An exploration of the relationship between insulin misuse and eating disorder psychopathology in adults with type 1 diabetes

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March 5th, 2019

33,296 Words

LIST OF TABLES AND FIGURES

LIST OF APPENDICES

Abstract for Thesis Portfolio

Insulin misuse in type 1 diabetes is frequently reported in the literature and is associated with poor health outcomes. The reasons for this behaviour have been under-researched; however, weight control and disordered eating are frequent themes. Little research has explored this in type 1 diabetes specifically, and most have focused on the experiences of females and adolescents. The research aims of this project are: 1. To critically review, assess, and evaluate whether insulin misuse for the purposes of weight loss or control is reported by males with type 1 diabetes and to what degree; 2. To explore the relationships between insulin misuse and gender, eating disorder psychopathology, body shape satisfaction and diabetes-related distress.

A systematic review was carried out to investigate insulin misuse for weight purposes amongst males with type 1 diabetes, and the prevalence of this. The evidence suggested that males report misusing insulin for weight purposes when assessed using self-report measures, but do not report this during clinical interviews. Prevalence rates could not be established from the studies included in the review due to the heterogeneity of the measures used.

An empirical study was carried out using a cross-sectional self-report design, and 219 completed datasets were included in the analysis (78% female). Insulin misuse was common, with women significantly more likely to misuse insulin than men. Those who had a current or historical diagnosis of an eating disorder were more likely to misuse insulin for weight loss or control than those with no history of an eating disorder. People who reported insulin misuse had significantly higher levels of disordered eating behaviours, more negative feelings about body shape and

greater degrees of diabetes-related distress. Diabetes-related distress was the only predictor of insulin misuse.

Theoretical and clinical implications are identified and recommendations for further research are discussed.

Acknowledgements

I would firstly like to thank the diabetes community for being the most supportive and helpful group of people to work with. You have all been an inspiration to me and have taught me so much about the realities of living with diabetes. I am so grateful to each and every person who participated in this study, but also to those who retweeted and shared the link to my study to such a wide audience.

Thank you to my research supervisors, Dr Sian Coker and Dr Bonnie Teague, for introducing me to this topic and supporting me through the long process of getting from an idea to a thesis. Your guidance and expertise have shaped my future career. Thanks to my fellow trainees, whose empathy, humour and support made this journey so much easier. Thank you to my friends and family, particularly my mum, for your patience and willingness to listen to me offloading, and for being understanding of the times when I dropped off the radar! And finally, thank you to my amazing husband, without whom I could never have made it through this process.

Introduction to Thesis Portfolio

This thesis portfolio consists of two main papers: a systematic review and an empirical paper, exploring insulin misuse in people with type 1 diabetes. A bridging chapter links these two papers. Extended Methods and Results chapter are included to provide further information, and a Discussion and Critical Evaluation chapter considers the wider implications of both the systematic review and the empirical paper.

Diabetes is a serious illness that places a significant burden on the NHS. It currently affects about 4.5 million people in the UK. It is currently estimated that about £10 billion is spent by the NHS on diabetes per year (Diabetes UK, 2016). Poor management of diabetes can cause significant physical health concerns, including: cardiovascular disease (Emerging Risk Factors Collaboration, 2010); eye disease (Liew, Michaelides & Bunce, 2014); amputations (Khanolkar, Bain & Stephens, 2008); and nerve damage (Boulton, 2005).

Diabetes may also have a considerable impact on mental health, particularly the impact of coming to terms with a diagnosis, dealing with complex medication regimes, and potential complications and side effects. A large-scale study by Mommersteeg, Herr, Pouwer, Holt and Loerbroks (2013) suggested that people with diabetes are twice as likely to suffer a depressive episode compared with a non-diabetic population, and these episodes may be longer-lasting and reoccur more frequently (Mezuk, Eaton, Albrecht & Golden, 2008).

Broadly speaking, diabetes consists of two types: Type 1 and Type 2 diabetes mellitus. Usually, the pancreas synthesises insulin, a hormone that converts glucose from food into energy for the body. In type 1 diabetes, the pancreas does not produce insulin. This leads to a build-up of glucose in the blood, which is eventually excreted

in urine (Atkinson, Eisenbarth & Michels, 2014). Once diagnosed, a person with type 1 diabetes must administer artificial insulin to regulate their blood glucose levels (National Institute for Health and Care Excellence [NICE], 2015). This is a complex procedure, requiring regular monitoring of blood glucose levels and following a structured insulin-therapy routine (NICE, 2015). Type 1 diabetes is generally diagnosed in childhood and accounts for approximately 10% of diabetes diagnoses (Atkinson *et al.*, 2014).

In Type 2 diabetes, the pancreas does not produce enough insulin (NICE, 2017). It can generally be managed through medication and careful control of diet; however, insulin treatment may be necessary as the disease progresses (NICE, 2017). Type 2 diabetes is typically diagnosed in adulthood, and it accounts for up to 90% of diabetes diagnoses (NICE, 2017).

For people with type 1 diabetes, three main insulin management approaches are used: a twice-daily regimen, multiple daily injection therapy (also known as a basal-bolus regimen) or an insulin pump (NICE, 2015). For those adhering to a twice-daily regimen, a strict routine is required. Although the lower number of daily injections may be preferable, this regimen does not allow for much flexibility. On the other hand, a basal-bolus regimen allows for greater flexibility, but also requires constant monitoring of blood sugar levels and an increased number of daily injections. Insulin pumps provide insulin throughout the day but are not available to everyone with type 1 diabetes under the NHS, with NICE guidelines suggesting that they should be provided by the NHS in the event that blood glucose levels cannot be managed through other means (NICE, 2015).

Research suggests that people with type 1 diabetes do not always adhere correctly to their prescribed insulin regime (e.g. Polonsky *et al.*, 1994; Schober *et al.*,

2011). The reasons for this have not been well-explored to date, although evidence suggests that it may often be related to weight loss or control behaviours (de Paoli & Rogers, 2017), or to the burden of type 1 diabetes on a lifestyle (Ames, 2017; Peyrot, Rubin, Kruger & Travis, 2010). Given that serious health complications, including comorbidities and fatalities, can arise from incorrect management of type 1 diabetes, gaining an understanding of this behaviour is important for health care professionals. Much of the research that has been conducted has been focused on women, and there is a paucity of research that explores men's reasons for poor insulin adherence.

The incidence of eating disorders (defined as the number of new cases diagnosed in a period of time) has increased for both males and females in the United Kingdom between 2000 and 2009, from an age-standardised incidence of 32.3 per 100,000 people in 2000 to 37.2 per 100,000 in 2009 ($p < .00001$; Micali, Hagberg, Petersen & Treasure, 2013). For males specifically, the incidence estimates increased from 5.6 per 100,000 to 7.1 per 100,000 in that time period (Micali *et al.*, 2013). However, the incidence rates of Anorexia Nervosa (AN) and Bulimia Nervosa (BN) remained quite stable for men, but the incidence of Eating Disorder Not Otherwise Specified (EDNOS) increased by 24% (from 3.1 to 4.2 per 100,000). A similar finding was seen for females, with rates of AN and BN remaining steady overall, but rates of EDNOS increased significantly from 17.7 per 100,000 in 2000 to 28.4 per 100,000 in 2009. By 2009, EDNOS was the most commonly diagnosed eating disorder for both males and females (Micali *et al.*, 2013).

Within people with type 1 diabetes, EDNOS has recently been found to be the most common diagnosis of an eating disorder, with 0.8% of females and 0.25% of males with type 1 diabetes diagnosed with EDNOS in a large-scale study (Scheuing *et al.*, 2014). Of note, this study only explored previously diagnosed

eating disorders that reached a clinical threshold and may have failed to account for sub-threshold or undiagnosed eating disorders. Nonetheless, this appears to be an increase in the reported proportion of cases at a given time (i.e. prevalence rates) reported in earlier studies, such as Bryden *et al.* (1999) who reported a prevalence rate of 0.025% for males with type 1 diabetes and comorbid EDNOS, and Fairburn *et al.* (1991) who found no presence of eating disorders in men with type 1 diabetes.

Taken together, these findings suggest that rates of eating disorders are increasing for both men and women, and that there is an increase in eating disorder psychopathology for men and women with type 1 diabetes. However, the available research has tended to focus on the experience of females and adolescents, with limited attention being given to insulin misuse as a method of weight loss or control, and little research exists that explores these behaviours in adults and men with type 1 diabetes.

The systematic review aims to address the gap in the research with regard to the experience of men and seeks to explore the prevalence of insulin misuse in men with type 1 diabetes for the purposes of weight control or loss. The empirical paper takes a broader approach in investigating the reasons for insulin misuse in adult men and women with type 1 diabetes, including exploring links to eating disorder psychopathology and diabetes-related distress, and a specific measure of insulin adherence is included to capture the nuances of the behaviour.

A note on language

The term “insulin misuse” is commonly used in the literature to describe the practice of not taking insulin as prescribed. This can include omitting doses or taking an incorrect dose (either too much or too little). Many people in the diabetes community find this language problematic as they feel it is blaming. This was

highlighted by lay members (Experts by Experience) of the diabetes community at the beginning of participant recruitment for the empirical paper. An amendment was submitted to the Ethics committee to adjust the language in the survey to remove the term “misuse”. However, given the requirement of concise language in published research, particularly when writing for journals with a limited word count, the decision was made to use the term “insulin misuse” throughout the Thesis portfolio, as no suitable concise alternative was found.

Glossary of terms

Diabetic Ketoacidosis. This is a serious medical condition where a lack of insulin means that glucose cannot be broken down for energy, and the body begins to target other body tissues as energy sources. Chemicals called “ketones” start to build up in the body which can be harmful and can ultimately lead to a coma or even death if not treated (Kitabchi & Wall, 1995).

Glycaemic Control. This refers to control of blood sugar levels in a person with diabetes (Herman, 1999).

HbA1c. This is a measurement that reflects an individual’s average blood glucose (sugar) level over the past two to three months, and it is considered the best way of monitoring glycaemic control (Marshall & Barth, 2000).

Hyperglycaemia (“Hyper”). Hyperglycaemia occurs when the blood glucose levels becomes too high. It can be caused by a number of factors, including omitting or taking too little insulin, or eating more carbohydrates than suitable for the insulin dose taken. Physical symptoms include increased urine output, rapid weight loss and dehydration. If serious and untreated, it can lead to diabetic ketoacidosis (Jarrett & Keen, 1976).

Hypoglycaemia ("Hypo"). Hypoglycaemia occurs when the blood glucose level falls too low. This can occur when the correct dose of insulin is not taken in relation to the food eaten or physical activity being carried out. It causes physical symptoms including trembling, sweating, tiredness, feeling hungry or faint and trouble concentrating (Cryer, Davis & Shamoon, 2003).

Insulin adherence. Insulin adherence generally refers to following the prescribed insulin regime correctly (Cramer, 2004).

Insulin misuse. Insulin misuse is an umbrella term that covers all the ways in which an insulin regime may not be followed correctly (Bryden et al., 1999), including insulin omission, underdosing and overdosing (see below).

Insulin omission. Insulin omission is generally understood to mean not taking one or more doses of insulin (Polonsky et al., 1994).

Insulin underdosing or overdosing. This refers to taking too little (underdosing) or too much (overdosing) insulin at a time (Bryden et al., 1999). Insulin underdosing may also be referred to as 'insulin restriction'.

Chapter One

Systematic Review

Insulin misuse for weight control purposes in males with type 1 diabetes: A systematic review

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Word Count: 5,000

This review has been written in accordance with formatting and word count guidance for Diabetes Care (Appendix A)

Abstract

Background

Insulin misuse in type 1 diabetes is a risky behaviour frequently reported in the literature. The reasons for insulin misuse have been under-researched; however, weight control emerges as a common theme in existing studies. There appears to be an association between eating disorders and insulin misuse, but little research has explored this in type 1 diabetes specifically. Previous research has tended to focus on the experience of females, resulting in males being under-represented in the published literature.

Purpose

This review aims to investigate whether males report misusing insulin for weight purposes, and to explore reported prevalence rates for this behaviour.

Data Sources

Multiple databases, including MEDLINE Complete, PsycINFO and Pubmed, were systematically searched.

Study Selection

Sixteen papers were identified that explored adherence to an insulin regimen in a population that included males with type 1 diabetes, where questions were also asked about weight loss or control behaviours.

Data Extraction

Data were extracted, including demographic details, study design, measures and results.

Data Synthesis

Information from the studies was tabulated and a narrative synthesis approach was used to qualitatively summarise the findings.

Limitations

The heterogeneity of the studies, particularly the assessment of insulin misuse, hampered interpretation.

Conclusions

The evidence suggested that males report misusing insulin for weight purposes when assessed using self-report measures, but do not report this during clinical interviews. Prevalence rates could not be established from the studies included in the review due to the heterogeneity of the measures used. Future research should aim to address this.

A diagnosis of type 1 diabetes produces a requirement to adhere to a regimen of insulin administration. Taking insulin as prescribed is generally referred to as adherence. Insulin misuse is an umbrella term that can refer to either deliberately under-dosing, over-dosing or omitting a scheduled dose of insulin (omission) (1). Omission and under-dosing can lead to hyperglycaemia and rapid weight loss may be seen through a combination of dehydration and caloric restriction (2). Due to the severity of the consequences, insulin misuse by people with type 1 diabetes is an area of particular concern for health professionals (3).

Limited research has been carried out into the reasons for which people may misuse insulin. One study found that the majority of insulin users, both males and females, report intentional insulin omission, and it was a common behaviour amongst 20% of these individuals (4). A global study found that 34.6% of respondents had intentionally omitted insulin at least once during the previous month, and men were more likely to omit insulin than women (5). Reasons for omission reported included interference with daily activities, pain and embarrassment related to injections, the perception of insulin therapy as interfering with one's lifestyle, difficulty with injections and frustration with the regimented nature of insulin treatment (4,5). Concerns about weight amongst women were associated with poorer insulin adherence (6). Other reasons for insulin misuse reported in the literature include: forgetting (7); embarrassment (8); emotional distress related to diabetes, avoidance related to fear or anxiety and as an adaptive response to fluctuating blood sugar levels (9).

The comorbidity of eating disorders and type 1 diabetes was first identified in the 1980s (10). Herpertz *et al.* (11) found a point prevalence for eating disorders of 7.9% for female respondents and 2% for males with type 1 diabetes, with an average

lifetime prevalence of 10% across both genders. The study identified that 4.1% of participants reported insulin omission. Nielsen (12) reported that rates of insulin misuse were increased when an eating disorder co-existed with type 1 diabetes. More recently, NICE released guidelines stating "…be alert to the possibility of bulimia nervosa, anorexia nervosa and insulin dose manipulation in adults with type 1 diabetes …" (13).

Insulin misuse for the purposes of weight loss or control has been reported several times in previous research (e.g. 14), and is referenced in the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) (15, p. 314). This practice has been referred to as "diabulimia" (16). However, research is currently very limited, and the area would benefit from further investigation to assess appropriate treatment implications, as standard treatment for eating disorders has been ineffective in reducing rates of insulin misuse (17).

To date, little research has explored the rate of insulin misuse within eating disorder psychopathology in people with type 1 diabetes specifically, and the research that has been undertaken has tended to focus on females. In a recent review (14), 13 studies of 31 (42%) involved only female participants. No studies involved only male participants. Incidence rates of eating disorders in males are increasing (18), and recent research into men with type 1 diabetes and comorbid eating disorders suggests that rates may be increasing compared to earlier research (19–21). Eating disorders in men may have different presentations to those typically seen in females, including a desire for muscularity over thinness (22), so results cannot be generalised across genders (23).

Aims and Objectives

To begin to address the gap in the literature regarding prevalence rates of insulin misuse for weight control or weight loss by men with type 1 diabetes, a systematic review was conducted. This study aims to add to the increasing empirical evidence regarding the misuse of insulin for weight control or loss (henceforth called 'weight purposes' for brevity), in order to improve awareness of this behaviour. This review appears to be the first of its kind as males have been under-represented in the research (14).

The review aims to address the following questions:

- Do men report misusing insulin for weight purposes?
- If so, what are the prevalence rates for this behaviour?

Methods

Data Sources and Searches

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (24) were used to shape a systematic review of literature that investigated insulin misuse for weight purposes in males with type 1 diabetes. A broad search strategy with no historical start date was implemented to maximise the yield of relevant papers. Databases searched included MEDLINE Complete, PsycINFO and PubMed in February and March 2018. The reference sections of relevant articles were screened for further literature that may have been missed. Unpublished research was considered provided the full-text paper was available. The search was restricted to articles available in the English language.

The search strategy is outlined in Table 1.

Table 1

Search Strategy for Systematic Review of Literature

Operator	Search Term	Field	All Databases Searched
AND	insulin misuse OR insulin omission OR insulin underdos* OR insulin adherence	Abstract	MEDLINE Complete Academic Search Complete Complementary Index CINAHL Complete Journals@OVID ScienceDirect Supplemental Index
AND	weight control OR weight loss OR weight manipulation OR weight	Abstract	PsycINFO Directory of Open Access Journals JSTOR Journals British Library EThOS ERIC
AND	type 1 diabetes or t1d OR diabetes mellitus OR juvenile diabetes OR insulin-dependent diabetes	Abstract	SCOPUS Pubmed Proquest American Doctoral Dissertations Child Development & Adolescent Studies eJournals PsychArticles

Eligibility Criteria

Eligibility criteria for inclusion in the review included: a population with type 1 diabetes who were prescribed an insulin regime, in which questions were asked regarding adherence to an insulin regime and weight loss or control behaviours. Studies with a mixed population that included people with type 1 and type 2 diabetes, or both male and female participants, were included, provided that separate analyses of insulin misuse were conducted that clearly identified type 1 male participants. All quantitative designs were considered.

Exclusion criteria included studies that exclusively studied a population with type 2 diabetes or gestational diabetes, due to the different pathophysiology and treatments compared to type 1 diabetes (4), or mixed populations in which analyses were not conducted separately. Studies that focused exclusively on female participants were also excluded. Qualitative and case studies were excluded on the basis of sample size, and review papers were excluded as they did not constitute new research.

Study Selection

The initial search yielded 3312 results, and 20 results identified through hand searching. Following duplicate removal, 949 results were screened against the inclusion criteria. Stage 1 involved screening the title and abstract of the paper for suitability based on the inclusion and exclusion criteria. Articles that clearly did not meet the inclusion criteria were removed ($N = 912$). In the event of ambiguity as to whether the article was appropriate, and for papers who passed Stage 1 screening, the full-text of the article was screened against the inclusion criteria. A further 21 papers were removed. A second reviewer (BT) independently reviewed the full text of the remaining papers against the inclusion criteria, with no disagreements

identified. Sixteen papers were considered eligible for data extraction and included in this review.

Figure 1 depicts this process in more detail.

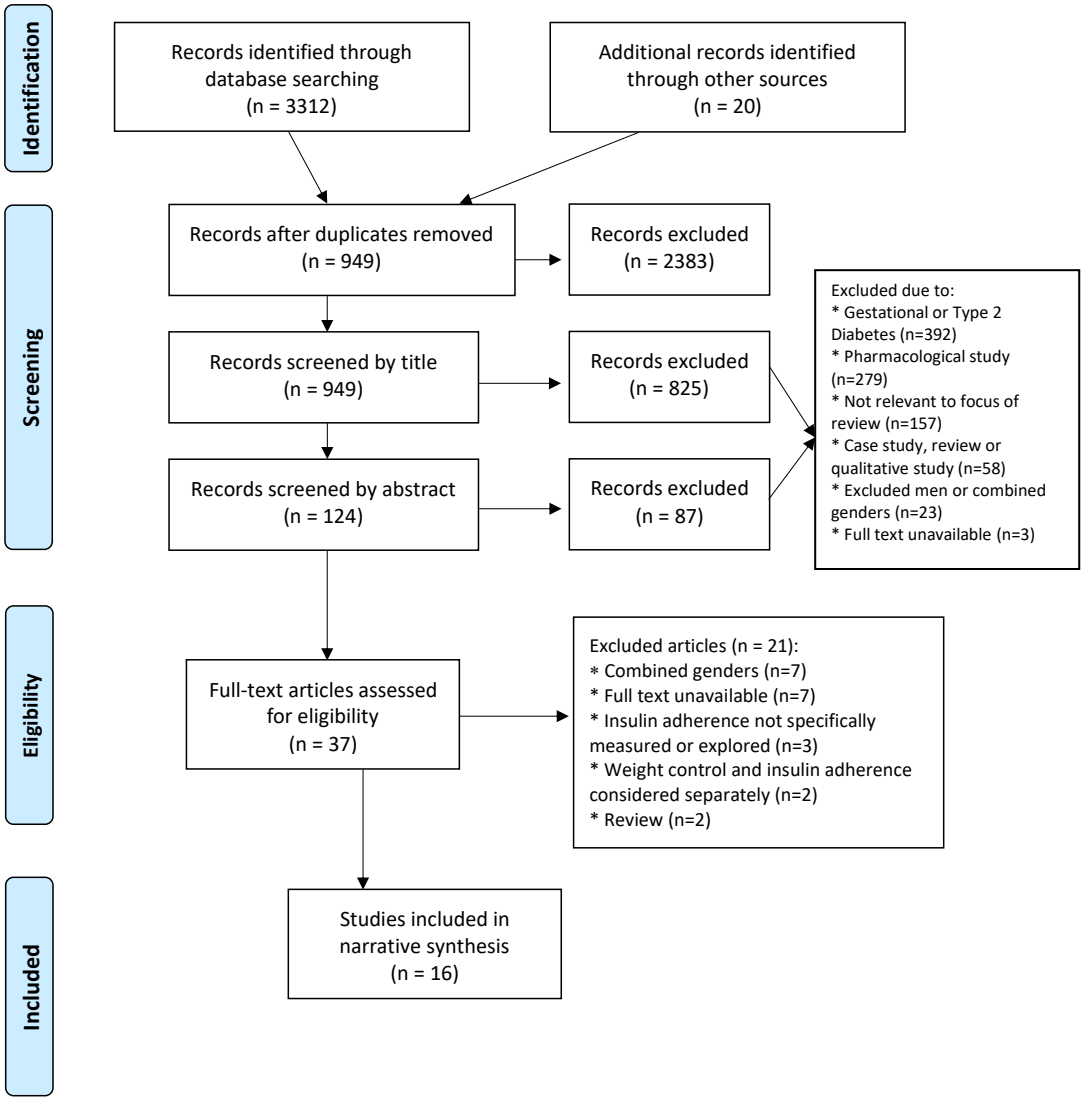

Figure 1. Study selection flowchart, based on PRISMA guidelines (24)

Data Extraction and Quality Assessment

Data were extracted by the first author (VM). Information extracted included demographic details, design, measures and results. A number of pre-existing quality assessment tools were considered, including the Quality Assessment Tool for Quantitative Studies (25). However, none of the tools were a perfect fit for this study, so relevant elements were extracted to create a novel Quality Assessment tool,

tailored specifically for this review. This tool was developed in discussion with SC and BT and subsequently piloted by another independent researcher who assessed a sample of papers using the tool. Two questions were found to be unhelpful in effectively assessing the quality of papers, so were removed and replaced with three new questions. See Supplementary Table 1 for full details of this tool.

A second rater (SC) independently rated 25% of the final studies ($N = 4$) that were randomly selected for the purposes of inter-rater reliability, using the same tool. One minor difference was found in ratings, which was discussed and resolved by amending a rating. See Supplementary Table 2 for full details of the quality assessment ratings.

Data Synthesis and Analysis

Given the heterogeneity of the studies included in this analysis, a meta-analysis was not appropriate (26). Instead, a narrative synthesis was considered suitable, which is a method of qualitatively summarising each study in order to generate an explanation of the findings.

Results

Sixteen studies were included in the final review. Thirty studies were excluded on the basis of combining the genders in the results or for focusing exclusively on female participants (Figure 1). No study was identified that focused exclusively on male participants. Rates of insulin misuse for weight purposes amongst men varied significantly across the included studies, as did the measures used to assess this. Table 2 lists the study characteristics of the included studies.

Supplementary Table 1

Quality Assessment Rating Scale

Category	Is the question or objective sufficiently described?	Was an appropriate study design identified and used?	Are participant characteristics described?	Were the general reliability and validity of measures reported?	How was insulin misuse assessed?	Were the study-specific reliability and validity of measures assessed and reported?	Were results analysed and reported in sufficient detail?	Do results support the conclusions?	Overall Scores
Description of Rating	2 = Yes 1 = Partially 0 = No	2 = Yes 1 = Not clearly identified, or not totally appropriate for the research questions 0 = Design not identified or does not answer research question	2 = At least two characteristics described 1 = One characteristic described 0 = Participant characteristics absent	2 = Yes, both reported 1 = Either reliability or validity reported, or not for all suitable measures 0 = Neither reliability or validity reported	2 = Two or more specific questions 1 = Single question asked 0 = Indirect or non-specific question (e.g. "Have you done anything else to control your weight?")	2 = Yes, both reported 1 = Either reliability or validity reported, or not for all suitable measures 0 = Neither reliability or validity reported	2 = Yes 1 = Partially (some information missing) 0 = No (e.g. reported for subsample only)	2 = Yes, all conclusions are supported by data 1 = Major conclusions are supported by data 0 = Conclusions are not well supported by data	14 - 16: Excellent 11 - 13: Very Good 8 – 10: Reasonable 0 – 7: Poor

Supplementary Table 2

Quality Rating of Included Studies

Authors and Date	Is the research question or objective sufficiently described?	Is an appropriate study design used?	Are general reliability and validity of measures reported?	Description of participant characteristics	Assessment of insulin misuse	Are study-specific reliability and validity reported?	Are results analysed and reported in sufficient detail?	Do the results support the conclusions?	Overall Quality Rating (0 – 16)
Neumark-Sztainer, D., Patterson, J., Mellin, A., Ackard, D. M., Utter, J., Story, M., & Sockalosky, J. (2002)	2	2	2	2	2	2	2	2	16 (Excellent)
Bryden K, Neil A, Mayou R, Peveler R, Fairburn C & Dunger D (1999)	2	2	2	2	2	0	2	2	14 (Excellent)
d'Emden, H., Holden, L., McDermott, B., Harris, M., Gibbons, K., Gledhill, A., & Cotterill, A. (2013).	2	2	2	2	2	1	1	2	14 (Excellent)
Fairburn, C. G., Peveler, R. C., Davies, B., Mann, J. I., & Mayou, R. A. (1991)	2	2	2	2	2	0	2	2	14 (Excellent)
Wisting, L., Frøisland, D. H., Skrivarhaug, T., Dahl-Jørgensen, K., & Rø, Ø. (2013)	2	2	2	2	2	0	2	2	14 (Excellent)

Supplementary Table 2 *continued*

Authors and Date	Is the research question or objective sufficiently described?	Is an appropriate study design used?	Are general reliability and validity of measures reported?	Description of participant characteristics	Assessment of insulin misuse	Are study-specific reliability and validity reported?	Are results analysed and reported in sufficient detail?	Do the results support the conclusions?	Overall Quality Rating (0 – 16)
Peveler, R. C., Fairburn, C. G., Boller, I., & Dunger, D. (1992).	2	2	1	2	2	0	2	2	13 (Very Good)
Bächle, C., Stahl-Pehe, A., & Rosenbauer, J. (2016).	2	2	1	2	2	0	2	2	13 (Very Good)
Baechle, C Castillo, K Straßburger, K Stahl-Pehe, A Meissner, T Holl, R Giani, G Rosenbauer, J (2014)	2	2	2	2	1	0	2	2	13 (Very Good)
Ackard, D. M., Vik, N., Neumark-Sztainer, D., Schmitz, K. H., Hannan, P., & Jacobs, D. J. (2008)	2	2	0	2	2	0	2	2	12 (Very Good)
Araia, E., Hendrieckx, C., Skinner, T., Pouwer, F., Speight, J., & King, R. M. (2017)	2	2	1	2	1	1	1	2	12 (Very Good)

Supplementary Table 2 *continued*

Authors and Date	Is the research question or objective sufficiently described?	Is an appropriate study design used?	Are general reliability and validity of measures reported?	Description of participant characteristics	Assessment of insulin misuse	Are study-specific reliability and validity reported?	Are results analysed and reported in sufficient detail?	Do the results support the conclusions?	Overall Quality Rating (0 – 16)
Falcão & Francisco (2017)	2	2	2	2	2	0	1	1	12 (Very good)
Snyder, L. L., Truong, Y. K. N., & Law, J. R. (2016).	2	2	1	2	2	0	1	1	11 (Very Good)
Wisting, L., Reas, D. L., Bang, L., Skrivarhaug, T., Dahl-Jørgensen, K., & Rø, Ø. (2017)	2	2	2	2	0	0	1	1	10 (Reasonable)
Philippi, S. T., Cardoso, M. G. L., Koritar, P., & Alvarenga, M. (2013)	2	2	1	2	1	0	0	1	9 (Reasonable)
Schober E, Wagner G, Berger G, Gerber D, Mengl M, Sonnenstatter S, Barrientos I, Rami B, Karwautz A & Fritsch M (2011)	1	2	0	1	2	0	0	2	8 (Reasonable)
Grylli, V., Hafferl-Gattermayer, A., Schober, E., & Karwautz, A. (2004)	1	1	2	2	0	0	0	1	7 (Poor)

Table 2

Summary of study characteristics in order of quality

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(21) Bryden *et al.*, (1999) United Kingdom	Adolescents with type 1 diabetes, followed up in young adulthood. All living within the catchment area of the study and all had been diagnosed with type 1 diabetes at least a year prior to the study. *N* at baseline: 76 (43 males). Mean age of males at baseline = 15.2 (*SD* = 2.2) *N* at follow up: 65 (39 males) Mean age of males at follow up = 23.7 (*SD* = 2.1)	Longitudinal study using a clinician-administered semi-structured interview.	EDE interview adapted for a diabetes-specific population*. Custom insulin misuse question*. Measurement of HbA1c	No male participants reported insulin misuse for weight purposes either baseline or follow up.	Excellent
(27) d'Emden *et al.* (2013). Australia	Adolescents aged 13 – 18 recruited at a diabetes clinic. *N* = 124 (58 males). Mean age = 15.4 (*SD* = 1.5)	Cross-sectional self-report written questionnaires.	Youth version of EDE-Q † ED-3 † SDQ † Custom insulin misuse questions †. Measure of HbA1c	15 males (25.9%) reported disturbed eating behaviours on at least one occasion. Of these, two males (3.4%) reported insulin misuse for weight or shape purposes.	Excellent

Table 2 *Continued*

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(20) Fairburn *et al.* (1991) United Kingdom	Young adults in the Oxfordshire region, who had a diagnosis of type 1 diabetes for at least a year prior to the study. *N* = 100 (46 men). Mean age of male participants = 22 (*SD* = 2.2)	Cross sectional design. Self-report questionnaires and a clinician-administered semi-structured diagnostic interview.	EDE* Custom insulin misuse questions*. EAT † Measurement of Hb1Ac	No males reported insulin misuse for weight purposes.	Excellent
(28) Neumark-Sztainer *et al.* (2002) United States of America	Adolescents aged 12 – 21, diagnosed with type 1 diabetes for at least a year and who were followed by a diabetes clinic. *N* = 143 (73 males). Mean age = 15.3 (*SD* = 2.3)	Cross-sectional self-report questionnaires distributed by post to all eligible participants.	Select questions from the following measures: Project EAT (Eating Among Teens) Survey † DEPS (Insulin misuse questions were drawn from this.) † FES-R † DFRQ †	One male participant (1.4%) reported insulin misuse for weight purposes.	Excellent

Table 2 *Continued*

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(29) Wisting *et al.* (2013) Norway	Children and adolescents with a diagnosis of type 1 diabetes. *N* = 770 (380 males). Mean age = 14.6 years (*SD* = 2.1)	Cross-sectional self-report questionnaires distributed manually when participants attended scheduled appointments at diabetes clinics	DEPS-R. Two questions specifically address insulin misuse were used to operationalise the behaviour. † A 12-item Norwegian version of EAT † HbA1c was analysed.	After overeating, 9.4% of males reporting underdosing insulin and 4.5% of males reported omitting a dose. Those who reported omitting insulin had significantly higher HbA1c levels, as well as higher scores on both the DEPS-R and the EAT-12.	Excellent
(30) Peveler *et al.* (1992). United Kingdom	Adolescents with type 1 diabetes selected from the records of a hospital that provided specialist services for the target population. *N* = 76 (43 males). Mean age = 15.2 (*SD* = 2.2)	Cross sectional design. Self-report questionnaires and a clinician-administered semi-structured diagnostic interview.	EQE adapted for a diabetic population* Custom insulin misuse questions. * EAT † Measurement of Hb1Ac	No males reported insulin misuse for weight purposes.	Very Good

Table 2 *Continued*

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(31) Ackard *et al.* (2008) USA	Adolescents with type 1 diabetes for at least one year and followed by a diabetes clinic. *N* = 143 (73 male; 70 female). Mean age = 15.3 (*SD* = 2.3 years).	Cross-sectional self-report paper-based survey.	Custom insulin misuse question in the context of weight control behaviours †	1.4% of males reported omitting insulin in order to lose or avoid gaining weight. 1.4% of males reported not taking insulin as prescribed in order to lose or avoid gaining weight.	Very Good
(32) Araia *et al.* (2017) Australia	Adolescents with type 1 diabetes identified via the national diabetes registry. *N* = 477 (180 males). Mean age = 16 (*SD* = 2)	Cross-sectional nationwide self-report web-based questionnaire.	DEPS-R † BMI-SMT † Custom insulin misuse question †. HbA1c measurement, as reported by participants	26 males (14%) reported omitting insulin on 1 – 3 days over the prior fortnight, and 7 males (4%) reported omitting insulin on 4 or more days of the prior fortnight. 33 (18%) males scored above the cut-off for disordered eating behaviours. It is not clear if there is a relationship between the male participants who scored above the cut-off for disordered eating and those who endorsed insulin omission.	Very Good

Table 2 *Continued*

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(33) Bächle *et al.* (2016). Germany	This study focused specifically on those with "early onset" type 1 diabetes– i.e. onset between birth and 4 years, and who were diagnosed at least 10 years prior to the beginning of the study. 819 participants (414 males). Mean age = 16.3 (*SD* = 2.3)	Population-based, Germany-wide cross-sectional design using postal-based self-report questionnaires.	SCOFF † Custom insulin misuse questions † HbA1c measurement	38 males (9.2%) scored above the cut-off for disordered eating but did not endorse insulin misuse 22 males (5.3%) endorsed insulin misuse but did not score above the cut-off for disordered eating. 8 males (1.9%) endorsed both frequent insulin misuse and disordered eating behaviours.	Very Good
(34) Baechle *et al.* (2014) Germany	Adolescents with "early-onset" type 1 diabetes. *N* = 629 (340 males). Mean age = 15.3 years (*SD* = 1.7)	Population-based, Germany-wide cross-sectional design using postal-based self-report questionnaires.	SCOFF † Custom insulin misuse question † HbA1c measurement	18.5% of male participants reported at least three instances of insulin underdosing within a week, and 6% reported underdosing insulin more than five times per week. Males who scored above the cut-off for disordered eating were significantly more likely to report insulin underdosing than males who did not (p=.018 for > five times per week; p=.003 for ≥ 3 times per week). Males who reported insulin underdosing has significantly higher HbA1c levels than those who did not report insulin underdosing ($p < .001$)	Very Good

Table 2 *Continued*

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(35) Falcão & Francisco (2017) Portugal	Young adults with type 1 diabetes. *N* = 55 (18 males). *M* = 24.78 years, *SD* = 4.18	Cross-sectional self-report questionnaires distributed online by snowball sampling.	EDE-Q † CDRS to assess body image dissatisfaction † Custom qualitative questionnaire regarding insulin misuse †.	No male participants reported misusing insulin for weight purposes.	Very Good
(36) Snyder *et al.* (2016). United States	Adolescents aged 12 – 20 with a diagnosis of type 1 diabetes for at least a year prior to recruitment, attending a diabetes clinic. *N* = 60 (29 males). Mean age = 16.1 (*SD* = 2)	Cross-sectional self-report written questionnaires.	C-DSMQ † Custom insulin misuse questions † Measure of HbA1c extracted from medical charts.	Four male participants (36.4%) reported misusing insulin. Of those, one male participant reporting under-dosing insulin, while three reported taking more than prescribed. Two participants who took less insulin than prescribed reported doing so for weight loss reasons, but the genders of these participants are not broken down in the paper. Eight participants reported taking more insulin than prescribed for the goal of being able to eat more food in one sitting. Again, the genders of these participants are not specified	Very Good

Table 2 *Continued*

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(37) Philippi *et al.* (2013) Brazil	People with a diagnosis of type 1 diabetes for at least a year prior to the study, who were receiving treatment from a diabetes service. *N*= 189 (48 males). Mean age = 26.0 (*SD* = 9.8 years)	Cross-sectional self-administered questionnaires	EAT † BITE † BES † Custom insulin misuse question †.	No males reported intention insulin omission or reduction for weight purposes.	Reasonable
(1) Schober *et al.* (2011) Austria	Children and young adults who had been diagnosed with type 1 diabetes for at least one year prior to the study and who had received treatment from a paediatric department with respect to diabetes. *N* = 241 (103 males) Whole group mean age was not provided. However, all participants were aged between 10 - 22.	Cross-sectional design. Participants completed initial self-report questionnaires and then took part in a semi-structured diagnostic interview over the telephone.	Custom insulin misuse question †. DSMP † Semi-structured phone interview*	31% of males reported intentionally manipulating their insulin dose. 37.3% of males reported unintentionally over- or under-dosing insulin. 15.5% of the whole cohort reported that weight loss was the primary reason for insulin manipulation.	Reasonable

Table 2 *Continued*

Authors, Date and Country	Population	Type of Study & Design	Measures Used	Results	Quality Score
(38) Wisting *et al.* (2017) Norway	Adolescents diagnosed with type 1 diabetes. *N* = 104 (44 males). Mean age = 15.7 (*SD* = 1.8 years)	Cross-sectional researcher-led semi-structured interview.	ChEDE *. Includes a question on insulin omission due to weight/shape concerns. Measurement of HbA1c level.	No significant associations were found between insulin underdosing and weight control behaviours in males.	Reasonable
(39) Grylli *et al.* (2004) Austria	Adolescents with type 1 diabetes. *N* = 199 (103 males). Whole group mean age was not provided.	Cross-sectional design. Initial self-report questionnaires followed by a semi-structured diagnostic interview for a subgroup who scored above a predetermined cut-off.	EAT † EDI-2 † EDE – this included a consideration of insulin misuse*.	This study only assessed insulin misuse in the subgroup who met the criteria for a subthreshold or clinical eating disorder. Only 1% of male participants met the criteria for a subthreshold eating disorder, and insulin misuse was not reported for this subgroup.	Poor

Key: EDE = Eating Disorder Examination Semi Structure Interview*; EDE-Q = Eating Disorder Examination Questionnaire †; ED-3 = Eating Disorder 3 †; SDQ = Strengths and Difficulties Questionnaire †; EAT = Eating Attitude Test †; DEPS = Diabetes Eating Problem Survey †; FES-R = Family Environment Scale-Revised †; DFRQ = The Diabetes and Family Responsibility Questionnaire †; DEPS-R = The Diabetes Eating Problem Survey–Revised †; BMI-SMT = Body Mass Index Silhouette Matching Test †; SCOFF = a screening tool for eating disorders †; CDRS = Contour Drawing Rating Scale †; C-DSMQ = The child version of the Diabetes Self-management Questionnaire †; BITE = Bulimic Investigation Test of Edinburgh †; BES = Binge Eating Scale †; DSMP = Diabetes Self-Management Profile †; ChEDE = Child version of Eating Disorders Examination *; EDI-2 = The Eating Disorders Inventory-2 †.

Note. * denotes clinician-administered measures. † denotes self-report measures.

Narrative Synthesis

The available evidence suggests that males do misuse insulin for weight purposes, but the included studies do not allow for firm conclusions to be drawn about the prevalence of this behaviour. This is due in part to methodological differences between the included studies, including a wide range of measures used, lack of standardised measure for assessment of insulin misuse and study design. Difficulties in interpretation arose as some studies reported rates of insulin misuse and weight behaviours but did not adequately investigate the relationship between these (1,32,34,36,39).

Within the included studies, males were well-represented in the populations (47.5%); however, the emphasis was on the experience of adolescents which hinders the generalisability of results to adult males. Equally, non-Western populations were not well-represented.

When a semi-structured interview was used, men reported nil rates of insulin misuse for weight purposes, but higher rates were reported when a self-report design was utilised. Overall, reported insulin misuse rates varied from 1.4% to 37.3% for males, and 1.4% to 9.4% specified that it was in relation to weight control, suggesting that this is an area that that would benefit from further research.

Populations

Of the 16 included studies, there were 1995 male participants of a total of 4205 participants with type 1 diabetes (47.5%). Twelve of the studies focused on children and adolescents, with mean ages ranging from 14.6 to 16.1 years. The remaining four studies looked at either young adults (20,33,35) or a broad age range (37). There was a reasonably broad spread of geographical areas covered in the studies: three from the United Kingdom and the United States; two from Australia,

Germany, Austria and Norway; and one from Brazil and Portugal. Participants were recruited from different sources, but generally identified through a diabetes clinic, hospital or a national registry.

Study design

Ten studies utilised a cross-sectional self-report questionnaire design, using a mixture of online, postal and in-clinic distributions (27–29,31–37). Four studies used a cross-sectional design with a mixture of self-report questionnaires and semi-structured interviews with a researcher (1,20,30,38). The final two studies utilised semi-structured interviews with no self-report aspect (21,38). Only one study used a longitudinal design (21).

Measures

A wide range of measures was used to assess insulin misuse, the majority of which were not validated measures. Twelve of 16 studies used customised questions, designed for the purposes of the study, to assess insulin misuse (1,20,36,37,21,27,30–35). Two studies (28,29) used questions from the Diabetes Eating Problems Survey (DEPS) and two used an indirect question in the semi-structured Eating Disorder Examination (EQE) to assess insulin misuse (38,39). Both the DEPS and EDE are standardised validated measures, commonly used in routine clinical practice.

Of those who designed their own questions, three studies only asked a single question about insulin misuse (32,34,37) and the remaining studies asked at least two specific questions regarding insulin misuse (e.g. ‘I take less insulin than I should to influence my shape or weight’; ‘I skip insulin shots to influence my shape or weight’ (27)).

Results

Reported rates of insulin misuse amongst men varied from 1.4% to 37.3%, with males reporting insulin omission, underdosing and overdosing, and up to 9.4% of males reported doing so for weight purposes. Seven of 16 studies reported no instances of males misusing insulin for the purposes of weight control or loss (20,21,30,35,37–39). Six of these seven studies used a variation of the clinician-administered EDE with additional custom insulin misuse questions, and three of these studies were carried out within the same research team in the UK (20,21,30). This may suggest that the EDE is not sensitive to detecting insulin misuse, or that males are less likely to disclose insulin misuse in a face-to-face setting. Additionally, four of those seven studies were more than 10 years old (20, 21, 30, 39), while in studies where insulin misuse was reported, only two of nine (28, 31) were more than 10 years old and neither of those studies used the EDE. It is possible that older studies were designed in a way that made them less sensitive to the detection of insulin misuse in males, compared to more recent studies.

In studies where insulin misuse for weight purposes was identified, interpretable prevalence rates ranged from 1.4% to 9.4% of the males who engaged in this. All these studies relied on self-report measures, with the exception of one that also included a follow-up semi-structured interview (1). Disordered eating behaviours were reported in 9.2% to 25.9% of males, and insulin misuse rates of 3.4% to 14% were reported by males in those studies, but it is not clear in all cases if it is the same participants engaging in both or if they are different groups. Six of 16 studies appeared to establish a relationship between insulin misuse and either weight and/or disordered eating behaviours (27–29,31,33,34). These studies all received a quality rating of “Excellent” or “Very Good”.

However, the results were not presented in a uniform fashion across the papers and it was difficult to determine the specific rates of insulin misuse for weight purposes in males, as this was not always clearly reported for each gender. When it was reported, it was based on a low number of respondents. Thus, a true estimate of prevalence rates cannot currently be determined from the included studies.

Quality

The overall quality of the included studies was generally strong, with five papers receiving a rating of "Excellent" (20,21,27–30) and seven receiving "Very Good" (31–36). The four weaker papers (rated as "Reasonable" or "Poor") did not report their findings in sufficient detail, and the results did not generally support the conclusions, with one exception (1). Two of these papers were judged to have failed to adequately assess insulin misuse (38,39), which limited the interpretation of the results.

Discussion

Misuse of insulin for weight purposes has been highlighted as an area of particular concern by professionals involved in diabetes care, due to the risk levels associated with this behaviour. The results of this review indicate an inconclusive body of evidence regarding the degree of the behaviour in male populations. Notably, measures used to assess insulin misuse varied widely, with some studies using questions that operationalised the behaviour in a clear and defined manner, whilst others relied on indirect questions in pre-existing measures that were not specifically designed for use in a diabetic population. Several studies asked a single question about insulin misuse, which may have failed to capture true prevalence rates by not exploring the behaviour in more detail.

It is interesting to note that men reported low to nil rates of insulin misuse when the behaviour was assessed by a semi-structured interview, but in self-report ratings, reported rates were generally higher, up to 37.3%. This may potentially suggest a reluctance to discuss this behaviour directly to a healthcare professional, which warrants further investigation.

Of the papers considered for inclusion in this review, 30 were excluded specifically because they either excluded men or did not sufficiently report the findings by gender. Of the papers included, several explored the results for females in depth, and merely acknowledged results for men with a brief sentence. The emphasis on the female experience in the literature is notable; however, research has indicated that prevalence rates of type 1 diabetes are higher for males than females in European populations aged 15-40, with a ratio of approximately 3:2 male:female (40). One possible explanation for this could be the conceptualisation of disordered eating, particularly relating to weight and shape, as being a predominantly female concern (e.g. 41). However, research indicates that between 10-25% of people with an eating disorder are male (42,43) and incidence rates of eating disorders in males are rising (18), so excluding men from research such as this should be discouraged. Differences have been identified in preferred body appearance between men and women (23,44), and this may affect how males misuse insulin compared to women. Studies that fail to account for this may miss these differences. Research suggests that gendered constructions of eating disorders may delay the identification of problematic eating behaviours in men (42). The same may be true of insulin misuse.

Strengths and Limitations

To our knowledge, this study represents the first review of this behaviour in males with type 1 diabetes. This alone is interesting, as type 1 diabetes affects both

men and women, yet men appear to be largely overlooked in research regarding insulin misuse for weight purposes.

However, the findings are based on a small number of heterogeneous studies which could not be directly compared through statistical means, which limited the scope of interpretation. This was further hampered by the degree of heterogeneity and generally poor assessment of insulin misuse, particularly in relation to weight control behaviours. Whilst a reasonably broad spectrum of countries was included, the majority of these were developed nations with predominantly white populations, and it is unclear what results might be seen in low-middle income countries with non-Western cultures. The mean age of the populations tended to be quite young so this study could not capture the experiences of an older population.

Theoretical and Clinical Implications

These findings highlight the need for a standardised self-report measure of insulin misuse. Such a clinical measure should allow for a sufficiently detailed and non-judgemental exploration into the frequency and reasons for insulin misuse, taking into account the potential reluctance of an individual to discuss engaging in this behaviour.

Equally, the development of tools to screen for the presence of eating disorder psychopathology specifically in men would be beneficial. As discussed, this may present in a different way between the genders and it is likely that eating disorder psychopathology is currently being under-diagnosed in men. A better awareness of the potential indicators and reasons for insulin misuse in men, particularly in the context of disordered eating behaviours, may aid healthcare professionals to identify concerns at an earlier stage.

Conclusions

This systematic review is the first review to attempt to gain an understanding of the prevalence of insulin misuse for the purposes of weight control or loss in men with type 1 diabetes. Inconsistent findings emerged, with interpretation hampered by the lack of a specific insulin misuse measure and heterogeneity of the measures used. It appears that men do report insulin misuse for the purposes of weight loss or control through self-report measures but may be less likely to report insulin misuse in interview-based environments, and prevalence rates for this behaviour could not be determined at this time.

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Chapter Two

Bridging Chapter

2.1 Introduction

Insulin therapy is a requirement for people with type 1 diabetes from the point of diagnosis (NICE, 2015), while research suggests that just over half of those with type 2 diabetes require insulin therapy, and it is generally considered only after other treatment options have been exhausted (United Kingdom Prospective Diabetes Study Group, 1995). Despite this discrepancy, much of the research on insulin misuse has either combined both type 1 and type 2 diabetes or focused on type 2 diabetes. A systematic review of factors affecting insulin adherence in diabetes by Davies *et al.* (2013) included 17 studies, of which 10 focused exclusively on adherence in type 2 diabetes, five investigated both type 1 and type 2 diabetes and only a single study explored adherence in type 1 diabetes alone. Another systematic review of insulin adherence measures by Stolpe, Kroes, Webb and Wisniewshi (2016) reviewed 58 papers (74%) that included patients with type 2 diabetes, 10 that combined type 1 and type 2 (13%) and just two papers that focused on type 1 diabetes (4%). This may reflect the fact that type 2 diabetes is more prevalent in the general population, with up to 90% of those diagnosed with diabetes having type 2, but this also means that conclusions and implications for practice may not be applicable for people with type 1 diabetes. Insulin misuse within type 1 diabetes would benefit from further specific investigation.

Another difficulty in the exploration of insulin misuse in diabetes is the lack of a standardised measure to assess the behaviour, resulting in a wide variety of methodological approaches. Two systematic reviews, examining medication adherence in both type 1 diabetes and type 2 diabetes, found a disparate array of methods, including: subjective assessments; medication monitoring systems; self-report logbooks; biochemical measurements of blood glucose levels; and data

collected from pharmacy records (Clifford, Perez-Nieves, Skalicky, Reaney & Coyne, 2014; Stolpe *et al.*, 2016). One standardised measure was employed in a small number of studies (the Morisky Medication Adherence Scale) but two different versions were used. Notably, the majority of these methods offer no insight into the reasons for insulin misuse. As can be seen from the systematic review, even research that is methodologically similar uses a broad range of approaches to assess insulin misuse with no clear preferred or gold standard measure available.

Recently, a measure of insulin adherence has been developed (Ames, 2017). This measure was created in collaboration with healthcare professionals and individuals with diabetes and explores both frequencies and reasons for insulin misuse, while also exploring the potential relationship between insulin and mood and factors impacting motivation. Use of this measure allows for an in-depth exploration of insulin misuse.

2.2 Consequences of Insulin Misuse

Insulin misuse leads to poor glycaemic control, which can result in either hyperglycaemia or hypoglycaemia. As outlined previously, hyperglycaemia is a serious physical health concern for people with type 1 diabetes and can lead to complications and fatalities (Marcovecchio, 2017). Chronic complications of persistent hyperglycaemia include microvascular complications such as damage to vision, kidneys and peripheral nerves, and macrovascular complications including cardiovascular disease (Marcovecchio, 2017). Ultimately, chronic or persistent hyperglycaemia can lead to blindness, kidney failure, loss of limbs or death. Understanding the risk factors for poor diabetic control, including insulin misuse, is crucial for enabling both healthcare providers and people with diabetes to best manage the condition.

2.3 Diabetes and Mental Health

Research suggests an association exists between psychological distress and type 1 diabetes. It has been proposed, as the diagnosis of type 1 diabetes commonly occurs in childhood or early adolescence, that the addition of the complex management of diabetes on top of pre-existing developmental demands of that age range may contribute to this increased rate of psychological distress observed (Danne *et al.*, 2014). This may also be linked to an increased incidence of eating disorders in adolescents with type 1 diabetes (Colton *et al.*, 2004; Neumark-Sztainer *et al.*, 2002). This association is discussed further below.

Managing diabetes may conflict with the normative demands of adolescence (Hamberg, 1998), and the gradual transfer of responsibility for the management of diabetes from parents to the adolescent may be a burden beyond the level of developmental maturation that results in poor adherence to the insulin regime (Comeaux & Jaser, 2010). Thus, psychological difficulties may begin to occur for children with type 1 diabetes (Reynolds & Helgeson, 2011).

Furthermore, there is an established relationship between type 1 diabetes and mental health difficulties. Mood and anxiety disorders amongst adolescents with type 1 diabetes were found to be two to three times higher than in a community setting, particularly for females (Northam, Matthews, Anderson, Cameron & Werther, 2005). A longitudinal study estimated that over 47% of a group of adolescents with type 1 diabetes developed mental health difficulties within 10 years of diagnosis, with major depression, conduct disorder and generalised anxiety disorder being most common (Kovacs, Goldston, Obrosky & Bonar, 1997). Externalising behaviour problems (i.e. ‘acting out’) were associated with poorer glycaemic control in adolescents (Leonard, Jang, Savik, Plumbo & Christensen,

2002). Anxiety and self-rated quality of life were associated with higher blood glucose levels (Mortensen, 2002). A history of mental health difficulties was associated with poorer glycaemic control and an increased incidence of retinopathy (damage to the blood vessels of the retina; Cohen, Welch, Jacobson, De & Samson, 1997).

In adults, comorbid depression was found at significantly higher rates in those with diabetes compared to a community sample (adults with diabetes were approximately twice as likely to have comorbid depression than those without diabetes), and rates of depression were significantly higher in the presence of poor glycaemic control than well-controlled diabetes, and higher for women with diabetes than men (Anderson, Freedland, Clouse & Lustman, 2001). Greater depression symptomology is associated with poorer medication adherence (Ciechanowski, Katon & Russo, 2000), poorer physical health outcomes (De Groot, Anderson, Freedland, Clouse & Lustman, 2001) and greater levels of hyperglycaemia (Lustman *et al.*, 2000). Self-efficacy appears to mediate the relationship between depression and glycaemic control in type 1 diabetes, but not type 2 diabetes (Sacco & Bykowski, 2010), and research suggests that depression may occur as a result of diabetes (Eaton, 2002). Taken together, this may suggest that feeling unable to manage the demands associated with good glycaemic control leads to depression.

A further association was found between insulin misuse and psychiatric comorbidity in people with type 1 diabetes. Proportionally, over twice as many people with psychiatric comorbidities misused insulin when compared to a group with no psychiatric comorbidity (Berger *et al.*, 2019). Those who misused insulin and had psychiatric comorbidity had diagnoses of specific phobia, social phobia, depression or eating disorders. Conversely, the group who adhered correctly to their

insulin regime had lower prevalence rates for psychiatric comorbidities than found in non-clinical samples (Berger *et al.*, 2019).

2.4 Diabetes-Related Distress

As noted above, research suggests that the burden of managing diabetes contributes to poorer psychological outcomes. That, along with the role of self-efficacy in mediating the relationship between depression and type 1 diabetes, suggests that it is possible that many of the mental health issues experienced by people with type 1 diabetes might be underpinned by their feelings about living with and managing diabetes. This has been described as diabetes-related emotional distress in the literature (Polonsky *et al.*, 1995).

Higher levels of diabetes-related distress were associated with reduced adherence to diabetes self-care, such as blood glucose testing, meal planning and insulin adherence, even when factors such as age and general emotional distress were controlled for (Polonsky *et al.*, 1995). Monitoring general well-being for people with type 1 diabetes improved overall well-being and mental health, but did not improve glycaemic control (Pouwer, Snoek, Van Der Ploeg, Adèr & Heine, 2001).

In a group with type 2 diabetes, diabetes-related distress, but not major depressive disorder or depressive symptoms, was associated with glycaemic control (Fisher *et al.*, 2010). Diabetes-related distress has been found to mediate the relationship between depression and glycaemic control in both type 1 and type 2 diabetes (Van Bastelaar *et al.*, 2010). Those who were depressed but did not have elevated diabetes-related distress were found to manage their glycaemic control adequately, while those with both depression and diabetes-related distress were at significantly increased risk of elevated HbA1c.

Taken together, these findings suggest that diabetes-related distress may be a predictor of poorer glycaemic control, which may also be related to insulin misuse. Diabetes-related distress should be considered when investigating the reasons for insulin misuse.

2.5 Diabetes and Eating Disorders

The comorbidity of eating disorders and type 1 diabetes will be discussed in detail the next chapter; however, this subsection provides an overview of the types of eating disorder commonly diagnosed in people with type 1 diabetes, along with published guidance about the comorbidity of insulin misuse and eating disorder psychopathology.

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5, American Psychiatric Association [APA], 2013, *p*. 329) defines an eating disorder as "… a persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning". Several different types of eating disorder defined by the DSM-5 and relevant to this study include:

Anorexia Nervosa (AN). This is defined as a persistent reduction in caloric intake, intense fear of gaining weight, and a disturbance in perceived body shape or weight (APA, 2013);

Bulimia Nervosa (BN). Defined as recurrent binge eating with inappropriate compensatory behaviours such as self-induced vomiting or laxative misuse, and disproportionate impact of body weight and shape on self-evaluation (APA, 2013);

Binge-Eating Disorder (BED). This is characterised by frequent consumption of a large amount of food in a short period of time, without

compensatory purging (APA, 2013). Binges are generally a distressing experience for the person, and they feel unable to stop or control their eating.

Other Specified Feeding or Eating Disorder (OSFED). This is a new diagnostic category in the DSM-5 (APA, 2013) and replaces the previous category of Eating Disorders Not Otherwise Specified (EDNOS). This is understood as occurring when symptoms of feeding or eating disorders do not meet clinical criteria for the above categories or are a mixture of several of the above (APA, 2013).

Subthreshold Eating Disorder. This term may be used when the eating disturbance is milder in severity or less frequent in occurrence than specified in the diagnostic criteria of the above categories (Jones *et al.*, 2000).

The DSM-5 further references the omission of insulin within eating disorders: "Individuals with anorexia nervosa may misuse medications, such as by manipulating dosage, in order to achieve weight loss or avoid weight gain. Individuals with diabetes mellitus may omit or reduce insulin doses in order to minimize carbohydrate metabolism" (APA, 2013, *p*.341). The National Institute for Health and Care Excellence (NICE) released guidelines which specifically refer to the comorbidity of eating disorders and T1DM (NICE, 2015; 2017): "…be alert to the possibility of bulimia nervosa, anorexia nervosa and insulin dose manipulation in adults with T1DM …" and "Address insulin misuse as part of any psychological treatment for eating disorders in people with diabetes".

Chapter Three

Empirical Paper

Insulin Misuse in Adults with Type 1 Diabetes: An Investigation into the Relationships with Gender, Eating Disorder Psychopathology and Diabetes-Related Distress.

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Word Count: 3,999

This review has been written in accordance with formatting and word count guidance for Diabetes Care (Appendix A)

Abstract

OBJECTIVE – This study investigates the prevalence rates of insulin misuse by adults with type 1 diabetes, and explores the relationships between insulin misuse and gender, eating disorder psychopathology and diabetes-related distress.

RESEARCH DESIGN AND METHODS – A cross-sectional, web-based survey was completed by 219 adults with type 1 diabetes living in the United Kingdom, recruited online. Participants completed a measure of insulin misuse, the Eating Disorder Examination Questionnaire, Body Shape Questionnaire and the Diabetes Distress Scale. Data were analysed statistically and compared using χ^2, independent samples t-tests, logistic regression and MANOVA.

RESULTS – Insulin misuse was reported by over 60% of respondents. Women were significantly more likely to misuse insulin than men overall and specifically for weight loss and control. Those who had a current or historical diagnosis of an eating disorder were more likely to misuse insulin for weight loss or control than those with no history of an eating disorder. People who reported insulin misuse had significantly higher levels of disordered eating behaviours, more negative feelings about body shape and greater degrees of diabetes-related distress. Diabetes-related distress was the only predictor of insulin misuse.

CONCLUSIONS – Disclosure of insulin misuse by adults with type 1 diabetes may be suggestive of the presence of disordered eating behaviours or clinical levels of diabetes-related distress. Insulin misuse occurs across the range of eating disorder categories and should be considered as a discrete difficulty. Insulin misuse should be investigated routinely in clinical practice.

Amongst people with type 1 diabetes, the misuse of insulin is a particularly concerning behaviour, as it can cause a number of serious health concerns (1). Insulin misuse typically refers to either deliberately under-dosing, over-dosing or omitting a scheduled dose of insulin (2). Under-dosing or omitting a dose can lead to hyperglycaemia, and significant and rapid weight loss may be seen through a combination of dehydration and caloric restriction (3).

Eating disorders are characterised by disturbed eating behaviours, such as severe restriction or rapid bingeing and purging of food, with the aim of weight loss or control, preoccupation with body shape and size, and distortion of body image (4). Eating disorders have high comorbidity and mortality rates (5,6). The comorbidity of eating disorders and type 1 diabetes was first identified in the 1980s (7,8). Herpertz *et al.* (9) found a point prevalence for eating disorders of 7.9% for females and 2% for males with type 1 diabetes, with an average lifetime prevalence of 10% across genders, and 4.1% of participants reported insulin misuse (9).

Two meta-analyses found increased prevalence rates of Bulimia Nervosa (BN) and Eating Disorder Not Otherwise Specified (EDNOS) in women with type 1 diabetes, compared to controls, and both failed to find a significant difference in rates of Anorexia Nervosa (AN) between the groups (10,11). Nielsen (10) reported that rates of insulin misuse were increased when an eating disorder co-existed with type 1 diabetes. More recently, NICE released guidelines which specifically refer to the comorbidity of eating disorders and type 1 diabetes, with reference to insulin misuse (12).

It has been proposed that the demands of managing type 1 diabetes necessitate heightened attention to food, dietary restraint and weight, which may contribute towards the association between disordered eating and type 1 diabetes

(13). Adolescent girls with type 1 diabetes are heavier than their non-diabetic peers, on average (14–16), possibly due to insulin use (17). Prior to diagnosis, many people with type 1 diabetes experience weight loss, which is typically regained when insulin therapy begins (18). This likely marks the beginning of the mental association between insulin therapy and weight gain for people with type 1 diabetes, which may lead to insulin misuse as a method of weight loss or control if body weight or shape dissatisfaction is a concern (19,20).

Prevalence rates of insulin misuse vary significantly, with limited previous literature reporting rates from 17%–59% (1,9,21,22). Two studies identified weight loss as a reason for insulin misuse in 6% – 7.5% of respondents (1,9). A recent systematic review reported weight as a reason for insulin misuse in 4.1% – 58% of people with type 1 diabetes who reported misuse (23). When co-morbid eating disorders were present, rates of misuse varied from 47.9% – 90%, and rates were higher for women than for men (23). Increased rates of insulin misuse are associated with a threefold increase in the risk of mortality in adult women with type 1 diabetes, exacerbated by the presence of disordered eating symptoms (24). Insulin misuse for the purposes of weight loss has been referred to as “diabulimia” (25).

In addition, other reasons for insulin misuse identified in previous research are: lifestyle burden and lack of flexibility of insulin regimen (26); forgetting (27); embarrassment (28); emotional distress related to diabetes and as an adaptive response to fluctuating blood sugar levels (22). Many of these may be categorised as diabetes-related distress (29).

To date, little research has explored the prevalence of insulin misuse within eating disorder psychopathology in people with type 1 diabetes specifically. Many studies have included people with type 2 diabetes (21,26,30) which may mask the

finer details of the individual groups. Further, the majority of research has focused on an adolescent female population. This study aims to gain a better understanding of the relationship between insulin misuse, disordered eating and perception of body shape in both male and female adults with type 1 diabetes. The impact of diabetes-related distress on insulin misuse will be explored. As such, the research questions that this study aims to address are:

In adults with type 1 diabetes:

1. What are the rates of insulin misuse reported?
2. Is there a relationship between gender and insulin misuse?
3. Is there a relationship between eating disorder psychopathology and insulin misuse?
4. Is there a relationship between perception of body shape and insulin misuse?
5. Is there a relationship between diabetes-related distress and insulin misuse?

These findings may help to guide a deeper understanding of some of the issues that people with type 1 diabetes experience and may contribute to better support and treatment services being developed.

Research Design and Methods

Design

A cross-sectional, web-based survey design was employed, consisting of validated self-report measures designed to capture demographic information, insulin misuse, diabetes-related distress, disordered eating, and body shape perception.

Participants and Procedure

Participants were recruited through online communities, primarily through Twitter or diabetes information and support organisations such as diabetes.org.uk and Diabetics with Eating Disorders (DWED), via an advertisement for the study and subject to gatekeeper's permission where necessary.

Inclusion/Exclusion criteria. Participants were eligible to participate if they self-described as being aged 18 or over, with a diagnosis of Type 1 diabetes and on a prescribed insulin regime. They were required to be at least one-year post-diagnosis, as people who have been prescribed insulin for less than one year may not have settled into a routine with insulin management and may mismanage their insulin unintentionally. Additionally, participants were required to reside within the UK, as this removed a potential confound of cost or resources as a barrier to accessing insulin.

People with a diagnosis of type 2 diabetes were excluded from the study, as the pathophysiology and treatment of the two illnesses are quite different. For example, as those with type 2 diabetes still produce some degree of insulin naturally, misuse of insulin is likely to have less of an immediate impact than for those with type 1 diabetes, who produce no insulin naturally (21).

Potential participants were provided with a link to the study which provided detailed information about the study, details of informed consent and their right to withdraw. When the survey was completed, or participants chose to exit, a debrief page was presented with signposts towards various supports and resources. Participants were offered the opportunity to receive a brief summary of findings from the study and given the chance to win a £25 Amazon gift voucher, both of which required an email address to be supplied through separate surveys, so as to protect the confidentiality of responses. Ethical approval for this study was granted

by the chair of the Ethics Committee for the Faculty of Medicine and Health Sciences at the University of East Anglia.

Statistical Analysis

Prior to beginning the study, an estimate of the minimum number of participants required was calculated using statistical power tables (31) and G*Power version 3.1. Based on previous research (22), a medium effect size (.5) was used to calculate sample sizes with a power of .8 (31), which generated a necessary sample size of 208. All analyses were adequately powered.

Data were analysed using IBM SPSS Statistics for Mac version 25.

Measures

Demographic Information. This section collected basic demographic information, including age; gender; country of residence; and current or historical diagnosis of an eating disorder. The data were screened to ensure participants met the inclusion criteria.

Insulin Measure. A 16-item questionnaire has been designed to assess rates and reasons for insulin misuse (22).

Eating Disorder Psychopathology. The Eating Disorder Examination-Questionnaire (EDE-Q) assesses eating disorder psychopathology, and data from this measure was key to informing the primary research questions. It was designed as a self-report version of the interview-based Eating Disorders Examination (EDE; 32), which is considered to be the gold standard measure (33). The EDE-Q assesses four subscales: Restraint, Eating Concern, Shape Concern, and Weight Concern. It was found to be an adequate alternative to the EDE (32).

Body Shape Questionnaire (BSQ). The Body Shape Questionnaire is a 34-item self-report measure, designed to assess concerns regarding body shape and the

phenomenological experience of "feeling fat" (34). The BSQ targets body image as a central feature of both AN and BN and thus is a useful supplementary measure of eating disorder psychopathology.

Diabetes Distress. The Diabetes Distress Scale (29) is a 17-item scale designed to measure diabetes-related emotional distress via four domains: emotional burden, physician distress, interpersonal distress and regimen distress. This measure was included on the basis of results from Ames (22), which identified diabetes-related emotional distress as a key reason for insulin omission in type 1 diabetes. Inclusion in this study allowed for further investigation of its role.

Results

Participant Characteristics

A total of 224 people completed the survey. Screening of the responses identified five participants who did not live in the United Kingdom, and these datasets were removed as they failed to meet the inclusion criteria. The remaining 219 datasets were included in the final analysis, comprising of 171 female respondents (78%) and 47 males (21.5%). The majority of respondents were aged 18 – 44 years (73.1%), 30% had completed an undergraduate degree and a further 22% had completed a postgraduate degree. The mean age of diagnosis of type 1 diabetes was 18 years (*SD*=12.96). The majority (51%) had been prescribed an insulin regime for over 15 years, 20% had been prescribed for 1-5 years and the remainder for 6-15 years. Insulin pumps were used by 42%, while 54% administered multiple daily injections of insulin (basal-bolus). Table 1 details the reported rates of eating disorders within the population.

Supplementary Table 1

Participant Characteristics

Variable		**N**	**%**
Age	18-24	60	28%
	25-34	54	25%
	35-44	44	21%
	45-54	35	16%
	55-64	16	7%
	65 or older	6	3%
Gender	Female	171	78%
	Male	47	21.5%
	Did not respond	1	0.5%
Highest level of education completed	Some secondary school	2	1%
	GCSEs or equivalent	8	4%
	A-Levels or equivalent	29	14%
	Trade/technical/vocational training	15	8%
	Some university	27	12.5%
	Undergraduate degree	65	30%
	Some postgraduate	18	8%
	Postgraduate degree	49	22%
	Other	1	0.5%
Current Employment Status	Full-time student	28	14%
	Part-time employee	32	14.5%
	Full-time employee	102	48%
	Self-employed	15	7%
	Unemployed	16	7.5%
	Other	20	9%
Length of time prescribed an insulin regime	1-5 years	44	21.5%
	6-10 years	31	14.5%
	11-15 years	30	14%
	More than 15 years	109	50%
Type of insulin regime	Twice-daily injections	5	3%
	Multiple daily injections	118	54%
	Insulin pump	92	42%
	Other	2	1%

Table 1

Reported rates of eating disorder diagnoses

Variable		Women *N* (%)	Men *N* (%)	Overall *N* (%)
Have you ever been formally diagnosed with an eating disorder?	Yes – Current	8 (4.7%)	1 (2.1%)	9 (4.1%)
	Yes – Historical	27 (15.8%)	0	27 (12.3%)
	No	135 (78.9%)	46 (97.9%)	183 (83.6%)
If yes, which eating disorders have you been diagnosed with? (Multiple choice question)	Anorexia Nervosa	9 (23.7%)	0	9 (23.7%)
	Bulimia Nervosa	9 (23.7%)	0	9 (23.7%)
	Binge-Eating Disorder	3 (7.9%)	0	3 (7.9%)
	Eating Disorder Not Otherwise Specified	12 (31.6%)	1 (2.6%)	13 (34.2%)
	Other	7 (18.4%)	0	7 (18.4%)

Two participants believed they have an undiagnosed eating disorder, both referring to it as diabulimia.

Results of Insulin Measure

For the sake of brevity, the act of omitting an insulin dose or intentionally taking an incorrect amount will be referred to as ‘insulin misuse’. Nearly half of respondents (47%) reported insulin omission and 60.7% reported taking too much or too little. Concerningly, over half of respondents (52%) said they would not tell their diabetes team about insulin misuse, were it to occur. Detailed results are presented in Table 1.

Table 2

Summary of Insulin Use Questionnaire Findings

Variable		Women		Men		Overall	
		N	%	*N*	%	*N*	%
Omitting doses	Yes	85	49.7	17	36.2	103	47
	No	86	50.3	30	63.8	116	53
Frequency in past 7 days	Once	29	17	5	10.6	34	15.5
	2 – 4 times	28	16.4	10	21.3	39	17.8
	5 – 6 times	11	6.4	2	4.3	13	5.9
	7 or more times	15	8.8	--	--	15	6.8
Reason for omitting *	Other things took priority at the time	53	31	11	23.4	65	29.7
	Negative feelings around diabetes	31	18.1	4	8.5	36	16.4
	As a method of weight control	24	14	1	2.1	25	11.4
	As a method of weight loss	18	10.5	2	4.3	20	9.1
	Avoidance or fear of physical effects	24	14	2	4.3	26	11.9
	Anticipating low blood sugar and planning around this	19	11.1	8	17	27	12.3
Taking more or less insulin than prescribed	No	61	35.7	24	51.1	86	39.3
	Yes – More	18	10.5	3	6.4	21	9.6
	Yes – Less	43	25.1	3	6.4	46	21
	Yes – Both	49	28.7	17	36.2	66	30.1
Frequency in past 7 days	Once	24	14	5	10.6	29	13.2
	2 – 4 times	58	33.9	13	27.7	71	32.4
	5 – 6 times	13	7.6	2	4.3	15	6.8
	7 or more times	15	8.8	3	6.4	18	8.2

Table 2 *Continued*

Variable		Women		Men		Overall	
		N	%	*N*	%	*N*	%
Reason for taking incorrect dosage*	Other things took priority at the time	38	22.2	6	12.8	44	20.1
	Negative feelings around diabetes	32	18.7	6	12.8	38	17.4
	As a method of weight control	18	10.5	1	2.1	19	8.7
	As a method of weight loss	18	10.5	2	4.3	20	9.1
	Avoidance or fear of physical effects	44	25.7	5	10.6	49	22.4
	Anticipating low blood sugar and planning around this	39	22.8	10	21.3	49	22.4
Do you consider insulin misuse a problem for you	Yes	59	34.5	12	25.5	72	32.9
	No	111	64.9	34	72.3	145	66.2
Would you, or do you, tell you diabetes team about missing doses?	Yes	49	28.7	16	34	65	29.7
	No	63	36.8	7	14.9	71	32.4
	Not applicable (I do not miss doses)	58	33.9	23	48.9	81	37

Note. *This was a multiple-choice option

Chi-squared tests for independence (with Yates Continuity Correction) indicated significant associations between gender and insulin misuse. Overall, women were significantly more likely to report the misuse of insulin overall, χ^2 (1, N = 218) = 4.72, p = 0.03, phi = .159. When insulin misuse data were separated out into those who misused purely for weight loss or control, women again were significantly more likely to misuse than men, χ^2 (1, N = 218) = 4.5, p = .034, phi = .159. For reasons other than weight, no significant associations were seen between insulin misuse and gender, χ^2 (1, N = 185) = 2.8, p = .095, phi = .136.

Of those who reported a current or historical diagnosis of an eating disorder (N = 36), 20 people (56%) reported omitting insulin doses for the purposes of weight loss (N = 13) and/or control (N = 17). Of those, ten people reported omitting insulin for both weight control and loss. This behaviour was reported across the range of eating disorders: EDNOS (N = 11); "Other" (N = 4); AN (N = 4); BN (N = 3); and BED (N = 1). However, for those who had never been diagnosed with an eating disorder (N = 181), the majority (93.4%) did not omit insulin for weight control or loss. Of the remainder, five people reported omitting doses for weight control, four for weight loss and three reported omitting doses for both weight loss and control.

Between-Groups Comparisons

Group comparisons were carried out to investigate differences between those who reported misusing insulin and those who did not. A Bonferroni correction was applied for the 11 variables in the analysis, resulting in a statistical significance threshold of $p < .0045$ (.05 ÷ 11). This did not impact the significances observed.

EDEQ. People who misuse insulin indicated significantly higher levels of disordered eating behaviours (M = 1.95, SD = 1.32) than those who did not misuse

insulin (M = 1.32, SD = 1.04), t (171.517) = -3.532, p = .001, d = -.54. Full details of these results can be seen in Table 3.

BSQ. Participants who misuse insulin had higher scores on the BSQ (M = 101.76, SD = 48.40) than those who do not misuse insulin (M = 71.89, SD = 36.18), indicating that people who misuse insulin have significantly more negative feelings about their body shape and a greater feeling of "fatness", t (178.972) = -5.102, p ≤ .001, d = -.76.

DDS. Overall, people who misuse insulin had significantly greater degrees of diabetes-related distress (M = 3.39, SD = 1.20) than those who did not misuse insulin (M = 2.19, SD = 1.07), t (217) = -7.181, p ≤ .001, d =.98. Full details can be seen in Table 3.

Table 3

Differences between insulin misuse group and no insulin misuse group on results for EDEQ, BSQ and DDS

	Insulin Misuse (*N* = 148)		No Insulin Misuse (*N* = 71)				
	M	*SD*	*M*	*SD*	Result	*p*	Cohen's *d*
EDEQ Restraint	1.81	1.66	1.70	1.49	*t* (217) = -.460	.646	-.06
EDEQ Eating Concern	1.57	1.54	.66	.92	*t* (206.795) = -5.452 *	≤ .001	-.76
EDEQ Shape Concern	2.42	1.43	1.57	1.28	*t* (217) = -4.237	≤ .001	-.58
EDEQ Weight Concern	2.02	1.33	1.35	1.11	*t* (163.102) = -3.920 *	≤ .001	-.61
EDEQ Global	1.95	1.32	1.32	1.04	*t* (171.517) = -3.532 *	.001	-.54
Total BSQ	101.76	48.40	71.89	36.18	*t* (178.972) = -5.102 *	≤ .001	-.76
DDS Total	3.39	1.20	2.19	1.07	*t* (217) = -7.181	≤ .001	-.98
DDS Emotional Burden	3.97	1.44	2.57	1.35	*t* (217) = -6.845	≤ .001	-.93
DDS Physician-related distress	2.83	1.50	2.03	1.47	*t* (217) = -3.751	≤ .001	-.51
DDS Regimen-related Distress	3.38	1.45	1.92	1.04	*t* (184.184) = -8.445 *	≤ .001	-1.25
DDS Interpersonal Distress	3.19	1.50	2.19	1.29	*t* (158.921) = -5.098 *	≤ .001	-.81

* = unequal variances assumed

Predictive Analysis

To determine the degree to which total scores on the EDEQ, BSQ and DDS, along with the impact of gender, could predict the likelihood that an individual will misuse insulin, a binomial logistic regression was performed. The model was found to be statistically significant, $\chi^2(4) = 50.935$, $p < .0005$. It explained 29.1% (Nagelkerke R^2) of the variance in insulin misuse and correctly classified 76.1% of cases. Specificity was 53.5% and sensitivity was 87.1%. The positive predictive value was 79.5% and the negative predictive value was 66.67%. Of the predictor variables, neither scores on the EDEQ or BSQ, nor gender, were statistically significant (as shown in Table 4). Diabetes-related distress was a significant predictor of insulin misuse, with higher scores associated with increased likelihood of insulin misuse.

Table 4

Logistic Regression Predicting Likelihood of Insulin Misuse

	B	SE	Wald	*df*	*p*	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
EDEQ	-.414	.270	2.355	1	.125	.661	.390	1.122
BSQ	.012	.008	2.457	1	.117	1.013	.997	1.028
DDS	.898	.188	22.745	1	.000	2.455	1.697	3.551
Gender	.217	.405	.287	1	.592	1.242	.562	2.748
Constant	-2.284	.522	19.159	1	.000	.102		

One-way multivariate analysis of variance (MANOVA)

To investigate differences between those who do not misuse insulin, those who misuse for weight purposes and those who misuse for other reasons on scores of the EDEQ, BSQ and DDS respectively, a MANOVA was performed. Tukey HSD post-hoc analyses indicated those who misuse insulin for weight purposes had significantly higher mean scores on the EDEQ than those who do not misuse insulin at all ($p < .0005$) and those who misuse insulin for non-weight reasons ($p < .0005$). However, EDEQ mean scores were not statistically significantly different between those who misuse insulin for non-weight purposes and those who do not misuse insulin ($p = .119$). There was a statistically significant difference between all groups for scores on the BSQ and DDS measures ($p < .01$), with the highest scores for all seen in the group that misuse insulin for weight purposes, followed by the misuse for non-weight reasons group.

Discussion

This study investigated relationships between insulin misuse in adults with type 1 diabetes and eating disorder psychopathology, perception of body shape, diabetes-related distress and gender. Overall, 47% of respondents reporting omitting insulin doses at times, and 60.7% indicated that they took either more or less than prescribed on occasion. Women were significantly more likely to report insulin misuse than men overall ($p = 0.03$) and specifically for weight purposes ($p = .034$). However, when those who misused insulin for weight purposes were removed from the sample, no significant associations were found between gender and insulin misuse. This suggests that insulin misuse for weight purposes amongst women is a significant contributor to the gender differences observed. Diabetes-related distress was the only predictor of insulin misuse. Those who misused insulin for weight

purposes had significantly higher scores on all measures, particularly on the EDEQ where no significant differences in scores were found between those who misuse insulin for non-weight reasons and those who don't misuse at all.

Previous research has suggested varying prevalence rates of insulin misuse, from 17.7% to 59% (1,9,21,22). The results of this study tally with the higher rates reported (21,22). Furthermore, the behaviour occurred relatively frequently. In the seven days prior to responding to the survey, 17.8% of respondents omitted an insulin dose 2-4 times. A further 6.8% had done so at least seven times. For taking an adjusted dose of insulin, frequencies rose: 32.4% had done so 2-4 times in the past week, and 8.2% had done so seven or more times. This is in line with findings from previous research (21).

A diagnosis of an eating disorder, either current or historical, was identified in 16.4% of respondents. Broken down by gender, this represents 2% of male respondents and 20.5% of female respondents. Lifetime prevalence rates for females with type 1 diabetes are higher in this study than in previous studies (9,11), but the rates for men agree with those reported by Herpertz and colleagues (9). However, very limited research exists as to the prevalence rates of eating disorders in adult males with type 1 diabetes, to the extent that males were excluded from a meta-analysis of eight studies due to insufficient sample size (11).

Those who had a current or historical diagnosis of an eating disorder had proportionally higher rates of omitting insulin doses for weight purposes than those with no diagnosis of an eating disorder (56% compared to 6.6%). This was seen across the various eating disorders diagnosed. Across the entire sample, people who misused insulin showed significantly higher degrees of eating disorder psychopathology, particularly the group who reported misuse for weight purposes, as

measured by the EDEQ, than those who did not report insulin misuse, in line with previous research (35). Those who present with type 1 diabetes with comorbid eating disorders are considered a particularly difficult group to treat effectively (36), and they do not appear to demonstrate improved glycaemic control or reduction in insulin misuse rates following standard treatment for eating disorders (37). This, taken together with the current findings, suggests that insulin misuse for weight purposes is not a characteristic of a particular eating disorder, but may be better understood as a discrete disorder in itself, as suggested by Allan and Nash (25).

The results indicate a relationship between insulin misuse and eating disorder psychopathology that is not characterised by food restriction. Were insulin misuse not a marker of eating disorder psychopathology, it would be expected that no significant differences would emerge between the insulin misuse group and those who use correctly. In this case, however, the presence or absence of insulin misuse, and the reasons for it, appear significantly related to the degree of eating disorder psychopathology endorsed by respondents. No significant differences were seen between the groups on the Restraint subscale of the EDEQ, which measures behaviours such as restricting food intake or going without food for long periods to influence weight or shape. This suggests that both groups have similar eating patterns and insulin misuse is not due to a discrepancy in the quantity of food eaten. Meanwhile, significant differences were seen between the groups for the subscales of Eating Concern, Shape Concern and Weight, with those who misuse insulin reporting significantly higher level of concern on these scales. A similar finding was seen with those who misuse insulin reporting greater levels of “feeling fat” and negative perceptions of their body shape.

However, it may be important to note that a dichotomy appeared to emerge between those who misuse insulin for weight purposes and those who misuse for other reasons, which replicates a trend observed by Polonsky *et al.* (35). Diabetes-related distress levels were significantly higher amongst those who misuse insulin than those who don't, and it was the only significant predictor of insulin misuse identified from the variables. The authors of the DDS suggest that a mean score greater than three represents distress that is worthy of clinical attention (29). The insulin misuse group had mean scores exceeding three on all but one scale of the DDS (physician-related distress), which suggests that a clinically concerning level of diabetes-related distress is experienced by people who misuse insulin, with the highest score being seen for the Emotional Burden subscale ($M = 3.97$, $SD = 1.44$). The questions that comprise this subscale may tap into a feeling of loss of control over one's life or health as a result of living with diabetes (e.g. "Feeling overwhelmed by the demands of living with diabetes" and "Feeling that I will end up with serious long-term complications, no matter what I do").

Research suggests that those who misuse insulin have lower levels of both general and diabetes-related self-efficacy (22), which is the belief of an individual that they can successfully execute and complete a behaviour in order to achieve the desired outcome (38), and these findings appear to support that. Further research suggested that insulin misuse is more likely when an individual feels that they have broken a strict dietary rule (39). Attempting to adhere to strict rules may decrease perceived self-efficacy, leading to a greater sense of being unable to manage the demands of diabetes and increasing the likelihood of insulin misuse. Targeting an individual's belief about their ability to manage diabetes, to empower them to feel more confident, may be a useful intervention in this scenario.

Strengths and Limitations

The findings of this study are strengthened by the large sample size, and by the inclusion of men, as much of the previous research was limited to females. However, men are underrepresented in the sample, and the results may not be generalisable to men with type 1 diabetes as a whole. The male sample size also limited the analyses available, as many analyses could not be carried out on males exclusively due to lack of statistical power. This limited investigations into insulin misuse in men and between-groups differences for men and women. The online recruitment strategy may have captured a group who are more likely to seek help and peer support, which may have influenced the findings. Equally, those who do not actively engage with online diabetes support communities were unlikely to be well represented in the sample.

The measures used may have been more appropriate for a female sample and may have failed to capture male concerns adequately, particularly the Body Shape Questionnaire. The shape and weight concerns of men and women may differ, with women aiming for thinness and men preferring to gain muscle (40); thus, caution must be exercised in interpreting the results for men on the basis of the measures used. Similarly, neither the EDEQ or BSQ were adapted for a diabetes-specific population, and this may have impacted the specificity of the data collected. The study also relied on anonymous self-report methods. This reduced participant burden and may have encouraged honest reporting, but it also prevents elaboration and clarification if needed. Finally, the cross-sectional nature of the study limits the interpretation of causality.

Clinical Relevance

This study has a number of implications for research and practice. It expands on the very limited body of evidence regarding insulin misuse in males and also provides insight into an adult population, which is also under-studied in this regard. Further research that specifically addresses insulin misuse practices in males would be valuable.

This study highlights the importance of understanding insulin misuse in people with type 1 diabetes. The disclosure of insulin misuse may be suggestive of a risk of disordered eating or difficulties managing the burden of diabetes and should be investigated further. Use of screening tools to identify the frequency and reasons for insulin misuse may be helpful for healthcare professionals working in both diabetes and eating disorder teams.

There is some evidence to suggest that insulin misuse for weight loss or control is a valid construct and should be considered separately from current eating disorder diagnostic labels. Patients who misuse insulin should be offered tailored treatment approaches where possible, designed to target the underlying reasons for insulin misuse. Given the relationship with diabetes-related distress, taking a less rigid approach to insulin management may be beneficial, as it may support some people in feeling better able to manage the demands of diabetes. Finally, given the high rates of diabetes-related distress experienced by those with type 1 diabetes, along with the increased prevalence of insulin misuse and eating disorder psychopathology, a multidisciplinary approach should be used to support both the physical and mental health of people with type 1 diabetes.

Acknowledgements

This paper was prepared as part of a thesis portfolio for a Doctorate in Clinical Psychology at the University of East Anglia. Diabetes.org.uk and Diabetics with Eating Disorders (DWED) supported participant recruitment by advertising the study on their websites and Twitter sites. There are no conflicts of interest to declare.

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Chapter Four

Extended Methodology

This chapter provides further information on the methodology employed in the empirical paper, including information on ethical considerations, procedure and statistical considerations.

4.1 Ethical Considerations

A number of ethical issues were considered for this study.

4.1.1 Ethical Approval. Ethical approval for this study was granted by the Faculty of Medicine and Health Sciences (FMH) at the University of East Anglia (UEA). See approval letter attached in Appendix B.

4.1.2 Language. The survey was initially entitled "Exploring the relationship between insulin misuse and eating attitudes and behaviour in adults with type 1 diabetes". Following feedback from participants at an early stage of the recruitment process regarding the perception of the term "misuse" as blaming, an amendment was submitted to the Chair of FMH Ethics requesting permission to alter the survey wording to "Exploring the relationship between insulin use and eating attitudes and behaviour in adults with type 1 diabetes". Permission for this amendment was granted, and the letter confirming this is attached in Appendix C.

4.1.3 Confidentiality. Participants were informed as to the anonymous nature of the study and information was provided regarding how their responses would be stored in a confidential and secure manner on the participant information sheet (PIS; Appendix D). No personally identifying information was required. Participants had the option of providing their email addresses at the end of the study for a chance to win a £25 Amazon gift card, and to receive a brief copy of the findings. The PIS outlined that the winner of the gift card would be chosen by a random lottery and contacted via the email address provided once the data collection had been completed. In order to ensure and protect anonymity, this information was

stored separately to the survey responses in a secure, password-protected file. This file will be destroyed as soon as those who have requested a copy of the results have been contacted by email.

4.1.4 Informed Consent. The PIS included information regarding the nature and duration of the study to allow for informed consent. Contact details for the author were provided to answer any questions that participants may have at any point. Participants read a short online consent form prior to beginning, in which they were asked to tick a box to indicate their understanding and consent (Appendix E).

4.1.5 Withdrawal. It was made clear that participants were free to withdraw from the study at any time they wish with no repercussions, by using the "Exit This Survey" button that was displayed on every page of the survey. Due to the inability of the author to identify specific responses, it was not possible to remove the data of any individual respondent once it had been submitted, but this was not requested by any participant.

4.1.6 Debriefing and Protection of Participants. A short debrief page was provided at the end of the survey with contact details for the author (Appendix F). The measures used in the study had the potential to cause mild distress for participants. Broad information regarding the nature of the measures was provided as part of the informed consent procedure. Along with their right to withdraw, the PIS clearly outlined the right of participants to not answer any question that they did not wish to. Furthermore, as part of the debrief, signposting towards support services was included. Due to the anonymous nature of the research, it was not possible for the author to make direct contact with participants in the event of concern, and this was outlined clearly in the consent form.

4.2 Psychometric Properties of Measures Used

4.2.1 Insulin Measure. Psychometric information for this measure is in development. Full details of this measure can be seen in Appendix G.

4.2.2 The Eating Disorder Examination-Questionnaire. A review of the psychometric properties of the EDE-Q (Berg, Peterson, Frazier, & Crow, 2012) indicated that test-retest reliability ranges from 0.66 to 0.94 for subscale scores, with acceptable internal consistency (Cronbach's α: 0.70 to 0.93). In this study, Cronbach's α was .94. Full details of this measure can be seen in Appendix H.

4.2.3 Body Shape Questionnaire (BSQ). Acceptable test-retest reliability (.88) was reported, along with good concurrent validity (Rosen, Jones, Ramirez, & Waxman, 1996). In this study, Cronbach's α was .98. The lead author, Dr Melanie Bash (nee Taylor) gave permission for the wording of the questionnaire to be altered to use gender-neutral terms (M. Bash, personal communication, May 16, 2017). Full details of this measure can be seen in Appendix I.

4.2.4 Diabetes Distress Scale (DDS). Internal consistency for the whole scale is excellent (Cronbach's α: 0.93), and good for the subscales (Cronbach's α: 0.88 – 0.9). The scale has good validity (Polonsky et al., 2005). In this study, Cronbach's α was .95. Full details of this measure can be seen in Appendix J.

4.3 Adjustments to Insulin Measure

The insulin measure designed by Ames (2017) was initially developed as a quantitative measure, with options for participants to include narrative responses. Participants provided qualitative information on the reasons that they did not take insulin as prescribed. This information was analysed using a thematic analysis approach and five themes were extracted: "a) Prioritising: forgetting and the demands of daily lifestyle, b) Diabetes related emotional distress, c) Weight control,

d) Avoidance: Fear of physical effects, and e) Adaptive responses to managing blood sugar levels" (Ames, 2017). With the author's approval (S. Ames, personal communication, April 2017), and based on these themes, the questions were transformed into quantitative questions for this study, using the above themes as multiple-choice options. "Weight Control" was split into "Weight Control" and "Weight Loss" to better capture the specifics of this behaviour. An "Other" option was added to allow for reasons that were not included in the multiple-choice options, where qualitative information could be provided by participants. Given that the changes made to the scale were minor and were made based on the findings of the thematic analysis carried out by the author (Ames, 2017), pilot testing of the adjustment was not considered necessary.

4.4 Extended Procedure

As described in the empirical paper above, a cross-sectional design using self-report questionnaires was used. Several advantages were afforded by this design, including the level of anonymity offered, which has been found to reduce levels of bias when reporting sensitive personal information (Schroder, Carey, & Vanable, 2003), and the generalisability of results and ease of data collection (Sturgis, 2006). In diabetes specifically, the accuracy of self-report has been found to be good (Huerta, Tormo, Egea-Caparrós, Ortolá-Devesa & Navarro, 2009). The presence of depressive symptoms has been identified as a predictor of accurate reporting in a diabetic population (Molenaar, Ameijden, Grobbee & Numans, 2006). Similarly, people with eating disorders self-report weight very accurately, on average (McCabe, McFarlane, Polivy & Olmsted, 2001). Thus, it is reasonable to expect that self-reporting would yield accurate results in this population. There were, however, some disadvantages to this method. There was a risk of a biased sample, as

this method only captured responses from those who have the means and interest to engage with online support communities.

Following ethical approval, the gatekeepers for online support communities, including diabetes.co.uk, diabetes.org.uk, Diabetics with Eating Disorders (DWED), Beat and JDRF (formerly known as Juvenile Diabetes Research Foundation) were initially approached by email. They were asked for permission to post information about the proposed study on their web forums, social media pages and online newsletters. JDRF declined to be involved and numerous attempts to make contact with both Beat and diabetes.co.uk yielded no response. Diabetes.org.uk and DWED both agreed to facilitate recruitment by posting details of the study online. Following discussion, details regarding the study and requests for participants were posted in the agreed locations.

In addition, a Twitter account was created for the study, as a strong online diabetes community was identified. Adverts for the study were posted on a frequent basis to Twitter using "hashtags" to widen the reach of the post. These posts were often "retweeted" by prominent members of the online diabetes community on an entirely voluntary basis. Approximately 230 retweets of the original tweets were recorded. The UEA email address of the author was provided to allow potential participants to get in touch with any questions, comments or concerns they may have had during the study.

The survey was hosted on Online Surveys (https://www.onlinesurveys.ac.uk) via a dedicated account for the study. Participants first read an information page regarding the study, consent, and their right to discontinue at any time (Appendix D). If they wished to continue, they read further statements regarding consent and were asked to indicate their consent to continue by selecting an option (Appendix E).

It was estimated that the survey would take no longer than 30 minutes to complete. Participants completed the measures outlined above, which were presented as follows: demographics; insulin measure; EDE-Q; BSQ; Diabetes Distress Scale. The decision was made to order the measures in this manner as a degree of discontinuation was expected, and it was hoped that this order would allow the maximum number of responses to the insulin questionnaire. However, Online Surveys does not currently have the facility to download incomplete datasets, and so only complete datasets were included in the final analysis.

4.5 Data Preparation and Screening

4.5.1 Assumption of Normality. The survey was conducted online, and the software used generated results that could be directly imported into SPSS, reducing the chance of errors in data entry. Nonetheless, the data were manually screened for errors, such as numbers that were outside the range of possible scores. No errors were identified.

The results for the continuous measures were assessed for normality. However, given the large sample size ($N = 219$), many standard indicators of normality (e.g. values of skewness and kurtosis) are not recommended for use as they will pick up on even minor deviations (Field, 2009). The Kolmogorov-Smirnov and Shapiro-Wilk tests both indicated a significant deviation from normality for all measures. Given that these tests are also sensitive to sample size, histograms were used to assist in the interpretation of normality. These suggested that the data were non-normal.

Consideration was given to using non-parametric test alternatives, which do not require a normal distribution. Nonparametric tests are less sensitive than parametric tests, however, and may fail to detect differences between groups that

parametric tests would pick up (Pallant, 2013). The decision on whether it is appropriate to use parametric or non-parametric analyses is a controversial one in the health sciences (Norman, 2010). The violation of the assumption of normality is a frequently cited reason as to why parametric statistics are not appropriate. Norman (2010) cites research dating back to 1931 that indicates that parametric analyses such as t-tests and ANOVA are robust to violations of normality. Furthermore, Lumley, Diehr, Emerson and Chen (2002) ran a number of simulations and concluded that parametric statistics such as t-tests are perfectly valid for non-normal data, given a large enough sample size (the authors did not specify what "large enough" is, but suggested that it would apply to sample sizes greater than 100). Having considered the literature, and in consultation with the programme's Statistics Tutor, the decision was made to proceed with parametric analyses, given the large sample size.

4.5.2 Outliers. At times, outliers in the data were detected. Given the method of data collection, along with prior manual screening, these outliers were not a result of data entry or measurement errors, which suggests that they reflected genuinely unusual scores. There are a number of options available to deal with outliers, including removing the problematic cases, transforming the data or changing the score (Field, 2009). Removing a case from an analysis because it is an outlier is a controversial approach that is only recommended in the event that there is strong evidence to suggest that the case does not belong to the population being targeted (Field, 2009). In this study, there was no identifiable evidence to suggest that this was the case.

It is possible to transform data in the event that data are also non-normal. However, transformation must be applied to all variables when they are to be used in an analysis (Field, 2009) and the type of transformation that is appropriate depends

on the skew of the data. The type of skew might differ between variables and transforming data might be successful for one particular variable but may negatively impact another variable in the analysis (Field, 2009). Finally, Field (2009) suggests that, in the event that transformation fails, the scores can be changed using a number of mathematical approaches.

After considering the available options, the decision was made to present the data as-is, without any transformations or adaptations for outliers. This facilitates a more honest description of the results and avoids highlighting any individual responses as 'problematic'.

4.6 Power Analyses

Calculating the power of statistical tests helps to avoid Type II errors (i.e. false negatives; Clark-Carter, 2010). A generally accepted power value is .8 (Clark-Carter, 2010) and this value can be used prospectively in conjunction with effect size (*d*) to determine appropriate sample sizes that are required to achieve the given level of power. As mentioned in the empirical paper, a medium effect size (.5) was used to calculate sample sizes, based on previous research (Ames, 2017) and discussion with the UEA Statistics Tutor. Power tables provided by Clark-Carter (2010) and G*Power version 3.1 were used for these calculations.

4.6.1 Chi-squared. Power analysis for a chi-squared test (df = 1) was conducted to determine a sufficient sample size using an alpha of .05, a power of .80 and a medium effect size (d = .5). Based on these assumptions, a total sample size of 32 was required.

4.6.2 Logistic Regression. Power analysis for a logistic regression was conducted to determine a sufficient sample size using an alpha of 0.05, a power of 0.80, an odds ratio of 1.5 and two-tailed test. Based on the aforementioned

assumptions, the desired sample size was 208. Guidance for this analysis was provided by Faul, Erdfelder, Lang and Buchner (2007) and Faul, Erdfelder, Buchner and Lang (2009).

4.6.3 *t*-tests. Power analysis for a two-tailed between-groups t-test was conducted to determine a sufficient sample size using an alpha of .05, a power of .80 and a medium effect size (d = .5). Based on these assumptions, a total sample size of 128 participants is required, or 64 per group.

4.6.4 One-way multivariate analysis of variance (MANOVA). Power analysis for a MANOVA with three levels and three dependent variables was conducted to determine a sufficient sample size using an alpha of .05, a power of .8. and a medium effect size (f2(V) = .0625). Based on these assumptions, a total sample size of 114 was required.

Chapter Five

Extended Results

This chapter elaborates on some of the findings from the empirical paper and provides details of further analyses that could not be included in the empirical paper due to a word count limit set by the chosen journal.

5.1 Discontinuations

Seventy-seven people discontinued the survey without finishing. Of these, three did so during the demographics section, 34 did so during the Insulin Measure, 31 did so during the EDEQ, 5 during the BSQ and 4 during the DDS. It must be noted that the study design allowed for participants to take a break from completing the survey and to return to it later. It is possible that people may have paused and intended to return, but either forgot or did so after the survey had been closed to further respondents. The curve was generally bell-shaped, indicating a normal distribution of discontinuations.

5.2 Insulin Measure

5.2.1 Characteristics of doses likely to be omitted. Of those who provided qualitative information about whether there is a particular insulin dose that they are likely to omit (N = 213), 117 (55%) replied that they do not omit a particular dose (or do not omit at all). Thirty-three people (15%) identified a period from ‘evening’ to ‘night’, including around dinner time, as the time that they’re likely to omit, 12 people (6%) endorsed omitting in the morning and another 12 people reported lunchtime as the most frequent time they omit a dose. Other occasions that were described including during work times, prior to exercise, when the person had been snacking and when they were in the presence of other people.

5.2.2 Associations with Mood. When asked if their mood affected their likelihood of taking insulin as prescribed, 99 (46%) people responded that it did not. Another 102 people (48%) agreed that their mood impacted their insulin adherence,

with low mood specified by 21 people as a reason and 11 people specifying frustration with diabetes as a reason. With regard to whether taking insulin affects their mood, 114 people (53%) of people denied this, while 79 people (37%) were clear that taking insulin impacts their mood. The remainder of the responses were unsure about the relationship between insulin and their mood. Some illustrative responses provided are described in Table 5.1. These responses indicate that the relationship between mood and insulin is a complex and personal one, with many factors that may have an impact.

Table 5.1

Select responses regarding the association between insulin and mood

Question	Sample Responses (Direct quotations)
Does your mood affect how you take insulin?	"Yes, low mood affects my level of attention/willingness to deal with my condition."
	"Occasionally, yes. More often than not it is apathy and ignorance as well as frustration about my diabetes that would affect how I take insulin"
	"Yes because I sometimes hate having diabetes and the way other people have made me feel about it can make me feel very self conscious"
	"Yes, when feeling negative it becomes overwhelming having to calculate carbs and having fear of hypos"
	"yes, bad/low/depressed mood stops me jabbing, as I don't see the point and when i feel and look fat."
	"Yes, depression happens then less inclined to take insulin, whereas mh team think not taking insulin is cause of my depression"
	"Yes even though i know i have to take it and what happens when i dont if im in a bad mood i dont take it either because i go into denial or i just dont care"
Does taking insulin affect your mood?	"Yes - it feels like such a burden and I am petrified of complications"
	"Yes - sometimes I feel frustrated by the inconvenience of it, especially if I am stressed or pushed for time."
	"Yes, usually makes me feel better when levels get in range."
	"Yes, I feel worse mentally when I've taken it almost as if I've given in or cheated"
	"Yes, I think when taking it regularly I feel slightly more upbeat"
	"I feel better when I do but I still resent it"
	"Yes, I feel happier when I take insulin and feel well, but anxious when I take it that I'll put on weight"

5.3 Predictive Analysis

Further details of this analysis are provided below, as this information could not be included in the Empirical Paper due to journal restrictions.

Given the categorical nature of the dependent variable (insulin misuse), a binomial logistical regression was appropriate. The Box-Tidwell (1962) procedure was used to assess the linearity of the continuous variables (EDEQ, BSQ and DDS scores) with respect to the logit of the dependent variable. As is recommended when multiple comparisons are being performed (Tabachnick & Fidell, 2007), a Bonferroni correction was applied for the eight terms in the model, resulting in a statistical significance threshold of $p < .00625$ being applied. As a result of this, the continuous independent variables were confirmed as linearly related to the logit of the dependent variable.

When testing for outliers, Field (2009) suggests that Standardised Residual values above 3 should be inspected more closely as they may represent outliers in the data. Four values exceeding 3 were identified and each dataset was examined individually. Each respondent denied purposefully misusing insulin. No datasets were removed from the analysis following this investigation.

The results of the model are described in detail in Chapter Three. However, to investigate if the results of this model would differ between males and females, the dataset was split and the analysis was repeated as above, with gender removed as a predictor variable.

5.3.1 Males. The model was statistically significant, $\chi 2(3) = 14.154$, $p = .003$. It explained 35% (Nagelkerke R^2) of the variance in insulin misuse and correctly classified 76.6% of cases. Specificity was 81.8% and sensitivity was 72%. The positive predictive value was 81.82% and the negative predictive value was

72%. However, none of the variables were significant predictors of insulin misuse in males. See Table 5.2 for full details.

5.3.2 Females. The model was again found to be statistically significant, $\chi 2(3) = 34.321$, $p < .0005$. It explained 26% (Nagelkerke R^2) of the variance in insulin misuse and correctly classified 77.2% of cases. Specificity was 42.9% and sensitivity was 91%. The positive predictive value was 79.9% and the negative predictive value was 65.6%. Again, neither EDEQ nor BSQ were predictors of the likelihood of insulin misuse in women, with diabetes-related distress acting as a significant predictor. See Table 5.3 for full details.

Table 5.2

Logistic Regression Predicting Likelihood of Insulin Misuse in Males

	B	SE	Wald	*df*	*p*	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
EDEQ	-.983	.747	1.732	1	.188	.374	.087	1.617
BSQ	0.58	.033	3.109	1	.078	1.060	.994	1.130
DDS	.708	.404	3.065	1	0.80	2.029	.919	4.483
Constant	-3.731	1.402	7.087	1	0.008	.024		

Table 5.3

Logistic Regression Predicting Likelihood of Insulin Misuse in Females

	B	SE	Wald	*df*	*p*	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
EDEQ	-.348	.295	1.396	1	.237	.706	.396	1.258
BSQ	0..9	.009	1.086	1	.297	1.009	.992	1.026
DDS	.933	.220	18.034	1	.000	2.541	1.652	3.909
Constant	-1.951	.583	11.219	1	.001	.142		

5.4 One-way multivariate analysis of variance (MANOVA)

Again, this section provides further details of this analysis that were not included in the Empirical Paper due to journal restrictions.

To investigate differences between those who do not misuse insulin, those who misuse for weight purposes and those who misuse for other reasons on scores of the EQEQ, BSQ and DDS respectively, a MANOVA was performed. The data were coded into groups depending on misuse. When a participant indicated that they misuse insulin for weight purposes, they were coded into that group regardless of any other reasons they may have provided for misusing insulin. Data are expressed as mean ± standard deviation.

When testing the assumptions of a MANOVA, a small number of univariate and multivariate outliers were identified by inspection of a boxplot. The datasets were further inspected, and the decision was made to include them in the analysis, as they appeared to reflect genuinely unusual values as opposed to an error. Violations of the assumptions of normality were found. However, a MANOVA is considered

quite robust to a violation of this assumption (Laerd Statistics, 2015) so the decision was made to proceed without transforming or otherwise manipulating the data. For further information on this decision, see the Data Preparation and Screening section (93). Pearson correlation was used to screen for multicollinearity, and none was detected. Linear relationships were confirmed between the variables, as assessed by scatterplots. Box's test of equality of covariance matrices confirmed homogeneity of variance-covariances matrices ($p = .310$).

People who misuse insulin for weight purposes scored more highly on all three measures (3.12 ± 1.11, 140.97 ± 42.53, 4.22 ± 1.14, respectively) than both the other insulin misuse group (1.63 ± 1.18, 91.00 ± 43.84. 3.14 ± 1.10) and the group who did not misuse insulin (1.29 ± 1.04, 70.50 ± 35.75, 2.18 ± 1.09).

The differences between the groups on the combined dependent variables was statistically significant $F(6, 430) = 16.255$, $p < .0005$, Pillai's Trace = .370, partial $\eta^2 = .185$. Given the unequal sample sizes between the groups, Pillai's Trace was used in preference to Wilks' Lambda.

Post-hoc tests were carried out to determine whether the variables were contributing in a statistically significant manner to the model. Each variable appeared to be acting in this manner. There was a statistically significant difference on EDEQ scores between all three insulin misuse groups, $F(2, 216) = 30.759$, $p < .0005$, partial $\eta^2 = .222$. There was also a statistically significant difference on BSQ scores, $F(2, 216) = 32.638$, $p < .0005$, partial $\eta^2 = .232$, and on DDS scores, $F(2, 216) = 40.313$, $p < .0005$, partial $\eta^2 = .272$. As there are three dependent variables in the model, the level of significance was adjusted to .017 using a Bonferroni correction.

As discussed previously, Tukey HSD post-hoc analyses indicated those who misuse insulin for weight purposes had significantly higher mean scores on the EDEQ than those who do not misuse insulin at all ($p < .0005$) and those who misuse insulin for non-weight reasons ($p < .0005$). However, EDEQ mean scores were not statistically significantly different between those who misuse insulin for non-weight purposes and those who do not misuse insulin ($p = .119$). There was a statistically significant difference between all groups for scores on the BSQ and DDS measures ($p < .01$).

5.5 Exploratory Analyses

Given that previously published research has tended to focus on the experience of females with type 1 diabetes, it would be beneficial to further explore the experiences and perceptions of males with type 1 diabetes. In this study, only 47 males with type 1 diabetes were recruited, despite a broad recruitment strategy. Between-gender analyses may be useful to guide future research, but the number of male datasets available for this study precluded adequately powered between-groups analyses being carried out, as a minimum of 64 per group is suggested (see Extended Methodology section for further details). Nonetheless, useful information may be gathered despite the limitation of being under-powered, with the understanding that the results presented below are intended only to guide future research and are intended to be interpreted with significant caution.

5.5.1 Scores on Individual Measures. The group scores on the individual measures are reported in Table 5.4.

Table 5.4

Mean Group Scores on Measures (N = 219)

Measure	*M*	*SD*	95% CI for Mean	
			Lower	Upper
EDEQ Total	1.78	1.27	1.58	1.92
EDEQ Restraint	1.77	1.60	1.56	1.99
EDEQ Eating Concern	1.27	1.43	1.08	1.46
EDEQ Shape Concern	2.15	1.44	1.95	2.34
EDEQ Weight Concern	1.80	1.29	1.63	1.98
BSQ Total	92.07	46.87	85.83	98.32
DDQ Total	2.99	1.29	2.83	3.17
DDS Emotional Burden	3.51	1.55	3.31	3.72
DDS Physician-Related Distress	2.57	1.53	2.37	2.78
DDS Regimen-Related Distress	2.91	1.49	2.71	3.10
DDS Interpersonal Distress	2.87	1.51	2.67	3.07

5.5.2 EDEQ. Norms have typically been calculated for the EDEQ using female samples (e.g. Fairburn & Beglin, 1994; Mond, Hay, Rodgers & Owen, 2006), and limited data is available for norms for combined genders. To compare group scores in this study with published norms, the dataset was split by gender and two-tailed independent samples t-tests were conducted to compare whether significant differences in scores were reported between the current group with type 1 diabetes

and norms established by gender for US college students (Quick & Byrd-Bredbenner, 2013). Results can be seen in Tables 5.5 and 5.6.

Table 5.5

*Comparison between mean EDEQ scores for males in the current group compared to norms**

Scale	*M*	*SD*	*M*	*SD*	*t*	*p*
	Type 1 Diabetes (*N* = 47)		Normed Sample* (*N* = 915)			
EDEQ Restraint	1.17	1.29	0.96	1.28	1.12	.26
EDEQ Eating Concern	0.600	0.90	0.40	0.71	1.86	.06
EDEQ Shape Concern	1.37	1.29	1.36	1.36	0.05	.96
EDEQ Weight Concern	1.14	1.04	1.07	1.18	0.39	.69
EDEQ Total	1.07	0.99	0.95	.98	0.82	.41

Note. df = 960. *Norms obtained from Quick & Byrd-Bredbenner (2013)

Table 5.6

*Comparison between mean EDEQ scores for females in the current group compared to norms**

Scale	*M*	*SD*	*M*	*SD*	*t*	*p*
	Type 1 Diabetes (*N* = 171)		Normed Sample* (*N* = 1,533)			
EDEQ Restraint	1.94	1.65	1.35	1.43	5.04	< .0001
EDEQ Eating Concern	1.46	1.50	0.89	1.09	6.22	< .0001
EDEQ Shape Concern	2.36	1.41	2.39	1.63	0.23	.82
EDEQ Weight Concern	2.00	1.30	1.98	1.60	0.16	.88
EDEQ Total	1.94	1.28	1.65	1.30	2.77	.0056

Note. df = 1702. *Norms obtained from Quick & Byrd-Bredbenner (2013)

No significant differences are seen on EDEQ scores between males with type 1 diabetes and a non-clinical sample of US college-age males. For females,

significant differences are seen between the type 1 diabetes population and a non-clinical sample of US college-age females for Restraint, Eating Concern and the Total score. When a Bonferroni correction was applied for the five items in the analysis, a significance level of .01 was required. The differences between groups remained statistically significantly different. However, the differences are non-significant on the Shape and Weight subscales, which may suggest that the differences could be related to the pressures of maintaining a healthy diet that come with type 1 diabetes as opposed to eating disorder psychopathology.

As the EDEQ is not designed with a clinical "cut-off" score, it is not possible to determine how many individuals may have indicated clinically concerning scores.

5.5.3 BSQ. The author of the BSQ suggests that a score of < 80 suggests no concern with body shape, while a score of 80 – 110 suggests "mild concern". Overall, the group scored in the "mild concern" range; however, differences were seen when the data were separated by gender. An independent t-test was performed to investigate differences between males (M = 58.36; SD = 27.34) and females (M = 101.56; SD = 46.92) with type 1 diabetes on the BSQ, which found that females scored statistically significantly higher than males, $t(127.935) = 8.051$, $p < .0001$ (assuming unequal variances). These results suggest that males with type 1 diabetes do not report body shape concern, while women report "mild concern". It must be noted that the wording of the BSQ does tend to align with female body shape concerns more than male concerns, so this result must be interpreted with caution.

Individually, seven males (15%) and 30 females (17.5%) scored within the "mild concern" range of the BSQ, and three men (6%) and 29 women (17%) scored within the "moderate concern" of 111 to 140. No males, but 43 females (25%), scored in the "marked concern with shape" range, requiring a score of 140 or higher.

5.5.4 DDS. Significant differences were seen between males and females for diabetes-related distress, with women reporting greater degrees of distress. The results of the between-groups t-test are reported in Table 5.7.

Table 5.7

Differences between males and females on DDS scores

	M	*SD*	*M*	*SD*	*t*	*p*
	Males (*N* = 47)		Females (*N* = 171)			
DDS Total	2.47	1.30	3.14	1.25	-3.199	.002
DDS Emotional Burden	2.91	1.62	3.67	1.49	-3.045	.003
DDS Physician-Related Distress	2.15	1.54	2.68	1.51	-2.089	.038
DDS Regimen-Related Distress	2.40	1.41	3.04	1.49	-2.620	.009
DDS Interpersonal Distress	2.29	1.55	3.03	1.46	-3.038	.003

Note. df = 216 (equal variances assumed).

Significant differences were seen on total score and all subscales. When a Bonferroni correction was applied for the five items in the analysis, a significance level of .01 was required, and a significant difference was no longer observed between groups for physician-related distress. The authors of the DDS suggest that a score of 3 or higher suggests a clinical level of distress (Polonsky *et al*., 2005). Clinical distress levels were not observed in mean scores for male participants, but the mean score for females was above 3 on all subscales, with the exception of physician-related distress.

Individually, 16 males (34%) and 91 females (53%) scored 3 or higher on the DDS total scale. Nineteen males (40%) and 109 females (64%) scored 3 or higher on the Emotional Burden subscale; 11 males (23%) and 72 females (42%) scored 3 or higher on the Physician-Related Distress subscale; 14 males (30%) and 86 females (50%) scored 3 or higher on the Regimen-Related Distress subscale; and nine males

(19%) and 85 females (50%) scored 3 or higher on the Interpersonal Distress subscale.

Chapter Six

Discussion and Critical Evaluation

This chapter will provide an overview of the whole thesis portfolio, including summary and discussion of the main findings reported, along with additional findings reported in the extended methodology and results chapters. It will provide links between these findings and previous literature, as well as critically appraising the strengths and limitations of this portfolio. Finally, clinical and theoretical implications of this research will be discussed, along with suggestions for future research.

6.1 Research Aims

This portfolio aimed to investigate insulin misuse in people with type 1 diabetes, with particular reference to the relationship between insulin misuse and eating disorder psychopathology, and the impact of diabetes-related distress. The systematic review aimed to address a gap identified in the literature with regard to the experiences of men with type 1 diabetes in relation to insulin misuse for the purposes of weight control or loss. It aimed to investigate whether men reported this behaviour, and the prevalence rates of the behaviour. The empirical paper aimed to explore insulin misuse amongst adults with type 1 diabetes in more detail, specifically exploring the rates of insulin misuse reported, the relationships between insulin misuse and eating disorder psychopathology, perception of body shape and diabetes-related distress, and whether gender differences existed.

6.2 Summary of Main Findings

The systematic review indicated that men do report insulin misuse for the purposes of weight loss or control. However, prevalence rates could not be determined due to the heterogeneity between the included studies. It was noted that men did not report insulin misuse for weight purposes when assessed via the use of a semi-structured interview, but varying rates were reported via self-report

questionnaires. A lack of standardised measure for insulin misuse was highlighted as a reason for difficulty in comparing between studies, as this meant that significantly different approaches were used between studies to operationalise the behaviour.

The empirical paper established that a significant proportion of respondents reported insulin misuse, with fewer than 35% of participants reporting adhering correctly to their insulin regime. Women were more likely to misuse insulin than men, both for weight control purposes and in general. Insulin misuse for weight purposes was common amongst participants with a current or historical diagnosis of an eating disorder (56%), but just over 6% of participants with no history of an eating disorder reported engaging in this behaviour. Significantly higher levels of disordered eating behaviours were seen amongst people who misused insulin than those who didn't report insulin misuse, along with significantly worse perceptions of their body shape and higher levels of diabetes-related distress. Regimen-related distress emerged as a particularly strong issue amongst people who misused insulin.

A logistic regression was carried out to understand whether and how the variables act together to affect insulin misuse. Including EDEQ scores, BSQ scores, DDS scores and gender in the model explained 29.1% of the variance, but the only significant predictor identified was diabetes-related distress, with greater levels of diabetes-related distress associated with higher likelihood of insulin misuse.

A MANOVA allowed the opportunity to investigate between insulin misuse groups. Three groups were identified, namely those who misused insulin for weight purposes, those who misused for other reasons but did not endorse misusing for weight, and those who denied misuse. As would be expected, the misuse for weight group scored significantly more highly than the other groups on the EDEQ and BSQ, but also significantly more highly on DDS. All three groups had scores that were

statistically significantly different from each other on the BSQ and DDS, while the misuse for weight group had significantly higher scores on the EDEQ than the other two groups, who did not differ significantly between each other on the EDEQ.

Overall, the most common reason for insulin omission reported by both men and women was that something else took priority at the time, followed by negative feelings about diabetes. However, taking an incorrect dose was most commonly done for either reasons of avoidance or fear of physical effects, or for planning around the potential for hypoglycaemia.

The findings gave support to the hypothesis that insulin misuse for weight purposes may not be a symptom of eating disorders as currently recognised by the DSM-5 but may be better understood as a distinct construct that deserves individual attention in order to inform and improve treatment outcomes.

6.3 Summary of Additional Findings

In general, no strong pattern was identified with regard to the characteristics of specific insulin doses that were likely to be omitted. Of those who felt there was a pattern to their omission, the evening or night-time dose appeared to be the most frequently omitted. This may be worth further investigation as the long period between dinner and breakfast may increase the risk of hyperglycaemia occurring while sleeping. Hyperglycaemia may negatively affect sleep by increasing the frequency of urination, and poor sleep may make it harder to closely monitor glycaemic control the following day. This has the potential to cause a vicious cycle for people with type 1 diabetes that makes it harder to regain good glycaemic control.

The sample was split evenly in perception of whether there was an association between insulin and mood. The dichotomy was striking, given that the

majority (53%) denied an association, but those that identified an association felt quite strongly about the link. One participant even commented “This is a daft question… Of course [taking insulin] does [affect my mood]”. Low mood and frustration with diabetes were identified as reasons for difficulty with correct adherence.

Further exploration through logistic regression, with gender removed as a variable and the dataset instead split by gender, indicated that the model explained 35% of the variance for males but none of the variables were significant predictors of insulin misuse. In females, the model explained 26% of the variance with diabetes-related distress again acting as the only significant predictor of insulin misuse. It must be noted that the small male sample size inhibits interpretation of the findings, as females may mask males in the overall model.

Finally, tentative exploratory analyses were carried out with the aim of guiding future research. These analyses suggested that males with type 1 diabetes did not differ from a non-clinical sample on EDEQ scores, while females with type 1 diabetes differed significantly from a non-clinical female sample for subscales related to eating, but not to weight and shape, which may be consistent with the demand of managing diabetes. Women with type 1 diabetes also scored significantly more highly than men with type 1 diabetes on the BSQ, but this may be influenced by the wording of the questions, which over-represent female shape concerns compared to males. Females also scored significantly more highly than males on the DDS, but again this must be interpreted with caution due to the underpowered nature of the analyses on the male group.

6.4 Strengths and Limitations

This portfolio has a number of strengths. Type 1 diabetes is relatively under-investigated compared to type 2 diabetes. This may be influenced by the relative numbers of people affected by each condition, with only 10% of people with diabetes having type 1. However, type 2 diabetes has the potential to be controlled or even reversed through lifestyle adjustments, while type 1 diabetes is a chronic disorder that cannot be cured at this time. Thus, an argument could be made that the psychological impact of type 1 diabetes is potentially greater than that of type 2 diabetes and is an area deserving of more attention in the research literature. This study provides an insight into the experiences of people with type 1 diabetes exclusively, avoiding the common approach in the literature of combining the two conditions and potentially masking the subtleties and nuances of living with type 1 diabetes.

The systematic review was the review was the first of its kind to focus on the experiences of males with type 1 diabetes with regard to insulin misuse for weight purposes. Previous studies in this area have focused on the experiences of females which has resulted in a poor understanding of insulin misuse and weight control in males. According to the Hierarchy of Evidence, a systematic review is generally considered to provide an excellent level of evidence which provides a strong scientific base for informing clinical practice (Evans, 2003). Carrying out this review allowed for the conclusion to be drawn with reasonable certainty that men do report misuse insulin for the purposes of weight loss or control, and this finding can inform clinical practice.

The empirical study was well-received by the type 1 diabetes community. A good sample size was gathered, allowing for statistically powered analyses to be

undertaken. Some feedback from participants included comments such as "*some issues very close to home here, which nobody speaks about so well done for reaching out to ask some rather taboo questions*", "*Going through anxiety / depression issues so the not taking my insulin part fitted in nicely with this questionnaire*" and "*It's an interesting side to* [type 1 diabetes]... *my diet is stupid just to keep my sugars normal, (and therefore my weight is low) but obviously the other way - high sugars and no food, is so much worse*".

Recruiting through online support communities allowed direct contact with potential participants, while maintaining confidentiality and anonymity in responding, and recruitment was bolstered by high-profile members of the community endorsing participation in the study. It was hypothesised that self-report measures may yield a more accurate representation of the prevalence of insulin misuse, and the results are in line with findings in other research that used self-report measures (e.g. d'Emden *et al.*, 2013; Neumark-Sztainer, 2002). The insulin measure used (Ames, 2017) was developed in collaboration with healthcare professionals and service users, allowing for a robust investigation into the reasons and frequency of insulin misuse based on both previous research and stakeholder input.

However, in common with most studies in this field, there were some limitations. Heterogeneity across studies included in the systematic review precluded the estimation of prevalence rates for insulin misuse in males for weight purposes, nor could the studies be directly compared statistically. Another limitation was that planning for the empirical study took place prior to completing the systematic review. The results of the systematic review lent themselves to further research and an emphasis may have been put on recruiting more male respondents had these been known at an earlier stage.

The measures used to assess eating disorder psychopathology were limited due to their female focus and lack of adaptation for a diabetes sample. The EDEQ was included on the basis of it being considered to be the gold standard self-report assessment tool for eating disorders; however, it may have been more suitable to use a measure such as the Diabetes Eating Problem Survey Revised (DEPS-R; Antisdel, Laffel & Anderson, 2001) which is specific to type 1 diabetes and includes a consideration of insulin misuse for weight purposes as a type of disordered eating behaviour. It is a 16-item measure with excellent internal consistency (Cronbach's $\alpha = 0.86$), construct validity and external validity (Markowitz *et al.*, 2010). However, internal validity has been found to be weaker for males than females (Cronbach's $\alpha = 0.81$ and 0.90, respectively), and it is a brief screening tool that explores behaviours in less depth than the EDEQ (Wisting, Frøisland, Skrivarhaug, Dahl-Jørgensen & Rø, 2013).

The BSQ was adapted with permission to use gender-neutral terms (the original refers specifically to "other women"), but it transpired that the questions were still quite specific to female concerns, and not representative of the range of shape concerns that may be present in both genders. This was highlighted in feedback from some participants. One female participant noted "*I did find the questions a bit hard to answer, because there weren't any options for wanting to lose weight, or being bothered about body shape, because of the fear of carrying too much visceral fat (having a thick waistline) which is what worries me if I put on a few pounds. All the questions that touched on body shape were whether you had a problem with what your bottom and thighs were like, which I don't have a problem with, but then it made my answers to some of the other questions look a bit strange.*", while an email received from a male participant stated "*a lot of the questions seemed*

geared to people feeling as though they are too large or too fat. I don't have that worry and, in my experience not too many people with type 1 diabetes do. Rather it's the opposite, I am very thin, and male, and fit more closely into the '9 stone weakling' or 'mr muscle' body shape than the muscular and brawny shape which is stereotypically seen as attractive or something to strive for among men".

This connects with a general limitation of research regarding eating disorders in males, as there are currently no known measures of eating disorder psychopathology specific to males, and none specific to men with type 1 diabetes. A further limitation was the lack of depth and detail that could be captured by self-report questionnaires.

Finally, the recruitment strategy for the empirical study had several advantages, as outlined above, but also had disadvantages. Recruitment was broadly restricted to those who engage with online support communities, which risked missing a subsection of the population who do not routinely engage with the diabetes community online. A selection bias may have been at play, with those motivated to complete the survey potentially being more likely to seek support overall and to be open about difficulties in managing type 1 diabetes (Greene, Choudhry, Kilabuk & Shrank, 2011). This may have yielded over-inflated scores on the Diabetes Distress Scale and failed to capture the perspectives of those who feel they are managing their diabetes successfully. Similarly, without a biological measure of glycaemic control, a potential for over- or under-reporting of insulin misuse could not be controlled for. However, research suggests that self-report regarding medication adherence correlates reasonably well with other measures of adherence and can significantly predict clinical outcomes (Stirratt *et al*, 2015).

6.5 Theoretical Implications

The systematic review confirms that insulin misuse for weight purposes is reported in men with type 1 diabetes, albeit with currently unclear prevalence rates. This has previously been dismissed by researchers who have failed to find evidence of the behaviour in individual studies (e.g. Fairburn *et al*, 1991). In the present study, three men (6.4%) reported omitting insulin for weight loss or control and the same proportion reported taking an incorrect dosage for this purpose. The findings lend support to the hypothesis that men are more likely to report engaging in this behaviour when given the opportunity to respond through a self-report measure, as opposed to reporting it directly to a clinician. To get a more detailed understanding of this, further research will be required.

Further, the systematic review highlights the difficulty in effectively assessing insulin misuse, while the empirical paper provides an insight into information that can be gathered through an effective measure of insulin misuse. However, psychometric properties of this measure are still in development, which limits its current scope. Both studies highlight the need for the development of tools for the assessment of eating disorder psychopathology in men. Current measures are failing to capture male concerns adequately, as they tend to emphasise a desire for thinness over muscularity. A lack of such a measure makes it more challenging to assess the relationship between insulin misuse and weight or shape concerns in men.

A striking finding was the differences in reported rates of insulin misuse amongst those with a current or historical diagnosis of an eating disorder, compared to those with no reported history of an eating disorder. Insulin misuse for the purposes of weight loss or control was reported across the spectrum of eating disorder categories. This suggests two possibilities: 1. That people with type 1

diabetes develop an eating disorder and may misuse insulin as a means to achieve their weight goals, or 2. That insulin misuse is not simply a symptom of an eating disorder but may be part of a discrete eating disorder experienced by people with type 1 diabetes that is currently under-recognised by healthcare professionals. Further exploration of this in future research may be beneficial.

A landmark study by Jones *et al.* (2000) found that binge eating occurred significantly more frequently in participants with diabetes compared to controls, but the control group engaged in significantly higher rates of dieting for weight loss. At the same time, significantly higher numbers of participants with diabetes met criteria for both threshold (2.4 times more likely) and subthreshold eating disorders (1.9 times more likely) compared to non-diabetic controls. The majority of those with diabetes were classified as having an Eating Disorder Not Otherwise Specified (EDNOS). For the group with diabetes, insulin omission was the most common form of weight loss behaviour reported. Taken together, these results suggest that people with type 1 diabetes are more likely to binge eat and to restrict insulin to lose weight, as opposed to dieting, which is preferred by a non-diabetic population.

Berger *et al.* (2019) found that those with type 1 diabetes and eating disorders were also likely to take too much insulin in order to facilitate uncontrolled and binge eating. This may link with the cognitive model of bulimia nervosa (Cooper, Wells & Todd, 2004) which suggests that the activation of a negative belief about the self leads to a cascade of negative automatic thoughts about acceptance by oneself or others with associated emotions of guilt, depression or anxiety. This may lead to a desire to 'comfort eat'. In bulimia, this causes a conflict due to both positive and negative beliefs held about eating. In diabetes, a similar conflict may emerge between the desire to eat and the awareness of the implications of over-

eating on diabetes. Cooper *et al.* (2004) suggest that this leads to the emergence of "permissive thoughts", which either provide permission to eat or absolve feelings of personal responsibility. This leads to binge eating and the development of a vicious cycle, as negative self-appraisals will likely follow a binge.

The results of the current study confirm that insulin misuse for the purposes of weight loss or control occurs in both males and females, and that it occurs in an adult population. This is significant as previous research has tended to focus on adolescent females, excluding males and adults with type 1 diabetes (e.g. Affenito *et al.*, 1997; Colton *et al.*, 2004; Peveler *et al.*, 2005; Rydall *et al.*, 1997). Increased recognition and understanding of this behaviour across the spectrum of people with type 1 diabetes may lead to earlier identification and improved outcomes.

These findings may lend support to the hypothesis that, for people with type 1 diabetes, the presence of insulin misuse for weight loss or control may be best understood not as OSFED, as it is commonly categorised, but possibly as a separate category such as diabulimia. However, the term diabulimia is controversial and is not commonly used by healthcare professionals for this reason. One argument is that it only represents bulimic symptomology and does not address other types of disturbed eating behaviours in people with diabetes (Colton, Rodin, Bergenstal & Parkin, 2009; de Paoli & Rogers, 2018). Another argument is it implies a distinction between eating disorders amongst those with diabetes and those without (Colton *et al.*, 2009). As insulin misuse is only available to people with diabetes, it could be argued that a distinction already exists between eating disorders amongst those with diabetes and those without, and this distinction is characterised by insulin misuse. Colton *et al.* (2009) proposed that the preferred nomenclature should be Eating Disorder – Diabetes Mellitus Type 1 (ED-DMT1).

Individuals with diabetes have reported rejection of the term diabulimia by professionals in healthcare settings as being "made up on the internet" (Allan, 2015). Despite this, the term appears to have been adopted by the diabetes community and is a preferred term to refer to the behaviour of insulin misuse for weight control or loss (Allan, 2015). It is beyond the scope of this study to suggest what the preferred term should be, but the views and experiences of individuals with type 1 diabetes should be considered when identifying preferred nomenclature. The lack of a clear diagnostic term poses difficulties for healthcare professionals, who have reported a lack of clarity about what constitutes "problematic" behaviour, combined with an lack of knowledge about the availability of specialist support services, which can cause a sense of anxiety in a healthcare professional when faced with a type 1 diabetes patient who reports disturbed eating and/or insulin misuse (Tierney, Deaton & Whitehead, 2009).

Group treatment programmes for eating disorder have been found to contribute to the development of normative changes to group identity, which can lead to improved outcomes (Cruwys, Haslam, Fox & McMahon, 2015), but someone with diabulimia may struggle to identify with the group, given the unique nature of their difficulties, and this may hinder their recovery (Hastings, McNamara, Allan & Marriott, 2016). On this basis, it has been suggested that treatment for insulin misuse and disordered eating behaviours for people with type 1 diabetes should involve the development of a shared recovery identity with similar others that emphasises treatment engagement and disclosure of illness (McNamara & Parsons, 2016). Such a group membership may be helpful in providing psychological resources that promote recovery, when carefully managed (Hastings *et al.*, 2016).

6.6 Clinical Implications

The results of this study support the previous research that insulin misuse, encompassing the omission of insulin doses, underdosing and overdosing of insulin, is a relatively widespread behaviour amongst people with type 1 diabetes, and it provides further evidence that this occurs across age groups and genders. As outlined above, the potential consequences of insulin misuse are serious and potentially life-threatening. The results strongly suggest that healthcare professionals working with individuals with type 1 diabetes should routinely screen for insulin misuse. The results of this study indicate that a large proportion of people with type 1 diabetes may be reluctant to admit insulin misuse to their diabetes team, meaning this behaviour may be shrouded in some secrecy with a reluctance to admit it in a face-to-face setting. Clinicians could consider administering a screening questionnaire at routine appointments, such as the insulin measure created by Ames (2017) and using the results of that measure to guide appropriate interventions.

The presence of insulin misuse may be suggestive of further difficulties, particularly disordered eating or diabetes-related distress. In the case of disordered eating, evidence suggests that psychoeducation may be useful in some regards, but it may not positively impact glycaemic control (Olmsted, Rodin, Rydall, Lawson & Daneman, 1997). For clinicians working in eating disorder services, it is important to be aware that type 1 diabetes necessitates paying close attention to portion size and calorie content of all food consumed, and treatments for eating disorders that encourage taking a relaxed approach to eating are unlikely to be beneficial for people with type 1 diabetes (Goebel-Fabbri, 2009). Equally, clinicians working in diabetes services should be sensitive to the negative feelings that may be associated with weight gain as a result of insulin therapy and the links between this and insulin

misuse (Goebel-Fabbri, 2009). Furthermore, the results of this current study suggest that diabetes-related distress should be screened for, and that the presence of insulin misuse may be suggestive of clinical levels of diabetes-related distress.

Interventions that have been shown to improve levels of self-efficacy may be beneficial (e.g. Snoek *et al.*, 2008). In a randomised controlled trial of patients with type 2 diabetes, higher regimen-related distress was associated with greater levels of medication nonadherence and higher HbA1c levels cross-sectionally, and reductions in regimen distress over time resulted in improved medication adherence and HbA1c (Hessler *et al.*, 2014). Taking a less rigid approach to diabetes self-management, such as being taught skills to integrate diabetes into one's life through a flexible diet with daily insulin adjustment, rather than trying to live a life around diabetes, has been shown to improve HbA1c levels, reduce the impact of diabetes on quality of life and improve general wellbeing (DAFNE Study Group, 2002). Less intensive approaches to dietary management may also be useful, as strict rules around diets have been found to be associated with eating disorder symptomology and higher BMIs in a non-clinical sample (Stewart, Williamson & White, 2002). Providing further skills to support self-efficacy through a carbohydrate-counting course was found to improve quality of life, knowledge of diabetes, coping abilities and HbA1c levels in people with type 1 diabetes (Trento *et al.*, 2009).

Overall, a multidisciplinary care team, including medical management, nutritional input and psychological support is considered the best way to support individuals with type 1 diabetes with disordered eating and/or insulin misuse, along with preventing the development of same (Larrañaga, Docet & García-Mayor, 2011).

As discussed previously, rates of mental health difficulties appear to be higher amongst people with type 1 diabetes than a non-clinical population. The same

appears to be true for paediatric populations with a variety of chronic illnesses (Chapman, Perry & Strine, 2005; Pinquart & Shen, 2010). The presence of depressive disorders, in particular, appears to contribute to more complications in the treatment of chronic illness (Chapman *et al.*, 2004). A recent systematic review found that children with chronic illnesses that are diet-treated, including but not limited to diabetes, are at risk of developing eating disorder psychopathology, and that the illness preceded the disordered eating. Again, the diagnosis of a chronic illness in childhood may benefit from multi-disciplinary input, particularly psychological support, from the point of diagnosis to attempt to mitigate the risk of mental health disorders, including disordered eating, developing.

Finally, the results of this study suggest that insulin misuse is a complex and multi-faceted problem. Using a formulation-based approach to understand the reasons behind insulin misuse for each individual may underpin the identification of appropriate treatment approaches.

6.7 Future Work

Despite a broad recruitment strategy, the majority of respondents for the empirical study were female (78%). This is in line with findings from similar research using an online recruitment strategy (e.g. Ames, 2017; Araia *et al.*, 2017). Overall, females have been over-represented in the research regarding insulin misuse in type 1 diabetes to date (de Paoli & Rogers, 2017). To balance this, it would be useful for future research to focus on the experience of males. Currently, very little is known about the reasons that men may misuse insulin, and a useful starting point may be to qualitatively investigate this to best inform and guide future quantitative studies.

Equally, much of the research to date has focused on adolescent populations, so further research that focuses on the experiences of adults would be beneficial. Recent longitudinal research suggests that the emergence of disordered eating in females with type 1 diabetes occurs in adulthood, with over 20% of the sample aged over 23 when disordered eating behaviours emerged, and 40% were over 25 when an eating disorder emerged (Colton *et al.*, 2015). Focusing on adolescent populations risks under-representing an important clinical issue in adult populations. Colton *et al.* (2015) also excluded males, which further emphasises the under-representation of males in studies of eating disorder psychopathology and type 1 diabetes.

The systematic review highlighted the use of custom, unvalidated questionnaires by researchers to assess insulin misuse. The insulin measure designed by Ames (2017) goes some way towards offering a standardised assessment. Further work to validate and generate norms for this measure would be beneficial, as a standardised measure would allow for more meaningful comparisons of data in future research. However, Ames' (2017) would also benefit from further refinement, including the separation of those who report careful and considered reasons for taking their insulin in a manner different to prescribed, such as anticipating low blood sugar due to reasons such as sport. This group is currently captured along with the broader "insulin misuse" group, which is generally aimed to identify problematic reasons for insulin misuse.

Insulin overdosing as an individual construct was not explored in detail in this paper. Preliminary evidence suggests that insulin overdosing may be used to facilitate binge eating (Berger *et al.*, 2019), while insulin underdosing or omission may be related to weight loss or control (Schober *et al.*, 2011; Snyder *et al.*, 2016).

Further research into the reasons for both behaviours would advance the knowledge base regarding these behaviours.

Diabetes-related distress emerged as a key factor in insulin misuse for people with type 1 diabetes. Previous research has identified diabetes-related distress as a factor in poor glycaemic control and poor self-care for people with diabetes, which has not been found for depression (Delahanty *et al.*, 2007; Fisher *et al.*, 2010; Hessler *et al.*, 2014). Further research focusing on interventions that reduce diabetes-related distress may be beneficial for identifying pathways to reduce insulin misuse.

Finally, this study also provides evidence for there being both 'proactive' reasons along with more 'reactive' reasons for insulin misuse. As such, and in line with feedback from people with diabetes, 'insulin misuse' as a term may be perceived as 'blaming' or 'shaming', particularly when many people take insulin differently than prescribed for planned reasons. Potentially appropriate terms for future research could include 'insulin use not as prescribed (NAP)' or 'insulin use not as directed (NAD)'. These terms both allow scope for discussion of taking insulin differently for both proactive reasons, such as planning ahead to prevent hypoglycaemia during exercise, and more reactive occurrences, such as not taking insulin due to embarrassment, fear of weight gain or for reasons related to diabetes distress. The terms also allow for the expertise of the person living with diabetes, without being judgemental or blaming. It would be useful to discuss these terms with members of the diabetes community to ensure that they align with lived experiences and are not perceived negatively by individuals with diabetes.

6.8 Conclusions

The current research investigated insulin misuse in people with type 1 diabetes. Insulin misuse occurs in both adult males and females with type 1 diabetes. It is associated with diabetes-related distress, and also with eating disorder psychopathology and body shape dissatisfaction. It occurs more frequently in women than men, and a variety of reasons were provided for the behaviour. Contrary to some previous research, men do report insulin misuse for the purposes of weight loss or control, but prevalence rates could not be established due to variation in methodology. Routine and regular screening for insulin misuse should be considered by clinicians working in both diabetes and eating disorders services, as it may be suggestive of further difficulties. Those who misuse insulin, particularly in the context of disordered eating, may benefit from individual and tailored treatment approaches to improve their overall wellbeing and physical health outcomes.

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Appendices

Appendix A

Formatting Guidance for Diabetes Care Journal

Available from http://care.diabetesjournals.org/content/instructions-for-authors#Section6

Diabetes Care **Instructions for Authors**

Original Articles

Original Articles should be arranged in the following order: title page, structured abstract, introduction (no heading), Research Design and Methods, Results, Conclusions, Acknowledgments, References, tables, and figure legends.

- A **structured abstract** is required for all Original Articles. Abstracts for an Original Article should not exceed 250 words. (This is not to be confused with abstracts submitted to the Annual Scientific Meeting, for which the word limit is higher.) The abstract must be self-contained and clear without reference to the text and should be written for a general journal readership. The abstract format should include four sections: Objective (the purpose or hypothesis of study), Research Design and Methods (the basic design, setting, number of participants and selection criteria, treatment or intervention, and methods of assessment), Results (significant data found), and Conclusions (the validity, limitations, and clinical applicability of the study and its results).
- The **Conclusions** section should discuss the findings of the study in the context of past research concerning the topic of the article, in particular highlighting how these findings add new information. Also, this section should, where possible, assess the possible clinical relevance of the findings avoiding any claim or terminology of

superiority, especially when statistically significant but quantitatively modest differences are found.

- The **word count limit** for Original Articles is 4,000 words, excluding words in tables, table legends, figure legends, title page, acknowledgments, and references.
- The article should contain no more than **40 references** and the reference section should be single spaced with justified margins.
- The article should contain no more than a combination of **4 tables and/or figures**.
- A conflict-of-interest statement for all authors must be included in the Acknowledgments section of the main document, which should follow the main text and precede the references. If there are no relevant conflicts of interest to disclose, authors should indicate as such in the Acknowledgments section.
- In the case of **multicenter studies**, authors should provide a list of participating investigators in an appendix to the paper. Papers will not be reviewed if this information is not included.
- Where appropriate, **clinical and epidemiological studies** should be analyzed to see if there is an effect of sex or ethnicity. If there is no effect, it should be stated as such in the Results section.
- **Randomized Clinical Trial Reporting**. Authors of reports on randomized controlled trials are required to use the instructions and checklist in the Consolidated Standards of Reporting Trials (CONSORT) Statement. The instructions and checklist are designed to ensure that information pertinent to the trial is included in the study report. CONSORT information may be included in a supplemental material online-only file so that it does not affect word count limitations.

- All **clinical trials** submitted to *Diabetes Care* for consideration of publication must be registered with a clinical trial registry approved by the International Committee of Medical Journal Editors (ICMJE). Please see Clinical Trials for more information.

Diabetes Care Guidelines for Systematic Reviews and Meta-Analyses

Systematic reviews and meta-analyses are systematic, critical assessments of literature and data sources pertaining to clinical topics that emphasize factors such as cause, diagnosis, prognosis, therapy, or prevention. Meta-analyses that address questions for which there is clinical equipoise are preferred.

All articles or data sources should be searched for and selected systematically for inclusion and critically evaluated, and the search and selection process should be described in the manuscript. The specific type of study or analysis, population, intervention, exposure, and tests or outcomes should be described for each article or data source (PICOS format). The data sources should be as current as possible, ideally with the search having been conducted within several months of manuscript submission.

For meta-analyses of randomized controlled trials, follow PRISMA reporting guidelines and checklist. For meta-analyses of observational studies in epidemiology, follow MOOSE reporting guidelines.

Meta-analyses and systematic reviews not following these guidelines will not be peer reviewed. Additional criteria appear below.

Title

Include either “meta-analysis” or “systematic review,” as appropriate, in a subtitle following the title.

Abstract

Word limit: 250 words

Structure with the following headings: Background, Purpose, Data Sources, Study Selection, Data Extraction, Data Synthesis, Limitations, Conclusions.

Manuscript

Word limit: 5,000 words (excluding abstract and references)

Please format with the following sections: Introduction, Methods, Results, and Discussion.

End the Introduction section with a clear statement of the study’s objectives or hypotheses.

The Methods section should include the following subheadings: • Data Sources and Searches

• Study Selection

• Data Extraction and Quality Assessment • Data Synthesis and Analysis

For studies that have numerical data and use statistical inference, include a section under Methods that describes the methods and specific statistical software used for the statistical analyses.

References: minimum 40, maximum 60 citations

Tables and figures: Any combination of 4 tables and/or figures will be accepted—Include a flow diagram that depicts search and selection processes, along with evidence tables.

MANUSCRIPT FORMAT AND STYLE

Articles must be in clear and understandable English. Nonnative English authors are encouraged to seek the assistance of an English- proficient colleague, or a communications agency, such as American Journal Experts, to help improve the clarity and readability of a paper before it is submitted to the journal.

For specific information on the parameters and limits for various manuscript categories (e.g., section headings, word limits, etc.), see Manuscript Categories.

Title Page

All submissions, regardless of article type, require a title page. The title page should include the following: full title; a short running title (less than 47 characters and spaces combined); the first name, middle initial, last name, and highest academic degree of each author; each author's affiliation (in English) during the time the study was conducted; contact information of the corresponding author (name, current address, telephone number, fax number, and email address); and the word count and number of tables and figures.

If two authors have equal authorship, it may be noted by * under the author list.

Main Document

The main document file includes the title page, abstract, main text, acknowledgements, references, tables, and figure legends, in that order. Please do not use headers, footers, or endnotes in your paper.

The Main Document should be in Word document format (not as a PDF). This will allow our Editorial Office to verify word count and our production staff to convert your paper (if accepted) into an article.

Text Composition

Articles should be written in clear, concise English following the recommendations for scientific writing found in *Scientific Style and Format*, the Council of Science Editors (CSE) style manual (7th ed., 2006, Reston, VA, Council of Science Editors). All accepted manuscripts will be edited according to the CSE style manual and *The Chicago Manual of Style* (16th ed., 2010, Chicago, IL, The University of Chicago Press) by ADA professional publications staff. The authors are responsible for all statements made in their articles or editorials, including any editing changes made by staff. Proof pages will be sent to the corresponding author and should be read carefully.

The designations *type 1 diabetes* and *type 2 diabetes* should be used when referring to the two major forms of diabetes. Abbreviations for diabetes, such as T2D for *type 2 diabetes*, should not be used. The term *diabetic* should not be used as a noun.

All manuscripts should be double-spaced, in Arial or Times New Roman 12-point font, and saved as a .doc, .txt, or .rtf file. In addition, please do not lock or page protect your document, and avoid using footnote and endnote functions.

Abbreviations and Units

Abbreviations should be used only when necessary, e.g., for long chemical names (HEPES), procedures (ELISA), or terms used throughout the article. See the list of abbreviations that need not be defined; all others must be defined at first use.

Abbreviate units of measure only when used with numbers. Abbreviations may be

used in tables and figures. The American Medical Association style manual contains lists of standard scientific abbreviations.

Clinical laboratory values and units should be in Système International (SI) form. Kilocalories should be used rather than kilojoules.

HbA1c values should be dually reported as "% (mmol/mol)." Please use the NGSP's HbA1c converter at http://www.ngsp.org/convert1.asp to calculate HbA1c values as both % and mmol/mol.

Font and Margins

Text, including title and author names, should be in 12-point Arial or Times New Roman. Please avoid using boldface font. Text in tables should be no smaller than 10-point font. Margins should be 1' at the top and bottom and 1" on the left and right sides.

Acknowledgments

The acknowledgments are located after the main text and before the reference list. Acknowledgments should contain the author contributions paragraph, brief statements of assistance, the guarantor's name (person[s] taking responsibility for the contents of the article), funding/financial support, conflict of interest statement, and reference to prior publication of the study in abstract form, where applicable.

References

Please place the reference list after the main text and acknowledgments (if applicable). Original Articles are limited to 40 references. Letters are allowed 5 references. Review articles are allowed 60 references, and meta-analyses should have no more than 40 references.

Reference numbers in the text should appear in chronological order in normal type and in parentheses [e.g., "In the study by Norton et al. (23)..."]. Please do not use the footnote or endnote function to cite studies or create a reference list. A reference manager must have the ability to customize the display of references. For example, the reference application should have the option to list the references at the end of the paper, as opposed to listing the references as endnotes or footnotes at the bottom of each page, and should not embed the list in the text as a series of endnotes/footnotes. When using a reference manager (e.g., Thomson's EndNote Reference Program), don't forget to generate the list as a bibliography in a style suitable to *Diabetes Care*, and then save and submit as the final step to creating the references. Otherwise, references should be manually inserted.

All authors must be listed by first initials and last name in each reference, and please provide inclusive page numbers. Journal titles should be abbreviated according to the National Library of Medicine's List of Journals Indexed for Medline; for unlisted journals, please provide complete journal titles. Material in press may be cited, but copies of such material may be requested. Authors are responsible for the accuracy of the references. Click here for examples of how references should be formatted.

Supplemental Material

Nonessential tables, figures, and/or videos may accompany articles as online-only supplemental material files, but authors are asked to include a comment to the editor at the time of manuscript submission that explains the rationale and justification for submitting and possibly posting the supplemental information.

All online-only supplemenal material files should be combined in one document file whenever possible and uploaded during the submission process. The file must be clearly labeled as "Online-Only Supplemental Material." In addition, supplemental

material online-only files must be referenced in the main text of the manuscript at least once (e.g., Supplemental Table S1).

All online-only supplemental material files are subject to peer review but will not be composed, copyedited, or proofread by production staff. As such, authors are encouraged to review supplemental material files carefully before submission.

Lists that include names of **principal investigators or writing groups** may appear in print or as online-only supplemental material. Lists of names exceeding 150 words should be submitted as online-only supplemental material. Names of principal investigators or writing groups should otherwise be included in an in-text appendix, located at the end of the main document before the references.
Supplemental material containing very large datasets should be cited in the text with a URL to the material hosted on an author-affiliated website or data repository or may appear with a note that the data is available upon request to the author.

Tables

Each table should be inserted on a separate page at the end of the document with the table number, title, and legend indicated. Table legends should be inserted below the table and should not be included inside the table. Tables should be created using Word and the "Insert Table" command. Please use Arial or Times New Roman font, no smaller than 10 point. Tables with internal divisions are not allowed (i.e., Tables 1*A* and *B*) and should be submitted as individual tables (Tables 1 and 2). Please avoid using shading within a table. If a table includes data that require explanation in the legend, apply the following sequence of symbols, from top to bottom, left to right: *, †, ‡, §, ||, ¶, #, **, ††, ‡‡.

Figures

Diabetes Care uses digital publishing methods throughout the production process. If your article is accepted, it will be published in both the print and online journal. The following sections provide information on how to format your figures to ensure the best possible reproduction of your images.

Size. Figures should be produced at the size they are to appear in the printed journal. Please make sure your figures will fit in one, two, or three columns in width. Multipaneled figures should be assembled in a layout that leaves the least amount of blank space.

- 1 column = 13 picas wide, 2.2 in, 5.6 cm
- 2 columns = 28 picas wide, 4.6 in, 11.7 cm
- 3 columns = 41 picas, 6.8 in, 17.3 cm

Font. At 100% size, fonts should be 8–10 points and used consistently throughout all figures.

Text. Information on the axes should be succinct, using abbreviations where possible, and the label on the *y*-axis should read vertically, not horizontally. Key information should be placed in any available white space within the figure; if space is not available, the information should be placed in the legend. In general, figures with multiple parts should be marked A, B, C, etc., with a description of each panel included in the legend rather than on the figure.

Line and bar graphs. Lines in graphs should be bold enough to be easily read after reduction, as should all symbols used in the figure. Data points are best marked with the following symbols, again assuring that they will be readily distinguishable after reduction: ○ ● □ ■ △ ▲. In the figure legend, please use words rather than the symbols; e.g., "black circles = group 1; white squares = group 2; black bars = blood glucose; white bars = C-peptide." Bars should be black or white only, unless

more than two datasets are being presented; additional bars should be drawn with clear bold hatch marks or stripes, not shades of gray.

Appendix B

Ethical Approval – granted following submission of required amendments

Faculty of Medicine and Health Sciences Research Ethics Committee

Victoria Matthews
MED

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16.1.18

Dear Victoria,

Title: Exploring the relationship between insulin misuse and eating disorder psychopathology in adults with type 1 diabetes
Reference: 2017/18 - 36

Thank you for your e-mail notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely,

Professor M J Wilkinson
Chair
FMH Research Ethics Committee

Appendix C

Ethical Approval granted for minor amendment

Faculty of Medicine and Health Sciences Research Ethics Committee

Victoria Matthews
MED

Research & Innovation Services
Floor 1, The Registry
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

6.3.18

Dear Victoria,

Title: Exploring the relationship between insulin misuse and eating disorder psychopathology in adults with type 1 diabetes
Reference: 2017/18 - 36

Thank you for your e-mail notifying us of the amendments you would like to make to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Please can you also arrange to send us a report once your project is completed.

Yours sincerely,

Professor M J Wilkinson
Chair
FMH Research Ethics Committee

Appendix D

Participant Information Sheet

Exploring the relationship between insulin use and eating attitudes and behaviour in adults with type 1 diabetes.

Researcher: Victoria Matthews (Trainee Clinical Psychologist)

Supervised by: Professor Sian Coker

Secondary Supervisor: Dr Bonnie Teague

Doctoral Programme in Clinical Psychology,

School of Medicine and Health Sciences,

University of East Anglia

Invitation and Brief Summary

We would like to invite you to take part in our research study, conducted at the University of East Anglia. Taking part in this study is entirely optional, and deciding not to participate will not affect you in any way. The study has been approved by the Faculty of Medicine and Health Sciences Ethics Committee at UEA (Final approval granted 16/01/18; Ref: 2017/18 - 36).

Before you decide, we would like to give you some information about the study, including why the research is being done, and what your involvement would be. You can then decide if you are interested in taking part. If you would like more time to think about it, you can close this window and return at a later date. Also, you can email us with any further questions that you might have about the study.

What is the study about?

We are interested in gathering information about what things might make following an insulin regime exactly as prescribed more difficult for people with type 1 diabetes. We are particularly interested in whether there is a relationship between not taking insulin as prescribed, and your eating attitudes and behaviours, how you feel about your body, your gender, and any distress experienced as a result of having and managing diabetes. The aim of the study is to try and understand whether any of these things might make managing your insulin regime more difficult. This research is being carried out as part of a Doctoral thesis in Clinical Psychology at the University of East Anglia (UEA). We hope that this kind of research can deepen our understanding and help us to better support people with type 1 diabetes.

Why have I been asked to take part?

We are interested in recruiting adults aged 18 and over, who have been using insulin to manage their **type 1** diabetes for at least 12 months. The study is open to anyone who lives in the United Kingdom. The focus of this study is on Adults with type 1 diabetes so we are **not** seeking to include adults with type 2 diabetes at this time**.** If you have type 2 diabetes we suggest that you exit the information sheet and thank you for your interest so far.

What would taking part involve?

This research will involve participants accessing online study questionnaires. You can do this on a phone, computer or tablet and complete it at your own pace. If you decide to take part, it may take you up to 45 minutes to minutes to complete the questionnaires. You can pause and exit the survey at any time by clicking the “Finish later” link. A link to finish the survey will be provided, which you can bookmark or

have emailed to yourself. Your answers will not be submitted until you finish the survey.

You will be asked some information about yourself, your insulin management, your eating attitudes and behaviours, your feelings about your body shape, and about any distress you experience that is related to your diabetes. Most of the questions involve selecting the response that you feel best fits your experience, and a small number of questions will have space for you to write in extra information if you'd like to.

There are no right or wrong answers. At the end of completing the questionnaires, you will have the option of providing an email address if you would like to be sent a summary of the study results on study completion. You can also provide your email should you wish to be entered into a prize draw as a thank you for your time completing the questionnaires.

What will happen to the information I provide?

You won't be asked to provide any information that could personally identify you (e.g. your name or date or birth). All of the information gathered will be stored on an encrypted memory stick that can only be accessed by the researchers. It will be stored as required by the Data Protection Act (1998) and UEA Policy, and all data will be destroyed after 10 years. We will not ask for any contact information, and your G.P. or any other healthcare professionals will not be informed that you are taking part; nor does the researcher have the ability to identify or contact them. There will be an opportunity to provide an email address for the chance to win a £25 amazon.co.uk gift card at the end of the study, chosen through a random lottery once the data collection phase is completed. Likewise, should participants wish to receive

a summary of the study findings, we will ask that they provide an email address for us to send these. Your email address, if you choose to provide one, will be collected and stored entirely separately from your responses to the questionnaires, and it will not be possible for anyone – including the researchers - to link your email address with your responses.

As above, your participation in the research is entirely voluntary and you may withdraw from the study at any point without giving a reason. However, as no individual's responses can be identified, once you have submitted your responses, it will not be possible for your responses to be later removed from the dataset.

What are the possible benefits and disadvantages of taking part?

There are no direct benefits to you to taking part in this research. We hope that your responses will help to guide a deeper understanding of some of the issues that people with diabetes experience, and may contribute to better support and treatment services being developed in the future.

Completing the questionnaires has the potential to provoke an emotional response, as some of the questions may relate to a delicate subject matter for you that trigger unpleasant thoughts or memories. The questionnaires are not intended to cause distress, but in the event that this occurs, you are reminded that you have the option of discontinuing the study at any at any point by clicking "Exit this survey" on any page, or you may wish to pause and re-visit the questionnaires at another time. At the point you finish or exit the study, an information sheet is provided that includes guidance on where to seek support from a variety of organisations, should you feel like you wish to do so.

What if I want to get in touch?

If you have a question or concern about any aspect of this study, you can email the researchers who will do their best to answer your questions. Their details are below. If you remain unhappy and wish to complain formally, you can do this through Professor Kenneth Laidlaw (Head of Department and Programme of the Doctorate in Clinical Psychology). Contact details are provided below

What will happen to the results of this study?

The results of this study will be written up and submitted as part of a Doctoral thesis in clinical psychology. The results may also be published in research journals and/or presented as academic conferences. All data reported, including any quotes used, will not allow personal identification of participants involved in the research. Your anonymous responses may be shared with future Clinical Psychology trainees working within the same research team for the purposes of future researchers.

Will this impact my future care?

Your future care will not be impacted at all by taking part in this study. Unless you tell them, no healthcare professionals will even be aware of your participation in this study.

Who is organising, funding and reviewing this study?

This study is organised and funded by the Doctoral programme in Clinical Psychology at the University of East Anglia. The study has been reviewed and approved by the Faculty of Medicine and Health Sciences Ethics Committee at UEA (Final approval granted 16/01/18; Ref: 2017/18 - 36).

Further information and contact details

If you have any questions or comments about the study, please first contact me directly using the contact details provided below. Alternatively, you may contact my research supervisors, Professor Sian Coker and Dr Bonnie Teague (see below for contact information). If you wish to make a complaint you can contact someone independent to the study, Professor Kenneth Laidlaw, Head of Department and Programme of the Doctorate in Clinical Psychology. Contact details are provided below

If you would like to retain this information pack and contact details for future reference, then please print this page or copy the relevant details into a file on your device. It will not be possible to return to this page once you begin the survey.

Contact Details:

Victoria Matthews

Doctoral Programme in Clinical Psychology,

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich Research Park

NORWICH, NR4 7TJ

v.matthews@uea.ac.uk

Professor Sian Coker

Doctoral Programme in Clinical Psychology,

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich Research Park

NORWICH, NR4 7TJ

s.coker@uea.ac.uk

Dr. Bonnie Teague

Doctoral Programme in Clinical Psychology,

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich Research Park

NORWICH, NR4 7TJ

b.teague@uea.ac.uk

Appendix E

Consent Form

Exploring the relationship between insulin use and eating attitudes and behaviour in adults with type 1 diabetes.

Researcher: Victoria Matthews (Trainee Clinical Psychologist)

Supervised by: Professor Sian Coker

Secondary Supervisor: Dr Bonnie Teague

Doctoral Programme in Clinical Psychology,

School of Medicine and Health Sciences,

University of East Anglia

If you do not agree with any of the following items, please feel free to exit this survey. You may return at a later date if you wish, and you may also contact the researcher to discuss any concerns that you may have by emailing v.matthews@uea.ac.uk

I confirm that I have read the participant information sheet for the above study on the previous page. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I agree

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

I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers who

are carrying out related research, such as future Clinical Psychology trainees working within this research team at the University of East Anglia. I agree

I agree to take part in the above study. I agree

Appendix F

Debrief

Thank you for taking part in this survey!

Your responses will go towards deepening our understanding of some of the issues that people living with type 1 diabetes experience on a regular basis. On behalf of myself and my fellow researchers, we really appreciate you taking the time to provide your perspective.

If you have experienced any distress as a result of any of the questions asked in this study, the following organisations may be able to provide support and/or guidance. We encourage you to reach out to these organisations if you do feel any distress.

If you would like to retain this information pack and contact details for future reference, then please print this page or copy the relevant details into a file on your device.

NHS Choices: Living with type 1 diabetes

Information and advice about living with type 1 diabetes

http://www.nhs.uk/Conditions/Diabetes-type1/Pages/living-with.aspx

Diabetes UK

Online information: https://www.diabetes.org.uk/

Local in-person support groups for people living with type 1 diabetes:

https://www.diabetes.org.uk/In_Your_Area/

Diabetes UK Online Communities:

https://www.diabetes.org.uk/How_we_help/Community/Online-communities

Diabetes UK also offer a counselling service:

Diabetes UK Helpline on 0345 123 2399 (Monday to Friday, 9am to 7pm)

helpline@diabetes.org.uk.

diabetes.co.uk

Diabetes.co.uk is a community of people with diabetes, family members, friends, supporters and carers, offering their own support and first-hand knowledge.

B-eat

Beat is the UK's eating disorder charity. They have a number of different support options available.

https://www.b-eat.co.uk/support-services

Diabetics with Eating Disorders (DWED)

DWED advocates for and represents those suffering from type 1 diabetes and eating disorders in the United Kingdom

http://dwed.org.uk/online-support

If you would like to contact the researcher to discuss any aspect of the study, please email v.matthews@uea.ac.uk. Please note that if you contact the research team you will no longer remain anonymous; however, any contact will remain confidential.

If you are experiencing significant distress, we would advise you to contact your GP.

If you would like to be emailed a brief summary of results when they are ready, please click here to provide an email address:

https://uea.onlinesurveys.ac.uk/research-findings

If you would like to be entered into a prize draw for a chance to win a £25 Amazon.co.uk gift card, please click here: https://uea.onlinesurveys.ac.uk/prize-draw

Appendix G

Insulin Questionnaire

Living with diabetes is hard work, practically, physically and psychologically. Research tells us that many people miss insulin doses sometimes. This questionnaire helps us understand why.

1. What insulin regime are you on?
    a. Long-acting
    b. Short-acting
    c. Both
2. Do you ever skip (miss out) insulin doses that you know you should take?
    a. Yes
    b. No
3. In the last 7 days, was this:
    a. Once
    b. 2 – 4 times
    c. 5 – 6 times
    d. 7 or more times
4. Were these at the same time of day?

5. How would you best describe the reason you missed an insulin dose you knew you should take (you may select more than one option)?
    a) Other things took priority at the time (e.g. travelling, work, parenting, lack of time, etc)
    b) Negative feelings around diabetes (e.g. frustration, resentment, a sense of hopelessness, loss of control, etc)

c) As a method of weight control (i.e. to avoid gaining weight)

d) As a method of weight loss

e) Avoidance or fear of physical effects (e.g. hypoglycaemia, pain around injection, etc)

f) Anticipating low blood sugar and planning around this

g) Other

6. Do you ever take less or more insulin than you know you should?

a) No

b) Yes – more

c) Yes – less

d) Yes – both

7. In the last 7 days, was this:

a) Once

b) 2 – 4 times

c) 5 – 6 times

d) 7 or more times

Were these at the same time of day?

8. How would you best describe the reason you took more or less insulin than you knew you should take? (you may select more than one option)

a) Other things took priority at the time (e.g. travelling, work, parenting, lack of time, etc)

b) Negative feelings around diabetes (e.g. frustration, resentment, a sense of hopelessness, loss of control, etc)

c) As a method of weight control (i.e. to avoid gaining weight)

d) As a method of weight loss

e) Avoidance or fear of physical effects (e.g. hypoglycaemia, pain around injection, etc)

f) Anticipating low blood sugar and planning around this

g) Other

For the following questions, please answer "Yes" or "No". Where your answer is "Yes", please elaborate where possible.

9. Is there a time of day where you would be likely to skip an insulin dose?
10. Is there a particular dose of insulin that you are likely to skip?
11. Do you feel that skipping doses, or taking more or less insulin than you should, is a problem for you?
    a) Yes
    b) No
12. Does your mood affect how you take insulin?
13. Does taking insulin affect your mood?
14. What makes you less likely to take insulin as you should?
15. What makes you more likely to take insulin as you should?
16. What would motivate you to take insulin as you should?
17. Would you, or do you, tell your diabetes team if you are missing doses?
    a) Yes
    b) No
    c) Not applicable (I do not miss doses)

Appendix H

Eating Disorders Examination Questionnaire

EATING QUESTIONNAIRE

Instructions: The following questions are concerned with the past four weeks (28 days) only. Please read each question carefully. Please answer all of the questions. Please only choose one answer for each question. Thank you.

Questions 1 to 12: Please circle the appropriate number on the right. Remember that the questions only refer to the past four weeks (28 days) only.

	On how many of the past 28 days ……	No days	1-5 days	6-12 days	13-15 days	16-22 days	23-27 days	Every day
1	Have you been deliberately trying to limit the amount of food you eat to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
2	Have you gone for long periods of time (8 waking hours or more) without eating anything at all in order to influence your shape or weight?	0	1	2	3	4	5	6
3	Have you tried to exclude from your diet any foods that you like in order to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
4	Have you tried to follow definite rules regarding your eating (for example, a calorie limit) in order to influence your shape or weight (whether or not you have succeeded)?	0	1	2	3	4	5	6
5	Have you had a definite desire to have an empty stomach with the aim of influencing your shape or weight?	0	1	2	3	4	5	6
6	Have you had a definite desire to have a totally flat stomach?	0	1	2	3	4	5	6
7	Has thinking about food, eating or calories made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?	0	1	2	3	4	5	6
8	Has thinking about shape or weight made it very difficult to concentrate on things you are interested in (for example, working, following a conversation, or reading)?	0	1	2	3	4	5	6
9	Have you had a definite fear of losing control over eating?	0	1	2	3	4	5	6
10	Have you had a definite fear that you might gain weight?	0	1	2	3	4	5	6
11	Have you felt fat?	0	1	2	3	4	5	6
12	Have you had a strong desire to lose weight?	0	1	2	3	4	5	6

Questions 13-18: Please fill in the appropriate number in the boxes on the right. Remember that the questions only refer to the past four weeks (28 days).

Over the past four weeks (28 days).....

13	Over the past 28 days, how many <u>times</u> have you eaten what other people would regard as an <u>unusually large amount of food</u> (given the circumstances)?	……..
14	….On how many of these times did you have a sense of having lost control over your eating (at the time that you were eating)?	……..
15	Over the past 28 days, on how many **<u>DAYS</u>** have such episodes of overeating occurred (i.e. you have eaten an unusually large amount of food and have had a sense of loss of control at the time)?	……..
16	Over the past 28 days, how many <u>times</u> have you made yourself sick (vomit) as a means of controlling your shape or weight?	……..
17	Over the past 28 days, how many <u>times</u> have you taken laxatives as a means of controlling your shape or weight?	……..
18	Over the past 28 days, how many <u>times</u> have you exercised in a "driven" or "compulsive" way as a means of controlling your weight, shape or amount of fat or to burn off calories?	……..

Questions 19-21: Please circle the appropriate number. <u>Please note that for these questions the term "binge eating" means</u> eating what others would regard as an unusually large amount of food for the circumstances, accompanied by a sense of having lost control over eating.

19	Over the past 28 days, on how many days have you eaten in secret (ie, furtively)?.....Do not count episodes of binge eating	No days	1-5 days	6-12 days	13-15 days	16-22 days	23-27 days	Every day
		0	1	2	3	4	5	6
20	On what proportion of the times that you have eaten have you felt guilty (felt that you've done wrong) because of its effect on your shape or weight? .....Do not count episodes of binge eating	None of the times	A few of the times	Less than half	Half of the times	More than half	Most of the time	Every time
		0	1	2	3	4	5	6
21	Over the past 28 days, how concerned have you been about other people seeing you eat? .....Do not count episodes of binge eating	Not at all		Slightly	Moderately			Markedly
		0	1	2	3	4	5	6

Questions 22-28: Please circle the appropriate number on the right. Remember that the questions only refer to the past four weeks (28 days)

	On how many of the past 28 days	Not at all		Slightly	Moderately			Markedly
22	Has your <u>weight</u> influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
23	Has your <u>shape</u> influenced how you think about (judge) yourself as a person?	0	1	2	3	4	5	6
24	How much would it have upset you if you had been asked to weigh yourself once a week (no more, or less, often) for the next four weeks?	0	1	2	3	4	5	6
25	How dissatisfied have you been with your <u>weight</u>?	0	1	2	3	4	5	6
26	How dissatisfied have you been with your <u>shape</u>?	0	1	2	3	4	5	6
27	How uncomfortable have you felt seeing your body (for example, seeing your shape in the mirror, in a shop window reflection, while undressing or taking a bath or shower)?	0	1	2	3	4	5	6
28	How uncomfortable have you felt about others seeing your shape or figure (for example, in communal changing rooms, when swimming, or wearing tight clothes)?	0	1	2	3	4	5	6

Appendix I

Body Shape Questionnaire

Over the past FOUR weeks:

Please don't select more than 1 answer(s) per row.

	Never	Rarely	Sometimes	Often	Very often	Always
Has feeling bored made you brood about your shape?						
Have you been so worried about your shape that you have been feeling you ought to diet?						
Have you thought that your thighs, hips or bottom are too large for the rest of you?						
Have you been afraid that you might become fat (or fatter)?						
Have you worried about your flesh being not firm enough?						
Has feeling full (e.g. after eating a large meal) made you feel fat?						
Have you felt so bad about your shape that you have cried?						
Have you avoided running because your flesh might wobble?						

Has being with thin people made you feel self-conscious about your shape?						
Have you worried about your thighs spreading out when sitting down?						
Has eating even a small amount of food made you feel fat?						
Have you noticed the shape of other people and felt that your own shape compared unfavourably?						
Has thinking about your shape interfered with your ability to concentrate (e.g. while watching television, reading, listening to conversations)?						
Has being naked, such as when taking a bath, made you feel fat?						
Have you avoided wearing clothes which make you particularly aware of the shape of your body?						
Have you imagined cutting off fleshy areas of your body?						
Has eating sweets, cakes, or other high calorie food made you feel fat?						
Have you not gone out to social occasions (e.g. parties) because you have felt bad about your shape?						

Have you felt excessively large and rounded?						
Have you felt ashamed of your body?						
Has worry about your shape made you diet?						
Have you felt happiest about your shape when your stomach has been empty (e.g. in the morning)?						
Have you thought that you are in the shape you are because you lack self-control?						
Have you worried about other people seeing rolls of fat around your waist or stomach?						
Have you felt that it is not fair that other people are thinner than you?						
Have you vomited in order to feel thinner?						
When in company have your worried about taking up too much room (e.g. sitting on a sofa, or a bus seat)?						
Have you worried about your flesh being dimply?						
Has seeing your reflection (e.g. in a mirror or shop window) made you feel bad about your shape?						

Have you pinched areas of your body to see how much fat there is?						
Have you avoided situations where people could see your body (e.g. communal changing rooms or swimming baths)?						
Have you taken laxatives in order to feel thinner?						
Have you been particularly self-conscious about your shape when in the company of other people?						
Has worry about your shape made you feel you ought to exercise?						

Appendix J

Diabetes Distress Scale

Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate answer.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would select "Not a problem". If it is very bothersome to you, you might select "A very serious problem".

To what degree has the following distressed or bothered you over the past month?
Please don't select more than 1 answer(s) per row.

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.						
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.						
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.						

4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.						
5. Feeling that I am not testing my blood sugars frequently enough.						
6. Feeling that I am often failing with my diabetes routine.						
7. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to						
eat the "wrong" foods).						
8. Feeling that diabetes controls my life.						
9. Feeling that my doctor doesn't take my concerns seriously enough.						
10. Not feeling confident in my day-to-day ability to manage diabetes.						
11. Feeling that I will end up with serious long-term complications, no matter what I do.						

12. Feeling that I am not sticking closely enough to a good meal plan.						
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.						
14. Feeling overwhelmed by the demands of living with diabetes.						
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.						
16. Not feeling motivated to keep up my diabetes self management.						
17. Feeling that friends or family don't give me the emotional support that I would like.						