THE ROLE OF PERFECTIONISM IN LIVING WITH A CHRONIC HEALTH CONDITION

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Abstract for Thesis Portfolio

Living with a chronic health condition may threaten existing goals or future plans, as symptoms such as pain or fatigue have the potential to affect goal attainment. People living with chronic conditions are often required to adopt goal-based self-management strategies to manage symptoms. Perfectionism is a trait associated with the pursuit and attainment of goals. This thesis portfolio aims to investigate the role of perfectionism in living with a chronic health condition; more broadly through a systematic review, and in relation to one condition – type 1 diabetes.

The systematic review aimed to investigate the role of perfectionism in functioning, symptoms, self-management, adjustment or distress in adults living with chronic health conditions. The evidence suggests that on the whole, perfectionism is associated with worse physical functioning, increased symptoms, maladaptive coping, higher levels of stress and dissatisfaction with social support across a range of conditions.

The empirical study aimed to investigate the relationship between perfectionism, self-efficacy and diabetes-related avoidance on diabetes-related distress in adults with type 1 diabetes. The study included a cross-sectional design based on 282 participants (77% female) who participated through an online survey. Perfectionism, lower levels of self-efficacy and higher levels of diabetes-related avoidance were predictors of diabetes-related distress. Adults with higher levels of diabetes-related distress had higher levels of perfectionism and diabetes-related-avoidance, and lower levels of self-efficacy compared to those with lower levels of

distress. Perfectionism was a significant predictor of avoidance in diabetes self-management, but not the frequency of blood glucose checking.

An additional results chapter addressed whether perfectionism is associated with subscales of the type 1 diabetes-related distress scale (not addressed in the empirical study). Perfectionism demonstrated statistically significant positive correlations with all subscales of the type 1 diabetes-related distress scale.

Theoretical and clinical implications based on results of the thesis portfolio are discussed.

Contents of Thesis Portfolio

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Chapter One: Introduction to the Thesis Portfolio

Introduction

This thesis portfolio aims to explore the role of perfectionism on living with a chronic health condition. The first part of the thesis addresses this aim more broadly, and the second part of thesis focuses on the role of perfectionism in a specific chronic health condition – type 1 diabetes.

The systematic review in chapter two will attempt to address the above aim in a broader sense, drawing together all of the known evidence so far on the role of perfectionism in chronic health conditions. The review will cover two areas. Firstly, the role of perfectionism in health-related outcomes in chronic health conditions (e.g. symptoms, quality of life, functioning, or management). Secondly, the role of perfectionism in adjustment to or distress associated with chronic health conditions. Findings on the chronic health conditions studied and types of perfectionism measures used are also discussed.

The bridging chapter in chapter three aims to link the results of systematic review to the rationale of the empirical study. The chapter outlines theoretical models of perfectionism applied in the context of chronic health conditions, their limitations, and introduces the rationale for the empirical study.

Chapters four, five and six explore the relationship between perfectionism and diabetes-related distress in a sample of adults with type 1 diabetes. Type 1 diabetes was chosen specifically (as opposed to considering type 2 alone or a mixed sample) as it relies heavily on self-management, managing a complex range of demands, and methods of blood glucose monitoring can provide instant feedback on how well the condition is being managed. Furthermore, self-management of diabetes

can conceptually be mapped onto a cognitive-behavioural model of perfectionism (clinical perfectionism).

They aim to address the following research questions:

1. Are perfectionism, self-efficacy, and diabetes-related avoidance predictors of diabetes-related distress in adults with type 1 diabetes?
2. Do adults with high levels of diabetes-related distress differ in levels of perfectionism, self-efficacy and diabetes-related avoidance than adults with low diabetes-related distress?
3. Is there an association between perfectionism and diabetes management behaviours (e.g., diabetes-related avoidance and frequency of blood glucose checking)?
4. Does perfectionism correlate with subscales on the type 1 diabetes-related distress scale?

The empirical study in chapter four will address the first three research questions using a cross-sectional design through an online-based survey. The extended methodology chapter in chapter five will cover material not reported in the empirical study. Namely, a detailed account of the recruitment process for the study, assumptions for statistical analysis for each research question, and the results of a priori sample size calculations. The extended results chapter in chapter six will present the results in relation to research question four.

The final discussion in chapter seven aims to summarise the findings from the systematic review, results from the empirical study and additional analysis chapter. The chapter will also provide a critical appraisal of the strengths and

limitations of the thesis portfolio, theoretical and clinical implications, and recommendations for future research.

Chapter Two: Systematic Review

The Role of Perfectionism in Health-Related Outcomes and Adjustment to Chronic Health Conditions: A Systematic Review

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This review has been written in accordance to guidelines for the Journal of Clinical Psychology in Medical Settings (Appendix A).

Abstract

Perfectionism is a trait relating to the striving and pursuit of goals, with distress experienced if goals are not achieved. There has been emerging evidence for perfectionism having a role in various outcomes for people living with chronic health conditions (CHC). This review investigated the role of perfectionism in functioning and psychological adjustment in adults with CHCs. PsychINFO, CINAHL, Medline and EMBASE databases were searched and included studies if they met the following criteria: a) were English language articles, b) included an adult CHC population, c) included an empirically validated measure of perfectionism, d) included an empirically validated measure of symptoms, management, functioning, adjustment, or distress. Thirteen studies met inclusion criteria and underwent data extraction and narrative synthesis, and quality assessment using the Observational Cohort and Cross-Sectional Studies' quality assessment tool from the National Heart, Lung and Blood Institute (2014). Maladaptive perfectionism was associated with impaired functioning and symptoms for fibromyalgia, arthritis, multiple sclerosis and irritable bowel disease, and poorer psychological adjustment, social support dissatisfaction and increased stress for people with chronic fatigue syndrome, fibromyalgia, arthritis, irritable bowel disease, coronary heart disease, and spinal cord injury. More adaptive types of perfectionism were associated with reduced mortality risk in type 2 diabetes, less fatigue in multiple sclerosis, and adaptive coping in coronary heart disease. Study quality was variable and results from chronic fatigue, fibromyalgia, arthritis and spinal cord injury populations must be considered with caution. Screening for perfectionism is recommended in instances of poorer physical health and psychological adjustment.

Keywords: perfectionism, personality, chronic health condition, functioning, psychological adjustment

Introduction

Being diagnosed with a chronic health condition (CHC) may threaten existing goals or future plans, as symptoms such as pain or fatigue have the potential to affect goal attainment (Molnar, Sirois, & Methot-Jones, 2016). As such, people living with such conditions are often required to adopt self-management strategies to manage symptoms, treatment regimens, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition in order to maintain optimal health (Glasgow, Davis, Funnell, & Beck, 2003; Rijken, Jones, Heijmans, & Dixon, 2008). Furthermore, psychological adjustment may also need to occur around the extent to which the condition impacts on functioning (social, occupational or physical), and manage any distress associated with this (Graham, Gouick, Krahé, & Gillanders, 2016).

Perfectionism is a personality trait related to the pursuit and achievement of goals (Frost, Marten, Lahart, & Rosenblate, 1990) and could be considered important to understand in those living with CHCs. In this context, striving to reach self-management goals could be considered vital to achieve optimum management and health outcomes. However, some of these goals may be unrealistic. Perfectionist cognitions may influence how symptoms associated with health conditions are interpreted. For example, experiencing unwanted physical symptoms despite adhering to a self-management regimen may be interpreted as failure to manage the condition effectively (Flett, Baricza, Gupta, Hewitt, & Endler, 2011). Some people

may have unrealistic expectations about their ability to reach non-illness related goals whilst contending with symptoms, placing them at a greater vulnerability in failing to reach these and increased distress (Molnar, Sirois, & Methot-Jones, 2016).

Frost and colleagues (1990) define perfectionism as a multidimensional construct relating to "high standards of performance which are accompanied by tendencies for overly critical evaluations of one's behaviour" (page 540; Frost et al., 1990). Their definition considers multiple intrapersonal aspects around high personal standards, the need for organisation, having doubts about actions, having concern or negative reactions over mistakes, as well as managing parental expectations and criticisms. Hewitt and Flett (1991) describe an interpersonal focus of perfectionism, introducing three dimensions – self-oriented perfectionism (setting high standards for the self), other-oriented perfectionism (unrealistic standards and expectations for others) and socially-prescribed perfectionism (the need to meet standards and expectations set by others).

Further evidence has emerged to suggest that perfectionism may consist of two higher factors – adaptive perfectionism, known as 'perfectionistic strivings' – setting and striving towards high standards for the self; and maladaptive perfectionism, known as 'perfectionistic concerns' – chronic self-criticism and a preoccupation with criticism from others. Various studies have found support for a two higher-factor conceptualisation (Dunkley, Blankstein, Halsall, Williams, & Winkworth, 2000; Stoeber & Otto, 2006; Terry-Short, Owens, Slade, & Dewey, 1995), with 'perfectionistic strivings' encompassing personal standards and organisation (Frost et al., 1990), and self-oriented and other-oriented perfectionism (Hewitt & Flett, 1991), and 'perfectionistic concerns' including doubts about actions,

concern over mistakes (Frost et al., 1990) and socially-prescribed perfectionism (Hewitt & Flett, 1991). Given this, perfectionism can be considered to be adaptive and a useful motivator in striving towards goals, or maladaptive by increasing the possibility of distress or vulnerability to criticism when goals are not reached.

Perfectionism is considered to be a transdiagnostic construct, whereby elevated levels are associated with psychopathology, and may also be a vulnerability and maintenance factor in psychopathology (Egan, Wade, & Shafran, 2011). Perfectionism has been linked to depression, anxiety and eating disorders (Egan et al., 2016; Handley, Egan, Kane, & Rees, 2014), and can been linked to negatively affecting treatment outcomes in depression (Blatt, Quinlan, Pilkonis, & Shea, 1995). There is emerging evidence that perfectionism is related to depression in chronic health populations such as chronic fatigue syndrome (CFS; Deary and Chalder, 2010; Valero et al., 2013), multiple sclerosis (MS; Smith and Arnett, 2013), psychological distress in cancer (Trudel-Fitzgerald et al., 2017), maladaptive coping in irritable bowel disease (IBD; Flett et al., 2011) and coronary heart disease (CHD; Shanmugasegaram et al., 2014), and impede the effectiveness of treatment programmes for chronic pain (Kempke, Luyten, Van Wambeke, Coppens, & Morlion, 2014). Perfectionism has also been associated with worse symptoms and daily functioning CFS, and considered an underlying factor behind ‘boom and bust’ activity commonly seen in this population (Kempke et al., 2013; Kempke et al., 2011; Luyten, Kempke, van Wambeke, et al., 2011). Despite this emerging evidence, no review has been carried out to assimilate this evidence together.

The aim of this review focused on the below two questions:

1. What is the role of perfectionism in health-related outcomes in chronic health conditions (e.g. symptoms, functioning, or self-management)?
2. What is the role of perfectionism in adjustment to or distress associated with chronic health conditions?

The aim of this review did not include the role of perfectionism in mood-related disorders as another systematic review is currently underway investigating this (Wright, Fisher, Cherry, Baker, & O'Rourke, 2019).

Methods

Search Strategy

The Preferred Reporting Instrument for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used to carry out this systematic review (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). PsychINFO, CINAHL, Medline and EMBASE databases were searched in September 2019 for English language studies, with no limits on publication dates. To ensure a breadth of research was being reviewed, the search originally included all types of articles. However, this was then restricted to peer-reviewed journals due to the number of relevant papers. Articles identified from database searches were screened to remove duplicates, and screened at title and abstract levels to identify relevant papers. Relevant abstracts were examined at a full-text level against eligibility criteria. Relevant full-text papers were included and underwent data extraction. Full-text papers included in the review also underwent forwards and backwards citation to identify other relevant studies not identified in the database search, through viewing citation searches on Google Scholar and screening reference lists of included articles.

Search Terms

Previous scoping searches identified that 'perfectionism' was identified as its own construct or categorised under the MeSH term 'personality'. Search terms varied slightly in line with different databases searched and also included MeSH terms (capitalised). The following search terms were used to identify relevant papers:

Perfection* OR PERFECTIONISM OR PERSONALITY OR PERSONALITY TRAITS

AND

"Chronic Health" OR "Chronic Illness*" OR "Chronic Disease*" OR CHRONIC DISEASE OR CHRONIC ILLNESS OR FATIGUE SYNDROME, CHRONIC OR CHRONIC PAIN OR CHRONIC FATIGUE SYNDROME OR "CFS" OR "Myalgic Encephalomyelitis" OR "ME" OR Fibromyalgia OR Diabet* OR "Chronic Obstructive Pulmonary Disease" OR "COPD" OR Asthma* OR Epilep* OR "Cystic Fibrosis" OR CYSTIC FIBROSIS OR "Multiple Sclerosis" OR MULTIPLE SCLEROSIS OR Cardiac OR Coronary OR Heart OR "Irritable Bowel" OR Crohn's OR "ulcerative colitis" OR "inflammatory bowel".

Chronic health conditions included as search terms for this review were determined through reviewing the World Health Organisation's (WHO, 2008) guidelines, prevalence rates reported in national healthcare reports and guidance (National Institute for Health and Care Excellence (NICE), 2009; NHS Digital, 2019), and through discussions with the research team. CHCs identified in these searches were included if the condition required an element of self-management, defined as the activities undertaken by individuals to manage symptoms, treatment

regimens, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition in order to maintain optimal health (Glasgow et al., 2003; Rijken et al., 2008). Studies identified from the search strategy on CHCs not included in the search terms were included if they met the above definitions.

Study Eligibility

Studies were included in the review if they met the following eligibility criteria:

- Articles published in the English language in peer-reviewed journals.
- Participants were adults (aged 18+ years) and diagnosed with a chronic health condition.
- Measured perfectionism using an empirically validated measure of perfectionism.
- Measured outcomes such as symptoms, management, functioning, adjustment, or distress associated with a chronic health condition using empirically validated measures.

'Functioning' was defined through the World Health Organisation's International Classification of Functioning (WHO, 2001) However, the ICF appears to be limited in its classification around psychological adjustment (Dekker & de Groot, 2018). Therefore 'adjustment' for this review was defined as "psychological processes in response to chronic disease and its associated treatment" (page 119; Dekker & de Groot, 2018), encompassing cognitive (e.g. worry), emotional (e.g. mood or distress) and behavioural responses (e.g. coping strategies). Coping strategies can also include social support (Hoyt & Stanton, 2012) and the ICF defines social functioning as the ability to create and maintain social relationships, with little indication on the satisfaction with them. Therefore measures identified in relevant full-text articles

which focused on social aspects were examined and classified either under functioning (provision of support) or adjustment (satisfaction of social relationships). Any uncertainty over classification was clarified by contacting study authors, as was the case of one of the included studies (Dunkley et al., 2012) who adapted items on a measure social functioning to focus more on social support satisfaction (D. Dunkley, personal communication, January 18th 2020).

Studies were excluded from the review if they focused on:

- Adults with a chronic health condition which does not appear to have an element of self-management.
- Participants below 18 years old.
- The main outcome for the study related to psychiatric diagnosis.
- Participants were from non-clinical populations, or those with a primary diagnosis of a psychiatric health condition.
- Not published in the English language.
- Qualitative studies.

Study Selection and Data Extraction

The search strategy and study selection procedure were informed by the four phase flow diagram included in the PRISMA guidelines (Moher et al., 2009) together with other published guidance (Boland, Cherry, & Dickson, 2013; Bramer, de Jonge, Rethlefsen, Mast, & Kleijnen, 2018). Following removal of duplicates, papers, titles and abstracts were screened against the eligibility criteria. Papers were then screened by full text and the reason for exclusion clearly documented.

Studies which met the eligibility criteria at full-text level underwent data extraction. Data on date published, country, study aims, chronic health population, participant characteristics, measures, data analysis methods, and results on the role of perfectionism in symptoms, management, or functioning, and adjustment or distress were extracted.

Ten percent (*N*= 507) of titles, abstracts and full texts were independently reviewed by LH. Inter-rater agreement was .95 (Cohen's kappa).

Quality Assessment

Quality assessment measures were carried out by KM and three (23%) papers were independently reviewed by BT. Disagreements were resolved through discussions.

Identified studies were evaluated according to the 'Observational Cohort and Cross-Sectional Studies' quality assessment tool studies from the National Heart, Lung and Blood Institute (NHLBI, 2014). This assessment tool was chosen as all included studies were cross-sectional or cohort in nature, and this tool includes both studies in their checklist. The tool was adapted slightly to ensure outcome criteria was a better fit for the studies. For example, references to 'exposure measures' interpreted as 'independent variables' and 'outcome variables' were interpreted as 'dependent variables'. The criteria of whether 'assessors were blind to the exposure status of participants' was interpreted as whether participants completed the measures in the presence of a researcher. Information about whether diagnoses were self-report or validated by a physician was also included.

Studies were examined to see if they adequately addressed a number of questions on the tool. Studies which had items rated as ‘no’ or ‘partially met’ were considered to determine the risk of bias this could introduce to that particular study.

Results

Results of Search Strategy

The initial search of four databases produced 5492 results. Following the removal of duplicates, 4439 results remained. After reviewing these articles by title and abstract, 125 articles were screened full-text level. Ten relevant papers were identified from the full-text search and included in the review. Forward and backwards citations of the included full-texts identified a further seven papers, three of which were met eligibility criteria and were included in the review. The search strategy identified 13 relevant papers in total.

Studies in the review were heterogeneous in the measurement of perfectionism and other outcomes. Therefore a meta-analysis was not carried out and the results were informed by Narrative Synthesis methods (Popay et al., 2006). Studies underwent tallying methods, or were clustered together by perfectionism measure, by CHC, and by outcome to ascertain wider themes. The results of the search strategy are outlined in the PRISMA diagram in Figure 1.

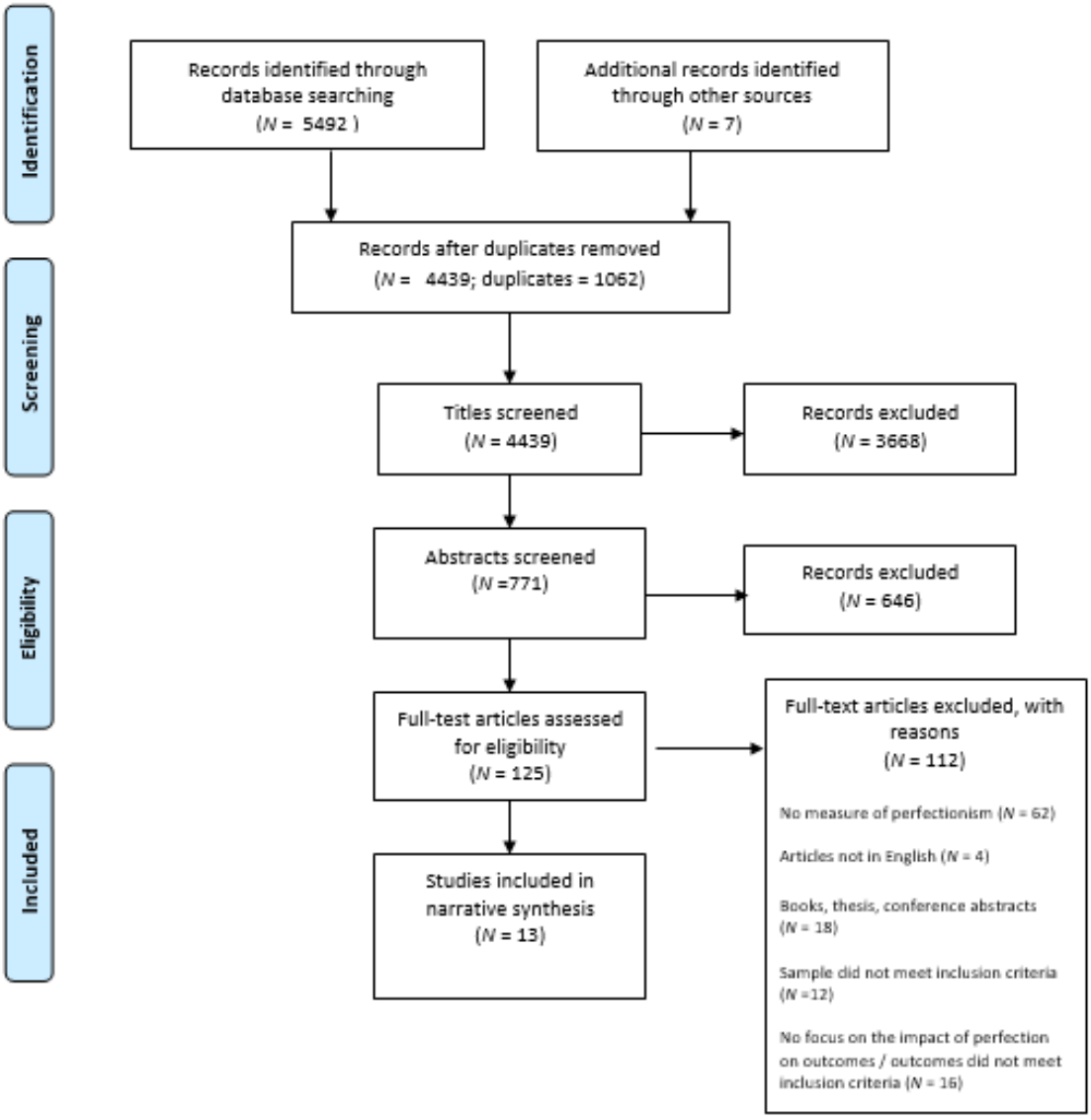

Figure 1. PRISMA diagram of search strategy

Characteristics and Results of Included Studies

Thirteen studies were included in the review. Table 1 outlines the characteristics, results, and quality rating for each study. As recommended by Cochrane guidelines (Ryan, 2013) studies were considered separately within the preliminary synthesis prior to narrative synthesis.

Table 1

Study characteristics and results

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality rating
Dunkley et al. (2012) Canada	**Aims**: to examine associations between perfectionism and psychosocial adjustment in coronary artery disease. **Design**: cross-sectional, quantitative design[a]. Outcomes completed as self-report measures.	Coronary Artery Disease† (*N* = 123) *N* = 93 men, mean age 66.38 years Recruited from Coronary Angiography Clinic. No control group	Frost MPS – personal standards subscale (Frost *et al.*, 1990).	**Functioning:** Short Form Health Survey (SF-36; (John E. Ware & Sherbourne, 1992) . Social Functioning and Social Support Survey (Sherbourne & Stewart, 1991) – four items related to support dissatisfaction. **Adjustment:** COPE Inventory (Carver, Scheier, & Weintraub, 1989) – problem-focused coping, positive reinterpretation and avoidant coping subscales.	**Perfectionism and functioning:** Relationship between SF-36 and Frost MPS not analysed. Personal standards subscale of Frost MPS a small and non-significant predictor of social support dissatisfaction. **Perfectionism and adjustment:** Personal standards subscale of the Frost MPS a positive and significant predictor of problem-focused coping and a close to significance predictor of positive reinterpretation, but not a significant predictor of avoidant coping.	Good.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Shanmugasegaram et al. (2014) Canada	**Aims:** examine the link between perfectionism and illness-specific coping styles in cardiac rehabilitation patients. **Design:** cross-sectional, quantitative design[b]. Outcomes completed as self-report measures.	Coronary Heart Disease† (*N* = 100). *N* = 74 men, mean age 63 years. Recruited from cardiac rehabilitation class. No control group.	Hewitt and Flett MPS (Hewitt & Flett, 1991) - self-oriented, other-oriented and socially-prescribed perfectionism subscales. Perfectionistic Self Presentation Scale (PSPS; Hewitt *et al.*, 2003) – perfectionistic self-promotion, non-display and non-disclosure of imperfection subscales	**Adjustment:** Coping with Health Injuries and Problems – Version 5 (CHIP; Endler and Parker, 2000) – distraction, palliative, instrumental and emotional preoccupation subscales.	**Perfectionism and adjustment**: Self-oriented and socially-prescribed of the Hewitt-Flett MPS perfectionism subscales had a significant and positive correlation with emotional reoccupation on the CHIP scale. No significant correlations for other-oriented perfectionism on any CHIP subscales. **Perfectionism and adjustment:** Perfectionist self-promotion subscale on the PSPS scale had a significant and positive correlation with palliative coping on the CHIP scale. Non-display and non-disclosure of imperfection subscales on the PSPS scale had a positive significant correlation with emotional preoccupation.	Fair.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Fry and Debats (2011) Canada	**Aims:** to investigate the link between perfectionism and mortality rates in type 2 diabetes. **Design:** longitudinal, quantitative design with ten waves of data collection over six years[a]. Baseline measures completed in person with research assistant. Remainder of data collection through questionnaires sent in post. Family members of participants informed research team when participant had died.	Type 2 diabetes† (*N* = 385). *N* = 133 men, mean age unknown. Recruited from diabetes clinic.	Hewitt and Flett MPS (Hewitt & Flett, 1991) - self-oriented, other-oriented and socially-prescribed perfectionism subscales.	**Functioning:** Mortality rates. Instrumental Activities of Daily Living – Index of Disability - self-reported 'yes/no' response for ability in 12 Activities of Daily Living (no reference given in study). **Adjustment:** Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988).	**Perfectionism and functioning:** Self-oriented perfectionism of the Hewitt-Flett MPS was inversely related to an increased risk of mortality. Relationship between perfectionism and Instrumental Activities of Daily Living not reported. **Perfectionism and adjustment:** Relationship between Hewitt-Flett MPS and Multidimensional Scale of Perceived Social Support not analysed.	Fair.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality rating
Besharat et al. (2011) Iran	**Aims:** to test whether specific dimensions of perfectionism were differentially related to fatigue symptoms in Multiple Sclerosis. To also address whether depression moderates the influence of depression on the relationship between perfectionism and fatigue. **Design:** cross-sectional, quantitative design[b]. Data collected through interviews with a research assistant.	Multiple Sclerosis‡ (*N* = 120). *N* = 21 men; mean age 32.9 years; *N* = 79 women, mean age 32.7 years). Recruited from Iranian MS Society. Control group (*N* = 120) of healthy volunteers from general population. *N* = 41 men, mean age 33.53 years	Positive and Negative Perfectionism Scale (PANPS; Terry-Short et al., 1995) – positive and negative perfectionism subscales.	**Symptoms:** Modified Fatigue Impact Scale (MFIS; Fisk et al., 1994). **Symptoms:** Fatigue Severity Scale (FSS; Krupp et al., 1989). **Other relevant measures:** Beck Depression Inventory – Short Form (Collet & Cotteaux, 1986). Thirteen item self-report scale.	**Perfectionism and symptoms:** Multiple Sclerosis group had higher levels of negative perfectionism and lower levels of positive perfectionism compared to control group. However, when depression was included in the model, only negative perfectionism differentiated between the Multiple Sclerosis and control group. Negative perfectionism on the PANPS had a significant and positive correlation with fatigue symptoms. Positive perfectionism on the PANPS had a significant negative relationship with fatigue.	Fair.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Valero et al. (2013) Spain	**Aims:** to explore the fitness of different structural equation modelling methods in relation to perfectionism, fatigue, neuroticism and depression in CFS. **Design:** cross-sectional, quantitative design[c]. Outcome measures completed with Psychiatrist and Clinical Psychologist over three sessions.	CFS† (*N* = 229). *N* = 209 women, mean age 48.21 years). Recruitment of participant unclear, although participants were assessed in a Psychiatry Department. Diagnosis validated by a physician working a Department of Internal Medicine. No control group.	Frost MPS (Frost et al., 1990) – used the doubts about actions and concern over mistakes subscales for 'maladaptive perfectionism'.	**Symptoms:** Modified Fatigue Impact Scale (MFIS; Fisk et al., 1994). **Other relevant measures:** Neuroticism subscale of the Zuckerman-Kuhlman Personality Questionnaire (ZKPQ; Zuckerman, Kuhlman and Camac, 1988; Zuckerman et al., 1991). Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) – depression subscale only.	**Perfectionism and symptoms:** Maladaptive perfectionism did not appear to be related to the MFIS in all structural equation models. The only model which demonstrated a good fit was a pathway between neuroticism and fatigue, mediated by depression.	Fair.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Luyten et al. (2006) Belgium	**Aims:** to explore the relationship between perfectionism, severity of depression and fatigue in a CFS patients and university students. To determine if CFS patients had higher levels of pre-morbid perfectionism than university students. **Design:** cross-sectional, quantitative data[d]. CFS patients completed self-reported measures during screening for CFS clinic. Students completed measures during lecture break.	CFS† (*N* = 43). *N* = 37 females, mean age 39.71 years. Recruited through multidisciplinary CFS clinic at a University Hospital. Control group (*N* = 80 psychology undergraduate students). *N* = 67 female, mean age 21.4 years.	Frost MPS (Frost et al., 1990) – translated into Dutch. Two versions completed at the same time –'Current Perfectionism' and 'Pre-morbid Perfectionism' which was measured by changing the Frost MPS to the past tense.	**Symptoms:** Checklist of Individual Strengths - (CIDS-20; Vercoulen et al., 1994) –measure of severity of fatigue.	**Perfectionism and symptoms:** CFS sample had higher levels of pre- and post- morbid Frost MPS scores than control group. However, none of the perfectionism dimensions were significantly associated with fatigue in CFS sample. Regression analyses showed that in CFS sample, demographics, severity of depression nor pre-morbid or post-morbid perfectionism predicted severity of fatigue.	Fair.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Sirois and Molnar (2014) USA and Canada	**Aims:** to examine perfectionism dimensions and maladaptive coping styles in CFS patients compared to healthy controls and two other chronic illness groups. **Design:** cross-sectional, quantitative data[b]. Outcome measures completed through a wider online survey on personality and health.	Mixed sample - CFS‡ (*N* = 79, mean age 32.8 years). Irritable Bowel Syndrome (IBS)‡; *N* = 85, mean age 37.5 years). Fibromyalgia/Arthritis‡ (*N* = 70, mean age 38.9 years). Control group (*N* = 94, mean age 31.1 years). Recruited from a wider survey on health. Selected from the survey if reported they had been diagnosed with a chronic health condition.	Revised Almost Perfect Scale (Slaney, Rice, Mobley, Trippi, & Ashby, 2001) – personal standards and maladaptive perfectionism subscales.	**Adjustment:** Brief COPE Inventory (Carver, 1997) – behavioural disengagement, substance use disengagement, denial and self-blame subscales.	**Perfectionism and adjustment:** **CFS group** – maladaptive perfectionism was significantly and positively correlated with self-blame coping. The same result was found in the control group although the magnitude of the correlation was significantly higher in the CFS group. **IBS group** - maladaptive perfectionism was correlated significantly with all four maladaptive coping styles, whereas personal standards perfectionism negatively and significantly correlated with denial and behavioural disengagement. **Fibromyalgia/Arthritis group** - maladaptive perfectionism significantly correlated with all negative coping styles but substance use. Personal standards perfectionism not significantly correlated with any coping styles.	Poor.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Kempke et al. (2011) Belgium	**Aims:** explore whether adaptive and maladaptive perfectionism were differently associated with severity of fatigue and depression in a large group of CFS patients using structural equation modelling. **Design:** cross-sectional, quantitative data[b] [c]. Outcome measures completed as self-report as part of a wider multidisciplinary screening.	CFS† (*N* = 192). *N* = 163 women, mean age 40.17 years. Recruited from CFS clinic. No control group.	Frost MPS (Frost et al., 1990) - Dutch Version from (Luyten, Van Houdenhove, Cosyns, & Van den Broeck, 2006) - personal standards subscale for 'adaptive perfectionism'; concern over mistakes and doubts about actions subscales for 'maladaptive perfectionism'.	**Symptoms:** Checklist of Individual Strengths - Dutch Version (CIDS-20; Vercoulen et al., 1994) – measure of severity of fatigue. **Other relevant measures:** Beck Depression Inventory (BDI; Beck et al., 1961).	**Perfectionism and symptoms:** Concern over mistakes and doubts about actions of Frost MPS had positive and significant correlations with severity of fatigue. Personal standards was not associated with severity of fatigue. Structural equation models found that maladaptive perfectionism was a direct predictor of fatigue severity. However a model which included maladaptive perfectionism was not a direct predictor of fatigue severity but mediated by depression was found to be a better fit.	Fair.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Molnar et al. (2012) Germany	**Aims:** test the hypotheses that socially prescribed and self-oriented perfectionism are associated with diminished health functioning among women with fibromyalgia. **Design:** cross-sectional, quantitative data[a]. Data collected through online survey.	Fibromyalgia ‡ (*N* = 489 women; mean age 48.78 years). Recruited through online survey. No control group.	Hewitt and Flett MPS (Hewitt & Flett, 1991) - self-oriented, other-oriented and socially-prescribed perfectionism subscales.	**Functioning:** Physical functioning - Short Form Health Survey (SF-36; John E. Ware & Sherbourne, 1992). **Symptoms:** Health symptoms - 21-items around general health symptoms, adapted from Macmillan (1957).	**Perfectionism and functioning:** Socially-prescribed perfectionism was associated with poorer health functioning (compared to other perfectionism subscales in a regression model). However, there was a U-shaped relationship between self-oriented perfectionism and health functioning.	Poor.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Sirois et al. (2019) Canada	**Aims:** to examine the role of perfectionism in Fibromyalgia patients in comparison to a control group by testing the Stress and Cyclical Coping Amplification Model for Perfectionism in Illness. Design: cross-sectional[a], quantitative data. Online survey.	Fibromyalgia‡ (*N* = 89). *N* = 88 females; mean age 57 years. Recruited through German Fibromyalgia Patient Association. Control group (*N* = 123). *N* = 100 females, mean age 44 years). Volunteers at the above organisation.	Frost MPS (Frost et al., 1990) - German version (Stoeber, 1995) – personal standards and organisation subscales for 'adaptive perfectionism'; concern over mistakes and doubts about actions for 'maladaptive perfectionism'. Frost MPS scores were then clustered into three groups based on Smith et al. (Smith, Saklofske, Yan, & Sherry, 2015) study –High Perfectionistic Strivings/ High Perfectionistic Concerns (High PS/PC);High Perfectionistic Strivings / Low Perfectionistic Concerns (High PS/Low PC); Low Perfectionistic Strivings / Low Perfectionistic Concerns (Low PS/ PC).	**Functioning:** Health Related Quality of Life – The Short Form 12 (SF-12; Ware, J. E., Kosinski, M., & Keller, 1995) – a measure of physical and mental health. **Distress:** Perceived Stress Questionnaire (PSQ; (Levenstein et al., 1993)– German version (Fliege, Rose, Arck, Levenstein, & Klapp, 2001).	**Perfectionism and functioning:** Fibromyalgia group - High PS/PC group were directly associated with poorer health outcomes compared to High PS/Low PC and Low PS/Low PC. Same result not found in the control group. **Perfectionism and distress:** Fibromyalgia group - High PS / High PC group showed higher levels of stress compared to High PS/Low PC and Low PS/Low PC. However, the levels of stress were not significantly higher in the High PS/Low PC group, who showed similar levels of stress as the control group. **Mediation model:** Fibromyalgia group - High PS/PC was indirectly associated with poorer mental and physical health, as mediated by stress. Control group – High PS/PC was indirectly associated with poorer mental health, as mediated by stress, but not for physical health. This indirect association with significantly larger in the Fibromyalgia group compared to the control group.	Fair.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Molnar et al. (2019) Canada, USA, UK	**Aims:** to examine Hewitt and Flett's conceptualisation of multidimensi-onal perfectionis-m in relation to health and wellbeing. **Design:** cross-sectional, quantitative data[e]. Data collected based through online survey.	Mixed sample (*N* = 775) *N* = 723 female, mean age 48.9 years. Participants reported having the following conditions (some were co-morbid): Fibromyalgia‡ (*N* = 605); CFS‡ (*N* = 388); Arthritis‡ (*N* = 326). Recruited through online support groups for CHCs (or through other websites such as Men's health). Chronic health and control groups were not compared with each other.	Hewitt and Flett MPS (Hewitt & Flett, 1991) - self-oriented (SOP), other-oriented (OOP) and socially-prescribed perfectionism (SPP) subscales. Cluster analysis revealed the following groups: High SPP; High SOP and OOP; Low SPP; Extreme Perfectionism (High SOP, OOP SOP); Non-Perfectionism. Low SOP, OOP, and SOP).	**Functioning:** Short Form Health Survey (SF-36; Ware et al., 1993). Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983). **Adjustment:** Satisfaction with Life Scale (SWLS; Diener et al., 1985) – a measure of subjective wellbeing. Positive and Negative Effect Scale (PANAS; Watson, Clark and Tellegen, 1988). Perceived stress – created by study authors. Two questions rating frequency and intensity of stress in the past week.	**Perfectionism and functioning:** High SPP and Extreme Perfectionism groups had significantly worse physical health compared to other perfectionism groups. **Perfectionism and adjustment:** High SPP and Extreme Perfectionism groups had significantly worse subjective wellbeing, perceived stress, and the least social support compared to the other perfectionism groups. **After controlling for personality:** High SPP and Extreme Perfectionism groups reported lower levels of social support and satisfaction with social support. High SPP group had significantly worse subjective wellbeing. The same result was not found for the Extreme Perfectionism group. High SPP group had significantly higher levels of perceived stress compared to other perfectionism groups.	Poor.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Read et al. (2019) UK	**Aims:** to examine the relationship between perfectionism and reactions to disability following Spinal Cord Injury. **Design:** cross-sectional, quantitative data[d]. Measures completed as self-report or with the assistance of a researcher.	Spinal Cord Injury § (*N* = 140). *N* = 108 male; mean age 48.18 years). Recruited from hospital and community healthcare settings, and community / online support groups. No control group.	Perfectionistic Self Presentation Scale (PSPS; Hewitt et al., 2003) – perfectionistic self-promotion, non-display and non-disclosure of imperfection subscales.	**Adjustment:** Reaction to Impairment and Disability Inventory (RIDI; Livneh and Antonak, 1990, 2008). Eight subscales – shock, anxiety, denial, depression, internalised anger, externalised hostility, acknowledgeme-nt and adjustment.	**Perfectionism and adjustment:** Non-display of imperfection was a medium-to-large predictor of all RIDI subscales other than denial and acknowledgement. Non-disclosure of imperfection was a small to medium predictor of depression and internalised anger RIDI subscales. Perfectionistic self-promotion was not a unique predictor of any RIDI subscales. Correlations found that PSPS was positively associated with non-adaptive reactions (shock, anxiety, depression, internalised anger, externalised hostility) and negatively associated with adaptive reactions (acknowledgement and adjustment).	Poor.

Table 1

Study characteristics and results continued

Authors, date and country	Study aims and design	Chronic Health Population	Perfectionism Measure	Outcome Measures	Results	Quality Rating
Flett et al. (2011) Canada	**Aims:** to examine the relationship between perfectionism and health-related coping in Irritable Bowel Disease. **Design:** cross-sectional, quantitative data[b]. Participants completed outcome measures either with physician, or were mailed to them by post.	IBS§ (*N* = 51; mean age 37.7 years). Crohn's Disease§, *N* = 27; *N* = 20 women. Ulcerative Colitis §, *N* = 24; *N* = 11 women. Recruited from a hospital clinic and charitable organisation. No control group identified.	Hewitt and Flett MPS (Hewitt & Flett, 1991) - Used a 15-item version by Cox, Enns and Clara (2002). 15-item measure still had three perfectionism subscales as the original measure. Perfectionistic Self Presentation Scale (PSPS; Hewitt et al., 2003) – perfectionistic self-promotion, non-display and non-disclosure of imperfection subscales.	**Adjustment:** Sickness Impact Profile (SIP; Bergner et al., 1981) – Psychosocial Impact subscale. Coping with Health Injuries and Problems – Version 5 (CHIP; Endler and Parker, 2000)– Distraction, Palliative, Instrumental and Emotional Preoccupation subscales.	**Perfectionism and adjustment:** All Hewitt and Flett MPS and PSPS subscales were all significantly and positively correlated with psychosocial impact subscale of SIP. Self-oriented perfectionism and Perfectionistic self-promotion had a positive and significant correlation with emotional preoccupation coping.	Fair.

Table 1 continued

Key: Frost MPS = Frost Multidimensional Perfectionism Scale; Hewitt and Flett MPS = Hewitt and Flett Multidimensional Perfectionism Scale; PSPS = Perfectionistic Self-Presentation Scale; PANPS = Positive and Negative Perfectionism Scale; APS-R = Almost Perfect Scale – Revised; SOP = self-oriented perfectionism; OOP = other-oriented perfectionism; SPP = socially-prescribed perfectionism; High PS/PC = high perfectionistic strivings / high perfectionistic concerns; High PS / Low PC = high perfectionistic strivings / low perfectionistic concerns; Low PS/PC = low perfectionistic strivings / low perfectionistic concerns; CFS = Chronic Fatigue Syndrome; IBS= Irritable Bowel Syndrome; SF-36 =Short-Form Health Survey; CHIP = Coping with Health Injuries and Problems; MFIS = Modified Fatigue Impact Scale; FSS = Fatigue Severity Scale; ZKPQ = Zuckerman-Kuhlman Personality Questionnaire; HADS = Hospital Anxiety and Depression Scale; CIDS = Checklist of Individual Strengths; BDI = Beck Depression Inventory; SF-12 = Health Related Quality of Life – The Short Form 12; PSQ = Perceived Stress Questionnaire; SWLS =Satisfaction with Life Scale; PANAS = Positive and Negative Effect Scale; RIDI = Reaction to Impairment and Disability Inventory; SIP = Sickness Impact Profile

[a] = regression-based analysis; [b] = correlation-based analysis; [c] = structural equation modelling analysis; [d] = correlation and regression-based analysis; [e] = Multivariate analysis of variance and analysis of covariance.

† = diagnosis validated by a clinician or physician; ‡ = self-reported diagnosis, § = mixed sample of some patients with a diagnosis validated by a clinician or physician and some participants with self-reported diagnoses.

Synthesis of Study Findings

Seven studies were undertaken in Canada, two in Belgium, USA and the UK, and one in Germany, Iran and Spain. All but one study were cross-sectional quantitative designs, with only one longitudinal prospective study (Fry & Debats, 2011). The majority of studies focused on CFS (N = 5) or Chronic Pain / Fibromyalgia (N = 4). Read et al's. (2019) study in Spinal Cord Injury (SCI) was included as chronic pain is a common consequence which affects physical functioning (Hadjipavlou, Cortese, & Ramaswamy, 2016). The majority of studies focused on one CHC, with two studies including mixed samples, either comparing between conditions (Sirois & Molnar, 2014) or combining participants (Molnar et al. 2019).

Some studies used other outcome measures in additions to those in our inclusion criteria. For example, the Type-D Scale (Denollet, 2005; in Shanmugasegaram et al., 2014) or the Beck Depression Inventory (Beck et al., 1961; in Luyten et al., 2006; Besharat et al., 2011; Kempke et al., 2011; Dunkley et al., 2012). Whilst these studies were included in the review, data relating to these areas were not extracted unless specifically linked to perfectionism and the outcomes outlined in this review.

The most commonly used measures of perfectionism were both Frost's MPS (Frost et al., 1990) and Hewitt and Flett's MPS (Hewitt & Flett, 1991) as both were used in five studies each. Some studies measured perfectionism as an entire construct (Flett et al., 2011; Fry & Debats, 2011; Luyten et al., 2006; Molnar, Flett, Sadava, & Colautti, 2012; Read et al., 2019; Shanmugasegaram et al., 2014), others used specific subscales or measures to distinguish between adaptive and maladaptive

perfectionism based on methods by Dunkley et al., (2000), Stoeber and Otto (2006) or Smith et al. (2015; Besharat et al., 2011; Luyten et al., 2011; Valero et al., 2013; Sirois and Molnar, 2014; Molnar et al., 2019; Sirois et al., 2019).

Outcomes around functioning and symptoms appeared to be the most commonly studied, with functioning (including social functioning) in five studies (Dunkley et al., 2012; Flett et al., 2011; Fry & Debats, 2011; Molnar et al., 2012, 2019), symptoms such as fatigue being measured in four studies (Besharat et al., 2011; Kempke et al., 2011, Luyten et al., 2006; Valero et al., 2013) and mortality (Fry and Debats, 2011).

Adjustment and distress outcomes included coping strategies (Dunkley et al., 2012; Read et al., 2019; Shanmugasegaram et al., 2014; Sirois & Molnar, 2014), satisfaction with social support (Fry and Debats, 2011; Molnar et al., 2019), stress, affect or quality of life (Molnar et al., 2019; Sirois et al., 2019).

What is the Role of Perfectionism in Functioning, Symptoms, or Management?

In a broad sense, higher levels of (maladaptive) perfectionism were associated with poorer physical health functioning and worse symptoms in Fibromyalgia, Arthritis, CFS, MS and IBD. In Fibromyalgia, higher levels of perfectionism were associated with poorer physical health (Molnar et al., 2012; Sirois et al., 2019). This result also appears to be consistent with a mixed sample including Fibromyalgia, CFS and Arthritis, where those with ‘extreme’ and socially-prescribed perfectionism had worse physical health (Molnar et al 2019).

The results appear to be mixed for CFS. Whilst Molnar et al. (2019) demonstrated worse health outcomes for a sample which included CFS, this group

formed a wider part of the chronic health sample and it is possible that the results may differ if the CFS group were examined alone. Kempke et al. (2011) found maladaptive perfectionism was associated with higher levels of fatigue, although this relationship was stronger when mediated by depression. On the other hand, Valero et al. (2013) and Luyten et al. (2006) found perfectionism was not associated with fatigue. In MS, negative perfectionism was associated with greater levels of fatigue (Besharat et al., 2011).

For patients with IBS, those with higher levels of perfectionism reported greater psychosocial impairment (Flett et al., 2011). This result was consistent across all perfectionism measures suggesting there was no distinction between the role of adaptive and maladaptive perfectionism.

In three studies, more adaptive types of perfectionism were associated with improved health outcomes. Self-oriented perfectionism appears to serve as a protective factor against mortality in type 2 diabetes (Fry and Debats, 2011), and positive perfectionism was associated with reduced fatigue in MS (Besharat et al., 2011). Molnar et al's (2012) study in Fibromyalgia found a U-shaped relationship between self-oriented perfectionism and health functioning. This suggests that more helpful types or optimum levels of perfectionism can have a positive effect on outcomes.

What is the Role of Perfectionism in Adjustment to or Distress associated with living with a Chronic Health Condition?

Synthesis of the results suggested that maladaptive types of perfectionism were associated with poorer coping, higher levels of stress and lower satisfaction

with social support. In terms of coping styles, maladaptive perfectionism was associated with maladaptive coping in CFS, IBS, fibromyalgia, and arthritis (Sirois & Molnar, 2014), maladaptive adjustment in SCI (Read et al., 2019), and ruminative coping in CHD (Shanmugasegaram et al., 2014) and IBD (Flett et al., 2011).

Maladaptive perfectionism also appears to be related to higher levels of stress, as found in two studies with a mixed chronic health sample of fibromyalgia, CFS and arthritis (Molnar et al., 2019) and fibromyalgia (Sirois et al, 2019).

With regards to social support, participants with higher levels of maladaptive perfectionism reported lower levels and satisfaction with social support compared to those with lower levels of maladaptive perfectionism in fibromyalgia, CFS, and arthritis (Molnar et al., 2019).

More adaptive types of perfectionism appear to be associated with more adaptive coping. Higher levels of personal standards perfectionism was associated with problem-focused coping in CHD (Dunkley et al., 2012) and less denial and disengagement coping in IBD (Sirois & Molnar, 2014).

Quality Assessment

As all included studies were cross-sectional or cohort, this review used the ‘Observational Cohort and Cross-Sectional Studies’ quality assessment tool studies from the National Heart, Lung and Blood Institute (NHLBI, 2014).

Study quality was considered within the context of each individual study as opposed to purely providing a numeric rating as evidence of study quality (NHLBI, 2014). Study quality results were then clustered together to identify certain themes

which distinguished between poorer and better quality studies. Quality ratings for each study (in order of lowest quality) can be found in table 2 below.

Table 2

Results of quality assessment

	Study sample							Measures – Independent variables		Measures – Dependent variables		Asses-ors	Analysis		Cohort study only				Quality Rating	
Authors and date	Research questions defined	Participation rate of eligible persons >50%	Study population clearly defined	Diagnosis validated by physician	Recruited from same population	Clear inclusion/ exclusion criteria	A priori sample size calculated	Evidence of psychometric reliability and validity	Implemented across all participants	Evidence of psychometric reliability and validity	Implemented across all participants	Assessors not present when participants completed measures.	Attrition rate <20%	Confounding variables controlled	Exposure assessed prior to outcome measurement	Sufficient timeframe	Repeated exposure measurement	Different levels of exposure measured	Number of items adequately addressed	Study quality rating (Poor, Fair, Good)
Sirois and Molnar (2014)	✓	CD	×	×	×	×	×	×	CD	×	CD	✓	CD	CD	NA	NA	NA	NA	2	Poor
Molnar et al. (2012)	✓	CD	✓×	×	×	×	×	✓×	✓	✓×	✓	✓	NA	✓×	NA	NA	NA	NA	4	Poor
Molnar et al. (2019)	✓	CD	✓×	×	×	×	×	✓	✓	✓×	✓	CD	CD	✓×	NA	NA	NA	NA	4	Poor
Read et al. (2019)	✓	CD	✓×	✓×	×	×	×	✓	CD	✓	CD	✓×	NA	✓	NA	NA	NA	NA	4	Poor
Sirois et al. (2019)	✓ ×	CD	✓×	×	✓	×	×	✓	✓	✓	✓	CD	NA	✓×	NA	NA	NA	NA	5	Fair

Table 2

Results of quality assessment continued

	Study sample							Measures – Independent variables		Measures – Dependent variables		Asses-ors	Analysis		Cohort study only				Quality Rating	
Authors and date	Research questions defined	Participation rate of eligible persons >50%	Study population clearly defined	Diagnosis validated by physician	Recruited from same population	Clear inclusion/ exclusion criteria	A priori sample size calculated	Evidence of psychometric reliability and validity	Implemented across all participants	Evidence of psychometric reliability and validity	Implemented across all participants	Assessors not present when participants completed measures.	Attrition rate <20%	Confounding variables controlled	Exposure assessed prior to outcome measurement	Sufficient timeframe	Repeated exposure measurement	Different levels of exposure measured	Number of items adequately addressed	Study quality rating (Poor, Fair, Good)
Valero et al. (2013)	✓	CD	✓×	✓	C D	✓	×	✓×	✓	✓×	✓	×	NA	✓	NA	NA	NA	NA	5	Fair
Shanmu-gasegaram et al. (2014)	✓	CD	✓×	✓	✓	✓	×	✓×	✓	✓×	✓	CD	NA	×	NA	NA	NA	NA	6	Fair
Luyten et al. (2006)	✓	✓	✓×	✓	✓	✓×	×	✓×	✓	✓×	✓	CD	NA	✓×	NA	NA	NA	NA	6	Fair
Flett et al. (2011)	✓	CD	✓	✓×	×	×	×	✓	✓	✓	✓	✓×	NA	✓	NA	NA	NA	NA	7	Fair

Table 2

Results of quality assessment continued

	Study sample							Measures – Independent variables		Measures – Dependent variables		Asses-ors	Analysis	Cohort study only				Quality Rating	
Authors and date	Research questions defined	Participation rate of eligible persons >50%	Study population clearly defined	Diagnosis validated by physician	Recruited from same population	Clear inclusion/ exclusion criteria	A priori sample size calculated	Evidence of psychometric reliability and validity	Implemented across all participants	Evidence of psychometric reliability and validity	Implemented across all participants	Assessors not present when participants completed measures.	Attrition rate <20%	Confounding variables controlled	Exposure assessed prior to outcome measurement	Sufficient timeframe	Repeated exposure measurement	Different levels of exposure measured	Number of items adequately addressed	Study quality rating (Poor, Fair, Good)
Kempke et al. (2011)	✓	✓	✓	✓	✓	CD	×	✓×	✓	✓	✓	CD	NA	✓×	NA	NA	NA	NA	8	Fair
Besharat et al. (2011)	✓	CD	✓	×	✓	CD	×	✓	✓	✓	✓	×	NA	✓	NA	NA	NA	NA	8	Fair
Fry and Debats (2011)	✓	CD	✓	✓	✓	✓	×	✓	✓	✓	✓	×	✓	✓×	✓×	✓	×	×	9	Fair
Dunkley et al. (2012)	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	NA	✓	NA	NA	NA	NA	11	Good

Table 2

Results of quality assessment continued

Key: ✓ Yes (item adequately addressed); ✗ No (item not adequately addressed); ✓✗ Item partially addressed; CD Cannot determine (description in study unclear); NS Not stated; NA Not applicable

The quality assessment overall seems to suggest that the majority of studies were a fair quality, namely studies focusing on CHD, MS and IBD. This suggests that results from the studies can be held with some confidence. Results from poorer quality studies are to be considered with caution, namely studies focusing on CFS, Fibromyalgia, SCI and Arthritis.

Four studies were rated as 'poor' (Molnar et al., 2012; Molnar et al., 2019, Read et al., 2019; Sirois & Molnar, 2014). Read et al. (2019) was rated poor as whilst it did have some characteristics relevant to a better quality study, most other items were rated as 'cannot determine' and therefore study quality could not be assessed appropriately. Three studies lacked sufficient information on participants, relied on self-report diagnoses and provided no clear inclusion or exclusion criteria. They recruited participants from multiple countries, which may introduce risk of bias about differences in healthcare provision between the countries and outcomes in this study.

Eight studies rated as 'fair' (Besharat et al., 2011; Flett et al., 2011; Fry and Debats, 2011; Kempke et al., 2011; Luyten et al., 2006; Valero et al., 2013; Shanmugasegaram et al., 2014;. Sirois et al., 2019). The majority of these studies recruited from clinical settings and / or had diagnoses which were validated by a healthcare professional or validated tools. One study recruited from both clinical and community settings for people with IBD, with only those recruited from clinical settings having diagnoses validated. Two studies recruited from chronic health charitable organisations and therefore relied on self-report diagnoses. Diagnoses being validated were judged to be an indicator of better study quality to ensure that studies were definitely investigating the role of perfectionism in chronic health conditions, as opposed to those with health difficulties. Better quality studies were

more likely to report clear inclusion or exclusion criteria. All studies recruited participants in person and in some studies, researchers or physicians were reported to be present when outcome measures were completed. It is possible that participants who completed measures with a physician or researcher may have been influenced by their presence.

Fry and Debats (2011) study was the only longitudinal design in the review, with the overall quality of the study being rated 'fair'. Whilst most of the study adequately met the quality assessment criteria, the study was prone to confounding variables. For example, health status was not assessed at baseline and thus not included in the analysis which may have acted as a confounding variable in relation to the mortality outcome.

One study was rated 'good' (Dunkley et al., 2012). This study validated participant diagnoses, had clear inclusion and exclusion criteria, reported psychometric properties of all outcome measures, controlled for confounding variables but also had the additional factor of a researcher not being present when outcome measures were completed. This study appeared to present with the least risk of variables which would bias the study.

Evidence to psychometric properties of independent and dependent variable measures varied throughout, and was rated 'partially met' if they did not report both reliability and validity values. Better quality studies reported more evidence of psychometric properties. One study made no reference to psychometric properties (Sirois and Molnar, 2014). The majority of studies made reference to psychometrics based on previous evidence but provided no evidence of reliability for the sample in

their study (Flett et al., 2011; Molnar et al., 2012; Molnar et al., 2019: Read et al., 2019; Shanmugasegaram et al., 2014). Some studies only made reference to internal consistency values for measures based on their study sample (Fry and Debats, 2011; Luyten et al., 2006; Valero et al., 2013) but not validity based on previous research. Two studies made reference to psychometric properties based on previous research and for their study sample (Besharat et al., 2011; Dunkley et al., 2012).

Discussion

This review aimed to explore the role of perfectionism in functioning, management and symptoms, and adjustment to or distress in people with a CHC. Based on the search strategy, thirteen articles were included.

The findings suggest that perfectionism is related to both positive and negative outcomes across a range of conditions (CFS, fibromyalgia, arthritis, IBD, CHD, SCI, and type 2 diabetes). The majority of results in this review suggest that higher levels of perfectionism were associated with impaired physical health functioning and symptoms, such as fatigue, and maladaptive adjustment and distress. These results appear to be consistent with research on the link between perfectionism and psychiatric conditions. This suggests that there is a wider notion that higher levels of perfectionism can be problematic across a range of domains and provides further support to perfectionism being a transdiagnostic construct (Egan et al., 2011).

Perfectionism has also been associated with more positive outcomes. Self-oriented perfectionism appeared to serve as a protective factor against mortality in type 2 diabetes (Fry and Debats, 2011). Non-adherence to diabetes regimens can result in poor glycaemic control and potentially fatal consequences. Compared to other conditions included in this review, non-adherence to self-management is more

likely to result in an exacerbation of symptoms (e.g. in CFS or IBS) as opposed to more fatal consequences. Therefore, perfectionism may serve as an important trait in good diabetic management. Perfectionism was also associated with reduced fatigue in MS (Besharat et al., 2011). Perfectionism was also associated with problem-focused coping in CHD (Dunkley et al., 2012). Dunkley et al. (2012) only used the personal standards subscale of the Frost MPS (Frost et al., 1990), which has been described as a more 'adaptive' form of perfectionism (Dunkley, Blankstein, Masheb, & Grilo, 2006) which may explain the results of the study. Furthermore, the study did not use other subscales in the Frost MPS and therefore the associations between these other subscales and coping in CHD is unknown. The three studies measure types of perfectionism (self-oriented perfectionism, Hewitt & Flett, 1991; positive perfectionism, Terry-Short et al., 1995; personal standards, Frost et al., 1990), which fall under 'perfectionistic' strivings, which has been associated with more positive outcomes across a range of domains (Stoeber & Otto, 2006).

Some studies found wider personality traits were better explanations for poor functioning than perfectionism (Luyten et al., 2006; Molnar et al., 2019; Valero et al., 2013). Study quality for these studies were either rated as 'poor' or 'fair', which may have biased the results. Perfectionism is related to wider personality traits such as conscientiousness and neuroticism (Hill, McIntire and Bacharach, 1997; Stumpf and Parker, 2000). As a result, it is possible that studies measuring personality in this review partialled out the effect of perfectionism on outcomes.

This review found outcomes relating to functioning, symptoms, adjustment and distress. However, no studies in this review focused on self-management outcomes. Given that self-management programmes often place goal setting at the

forefront of their agenda (Lawn & Schoo, 2010) it would be important to understand if patients with higher levels of perfectionism set unrealistically high goals for in their management, or how they respond to perceived failures when not meeting these goals. To evade the fear of failure, those with higher levels of perfectionism may be likely to engage in avoidance behaviour (Lo & Abbott, 2013; Shafran, Cooper, & Fairburn, 2002). In the context of chronic health, such avoidance may be understood as non-adherence (Graham et al., 2016) which may lead to further complications or exacerbating symptoms, which may in turn be perceived as evidence of failing to manage their condition, or serving as a barrier to achieve non-illness related goals.

Strengths and Limitations

To our knowledge, this is the first review of its kind to investigate the role of perfectionism in health-related and psychological adjustment outcomes. A strength of this review was that it adopted explicit inclusion and exclusion criteria, with clear definitions for outcomes in order to ensure a clear focus.

This review considered a broad range of CHCs, although the wide range of heterogeneity between conditions may have compromised the findings. Some conditions included in the review require optimal self-management to prevent adverse outcomes, such as mortality and serious physical health complications (e.g., type 2 diabetes). This is in contrast to other conditions included where poor self-management leads to higher functional impairment and distress, but not mortality (e.g., Fibromyalgia, CFS). Whilst the overall results suggest that maladaptive perfectionism is associated with worse outcomes, it may be that differences in the self-management of conditions and the consequences of poor self-management may affect how perfectionism functions within such conditions. For example, higher

levels of perfectionism in diabetes may be functional when the most serious complication is death.

Quality assessment in this review also has limitations. Study quality was variable and findings from studies for Fibromyalgia, CFS, Arthritis and SCI may need to be considered with caution due to their poorer quality ratings. The quality assessment tool was chosen as it allowed inclusion of both cross-sectional and cohort studies together compared to other quality assessment tools. The quality assessment tool used in this review does not rate study quality solely on the numeric value of items adequately addressed. Quality assessment relies on the reviewer's opinion about whether items which are not adequately addressed are sufficient enough to bias the results of the study (NHLBI, 2014). It is therefore possible that the assessment of study quality is subject to reviewer interpretation, which could also be biased. Furthermore, a small percentage of papers were subjected for independent checking for eligibility and quality ratings. Whilst agreement between raters was good, having a small number of papers checked may also introduce a further source of bias.

This review is limited in being able to provide any firm conclusions about causal relationships between perfectionism and health-related outcomes. All but one of the studies included in the review were cross-sectional in nature, and therefore unable to shed light on the mechanisms involved in perfectionism and how it affects chronic health outcomes, or into the predictive nature of perfectionism on such outcomes. Future studies should focus on prospective cohort based studies following newly diagnosed patients to ascertain the role of perfectionism in later outcomes.

Studies in this review used a wide range of perfectionism measures. Whilst some studies categorised subscales to distinguish between adaptive and maladaptive perfectionism, the variety of measures used to capture these two factors may explain why some results may appear inconsistent with each other. Future research may wish to consider investigating how different facets of perfectionism relate to outcomes, or come to a consensus about which measures are most appropriate.

Theoretical Implications

The results of this review do not provide a clear theoretical framework to explain how perfectionism affects health-related and psychological outcomes. The Stress and Coping Cyclical Amplification Model of Perfectionism (SCCAMPI; Molnar et al., 2016) proposes that for those with chronic illnesses, perfectionists may be more vulnerable towards maladjustment and poorer health outcomes through intrapersonal (e.g., perceived control and negative self-evaluation) and interpersonal (e.g., social support and self-concealment) factors interacting with stress and maladaptive coping strategies which impacts on health-related outcomes (see Molnar et al., 2016 for a review of the model).

Findings from this review would appear to be consistent with this model. People with CHCs may engage in unhelpful ways of coping through hiding their symptoms from others to avoid criticism (i.e. self-concealment). In this review, perfectionistic self-presentation (concealing flaws from others) and socially-prescribed perfectionism (adhering to standards set by others) are associated with greater emotional preoccupation or ruminative coping in IBD and CHD (Flett et al., 2011; Shanmugasegaram et al., 2014), where such rumination may be a private experience and not shared with others. This finding is also consistent with other

research on the relationship between perfectionism and ruminative thinking styles (Flett et al., 2002; Flett, Nepon and Hewitt, 2016).

The SCCAMPI model also highlights the importance of social support for adaptive coping, and how interpersonal aspects of perfectionism (unrealistically high standards for others, and from others) may place greater strain on relationships. High socially-prescribed perfectionism was related to lower levels of social support satisfaction (Molnar et al., 2019). Those with CHCs who feel under pressure to adhere to standards set by others, or are overly concerned with negative evaluation from others may report feeling dissatisfied with the support offered by others, or may report a greater sense of social disconnection (Sherry, Mackinnon, & Gautreau, 2016).

Clinical Implications and Conclusion

Perfectionism appears to have a role in outcomes for CHCs. Being diagnosed with a CHC may affect current goals or plans for the future, and those with high levels of perfectionism may continue to strive or overexert themselves to achieve their goals at the expense of exacerbating symptoms. Symptoms associated with CHCs may threaten people's ability to achieve goals, leading to distress and maladaptive coping. As a result, people may have to make adjustments between their ideal goals and what can realistically be achieved. Clinicians working with chronic health populations may wish to explore perfectionism, and whether this affects effective self-management and functioning (either through non-adherence or over-exertion), or as a way to reduce distress when discrepancies arise between current and ideal functioning.

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Conflict of Interest

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Chapter Three: Bridging Chapter

Bridging Chapter

The results of the systematic review suggest that in general, people living with chronic health conditions who have higher levels of maladaptive perfectionism are more likely to experience increased symptoms associated with their condition, reduced functioning and engage in more maladaptive coping styles. Conversely, perfectionism was protective against mortality in type 1 diabetes (Fry & Debats, 2011), lead to more adaptive ways of coping (Dunkley et al., 2012; Shanmugasegaram et al., 2014), and reduced fatigue (Besharat et al., 2011). Differences in these results may reflect the heterogeneity with which perfectionism has been measured. Some studies measured perfectionism as a global personality trait (Dunkley et al., 2012; Flett et al., 2011; Fry & Debats, 2011; Luyten et al., 2006; Molnar et al., 2012; Shanmugasegaram et al., 2014), others divided perfectionism into adaptive and maladaptive counterparts (Besharat et al., 2011; Kempke et al., 2011; Molnar et al., 2019; Sirois & Molnar, 2014; Sirois et al., 2019; Valero et al., 2013), whereas others focussed specifically on behavioural aspects, such as concealing imperfection from others (Flett et al., 2011; Read et al., 2019; Shanmugasegaram et al., 2014). The heterogeneity in measurement of perfectionism and by chronic health condition may explain the differences in the findings.

Research into the mechanisms underlying perfectionism in chronic health appears scarce. The Stress and Coping Cyclical Amplification Model of Perfectionism in Illness (SCCAMPI) model provides a conceptual framework for how perfectionism and other interpersonal mechanisms may pose as risk factors to adjustment and coping when living with a chronic health condition. The model suggests that perfectionism may interact with internal (such as perceptions of

control, self-evaluation) and interpersonal processes (such as social support, and self-concealment of illness), and serve as potential pathways which link perfectionism to health outcomes (illness symptoms and health-related behaviours) through stress and maladaptive coping (Molnar et al., 2016). For a more detailed explanation of the model, please refer to Molnar et al. (2016).

Molnar et al. (2016) suggests that perfectionism has an impact on 1) symptoms; and 2) health-related behaviours. Illness symptoms can be perceived as stressful due to their unpredictability, which may impact on personal goals or daily functioning, leading to further stress and exacerbating symptoms. In the context of health-related behaviours, the authors suggest that perfectionism leads to increases in stress and negative affect. This negative affect creates narrowing of temporal (time) focus, with the goal to alleviate the negative affect in the short-term, and longer-term health goals are ignored. This shift in temporal focus determines whether or not people engage in health-promoting behaviours.

Whilst the model provides a theory into how perfectionism affects health-related behaviours, it does not appear to clearly explain whether perfectionism has a role in how people self-manage their condition. If anything, the model hints towards the notion that perfectionism may lead to an avoidance of self-management, if negative affect leads to longer-term benefits of health-promoting behaviours being ignored. Furthermore, the mechanism between perfectionism, stress and health-promoting behaviours is based upon research on health behaviours across a wide range of settings (including health-promoting behaviours in healthy populations) and it is unclear whether the same mechanisms apply for those with chronic health conditions. It is worth noting that empirical support for the SCCAMPI model is still

in its infancy, with empirical support largely coming from the authors themselves. Overall, whilst this model serves as a useful framework, other models of perfectionism may prove useful in understanding if perfectionism has a role in chronic health outcomes.

The systematic review found that no study had to date investigated the role of perfectionism in self-management of conditions. Self-management of chronic health conditions appears to be largely goal-based (Fredrix, McSharry, Flannery, Dinneen, & Byrne, 2018; Lawn & Schoo, 2010; Vasta, 2003). Goal setting theorists Locke and Latham (2002) outline four main mechanisms for effective goal attainment - goal choice, effort, persistence, and strategy. Goal choice entails focusing attention towards goal-relevant activity; the more difficult the goal, the greater amount of effort and persistence required. Strategies may be utilised in order to reach the goal, which can be drawn upon based on previous knowledge, or acquiring new knowledge and skills. These four mechanisms are moderated by five factors – task complexity, importance, self-efficacy, feedback, and task complexity. More complex goals require a higher level of commitment and may need to be personally important to an individual. Self-efficacy, defined by Bandura (1977) is the beliefs one has in their own abilities in task performance, ensures people have the skills and ability for goal attainment. Feedback is a crucial mechanism in being able to monitor performance and progress in relation to the goal, and adjust the complexity of the goal if needed.

Diabetes is a chronic health condition which requires complex treatment and management regimens. In general, there are two main types of diabetes: type 1, where the pancreas is unable to produce insulin, and accounts for up to 8% of

diabetes diagnoses in the UK (National Institute for Health and Care Excellence; NICE, 2015); and type 2, where the pancreas either makes insufficient or ineffective insulin, and accounts for approximately 90% of diabetes diagnoses in the UK (NICE, 2015). Type 2 diabetes can generally be managed through medication and changes to diet, with insulin treatment only in cases of disease progression (NICE, 2015). Management of type 1 however, diabetes appears to be more complex. Given that the pancreas cannot produce insulin, people must administer artificial insulin (usually via injections) in order to regulate their blood glucose levels. Multiple insulin regimens are available: such as a twice-daily regimens, multiple daily injection therapy, or an insulin pump. These insulin regimens require taking a combination of short and intermediate acting insulin and regular blood glucose testing to ensure optimal glycaemic control (NICE, 2015).

Good management of type 1 diabetes relies heavily on self-management. Current guidelines recommend blood glucose levels remain between 4 -7 mmol/litre for optimum health, which requires a combination of self-monitoring of blood glucose (e.g. through using finger prick tests, continuous blood glucose monitoring devices, or devices activated by a sensor – 'Flash glucose monitoring'[1]) and self-administering of insulin in response (NICE, 2015). This, in addition to exercise, diet, alcohol, illness, stress, menstruation, pregnancy, medications, amongst other factors can make managing blood glucose levels a complex task (Brown, 2018). Type 1 diabetes appears to be unique in that methods which monitor blood glucose levels can provide instant feedback on how well people are meeting the recommended targets.

[1] An explanation for 'flash glucose monitoring' can be found in table 3 of the empirical study.

Given its complexity, people with type 1 diabetes are at greater risk of developing depression and anxiety (NICE, 2015; van Duinkerken, Snoek, & de Wit, 2019). Separate to this, people are at also risk of developing 'diabetes-related distress', where people feel overwhelmed and burdened as a consequence of living with diabetes and treatment regimens, and feeling powerless as a result (Polonsky et al., 1995). Diabetes-related distress appears to be distinct from depression and is associated with poorer glycaemic control (Fisher et al., 2010; Van Bastelaar et al., 2010).

Whilst providing targets for glycaemic control may provide people with greater certainty and motivation (Rankin et al., 2012), some people view them as being unrealistic or unattainable to them, particularly when advances in diabetes technology allow for more stringent targets (Pyatak, Florindez, & Weigensberg, 2013; Snow, Sandall, & Humphrey, 2014). Qualitative studies have shown that people with type 1 diabetes report feelings of failure when their efforts at management do not meet these targets (Pyatak et al., 2013; Rankin et al., 2012; Sparud-Lundin, Öhrn, & Danielson, 2010). Fear of failure has been identified as a driver of non-adherence in type 1 diabetes. As a result, people opted to avoid monitoring their blood glucose to avoid facing this possibility (Pyatak et al., 2013).

Diabetes self-management is underpinned by effective goal-setting and goal attainment (Fredrix et al., 2018; Miller & Bauman, 2014). Perfectionism is a trait relating to the pursuit of personally demanding goals, and distress when these goals are not reached. Given that some people perceive not meeting diabetes-related targets as evidence of failure, it may not be unreasonable to consider whether perfectionism plays a role in distress associated with diabetes and self-management.

Most studies investigating the link between perfectionism and outcomes in chronic health have used perfectionism measures by Frost et al., (1990) or Hewitt and Flett (1991) as evidenced by the results of the systematic review in the previous chapter. However, these conceptualisations (and therefore measurements) of perfectionism are not without criticism. Shafran, Cooper and Fairburn (2002) disputed the above conceptualisations and measures, suggesting that perfectionism is a construct where people are self-motivated to pursue demanding, self-imposed standards, and self-evaluation is dependent on achieving these standards. Therefore, interpersonal aspects relating to high expectations towards others (other-oriented perfectionism) and from others (socially-prescribed perfectionism) measure aspects relating to perfectionism, as opposed to perfectionism itself.

They also argued that people with high levels of perfectionism are likely to show concern over making mistakes for fear of failure, and such failure would lend itself to negative self-evaluation. However, Frost et al.'s (1990) 'concern over mistakes' subscale appears to measure negative emotional reactions towards making mistakes and the impact of making mistakes on other people, as opposed to the impact of mistakes on self-evaluation. Again, they argued these items measure aspects relating to perfectionism, as opposed to perfectionism itself.

In addition to issues around measurement, neither conceptualisation has provided a clear theoretical framework around how perfectionism is maintained. Moreover, whilst higher levels of perfectionism (as assessed through these measures) were associated with greater psychopathology, neither conceptualisations provided detail as why perfectionism becomes problematic. Given the above critique, Shafran and colleagues (2002) developed their own model of perfectionism. Clinical

perfectionism, defined as 'the overdependence of self-evaluation on the determined pursuit of personally demanding, self-imposed, standards in at least one highly salient domain, despite adverse consequences' (page 778) aims to provide a cognitive-behavioural maintenance model detailing how perfectionism can prove problematic, and how it is maintained. The authors also devised their own measure based on this model, known as the 'Clinical Perfectionism Questionnaire' (CPQ; Fairburn, Cooper, & Shafran, 2003). Their cognitive-behavioural model of clinical perfectionism may prove to be a useful theoretical framework for type 1 diabetes, as aspects of self-management could map onto cognitive and behavioural constructs of the model. The remainder of this chapter will outline the clinical perfectionism model, and how it may relate to type 1 diabetes.

Shafran and colleagues (2002) suggest that people with clinical perfectionism are overly dependent on their self-evaluation being based on the striving and achievement of personally demanding goals. As such, these standards are operationalised as rules, 'shoulds' or 'musts'. People with clinical perfectionism are likely to have a morbid fear of failure, have an overdeveloped memory for mistakes, are hypervigilant towards mistakes and are thus more biased to interpreting information as evidence of failure (Flett et al., 2016). As such, they strive excessively to prevent this outcome from happening. People may engage in extreme hypervigilance through repeated checking of their performance, continual list-making or extreme thoroughness (Shafran et al., 2002). Given the fear of failure is so aversive, people with clinical perfectionism may also engage in avoidance or procrastination. However, such behaviour inevitably results in standards failing to be met. Failure to meet standards results in distress and self-criticism (Shafran et al.,

2002). Given that people with clinical perfectionism are hypervigilant and are more likely to interpret information as evidence of failure, this maintains self-criticism, negative self-evaluation and strengthens the need to set personally-demanding standards to avoid further failure. In some cases, the pursuit towards these high standards may be successful, which results in two consequences. First, it improves self-evaluation and reinforces the need to pursue high standards. Second, standards which have been achieved may be appraised as not being high enough. Therefore, the standards are elevated for next time around (Shafran et al., 2002; Shafran, Coughtrey, & Kothari, 2016). Evidence suggests that high levels of clinical perfectionism have been found in depression, anxiety disorders and eating disorders (Egan et al., 2016; Fairburn, Cooper, & Shafran, 2003; Hoiles, Kane, Watson, Rees, & Egan, 2016).

In the case of type 1 diabetes, the standard for blood glucose remaining between 4-7 mmol/litre could be perceived as a rigid standard. Furthermore, language used by health professionals may lend itself to people evaluating themselves on the basis of their glycaemic control (Dickinson, 2017). A wide range of factors can affect blood glucose levels and make it difficult to remain within recommended targets (Brown, 2018). In some cases, difficulties in keeping blood glucose levels between this range can lead to hypoglycaemia (low blood glucose) or hyperglycaemia (high blood glucose), both of which can be physically aversive and dangerous (Myers, Boyer, Herbert, Barakat, & Scheiner, 2007; Polonsky, Davis, Jacobson, & Anderson, 1992; Vanstone, Rewegan, Brundisini, Dejean, & Giacomini, 2015). To avoid failure to meet blood glucose targets and potentially aversive consequences, people may engage in rigid or excessive blood glucose

monitoring to evaluate their performance on glycaemic control (Gallichan, 1997; Hendrieckx, Halliday, Beeney, & Speight, 2019). Whilst frequent checking can be a useful way to ensure optimal control, for people with clinical perfectionism this may provide a greater opportunity to selectively attend to blood glucose readings as evidence for failure. Failing to meet blood glucose targets may result in self-criticism, feelings of frustration and powerlessness, which may reflect diabetes-related distress (Fisher et al., 2015; Hendrieckx et al., 2019). The fear of failure or levels of distress may be so aversive that people may engage in avoidance of diabetes management and blood glucose monitoring to avoid reminders of failure, which can lead to adverse health outcomes (Pyatak et al., 2013).

The clinical perfectionism model also posits that the pursuit to achieve these goals may lead to adverse consequences in other areas of life. A meta-synthesis found that episodes of hypoglycaemia can have a negative impact on health, wellbeing and quality of life. As a result, people who engaged in rigid regimens to avoid hypoglycaemia reported adverse impacts on social engagement and employment, suggesting that striving for ‘perfect’ glycaemic control may compromise other life domains (Vanstone et al., 2015).

The clinical perfectionism model could serve as a useful theoretical and clinically-relevant framework in understanding the role of perfectionism in the emotional and self-management aspects of type 1 diabetes. However, it remains a model without empirical testing for this population. The next chapter (the empirical research paper) sets out two aims 1) to determine whether there is a relationship between perfectionism (as measured by the CPQ) and diabetes-related distress; 2) to consider if, and how perfectionism has a role in diabetes self-management, using

ideas driven by the clinical perfectionism model. The study focused on type 1 diabetes, due to its increased complexity in its self-management.

Chapter Four: Empirical Study

The Relationship Between Perfectionism, Self-Efficacy and Diabetes-Related Distress in Adults with Type 1 Diabetes – An Exploratory Study

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Abstract

Objective: Diabetes-related distress in type 1 diabetes has been an emerging research area. Conceptually there may be some evidence to suggest that perfectionism is related to diabetes-related distress. However, empirical evidence for this relationship is still in its infancy, and focuses on its relation to eating disorder pathology (Powers, Richter, Ackard, & Craft, 2017). This current study aimed to examine the role of perfectionism, self-efficacy and diabetes-related avoidance with diabetes-related distress in adults with type 1 diabetes without a diagnosis of an eating disorder.

Design: A cross-sectional study examined the role of perfectionism in 282 adults with type 1 diabetes without a diagnosis of an eating disorder. All were residents in the United Kingdom.

Methods: Participants completed an online survey including measures on demographics, diabetes-related distress, self-efficacy, perfectionism, and diabetes self-management (frequency of blood glucose checking, and diabetes-related avoidance).

Results: Perfectionism, self-efficacy and diabetes-related avoidance were predictors of diabetes-related distress. Adults with higher levels of diabetes-related distress had higher levels of perfectionism, lower levels of self-efficacy and higher levels of diabetes-related avoidance compared to those with lower levels of distress. Perfectionism was a predictor of increased diabetes-related avoidance, but not the frequency of blood glucose checking, although this result may be down to the quality of data collected.

Conclusions: Perfectionism would appear to be a factor in diabetes-related distress in adults with type 1 diabetes, and appears to be related to avoidance of diabetes self-management. It remains unclear, however, if perfectionism is a causal factor for the development of diabetes-related distress.

Statement of Contribution

What is already known on this subject?

- Understanding the relationship between perfectionism and diabetes-related distress is still in its infancy.
- Existing research has explored the relationship between the two in eating disordered pathology in type 1 diabetes.
- Evidence for the role of perfectionism in diabetes-related distress in those without eating disorders remains undetermined.

What does this study add?

- Perfectionism appears to be related to elevated levels of diabetes-related distress in type 1 diabetes.
- Perfectionism appears to be a predictor of avoidance of diabetes self-management.

Keywords

Perfectionism, diabetes-related distress, type 1, diabetes, self-efficacy

Introduction

Managing type 1 diabetes involves ongoing attention to a range of complex and demanding self-management tasks around diet, activity levels and insulin regimens. Diabetes-related distress (DRD) relates to the emotional burden of living with diabetes, including feeling overwhelmed with its relentless daily self-management (Fisher et al., 2015; Hendrieckx et al., 2019). DRD appears to be distinct from clinical depression as it specifically related to negative perceptions of diabetes, rather than an underlying psychopathology and negative evaluations across a range of life domains as seen in depression (Gonzalez, Fisher, & Polonsky, 2011) and is linked with poor glycaemic control (Fisher et al., 2010; Van Bastelaar et al., 2010). Prevalence of DRD appears relatively high, with studies reporting prevalence rates between 20-41% in adults with type 1 diabetes (Dennick et al., 2015; Fisher et al., 2015) and 36% in type 2 diabetes (Perrin, Davies, Robertson, Snoek, & Khunti, 2017).

A psychometric measure developed specifically for adults type 1 diabetes identified seven sources of diabetes-related distress: powerlessness, management distress, hypoglycaemia distress, negative social perceptions, eating distress, physician distress and friend/family distress (Fisher et al., 2015). Management, eating and hypoglycaemia distress appear to relate to self-confidence in being able to manage diabetes, which appears akin to self-efficacy, defined as the beliefs one has in their own abilities in task performance (Bandura, 1977). Given the complexity of diabetes self-management, higher levels of self-efficacy may be required to feel confident in managing these demands effectively. Lower levels of self-efficacy have

been linked to higher levels of DRD in adults with diabetes (Devarajooh & Chinna, 2017; Van Der Ven, Weinger, & Pouwer, 2003).

Powerlessness in diabetes-related distress relates to not doing a good enough job in managing their diabetes (Fisher et al., 2015). People with type 1 diabetes describe feeling one needs to be 'perfect' with managing their diabetes by keeping blood glucose levels in recommended range (Abdoli, Hessler, Vora, Smither, & Stuckey, 2017; Fisher et al., 2015), and report feelings of failure when efforts to towards this are not achieved (Pyatak, Florindez, & Weigensberg, 2013; Rankin et al., 2012; Sparud-Lundin, Öhrn, & Danielson, 2010). Perfectionism is a trait relating to the pursuit of personally-demanding standards, and distress if these are not reached (Frost, Marten, Lahart, & Rosenblate, 1990). Given that people with diabetes need to adhere to complex and demanding standards, and feelings of failure if these are not reached, perfectionism may be a relevant trait to DRD.

Perfectionism has been described in multiple ways. Frost et al. (1990) describes perfectionism as a multidimensional construct, whereby individuals demonstrate orderliness, high personal standards, doubts about their actions, concerns over mistakes, and place considerable value on the expectations of others. Hewitt and Flett (1991) emphasise the interpersonal context. They argue that not only do perfectionists demonstrate high internal standards (self-orientated), but high standards of others (other-orientated) and believe others have high expectations of them (socially prescribed).

Shafran, Cooper and Fairburn, (2002) suggest a different approach – 'clinical perfectionism', defined as "the overdependence of self-evaluation on the determined

pursuit of personally demanding, self-imposed, standards in at least one highly salient domain, despite adverse consequences" (page 778). They suggest that striving to achieve standards leads to a heightened fear of failure, and people may engage in unhelpful behaviours, such as repeated checking of performance or avoidance to evade the possibility of failure. Actual or perceived failure results in self-criticism, negative self-evaluation and reinforces a drive for high standards.

Perfectionism has been linked to distress in other chronic health conditions. Higher levels of perfectionism are associated with increased symptoms in chronic fatigue syndrome (CFS) and pain (Deary & Chalder, 2010; Kempke et al., 2011; Kempke et al., 2013), and associated with less optimal outcomes in psychological interventions for chronic pain (Kempke, Luyten, Van Wambeke, Coppens, & Morlion, 2014). Perfectionism may have a role in maladaptive coping strategies, and in the 'boom and bust' activity cycles commonly seen in this population (Kempke et al., 2013; Kempke et al., 2014).

Perfectionism has been implicated as being a vulnerability and maintenance factor for distress and psychopathology across a range of disorders (Egan, Wade, Shafran, 2011). It could be possible that perfectionism serves a similar role in DRD. To date, only one study has investigated the relationship between the two. Powers, Richter, Ackart and Craft (2017) investigated the relationship between DRD and other psychological factors (perfectionism, mood, self-esteem, self-efficacy, eating disordered pathology) in adolescents and adults with type 1 diabetes. Regardless of age, participants with higher DRD reported higher eating disorder pathology, perfectionism, and lower mood and self-esteem. The link between perfectionism and eating disorder pathology has been well-documented (Dahlenburg, Gleaves, &

Hutchinson, 2019; Treasure et al., 2015), but remains unclear whether the relationship between perfectionism and DRD is similar in those with type 1 diabetes without eating-disordered pathology.

Type 1 diabetes management requires reaching certain targets around blood glucose levels, needing frequent monitoring of blood glucose and adjustment via insulin regimens in order to keep the microvascular and macrovascular complications associated with diabetes to a minimum (National Institute for Health and Care Excellence; NICE, 2015). Perfectionistic traits and higher self-efficacy may provide the motivation and confidence to achieve such targets (Lo & Abbott, 2013; Yi-Frazier, Hilliard, Cochrane, & Hood, 2012). Conversely, high levels of perfectionism may be unhelpful, particularly if coupled with a fear of failure as described in clinical perfectionism (Shafran et al., 2002). To avoid the likelihood of failure, those with clinical perfectionism may be hypervigilant and repeatedly checking their performance (Shafran et al., 2002, 2016). In the case of diabetes, this may lead to increased, or excessive, blood glucose monitoring Given the relatively small target ranges suggested for blood glucose levels (NICE, 2015), alongside the high number of variables that may affect blood glucose levels (Brown, 2018) the unavoidable out-of-target-range results may result in feelings of failure, self-criticism, and powerlessness which may reflect DRD (Fisher et al., 2015; Hendrieckx et al., 2019; Sparud-Lundin et al., 2010). Alternatively, people may engage in avoidance of diabetes management and blood glucose monitoring to avoid reminders of failure, which can lead to serious health implications (Pyatak et al., 2013).

With little research on the link between perfectionism and DRD, it is important to investigate these relationships empirically in order to provide a greater understanding of the potential relationship between the two factors. This may contribute to the development of clear, focused targets for psychological interventions to reduce distress and achieve optimal diabetes management.

This study aimed to answer the following questions:

1. Are perfectionism, self-efficacy, and diabetes-related avoidance predictors of diabetes-related distress in adults with type 1 diabetes?
2. Do adults with high levels of diabetes-related distress differ in levels of perfectionism, self-efficacy and diabetes-related avoidance than adults with low diabetes-related distress?
3. Is there an association between perfectionism and diabetes management behaviours (e.g., diabetes-related avoidance and frequency of blood glucose checking)?

Methods

Participants

Two hundred and ninety-five participants completed an online survey. Inclusion criteria for the study were 1) to be aged at least 16 years; 2) diagnosed with Type 1 diabetes; 3) diagnosed for at least one year; 4) self-managing their own diabetes care, using insulin for glycaemic control; 5) a good command of the English language; and 6) a UK resident (to control for the effect of healthcare provision on diabetes management and as a potential source of distress). Participants were ineligible for the study if they were 1) aged below 16 years; 2) had a diagnosis of Type 2 diabetes; 3) had a current diagnosis of an eating disorder and 4) a non-UK

resident. Participants diagnosed with an eating disorder were excluded as the relationship between perfectionism and eating disorder pathology has been established (Dahlenburg et al., 2019; Treasure et al., 2015).

Out of 295 participants, data for $N = 13$ participants were removed as they failed to complete the demographics ($N = 3$) or meet the inclusion criteria ($N = 10$). The final sample resulted in $N = 282$ participants (77.3% female) with a mean age of 36.91 years (SD 13.94). The majority of participants identified themselves as White British ($N = 249$; 88.3%), had at least an undergraduate degree ($N = 196$; 69.5%) and were employed full-time ($N = 149$; 52.84%). Participants had on average (mean) been diagnosed with Type 1 diabetes for 19.91 years (SD 13.55). The majority of participants managed their blood glucose levels by a combination of finger prick testing and flash glucose monitoring ($N = 94$, 37.3%) or finger prick tests only ($N = 78$; 27.66%).

Sample Size Calculation and Data Analysis

A priori sample size calculations were derived using power tables by Clark-Carter (2009) and Green (Green, 1991). A minimum of $N = 208$ participants were required to adequately power all analyses based on a power of 0.8, $\alpha = 0.05$ with a small to medium effect size based on previous research (Powers et al., 2017). Data were analysed using IBM SPSS Statistics version 25.

Measures

Diabetes-related distress scale in type 1 diabetes (T1-DDS; Fisher et al., 2015).

The T1-DDS is a 28-item self-report measure of diabetes-related distress for adults with type 1 diabetes. The measure has seven subscales, identified as sources

of distress: powerlessness, management distress, hypoglycaemia distress, negative social perceptions, eating distress, physician distress and friend/family distress. Responses are rated on a Likert scale from 1 = a slight problem to 6 = a very serious problem. Subscale scores can be calculated by calculating mean scores across items in each subscale, and a total score based on the mean of the seven subscales. Higher scores indicate higher levels of DRD. The measure provides cut-off scores to distinguish between four DRD groups (none, mild, moderate, high).

Confidence in diabetes self-care scale (CIDS; Van Der Ven et al., 2003).

The CIDS is a 20-item self-report measure of diabetes-specific self-efficacy for adults with type 1 diabetes. Responses are rated on a Likert scale from 1 = "No, I am sure I cannot" to 5 = "Yes I am sure I can" with an overall score being calculated by summing all of the items. Higher scores indicate higher levels of self-efficacy.

Clinical perfectionism questionnaire (CPQ; Fairburn et al., 2003).

The CPQ is a 12-item self-report measure of clinical perfectionism. Responses are rated on a Likert Scale from 1 = not at all to 4 = yes, all the time. A perfectionism score is calculated by summing all items together (questions two and eight are reverse-scored), with higher scores indicating higher levels of perfectionism.

Diabetes management behaviours.

Diabetes-related avoidance.

Acceptance and action scale in diabetes (AAD-Q; Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007).

The AAD-Q is an 11-item self-report measure based on principles of Acceptance and Commitment Therapy (ACT), assessing psychological flexibility (an openness or acceptance towards) and avoidance of unwanted thoughts and emotions in diabetes. ACT principles would suggest that unwanted thoughts and feelings are likely to lead to attempts to rid of these, such as avoidance of activities which serve as reminders to these unwanted experiences (Harris, 2009). In diabetes, this may include avoiding unwanted thoughts related to their condition. Therefore measuring psychological avoidance may indicate that participants are likely to avoid diabetes management (Lindholm-Olinder et al., 2015; Schmitt et al., 2014). In addition to avoidance of thoughts, some items on the measure address avoidance behaviours directly, such as "I do not take care of my diabetes because it reminds me that I have diabetes", "I avoid taking or forget to take my medication because it reminds me that I have diabetes"; and "I don't exercise regularly because it reminds me that I have diabetes". The measure was used as a measure of diabetes-related avoidance.

Responses are rated on a Likert scale from 1 = never true to 7 = always true. The overall score is created by summing all item scores (all questions except question two are reverse-scored). Higher scores indicate greater psychological flexibility, and thus reduced avoidance.

Frequency of blood glucose checking.

To investigate the relationship between perfectionism and frequency of blood glucose checking, participants were asked the following questions (devised by the study authors):

"On average, how many times a day in the last month would you say that you check your blood glucose levels?" Participants were required to provide a numeric

answer about their average daily frequency and indicate whether this frequency was typical. If not, participants were asked to provide a response about their typical daily frequency.

Procedure

Participants were recruited via social media to complete an online survey. National charities, and online support groups were also contacted and agreed to promote the study through their social media, newsletters and online forums. Participants were given information on the study and provided informed consent online through ticking a series of statements. Participants were then directed to the study itself and asked to complete all of the questionnaire measures. Participants were free to exit the survey at any time, with the option to complete it later by saving the link to the study. Following completion, participants were directed to a debrief page with details for various support networks and contact details for the study authors, and the option to receive the study results and / or enter a prize draw for a £25 Amazon.co.uk voucher. Details of participants who opted to receive the results or enter the prize draw were kept separately from the study data to ensure anonymity.

Ethical approval

This study received favourable ethical approval from the Faculty of Medicine and Health Sciences Ethics Committee, University of East Anglia.

Results

Participant Characteristics

Table 3 reports participant demographics and is grouped according to levels of DRD as measured using the T1-DDS scale. Groups were defined based on four cut off points by Fisher et al. (2015). The results indicate that 37.94 % of participants reported moderate levels of DRD and 35.81% reported high levels of DRD. Differences in demographics were compared using χ^2 or one-way analysis of variances (ANOVAs) with post-hoc tests. Significant main effects were found in age, with participants in the 'no DRD' group being older than those with 'moderate' and 'high DRD'. Significant differences between groups were also found for gender and employment. A higher proportion of females were found in the moderate and high DRD groups compared to the lower DRD groups. The high DRD group had the lowest proportion of those who are employed full-time and more students compared to the other groups.

The means and standard deviations for each measure for each DRD group are outlined in table 4. Participants in the 'high DRD' group had clinical perfectionism scores comparable to those with anxiety, depressive and eating disorders (Egan et al., 2016; Hoiles et al., 2016) suggesting very high levels of clinical perfectionism.

Table 3

Participant demographics

	T1-DDS classification				
	No DRD < 1.49 *n* = 21 *n or M (SD)*	Mild DRD 1.50 – 1.99 *n* = 52 *n or M(SD)*	Moderate DRD 2 - 2.95 *n* = 107 *n or M (SD)*	High DRD >3.00 *n* = 101 *n or M (SD)*	Significant difference across the four groups
Age (years)	47.24 (13.85)	39.39 (14.92)	37.51 (13.04)	32.75 (12.97)	F (3, 276) = 8.03, p < 0.001
Gender					
Male	10	15	25	14	χ^2 (6) = 14.6, p < 0.05
Female	11	38	82	86	
Other	.	.	.	1	
Years since diagnosis	25.52 (14.91)	20.58 (14.92)	19.26 (13.61)	19.07 (12.31)	F (1,3) = 270.96, p = .219
Ethnicity					χ^2 (21) = 22.94 p = .347
White British	19	47	91	92	
White Irish	.	2	11	4	
Asian (Indian, Pakistani, Bangladeshi, Chinese, Other)	1	1	.	.	
Mixed ethnicity	.	1	1	1	

Table 3:

Participant demographics continued

	T1-DDS classification				
	No DRD < 1.49 *n* = 21 *n or M (SD)*	Mild DRD 1.50 – 1.99 *n* = 52 *n or M (SD)*	Moderate DRD 2 - 2.95 *n* = 107 *n or M (SD)*	High DRD >3.00 *n* = 101 *n or M (SD)*	Significant difference across the four groups
Education					χ^2 (18) = 17.51, p = .488
Some secondary education (no qualifications)	.	1	.	.	
GCSEs or equivalent	1	.	5	8	
A Levels or equivalent	2	10	17	19	
Trade / technical / vocational training	4	3	8	6	
Undergraduate degree	6	21	41	42	
Postgraduate degree	8	18	35	25	
Employment					χ^2 (15) = 29.41, p < 0.05
Full time employed	11	31	65	42	
Part time employed	4	8	14	22	
Self employed	1	1	8	6	
Unemployed	.	1	1	5	
Student		3	15	19	
Other	5	7	5	7	

Table 3:

Participant demographics continued

	T1-DDS classification				
	No DRD < 1.49 *n* = 21 *n or M (SD)*	Mild DRD 1.50 – 1.99 *n* = 52 *n or M(SD)*	Moderate DRD 2 - 2.95 *n* = 107 *n or M (SD)*	High DRD >3.00 *n* = 101 *n or M (SD)*	Significant difference across the four groups
Blood glucose monitoring method					χ^2 (15) = 14.57, p = .483
Finger prick tests only	5	14	30	29	
Continuous blood glucose monitoring (CGM) only	1	5	8	6	
Flash glucose monitoring only †	3	9	15	12	
Finger prick test + CGM	5	10	12	15	
Finger prick tests + flash glucose monitoring	5	14	36	39	
Other	2	1	6	.	

† Flash glucose monitoring is a novel system for blood glucose monitoring. It is a small sensor worn under the skin and measures the amount of glucose in the fluid below the skin, known as interstitial fluid. Readings from the sensor are activated when a reader is swiped over the sensor (National Health Service, 2018)

Table 4:

Means and standard deviations for each questionnaire for each diabetes-related distress group

Diabetes-related distress group	*n*	T1-DDS *M (SD)*	CPQ *M (SD)*	CIDS *M (SD)*	AAD-Q *M (SD)*
No DRD	21	1.32 (.13)	22.29 (5.36)	92.05 (5.98)	66.19 (4.61)
Mild DRD	53	1.74 (.13)	25.32 (5.97)	86.57 (7.79)	61.49 (6.08)
Moderate DRD	107	2.46 (.29)	28.44 (5.82)	78.22 (9.28)	58.50 (6.67)
High DRD	101	3.65 (.59)	33.03 (5.83)	68.77 (11.13)	51.55 (10.40)

Are Perfectionism, Self-Efficacy, and Diabetes-Related Avoidance Predictors of Diabetes-Related Distress in Adults with Type 1 Diabetes?

A multiple regression was conducted to analyse the predictive values of demographic variables (age, gender, years since diagnosis, ethnicity, education, employment and method of blood glucose monitoring), self-efficacy, diabetes-related avoidance, and perfectionism on DRD. Categorical variables with more than one level were re-coded as dichotomous variables. The regression model appeared to be statistically significant, predicting 54.7% of the variance, $F (10, 268) = 34.58$, $p < 0.001$, $r^2 = .563$, adjusted $r^2 = .547$. Age ($\beta = -.12$, $p < 0.05$), blood glucose monitoring method ($\beta = .087$, $p < 0.05$), self-efficacy ($\beta = -.341$, $p < 0.001$) psychological flexibility ($\beta = -.279$, $p < 0.001$) and perfectionism ($\beta = .289$, $p < 0.001$) were statistically significant predictors of DRD. This suggests that that being younger, using manual blood glucose monitoring methods (e.g. finger prick or flash glucose monitoring as opposed to Continuous Blood Glucose Monitoring (CGM), a reduction in self-efficacy and psychological flexibility (and thus increased

avoidance) and increased perfectionism were predictors of DRD. Psychological variables (particularly self-efficacy) appear to be greater predictors of DRD compared to demographic variables. Regression coefficients, standard errors and p-values can be found in table 5.

Table 5. Multiple Regression results

Model	*B*	*SE* $_{\beta}$	β
(Constant)	5.391	.483	.
Age	-.008	.004	-.120*
Gender	.026	.090	.012
Years since diagnosis	.005	.004	.075
Ethnicity	.038	.115	.014
Education	-.270	.167	-.067
Employment	-.127	.088	-.060
Method of blood glucose monitoring	.181	.088	.087*
Self-efficacy (CIDS)	-.025	.004	-.341**
Diabetes-related avoidance (AAD-Q) ‡	-.027	.005	-.279**
Perfectionism (CPQ)	.039	.006	.289**

* $p < 0.05$; ** $p < 0.001$; ‡ Negative relationship outlined by β value indicates a reduction in psychological flexibility, and thus an increased in diabetes-related avoidance.

Do Adults with High Levels of Diabetes-Related Distress Differ In Levels of Perfectionism, Self-Efficacy and Diabetes-Related Avoidance than Adults with Low Diabetes-Related Distress?

A one-way multi-analysis of variance (MANOVA) was carried out to investigate whether there were differences between the four DRD groups on perfectionism (CPQ), self-efficacy (CIDS) and diabetes-related avoidance (AAD-Q). Examination of assumptions highlighted that the data met parametric assumptions other than equality of variances, as highlighted by Box's M test, which may be as a result of the unequal sample sizes in each group. Therefore, Pillai's Trace statistic for the MANOVA model and Games-Howell post-hoc tests were used for any significant main effects as these are robust against violations of homogeneity of variance.

MANOVA analysis revealed a significant difference between DRD groups on the combined dependent variables ($F (9, 834) = 19.26$, $p < 0.001$, Pillai's Trace = .516, $\eta^2 = .172$). Post-hoc one-way ANOVAs demonstrated that perfectionism ($F (3, 278) = 60.4$, $p < 0.001$, $\eta^2 = .395$), self-efficacy ($F (3, 278) = 31.46$, $p < 0.001$, $\eta^2 = .25$) and diabetes-related avoidance ($F (3, 278) = 32.82$, $p < 0.001$, $\eta^2 = .26$) were significantly different between the DRD groups. Games-Howell post-hoc tests showed that participants with 'high DD' had statistically significant higher levels of perfectionism than those with 'moderate', 'mild' and 'no DRD' (all $p < 0.001$). No statistically significant difference in perfectionism levels between 'no DRD' and 'mild DRD' groups were found ($p = .162$). Participants with 'high DRD' had statistically significantly lower levels of self-efficacy and lower levels of psychological flexibility (and thus higher levels of diabetes-related avoidance) than those with 'moderate', 'mild' and 'no DRD' (all $p < 0.001$).

Is There an Association between Perfectionism and Diabetes Management Behaviours (e.g., Diabetes-Related Avoidance and Frequency of Blood Glucose Checking)?

Linear regressions were carried out between perfectionism (CPQ) on diabetes-related avoidance (AAD-Q) and the frequency of blood glucose checking. Increased perfectionism was associated with a reduction in diabetes-related avoidance ($F (1, 280) = 27.26$, $p < 0.001$, $r^2 = .089$, adjusted $r^2 = .085$), accounting for around 8.5% of the variance. The AAD-Q measures psychological flexibility, and therefore reductions in psychological flexibility indicate increased avoidance. Psychological flexibility reduced by -.408 for every point increase on the CPQ, suggesting that as perfectionism increased, diabetes-related avoidance did too.

Increased perfectionism was not a significant predictor of increased frequency of blood glucose checking ($F (1,273) = .071$, $p = .791$, $r^2 = .00$, adjusted $r^2 = -.003$). The results should be interpreted with caution as scatter and box plots identified a number of extreme values ($N = 25$, range 250-556 blood glucose checks day) and violated normal distribution assumptions. Frequency tables found that the modal value for the frequency of blood glucose checking was $N = 8$ times a day ($N = 36$ participants), with 52.7% participants reporting higher blood glucose checking frequencies. Frequency scores tapered off when scores were above $N = 25$ times a day ($N = 8$ participants). Those with more extreme scores had fewer frequency counts (between one to two participants each), and is possible that these scores biased the analysis.

The $N = 25$ extreme values were examined to ascertain how influential they were in the regression model. Standardised residuals for these extreme values identified $N = 9$ of these had a value > 3. Examination of Leverage and Cook's

values for these nine below suggested that these data points were not overly influential. Data quality was not improved by winsorising, trimming nor transforming the data.

Discussion

Managing type 1 diabetes requires complex self-management tasks around diet, exercise and insulin regimens. Studies have shown that people with type 1 diabetes report needing to be 'perfect' in managing their diabetes (Fisher et al., 2015) and report feelings of failure when their efforts fall below this (Pyatak et al., 2013; Rankin et al., 2012; Sparud-Lundin et al., 2010). People with diabetes are also at risk of developing DRD, reporting feelings of powerlessness over their diabetes (Fisher et al., 2015). As people with diabetes need to adhere to rigid standards around glycaemic control, and report feelings of failure and distress if not reached, perfectionism may conceptually be linked to DRD. Previous research investigating links between the two focused on eating disorder pathology and was not clear whether the results would be similar for those without eating disorder pathology (Powers et al., 2017).

This study examined the extent to which perfectionism was a predictor of DRD alongside other variables such as self-efficacy and diabetes-related avoidance. It also explored whether adults with type 1 diabetes who had high DRD differed in levels of perfectionism, self-efficacy and diabetes-related avoidance compared to those with lower levels of DRD. Finally, it investigated whether perfectionism was a predictor of diabetes management, through diabetes-related avoidance or the frequency of blood glucose checking.

Multiple regression results showed that age, manual blood glucose monitoring, reduced self-efficacy, increased diabetes-related avoidance and increased perfectionism were statistically significant predictors of DRD. Those with high levels of DRD had lower levels of self-efficacy, higher diabetes-related avoidance, and higher levels of perfectionism. Perfectionism was a predictor of avoidance in diabetes, but not the frequency of blood glucose checking.

The results of this study regarding perfectionism and other psychological variables on DRD could map onto Shafran and colleagues' (2002) cognitive-behavioural model of clinical perfectionism. People with high levels of perfectionism report a fear of failure and perceived failure is accompanied with increased self-criticism and distress. Whilst self-criticism was not directly measured in this study, perfectionism was a significant predictor of distress, and participants with high levels of diabetes-related distress exhibited higher levels of perfectionism. As failure is aversive, people may either become hypervigilant with their performance and engage in increased self-monitoring, or engage in avoidance entirely.

The results of this study highlight that increased levels of perfectionism were associated with increased diabetes-related avoidance, and those with high DRD were more likely to report higher levels of avoidance. This appears consistent with other research where high levels of DRD were associated with an increased avoidance of type 1 diabetes management (Hessler et al., 2017). The results between perfectionism and increased blood glucose checking are less conclusive, however multiple regression analysis demonstrated that manual blood glucose checking was associated with greater levels of DRD. People using manual blood glucose monitoring methods demonstrate higher levels of DRD compared to those using

CGM (Polonsky, Hessler, Ruedy, & Beck, 2017; Vesco, Jedraszko, Garza, & Weissberg-Benchell, 2018). People with high levels of perfectionism often doubt their actions, and engage in frequent checking of their performance for greater certainty (Frost et al., 1990). This may suggest that manual blood glucose monitoring methods provide greater opportunity for checking, but also provide a greater opportunity to overestimate failure or doubt their performance. Standards set by those with high levels of perfectionism are often dichotomous and operationalised as 'shoulds' and 'musts' (Shafran et al., 2002, 2016). Good glycaemic control in type 1 diabetes relies on blood plasma glucose levels being between 4 – 7mmol/litre (NICE, 2015), and to many is considered a 'must' for diabetes management. Blood glucose monitoring methods have the advantage of providing instant feedback on the effectiveness of glycaemic control but anything outside of this small 'must' range may be perceived as failure and contribute to feelings of powerlessness and lower self-efficacy associated with DRD. This appears consistent with qualitative studies which have shown that people with type 1 diabetes report feelings of failure when efforts to manage blood glucose do not meet the recommended guidelines (Pyatak, Florindez, .& Weigensberg, 2013; Rankin et al., 2012; Sparud-Lundin, Öhrn, & Danielson, 2010).

Theoretical Implications

Findings from this study may add to theoretical models on the development of DRD. Fisher, Hessler, Polonsky, Strycker, et al. (2018) suggest that DRD may be a result of the emotion regulation difficulties in response to the burden of diabetes, including reacting to emotional experiences impulsively, self-criticism, or engaging in rumination. Emotion dysregulation can lead to avoidance of diabetic management, which impacts on metabolic outcomes (Fisher et al., 2018; Ruiz-Aranda et al., 2018).

The results of this study further add to this theory, as perfectionism was a predictor of DRD. Perfectionism is associated with self-critical rumination in response to perceived failure or negative outcomes (Flett et al., 2016), and self-criticism appears to mediate the relationship between perfectionism and distress (James, Verplanken, & Rimes, 2015). The relationship between perfectionism and DRD in this study may further add to this theory, whereby perfectionism may serve as a vulnerability factor to DRD due to its links with rumination, self-criticism and distress.

Findings from this study may contribute to existing models of self-management in health conditions. The Common-Sense Model of Self-Regulation (Leventhal, Meyer & Nerenz, 1980) is a model used to understand how individuals interpret and respond to symptoms and how a series of emotional and behavioural goals and strategies is set to self-manage these. A central component to the model is 'coherence', which refers to the need for consistency between patients' interpretation of symptoms, and the perception that their efforts of self-management are effective in controlling symptoms (Benyanami & Karademas, 2019). Any discrepancy between the two may lead to negative affect. Perfectionism may serve a role within this concept of coherence, whereby distress may arise as a result of a discrepancy or lack of coherence when efforts of self-management fail to meet expected aims. Within diabetes, fluctuating blood glucose levels despite efforts to monitor and adjust insulin regimens accordingly, may be perceived as efforts falling short of expectations, leading to high levels of distress.

Clinical Implications

Around one fifth of patients with type 1 diabetes in healthcare clinics will experience elevated levels of DRD (Dennick et al., 2015), therefore routine screening for this is recommended (Hendrieckx et al., 2019). Findings from this

research suggest that screening for perfectionism to ascertain whether perfectionism is a risk factor in DRD is warranted. Interventions for DRD focus on goal-setting or improving confidence in blood glucose management though psychoeducation, and appear to demonstrate at least modest effects in a reduction in DRD and improved glycaemic control (Schmidt, van Loon, Vergouwen, Snoek, & Honig, 2018; Sturt et al., 2015).Whilst these interventions address the behavioural aspects and improve self-efficacy, they may not address the emotional burden of living with diabetes. Compassion-focused interventions show some promise in the reduction of DRD, through addressing self-criticism over actual or perceived failures (Friis, Johnson, Cutfield, & Consedine, 2016). Furthermore, interventions for perfectionism also focus on challenging cognitive biases around failure and self-compassion (Egan, Wade, Shafran, & Antony, 2014). Compassion-focused or cognitive-behavioural focused interventions may address the high levels of perfectionism as found in this study and its link with distress. On a service-level, practitioners delivering psychological therapy may wish to consider compassion-focused or cognitive-behavioural interventions if perfectionism is related to their DRD.

Skinner, Joensen and Parkin (2020) highlight potential challenges in implementing the above clinical implications. Consultations focused solely on the practical aspects of self-management of diabetes may lead to missed opportunities for discussions of the emotional aspects of living with diabetes and therefore, fewer conversations about identifying and screening for DRD. As a result, opportunities for intervention and improving the emotional experience for those living with diabetes may be missed. Poor communication within consultations has also been consistently linked to the development of DRD, whereby highlighting impending threats of complications, as a means to encourage self-care, may further add to feelings of

powerless or the need for perfectionism in diabetes management (Skinner et al., 2020). It is worth considering whether communication styles with healthcare professionals have a role in developing or maintaining high levels of perfectionism in those with high levels of DRD.

Strengths and Limitations

To our knowledge, this is one the first studies to investigate and demonstrate the role of perfectionism and distress in diabetes outside an eating disorder context. This study recruited a high number of participants and analyses were well-powered. However, the sample itself may not be representative of the clinical population. Participants were recruited through social media and potential participants who do not use social media may have been missed. The majority of participants reported moderate or high levels of DRD, were educated above secondary school level and employed, suggesting a sample which is naturally high achieving. Furthermore, DRD groups differed by age, gender and employment levels. These findings appear to be consistent with other research, whereby being younger and female is associated with higher levels of distress (Dennick et al., 2015; Fisher et al., 2015), although this does not account for why employment would differ across DRD groups. Whilst those with an eating disorder diagnosis were excluded from the study, there was no way of validating this. People with diabetes may have undiagnosed eating disorders, or have sub-clinical disordered eating symptomatology (Colton, Rodin, Bergenstal, & Parkin, 2009; Young-Hyman & Davis, 2010). It is possible a proportion of the sample may include this subgroup of participants, which may affect the results as the relationship between perfectionism and eating disorders may act as a confounding variable between perfectionism and DRD.

The results for the relationship between perfectionism and the frequency of blood glucose checking must be treated with caution due to the extreme values given by some participants. Removing outliers had the potential to bias the analysis. It could be possible that participants misinterpreted the question and provided an overall total of the number of times they checked their blood glucose levels per day over the last month, as opposed to providing an average per day. However, this cannot be assumed and therefore the results must be interpreted with care.

DRD is associated with poorer glycaemic control (Fisher et al. 2010). This study did not assess glycaemic control, and therefore whether perfectionism has a role in this remains unknown. Furthermore, this study was cross-sectional in nature and thus causality and direction of causality for the relationship between perfectionism and DRD cannot be determined.

Conclusions and Recommendations for Future Research

This study forms part of a wider picture to investigate the relationship between perfectionism and other psychological variables with DRD. The study makes a contribution to current research by building on previous evidence that perfectionism is associated with DRD. The results of the study have implications in theoretical models which aim to understand the development of DRD. Future research could include longitudinal designs to investigate whether perfectionism is associated with glycaemic control over time. Case studies could also be used using data from blood glucose monitoring methods to investigate how those with high levels of perfectionism respond to perceived successes or failure in blood glucose management through insulin adjustment regimens, or the frequency of blood glucose checking.

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Chapter Five: Extended Methodology and Analysis

Extended Methodology and Analysis

This chapter provides further information on the methodology employed in the empirical study, statistical analysis assumptions and sample size calculations related to the research questions in the empirical study, and those not included in the empirical study due to word count journal restrictions.

Psychometric Properties of Measures

Diabetes-related distress scale in type 1 diabetes (T1-DDS). The measure was developed and validated in adults with type 1 diabetes. Authors of the measure indicate that T1-DDS has good total scale reliability (total scale, α = .91, subscale range α =.76 -.88), test-retest reliability (total scale r = .74) and good convergent validity (Fisher et al., 2015). Reliability for the empirical study was α =.93.

Confidence in diabetes self-care scale (CIDS). The measure was developed for adults with type 1 diabetes. Psychometric properties of the CIDS were tested between Dutch and US samples and demonstrated good internal consistency (α = 0.86 for Dutch sample and 0.90 U.S. sample), test-retest reliability (Spearman's r = 0.85), and good convergent validity (Van Der Ven et al., 2003). Reliability for the empirical study was α =.88.

Clinical perfectionism questionnaire (CPQ). The measure was developed by Fairburn et al. (2003). The CPQ demonstrates adequate internal consistency (α =.71), good convergent validity, and is valid in an eating disorder and community. Reliability in the empirical study was α =.81.

Acceptance and action scale in diabetes (AAD-Q). The measure was developed by Gregg et al. (2007) for adults with type 2 diabetes. Internal consistency

is high (α = .94; Gregg et al., 2007) and no other psychometrics were reported. Reliability in the empirical study was α =.72.

Extended Procedure for Empirical Study

Recruitment took place over six months between March – September 2019. Following ethical approval, a Twitter and Facebook account was created for the purposes of this study as both social media platforms have a strong online community for diabetes. Adverts on Twitter and Facebook were advertised on a frequent basis (see Appendix L). Twitter adverts included "hashtags" to widen the accessibility of the post and a request for people to 're-tweet' the study. These posts were often 're-tweeted' by members of the diabetes community, with the study advertisement being re-tweeted around 140 times.

Gatekeepers for online communities on Twitter and Facebook were approached for permission to advertise the study or to re-tweet the study. One support group on Facebook with over 20, 000 followers agreed to promote the study. Gatekeepers for charities such as Diabetes UK, diabetes.org.uk and JDRF (Juvenile Diabetes Research Foundation) were approached by email requesting the study to be advertised in their newsletters, online support groups and social media platforms. Diabetes UK and JDRF agreed to advertise the study on their research webpages, social media platforms (including Instagram and LinkedIn) and newsletters. Advertisement on these social media platforms led to a further 33 re-tweets.

The advert contained a link to the study, which was hosted by Online Surveys (www.onlinesurveys.ac.uk) as this platform was compliant with General Data Protection Regulations of the Data Protection Act (GDPR; Information Commissioner's Office, 2018). Participants were presented with information regarding the study, what was involved, how the data they provided would be used,

the right to withdraw from the study and details to contact the research team with any questions (see Appendix D). If participants wished to continue, they were directed to the consent page and were asked to provide their consent by selecting options stating they agreed with various statements regarding reading information about the study, being provided with the opportunity to ask questions, they understood how data they provided was being used, withdrawal from the study and consent into the study (see Appendix E). After providing consent, participants completed the measures in the following order: demographics, T1-DDS, CIDS, AAD-Q, CPQ and frequency of blood glucose checking (see Appendix F, G, H, I, and J). Piloting of the online study found that the study could be completed in 10-15 minutes, however further time was added onto the information sheet to allow for those who may take longer to complete all items.

Throughout the study, participants were given the option to pause and exit the survey at any time by clicking the “Finish later” link. A link to finish the survey was provided, which could be saved by participants. Participants were told their answers would not be submitted unless they finished the survey and pressed the ‘Submit’ button.

Ethical Considerations

The study was granted by the Faculty of Medicine and Health Sciences at the University of East Anglia. Details of ethical approval and subsequent amendments are in Appendix C.

Participant information and informed consent.

The study did not require face-to-face contact with participants. Informed consent was managed through providing an information page prior to the study with

an opportunity to contact the research team for questions. Participants were asked to indicate their consent by clicking ‘I agree to take part in this study’ button on the consent section of the study. Participants were not able to proceed to completing the survey without doing so.

Confidentiality.

Data was managed in line with General Data Protection Regulations (GDPR; Information Commissioner’s Office, 2018). Participants were informed in the information sheet (Appendix D) that their data would be anonymous and held in a secure manner. Email addresses provided for the results of the study and the prize draw were held separately to the questionnaire data. Participant email addresses could not identify them to their data. Email addresses for the prize draw and to receive a copy of the results will be destroyed once the winner has been announced and the results have been sent to participants. It is worth noting that participants who had completed the study sometimes re-tweeted the researcher to inform them of this. This may be seen as a breach of confidentiality. However, this was down to participant choice to inform the researcher, as opposed to breaches on the researcher’s behalf. It was not possible to identify participant questionnaire data based on ‘tweets’.

Coercion.

Given the large sample size required for the study, a decision was made to offer participants the opportunity to win a £25 Amazon.co.uk voucher as a means to enhance recruitment. The UEA Postgraduate Research Department guidelines suggested that this amount was appropriate to the time invested in the study by participants without it being coercive.

Distress and debriefing.

There was the potential for participants to disclose high levels of distress, or concerns around their diabetes. A debrief page (Appendix K) was offered to participants following completion or withdrawal from the study, advising them to contact the researcher and research supervisors for any concerns about the study. Participants were encouraged to contact their GP, local diabetes clinic, or charitable support organisations for concerns around their diabetes. Participants who wished to make a formal complaint about the study were provided with contact details of a research member of staff in the Department of Clinical Psychology independent to the research team.

Withdrawal.

Participants were reminded in the information page that they can withdraw from the study at any time by exiting the survey without submitting their responses. However, participants were made aware that as their responses could not be identified, once they have submitted their responses it was not possible to remove these from the dataset after this point.

Additional Statistical Analysis

Data preparation.

Data were manually screened for maximum and minimum values to identify any numbers outside the range of possible for scores for each questionnaire measure – no errors were identified. Data were also examined for any multiple values for a single item, or missing values. A very small proportion of the data provided multiple values for single items. In these cases, the upper of the two values were taken, based on the advice of an independent statistician. Less than 0.07% of the overall data were missing on the CIDS scores. Missing data needs to be examined to determine whether the nature of missing data is related to outcome variables or the sample

(Jakobsen, Gluud, Wetterslev, & Winkel, 2017). Examination of the missing data suggested the data was 'missing completely at random'. To ensure completeness of the dataset, individual mean imputation methods were used for missing items of the CIDS measure, as this method has been demonstrated to have near perfect agreement for up to 30% of data missing (Shrive, Stuart, Quan, & Ghali, 2006).

Assumption of normality.

The T1-DDS, CIDS, AAD-Q and CPQ results were assessed for normality through visual inspections of histograms and Q-Q plots, at a whole sample and diabetes-DRD subgroup level. This method was preferred over statistical tests such as Kolmogorov-Smirnov and Shapiro-Wilks tests, as both tests are sensitive to any deviations from normality for large sample sizes, and are therefore likely to provide a statistically significant results even if this is not the case (Field, 2009). Examination of histograms demonstrated a roughly bell-shaped curve for all measures, and examination of Q-Q plots found observed values to be close along the expected values line. Therefore data was assumed to meet the assumptions of normal distribution.

Assumption of independence.

As participants completed the survey separately, the influence of one participant on another was considered very unlikely. Therefore data were assumed to be independent from one another.

Homogeneity of variance.

Examination of the homogeneity of variance for the T1-DDS, CIDS, AAD-Q and CPQ were examined through Levene's test. The results showed that all measures except the CPQ violated the assumption. However this test is sensitive to small deviations when sample sizes are large (Field, 2009). For larger sample sizes,

calculating Harley's F-Max ratios is recommended (Field, 2009). However, this test assumes there are equal sample sizes between each group, whereas sample sizes between the four DRD groups varied greatly. The option to combine all scores for the 'no DRD' and 'mild DRD' groups together was explored, to create a sample size (N = 74) which could be comparable to the sample size to the 'medium' and 'high DRD' groups. However, t-tests between 'no DRD' and 'mild DRD' groups found that scores differed across all the variables and therefore appeared to be distinct groups. There is some evidence to suggest that F-ratios are more robust when groups with the largest sample size have the largest variance values and groups and the smallest group size has the smallest ratio (Blanca, Alarcón, Arnau, Bono, & Bendayan, 2018) which was the case for this dataset. Given the above, the decision was made to keep all four groups but account for the unequal sample sizes when interpreting the results.

Multiple regression analysis.

A multiple regression analysis was used for research question one – are perfectionism, self-efficacy, and diabetes-related avoidance predictors of diabetes-related distress in adults with type 1 diabetes?

Data preparation.

Multiple regression analysis relies on that the dependent variable is continuous, and independent variables continuous or categorical in nature (Laerd Statistics, 2015a). Demographic variables were included as independent variables in the regression analysis. However, these variables were categorical or ordinal in nature with more than one level, which can pose problems in the interpretation of multiple regression results, as codes assigned to distinguish between different levels are interpreted as numeric values instead (Laerd Statistics, 2015a). One solution around

this is to re-categorise any categorical or ordinal variables into dichotomous variables. Data from these variables were re-categorised into the following based guidance from previous research and examining the frequencies of participants in different groups:

- Gender – kept as male or female
- Ethnicity – re-categorised as ‘White British’ or ‘Not White British’.
- Education – re-categorised as ‘secondary school education’ or ‘post-secondary school education’.
- Employment – re-categorised as ‘employed’ or ‘not employed’.
- Method of blood glucose monitoring – re-categorised as ‘manual blood glucose monitoring methods (e.g. finger prick tests or Flash glucose monitoring compared to those using Continuous Blood Glucose Monitoring systems). Fisher et al. (2015) distinguished between those using CGM and those who were not when developing the T1-DDS scale.

Assumptions for multiple regression.

In addition to data assumptions of normality, independence of observations and homogeneity of variance outlined earlier in this chapter, data for multiple regression must also meet assumptions of linear relationships between the dependent variable and all independent variables, independence of residuals, homoscedasticity, no multicollinearity, no major outliers and normally distributed errors (Field, 2009; Laerd Statistics, 2015a).

Scatterplots between diabetes-related DRD and continuous independent variables identified linear relationships. Independence of residuals was assessed using the Durbin-Watson test statistic, which gave a value of 1.4. Durbin-Watston statistic values between one and three suggest independence of residuals (Field,

2009). Plotting of residuals identified that the data met assumptions for homoscedasticity (which as verified by an independent statistician). Correlations between DRD and continuous independent variables highlighted were below 0.8, providing no evidence for multicollinearity. Evidence of outliers were assessed using Leverage values, Cook's and Mahalanobis' distance values. Examination of residuals identified one standardised residual value greater than three. Any value greater than three is considered a deviation from normal variance (Field, 2009). However, given this participant was in a very small minority, following advice, their datum was still included the in the analysis. Examination of Leverage values for the data were below 0.2, values for Cook's distances were below 1 and Mahalanobis' values were below the critical value, suggesting no major outliers in the data. Examination of P-P plots for the residuals identified a normal distribution.

Multivariate analysis of Variance (MANOVA) analysis.

A MANOVA analysis was used for research question two – do adults with high levels of diabetes-related distress differ in levels of perfectionism, self-efficacy and diabetes-related avoidance than adults with low diabetes-related distress?

Assumptions for MANOVA.

In addition to assumptions of normality, homogeneity of variance and independence, MANOVA analyses must also meet assumptions of no multivariate outliers, multivariate normality, and no multicollinearity, linear relationships between dependent and independent variables and homogeneity of (co) variances (Laerd Statistics, 2015b).

Outliers were examined for using boxplots for each variable and Mahalanbobis distances. Boxplots for independent variables found evidence of three

outliers. Further examination of these outliers suggested that these were genuinely unusual values and not a result of measurement error given the method of data collection, and prior examination of maximum and minimum values for CIDS, AAD-Q and CPQ results identified that no scores were outside of the possible scoring ranges. Mahalanobis values were below the critical value. Given the small minority of outliers identified, a decision was made to include them in the analysis as removing them may result in biasing the data (Field, 2009). Scatterplots identified linear relationships between DRD and the CIDS, AAD-Q and CPQ and correlations between each of these variables identified no evidence of multicollinearity. Multivariate normality was assumed based on visual inspections of histograms and Q-Q plots.

Box's M test was used to test for the homogeneity of covariances assumption. Box's M test result was statistically significant ($p < 0.001$), violating this assumption. This result was also confirmed by Levene's test for the CIDS, AAD-Q and CPQ scores. As a result, Pillai's Trace test statistic and Games-Howell post-hoc tests were used to interpret the MANOVA analysis as these are recommended when equal variances are not assumed and sample sizes are unequal (Field, 2009; Laerd Statistics, 2015b).

Linear regression analysis.

Linear regressions were used for research question three – is there an association between perfectionism and diabetes management behaviours (e.g., diabetes-related avoidance and frequency of blood glucose checking)? Two separate linear regressions were carried out – 1) between CPQ and AAD-Q scores and 2) between CPQ and checking of blood glucose frequency scores.

Assumptions for linear regression.

In addition to assumptions of normality, independence and homogeneity of variances, assumptions for linear regressions are the same as those for multiple regressions other than the assumption of homoscedasticity.

Linear regression between perfectionism and avoidance.

Scatterplots between CPQ and AAD-Q scores highlighted a linear relationship between the two variables. Independence of observations was assessed using the Durbin-Watson test statistic, which gave a value of 1.74, suggesting observations were independent of each other. Visual inspection of a scatterplot for residuals indicated evidence of homoscedasticity, no outliers were identified and histogram and P-P plots indicated that the residuals were normally distributed.

Linear regression between perfectionism and checking of blood glucose frequency.

Independence of observations was assessed using the Durbin-Watson test statistic, which gave a value of 2.07, suggesting observations were independent of each other. Examination of scatter and boxplots highlighted a number of extreme values. As a result of these extreme values, it was difficult to ascertain whether a linear relationship between the two variables or whether there was a normal distribution of the residuals. Examination of these extreme values highlighted that there were $N = 25$ in total (range = 250-556 blood glucose checks day). These values were examined to ascertain how influential they were in the regression model. Standardised residuals for these extreme values identified $N = 9$ of these had a value greater than three, suggesting that these were deviations from usual variance. Examination of Leverage and Cooks's values of the nine values were below the

critical values and suggested that these data points were not overly influential on the regression model.

Considerations were made as to whether to transform the variables, remove the outliers, or employ methods for as Winsorising (pulling extreme scores closer to the mean whilst maintaining their position at the higher end of the normal distribution, but not as extreme; Reifman & Keyton, 2010) or trimming the data by removing these higher extreme values and removing a similar proportion of values from the lower end of the distribution. These methods are recommended in the context of extreme values (Field, 2009; Kwak & Kim, 2017). Data quality did not improve though winsorising, trimming or transforming the data. Whilst removing the outliers appeared to improve data quality, 9.09% of the data needed to be removed. Removing outliers can be a controversial approach if there is no strong evidence that each case does not belong with the sample population (Field, 2009). Whilst it was possible for participants to have misinterpreted the question and provided a total frequency of checks done each day over the last month, there was no certain way of knowing this. Based on the advice of an independent statistician, the decision was made to include all data but to highlight the limitations of the regression analysis and any conclusions made from the results.

Correlation analysis.

Correlation analysis was used for research question four, not included in the empirical study (due to journal restrictions) – does perfectionism correlate with subscales on the type 1 diabetes distress scale? This involved correlations between the seven subscales for the T1-DDS and the overall CPQ score.

Assumptions for correlation.

Pearson's *r* is a parametric version of a correlation analysis. Assumptions for Pearson's *r* require the data being normally distributed, linear relationships between variables, and the absence of outliers.

Scatterplots were created for each T1-DDS subscale with the CPQ score, which indicated evidence of a linear relationship. Boxplots found evidence for some outliers for each T1-DDS subscale, although further examination suggested these were genuinely unusual values as opposed to measurement error (see explanation in 'Assumptions for MANOVA' section). Histograms and Q-Q plots for each T1-DDS subscale indicated that five out the seven subscales (management distress, hypoglycaemia distress, negative social perceptions, physician distress, friends and family distress) showed some evidence of skewed distributions. Spearman's correlation co-efficient was carried out for these subscales instead as this not rely on the assumption of normal distribution (Field, 2009). Pearson's *r* was carried out for the powerlessness and eating distress subscales as these met normal distribution assumptions.

Power Analyses

A priori power calculations for statistical tests were conducted to avoid Type II errors (Clark-Carter, 2010). An accepted power value is $\alpha = 0.8$ (Clark-Carter, 2010) which can be used alongside effect sizes (*d*) to determine the minimum sample size to achieve a given the given level of power for different analyses. Small to medium effect sizes were used for all tests as a conservative precaution, based on previous research (Powers et al. 2017) and the advice of an independent statistician. Power tables by Clark-Carter (2010) and research by Green (1991) were used. All power calculations were based on a two-tailed hypothesis.

Multiple regression. Power analysis for a multiple regression was conducted. Green (1991) provides the formula 50 + (8 x *n*), with *n* being the number of predictors as a guide for sample size. Based on an analysis of $N = 10$ predictors, a minimum sample size of 130 was required.

MANOVA. Power analysis for a one-way MANOVA based on one independent variable with four levels (based on the four DRD groups as suggested by Fisher et al., 2015) and three dependent variables was conducted. Assuming an alpha of 0.05, a power of 0.8 and a medium effect size ($\eta^2 = 0.06$), a sample size of $N = 208$ was required.

Linear Regression. Power analysis for a linear regression was conducted. Assuming an alpha of 0.05, a power of 0.8 and a medium effect size ($F = 0.13$), a sample size of $N = 58$ was required.

Pearson's Correlation. Power analysis for a Pearson's correlation was conducted. Assuming an alpha of 0.05, a power of 0.8 and a medium effect size of $d = 0.3$, a sample size of $N = 90$ was required.

Chapter Six: Extended Results

Extended Results

This chapter details further analysis from research question four, which was not reported in the empirical study due to the word count restrictions of the selected journal. This chapter also provides extended results from the empirical study for research question three.

Research Question Four - Does Perfectionism Correlate with Subscales on the Type 1 Diabetes-Related Distress Scale?

Correlations were conducted between each T1-DDS subscale and CPQ scores. Examination of normality for each T1-DDS subscales showed that five out of seven subscales (management distress, hypoglycaemia distress, negative social perceptions, physician distress, friends and family distress) showed some evidence of skewed normal distributions. Therefore Spearman's Rho correlations were carried out for these subscales and Pearson's *r* for subscales which met parametric assumptions. All diabetes-related distress scales demonstrated statistically significant positive correlations with perfectionism, with powerlessness (r = .577), negative social perceptions (r = .421), and eating distress (r = .402) demonstrating moderate effect sizes, management distress (r = .363), hypoglycaemia distress (r = .356), and physician distress (r = .370) demonstrating small effect sizes, and friends and family distress (r = .149) demonstrating a very small effect size. Results of all correlations can be found in Table 6.

Table 6.

Results of Pearson's r and Spearman's rho correlations for diabetes-related distress subscales and perfectionism

	T1-DDS Subscales						
	Powerlessness	Management distress	Hypoglycaemia distress	Negative social perceptions	Eating distress	Physician distress	Friends and family distress
Perfectionism (CPQ)	.577**[b]	.363**[a]	.356**[a]	.421**[a]	.402**[b]	.370**[a]	.149*[a]

[a] = Spearman's rho, [b] = Pearson's *r*, *p < 0.05, **p < 0.001

The above results suggest that perfectionism may have a role in DRD, and could conceptually be mapped onto perfectionism. The relationship between perfectionism and powerlessness was found to be the strongest in the empirical study. Powerlessness highlights wider themes of feeling under pressure to manage diabetes perfectly, and feelings of discouragement or distress when efforts to manage diabetes fall short of their standards. This appears similar to perfectionism, particularly around feelings of distress in response to standards not being met (Frost et al., 1990; Shafran et al., 2002).

Negative social perceptions appear to relate the concerns about negative judgements from others, and may map onto perfectionistic self-presentation, another conceptualisation by Hewitt et al. (2003) which focuses on compulsive striving to appear flawless in the presence of others, hide mistakes from others and not disclosing shortcomings. Some people with diabetes report feelings of stigma around their condition (Balfe et al., 2013; Hortensius et al., 2012) and report finding it difficult to adhere to their self-management routines whilst still concealing the confidentiality of their diabetic status (Vanstone et al., 2015). Other interpersonal sources of distress (friends and family distress) focus on fears from family members about the short and long term consequences around diabetes (Fisher et al., 2015), not, per se, around negative evaluations and therefore may explain why this result showed the smallest effect size.

Eating distress alludes to concerns that one's eating is out of control (Fisher et al., 2015). Different conceptualisations of perfectionism view personal control as being an integral in perfectionism (Flett, Hewitt, & Martin, 1995). Chronic conditions which cannot be cured are likely to feel unpredictable and may violate perceptions of feeling in control, which is likely to cause distress for those with

higher levels of perfectionism (Molnar et al., 2016). As such, this may explain the moderate effect size between perfectionism and eating distress.

Research Question Three - Is There an Association between Perfectionism and Diabetes Management Behaviours (e.g., Diabetes-Related Avoidance and Frequency of Blood Glucose Checking)?

Prior to the regression between perfectionism and the frequency of blood glucose checking, one-way ANOVAs were carried out to determine whether the frequency of blood glucose checking differed between diabetes-related distress groups, or by blood glucose monitoring method, which may have acted as confounding variables. Both models showed no statistically significant overall effects for diabetes-related distress group ($F (3, 271) = 1.19$, $p = .127$) or blood glucose monitoring method ($F (5, 269) = .754$, $p = .584$). Therefore the regression was carried out in the absence of potential confounding variables. As outlined in the previous chapter, the results of the regression analysis between perfectionism and the frequency of blood glucose checking must be considered with caution due to the number of extreme values.

In addition to being asked about their average daily frequency of blood glucose checking, participants were asked to indicate whether this was a typical frequency for them and if not, what would be a typical frequency. Two hundred and seventy eight participants (98.58% of the total sample) provided data on blood glucose checking frequency. Of these, $N = 252$ (90.65%) indicated that this was typical for them and $N = 25$ (9.19%) indicated that this was not. Differences between usual typical frequency and reported typical frequency at the time of completing the study were calculated to assess the level of discrepancy between the two scores.

The number of participants whose blood glucose checking frequency was discrepant with their typical frequency could not have been anticipated at the start. Therefore, the results will be described descriptively. Of the *N = 25* participants who reported a different typical frequency, *N* = 14 (56%) reported that they typically checked their blood glucose less frequently than indicated in the study and *N* = 9 (36%) reported that they checked their blood glucose more frequently. Data were missing for *N* = 2 (8%) of participants. The discrepancy between typical and reported and typical blood glucose checking frequency lay within a range of ±5 times a day for *N* = 17 (68%) participants. Two participants reported a discrepancy of *N* = 12 times less a day.

Four participants reported more extreme discrepancies, between 150 more and 240 times less a day. It is unclear whether these values were genuine, or whether these were a mis-entry or misinterpretation of the question by participants.

The sample size was small and potentially prone to outliers and therefore inferential analysis for this subgroup may be underpowered. A visual examination of the data suggested that people with moderate or high DRD were more likely to report a checking frequency reported in the study as not being typical for them. For those with moderate DRD, *N* = 4 reported checking less than usual, and *N* = 3 reported checking more. For those with high DRD, *N* = 7 reported checking less than usual and *N* = 4 reported checking more.

Reasons for this discrepancy are unknown and are speculative at best. DRD can fluctuate over time (Hendrieckx et al., 2019), which may affect how people manage and monitor their diabetes at the time. There are also multiple factors which can affect blood glucose levels, such as menstruation, medication, illness, weather, stress and therefore the frequency of blood glucose monitoring (Brown, 2018). It is

possible that the month prior to participants completing the study one of the above events may have occurred, which affected the typical frequency of their blood glucose monitoring.

Chapter Seven: Final Discussion

Discussion and Critical Evaluation

Introduction

This chapter will provide an overview of the whole thesis portfolio, including a summary and discussion of the findings in the systematic review, empirical research paper, and extended results chapter. Strengths and limitations of the portfolio will be discussed, alongside theoretical and clinical implications, with recommendations for future work.

Research Aims

This thesis portfolio aimed to investigate the role of perfectionism in living with a chronic health condition. The systematic review aimed to address this question more broadly, through drawing together the existing evidence across a range of chronic health conditions. The systematic review focused on the role of perfectionism in functioning, symptoms, self-management, adjustment to and distress associated with a chronic health condition. The review did not address the role of perfectionism in depression, anxiety or other psychiatric diagnoses in chronic health conditions as this is currently being addressed in another review (Wright et al., 2019). The empirical study focused on examining the relationship between perfectionism and diabetes-related distress in adults with type 1 diabetes, and the relationship between perfectionism and diabetes self-management. Specifically, it investigated whether perfectionism, self-efficacy and diabetes-related avoidance predicted diabetes-related distress, whether adults with higher levels of diabetes-related distress differed in levels of perfectionism, self-efficacy and diabetes-related avoidance compared to those with lower diabetes-related distress, and whether

perfectionism predicted diabetes self-management, through frequency of blood glucose checking, and avoidance of diabetes management.

Summary of Main Findings

The systematic review found that the role of perfectionism had been studied in a wide range of chronic health conditions – chronic fatigue syndrome, fibromyalgia, arthritis, type 2 diabetes, multiple sclerosis, coronary heart disease, irritable bowel disease and spinal cord injury.

Perfectionism (particularly maladaptive perfectionism) was associated with greater impairments in physical functioning and worse symptoms in fibromyalgia, irritable bowel disease, multiple sclerosis and arthritis. Alternatively, perfectionism (particularly adaptive perfectionism) appeared to serve as a protective factor against mortality in type 2 diabetes, and reduced fatigue in multiple sclerosis. One study found that perfectionism appeared to be protective against impaired health functioning in fibromyalgia but this relationship was curvilinear, suggesting that an optimal level of perfectionism was protective but higher levels of perfectionism led to impaired outcomes. Studies investigating the role of perfectionism in functioning in individuals with chronic fatigue syndrome were less consistent - study quality was variable, and often included wider personality traits which may have influenced the unique contribution that perfectionism had.

Perfectionism was associated with maladaptive coping in chronic fatigue syndrome, irritable bowel syndrome, fibromyalgia, arthritis, spinal cord injury and coronary heart disease. Those with higher levels of perfectionism were more likely to engage in emotional preoccupation or ruminative coping styles, although one study in coronary heart disease found that perfectionism was associated with

adaptive (problem-focused) coping. Perfectionism was related to higher levels of stress and less satisfaction with social support in fibromyalgia, chronic fatigue syndrome and arthritis.

On the whole, the results of the systematic review suggest that perfectionism is more likely to lead to impaired outcomes for those with chronic health conditions.

The empirical study found that a significant proportion of adults with type 1 diabetes who participated in the study reported elevated levels of diabetes-related distress, with 37.94 % of participants reported moderate levels of distress and 35.81% reported high levels of distress. The results of a multiple regression indicated that age, method of blood glucose management, self-efficacy, diabetes-related avoidance and perfectionism predicted diabetes-related distress, explaining 54.7% of the variance. Participants who were younger, using non-continuous blood glucose monitoring methods, had lower levels of self-efficacy, higher levels of diabetes-related avoidance and perfectionism predicted greater levels of diabetes-related distress.

A MANOVA analysis was used to investigate whether perfectionism, self-efficacy and avoidance differed between the different groups reporting different levels of diabetes-related distress. The results indicated that all four groups differed on each of the three variables. Specifically, those with higher levels of diabetes-related distress also had higher levels of perfectionism and diabetes-related avoidance, and lower levels of self-efficacy compared with those with lower levels of diabetes-related distress.

Separate linear regressions were carried out to investigate whether perfectionism was a predictor of avoidance of diabetes management, and the

frequency of blood glucose checking. Perfectionism was a small but significant predictor of avoidance, accounting for 8.5% of the variance. Perfectionism was not a significant predictor for the frequency of blood glucose checking, although this may have been influenced by the number of extreme values distorting the data.

Summary of Results from Extended Results Chapter

Pearson's *r* and Spearman's rho correlations were used to determine whether perfectionism correlated with subscales of the diabetes-related distress scale. Statistically significant positive correlations were found between perfectionism and all subscales of the diabetes-related distress scale. Moderate effect sizes were found for powerlessness (r = .577), negative social perceptions (r = .421), and eating distress (r = .402). Small effect sizes were found for management distress (r = .363), hypoglycaemia distress (r = .356), and physician distress (r = .370), and a very small effect size was found for friends and family distress (r = .149).

The above results suggest that perfectionism appears to be related to many different aspects of diabetes-related distress. The subscales with the largest effect sizes were powerlessness, negative social perceptions and eating distress. These results appear to map onto concepts particularly relevant to perfectionism, namely feeling discouraged or distressed standards are not reached (powerlessness), concealing imperfection from others to avoid negative evaluation (negative social perceptions), and the importance of self-control in the pursuit of goals (eating distress).

Discussion of Results

This section will discuss the findings in the thesis portfolio in context with other research. Particularly, how perfectionism may function in chronic health conditions, and wider difficulties in the conceptualisation of perfectionism.

The results of the systematic review suggest that higher levels of perfectionism had a role across a wide range of outcomes. The empirical study found that higher levels of perfectionism were linked with higher levels of diabetes-related distress and increased diabetes-related avoidance. Whilst elevated levels of perfectionism appear to be associated with largely impaired outcomes, theoretical explanations for these associations remain unclear.

An examination of the discussion sections for papers included in the systematic review highlighted that only four specifically consider how perfectionism functions in the context of chronic health conditions. In fibromyalgia, Sirois et al. (2019) considers how high levels of perfectionistic striving, when faced with pain and fatigue may no longer be realistic, leading to self-criticism when striving is no longer an option. This results in higher levels of stress and poorer physical and mental health as found in their study. In multiple sclerosis, Besharat et al. (2011) in its study between perfectionism and fatigue suggests that perfectionism leads to a lower threshold for distress, and such distress can trigger fatigue symptoms. These symptoms may be perceived as evidence of failure, which can affect self-worth. In order to re-gain self-worth, people may be likely to pursue higher standards for future performance. Fry and Debats' (2011) study into type 2 diabetes suggest that perfectionism may provide the motivation to achieve good standards with health, and therefore may be protective against mortality. Read et al's. (2019) study on adjustment and coping in spinal cord injury offered the explanation that striving to

appear flawless in front of others since having an injury (perfectionistic self-presentation) may lead people to suppress difficult emotions and ruminate, and this may inhibit the proper processing of shock and anger (Read et al., 2019). This may explain their findings as to how perfectionism was related to less adaptive coping (Read et al., 2019).

The four above studies highlight that all explanations are different, although this may be as a result of the outcome being measured. Other studies included in the systematic review appear to discuss the findings of perfectionism on outcomes and draw upon previous research consistent with the findings, adding to what is already known about perfectionism or outcomes in chronic health conditions as opposed to considering the function of perfectionism in chronic health conditions.

Chronic fatigue syndrome was the most studied condition in the systematic review. A review of the literature suggests perfectionism may be implicated through: 1) increased stress sensitivity, stress generation and depression; and 2) impairments in emotion regulation (of stress and low mood) which lead to overexertion, which exacerbate and maintain symptoms (Kempke, Van Houdenhove, Claes, & Luyten, 2016). As a maintenance factor, evidence seems to suggest that perfectionism maintains “boom and bust” activity cycles commonly observed in this population (Kempke et al., 2016).

Boom and bust activity could conceptually map onto the cognitive behavioural model of clinical perfectionism (Shafran et al., 2002). ‘All or nothing’ behaviour has been linked to chronic fatigue (Fakuda et al., 1994; Moss-Morris, Spence, & Hou, 2011), particularly those with higher levels of perfectionism (Kempke et al., 2013). All or nothing behaviour may link with the dichotomous

thinking styles often observed with high levels of perfectionism (Shafran et al., 2002). When patients are feeling well, they may be able to achieve their standards, and perhaps go beyond these. However, pursuing these standards through 'outbursts of activity' is likely to lead to over-exertion and subsequent fatigue, but perfectionists may continue to push through this (Luyten et al., 2011; Van Campen et al., 2009). Patients with chronic fatigue are less likely to tolerate inactivity and to associate it with feelings of guilt due to a lack of productivity (Kempke et al., 2013). Furthermore, inactivity may pose a threat to patients of falling below their standards (Brooks, Rimes, & Chalder, 2011; Deary & Chalder, 2010; Kempke et al., 2011). As such, if patients become physically constrained by their exhaustion, they may fall short of these standards leading to distress and self-criticism (Brooks et al., 2011; Kempke et al., 2013). However, it was not the aim of this thesis portfolio to test out the cognitive-behavioural model of clinical perfectionism for chronic fatigue syndrome. The application of this model in chronic fatigue syndrome warrants further research.

The bridging chapter in this thesis portfolio introduced the idea that heterogeneity of findings in the systematic review may be as a result of the differences of how perfectionism is conceptualised and measured. The conceptualisation of perfectionism appears to vary, which also affects how it is measured. The remainder of this discussion section shall explore these two points in more detail.

The conceptualisation of perfectionism has been debated between Shafran et al. (2002) and Hewitt, Flett, Besser, Sherry, & McGee (2003). The main issue of this discussion is whether perfectionism is a unidimensional construct, whereby it exists solely on an intrapersonal level, or multidimensional, where it also has interpersonal

influences (Frost et al., 1990; Hewitt and Flett, 1991). Based on criticisms of both multidimensional perfectionism scales (see the bridging chapter of the thesis portfolio for further information), Shafran et al. (2002) proposed clinical perfectionism, a concept to advance the understanding and treatment of psychiatric disorders. They stipulated that if anything, self-oriented perfectionism from Hewitt and Flett (1991) was the most clinically useful construct of perfectionism in line with their proposal.

This approach was criticised by Hewitt et al. (2003), suggesting that Shafran et al. (2002) have ignored evidence that other-oriented and socially-prescribed perfectionism are associated with psychopathology, and the implication that perfectionism is solely a unidimensional construct. Shafran, Cooper, and Fairburn (2003) rebutted this, and maintained that their model did not serve to replace other conceptualisations or stipulate perfectionism is only a unidimensional construct – their conceptualisation had cognitive, emotional and behavioural elements, but more to consider a construct which had applications in psychopathology. Specifically, that perfectionism in the context of psychopathology may be self-focused, and interpersonal processes are not necessary in the maintenance of perfectionism, but standards from others may be adopted by the individual as their own which they subsequently strive to maintain (Shafran et al., 2003).

Different measures of perfectionism appear to focus on different levels. Multidimensional perfectionism by Frost et al. (1990) and Hewitt and Flett (1991) appear to focus on perfectionism on a trait level, around high standards and harsh self-criticism across a range of domains (Hewitt et al., 2003). Other measures appear to focus on the frequency in which individuals experience perfectionistic cognitions, for example the Perfectionistic Cognitions Inventory (Flett, Hewitt, Blankstein, &

Gray, 1998) or the Multidimensional Perfectionism Cognitions Inventory (Stoeber, Kobori, & Tanno, 2010). Measures focusing specifically on perfectionistic cognitions were not found in the systematic review, although this may be due to studies focusing on outcomes which are not on a cognitive level (such as functioning, coping, symptoms), nor do they focus on how individuals appraise these outcomes. Perfectionistic self-presentation (Hewitt et al., 2003) focuses on a behavioural level, particularly around efforts to conceal imperfection or flaws from others.

The above debate on perfectionism highlights the complexity of the concept but also raises wider questions about which conceptualisation is most appropriate in the context of chronic health. The results of the systematic review found that a multidimensional, trait level conceptualisation was most commonly measured. Perfectionism on a behavioural level was also measured, as some studies included perfectionistic self-presentation (Hewitt et al., 2003). However, it is worth noting that Gordon Flett and Paul Hewitt (authors of the Hewitt and Flett multidimensional perfectionism scale) were listed as authors in four out of thirteen of the included studies, using their measure of perfectionism each time. This has the potential to bias this conceptualisation as relevant to chronic health, by only providing evidence for a trait-level, multidimensional construct.

Strengths and Limitations

Strengths.

The systematic review appears one of the first to investigate the role of perfectionism across a range of chronic health conditions and outcomes, although it is important to acknowledge that similar systematic reviews are underway (Wright et

al., 2019). Whilst some of the studies included in the review have been referenced by Molnar and colleagues (2016) to support their Stress and Coping Cyclical Amplification Model of Perfectionism in Illness (SCCAMPI), using systematic review methodology as undertaken in this portfolio may be considered a more reliable and superior form of evidence assimilation, according to the Hierarchy of Evidence (Evans, 2003).

The empirical study was well-received by the diabetes community and endorsed by Diabetes UK and the JDRF, which boosted recruitment numbers. A high number of participants were recruited, allowing for analyses to be well-powered. Recruiting through social media platforms enables participants to provide instant feedback on the experience of completing the study, and promote the study on the researcher's behalf. Comments from Twitter include:

"*Quite a good survey that, not your usual type of questions*"

"*Took this survey and really think this research is onto something. I'm a goody two shoes, homework doing, deadline meeting, exam slaying sort of person and getting the "wrong results" often in my diabetes life has been really tough to deal with at times*"

"*What a wonderful study! Let's have many more of these projects please!"*

Evidence on the experience of perfectionism, diabetes-related distress and its role in self-management appear to be in its infancy. Discussions on this area are primarily blog-based led by those living with type 1 diabetes (Mercer, 2014; Soroka, 2019), commentaries based on hypothetical case studies (Ramirez Basco, 1998), or alluded to in themes generated by qualitative studies on the lived-experience of type 1 diabetes (Pyatak et al., 2013; Rankin et al., 2012; Sparud-Lundin et al., 2010). The

results in the empirical study provide evidence for the relationship between perfectionism and diabetes-related distress beyond anecdotal narratives. They also extend Powers et al's. (2017) findings to suggest that this relationship exists outside of those with eating disordered pathology.

Limitations.

Methodology in both the systematic review and empirical study are not without limitations. The systematic review did not investigate the role of perfectionism in mood-related outcomes or psychopathology in chronic health conditions. Therefore it is difficult to provide a complete picture of the experience of living with a chronic health condition when mental health conditions are highly comorbid (Naylor et al., 2012). Whilst there was heterogeneity in the type of conditions included in the review, the proportion of studies per condition was biased towards chronic fatigue syndrome and related conditions. Therefore, findings for diabetes, multiple sclerosis, spinal cord injury, and irritable bowel disease are best held with caution as these were based on single studies.

Other limitations in the systematic review include the quality assessment process being affected by reporting quality. Many studies had aspects where it was difficult to determine the amount of bias introduced into the study as information was not clearly reported (rated as 'cannot determine'). Whilst the choice of search terms were broad, having clear definitions about which health conditions were included inevitably meant that some conditions were excluded, such as cancer (Trudel-Fitzgerald et al., 2017). Cancer was excluded from review as often patients are often self-managing symptoms / side effects associated with treatment as opposed to the condition itself. There were challenges in the synthesis of results due to heterogeneity in a number of areas. This included differences in the types of

conditions included and how they were managed, a broad range of data analysis methods employed, different types of perfectionism measure used, and the heterogeneity in outcome measures. Taken together, this meant that direct comparisons between studies was not possible which may affect how findings are synthesised and interpreted.

The recruitment strategy was successful in recruiting a large sample size. However, the method itself has limitations; namely, recruiting a self-selecting sample and missing a subgroup of participants. It is possible that those with elevated levels of diabetes-related distress are more likely to engage with research in this area, as evidenced by the uneven sample sizes and majority of participants reporting elevated levels of diabetes-related distress. As a result, the sample may be biased with higher distress and perfectionism scores. Recruitment was largely restricted to online social media platforms, and platforms used by charitable organisations (social media and newsletters). There is the potential that a proportion of participants do not engage in these online communities or subscribe to charitable organisations and therefore were a missed opportunity for recruitment.

Measures to capture diabetes self-management in the empirical study may not have been the most appropriate. The AAD-Q measure (Gregg et al., 2007) was problematic in how participants received the measure, and its utility in this study. Some participants raised concerns about some of the questions in the AAD-Q, particularly questions four and seven. Comments from emails to the author or research supervisors include *"as a T1D there is nothing I "cant/shouldn't" eat, so I don't "just eat something I shouldn't" as a stress release, so long as I bolus for it there shouldn't be a problem."*

The AAD-Q was originally developed and validated for type 2 diabetes, where careful control of diet is required as insulin is used less routinely to manage blood glucose levels (NICE, 2015). Participants in this study commented that providing they are adjusting their insulin appropriately, they have greater flexibility in diet compared to type 2 diabetes. Internal consistency for the measure in the empirical study was good, although this does imply that this measure is entirely valid for type 1 diabetes.

The AAD-Q was originally chosen to explore whether those with higher levels of perfectionism are more likely to engage in avoidance to alleviate anxiety over fear of failure, as suggested by Shafran et al. (2002). The measure predominantly focuses on avoidance of diabetes-related thoughts, with only a small number of items focusing on avoidance of diabetes-related behaviours. Whilst the AAD-Q does correlate with measures of diabetes self-care (Schmitt et al., 2014) there may be some limitations to the extent the measure itself assesses avoidance of diabetes self-management. Other measures do exist, although these appear to measure whether someone engages in a particular behaviour, but not necessarily active avoidance (e.g., Summary of Diabetes Self-Care Scale: Toobert, Hampson, & Glasgow, 2000). The Diabetes Self-Management Questionnaire may have been a more appropriate measure, as this measures both levels of engagement and avoidance with diabetes self-care behaviours (Schmitt et al., 2013).

The ranges to distinguish between groups on the diabetes-related distress scale (T1-DDS) in the empirical study warrants discussion. Specifically, whether the cut-off scores to distinguish between different distress groups are realistic. Items on the measure are rated on a 1 - 6 scale, and the division of scores to distinguish between groups is tight. The difference in scores distinguishing between no distress (scores <

1.49) and mild distress (1.50 – 1.99) is small, whereas the range in scores to distinguish between moderate distress (2 – 2.99) and high distress (3 – 6) is greater. The division of these cut-off points appear to allow greater room for people to score in the moderate to high distress range, and may be one of the reasons why a higher proportion of participants in the empirical study scored moderate or high distress levels. An exploration of other diabetes-related distress assessment tools suggests that this distribution for cut-off scores is similar in the Diabetes Distress Scale – 17 items (DDS17; Polonsky et al., 2005), another 1 – 6 scale where a score above three indicates high levels of distress. The development of these cut-off points in both the T1-DDS and DDS were validated alongside HbA1c scores[2] in order to establish meaningful cut-offs. Whilst the difference between scores is small, validation of these cut-offs suggest that they are clinically meaningful. The Problem Areas in Diabetes scale (PAID; Polonsky et al., 1995) has a range between 0 – 100, with scores higher than 40 indicating high levels of distress (Snoek et al., 2012). The T1-DDS, DDS-17, and PAID share the same notion that the scoring range for high levels of distress is greater compared to lower levels of distress. Overall, whilst the range of scores distinguishing between different distress groups are low, evidence suggests that are clinically meaningful.

The lack of linear relationship between perfectionism and the frequency of blood glucose checking may have been as a result of data quality. Whilst the modal frequency was eight checks a day, the maximum recorded frequency was $N = 556$ times a day. It is possible that participants may have misinterpreted the question and provided a total frequency based on the last month, although this is impossible to

[2] HbA1c is glycaemic haemoglobin and is used clinically as a measure of average blood glucose levels every 2 – 3 months. HbA1c values are 48mmol/mol (6.5%) or lower is considered the target for good glycaemic control (NICE, 2015).

determine. In hindsight, further piloting for questions on checking frequency for misinterpretations may have be warranted.

Theoretical Implications

Findings from the thesis portfolio have implications for theory in perfectionism as a transdiagnostic construct, theoretical models of perfectionism, and implications in the conceptualisation of perfectionism.

Perfectionism has been described as a risk and maintenance factor across a range of psychopathology. Specifically, elevated levels of perfectionism are associated with psychopathology, perfectionism serves as a vulnerability or maintenance factor, and predicts treatment outcomes for psychiatric conditions (Egan et al., 2011). Findings from this thesis portfolio further contribute to this notion. The systematic review found perfectionism was associated with (primarily) adverse outcomes in those with chronic health conditions. Furthermore, participants in the high diabetes-related distress group in the empirical study had levels of clinical perfectionism comparable with anxiety, depression and eating disorders. This may provide further evidence to the notion that perfectionism is a transdiagnostic construct, due to its role in a wide range health conditions and health-related outcomes outside of psychopathology. Despite these links, underlying mechanisms demonstrating how perfectionism leads to or maintains adverse outcomes still remains largely unknown, other than suggesting that raised levels of perfectionism is linked to adverse outcomes.

Findings from the thesis portfolio also have implications for theoretical models of perfectionism. The SCCAMPI model (Molnar et al., 2016) introduced in the systematic review and bridging chapter is a theoretical model exploring how

perfectionism may impact on outcomes in the context of a chronic health condition, and seems to suggest potential applications across a wide range of conditions. Findings from the systematic review and how these are consistent with the model have been discussed in the review itself but shall be repeated briefly here.

The model hypothesises that perfectionism interacts with internal (perceptions of control, self-evaluation) and interpersonal factors (social support, self-concealment of illness), which lead to stress and maladaptive coping and influences health outcomes. Self-concealment (striving to appear flawless in front of others) is suggested to serve as one of these interpersonal pathways between perfectionism, stress and maladaptive coping (Molnar et al., 2016). The systematic review found that perfectionistic self-presentation (Hewitt et al., 2003) was linked to ruminative coping styles in irritable bowel and coronary heart disease. Social support has also been suggested as another critical pathway. The review also found that high levels of perfectionism were associated with greater social support dissatisfaction, and higher stress in a mixed sample of fibromyalgia, chronic fatigue syndrome and arthritis.

Findings from the extended results chapter may contribute to certain aspects of the model. The model suggests that perceptions of control is an internal pathway which links perfectionism to stress and health-related outcomes. Perfectionism was correlated with powerlessness and eating distress subscales on the diabetes-related distress scale which represent feelings of discouragement or feeling out of control, and may map onto this pathway. Perfectionism was also correlated with negative social perceptions subscale, where those with diabetes may experience distress relating to negative judgement from others. This result may provide some preliminary evidence for the role of self-concealment in the SCCAMPI model.

The results from the empirical study provide some preliminary support for the application of the cognitive behavioural model for clinical perfectionism (Shafran et al., 2002) in type 1 diabetes. Again, these have been described in the empirical study but shall be summarised here. The model suggests that perfectionists have a fear of failure, and may engage in increased checking to monitor their performance in relation to their goal, or may engage in avoidance behaviour to avoid the possibility of failure. Perceived or actual failure is likely to lead to increased distress and negative self-evaluation. Perfectionism was a predictor of diabetes-related distress and diabetes-related avoidance, however the relationship between perfectionism and increased checking was in the empirical study was not statistically significant, although it is possible that this was a result of data quality. These results provide some preliminary evidence that facets associated with clinical perfectionism are associated with diabetes-related distress in adults in type 1 diabetes. The findings from the systematic review are difficult to link with this model, as central tenets such as increased checking, avoidance or self-criticism were not measured in those studies.

One overarching problem for the systematic review and empirical study reflects wider issues in how perfectionism is conceptualised and measured. Molnar and Sirois (2016) summarises these issues on three-levels. Firstly, whether perfectionism exists at a trait, cognitive or behavioural level. Secondly, whether perfectionism is a unidimensional or multidimensional construct, consisting of inter- and intrapersonal aspects. Finally, whether existing measures for perfectionism actually measure two wider factors –'perfectionistic strivings and perfectionistic concerns. Aspects of this debate have been discussed earlier in this chapter (see 'discussion') but findings from the thesis portfolio provide further support for the

theory on ‘perfectionistic strivings’ and ‘perfectionistic concerns’ (an explanation of these can be found in the systematic review in chapter two).

‘Perfectionistic concerns’ are generally related to worse outcomes, whereas ‘perfectionistic strivings’ are related to more positive outcomes (Sirois & Molnar, 2016). Results from a meta-analysis suggest that both ‘perfectionistic strivings’ and ‘concerns’ are related to psychopathology, but ‘perfectionistic concerns’ are a larger predictor of this (Limburg, Watson, Hagger, & Egan, 2017). The systematic review in this portfolio provides evidence that ‘perfectionistic strivings’ and ‘perfectionistic concerns’ are differentially related to better and worse outcomes. On the whole, subscales of perfectionism measures which encompassed ‘perfectionistic strivings’ were associated with more positive outcomes (e.g., adaptive coping, reduced mortality and reduced fatigue). Subscales of which encompassed ‘perfectionistic concerns’ were associated with greater impairments in functioning and maladaptive coping across a range of chronic health conditions. Taken together, these results provide some further support to the theory that ‘perfectionistic concerns’ are related to worse outcomes than ‘perfectionistic strivings’. It is worth noting that in a small minority of studies, facets of ‘perfectionistic strivings’ (personal standards and self-oriented perfectionism), or those with high ‘perfectionistic strivings’ and ‘concerns’ were also associated with adverse outcomes (Flett et al., 2011, Shanmugasegaram et al., 2014; Sirois et al., 2019). There is evidence to suggest these factors share some joint variance (Molnar & Sirois, 2016; Stoeber, Kobori, & Brown, 2014), which will be discussed in the ‘recommendations for future research’ section below.

Clinical Implications

The results of the thesis portfolio provide evidence that perfectionism has a role in a range of outcomes for those with chronic health conditions. The empirical

study demonstrated that levels of clinical perfectionism were comparative to those with anxiety, depression and eating disorders, suggesting that some adults with type 1 diabetes also have high levels of clinical perfectionism. Screening for perfectionism in patients who are showing adverse outcomes such as poor psychological adjustment, high levels of distress, poor self-management and health functioning, or who are not responding to psychological intervention may prove worthwhile to understand whether perfectionism is implicated in these outcomes.

If perfectionism is detected, a further exploration with patients may be warranted to understand at which level perfectionism is operating at, whether it's pertaining to reaching self-management goals or wider non-illness related goals. Symptoms such as pain and fatigue can present as barriers to self-management across a range of chronic health conditions (Jerant, Von Friederichs-Fitzwater, & Moore, 2005), or can act as a barrier in the pursuit of non-illness related goals (Molnar et al., 2016).

In context of diabetes, the results of the empirical study suggest that perfectionism may affect self-management goals, due to the relationship between perfectionism and diabetes-related avoidance. Findings from the extended results chapter further support this, as perfectionism was related to distress in a range of areas associated with self-management (e.g., eating distress, management distress, hypoglycaemia distress). Understanding which level of goal pursuit perfectionism affects may prove useful in developing idiosyncratic psychological formulations. This may lead to more targeted interventions.

The discipline of implementation science has highlighted that findings from research are not always translated into routine clinical practice (Bauer, Damschroder,

Hagedorn, Smith & Kilbourne, 2015). In order to ensure that screening for perfectionism in chronic health conditions occurs in clinical practice, additional practices may need to be put in place. For example, routinely sending questionnaire measures of perfectionism for patients to complete prior to consultations or annual reviews could be a valuable addition. Furthermore, promoting a culture that places value on discussing the emotional aspects of managing a chronic health condition within consultations is warranted. This may facilitate discussions of the role of dysfunctional perfectionism in self-management and referral onto specialist psychological support, where appropriate.

Recommendations for Future Work

Given that the application of theoretical models for perfectionism in chronic illness are still in their infancy, future research should aim to test these theoretical models in this context. The empirical study did demonstrate some evidence for the cognitive behavioural model of clinical perfectionism in type 1 diabetes. However, the study was limited in that it did not test each component of the model and its predictive value on other components. For example, the relationship between perfectionism and fear of failure, and the predictive value of fear of failure on checking or avoidance behaviours in diabetes. Structural Equation Modelling is an analysis method which tests direct and indirect relationships between variables, and is frequently used in the building and testing of theoretical models in psychological research (Schumacker & Lomax, 2010). Such methods could be applied to empirically test whether theoretical models of perfectionism are valid and appropriate in understanding the role of perfectionism in chronic health.

It is also worth noting that chronic health conditions may share some similarities in self-management between conditions. Self-monitoring appears to be a self-management target across many conditions, such as blood glucose levels in type 1 diabetes (NICE, 2015), blood pressure in hypertension (NICE, 2011), heart failure (NICE, 2018) and asthma (Huygens et al., 2017). However, adherence to diet may be less relevant to some conditions such as asthma (NICE, 2017). It would therefore be worth considering whether particular different aspects of perfectionism models apply across a range of conditions, or whether idiosyncratic models specific to that condition need to be developed.

Most measures of perfectionism appear to fall into two higher factors - perfectionistic strivings and perfectionistic concerns. The future direction of studying perfectionism could usefully focus on these factors, as results of the systematic review provide preliminary evidence to suggest that these factors are associated with better and worse outcomes. Research could consider the role of these two facets of perfectionism in chronic health outcomes. Despite the existence of these two factors, there appears to be a joint variance between the two and potentially adaptive effects of perfectionistic strivings are uncovered when this joint variance is accounted for in the analysis (Molnar & Sirois, 2016; Stoeber, Kobori, & Brown, 2014). With this in mind, it could be possible that perfectionistic strivings provide the motivation to achieve high standards, however if part of this striving is motivated due to concerns over failure or self-criticism (i.e. coupled with perfectionistic concern), perfectionistic strivings may become the compulsive need to be perfect. Future research should make efforts to investigate and account for this joint variance in statistical models.

Conclusions

This thesis portfolio aimed to investigate the role of perfectionism in chronic health. The systematic review investigated this more broadly and found in the majority of cases, perfectionism was associated with impaired outcomes in functioning, symptoms, adjustment, or distress across a range of chronic health conditions. The empirical study investigated the role of perfectionism in adults with type 1 diabetes on diabetes-related distress and self-management (diabetes-related avoidance and frequency of blood glucose checking). Those with higher levels of diabetes-related distress had higher levels of perfectionism, lower levels of self-efficacy and higher diabetes-related avoidance. Those in the high diabetes-related distress group had levels of perfectionism comparable to other psychopathology. Perfectionism was a predictor of diabetes-related avoidance, but not the frequency of blood glucose checking. These results suggest perfectionism may have an adverse role in distress and aspects of self-management in type 1 diabetes. Clinicians should consider screening for perfectionism in patients with chronic health conditions if they show high levels of distress, poor psychological adjustment, poor self-management and health functioning, or who are not responding to psychological interventions in order to understand whether perfectionism is a factor in order to provide beneficial, targeted interventions.

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Appendices

Appendix A

Journal of Psychology in Medical Settings – Author Guidelines

Instructions for Authors

General

In general, the journal follows the recommendations of the 2010 Publication Manual of the American Psychological Association (Sixth Edition), and it is suggested that contributors refer to this publication.

Manuscript Style

Submit the original, including copies of all illustrations and tables.

Add continuous line numbering and page numbering to the manuscript.

Title Page

A title page is to be provided and should include:

the title of the article

author’s name (no degrees)

author's affiliation

and suggested running head

The affiliation should comprise:

the department

institution (usually university or company)

city

and state (or nation)

and should be typed as a footnote to the author’s name. The suggested running head should be less than 80 characters (including spaces) and should comprise the article title or an abbreviated version thereof. For office purposes, the title page should

include the complete mailing address, telephone number, and e-mail address of the one author designated to review proofs.

Abstract

An abstract is to be provided, preferably no longer than 150 words.

Key Words

A list of 4–5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.

References

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order):

last names and initials of all authors,

year published

title of article

name of publication

volume number

and inclusive pages

The style and punctuation of the references should conform to strict APA style and follow guidelines of the Publication Manual of the American Psychological Association, Sixth Edition – illustrated by the following examples:

Journal Article

Burns, J. W., & Katkin, E. S. (1993). Psychological, situational, and gender predictors of cardiovascular reactivity to stress: A multivariate approach. Journal of Behavioral Medicine, 16, 445−465.

Book

Ray, R. (2006): Chronic Pain and Family: A Clinical Perspective. New York: Springer.

Contribution to a Book

Bleiberg, J., Ciulla, R., & Katz, B. L. (1991). Psychological components of rehabilitation programs for brain−injured and spinal−cord−injured patients. In J. J. Sweet, R. H. Rozensky, & S. M. Tovian (Eds.), Handbook of clinical psychology in medical settings (pp. 375−400). New York: Plenum Press.

Footnotes

Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered consecutively using Arabic numerals and should be typed at the bottom of the page to which they refer. Place a line above the footnote, so that it is set off from the text. Use the appropriate superscript numeral for citation in the text.

Illustration Style

Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals. The captions for illustrations should be typed on a separate page. Photographs should be large, glossy prints, showing high contrast. Drawings should be prepared with India ink. Either the original drawings or good−quality photographic prints are acceptable. Artwork for each figure should be provided on a separate page. Identify figures with the author's name and number of the illustration. Electronic artwork should be in the TIFF or EPS format (1200 dpi for line and 300 dpi for half−tones and gray−scale art). Color art should be in the CYMK color space.

Tables should be numbered (with Arabic numerals) and referred to by number in the text. Each table should be typed on a separate page. Center the title above the table,

and type explanatory footnotes (indicated by superscript lowercase letters) below the table.

Standards of reporting

Springer Nature advocates complete and transparent reporting of biomedical and biological research and research with biological applications. Authors are recommended to adhere to the minimum reporting guidelines hosted by the EQUATOR Network when preparing their manuscript.

Exact requirements may vary depending on the journal; please refer to the journal's Instructions for Authors.

Checklists are available for a number of study designs, including:

Randomised trials (CONSORT) and Study protocols (SPIRIT)

Observational studies (STROBE)

Systematic reviews and meta-analyses (PRISMA) and protocols (Prisma-P)

Diagnostic/prognostic studies (STARD) and (TRIPOD)

Case reports (CARE)

Clinical practice guidelines (AGREE) and (RIGHT)

Qualitative research (SRQR) and (COREQ)

Animal pre-clinical studies (ARRIVE)

Quality improvement studies (SQUIRE)

Economic evaluations (CHEERS)

Appendix B

British Journal of Health Psychology – Author Guidelines

2. AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

experimental and clinical research on aetiology

management of acute and chronic illness

responses to ill-health

screening and medical procedures

psychosocial mediators of health-related behaviours

influence of emotion on health and health-related behaviours

psychosocial processes relevant to disease outcomes

psychological interventions in health and disease

emotional and behavioural responses to ill health, screening and medical procedures

psychological aspects of prevention

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

The types of paper invited are:

papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;

theoretical papers which report analyses on established theories in health psychology;

we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses); and

methodological papers dealing with methodological issues of particular relevance to health psychology.

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

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

All systematic reviews must be pre-registered. The pre-registered details should be given in the methods section but blinded for peer review (i.e., ‘the review was preregistered at [BLINDED]’); the details can be added at proof stage. Registration

documents should be uploaded as title page files when possible, so that they are available to the Editor but not to reviewers.

Please refer to the separate guidelines for Registered Reports.

Title Page

You may like to use this template for your title page. The title page should contain:

A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);

A short running title of less than 40 characters;

The full names of the authors;

The author's institutional affiliations where the work was conducted, with a footnote for the author’s present address if different from where the work was conducted;

Abstract;

Keywords;

Acknowledgments.

Abstract

For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found here.

Keywords

Please provide appropriate keywords.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Statement of Contribution

All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

Main Text File

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

Title

Main text

References

Tables and figures (each complete with title and footnotes)

Appendices (if relevant)

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.

The journal uses British spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper. Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page 1, and a DOI should be provided for all references where available.

For more information about APA referencing style, please refer to the APA FAQ.

Reference examples follow:

Journal article

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. The American Journal of Psychiatry, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Book

Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from http://www.youtube.com/watch?v=Vja83KLQXZs

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Colour figures. Figures submitted in colour may be reproduced in colour online free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white. If an author would prefer to have figures printed in colour in hard copies of the journal, a fee will be charged by the Publisher.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

Click here for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association. The following points provide general advice on formatting and style.

Language: Authors must avoid the use of sexist or any other discriminatory language.

Abbreviations: In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.

Units of measurement: Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.

Effect size: In normal circumstances, effect size should be incorporated.

Numbers: numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Research Reporting Guidelines

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are encouraged to adhere to recognised research reporting standards. The EQUATOR Network collects more than 370 reporting guidelines for many study types, including for:

Randomised trials: CONSORT

Systematic reviews: PRISMA

Interventions: TIDieR

We encourage authors to adhere to the APA Style Journal Article Reporting Standards for:

Manuscripts that report primary qualitative research

Manuscripts that report the collection and integration of qualitative and quantitative data

Manuscripts that report new data collections regardless of research design

We also encourage authors to refer to and follow guidelines from:

Future of Research Communications and e-Scholarship (FORCE11)

The Gold Standard Publication Checklist from Hooijmans and colleagues

FAIRsharing website

Conflict of Interest

The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature:

https://www.crossref.org/services/funder-registry/

Appendix C

Ethical Approval and Amendments

Faculty of Medicine and Health Sciences
Research Ethics Committee

University of East Anglia

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

Katherine Moran
MED

28 March 2019

Dear Katherine

Title: The Relationships between Perfectionism, Self-efficacy, and Diabetes Distress in Adults with Type 1 Diabetes

Reference: 201819 - 047

Thank you for your e-mail dated 26 March 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.

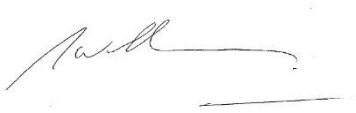
Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need

guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

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

Faculty of Medicine and Health Sciences
Research Ethics Committee

Katherine Moran

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

19 March 2019

Dear Katherine

Title: The Relationships between Perfectionism, Self-efficacy, and Diabetes Distress in Adults with Type 1 Diabetes

Reference: 201819 - 047

Thank you for your e-mail dated18 March 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.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

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

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

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Norwich, NR4 7TJ

Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

Katherine Moran

MED

18 February 2019

Dear Katherine

Title: The Relationships between Perfectionism, Self-efficacy, and Diabetes Distress in Adults with Type 1 Diabetes

Reference: 201819 - 047

Thank you for your response to the recommendations from the FMH Ethics Committee to your proposal. I have considered your amendments and can now confirm that your proposal has 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.

Approval by the FMH Research Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

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

Faculty of Medicine and Health Sciences
Research Ethics Committee

Katherine Moran
MED

University of East Anglia

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Email: fmh.ethics@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

3 January 2019

Dear Katherine

Title: The Relationships between Perfectionism, Self-efficacy, and Diabetes Distress in Adults with Type 1 Diabetes

Reference: 201819 - 047

The submission of your research proposal was discussed at the Faculty Research Ethics Committee meeting on 13 December 2018.

The Committee were happy to approve your application in principle but have the following concerns which they would like you to address and amend accordingly:

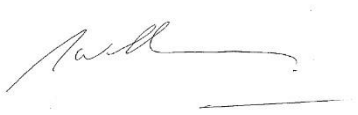
- Information Sheet - Recruitment at 18 and over. Why not younger? You may be excluding too many. Sixteen year olds have capacity to take part.
- Information Sheet – It is suggested that you explain why you are excluding people with Type 2 diabetes or an eating disorder diagnosis. Otherwise it sounds abrupt.
- Appendix C (Demographic variables) - How well are they managing their diabetes? There needs to be an objective assessment of this. Also, it might be useful to include the questions, 'Do you know what your HbA1c is and what does that mean?' to gauge how well they are managing their diabetes.

- Data storage. Using encrypted memory sticks for data storage is not encouraged, rather state that information will be kept on the UEA servers and password protected.

Please write to me once you have resolved/clarified the above issues. I require documentation confirming that you have complied with the Committee's requirements. The Committee have requested that you detail the changes below the relevant point on the text in this letter and also include your amendments as a tracked change within your application/proposal. The revisions to your application can be considered by Chair's action rather than go to a committee meeting, which means that the above documentation can be resubmitted at any time. Please could you send your revisions to me as an attachment in an email as this will speed up the decision making process.

As your project does not have ethics approval until the above issues have been resolved, I want to remind you that you should not be undertaking your research project until you have ethical approval by the Faculty Research Ethics Committee. Planning on the project or literature based elements can still take place but not the research involving the above ethical issues. This is to ensure that you and your research are insured by the University and that your research is undertaken within the University's 'Guidelines on Good Practice in Research' approved by Senate in July 2015.

Yours sincerely



Professor M J Wilkinson

Chair

FMH Research Ethics Committee

Appendix D

Participant Information Sheet: version 3.9 26.03.2019

The Relationships between Perfectionism, Self-efficacy, and Diabetes Distress in Adults with Type 1 Diabetes.

Researcher: Katherine Moran (Trainee Clinical Psychologist)

Supervised by: Dr Gemma Bowers

Secondary Supervisor: Professor Sian Coker

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 by the University of East Anglia. Taking part in this study is optional, and deciding not to take part will not affect you in any way. The study has been reviewed by the Faculty of Medicine and Health Sciences ethics committee and approval from the study to go ahead was granted on 18th February 2019.

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. You can also email us with any questions that you might have about the study.

What is the study about?

This research study is aiming to develop a greater understanding behind factors that affect who develop diabetes-related distress. Diabetes-related distress is

an emotional reaction to diabetes whereby people feel frustrated, angry, overwhelmed, and at times may feel like giving up on their diabetes management. Research has shown that those who experience diabetes–related distress may struggle with following their diabetes regimen.

There are some psychological factors which may explain why people may be at greater risk of experiencing diabetes-related distress, such as those who believe that they lack self - confidence in their ability to manage their diabetes.

We are interested in understanding more about what those psychological factors might be and how these are related to diabetes-related distress

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 help deepen our understanding of the psychological factors associated with diabetes-related distress 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 16 and over, who have been living with type 1 diabetes for at least 12 months, is responsible for managing their own diabetes, who uses insulin to manage their diabetes, and who do not have a diagnosis of an eating disorder. 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. This is because we are focusing on people who need to check their blood glucose levels more regularly. We are also not seeking to include adults with an eating disorder (e.g. ‘diabulimia’,

anorexia nervosa, bulimia nervosa, binge eating disorder).This is because the study is looking at the role of perfectionism in diabetes management, and it is known that people with eating disorders have higher levels of perfectionism than the general population. If you have type 2 diabetes or an eating disorder diagnosis 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 an online survey. You can do this via a phone, computer or tablet and complete it at your own pace. If you decide to take part, it is likely to take you 20-25 minutes to complete. 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 general information about yourself, your diabetes management, and questions on your confidence in managing your diabetes. You will also be asked to complete some psychological measures on perfectionism and an assessment of diabetes-related distress. Most of the questions involve selecting the response that you feel best fits your experience.

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 £25 amazon.co.uk gift card prize draw as a thank you for your time completing the questionnaires. Once you have submitted your answers, you will not be contacted again about the research

unless you have provided your email address for the prize draw or to be informed about the results of this research.

What will happen to the information I provide?

You will not be asked to provide any information that could personally identify you (e.g. your name or date or birth). All of the information you provide will be anonymous. We would ask you to complete the questionnaires as honestly and completely as possible. All of the information gathered will be stored on a secure network at the university, which is password protected and can only be accessed by the researchers. It will be stored as required by the General Data Protection Regulations of the Data Protection Act (2018) and UEA Policy, and all data will be destroyed after 10 years. We will not ask for any contact information, and we will not ask for details of your G.P. or any other healthcare professionals involved in your care. 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 prize draw once the data collection phase is completed. Likewise, should you wish to receive a summary of the study findings, we will ask that you provide an email address for us to send these to you. 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.

Your participation in the research is entirely voluntary and you can withdraw from the study at any point without giving a reason by exiting the online survey without submitting your responses. 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 psychological factors associated with diabetes-related distress, and may contribute to better support and treatment services in the future.

Some of the questions may relate to a personally sensitive subject matter and may evoke an emotional response. The questionnaires are not intended to cause distress, but in the event that this occurs, you can discontinue the study at any at any point by clicking “Exit survey” on any page, or you can pause and re-visit the questionnaires at another time. At the point you finish or exit the study, an information sheet will be provided that includes guidance on where to seek support from a variety of organisations, should 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 Chief Investigator or the research team who will do their best to answer your questions. If you wish to make a formal complaint, you can do this by contacting the Head of Department who is independent to the study. Contact details are provided at the bottom of this page.

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 will not include or 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 continuing this research.

Will this impact my future care?

Your future care will not be impacted in any way taking part in this study. Unless you tell them, no healthcare professionals will 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 (Reference number 201819 – 047).

Further information and contact details

If you have any questions or comments about the study, please contact the Chief Investigator directly. Alternatively, you may contact the projects' research supervisors Dr Gemma Bowers and Professor Sian Coker see below for contact details). If you wish to make a complaint you can contact Professor Niall Broomfield who is independent to the study. 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:

If you have further questions about the study contact the Chief Investigator

Katherine Moran

Doctoral Programme in Clinical Psychology,

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich Research Park

NORWICH, NR4 7TJ

k.moran@uea.ac.uk

If you have any concerns about the project please discuss these with the Chief Investigator in the first instance and then contact;

Dr. Gemma Bowers

Doctoral Programme in Clinical Psychology,

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich Research Park

NORWICH, NR4 7TJ

g.bowers@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

If you wish to make a complaint about the study please contact:

Professor Niall Broomfield

Head of Programme

Doctoral Programme in Clinical Psychology,

Department of Clinical Psychology

Norwich Medical School

University of East Anglia

Norwich Research Park

NORWICH, NR4 7T

n.broomfield@uea.ac.uk

Version 3.9_26.03.2019

Appendix E

Consent Form: version 3.9_26.03.2019

Title of Project: The Relationships between Perfectionism, Self-efficacy, and Diabetes Distress in Adults with Type 1 Diabetes.

Researcher: Katherine Moran (Trainee Clinical Psychologist)

Supervised by: Dr Gemma Bowers

Secondary Supervisor: Professor Sian Coker

Doctoral Programme in Clinical Psychology, School of Medicine and Health Sciences, University of East Anglia

If you do not agree with any of the below statements and feel unable to click the 'I agree' button, please feel free to exit the survey. Your responses will not be submitted and we thank you for your time so far. You may want to return to the survey at a later date, and you may wish to contact the researcher directly with any concerns or questions you may have by emailing: k.moran@uea.ac.uk

(An option will be included in which participants will click "I agree" after each statement. It will be stated on the consent page in the survey that a response to these statements is required before continuing)

1. I confirm that I have read the 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.

2. 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.

3. I understand that the information collected as part of this research project may be used to support other research in the future, and may be shared anonymously with other researchers.
4. I agree to take part in the above study.

Appendix F

Demographic Questions

What age are you?

Box to type age

What is your gender?

Male

Female

Transgender

Other

Prefer not to say

If you have answered ‘other’, please specify:

Box to type gender information if answered ‘other’

What is your ethnicity?

White British

White Irish

White Other

Black African

Black Caribbean

Black Other

Indian

Pakistani

Bangladeshi

Chinese

Other Asian

White and Black Caribbean

White and Black African

White and Asian

Other Mixed

Any other ethnic group

If you have answered ‘Any other ethnic group’, please specify:

Box to type ethnicity if answered ‘Any other ethnic group’

What is your current country of residence?

United Kingdom

Other

If you selected Other, please specify:

Box to type country of residence if answered ‘Other’.

What is the highest level of education that you have completed?

Some secondary school (no qualifications)

GCSEs or equivalent

A-Levels or equivalent

Trade/technical/vocational training

Undergraduate degree

Postgraduate degree

Other

If you selected Other, please specify:

Box to type in level of education if answered ‘Other’.

What is your current employment status?

Full-time employee

Part-time employee

Self-employed

Unemployed

Full-time student

Other

If you selected Other, please specify:

Box to type in employment status if answered 'Other'.

How many years has it been since you were diagnosed with type 1 diabetes?

Box to type number of years since diagnosis

How do you monitor your blood glucose levels?

Finger prick tests only

Continuous blood glucose monitoring only *(e.g. Freestyle Navigator, Dexcom G4 Platinum, Dexcom Seven Plus, Medtronic Enlite Sensor, Medtonic Guardian REAL-Time)*

Flash glucose monitoring only *(e.g. Freestyle Libre)*

Finger prick test + Continuous blood glucose monitoring

Finger prick test + flash glucose monitoring

Other

If you selected Other, please specify:

Box to type in blood glucose monitoring method if answered 'Other'.

Appendix G

Type 1 Diabetes Distress Scale

Instructions

Living with type 1 diabetes can be tough. Listed below are a variety of distressing things that many people with type 1 diabetes experience. Thinking back **over the past month,** please indicate the degree to which each of the following may have been a problem for you by selecting the appropriate number. For example, if you feel that a particular item was not a problem for you over the past month, you would select '1'. If it was very tough for you over the past month, you might select '6'.

		Not a problem	A slight problem	A moderate problem	A somewhat serious problem	A serious problem	A very serious problem
1	Feeling that I am not as skilled at managing diabetes as I should be.	1	2	3	4	5	6
2	Feeing that I don't eat as carefully as I probably should.	1	2	3	4	5	6
3	Feeling that I don't notice the warning signs of hypoglycaemia as well as I used to.	1	2	3	4	5	6
4	Feeling that people treat me differently when they find out I have diabetes.	1	2	3	4	5	6
5	Feeling discouraged when I see high blood glucose numbers that I can't explain.	1	2	3	4	5	6
6	Feeling that my family and friends make a bigger deal out of my diabetes than they should.	1	2	3	4	5	6

7	Feeling that I can't tell my diabetes doctor what is really on my mind.	1	2	3	4	5	6
8	Feeling that I am not taking as much insulin as I should.	1	2	3	4	5	6
9	Feeling that there is too much diabetes equipment and stuff I must always have with me.	1	2	3	4	5	6
10	Feeling like I have to hide my diabetes from other people.	1	2	3	4	5	6
11	Feeing that my friends and family worry more about hypoglycaemia than I want them to.	1	2	3	4	5	6
12	Feeling that I don't check my blood glucose level as often as I probably should.	1	2	3	4	5	6
13	Feeling worried that I will develop serious long-term complications, no matter how hard I try.	1	2	3	4	5	6
14	Feeling that I don't get help I really need from my diabetes doctor about managing diabetes.	1	2	3	4	5	6
15	Feeing frightened that I could have a serious hypoglycaemic episode when I'm asleep.	1	2	3	4	5	6
16	Feeling that thoughts about food and eating control my life.	1	2	3	4	5	6
17	Feeling that my friends or family treat me as if I were more fragile or sicker than I really am.	1	2	3	4	5	6

18	Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.	1	2	3	4	5	6
19	Feeling concerned that diabetes may make me less attractive to employers.	1	2	3	4	5	6
20	Feeling that my friends or family act like "diabetes police" (bother me too much).	1	2	3	4	5	6
21	Feeling that I've got to be perfect with my diabetes management.	1	2	3	4	5	6
22	Feeling frightened that I could have a serious hypoglycaemic event while driving.	1	2	3	4	5	6
23	Feeling that my eating is out of control.	1	2	3	4	5	6
24	Feeling people will think less of me if they knew I had diabetes.	1	2	3	4	5	6
25	Feeling that no matter how hard I try with my diabetes, it will never be good enough.	1	2	3	4	5	6
26	Feeling like my diabetes doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
27	Feeling that I can't ever be safe from the possibility of a serious hypoglycaemic event.	1	2	3	4	5	6
28	Feeling that I don't give my diabetes as much attention as I probably should.	1	2	3	4	5	6

Appendix H

Confidence in Diabetes Scale

Instructions:

After each of the following statements, circle the number that best indicates how much **you believe** you can or cannot do what is asked. Please note that the questions ask not what you should do but what you **believe** you can do.

(The measure does not give any time frame for participants to base their answers on)

	I believe I can…	No, I am sure I cannot	No, I don't think I can	I am not sure	Yes, I think I can	Yes, I am sure I can
1	Plan my meals and snacks according to dietary guidelines.	1	2	3	4	5
2	Check my blood glucose at least 2 times a day.	1	2	3	4	5
3	Perform the prescribed number of daily insulin injections.	1	2	3	4	5
4	Adjust my insulin for exercise, travelling, or celebrations.	1	2	3	4	5
5	Adjustment my insulin when I am sick.	1	2	3	4	5
6	Detect *high* levels of blood sugar in time to correct.	1	2	3	4	5
7	Detect *low* levels of blood sugar in time to correct.	1	2	3	4	5
8	Treat a *high* blood sugar correctly.	1	2	3	4	5

9	Treat a *low* blood sugar correctly.	1	2	3	4	5
10	Keep daily records of my blood sugars.	1	2	3	4	5
11	Decide when it's necessary to contact my doctor or diabetes educator.	1	2	3	4	5
12	Ask my doctor questions about my treatment plan.	1	2	3	4	5
13	Keep my blood sugars in the normal range when under stress.	1	2	3	4	5
14	Check my feet for sores or blisters daily every day.	1	2	3	4	5
15	Ask my friends or relatives for help with my diabetes.	1	2	3	4	5
16	Inform colleagues/others of my diabetes, if needed.	1	2	3	4	5
17	Keep my medical appointments.	1	2	3	4	5
18	Exercise 2 to 3 times weekly.	1	2	3	4	5
19	Figure out what foods to eat when I am dining out.	1	2	3	4	5
20	Read and hear about diabetes complications without getting discouraged.	1	2	3	4	5

Appendix I

Acceptance and Action Question - Diabetes

According to the measure, there are no specific instructions to give in completing the measure. Instructions for the online survey have been generated by the researcher.

These next questions are around the thoughts and feelings you may have about your diabetes. Please indicate the degree to how true the following statements are for you. For example, if you do not believe a statement is true for you, please select '1 = Never true'. If you always believe a statement is true, please select '7 = Always true'.

		Never true	Very seldom true	Seldom true	Sometimes true	Frequently true	Almost always true	Always true
1	I try to avoid reminders of my diabetes.	1	2	3	4	5	6	7
2	I have thoughts and feelings about being diabetic which are distressing.	1	2	3	4	5	6	7
3	I do not take care of my diabetes because it reminds me that I have diabetes.	1	2	3	4	5	6	7
4	I eat things I shouldn’t eat when the urge to eat them is overwhelming.	1	2	3	4	5	6	7

5	When I have an upsetting feeling or thought about my diabetes, I try to get rid of that feeling or thought.	1	2	3	4	5	6	7
6	I avoid taking or forget to take my medication because it reminds me that I have diabetes.	1	2	3	4	5	6	7
7	I avoid stress or try to get rid of it by eating what I know I shouldn't eat.	1	2	3	4	5	6	7
8	I often deny to myself what diabetes can do to my body.	1	2	3	4	5	6	7
9	I don't exercise regularly because it reminds me that I have diabetes.	1	2	3	4	5	6	7
10	I avoid thinking about what diabetes can do to me.	1	2	3	4	5	6	7
11	I avoid thinking about diabetes because someone I	1	2	3	4	5	6	7

	knew died from diabetes.							

Appendix J

Clinical Perfectionism Questionnaire

This questionnaire is not specific to your diabetes. This questionnaire is looking at your thoughts and feelings around personal standards and goals you set yourself in different areas of your life over the last month. If you think an item is particularly relevant to you, you may want to select '4 - All of the time'. Likewise, if an item is not relevant at all, you may want to select '1 – Not at all'. Over the past month….

		Not at all	Some of the time	A lot of the time	All of the time
1	Over the past month, have you pushed yourself really hard to meet your goals?	1	2	3	4
2	Over the past month, have you tended to focus on what you have achieved, rather than on what you have not achieved?	1	2	3	4
3	Over the past month, have you been told that your standards are too high?	1	2	3	4
4	Over the past month, have you felt a failure as a person because you have not succeeded at meeting your goals?	1	2	3	4
5	Over the past month, have you been afraid that you might not reach your standards?	1	2	3	4
6	Over the past month, have you raised your standards because you thought they were too easy?	1	2	3	4
7	Over the past month, have you judged yourself on the basis of your ability to achieve high standards?	1	2	3	4
8	Over the past month, have you done just enough to get by?	1	2	3	4
9	Over the past month, have you repeatedly checked how well you are doing at meeting your standards (for example, by comparing your performance with that of others)?	1	2	3	4
10	Over the past month, do you think that other people would have thought of you as a "perfectionist"?	1	2	3	4
11	Over the past month, have you kept trying to meet your standards, even if this has meant that you have missed out on things?	1	2	3	4

12	Over the past month, have you avoided any tests of your performance (at meeting your goals) in case you failed?	1	2	3	4

Appendix K

Debrief sheet

Thank you for taking the time to complete the survey! Your responses to this survey will go towards developing a deeper understanding towards whether high levels of perfectionism are associated with diabetes distress. If you have any questions or concerns about the survey please contact the research team:

Chief Investigator:	Primary Supervisor	Secondary Supervisor:
Katherine Moran	Dr Gemma Bowers	Professor Sian Coker
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k.moran@uea.ac.uk	g.bowers@uea.ac.uk	s.coker@uea.ac.uk

If you have any questions or concerns about your diabetes, we suggest you contact your GP or local diabetes clinic.

You may also find the below organisations helpful:

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 Helpline: 0325 123 2399 (Monday to Friday, 9am to 7pm)

helpline@diabetes.org.uk

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

JDRF, the type 1 diabetes charity

Online information: https://jdrf.org.uk/

Contact details for regional offices can be found: https://jdrf.org.uk/about-us/contact-us/

Email: info@jdrf.org.uk

Appendix L

Social Media Adverts

Twitter

Are you a #UK adult (16+) living with #type1diabetes? If so, please take part in an online #research study looking at #perfectionism and #diabetesdistress in #T1D! (Insert link to survey). Please RT!

The tweet will also have an attached image.

> Are you an adult (16+) living with Type 1 Diabetes? I am recruiting research participants for an online study based in the UK looking at #perfectionism and #diabetesdistress in #T1D. For more details see:
>
> *Insert link to survey*
>
> Thank you! Please RT!

Facebook

Are you an adult (16+) in the UK living with Type 1 Diabetes? I am recruiting participants for an online study looking at the relationship between perfectionism and diabetes distress in Type 1 Diabetes, as part of my doctoral thesis in Clinical Psychology. . For more details see:

(Insert link to survey)

Thank you in advance!