

‘Living Well’ With Insulin- Dependent Diabetes in Adolescence

Adam J. Welsh

Supervised by: Dr Gundi Kiemle

Dr Jen Unwin

Submitted in partial fulfilment of the degree of Doctorate in
Clinical Psychology at the Division of Clinical Psychology,
School of Psychology, Liverpool University.

Submitted 19th June 2017

Acknowledgements

It was a pleasure to interview the adolescents involved in this study. I would like to thank them for taking part and sharing their inspirational stories. I would also like to thank the Paediatric Diabetes Team at Ormskirk General Hospital for embracing and valuing the opportunity to facilitate research in their department.

I would like to thank my supervisors, Dr Gundi Kiemle and Dr Jen Unwin, for their genuine interest in my development and this research. Thank you for the support, encouragement, guidance and feedback you provided.

I would also like to thank clients, colleagues and supervisors (past and present) who have influenced and shaped my practice.

Finally, I would like to thank my mum, dad, brother, my fiancée Claire, and family and friends, for their love and support.

Table of contents

Introductory Chapter: Thesis Overview	1
Chapter 1: Systematic Review	4
Abstract	5
Key Words	5
Introduction	6
Method	11
Results	14
Discussion	25
Conclusion	30
Further research	31
References	32
Chapter 2: Empirical Paper	37
Abstract	38
Key words	38
Introduction	39
Method	42
Results	49
Discussion	57
Conclusion	61
References	65
List of Tables:	
Systematic review:	
Table 1 A summary of the design and outcomes for each of the studies	16
Table 2 Quality assessment ratings for the selected seven studies	18

Empirical Paper:

Table 1 Participants characteristics	43
Table 2 Transcript extract to illustrate the analytic process	47
Table 3 Master themes and subthemes	49

List of figures:

Systematic review:

Figure 1. PRISMA flow diagram.	12
--------------------------------	----

Appendices:

Appendix 1: Author guidelines for The British Journal of Health Psychology	68
Appendix 2: Interview Guide	74
Appendix 3: University of Liverpool Sponsorship Approval	77
Appendix 4: Health Research Authority Approval	78
Appendix 5: Recruitment Flyer	80
Appendix 6: Participant Information Sheet	81
Appendix 7: Participant Consent Form	85
Appendix 8: Assent Form	87
Appendix 9: Parent Information Sheet 13-15 Year Olds	89
Appendix 10: Participant Debrief Sheet	93
Appendix 11: Excerpt from Reflexive Journal	95
Appendix 12: Excerpt from analysis (Amber)	98
Appendix 13: Emergent Themes from Amber's Transcript	104

WORD COUNT:	Introductory Chapter	654
	Systematic Review	5, 996
	Empirical Paper	5,998
Total excluding References:		23, 811

1. Introductory chapter

Chapter One is a systematic review that aims to investigate the relationship between glycaemic control and quality of life (QoL) in adults with Type 1 Insulin-Dependent Diabetes Mellitus (IDDM). The National Institute for Health and Care Excellence (NICE, 2015) proposes that adults with IDDM should aim to achieve a near-normal glycaemic range, as indicated by the measurement of glycated haemoglobin (HbA1c), to reduce the risk of severe life-changing complications. Anecdotally, in clinical practice, it is assumed that those who achieve good glycaemic control and meet the required HbA1c target also have good QoL; however, striving for a near normal HbA1c, and the associated treatment burden, may have a negative impact upon QoL. The negative impact of treatment burden on QoL may be a necessary compromise, as achieving a near normal HbA1c is likely to safeguard the person from IDDM- related complications in the long-term, which will inevitably impact upon QoL later (Rubin & Peyrot, 1999). Therefore, it is not yet established how achieving a near-normal HbA1c impacts upon QoL. These issues were brought to life clinically, as the lead researcher spent time in the Paediatric Diabetes Department, and this fuelled their interest in investigating the relationship between HbA1c and QoL in adults with IDDM.

Seven studies are included in the review. Few studies set out to investigate the relationship between HbA1c and QoL. The overall quality of the research is poor. Three of the seven studies indicated that there was no relationship between HbA1c and QoL, one study identified a negative correlation, one study offered mixed results, and two studies proposed that a curve-linear relationship best described their data. Therefore, the review is unable to provide a conclusive statement regarding the nature of the relationship between HbA1c and QoL. The review does not support the commonly held anecdotal assumption that good glycaemic control, as indicated by HbA1c, equates to good QoL. Furthermore, the review highlights the limitations of quantitative research design and methodology when investigating

a subjective and dynamic phenomenon such as QoL. The limitations found in the quantitative studies included in the systematic review informed the design of the empirical investigation that employs qualitative methods.

Chapter Two is an empirical paper that describes a qualitative study that explored how adolescents aged 13 to 19 with IDDM experience themselves as able to ‘live well’ despite their chronic condition. IDDM is one of the most common childhood conditions in the UK, and it requires careful management to reduce the risk of life limiting and life changing complications (Spencer, Cooper & Milton, 2010). As with adults, UK healthcare policy proposes that young people aim to achieve near normal glycaemic control to reduce the risk of IDDM complications (NICE, 2015).

Adolescents with IDDM typically have poor glycaemic control and this poses a significant challenge to diabetes healthcare teams (Burke & Dowling, 2007). The extant literature explores ‘barriers’ to control and focuses upon the negative impact of IDDM; it is ‘problem saturated’ (Balfe et al., 2013). The purpose of this paper was to explore qualitatively how some young people are able to experience themselves as living well in adolescence despite IDDM. In contrast to the systematic review of quantitative research regarding HbA1c and QoL in adults, this paper uses a qualitative design that specifically explores the experiences of adolescents; a population who generally have poor control. Furthermore, it is hoped that this positive psychological approach will address a gap in the literature and may help deepen the understanding of the psychological and social processes that enable some young people to live well with a chronic condition. The lead researcher has a longstanding interest in working with adolescents.

The empirical paper will be submitted for publication to the British Journal of Health Psychology, as it is in keeping with their scope and readership. The British Journal of Health Psychology publishes “original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan”.

2. Chapter One

A systematic review of the relationship
between glycaemic control and quality of life
in adults with Type 1 Insulin-Dependent
Diabetes Mellitus

Abstract

Purpose: Adults with Type 1 Insulin-Dependent Diabetes Mellitus (IDDM) aim to achieve a near-normal glycaemic range, as indicated by the measurement of glycated haemoglobin (HbA1c), to reduce the risk of severe life-changing complications. It is not yet established how achieving a near-normal HbA1c impacts upon quality of life (QoL). The purpose of this review was to systematically search for, review and synthesise published research that has explored the relationship between glycaemic control (HbA1c) and QoL.

Method: Research papers were identified via searching four electronic databases and reference lists. Studies were included if they were quantitative and available in English; included adult participants over the age of 18 diagnosed with IDDM; used a standardised self-report measure of QoL or well-being; reported HbA1c and the correlation or regression. Seven papers were eligible for inclusion in the review.

Results: Three of the seven studies indicated that there was no relationship between HbA1c and QoL, although correlations with specific subscales were identified. One study identified a negative correlation between HbA1c and QoL. A further study offered mixed results: no correlation was found between HbA1c and well-being, anxiety and depression; however, a positive correlation was identified between HbA1c and diabetes related distress. Two studies proposed that a curve-linear relationship best described their data and suggested that those with an acceptable HbA1c reported the greatest QoL.

Conclusions: The review was unable to provide a conclusive statement regarding the nature of the relationship between HbA1c and QoL. Further research needs to be undertaken to capture the multifaceted and dynamic nature of QoL and how this relates to glycaemic control for people with IDDM.

Key words: Type 1 Diabetes, Adults, Glycaemic Control, HbA1c, Quality of Life,
Systematic Review

Word count 5,996

Introduction

Type 1 Insulin-Dependent Diabetes Mellitus

Diabetes UK (2016) estimate that there are 3.5 million people diagnosed with diabetes in the UK. They propose that this estimate is conservative and that the actual number of people with diabetes is almost 4 million, as a large number are undiagnosed. The figure of 3.5 million is an increase of 1.4 million people since 1996, and is expected to exceed 5 million by the year 2025. Diabetes is a growing public health concern that costs the NHS an estimated 10 billion pounds annually (Diabetes UK, 2016).

Most people are diagnosed with Type 2 diabetes, which often occurs in older people with other medical problems, such as obesity (Hanas, 2015). In Type 2 diabetes, the body is unable to produce enough insulin, or does not respond to the insulin that is produced (Hanas, 2015). Type 1 Insulin-Dependent Diabetes Mellitus (IDDM) is used to describe diabetes when the body is unable to produce insulin. In the UK, an estimated 350,000 people are diagnosed with IDDM (Diabetes UK, 2016). People are more likely to develop the condition in childhood and it is thought that certain people may be genetically predisposed. It is understood as an autoimmune disease in which the body destroys the beta cells of the pancreas and they subsequently fail to produce any insulin (Hanas, 2015). Blood glucose is controlled by synthetic insulin that must be administered via injections or an insulin pump. Type 2 diabetes can also develop into IDDM, when the diabetes progresses and it is no longer possible to achieve satisfactory glycaemic control through oral medication alone (Hanas, 2015).

Self-care to reduce the risk of complications

People who are diagnosed with IDDM must cope with a daily regimen of blood tests, understand nutritional information and diet, monitor activity and energy expenditure, calculate the required insulin dose, and finally, inject themselves with insulin (Hanas, 2015). IDDM requires careful management to reduce the risk of severe, life-changing consequences, for example heart and blood vessel disease, neuropathy (nerve damage), nephropathy (kidney damage), eye damage, foot damage, skin and mouth conditions and complications during pregnancy (Diabetes UK, 2016).

The Diabetes Control and Complication Trial (DCCT, 1993) indicated that the risk of complications can be reduced by aiming to achieve a near normal glycaemic range, as indicated by the measurement of glycated haemoglobin (HbA1c). HbA1c is a measure of the percentage of the haemoglobin in the red blood cells that has glucose bound to it. It is an average measure of how well a person's diabetes has been controlled over the previous three months (Hanas, 2015). The findings in the DCCT (1993) have been replicated and this strengthened the robust evidence base that advocates that people should aim to achieve a near normal glycaemic range (EURODIAB IDDM Complications Study Group, 1994).

Healthcare policy

Healthcare for adults with IDDM focuses upon achieving near normal glycaemic control to reduce the risk of complications (The National Institute for Health and Care Excellence; NICE, 2015). NICE (2015) advises HbA1c levels to be checked every three to six months and that the target should be 48mmol/mol (6.5%) or lower, to minimise the risk of long-term vascular complications. It is important to note that the guidance also advises that an 'individual target' should be agreed and to monitor self-reported episodes of hypoglycaemia (low blood glucose); however, the emphasis is upon achieving a near normal HbA1c (NICE,

2015). Most adults with IDDM fail to meet their HbA1c target (NICE, 2015). It is unclear what impact this may have on QoL. Anecdotally, in healthcare, there appears to be an assumption that achieving the required HbA1c target equates to improved QoL. However, striving to achieve the set HbA1c target may be experienced as a burden which diminishes QoL, albeit reducing the risk of complications that may impact upon QoL in later life (DCCT, 1993; Rubin & Peyrot, 1999).

Quality of Life (QoL)

The World Health Organisation (1997:5) defines QoL as:

“an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment”. (p. 5)

Speight, Reaney and Barnard (2009) proposed that there is a general consensus that quality of life is multidimensional (physical, psychological and social), subjective (each individual has their own perceptions about different aspects of their life) and dynamic (changing over time or in response to various influences).

QoL in IDDM

Tahbaz, Kreis and Calvert (2006) state that some studies indicate that people with IDDM have the same QoL as those without the condition, whilst other studies suggest that people with IDDM have a poorer quality of life than the general population, but not as poor as that experienced by others with a chronic health condition. It is acknowledged that those with IDDM are likely to die earlier than those without it (NICE, 2015). People with IDDM are vulnerable to painful and debilitating complications and other illnesses, they may experience

stigma, or a sense that they have lost their independence and freedom (NICE, 2015).

Furthermore, people with IDDM may experience poor self-image, IDDM may impact upon their relationships, and they may experience economic disadvantage, poor education and poor social support (Tahbaz et al., 2006).

A variety of factors have been evidenced to influence QoL in people who have been diagnosed with diabetes. Rose, Fliege, Hildebrandt, Schirop and Klapp (2002) indicated that age, complications, related illnesses, family support, marital relationships, poverty and education all influence quality of life. Other factors that have also been found to influence QoL include the clinic environment, the doctor, the relationship between doctor and patient, patient personality, coping and characteristics of the illness (Rose et al., 2002).

Rubin and Peyrot (1999) reviewed QoL in diabetes studies, proposing that published results have generally indicated that better glycaemic control ‘occurs alongside’ better QoL, particularly as the burden of a strict treatment regimen may offset debilitating and painful complications that would inevitably impact upon QoL. This is the argument proposed by the DCCT (1993); however, the research cited by Rubin and Peyrot (1999) mainly uses participants with Type 2 diabetes. Two of the studies with IDDM involve adolescents. Braga De Souza et al. (2015) states that the majority of the research undertaken is with people diagnosed with Type 2 diabetes, or with mixed samples.

QoL measures in IDDM

Speight et al. (2009) reviewed the use of QoL measures with the diabetic population. The authors aimed to provide clarity regarding the conceptualisation of QoL, terminology, and psychometric properties of the measures, and to review the measures and offer recommendations as ‘QoL’ is often ambiguous and misunderstood. There is little agreement about what ‘QoL’ is, the key components, and how it should be defined and measured.

Of the tools available to measure QoL in quantitative research, Speight et al. (2009) argued that only three of the ten most commonly used tools in research actually measure QoL. These were: the World Health Organisation Quality of Life Scale (WHOQoL; WHO, 1997), Diabetes Related Quality of Life (DRQoL; Jacobson, 1994) and the Audit of Diabetes Dependent Quality of Life (ADDQoL; Bradley et al., 1999). They proposed that other, widely used measures, more accurately capture general physical health status, such as the SF-36 (Ware & Sherbourne, 1992) and the EURO-QoL (EURO QoL Group, 1990). Other measures focus upon psychological well-being, such as the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), Well-Being Questionnaire (Bradley, 1994) or the Problem Areas in Diabetes Scale (PAID; Polonsky et al., 1995). Speight et al. (2009) argued that if the measures are inappropriately selected, then data may be misinterpreted and any conclusions drawn will be fundamentally flawed.

Rubin and Peyrot (1999) proposed that if generic measures had been used in a study, they would have been less sensitive to QoL than diabetes-specific QoL measures. Speight et al. (2009) explored this in greater depth in their more recent review of measures, discussing the strengths and limitations of both generic and diabetes-specific tools and concluding that the measure must be fit for purpose in light of the research question.

The relationship between HbA1c and QoL

Wikblad, Leksell and Wibell (1996) indicated that focusing on HbA1c fails to effectively capture the impact of hypoglycaemic episodes that may impact upon QoL. In this respect it may be that the condition could be over-managed and the low HbA1c may impact upon QoL. Therefore, the relationship between HbA1c and QoL is subject to debate (Camacho, Anderson & Bell, 2002). It is not clear if achieving a near normal HbA1c is associated with an improved or diminished QoL for people with IDDM.

Summary and rationale for the review

IDDM is a chronic condition that typically develops in childhood. It requires careful management to minimise the risk of short, medium and long-term complications. Evidence indicates that achieving a near normal HbA1c reduces the risk of complications and this informs current healthcare policy. However, it is yet to be established how striving to achieve a near normal HbA1c relates to QoL. It appears that research in this area is compromised by a lack of clarity regarding QoL and the various tools used to measure it. The extant literature is dominated by research with participants with Type 2 diabetes or a wide age range.

An understanding of the relationship between QoL and HbA1c may have implications for healthcare services and the anecdotal assumption that a near normal HbA1c relates to good QoL. The aim of this systematic review therefore is to review the evidence regarding the relationship between HbA1c and quality of life in adults with IDDM.

Method

Study identification and search terms

The Preferred Method for Reporting Systematic Reviews and Meta Analyses (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009) guidelines were followed in the search strategy and reporting of this review (see Figure 1).

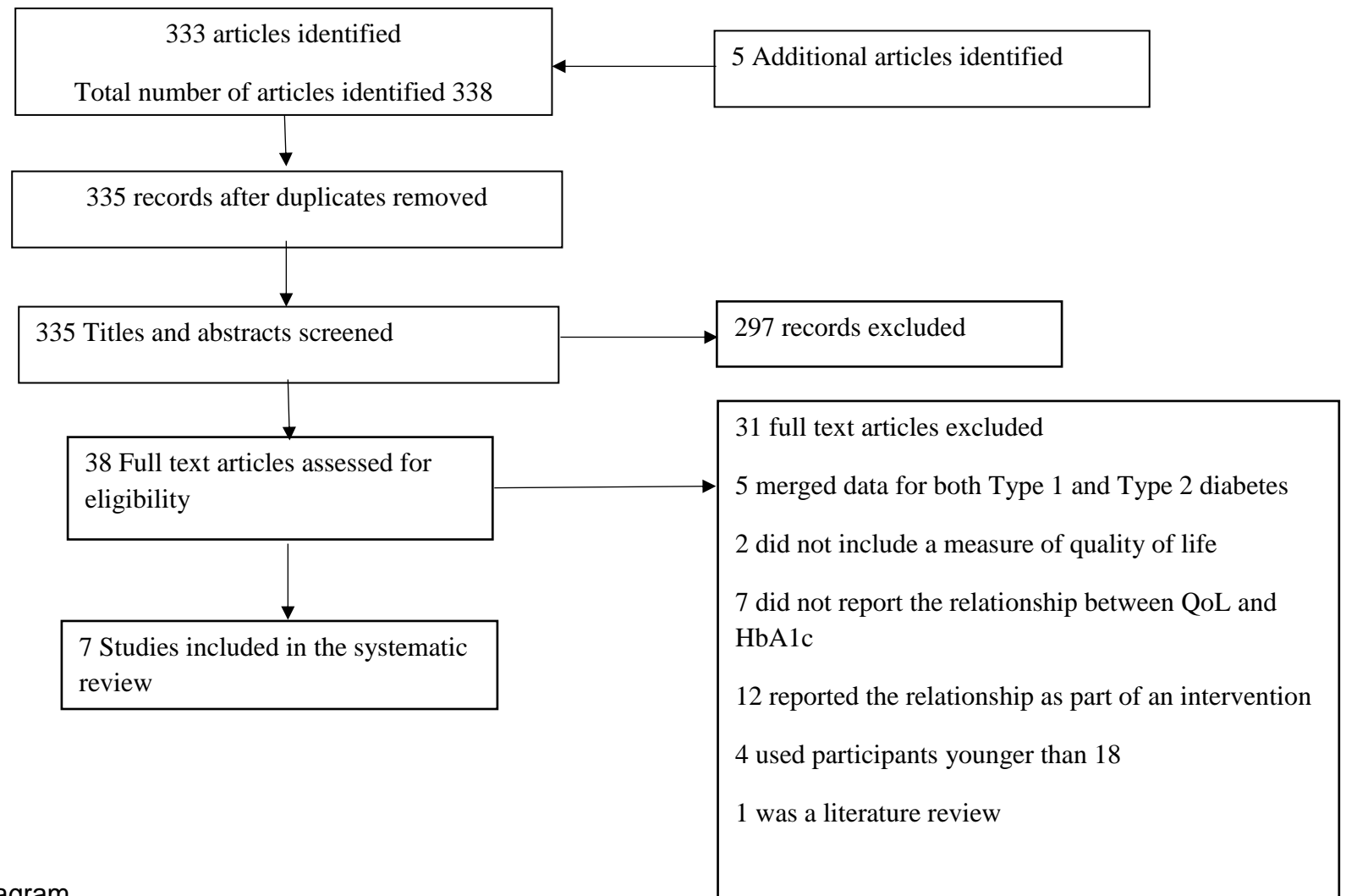


Figure 1. PRISMA flow diagram.

An extensive literature search was undertaken following a series of scoping searches and advice from local experts and a specialist librarian. The electronic databases CINAHL (1937-current), MEDLINE (1949-current), PsycARTICLES (1894-current) and PsycINFO (1887-current) were searched using the platform EBSCO. The searches at this stage were undertaken solely by the main researcher. The search was conducted using the following terms: HbA1c OR glycaemic control OR glycemic control OR metabolic control AND quality of life OR health related quality of life AND Type 1 diabetes OR IDDM OR insulin dependent diabetes AND Adults. The search was undertaken October 2016 and updated March 2017.

Eligibility criteria

The following criteria were used to identify potential studies: Quantitative studies; full text available in English; adults over the age of 18; diagnosed with IDDM; using a standardised self-report measure of QoL and reported HbA1c (self-report or from medical records); and analysed via correlation or regression analyses. The following exclusion criteria were used: Qualitative studies; studies involving children and adolescents; studies exploring multiple physical health problems, for example diabetes, obesity, high blood pressure and other conditions; randomised control trials and studies measuring the effectiveness of an intervention. Table 1 summarises the main characteristics of the seven studies selected for review and provides details of the authors, year of publication and country, the primary focus of the article, sample characteristics, the design, methodology, measurement tools, outcomes and quality rating. The studies are in alphabetical order.

Assessment of quality

Study quality was assessed using the 16 item Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh, Lawton, Gardner & Armitage, 2011); therefore,

all of the studies could be appraised using one tool. Sirriyeh et al. (2011) developed the tool after reviewing the many tools that are available, and in this respect it appears comprehensive and helps structure the quality appraisal. Two of the items (interview procedure and qualitative analysis) were omitted as they were only applicable to qualitative studies. Each item was scored between 0 and 3 depending on if they met the criteria (0 = not met, 1 = very slightly met, 2 = moderately met & 3 = completely met) and each paper was given an overall quality rating. The higher the score, the higher the quality of the research. The tool provided guidance on how to score each item, and in order to increase reliability, a second, independent reviewer (D.Clin.Psy trainee colleague) also undertook the quality assessment. The results of the QATSDD quality appraisal are summarised in Table 2 below.

Data abstraction and synthesis

None of the studies used the same QoL measure. The measures varied in their measurement of QoL; some focused on health-related QoL whilst others focused upon physical health or QoL more broadly. The analyses also varied from correlation to regression analysis. In this respect, the findings were considered unsuitable for meta-analysis.

Results

Search results

The electronic search identified 335 records after duplicates were excluded. The titles and abstracts were screened by the main author and a further 297 articles were deemed to be unsuitable for inclusion. The main reasons for exclusion were mixed samples of IDDM and Type 2 diabetes, mixed samples of young people and adults, reported as part of a trial or intervention, and not reporting the correlation or regression. Thirty-eight full text articles were obtained. The main author reviewed each article and excluded a further 31 papers.

Assistance was sought via an independent reviewer (D.Clin.Psy trainee colleague) or expert advice, where it was unclear if an article fully met the inclusion criteria or if it should be excluded. The article selection process and the reasons that articles were excluded are illustrated in Figure 1. The following seven papers fulfilled the criteria for inclusion: Aalto, Uutela and Aro (1997); Gawlik, Elias and Bond (2015); Hendricks, Monaghan, Soutor, Chen and Holmes (2013); McQueen et al. (2014); Strandberg, Graue, Wentzel-Larsen, Petrot and Rokne (2014); Wikblad, Leksell and Wibell (1996); and Wikby, Hornquist, Stenstrom and Andersson (1993).

Table 1
A summary of the design and outcomes for each of the studies

First author Country Year of publication	Primary focus of article	Sample charact- eristics	Control group	Age	Design	Data collection methodology	Measurement tools	Reported outcomes	Quality rating
Aalto, Uutela and Aro Finland 1997	Health and psychosocial correlates of health related quality of life	385 Adults	N/A	20-64 (range). Mean age 33 (SD 8.9).	Cross sectional	Self-report Questionnaires.	MOS-SF 20 health survey and HbA1c.	No overall relationship between quality of life and HbA1c. Significant associations were found between metabolic control and role functioning ($X = 7.02$, $df = 2$, $P < 0.05$). Problems in role functioning were reported more often among those in poor control (17%) and tight control (13%) than among those in moderate control (5%).	57%
Gawlik, Elias and Bond. Adelaide, Australia 2015	To explore the relationships between body image, QoL, HbA1c and insulin restriction as a weight control strategy	177 Adult Women	N/A	18-68 (range). Mean age 36.32 (SD 11.33).	Cross sectional	Self-report questionnaires and participants self-reported their most recent HbA1c result.	Appearance Schemas Inventory; Diabetes Quality of Life Brief Clinical Inventory and HbA1c.	A negative correlation between QoL and HbA1c $r = -.30$, $P < .001$. Further analysis identified that the relationship was best described as curve-linear. A one-way ANOVA between categories: low, ideal, somewhat high and very high: Low ($n=24$) mean (SD) = 53.00 (8.13), Ideal ($n=31$) mean (SD) = 54.17 (8.07), somewhat high ($n=62$) mean (SD) 53.44 (8.15) and very high ($n=52$) mean (SD) 46.59 (8.65) = F linear 9.64** = F quadratic 10.77*** = $\eta^2 = .058$. ** $P \leq .01$. *** $P \leq .001$.	59.5%
Hendricks, Monaghan, Soutor, Chen and Holmes. Baltimore, USA 2013	To explore the relationship between daily self-care behaviors and psychosocial adjustment and HbA1c	49 'emerging adults'	N/A	18-26 (range). Mean age 20.6. (SD 1.9).	Cross sectional	Interviews and self-report questionnaires. HbA1c was measured via blood sample.	24 hour diabetes interview; The Brief Symptom Inventory; The Diabetes Quality of Life Measure; HbA1c	There was no correlation between QoL and HbA1c; however, better psychological well-being on the Brief Symptom Inventory correlated with more favourable diabetes quality of life on the Diabetes Quality of life Measure, $r = -0.33$, $P < .05$.	62%
McQueen, Ellis, Maahs, Anderson, Nair, Libby and Campbell. Switzerland 2014	To explore the relationship between HbA1c and health utility	176 Adults	N/A	Mean age 38 (SD 12.2).	Cross sectional	Self-report questionnaires and HbA1c was obtained from medical records.	Diabetes related complications; duration of diabetes; Euro-QOL and HbA1c.	Negative correlation: After adjusting for demographics, medications, and diabetes related complications, on average, a 1% point increase in HbA1c was associated with a disutility of -0.03 (95% confidence interval -0.049, -0.006) $P < .05$.	69%

Strandberg, Graue, Wentzel-Larsen, Peyrot and Rokne. Norway 2014	To explore the relationships between diabetes specific emotional distress, depression, anxiety, and overall well-being with HbA1c in adults with type 1 diabetes	235 Adults 185 (after exclusions for missing data)	Comparison with non-respondents. No significant difference in terms of sex, age and HbA1c.	18-69 (range). Mean age 39 (SD 13.7).	Cross sectional	Self-report questionnaires. HbA1c measured via blood sample	HbA1c. Diabetes Distress Scale (DDS); The Problem Area in Diabetes Survey (PAID); The Hospital Anxiety and Depression Scale (HADS); the World Health Organization- Five well-being Index (WHO-5).	Mixed results: PAID and DDS total scores (unstandardized coefficient 0.020, $P = .001$, and 0.033, $P < .001$ respectively) and regimen related distress subscale (DDS) and emotional burden subscale (DDS) (0.039, $P < .001$, and 0.014, $P = .005$ respectively) were significantly related to HbA1c. HADS anxiety, HADS depression and WHO-5 were not significantly related to HbA1c.	52%
Wikblad, Leksell and Wibell Sweden 1996	To explore HbA1c, late complications and quality of life	108 Adults	Unclear comparison with non-respondents	Mean age 43.5 (SD 5.7).	Cohort study	Self-report questionnaires. HbA1c mean value in one year calculated via blood samples	HbA1c, SWEDQOL, number of hypoglycemic events, late complications, duration of diabetes and age.	Curve linear relationship: When HRQOL was compared among patients with different levels of metabolic control, those with acceptable metabolic control had the highest rating on most scales (no statistical analysis available). People who reported hypoglycemic episodes rated their general health as being poorer compared with those without hypoglycemic episodes (57.7, SD 9.2 Vs 74.9 SD 3.2; $F = 4.2$, $P = 0.04$). They proposed that a curve linear relationship existed between Quality of life and HbA1c, and that poor metabolic control was related to poorer physical and emotional health.	45%
Wikby, Hornquist, Stenstrom and Andersson Switzerland 1993	To explore the factors related to health-related quality of life: demographic and social factors, complications and metabolic control	66 Adults	N/A	Mean age 42.6 (SD 14).	Cohort study	Self-report questionnaires. Does not state how HbA1c obtained.	Quality of life composite score and scaled scores for: illness, somatic health, psychological, social, behavioural, habits and global life satisfaction.	No overall relationship between quality of life and HbA1c. HbA1c was associated with the subscale of somatic health but no other QoL scales ($r = -0.34$, $P < .005$.)	57%

Table 1 summarises the main characteristics of the seven studies selected for review.

Table 2.

Quality assessment ratings for the selected seven studies

Quality criteria	Study One	Study Two	Study Three	Study Four	Study Five	Study Six	Study Seven
	Aalto 1997	Gawlik 2015	Hendricks 2013	McQueen 2014	Standberg 2014	Wikblad 1996	Wikby 1993
Explicit theoretical framework	2	2	2	2	2	2	3
Statement of aim/objectives in main body of report	2	3	2	3	2	3	2
Clear description of research setting	2	3	3	3	1	2	2
Evidence of sample size	0	0	0	3	0	0	2
Representative sample of target group of a reasonable size	3	2	2	2	1	1	1
Description of procedure for data collection	1	1	3	2	1	1	2
Rationale for choice of data collection tools	1	2	2	2	2	1	2
Detailed recruitment data	2	1	2	2	2	2	0
Statistical assessment of reliability and validity of measurement tools	2	3	3	0	3	2	2
Fit between stated research questions and method of data collection	3	3	3	3	2	2	3
Fit between research questions and method of analysis	2	2	2	3	2	2	2
Good justification for analytical method section	2	1	1	2	2	1	2
Evidence of user involvement	0	0	0	0	0	0	0
Strengths and limitations critically discussed	2	2	1	2	2	0	1
Total quality rating (out of 42)	24 = 57%	25 = 59.5%	26 = 62%	29 = 69%	22 = 52%	19 = 45%	24 = 57%

Table 2 details the individual quality assessment for each study using the 16 item Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh et al., 2011).

Country of origin, design and focus of research

None of the research was undertaken in the UK and this may have implications for the generalisability of any results. The studies were carried out in the USA, Australia, Finland, Sweden, Norway and two in Switzerland. Three studies were undertaken in the 1990s (1993, 1996 and 1997), and the remainder were undertaken more recently (2013, two in 2014 and 2015). They were mostly cross-sectional in design whilst two were cohort studies. In most cases the research aimed to explore the relationships between many variables, in addition to the two variables the present review focused upon (HbA1c and QoL). For example, Hendricks et al. (2013) explored the relationships between a range of self-care behaviours, psychosocial adjustment and HbA1c. A further example is Gawlik et al. (2015), who explored body image and insulin restriction as a weight control strategy, in addition to QoL and HbA1c. Only one study focused upon the relationship between HbA1c and 'health utility' (McQueen et al., 2014). This was heavily weighted towards the physical health construct of QoL and its aim was to explore cost effectiveness.

Participant characteristics

The sample sizes varied from 49 to 385. Participants were mostly recruited from specialist diabetic clinics or centres. One of the studies specifically targeted emerging adults whilst another included women only, which may have implications for the generalisability of the findings, although the remainder focused more broadly upon adults. Two studies had control groups; one compared basic details between respondents and non-respondents whereas the other did not provide details about the control group.

Measures

The studies used self-report questionnaires to measure QoL. Some of these tools had been specifically developed to measure QoL in diabetes (DQoL; Jacobson, 1994 & DQoL Brief Clinical Inventory; Burroughs, Desikan, Waterman, Gilin & McGill, 2004), two measures focused upon health-related QoL (MOS-SF; Steward, Hays & Ware, 1988 & EURO-QoL; EURO QoL Group, 1990), two measured QoL more broadly (SWEDQoL; Brorsson, Ifver, Hays, 1993 & WHO-5; Bech, Olsen, Kjoller & Rasmussen, 2003). Wikby et al. (1993) used a measure that had been designed and used previously by one of the authors (Hanestad, Hornquist & Albrektsen, 1991). Therefore, the self-report measures used varied in their focus, from diabetes-related QoL, health-related QoL or simply QoL. They also varied in how comprehensive they were, with two of the measures asking only five questions; for example, McQueen et al. (2014) used the EURO-QoL and did not report a measure of internal reliability (Cronbach's alpha). All of the other studies reported the Cronbach's alpha of the measures used, and these varied from 0.77 to 0.93. No studies used the same measure.

Whilst it is generally accepted that HbA1c is a universally agreed measure, the means for obtaining this result also varied between studies. For example, some used medical records to obtain a single result or an average from the previous 12 months, some used a single blood test, some used more than one blood test to obtain an average, some self-reported their most recent result and some used a 'home testing kit'. Only three studies stated if their equipment was calibrated to an agreed standard.

Analysis

The studies were analysed using correlation or regression analyses to explore the relationships between the various variables.

Outcome: No relationship between HbA1c and overall QoL

Hendricks et al. (2013) proposed that psychological well-being and QoL were not significantly correlated with HbA1c. The study used a small sample (N=49) of emerging adults (18-26 years of age) and measured HbA1c on a single occasion. Whilst there was no evidence of an overall relationship between QoL and HbA1c, the authors identified that better psychological well-being on the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) correlated with more favourable diabetes QoL on the Diabetes Quality of Life Measure (DQOL; Jacobson, 1994), $r = -0.33$, $P < .05$. This may demonstrate that better psychological well-being occurs alongside better QoL, as measured by the DQoL.

Wikby et al. (1993) also identified that there was no correlation between HbA1c and QoL. They used a measure that had been designed and previously used by one of the authors (Hanestad et al., 1991). The measure explored seven domains: illness, somatic health, psychological, social, behaviour and activity, habits and global life satisfaction. HbA1c was only associated with the somatic health subscale of QoL but none of the other subscales ($r = -0.34$, $P < .005$). Therefore, perceived somatic health was positively associated with greater metabolic control, meaning the greater the perceived somatic health, the greater the metabolic control (and therefore, the lower the HbA1c). This study also used a small number (N=66) of adults, although the sample was general adults, with a mean age of 42.6 years. It is not indicated how HbA1c was obtained.

Aalto et al. (1997) failed to identify a relationship between HbA1c and health-related QoL as measured by the MOS 20 SF (Steward et al., 1988). The measure conceptualises QoL via assessing the domains of physical functioning, role functioning, social functioning, mental health and lack of pain. Whilst no overall relationship was identified between HbA1c and QoL, the authors identified a relationship between HbA1c and a domain of QoL, namely

role functioning ($X = 7.02$, $df = 2$, $P < 0.05$). Role functioning was defined as limitations in performing one's usual role due to poor health. The authors noted that problems in role functioning were reported more often among those with poor control (17%) and tight control (13%) than among those with moderate control (5%). This indicated that role functioning is an important component of QoL and that this effect was more marked for those with poor control and tight control. It is important to note that the role functioning subscale contains only two questions. The study used a larger sample of 385 adults with a mean age of 33.

Outcome: Mixed results

Strandberg et al. (2014) offered mixed results. They were unable to find a correlation between HbA1c and well-being (WHO 5 well-being), or anxiety and depression (HADS; Zigmond & Snaith, 1983); however, they identified a positive correlation between HbA1c and diabetes-related distress. The authors concluded that Problem Areas In Diabetes (PAID; Welch et al., 1995) and Diabetes Distress Scale (DDS; Polonsky et al., 2005) total scores (unstandardized coefficient 0.020, $P = .001$, and 0.033, $P < .001$ respectively) and regimen related distress subscale (DDS) and emotional burden subscale (DDS) (0.039, $P < .001$, and 0.014, $P = .005$ respectively) were significantly related to HbA1c. As HbA1c increased, the following increased: PAID score, DDS score, regimen-related distress and emotional burden. This indicated that distress related to diabetes, particularly concerning the emotional impact and regimen-related distress, were related to HbA1c whilst anxiety, depression and overall well-being were not. This study started with a sample of 235, but this was reduced to 185 after exclusions for missing data. It used a comparison group and there were no significant differences between respondents and non-respondents regarding sex, age and HbA1c.

Outcome: Negative correlation

McQueen et al. (2014) proposed that after adjusting for demographics, medications, and diabetes related complications, an increase in HbA1c was associated with an increase in health disutility. This cost effectiveness study used health utilities (measured by the EURO QoL) and costs over time to calculate the long term quality adjusted life years (QALYs) and costs. Health utility reflects the state of living in a healthy state with diabetes. Health disutility is a term used to define the difference between the IDDM population and the general population. Both terms are used alongside QALYs in cost effectiveness models to calculate disability and costs associated with health conditions and interventions. Whilst the main aim of this study was to explore cost effectiveness, it indicated a clear negative correlation between HbA1c and 'health utility', or health related QoL as measured by the EURO-QoL. Therefore, as HbA1c increased, health related QoL decreased. The authors used a sample of 176 adults with a mean age of 38 years. This study scored the highest in the quality rating with a percentage of 69; however, whilst HbA1c was taken from medical records, QoL was measured using the five question EURO-QoL that purports to measure general physical health status. The EURO-QoL has only 5 items, these are very basic and therefore, it is a crude instrument for measuring QoL compared to studies with a lower % quality rating that used more sensitive measures.

Outcome: Curve-linear correlation

Wikblad et al. (1996) argued that a curve-linear relationship existed between QoL and HbA1c. When health-related QoL was compared among patients with different levels of metabolic control (good HbA1c <7%, acceptable HbA1c 7.1-8%, unacceptable 8.1-9% and unsatisfactory >9%), those with acceptable metabolic control (HbA1c 7.1-8%) had the highest rating on the subscales of the SWEDQUAL (Brorsson et al., 1993), including

physical functioning, mobility, satisfaction with physical health, role limitation due to physical health, pain, positive feelings, negative feelings, role limitations due to emotional health, sleep problems, satisfaction with family life, marital functioning, sexual functioning and general health. Wikblad et al. (1996) fail to offer any statistical analysis to support their assertion that those with acceptable metabolic control reported the greatest QoL, although this is demonstrated pictorially in a graph in the paper. This paper had the lowest scoring quality rating of 45%. The authors acknowledged that HbA1c may be misleading as it fails to capture the number of hypoglycaemic events people may experience. Statistical analysis was available regarding participants who reported hypoglycaemic episodes, who rated their general health as being poorer compared to those without hypoglycaemic episodes (57.7, SD 9.2 Vs 74.9 SD 3.2; $F=4.2$, $P=0.04$). The authors proposed that a curve-linear relationship exists between QoL and HbA1c, meaning that those with an 'acceptable' HbA1c of between 7.1% and 8% report the greatest QoL, and that both low and high HbA1c are related to lower QoL.

Gawlik et al. (2015) initially identified a significant negative correlation between QoL (Diabetes Quality of Life Brief Clinical Inventory; Burroughs et al., 2004) and HbA1c: $r=-.30$, $P<.001$. However, they investigated further as they believed that a curve-linear relationship may better describe their data. They undertook a one-way ANOVA using the categories of low, ideal, somewhat high and very high; they identified a highly significant result with a medium effect size. This study included only women and focused upon body image, insulin restriction as a weight control strategy and HbA1c. The study used a diabetes-specific QoL measure (Diabetes Quality of Life Brief Clinical Inventory; Burroughs et al., 2004); however, participants self-reported their most recent HbA1c result.

Discussion

Theoretical framework

Only one of the seven studies explored QoL as a theoretical construct (Wikby et al., 1993); therefore, the studies could be seen as theoretically weak. This may have been because the focus of the articles varied. For example, whilst all of the articles included HbA1c and a measure of QoL or well-being, the focus varied from self-care behaviours and adjustment, body image and insulin as a weight control strategy, psychosocial factors, social factors, complications and cost effectiveness. Whilst the studies described the theory relevant to their focus, they failed to conceptualise QoL. This has implications for the present review and is in keeping with Speight et al.'s (2009) findings, who state that there are inherent difficulties when investigating a subjective, dynamic and multi-dimensional concept such as QoL. Therefore, it is imperative that studies clearly indicate their understanding of QoL. This is discussed further in relation to measures and problems, i.e. whether the measure focused upon health related QoL, diabetes-related QoL or generic QoL.

Strengths and limitations

Aims, participants, recruitment and sample size

A relative strength of each of the studies concerned their explicitly stated aims and objectives, as well as a detailed description of the research setting. Very few provided sufficient detail regarding participant recruitment. Only one of the studies (McQueen et al., 2014) considered sample size and indicated a minimum sample size, although they did not indicate how they calculated statistical power. Sample size varied, for example one study had a sample size of 49 (Hendricks et al., 2013) whilst another had 66 (Wikby, et al., 1993), the remainder had between 100 and 300 participants. Two of the seven studies were concerned with particular samples: Hendricks et al. (2013) focused upon emerging adults whilst Gawlik

et al. (2015) included only women. Both studies provided a rationale for their respective sampling strategy, although this may have had implications for the generalisability of such results.

Data collection and rationale for data collection tools

Only one of the studies scored the maximum for detailing the procedure for data collection (Hendricks et al., 2013), which has implications for reliability and the ability to replicate the studies. No studies scored the maximum for offering a rationale for the data collection tools. This was a significant flaw in all the studies, particularly in light of the findings of Speight et al. (2009) and the lack of a theoretical framework.

Reliability and validity of tools

A strength of the studies was that most offered statistical assessment of the measures used; however, this is of little value if the measures were incorrectly employed. It is important to note that the measures of QoL were all self-report measures and no two studies used the same measure. It could be argued that some purported to measure QoL but may more accurately have assessed physical health status. This means that synthesis of the results from the papers is difficult. The lack of a theoretical framework and poor justification of the tools used to measure QoL is in keeping with the earlier criticisms proposed by Speight et al. (2009).

HbA1c was typically measured via a blood sample on one occasion, some accessed medical records and calculated a mean HbA1c result throughout the past 12 months, some used a single blood test, one used a 'HbA1c now kit' whilst another asked participants to self-report their last HbA1c result.

Goodness of fit between research question and analysis

There was generally a good fit between the stated research questions and data collection (or measurement); although this had to be inferred and was not explicitly discussed. The research undertaken was typically cross-sectional and used to explore the relationship between a number of variables, which has implications for inferring causality or gaining a deeper understanding of the direction of potential relationships.

Justification of analysis

The analysis was a relative strength of all of the studies as this suited the design of the studies; although (as above) correlation or regression analysis means that one cannot infer causality. Furthermore, correlation is based upon the assumption of the general linear model and this may not accurately capture the relationship between the two variables in question. Gawlik et al. (2015) undertook a one-way ANOVA using the categories of low, ideal, somewhat high and very high to identify a curve-linear relationship. If QoL is understood as a subjective concept that is multi-dimensional, dynamic and influenced by numerous, interrelated factors that change over time, an alternative research methodology may allow for more flexibility in exploring such relationships.

User involvement and discussion of strengths and limitations

A major limitation of all of the studies was that they did not have any involvement from service users. Only one study scored the maximum for discussing both the strengths and limitations to their research.

Summary of quality and quality assessment tool

The aims of the studies and research setting were generally clear; although the focus of the studies varied and only one focused specifically upon HbA1c and QoL (the emphasis was upon demonstrating cost effectiveness, and it used the EURO-QoL that focuses upon physical health). All but one of the articles failed to explicitly discuss and define QoL. This is a major limitation, exacerbated by the use of inappropriate tools that purport to measure QoL, and the absence of any rationale for their use, although most used a measure of validity. No studies used the same measure, indicating the diverse measures available. The measures of QoL were all self-reported and some placed greater emphasis on physical health. Studies varied in how they obtained an HbA1c value. Few studies considered sample size and the size varied between studies. Two targeted a specific sample and there was inadequate detail regarding recruitment procedures. Most studies were cross-sectional and this has implications for inferring causality. There appeared an overall fit between question, data collection and method of analysis but there was poor justification of the analysis. All seven studies were weak regarding service user involvement and discussion of strengths and limitations.

The 16 item Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh et al., 2011) helped to structure and guide the critical appraisal of each study. Whilst the tool provides an overall quality rating, this can be misleading, as it does not specify the individual strengths or weaknesses of each study. An example of this is the McQueen et al. (2014) study that scored the highest for quality, despite it using a brief measure of QoL that focused upon physical health (EURO-QoL).

Summary of outcomes

Three of the seven studies did not identify a relationship between QoL and HbA1c; although some studies identified relationships between the subscales of somatic health

(Wikby et al., 1993) and role functioning (Aalto, 1997). Whilst there may have been no significant relationship identified with QoL overall, there were relationships with some of the subscales. Strandberg et al. (2014) offered mixed results; there were no correlations identified between HbA1c and well-being, anxiety or depression. However, the Problem Areas in Diabetes Scale (PAID; Polonsky et al., 1995) and the Diabetes Distress Scale (DDS; Polonsky et al., 2005) were related to a higher HbA1c.

McQueen et al. (2014) identified a negative correlation between QoL and HbA1c. Whilst this was a robust piece of research, the authors used the EURO-QoL and it has been argued that this is a crude measure that focuses upon general physical health. Wikblad (1996) and Gawlik (2015) proposed a curve linear relationship. Wikblad's (1996) analysis was poor, although they considered the impact of hypoglycaemic events and their argument makes intuitive sense. Gawlik (2015) focused upon women specifically with self-reported HbA1c, but the study used a diabetes specific QoL measure.

Limitations and strengths of the present review

This systematic review could have been strengthened by employing another researcher to independently screen the titles and abstracts using the given search terms. The full-text articles could then also have been independently reviewed to ensure no articles were excluded by mistake. Even though a quality tool was used, the review was still vulnerable to bias through lack of independent verification.

However, careful attention was given to search terms and assistance was sought via local experts and a specialist librarian. Where there was doubt regarding excluding a study, an independent member of the University research team was consulted. All seven of the included studies were independently quality assessed.

Conclusion

Three studies indicated that a relationship between HbA1c and QoL could not be identified. One study offered mixed results. A further study identified that a negative correlation existed: as HbA1c increased QoL (general health status) decreased. Two studies proposed that a curve-linear relationship existed: those people with acceptable control had the best QoL whilst those with low HbA1c and high HbA1c reported poorer QoL. Given the findings, it is difficult to provide a conclusive statement regarding the relationship between QoL and HbA1c.

Current healthcare policy focuses on achieving a near normal range for HbA1c to lower the risk of associated complications (NICE, 2015). The impact of this on QoL remains unclear. Whilst achieving the required target for HbA1c may lower the risk of physical complications and subsequent deterioration in QoL in the long-term, it may be that more attention needs to be given to QoL in the short-term, particularly regarding the psychological, emotional and social needs of those with IDDM. This may be particularly salient for some groups, for example adolescents or young adults.

None of the studies set out to specifically explore the relationship between HbA1c and QoL. The research included in this review is generally of a poor quality. The main reasons for this are that few explored the theoretical construct of QoL and there was little rationale to justify the use of measures (all QoL measures were self-reported). Some of the measures (EURO-QoL and MoS 20 SF) more accurately assessed physical health status (Speight et al., 2009). Sample size varied, some targeted specific samples, and none of the research was undertaken in the UK. The studies largely captured a cross section of participants and this, as well as the correlational analysis, meant that one is unable to infer causality. It could be argued that such a design and analysis fails to capture the complexity of the relationship between HbA1c and QoL. None of the research involved service users themselves, who may

be key to guiding future research, particularly if future research employed a different methodology.

Further research

There is an urgent need for a well-designed study to further explore the relationship between HbA1c and QoL. Particular attention needs to be given to the limitations that exist in the current research, for example a lack of clear theoretical constructs and appropriate measures, and limitations of cross-sectional studies and correlational analyses. Robust, quantitative, longitudinal research might be able to generate more reliable results and allow for conclusions regarding causality to be drawn.

In addition, there are inherent problems when investigating QoL using quantitative methodology. Future research could employ a qualitative approach to gain a rich understanding of people with IDDM and their experiences of QoL, what it means to them and how they manage to live well with IDDM. This may help to explore the complex relationship between HbA1c and QoL and provide a useful insight into how people manage to live well with a chronic health condition. This may be particularly salient in an adolescent population. The onset of IDDM often occurs in childhood and four out of five adolescents are unable to achieve the advised target for glycaemic control (Spencer, Cooper & Milton, 2010). It may prove fruitful to take a positive psychology approach and explore with adolescents themselves how they manage to 'live well' with IDDM.

References

- Aalto, A. M., Uutela, A., & Aro, A.R. (1997). Health related quality of life among insulin-dependent diabetics: Disease-related and psychosocial correlates. *Patient Education and Counseling, 30*, 215-225.
- Bech, P., Olsen, L. R., Kjoller, M., & Rasmussen, N. K. (2003). Measuring well-being rather than the absence of distress symptoms: A comparison of the SF-36 mental health subscale and the WHO-five well-being scale. *International Journal of Methods in Psychiatric Research, 12*(2), 85-91.
- Bradley, C. (1994). The Well-being Questionnaire. In C. Bradley (Ed.), *Handbook of psychology and diabetes: A guide to psychological measurement in diabetes research and practice*. PP 89-109. Chur, Switzerland: Harwood Academic Publishers.
- Bradley, C., Todd, C., Gorton, T., Symonds, E., Martin, A., & Plowright, R. (1999). The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: The ADDQoL. *Quality of Life Research, 8*, 79-91. doi: 10.1023/A:1026485130100
- Braga De Souza, A. C. C., Felício, J. S., Koury, C. C., Neto, J. F. A., Miléo, K. B., Santos, F. M.,...Gomes, M. B. (2015). Health-related quality of life in people with type 1 Diabetes Mellitus: Data from the brazilian type 1 diabetes study group. *Health and Quality of Life Outcomes*. doi 10.1186/s12955-015-0396-0
- Brorsson, B., Ifver, J., & Hays, R. D. (1993). The swedish health related quality of life survey (SWED-QUAL). *Quality of Life Research, 2*(1), 33-45.

- Burroughs, T. E., Desikan, R., Waterman, B. M., Gilin, D., & McGill, J. (2004). Development and validation of the diabetes quality of life brief clinical inventory. *Diabetes Spectrum, 17*, 41-49.
- Camacho, F., Anderson, R. T., & Bell, R. A. (2002). Investigating correlates of health related quality of life in a low-income sample of patients with diabetes. *Quality of Life Research, 11*(8), 783-796.
- DCCT. The Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine, 329*, 977-986.
- Derogatis, L., & Melisaratos, N. (1983). The brief symptom inventory: An introductory report. *Psychological Medicine, 13*(3), 595-605.
- Diabetes UK (2016). What is type 1 diabetes? Retrieved from:
<https://www.diabetes.org.uk/Diabetes-the-basics/What-is-Type-1-diabetes/>
- EURODIAB IDDM Complications Study Group. (1994). Microvascular and acute complications in insulin dependent diabetes mellitus: The EURODIAB complications study. *Diabetologia, 37*, 278-285.
- EuroQoLGroup. (1990). EuroQol – a new facility for the measurement of health-related quality of life. *Health Policy, 16*, 199-208.
- Gawlik, N. R., Elias, A. J., & Bond, M. J. (2015). Appearance investment, quality of life, and metabolic control among women with type 1 diabetes. *International Society of Behavioral Medicines, 23*, 348-354. doi: 10.1007/s12529-015-9524-9

- Hanas, R. (2015). *Type 1 diabetes in children and young adults (6th ed.)*. Class publishing, UK: Brigg.
- Hendricks, M., Monaghan, M., Soutor, S., Chen, R., & Holmes, C. S. (2013). A profile of self-care behaviors in emerging adults with type 1 diabetes. *The Diabetes Educator*, 39(2), 195-203.
- Hanestad, B. R., Hornquist, J. O., & Albrektsen, G. (1991). Self-assessed quality of life and metabolic control in persons with insulin-dependent diabetes mellitus. *Scandinavian Journal of Social Medicine*, 19, 57-65.
- Jacobson, A. M. (1994). The DCCT research group. The diabetes quality of life measure. In C. Bradley (Ed.) *Handbook of psychology and diabetes: A guide to psychological measurement in diabetes research and practice*. Chur, Switzerland: Harwood Academic Publishers.
- McQueen, R. B., Ellis, S. L., Maahs, D. M., Anderson, H. D., Nair, K. V., Libby, A. M., & Campbell, J. D. (2014). Association between glycosylated hemoglobin and health utility for type 1 diabetes. *The Patient Centered Outcomes Research*, 7, 197-205. doi: 10.1007/s40271-014-0045-4
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *The British Medical Journal*. doi: <https://doi.org/10.1136/bmj.b2535>
- NICE. (2015). *Type 1 diabetes in adults: diagnosis and management*. Retrieved from: <https://www.nice.org.uk/guidance/ng17>

- Polonsky, W. H., Anderson, B. J., Lohrer, P.A., Welch, G., Jacobson, A. M., Aponte, J. E., *et al.* (1995). Assessment of diabetes-related distress. *Diabetes Care*, *18*, 754-760.
- Rose, M., Fliege, H., Hildebrandt, M., Schirop, T., & Klapp, B. (2002). The network of psychological variables in patients with diabetes and their importance for quality of life and metabolic control. *Diabetes Care*, *25*(1), 35-42.
- Rubin, R. R., & Peyrot, M. (1999). Quality of life and diabetes. *Diabetes/Metabolism Research and Reviews*, *15*. 205-218.
- Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2011). Reviewing studies with diverse design: the development and evaluation of a new tool. *Journal of Evaluation in Clinical Practice*, *18*, 746-752. doi: 10.1111/j.1365-2753.2011.01662.x
- Speight, J., Reaney, M. D., & Barnard, K. D. (2009). Not all roads lead to Rome – a review of quality of life measurement in adults with diabetes. *Diabetic Medicine*, *26*, 315-327. doi: 10.1111/j.1464-5491.2009.02682.x
- Spencer, J., Cooper, H., & Milton, B. (2010). Qualitative studies of type one diabetes in adolescence: A systematic literature review. *Pediatric Diabetes*, *11*, 364-375. doi: 10.1111/j.1399-5448.2009.00603.x
- Steward, A. L., Hays, R. D., & Ware, J. E. (1988). Communication: The MOS short-form general health survey. *Medical Care*, *26*, 724-735.
- Strandberg, R. B., Graue, M., Wentzel-Larsen, T., Petrot, M., & Rokne, B. (2014). Relationships of diabetes-specific emotional distress, depression, anxiety, and overall well-being with HbA1c in adult persons with type 1 diabetes. *Journal of Psychosomatic Research*, *77*, 174-179.

- Tahbaz, F., Kreis, I., & Calvert, D. (2006). An audit of diabetes control, dietary management and quality of life in adults with type 1 diabetes mellitus, and a comparison with nondiabetic subjects. *Journal of Human Nutrition and Dietetics*, *19*, 3-11.
- Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short form health survey (SF-36): Conceptual framework and item selection. *Medical Care*, *25*, 473-483.
- Wikblad, K., Leksell, J., & Wibell, L. (1996). Health-related quality of life in relation to metabolic control and late complications in patients with insulin dependent diabetes mellitus. *Quality of Life Research*, *5*(1), 123-130.
- Wikby, A., Hornquist, J. O., Stenstrom, U., & Andersson, P. O. (1993). Background factors, long-term complications, quality of life and metabolic control in insulin dependent diabetes. *Quality of Life Research*, *2*, 281-286.
- WHOQOL Group. (1998). The world health organisation quality of life measure (WHOQOL). World Health Organisation Quality of Life Scale: Development and general psychometric properties. *Social Science and Medicine*, *46*, 1569-1585.
- World Health Organisation Group. (1997). *Programme on Mental Health. Measuring quality of life*. Retrieved from <http://www.who.int/mental.health/media/68.pdf>.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*, 361-370.

3. Chapter Two

‘Living Well’ With Insulin- Dependent Diabetes in Adolescence

Abstract

Objectives: This qualitative study explored how adolescents aged 13 to 19 with insulin-dependent diabetes (IDDM) experience themselves as able to ‘live well’ despite their chronic condition.

Design: Qualitative.

Methods: Data were gathered through face-to-face semi-structured interviews, with a purposive sample of eight adolescents, aged 13-19, who self-identified as living well with IDDM.

Results: Interpretative Phenomenological Analysis (IPA) identified the following four main themes: *Emotional security in and from close personal relationships*, *The journey from denial and avoidance to acceptance and control*, *“Living a normal life: Doing the same things that other kids do”* and *Psychological resilience: The importance of a positive mind-set*. Each theme had between four and six subthemes.

Conclusions: Participants wanted a ‘normal’ life and each individual had their own subjective view of living well. Living well occurred in the context of close personal relationships. Adjustment and adolescent development were reviewed with particular emphasis on identity and coping. Participants expressed a number of seemingly paradoxical statements and had a range of personal characteristics that promoted living well; they were psychologically resilient and had a range of support available.

Key words: Type 1 Insulin-Dependent Diabetes Mellitus, Adolescence, ‘Living well’, Quality of Life, Psychological wellbeing

This article will be submitted to the British Journal of Health Psychology. Maximum word count 6,000 (Appendix 1). Word count: 5,998.

Introduction

Insulin-Dependent Diabetes Mellitus (IDDM) is one of the most common chronic childhood conditions in the UK, affecting one adolescent per 550. The peak age for diagnosis is between 10-14 years (Department of Health; DoH, 2007). IDDM is a chronic condition that requires careful management to reduce the risk of severe, life-changing consequences (The Diabetes Control and Complication Trial; DCCT, 1993). Aiming to achieve a near normal glycaemic range lowers the risk of such complications, and this finding has informed UK healthcare policy (DCCT, 1993, National Institute for Health and Care Excellence; NICE, 2015).

Adolescence is a notoriously challenging time of biological, psychological and social changes, and adolescents with IDDM must manage such changes in the context of a strict regimen of blood tests, diet, activity and insulin injections (Burke & Dowling, 2007). This developmental period is often characterised by poor glycaemic control, with four out of five adolescents unable to achieve their target for control (Spencer, Cooper & Milton, 2010). Generally, adolescents have poor glycaemic control and this poses a significant challenge to diabetes healthcare teams regarding how best to intervene to prevent potential life-changing or life-limiting complications (Burke & Dowling, 2007). Given the size of this health problem, and in order to improve service delivery and the quality of care provided, previous research has endeavoured to identify reasons why young people are non-adherent to treatment regimens (Scholes et al., 2013). The existing literature explores 'barriers' to control and focuses upon the negative impact of IDDM; it is 'problem saturated', focusing upon distress and the subsequent negative psycho-social consequences of IDDM (Balfe et al., 2013). The extant quantitative research is dominated by correlational studies that aim to measure various psychological constructs associated with distress (Balfe et al., 2013). In the past decade there has been a renewed focus on qualitative investigations, although they have continued to

explore perceptions and experience of IDDM in the context of distress and negative impact (Balfe et al., 2013; Samson, 2006; Scholes et al., 2013).

The NHS defines ‘healthy living with diabetes’ as the successful management of the condition, for example: managing blood glucose levels and taking action to lower other physiological risk factors such as losing weight, stopping smoking, eating a balanced diet and being active (NHS, 2015). This medical definition places emphasis on the control of symptoms and fails to take into account the psychological, emotional and social aspects of wellbeing. Such an approach is evident in healthcare policy that places great emphasis on HbA1c results and assumes that a near normal HbA1c value is indicative of one living their life well (NICE, 2015). Northam, Matthews and Anderson (2004) propose that the psychological wellbeing of young people with IDDM should not be compromised at the expense of striving for near normal bio-medical indicators such as HbA1c. The relationship between HbA1c and quality of life in adults is unclear (Camacho, Anderson & Bell, 2002). It cannot be assumed that young people who are managing their blood glucose levels are, therefore, ‘living well’. Harris and Wallace (2012) on behalf of The Institute of Medicine consider the mental health and social aspects of ‘living well’ as:

‘the best achievable state of health that encompasses all dimensions of physical, mental, and social well-being. Living well is shaped by the physical, social, and cultural surroundings and by the effects of chronic illness—not only on the affected individual, but also on family members, friends, and caregivers’. (p. 3)

Spencer et al. (2010) identified that developing independence and autonomy in adolescence with IDDM was a complex process, and parents and peers could help facilitate such a process as well as hinder it. The successful management of IDDM occurred in the context of positive relationships with significant others in social environments (Spencer,

Cooper & Milton 2013). Samson (2006) identified the importance for adolescents of accepting the condition and integrating it into their life, and this was aided by having knowledge, coping skills and support.

Socially, adolescents were concerned about the impact of IDDM upon the sense of self, stigma, feeling different and being judged (Spencer et al., 2013). Balfe et al. (2013) proposed that IDDM could impact upon identity and identified the influence of the public view of IDDM and negative media representations.

Balfe et al. (2013) proposed that adolescents had strong fears of diabetes related complications and death. Kyngas and Barlow (1995) and Samson (2006) identified how IDDM posed a threat to their physical, psychological and social wellbeing, and that they experience worry and fear in regard to pain, death, fear of going blind and the impact upon their mood. Paradoxically, some adolescents viewed IDDM as a unique opportunity to live a healthy lifestyle.

The existing research reported conflicting findings that are littered with inconsistencies in theoretical and conceptual approaches, methodology, design, setting, reflexivity and further compounded by narrow definitions of health, quality of life and wellbeing (Spencer et al., 2010). There is a need for positively framed qualitative research exploring the lived experience of young people in the UK (Spencer, et al., 2010). The focus of this research is to explore qualitatively how some young people are able to experience themselves as living well in adolescence despite IDDM. It is hoped that this positive psychological approach will address a gap in the literature. It may help deepen the understanding of the psychological and social processes that enable some young people to live well with their condition and this, in turn, may help inform clinical practice.

Study aims

To explore what ‘living well’ with IDDM means to a group of adolescents, and to offer an interpretative account of their experience at such a challenging time of development.

Method

Design

The present study explored qualitatively how adolescents aged 13 to 19, who experience themselves as living well with IDDM, successfully negotiate the developmental challenges of adolescence and experience themselves as able to ‘live well’ despite their chronic condition.

Sample and recruitment

A purposive sample of eight participants was recruited from a paediatric community diabetes service in the north of England. Smith, Flowers and Larkin (2009) propose that participant sample size is determined by “data richness”, although a sample between four and ten participants is sufficient for doctoral research. Whilst the definition of “rich data” is a subjective one, the decision was made after seven interviews that an eighth would offer sufficiently rich and reflective accounts of the participants’ lived experience.

The inclusion criteria comprised: aged from 13 to 19, diagnosed with IDDM, self-identifying as ‘living well’ with IDDM. The exclusion criteria consisted of: unable to converse in English, adolescents looked after by the local authority, complex social care histories, significant and known mental health difficulties, behavioural difficulties or other complex medical needs.

Participants

Table 1

Participant characteristics

Name	Sex	Age at interview	Age at Diagnosis (years)	Duration of IDDM (years)	Treatment
Amber	Female	18	9	9	Injection
Fiona	Female	16	9	7	Pump
Charlotte	Female	14	11	3	Pump
Harriet	Female	17	7	10	Pump
Ellis	Male	18	15	3	Injection
Barry	Male	18	13	5	Injection
Gary	Male	14	4	10	Pump
Dean	Male	17	1	16	Injection

Table 1 describes the sex, age, age of diagnosis (years), duration of IDDM (years) and treatment method.

Data collection

Data were collected using semi-structured interviews undertaken by the main researcher. This allowed the freedom and flexibility to respond to, and explore, what the participants felt important, and this facilitated a thoughtful and reflective account of their experience.

Interview guide

The interview guide (Appendix 2) was developed in keeping with the aims of the study. Initially, it explored the participant and their family, interests and hobbies, as well as school or college and strengths. The guide progressed to questions concerning participants' understanding of IDDM and the diagnosis. The focus of the interview was their experience of living well physically, emotionally, psychologically, socially and behaviourally, as well as exploring family, school and peers. The interview concluded with coping and resources, and participants'

strengths and qualities, as well as allowing them time to add anything they felt the interview failed to explore or capture.

NHS ethical and research governance approval

Sponsorship was provided by the University of Liverpool (UoL001214; Appendix 3) and NHS ethical and research governance approval (IRAS ID 200898; Appendix 4) was attained in accordance with requirements.

Procedure

Recruitment posters and flyers were left in the clinic waiting area in the paediatric diabetes outpatient clinic. Clinic staff were briefed prior to commencing recruitment, and it was clinic staff facilitating review appointments who offered an information flyer to those whom met the inclusion criteria. The lead researcher was often present in the department to offer further information. Interviews were arranged via telephone or email approximately two weeks after the potential participants first expressed an interest. One interview took place at the hospital site, the remaining were undertaken at participants' homes. Those aged 16 or over provided written consent, whilst those who were younger provided assent and parental consent, after being given time to consider the recruitment flyer (Appendix 5), participant information sheet (Appendix 6), consent and assent forms (Appendix 7 and 8), parent information sheet (Appendix 9), and ask any questions. The interview guide was used flexibly to promote self-reflection and discovery. Interviews varied in length from 35 to 63 minutes. Following the interview, a debrief sheet was given that detailed hospital contact details, complaints and helplines (Appendix 10). Interviews were recorded with a digital Dictaphone and transcribed verbatim. Each participant was given a pseudonym to preserve their confidentiality and anonymity; therefore, the quotes used have been carefully selected in keeping with this. Interviews were conducted between January and May 2017.

Methodology

Interpretive Phenomenological Analysis (IPA; Smith et al., 2009) aims to understand how people make sense of their personal and social world; it draws upon phenomenology, hermeneutics and idiography (Smith, 2011). Acknowledging that there is no direct route to capture experience, IPA aims to get as “experience close” as possible to the phenomenon. IPA allowed an exploration of an “experience close” phenomenon (living well) from which the researcher interprets meaning. Therefore, the researcher is making sense of the individual who is making sense of themselves as an adolescent who lives well with IDDM. The researcher meaning-making is what constitutes the ‘interpretative’ aspect of IPA. IPA shifts between staying close to the individual’s account and meaning-making, to analysis of aspects of the individual’s experience that they may not be aware of or choose to share (Smith & Osborn, 2008). IPA provides a means to capture the complexity of human nature, experience and relationships.

The theoretical underpinnings of IPA position it well to offer an interpretation of how adolescents live well with IDDM. The lead researcher engaged in a reflexive process throughout via a reflexive journal (Appendix 11) and regular supervision.

Reflexive statement

The lead researcher is a 34-year-old white British male who had very little knowledge of IDDM and clinical health psychology prior to the research, although he had clinical experience of working with adolescents for a number of years, and had a longstanding interest in adolescent development and developmental psychology theories. The lead researcher was curious about how young people experience themselves as able to live well with a chronic condition, paying particular attention to issues such as quality of life, coping, resilience and applying psychological theory. Attempts were made to ‘bracket’ the lead

researcher's previous experience of working with adolescents, particularly regarding interviewing and analysis, although his own life experience, beliefs, values, assumptions and experience of adolescence, illness and the health service would have inevitably and reflexively influenced the interpretation. Access to regular supervision, a reflexive journal and a transparent analysis with a clear audit trail mitigated such influence. It was anticipated that adolescents would prioritise their life and not be too concerned regarding blood glucose control or HbA1c results; however, what was found, on the whole, was the opposite.

Analysis

The IPA process of analysis was undertaken according to Smith et al.'s (1999) guidelines. Transcripts were analysed individually. First each transcript was read multiple times with initial noting of descriptive comments, linguistic comments and themes (Appendix 12). From this, emergent themes were identified and clustered to form superordinate themes for each transcript (Appendix 13). The superordinate themes were clustered across all eight transcripts to provide a set of master themes and associated sub themes.

Table 2
Transcript extract to illustrate the analytic process

Quote (Amber)	Exploratory coding	Emergent themes	Superordinate themes	Subtheme	Main theme
Yeah, well, just in case, say if my sugars were to go low, and I didn't have any sugar with me, that could lead to me passing out or even worse it, err, (intake of breath), I could go into a diabetic induced coma	"just in case" – always having to be prepared / on guard. Fear regarding lack of control – fear of consequences of low blood sugar. Intake of breath – death. Risk of life limiting consequences and death	Always prepared Perpetual anxiety regarding control Dodging death Fighting the risk of life changing complications or death	'no escape' – perpetual anxiety regarding blood glucose control Fear of death and life-limiting consequences and death	Using control to reduce the fear associated with life-limiting complications and death	The day to day management of the dynamic nature of IDDM

Table 2 illustrates an example of the analytic process.

Quality and validity

All Transcripts, notes, reflections, individual analyses and final analysis were shared and discussed in supervision with the primary supervisor, and shared via email with the second supervisor. In addition to quality supervision, a reflexive journal helped raise awareness of the lead researcher's relationship with the research, interpretation and findings. "Yardley's (2008) framework for quality in qualitative research was considered with particular attention to the four broad principles: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. In practice, the lead researcher paid attention to sensitivity to context during the interviews and analyses. During the interviews and analyses the lead researcher reflected upon the sociocultural and linguistic context of participants as well as reflexivity and power, and how these may have influenced what participants said and how it was interpreted. The lead researcher considered commitment and rigour by adhering to the process of the research and undertaking a systematic and thorough overall analysis that remained true to the principles of IPA; the

details of this process are described throughout the methods section. Furthermore, the analytic process was undertaken in the context of supervision and was open and transparent, which means that it had a clear audit trail. Finally, impact and importance were considered. Great care was taken to produce findings that would be of use clinically and inform practice, and these are offered in the paragraph on clinical implications.”

Results

Table 3
Master themes and Subthemes

Master themes	Subthemes
1. Emotional security in and from close personal relationships	1.1 Family relationships as a secure base to living well 1.2 Using close personal relationships to manage distress 1.3 The importance of friends and social activities
2. The day to day management of the dynamic nature of IDDM	2.1 Becoming unwell: Fear of the unknown 2.2 IDDM and the impact on identity in adolescence 2.3 Accepting the diagnosis of IDDM 2.4 Using control to reduce the fear associated with life-limiting complications and death 2.5 Self- imposed limits in order to have a life without limits 2.6 Living in an uneducated society
3. "Living a normal life: Doing the same things that other kids do"	3.1 A life of love, passion, happiness, purpose and meaning 3.2 Living well as defined by a HbA1c target 3.3 Looking to the future with hope and optimism
4. Psychological resilience: The importance of a positive mind-set	4.1 Learning to live well 4.2 Personal characteristics that promote living well 4.3 Knowing your own mind 4.4 Knowing where to turn for support

Table 3 illustrates the four master themes and their constituent themes.

Master theme 1: Emotional security in and from close personal relationships

The first master theme captures the fundamental influence of close personal relationships and how they promote emotional security.

1.1 Family relationships as a secure base to living well

Family relationships fostered a sense of security, safety and stability. Amber:

“I have always had my family with me... I have always been very close to my sister and that is something that has never changed, and my mum too, and also my dad...we are a happy family.”

In addition to stability and security, parents offered emotional and practical support; they often co-regulated blood glucose in the early stages, and in this respect parents modelled good care and adjustment. Barry illustrated this: *“My mum, she tackled it head on... for the first year she tested a few times during the night to make sure my blood hadn't gone down.”* Barry later acknowledged that his mother's behaviour may have been fuelled by her anxiety in regard to him having IDDM.

1.2 Using close personal relationships to manage distress

Distress was communicated and regulated in the context of close personal relationships, it was often the main carer who helped regulate difficult, negative emotions; although, this also applied to peer relationships. Harriet: *“If I... feel down I can speak to my parents or speak to my friends. My friends... they'll distract me or they'll just remind me of good things and help me feel better... [parents] they approach it more head on... talk through it and work out any issues that I might have.”*

The main carer and clinic staff were available in times of crisis. Charlotte: *“I didn’t know what to do, I was like crying, in the end my mum had to come home from work to come and sort me out.”*

1.3 Importance of social activities and friends

Socialising was important to each participant; furthermore, a supportive peer group appeared to help the participants feel socially accepted and experience a sense of acceptance in regard to IDDM. Amber: *“Socialising is really important to me and friends... my friends were all accepting of it... I am fortunate enough to have friends who I was surrounded with that were just very accepting of it.”*

Master theme 2: The day to day management of the dynamic nature of IDDM

Participants described several challenges as they managed IDDM on a day to day basis. Experiencing serious physical health problems, having contact with health professionals and being told they were ‘ill’ with a condition for which there is no ‘cure’, was experienced as frightening and confusing. All participants described IDDM as having an impact on their identity and the importance of accepting the condition. Furthermore, participants described controlling their blood glucose (often out of fear) and this involved self-imposed limits, as well as living in the context of an ‘uneducated’ society.

2.1 Becoming unwell: fear of the unknown

Participants described the experience of being ‘ill’, going to hospital and then being told they had IDDM as frightening. Amber: *“It was really scary... I had never had anything wrong with me, so that was my first time being admitted to hospital with something that was serious – it was quite scary for me.”* Furthermore, this had implications for adjustment and loss, for example, the loss of freedom and being able to eat freely.

2.2 IDDM and the impact on identity in adolescence

IDDM posed a threat to the physical and psychological wellbeing of participants; they questioned why they had developed the condition, experienced powerful emotions such as anger, and longed to be ‘normal’. This impacted upon identity and the sense of self. Amber describes how she accepted and integrated IDDM as part of her identity:

“As I have got older, I look at diabetes as something that just defines me, it’s part of me, and when I was younger... I just thought I have to be like everyone else... [as I have] grown through all of my adolescent years... if I didn’t have diabetes I wouldn’t be me... it is a part of who I am.”

2.3 Accepting the diagnosis of IDDM

Accepting the condition appeared important in the process of gaining the knowledge to manage the dynamic nature of IDDM and integrating self-care into a daily routine. Barry helpfully summarises this, as well as some previous themes: *“I think that accepting it and it being part of your lifestyle, not being in denial, helps quite a bit... at the end of the day it is a part of you.”*

2.4 Control as a strategy to reduce the fear associated with life limiting complications and death

Failure to control blood glucose often meant feeling physical unwell, serious illness and potentially, risk of death. There was perpetual anxiety regarding control. Amber: *“It does impact everything I do, if I ever want to leave the house... I always have to have... all of my equipment just in case, there is always that element of just in case, you just have to carry it with you all of the time, there is never an escape from it is what I am trying to say, it is always there.”*

The fear of complications motivated participants to stay in control. Ellis: *“That’s one of the reasons why I mainly keep on top of it. When I think about going blind I just think no! Not going blind, so try and keep me bloods the best I can.”*

2.5 Self- imposed limits

Amber described self- imposed limits: *“I feel like with diabetes, I can drink, but I know my limits, I feel as though my diabetes never stops me from [drinking alcohol] ... I always try not to drink too much or if I have a couple of drinks I will always know when to stop.”* Most participants did not drink alcohol and enforced their own limitations and restrictions. Furthermore, this allowed them to feel in control of the IDDM, rather than them feeling controlled by the IDDM.

Participants described benefits to IDDM; for example, being more health conscious. Barry: *“knowing that it benefits you in the long term, cos, a lot people [without IDDM] ... don’t eat healthily or exercise.”*

2.6 Living in an uneducated society

Participants described a lack of understanding from the public, and that this may be fuelled by negative media images, and at times may influence how the participants themselves make sense of their condition. Charlotte: *“When I first went to hospital, I didn’t even know it was a thing, I had heard briefly about it – but I thought it was just this thing that fat people got.”* Participants described how IDDM is an invisible condition and that you do not know what it is like to live with IDDM unless you have it; therefore, participants described feeling uncomfortable at misinformed or inappropriate comments or jokes, for example, a person referring to a bowl of sweets as “a bowl of diabetes” (Amber).

Master theme 3: “Living a normal life: doing the same thing that other kids do”

Participants’ lives were often full of enjoyable and varied interests and activities, and similar to the lives of adolescents who do not have IDDM. It was important that adolescents with IDDM enjoyed “*living a normal life, doing the same things that other kids do*” (Dean).

3.1 A life of love, passion, happiness, purpose and meaning

Participants described living a life of love, passion, happiness, purpose and meaning; therefore, the nature of living well was subjective. Dean: “*People have their own way of living well... Everyone has to have something they like to do and everyone has to have something they have to love.*”

This theme was social in nature and closely related to the previous theme highlighting the importance of friendships and social activities; therefore, living well was influenced by popular culture and society.

3.2 Living well as defined by a HbA1c target

Steady blood glucose was important in living well and could be quantified by HbA1c results and targets. Therefore, living well was defined by blood glucose level and an HbA1c target. Most participants were goal orientated and valued this, others experienced guilt and shame when they failed to meet the set target. Amber was target driven: “*With my average when I come to clinic, if they are a point higher than they were, I would be driven to get them back down, doing more exercise, being more conscious of my insulin.*” Gary found meeting the target difficult: “*I’d like slip up and forget or something and then I’d get in trouble with the doctors and that.*”

3.3 Hope and excitement about the future

Participants were hopeful, optimistic and excited about the future. Achieving goals and succeeding appeared to promote a sense of mastery and success, which in turn promoted confidence and self-esteem. Charlotte: *“I’m in set one for a lot of subjects, so I do quite well at school... I wanna go to university and college and do all that...I wanted to be a doctor.”*

Master theme 4: Psychological resilience: The importance of a positive mind-set

Participants described a range of cognitive strategies that they used to help themselves live well, generally, this comprised of always trying to remain positive: “a positive mind-set”, and this included focusing upon the positives rather than the negatives.

4.1 Learning to live well

Participants had learned from experience, they described the ability to be self-aware, reflect, value feedback, face difficulties and overcome them. Amber: *“I have just taught myself to, erm, live with it... I think that just going through the experience, just growing with it.”*

4.2 Personal characteristics that promote living well

Participants described a range of personal characteristics that promoted living well; they were mature, involved in education, often creative and took personal responsibility for independently managing blood glucose. Amber: *“it made me grow up in a sense that I wanted to be independent doing my own medication, so I think that’s probably just the type of person that I am anyway.”*

Participants experienced themselves as perfectionistic, well-motivated and determined. Amber continues: *“After kinda accepting that I had it, I was just determined to*

take it on, learn more about it and treat it myself... I'd say that I am a bit of a perfectionist... most days I am a go getter, yeah, I can do this."

Participants developed confidence practicing self-care in front of others and talking to other people about IDDM; furthermore, they appeared socially skilled and felt comfortable asking for help.

4.3 Knowing your own mind (cognitive strategies)

Participants described using a range of cognitive strategies they would employ to cope; they were aware of their own thoughts and thinking style, and what thoughts to engage with and how this left them feeling and behaving. They were aware of the downward spiral of negative thoughts and negative behaviours, and in this respect they felt it best to avoid engaging in rumination. Barry: *"I think a negative outlook can lead to negative behaviour, kinda self-deprecating behaviour in a way, because, if you think in a negative way you are going to generally have negative habits."*

Distraction and the use of positive self-talk were frequently mentioned as strategies to manage negative emotions.

4.4 Knowing where to turn for support

Each participant had a subjective view in regard to what they found supportive. The participants felt supported at the clinic; it was clinic staff who directed them towards particular resources such as literature, online groups, new technology and diabetic events or holidays. Ellis: *"you can go to them for support, [online groups] you can ask them stuff and that's great like, I don't really use it much because I get by fine, but it's nice knowing they're there for you."*

Discussion

This study identified that the experience of ‘living well’ for adolescents with IDDM encompassed having a ‘normal’ life in which one lived how one wanted to, similar to someone without IDDM, experiencing pleasure and enjoyment in pursuit of interests. Paradoxically, some participants restricted themselves in order to feel unrestricted by IDDM, and in this respect self-imposed limits provided the freedom for them to do whatever they wanted to. Living well was characterised by a happy and enjoyable life, which has purpose, meaning, love and where one can pursue passions, interests and activities, particularly social activities with friends. Participants found goals and targets helpful, they wanted to achieve and succeed, and looked to their future with hope and optimism. ‘Living well’ was subjective and comprised many aspects of the person’s life, and was influenced by popular culture and society. This is in keeping with The Institute of Medicine (Harris & Wallace, 2012) definition of living well.

Participants described how steady blood glucose and an acceptable HbA1c was commensurate with living well. Whilst some participants valued HbA1c targets, others described how failing to meet such a target left them with feelings of guilt and shame. Furthermore, meeting the HbA1c target does not necessarily equate to living well, as good control may be fuelled by fear of IDDM complications or death.

Living well meant feeling emotionally secure and stable, and managing negative emotions; this occurred in the context of close personal relationships with family, peers and clinic staff. This is in keeping with earlier studies by Spencer et al. (2013), Burke and Dowling (2007), Samson (2006), Balfe et al. (2013) and Scholes et al. (2013); therefore, this study supports previous evidence that supportive family and peer relationships are experienced as promoting living well with IDDM. This emphasises the relational context of

life as an adolescent with IDDM, and the developmental psychology theory of attachment may help to improve the understanding of the fundamental role of significant others and relationships in living well. According to Bowlby (1958), an attachment is a bond or tie based on the need for safety, security and protection. Infants are born with basic instincts, they are immature and vulnerable, and entirely dependent upon their caregivers for protection and survival. Infants seek proximity to their caregiver at times of threat, and secure attachment is characterised by sensitive and responsive caregivers that are emotionally available, offer reassurance, warmth, protection and the provision of comfort (Ainsworth, Blehar, Waters & Wall, 1978; Cassidy & Shaver, 2008).

Ainsworth et al. (1978) proposed that caregivers offer a secure base which allows the child to develop and explore, and attachment has been associated with emotional regulation, reflective functioning, positive self-concept and prosocial behaviour; therefore, it could be argued that healthy relationships at home promoted the development of positive social relationships with peers and this may explain the findings in this study (Cassidy & Shaver, 2008). This may indicate the importance of secure attachment in facilitating living well in adolescence with IDDM, particularly the activation of attachment behaviour in times of threat, for example being diagnosed with IDDM, and the need for an appropriate response from significant others.

Family and peers offered both practical and emotional support; this is in keeping with the seminal text of Lazarus and Folkman (1984) and their model of stress appraisal and coping. Parents and peers provided practical assistance and reminders to help regulate blood glucose, as well offering emotional support.

The challenging journey from denial and avoidance to accepting the condition illustrated the powerful, negative emotions associated with the diagnosis of IDDM. Denial

and avoidance appeared protective in the short term, and these are common psychological defence mechanisms (Leiper, 2014). Kübler-Ross (1969) proposed a series of emotions are experienced by those facing the onset of disease and typically include denial, anger, bargaining, depression and acceptance. Participants in this study described denial and avoidance when diagnosed, and this progressed to anger and ‘why me?’ Participants appeared to accept the condition but continued to experience negative emotions. This may help understand the challenges faced by an adolescent who has been diagnosed with IDDM (Kübler-Ross, 1969).

Socialising and social friendships were of prime importance, and this can be understood in the context of adolescent development. This is also in keeping with previous research by Spencer et al. (2013), where participants wanted to be seen as normal and social relationships influenced their identity. This is supported by Erickson (1963) and his theory of psycho-social development. Stage five occurs in adolescence: identity versus role confusion. Positive social relationships allow the person to develop a sense of self, personal identity, independence and control. This relates directly to Amber’s transcript and the importance of peers, socialising, being accepted and acceptance, as well as wanting to be independent, wanting to control her IDDM and integrating IDDM as part of her identity.

Participants described experiencing low mood and anxiety in regard to adolescent development, wanting to be normal, and adjusted. Therefore, despite participants self-identifying as living well, they still experienced powerful negative emotions, particularly fear. This was largely a fear of life-changing complications such as going blind, and this was used as motivation for good control. This suggests that even those adolescents who appear to live well, present with good glucose control and meet the required HbA1c targets, do so because they fear the consequences of not being in control. Therefore, they experience and

manage high levels of anxiety on a daily basis and control their diabetes out of fear. This is in keeping with earlier research by Kyngas and Barlow (1995) and Samson (2006).

Participants described paradoxical statements, such as self-imposed limits in order to have a life without limits. Therefore, some participants restricted themselves in order to feel unrestricted by IDDM, and this may have allowed them to feel in control of the IDDM rather than them feeling controlled by the IDDM. Some participants believed that IDDM offered an opportunity to live well, and this is in keeping with prior research by Kyngas and Barlow (1995).

Participants endeavoured to have a positive mind-set and in this respect the adolescents involved in this study were psychologically resilient. They strived to be the healthiest they could be and learned from set-backs and difficult times. Each participant had a range of personal characteristics that seemed to promote living well, for example: being involved in education, mature, independent, responsible, perfectionistic, well-motivated, determined, socially skilled, confident and able to ask for help.

Participants described an awareness of the interaction of thoughts, feeling and behaviours. They recognised that rumination was unhelpful and used distraction and positive self-talk to cope with the powerful, negative emotions. Each participant had to recognise that they needed further support and know where and how to access support. Participants had a support network that included family, peers, clinical staff, using technology, literature, online support, and diabetic events and holidays. The participants described the importance of helping themselves and talking to their support network.

Conclusions

This IPA study offered an interpretive account of how adolescents experience themselves as able to live well with IDDM. Participants wanted a 'normal' life and each individual had their own subjective view of living well. Generally, living well was a life like any other, with love, passion, interests, enjoyment and happiness. Living well meant steady blood glucose management and this often meant achieving a near normal HbA1c. HbA1c targets were beneficial for most but meant guilt and shame for some; therefore, there is more to living well than an HbA1c result. This study proposed that good blood glucose control could be fuelled by anxiety and the fear of life-changing complications such as going blind. Those who may appear to be living well may still experience powerful, negative emotions. Such emotions were often regulated in close personal relationships, and such relationships with family, peers and clinic staff fostered a sense of emotional safety and security, in keeping with attachment theory (Bowlby, 1958) and previous studies by Spencer et al. (2013), Burke and Dowling (2007), Samson (2006), Balfe et al. (2013) and Scholes et al. (2013).

Family and peers provided practical and emotional support (Lazarus & Folkman, 1984) and participants described powerful emotions throughout their adjustment, for example denial, anger, bargaining, depression and acceptance (Kübler-Ross, 1969). The participants described the importance of living a 'normal life', a fear of being seen as 'not normal', wanting to be accepted, independent and have a robust sense of self and identity (Erickson, 1963). Participants expressed a series of seemingly paradoxical statements and had a range of personal characteristics that promoted living well. They were psychologically resilient and had a range of support available.

Strengths and limitations

This is the first study to explore how adolescents experience themselves as able to live well with IDDM; therefore, this study adds to the limited research in this area.

This qualitative research offers an interpretative account of how adolescents experience themselves as able to live well with IDDM, therefore, it is a subjective account of the experience of a small, homogenous group of adolescents and does not aim to be generalizable, and this may be seen as a limitation. A further limitation was the lack of service user involvement in the design of the study. The lead author approached local NHS service user involvement groups with the intention of involving young people in the design and layout of the participant information sheet, consent documentation and interview schedule; unfortunately, access could not be facilitated. Informal feedback regarding the interview schedule was elicited from young people and their families using the department. Recruiting participants that self-identify as living well may have meant that a particular type of person decided to participate, and it potentially failed to capture the experiences of less 'confident' adolescents who are able to live well. Furthermore, adolescents may have wished to present themselves in a positive light and this may have meant that they presented themselves a particular way in the interview. Interviewer effects may have meant that participants were influenced by the interviewer (lead researcher).

Clinical implications

Participants valued the significant people in their lives and their relationships with them; this included clinical staff. It was important that these people were easily accessible at times of crisis. Participants wanted to live a normal life; living well and what participants found helpful was subjective, although participants generally valued literature, access to support groups, diabetic events or holidays and technology. Given that living well, and the

nature of what was experienced as supportive, were subjective, it is a reminder that each adolescent must be treated as an individual. For example, an HbA1c target was generally useful for those who valued goals, but the negative impact of failing to meet such targets meant guilt and shame for some. Therefore, clinical staff must consider the potential negative impact of setting such goals for everyone. Furthermore, the findings indicate that good glucose control may be motivated by fear of IDDM related complications, and that even those who may be living well, may still experience high levels of distress and negative emotion that may not be overtly expressed. Clinical staff must remain vigilant to the potential distress experienced by all adolescents, even those who may achieve HbA1c targets or appear to be living well. Psychologically informed individualised care plans may help mitigate the risk of distress and help conceptualise living well psychologically, emotionally, socially and behaviourally, as well as biologically.

More broadly, participants described IDDM as an ‘invisible condition’ that is often confused with type 2 diabetes and associated conditions, as well as a general lack of understanding from the public and those without IDDM. Such ignorance is likely to impact on the potential for young people to live well; therefore, there is an urgent need to educate the public and society to address such misconceptions. This might be achieved via a general public health education campaign that offers greater clarity regarding the types of diabetes; for example tackling the stigma and misconceptions associated with IDDM. This may build on the existing campaign that encourages parents to look for the “four T’s” that are indicative of IDDM: becoming tired, increased thirst, increased toilet visits and becoming thinner. Existing paediatric diabetes teams could continue to offer educational programmes for children and families, as well as visiting schools and colleges to offer workshops to support staff and students. Furthermore, supportive literature and groups could be devised and facilitated to offer psychologically informed education and information.

Future research

Future research may wish to develop a developmentally appropriate and comprehensive measure to assess QoL in children and young people with IDDM. Future research could explore the relationships between attachment style, coping style and QoL in adolescents with IDDM.

References

- Ainsworth, M. D. S., Blehar, M. C., Waters, E., & Wall, S. (1978). *Patterns of attachment: A psychological study of the strange situation*. Hillsdale, NJ: Erlbaum.
- Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D., & Conroy, R. (2013). What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *Biomedical Central Endocrine Disorders*, *13*(25). doi: 10.1186/1472-6823-13-25
- Bowlby, J. (1958). The nature of the child's tie to his mother. *The International Journal of Psychoanalysis*, *39*, 350-373.
- Burke, H., & Dowling, M. (2007). Living with diabetes: Adolescents' perspectives. *Journal of Diabetes Nursing*, *11*(3), 90-96.
- Camacho, F., Anderson, R. T., & Bell, R. A. (2002). Investigating correlates of health related quality of life in a low-income sample of patients with diabetes. *Quality of Life Research*, *11*(8), 783-796.
- Cassidy, J., & Shaver, P. R. (2008). *Handbook of attachment: Theory, research, and clinical applications* (2nd Ed.). London: The Guilford Press.
- Department of Health. (2007). *Making every young person with diabetes matter*. London: Department of Health.
- DCCT. The Diabetes Control and Complications Trial Research Group. (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine*, *329*, 977-986.

- Erikson, E. H. (1963). *Childhood and society* (2nd ed.). New York: Norton.
- Harris., J. R., & Wallace., R. B. (2012). The institute of medicine's new report on living well with chronic illness. *Preventing Chronic Diseases: Public Health Research, Practice and Policy*. 9. doi: <http://dx.doi.org/10.5888/pcd9.120126>
- Kubler-Ross, E. (1969). *On death and dying*. New York: The Macmillan Company.
- Kyngas, H., & Barlow, J. (1995). Diabetes: An adolescent's perspective. *Journal of Advanced Nursing*, 22, 941-947.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal and coping*. Springer: New York.
- Leiper, R. (2014). Psychodynamic formulation: Looking beneath the surface. In L. Johnstone & R. Dallos (Eds.) *Formulation in Psychology and Psychotherapy: Making Sense of People's Problems*. London: Routledge.
- National Institute for Health and Care Excellence. (2015). Diabetes (type 1 and type 2) in children and young people: Diagnosis and management, methods, advice and recommendations [NG18]. Retrieved from: <https://www.nice.org.uk/guidance/ng18>.
- NHS. (2015). Living well with type 1 diabetes. Retrieved from: <http://www.nhs.uk/Livewell/diabetes/Pages/diabeteshome.aspx>
- Northam, E. A., Matthews, L. K., & Anderson, P. J. (2004). Psychiatric morbidity and health outcome in type 1 diabetes: Perspectives from a prospective longitudinal study. *Diabetic Medicine*, 22, 152–157.
- Samson, J. (2006). Exploring young people's perceptions of living with type 1 diabetes, *Journal of Diabetic Nursing*, 10(6), 351-358.

- Scholes, C., Mandleco, B., Roper, S., Dearing, K., Dyches, T., & Freeborn, D. (2013). Young people's experiences of living with type 1 diabetes. *Nursing Times*, 109(45), 23-25.
- Smith, J.A. (2011). Evaluating the contribution of interpretive phenomenological analysis, *Health Psychology Review*, 5(1), 927.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In JA Smith (Ed.) *Qualitative Psychology: A Practical Guide to Methods* (2nd ed.). London: Sage.
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Smith, J., Jarman, M. & Osborn, M. (1999). Doing interpretive phenomenological analysis. In M. Murray & K. Chamberlain (Eds.) *Qualitative health psychology*. London: Sage.
- Smith, J. & Osborn, M. (2003). Interpretive phenomenological analysis. In J.A. Smith (Ed.) *Qualitative psychology: A practical guide to research methods* (pp.51-80). London: Sage.
- Spencer, J., Cooper. H., & Milton, B. (2010). Qualitative studies of type one diabetes in adolescence: A systematic literature review. *Pediatric Diabetes*. 11, 364-375 doi: 10.1111/j.1399-5448.2009.00603.x
- Spencer, J., Cooper. H., & Milton, B. (2013). Type one diabetes in young people: The impact of social environments on self-management issues form young people's and parents' perspectives. *Journal of Diabetes Nursing*. 18(1), 22-31.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J.A. Smith (Ed.) *Qualitative psychology: A practical guide to methods* (pp.235–251). London: Sage.

Appendix 1

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal [Overview](#).

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which report analyses on established theories in health psychology;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes but excluding the abstract, tables, figures and references). The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal

- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words, or 6,000 words for qualitative papers)

4. Submission and reviewing

All manuscripts must be submitted via [Editorial Manager](#). The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the [terms and conditions of submission](#) and the [declaration of competing interests](#). You may also like to use the [Submission Checklist](#) to help you prepare your paper.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. You may like to use [this](#) template. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the [Project CRediT](#) website for a list of roles.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).
- Statement of Contribution: All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.
- Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.

- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book*. City, Country: Publisher.

Author, A. (2013). Title of journal article. *Name of journal*, 1, 1-16. doi: 10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the [CONSORT statement](#) on reporting randomised controlled trials.
- Manuscripts reporting systematic reviews and meta-analyses are encouraged to submit in accordance with the [PRISMA statement](#).
- Manuscripts reporting interventions are encouraged to describe them in accordance with the [TIDieR checklist](#).

If you need more information about submitting your manuscript for publication, please email Hannah Wakley, Managing Editor (bjhp@wiley.com) or phone +44 (0) 116 252 9504.

6. Supporting information

We strongly encourage submission of protocol papers or trial registration documents, where

these are in the public domain, to allow reviewers to assess deviations from these protocols. This will result in reviewers being unblinded to author identity.

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.

For further information on recommended file types and requirements for submission, please visit the [Supporting Information page](#) on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of [terms and conditions](#) is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the [payment form](#).

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

8. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. You can then access [Kudos](#) through Author Services, which will help you to increase the impact of your research. Visit [Author Services](#) for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

9. Copyright and licences

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the [Copyright FAQs](#).

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA):

- Creative Commons Attribution Non-Commercial Licence (CC-BY-NC)
- Creative Commons Attribution Non-Commercial -NoDerivs Licence (CC-BY-NC-ND)

To preview the terms and conditions of these open access agreements please visit the [Copyright FAQs](#) and you may also like to visit the [Wiley Open Access Copyright and Licence](#) page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY licence supporting you in complying with your Funder requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit our [Funder Policy](#) page.

10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a [Colour Work Agreement](#) form upon acceptance of the paper.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in [Author Services](#). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat

Reader will be required in order to read this file. This software can be downloaded (free of charge) from [Adobe's web site](#). This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Further information about the process of peer review and production can be found in this document. [What happens to my paper?](#) Appeals are handled according to the [procedure recommended by COPE](#).

Appendix 2

Interview Guide

IRAS Project ID: 200898

Topic Guide

Version 3: 20/06/2016

Introduction

My name is Adam. I am the main researcher and will be interviewing you today. I wanted to tell you a little bit about what to expect.

The main aim of the interview is to get a really good understanding of what it is like to be you, and how you live well with diabetes. There are no right or wrong answers. I want to know about your experiences and how you felt. I have some questions to help us. Some of them may sound unusual because they ask about your experiences –the questions are not made to try to trick you– if you do not understand, let me know, and I will ask the question differently. They start by asking about you, then they ask about the diagnosis, diabetes, living well and coping. This is just a guide, it is important that you talk about what is important to you, your experiences and feelings. The interview will probably not last longer than an hour – but that depends upon how much you talk! If you need a break or a rest then please let me know. I want you to be comfortable. Just like it says in the participant information sheet – if you wish to stop the interview at any point please let me know.

1) Something about you

1.1 Tell me about yourself and your family (who lives with you in the family home?)

- Prompts:
- What are you interested in?
 - What do you enjoy doing in your spare time?
 - What are you good at?
 - What about school / college?
 - Are there others in your family with diabetes?

2) Diagnosis and your diabetes

2.1 Can you tell me, in your own words, what is your understanding of diabetes?

2.2 What do you remember about being told you have diabetes?

- Prompts:
- How old were you at the time?
 - What was that like?
 - How did that feel?

Can you give me an example of that?

2.3 How did you feel about the diagnosis at the time you were diagnosed?

(or at the time when you remember being told that you have diabetes)

2.4 How did your diabetes affect you, when you were first diagnosed?

(Physically, emotionally, socially & psychologically) ask as separate questions

(At home, school & with friends) ask as separate questions

2.5 How did that change over time?

2.6 Have you had any particular health problems related to your diabetes, since you were first diagnosed?

3) Living well with diabetes

3.1 Can you tell me what it is like for you, having diabetes?

3.2 Please talk me through a typical day, from when you get up in the morning to when you go to bed at night.

Prompts: What is that like?

How does that feel?

Can you give me an example of that?

3.3 What does the idea of living well mean to you?

Prompt: how would you describe someone who is 'living well'?

Think of someone you would describe as living well – how would you describe them?

3.4 Tell me how you are able to manage your diabetes and live well (achieve your goals...).

Prompts: What do you do in order to achieve that (living well) (i.e. achieve managing your diabetes and living well with it)? Give examples.

3.5 How does it actually feel to be living well with your diabetes? (How does it feel physically emotionally, psychologically, socially, behaviourally ?) ask as separate questions

Prompts: How did you learn to do that? Give examples

What helped most in learning to live well? Give examples

3.6 Who helped or helps you to learn how to live well with diabetes? How did/do they do that?

4) Coping / resources

4.1 What qualities or strengths do you have that helped you live well?

Prompts: What is it about you that means you have been able to live well?

Give me some examples

4.2 What would your parents/carers/ brothers or sisters/ teachers/ friends say your strengths / qualities are?

4.3 What were the worst (most difficult or challenging) bits of your journey to living well?

4.4 How did you manage to get through those worst bits of your journey to living well?

Give examples

4.5 What advice would you give to other young people to help them manage? {and/or what advice would you give to others that might struggle to live well?}

4.6 Tell me about your main sources of support?

Prompts: Who are they?

In what way are they supportive?

What do they do to be supportive?

Anything else

Is there anything else that you would like to say?

Is there something that I have not asked about and you thought that I might have asked some question about that?

Have I missed anything that you feel is important?

Neutral prompts:

Can you tell me some more about that?

Please could you say more?

Please could you give me an actual example of that?

Tell me about a time when...

How did that feel?

Appendix 3

University of Liverpool Sponsorship Approval



Dr Kiemle
Whelan Building
University of Liverpool
Liverpool
L69 3GB

Mr Alex Astor
Head of Liverpool Joint Research
Office

University of Liverpool
Research Support Office
2nd Floor Block D Waterhouse
Building
3 Brownlow Street
Liverpool
L69 3GL

12 July 2016

Sponsor Ref: UoL001214

Tel: 0151 794 8739
Email: sponsor@lv.ac.uk

Re: Sponsorship Approval

"Living well with insulin-dependent diabetes in adolescence"

Dear Dr Kiemle

After consideration by the Chair of the JRO Non Interventional Sponsorship Sub Committee I am pleased to confirm that the University of Liverpool is prepared to act as Sponsor under the Department of Health's Research Governance Framework for Health and Social Care 2nd Edition (2005) for the above study.

The following documents have been received by the Joint Research Office

Document title	Version	Date
Protocol	Version 2	27 th July 2015
Participation information sheet	Version 1	27 th July 2015
Parent / carer information sheet: 13 – 15 year olds	Version 1	27 th July 2015
Parent / carer information sheet: 16-19 years old.	Version 1	27 th July 2015
Participant consent form 16+	Version 2	27 th July 2015
Participant assent form 13-15	Version 2	27 th July 2015
Topic guide	Version 3	No date
Debrief sheet	No Version	No Date

Please note this letter does **NOT** allow you to commence recruitment to your study. A notification of Sponsor Permission to Proceed will be issued when governance and regulatory requirements have been met. Please see Appendix 1 to this letter for a list of the documents required.

If you have not already applied for regulatory approvals through IRAS you may now do so at <https://www.myresearchproject.org.uk/Home.aspx>.

In order to meet the requirements of the Research Governance Framework 2nd Ed 2005, the University requires you to agree to the following Chief Investigator responsibilities:

Appendix 4

Health Research Authority Approval

Page 1

NHS
Health Research Authority

North West - Preston Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 020 71048008

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

27 July 2016

Mrs Gundi Kiemle
Doctorate in Clinical Psychology
Whean Building
Liverpool
L69 3GB

Dear Mrs Kiemle

Study title: 'Living Well' With Insulin-Dependent Diabetes in Adolescence
REC reference: 16/NW/0595
Protocol number: NA
IRAS project ID: 200898

The Proportionate Review Sub-committee of the North West - Preston Research Ethics Committee reviewed the above application in correspondence.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Carol Ebenezer, nrescommittee.northwest-preston@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.



Health Research Authority

Mrs Gundi Kiemle
Whelan Building
University of Liverpool
Liverpool
L69 3GB

Email: hra.approval@nhs.net

31 October 2016

Dear Mrs Kiemle

Letter of HRA Approval

Study title:	'Living Well' With Insulin-Dependent Diabetes in Adolescence
IRAS project ID:	200898
REC reference:	16/NW/0595
Sponsor	University of Liverpool

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

Appendix 5

Recruitment Flyer



Living well with insulin dependent diabetes in adolescence

Version 1 27/07/2015

IRAS ID: 200898

Are you between 13-19 years old?

Do you have insulin dependent diabetes?

Do you feel you are living well with diabetes?

If the answer to all of the above questions is yes... You may be able to help!

As part of a research project, I would like to speak with young people to learn more about how they live well with diabetes...

If you can help, please speak with a member of the team to find out more...

Appendix 6

Participant Information Sheet



Participation information sheet. Version: 2. Date: 31/07/2016
IRAS Project ID: 200898

'Living well with insulin dependent diabetes in adolescence'

Part 1

What is research?

- Research is done to try to answer important questions.

Why is this research being done?

- There is lots of research that says having diabetes is difficult to get used to.
- There is very little research looking at how young people 'live well' with diabetes.
- If you feel that you 'live well' with diabetes, we think you might be able to help.
- The important question we want to look at is:

How do young people manage to 'live well' with diabetes?

We hope to find out the answer to this question so that young people get the best help possible.

Why have I been asked to take part?

- You have been asked to take part because you are between 13 – 19 years old and have insulin dependent diabetes.

Do I have to take part?

- **No.** It is entirely up to you.
- Before you decide to take part, you need to understand more about the study. If you are interested, please read Part 2.

Part 2

It is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask if there is anything that you do not understand, or would like more information about. Please take time to talk to your parents, family, friends and health professionals if you would like to, so that you make the choice that is right for you.

It is important that you know you do not have to take part, you should only take part if you would like to. If you do not take part it will not affect your treatment at the hospital.

What will happen to me if I take part? What will I be asked to do?

If you decide to take part and are able to take part in this study, then you will be asked to meet with me so that I can ask you some questions about what 'living well' with diabetes means to you, and how you manage to live well with diabetes. We can meet at Ormskirk hospital, at the University of Liverpool or at your home. We will usually try to meet you during office hours (9am – 5pm, Monday to Friday); although, we can be flexible so that the timing of the interview does not interfere with your usual commitments.

Whilst there will be some questions to guide the interview, the main aim is to hear from you what is important to you. **There are no right or wrong answers. You can talk for as little or as much as you like. The interview is not likely to last longer than an hour. If you decide to start the interview but then want to stop – you can stop without having to give a reason. You can stop the recording at any time and ask that words are deleted or replaced.**

Is there anything else to be worried about if I take part?

We cannot foresee any risks to your health by taking part. It is unlikely – but you may feel upset when talking about your life - if you do get upset, you will be offered information about how to get further support, and if you would like to continue the interview or stop.

The information that you give will be confidential - this means that it will be private – unless you are at serious risk of harm. If we find out something that we think is important about your health that may be relevant to your care we will talk to your mum, dad or carer. If you are at serious risk of harm, then information will be shared with other professionals.

Will the study help me?

No, but the information we get will help us understand how young people manage to live well and enjoy life, even though they have diabetes. This might help improve the treatment offered to young people with diabetes.

What if I don't want to do the research anymore?

You can stop the interview at any time. You can withdraw from the study up until the information has started to be analysed.

What if there is a problem or something goes wrong?

Tell us if there is a problem and we will try and sort it out straight away. You can either contact the project co-ordinator or chief investigator, their details are at the end.

You can also contact the Patient Experience and Complaints Team, they are independent of the research team. You can contact them at Southport and Ormskirk Hospital NHS Trust, Town Lane, Southport, PR8 6PN. Email: soh-tr.complaints@nhs.net. Telephone: 01704 704958.

Will anyone else know I'm doing this?

The interview will be audio recorded and turned into words to form a transcript (a written record of the interview). The transcript will be analysed to find out how you live well with diabetes. The transcript will be given a pretend name so that no one will know what you have said. All information that is collected about you during the research will be kept strictly confidential. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it.

What happens after? What will happen to the results of the research study?

When the study has finished, we will present our findings to other healthcare professionals in medical magazines, websites and at conferences. The findings will be anonymous, which means that you will not be able to be identified from them. If you would like, we can send you a brief summary of the findings. The results will also be included as part of the main researcher's educational qualification.

Who is organising and funding the research?

The research is part of the main researcher's qualification and is paid for by the NHS. No one will get any extra money for doing this research.

Who has checked the study?

Before any research goes ahead, it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do and that it does

not cause any harm to anyone taking part. This study has been looked at by the University of Liverpool, the local NHS and it has also been checked by the Research Department at this hospital.

How can I find out more about research?

For more information contact Adam Welsh at awelsh@liverpool.ac.uk

If you would like to complain you can contact the project supervisor, Dr. Gundi Kiemle, via email: gkiemle@liverpool.ac.uk.

Appendix 7

Participant Consent Form



Committee on Research Ethics

PARTICIPANT CONSENT FORM

Living well with insulin dependent diabetes in adolescence IRAS Project ID: 200898

Researchers: Adam Welsh, Dr. Gundi Kiemle, Dr. Jen Unwin, Dr. May Ng and Dr. Becky Simm

**Please
initial
box**

1. I have read and understood the information sheet dated: 27/07/2015. I have been given time to think about the information. I have been able to ask any questions that I wanted to and I am happy with the answers.
2. I understand that I must be 16 years old to consent to take part. If I want to take part and I am over 16 then I can make the decision myself and will write my own name at the end of this form.
3. I know that I can decide not to take part and it won't affect the treatment that I get at the hospital. I don't even have to give a reason why I don't want to take part.
4. If I do decide to take part I don't have to answer anything that I don't want to. I can stop at any time and I do not need to give a reason why.

Appendix 8

Assent Form



Committee on Research Ethics

ASSENT FORM

Living well with insulin dependent diabetes in adolescence IRAS Project ID: 200898

Researchers: Adam Welsh, Dr. Gundi Kiemle, Dr. Jen Unwin, Dr. May Ng and Dr. Becky Simm

**Please
initial
box**

1. I have read and understood the participant information sheet dated: 27/07/2016. I have been given time to think about the information. I have been able to ask any questions that I wanted to and I am happy with the answers.
2. I understand that because I am under 16 years old then my parent / carer will give signed consent for me to take part.
I must not take part if I am under 16 and no one is legally able to sign for me to take part.
3. Even though an adult may write their name so that I can take part, I understand that it is up to me to choose if I want to take part or not. Just because my parent or carer thinks that it is a good idea for me to take part, it does not mean that I have to. If I do wish to take part then I can sign this assent form to show that I wish to take part.
4. I know that I can decide not to take part and it won't affect the treatment that I get at the hospital. I don't even have to give a reason why I don't want to take part.

5. If I do decide to take part I don't have to answer anything that I don't want to. I can stop at any time and I do not need to give a reason why.
6. I know the interview will be audio recorded and a trained professional will then listen to the tape and type everything that I have said. The typed sheets will then be analysed to explore how young people 'live well' with diabetes. I know there are laws that mean the information that I give you must be protected. This means that my interviewer will give the information a pretend name so that no one will know that it is me. I could try to help by not mentioning my details, other than my first name, in the interview.
7. I know that I must not take part if I do not feel well or if I am in local authority care or if I have significant mental health problems. I must be able to speak English.
8. The interviewer will ask about how I live well with diabetes. If I happen to get upset, I understand that you care about my welfare and together we will make a decision about whether or not to stop the interview. It might be that you decide that it is in my best interest to stop the interview and I will respect that.
9. In the interview, if I say that I am unhappy with my treatment my parents will be told to contact the hospital patient advice and liaison team. If I say that I am being hurt by someone or I have hurt others, or I am taking part in serious crime, I understand that this information will be shared with other professionals. If I say that I am behaving in a way that may cause serious harm to myself, like not managing my condition, this information may also be shared with my healthcare team. Such decisions will be made in my best interest.
10. I am aware that I can contact the student researcher, Adam Welsh, to request a summary of the results.
11. I agree to take part in the above study.

_____	_____	_____
Participant Name	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Principal Investigator:
 Dr. Gundi Kiemle
 Doctorate in Clinical Psychology Training Programme
 Whelan Building University of Liverpool
 Liverpool
 L69 3GB
 Tel: 0151 794 5877/ 5534
g.kiemle@liverpool.ac.uk

Student Researcher:
 Adam Welsh

awelsh@liv.ac.uk

Version 3. 31/07/2016.

Appendix 9

Parent Information Sheet 13-15 Year Olds



Parent / carer information sheet: 13 – 15 year olds

Version: 2. Date: 31/07/2016 IRAS Project ID: 200898

'Living well with insulin dependent diabetes in adolescence'

We would like to invite your son/daughter to take part in our research study.

This study is interested in the experiences of young people aged 13-19 who have insulin dependent diabetes. Your son/daughter has been asked to take part because they are aged 13-15 years old, have insulin dependent diabetes, and are legally unable to provide informed consent for themselves.

Before you decide if they can take part, we would like you to understand why the research is being done and what it will involve. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the research?

There is lots of research that says having diabetes is difficult for young people to get used to. There is very little research looking at how young people 'live well' with diabetes.

If you feel that your son/daughter is able to 'live well' with diabetes they may be able to help us. We want to find out more about how young people manage to 'live well' with diabetes.

Why has my son/daughter been asked to take part?

Your son/daughter has been asked to take part because they are aged 13-15 and have insulin dependent diabetes. Legally, they are unable to consent for themselves, therefore, you must be their parent or legal guardian and, if you would like them to take part, sign the consent form.

Do they have to take part?

No. It is entirely up to you and your son/daughter. Before you decide that your son/daughter can take part you need to understand more about the study.

It is important that you know your son/daughter does not have to take part, they should only take part if you would like them to. If they do not take part it will not affect their treatment at the hospital.

What will happen to my son/daughter if they take part? What will they be asked?

If you decide you wish for your son/daughter to take part (and they are able to take part in this study), then you will be asked to meet with me so that I can interview them. The interview could happen at the hospital (Ormskirk), at the University of Liverpool or at your home.

So that your son/daughter can talk freely it is planned that they will be interviewed alone – with your permission.

In the interview I will ask them questions about what 'living well' with diabetes means to them, and how they manage to live well with diabetes. Whilst there will be some questions to guide the interview, the main aim is to hear from them what they believe is important. There are no right or wrong answers. They can talk for as little or as much as they like. The interview is not likely to last longer than an hour. If they decide to start the interview but then want to stop – they can stop without having to give a reason. They can stop the recording at any time and ask that words are deleted or replaced.

Is there anything else to be worried about if they take part?

We cannot foresee any risks to your son's/daughter's health by taking part. It is unlikely – but they may feel upset when talking about their life - if they do get upset, they will be offered information about how to get further support, and if they would like to continue the interview or stop. At the end of the interview there will be a 'debrief' and we will ask you to join us at that point. The 'debrief' will be a short conversation to discuss how your son/daughter found the interview and to make sure that they are OK. All participants will be given a debrief information sheet – this has useful telephone numbers for the hospital, and other telephone numbers and websites so that further support is available.

The information that your son/daughter offers will be confidential - this means that it will be private – unless they are at serious risk of harm. If we find out something that we think is important about their health that may be relevant to their care we will discuss this with you in the 'debrief'. If they are at serious risk of harm, then information will be shared with other professionals.

Will the study help my son/daughter?

No, but the information we get will help us understand how young people manage to live well and enjoy life, even though they have diabetes. This might help improve the treatment offered to young people with diabetes.

What if I don't want my son/daughter to be part of the research anymore?

Your son/daughter can stop the interview at any time. You can withdraw them from the study up until the information has started to be analysed.

What if there is a problem or something goes wrong?

Tell us if there is a problem and we will try and sort it out straight away. You can either contact the project co-ordinator or chief investigator, their details are at the end.

You can also contact the Patient Experience and Complaints Team, they are independent of the research team. You can contact them at Southport and Ormskirk Hospital NHS Trust, Town Lane, Southport, PR8 6PN. Email: soh-tr.complaints@nhs.net. Telephone: 01704 704958.

Will anyone else know my son/daughter is taking part?

The interview will be audio recorded and transcribed (a written record of the interview). The transcript will be analysed to find out how young people live well with diabetes. The transcript will be given a pretend name so that no one will know what your son/daughter has said. All information that is collected about your son/daughter during the research will be kept strictly confidential. Any information about your son/daughter that leaves the hospital will have their name and address removed so that they cannot be recognised from it.

What happens after? What will happen to the results of the research study?

When the study has finished, we will present our findings to other healthcare professionals in medical magazines, websites and at conferences. The findings will be anonymous, which means that your son's/daughter's details will not be able to be identified from them. If you would like, we can send you a brief summary of the findings. The results will also be included as part of the main researcher's educational qualification.

Who is organising and funding the research?

The research is part of the main researcher's qualification and is paid for by the NHS. No one will get any extra money for doing this research.

Who has checked the study?

Before any research goes ahead, it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do and that it does not cause any harm to anyone taking part. This study has been sponsored by the

University of Liverpool, and approved by the local NHS and the Research Department at this hospital.

How can I find out more about research?

For more information contact Adam Welsh at awelsh@liverpool.ac.uk

If you would like to complain you can contact the project supervisor, Dr. Gundi Kiemle, via email: gkiemle@liverpool.ac.uk.

Appendix 10

Participant Debrief Sheet



IRAS Project ID: 200898

Living well with insulin dependent diabetes in adolescence. Version 1 27/07/2015

Participant debrief sheet

Thank you for taking part. We really appreciate you giving up your time to talk to us. We hope that you are feeling alright, now that we have come to the end of the interview. Please let me know if you are not feeling well right now.

We would like you to know that if you have any questions about the research study, you can contact Adam Welsh at awelsh@liverpool.ac.uk

If you would like to complain, you can contact the project supervisor, Dr. Gundi Kiemle, via email: gkiemle@liverpool.ac.uk.

For further support, please see your named worker from the hospital:

You can contact them on:

You can also visit the following websites:

The NHS: www.nhs.uk/Conditions/Diabetes

Diabetes UK: <https://www.diabetes.org.uk>

Diabetes UK also have a Careline so that people can telephone. The Careline is a support helpline for anyone with diabetes, their friends, family and carers.

Telephone: 0345 123 2399 (Monday to Friday, 9am–7pm).Email:

careline@diabetes.org.uk

Other helplines are:

Young minds. Info line: 0300 123 3393. Text: 86463 (Monday to Friday, 9AM-6PM)

Samaritans. Freephone: 116 123. (24 hours a day). Email: jo@samaritans.org.

Appendix 11

Excerpts from reflexive journal

Except One

January 2017

Following the first interview with Amber:

It was a pleasure to meet with Amber. She seemed really keen to be interviewed and wanted to contribute to the research as much as possible. This left me wondering if the recruitment strategy (posters in waiting areas – seeking participants who self-identify as living well) may mean that a certain ‘type’ of person (i.e. confident, sociable and outgoing) may be more likely to come forward to participate. Interestingly, Amber asked – “is it OK to mention the times when it isn’t good?”. This made me realise that although she feels that she lives well, there are times when it is still very tough, and that she wishes to talk about these issues too.

I was struck by Amber’s maturity, she seemed really organised and I remember thinking that she will definitely come to the appointment to be interviewed. She had a unique style and obviously took pride in her appearance. She was achieving all that she wanted to achieve, she valued her family, friends, good college, partner, work, driving and leisure opportunities such as hobbies and interests (music, guitar). She accepted the condition, was positive, looked forward to her future, she seemed perfectionistic and was compassionate. She seemed highly socially skilled and appeared to be very intelligent, thoughtful and articulate. Although she described how she was able to live well, it was not overly positive and it did not feel for my benefit or as though she was trying to impression manage – it felt very genuine. She was able to acknowledge the distress – there was an acceptance of the diabetes and the distress – and an acceptance that it was ok to have tough times – she would be compassionate to herself – she would sit and cry and believed that this was healthy. She was able to pick herself up and

to have a certain mind-set and use cognitive skills. My overall impression was that she was inspirational. I remember thinking that she should speak at a conference to enthuse staff and inspire other young people. I need to be aware of how positive and inspirational Amber's story was to limit the impact on the analysis.

Excerpt two

Following supervision after the interview

February 2017

I was apprehensive about the interview guide and my interview technique, and for these reasons I wanted to discuss my interview technique in supervision. The interview and good interview technique is vital to generating data, and I did not wish to lead the participant. I wanted the participant to be able to be open and honest regarding their experiences. During the first interview, on occasions, I answered my own question, as well as offering some interpretation during the interview – this is something I need to be mindful of in future interviews. On the whole the interview was data rich, although, this may be because of what Amber brought to the interview.

Excerpt three

Analysis

March 2017

I have really enjoyed immersing myself in the data analysis; although, it has been a real challenge finding the right level of interpretation. I felt confident capturing the phenomenon

of living well but struggled to put 'my stamp' on it. With this, there is a risk of simply describing the data and thus risks not being IPA, as there will be a lack of 'I' – the interpretation. I have found this to be a real stumbling block. I feel that I have made some progress by stepping back from the data and the person (as I interviewed them and built a relationship with them) and this helped me - in some respects this is similar to offering an 'interpretation' clinically – throughout assessment, formulation and intervention. It is difficult as I want to 'get it right', but this is influenced by positivist assumptions rather than the interpretivist approach that I am using. Yardley's (2008) framework offers some clarity regarding what quality looks like in qualitative research.

Appendix 12

Emergent Themes Text Descriptive Comments Linguistic Comments Conceptual Comments

<p>A life with restrictions.</p> <p>Self-limiting to avoid limitations.</p> <p>Always having to be in control.</p> <p>Taking personal responsibility for blood glucose control.</p> <p>Only I can give myself the care that I need.</p>	<p>A: We just go out for food sometimes and arrange things like, we also like to go to concerts, going to events, or just go out for a night out.</p> <p>I: OK, brilliant, and err, are you in a relationship with anybody?</p> <p>A: I am yeah, I have been going out with somebody for four months now.</p> <p>I: so you are in a relationship with a partner... is there anything that we have not mentioned about you, it sounds like we have covered everything, so you are in a relationships with somebody, you live at home with sister, mum and dad, you have lots of varied interests, you are at college, you like going out eating, socialising – you are 18, so I suppose, we have not mentioned alcohol?</p> <p>A: I am Yeah. I know, yeah, I feel like with diabetes, I can drink, but I know my limits, I will have a couple or I will know not to ever kind of get too crazy with that.</p> <p>I: OK.</p> <p>A: I always like to remain sober enough so that I can still check my sugars and look after myself, independently.</p> <p>I: Ok, Yeah, Brilliant, anything, so yeah that's just really interesting, in terms of your age, and being aware of where you are at, and what's happening in your life. Is there anything else that you think <u>its</u> important for me to know, that we have not sort of mentioned, in terms of me getting to know you?</p>	<p>In a relationship</p> <p>I can drink</p> <p>Remain sober</p> <p>Theme – why can't I be normal – in the context of social comparison – society and cultural norms</p>	<p>Alcohol</p> <p>Have a couple</p> <p>'know my limits</p> <p>'Know not to ever get too crazy</p> <p>Look after myself</p> <p>Independently</p>	<p>I have just noticed all of the words/statements below: trying to be the best person that she can be: is it too good to be true? Strict moral code? I wonder if part of her wants to go crazy? ?impression manage</p> <p><u>Sensible and responsible</u></p> <p><u>I can...</u></p> <p><u>Balance / restriction</u></p> <p><u>Self – care</u> <u>Health</u> <u>Responsibility</u> <u>Independence</u> <u>values health</u></p>
--	---	---	---	--

<p>Others don't understand and can't help.</p> <p>Being in control as a strategy to manage anxiety and reduce the risk of life changing consequences and death.</p> <p>A life with restrictions, rules and routine. Preoccupied with control.</p> <p>Understanding restrictions as a positive enabler to improve health.</p> <p>The paradox of managing the condition.</p> <p>The dynamic nature of IDDM.</p> <p>Taking the good days with the bad days.</p>	<p>A: Yeah, I feel as though living with diabetes, cos I am 18, and a lot of my friends go out, so erm, I know its quite the norm to go to clubs and everything, which I do, and I feel as though my diabetes never stops me from doing, erm, but I feel as though sometimes the only impact that can have, is the drinking or the taking of yourself, I always try not to drink too much or if I have a couple of drinks I will always know when to stop. <i>strict/rigid rules - independence/responsible/discipline - rules to promote safety - without such rules I might 'go crazy' - pre-occupied with control - hypervigilance is theme that develops later - fear of being out of control</i></p> <p>I: OK</p> <p>A: But always try and look at that as a positive thing, because, by controlling what I drink, if I do ever drink anything, I know not to kinda go over my limits, so, it is healthy for my body as well, I just kind of have to look at it that way.</p> <p>I: Erm, so if we move on a little bit then and talk about, erm, diabetes, erm - so what is your understanding - so it is type 1 insulin dependent diabetes - to give its sort of full long title - so what's your understanding of that?</p> <p>A: Well, I was diagnosed when I was 9 years old so I have had quite a long, you know I have had quite a few years to grasp what it is all about. Erm, for me it is kinda just controlling my blood sugar levels, so that it the main aim for me, so that my sugars remain normal, if that's the right word, they say between 6-10, but I always found diabetes is really hard to get it between them perfect</p>	<p>Socially</p> <p>Friends go out</p> <p>Norm - normal</p> <p>Diabetes never stops me...</p> <p>Impact...</p> <p>Previous themes of taking care of self, health, limitations/limits</p> <p>If I do ever drink anything - does she drink?</p> <p>Positive</p> <p>Controlling drink is a good thing</p> <p>Had it a long time</p> <p>Knowledge and confidence</p> <p>Simple vs complex</p> <p>Some days hypo - some days hyper / good days vs bad days</p>	<p>quite the norm to go to clubs - what is normal - influence of family, friends, and culture what is socially acceptable</p> <p>view - I have to look at it I have to look at it that way - like a rule - always</p> <p>'grasp what it is all about'</p> <p>Just controlling my blood sugar levels</p> <p>Normal</p> <p>I have to try to control that</p> <p>'I do find it hard'</p>	<p>? state or trait - parents?</p> <p>Diabetes never stops me</p> <p>Health</p> <p>Self-care</p> <p>Limits</p> <p>Positive</p> <p>Benefit to diabetes</p> <p>Healthy for my body</p> <p>9 years old - development, identity - death</p> <p>Knowledge</p> <p>Confidence</p> <p>Simple - controlling blood sugar levels or really hard</p>
--	--	--	---	--

<p>Confidence and knowledge increased via experience over time. Learning to live well.</p> <p>Because I am worth it</p> <p><u>Rules and routine to keep me healthy.</u></p> <p>Having to make sensible choices.</p> <p><u>The challenges of keeping on top of the daily self-care tasks.</u></p> <p>Diabetes as a dark cloud over me.</p> <p>Longing to be normal.</p> <p>Comparing yourself to normal people.</p>	<p>numbers. <u>Keeping on top of it – day to day tasks:</u> So I will have some days when I have hypo's and I have to try to control that by having snacks or trying to do less, or some other meal, and then there are others days, sometimes when for no reason, sometimes it might just be something that my body is doing it will go very high and then I will have to do more insulin or watch what I eat, so there is that aspect of it, so I have to just find a balance between diet and exercise and taking insulin, I do find it quite hard sometimes but I do have to always look at it, (as though) to keep my body healthy, so you know, it is always worth it I just have to stick to it, you know not eat too much, and trying to regulate my insulin if I do do things that are, for example, if I have a massive slice of cake then I will need more insulin or if my blood sugar is already high then it is probably more sensible not to have the slice of cake – I think that is sometimes where the restrictions can kick and with things like alcohol as well I always just have to watch everything and just kind of balance everything out in my life.</p> <p>I: So what's that like then – the restriction side of things? I get the impression that you are saying to me that you have a really good understanding of being in tune with your body where you are physically and almost, sort of, balancing everything, and that there might be times that to take good care of yourself, to prioritise your physical health, you make a choice whether you have that big slab of cake or not, and sometimes to eat that big slab of cake may be ok you can increase your insulin but there might be times, where at the back of your mind, on a day where your blood sugars are already high, it might be a bit of a</p>	<p>Monitoring Always there - aware Dynamic and changing</p> <p>Theme – positive mind-set have to always look at it, to keep my body healthy, to stick to it, it is always worth it – previous theme of self-control – I wonder if there are times when it is not worth it – QoL issues</p> <p>Sometimes no reason – my body</p> <p>If I do do things [that I know I shouldn't] – like eat cake</p>	<p>'I do have to always look at it' – like a rule</p> <p>It is always worth it – I just have to stick to it</p> <p>'keep my body healthy'</p>	<p>– to get it between those perfect numbers</p> <p>Balance – diet, insulin and exercise</p> <p>Limitation / choice / sensible</p> <p>Monitoring and balancing =?conflict</p> <p>Restrictions / limitations ?anxiety ?stress</p>
--	--	--	---	--

<p>Being dependent upon insulin to feel well.</p> <p>Loss of freedom.</p> <p>Other people don't worry about what they eat or drink.</p> <p>Paradox of managing the condition (difficult but liveable).</p> <p>Knowledge and knowing what to do, and then doing it facilitates good health.</p> <p>The importance of having a Positive mind-set.</p>	<p>restriction, because you would be telling yourself - I know I shouldn't have that – what is that like?</p> <p>A: <i>Its</i> quite difficult at times, but I always feel as though, if it's like a birthday or everyone going on a night out, it can get quite annoying, and there have been times when I have got upset over it, because, <i>erm</i>, <i>its</i> hard to kinda see, you can't really say normal people, but to see people without diabetes kind of, they can drink what they want an not have to worry if their sugars are going to go crazy, or, they can eat whatever they want and then not have to worry about the effects of that, so If I ever ate without doing my insulin, my sugars would go very high and I would feel really unwell, <i>erm</i>, so <i>its just important to keep on top of that and keep myself healthy</i>. It can get, it is always easier said than done as well, like actually doing it (Laughs)...</p> <p>I: That makes sense.</p> <p>A: It does get hard sometimes but it is 'livable', you can, it is easy to live with if you know what you are doing, it is, it is, <i>erm</i>, trying to think, its difficult but it is manageable if you have the right mind-set, I feel</p> <p>I: OK, there is something around, almost psychologically, you, you, (pause) – so you have mentioned the word mind-set, you feel that it is easier should you have the right mind-set – so what might be the right mind-set then?</p> <p>A: Well I always say, it is always hard to have a positive mind-set about because there are times when I have, you know, I am annoyed with it – why can't I be normal</p>	<p>Social comparison – socially acceptable at birthdays and Christmas to over eat and drink alcohol</p> <p>Difficult, annoying, upset</p> <p>Different</p> <p>See normal people – people without diabetes – eat/drink what they want with no worries</p> <p>No worries</p> <p>Freedom</p> <p>Keep on top of it</p> <p>Feel unwell</p> <p>Easy to live with if you know what you are doing – knowledge</p>	<p>Difficult</p> <p>Annoying</p> <p>Birthday / night out – celebration</p> <p>Normal people</p> <p>No worries</p> <p>Keep myself healthy</p> <p>'easier said than done' – humour / laughs</p> <p>'livable' – life - QoL</p> <p>Mindset – attitude/beliefs/personality</p> <p>?positive mind-set</p>	<p>Social comparison</p> <p>Sugars go crazy – must stay in control</p> <p>Normal people</p> <p>Worry</p> <p>Keep the self-healthy health</p> <p>Dependence on insulin or would feel unwell</p> <p>Knowledge</p> <p>Mind-set</p> <p>Being positive</p>
---	---	---	---	---

<p>Longing to be normal.</p> <p>Mourning the life that I had.</p> <p>Searching for answers for why me.</p> <p>Accept what you can't change and do your best to change what you can change.</p> <p>The challenge to stay motivated to practice good self-care.</p> <p>IDDM as a positive enabler as it makes you more health conscious.</p> <p>Choosing which thoughts to engage with.</p> <p>No knowledge of IDDM prior to diagnosis.</p>	<p>and go out and not have to worry about it – but then I also have the mind-set where I just think you have this condition and its just, and its something that you can't change, so you might as well do what you can and power through. And kind of, see it in a good way cos even though there are restrictions there are positive sides to those restrictions too, like the drinking thing, that is like a positive thing for me, and with other things as well, it does make you more conscious about what you eat, and it makes you more conscious about exercise, so it can make you healthier as a person if you manage it. Erm, which for me, I think that is the mind-set that you have to have. So just think to yourself, right, what can I do to look after myself, and you know you can't change it so you might as well just accept it and live with it.</p> <p>I: Brilliant, and what about the times, when you mentioned there, the times when you have found it quite upsetting, challenging, erm, and I'm interested in that... erm... it might relate... to what it was like when you first told, What was that like?</p> <p>A: It was hard, because, I think because I was so young, I was 9 years old, I didn't really know at all what diabetes was, I just remember losing a lot of weight, but my mum was the one to pick up on that first, because, again, I was just too young to realise because it was my own body, but I remember just being constantly being really thirsty and being really tired, and took an impact when I was in primary school, I would be running around the playground and then I would have to stop because I would just be so out of breath and not know why. So when I was diagnosed, I went to the doctors with my</p>	<p>Manageable with the right mind-set</p> <p>Hard to be positive all of the time</p> <p>Be normal Social comparison</p> <p>Powerless to change – able to harness power to manage the condition accept it</p> <p>understanding the condition – positive re-frame – restrictions – more aware of health – exercise/diet – potential for it to make you 'healthier as a person'.</p> <p>Drinking example</p>	<p>Normal</p> <p>'condition' not illness Accept it</p> <p>'power through' 'Do what you can' – control what you can</p> <p>'See it in a good way'</p> <p>'what can I do to look after myself'</p> <p>'Think to yourself'</p> <p>Too young to realise</p> <p>Could be diabetes</p>	<p>Socially – looking at others – normal – understanding self in the context of others – without diabetes Why me?</p> <p>Mind-set Making sense of the condition Process of adjustment</p> <p>Make you healthier Benefits of diabetes</p> <p>Acceptance - change what you can</p> <p>knowledge Adjustment Journey to living-well Development – maturation dynamic</p> <p>family – mum noticed- mum had knowledge – mum helped</p>
---	---	---	--	--

<p>The age of diagnosis and the associated developmental challenges to understanding the condition.</p> <p>Physical symptoms prior to diagnosis.</p> <p>The transition from health to illness.</p> <p>Nurses offering practical advice and support.</p> <p>Mum as co-regulator of blood glucose.</p>	<p>and being really tired, and took an impact when I was in primary school, I would be running around the playground and then I would have to stop because I would just be so out of breath and not know why. So when I was diagnosed, I went to the doctors with my symptoms, and then they told me that it could be diabetes, they did a blood test and then sent me off to the hospital and when it came back it my sugars where much higher than they should be and from there I just remember being admitted and, erm, I remember a lot of nurses sitting down with me and just talking me through what I had, erm, and saying that from now on I would have to inject myself and do sugars, I mean finger pricks, so that was hard for me, being so young and thinking so ok I have to do needles. When you are that young you just think of a condition with needles, that's what plays on your mind the most. Erm, I think I was too young to realise all of the things that would come with that, having to balance all of your diet and having to kind of control everything. But erm, yep, at the time, just because I was really confused why I had to inject myself and erm my mum obviously knew a lot more about than me, because I was quite young, but as I grew up I kept learning and as I came to clinic I got a lot of help with the nurses they just kept telling me what the best ways to deal with it was.</p> <p>I: I'm just trying to think of all of the themes that you have mentioned, erm, and how long was it that you were experiencing the losing weight and physically, like you would run around and then have to stop, and you were really thirsty - how long where you experiencing that before you went to see your GP.</p>	<p>Diagnosis Physical symptoms – tired, thirst, out of breath, weight loss – have to stop running around Not knowing what it was Mum noticed first NHS Tests – hospital</p> <p>Admitted to hospital Nurses</p> <p>It was hard 'treatment' – inject -needles</p> <p>Play on your mind Too young – to realise – all the things that would come with it</p>	<p>NHS – GP, hospital, nurses</p> <p>Lot of nurses sitting me down and talking me through</p> <p>'from now on'</p> <p>Treatment - needles</p> <p>'playing on your mind'</p> <p>'as I grew up I kept learning'</p>	<p>NHS – GP, hospital, nurses</p> <p>Adjustment – confusion</p> <p>Help Help for nurses advice and guidance – best way to manage it</p> <p>Process of adapting and adjusting – journey Development - Maturation learning</p> <p>Balance and control</p>
--	---	--	---	---

Appendix 13

Emergent Themes from Amber's Transcript

Amber F 18

List of emergent themes - Themes grouped

Family as a secure base	<p>security and stability at home</p> <p>Economic stability at home</p> <p>Belonging to a happy family</p> <p>Close family relationships</p> <p>Mum as co-regulator of difficult emotions</p> <p>Mum as co-regulator of blood glucose</p>
Living the life one wishes to live	<p>A life well-lived with meaningful activities and interest that the person values</p>
Personal characteristics that appear to promote living well	<p>Trying to be a positive person</p> <p>The importance of having a positive mind-set</p> <p>Taking personal responsibility for blood glucose control</p> <p>A determination to independently manage the condition</p> <p>Proactive response to diagnosis – accepting the condition, learning more about it and a personal zeal to manage it</p> <p>Being goal orientated and target driven as a positive enabler for good blood glucose control</p> <p>Self-awareness and an improved understanding of the self</p> <p>Taking personal responsibility for living well</p> <p>Self- belief to live the life one wishes to live</p> <p>Doing everything one can to stay healthy</p> <p>Valuing and respecting the self: Self-esteem, self-worth and self-care</p> <p>Perfectionism as a positive enabler for good glucose control</p>
An extensive repertoire of coping strategies and skills	<p>Accept what you can't change</p>

Do your best to change what you are able to change
 Choosing what thoughts to engage with
 Focusing upon the positives one has in their life
 Focusing upon one's existing achievements
 Focusing upon the positive rather than the negative
 Feeling part of the diabetic community
 Thinking that you are not the only one with diabetes
 Thinking of people less fortunate as a coping strategy
 Looking up to inspirational others demonstrates that
 Believing that anything is possible
 Putting on a front as a coping strategy
 Expressing negative emotion as a coping strategy
 Distraction as a coping strategy
 Avoidance as a coping strategy
 Gratitude as a protective factor

**The prime importance of social
 Relationships and social activity**

Friend's promoting resilience via their acceptance of the
 person and the diabetes
 Relationships with other people with diabetes

Learning to live well

Learning to live well from experience
 Learning to live well by doing
 Knowledge and knowing what to do, and then doing it
 facilitates good health
 The dynamic nature of IDDM
 Taking the good days with the bad days

Transition from health to illness

Mourning the life a person had prior to diagnosis
 The emotional impact of IDDM
 No knowledge of IDDM prior to diagnosis
 The age of diagnosis and associated developmental
 challenges to understanding the condition

	Fear of negative appraisal from peers due to diabetes
	Denial, avoidance and silence to cope in the early stages of diagnosis
	Fear of standing out due to diabetes
	Physical symptoms prior to diagnosis
	Adjusting to the condition
Diabetes never stops me	Diabetes management becoming routine
Related to later theme:	Understanding diabetes as a condition not an illness
Paradox of IDDM	Wanting to lead a healthy lifestyle
	Putting the diabetes in the context of what is important in life
	Anything is possible as long as diabetes comes first
	Diabetes comes first and you can achieve anything
	Diabetes does not stop the person – because they stop themselves
Confidence	Confidence increase over time
	Self-confidence as a positive enabler for good blood glucose control
	‘opening up’ about diabetes improves confidence
	Talking to other about diabetes to educate them
	Talking to others to increase empathy
	Practicing self-care in front of others to boost confidence
The perks of IDDM	The physical benefits of being in good glucose control
	IDDM as positive enabler as it make you more health conscious
	Understanding restrictions as a positive enabler to improve health
	Diabetes as a catalyst to personal maturity
	Special treatment because of diabetes
The challenges of keeping on top of the daily self-care tasks	The challenge to stay motivated to practice good self-care

A life with restrictions, rules and**Routine**

A life with restrictions

Self-limiting to avoid limitations

Having to make sensible choices

Rules and routine as a positive enabler to stay healthy

Diabetes is something that needs caring for

The paradox of managing the**Condition (difficult but livable)**

Diabetes as a condition that limits achievements

IDDM means you sometimes miss out

Diabetes as a dark cloud over the**Person**

Longing to be normal

'I'm different'

Searching for answers – why me

Fear of missing out

Negatives appraisal of one's life in comparison to others who are normal

Dodging death

realising that one is mortal

Diabetes as a threat to physical health

Fighting the risk of life changing complications or death

Diabetes as a ball and chain /**Imprisoned by diabetes**

Loss of freedom

The fear of life changing complications as a motivator for good diabetes management

Perpetual anxiety regarding managing blood glucose

Always having to be in control

Staying in control to limit risks and stay safe

Pre-occupied with control

Being in control as strategy to manage anxiety and reduce risk of complications, and death

One must be prepared at all times

**Lack of understanding from the
general public**

The general public as uneducated and ignorant regarding diabetes

people that don't have diabetes do not truly know what it is like

you don't know about diabetes until you have it

The general public would be inept if one was to become Unwell

The general public are judgemental regarding IDDM

The intolerance of others

IDDM as an invisible condition

Public situations as a barrier to self-care activities

The challenges of managing IDDM

in school

Exam pressure and stress and the impact on blood glucose

Bullying

Identity

Accepting the condition as part of the self

Diabetes as accepted and integrated as part of the self

The person feeling that only they can give themselves the care that they need

Being depended upon insulin to feel well

Stress influences blood glucose

The importance of good engagement with healthcare services - Nurses offering practical advice and support