

THE UNIVERSITY OF HULL

**Exploring compassion, shame and the healthcare system in
relation to self-care in Type 2 Diabetes**

Being a thesis submitted in partial fulfilment of the requirements for
the degree of Doctor of Clinical Psychology
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By

Cara Jane Childs
BSc (Hons) Psychology
University of York

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Acknowledgments

There are a few people I would like to mention, who I feel have helped me along the way in producing this portfolio thesis.

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Overview

This portfolio thesis is comprised of three parts: 1) a systematic literature review, 2) an empirical report and, 3) supporting appendices.

Part one is a systematic literature review which aimed to explore healthcare system factors that are related to self-care in individuals with Type 2 Diabetes. A systematic search of four key databases identified nineteen empirical papers for review. A narrative analysis of the evidence is provided and key factors relating to self-care are identified and summarised. A review of methodological quality and standard of reporting of reviewed studies is also provided. Implications for the field of research and for clinical practice are discussed.

Part two is an empirical report of an original piece of research exploring compassion and shame in relation to self-care in individuals with Type 2 Diabetes. Quantitative analysis aimed to investigate whether shame has a negative effect on self-care, and whether compassion has a role in buffering the impact of shame. In an additional qualitative element, experiences of shame in individuals with Type 2 Diabetes were explored. The findings of the study are discussed in relation to previous literature and theory, and implications for future research and clinical practice are considered.

Part three contains the appendices relating to the systematic literature review and the empirical report. It additionally includes an epistemological statement, and a reflective statement focussing on the research process.

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Part One
Systematic Literature Review

Healthcare system factors related to self-care in Type 2 Diabetes: A systematic literature review

Cara Jane Childs^{1*}, Philip Molyneux¹ and Tim Alexander¹

¹School of Health and Social Work, University of Hull, Cottingham Road, Hull,
United Kingdom, HU6 7RX

* Corresponding Author. Email address: C.Childs@2015.hull.ac.uk

This paper is written in the format outlined for submission by

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Please see Appendix C for the Author Guidelines.

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Abstract

Purpose: this review aimed to provide an up-to-date and systematic review of the literature on healthcare system factors that influence self-care in individuals with Type 2 Diabetes.

Methods: A systematic review was conducted using Academic Search Premier, Medline, CINAHL Complete and PsycINFO databases between July and September 2017. Of 886 articles found, 19 met the inclusion criteria for the current review. Narrative analysis was employed to examine the data.

Results: Two broad categories of healthcare system emerged from the data; personal and professional. The personal healthcare system included; partner factors, family factors, and wider support network factors. The professional healthcare system included; patient-provider relationship factors, continuity of care, and characteristics of the care received. Findings were limited by reliance on cross-sectional design and self-report methodology. Other limitations in regard to measurement of self-care as an outcome, methodology, and reporting were highlighted.

Conclusions: A complex interplay of both personal and professional healthcare system factors were associated with self-care in those with Type 2 Diabetes. This has important implications for policy and service delivery with the aim of improving outcomes for those with the condition. Future research should address common methodological issues and begin to explore potential interventions based upon the findings.

Type 2 Diabetes Mellitus (T2DM) is a chronic health condition characterised by the body becoming unable to produce enough of the hormone insulin, or when the insulin produced does not work effectively.¹ It develops over the lifespan as a result of factors such as genetics, age, weight and lifestyle.² Similarly to the rest of the world, the UK is facing an epidemic of T2DM diagnoses; reports suggest that as many as 1 in 16 people in the UK are currently living with the condition, and this is set to increase by around 5% each year.³ Uncontrolled T2DM can result in complications, such as; blindness, limb amputation, heart disease, stroke, kidney disease,² and in the UK, T2DM is believed to be causing over 22,000 additional deaths each year.³ At present, 99% of the management of T2DM occurs through engagement with self-care behaviours,⁴ defined as “activities performed by individuals or communities to achieve, maintain, or promote maximum health” (Lipson and Steiger, 1996; pg. 16).⁵ This may involve; a specific diet, exercise, blood glucose monitoring and medication as well as frequent appointments with medical professionals for health monitoring and medication reviews. However, despite the necessity of such behaviours, current figures suggest that adherence rates to these behaviours are around only 50%.⁶ This is not only causing serious problems for health outcomes, but is additionally putting financial strain on the National Health Service (NHS) in the UK. Reports suggest that, in 2010/2011, the condition cost the NHS £9.8billion in direct costs, which represents 10% of the entire healthcare expenditure for this period and it is estimated that 80% of these costs are incurred from treating potentially avoidable complications. The cost of diabetes care is only set to increase as the incidence of diagnoses rise.⁷

In light of the published figures surrounding engagement with self-care behaviours, a number of reviews have aimed to bring together the existing research regarding factors associated with poor self-care in an attempt to highlight areas for intervention. ^{6,8-11} These reviews have demonstrated, for example, that being male, young, having lower education levels, being part of an ethnic minority group, or of lower socio-economic status and having comorbid physical and/or mental health conditions, in general make individuals more at risk of poorer engagement with self-care. Current guidelines from the National Institute for Health and Care Excellence (NICE) ¹² appear to be taking such research into account, outlining specific medical interventions for those with T2DM, taking into account individual factors such as comorbidity, polypharmacy, disability, and education.

However, to assume that an individual's self-care behaviour, like any other behaviour, occurs in isolation may be reductionist. According to System's Theory, ¹³ an individual's behaviour occurs as a product of factors in the environment and interactions with and between those factors. In the case of long term health conditions, like T2DM, the management of the condition requires an ongoing relationship and interaction between the individual and multiple healthcare professionals; General Practitioners, nurses, dieticians, pharmacists, and other Allied Health Professionals, through regular health appointments. Furthermore the behaviours involved in T2DM management represent significant lifestyle change and challenges on a daily basis for individuals living with the condition, ¹⁰ with the majority of the behaviours being carried out at home and in other social settings. Therefore, it is important to recognise the role of those in the individual's personal system, such as family

and friends, in supporting and influencing self-care behaviour in individuals with T2DM.¹⁴

In their World Health Report (2000), the World Health Organisation (WHO) defined the healthcare system as a system including “activities whose primary purpose is to promote, restore or maintain health ... Formal health services, including the professional delivery of personal medical attention, are clearly within these boundaries; as are actions by traditional healers, and all use of medication, whether prescribed by a provider or not. Home care of the sick is another example, which is how between 70% and 90% of all sickness is managed” (pg. 5)¹⁵. Thus, given this definition, individuals, families, friends, professional organisations, societies and other systems are considered part of the healthcare system and will therefore be involved in influencing diabetes self-management. They all should, therefore, be considered when trying to understand and assist the individual towards effective self-care.¹⁶

Previous reviews have touched upon some of these factors and their role in influencing self-care,^{10, 17-18} and a recent meta-analysis demonstrated that social support from healthcare providers, as well as from family and friends was implicated in aiding improved self-care.¹⁹ Such findings have been somewhat reflected in recent publications and service recommendations. In 2016, the WHO published a Global Report on Diabetes which highlighted the need to move towards integrated healthcare services that are able to provide up-to-date diabetes care plans in a way that is person-centred and provided by a team made up of professionals from multiple disciplines.²⁰ In the UK, NHS England set out aims for more consistent care for those with diabetes, enabling them to live lifestyles that would reduce or delay complication and promote a good quality of life.³ They proposed to do this by promoting holistic and personalised

care plans in which the patient's individual needs are considered and taken into account via shared decision making and ongoing support.

Although previous reviews have highlighted systemic influences on self-care to an extent, to date no systematic literature review has been conducted focussing solely on healthcare system factors influencing self-care. Rather, in most cases, previous reviews have focussed exclusively on the role of particular elements or relationships on self-care. Furthermore, previous reviews have not considered the role of friends, family and peers as part of an individual's healthcare system. This is reflected in the absence of such considerations in service delivery recommendations. By integrating the available evidence in this field, it may be possible to think about areas for support and intervention, at both the personal and professional level, that may help to improve the poor self-care in those living with T2DM, and subsequently improve long term health outcomes.

Therefore, the aim of the current review is to provide an up-to-date, rigorous and systematic review of the literature around healthcare system factors that influence self-care in T2DM. In order that the outcomes of this review are applicable and clinically relevant to the UK healthcare context, the review based its conclusions on studies that were conducted with samples taken from free and universal healthcare systems. This is in respect of the additional financial burden that privatised healthcare places on those with T2DM and how high costs of self-care and medication has been shown to have a significant negative impact on effectiveness of self-care ²¹⁻²²; an issue that is not pertinent in the UK population. The research question for this review was; what healthcare system factors are related to self-care in Type 2 Diabetes?

Method

Search strategy

Between July and September 2017, the following databases were searched for relevant literature via EBSCOhost literature search service: Academic Search Premier, Cumulative Index to Nursing and Allied Health Literature (CINAHL Complete), MEDLINE, and PsycINFO. These databases were chosen in combination in order to increase the likelihood of identifying all relevant literature within schools of psychology, medicine, nursing and allied health. As an initial stage, a scoping search was conducted in order for the researcher to become familiar with the literature and to identify key search terms to be included in the final search.

Search terms were identified using the PICO (Patient/Problem/Population, Intervention, Comparison/Control/Comparator, Outcome) strategy.²³ Previous reviews were consulted in regards to the search terms used and synonyms were considered alongside Medical Subject Heading (MeSH) terms for “self-care.” Different combinations of search terms and levels of specificity were employed during pilot searches to explore the impact on the relevance of papers returned (e.g. “DM vs “T2DM”). Final search terms were peer-reviewed and agreement reached. The following terms were searched for within an article’s title and keywords: “Type 2 diabetes mellitus” OR Type 2 diabet**” OR “t2dm” N5 “self#care” OR “self#manag**” OR “self#administrat**” OR “self#medicat” OR complia* OR adhere* OR concordan* OR persist*

Selection Strategy

The selection strategy for the current review had four main stages. Firstly, all titles from the final search were reviewed for relevance and duplicates were removed. Secondly, abstracts of remaining papers were reviewed, and the following inclusion criteria were applied: use of a sample with a primary diagnosis of T2DM who were over the age of 18; published in a peer-reviewed academic journal; and available in English. Articles were excluded if they came from any of the following sources: unpublished material, case studies, reviews, discussions, conference proceedings, other secondary sources, or if the abstract only was published. These criteria were important for ensuring quality and rigour in the studies included. Qualitative and intervention studies were also excluded at this stage due to their inconsistency with the aims and epistemology of the current research question and to ensure fluent integration of results. Thirdly, full text articles were reviewed with particular focus on their sample, methodology and results. Articles were eligible for inclusion if; key variables were consistent with the broad approach to defining a healthcare system according to the WHO definition; they utilised a direct measure of self-care; and were conducted in a country with a free and universal healthcare system. This was important to ensure results of the review were applicable to the health system in the UK. Articles were excluded if they; did not allow for separation of results based on diagnostic categories; or if they did not directly relate relevant variables to the outcome of self-care. Finally, the reference lists of included papers were then hand searched for other key papers and these were assessed for eligibility via the same criteria. See Figure 1 for a diagrammatic summary of this process.

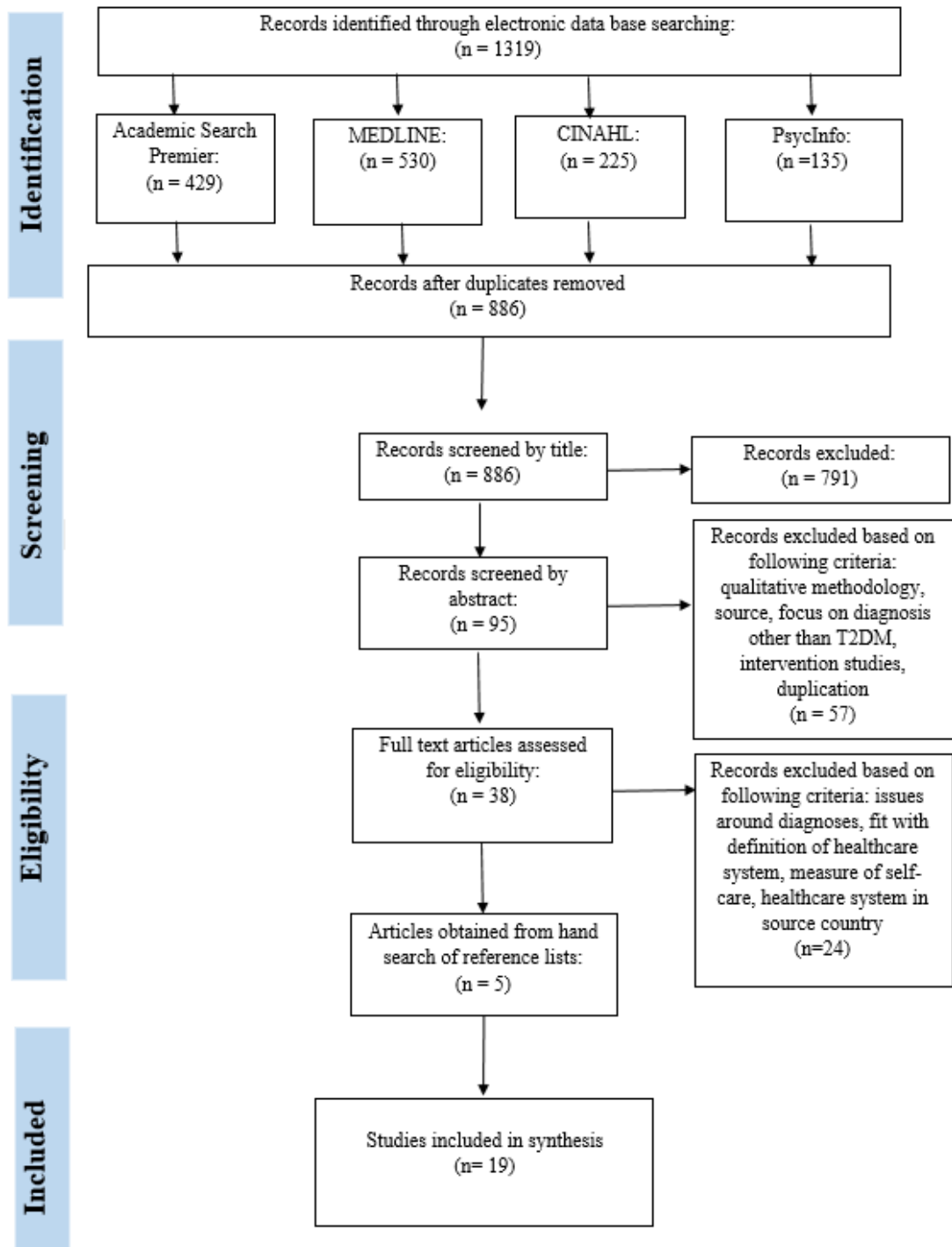


Figure 1: Diagrammatic representation of the paper search and selection strategy

Data Extraction and Quality Assessment

Information about aims, design, methodology, sample characteristics, measurement of self-care, relevant findings and key limitations were extracted for each study (see data extraction form; Appendix D). A quality assessment was applied to all articles included in the review. The framework employed was the NICE guidelines recommended quality checklist for reviews of quantitative studies reporting predominantly correlations and associations (see Appendix E).

²⁴ The checklist was developed based on the appraisal step of the 'Graphical appraisal tool for epidemiological studies' (GATE).²⁵ The checklist enables assessment of a study's internal and external validity based upon key elements of the study's design. Where the essential criteria for adequate internal and/or external validity is met by a study, a score of "++" is given. Where a study meets some of the desired criteria, a score of "+" is given. Where significant flaws or bias in design or generalisability are recognised, or a study fails to meet the criteria for validity, a score of "-" is given. Regardless of quality score, all eligible studies were included in the review. The quality scores were therefore predominantly used to inform the review of any bias or error that might impact the interpretation of the results. Quality ratings of studies were checked for inter-rater reliability by an independent party who reviewed 25% of the included papers. An agreement rate of 87.5% was demonstrated. Where there were disagreements, the differences were discussed and an agreement was reached in all cases.

Data analysis

An integrative approach to Narrative Analysis was used to describe, aggregate and summarise the findings of the studies included in the current review in order

to deduce key factors related to self-care.²⁶ Narrative Analysis was chosen as the most appropriate method of data analysis for answering the current research question, in order to produce findings that could be used to inform clinical practice and policy making. Meta-analysis was considered inappropriate given the wide variety of outcome measures used within the methodology of studies reviewed. The Narrative Analysis conducted followed three key steps. Firstly, the WHO's definition of a healthcare system was used as an initial framework for organising and synthesizing findings into two broad categories (personal factors and professional factors). Secondly, findings from each study were summarised in a textual description then organised thematically into clusters according to the key concepts highlighted in the findings. Lastly, the relationships between studies in each cluster were explored based upon similarities, contradictions and heterogeneity. Where correlations were reported between study variables, the strength of the relationship was assessed based on the following guidelines; weak: $r = 0.3$; moderate: $r = 0.5$; and strong: $r = 0.7$. The current review was written in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).²⁷

Results

Primary study characteristics

A total of 19 studies (n = 219,406 participants) were included based on the search strategy and inclusion/exclusion criteria outlined. Samples ranged from 34-66% female and mean age of participants ranged from 56-66 years; which is consistent with the increased risk of developing T2DM with age.²⁸ Average duration of diabetes ranged across the studies from newly diagnosed to 11.3 years. Studies took place in 12 different countries all identified as having free

and/or universal healthcare systems; Portugal (n=5), Malaysia (n=2), Canada (n=2), France (n=2), Spain (n=1), South Korea (n=1), Poland (n=1), Taiwan (n=1), Iran (n=1), Denmark n=1), UK (n=1), and China (n=1). Based on the inclusion criteria for the current review, all studies included were quantitative. The majority of studies (n=17) utilised a cross-sectional design, with the remaining studies (n=2) using a longitudinal design. Within this, surveys were the most commonly used methodology (n=16), with the remaining studies (n=3) utilising information from medical databases.

Quality of studies

Only one study met the criteria for a full score (indicated by ‘++’) in both internal validity (IV) and external validity (EV). Overall scores for EV were better than scores for IV, suggesting that whilst studies were largely generalizable, there were potential sources of flaws and bias across the sample. The vast majority of studies relied solely on self-report in measuring their outcomes. This raises issues around potential response bias, and thus whether the outcome scores are a true representation of engagement with self-care. Furthermore, some studies made use of unstandardized and idiosyncratic self-report measures, which adds further limitations in this respect. In addition, the vast majority of evidence came from correlational analyses, and therefore few causal attributions can be drawn from the data. However, overall explanatory variables included in analyses across the sample were generally well-grounded in theory and previous research, and ideas for future research in exploring causal attributions were regularly outlined. Whilst generally EV scores were stronger than IV, they were not immune to critique. A few studies in the sample provided poor descriptions of their source populations and/or outlined strict inclusion and

exclusion criteria (e.g. only including newly diagnosed patients and those taking medication, and excluding participants who use insulin or have spent time in hospital). In the absence of rationale for such criteria, it raises concerns around whether or not sample populations can be viewed as representative of the wider T2DM population in that country.

Measures of self-care

Across the studies, the way in which self-care was approached as a concept varied greatly, with studies exploring '*adherence*', '*compliance*', '*persistence*', '*glycaemic index*', '*glycaemic control*', and '*self-care*'. Some studies (n=7), for example, measured just medication adherence as an indication of self-care,²⁹⁻³⁵ whilst others measured just adherence to dietary recommendations,³⁶⁻³⁷ or combinations of behaviours, such as diet and exercise.⁴⁵ In a similar fashion, the ways in which the studies measured self-care also varied. The majority of studies utilized self-report, with 12 of these relying solely on this methodology. These studies varied in terms of the self-report tools used as well as the behaviours measured; be that dietary adherence, exercise, foot care, blood glucose monitoring or medication taking.^{29-30, 33, 35-47} A few studies utilised biological outcome measures of self-care, most commonly A1C (blood glucose) readings.^{38-40, 46}

Personal healthcare system

Within the personal level of the healthcare system, three key factors emerged from the data; 1) Partner factors, 2) Family factors, and 3) Wider support network factors.

Partner factors

Relationship status

Four studies reported the relationship between marital status and effective self-care and in the majority of cases, it was concluded that being single was associated with poorer self-care.^{35, 40, 44} Each study measured self-care by different means (e.g. self-report self-care vs medication adherence vs A1C), suggesting that the role of marital status in influencing self-care is consistent across sample type and outcome measure. However, Schiøtz and colleagues only found a correlation between relationship status and smoking, which is not consistently identified within the literature as a key self-care behaviour.⁴⁴ In addition, in a large, high quality study, Chew et al demonstrated no relationship between marital status and self-care.³⁰ Therefore the relationship may not be as consistent as it initially appears and the clinical implications of this finding are limited.

Partner support

Two large scale studies used self-report methodology to assess both positive partner support (e.g. encouragement to engage in self-care activities) and negative partner support (e.g. warning about potential complications) in relation to self-care.^{36, 38} Both types of partner support were found to be related to the intention to and actual adherence to self-care recommendations; however the association was relatively weak. Costa and colleagues further demonstrated that in individuals with the intention to self-care effectively, high levels of positive partner support meant they were more likely to actually self-care and this subsequently resulted in better health outcomes.³⁸ The beneficial effects of positive partner support were supported by Pereira and colleagues, who

demonstrated a role for it in buffering the negative effect of psychological morbidity (e.g. presence of depression or anxiety symptoms) on self-care; such that when support was high, psychological morbidity had a lessened negative impact on self-care.³⁶

Dyadic adjustment

Two studies reported findings that dyadic adjustment relates to self-care. Pereira et al defined dyadic adjustment as involving satisfaction, cohesion, consensus and affection within a couple and state that, in chronic disease, this plays out in couples finding adaptive ways to overcome adversity and change.⁴² They found that effective dyadic adjustment was related to improved self-reported dietary adherence, however this is drawn from relatively weak correlations. An earlier study demonstrated similar results, finding that effective dyadic adjustment influenced adherence to glucose monitoring recommendations by reducing negative beliefs about medication in patients and their partners.³⁶ However, the authors report no other findings linking dyadic adjustment to other vital self-care behaviours, such as exercise and medication taking. The studies were additionally both conducted in samples of newly diagnosed individuals and as adjustment is recognised as an ongoing and developing process, it is unfortunately not possible to predict from these findings the long-term relationship between dyadic adjustment and self-care as disease duration increases.

Partner illness representations

Two studies reported on the role of the illness representations of partners of those with T2DM as a factor related to self-care. Pereira et al demonstrated a

mediating role of partner representations of diabetes consequences on the relationship between patient representations and self-care; such that where there was greater convergence in patient and partner representations, patients reported better engagement with exercise, blood glucose monitoring and foot care, in a newly diagnosed sample.⁴³ The same was found in respect to other aspects of illness representation; personal control (the extent to which an individual feels they have control over the condition) and treatment control (the extent to which an individual feels they have control over the treatment of the condition). These relationships were supported by Searle et al who found that partner illness representations were related to engagement with physical activity.⁴⁵ Furthermore, they demonstrated that partner timeline representations (the individual's beliefs about the course of the condition) were also related to dietary intake. However, the findings are underpinned by correlation coefficients that are, at best, moderate. Nonetheless, there appears to be some relationship whereby partner illness representations mediate the relationship between the patient's representations of the illness and their self-care behaviour. Unlike Pereira et al's newly diagnosed sample,⁴³ Searle et al conducted their study with a sample of patients with an average disease duration of 8.8 years.⁴⁵ Therefore, taken together, the findings suggest that, the influence of partner illness representations may be maintained over the course of the condition.

Family factors

Family stress and coping

Pereira et al found that patients who hold negative beliefs about their diabetes medication (such as overuse of medication, or beliefs that they are harmful) are less likely to engage with their self-care behaviours.⁴¹ However, this

relationship was moderated by family stress; such that when family stress is high, patients who hold negative beliefs about their medication are less likely to take them as recommended, and thus family stress was concluded to have a negative impact. In contrast Pereira et al found family stress to be positively related to adherence to exercise recommendations.⁴² This led the authors to an alternative conclusion that increased family stress may be beneficial in some cases in encouraging families to engage in more active coping strategies. Indeed they found that family coping was positively related to engagement with exercise; however this is based upon a weak positive association between the two variables. This may go some way to explaining such discrepancy in findings in two studies that were conducted in very similar samples, using largely the same scales to measure key variables, and of similar methodological quality.

Family support

Three studies in the sample reported findings in regard to the influence of family support on self-care, however there are inconsistencies across the conclusions drawn. Schiøtz and colleagues found no relationship between the frequency with which individuals with T2DM saw their family and self-management and concluded that the involvement of family had potential to help or to hinder self-care.⁴⁴ Other studies suggested that merely seeing family does not automatically denote the presence of support. Pirdehghan and Poortalebi conducted a broad and exploratory investigation which included family support and family disease related advice as predictors of self-care.³⁵ They found that, where family support and advice was poor, adherence to medication was negatively affected. However this was not explored in relation to self-care behaviours other than medication taking. Shahar et al went some way towards

filling this gap by demonstrating a significant moderate positive relationship between family support and dietary compliance.³⁷ However, this did not translate into a positive effect on glycaemic control. These conclusions are drawn with caution however, as Shahar et al's findings are based on a sample size of just n=35, which creates significant issues for data analysis and generalisability of findings. Overall, a role for family support is suggested, however it is unclear how this role manifests and whether it is beneficial, or a hindrance, or both.

Wider support network factors

Several studies found that social support beyond partners and family is related to more effective self-care. Kasznicki et al demonstrated that having support from other people resulted in a 7-fold increase in compliance with medication, as measured via self-report methodology and glycaemic index.³⁴ Despite the strong results, Kasznicki et al's reporting of their results was poor relative to other studies in this area and issues around both internal and external validity hinder the usefulness of the results. However, a later study by Tiv and colleagues,⁴⁷ which was conducted with good methodological rigour and in a large population based sample, support Kasznicki's findings. Tiv et al found that greater access to social support improved participants' engagement with medication regimes. Schiøtz and colleagues also found a positive influence of social support on not only medication taking, but also on other self-care behaviours including diet, exercise, smoking, blood glucose monitoring and foot care.⁴⁴ Schiøtz and colleagues additionally explored the role of friendships on engagement with these essential self-care activities. They found that those who saw friends more than once a month and were confident that their friends would

be useful when the individual is struggling had a significantly better self-care. Shao et al sought to explain this relationship and demonstrated that it may occur as a function of self-efficacy and adherence; such that social support has an effect on an individual's belief in their ability to self-manage their condition and in turn this has a positive effect on their adherence to self-care recommendations and subsequent glycaemic control. ⁴⁶

Professional healthcare system

Within the professional level of the healthcare system, three key factors emerged from the data; 1) Patient-provider relationship factors, 2) Continuity of care, and 3) Characteristics of care received.

Patient-provider relationship factors

Tiv et al and Barba et al explored factors related to medication adherence using self-report methodology in samples of patients and physicians.^{29, 47} Both studies demonstrated that shared decision making regarding diabetes treatment promoted better outcomes and Barba and colleagues reflected that both patients and physicians were in agreement regarding this. However, it is important to consider that this finding was based on a sample of individuals with T2DM amongst other comorbid conditions, and it is therefore not possible to ensure that the findings were specific to the T2DM population. Lee and Lin tested a theoretical model of trust in relation to the patient-provider relationship.³⁹ They reported weak-moderate relationships between trust and self-care; such that where patients had greater trust in their physician, they displayed better self-reported health outcomes. This relationship was mediated by self-efficacy and outcome expectations. Unfortunately the same relationship

was not observed for objective outcomes, as measured via A1C levels.

However all of these studies excluded participants who were not taking diabetes medication. This may limit the generalisability of the findings to those in the T2DM population who are not prescribed medication to manage their condition.

Continuity of care

Dossa and colleagues defined Continuity of Care (COC) as the "ongoing relationship between a patient and an individual physician" (pg. E359).³² Four studies in the sample investigated the relationship between this and self-care. Two studies used a longitudinal design and found that COC was positively related to adherence.³²⁻³³ Dossa and colleagues reported that, over the two years following treatment initiation, those with intermediate and low COC were 3% and 4% less likely to persist and 2% and 5% less likely to comply with medication, respectively.³² Similarly, Hong and colleagues tracked this over four years and found that, whilst generally, adherence improved over this period it especially improved for those with better COC.³³ Other studies considered the role of COC in relation to health professionals other than primary physician. Dossa et al found that pharmacy loyalty was related to self-care outcomes, with patients who were not loyal to filling their prescriptions at one pharmacy being 11% and 18% less likely to be persistent and compliant, respectively, with their medication.³¹ The authors concluded that the pharmacist may also play an important role in ongoing self-care in T2DM. A caveat to this, however, is that these studies relied on medication refill data as an outcome measure. This is problematic, as it is only able to provide an indication that patients filled their prescriptions, not that they took their medication as recommended, potentially leading to an overestimation of adherence.

Characteristics of the care received

Tiv and colleagues found that in cases where patients were in need of more information about their condition and its treatment and more support from medical professionals, they had poorer medication adherence.⁴⁷ In addition, they demonstrated that how acceptable a patient perceived medical recommendations to be impacted how well they engaged with them. However, the use of an idiosyncratic survey as an outcome measure within this context raises issues around internal validity in regard to whether the questionnaire was able to measure adherence to diabetes medication as distinguishable from other prescriptions. Yet, similar conclusions were drawn by Pereira et al who demonstrated that where patient satisfaction with the communication and information they received from healthcare services is higher there was a positive effect on self-care in a sample of newly-diagnosed individuals.³⁶ Furthermore, they found that satisfaction moderated the relationship between psychological morbidity and adherence to diet; such that where patient satisfaction with services is high, the negative impact of psychological morbidity on adherence was reduced. However both studies restricted their samples based on the type of medication they were prescribed and this therefore raises questions about the generalisability of the findings to the rest of the T2DM population.

Table 1: Characteristics and key findings of reviewed studies

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
Barba <i>et al</i> (2017)²⁹	To identify views of patients, physicians and pharmacists about factors that may be associated with/improve medication adherence and persistence	Patients=963 Physicians=998 Pharmacists=419 Spain	Diagnosis: T2DM Age: 60.4 (patient mean) Gender: 50.1% female (patients) Diabetes duration: 11.3 years (mean)	Design: CS Method: Electronic survey with 11 questions developed from review of literature. Two parts: 1) Factors associated with adherence and persistence; 2) Strategies to improve adherence and persistence	SR; MMAS	Factors associated with adherence to medication from the perspective of the patient, the physician and the pharmacist	Factors seen as important included: Patient characteristics (e.g. patient-physician shared decision making) and environmental characteristics (e.g. a family member/friend has the condition, administration supervision). However there were significant differences in answers given by patients, physicians and pharmacists ($p < .001$).	IV: + EV: ++
Chew <i>et al</i> (2015)³⁰	To examine factors associated with medication adherence at primary care level	N=668 Malaysia	Diagnosis: T2DM Age: 30+ Gender: 52.8% female Diabetes duration: NR	Design: CS Method: Questionnaire	SR; MMAS	Marital status	Marital status is not related to medication adherence ($p = 0.547$)	IV: + EV: ++
Costa <i>et al</i> (2012)³⁸	To analyse the relationship between partner support, social-cognitive variables, self-monitoring of blood glucose (SMBG) adherence and glycaemic control	N=179 Portugal	Diagnosis: T2DM Age: 59.6 (mean) Gender: 57.5% male Diabetes duration: NR	Design: CS Method: Questionnaires completed individually by patients and their partners	SR; RSDSCA A1C	Spousal support (MDQ)	Weak-moderate positive correlations found between positive and negative partner support and the intention to SMBG ($r = 0.36, p < 0.01$; $r = 0.31, p < 0.01$ respectively) and adherence to SMBG ($r = 0.46, p < 0.01$; $r = 0.35, p < 0.01$ respectively). Positive support mediated the relationship between intention and adherence to SMBG ($\beta = 0.388; p < 0.01$).	IV: + EV: +
Dossa <i>et al</i> (2015)³¹	To assess the association between pharmacy loyalty and medication use among new users.	N=124,009 Canada	Diagnosis: T2DM Age: 66.5 (median) Gender: 47.6% male Diabetes duration: NR	Design: CS Method: Reviewed administrative data from Quebec's provincial health	OAD compliance and persistence	Pharmacy loyalty	Patients who are not loyal to single pharmacy are 11% less likely to be persistent and 18% less likely to be compliant.	IV: + EV: +

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
				insurance agency (RAMQ)				
Dossa et al (2017) ³²	To assess the association between continuity of care and medication adherence among new users of OADs	N=60,924 Canada	Diagnosis: T2DM Age: 64.8 (mean) Gender: 52.6% female Diabetes duration: NR	Design: CS Method: Reviewed data from the Quebec drug plan database. Measured COC in the first year of treatment and assessed medication adherence in the second year of treatment.	Medication persistence and compliance	Continuity of care	Compared to high level of COC, intermediate and low level of COC were 3 and 4% less likely to persist and 2 and 5% less likely to comply, respectively.	IV: + EV: +
Hong et al (2014) ³³	To examine the relationship between COC and medication adherence in those with a new hypoglycaemic prescription	N=23034 South Korea	Diagnosis: T2DM Age: 23.3% 20-44 31.2% 45-54 27% 55-64 18.5% 65+ Gender: 58.3% male Diabetes duration: Newly diagnosed	Design: L Method: Patients were followed up for 4 years using claims data via the KNHI Claims Database 2004-2008 to measure COC and adherence.	MPR	Continuity of care	Mean MPR increased as a function of continuity of ambulatory care each year	IV: ++ EV: ++
Kasznicki et al (2007) ³⁴	To evaluate the effect of demographic, medication, social, diabetes knowledge, and treatment factors on compliance with drug therapy and glycaemic control.	N=200 Poland	Diagnosis: T2DM Age: 66.1 (mean) Gender: 62% female Diabetes duration: 60.5% >5years	Design: CS Method: Questionnaires used to gather key data	SR; Medication compliance Glycaemic control	Social support	Support from other people caused a 7-fold increase in compliance ($p < .050$).	IV: - EV: -
Lee et al (2009) ³⁹	To test a theoretical model of variables influencing the	N=480 Taiwan	Diagnosis: T2DM Age: 59.2 (mean)	Design: CS Method: Questionnaires	SR; DSAS A1C	Trust in physician (SR: measure developed by	A weak but significant positive relationship was found between trust in physician and	IV: + EV: ++

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
	relationship between trust and both objective and self-rated health		Gender: 36.9% female Diabetes duration: 6.8years (mean)	administered at clinic appointments. Medical records reviewed.		Anderson & Dedrick, 1990).	self-reported adherence ($\beta = 0.41, p < .010$). Trust was moderately positively related to mediators self-efficacy ($\beta = 0.45, p < .010$) and outcome expectations ($\beta = 0.46, p < .010$) and these mediators displayed significant positive relationships with adherence ($\beta = 0.77, p < .010$; $\beta = 0.13, p < .010$ respectively). The relationship between trust and A1C was weak and non-significant ($\beta = -.06$)	
Moreau et al (2009)⁴⁰	To identify clinical and psychosocial factors associated with adherence and to investigate degree of agreement between patient- and GP-perceived adherence	Patients=521 GPs=39 France	Diagnosis: T2DM Age: 65 (patient mean) Gender: NR (patient) Diabetes duration: NR	Design: CS Method: Individual self-report surveys for patients and GPs	SR; Adherence problems A1C	Marital status Level of agreement between patient and GPs reports of adherence problems	Single life associated with adherence problems (Odds Ratio=1.86; $p=.026$) Agreement between patient and GP perception of adherence difficulties was 70%	IV: + EV: +
Pereira et al (2014)⁴¹	To analyse whether contextual variables moderate the relationship between negative beliefs about medicines and self-care.	N=387 patients and their partners Portugal	Diagnosis: T2DM Age: 59 (patient mean) Gender: 58% male (patients) Diabetes duration: NR	Design: CS Method: Individual surveys completed by patients and their partners when attending regular medical appointments	SR; RSDSCA SR; MARS	Family support: 1. Coping (F-Copes) 2. Stress (FILE) 3. Adjustment (RDAS)	Marital adjustment moderated the relationship between negative beliefs about medication and glucose monitoring ($t = 2.55, p = .011$). Family coping moderated the relationship between negative beliefs and blood glucose monitoring ($t = 3.44, p = .006$). Positive ($t = -2.32, p = .020$) and negative ($t = -2.77, p = .010$) partner support moderated the relationship with negative beliefs and diet. Family stress moderated the relationship between negative beliefs about medicine and	IV: + EV: +

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
							medication adherence ($t = -4.10, p \leq .001$).	
Pereira <i>et al</i> (2014)³⁶	To analyse the moderating role of partner's support and satisfaction with healthcare services in the relationship between psychological morbidity and adherence to diet	N=387 patients and their partners Portugal	Diagnosis: T2DM Age: 59 (patient mean) Gender: 58% male (patients) Diabetes duration: 59.8% <6months, 40.2% 7-12months	Design: CS Method: Individual surveys completed by patients and their partners when attending regular medical appointments	SR; RSDSCA (general diet subscale only)	Frequency of partner supportive behaviours (MDQ) Patient satisfaction with healthcare services (QUASU)	Partner's positive support ($\beta = 0.13, p = .009$) and satisfaction with interpersonal relationships ($\beta = 0.18, p = .020$) predicted adherence. Positive ($\beta = 0.14, p = .006$) and negative support ($\beta = 0.15, p = .003$), satisfaction with healthcare services ($\beta = 0.11, p = .040$), and patient satisfaction with interpersonal relationships ($\beta = 0.11, p = .036$) moderate the relationship between psychological morbidity and adherence to diet.	IV: + EV: +
Pereira <i>et al</i> (2015)⁴²	To analyse the influence of psychological morbidity, family stress towards diabetes, family coping, partner support, and dyadic adjustment in patients and partners on self-care.	N=104 patients and their partners Portugal	Diagnosis: T2DM Age: 59 (patient mean) Gender: 57.7% male (patients) Diabetes duration: up to 12months	Design: CS Method: Individual surveys completed by patients and their partners when attending regular medical appointments	SR; RSDSCA	Family coping (F-COPES) Family stress (FILE) Dyadic adjustment (RDAS) Cognitive and social factors associated with diabetes (MDQ)	Weak correlations were demonstrated between patient rated dyadic adjustment ($r = 0.32, p < .010$), partner rated dyadic adjustment ($r = 0.21, p < .050$), patients with more positive support ($r = 0.22, p < .050$), patients ($r = -0.25, p < .010$); $r = -0.27, p < .010$) and partners ($r = -0.22, p < .050$; $r = -0.27, p < .010$) with less anxiety and depression (respectively) and adherence to diet. Weak positive correlations were found between patient family stress ($r = 0.24, p < .050$) and family coping ($r = 0.19, p < .05$) and adherence to exercise. Weak correlations were found between patient positive support ($r = 0.27, p < .010$),	IV: + EV: +

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
							partner positive ($r=0.24, p <.05$) and negative ($r=0.23, p <.05$) support and glucose monitoring.	
Pereira et al (2016)⁴³	To analyse partners' representations of diabetes as a mediator between patients illness representations and self-care	N=340 patients and their partners Portugal	Diagnosis: T2DM Age: 59.41 (patient mean) Gender: 40% female (patient) Diabetes duration: 60.8% <6 months; 39.2% 7-12 months	Design: CS Method: Individual surveys completed by patients and their partners when attending regular medical appointments	SR; SDSCA SR; MARS	Marital status Quality of marital relationship Partner support Partner's illness perceptions (IPQ)	Partner's representation of diabetes consequences mediated relationship between patient representations and exercise ($\beta = -0.05, p = .047$), foot care ($\beta = 0.09, p = .005$) and Self-Monitoring Blood Glucose (SMBG) ($\beta = 0.06, p = .023$) adherence. Partner's representation of personal control mediated relationship between patient's representation and SMBG ($\beta = 0.05, p = .004$). Partner's treatment control representations mediated relationship between patient representation and SMBG ($\beta = 0.10, p = .003$)	IV: + EV: +
Pirdaghan et al (2016)³⁵	To determine factors influencing the medication adherence and dietary regimen	N=300 Iran	Diagnosis: T2DM Age: 55.84-59.42 Gender: 29.7 – 70.3% female Diabetes duration: 7.07-9.78 years (all values are means across patients grouped as per adherence score)	Design: CS Method: Interviewed using questionnaire in three sections: 1) Social-demographic, 2) Medication adherence, 3) Disease and medication beliefs. Additional questions assessed familial support and access to medication	SR; MMAS	Marital status Familial support Family disease related advice	Being married is related to better adherence ($p = .007$) (compared to being single or divorced). Poor familial support ($p = .001$) and family disease related advice ($p = .001$) were significantly related to poor adherence.	IV: + EV: +

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
Schiøtz et al (2012) ⁴⁴	To investigate the relationship between structural and functional social support, psychosocial problems and self-care.	N=2572 Denmark	Diagnosis: T2DM Age: 60.5 (mean) Gender: 34% female Diabetes duration: 10 years (mean)	Design: CS Method: Survey administered predominantly online, but hard copies also available for those recruited through the clinic	SR; RSDSCA	Care received by patients (PACIC) Social network; structural and functional aspects (measured using validated questions from Danish population health-profile studies)	Frequent contact with friends was associated with better self-management. Ps who met with friends less reported fewer days of exercise ($p < .001$) and had not examined their feet ($p = .023$). Living with a partner was associated with 7% less chance of smoking ($p = .033$). Poor functional social network was associated eating less well ($p < .001$) and low frequency foot examinations ($p = .034$). No relationship between seeing family frequently and self-management.	IV: + EV: ++
Searle et al (2007) ⁴⁵	1. To assess the illness representations of patients and their partners 2. To determine the extent of agreement between patient and partner representations, and 3. To examine whether partners' representations mediate the relationships between patients' representations and self-care.	N=134 dyads UK	Diagnosis: T2DM Age: 67 (patient mean) Gender: 59% male (patient) Diabetes duration: 8.8 years (mean)	Design: L Method: Questionnaires sent to dyads. Patients and partners completed questionnaire separately. Data on illness representations collected at baseline and data on self-care collected at 12month follow up	SR; The Health Education Authority food intake questionnaire SR; Baecke Habitual Physical Activity Questionnaire SR; MARS	Illness representations of patients and partners (IPQ-R). Some items replaced with items from the Personal Models of Diabetes Interview (PMDI) in order to make it diabetes specific.	There was a weak positive correlation between patient and partners' timeline representations ($r = 0.31, p < .010$) and they were both weakly correlated to physical activity ($r = 0.24, p < .010$) and dietary intake of fruit ($r = 0.23, p < .010$), vegetables ($r = 0.30, p < .010$) and fibre ($r = 0.27, p < .010$). There was a weak positive correlation between patient and partners' personal control representations ($r = 0.37, p < .010$) and each was weakly correlated to physical activity ($r = 0.26, p < .010$). There was a weak-moderate positive correlation between patient and partners' representations of treatment control ($r = 0.40, p < .010$) and each was	IV: + EV: +

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
							weakly correlated with physical activity ($r = 0.27, p < .010$; $r = 0.21, p < .010$ respectively). Partners' timeline mediated the influence of patient timeline on diet and engaging in physical activity ($\beta = 0.01, p = .033$) and dietary intake of fruit and vegetables ($\beta = 0.01, p = .004$) and fibre ($\beta = 0.01, p = .004$). Partners personal control representation mediated the influence of patients personal control on physical activity ($\beta = 0.01, p = .004$).	
Shahar et al (2016) ³⁷	To determine the association between self-motivation, social support and dietary compliance and glycaemic control	N=35 Malaysia	Diagnosis: T2DM Age: 56.37 (mean) Gender: 65.7% female Diabetes duration: NR	Design: CS Method: Patients completed questionnaire measuring key variables	SR; SDSCA SR; Diet recall A1C	Social support (DSSQ-FV)	A moderate positive correlation was found between family support and dietary compliance ($r = 0.46, p = .005$). The correlation between family support and glycaemic control was not significant ($r = -0.11, p = .543$).	IV: - EV: -
Shao et al (2017) ⁴⁶	To examine whether the effects of social support on glycaemic control are mediated sequentially by self-efficacy and adherence	N=532 China	Diagnosis: T2DM Age: 63 (mean) Gender: 41.9-42.2% male Diabetes duration: NR	Design: CS Method: Patients completed questionnaires measuring social support, self-efficacy and adherence. Medical records were also reviewed	SR; Idiosyncratic measure developed according to the treatment principle of diabetes and previous work A1C	Social support (SSRS)	There was a significant but weak correlation between overall social support and dietary adherence ($r = 0.16, p < .010$), but not medication or lifestyle. Better social support is linked to better self-efficacy ($\beta = 0.27, p < .010$) which in turn is linked to better dietary adherence ($\beta = 0.10, p < .050$), which is related to better glycaemic control ($\beta = -0.19, p < .050$).	IV: + EV: +

First author (year)	Aims	Sample size and location	Sample characteristics	Methodology	Measure of self-care	Relevant variables measured	Main findings	Quality score
Tiv et al (2012)⁴⁷	To evaluate self-reported medication adherence and to identify factors linked to poor adherence	N=3637 France	Diagnosis: T2DM Age: 65 (mean) Gender: 58.7% male Diabetes duration: NR	Design: CS Method: Survey sent to all patients measuring medication adherence, demographics, and disease and therapy characteristics. Medical questionnaire sent to providers to obtain most recent clinical measurements.	SR; Idiosyncratic six item questionnaire drawing on work by Girerd et al.	Marital status Medical care (decision making, follow-ups, acceptability of medical recommendations, ability to take medicine alone, need for support)	The following factors were associated with poor adherence: Decision making by patient only (Odds ratio = 3.3, $p < .001$), poor acceptability of medical recommendations (Odds ratio = 2.7, $p = .004$), lack of family or social support (Odds ratio = 2.5, $p < .001$), need for information on treatment (Odds ratio = 2.0, $p < .001$), need for medical support (Odds ratio = 1.6, $p = .002$), and follow-up by specialist physician (Odds ratio = 1.4, $p = .005$).	IV: + EV: ++

CS: Cross-sectional; L: Longitudinal

SR: Self-Report; OR: Other Report

MMAS: Morisky Medication Adherence Scale; RSDSCA: Revised Summary of Diabetes Self Care Activities; OAD; Oral Anti-Diabetic Medication; MPR: Medication Possession Ratio; DSAS: Diabetes Specific Adherence Scale; MARS; Medication Adherence Report Scale

MDQ: Multidimensional Diabetes Questionnaire; COCI: Continuity of Care Index; F-COPES: Family Crisis Oriented Personal Evaluation Scale; FILE: Family Inventory of Life Events; RDAS: ; Revised Dyadic Adjustment Scale; QUASU: The Patient Satisfaction Questionnaire; IPQ-R: Revised Illness Perception Questionnaire; PACIC: Patient Assessment of Chronic Illness Care; PMDI: Personal Models of Diabetes Interview; DSSQ-FV: Diabetes Social Support Questionnaire-Family Version; SSRS: Social Support Rating Scale

Discussion

This review aimed to explore and summarise the healthcare system factors that are related to self-care in individuals with T2DM. The factors identified in the studies reviewed fell into two broad categories; 1) personal healthcare system factors, and 2) professional healthcare system factors. In accordance with the WHO's definition of a healthcare system, the findings support the notion that an individual's family and friends as well as their healthcare professionals and provision of services have a role to play in their engagement with vital self-care activities.¹⁵ Fifteen of the nineteen studies included in the current sample reported findings that were categorised as personal healthcare system factors. This demonstrates the saliency of such factors, suggesting that in this research field, characteristics of the personal system are being considered as central to effective self-care. However, the relationships demonstrated between partner factors, such as support, adjustment, and illness representations, as well as family support, were generally quite weak, or at best moderate. Furthermore, the studies that fell into this category included those with the poorest methodological quality, meaning that drawing implications should be done so with considerable caution. The evidence for the role of professional healthcare system factors, such as the patient-provider relationship and continuity of care, is not immune to these issues, however was, on the whole characterised by better methodological rigour, greater consistency across studies as well as stronger and clearer relationships to self-care. On balance, this suggests that both personal and professional factors are important, but that at the present time, the empirical evidence supports placing greater emphasis on the evidence for the role of professional healthcare system factors when developing implications for clinical practice and education.

At the professional healthcare system level, the association between the quality of the relationship between the patient and provider and self-care supports the findings of another recent review where, much like the current review, shared decision making and trust were highlighted as key to a high quality relationship.⁴⁸ The authors suggest such qualities enable providers to understand the adherence problems patients are facing. It may be theorised that greater continuity of care plays into this, by creating a setting in which a more effective working relationship between the patient and provider can be fostered. The evidence for the role of continuity of care was amongst the strongest evidence in the studies reviewed, however was only investigated in relation to adherence to medication. Future research exploring the effect of continuity of care on other self-care behaviours may be informative. It is also important to recognise however, that good objective quality of care seems not to be sufficient, as patient satisfaction with care received was also demonstrated to be positively related to self-care. In some cases, patient satisfaction moderated the relationship between other characteristics of the individual (e.g. psychological morbidity) and self-care outcomes, bringing to light a complex interplay between personal characteristics and systemic factors.

At the personal healthcare system level, the findings that being in a relationship where the partner shares similar illness representations, who provides support in relation to engagement with self-care, and where there is successful dyadic adjustment to the diagnosis is positively correlated with effective self-care is consistent with previous research.⁴⁹ These relationships were, in some cases, moderated by factors such as intention to self-care, psychological morbidity,

and beliefs about medication, again demonstrating the complex interplay between personal characteristics and systemic factors. Future research may benefit from more in depth, qualitative exploration of these relationships to understand further the mechanisms by which they function. The finding that support from family is related to self-care is consistent with recommendations made by previous researchers for the involvement of family as an intervention for ineffective self-care in the field of chronic health.⁵⁰ Qualitative research in the field helps to dissect this relationship by demonstrating that the support provided by family members has an important role in reminding patients about necessary self-care and aiding in food preparation.⁵¹ Furthermore, the review highlighted the positive effect of increased social support on a wider level, highlighting the role of friends and peers as well as family. Chlebowy suggested that friends and peers, alongside family and health care professionals can improve engagement with self-care, as all sources have the potential to provide cues to action and direct assistance with necessary behaviours and changes, as well as providing knowledge and reinforcement.⁵² For example, where professionals are able to provide the patient with expert knowledge, a peer may take an exercise class with them and a family member may help encourage healthy eating at a gathering.

Overall, the findings of the review are consistent with findings of other recent reviews which have demonstrated the role of factors across both personal and professional relationships on engagement with self-care.⁵³ However, where previous reviews have touched upon specific factors in relation to both personal and professional systems, this is the first review to provide a broad and inclusive summary of systemic factors associated with self-care. In doing so, it

is able to collate up to date evidence regarding the healthcare system, under the broadest of definitions, and how it relates to self-care in those living with T2DM. This assists in developing current understandings of the complex factors influencing how well someone is able to manage their condition. In taking a broader approach, this review can provide more holistic and inclusive implications for diabetes care and education.

Overall assessment of the strength of the review

Within the literature reviewed, there are several limitations in regard to the methodology and quality of reporting. Firstly, the use of 'self-care' as an outcome measure raises potential issues. Across the literature base, there is not one single agreed definition of what 'self-care' is, nor what is involved in it. Self-care, therefore, appears to be a complex umbrella term, under which a variety of behaviours may or may not be included. Secondly, reliance on self-report for measuring outcomes was one of the most common concerns with the potential for inaccurate answering and social desirability bias, especially in a condition that is becoming increasingly stigmatised.⁵⁴ Further issues in regard to the validity of self-report data were highlighted in two studies where they found that, whilst factors were linked to self-reported self-care, they were not linked to glycaemic control.^{37, 39} This highlights discrepancies between subjective and objective outcomes and potentially raises a wider issue in regard to how current research is measuring self-care. Thirdly, where studies set out to determine the influence of a specific factor on self-care, the majority utilised correlational analyses, which do not allow for causal attributions to be drawn. For example, it is feasible that the link demonstrated between the patient-provider relationship and self-care may be attributed to the idea that those with poorer self-care are

less likely to foster positive relationships with their physicians.⁵⁵ Future research would benefit from more randomised controlled trials to establish direction of causality. Lastly, other common concerns centred on the lack of reporting of sample size calculations estimating the required number of participants needed to effectively explore hypotheses and lack of consideration for potentially confounding variables when examining relationships between healthcare system factors and outcomes. Previous research has highlighted individual factors that significantly influence engagement with self-care, such as age, diabetes duration and personality type,⁵⁶⁻⁵⁷ and the current review draws attention to the complex interplay between such factors and systemic influences. Therefore, studies that failed to take into account the influence of such factors may be reporting biased findings, overinflating the role of their factor of interest. It seems important to note, the common concerns highlighted in this review are similar to those raised in previous reviews in the field of chronic health,⁵⁸⁻⁵⁹ highlighting the potential need for revision of approaches currently used to conduct research in this area.

Limitations of the review

The current review is subject to some limitations. Whilst the aim of this review was to provide an up-to-date systematic examination of the literature, this review is only as up-to-date as is possible in the given time frame. This is a particular issue in an area of research, like T2DM, which is rapidly developing with new publications as a result of the marked increases in diagnoses.

Furthermore the current review excluded qualitative research and therefore did not benefit from the more in depth understanding of concepts that this kind of research can provide. The decision to exclude intervention studies meant that

the majority of included studies were correlational in nature and therefore it has been difficult to draw any causal implications from the data. Finally, the decision to eliminate studies based upon the type of healthcare system in the country of authorship does create issues for generalisability. Given that the studies included were conducted in countries which provide free and universal healthcare, such as the UK, extrapolation of the findings to other types of healthcare system must be done with caution. It is also important to recognise that, whilst included countries shared healthcare system similarities, the countries will vary considerably in terms of culture in ways that may impact the generalisability of the findings. For example, western and individualistic cultures, such as that in the UK, may place more demand on professional services for the provision of healthcare, whilst eastern and collectivist cultures may place more emphasis on the role of the family and the community for caring for those with ill-health.

Implications for diabetes care and education

Overall, this review supports the key ideas of System's theory; that an individual exists within a complex system and their behaviour is influenced by their relationships with the system. Brunton and Polonsky highlighted that this may be complicated in individuals with T2DM due to barriers to effective self-care varying from person to person, and fluctuating over time and over the course of the condition.⁴⁸ Therefore, assessment of those who are 'at risk' of poor adherence needs to be based on a combination of individual characteristics, in addition to the interactions the individual is having with their healthcare system, both personal and professional. WHO state that there is a need to focus on increasing the effectiveness of adherence interventions, and that this will be

more effective than improvements in specific medical treatments in chronic health conditions.⁶⁰ Based on the findings of the current review, interventions for poor adherence targeting the individual alone may not be effective. Rather, it may be imperative to work more systemically, directing interventions at the healthcare system.

Given the strength of findings regarding the role of factors within the professional healthcare system, it may be beneficial to target interventions at this level. The review supports the notion, as highlighted in focus group findings, that developing a patient-provider relationship where care planning is collaborative and there is continuity of care allows for the development of a trusting relationship where adherence is seen as a shared responsibility.⁶¹ Lawn and Schoo highlighted that an approach aiming to improve assessment and communication between care providers and patients, and enhancing physician-patient relationships by training professionals in specific skills, such as empathy, trust, effective exchange of information and compassion may be beneficial.⁶²⁻⁶⁴ Current policy in the UK appears to be heading in the right direction, outlining the need for personalised care and emphasizing the importance of a good relationship with a physician who provides a high level of education and information.³ Additionally, the NHS in the UK outlines that primary care teams working with individuals with T2DM should aim to provide a multi-disciplinary approach and the current review highlights in particular the potential role of the pharmacist in recognising adherence problems and providing education and counselling.⁶⁵ However, it is recognised that there are caveats to the implementation of such findings in the UK, with an NHS under

increasing demand and strain. Future research will need to take this into consideration when designing interventions.

Despite weaker evidence for the role of personal healthcare system factors, there are nonetheless clinical implications worth consideration. Lawn and Schoo highlighted approaches to supporting effective self-management including group programmes emphasising peer support.⁶² In the 'Action for Diabetes' initiative,³ everyone diagnosed with diabetes in the UK is offered an educational course and the findings of this review suggest that it may be beneficial to invite family and peers to this, as well as to assessments and appointments, given their role in the promotion of self-care. In cases where there are particular problems with self-care, it may be helpful to include families in care plans or to consider couple or family therapy as a way to understand and challenge current behaviour.⁶⁴ In their meta-analysis, Martire et al found that, in some cases, involving a family member in chronic health interventions had a positive impact on mortality.⁵⁰ Family interventions for poor self-care in T2DM may, therefore, be a valuable focus for future research as well as clinical practice.

Conclusion

This review provides a summary of the research into the relationship between healthcare system factors on engagement with self-care behaviours in those with T2DM. The conclusions of the review are based upon and therefore applicable to free and universal healthcare systems, such as that in the UK. There is room for improved clarity in regards to what is meant by 'self-care,' what it entails and how best to conduct and report associated research. Nonetheless, the current review demonstrated that engagement with self-care

in T2DM is influenced by a number of complex factors within the healthcare system, at both personal and professional levels; from the type of support provided by the patient's partner, to the characteristics and continuity of services provided by healthcare professionals. This is an important finding for a number of reasons, but mostly because it can influence policy recommendations as to how services for individuals with T2DM should be structured and delivered. It can also guide future research towards thinking in more depth about how the systemic factors highlighted in the current review exert their influence on individuals, and in designing interventions aiming to improve self-care in those living with the condition. Improving healthcare provision for those living with T2DM, and finding effective interventions for those with self-management difficulties will not only improve public health, but will also reduce the financial strain of the condition on already struggling healthcare systems.

References

References marked with a * are included in the review

1. Diabetes UK. *What is Type 2 diabetes?* London, England; 2017.
<https://www.diabetes.org.uk/diabetes-the-basics/what-is-type-2-diabetes>.
Accessed March, 2018.
2. NHS Choices. *Type 2 diabetes*. UK; 2017.
<https://www.nhs.uk/conditions/type-2-diabetes/>. Accessed March, 2018
3. NHS England. *Action for diabetes*. London: NHS England; 2014.
4. Speight J, Conn J, Dunning T, & Skinner TC. Diabetes Australia position statement. A new language for diabetes: improving communications with and about people with diabetes. *Diabetes Res Clin Pract*. 2012;97(3):425-431.
5. Lipson JG, & Steiger NJ. *Self-care nursing in a multicultural context*. Thousand Oaks, CA: Sage; 1996
6. García-Pérez LE, Álvarez M, Dilla T, Gil-Guillén V, & Orozco-Beltrán D. Adherence to therapies in patients with type 2 diabetes. *Diabetes Ther*. 2013;4(2):175-194.
7. Hex N, Bartlett C, Wright D, Taylor M, & Varley D. Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. *Diabet Med*. 2012;29(7):855-862.
8. Krass I, Schieback P & Dhippayom T. Adherence to diabetes medication: a systematic review. *Diabet Med*. 2015;32(6): 725-737.
9. Nam S, Chesla C, Stotts NA, Kroon L, & Janson SL. Barriers to diabetes

- management: patient and provider factors. *Diabetes Res Clin Pract.* 2011;93(1):1-9.
10. Wilkinson A, Whitehead L, & Ritchie L. Factors influencing the ability to self-manage diabetes for adults living with type 1 or 2 diabetes. *Int J Nurs Stud.* 2014;51(1): 111-122.
11. Korhonen EE, Alahuhta MA, & Laitinen JH. Barriers to regular exercise among adults at high risk or diagnosed with type 2 diabetes: a systematic review. *Health Promot Int.* 2009;24(4):416-427.
12. National Institute of Health and Care Excellence. *Type 2 diabetes in adults: management*; 2018
13. Bateson G. *Steps to an ecology of mind: Collected essays in anthropology, psychiatry, evolution, and epistemology.* USA: University of Chicago Press; 1972.
14. Halali F, Mahdavi R, Mobasser M, Jafarabadi MA, & Avval SK. Perceived barriers to recommended dietary adherence in patients with type 2 diabetes in Iran. *Eat Behav.* 2016;21:205-210.
15. World Health Organization. *The world health report 2000: health systems: improving performance.* World Health Organization; 2000.
16. Dallos R, & Draper R. *An Introduction to Family Therapy* Maidenhead: Open University Press; 2005
17. Polonsky WH, & Henry RR. Poor medication adherence in type 2 diabetes: recognizing the scope of the problem and its key contributors. *Patient Prefer Adherence.* 2016;10:1299-1307.

18. Steyl T, & Phillips J. Management of type 2 diabetes mellitus: Adherence challenges in environments of low socio-economic status. *Afr J Prim Health Care Fam Med.* 2014;6(1):1-7.
19. Song Y, Nam S, Park S, Shin IS, & Ku BJ. The Impact of Social Support on Self-care of Patients With Diabetes: What Is the Effect of Diabetes Type? Systematic Review and Meta-analysis. *Diabetes Educ.* 2017;43(4): 396-412.
20. World Health Organization. *Global report on diabetes.* World Health Organization; 2016.
21. Curkendall SM, Thomas N, Bell KF, Juneau PL, & Weiss AJ. Predictors of medication adherence in patients with type 2 diabetes mellitus. *Curr Med Res Opin.* 2013;29(10):1275-1286.
22. Sontakke S, Jadhav M, Pimpalkhute S, Jaiswal K, & Bajait C. Evaluation of adherence to therapy in patients of type 2 diabetes mellitus. *J Young Pharm.* 2015;7(4):462-469.
23. Huang X, Lin J, & Demner-Fushman D. Evaluation of PICO as a knowledge representation for clinical questions. *MIA annual symposium proceedings.* 2006;359-363.
24. National Institute of Health and Care Excellence. *Methods for the development of NICE public health guidance (third edition).* National Institute for Health and Care Excellence; 2012.
25. Jackson R, Ameratunga S, Broad J, et al. The GATE frame: critical appraisal with pictures. *ACP journal club.* 2006;144(2):A8-A8.
26. Popay J, Roberts H, Sowden A, et al. *Guidance on the conduct of*

narrative synthesis in systematic reviews. A product from the ESRC methods programme. Vol 12006.

27. Moher D, Liberati A, Tetzlaff J, Altman DG, & Prisma Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*. 2009; 6(7): e1000097.
28. American Diabetes Association. Diagnosis and classification of diabetes mellitus. *Diabetes care*. 2010; 33(Suppl 1): S62.
29. *Barba EL, de Miguel MR, Hernández-Mijares A, et al. Medication adherence and persistence in type 2 diabetes mellitus: perspectives of patients, physicians and pharmacists on the Spanish health care system. *Patient Prefer Adherence*. 2017;11:707-718
30. *Chew BH, Hassan NH, & Sherina MS. Determinants of medication adherence among adults with type 2 diabetes mellitus in three Malaysian public health clinics: a cross-sectional study. *Patient Prefer Adherence*. 2015;9:639-648
31. *Dossa AR, Grégoire JP, Lauzier S, Guenette L, Sirois C, & Moisan J. Association between loyalty to community pharmacy and medication persistence and compliance, and the use of guidelines-recommended drugs in type 2 diabetes: a cohort study. *Medicine*. 2015;94(27):1-8.
32. *Dossa AR, Moisan J, Guénette L, Lauzier S, & Grégoire JP. Association between interpersonal continuity of care and medication adherence in type 2 diabetes: an observational cohort study. *CMAJ open*. 2017;5(2):359-364

33. *Hong JS, & Kang HC. Relationship between continuity of ambulatory care and medication adherence in adult patients with type 2 diabetes in Korea: a longitudinal analysis. *Med care*. 2014;52(5):446-453.
34. *Kasznicki J, Głowacka A, & Drzewoski J. Type 2 diabetic patients compliance with drug therapy and glycaemic control. *Diabetologia Doświadczalna i Kliniczna*. 2007;7(4):199-198.
35. *Pirdehghan A, & Poortalebi N. Predictors of Adherence to Type2 Diabetes Medication. *J Res Health Sci*. 2016;16(2):72-75.
36. *Pereira MG, Ferreira G, & Machado JC. Spousal Support and Satisfaction with Healthcare Services as Moderators between Psychological Morbidity and Adherence to Diet in Type 2 Diabetes Patients. *Health Behav Policy Rev*. 2014;1(4):278-289.
37. *Shahar S, Fakhruddin N, Hui KJ, et al. Family support and self-motivation influence dietary compliance and glycaemic control among type 2 diabetes mellitus outpatients. *Malays J Health Sci*. 2016;14(2):39-47.
38. *Costa V, Pereira MG, & Pedras S. Partner support, social-cognitive variables and their role in adherence to self-monitoring of blood glucose in type 2 diabetes. *European Diabetes Nursing*. 2012;9(3):81-86.
39. *Lee YY, & Lin JL. The effects of trust in physician on self-efficacy, adherence and diabetes outcomes. *Soc Sci Med*. 2009;68(6):1060-1068.
40. *Moreau A, Aroles V, Souweine G, et al. Patient versus general practitioner perception of problems with treatment adherence in type 2

diabetes: from adherence to concordance. *European J Gen Pract.* 2009;15(3):147-153.

41. *Pereira MG, Pedras S, & Machado JC. Family variables as moderators between beliefs towards medicines and adherence to self-care behaviors and medication in type 2 diabetes. *Fam Syst Health.* 2014;32(2):198-206.
42. *Pereira MG, Costa, V, Oliveira D, et al. Patients' and spouses' contribution toward adherence to self-care behaviors in type 2 diabetes. *Res Theory Nurs Pract.* 2015;29(4):276-296.
43. *Pereira MG, Pedras S, Machado JC, & Ferreira G. Partners' representations of diabetes as mediators between patients' representations and adherence to self-care behaviors, in type 2 diabetes. *Psychol Health Med.* 2016;21(6):707-714.
44. *Schjøtz ML, Bøgelund M, Almdal T, Jensen BB, & Willaing I. Social support and self-management behaviour among patients with Type 2 diabetes. *Diabetic Med.* 2012;29(5):654-661.
45. *Searle A, Norman P, Thompson R, & Vedhara K. Illness representations among patients with type 2 diabetes and their partners: relationships with self-management behaviors. *J Psychosom Res.* 2007;63(2):175-184.
46. *Shao Y, Liang L, Shi L, Wan C, & Yu S. The Effect of Social Support on Glycemic Control in Patients with Type 2 Diabetes Mellitus: The Mediating Roles of Self-Efficacy and Adherence. *J Diabetes Res.* 2017;2017:1-8.

47. *Tiv M, Viel JF, Mauny F, et al. A. Medication adherence in type 2 diabetes: the ENTRED study 2007, a French Population-Based Study. *PLoS One*. 2012;7(3):e32412.
48. Brunton SA, & Polonsky WH. Medication adherence in type 2 diabetes mellitus: real-world strategies for addressing a common problem. *J Fam Pract*. 2017;66(4):S46-S46.
49. Finley MA. Spousal pressure and persuasion and diet adherence in patients with type 2 diabetes: The role of patients' self-efficacy. *Doctoral dissertation, Purdue University*. 2014.
50. Martire LM, Lustig AP, Schulz R, Miller GE, & Helgeson VS. Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychol*. 2004;23(6):599-611.
51. Song M, Lee M, & Shim B. Barriers to and facilitators of self-management adherence in Korean older adults with type 2 diabetes. *Int J Older People Nurs*. 2010;5(3):211-218.
52. Chlebowy D, Hood S, & LaJoie AS. Facilitators and barriers to self-management of type 2 diabetes among urban African American adults. *Diabetes Educ*. 2010;36(6):897-905.
53. Song Y, Nam S, Park S, Shin IS, & Ku BJ. The Impact of Social Support on Self-care of Patients With Diabetes: What Is the Effect of Diabetes Type? Systematic Review and Meta-analysis. *Diabetes Educ*. 2017;43(4):396-412.
54. Schabert J, Browne JL, Mosely K, & Speight J. Social stigma in diabetes. *The Patient-Patient-Cent Outcomes Res*. 2013;6(1):1-10.

55. Thorne SE, & Robinson CA. Guarded alliance: health care relationships in chronic illness. *J Nurs Scholarsh.* 1989;21(3):153-157.
56. Guénette L, Breton MC, Guillaumie L, Lauzier S, Grégoire JP, & Moisan J. Psychosocial factors associated with adherence to non-insulin antidiabetes treatments. *J Diabetes Complications.* 2016;30(2):335-342.
57. Li X, Zhang S, Xu H, et al. Type D personality predicts poor medication adherence in Chinese patients with type 2 diabetes mellitus: a six-month follow-up study. *PloS one.* 2016;11(2):1-16.
58. Gallant MP. The influence of social support on chronic illness self-management: a review and directions for research. *Health Educ Behav.* 2003;30(2): 170-195.
59. Warsi A, Wang PS, LaValley MP, Avorn J, & Solomon DH. Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. *Arch Intern Med.* 2004;164(15):1641-1649
60. World Health Organization. *The world health report 2003: shaping the future.* World Health Organization; 2003.
61. Vermeire E, Van Royen P, Coenen S, Wens J, & Denekens J. The adherence of type 2 diabetes patients to their therapeutic regimens: a qualitative study from the patient's perspective. *Practical Diabetes.* 2003;20(6):209-214.
62. Lawn S, & Schoo A. Supporting self-management of chronic health conditions: common approaches. *Patient Educ Couns.* 2010;80(2): 205-211.

63. Khawaja MS. The mediating role of positive and negative emotional attractors between psychosocial correlates of doctor-patient relationship and treatment adherence in type 2 diabetes. *Case Western Reserve University*. 2011.
64. Jeragh-Alhaddad FB, Waheedi M, Barber ND, & Brock TP. Barriers to medication taking among Kuwaiti patients with type 2 diabetes: a qualitative study. *Patient Prefer Adherence*. 2015;9:1491-1503.
65. Vivian E. The Pharmacist's Role in Maintaining Adherence to Insulin Therapy in Type 2 Diabetes Mellitus Clinical Review. *Consult Pharm®* 2007;22(4):320-332.

Part Two
Empirical Paper

Exploring shame and self-care in Type 2 Diabetes and the moderating effect of compassion

Cara Jane Childs^{a*}, Philip Molyneux^a and Tim Alexander^a

^aSchool of Health and Social Work, University of Hull, Cottingham Road, Hull,
United Kingdom, HU6 7RX

* Corresponding Author. Email address: C.Childs@2015.hull.ac.uk

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Abstract

Aims: This study aimed to explore the role of shame and compassion in influencing self-care in individuals with Type 2 Diabetes. It was hypothesised that shame would have a negative impact on self-care, and that compassion would moderate this relationship.

Methods: This study involved an international sample of adults with T2DM (n=166; 63.3% female; age 60.3 ±11.10years). Participants completed an online survey assessing self-care, and levels of shame and compassion. An open-ended question collected qualitative data regarding experiences of shame. Moderation effects were tested using multivariate hierarchical regression and qualitative data was analysed using content analysis.

Results: The negative relationship found between shame and self-care was not significant ($p=.075$). No significant moderation effects were found, therefore hypotheses were not supported. However, a significant direct relationship between self-compassion and self-care was shown ($p=.002$). Qualitative data revealed experiences of shame in 53% of respondents and themes around the sources of and attempts to avoid shame emerged.

Conclusions: Whilst the results failed to support the hypotheses, interesting findings on experiences of shame and the potential benefits of self-compassion were displayed, complementing previous research. The implications for future research, intervention and service delivery were highlighted.

Key words: Type 2 diabetes, self-care, shame, compassion

1. Introduction

Reports suggest that, in the UK, 1 in 16 people are living with Type 2 Diabetes Mellitus (T2DM) and increasing prevalence rates have been described as an 'epidemic' (Wild et al, 2004). It is projected that by 2035 the condition will cost the National Health Service (NHS) in the UK £35.6billion per year (Hex et al. 2012). Given the association between T2DM, lifestyle, obesity, and the so-called 'financial burden' of the condition, it is becoming increasingly stigmatised (Schabert et al, 2013). Sixty percent of those with the condition report that they have experienced health-related stigma from the media, healthcare professionals, family and friends. As a result, feelings of shame are becoming salient (Browne et al, 2013).

Attempts to define shame suggest it is "a major, self-conscious emotion that impacts on people's sense of self, well-being and vulnerability to psychopathology" (Matos et al, 2015, p. 6). Evolutionary perspectives suggest that shame is an adaptation designed to protect an individual against the threat of being socially devalued. Paul Gilbert (2003) breaks down the concept of shame into 'external' and 'internal' shame. External shame relates to feelings of shame that arise due to how an individual believes they are perceived by others and by the direct shaming of the self by others, whilst internal shame is related to the judgements one makes about the self. This perspective on shame has been previously applied to the field of chronic health; Else-Quest et al (2009) found that internalised judgements predicted adjustment in patients with cancer. They demonstrated that those who attributed the cause of their disease to themselves had greater difficulty adjusting to the diagnosis, and this effect was

strongest in those with lung cancer, due to societal stigma around the association with lifestyle.

Experiences of shame in those with T2DM are potentially problematic, as shame is thought to interfere with effective self-management of the condition. Ninety-nine percent of T2DM management occurs via essential self-care activities (Speight et al, 2012) aimed at regulating blood glucose levels and avoiding complications. Self-care recommendations generally include lifestyle changes, such as a specific diet, exercise, and blood glucose monitoring, as well as adherence to pharmacological interventions; oral hypoglycaemic agents and/or insulin injections. Despite the vital importance of self-care, literature suggests that engagement with recommendations is poor, with rates averaging around 50% (García-Pérez et al, 2013). Research suggests that the way in which individuals with T2DM are talked about in society can define not only their view of themselves, but also their long term health outcomes (Speight et al, 2012) and that shame may be a direct barrier to effective self-care (Scollan-Kolipoulos et al, 2007). Shame is thought to result in reluctance to engage in self-care behaviour in public, such as refusal of certain foods and injecting insulin (Wellard et al, 2008). Shame can discourage individuals from sharing their diagnosis openly with others (Schabert et al, 2013), despite social support being beneficial in promoting effective self-care (Larkin et al, 2015). Lastly, shame is associated with distress and psychopathology (Matos & Pinto-Gouveia, 2010), which are often linked to poor self-care (Rubin et al, 2005).

In line with his evolutionary perspectives on shame, Gilbert theorised that humans are able to utilise altruistic motives to combat feelings of shame; this is

the notion of compassion. As a psychological concept, compassion has been defined as “being open to the suffering of self and others [and] ... a desire to relieve suffering” (Gilbert, 2005, pg. 1). It is regarded as beneficial for both mental and physical health in the face of difficult life events by encouraging individuals to view suffering as a common human experience that should be responded to with empathy. Gilbert theorises that treating the self and being treated by others in a compassionate way enables individuals to foster more positive attitudes towards the self, leading to reductions in the negative impact associated with shame. A recent review supported this notion (Leaviss & Uttley, 2015). However, Gilbert and colleagues (2011) observed that for those who are particularly high in shame, such as those diagnosed with ‘lifestyle conditions,’ there may be difficulty in making use of compassion they receive; this is termed ‘fear of compassion.’

Based on the literature reviewed, the current study aimed to address the following research questions; does the shame experienced by individuals with T2DM relate to their engagement with self-care? And, does engagement with compassion have a moderating effect on the way in which shame interacts with self-care? In line with these, the following hypotheses were made; 1) There will be a significant negative relationship between shame and self-care; 2) Compassion will have a significant moderating effect on the relationship between shame and self-care, and; 3) the moderating effect of compassion will be moderated by level of fear of compassion. The study additionally aimed to answer a third research question; what are the experiences of shame in relation to self-care activities in those with T2DM?

2. Subjects, Materials and Methods

2.1 Participants and recruitment

Ethical approval was granted through the Faculty of Health and Social work at the University of Hull (see Appendix H). The volunteer sample were recruited online via an advert published on the Diabetes UK website and magazine, via emails circulated to Diabetes UK support groups and staff at the University of Hull and on social media. In order to take part, participants were required to have a diagnosis of T2DM and be over the age of 18. Recruitment continued until the desired sample size was achieved. This was based on the sample size calculations based approximately upon R^2 statistics obtained in similar previous research (Hermanto et al, 2016). A sample size of 167 was recruited in order to achieve 80% power to detect a small effect size f -squared = 0.05 using a 5% significance level. Calculations were performed using G*Power Version 3.1.9.2 (Faul et al, 2009).

2.2 Procedure

The questionnaire was piloted prior to study commencement (see Appendix R for details). Participants accessed the study website via a hyperlink included within the advertisement. The website contained information regarding the study and the link to the questionnaire. When participants accessed the questionnaire they were presented with an information sheet (Appendix J) and consent form (Appendix K). Once the questionnaire was completed, participants were directed to a debrief screen (Appendix L).

2.3 Measures

2.3.1 *Engagement with self-care*

The Summary of Diabetes Self-Care Activities (SDSCA; Toobert, Hampson & Glasgow, 2000; Appendix N) was used to assess self-care. Individuals are asked to rate on an 8-point scale how often over the last seven day period they engaged in self-care activities. Example items include; “How many of the last seven days have you followed a healthful eating plan?” Items cover a variety of activities including diet, exercise, blood-glucose testing, smoking, and foot care. Additional items on medication were included. The SDSCA was used to calculate an overall self-care score, by combining the scores from all items. Scores ranged from 0-78, where 78 represents complete engagement with all self-care recommendations on every day of the given period. This questionnaire has been used widely and is a validated measure of self-care (Mayberry, 2013) that can be generalised in terms of insulin status, sex, comorbidity and illness duration (Toobert, Hampson & Glasgow, 2000). The scale has acceptable internal consistency (Cronbach’s $\alpha = 0.47$) and a moderate test-retest reliability ($r = 0.40$). Accumulated, the subscales are reported to account for 77% of the variance in the data (Aljohani, Kendall & Snider, 2014).

2.3.2 *Shame*

The Other as Shamer Scale (OAS; Goss, Gilbert & Allan, 1994; Appendix O) was used to assess levels of shame. The OAS was originally developed based on the Internalised Shame Scale (ISS; Cook, 1996) and has been shown to correlate highly with it (Goss, Gilbert & Allen, 1994), suggesting the two forms of shame co-exist closely. Due to this, and theory demonstrating greater incidences of external, rather than internal shame, in relation to health (Gilbert,

2003), just the OAS was used. The OAS contains 18 questions in which participants are asked to rate a series of statements on a 5-point scale (ranging from 'never' to 'almost always') in regards to how often they feel that way. Example items include; "I feel other people see me as not good enough." Scores on the OAS can range from 0-72, where a score of 72 represents high levels of shame. The OAS has impressive internal validity (Cronbach's $\alpha = 0.92$) and good convergent validity, showing high correlations with other measures of shame (Goss et al, 1994).

2.3.3 Compassion

The Compassionate Engagement and Action Scales (TCEAS; Gilbert et al, 2016; see Appendix P) aim to measure motivation to engage in and act with compassion. It is made up of three subscales, each of which focusses on a different direction in which compassion flows; compassion to self (e.g. "I am motivated to engage and work with my distress when it arises"), compassion to others (e.g. "I am motivated to engage and work with other people's distress when it arises"), and compassion from others (e.g. "Other people are actively motivated to engage and work with my distress when it arises"). For the purposes of the current study, only the compassion to self and compassion from others subscales were used. Each subscale comprises of eight items reflecting the six attributes of compassion (empathy, sympathy, distress tolerance, non-judgement, sensitivity, care for well-being) and five items relating to compassionate actions. The respondent is asked to rate each statement on a Likert scale according to the frequency with which it occurs (where 1 represents 'never' and 10 represents 'always'). Scores on the TCEAS can range from 10-100, where a score of 100 represents high compassion. Preliminary

assessments supported the psychometric properties of TCEAS with high internal reliability ($\alpha = .83 - .90$) and modest concurrent validity (.28 - .53; Gilbert et al, 2015; cited in Kleissen, 2016).

2.3.4 Responding to compassion

The Fears of Compassion Scale (FOCS; Gilbert et al, 2011; see Appendix Q) was used to assess an individual's response to compassion. It measures an individual's views on the expression of compassion; whether it is important to show kindness and compassion, or whether caution should be taken when expressing compassion, be it with the self or others. It is made up of three subscales; (1) expressing compassion for others, (2) Responding to compassion from others, (3) Expressing compassion towards yourself. In the current research, only the 'responding to compassion from others' subscale was used. This subscale contains 13 statements such as; "I often wonder whether displays of warmth and kindness from others are genuine" which respondents are asked to rate on a Likert scale from 0-4 where 0 represents "don't agree at all" and 4 represents "completely agree." Scores on the FOCS can range from 0-52, where a score of 52 represents high fear of compassion. For the subscale used, a Cronbach's alpha of .80 has been recorded in a student sample (Gilbert et al, 2011).

2.3.5 Covariates

Participants were required to provide information regarding their gender, age (years), and diabetes duration (years since diagnosis; see Appendix M).

2.3.6 Experience of shame

Qualitative data regarding experience of shame in relation to T2DM and self-care was collected via an optional open question at the end of the questionnaire: "Some people with Type 2 Diabetes report experiencing feelings of shame in relation to their condition and to the actions involved in caring for their condition. Please use the space below to express any experience you may have of this."

2.4 Statistical analysis

Prior to analysis, basic data checks were conducted to check for outliers and missing data. Descriptive statistics were computed for all variables. Bivariate correlations and t-tests were examined to assess the relationships between the study variables. Multivariate hierarchical regression analyses were conducted to test whether there was a relationship between shame and self-care (hypothesis 1), whether compassion moderated the relationship between shame and self-care (hypothesis 2) and whether fear of compassion moderated the moderating effect of compassion on the relationship between shame and self-care (hypothesis 3). The predictor variables; Shame, Self-Compassion, Compassion from Others and Fear of Compassion, were centred and interaction terms were created by multiplying the centred variables. An additional three-way interaction term was created between Shame, Compassion from Others and Fears of Compassion in a similar fashion. Variables were added to the model in four blocks. Age, gender and diabetes duration were entered in the first block. Shame, Self-Compassion, Compassion from Others and Fear of Compassion were entered in the second block. Two-way interactions were entered in block

three and the three-way interaction was entered in block four. F-tests were used to examine the fit of the model with the addition of each block. Moderation effects were supported if the interaction terms were statistically significant at $p < .050$. All statistical analyses were conducted using SPSS for Windows Version 24 (IBM Corp., 2016).

2.5 Qualitative analysis

The aim of the qualitative analysis was to identify and categorise experiences of shame. The responses to the open-ended question were analysed using content analysis. There is no consensus on a single approach to content analysis, therefore directed content analysis as described by Hsieh & Shannon (2008) was used as a framework, and involved three steps. Firstly, the author familiarised themselves with the data set as a whole and highlighted all instances that appeared to represent shame, based on definitions and previous theory. Secondly, codes were developed (e.g. experience of shame; internal shame; external shame) and all highlighted text was coded using these. Any data that could not be categorised within these codes was given a new code. Thirdly, instances of each code were counted to determine the frequency with which they appeared in the data.

3. Results

One hundred and sixty seven participants completed the survey. The data was examined for missing data, and one participant was removed from the analysis leaving $n=166$ participants analysed. Data on medication and smoking were removed from the analysis due to missing data and concerns around reliability.

3.1 Internal consistency

Cronbach alphas were calculated to determine the internal consistency of the scales used in the current study. The following values were obtained; OAS: $\alpha = .97$; TCEAS: self-compassion: $\alpha = .86$, compassion from others: $\alpha = .89$; and fears of compassion: $\alpha = .89$. All scales analysed demonstrated impressive internal consistency, with values coherent with previous research. Furthermore, the analysis demonstrated that none of the alpha values were increased markedly by the removal of any scale items. A Cronbach alpha was not calculated for the SDSCA as, in the current study, this measure was used to give a full scale score for self-care. When used in this way, the scale does not provide a measure of one single common construct, rather it contains items relating to a variety of different aspects of self-care. Therefore it is not appropriate to assess internal consistency in this way.

3.2 Descriptive statistics

Sample characteristics are summarised in Table 1. Of the 166 participants, 105 were female. An independent samples T-test demonstrated no significant relationships between gender and any other variables. Relative to scale ranges, the majority of participants reported sub-optimal self-care, consistent with previous research (e.g. Garcia-Perez, 2013), and low to medium levels of shame (Figure 1).

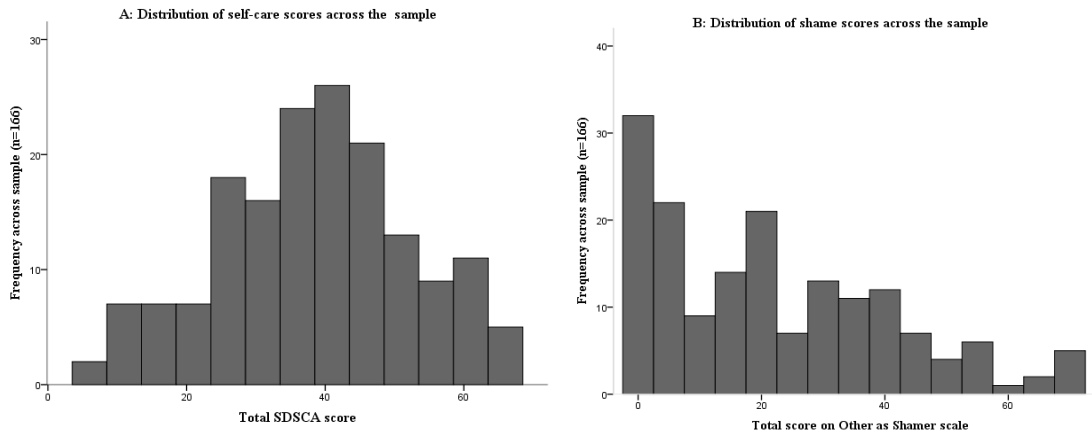


Figure 2: Histograms displaying the distribution of scores across the sample (n=166) in; A: Self-care (total SDSCA score), and B: Shame (Total OAS score)

3.3 Bivariate analysis

Table 1 summarises a series of bivariate correlations between key variables. The analysis demonstrated that older age is associated with greater self-care, lower levels of shame and greater self-compassion. Higher levels of shame were shown to be associated with lower levels of compassion, both from oneself and from others; as well as with greater fear of compassion. The analysis demonstrated no significant association between level of shame and self-care, however there was a significant positive correlation between self-compassion and self-care, such that those higher in self-compassion engaged better in self-care behaviours.

Table 1. Summary of univariate descriptive statistics and bivariate correlations between across the whole sample (n=166)

Variable	2	3	4	5	6	7	M	SD
1. Age	.400**	-.007	-.226**	.179*	.026	-.076	60.03	11.10
2. Diabetes duration (years)		-.028	.028	.043	-.016	.064	9.61	7.97
3. SDSCA			-.139	.241**	.095	-.113	38.39	13.69
4. Other as Shamer				-.204**	-.347**	.598**	21.98	19.02
5. Self-Compassion					.399**	-.272**	61.19	19.68
6. Compassion From Others						-.354**	47.40	24.82
7. Fear of Compassion							19.47	14.12

* $p \leq .050$; ** $p \leq .010$

M = mean; SD = standard deviation

3.4 Regression

The results of the regression analysis are presented in Table 2. Based on the model controlling for age, gender and diabetes duration, the inclusion of the variables at block 2 created a model that was a significantly better fit ($p=.019$).

The regression coefficient for shame had the expected sign although it was not statistically significant, and therefore does not offer support for hypothesis 1.

The inclusion of the three-way interaction term at block 4 did not create a model of significantly better fit than block 3, and therefore does not support hypothesis 3; that fear of compassion would moderate the moderating effect of compassion on the relationship between shame and self-care. Similarly, the inclusion of the two-way interaction terms in block 3 did not provide a model of significantly better fit than block 2, failing to provide support for hypothesis 2; that compassion would moderate the relationship between shame and self-care.

Correlations and Variance Inflation Factors were calculated to check for collinearity, and these tests indicated that this was not violated. Residual scatterplots indicated that the data was normally distributed.

Table 2. Hierarchical multivariate regression analysis examining associations between age, gender, diabetes duration, shame, self-compassion, compassion from others and fear of compassion on self-care

Included variables	B	SE	p-value	95% CI	
				Lower	Upper
Block 1					
Age	-0.016	0.106	.880	-0.23	0.19
Gender	-3.232	2.250	.153	-7.68	1.21
Diabetes duration	-0.062	0.146	.673	-0.35	0.23
Block 2					
Shame	-0.081	0.072	.265	-0.22	0.06
Self-Compassion	0.175	0.059	.004**	0.06	0.29
Compassion for Others	-0.020	0.049	.676	-0.12	0.08
Fear of Compassion	0.010	0.095	.916	-0.18	0.20
Block 3					
Shame x Self-Compassion	-0.005	0.003	.169	-0.01	0.00
Shame x Compassion for Others	-0.003	0.002	.178	-0.01	0.00
Shame x Fear of Compassion	-0.001	0.004	.753	-0.01	0.01
Block 4					
(Fear of Compassion x Compassion from Others) x Shame	1.226 ^a	1.163 ^a	.293	-1.07 ^a	3.52 ^a

B: unstandardized regression coefficients; SE: standard errors; CI: confidence intervals
***p≤.050; **p≤.010**

Values marked with ^a are multiplied by 10x⁻⁴

R² values: Block 1 = .013; Block 2 = .084; Block 3 = .124; Block 4 = .130

3.5 Qualitative results

Eighty-seven (52%) participants responded to the open question.

3.5.1 Experience of shame

Of those who answered the question, over half (n=46; 53%) described experiences of shame in relation their condition. These responses included references to the impact of the condition as well as to the behaviours involved in self-management. Participants shared the following;

“I feel that it is all my fault. I could have changed the outcome but I was too lazy and uncaring about myself and I find my behaviour shameful but I seem to be unwilling to change. I am very distressed.”

“I feel shame with every spoonful of food I put in my mouth!”

Conversely, just over a quarter of those who answered the question (n=24; 28%) reported that they do not experience any shame. For example;

“I feel absolutely no sense of shame whatsoever regarding my type 2 diabetes. It is not even a consideration ... It is the way it is. Frankly, I'm puzzled at the notion of someone feeling 'shame' because they have a certain condition.”

“No feelings of shame, it's a damn nuisance, inconvenient, frustrating and worrying, but it's not my fault (I have never been overweight) and I have to get on with it.”

3.5.2 Sources of shame

Many participants (n=36; 41%) made reference to the sources from which shame is experienced. In line with previous theory, these experiences were coded into two categories; 1) internal sources, and 2) external sources. These categories were further coded into sub-categories. Table 3 summarises the findings.

3.5.3 Self-protection from further shame

Some participants (n=11; 12%) talked about the ways in which they attempt to protect themselves from further shame. Three participants talked about not engaging in certain help-seeking behaviours, such as attending medical appointments or support groups. They offered the following;

“Shame results in not going to GP/nurse when I really should.”

“It's difficult because I've not been able to find any local support groups for the disease and I know I would benefit from attending such a group. But then again, my shame over having the disease may make this a difficult thing for me to actually do.”

Eight participants said that they are not open with others about their diagnosis in order to avoid potentially shaming experiences. For example;

“I've told very few people about my diagnosis because of the shame of feeling that I brought this disease upon myself.”

“I would feel embarrassed if people knew I have type 2 so I say I have type 1 instead then they don't judge or offer bad advice so much”

Table 3: Summary of sources of shame including example quotes

Main category	Generic category	Sub-category	N	Example
Sources of Shame	Internal shame	Shame linked to self-blame for diagnosis and diabetes management	12	“It’s my fault I have diabetes. I’m doing something wrong or I would be getting better. I must be dumb otherwise I could change my health.” “Yes, some shame because the diabetes is partly self-induced by being obese and I’m unable (psychologically?) to fix it.”
		Shame linked to weight and body shape	6	“There is shame for me because of my weight” “I feel it’s a fat person’s disease and I feel I am being punished for being overweight.”
		Shame linked the effects of diabetes and diabetes management	3	“The main issue of the condition for me is the matter of erectile dysfunction ... I feel frustrated and to a certain degree, shame that I am no longer able to 'perform', and my wife feels she is unable to 'stimulate' me.” “Side effect of the condition and medication is flatulence, I constantly feel ashamed whilst at work as I plan loo breaks and journeys meticulously”
	External shame	Attitudes and behaviours of others in society	10	“I think people look at me as being weak and less able than I am.” “I feel shame when I see people looking at my body shape and judging me.”
		Media portrayal of T2DM	9	“I definitely feel ashamed about my type 2 diabetes. I feel guilt ridden when I see reports on television about how diabetes is crippling the NHS.” “Magazine articles about diabetes always make me feel it’s my fault. The progressive nature of the condition makes me feel I’m a failure and a drain on the NHS.”
		Attitudes and behaviours of medical professionals	4	“Some medical professionals can make you feel it’s all your fault and you have brought this on yourself.” “I felt that the medical profession treated me as a lesser person”
	Attitude and behaviours of family	3	“Tremendous shame. My mother reinforces this.” “My children tell me diabetes is my fault”	

4. Discussion

The aim of the current study was to investigate experiences of shame and its effect on T2DM self-care, and to explore the role of compassion in moderating this effect. The statistical analysis did not demonstrate a significant relationship between shame and self-care, and did not find a moderating effect of compassion. However, the results did demonstrate relationships between compassion and self-care which will be discussed. The results of the qualitative analysis revealed shame experiences in those with T2DM, and themes around sources of and self-protection from shame were derived.

The results of the analysis demonstrated that individuals who had higher levels of shame did have poorer engagement with self-care, however this relationship was not significant. Therefore hypothesis 1, i.e. that there will be a significant negative relationship between shame and self-care, was not supported. Overall, levels of shame across the sample were relatively low which was unexpected given reports that T2DM is becoming increasingly stigmatised (Schabert et al, 2013). This is also inconsistent with the qualitative findings, which demonstrated salient feelings of shame in relation to multiple aspects of the condition, including dietary restriction, side effects of medication, weight and self-blame. Based on the proportion of those who responded to the qualitative question, over a quarter (28%) of the whole sample had experienced shame in relation to their T2DM. This is consistent with previous qualitative evidence from this population (Lawton et al, 2005). Such discrepancies raise issues around how shame was measured in the current study, and whether universal shame tools are specific enough to capture the experiences of those with T2DM, or whether the use of only a measure of external shame meant important data on internal

shame was missed. This will be an important consideration for future research in this area.

The results of the qualitative analysis suggested that feelings of shame can arise from internal sources, such as self-blame for the diagnosis, issues around body weight and the direct impact of the condition and its management. This is consistent with previous research in the field of chronic health; for example the role of self-blame in the shame associated with lung cancer (LoConte et al, 2008) and the impact of beliefs around weight on feelings of shame in obesity (Conradt et al, 2008). Gilbert (2003) theorises that internal shame can arise from a perceived discrepancy between the 'desired self' and the 'actual self'; in other words, humans experience shame when they perceive themselves as not living up to how they would like to be. This helps to understand the current finding that, for many, shame arises from a perception of themselves being to blame for their diagnosis, or being unable to manage effectively. For others, shame originates from external sources, e.g. the media, healthcare professionals and family. According to Gilbert's (2003) evolutionary theories, stigmatization, which leads to feelings of shame, is often used to exclude individuals who are 'flawed,' and therefore shame in relation to disease and to cultural ideals, such as those around body shape, is common. This helps to understand the finding that T2DM related shame was experienced via interactions with others, and with society. Gilbert additionally suggests that individuals can experience shame when in the company of others who they perceive as superior. This may be the case when individuals are in the company of healthcare professionals, where there is often an inherent power imbalance (Henderson, 2003) and may help to understand the shame participants reported in relation to interactions with healthcare professionals.

Gilbert suggests that shame, whether internal or external, can impact the individual's well-being. He suggests that shame can lead to a sense of disconnection with others, in an attempt to hide the 'actual' self and protect from further shame. It may be understood therefore, that those who reported avoidance of healthcare appointments and support groups, as well as disclosing their diagnosis, may be attempting to protect themselves from further shame. Gilbert acknowledges that such behaviours are, in the short term, protective for the individual. However, these behaviours can also have unintended, and often detrimental consequences for long term well-being. In the current findings, such behaviours may have a negative effect on the management of the condition and long term health outcomes. This is consistent with previous research demonstrating the importance of social support and regular health check-ups (Larkin et al, 2015) on outcomes in T2DM. Further research into the direct impact of shame on help-seeking behaviours may help to develop a greater understanding of this relationship.

The results of the regression analysis did not offer support for either hypothesis 2, i.e. that compassion will have a significant moderating effect on the relationship between shame and self-care, and therefore not for hypothesis 3, i.e. that the moderating effect of compassion will be moderated by the fear of compassion. This means that for individuals with T2DM, the effect of shame on self-care is not dependent on the level of compassion they receive, either from themselves or from others. Furthermore, this relationship does not appear to be further influenced by how able an individual is to accept and make use of compassion.

The correlational analyses revealed alternative relationships between compassion and self-care. Previous research around the direct relationship between self-compassion and self-care is limited, however one study demonstrated a positive effect of self-compassion on metabolic outcomes in T2DM, via diabetes related distress (Friis et al, 2015). It may be interesting, therefore, in future research, to explore other mechanisms by which self-compassion influences self-care. However, the finding that shame and fears of compassion were moderately correlated suggest that those who are high in shame are also high in fears of compassion. This may mean, that for those who are high in either of these concepts, the benefits of self-compassion may be restricted.

4.1 Clinical implications

Despite failing to offer support for the hypotheses, the findings have some important implications for clinical practice in supporting individuals with T2DM to self-manage their condition. Firstly, the finding that younger age was associated with greater shame and poorer self-care means that subsequent implications may be particularly pertinent in a T2DM population which is gradually becoming younger. Secondly, whilst shame was not found to have a significant impact on self-care, the finding that a considerable number of participants experience shame is important as health-related shame is argued to be sufficiently powerful to determine the overall health of an individual (Dolezal & Lyons, 2017). The finding, demonstrated by the content analysis conducted in the current study, that the majority of shame experiences came from an external source has implications for how T2DM is portrayed at a societal level and in the media; awareness and education may see a decrease in the shame associated with

this condition. Furthermore it seems important to consider the way in which services for people with T2DM are delivered. Professionals may need to consider their own views and conceptions of T2DM and how they may be relating to patients accordingly. Including family and/or friends in the provision of care may help to foster a greater understanding of the condition in the individual's personal system, further reducing potential shame.

Lastly, the direct relationship between self-compassion and self-care suggests this may be a promising avenue for intervention for those having difficulties with management. This supports the rationale for the inclusion of key principles of Compassionate Mind Training (CMT; Gilbert & Procter, 2006) into the care provided for those with the condition. An appropriate platform for this may be, for example, the educational programmes which are provided for everyone diagnosed in the UK under 'Action for Diabetes' (NHS, 2014). A recent RCT has already demonstrated benefits of a self-compassion intervention in improving metabolic outcomes in a diabetic population (Friis et al, 2016). However, it is important to consider that for individuals who are particularly high in shame and/or fear of compassion, there may be great difficulty in utilising compassion-focussed interventions, and therefore it will be important to identify these individuals via thorough assessment.

4.2 Strengths and limitations of the study

The current study is subject to some limitations. Firstly, due to the reliability of self-report, it is impossible to guarantee that all participants had a diagnosis of T2DM. Reliance on self-report raises additional concerns in regard to social desirability bias and therefore implications drawn from the study should be done with consideration of this. In future research using self-reported self-care, it may

be best practice to do so in conjunction with an objective measure. Secondly, whilst the SDSCA is widely recognised and used in studies of both T1 and T2DM, issues were highlighted around the applicability of some items to the T2DM population, due to variability in advice around dietary regimen and blood glucose testing. This raises further considerations for the internal validity of the current study.

4.3 Future research

In light of the findings of the current study, more extensive qualitative research into the psychological and emotional experience of those living with T2DM is in demand. The response to the current study highlights that many individuals with T2DM would benefit from the opportunity to tell their story. In turn, this may help to improve the current understanding of the experiences of this client group.

Once a better understanding is achieved, implications for promotion of awareness, service delivery and interventions may be clearer. Future research may also attempt to better understand the relationship between shame and help-seeking behaviour proposed by the current study. It may additionally attempt to further explore the relationship between self-compassion and self-care such that the mechanisms by which this functions may be better understood.

4.4 Conclusion

In summary, the current study was the first to explore the relationship between shame, compassion and self-care in T2DM. Whilst the results failed to offer support for the hypotheses, interesting findings around the experiences of shame and the direct links between compassion and self-care were highlighted.

The findings complement previous theory and research in the fields of diabetes and chronic health, and may have important implications for the provision of T2DM services and care. Such findings may also have implications for the design and development of interventions for those who are at risk of poor management. Future research will do well to build upon the ideas highlighted in the current study and work towards improving health outcomes for those living with T2DM, in turn reducing the financial implications of poor self-care.

5. References

- AlJohani, K. A., Kendall, G. E., & Snider, P. D. (2014). Psychometric Evaluation of the Summary of Diabetes Self-Care Activities–Arabic (SDSCA-Arabic) Translation and Analysis Process. *Journal of Transcultural Nursing*, 27(1), 65-72
- Browne, J. L., Ventura, A., Mosely, K., Speight, J. (2013). 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open*, 3, 1-11.
- Conradt, M., Dierk, J. M., Schlumberger, P., Rauh, E., Hebebrand, J., & Rief, W. (2008). Who copes well? Obesity-related coping and its associations with shame, guilt, and weight loss. *Journal of Clinical Psychology*, 64(10), 1129-1144.
- Cook, D. R. (1996). Empirical studies of shame and guilt: The Internalized Shame Scale. In D. L. Nathanson (Ed.), *Knowing feeling: Affect, script, and psychotherapy* (pp. 132-165). New York, NY, US: W Norton & Co.
- Dolezal, L., & Lyons, B. (2017). Health-related shame: an affective determinant of health? *Medical humanities*, 0, 1-7.
- Else-Quest, N. M., LoConte, N. K., Schiller, J. H., Hyde, J. S. (2009). Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology & Health*, 24(8), 949-964.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). G* Power Version 3.1. 2 [computer software]. Universität Kiel, Germany.

Friis, A. M., Johnson, M. H., Cutfield, R. G., & Consedine, N. S. (2015). Does kindness matter? Self-compassion buffers the negative impact of diabetes-distress on HbA1c. . *Diabetic Medicine*, 32(12), 1634-1640.

Friis, A. M., Johnson, M. H., Cutfield, R. G., & Consedine, N. S. (2016). Kindness matters: a randomized controlled trial of a mindful self-compassion intervention improves depression, distress, and HbA1c among patients with diabetes. . *Diabetes care*, 39(11), 1963-1971.

García-Peírez, L., Álvarez, M., Dilla, T., Gil-Guillén, V., Orozco-Beltrán, D. (2013). Adherence to Therapies in Patients with Type 2 Diabetes. *Diabetes Therapy*, 4, 175-194.

Gilbert, P. (2003). Evolution, social roles, and the differences in shame and guilt. *Social Research*, 70(4), 1205-1230.

Gilbert, P. (Ed.). (2005). *Compassion: Conceptualisations, research and use in psychotherapy*. Routledge.

Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: Overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy*, 13(6), 353-379.

Gilbert, P., Catarino, F., Duarte, C., Matos, M., Kolts, R., Stubbs, J., ... Pinto-Gouveia, J. (2016). Three orientations of compassion, the development of self-report measures and their link to depression. *Manuscript submitted for publication.*

Gilbert, P., McEwan, K., Matos, M., & Ravis, A. (2011). Fears of compassion: Development of three self-report measures. *Psychology and psychotherapy: theory, research and practice, 84*(3), 239-255.

Goss, K., Gilbert, P., Allan, S. (1994). An exploration of shame measures— I: The ‘Other As Shamer’ scale. *Personality and Individual Differences, 17*, 713-717.

Henderson, S. (2003). Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *Journal of clinical nursing, 12*(4), 501-508.

Hermanto, N., Zuroff, D. C., Kopala-Sibley, D. C., Kelly, A. C., Matos, M., Gilbert, P., Koestner, R. (2016). Ability to receive compassion from others buffers the depressogenic effect of self-criticism: A cross-cultural multi-study analysis. *Personality and Individual Differences, 98*, 324-332.

Hex, N., Bartlett, C., Wright, D., Taylor, M., Varley, D. (2012). Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs.

Diabetic Medicine, 29, 855-862.

Hsieh, H., Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.

IBM Corp. (2016). IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp.

Kleissen, Y. Further validation of The Compassionate Engagement and Action Scales. *in press*.

Larkin, A. T., Hoffman, C., Stevens, A., Douglas, A., Bloomgarden, Z. (2015). Determinants of adherence to diabetes treatment. *Journal of Diabetes*, 7, 864-871.

Lawton, J., Ahmad, N., Hanna, L., Douglas, M., & Hallowell, N. (2005). 'I can't do any serious exercise': barriers to physical activity amongst people of Pakistani and Indian origin with Type 2 diabetes. *Health education research*, 21(1), 43-54.

Leaviss, J., & Uttley, L. (2015). Psychotherapeutic benefits of compassion-focused therapy: An early systematic review. *Psychological medicine*, 45(5), 927-945.

LoConte, N. K., Else-Quest, N. M., Eickhoff, J., Hyde, J., & Schiller, J. H. (2008). Assessment of guilt and shame in patients with non-small-cell

lung cancer compared with patients with breast and prostate cancer. *Clinical lung cancer*, 9(3), 171-178.

Matos, M., & Pinto-Gouveia, J. (2010). Shame as a traumatic memory. *Clinical Psychology & Psychotherapy*, 17(4), 299-312.

Matos, M., Pinto-Gouveia, J., Gilbert, P., Duarte, C., Figueiredo, C. (2015). The Other As Shamer Scale - 2: Development and validation of a short version of a measure of external shame. *Personality and Individual Differences*, 74, 6-11.

Mayberry, L. S., Gonzalez, J. S., Wallston, K. A., Kripalani, S., & Osborn, C. Y. (2013). The ARMS-D out performs the SDSCA, but both are reliable, valid, and predict glycemic control. *Diabetes research and clinical practice*, 102(2), 96-104.

NHS England. (2014). Action for diabetes. London: NHS England.

Rubin, R. R. (2005). Adherence to pharmacologic therapy in patients with type 2 diabetes mellitus. *The American Journal of Medicine*, 118(5A), 27S-34S.

Schabert, J., Browne, J. L., Mosely, K., & Speight, J. (2013). Social stigma in diabetes. *The Patient-Patient-Centered Outcomes Research*, 6(1), 1-10.

Scollan-Koliopoulos, M., O'Connell, K. A., & Walker, E. A. (2007). Legacy of diabetes and self-care behavior. *Research in nursing & health*, 30(5),

508-517.

Speight, J., Conn, J., Dunning, T., Skinner, T. C. (2012). Diabetes Australia position statement. A new language for diabetes: Improving communications with and about people with diabetes. *Diabetes Research and Clinical Practice*, 97, 425-431.

Toobert, D. J., Hampson, S. E., & Glasgow, R. E. (2000). The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. *Diabetes Care*, 23(7), 943-950.

Wellard, S. J., Rennie, S., King, R. (2008). Perceptions of people with type 2 diabetes about self-management and the efficacy of community based service. *Contemporary Nurse*, 29(2), 218-226.

Wild, S., Roglic, G., Green, A., Sicree, R., & King, H. (2004). Global prevalence of diabetes estimates for the year 2000 and projections for 2030. *Diabetes Care*, 27(5), 1047-1053.

Part Three
Appendices

Appendix A: Reflective statement

I found putting this statement together really quite difficult; I just didn't seem to know where to start. My thought processes seemed chaotic and complicated and I felt there was so much to say in such a short space. Now I reflect on this, I can draw parallels between this and the overall process of completing this thesis. I hope that this statement will help me to reflect on both the positives and the negatives of producing this work, and I hope it will give the reader insight into the journey I went on.

Knowing where to start

The feeling of 'not knowing where to start' appears to be a theme in my experience, and is certainly how I felt upon embarking on this project. I feel that I have been very open from the start, with my peers and supervisors, that research is not my forte and not something that I easily feel passionate about. I therefore knew from the start, that completing a thesis would be the most challenging piece of academic work I had ever done and that sustaining motivation for three years would be something I would have to work at. Given this, it is unsurprising that at first I struggled to come up with an idea and I was concerned that my lack of enthusiasm might show to potential supervisors. However, after completing my undergraduate dissertation with a research project looking at ideas of compassion in body image and eating behaviour, I was drawn to following this area of interest through into my doctoral research. Securing Tim and Philip as my research supervisors, and having them interested in my ideas, boosted my motivation for the project, but it is safe to say that the whole idea of a thesis was very effective in triggering my threat system.

In the early stages, the development of my research topic took twists and turns, some of which didn't always sit that well with me. For example, Type 2 Diabetes was not a field I had a previous interest in; rather it provided a topic that brought together a number of my clinical interests. I did, at times, feel I had become somewhat detached from my project and my motivation plummeted. I thought "if I'm not interested now, how will I get through the next two and a half years?" I didn't like feeling this way – it wasn't like me. Now, on reflection and with greater insight into compassion theory, I can see that my threat system was hypersensitive and overpowering my drive system, leaving me feeling deflated and uninterested. However, I started to find that the more I read about diabetes, the more interesting I found it and the more I started to see the relevance of my project. I became attuned to any mention of it, and noticed that talk of the condition was everywhere; reports of the "burden on the NHS" on the television, and hearing it described as a "walking deficiency disease" on the radio. I spoke with a professional working in the field who told me about the individuals she sees struggling to come to terms with the shame they feel around their condition. I started to understand. I got in touch with a local Diabetes Support Group and attended their meetings and events. I chatted to members about why I was there, and they shared their stories with me, expressing real interest in my project. I started to see how my research could make a difference to these people, and realised that *this is why I was doing it*.

How were we going to do it?

Initially, I was drawn to qualitative research; I had never done it before and, from the teaching we had about it, it sounded novel and exciting. However, upon presenting my ideas, I was quickly told by peers and supervisors that my

research questions fitted far better with a quantitative design, with a qualitative element. On reflection now, I am pleased that this decision was made as I am a lot more comfortable and confident with quantitative research. Yet the inclusion of a qualitative element gave me an opportunity to try this approach out and extend my repertoire as a researcher. I am grateful for these skills that I can carry through to future projects.

If I were to pinpoint the part of the process that I found most stressful, it would be recruitment. Launching my study was anxiety-provoking and, despite knowing my survey was ready, it felt like standing on the edge of a pool, swimsuit and goggles on, trying to convince myself to jump in. The nature of online recruitment, whilst in some respects very simple, I found to be a very passive process over which I felt I had very little control. The knowledge that I like to be in control was nothing new to me, but it further demonstrated how difficult I find it to sit with uncertainty, given the obsessive nature with which I checked my Bristol Online Survey account. In the end, recruitment was very successful, however this was largely attributable to social media advertising, which was originally planned to be a last resort. Looking back now, I wonder if I overestimated the ease with which I would recruit from a clinical group that, whilst relatively high in number, was quite niche. If I were to be starting again, knowing what I know now, I would either allow more time for recruitment or take a more active role in recruiting face-to-face at diabetes events.

I was also nervous about my qualitative element; I thought that nobody would write anything and that I would be sat here now reflecting on why this had gone wrong. Fortunately people did respond. Some responses were negative however; participants questioned why I was “analysing” them, calling my questions “stupid” and “irrelevant.” As a novice researcher, this knocked my

confidence. It triggered my threat system, made me anxious that I had made a mistake and left me catastrophizing that I would never complete my thesis. However, I reached out to peers and supervisors who helped me to engage my affiliative system, to accept that I am only human, and to see that no project is perfect and that you are always open to criticism. They encouraged me instead to focus on the positive responses from participants. Some wrote full paragraphs, telling me their stories and thanking me for allowing them the opportunity to share their experiences. Some of the stories were moving and upsetting, and left me wanting to reach out to these individuals. This taught me another important lesson about the boundary that exists between being a researcher and a practicing clinician and how you have to adapt between roles. This is certainly something I will take forward into future research, and is a reflection I would pass on to others who are embarking on similar projects. Overall, I feel I encountered few major problems throughout the research process and, whilst I feel lucky, I also believe that was the result of some of the decisions made at this early stage of the process. For example, the decision to use online questionnaire methodology was made based on the rationale that it was an effective, but relatively straightforward way to answer my research question. I feel that it is really easy when embarking on a thesis to get engrossed in complex ideas, niche populations, and innovative designs and methodologies; but I knew that I would have to balance this work with the other demands of doctoral training and that it is possible to produce a high quality and meaningful piece of work without making it overcomplicated. This pragmatic approach is one that I intend to carry forward and is a reflection I would share with other novice researchers.

Systematic literature review

If I could give one piece of advice to anyone embarking on a systematic literature review, in particular to future trainees, it would be to never underestimate how big this piece of work is. Despite knowing that the SLR was equal in weighting to the empirical paper, I still maintained this idea that it was “bit on the side” that wouldn’t take too long to do. I can only thank my conscientious nature for starting my literature search early. Finding a topic that met the requirements and that fitted with my empirical paper was a challenge. Equally challenging was finding an area of T2DM literature that wasn’t too niche, but equally specific enough to produce a manageable number of papers. Once I had my topic and my search terms I thought it would be plain sailing, but that was where the hard bit started; the iterative process of trawling through titles, abstracts, full papers, refining and revising your approach. I found that just as I thought I had the worst bit over, the next stage would be equally, if not more, repetitive and frustrating. I cannot honestly say that I enjoyed any part of completing the SLR, however on reflection, I feel incredibly proud of myself for my relentless effort and self-discipline exerted over countless hours to a point where I feel I have produced a high quality document that carries an important message.

Producing the goods

Thinking about starting to write up my research made me feel, once again, like I was standing on the edge of the pool, reluctant to jump in. However, writing up, if anything, was the stage I found least stressful. I felt it played to my strengths; it was in my control, there was less uncertainty about it and I knew that my supervisors would support me. Despite this, I couldn’t help but feel I was going to run out of time. However, in writing up I realised how small a part it is of the

overall process, and how much more work goes into the planning, the preparation and undertaking of the research. Certainly, if I were to approach my research again now, knowing what I know, I wouldn't let myself think about the write up until I really needed to. I would instead see the benefits of channelling my focus into the preparation, because I believe that if you get that right the research will, to an extent, write itself.

Choosing journals

When I began thinking about my choice of journal for publication, I was drawn instinctively to Health Psychology journals, believing this was the most obvious route. However, when confronted with the question; "Who do you want to read your papers?" I knew that my target audience was not necessarily a group of Health Psychologists; I wanted my papers to be read by medical professionals working in diabetes on a daily basis. However, this was easier said than done. In choosing a journal for my empirical paper, I found that most diabetes journals of a decent impact factor would be unlikely to accept psychosocial research. *Diabetes Research and Clinical Practice*, however, is an international journal, of a good impact factor, that aims to discuss research, including psychosocial, in terms of improving patient care. For the publication of my SLR, I was adamant that I wanted to aim to publish in *Families, Systems, and Health* as I felt this journal and their audience captured my topic perfectly. Unfortunately, practicalities (in the form of a small word count) stood in my way. I therefore chose the *Diabetes Educator*, which publishes articles relating to all aspects of patient care and education, taking a multi-disciplinary and patient oriented approach.

It's not perfect, but it's good enough

At times during this process, I could not see the wood for the trees, however as the deadline approaches I feel I can see the bigger picture and feel incredibly proud of myself. I can also see what I have learnt from this process. Firstly, I know that despite an initial lack of enthusiasm for research, I would like it to remain a part of my role in the future. Designing, undertaking, and producing research from start to finish is challenging, but incredibly rewarding. I think for me, the closer the research is linked to clinical practice and the more I can visualise the people it will benefit, the more motivated I will be. I have learnt how important it is, when in the depths of your research, to sometimes take a step back and remember why you are doing it. Secondly, I hope I can take forward all I have learnt about the research process into future projects so that I am better prepared for the ups and downs. Tolerance of uncertainty, the importance of your peers and colleagues in helping to refine and revise your ideas and taking each step of the research process one at a time, making small achievable goals, rather than looking to the finish line too soon. Lastly, for me, the most important lesson has been the acceptance that being "good enough" really is good enough. I feel that this is something that the doctorate course tries to instil in you throughout the entire three years; across academic, clinical and research domains. But for me, it is the thesis process that has finally meant that lesson has clicked. This process has helped me to become more compassionate to myself and to let go of my self-critic and the perfectionism that has driven much of my academic career so far. Instead, when I look back at my thesis journey, I tell myself "I did the best I could, in the situation I was in, and whilst this thesis might not be perfect, I believe it is good enough."

Appendix B: Epistemological statement

Ontology refers to our beliefs about *what* we know about the world, whilst epistemology refers to our beliefs about *how* we can know and learn about the world (Snape & Spencer, 2003). It is important that researchers are clear about the beliefs and assumptions that underpin the research they conduct, as these will shape the view the researcher takes of the world and will inform their research paradigm (Falconer & Mackay, 1999). Therefore, the purpose of this statement is to detail and make clear both the ontological assumptions and epistemological stance that underpin this thesis.

Quantitative and qualitative research are classically underpinned by contrasting ontologies and epistemologies. Quantitative research subscribes to a realist approach and positivist epistemology; the belief that 'facts' can be derived from scientific methods of research and seeks to understand the social world by searching for commonalities and relationships (Burrell & Morgan, 1979). A positivist approach will take on an objective view of the social world and will involve identifying a research question, controlling variables and testing hypotheses (Falconer & Mackay, 1999). On the other hand, qualitative research is associated with the ontological stance of 'relativism'; it aims to explore the phenomenology of the social world, driving at a rich understanding of an individual's experience (Falconer & Mackay, 1999), rather than aiming to measure generalizable findings. Given such fundamental differences, many theorists argue that the two are incompatible (Bryman, 1984).

However, some argue that such polarisation of the two approaches is unhelpful (Bryman, 1984). Pragmatists argue that it is false to see the two approaches as

mutually exclusive and that there are advantages of using both (Onwuegbuzie & Leech, 2005). They suggest that the decision of which approach to use should be driven predominantly by the research question the researcher is attempting to answer. Mixed methods approaches to research design build upon this pragmatist opinion by combining both quantitative and qualitative approaches in such a way that is complementary and aims to address a specific question for which both approaches are necessary (Johnson & Onwuegbuzie, 2004).

When reflecting on these viewpoints in relation to my approach to research, I feel that I do not identify with either a strongly positivist or relativist epistemology. Rather, I believe that there are benefits to be gained from both, and therefore find a pragmatist approach fits best with my personal beliefs. I feel that this view is not uncommon within the field of clinical psychology, in which individuals are often both researchers and clinicians; taking a 'scientist practitioner' approach to study and practice, whilst at the same time being required to consider conflicting 'truths,' explore the experience of an individual and hold multiple perspectives at any one time.

First and foremost, I wanted to ensure that the approach I took to my portfolio thesis was driven by my research question, but I also wanted to take a flexible approach. The primary aim of my research was to test the hypothesised relationships between shame, compassion and self-care. These hypotheses were derived from previous literature and theory, and therefore a predominantly quantitative approach was appropriate for testing this. However, this area of research; applying psychological theories of shame and compassion to the field of chronic health, remains relatively novel and therefore there was opportunity for a more exploratory approach to better understanding the lived experience of

shame in those living with T2DM. The addition of a qualitative element also added a depth to the interpretation and understanding of the relationship between shame and self-care that could not be derived from the quantitative analysis alone. Therefore a combination of methodologies was felt to be the most apt in answering the current research questions.

Given the mixed methodology used in my thesis, the choice of method for qualitative analysis had to be chosen accordingly. Content analysis (Hsieh & Shannon, 2008) was selected as an appropriate methodology as it is a flexible approach used to analyse text, and can be applied across many theoretical and epistemological stances; from more impressionistic and interpretive, to more strict categorical analysis. Content analysis is often viewed as a hybrid methodology and can actually be used as either a quantitative or qualitative methodology (Elo & Kyngäs, 2007). Content analysis can be either deductive or inductive; where *deductive* content analysis uses predefined categories or theory to direct the analysis, *inductive* content analysis is more data-driven. In addition, Hsieh and Shannon (2008) outline three main methods of conducting content analysis. *Conventional* content analysis is used when the aim of the study is to describe a phenomenon and is appropriate when existing literature is limited. *Directed* content analysis is used to test an existing theory about a phenomenon that would benefit from further description and aims to extend the understanding of a concept. *Summative* content analysis aims to infer an understanding of the contextual use of words. Deductive, directed content analysis was chosen as the most appropriate approach in the current instance, as the aim of the qualitative analysis was to add further information and understanding to the pre-existing theoretical links between shame and self-care.

In summary, this thesis is underpinned by a pragmatic view point which emphasised the benefits of both quantitative and qualitative research methodologies. Indeed, I feel that the combined use of both methods has been fruitful, resulting in a stronger and deeper understanding of the relationships between compassion, shame and self-care in T2DM.

References

- Bryman, A. (1984). The debate about quantitative and qualitative research: a question of method or epistemology? *British journal of Sociology*, 35(1), 75-92.
- Burrell, G., & Morgan, G. (1979). *Sociology paradigm and organisational analysis: Elements of the Sociology of Corporate Life*. England: Heinemann Educational Books
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of advanced nursing*, 62(1), 107-115.
- Falconer, D. J., & Mackay, D. R. (1999). The key to the mixed method dilemma. In *Proceedings of the 10th Australasian Conference on Information Systems* (pp. 286-297).
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research*, 15(9), 1277-1288.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational researcher*, 33(7), 14-26.
- Onwuegbuzie, A. J., & Leech, N. L. (2005). On becoming a pragmatic researcher: The importance of combining quantitative and qualitative

research methodologies. *International journal of social research methodology*, 8(5), 375-387.

Snape, D. & Spencer, L. (2003) The Foundations of Qualitative Research. In J. Ritchie & J. Lewis (Eds.), *Qualitative Research Practice: A guide for social science students and researchers* (pp. 1-23). London: Sage Publications Ltd.

Appendix C: Author guidelines for submission to The Diabetes Educator

1. What Do We Publish?

1.1 Aims and Scope

The Diabetes Educator is the official journal of the American Association of Diabetes Educators (AADE). It is a peer-reviewed journal intended to serve as a reference source for the science and art of diabetes management. The Diabetes Educator publishes original articles that relate to (1) aspects of patient care and education, (2) clinical practice and/or research, and (3) the multidisciplinary profession of diabetes education as represented by nurses, dietitians, physicians, pharmacists, mental health professionals, podiatrists, and exercise physiologists.

1.2 Article Categories

Features

All feature articles must include a structured abstract of 150-200 words. Feature articles include: Original Research, Meta-analysis, Systematic Reviews, Integrative Reviews, and Perspectives in Practice. There is no limit on the number of references allowed for Original Features.

Original Research

This type of feature reports original investigations that are relevant to the education and care of people with diabetes. Research papers should be 12-14 double-spaced pages, excluding tables, figures, and references. The following elements should be included in reports of original research: (1) structured abstract; (2) introduction with statement of the purpose of the study; (3) complete description of the methods (eg, design, sample, evaluation instruments, procedures, statistical analyses); (4) clear report of the results; (5) conclusions/discussion of the findings; and (6) implications and/or recommendations that summarize how the findings can be applied to the practice of diabetes education. All randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file.

Meta-analysis, Systematic Reviews, and Integrative Reviews

Meta-analysis manuscripts are systematic, critical assessments of literature and data sources. Integrative and Systematic reviews address a specific question or issue that is relevant for clinical practice and provide an evidence-based, balanced, patient-oriented review on a focused topic. Reviews should include the clinical question or issue and its importance for diabetes care and education, description of how the relevant evidence was identified, assessed for quality, and selected for inclusion; synthesis of the available evidence such that the best-quality evidence (eg, well-conducted clinical trials, meta-analyses, and prospective cohort studies) should receive the greatest emphasis; and discussion of controversial aspects and unresolved issues. The specific type of study or analysis, population, intervention and outcomes should be described for each article or data source. Grading of scientific evidence of studies along with a description of the grading system used should be included in the table. Authors should submit the PRISMA flow diagram and checklist. A structured abstract is required. The Diabetes Educator journal publishes reviews using a scientific method and does not publish comprehensive literature reviews.

Perspectives in Practice

Perspectives in Practice may take the form of a detailed case study in which clinical situations illustrate distinguishing, unique, or atypical features that provide a lesson to be learned. Papers in this category should be 8-10 double-spaced pages, excluding tables, figures, and references. Literature reviews should provide a comprehensive summary and critique of information on a relevant topic from a representative collection of resources. The most current findings should be presented along with a history of the literature on the given topic. Controversies, issues, and questions should be addressed as well as standard practices and opinions. Perspectives in practice may take the form of a detailed case study in which clinical situations illustrate distinguishing, unique, or atypical features that provide a lesson to be learned.

Departments

Articles concerning the application of principles and concepts as well as letters to the editor are published in specific departments. Papers may be submitted to the individual departments within The Diabetes Educator and should be 4-8

double-spaced pages. Departments include: Professional Development, Tool Chest, and Letters to the Editor.

Professional Development. These articles provide a forum for sharing ideas, insights, and individual expertise on a broad range of topics related to professional growth as a diabetes educator. Papers might address specific strategies and/or practical approaches concerning the responsibilities of the diabetes healthcare professional.

Tool Chest. These articles provide a format for sharing innovative educational strategies or tools that are relevant for use in patient and professional education. Papers might describe a particular teaching technique or tool and its application in practice.

Letters to the Editor

These letters provide a forum for commenting on articles published in The Diabetes Educator and topics of general interest in diabetes care and education. The length should not exceed 800 words of text with a minimal number of references. One table or figure may be included, if necessary. Any comments regarding a specific article must include the title, author(s), and date of publication. Letters that contain questions or criticisms in response to a previously published paper will be forwarded to the author(s) of that article for a reply. The sharing of ideas, experiences, opinions, and alternative views is encouraged. The editor-in-chief reserves the right to accept, reject, or excerpt letters for clarity and appropriateness of content, and to accommodate space requirements.

1.3 Writing Your Paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make Your Article Discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to

title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial Policies

2.1 Peer Review Policy

The Diabetes Educator is a peer-reviewed journal. The Editors review manuscripts that have been submitted and assign them to selected peers for additional review. The review decision is sent to the corresponding author; additional information and/or clarification may be required before a manuscript is accepted for publication. Periodically, authors may be asked to provide the names of peers who specialize in a narrow field and could be called upon to review the manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

You may also be asked to nominate peers who you do not wish to review your manuscript (opposed reviewers). Please note that the Editors are not obliged to invite/ reject any recommended/opposed reviewers to assess your manuscript. The Editor or members of the Editorial Board may occasionally submit their own manuscripts for possible publication in the journal. In these cases, the peer review process will be managed by alternative members of the Board and the submitting Editor/Board member will have no involvement in the decision-making process.

2.2 Authorship

2.2.1 Authorship Credit

Authorship credit should be based on (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content; and (3) final approval of the version to be published. Authors should meet conditions

1, 2, and 3. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. When a large, multicenter group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship/ contributorship defined above, and editors will ask these individuals to complete journal-specific author and conflict-of-interest disclosure forms. When submitting a manuscript authored by a group, the corresponding author should clearly indicate the preferred citation and identify all individual authors as well as the group name. Other members of the group are listed in the Acknowledgments. Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

2.2.2 Contributors Listed in Acknowledgments

All contributors who do not meet the criteria for authorship should be listed in an acknowledgments section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chairperson who provided general support. Financial and material support should also be acknowledged. Groups of persons who have contributed materially to the paper but whose contributions do not justify authorship may be listed under such headings as “clinical investigators” or “participating investigators,” and their function or contribution should be described—for example, “served as scientific advisors,” “critically reviewed the study proposal,” “collected data,” or “provided and cared for study patients.” Because readers may infer their endorsement of the data and conclusions, these persons must give written permission to be acknowledged.

2.2.3 Acknowledgment of a Medical Writer

The Diabetes Educator editorial board and American Association of Diabetes Educators recognize the valuable contributions of medical writers to the publication team. Individuals who provided writing or editing assistance, eg, from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgments section. Authors must disclose any

writing assistance—including the individual’s name, company, and level of input—and identify the entity that paid for this assistance.

2.2.4 Personal Acknowledgments

Please supply any personal acknowledgments on the Title Page (not in the main document) to facilitate anonymous peer review. It is not necessary to disclose use of language polishing services.

2.3 Funding

The Diabetes Educator requires all authors to acknowledge their funding in a consistent fashion under a separate heading on the Title Page. Please visit the Funding Acknowledgments page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.4 Declaration of Conflicting Interests

It is the policy of The Diabetes Educator journal to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a “Declaration of Conflicting Interests” statement is included on your Title Page. If no conflict exists, please state that “The Author(s) declare(s) that there is no conflict of interest.”

2.5 Research Ethics and Patient Consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki. Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number. For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal. Information on

informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.6 Clinical Trials

The Diabetes Educator journal endorses the ICMJE requirement that clinical trials are registered in a WHO approved public trials registry at or before the time of first patient enrolment. However, consistent with the AllTrials campaign, retrospectively registered trials will be considered if the justification for late registration is acceptable. The trial registry name and URL, and registration number must be included at the end of the abstract.

3. Publishing Policies 3.1 Publication Ethics

The Diabetes Educator (TDE) journal is a member of the Committee on Publication Ethics. TDE recommends that authors follow the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals formulated by the International Committee of Medical Journal Editors (ICMJE) and view the Publication Ethics page on the SAGE Author Gateway. As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

3.1.1 Plagiarism

The Diabetes Educator and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarized other work or included third-party copyright material

without permission or with insufficient acknowledgment, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.2 Contributor's Publishing Agreement

After a manuscript has been accepted for publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. The corresponding author signs on behalf of all authors. SAGE's Journal Contributor's Publishing Agreement is an exclusive license agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and license to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

4. Preparing Your Manuscript for Submission

4.1 Formatting

Manuscripts should be prepared in Word format and in accordance with the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" (Ann Intern Med. 1997;126:36-47) or American Medical Association Manual of Style: A Guide for Authors and Editors, 10th edition (New York, NY: Oxford University Press, 2007). All accepted manuscripts will be edited according to the American Medical Association Manual of Style. In consultation with the author(s), the journal reserves the right to edit manuscripts for clarity, length, readability, and consistency with the style of the journal. Manuscripts must be typed double-spaced throughout (including references). Use margins of at least 1 inch on the top, bottom, and sides of each page. Nothing should be typed in all upper case letters. Number pages consecutively in the upper right-hand corner, beginning with the title page, and provide a running head (not exceeding 50 characters) at the top of each page. The manuscript should be organized in the following manner:

1. Title Page (including Acknowledgments)
 2. Structured Abstract
 3. Introduction (no heading)
 4. Research Design, Methodology, Results, Conclusions (for features)
 5. Text Divided into Logical Headings and Subheadings as Appropriate
 6. Implications/Relevance for Diabetes Educators
 7. References
 8. Tables, Figures, Legends, and Illustrations/photos on Separate Pages
- Upload each of the following separately: Title page, Main document (abstract, body of manuscript and references), each table, each figure.

Title Page

The title page should include (1) title of the manuscript; (2) suggested running head; (3) full name and academic degree(s) for each author; (4) institutional affiliation, including department name and city/state; (5) complete mailing address, with daytime telephone and fax numbers, and email address for corresponding author; (6) acknowledgment of financial and/or other support; and (7) any acknowledgments. The title page is the only place in the manuscript where the author(s) should be identified by name. The title should be written in a brief, concise manner that accurately reflects the main idea of the paper. The running head is a shortened version of the title that should not contain the names or initials of any authors.

Structured Abstract

All feature articles must include a structured abstract of no more than 250 words using the following headings:

- Purpose (Begin this section with the sentence: The purpose of this study is to. . . . Include the rationale for the study, hypotheses, objectives)
- Methods (study design, setting, characteristics of the sample, intervention, data collection procedures, evaluation measures)
- Results (key findings only, no details or statistics)
- Conclusions (information supported by the data, implications)

4.2 Author Guidelines

- Throughout the manuscript, avoid using the personal pronouns I or we.
- Employ nonsexist language.
- Spell out abbreviations and acronyms on first mention followed by the abbreviation in parentheses. Limit the overall use of abbreviations in the text.
- Avoid jargon. For example, instead of the patient was on insulin use the patient was taking insulin or injecting insulin.
- In general, authors should use the active voice. If the subject is mentioned in the sentence, the active voice is preferred over the passive voice. For example, Passive voice: The definition of target blood glucose range used in the survey was taken from previous studies. Active voice: The authors used previous definitions of the target blood glucose range in the survey.
- Throughout the text, use generic, nonproprietary names for medications and devices.
- Use brief headings and subheadings to divide the text into logical sections and enhance readability. Indicate placement of tables, figures, illustrations, and photos in the text by referring to the graphic with the appropriate designation in parentheses (eg, Table 1, Figure 1) following the referent sentence.

4.3 Terminology

- The Diabetes Educator journal supports person-first language. Do not use the word diabetic. Please refer to: Dickinson JK, Guzman SJ, Marynuik MD, et al. The use of language in diabetes care and education. *Diabetes Educ.* 2017; 43(6):551-564.
- Use blood glucose monitoring (not blood sugar monitoring), blood glucose check not test, and blood glucose not blood sugar.
- Use type 1 (Arabic numeral) diabetes and type 2 diabetes. Do not use Type I or II nor IDDM or NIDDM.
- T1DM and T2DM are acceptable abbreviations for type 1 diabetes and type 2 diabetes.
- A1C (not A1c or HbA1c) should be used.

4.4 Laboratory Data

All clinical laboratory data including A1C should be given in traditional units followed in parentheses by units in the metric system according to the Systéme International d'Unités (SI units). Use the NGSP's A1C converter at <http://www.ngsp.org/convert1.asp> to calculate A1C values as both percent and mmol/mol. For example, a blood glucose level should be stated in the following manner: 80 mg/dL (4.44 mmol/L). Abbreviate units of measure in the text only when accompanied by numbers; units of measure should be abbreviated in tables.

4.5 Artwork, Figures, and Other Graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.6 Supplemental Material

This journal is able to host additional materials online (eg, datasets, podcasts, videos, images, etc) alongside the full text of the article.

4.7 Reference Style

Authors are responsible for the accuracy and completeness of all reference citations. Format the reference list according to the style shown in the American Medical Association Manual of Style. Reference numbers should be typed in Arabic superscript numerals in the text, outside periods and commas and inside colons and semicolons. A hyphen should be used to join a series of references. For example, As supported by previous research^{1,5-8,23} The reference list should be typed double-spaced and start on a separate sheet immediately following the end of the text. Number references consecutively in the order they appear in the text, including references cited in tables, figures, and other graphics. All references included on the reference list must be cited at least once in the text. Abbreviate journal names and italicize. Search www.ncbi.nlm.nih.gov/nlmcatalog/journals for journal title abbreviations. Inclusive page numbers must be provided (eg, 88-104) for all print references.

References to personal communication (including e-mail) may be cited parenthetically in the text but not in the reference list; include the name of the person, the e-mail address, and the date of the communication. Material that has been accepted for publication but not yet published may be cited in the reference list with the journal name followed by “In press.” Unpublished material may not be cited. Electronic forms of documents may be included in the reference list and should be cited according to the style for each type of electronic source. Following are some examples of correct forms of references:

Journal Article

List all authors if six or less; for more than six, list only first three authors followed by “et al.” Beck J, Greenwood DA, Blanton L, et al. 2017 National standards for diabetes self-management education and support. *Diabetes Educ.* 2017; 2017;43(5):449-464. <https://doi.org/10.1177/0145721717722968> Powers MA, Bardsley J, Cypress M, et al. Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators and the Academy of Nutrition and Dietetics. *Diabetes Educ.* 2015;41(5):417-430.

Book With Editor(s)

Cornell S, Halstenston C, Miller DK, eds. *The Art and Science of Diabetes Self-Management Education Desk Reference*. 4th ed. Chicago, IL: American Association of Diabetes Educators; 2017.

Electronic Citations

Centers for Disease Control and Prevention. National Diabetes Statistics Report: Estimates of Diabetes and Its Burden in the United States. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services; 2014. <https://www.cdc.gov/diabetes/data/statistics/2014statisticsreport.html>. Accessed Month Day, Year.

4.8 English Language Editing Services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider

using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

4.9 Manuscript Submission Checklist

- Review and follow TDE author guidelines.
- Review manuscript submission guidelines on our webbased submission and review system (<http://mc.manuscriptcentral.com/tde>).
- Designate a corresponding author. Please note TDE contributorship policy.
- Provide an abstract for all manuscripts. For non-research manuscripts, divide abstract into two sections labeled Purpose and Conclusions.
- Double-space manuscript and references.
- Check all references for accuracy and completeness. Italicize and abbreviate journal names according to AMA Manual of Style.
- Include a title for each table and figure and explanatory legend as needed. □
- Upload the title page, main document including references, and each table and figure separately.
- Include research or project support/funding on the title page in the Acknowledgment.
- Include permission agreements for use of third party material requiring permission.
- If appropriate, include information on institutional review board/ethics committee approval or waiver and informed consent.
- For clinical trials, add the clinical trial identification number and the URL of the registration site.

Appendix D: Data extraction form

General Information	
Title	
Author	
Year published	
Brief Summary of study	
Methodology	
Aims	
Design	
Method	
Statistical Analysis	
Sample characteristics	
Target population	
Inclusion/Exclusion criteria	
Sample size	
Country	
Age	
Gender	
Years since diagnosis	
Healthcare system in country of origin. <i>(Is it applicable to the UK?)</i>	
Outcomes	
Control variables	
Relevant variables measured <i>(e.g. marital status, spousal relationship, continuity of care)</i> <i>Include key definitions if necessary</i>	
How were the relevant variables measured?	
Healthcare system level <i>(e.g. personal/home care, professional care)</i>	
Measure of self-care <i>(e.g. HbA1c, self-report, medication refills)</i>	
How they measured self-care	
Relevant findings	
Conclusions	
Key limitations	
Gaps for future research highlighted	

Appendix E: Quality Checklist

Quality Checklist

Study identification: Include full citation details	
Study design: Refer to the glossary of study designs (appendix D) and the algorithm for classifying experimental and observational study designs (appendix E) to best describe the paper's underpinning study design	
Guidance topic:	
Assessed by:	

Section 1: Population		
1.1 Is the source population or source area well described? <ul style="list-style-type: none"> Was the country (e.g. developed or non-developed, type of health care system), setting (primary schools, community centres etc), location (urban, rural), population demographics etc adequately described? 	++ + - NR NA	Comments:
1.2 Is the eligible population or area representative of the source population or area? <ul style="list-style-type: none"> Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)? Was the eligible population representative of the source? Were important groups underrepresented? 	++ + - NR NA	Comments:
1.3 Do the selected participants or areas represent the eligible population or area?	++ + -	Comments:

<ul style="list-style-type: none"> • <i>Was the method of selection of participants from the eligible population well described?</i> • <i>What % of selected individuals or clusters agreed to participate? Were there any sources of bias?</i> • <i>Were the inclusion or exclusion criteria explicit and appropriate?</i> 	NR NA	
Section 2: Method of selection of exposure (or comparison) group		
2.1 Selection of exposure (and comparison) group. How was selection bias minimised? <ul style="list-style-type: none"> • <i>How was selection bias minimised?</i> 	++ + - NR NA	Comments:
2.2 Was the selection of explanatory variables based on a sound theoretical basis? <ul style="list-style-type: none"> • <i>How sound was the theoretical basis for selecting the explanatory variables?</i> 	++ + - NR NA	Comments:
2.3 Was the contamination acceptably low? <ul style="list-style-type: none"> • <i>Did any in the comparison group receive the exposure?</i> • <i>If so, was it sufficient to cause important bias?</i> 	++ + - NR NA	Comments:
2.4 How well were likely confounding factors identified and controlled? <ul style="list-style-type: none"> • <i>Were there likely to be other confounding factors not considered or appropriately adjusted for?</i> • <i>Was this sufficient to cause important bias?</i> 	++ + - NR NA	Comments:
2.5 Is the setting applicable to the UK? <ul style="list-style-type: none"> • <i>Did the setting differ significantly from the UK?</i> 	++ +	Comments:

	- NR NA	
Section 3: Outcomes		
3.1 Were the outcome measures and procedures reliable? <ul style="list-style-type: none"> • <i>Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking -)?</i> • <i>How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)?</i> • <i>Was there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)?</i> 	++ + - NR NA	Comments:
3.2 Were the outcome measurements complete? <ul style="list-style-type: none"> • <i>Were all or most of the study participants who met the defined study outcome definitions likely to have been identified?</i> 	++ + - NR NA	Comments:
3.3 Were all the important outcomes assessed? <ul style="list-style-type: none"> • <i>Were all the important benefits and harms assessed?</i> • <i>Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison?</i> 	++ + - NR NA	Comments:
3.4 Was there a similar follow-up time in exposure and comparison groups? <ul style="list-style-type: none"> • <i>If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison.</i> 	++ + - NR NA	Comments:

<ul style="list-style-type: none"> Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years). 		
3.5 Was follow-up time meaningful? <ul style="list-style-type: none"> Was follow-up long enough to assess long-term benefits and harms? Was it too long, e.g. participants lost to follow-up? 	++ + - NR NA	Comments:
Section 4: Analyses		
4.1 Was the study sufficiently powered to detect an intervention effect (if one exists)? <ul style="list-style-type: none"> A power of 0.8 (i.e. it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard. Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate? 	++ + - NR NA	Comments:
4.2 Were multiple explanatory variables considered in the analyses? <ul style="list-style-type: none"> Were there sufficient explanatory variables considered in the analysis? 	++ + - NR NA	Comments:
4.3 Were the analytical methods appropriate? <ul style="list-style-type: none"> Were important differences in follow-up time and likely confounders adjusted for? 	++ + - NR NA	Comments:
4.4 Was the precision of association given or	++ +	Comments:

<p>calculable? Is association meaningful?</p> <ul style="list-style-type: none"> • <i>Were confidence intervals or p values for effect estimates given or possible to calculate?</i> • <i>Were CIs wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered?</i> 	<p>– NR NA</p>	
<p>Section 5: Summary</p>		
<p>5.1 Are the study results internally valid (i.e. unbiased)?</p> <ul style="list-style-type: none"> • <i>How well did the study minimise sources of bias (i.e. adjusting for potential confounders)?</i> • <i>Were there significant flaws in the study design?</i> 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>5.2 Are the findings generalisable to the source population (i.e. externally valid)?</p> <ul style="list-style-type: none"> • <i>Are there sufficient details given about the study to determine if the findings are generalisable to the source population?</i> • <i>Consider: participants, interventions and comparisons, outcomes, resource and policy implications.</i> 	<p>++ + – NR NA</p>	<p>Comments:</p>

Appendix F: Quality assessment summary table

Table 1: Summary of quality assessment results

<i>Study</i>	<i>Checklist item</i>																			
	1.1	1.2	1.3	2.1	2.2	2.3	2.4	2.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	5.1	5.2	
<i>Barba et al (2017)</i>	+	+	-	N/A	++	N/A	+	+	-	++	N/A	N/A	N/A	++	++	++	+	+	++	
<i>Chew et al (2015)</i>	++	++	++	N/A	++	N/A	+	+	-	++	N/A	N/A	N/A	++	++	++	++	+	++	
<i>Costa et al (2012)</i>	+	++	-	N/A	NR	N/A	+	+	++	+	N/A	N/A	N/A	NR	++	++	+	+	+	
<i>Dossa et al (2015)</i>	++	+	+	N/A	+	N/A	++	+	+	++	N/A	N/A	N/A	+	++	++	++	+	+	
<i>Dossa et al (2017)</i>	++	++	+	N/A	++	N/A	++	-	-	+	N/A	N/A	N/A	+	++	++	++	+	+	
<i>Hong et al (2014)</i>	++	+	++	N/A	++	N/A	++	+	+	++	N/A	N/A	N/A	+	++	++	++	++	++	
<i>Lee et al (2009)</i>	+	++	++	N/A	++	N/A	++	+	++	++	N/A	N/A	N/A	+	++	++	++	+	++	
<i>Moreau et al (2009)</i>	++	++	+	N/A	+	N/A	+	+	-	++	N/A	N/A	N/A	+	+	++	+	+	+	
<i>Pereira et al (2014)</i>	+	+	+	N/A	++	N/A	+	+	-	++	N/A	N/A	N/A	+	++	++	+	+	+	
<i>Pereira et al (2014)</i>	++	+	+	N/A	+	N/A	++	+	-	+	N/A	N/A	N/A	+	++	++	+	+	+	
<i>Pereira et al (2015)</i>	+	+	+	N/A	++	N/A	+	+	-	++	N/A	N/A	N/A	-	++	++	+	+	+	
<i>Pereira et al (2016)</i>	+	+	+	N/A	++	N/A	-	+	-	NR	N/A	N/A	N/A	+	+	+	+	+	+	
<i>Pirdehghan et al (2017)</i>	+	+	+	N/A	+	N/A	NR	+	-	++	N/A	N/A	N/A	NR	+	+	++	+	+	
<i>Schiotz et al (2012)</i>	++	++	+	N/A	++	N/A	++	+	-	++	N/A	N/A	N/A	+	++	++	+	+	++	
<i>Searle et al (2007)</i>	++	+	+	N/A	++	N/A	++	++	-	++	N/A	N/A	N/A	+	++	++	+	+	+	
<i>Shahar et al (2016)</i>	+	-	-	N/A	+	N/A	+	-	+	+	N/A	N/A	N/A	-	+	-	-	-	-	
<i>Shao et al (2017)</i>	+	+	+	N/A	++	N/A	++	+	+	++	N/A	N/A	N/A	+	++	++	+	+	+	
<i>Tiv et al (2012)</i>	++	+	+	N/A	+	N/A	++	+	-	++	N/A	N/A	N/A	+	++	++	++	+	++	

Appendix G: Author guidelines for submission to Diabetes Research and Clinical Practice

GUIDE FOR AUTHORS

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Ensure that the following items are present:

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- E-mail address
- Full postal address

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- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any figures in print

Graphical Abstracts / Highlights files (where applicable)

Supplemental files (where applicable)

Further considerations

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- A competing interests statement is provided, even if the authors have no competing interests to declare
- Journal policies detailed in this guide have been reviewed

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

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Users of Mendeley Desktop can easily install the reference style for this journal by clicking the following link: <http://open.mendeley.com/use-citation-style/diabetes-research-and-clinical-practice>

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Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct. If you do wish to format the references yourself they should be arranged according to the following examples:

Text: Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.

List: Number the references (numbers in square brackets) in the list in the order in which they appear in the text.

Examples:

Reference to a journal publication:

[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. *J Sci Commun* 2010;163:51–9.

Reference to a book:

[2] Strunk Jr W, White EB. *The elements of style*. 4th ed. New York: Longman; 2000.

Reference to a chapter in an edited book:

[3] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. *Introduction to the electronic age*, New York: E-Publishing Inc; 2009, p. 281–304.

Reference to a website:

[4] Cancer Research UK. *Cancer statistics reports for the UK*, <http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/>; 2003 [accessed 13 March 2003].

Reference to a dataset: [dataset]

[5] Oguro M, Imahiro S, Saito S, Nakashizuka T. Mortality data for Japanese oak wilt disease and surrounding forest compositions, Mendeley Data, v1; 2015. <https://doi.org/10.17632/xwj98nb39r.1>.

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are

referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (J Am Med Assoc 1997;277:927–34) (see also Samples of Formatted References).

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Supplementary material such as applications, images and sound clips, can be published with your article to enhance it. Submitted supplementary items are published exactly as they are received (Excel or PowerPoint files will appear as such online). Please submit your material together with the article and supply a concise, descriptive caption for each supplementary file. If you wish to make changes to supplementary material during any stage of the process, please make sure to provide an updated file. Do not annotate any corrections on a previous version. Please switch off the 'Track Changes' option in Microsoft Office files as these will appear in the published version.

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Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your manuscript. If you are sharing data in one of these ways, you are encouraged to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

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There are different ways to link your datasets to your article. When available, you can directly link your dataset to your article by providing the relevant information in the submission system. For more information, visit the database linking page.

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In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

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Authorship

The Corresponding Author must submit a completed Author Consent Form to DRCP with their manuscript. All authors must sign the Author Consent Form.

All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

Appendix H: Confirmation of ethical approval

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Appendix I: Advertisement for recruitment



DO YOU HAVE TYPE 2 DIABETES?

WOULD YOU LIKE TO SHARE YOUR
EXPERIENCE TO HELP IMPROVE CARE FOR
OTHERS?

WE ARE INTERESTED IN UNDERSTANDING THE
EMOTIONAL IMPACT OF TYPE II DIABETES.

THIS KNOWLEDGE MAY HELP IMPROVE
SUPPORT FOR THOSE WITH THE DIAGNOSIS.

YOU ARE ELIGIBLE IF
YOU:

HAVE A DIAGNOSIS
OF TYPE 2 DIABETES

ARE AGE 18+

CAN READ AND
WRITE ENGLISH

PARTICIPATION
ONLY REQUIRES
COMPLETION OF
AN ONLINE
QUESTIONNAIRE

FOR MORE
INFORMATION,
PLEASE VISIT THE
STUDY WEBSITE:

<https://compassionindiabetes.wordpress.com/>

Appendix J: Participant information sheet

Welcome and thank you for taking time to visit this page.

Below is some important information about this study. Please read this information carefully before deciding whether to take part.

Title of the study: Exploring shame and self-care in Type 2 Diabetes and the moderating effect of compassion.

We would like to invite you to take part in a research study that is looking at experiences of people with a diagnosis of Type 2 Diabetes. Before deciding whether to take part, we would like you to understand why the research is being done and what it will involve for you. You can have as much time as you need to think whether or not you would like to take part. We are happy to answer any questions you may have.

What is the purpose of the study?

As a result of type 2 Diabetes being labelled as a “lifestyle condition” in the media, some people with the condition report experiencing some negative feelings, attitudes, and even shame, around their diagnosis. These attitudes and feelings can come from themselves or others. We recognise that these feelings and attitudes can be difficult, and can impact how able someone feels to do the self-care needed to manage the condition.

Therefore, we believe it is really important to find ways to combat these negative feelings and attitudes, and this is what this study is interested in. Specifically, this study is looking at whether being compassionate may help to reduce the negative impact of the difficult feelings and attitudes that can come with a diagnosis of Type 2 Diabetes. We hope that this research can provide important information about how best to provide emotional support to those with the condition, in turn improving physical health outcomes.

Why have I been invited?

We are inviting anyone over the age of 18 who has a diagnosis of Type 2 Diabetes to take part in this study.

Do I have to take part?

Participation in this study is completely voluntary. You are under no obligation to take part.

If you decide you do not wish to participate, you can simply exit this screen. Should you change your mind at a later date, the link available on the study website will allow you to re-access the questionnaire from the beginning.

Should you change your mind about taking part whilst filling out the questionnaire, you will be able to exit the questionnaire and this will terminate your participation.

However, as the study is anonymous, once you have submitted your completed questionnaire you **will not** be able to withdraw your contribution to the study.

What will happen if I decide to take part?

If you decide to take part, please click **Next** as seen below. You will then be asked to read and complete a consent form. Once you have completed this short form, you will be invited to complete the online questionnaire.

It will ask you to answer a few short questions about yourself (e.g. age, gender, time since diagnosis); please note you **will not** be asked for your name. The main body of the questionnaire will ask you to rate a series of statements in relation to how you relate to yourself, how you relate to others, and any negative feelings in response to your condition. Finally it will ask you to rate statements in relation to your diabetes self-care behaviours. The questionnaire will contain clear instructions about how to complete it.

You do not have to complete the questionnaire in one sitting. The option to **finish later** will be available at the bottom of each page of the questionnaire. By clicking on this, your answers will be saved and you will be able to return to complete the questionnaire at a later date using the link provided.

What are the possible disadvantages and risks of taking part?

This study will require up to 30 minutes of your time (this can vary). Some people may at times find it difficult to answer questions about their experiences. If you should find yourself upset, support details will be available at the end of the questionnaire, and also on the study website.

What are the possible benefits of taking part?

Whilst there will be no direct benefit or payment for taking part in this study, some people find answering these questions helpful for reflecting on their experiences. It will also give you the opportunity to share your experiences in a project that will hopefully go on to help improve the understanding of the emotional impact of Type 2 Diabetes, and to help improve the support available.

What if there is a problem?

If you have any concerns about the study, it might be helpful to discuss these with the researcher who will do their best to answer your questions. You may also contact either of the researcher's supervisors at the University of Hull. Please see below for contact details.

What will happen to the results of the study?

After the study is completed, the results will be written up as part of the researcher's thesis and may be submitted for publication in an academic journal or presented at conferences.

Will my taking part in this study be kept confidential?

All of the answers you give throughout the questionnaire will remain anonymous and confidential. You **will not** be asked to provide any non-anonymised personal information. All data from the study will be stored securely at the University.

Some direct quotes from your answers may be used in the write-up of the study or in the presentation of the study at conferences, but none of your personal details or any identifiable data will be included. Any quotes that risk breaching confidentiality will not be used.

Who is organising and funding the research?

The researcher is a doctoral student in Clinical Psychology at the University of Hull and an employee of Humber NHS Foundation Trust. This study is part of her doctoral research project and is funded by the University of Hull.

Who has reviewed the study?

Independent Research Ethics Committees protect the interests of people who participate in research. This study has been reviewed by the School of Health and Social Work Research Ethics Committee at the University of Hull and received a favourable opinion.

Further information and contact details

If you are interested in participating, you can proceed to the questionnaire by pressing **Next**

If you would like more information, feel free to contact the researcher directly via the contact details below.

Contact Details

Researcher: Cara Childs

Trainee Clinical Psychologist

Clinical Psychology Programme, School of Health and Social Work, Aire Building, University of Hull, Cottingham Road, Hull, HU6 7RX

Email: info.diabetesresearch@gmail.com

Research supervisors

Dr Tim Alexander	Dr Philip Molyneux
Research Co-ordinator	Clinical Practice Co-ordinator
Email: t.alexander@hull.ac.uk	Email: p.molyneux@hull.ac.uk
01482 464030	01482 464170

Thank you very much for your interest.

(14.07.17, version 2.3)

Appendix K: Participant consent form

CONSENT FORM

1. I confirm that I have read and understand the information sheet dated 14/07/17 (version 2.3) for the above study. I have information for the individuals to contact if I have any further questions and I understand I can do so before starting the questionnaire.
2. I understand that my participation is voluntary and that I am free to withdraw at any point, without giving any reason.
3. I understand that once I have submitted my questionnaire, it is not possible for my answers to be withdrawn as all the data is anonymous.
4. I confirm that direct quotes from my answers to the questionnaire may be used in future publications or conference presentations and understand that if so, they will be anonymised. Any quotes that risk breaching confidentiality will not be used in publications.
5. I confirm that I am 18 years or older
6. I can confirm that I have a diagnosis of Type 2 Diabetes
7. I agree to take part in the above study

Appendix L: Participant debrief information

Thank you very much for taking the time to complete this questionnaire.

If you have any remaining questions, contact details for the researcher are available on the study website:

<https://compassionindiabetes.wordpress.com/>

The results of this study will be available in Summer 2018.

If you are affected in any way by the content of this study, support can be found from the following sources:

Diabetes UK helpline

The Diabetes UK Helpline is a dedicated diabetes helpline for all people with diabetes, their family or friends, and people who are worried they might be at risk. The confidential helpline is staffed by trained counsellors who have extensive knowledge of diabetes. They can provide information about the condition, take the time to talk things through and explore emotional, social, psychological or practical difficulties.

Call:

0345 123 2399

0141 212 8710 (Scotland)

Email:

helpline@diabetes.org.uk

helpline.scotland@diabetes.org.uk

Appendix M: Demographics questionnaire

Page 3: Demographic information

Which gender do you identify with?

- Male
- Female
- Other

What is your age (years)?

How long ago were you diagnosed with Type 2 Diabetes (years)?

Following your diagnosis, did you attend an NHS Type 2 Diabetes Educational Programme?

- Yes
- No

Appendix N: Summary of Diabetes Self Care Activities (SDSCA)

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Appendix O: Other As Shamer Scale (OAS)

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Appendix P: The Compassionate Engagement and Action Scales (TCEAS)

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Appendix Q: Fear of Compassion Scale (FOCS)

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Appendix R: Pilot study information

In August 2017, prior to the commencement of the main study, the questionnaire was piloted. This was done in order to receive feedback regarding the nature and ordering of the questions, the length, the usability, as well as any technical issues with the online format. In the first pilot, the questionnaire was completed by a non-clinical sample of n=4 volunteers, including research supervisors. These individuals provided feedback on the length of the questionnaire and time taken to complete each part of the questionnaire. This information was used to shape the information participants were provided with. In a second pilot, the questionnaire was then completed by a volunteer sample of n=3 individuals with a diagnosis of Type 2 Diabetes. These individuals provided overall feedback on the questionnaire, plus any reflections around how it applied to them as a member of the population of interest. Of note, these individuals suggested that some of the self-care questions for the SDSCA may not be applicable to all individuals with T2DM, such as the questions about medication. As a result of their feedback the option to answer 'Not Applicable' was added to certain items on the questionnaire. All individuals were thanked and debriefed for their involvement in the pilot.

Appendix S: Additional detail of qualitative analysis process

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