sad when I see an animal being hurt', with 1 = Yes and 0 = No or negatively e.g. 'Girls who cry because they are happy are silly', with Yes = 0 and No = 1. The empathy score is the total of all the 22 items, with a higher score indicating a higher level of empathy. See Appendix O for a copy of the measure.

Sibling Relationship Questionnaire – revised (brief version) (Furman and Buhrmester, 1985).

Both siblings in the dyad completed this questionnaire to assess their perception of their sibling relationship. The questionnaire can be used with children aged 8 years and older (Buhrmester and Furman, 1990). It consists of 39 questions which relate to four factors; warmth/closeness (15 items), conflict (6 items), rivalry (6 items), relative status/power (12 items). For the rivalry factor, children rate their answers on a five point scale (1= my sibling almost always gets treated better to 5 = I almost always get treated better, with a midpoint of 3 = we get treated the same). For the remaining factors the five point scale ranged from 1 = Hardly at all to 5 = Extremely much. The original version was reported by Furman and Buhrmester (1985) to have a reliability of mean r= .71 and internal consistency coefficients with mean α = .80. There are no psychometric properties reported for the revised version, but it is only minimally different from the original version. Cronbach's alpha was calculated for the SRQ-R for this pilot study and demonstrated good reliability for warmth (α = .91), conflict (α = .78), relative status/power (α = .78) and rivalry (α = .80). An alpha value of 0.80 or above demonstrates good reliability (Field, 2009). (See appendix N for a copy of the measure). **Statistical Analyses**

The Statistical Package for the Social Sciences version 17.0 (SPSS Inc, 2008) was used for the pilot study's statistical analyses. A 5% (p = .05) significance level was used throughout. Four General Linear Models (GLM) were firstly performed to determine if the healthy siblings' empathy in the clinical group and a sibling in the control group were predictors for the quality of the sibling relationship. Interaction effects between empathy and group were explored.

T-tests and analyses of covariance (ANCOVA) were then conducted to calculate (a) the difference in empathy between the healthy sibling in the clinical group and a sibling in the control group; (b) the difference in empathy between the healthy sibling and diabetic child and (c) the difference in empathy between the siblings in clinical group compared to the difference between the siblings in the control group.

Results

The two groups were compared on demographic variables using chi square (X^2) .
The results are shown in table 1. No significant differences were found between the
groups on variables of interest.

Variable	Clinical group				Control group			Significance
Economic class	1	2	•	3	1	2	3	.341
(%)	17.9	50.	.0	32.0	32.0	48.0	19.0	
No. of siblings in	2	3	4	5	2	3	4	.472
the family (%)	46.4	39.3	7.1	7.2	64.5	29.0	6.5	
Parent structure	1	2		3	1	2	3	.509
(%)	89.3	10.	.7	0.0	80.6	16.1	3.2	
Ethnic origin	1	2	•	3	1	2	3	.548
(%)	96.4	3	3.6	0	90.3	6.5	3.2	
Sex of dyads	1	2		3	1	2	3	.490
(%)	28.6	21	.4	50	22.6	35.5	41.9	

Table 1. X^2 results (significance level p < .05)

Note. Socio economic class 1 = managerial and professional occupations 2 = intermediate occupations 3 = routine and manual occupations. Parent structure 1 = two parent family 2 = single mother 3 = single father, Ethnic origin 1= White British 2= British Asian 3= British Pakistani. Sex of dyads: 1 = two boys 2 = two girls 3= opposite sex siblings.

Empathy as a predictor of the quality of the sibling relationship

As both siblings' perspective of the sibling relationship was to be included in the regressions, initially ANCOVAs were conducted to ensure there were no significant differences in their perspectives of the sibling relationship. After controlling for gender combination and age difference, no significant differences were found for warmth (t = -.33, df = 25, p = .742), conflict (t = -.903, df = 25, p = .375, rivalry (t = -1.503, df = 24, p = .146) and relative status/ power (t = -.423, df = 25, p = .676). The lack of significant difference in the perspective of the relationship between the siblings in the clinical dyad was mirrored when comparisons were made with the siblings in the control group i.e. no significant difference were found for warmth (F (1, 55) = .021, p = .885), conflict (F (1, 55) = .157, p = .693), rivalry (F (1, 54) = .767, p = .385), or relative status/power (F (1, 55) = 3.321, p = .074).

As no significant differences were found in the perspective of the sibling relationships, for the General Linear Models, the warmth, rivalry, conflict and relative/status power in each sibling dyad was averaged to give a mean score. For the rivalry factor, results were converted into a linear scale from 0 to 2 with siblings who perceived no rivalry gaining a score of 0, those who perceived rivalry to often occur, gaining a score of 1 and those who always perceived rivalry to occur gaining a score of 2. Therefore, a higher score on the scale reflected the perception of greater rivalry.

Bivariate correlations were conducted with the four factors of the quality of the sibling relationship and empathy to examine the relationships between these variables. Significant positive correlations were found between status/power and warmth (r = .265, p = .042) and rivalry and conflict (r = .301, p = .022). Significant negative correlations

were found between warmth and conflict (r = -.508, p < .001) and rivalry and warmth (r = -.274, p = .038).

GLMs were then conducted to investigate whether empathy predicted the quality of the sibling relationship similarly for both groups (clinical and control) by exploring interaction effects. For each of the regressions, one of the four factors was the outcome variable. Age difference between the siblings and gender combination (same or opposite sex dyads) were controlled for in these analyses. Results showed that the interaction between empathy and group was not significant for warmth (F(1, 53) = .525, p = .472, partial $\eta^2 = .010$, beta estimates = .032, 95% CI = (-.057, .122); conflict (F(1, 53) = 1.272, p = .264, partial η^2 = .023, beta estimates -.059, 95%, CI = (-.164, .046); rivalry $(F(1, 52) = .025, p = .876, partial n^2 = .000, beta estimates = .003, 95\%, CI = (-.040, -.040)$.047); or relative status/power (F(1, 53) = 1.313, p = .257, partial η^2 = .024, beta estimates = .018, 95%, CI = (-.013, .049). Therefore the hypothesis was not supported. See appendix R for the interaction outputs. For each of the four relationship factors, this interaction was removed to simplify the model and investigate whether there were any main effects of empathy or group independently (whilst still controlling for gender combination and age difference). A main effect of empathy was found when sibling warmth was the outcome variable (F(1, 54) = 4.459, p = .039, partial η^2 = .076, beta estimates = .051, 95% CI = (.003, .100). Results indicated (with 95% confidence) that higher levels of empathy predict greater levels of warmth in the sibling relationship similarly in each group. No further main effects were found for group or empathy.

Healthy siblings' empathy

Using an independent t-test to test for differences in empathy, no significant difference was found between the healthy siblings score in the clinical group (M = 13.86, SD = 3.44) and the siblings in the control group (M = 14.68, SD = 3.38), t= -.923, df = 57, p=.360). After controlling for age and gender in a ANCOVA, there remained no significant difference (F(1,55) = .502, p= .482, partial η^2 = .009, beta estimates = -.531, 95%, CI = (-2.032, .970) thus not supporting the hypothesis. Both age (F(1, 55) = 12.32, p = .001, partial η^2 = .183) and gender F(1, 55) = 9.30, p = .004, partial η^2 = .145) were found to have an effect with older siblings and girls displaying higher levels of empathy.

Empathy difference between the siblings

The mean empathy score of the diabetic children was compared to the empathy score of their healthy siblings. Using a paired t-test, no significant difference was found (t = -1.536, df = 27, p = .136).

The difference in the level of empathy between the diabetic child and their healthy sibling was compared to the difference between the siblings in the control group. An independent t-test showed no significant difference between the two groups (t = -1.143, df = 27, p = .258) After controlling for age difference between the siblings and gender combination (i.e. same sex or opposite sex), there remained no significant difference (F(1,55) = 3.321, p = .074, partial η^2 = .057, beta estimates = -1.691, 95% CI = (-3.550, .168). However, this result is approaching significance with the mean difference between the siblings in the clinical group larger than the mean difference in the control group (as shown in table 2). A main effect of age difference between the siblings was found (F(1, 55) = 10.63, p = .002, partial η^2 = .162), with the empathy difference increasing as the age gap between the siblings increased and older siblings gaining a higher empathy score.

	Clinical g	group	Control group		
	М	SD	М	SD	
Empathy difference					
between siblings	-1.07	3.69	0.06	3.92	

 Table 2. Mean and standard deviation of difference in the level of empathy between
 siblings in each group

Discussion

This preliminary pilot investigation explored the relationship between empathy and the quality of the sibling relationship when one child has a diagnosis of type 1 diabetes. The results suggest that empathy does not predict the quality of the sibling relationship differently when one child had diabetes and when both children were healthy. Across the four factors of the relationship, a main effect of empathy was only found for the warmth in the sibling relationship. The remaining questions of this pilot investigation found that healthy siblings do not display increased levels of empathy in comparison to healthy controls. Furthermore, there was no difference in the level of empathy between diabetic children and their healthy siblings and that the difference between these siblings was no greater or less than is observed between two healthy siblings. These findings will be discussed.

With regard to the predictive effect of empathy on the sibling relationship, siblings' empathy predicted the level of warmth. This is not surprising, given that previous research has reported that empathy is essential for the development of caring

sibling relationships (e.g. Dunn and Kendrick, 1992). What is important to note, however, is that empathy similarly predicted the warmth in the relationship, regardless of the sibling group and therefore the hypothesis was not supported. This suggests that empathy is no more important for the sibling relationship when one child has diabetes compared to when both children are healthy. However, it is important to note that a significant difference may not have been highlighted due to the small sample size and because a small effect size was highlighted. Nevertheless, this finding lends further support to Furman and Buhrmester's (1985) model, in that the individual characteristics of the child predicted warmth in the relationship even when one child has diabetes. The fact that no significant interaction between empathy and group was found may be a positive finding. This may suggest that healthy siblings do not need to display higher levels of empathy in order to maintain the quality of the sibling relationship.

With regard to empathy predicting warmth (regardless of whether both siblings are healthy or when one child has diabetes), the confidence interval suggests that it is possible to be 95% sure that a positive relationship exists between these variables i.e. an increase in empathy results in an increase in warmth in the sibling relationship. However, the beta value and the confidence interval suggest that this is not a particularly strong relationship.

Interestingly, the findings suggest that empathy does not predict the three other factors of the sibling relationship when one child has diabetes. However, contrary to expectation, the absence of the predictive effect of empathy was also true when both siblings were healthy. A number of reasons may help to explain this finding. Firstly, it is possible that empathy has a more pronounced influence in the development of a warm

relationship, in comparison to the other facets of sibling relationship. Indeed, it has been stated that prosocial behaviour is linked to an ability to empathise (Vreek and Van der Mark, 2003). Furthermore, the reduced power in the analyses may have limited the possibility of finding a main effect of empathy on the other factors of the relationship. Indeed, the effect sizes for the other facets of the sibling relationship were smaller than for warmth.

Secondly, it is important to highlight that "the quality of the sibling relationship is determined by no single factor" (Brody, 1998, p9) and this is clearly shown in Furman and Buhrmester's (1985) model. Therefore, it is not surprising that empathy alone did not solely predict all aspects of the quality of the sibling relationship. However, it is possible that empathy in addition to other variables may have demonstrated a predictive effect on the other factors of the sibling relationship. Indeed, Volling, McElwain and Miller (2002) reported that with regard to sibling rivalry, both a higher level of emotional understanding and the quality of the marital relationship predicted the older siblings' rivalry for the mothers' attention.

The results from this pilot study do not support the hypothesis that siblings of diabetic children would display differences in their level of empathy compared to siblings of healthy children. However, the pilot study did find that older siblings and girls were found to have higher levels of empathy, which is consistent with Bryant's (1982) findings that empathy is further developed in older children and girls. The results from this pilot investigation contrast with previous research (and the initial hypothesis) within the chronic illness and developmental disability literature, in which higher levels of empathy have been reported (e.g. Cuskelly and Gunn, 2003, Sargent et

al, 1995). A number of reasons may help to explain this. With reference to the paediatric cancer literature, it has been reported that siblings who have a more in depth understanding of the illness, display higher levels of empathy (Labay and Walco, 2004). Given the unpredictable nature of diabetes (e.g. events of hypoglycaemia) and the complexity of the treatment (Donnelly et al, 2005), it is possible that healthy siblings have little understanding of illness, which may thus impact on their level of empathy. Both Adams (1991) and Loos and Kelly (2006) have reported this to be the case. Moreover, Minagawa (1997) reported that it may be difficult for siblings of diabetic children to display positive effects given the strain this illness can place on the family.

Secondly, within the literature, the way in which empathy has been measured has been inconsistent. Cuskelly and Gunn (2003) for example measured empathy using a subscale of a sibling relationship questionnaire. On the other hand, Sargent et al (1995) utilised a qualitative design. These variations in measurement may inhibit the development of consistent findings across studies.

It is important to note that positively, the results suggest that empathic responding is not negatively affected in siblings of children with diabetes. This is encouraging given that emotional difficulties may hinder the ability to empathise (American Psychiatric Association, 1987) and siblings of chronically ill children are at risk for the development of mental health problems (Sharpe and Rossitier, 2006). It may also be helpful that increased empathy was not found as Zahn-Waxler and Radke-Yarrow (1990) report that over empathising with others can result in experiencing too much distress and may hinder one's own development.

This pilot study's results found that healthy siblings do not display differences in their levels of empathy in comparison to the diabetic child, which according to equity theory is positive for the wellbeing of the diabetic children and the healthy siblings. However, a significant finding may not have been highlighted due to the small sample size in this pilot study.

The statistical analysis of the empathy difference between the siblings in the clinical group compared to the siblings in the control group further support the finding that the empathy difference was no greater or less than would be expected between two healthy siblings. The pilot study's hypothesis was therefore not supported. Given that inequities between individuals can negatively impact on each individual within the relationship (Walster et al, 1973), the findings are promising as they suggest that childhood diabetes does not impact on empathy inequities between siblings.

It is important to observe however, that the empathy difference between the two groups was approaching significance, with the difference between the siblings in the clinical group larger than the control group. As the sample size target was not met in this pilot investigation and the effect size highlighted for this calculation was small, a significant difference may not have been highlighted. Furthermore, it is important to note that the confidence interval appears to be relatively large ranging from negative to positive which thus questions the reliability of the beta value. Given these limitations, the results need to be interpreted with caution. It would be beneficial to repeat this analysis in future research.

Clinical Implications

Although siblings of diabetic children are at risk of developing of anxiety and depression (Sharpe and Rossiter, 2002), results from this pilot investigation suggest that living with a diabetic child does not negatively affect all aspects of their functioning. More specifically, the results suggest that these siblings do not show difficulties with empathic responding in comparison to a normative sample. It is well documented that parents express concerns about healthy siblings of ill children (Loos and Kelly, 2006). Given parental concerns, the findings from this pilot study suggest that it would be helpful for paediatric teams to be mindful of parents' worries regarding their healthy sibling and inform parents that these siblings do not have difficulties in emotionally responding to others. Furthermore, the findings from this pilot study found that empathy is further developed in older children and in girls. In terms of psycho education it would be helpful for paediatric teams to be aware of this and inform parents if, for example, younger siblings do not appear empathic towards their diabetic sibling.

The findings from this preliminary pilot study found that the healthy siblings' empathy has a statistically significant impact on the level of warmth in the sibling relationship, which can protect both children from psychological difficulties (Gass, Jenkins and Dunn, 2005). Given that it has been reported that a child's understanding of their siblings' illness has been found to predict the healthy siblings level of empathy (Labay and Walco, 2004), the findings support that all members of a family, including siblings should be included in diabetes interventions (Delamater, 2009). However, taking into account the clinical significance of these findings, as the beta value and

confidence interval suggest that the predictive relationship of empathy on the warmth in the sibling relationship is not particularly strong, it would be important for paediatric teams to be aware that it is unhelpful for them to spend further time in developing healthy siblings' empathy. This is further supported as the results suggest that empathy is not significantly more important in sibling relationships when one child is diabetic compared to when both children are healthy.

Limitations of the study

The results of the current study can only be meaningfully interpreted in the context of highlighting the methodological limitations (Barker, Pistrang and Elliot, 2002). Given that the sample size target was not met in this preliminary study, the statistical tests were under-powered. It is therefore important to note that statistical differences may not have been detected due to the reduced sensitivity of the analyses and thus type 2 errors may have been made. A type 2 error occurs when it is thought that no difference exists when actually a difference is present but undetected (Field, 2009). This may have been particularly true for the analyses examining the empathy differences between siblings, which was particularly close to statistical significance. Given the possibility of a type 2 error being made, it therefore limits the researcher's ability to state that no difference exists and thus the results have to be interpreted with caution. For firm conclusions to be stated, further research particularly those that were close to statistical significance, would be required to confirm these findings before such conclusions could be offered. Nevertheless, the results do suggest interesting findings and have highlighted areas of further study.

With regard to the participant sample, some children did not perfectly match the inclusion criteria. Such children included those with additional chronic illnesses, such as mild asthma. However, there is no literature to report the negative or indeed positive effects of mild asthma on sibling relationships. Furthermore, co-morbidities with chronic illnesses are not uncommon (Grumbach, 2003) and therefore the exclusion of all of these children may have questioned the external validity of the selected sample.

It has been reported that the reliability of a scale increases as the number of response choices increase (Nunnally and Bernstein, 1994). It is therefore possible that the reliability of the rivalry scale may have been reduced following its conversion into a linear scale for the regression analyses. However, this procedure was necessary to produce meaningful results.

There are a number of variables which can influence the quality of the sibling relationship. It is therefore likely that all confounding variables were not controlled for within the analyses. With regard to confounding variables, it was questioned whether 'time since the diabetes diagnosis' should be included as a covariate in the statistical analyses. This factor has been found to be important when considering parents' psychological wellbeing (e.g. Kovacs et al, 1990), however, thus far no research has examined the possible difference in siblings' psychological wellbeing from diagnosis and over time, therefore including this factor was deemed not essential. Furthermore, given the small sample size and thus reduced power in the analyses, it would have been unhelpful to include further covariate to control for in the statistical tests. Moreover, it would be nearly impossible to control for every confounding variable within a study (Grimes and Schulz, 2002).

Lastly, a limitation may relates to the feasibility of the study. This pilot study set out to explore certain relationships between empathy and the sibling relationship and clarify the feasibility of examining these concepts in a cross sectional study. This pilot study highlighted that there were certain aspects which may question the feasibility of this study. For example, with regard to the recruitment, there were difficulties in obtaining the planned sample size which may question the feasibility of this study. However, this may be due to limitations of this pilot study rather than reflecting that a study in this area is not feasible, for example it may have been helpful to provide a brief initial letters to parents regarding the study, to prevent families from feeling overwhelmed by lengthy information letters, which is likely to have been the case in this pilot investigation.

With regard to the measurement of the concepts in this study, The Index of Empathy is a suitable measure of empathy in cross sectional research and is widely used (Labay and Walco, 2004). Furthermore, the Sibling Relationship Questionnaire is a suitable measure to assess sibling relationships at one time point and therefore suitable for cross sectional research. However, assessing sibling relationships in a longitudinally designed research may be more meaningful and insightful. Furthermore, assessing the predictive effect of empathy on the sibling relationship maybe more feasible in longitudinally designed research given that only longitudinal research can establish a cause and effect relationship (Gass et al, 2005). Areas for future research will now be discussed.

Areas for future research

The findings from this preliminary pilot study provide invaluable information to inform future research. With regard to the questions posed in this preliminary study, it would be particularly helpful to further investigate the empathy difference between siblings, with appropriately powered statistical analyses. Further investigation of this question is necessary given that the results were close to statistical significance with a large confidence interval. In terms of the design of the study, a cross sectional study would be appropriate. With regard to empathy measurement, The Index of Empathy is a good measure for future research given its psychometric properties (Bryant, 1982). However, as empathy can vary in different situations (Eisenberg and Strayer, 1987), it would be helpful to measure empathy directly towards children's siblings, rather than empathy as a general construct. However, to date, no such measure exists and therefore this would be dependent on a questionnaire being devised and validated. With regard to sample sizes, based on the effect sizes detected in this pilot study, future research should aim to recruit at least 60 sibling dyads in both the clinical and control groups to have an 80% of gaining significant findings and drawing more reliable conclusions.

However, with regard to exploring whether empathy is significantly more important in predicting the quality of the sibling relationship when one child has diabetes, substantially more participants would need to be recruited. More specifically, based on effect size calculations from this pilot study, 360 sibling dyads in each group would need to be recruited. Based on the recruitment difficulties for this preliminary study, a localised, unfunded study would not be feasible and therefore a large scale, multi-site, longitudinal study would be necessary to explore this question further.

This preliminary study can help inform future research into sibling relationships. Firstly, with regard to the measurement of sibling relationships, the Sibling Relationship Questionnaire is a good measure (Labay and Walco, 2004) and this was reflected in the Cronbach's alpha obtained in this preliminary study. Furthermore, continued use of this measure would assist in the cross comparison of sibling studies. Secondly, given that this pilot study was limited in determining a cause and effect relationship between empathy and warmth, future research on sibling relationships should aim to overcome this difficulty by conducting longitudinal research.

Given that warmth in the sibling relationship can protect against the development of psychological difficulties (Gass et al, 2005), this aspect of a sibling relationship is particularly important to investigate. However, with regard to the process and feasibility of cross sectional quantitative research in this particular field, a better understanding of the predictive nature of certain factors on sibling relationships is likely to be obtained in longitudinal research. This is particularly true given a cause and effect relationship cannot be determined in cross sectional research (Field, 2009). Furthermore, sibling relationships continually change over childhood and adolescence (Dunn and Kendrick, 1992). Consistent with high quality previous research on siblings (e.g. Gass et al, 2005), future research may benefit from investigating sibling relationships in a two-wave longitudinal study with an interval of two years. This would allow an examination of sibling relationships as they change over middle childhood. Moreover, it is likely that this is a more feasible way to understand the predictive nature of certain factors on the sibling relationship.

Conclusions

The findings of this preliminary pilot investigation provide further insight regarding empathy and sibling relationships of children with diabetes. In summary, results suggest that healthy siblings do not show positive effects of increased empathy. Furthermore, the empathy difference between the healthy and diabetic child is not significantly different from that of healthy controls. However, further investigation of this question is necessary. Interestingly, empathy only predicted warmth in the sibling relationship and the predictive effect of empathy did not differ when one child had diabetes. This pilot study is not without its limitations but provides invaluable information for research within this area of the literature.

References

- Adams, R., Peveler, R. C., Stein, A., & Dunger, D. B. (1991). Siblings of Children with Diabetes: Involvement, Understanding and Adaptation. *Diabetic Medicine*, 8, 855 859.
- American Psychiatric Association (1987). Diagnostic and statistical manual of mental disorders. In Zahn-Waxler, C., & Radke-Yarrow, M. (1990). The Origins of Empathic Concern. *Motivation and Emotion*, 14, 107-130.
- Barker, C., Pistrang, N., & Elliot, R. (2002). Research Methods in Clinical *Psychology: An introduction for students and practitioners*. Chichester: John Wiley & Sons
 Ltd.
- Brody, G. H. (1998). Sibling relationship quality: Its Causes and Consequences. *Annual Review of Psychology*, 49, 1-24.

- Bryant, B. (1982). An index of empathy for children and adolescents. *Child Development*, 53, 413-425.
- Buhrmester, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescents. *Child Development*, 61, 1387-1398.
- Cooper, C. (1999). *Continuing care of sick children: Examining the impact of chronic illness*. UK: Cromwell Press.
- Crane , A., Sussman, M., & Weil, W. B. (1966). Family interaction, diabetes and sibling relationships. *International journal of social psychiatry*, 12, 25-43
- Cuskelly, M., & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspectives of mothers, fathers and siblings. *American Journal on mental retardation*, 108, 234-244.
- Dadds. M, R., Hunter, K., Hawes, D. J., Frost, A. D. J., Vassallo, S., Bunn, P., Merz, S., & Masry, Y. L. (2008). A measure of cognitive and affective empathy in children using parent ratings. *Child psychiatry and human development*, 39, 111-122
- Dallos, D., & Draper, R. (2005). An introduction *to family therapy: systemic theory and practice* (2nd edition). London: Open University Press.
- Delamater, A. M. (2009). Psychological care of children and adolescents with diabetes. *Paediatric diabetes*, 10, 175-184.

Department of Health (2010). *Six Years On Delivering the Diabetes National Service Framework*. Retrieved June 2010 from http://www.dh.gov.uk/en /Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_112 509

- Donnelly, L. A., Morris, A. D., Frier, B. M., Ellis, J. D., Donnan, P. T., Durrant, T., Band, M. M., Reekie, G., & Leese, G. P. (2003). Frequency and predictors of hypoglycaemia in Type 1 and insulin-treated Type 2 diabetes: a populationbased study, *Diabetic Medicine*, 22, 749–755
- Dunn, J., & Kendrick, C. (1982). *Siblings: Love, envy & understanding*. UK: Grant McIntyre Ltd.
- Eisenberg, N., & Strayer, J. (1987). *Empathy and its development*. New York: Cambridge University Press.
- Ferrari, M (1987) The diabetic child and well sibling: Risks to the well child's self concept. *Childrens health care*, 15, 141-148.
- Field, A. (2009). Discovering Statistics Using SPSS. (3rd edition). London: SAGE
- Furman, W., & Buhrmester, D., (1985). Children's perceptions of the qualities of sibling relationships. *Child Development*, 56, 448-461
- Gass, K., Jenkins, J., & Dunn, J. (2007). Are sibling relationships protective? A longitudinal study. *Journal of Child Psychology and Psychiatry*, 48, 167-175.
- Grimes, D. A., & Schulz, K. F. Bias and causal associations in observational research. *The Lancet*, 359, 248-252.
- Grumbach, K. (2003). Chronic Illness, Comorbidities, and the Need for Medical Generalism. *Annals of Family Medicine* 1, 4-7.
- Hanson, C. L., Henggeler, S, W., Harris, M, A., Cigrang, J, A., & Schinkel, A, M.
 (1992). Contributions of sibling relations to the adaptation of youths with Insulin dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 60, 104-112.

- Hollidge, C. (2001). Psychological adjustment of siblings to a child with diabetes. *Health and social work, 26, 15-25.*
- Labay, L. E., & Walco, G. A. (2004). Brief report: Empathy and psychological adjustment in siblings of children with cancer. *Journal of Pediatric Psychology*, 29, 309-314.
- Loman, P. A. (2001). Relationship quality between healthy and chronically ill siblings: The differential impact of Tourette's syndrome and diabetes. *Dissertation abstracts international: Section B: The sciences and engineering*, 61, 5597.
- Loos, M., & Kelly, S. (2006). Social well- being of siblings living with a child with diabetes: A qualitative study. *Social work in health care*, 43, 53-69.
- Minagawa, M. (1997). Sibling Relationships of Japanese Children With Diabetes. Journal of Pediatric Nursing, 12, 311-316.
- NICE (2004). Type 1 diabetes: diagnosis and management of type 1 diabetes in children and young people to adherence and metabolic control. London: National Collaborating Centre for Women's and Children's Health.
- Nunnally, J. C., & Berstein, I. H. (1994). Psychometric theory. In Barker, C., Pistrang,
 N., & Elliot, R. (2002). *Research Methods in Clinical Psychology: An introduction for students and practitioners*. Chichester: John Wiley & Sons Ltd.
- Ryff, C. D. (1989). Happiness Is Everything, or Is It? Explorations on the Meaning of Psychological Well-Being. *Journal of Personality and Social Psychology* 57, 1069-1081.
- Sanders, R. (2004). *Sibling relationships: Theory and issues for practice*. London: Palgrave Macmillan.
Sargent, J.R., Sahler, O. J., Roghmann, K. J., Mulhern, R. K., Barbarian, O. A.,

Carpenter, P. J., Copeland, D. R., Dolgin, M. J., Zeltzer, L. K. (1995). Sibling adaptation to childhood cancer Collaborative Study: Siblings' perceptions of the cancer experience. *Journal of Pediatric Psychology*, 20, 151-164

- Seligman, M., & Csikszentmihalyi, M. (2000). Positive Psychology: An introduction. *American Psychologist*, 55, 5-14.
- Sharpe, D., & Rosssiter, L. (2002). Siblings of children with a chronic illness: a metaanalysis. *Journal of Pediatric Psychology*, 27, 669-710.
- SPSS for Windows Version 17.0. 2009 (computer software). Chicago: SPSS Inc.
- Tritt, S. G., & Esses, L. M. (1998). Psychosocial adaptation of siblings of children with chronic medical illnesses. *American journal of orthopsychiatry*, 58, 211-220.
- Vogt, M. A. (2001). A comparative study of the sibling relationship, coping and adaptation of school-age children with insulin dependent diabetes and their siblings. *Dissertation abstracts international: Section B: The sciences and engineering*, 61, 4082.
- Volling, B. L., McElwain, N. L., Miller, A. L. (2002). Emotion Regulation in Context: The Jealousy Complex between Young Siblings and Its Relations with Child and Family Characteristics. *Child Development*, 2, 581–600.
- Vreekea, G. J., & Van Der Mark, I. L. (2003). Empathy, an integrative model. *New Ideas in Psychology*, 21, 177–207
- Walster, E., Berscheid, E., and Walster, G. W. (1973). New directions in equity research. *Journal of Personality and Social Psychology*, 25, 151–176.

Zahn-Waxler, C., & Radke-Yarrow, M. (1990). The Origins of Empathic Concern.

Motivation and Emotion, 14, 107-130.

Part 3

Appendixes

- Appendix A: Guidelines for authors for the systematic literature review
- Appendix B: Guidelines for authors for the empirical paper
- Appendix C: Quality checklist for systematic literature review
- **Appendix D: Review data collection form**
- **Appendix E: Information on excluded studies**
- **Appendix F: Ethical approval letter**
- **Appendix G: Trust research governance approvals**
- **Appendix H: Cover letters (clinical and control group)**
- **Appendix I: Parents information letters (clinical and control group)**
- **Appendix J: Parent consent form (clinical and control group)**
- **Appendix K: Demographic data form (clinical and control group)**
- **Appendix L: Child information letters**
- **Appendix M: Child assent form**
- **Appendix N: Sibling Relationship Questionnaire**
- **Appendix O: The Index of Empathy**
- **Appendix P: Thank you letter**
- **Appendix Q: GP letter**
- **Appendix R: Selected SPSS output**
- **Appendix S: Reflective statement**
- **Appendix T: Glossary of medical terms**

Appendix A: Guidelines for the authors for the systematic literature review

Instructions for Authors

INTRODUCTION

Submission of a paper to *Psychology & Health* will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of editor and publisher. It is a condition of the acceptance by the editor of a typescript for publication that the publisher automatically acquires the copyright of the typescript throughout the world.

SUBMISSION OF MANUSCRIPTS

All submissions should be made online at *Psychology & Health's* <u>ScholarOne</u> <u>Manuscripts site</u>. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Submitted papers will be subject to blind review. Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all information identifying the author should be removed from files to allow them to be sent anonymously to referees. When uploading files authors should define the non-anonymous version as "File not for review".

Each paper will be read by at least two referees. Authors will be invited to suggest preferred and non-preferred reviewers when they submit the manuscript, but the editors reserve the right to make the final decision regarding choice of reviewers. Authors should not suggest reviewers with any conflict of interest (e.g. reviewers with whom they have recently collaborated, or from their own institution).

FORMAT OF MANUSCRIPTS

Manuscripts should be typed according to the guidelines in the Publication Manual of the American Psychological Association (5th edition, 2001). Manuscripts should be double-spaced throughout (including tables and references), and each page should be numbered consecutively. Manuscripts should not exceed 30 pages (including references, tables, and figures), with a font size of 12 in New Times Roman, and all margins should be at least 2.5cm.

Title page: This should contain the title of the paper, a short running title, the name and full postal address of each author and an indication of which author will be responsible for correspondence, reprints and proofs. Abbreviations in the title should be avoided.

Abstract: This should not exceed 200 words and should be presented on a separate page.

Key words: Abstracts should be accompanied by between three and six key words or phrases. These will be used for indexing and data retrieval, and so where appropriate we recommend using standard MeSH terms (the terms used for indexing articles for MEDLINE)..

Reports of statistical tests should include an indication of effect size whenever possible. Reports of randomised controlled trials should state any registration details of the trial and should follow CONSORT guidelines where relevant (see Moher, D., Schulz, K.F. & Altman, D.G. for the CONSORT group, 2001. The CONSORT statement: Revised recommendations for improving the quality of reports of parallel-group randomized trials. *Annals of Internal Medicine*, *134*, 657-662).

Style guidelines

Description of the Journal's <u>article style</u>

Description of the Journal's reference style, Quick guide

Please use British spelling (e.g. colour, organise) and punctuation. Use single quotation marks with double within if needed.

If you have any questions about references or formatting your article, please contact <u>authorqueries@tandf.co.uk</u> (please mention the journal title in your email).

Word templates

<u>Word templates</u> are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact <u>authortemplate@tandf.co.uk</u>

FIGURES

All figures should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. Figures should be kept separate from the text but an approximate position for each should be indicated in the text. It is the author's responsibility to obtain permission for any reproduction from other sources.

Preparation: All figures must be of a high enough standard for direct reproduction. Axes of graphs should be properly labelled and appropriate units given. Electronic figures should be submitted as Tiff, EPS or Powerpoint illustrations, with a minimum line weight of 0.5. Photographs must be high quality glossy originals of maximum contrast, about twice the final size of the figure. Figures should be planned so that they reduce to 10.5 cm column width. A list of figure captions should be typed on a separate page and included in the typescript.

TABLES

Number tables with consecutive arabic numerals and give each a clear descriptive heading. Avoid the use of vertical rules. Table footnotes should be typed below the table, designated by superscript lower-case letters. Tables should be kept separate from the text but an approximate position for each should be indicated in the text. It is the author's responsibility to obtain permission for any reproduction from other sources.

SUPPLEMENTARY ONLINE MATERIAL

Authors are strongly encouraged to submit for online publication any information that can provide valuable additional detail about their research. This is likely to include: materials and procedures used for interventions (e.g. text of manuals or leaflets; details

of intervention mapping or training packages); questionnaires used that are not publicly available elsewhere; additional details of analyses (e.g. full descriptive data and correlation matrices); visual images or videos of stimuli used in experiments or interventions.

• Information about supplementary online material

PROOFS

Authors will receive proofs (including figures) for correction, which must be returned within 48 hours of receipt. Authors' alterations in excess of 10% of the original composition cost will be charged to authors.

Free article access: Corresponding authors will receive free online access to their article through our website (<u>www.informaworld.com</u>) and a complimentary copy of the issue containing their article. Reprints of articles published in this journal can be purchased through Rightslink® when proofs are received. If you have any queries, please contact our reprints department at <u>reprints@tandf.co.uk</u>

PAGE CHARGES

There are no page charges to individuals or to institutions.

CONFLICT OF INTEREST

On submission of the manuscript authors will be required to indicate whether there were any possible conflicts of interest in the conduct and reporting of research (e.g. funding by an organisation or participation by an individual that might benefit financially from the research). Potential conflicts of interest must be reported in the Acknowledgements section of the manuscript.

ETHICAL POLICY

All manuscripts must include a statement confirming that the research had obtained relevant local ethical approval and was carried out in accordance with universal ethical principles (see Emanuel, E.J., Wendler, D. & Grady, C., 2000. What makes clinical research ethical? *Journal of the American Medical Association*, 283, 2701-2711).

INFORMED CONSENT

Manuscripts must include a statement that informed consent was obtained from human subjects. Authors should protect patient anonymity by avoiding the use of patients' names or initials, hospital number, or other identifying information.

COPYRIGHT

It is a condition of publication that authors assign copyright or licence the publication rights in their articles, including abstracts, to Taylor & Francis. This enables us to ensure full copyright protection and to disseminate the article, and of course the Journal, to the widest possible readership in print and electronic formats as appropriate. Authors retain many rights under the Taylor & Francis rights policies, which can be found at <u>www.informaworld.com/authors_journals_copyright_position</u>. Authors are themselves responsible for obtaining permission to reproduce copyright material from other sources.

Appendix B: Guidelines for authors for the empirical paper

Instructions for authors

Please consult APA's Instructions for All Authors for information regarding

- Manuscript Preparation
- Submitting Supplemental Materials
- Abstract and Keywords
- References
- Figures
- Permissions
- Publication Policies
- Ethical Principles

Submission

Please submit manuscripts electronically, either using Microsoft Word (.doc) or Rich Text Format (.rtf) via the Manuscript Submission Portal.

If you encounter difficulties with submission, please e-mail Michelle Calderon at the Editorial Office or call 404-616-2895.

General correspondence with the journal should be addressed to:

Nadine J. Kaslow, PhD, ABPP Editor, Journal of Family Psychology Emory University School of Medicine Department of Psychiatry and Behavioral Sciences Grady Health System Room 13D018 80 Jesse Hill Jr. Drive NE Atlanta, GA 30303

In addition to addresses and phone numbers, please supply fax numbers and e-mail addresses for potential use by the editorial office, and later by the production office.

Keep a copy of the manuscript to guard against loss.

Article Requirements

For general guidelines to style, authors should study articles previously published in the journal.

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. The title of a manuscript should be accurate, fully explanatory, and preferably no longer then 12 words. The title should reflect the content and population studied (e.g., "family therapy for depression in children"). If the paper reports a randomized clinical trial (RCT), this should be indicated in the title, and the CONSORT criteria must be used for reporting purposes. After the abstract, please supply up to five keywords or brief phrases.

Research manuscripts and review and theoretical manuscripts that provide creative and integrative summaries of an area of work relevant to family psychology should not exceed 25–30 pages total (including cover page, abstract, text, references, tables, figures), with margins of at least 1 inch on all sides and a standard font (e.g., Times New Roman) of 12 points (no smaller). The entire paper (text, references, tables, figures, etc.,) must be double spaced.

Manuscripts exceeding the space requirement will be returned to the author for shortening prior to peer review.

Brief reports are encouraged for innovative work that may be premature for publication as a full research report because of small sample size, novel methodologies, etc. Brief reports also are an appropriate format for replications and for clinical case studies. Authors of brief reports should indicate in the cover letter that the full report is not under consideration for publication elsewhere. Brief reports should be designated as such and should not exceed a total of 12 pages, all inclusive.

All research involving human participants must describe oversight of the research process by the relevant Institutional Review Boards (IRBs) and should describe consent and assent procedures briefly in the Method section.

It is important to highlight the significance and novel contribution of the work. The translation of research into practice must be evidenced in all manuscripts. Authors should incorporate a meaningful discussion of the clinical and/or policy implications of their work throughout the manuscript, rather than simply providing a separate section for this material.

Masked Review

The *Journal of Family Psychology* uses a masked reviewing system for all submissions. The cover letter should include all authors' names and institutional affiliations. However, in order to permit anonymous review, the first page of text should omit this information. This cover page should only include the title of the manuscript and the date it is submitted. Please make every effort to see that the manuscript itself contains no clues to the authors' identities.

Cover Letter

Authors should indicate in their cover letter that the work has not been published previously and is not under consideration for publication elsewhere. The relationship of the submitted manuscript with other publications and/or submissions of the author, if any, should be explained.

The cover letter should include a statement indicating that the manuscript has been seen and reviewed by all authors and that all authors have contributed to it in a meaningful way.

The cover letter must include the full mailing address, telephone, fax, and e-mail address for the corresponding author.

CONSORT Criteria

The *Journal of Family Psychology* requires the use of the CONSORT reporting standards (i.e., a checklist and flow diagram) for randomized clinical trials, consistent with the policy established by the Publications and Communications Board of the American Psychological Association.

CONSORT (Consolidated Standards of Reporting Trials) offers a standard way to improve the quality of such reports and to ensure that readers have the information necessary to evaluate the quality of a clinical trial. Manuscripts that report randomized clinical trials are required to include a flow diagram of the progress through the phases of the trial and a checklist that identifies where in the manuscript the various criteria are addressed. The checklist should be placed in an Appendix of the manuscript for review purposes.

When a study is not fully consistent with the CONSORT statement, the limitations should be acknowledged and discussed in the text of the manuscript. For follow-up studies of previously published clinical trials, authors should submit a flow diagram of the progress through the phases of the trial and follow-up. The above checklist information should be completed to the extent possible, especially for the Results and Discussion sections of the manuscript.

Visit the CONSORT Statement Web site for more details and resources.

Appendix C: Quality checklist for the systematic literature review

Quality checklist

Title of the paper _____

	Question		No=0	N/A
1	Has the abstract provided an informative and			
	balanced summary of what was done and what was			
	found?			
2	Has the scientific background and rationale for the			
	investigation being reported/ explained?			
3	Is the hypothesis/aim/objective of the study clearly			
	described?			
4	Are the main outcomes to be measured clearly			
	described in the Introduction or Methods section? (If			
	the main outcomes are first mentioned in the Results			
	section, the question should be answered no)			
5	a) Are the characteristics of the participants			
	included in the study clearly described? E.g.			
	mother and/or father, age of child, disease			
	duration etc?			
	b) Is the type of treatment specified? (e.g.			
	injection or insulin pump)			
	c) Is there a clear inclusion/exclusion criterion?			
6	Were the subjects asked to participate in the study			
	representative of the entire population from which			
	they were recruited?			
7	Were those subjects prepared to take part in the study			
	representative of the entire population from which			
	they were recruited?			
8	Is the proportion of those who agreed to take part			
	reported?			
9	Have the characteristics of patients lost to follow-up			
	been reported/ described?			
10	Are the main findings of the study clearly described?			
11	Have the statistical methods been described?			
12	Have statistical methods used to control for			
10	contounding variables been described?			
13	Have actual probability values been reported for the			
	main outcomes except where the probability value is $1000000000000000000000000000000000000$			
	less than 0.001 ()			
1		1		

14	Were the main outcome measures used accurate? (valid and reliable)		
15	Have the limitations of the study, taking into account sources of potential bias or imprecision been discussed?		
16	Have the key results with reference to study objectives been summarised in the discussion?		

Appendix D: Data collection form

Data collection form			
Author (s)			
Title of paper			
Research aim(s)			
Participants			
Children's age			
Disease duration and treatment regime			
Sample size			
Questionnaire(s)			
Statistical analyses			
Main findings			
Conclusions			
Study limitations			

Appendix E: Information of excluded studies

Study	Reason for exclusion
Stoppelbein & Greening et al (2007)	No specific reference to diabetes
William et al (2002)	No specific reference to diabetes
Holm et al (2008)	No specific reference to diabetes
Frank et al (1998)	No specific reference to diabetes
Horton and Wallander (2001)	No specific reference to diabetes
Dewey and Crawford (2007)	No specific reference to diabetes
Ribi et al (2007)	Newly diagnosed
Thernlund et al (1996)	Newly diagnosed
Landolt et al (2005)	Newly diagnosed
Landolt at al (2002)	Newly diagnosed
Landolt et al (2003)	Newly diagnosed
Goldbeck (2006)	Newly diagnosed
Chimholm et al (1994)	Family functioning
Vandagriff et al (1992)	Correlation analyses
Lewin et al (2005)	Correlation analyses
Powers et al (2002)	Correlation analyses
Rodrigue et al (1994)	Correlation analyses
Whittemore et al (2003)	Quality of life
Faulkner & Clark (1998)	Quality of life
Abdel et al (2006)	Quality of life
Boman et al (2004)	Compared diabetes and cancer

Appendix F: Ethics approval letter (removed for hard binding)

Appendix G: Trust research governance approval letter (removed for hard binding)

Appendix H: Cover letters

Cover letter for control group

Dear Family

This letter is about research that is taking place at your child's school. If you would like to learn more about the research, the details are attached. Once you have read the information and if you feel that you and your children would like to take part then please sign the consent form and complete the questions about your family. You can then send these back in the stamped addressed envelope.

If you would like to ask any questions about the research then you can contact the researcher (their phone number and email is on page 3).

Yours Faithfully,

Head teacher

Cover letter (clinical group)

Dear Family

This letter is about research that is taking place in the paediatrics diabetes clinic. If you would like to learn more about the research, the details attached. Once you have read the information and if you feel that you and your children would like to take part in the research then please talk to us when you next visit the diabetes clinic. If you would like to ask any questions about the research then you can either:

- 1. Contact the researcher (their phone number and email is on page 3)
- 2. Speak to us when you visit the diabetes clinic
- 3. Speak to the researcher when you visit the diabetes clinic.

Many Thanks

Paediatric diabetes nurse(s)

Brother and sister relationships when a one child has diabetes type 1



Information about the research

My name is Faye Melbourne and I am training to be a Clinical Psychologist. I would like to invite you and your children to take part in a research study which is about brother and sister relationships when one child has Diabetes Type 1. Before you decide you need to understand why the research is being done and what it would involve for you and your children. Please take time to read the following information carefully.

What will the research be looking at?

The research will be looking at:

- 1. How well brothers and sisters can understand how other people feel when one child has diabetes.
- 2. How well brothers and sisters get on when one child has diabetes.
- 3. If brothers and sisters get on better if they understand how other people feel.

Why have we been asked to take part?

You have been invited to join this study because one of your children has diabetes type 1. 160 brothers and sisters will be asked if they would like to take part

Are there any benefits of taking part?

Sometimes when a child has an illness such as diabetes, they and their brother/sister can develop emotional difficulties. However, a better brother and sister relationship can protect them both from these difficulties. The researcher cannot promise the study will help you and your family but the information we get from this study will help us to understand how we can help to improve brother and sister relationships when one child has diabetes in the future.

Are there any disadvantages of taking part?

Most people enjoy talking about themselves. However, in a few cases answering questions about brother and sister relationships may make adults or children feel upset

or worried. In the unlikely event that this happens to your family, the researcher will talk about this with you and let you know where you can get more support.

Do we have to take part?

It is up to you if you would like to take part in this study. If you or your children do not want to, this would not affect the standard of care you receive. If you want to take part, you are free to stop at any time, without giving a reason.

If my children and I want to take part, what will we be asked to do?

If you would like to take part in the research, one parent or carer in the family would be asked to fill out a list of questions about the family, for example, the age of the children. You would only be asked to do this once. This would be to see if your family can be included in the research. After this, both children/two children in your family would be asked to fill out 2 (tick box) lists of questions. These 2 lists of questions are about how well they can understand how other people feel and how well they think they get on with their brother or sister. It will usually take up to 1 hour to go through the questions with your children.

Where can we fill the questionnaires out?

I can help you (parent/carer) fill the questions about your family in at the diabetes clinic. This will take 10 minutes. There are 2 options (below), which you can choose from for your children to fill in the questions. I will ask you which one would be best for your family after you have given your consent.

1. The researcher can come to your house to help the children fill in the lists of questions

Or

2. The researcher can visit your children at school to help them fill in the questions.

What will happen after we have taken part?

You will be asked if you would like a summary of the results from the study. If you would like to know the results, you will be able to get these from the diabetes clinic when you next visit or from the researcher.

Will the information my children and I give be kept private?

Yes. We will follow ethical and legal practice and personal information that you and your children give will not be shared with anybody else. No personal information will be published. Your personal information will be stored securely and will be destroyed once the research is finished.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the South Humber Research Ethics Committee.

If you would like to take part, please ask the nurse(s) at your child's diabetes clinic and they can give you a consent form.

If you would like to discuss the research before consenting, please feel free to ring me or email me or I would be happy to answers any questions you may have at the diabetes clinic.

My phone number

is.....

(This number is for research only and will be deleted once the research has finished) My email is:



Parent information letter – control group (on university headed paper)

Brother and sister relationships when one child has diabetes type 1

Information about the research

My name is Faye Melbourne and I am training to be a Clinical Psychologist. I would like to invite you to take part in a research study which is about brother and sister relationships (*i.e. 2 brothers, 2 sisters or a brother and a sister*) when both children are healthy and when one child has diabetes Type 1. This letter is being sent to invite families to take part when both (or 2) children are healthy and both (or 2) children are between 8-13 years old. Below is some information on the research study. Before you decide you need to understand why the research is being done and what it would involve for you and your children. Please take time to read the following information carefully. What will the research be looking at?

The research will be looking at:

- 1. How well brothers and sisters can understand how other people feel
- 2. How well brothers and sisters get on
- 3. If brothers and sisters get on better if they understand how other people feel.

Are there any benefits of taking part?

Sometimes when a child has an illness such as diabetes, they and their brother/sister can develop emotional difficulties. However, a better brother and sister relationship can protect them both from these difficulties. We cannot promise the study will help you but the information we get from this study will help us to understand how we can help to improve brother and sister relationships in the future.

Are there any disadvantages of taking part?

Most people enjoy talking about themselves. However, in a few cases answering questions about brother and sister relationships may make adults or children feel upset or worried. In the unlikely event that this happens to your family, the researcher will talk about this with you and let you know where you can get more support.

Do we have to take part?

It is up to you if you would like to take part in this study. If you or your children do not want to, that is fine. If you want to take part, you are free to stop at any time, without giving a reason.

If my children and I want to take part, what will we be asked to do?

If you would like to take part in the research, one parent or carer in the family would be asked to fill out a list of questions about the family, for example, the age of the children. You would only be asked to do this once. This would be to see if your family can be included in the research. After this both children/two children in your family would be asked to fill out 2 (tick box) lists of questions. These 2 lists of questions are about how well they can understand how other people feel and how well they think they get on with their brother or sister. It will usually take up to 1 hour to go through the questions with your children.

Where can we fill the questionnaires out?

There are 2 options (below), which you can choose from.

1. The researcher can come to your house to help you all fill in the lists of questions

Or

2. The researcher can help your children complete the lists of questions at their school (your children do NOT need to be at the same school)

What will happen after we have taken part?

You will be asked if you would like a summary of the results from the study. If you would like to know the results, you will be able to get these from your child's school or from the researcher.

Will the information my children and I give be kept private?

Yes. We will follow ethical and legal practice and personal information that you and your children give will not be shared with anybody else. No personal information will be published. The personal information you give will be stored securely and will be destroyed once the research is finished. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given a favourable opinion by the South Humber Research Ethics Committee.

What would happen if my child told the researcher they were being bullied or abused?

If either of your children told the researcher they were being bullied, the researcher would encourage the child to inform their parents/carers. If they did not want to tell the parents/carers, then the researcher would have to tell the parents/carers. If either of the children told the researcher they were being abused, the researcher would have to tell the parents/carers as this is required under the child protection law. The researcher would also help put the family in contact with relevant helping agencies.

What do I do if I want to ask some questions about the research?

If you would like to discuss the research before consenting, please feel free to ring me or email me. I am happy to meet with you at your child's school or your home, if you would like to do this, please ring me or email me.

My phone number is:

(This number is for research only and will be deleted once the research has finished) My email is:

What if we want to take part?

If you and your children would like to take part

- 1. Please turn the page to find the consent form and sign this at the bottom of the page.
- 2. Once you have signed this, please fill in the list of questions about your family.

Send the <u>consent form</u> and <u>questions about your family</u> back in the freepost envelope or you can hand it in at the reception of your child's school.

If you lose any of these sheets and you want to take part, contact the head teacher at your child's school and this information can be sent again.



Appendix I: parent consent forms (clinical group – on university headed paper)

Brother and sister relationships when one child has diabetes type 1

Consent form

Family Identification Number:

Name of researcher: Faye Melbourne

- 1. I confirm that I have read and understand the information sheet dated 16/06/09 (version 2) for the above study. Any questions that I had were answered in a way that I could understand.
- 2. I understand that it is up to us if we want to take part and that we are free to stop taking part at any time without giving any reason, without our medical care or legal rights being affected.
- 3. I understand that relevant sections of my child with diabetes medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to them taking part in this research. I give permission for these individuals to have access to my child's records.
- 4. I understand that the researcher will also ask for consent from both my children after I have given my consent.
- 5. I understand that my children and I can ask questions at any time when we are filling in the questions.
- 6. I agree to my children's GP being informed of their participation in the study.

If you feel happy to consent, please sign and date on the lines below

••••••••••••••••	••••••••••••••••••	•••••••••••••••••••••••••••••••••••••••
Name of Parent/carer	Date	Signature

97





_
- 1

Parent consent form (control group – printed on University headed paper)

Brother and sister relationships when one child has diabetes type 1

Consent form

Family Identification Number: (to be completed by the researcher)

Name of researcher: Faye Melbourne

- 1. I confirm that I have read and understand the information sheet dated 18/07/09 (version 3) for the above study. Any questions that I had were answered in a way that I could understand.
- 2. I understand that it is up to us if we want to take part and that we are free to stop taking part at any time without giving any reason, without our medical care or legal rights being affected.
- 3. I understand that the researcher will also ask for consent from both my children after I have given my consent.
- 4. I understand that my children and I can ask questions at any time when we are filling in the questions.

If you feel happy to consent, please sign and date on the lines below

		•••••
Name of Parent/carer	Date	Signature

My phone number for the researcher to contact me on is

.....

Appendix K: Demographic information questionnaire (clinical group – printed on University headed paper)

Brother and sister relationships when one child has diabetes type 1

Questions about your family

Family identification number:

Please answer the following questions about your family. Your answers will remain private

1. What is the name and age of your child with Diabetes type 1?

- Name.....
- 2. In what year was your child diagnosed with diabetes?.....
- 3. What treatment for diabetes does your child have? (please tick)

 Daily injections
 My child has.....(number) of injections every day

Insulin pump

4. Does your diabetic child suffer from any other illnesses? Yes / No (please circle)

If 'Yes', please say what other illness they suffer from

.....

5. Who is in your family?

	Name	Sex (male or	Date of birth e.g.
		female)	19/10/97
Mother			
Father			
Child			

6. Have any of your other children been diagnosed with a chronic illness? Yes / No (please circle) If yes, please specify their name and what illness they have

Name.....Diagnosed with....

Name.....Diagnosed with....

7. Have **ANY** of your children (including your child with diabetes) been diagnosed with an attention problem, Down's syndrome, Autism, a developmental problem, a language disorder or a learning difficultly? Yes / No (please circle)

If 'Yes' please write the name(s) of who has been diagnosed and what they were diagnosed with

Name.....Diagnosed with....

Name.....Diagnosed with....

8. Are any of your children half- or step -brothers and sisters? Yes / No (please circle) If 'Yes' please write the names of the children that are half or step brothers and sisters

Names.....

9. Do your children live together? Yes / No (please circle) If you answered 'No', please write the name(s) of the children that do not live together.

Names.....

10. Do you work? Yes / No (please circle) If you answered 'Yes' please write what job you do. I am a.....

11. Does your partner / wife / husband work? Yes / No (please circle)

My Partner/husband/wife is a.....

12. Do all the members of your family speak English? Yes / No (please circle)

If you answered 'No' who in your family does not speak English?

Names.....

- 13. What is your family's ethnicity?.....
- 14. What is your marital status? (please tick all that apply)

Married

Divorced

Widowed

Separated

Living with someone

Demographic data form (control group - printed on University headed paper)

Brother and sister relationships when one child has diabetes type 1.

Questions about your Family

Family identification number:

Please answer the following questions about your family. Your answers will remain confidential.

1. Who is in your family?

	Name	Sex (male or	Date of birth e.g. 19/10/97
Mother			
Father			
Child			

2. Have **ANY** of your children been diagnosed with an attention problem, chronic illness, Down's syndrome, Autism, a developmental problem, a language disorder or a learning difficultly? Yes / No (please circle)

If 'Yes' please write the name(s) of who has been diagnosed and what they were diagnosed with

Name..... Diagnosed with..... Name..... Diagnosed with.....

3. Are ANY of your children receiving psychological help? Yes / No (please circle) If 'Yes' please write the name(s) of the child(ren)

Names.....

 Are any of your children half- or step -brothers and sisters? Yes / No (please circle). If 'Yes' please write the names of the children that are half or step brothers and sisters.
Names
 Do your children live together? Yes / No (please circle) If you answered 'No', please write the name(s) of the children that do not live together.
Names
6. Do you work? Yes / No (please circle)If you answered 'Yes' please write what job you do.
I am a
7. Does your partner / wife / husband work? Yes / No (please circle)
My Partner/husband/wife is a
8. Do all the members of your family speak English? Yes / No (please circle) If you answered 'No' who in your family does not speak English? Name(s)
9. What is your family's ethnicity?
10. What is your marital status? (please tick all that apply)
Married Divorced Widowed
Separated Living with someone

Appendix L: Child information letter

(Clinical group - On University headed paper)

Brother and sister relationships when one child has diabetes type 1



Information about the research

My name is Faye and I am training to be a Clinical Psychologist. I doing some research on brothers and sister relationships. I am inviting you to take part in my research. Research is a way we try to find out the answers to questions. Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you.

What is the research about?

I am looking at how easy it is for brothers and sisters to understand how other people feel and how well brothers and sisters get on with each other when one child has diabetes. This is important because if brothers and sisters are friends, it can help them to feel happy. This can help when one child has diabetes.

Why have I been asked to take part?

You have been invited to join my study because you or your sister/brother has diabetes. 160 children will be asked if they would like to take part.

Do I have to take part?

No, it is up to you if you would like to take part! You can stop at any point during the research.

What will I have to do if I would like to take part?

If you would like to take part, I will show you some questions and you will be asked to tick a box. The questions will be about how easy it is for you to understand how other people feel and your friendship with your brother and sister. It will take about 30 minutes.

Will my answers be private?

Yes. Only the researcher will know what you put. Your parent/carer will not see your answers if you do not want them to.

Did anyone check that the study is ok to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research has been checked by the South Humber Research Ethics Committee.

Will joining in help me?

I cannot promise the study will help you but the information we get will hopefully help brother and sister relationships when one child has diabetes.

Will anything upset me?

It is unlikely that anything will upset you but if it does I will talk about this with you.



Child information letter (Control group – on University headed paper

Brother and sister relationships when one child has diabetes type 1



Information about the research

My name is Faye and I am training to be a Clinical Psychologist. I am doing some research on brothers and sisters relationships. I am inviting you to take part in my research. Research is a way we try to find out the answers to questions. Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you.

What is the research about?

I am looking at how easy it is for brothers and sisters to understand how other people feel and how well brothers and sisters get on with each other when one child is poorly and when both children are healthy. This is important because if brothers and sisters are friends, it can help them to feel happy.

Why have I been asked to take part?

You have been invited to join my study because you and your brother/sister are healthy. 160 children will be asked if they would like to take part.

Do I have to take part?

No, it is up to you if you would like to take part! You can stop at any point during the research.

What will I have to do if I would like to take part?

If you would like to take part, I will show you some questions and you will be asked to tick a box. The questions will be about how easy it is for you to understand how other people feel and your friendship with your brother and sister. It will take about 30 minutes.

Will my answers be private?

Yes. Only the researcher will know what you put. Your parent/carer will not see your answers if you do not want them to.

Did anyone check that the study is ok to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research has been checked by the South Humber Research Ethics Committee.

Will joining in help me?

I cannot promise the study will help you but the information we get will hopefully help brother and sister relationships when one child has diabetes.

Will anything upset me?

It is unlikely that anything will upset you but if it does I will talk about this with you.





Appendix M: Child assent form

(Clinical and control group – on University headed paper)

Assent form for children

Brother and sister relationships when one child has diabetes 1

Family identification number:

Child to circle all they agree with:

Have you read (or had read to you) about this project?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have all your questions been answered?	Yes/No
Are you happy to take part?	Yes/No

If you would like to take part, you can write you name below

Your name Date.....
Appendix N: Sibling Relationship Questionnaire (removed for hard binding)

Appendix O: Index of Empathy (removed for hard binding)

Appendix P: Thank you letter

(clinical and control group – on University headed paper)

Dear Family

Thank you for offering to take part in my research study.

I am writing to inform you that unfortunately your children will <u>not</u> be recruited for this study. Due to the nature of the research only a few families will meet the study's criteria. However, I would like to thank you for taking the time and effort to complete the consent form and family questions form.

If you have any questions, please do not hesitate to contact me.

Many thanks for your time

Faye Melbourne Trainee Clinical Psychologist

Researcher's phone number.....

Researcher's email address.....

Appendix Q: GP letter

(clinical group – on University headed paper)

Dear GP

I am writing to inform you about a research project that...... are taking part in. I am a Trainee Clinical Psychologist and I am conducting this research as part of a doctoral thesis. Detailed below is information about the purpose of the research and what participants will be required to do.

Research has recognised that siblings of children with chronic illnesses such as Diabetes Type 1 are vulnerable to emotional difficulties. However, having an ill sibling in the family may have positive effects for the healthy sibling. Research has found that siblings of ill children may show higher levels of empathy and patience. This has not been explicitly studied in siblings of children with diabetes.

Sibling relationships are important in childhood. Research has found that positive sibling relationships may protect children from emotional difficulties during stressful life events and can help diabetic children's psychological functioning. One child being ill may affect this special relationship. It has been found that sibling relationships may become closer, strained or may not differ from healthy sibling relationships. The research questions will discover if empathy is increased in siblings of children with diabetes, in comparison to healthy controls and their diabetic sibling. The research will examine whether siblings hold a similar view of the quality of the sibling relationship and how the level of empathy in the healthy sibling relates to the quality of the sibling relationship. This study may show a positive effect of having an ill sibling and may help us to understand how we can improve the quality of the sibling relationships when one child has diabetes type 1.

The children in the study will be asked to complete 2 questionnaires one of which assesses the child's level of empathy and the other assesses the child's perception of the sibling relationship. Parents of the children will also be asked to complete a demographic data form. It will take approximately 30 minutes for each child to complete the questionnaires.

The parent of the children named above has consented for you to be informed about their participation in the research.

If you have any queries, please do not hesitate to contact me.

Yours Sincerely

Faye Melbourne Trainee Clinical Psychologist

Appendix R – SPPS interaction outputs

Tests of Between-Subjects Effects

Dependent Variable:warmth

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	3.591 ^a	5	.718	2.207	.067
Intercept	17.258	1	17.258	53.040	.000
gendercomb1	.918	1	.918	2.822	.099
code	.194	1	.194	.597	.443
EmpathyTotalH	1.448	1	1.448	4.450	.040
Agedifference	1.016	1	1.016	3.123	.083
code * EmpathyTotalH	.171	1	.171	.525	.472
Error	17.244	53	.325		
Total	668.194	59			
Corrected Total	20.835	58			

a. R Squared = .172 (Adjusted R Squared = .094)

Tests of Between-Subjects Effects

	Type III Sum of			-	
Source	Squares	df	Mean Square	F	Sig.
Corrected Model	2.533 ^a	5	.507	1.145	.348
Intercept	32.288	1	32.288	72.993	.000
gendercomb1	.463	1	.463	1.046	.311
code	.510	1	.510	1.152	.288
EmpathyTotalH	.250	1	.250	.566	.455
Agedifference	.732	1	.732	1.655	.204
code * EmpathyTotalH	.563	1	.563	1.272	.264
Error	23.444	53	.442		
Total	641.604	59			
Corrected Total	25.977	58			

Dependent Variable:conflict

a. R Squared = .098 (Adjusted R Squared = .012)

Tests of Between-Subjects Effects

Source	Type III Sum of	dt	Maan Squara	Г	Sia
Source	Squares	ai	Mean Square	Г	Sig.
Corrected Model	.017 ^a	5	.003	.044	.999
Intercept	.145	1	.145	1.900	.174
gendercomb1	.001	1	.001	.009	.925
code	.002	1	.002	.028	.868
EmpathyTotalH	.010	1	.010	.137	.712
Agedifference	.004	1	.004	.051	.821
code * EmpathyTotalH	.002	1	.002	.025	.876
Error	3.973	52	.076		
Total	5.743	58			
Corrected Total	3.990	57			

Dependent Variable:rivalry

a. R Squared = .004 (Adjusted R Squared = -.092)

Tests of Between-Subjects Effects

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	
Corrected Model	.353 ^a	5	.071	1.823	.124	
Intercept	.110	1	.110	2.851	.097	
gendercomb1	.049	1	.049	1.253	.268	
code	.076	1	.076	1.962	.167	
EmpathyTotalH	.095	1	.095	2.461	.123	
Agedifference	.121	1	.121	3.129	.083	
code * EmpathyTotalH	.051	1	.051	1.313	.257	
Error	2.054	53	.039			
Total	2.429	59				
Corrected Total	2.407	58				

Dependent Variable:status/power

a. R Squared = .147 (Adjusted R Squared = .066)

Appendix S

Reflective statement

This reflective statement will try to capture my research journey. I will begin by reflecting on my experience in the development of an empirical project. I will then move on to explore my experience of recruitment. Finally, I will reflect on the process of writing this portfolio thesis and my choice of journals.

In the initial stages of planning my empirical project, I wanted to focus on the conceptual framework of positive psychology, as this is an area that I am particularly interested in. However, I found myself going round in circles. Although there was a clear message in the literature stating that further research should be done in this field, there appeared to be an obvious lack of measures to assess positive traits. I therefore had to balance conducting a project in an area of the literature that I was interested in, whilst developing a project which enabled me to use recognised measures. Reflecting back on the planning stages of the empirical project, I also remember trying to set out to produce a 'perfect' research project. However, it has been stated that it is "...impossible to design a perfect study. The art of outcome research design thus becomes one of creative compromise based upon explicit understandings of the implications of choices made" (Shapiro, 1996, p202). Indeed, overtime I realised that perfect research does not exist and part of developing high quality research includes having the ability to recognise the weaknesses of a study for future research to build on. One area of the planning that I feel I have learnt from is how to implement a research project. In the development of my project I found myself spending most of my time in the academic aspects of the

115

planning. However, with hindsight I should have perhaps spent more time thinking about how a project would be implemented. This leads on to my second point of reflection, the process of recruitment.

Recruitment for the empirical project was a particular challenge. Firstly, families that matched the inclusion criteria were somewhat limited. The particular restriction related to the ages of the children that could be included in the research. Luckily, I was able to identify this problem in the early stages of recruitment and was therefore able to take the necessary steps in order to increase the chance of recruitment. In terms of the clinical group, I sent applications to a number of research and development departments. For the control group, I found myself sending out numerous information packs. Although this process offered me a sense of relief about the opportunities I would have to recruit, at times it felt particularly demanding given the need to conduct home visits in the evening across several different geographical areas. However, on a positive note, during the process of recruitment I had the opportunity to meet many inspirational families.

With regard to the write up of this portfolio, initially it felt like a huge hill to climb. I remember wondering how I would bring together three years of work in a way that I would feel proud of. However, seeing it all come together was one of the most uplifting parts of the research journey.

Finally, I will move on to reflect on my choice of journals for the systematic review and empirical paper. The systematic review was written for the Journal of Psychology and

116

Health as I felt it would be ideal in reaching an audience interested in both physical health and psychology. For the empirical paper, I chose the Journal of Family Psychology. Initially, I wondered whether a journal with a medical basis may be more suitable, such as the Journal of Pediatric Psychology. However, I felt that the chosen journal would be ideal given the emphasis that is placed on sibling relationships and healthy siblings in my study. Furthermore, the Journal of Family Psychology has published papers similar to mine and therefore I felt that it would be an interesting addition.

Looking back on my experience of research, although at times it has been particularly challenging, I feel I have developed both academically and personally. In terms of the process of conducting research I feel that I have developed a good grounding in conducting high quality research. In terms of my personal development, I feel that I have developed confidence in tackling the challenges that often arise during research and finding solutions to move forward. In short, this has been an invaluable learning experience that I will never forget.

Reference

Shapiro, D. A. (1996). Outcome research. In Barker, C., Pistrang, N., & Elliot, R.(2002). Research Methods in Clinical Psychology: An introduction for students and practitioners. Chichester: John Wiley & Sons Ltd.

Appendix T

Glossary of Medical Terms

(All the terms are directly quoted from Medline Plus)

"HbA1c is a test that measures the amount of glycated hemoglobin in your blood.Glycated hemoglobin is a substance in red blood cells that is formed when blood sugar (glucose) attaches to <u>hemoglobin</u>.

"Hypoglycemia - is a condition that occurs when your blood sugar (glucose) is too low"

"**McCune-Albright** syndrome is a genetic disease that affects the bones and color (pigmentation) of the skin."

"**Blood glucose monitoring** refers to the ongoing measurement of blood sugar (glucose)."

Reference

MedLine Plus (2010). Retrieved July 2010 from http://www.nlm.nih.gov/medlineplus/