

A Thesis Submitted for the Degree of PhD at the University of Warwick

Permanent WRAP URL:

<http://wrap.warwick.ac.uk/147192>

Copyright and reuse:

This thesis is made available online and is protected by original copyright.

Please scroll down to view the document itself.

Please refer to the repository record for this item for information to help you to cite it.

Our policy information is available from the repository home page.

For more information, please contact the WRAP Team at: wrap@warwick.ac.uk

Voices of Diabetes: Hearing the Lived Experience

Laura Onens

This thesis is submitted in partial fulfilment of the requirements for the
degree of
Doctorate in Clinical Psychology

Coventry University, Faculty of Health and Life Sciences
University of Warwick, Department of Psychology

May 2019

Contents

Contents	ii
List of Tables	v
List of Figures	v
List of Abbreviations	vi
List of Appendices	vii
Acknowledgments	viii
Declaration	ix
Summary	x

Chapter 1: Extending our knowledge of women's experiences of gestational diabetes and self-management in the context of maternity care: A qualitative systematic review	1
1.0 Abstract	2
1.1 Introduction	3
1.1.1 Background	3
1.1.2 Impact	3
1.1.3 Women's Experiences of GDM	4
1.1.4 Rationale	5
1.1.5 Aims	7
1.2 Method	7
1.2.1 Search strategy	7
1.2.2 Inclusion and exclusion criteria	10
1.2.3 Quality assessment	12
1.2.4 Analysis	12
1.3 Results	13
1.3.1 Quality assessment outcome	13
1.3.2 Characteristics of Studies	14
1.3.3 Themes	23
1.3.3.1 Theme 1: A Transformed Pregnancy	24
1.3.3.2 Theme 2: The influence of the patient-provider experience	33
1.4. Discussion	41
1.4.1 Theme 1: A transformed pregnancy	41
1.4.2 Theme 2: The influence of the patient-provider experience	42

1.4.3 Limitations of the Review	44
1.4.4 Clinical Implications and future research	44
1.5 Conclusion	46
1.6 References	47

Chapter 2: The lived experience of males with complications of Type-2 Diabetes and symptoms of low mood: An Interpretative Phenomenological Analysis 55

2.0 Abstract	56
2.1 Introduction	57
2.1.1 Background	57
2.1.2 Clinical Implications of Depression	58
2.1.3 Unmet psychological need	59
2.1.4 Rationale	60
2.1.5 Aims	61
2.2 Method	61
2.2.1 Research Design	61
2.2.1.1 <i>Interpretative Phenomenological Analysis</i>	61
2.2.2 Participants	62
2.2.2.1 <i>Inclusion/exclusion criteria</i>	62
2.2.3 Procedure	64
2.2.3.1 <i>Ethical procedures</i>	64
2.2.3.2 <i>Materials</i>	65
2.2.3.3 <i>Recruitment Procedure</i>	65
2.2.3.4 <i>Interview Procedures</i>	66
2.2.4 Analysis	66
2.2.4.1. <i>Reflexivity</i>	67
2.3 Results	68
2.3.1 Theme 1: “My needs are not important”	69
2.3.1.1 <i>“I don’t think I can get any help with it”</i>	69
2.3.1.2 <i>“It’s a childhood thing”</i>	74
2.3.2 Theme 2: “I know but I don’t want to know”	76
2.3.2.1 <i>“Behaving like I don’t have it but knowing that I have”</i>	77
2.3.2.2 <i>“It’s easy to sweep under the carpet”</i>	81
2.4 Discussion	83
2.4.1 Summary of main findings	83

2.4.1.1 Theme 1: “My needs are not important”	84
2.4.1.2 Theme 2: “I know but I don’t want to know”	85
2.4.2 Methodological Limitations	87
2.4.3 Clinical Implications and future research	88
2.5 Conclusion	90
2.6 References	91
 Chapter 3: Reflections on my lived research experience: Lessons learned	 98
3.0 Introduction	99
3.1 Reflexivity in research	99
3.2 Research design	101
3.2.1 Personal motivation	101
3.2.2 Development of epistemological position	102
3.3 My lived experience	103
3.4 A future within an inequitable system	107
3.5 Conclusion	107
3.6 References	109
Appendices	111

List of Tables

Table 1.1: Search terms and boolean operators	8
Table 1.2: Inclusion and exclusion criteria	11
Table 1.3: Stages of interpretative thematic analysis	13
Table 1.4 Summary of the included studies key characteristics	15
Table 1.5: Summary of themes	23
Table 2.1: Inclusion and exclusion criteria	63
Table 2.2: Participant characteristics	64
Table 2.3: Superordinate and subordinate themes	68

List of Figures

Figure 1.1. PRISMA flow diagram	9
---------------------------------	---

List of Abbreviations

UK	United Kingdom
UKPDS	UK Prospective Diabetes Study Group
DAWN	Diabetes Attitudes Wishes and Needs Project
T2DM	Type 2 Diabetes Mellitus
GDM	Gestational Diabetes Mellitus
NHS	National Health Service
IPA	Interpretative Phenomenological Analysis
BPS	British Psychological Society
CBT	Cognitive Behavioural Therapy
IAPT	Improving Access to Psychological Therapy
DoH	Department of Health
HRA	Health Research Authority
NCCCC	National Collaborating Centre for Chronic Conditions
HCP	Health Care Professional
NICE	National Institute of Clinical Excellence
BGL	Blood Glucose Level
GP	General Practitioner

List of Appendices

Appendix A: Author guidelines: BMC Pregnancy and Childbirth	111
Appendix B: Systematic Literature Review Ethical Approval, University	113
Appendix C: Qualyst Quality Assessment Tool	114
Appendix D: Qualsyst Scores and Kappa Coefficient Calculations	115
Appendix E: Qualitative Health Research Author Guidelines	119
Appendix F: Ethical approval: Coventry University	121
Appendix G: National Health Service Research Ethics Committee Approval	122
Appendix H: Health Research Authority Approval	126
Appendix I: Host NHS Trust Approval – Letter of Access	129
Appendix J: Interview Guide	131
Appendix K: Demographic Questionnaire	132
Appendix L: Recruitment Poster	133
Appendix M: Health Care Professional guidance and recruitment material	134
Appendix N: Recruitment letter	135
Appendix O: Participant Information Sheet	137
Appendix P: Consent to contact form	142
Appendix Q: GP letter	143
Appendix R: Consent form	144
Appendix S: Debrief	145
Appendix T: Interpretative Phenomenological Analysis Framework	146
Appendix U: Initial coding example	147
Appendix V: Development of themes	148
Appendix W: Clustering emerging themes	149

Acknowledgments

Firstly, I would like to thank the participants who kindly took part in this research. I feel honoured to have had opportunity to hear your experiences, some of which required great courage to share. Many of you explained that your participation and subsequent honesty was motivated by wanting to help others and improve care. I am deeply thankful for the insight you have given me and I feel privileged to carry your voices forward, giving testimony to your experiences.

I would also like to thank my research team, Dr. Carolyn Gordon and Ms. Jo Kucharska. Beyond your academic guidance, you supported me through the personal challenges of this research. I will be forever grateful for the cheers of support you provided along the way.

Another vote of thanks goes to two wonderful past colleagues and specialist psychologists in diabetes. Dr. Jess Twyford, when I worked in the IAPT diabetes services you always valued my opinion, interests and were so open-minded about how we could better meet the needs of service users. This enabled passion within my work, which I carried forward into this research. Thank you for agreeing to host the research within your service, I am so grateful to you and the staff who assisted me with recruitment. Dr. Helen Mortimer, in the very short time we worked together, you had a great influence on my practice, and I am very grateful for the times you stepped in to provide support and specialist advice.

To all three of my cohorts, pregnancy not only blessed me with two beautiful babies over the course of training, but a unique position of being part of three different year groups. I feel very lucky to have met you all and be a part of your journey. Training is certainly a rollercoaster ride at times, and I couldn't have survived it without you. A special thank you to two special friends, Dr. Suzanne Brown and (soon to be) Dr. Eleanor Gunn, you are both incredible psychologists and despite my transition from cohort to cohort you have been there for me all the way.

To my parents, you have always prioritised me and supported my ambitions, while keeping my feet on the ground and reminding me I am loved in whatever shape or form. I know secretly you will be so proud to see me qualify and I am looking forward to sharing the joy of that forthcoming occasion with you.

Finally, to my husband Lee, it hasn't been easy...but we are there! Thank you so much for your love, support, holding the fort and personal sacrifices while letting me achieve my aspirations. I'm glad to be back! To my two children, Ottilie and Reuben, thank you for your relentless cuddles, love, play and sense of adventure. You have fulfilled my life in ways I never knew were possible and I feel so blessed to have you.

Declaration

This thesis has not been submitted for any other degree or to any other institution. The thesis was conducted under the academic and clinical supervision of Dr Carolyn Gordon (Academic Tutor, Clinical Psychology Doctorate Course, Coventry University), Ms. Jo Kucharska (Clinical Director, Clinical Psychology Doctorate Course, Coventry University) and Dr. Jess Twyford (Health Psychologist, National Health Service). Apart from the collaborations stated, all the material presented in this thesis is my own work. The literature review is written for submission to: **BMC *Pregnancy and Childbirth***. The empirical article is written for submission to: ***Qualitative Health Research***.

Summary

Diabetes is a health issue of rising prevalence across the world, alongside an obesity epidemic and aging population. It is a complex condition which requires proactive self-management in order to achieve glycaemic control¹ and reduce risk of life-changing complications. This thesis addresses two types of diabetes, Type-2 Diabetes Mellitus (T2DM) and Gestational Diabetes Mellitus (GDM). Although the cause and development are different, both these forms of diabetes often require significant lifestyle and behavioural change. It is therefore important to understand the experiences of patients to ensure they are adequately supported. This thesis aimed to inform understanding of their experiences.

Chapter one presents a systematic review of the qualitative literature to understand the experiences of pregnant women self-managing GDM in the context of western maternity care services. Sixteen articles were included and critiqued in the review. Women described the sudden unexpected disruption of pregnancy and the challenges they faced both personally, and with their maternity care. The findings reinforced need for individualised, culturally-sensitive assessment and interventions, however, raised attention to potential challenges in their delivery. Steps that could be taken to address barriers to self-management are discussed and future research directions considered.

Chapter two presents a qualitative research study that explores the lived experiences of men who had T2DM, low mood and diabetic complications. Interpretative Phenomenological Analysis provided opportunity to gain a deep insight into complexity in the men's experiences, with many conceptualising early life experiences as negatively influencing diabetes self-care and help seeking. Implications for clinical practice and future research are discussed.

Chapter three offers a personal reflection of the author's experience over the course of the research, from research design to steep learning curves. The author considers the personal meaning of the research and their development as both researcher and clinician.

Overall word count at time of submission: 18567

¹ Control of blood glucose levels, usually through diet, exercise and/or medication

Chapter 1: Systematic Review Paper

Extending our knowledge of women's experiences of gestational diabetes and self-management in the context of maternity care: A qualitative systematic review

Written in preparation for submission to: BMC Pregnancy and Childbirth
(see Appendix A for author guidelines)

Overall word count at time of submission (excluding tables, figures, footnotes and references): 7971

1.0 Abstract

Objective: The systematic review aimed to synthesise qualitative literature to understand the experiences of women self-managing gestational diabetes mellitus (GDM) in the context of western maternity care services.

Background: GDM accounts for 87.5% of pregnancies complicated by diabetes. It is associated with significant adverse foetal, maternal and neonatal outcomes. Proactive self-management practices (e.g., diet, exercise, medication) can help reduce risks. Knowledge how women experience self-management in the context of Western maternity services is limited.

Method: A literature search was conducted within PsychINFO, EMBASE, CINAHL, British Nursing Index, EBSCO, Google Scholar and Web of Science, in addition to bibliographic searches. Sixteen articles were extracted which met the inclusion criteria, and their quality assessed. Findings were synthesised using interpretative thematic analysis.

Results: The experiences of the women were identified in two overarching themes: *A transformed pregnancy* and *the influence of the patient-provider experience*. Factors that influenced women's self-management were referenced but restricted by limitations of the original literature.

Conclusion: Recognising individual needs and personal preference is necessary to encourage optimal self-care. The findings reinforce need for individualised, culturally-sensitive assessment and interventions, however, raise attention to potential challenges in their delivery. Steps that could be taken to address barriers to self-management are discussed and future research directions considered.

Keywords: Gestational diabetes mellitus; Management; Healthcare; Experiences

1.1 Introduction

1.1.1 Background

Gestational Diabetes Mellitus (GDM) is defined as a glucose intolerance which develops during pregnancy. This condition, which often resolves after birth, is receiving increased attention due to growing prevalence and association with serious perinatal health outcomes. In England and Wales approximately 35,000 pregnancies per year will be complicated by diabetes, with GDM accounting for 87.5% (NICE, 2015). One risk factor for GDM is overweight body mass index and GDM prevalence is increasing in line with the global obesity epidemic (Ferrara, 2007). Moreover, GDM has high prevalence in women of minority ethnic origin, of which there are a growing number in the United Kingdom (Office for National Statistics, 2011). Lower recommended diagnostic thresholds additionally contribute to an increased number of women receiving GDM diagnoses (NICE, 2015). In combination, these factors have increased the number of women requiring treatment and pressure on maternity healthcare services.

1.1.2 Impact

Hyperglycaemia² in GDM is associated with significant adverse foetal, maternal and neonatal outcomes. These include miscarriage, stillbirth, macrosomia (excessive foetal growth increasing the risk of obstructed labour and caesarean section), pre-eclampsia, and for neonates, risk of hypoglycaemia³ (Buchanan, Xiang & Page, 2012). It is understood that women with GDM also have a seven-fold increased risk of

² High blood glucose level

³ Low blood glucose level

developing Type-2 Diabetes Mellitus (T2DM) (Bellamy, Casas, Hingorani & Williams, 2018). Public health evidence also suggests potential health implications for offspring well beyond infant years (Garcia-Vargas, Addison, Nistala, Kurukulasuriya & Sowers, 2012).

Maintaining optimal glycaemic control within recommended targets during pregnancy can reduce morbidity in the perinatal period and beyond. Adequate management is dependent on women pro-actively engaging with positive self-care practices. Examples include adherence to a GDM friendly diet, regular exercise, monitoring blood glucose levels (BGLs) and if appropriate taking medication, for example, insulin. Despite this, research has demonstrated that some women experience personal and practical barriers to adapting their lifestyles, reducing adherence to recommendations (Martis, Brown, McAra-Couper & Crowther, 2018). Provision of specialist services is central in supporting women to successfully make changes to achieve glycaemic control and improve perinatal outcome (Crowther et al., 2005).

1.1.3 Women's Experiences of GDM

Women's perceptions and beliefs about GDM may influence their commitment to lifestyle changes and adherence with treatment (Devsam, Bogossian & Peacock, 2013). Socio-economic issues, poor support networks and psychological distress are also reported to negatively impact adherence (e.g., Perrson, Winkvist & Mogren, 2010; Ruggiero, Spirito, Bond, Coustan & McGarvey, 1990). In order to understand how these issues might impact on women with GDM, a growing body of qualitative research has anthropologically explored women's experiences. A recent interpretative synthesis concluded that although the women's experiences were highly unique and

personal, they often presented with many commonalities (Devsam et al., 2013). One unexpected finding related to perceived shortfalls in the provision of individually focussed assessment by midwives. This was illustrated by women's reports of not feeling fully informed, or their lifestyles understood. This was further identified in two systematic reviews conducted in 2012 and 2013 respectively (Parsons, Ismail, Amiel & Forbes, 2014; Van Ryswyk, Middleton, Shute, Hague & Crowther, 2015). Although these reviews aimed to understand women's health behaviours once GDM had resolved, both highlighted negative experiences of antenatal care, which deterred postpartum help seeking. In 2015 a new guideline "Diabetes in Pregnancy: Management from preconception to the postnatal period" was published by the National Institute for Health and Care Excellence (NICE, 2015). This document called for more research qualitative research to help deepen understanding of women's experiences of managing GDM, maternity care and barriers to glycaemic control.

1.1.4 Rationale

The aforementioned NICE (2015) guideline does not currently make recommendation for individualised psychosocial assessments in the maternity care of women with GDM. It does however acknowledge that psychosocial factors influence women's adjustment to GDM, self-management and glycaemic control. The publication called for more high-quality qualitative research to help improve understanding. Since this recommendation, a number of qualitative studies have emerged. These studies have aimed to address gaps in knowledge. Firstly, previous reviews have suggested that women encounter difficulties with care during antenatal period that may negatively influence their self-management (Devsam et al., 2013; Parsons et al., 2014; Van Ryswyk et al., 2015). Subsequent research has therefore aimed to increase

understanding (through the richness of women's narratives) about how women experience maternity care. Secondly, a lack of qualitative research has limited understanding about how women manage certain aspects of their GDM treatment (e.g., diet, activity and using insulin). To expand understanding, qualitative research has emerged with more specific focus on these areas of GDM management. Finally, to address lack of diversity in previous research, more recent research has recruited a broader range of women from minority ethnic backgrounds. Altogether, these more recent studies may have identified novel findings that are yet to be synthesised.

Reviewing the recent literature could constructively inform clinical guidelines and offer an important central resource for patients, clinicians, researchers and policy makers. A focus on patient experience aligns with calls for increased service-user involvement in healthcare policy making (The Kings Fund, 2018). Synthesising qualitative research, which is more focussed on the narrative could provide a deeper insight of experiences (Smith, 2015). Literature from 2012 and onwards will be extracted to avoid including literature synthesised by previous reviews. As healthcare delivery undergoes continual change, recent articles will also be more relevant to the current context of maternity care services. As healthcare provision for GDM and pre-existing diabetes is practically and experientially different (NICE, 2015), this review will only focus on women with GDM.

1.1.5 Aims

The aim of the current research is to systematically review and synthesise the existing qualitative literature to address the question: “How do women experience self-management of GDM in the context of Western maternity care services?”

1.2 Method

This systematic review was concerned with exploring research on the experiences of women with GDM in relation to self-management and provision of maternity care. To ensure this review satisfied an original contribution to pre-existing reviews, a search was performed using the Cochrane Database of Systematic Reviews and The Centre for Reviews and Dissemination (DARE). Following this, ethical approval was granted from Coventry University Ethics Committee (Appendix B).

1.2.1 Search strategy

Search terms relating to the research question were extracted by performing a soft search of relevant literature. Key search terms were then developed and refined during meetings with a subject librarian and the research supervisory team. Thesaurus checks on key terms using Healthcare Databases Advanced Search (HDAS) ensured shared synonyms were identified and included. Terms were organised using the ‘Population, Context, Outcome’ framework (Butler, Hall & Copnell, 2016). See Table 1.1 for illustration of the configuration of key terms and Boolean search strategy.

Table 1.1: Search terms and boolean operators

Main Concept	Synonyms	Location
Population: Gestational Diabetes	Gestational OR Gestation* OR Maternity OR antenatal OR perinatal OR prenatal OR pregnancy AND diabetes OR diabet*	Title Abstract
Context: Management and Care	coping (cop*) OR care OR support OR management (manag*) OR living (liv*) OR lifestyle (life*) OR efficacy OR intervention OR treatment (treat*) OR insulin OR dietary (diet*) OR monitoring (monitor*) OR advice OR programme (program*) OR help* OR guidance (guide*)	Title Abstract
Outcome: Experience (methodology)	Qualitative OR experience OR exploration or discourse OR interpretative (interpret*) OR IPA OR grounded theory OR thematic OR knowledge OR perception (perce*) OR interview	Title Abstract Main text

Searches were performed on databases⁴ relevant to academic research and the healthcare profession. Reference lists of extracted articles were manually searched. Although only peer reviewed articles were extracted, preliminary scoping searches of grey literature were performed using the University of Warwick Library electronic search engine, Google Scholar and the NICE Evidence database. This was to aid the researcher's understanding of any noteworthy recent changes or novel commentary in the topic area that were yet to be formally published. To minimise bias and allow for replication this review was guided by the 'Preferred Reporting Items for Systematic Review and Meta-analysis' (PRISMA) process as illustrated in Figure 1.1 (Moher, Liberati, Tetzlaff & Altman, 2009).

⁴ Databases searched included: PsychINFO; Excerpta Medica Database (EMBASE); Cumulative Index of Nursing and Allied Health (CINAHL); British Nursing Index (BNI); EBSCO, Google Scholar and Web of Science.

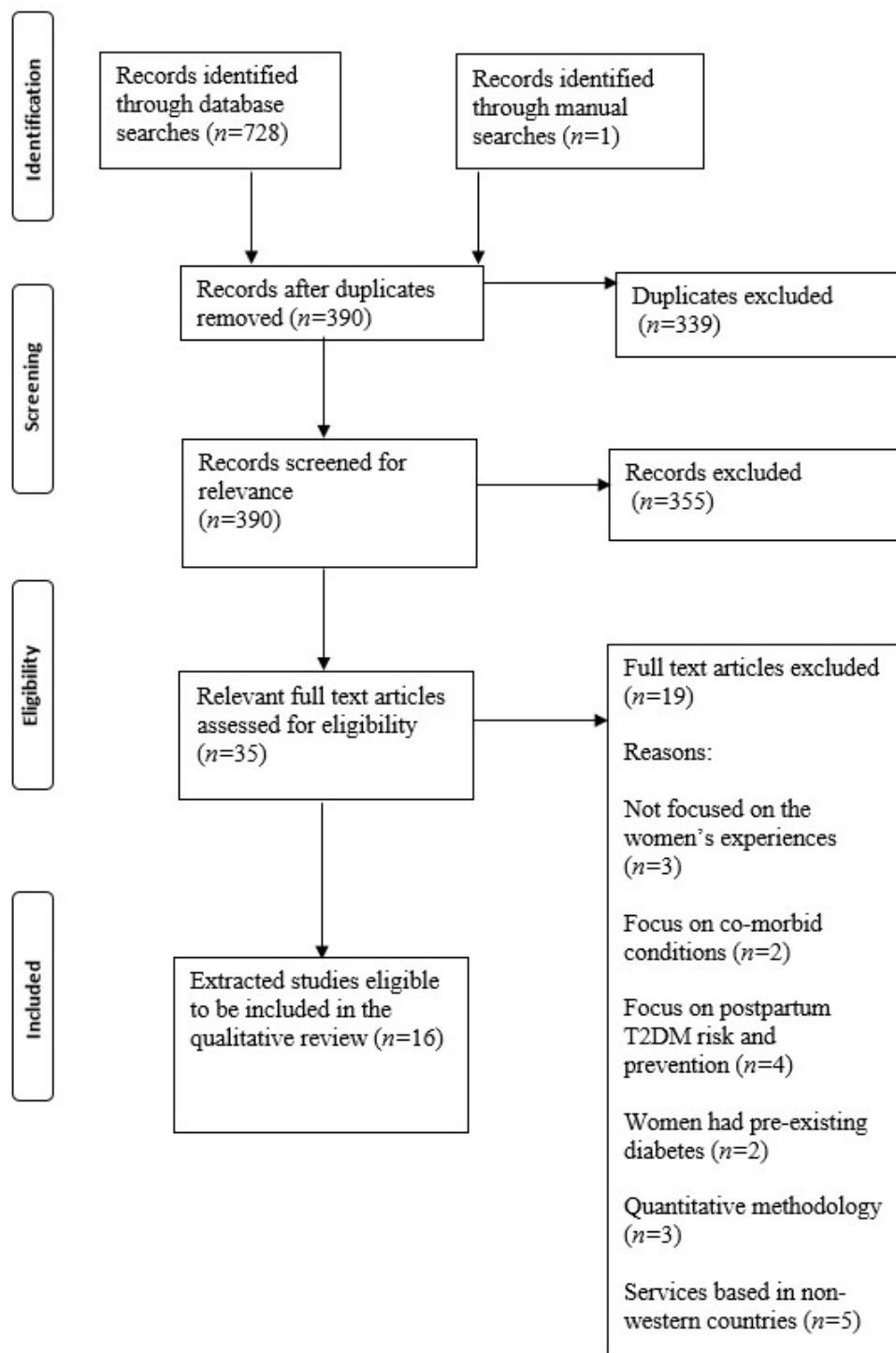


Figure 1.1: PRISMA flow diagram (Moher et al., 2009)

1.2.2 Inclusion and exclusion criteria

A total of 729 studies were generated from the initial searches performed across databases and 339 duplicates were removed. Of the remaining 390 articles, titles and abstracts were reviewed for relevance. In addition, some fundamental exclusion criteria applied. This included ensuring articles were in English language; articles were peer-reviewed and accessible; and of qualitative methodology.

Following initial screening and removal of duplicates and non-relevant articles, 35 full-text articles were obtained and reviewed in more detail for further eligibility factors. A further 19 articles were excluded for not being directly relevant to the review question or failing to meet the inclusion criteria. Full details of inclusion and exclusion criteria are presented in Table 1.2. In total, 16 remaining articles remained for review.

Table 1.2. Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Gestational Diabetes Mellitus	Focused on women's lived experience of GDM during the antenatal period	<p>Studies where women's experiences were not extractable (e.g. healthcare professional perspectives)</p> <p>Studies focused on comorbidity rather than GDM e.g. pre-eclampsia, obesity</p> <p>Studies where women discussed experiences of postpartum health (e.g. prevention of T2DM) without referring to the antenatal period</p>
Participants	Females with GDM interviewed in the antenatal or recent postpartum period	Females who had pre-existing diabetes ⁵
Year of publication	Dated 2012 to 2019	Pre 2012 ⁶
Age	Participants aged > 18 years	Participants aged <18
Language	Accessible in English	Non-English
Research design	<p>Qualitative</p> <p>Mixed methods, where the qualitative contribution was extractable</p>	<p>Quantitative</p> <p>Mixed methods, where qualitative data was unextractable</p>
Publication type	Full-text peer-reviewed published literature	Unpublished literature, abstracts, grey literature, academic theses.
Area of focus	Participants' experience of receiving maternity care in Western countries	Participants' experience of receiving maternity care in Western countries ⁷

⁵ Women with pre-existing diabetes require different maternity care (NICE, 2015) and have knowledge of managing diabetes prior to the antenatal period.

⁶ To avoid inclusion of studies included in previous reviews (Devsam et al., 2013; Parsons et al., 2014). As healthcare delivery undergoes continual change, recent articles will also be more relevant to the current context of maternity care services.

⁷ With the aim of informing service provision, this review acknowledges provision of maternity care services in non-western countries may differ. For the purpose of this review Western countries were defined as counties with similar economic, cultural and population characteristics as the European Economic Area (EEA).

1.2.3 Quality assessment

The quality of articles was determined using a formal quality assessment framework. Historically, evaluating the quality of qualitative research has been subject to debate (Carroll & Booth, 2015). The purpose of quality assessing qualitative research raises ambiguity and historical structured assessment frameworks designed for quantitative methodology are challenging to apply (Caldwell, Henshaw & Taylor, 2011). It is argued that qualitative research requires more subjective criteria such as establishing authenticity and credibility of accounts (Attree & Milton, 2006). Although there is no established protocol for assessing qualitative literature, several standardised assessment tools have been developed. The current review selected QualSyst (Kmet, Cook & Lee, 2004). QualSyst offers reproducible and quantitative means of assessment, suitable to the context of healthcare-related research and facilitates inter-rater reliability analysis (Appendix C). Following recommendations by Thomas & Harden (2008) this tool was used to guide interpretation of study findings rather than immediately exclude based on scores. To verify reliability of quality scores, articles were rated by a second researcher. Inter-reliability analysis was conducted using Kappa coefficients (Cohen, 1960).

1.2.4 Analysis

Qualitative methods of analysis permit opportunity to understand patient experiences and unearth complex phenomena that may not have had opportunity to emerge in more structured quantitative methodology (Bearman & Dawson, 2013). Although systematic synthesis of qualitative studies is becoming a popular way to inform evidence-based health care, there is no agreed preferred approach (Barnett-Page &

Thomas, 2009). Many methods share the same features in epistemological position and process; however, some are more appropriate to specific research aims. As this review aimed to interpret key themes relating to women's experiences of self-management and maternity care, interpretative thematic synthesis was selected (Britten et al., 2002; Thomas & Harden, 2008). This method seeks to thematically synthesise in order to contribute new insight and knowledge to the area of research. The process of this method is illustrated in Table 1.3

Table 1.3: Stages of interpretative thematic analysis (Thomas & Harden, 2008)

Stages	Description
Stage 1: Coding	Verbatim findings of the studies are extracted. The reviewer then codes each line of text according to its meaning and content.
Stage 2: Developing descriptive themes	Descriptive themes developed by looking for similarities and differences between the codes in order to start grouping them into a hierarchical tree structure. New codes were created to capture the meaning of groups of initial codes.
Stage 3: Developing analytical themes	New concepts, understanding, defining characteristics or hypotheses are generated to 'go beyond' the content of the original studies further interpret the data in the context of the research aims.

1.3 Results

1.3.1 Quality assessment outcome

Sixteen articles were included in this review. Quality scores ranged from 12 - 18 as presented in Table 1.4. Lower scoring studies lacked narrative on epistemological position, sampling strategy or use of methods to ensure credibility (e.g., an

independent researcher to code and analyse transcripts). None of the studies were eligible to score full points, due to a lack of narrative about processes of reflexivity (e.g., bracketing interviews) in order to reduce investigator bias (Mays & Pope, 2000). Kappa coefficients calculated from the scores of the second assessor are illustrated in Table 1.4 (Appendix D). An overall score of $k=0.82$ suggested a ‘very good’ strength of agreement (Altman, 1999).

1.3.2 Characteristics of Studies

An overview of the key characteristics of the remaining 16 studies and systematically extracted findings are presented in Table 1.4.

Table 1.4: Summary of the included studies key characteristics

Author	Quality Ax	Aim	Sample and Recruitment Method (demographic information and stage of pregnancy where provided)	Data Collection and Analysis	Key Findings
Carolan (2013) Australia	16/20 ($k=0.63$)	To explore women's experiences of self-managing Gestational Diabetes Mellitus (GDM)	Age: 23-40 $N=15$ Ethnicity: Arabic ($n=1$), Cambodian ($n=1$), Caucasian ($n=5$), Chinese ($n=1$), Filipino ($n=1$), Indian ($n=4$), Vietnamese ($n=2$) GDM Stage: 3 weeks post GDM diagnosis Recruitment method: Purposive from antenatal clinic	10 phone interviews, 1 face-to-face interview informed by phenomenology Thematic Analysis	Women go through a process of adjustment incremental over four discrete themes: The shock of diagnosis, coming to terms with GDM, working it out/learning new strategies, looking to the future. All adjustment phases were underpinned by a fifth theme, having a supportive environment.
Dayyani, Maindal, Rowlands, Lou (2019) Denmark	15/20 ($k=0.75$)	To explore how non-western ethnic minority women with GDM in Denmark experience the hospital-based information about GDM and how they integrate this information into their everyday life	Age: 24-42 $N=11$ Ethnicity: Asia and Middle East ($n=5$), Somali ($n=3$), South and East European ($n=3$) GDM stage: 1 to 18 weeks after gestational diagnosis Recruitment: Purposive from diabetes nurse	Semi-structured interviews (21 to 60-minute duration) grounded in the phenomenology-hermeneutic tradition Thematic Analysis	Three themes: Reaction to the diagnosis, Everyday life, Information needs.
Draffin, Alderice,	16/20 ($k=0.80$)	To explore the concerns, needs and knowledge of	Age: 29-43 $N=19$	Five Focus Groups (45 to 75-minute duration)	Five themes: dealing with the diagnosis of GDM, adapting to blood glucose monitoring and medication to

McCance, Maresh, Harper, McSorley, Holmes (2016)		women diagnosed with GDM	Ethnicity: Bangladeshi ($n=1$), Black African ($n=3$), Indian ($n=1$), Latin American ($n=2$), Pakistani ($n=3$), White ($n=9$) GDM Stage: pregnant ($n=13$), up to 12 months postpartum ($n=6$) Recruitment method: Purposive at antenatal clinic	Content Analysis	treat GDM, having adequate support, challenges associated with lifestyle change, consequences of having GDM.
United Kingdom					
Gray, Marlaine, Hsu, Kiel, Dublin (2017)	17/20 ($k=1.00$)	To explore women's lived experiences of their treatment experience with insulin	Age: 25-49 $N=16$ Ethnicity: African American ($n=1$), Asian ($n=3$), White ($n=14$) GDM Stage: Pregnant Recruitment method: Purposive	Two Focus Groups (90-minute duration) Thematic Analysis	Five themes: diagnosis experience, treatment experience, treatment concerns, interest in other treatment options, need for social support.
USA					
Harrison, Taylor, Frawley, Shields (2019)	17/20 ($k=0.63$)	To explore the attitudes of women diagnosed with gestational diabetes mellitus (GDM) towards physical activity during pregnancy	Age: 18-40 ($M=32$, $SD=3$) $N=27$ Ethnicity: Asian ($n=17$), Australian ($n=9$), unspecified ($n=1$) GDM Stage: Pregnant Recruitment method: Purposive	Semi Structured Interviews (30 to 34- minute duration) Thematic Analysis grounded in phenomenology and interpretative stance	In order to embrace physical exercise during GDM women wanted better information. Subthemes included: wanting information from credible sources, wanting clear information specific to a GDM pregnancy, receiving information at the time of diagnosis, understanding why exercise would improve outcomes,
Australia					

					convenient activity recommendations.
Hjelm, Bard, Apelqvist (2012)	18/20 (<i>k=1.00</i>)	To explore the development over time of beliefs about health, illness and health care in migrant women with gestational diabetes mellitus born in the Middle East and living in Sweden and to study the influence on self-care and care seeking.	Age: 28-44 (<i>M</i> =35 years) <i>N</i> =14 Ethnicity: Iraq (<i>n</i> =10), Iran (<i>n</i> =2), Lebanon (<i>n</i> =2) GDM Stage: Interviewed during pregnancy and in the postpartum period Recruitment method: Hospital based consecutive sampling.	Semi Structured Interviews (1.5 to 2-hour duration) Thematic Content Analysis	Beliefs changed over time and influenced health-related behaviour. Discussed within three main themes: Beliefs about illness, beliefs about health, beliefs about care.
Hjelm, Bard, Apelqvist (2018)	18/20 (<i>k=1.00</i>)	To explore development over time, during and after pregnancy, of beliefs about health, illness and healthcare in migrant women with GDM born in Africa living in Sweden and the influence on self-care and care seeking.	Age: 23-40 (<i>M</i> =31 years) <i>N</i> =9 Ethnicity: African Gestation: Interviewed during both pregnancy and postpartum Recruitment method: Convenience based (hospital setting)	Semi Structured Interviews Thematic Analysis	Beliefs were stable over time and mainly related to individual and social factors. Discussed within three main themes: Beliefs about illness, beliefs about health, beliefs about care.
Hui, Sevenhuysen, Harvey, Salamon (2014)	17/20 (<i>k=1.00</i>)	To explore the barriers and coping strategies of women with gestational diabetes (GDM) to follow dietary advice	Age: 20-42 (<i>M</i> =29 years) <i>N</i> =30 Ethnicity: Aboriginal (<i>n</i> =3), African (<i>n</i> =3), Asian (<i>n</i> =8), Caucasian (<i>n</i> =16) Gestation: 26-38 weeks gestation	Semi Structured Interviews Thematic Analysis	Three themes: Personal food preference conflicted with dietary advice, eating in different social environments where food choice and portions were out of control and food

Canada			Recruitment method: Clinic based purposive sampling		choice decisions were affected by social norms, lack of knowledge and skills in dietary management and lack of a tailored dietary plan.
Jirojwong, Brownhill, Dahlen, Schmied, Johnson (2017)	13/20 (<i>k</i> =0.82)	To explore Southeast Asian migrant women's experience and management of GDM	Age: 19-46 <i>N</i> =19 Ethnicity: Cambodia (<i>n</i> =7), Laos (<i>n</i> =1), Thailand (<i>n</i> =3), Vietnam (<i>n</i> =8) GDM Stage: From 12 weeks gestation to 4 months postpartum Recruitment method: Flyers at antenatal clinic	Semi structured interviews (45 to 120-minute duration) Thematic Analysis	Four themes identified: Going up going down, controlling GDM with insulin, controlling GDM with information, managing blood glucose levels, dietary, exercise and anxiety levels.
Australia					
Kaptein, Evans, McTavish, Banerjee, Feig, Lowe, Lipscombe (2015)	16/20 (<i>k</i> =0.71)	To explore the reactions and experiences of ethnically diverse women diagnosed with GDM	Age: 29-50 (<i>M</i> =36.8, <i>SD</i> =4) <i>N</i> =19 Ethnicity: Non-Caucasian (<i>n</i> =15) GDM stage: pregnant Recruitment method: Convenient sampling at routine clinic appointments	Semi structured telephone interviews (30 to 60-minute duration) Thematic Analysis	Two main themes: A diagnosis of GDM had significant adverse effects on women, women perceived benefits of GDM diagnosis e.g. lifestyle change
Canada					
Martis,	17/20 (<i>k</i> =0.63)	To identify enablers and barriers for women with	Age: <i>M</i> =33 years <i>N</i> =60	Semi Structured interviews (40-minute duration)	Women with GDM report multiple enablers and barriers to achieving optimal glycaemic control relating to

Brown, McAra-Couper, Crowther (2018)		GDM to achieve optimal glycaemic control	Ethnicity: Asian ($n=22$), European ($n=24$), Māori ($n=6$), MELAA ($n=1$), Pacific people ($n=7$) GDM Stage: Pregnant Recruitment method: Convenience sampling	Thematic Analysis	social factors and information/ care provided by maternity services.
New Zealand					
Nielsen, Olesen, Kristiansen, Mechlenborg, Bak, Overgaard (2015)	14/20 ($k=0.78$)	To explore women's experiences with treatment and care during pregnancy and to understand how these experiences influence participation in follow-up screening for Type 2 Diabetes Mellitus	Age: 27-36 $N=7$ Ethnicity: Asian ($n=1$) Caucasian ($n=6$) GDM Stage: Postpartum (within 2 years) Recruitment method: Random selection	Semi structured interviews Thematic Analysis	Four themes identified: fragmented care, insufficient information, focus on women and their participation, risk perceptions in everyday life.
Denmark					
Oza-Frank, Conrey, Bouchard, Shellhaas, Weber (2018)	13/20 ($k=0.80$)	To explore the healthcare experiences of a diverse, low-income sample of women with prior GDM, including their suggestions for improving care.	Age: 18-45 ($M=34$) 4 focus groups (mean $n=7.2$ per group) Ethnicity: African American, Appalachian, Hispanic GDM Stage: Postpartum (up to 10 years) Recruitment method: online advertising	Four Focus Groups (2-hour duration) Thematic Analysis	Three themes identified: Communication issues, personal and environmental barriers, type and quality of healthcare
USA					
Parsons, Sparrow,	16/20	To inform targeted interventions for women	Age: $M=37.7$ $N=50$	Focus groups ($n=35$ in six groups) and	Eight themes that influenced health behaviour identified: psychological

Ismail, Hunt, Rogers, Forbes (2018a)	($k=1.00$)	with gestational diabetes mellitus (GDM) by exploring the factors that influence their health behaviours and their preferences for lifestyle support.	Ethnicity: African/Caribbean/Black British ($n=25$), Asian/Asian British ($n=9$), mixed ethnicity ($n=3$), White/White British ($n=13$) GDM Stage: Postpartum (maximum 5 years) Recruitment method: Purposive	semi structured interviews ($n=15$) Framework Analysis	legacy of pregnancy, relationships with healthcare professionals, physical impacts of pregnancy, social support and cultural norms, life-scheduling, understanding and risk perception, appetite regulation, prioritisation of the baby.
United Kingdom					
Parsons, Sparrow, Ismail, Hunt, Rogers, Forbes (2018b)	16/20 ($k=1.00$)	To explore the experiences of GDM and GDM care for a group of women attending a large diabetes pregnancy unit in southeast London, UK, in order to improve care.	Age: $M=37.7$ $N=50$ Ethnicity: African/Caribbean/Black British ($n=25$), Asian/Asian British ($n=9$), mixed ethnicity ($n=3$), White/White British ($n=13$) GDM Stage: Postpartum (maximum 5 years) Recruitment method: Purposive	Focus groups ($n=35$ in six groups) 60 to 100-minute duration and semi structured interviews ($n=15$) 20 to 120-minute duration Framework Analysis	Seven themes identified: The disrupted pregnancy, projected anxiety, reproductive asceticism, women as baby machines, perceived stigma, lack of shared understanding, postpartum abandonment.
United Kingdom					
Wah, McGill, Wong, Ross, Harding, Krass (2019)	16/20 ($k=0.71$)	To explore the understanding and self-management experiences of Gestational diabetes among Chinese migrants.	Age: 29-41 ($M=34$, $SD=3.6$) $N=18$ Ethnicity: Chinese GDM Stage: Pregnant Recruitment Method: Opportunity (flyers) at antenatal clinic	Semi structured interviews Thematic Analysis	Four themes identified: Knowledge of gestational diabetes, self-management issues, social support, cultural influences on self-management
Australia					

The included research articles had similar research aims; focussing on the experiences of women managing GDM in the context of maternity services in Western countries. For some, details of participant characteristics were inconsistently described or absent, and it was not always possible to determine median age and socio-economic background. Studies reflected broad ethnic diversity, with some studies specifically aimed at exploring the experiences of ethnic minority groups. For studies where ethnic focus was not specified, characteristics relating to heritage were sometimes ambiguously described, for example, non-Caucasian (Kaptein et al., 2015) or mixed ethnicity (Parsons et al., 2018a, 2018b). Further Kaptein et al. (2015) did not consistently describe ethnicity in the prose. This limited interpretation of any culturally relevant nuance in this review.

Overall, most studies recruited women who were pregnant and actively managing GDM. Four studies (Nielsen et al., 2015; Oza-Frank et al., 2018; Parsons et al., 2018a, 2018b) recruited women in the postpartum period and contained retrospective accounts of antenatal experiences. None of the studies applied age-related exclusion criteria or attempted to separate the experiences of young and mature pregnant women. Ages (where quoted) ranged from 18 to 49. For studies where a wide age-range applied, this may have limited homogeneity and opportunities to explore unique age-related experiences. This may be a limitation of the studies considering evidence that suggests older maternal age predicts positive pregnancy adaption and psychological maturity (Camberis, McMahon, Gibson & Boivin, 2014) but also higher medical risk (Carolan & Nelson, 2007).

All studies appeared to employ purposive or convenience/opportunity-based sampling. Strategies included identification of participants during routine attendance

to their local antenatal clinic or use of flyers. Two studies did not specify the methodology of their sampling, although opportunist sampling was inferred in prose (Jirojwong et al., 2017; Oza-Frank et al., 2018). Studies that recruited women in the post-partum period identified participants through historical medical records and recruited via information letters. Although qualitative research is less concerned with generalisability, one good-quality study (14/20) which employed this method described their strategy as ‘random selection’. This description, which is perhaps misleading, referred to selecting women randomly who had responded to letters purposely inviting them to participate based on set characteristics (Nielsen et al., 2015).

All studies collected women’s experiences by in-depth interviews or focus groups. Two studies conducted the majority of interviews by telephone (Carolan, 2013; Kaptein et al., 2015). Sample sizes varied from 7 to 60 women. Two of the highest quality studies both scoring 18/20, interviewed women prospectively at multiple points in time during their pregnancy and the postpartum period (Hjelm et al., 2012, 2018). Two studies analysed verbatim transcripts using methods of content analysis (Draffin et al., 2016; Hjelm et al., 2012). Two further studies, which analysed primary data from the same sample, applied framework analytical approaches to each. Frameworks were structured around contrasting research aims (Parsons et al., 2018a, 2018b). The rest of the studies used thematic analysis. All studies declared ‘saturation of themes’ as the reason for terminating recruitment.

Non-probability sampling and small sample sizes limited the findings of these studies to be generalised to a wider population and were considered as hypotheses warranting further investigation. Further, even though developed Western countries may operate

similar healthcare services, they may have unique differences. The findings were therefore considered in the context they emerged.

1.3.3 Themes

Two main themes emerged from the studies of women's experiences of self-management of GDM and maternity care. The first theme "*A transformed pregnancy*" depicts how women experienced the unexpected diagnosis of GDM and sudden transformation of their pregnancies. Followed by the second theme "*The influence of the patient-provider experience*" that illustrates the influence of the patient-provider experience on women's health behaviours. These themes and their subthemes summarised in Table 1.5.

Table 1.5: Summary of themes

Main themes	Subthemes
Theme 1: A transformed pregnancy	<i>Diagnosis and disruption</i>
	<i>Incompatibility of personal constructs</i>
	<i>Systemic social influences</i>
Theme 2: The influence of the patient-provider experience	<i>Trusting and trusted</i>
	<i>Women's intersects and unmet needs</i>

1.3.3.1 Theme 1: A Transformed Pregnancy

This theme describes the impact of an unexpected diagnosis of GDM and transformation of women's experiences of pregnancy. Emotional disruption, a sudden fear for their unborn babies, and competing life demands appear to have implications on women's capacities to self-manage their condition. The theme also reflects a divergence in women's personal constructs and ways in which they adjust. Within this theme, three subthemes are discussed: *Diagnosis and disruption*; *Incompatibility of personal constructs*; and *Systemic social influences*.

Diagnosis and disruption

This subtheme presents women's reactions to a diagnosis of GDM and subsequent disruption of pregnancy. All sixteen studies of varying quality reported women feeling emotionally disrupted upon diagnosis of GDM. Women referenced feeling “*upset*” and “*shocked*” as common experiences. A high-quality study, with a clearly defined rationale and coherent methodology, discussed a theme “*The disrupted pregnancy*” (Parsons et al., 2018b), which reflected women feeling overwhelmed about what GDM meant for them and their babies. This appeared to limit their ability to digest the complex information routinely provided by the health care professional (HCP) at the time of diagnosis:

It was like really intense, you know, I'd gone to [the hospital] just for a booking in appointment with the midwife and then immediately I was sent through to a dietician and then the dietician said, 'from now on you're going to be just with this team and this team will make sure that

this happens and that happens and the baby's at risk of this and that and people who have gestational diabetes, some have babies die...

(Parsons et al., 2018b; p.4)

Women were more likely to experience distress if they were healthy or unaware of their risk factors for GDM. Knowledge of risk factors appeared to facilitate adjustment and helped women feel better prepared (Martis et al., 2018; Parsons et al., 2018b). One woman described feeling more prepared for the diagnosis having parents with diabetes:

...I was shocked and not shocked....The reason I wasn't shocked is because I was warned that, you know, your parents have got diabetes, it might be hereditary...

(Parsons et al., 2018b; p.4)

Gray et al. (2018) described that when women discovered their risk factors they were “heartbroken”, perceiving GDM as their fault. This finding was echoed by three other articles (Draffin et al., 2016; Harrison et al., 2019; Parsons et al., 2018b). One woman disclosed how fears for her baby disrupted her emotional wellbeing:

...I remember that weekend, talking to my husband, and being in tears, thinking is it something I've done, have I harmed our baby?

(Draffin et al., 2016; p.5)

Nine other studies reported how women (now classed with high risk pregnancies) feared for the health of their babies, resulting in subsequent distress (Carolan, 2013; Dayyani et al., 2019; Draffin et al., 2016; Harrison et al., 2019; Hjelm et al., 2012,

2018; Nielsen et al., 2015; Parsons et al., 2018a, 2018b). Nielsen et al. (2015) identified how most women felt more apprehension for the baby's health than their own. Three studies attributed concern for the baby as a motivator to women making changes aligned with HCPs recommendations (Carolan, 2013; Dayyani et al., 2019; Parsons et al., 2018a).

For women who were anxious about the impact of GDM, fears did not appear to dissipate until after birth. Further stress-related events over the course of pregnancy led to continual emotional disruption for many women. Examples of stress included, fears about giving birth to a large baby (macrosomia) (Martis et al., 2018), concerns about miscarriage or stillbirth (Dayyani et al., 2019), distress about making dietary changes (Martis et al., 2018; Oza-Frank et al., 2018; Parsons et al., 2018b; Wah et al., 2019) and anxieties about taking insulin (Gray et al., 2017; Martis et al., 2018; Parsons et al., 2018b).

Experiencing hunger due to reduced portion sizes was also commonly cited as a source of distress in seven studies (Dayyani et al., 2019; Draffin et al., 2016; Hui et al., 2014, Martis et al., 2018; Oza-Frank et al., 2018, Parsons et al., 2018b; Wah et al., 2019). This was further compounded by feelings of failure when blood glucose levels (BGLs) did not reflect perceived dietary effort (Martis et al., 2018, Parsons et al., 2018b). Some women found hunger so difficult to manage that they would eat more, creating a dilemma between adhering to the regime and coping with hunger (Dayyani et al., 2019).

The studies reported divergence in how women responded to their distress at the time of diagnosis. Even if unsustainable, most women discussed an initial effort to establish pragmatic and positive self-management behaviours (Carolan, 2013; Hui et al., 2014;

Martis et al., 2018, Parsons et al., 2018a). A minority felt they were “*living in self-denial*” (Dayyani et al., 2019; Parsons et al., 2018a). Positive strategies included cleaning out the kitchen cupboards and meal prepping (Carolan, 2013), setting visual reminders for checking BGLs (Martis et al., 2018) and eating a strict and simple diet:

...I just ate plain and boring for a little period of time, then after delivery I will be fine...

(Hui et al., 2014; p.296)

In a high-quality that used inter-rater reliability strategies to enhance credibility, Hui et al. (2014) noted that women who were able to sustain strict diets appeared to gorge on “*forbidden foods*” post birth. This finding was echoed by Parsons et al. (2018a).

Incompatibility of personal constructs

Even when women demonstrated knowledge of the risks of GDM most struggled to sustain the recommended GDM regime (including self-monitoring BGLs, diet, activity and medication). In fact, only one study (with the lowest quality score 13/20) found that women underestimated the potential severity of GDM (Oza-Frank et al., 2018). This unique finding may have reflected inaccuracy in the women’s recollections due to the study recruiting women up to 10 years post-partum. A further explanatory factor may be related to the evolution of healthcare services and awareness about risk over time.

Twelve studies explicitly referred to women’s personal constructs about the meaning of pregnancy (e.g., a time to rest and indulge), activity, insulin and diet as having more power than the knowledge of risk (Dayyani et al., 2019; Draffin et al., 2016; Harrison et al., 2019; Hjelm et al., 2012, 2018; Hui et al., 2014; Jirojwong et al., 2017; Kaptein

et al., 2015; Oza-Frank et al., 2018; Parsons et al., 2018b; Wah et al., 2019). These constructs, which appeared formed from societal norms and sometimes culturally-specific traditions were often incompatible with the advice of Western medicine.

One woman discussed normative ideas that pregnant women needed to relax, which inhibited her engagement in activity (Dayyani et al., 2019). These sentiments were echoed by a South Asian woman in a further study who attributed this to her family's traditional constructs:

...My aunties, they are very traditional, they go....and my mum, she goes 'you shouldn't be doing this, you shouldn't be doing that'...

(Harrison et al., 2019; p.40)

Martis et al. (2018) described how some women reported ideas that exercise would bring on pre-term labour and would only engage in short walks. Further, Wah et al. (2019) found women tended not to exercise if their BGLs were already at target level.

From the perspective of dietary change, three studies identified women who struggled control their diets due to normative beliefs that cravings should be a permissible part of pregnancy (Harrison et al., 2019; Hui et al., 2014; Jirojwong et al., 2017):

...if you're pregnant, guess what, you're eating ice-cream. It just goes hand-in hand...

(Hui et al., 2014; p.294)

There was a diverse range of preconceived ideas about the use of medication to self-manage GDM both within and across studies. Four studies identified beliefs around insulin which appeared to prompt avoidance and the women to modify their treatment

without medical advice or support (Draffin et al., 2016; Hui et al., 2014; Martis et al., 2018; Wah et al., 2019). Some women believed insulin could be harmful to their baby (Wah et al., 2019). Others reported feeling like being prescribed insulin made them a “failure” (Hui et al., 2014). One woman was concerned that taking insulin would make her a confirmed diabetic:

...I had to be coerced to add insulin to my medication. I had this preconceived mindset that once you go on insulin, you become a confirmed diabetic, so I said no no declined it like 400 times...

Draffin et al., 2016; p.7)

In a high-quality study of university educated Chinese migrant women living in Australia, some discussed “making up” BGL records to avoid being prescribed insulin (Wah et al., 2019). Others dramatically reduced their carbohydrate intake (Hui et al., 2014) or completely skipped meals following high readings (Draffin et al., 2016). Due to a fear of the effect insulin might have on the baby, one woman decided to reduce her insulin dose without medical consultation:

...They wanted me to start injecting 10 units, I thought 10 was too much so I started with 6...

(Wah et al., 2019; p.20)

Using herbal alternative medicines was another method of trying to avoid insulin, which was particularly common among women of Asian descent:

...I read very much about and thought, wow, you know this is going to work, no insulin, nothing and it's going to get my blood sugars

down....So I did that for a few days, but I began to read about it, and then it said that pregnant women shouldn't eat fenugreek because it initiates contractions!

(Draffin et al., 2016; p.8)

Conversely, other women did not express the same concerns and used insulin as a substitute to paying attention to their diet and exercise (Martis et al., 2018; Wah et al., 2019).

Systemic Social Influences

In terms of modifying lifestyle, women reported finding advice from HCPs to be incompatible with their competing responsibilities of daily life. Therefore, personal obligations appeared to inhibit women's capacities to sustain changes. Six studies described the problem of work commitments (Draffin et al., 2016; Gray et al., 2017; Harrison et al., 2019; Kaptein et al., 2015; Martis et al., 2018; Wah et al., 2019). Scheduling mealtimes and BGL testing during work hours had particular impact on adherence:

...well I was a teacher and I found like you have to eat at a certain time, check your levels at certain times, and sitting in a classroom full of kids, it's not easy to do...

(Draffin et al., 2016; p.7)

Another woman discussed the burden of using insulin as a full-time working mother:

...I had to carry a little refrigerator everywhere with me and the insulin to work every day...

(Gray et al., 2017; p.1682)

In the majority, women's families appeared encouraging of positive health behaviours GDM. Some women however described struggling to “*strike a balance*” between GDM management and upholding the role of caring for their families (Draffin et al., 2016; Hui et al., 2014; Gray et al., 2017; Kaptein et al., 2015; Parsons et al., 2018b; Wah et al., 2019). One woman reflected on the challenges of self-care due to prioritising the needs of her young children:

I even had a problem with bleeding...the doctor used to tell me I had to stay in bed and rest. I tried to not go down the steps, and at home I tried to clean not perfectly but some, I had to cook for my kids, and send them to school...

(Oza-Frank et al., 2018; p.1063)

Further, if spouse and children wanted their usual diet, women struggled to comply with dietary advice as making two sets of meals was very time consuming (Dayyani et al., 2019). These findings were supported by Wah et al. (2019) who reported that women without the responsibilities of work or children were more successful at adhering to the GDM regime.

Women from both higher-income and low-income groups criticised the dietary recommendations (which encouraged increased proteins, fruits and vegetables) as financially expensive to adhere to (Dayyani et al., 2019; Hjelm et al., 2012; Kaptein

et al., 2015). For lower income women, this was a barrier for them sustaining the diet altogether:

...groceries are way more expensive...everything that's on sale is like sugar stuff...

(Kaptien et al., 2015; p.120)

In six studies of varied quality, women described practical issues in participating in social engagements (Dayyani et al., 2019; Draffin et al., 2016; Hjelm et al., 2012; Hui et al., 2014; Martis et al., 2018; Wah et al., 2019). It appeared women were reluctant to abstain from social events, however activities such as eating out with family and friends were problematic due to ambiguity about ingredients used by restaurants:

My anxiety and my discomfort come when someone says let's go for lunch and then I sort of panic (...) Even a salad in a restaurant could be not good, you know, like depending on how much sugar is in the dressing...

(Hui et al., 2014; p.295)

Part of the reluctance to abstain from socialising may have been related to peer pressure (Hui et al., 2014). There were however alternative explanations presented in Hjelm et al.'s (2012) study. Islamic women spoke about the difficulties in adhering to the diet when attending religious celebrations that centred around 'feasting' but appeared to prioritise the emotional benefits of seeing relatives.

Some systemic social influences had beneficial effects on GDM self-management. Peer support from other women with GDM appeared an important enabler to women

who had access. Some women in the high-quality study by Martis et al. (2018) discussed their experiences engaging with an online GDM social media group on Facebook. Sharing achievements on this group was a strong motivator in regulating behaviour. It also provided a space for women to share recipes, tips about testing, and receive encouragement or troubleshoot common everyday challenges with others:

So, I soon realised, after joining a [American] Facebook group, that most people struggle with cereals. So, I removed the cereal and just went to a two-egg breakfast, and that just evened it out. So, then I felt a bit better again.

(Martis et al., 2018; p.16).

Although social media was not specifically detailed in any other studies, having access to support groups was desired by many women (Gray et al., 2017; Martis et al., 2018; Oza-Frank et al., 2018; Wah et al., 2019). The following disclosure pertains to the possible function of this:

...peer support and medical advice. They're two very different things, and both are really important. Because the doctor, you're only going to see them every couple of weeks, but [managing GDM] is a minute-to-minute decision making process.

(Gray et al., 2017; p.1683)

1.3.3.2 Theme 2: The influence of the patient-provider experience

This theme describes the influence of the patient-provider experience which women describe as enabling or inhibiting positive health behaviours. It consists of two subthemes: *Trusting and Trusted*; and *Women's intersects and unmet needs*.

Trusting and Trusted

This subtheme encompasses an issue about trust in the patient-provider relationship which influenced women's health behaviour. Across ten studies, women appeared to both doubt and feel doubted by the HCP (Draffin et al., 2016; Gray et al., 2017; Hjelm et al., 2012; Hui et al., 2014; Jirojwong et al., 2017; Martis et al., 2018; Oza-Frank et al., 2018, Nielsen et al., 2015; Parsons et al., 2018a, 2018b).

For example, women described inconsistencies with advice received from HCPs making them question their reliability:

...I got confused because I had received two different messages: like, any fruit is good, and then, no, you cannot eat bananas, so I was confused.....

(Draffin et al., 2016; p.11)

Some women reported feeling that HCPs were withholding information or downplaying GDM (Gray et al., 2017; Jirojwong et al., 2017; Oza-Frank et al., 2018), which also undermined their trust:

So then the OB [obstetrician] says, "You need twice a week nonstress test." I said, "Why?" "Because of the insulin." "Well, you just told me that this doesn't harm my child; but now you want to put me on a non-stress test to make sure no harm is being done." So I'm getting conflicting information, which I question. And then she says, "Well, the insulin ages the placenta...

(Gray et al., 2017; p.1682).

Conversely, women described feeling doubted by their HCPs which was not conducive to self-management and reduced their confidence in disclosing issues or concerns. Some women commonly reported feeling mistrusted about BGL recordings. One woman stated the HCP questioned her eating behaviours when her BGLs were so high:

...yeah like insinuating that I eat overnight, because my levels are high in the morning, like no, I am busy sleeping actually, but yeah that I struggled with, not being believed by the diabetes consultant. Why should I continue testing then?

(Martis et al., 2018; p. 12).

Some women described feeling chastised if they were not compliant and this had a negative consequence on their self-management:

...So we're already stressed. And now you're going to shout at us for not bringing the monitor and having a KFC...it just feels like you're getting in trouble.

(Parsons et al., 2018b; p.4)

Close monitoring was also interpreted as HCPs demonstrating lack of trust, with some women describing feeling undermined and scrutinised (Oza-Frank et al., 2018; Parsons et al., 2018b)⁸. What women reported as even more confusing and inconsistent was the sudden feeling of abandonment following birth. Some women experienced

⁸ Parsons et al. (2018b) suggested that the HCPs' knowledge of risks and drive to ensure the safe delivery of health babies resulted in a process they described as "projected anxiety". As the experiences of HCPs was not investigated, there is no evidence to support this assertion.

receiving directly opposite care to that advised prior to birth (Nielsen et al., 2015; Parsons et al., 2018b):

...It's actually quite odd that during birth they monitored everything closely, and as soon as I had delivered, they served me a slice of white bread...

(Nielsen et al., 2015; p.159)

Contrary to other studies, Carolan (2013) found all participants reported feeling positive and well supported by their GDM maternity care provider. This unique finding may highlight a limitation of a relatively short three-week period between the women's GDM diagnosis and subsequent interviews. Five articles reported that consistent care from a regular clinician appeared to increase trust in the patient-provider relationship (Carolan, 2013; Martis et al., 2018; Nielsen et al., 2015; Oza-Frank et al., 2018; Parsons et al., 2018b).

Women's intersects and unmet needs

Many women reported feeling that HCPs paid little attention to the intersection of their personal lives and preferences with their maternity care. The women, now considered as having a high-risk pregnancy, described disempowerment, feeling like “*baby machines*” and perceiving the baby's wellbeing as sole focus (Nielsen et al., 2015). Some even reported feeling the hospital “*claimed ownership*” of the baby (Parsons et al., 2018b). Women's perceptions of their preferences being unheard or disregarded highlighted their unmet needs. Some women discussed being stripped of their agency to make important decisions about their maternity care and birth:

...I was really trying for a VBAC [vaginal birth after caesarean] but I felt I had no choice...no choice whether or not to take the medicine...no choice whether or not to go with midwives... no choice on what I was eating or how I was going to have my baby anymore...

(Gray et al., 2017; p.1681)

When women asserted themselves, some reported experiencing the HCPs as “heavy-handed” and perceived threat that their non-adherence could result in their baby being stillborn (Gray et al., 2017; Parsons et al., 2018a). Some women described feeling that they were not given enough opportunity to try and make lifestyle changes before being pressurised into starting insulin (Carolan, 2013). Parsons et al. (2018a) found women’s negative antenatal experiences led them to disengage with services post birth:

If you've had a bad experience during pregnancy, then you felt like you hadn't had the support that you needed then why are you going to think all of a sudden, oh I'll go and get support now...

(Parsons et al., 2018a; p.206)

Functional gaps in service provision were also identified, with some women experiencing inequalities in maternity care. Services appeared to be attempting to meet needs of women with a one-for-all approach, without considering women’s layered characteristics and intersects of power (e.g., ethnicity, occupations, abilities and other personal factors). Working women appeared disadvantaged by inflexibility in appointment times (e.g., during working hours) and wait times (Hjelm et al., 2018; Kaptein et al., 2015; Martis et al., 2018; Oza-Frank et al., 2018):

It makes our life [with a demanding job] very difficult because I would have some weeks where I am having an ultrasound on Monday, seeing the endocrinologist on Wednesday and obstetrician on Thursday. So I am missing 3 days in a week (...) and you go and sit there for 3 hours...

(Kaptein et al., 2015; p.120)

Further, some women found accessing advice outside of their consultation times difficult, with unanswered and unreturned phone calls (Martis et al., 2018).

Thirteen studies referenced insufficiencies in the provision of information tailored to individual needs (Carolan, 2013; Draffin et al., 2016; Dayyani et al., 2019; Gray et al., 2017; Harrison et al., 2019; Hui et al., 2014; Jirojwong et al., 2017; Kaptein et al., 2015; Martis et al., 2018; Oza-Frank et al., 2018; Parsons et al., 2018a, 2018b; Wah et al., 2019).

The consequences of insufficient information also put women at disadvantage, leading them to seek information from unregulated sources. Three studies identified this as a particular issue when English was not the women's first language (Dayyani et al., 2019; Jirojwong et al., 2017; Wah et al., 2019):

...I talked to [dietitian] ...but ...it didn't help me. It didn't make sense and I just took everything on board to teach myself, not for them to teach me. I didn't think they teach me good enough. It [information] wasn't clear.

(Jirojwong et al., 2017; p.127)

For women who required interpreters, standard consultation times reduced their opportunities in receiving advice from clinicians (Hjelm et al., 2012, 2018). Dayyani et al. (2019) discussed how women researched information in their native language online, however, did not always question credibility. This finding was supported by Wah et al. (2019) where only a few women were able to name a nationally recognised, regulated resource which provided translated GDM materials. Language barriers also increased difficulties with interpreting food labels, understanding glycaemic targets and recording BGLs in English diaries (Martis et al., 2018). Culturally inappropriate advice also led women to seek information elsewhere (Carolan, 2013; Draffin et al., 2016; Martis et al., 2018; Parsons et al., 2018b). Some women felt information provided by the HCP was too centred around European culture:

...I remember when I first met the nutritionist. I was trying to describe a yam to her - she didn't know what it was...

(Draffin et al., 2016; p.10).

Women who didn't seek information elsewhere appeared disadvantaged by using a “*trial and error*” approach to test the effects their food options had on their BGLs, sometimes testing multiple times after meals (Carolan et al., 2013). Even when women received dietary information from HCPs that was more culturally specific, it was partial, and women still felt they needed further information:

The dietician did know about South Asian cuisine...she knew we consumed a lot of roti and what carb portions that they are. But the composition of roti, I could have a better flour for the roti that would

control my diabetes better. That information I got from India.

(Kaptein et al., 2015 p. 120)

In all 16 studies, women of all ethnicities described receiving insufficient information about insulin and other medication:

I wasn't sure about the difference between metformin and insulin in terms of the medication interaction and on my baby's health.

(Gray et al., 2017; p.217)

Harrison et al. (2019) who exclusively explored women's experiences of engaging in physical activity identified that women felt advice lacked credibility. One woman suggested that advice tailored to her personal circumstances from physiotherapists would have improved her adherence:

...I exercise in my home...being with my son only two years old...I feel too hard, so after dinner I walk inside...

(Harrison et al., 2019; p.20)

In the study by Martis et al. (2018) women discussed potential practical ideas that may have enhanced their opportunity to access care. Some of these included, a hospital creche, involving partners in teaching sessions, offering teaching in first languages, better transport or a shuttle to the hospital and improved parking facilities. Transport and parking issues were identified as a particular issue for low-income women (Oza-Frank et al., 2018).

Relating to BGL monitoring, women suggested “*visual*” demonstrations of using glucometer meters and injecting insulin, could help overcome misunderstandings and language barriers (Carolan, 2013). One woman proposed practical changes to BGL recording booklets as she found them too big for her glucometer bag and would forget to take it out (Wah et al., 2019). Another issue related to too little space to accurately record meals in the food diary which also discouraged adherence (Martis et al., 2018).

1.4. Discussion

The purpose of the current systematic review was to synthesise and critically review qualitative literature related to women’s experience managing GDM within the context of western maternity care services. The review of 16 articles led to the identification of two overarching themes: (1) A transformed pregnancy, and (2) The influence of the patient-provider experience. These themes are described below, and their relevance discussed in the context of previous research findings.

1.4.1 Theme 1: A transformed pregnancy

The overarching theme “*A transformed pregnancy*” presents GDM as an overwhelming experience that unexpectedly transports women from the joys of pregnancy, to fear for their unborn child. The perceived pressure to ensure healthy pregnancies and avoid risk to their babies lead many women to experience heightened anxiety. This anxiety is further compounded by the need to make substantial behavioural changes as a matter of immediacy with little time for adjustment. This supports previous findings which have highlighted the significant impact GDM has on the women, which can directly impact their adherence to HCP guidance (Devsam et al., 2013; Perrson et al., 2010; Ruggiero et al., 1990). Women’s competing personal

life demands and personal constructs about pregnancy, diet, activity and medication, also depict psychosocial complexity in their experiences. These findings support social cognitive theories of human agency (e.g., Bandura, 1989) that specify health behaviour as determined by socially derived personal constructs and beliefs. Attempting to understand women's personal constructs and life circumstances may be fundamental to addressing barriers to self-care behaviours. This supports previous recommendations for individualised psychosocial assessment and tailored care plans in the maternity care of women with GDM (Devsam et al., 2013). The findings from this synthesis however suggest that this may only partially solve the problem, as noted in the theme below.

1.4.2 Theme 2: The influence of the patient-provider experience

The second theme "*the influence of the patient-provider experience*" draws attention to potential complexity of women's experiences with the healthcare provider. Women reported feeling misunderstood and perceived a paternalistic model of care, leaving little power to exert their personal preferences or choices about their pregnancy. Women discussed feeling reprimanded if personal preferences were misaligned from HCP recommendations. This often resulted in them feeling alienated, disempowered and sometimes ambivalent towards advice and care. This rupture in the patient-provider relationship prompted women to withhold information through fear of judgment. The disclosures from the women did not sufficiently explain what underpins these perceived negative dynamics. Parsons et al.'s (2018b) hypothesis of 'projected anxiety', which postulates that HCPs' behaviours are driven by risk and concerns for the baby's wellbeing, may offer plausible explanation. Regardless of cause, these reported experiences are incongruent with the person-centred approach

required for individualised psychosocially informed care (Richards, Coulter & Wicks, 2015). This synthesis therefore brings attention to a potential challenge that may arise when instigating proposed person-centred psychosocial assessments in the context of difficult patient-provider dynamics.

This review further extends upon the knowledge presented in previous reviews, by including studies that have focussed upon experiences of women from non-western descent. The difficulties identified about women obtaining culturally-appropriate information are concerning given the growing number of ethnic minority women living and receiving treatment in Western societies (Office for National Statistics, 2011). Further, ignorance about cultural nuances, for example, taking herbal medication without advice or eating inappropriate foods without awareness of the risk, may leave women from marginalised groups and their babies physically disadvantaged. This finding is an example of a wider problem identified in Western healthcare systems (Egede, 2006). Along similar lines, although the system is meant to assist all woman, its inflexibility (e.g., to consider women's individual needs) reflected an unequal distribution of power and resulted in some women being disadvantaged by inequitable access and care. This finding supported more general findings in wider research that have called for intersectional approaches to address inequalities in healthcare provision (Bauer, 2014).

Another important finding of this review relates to women's preconceived ideas about taking insulin, resulting in women withholding information or misleading their HCPs to avoid insulin treatment. This further demonstrated the fragility of the patient-provider experience. Conversely, for women overusing insulin as substitution for a

healthy diet, the apparent lack of medical consultation could lead to life-threatening hypoglycaemia (Lee, 2014).

1.4.3 Limitations of the Review

Methodological limitations of this review should be noted when considering the findings. The review focussed on women with GDM. Studies that focussed on pregnant women with pre-existing diabetes were excluded. Two studies were excluded that recruited both women with GDM and pre-existing diabetes, but inextricably combined their experiences within the data. This meant that experiences relating specifically to women with GDM could not be extracted. Data was therefore lost that may have been relevant to the findings. Further the researcher acknowledges a body of research conducted in non-western developing countries and the East. As this review aimed to derive experiences of women receiving care from Western maternity services these articles were not included. This limits development of a broader understanding on how women experience GDM and maternity care in other parts of the world, which could be addressed by future research. Finally, the quality of this review could have been further improved by recruiting a second researcher to independently extract articles and analyse the data. This approach would have ensured transparency and credibility by addressing any bias that may have occurred during the development and interpretation of themes beyond reflexive activities and supervision (Thomas & Harden, 2008).

1.4.4 Clinical Implications and future research

This review has highlighted women's perceptions of disempowerment relating to their pregnancy choices and inequitable access to care. This is a contrast to movements in Western medicine towards patient-centred care models which respect patients'

opinions in the planning, co-ordination and delivery of care (Gluyas, 2015). HCPs should therefore consider ways in which women can be involved with decision-making to allow them to retain some control over their pregnancies.

Further to this, many women discussed withholding information about non-compliant behaviour, for fear of HCPs responses. In circumstances like these, upskilling HCPs through reflective practice to be conscious about patient-provider dynamics, may help the women feel more empowered and able to confide. In light of women's negative perceptions of their maternity care, researching the perspectives of HCPs would help deepen understanding into this matter.

When the patient-provider experience did not appear to meet women's needs, this synthesis revealed a trend for women to seek information and support elsewhere. The most common source appeared to be the internet. This is concerning due to online availability of inaccurate and unregulated content. This was particularly pertinent for women of minority ethnic backgrounds who experienced language barriers, or felt advice was too westernised. This issue could be addressed by providing women with a list of pre-approved online resources. Several models have emerged to assist with the challenges of providing healthcare to populations of increasing ethnic diversity (Campinha-Bacote, 1999; Devore & Schlesinger, 1996; Purnell, 2002). Upskilling HCPs to further enhance their cultural competence may help address misunderstandings.

Other issues that did not appear specifically supported by routine care, for example, hunger and pregnancy cravings led some women to seek support through GDM social media groups. This type of peer support of 'mothers-supporting-mothers' appeared extremely valuable to women. Further research focussed on the safety and efficacy of

such groups should be conducted before professional recommendations are made to women. In the meantime, HCPs could consider providing ‘troubleshooting’ advice about these commonly discussed problems. A lack of information about insulin and other medications, for example, metformin was also reported as a concern. It is important therefore that HCPs thoroughly counsel women about such medications.

1.5 Conclusion

This systematic review has synthesised literature that has emerged since the National Institute of Clinical Excellence called for more qualitative research to deepen understanding of the barriers women face in the self-management of GDM (NICE, 2015). The rich narratives provide increased insight into women’s unique experiences of managing GDM in the context of Western maternity care services. Bringing together research on this topic has raised important findings and recommendations that may benefit women in attaining optimal health for both themselves and their babies. This review goes beyond previous reviews by including the most up to date research which has addressed previous limitations in knowledge. The findings reinforce the need for individualised, culturally sensitive assessments and interventions, however, raise attention to potential challenges in their delivery. Such challenges include women withholding themselves from HCPs due to perceiving difficult dynamics in the patient-provider relationship. Further, inflexibility in healthcare delivery may leave some women disadvantaged by inequitable access to care. Clinicians can make immediate steps to address some of the issues described by women, which includes both practical changes and ways to encourage trust and collaboration in the patient-provider relationship.

1.6 References

- Altman, D. (1999). *Comparing groups-categorical data. Practical Statistics for Medical Research*. CRC Press.
- Attree, P., & Milton, B. (2006). Critically appraising qualitative research for systematic reviews: Defusing the methodological cluster bombs. *Evidence & Policy: A Journal of Research, Debate and Practice*, 2(1), 109-126.
- Bandura, A. (1989). Human agency in social cognitive theory. *American Psychologist*, 44(9), 1175.
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: A critical review. *BMC Medical Research Methodology*, 9(1), 59.
- Bauer, G. R. (2014). Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity. *Social Science & Medicine*, 110, 10-17.
- Bearman, M., & Dawson, P. (2013). Qualitative synthesis and systematic review in health professions education. *Medical Education*, 47(3), 252-260.
- Bellamy, L., Casas, J., Hingorani, A. D., & Williams, D. (2009). Type 2 diabetes mellitus after gestational diabetes: A systematic review and meta-analysis. *The Lancet*, 373(9677), 1773-1779.
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: A worked example. *Journal of Health Services Research & Policy*, 7(4), 209-215.

- Buchanan, T. A., Xiang, A. H., & Page, K. A. (2012). Gestational diabetes mellitus: Risks and management during and after pregnancy. *Nature Reviews Endocrinology*, 8(11), 639.
- Butler, A., Hall, H., & Copnell, B. (2016). A guide to writing a qualitative systematic review protocol to enhance evidence-based practice in nursing and health care. *Worldviews on Evidence-Based Nursing*, 13(3), 241-249.
- Caldwell, K., Henshaw, L., & Taylor, G. (2011). Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today*, 31(8), e1-e7.
- Camberis, A., McMahon, C. A., Gibson, F. L., & Boivin, J. (2014). Age, psychological maturity, and the transition to motherhood among English-speaking Australian women in a metropolitan area. *Developmental Psychology*, 50(8), 2154.
- Campinha-Bacote, J. (1999). A model and instrument for addressing cultural competence in health care. *Journal of Nursing Education*, 38(5), 203-207.
- Carolan, M. (2013). Women's experiences of gestational diabetes self-management: A qualitative study. *Midwifery*, 29(6), 637-645.
- Carolan, M., & Nelson, S. (2007). First mothering over 35 years: Questioning the association of maternal age and pregnancy risk. *Health Care for Women International*, 28(6), 534-555.
- Carroll, C., & Booth, A. (2015). Quality assessment of qualitative evidence for systematic review and synthesis: Is it meaningful, and if so, how should it be performed? *Research Synthesis Methods*, 6(2), 149-154.

- Cohen, J. (1960). Kappa: Coefficient of concordance. *Educ Psych Measurement*, 20, 37.
- Crowther, C. A., Hiller, J. E., Moss, J. R., McPhee, A. J., Jeffries, W. S., & Robinson, J. S. (2005). Effect of treatment of gestational diabetes mellitus on pregnancy outcomes. *New England Journal of Medicine*, 352(24), 2477-2486.
- Dayyani, I., Terkildsen Maindal, H., Rowlands, G., & Lou, S. (2019). A qualitative study about the experiences of ethnic minority pregnant women with gestational diabetes. *Scandinavian Journal of Caring Sciences*, 1-11.
- Devore, W., & Schlesinger, E. G. (1996). *Ethnic-sensitive social work practice*. Allyn & Bacon.
- Devsam, B. U., Bogossian, F. E., & Peacock, A. S. (2013). An interpretive review of women's experiences of gestational diabetes mellitus: Proposing a framework to enhance midwifery assessment. *Women and Birth*, 26(2), e69-e76.
- Draffin, C., Alderdice, F., McCance, D., Maresh, M., Harper, R., McSorley, O., et al. (2016). Exploring the needs, concerns and knowledge of women diagnosed with gestational diabetes: A qualitative study. *Midwifery*, 40, 141-147.
- Egede, L. E. (2006). Race, ethnicity, culture, and disparities in health care. *Journal of General Internal Medicine*, 21(6), 667-669.
- Ferrara, A. (2007). Increasing prevalence of gestational diabetes mellitus: A public health perspective. *Diabetes Care*, 30 Suppl 2, S141-6.

- Garcia-Vargas, L., Addison, S. S., Nistala, R., Kurukulasuriya, D., & Sowers, J. R. (2012). Gestational diabetes and the offspring: Implications in the development of the cardiorenal metabolic syndrome in offspring. *Cardiorenal Medicine*, 2(2), 134-142.
- Gluyas, H. (2015). Patient-centred care: Improving healthcare outcomes. *Nursing Standard* (2014), 30(4), 50.
- Gray, M. F., Hsu, C., Kiel, L., & Dublin, S. (2017). "It's a very big burden on me": Women's experiences using insulin for gestational diabetes. *Maternal and Child Health Journal*, 21(8), 1678-1685.
- Harrison, A. L., Taylor, N. F., Frawley, H. C., & Shields, N. (2019). Women with gestational diabetes mellitus want clear and practical messages from credible sources about physical activity during pregnancy: A qualitative study. *Journal of Physiotherapy*, 65(1), 37-42.
- Hjelm, K., Bard, K., & Apelqvist, J. (2012). Gestational diabetes: Prospective interview-study of the developing beliefs about health, illness and health care in migrant women. *Journal of Clinical Nursing*, 21(21-22), 3244-3256.
- Hjelm, K., Bard, K., & Apelqvist, J. (2018). A qualitative study of developing beliefs about health, illness and healthcare in migrant African women with gestational diabetes living in Sweden. *BMC Women's Health*, 18(1), 34.
- Hui, A. L., Sevenhuysen, G., Harvey, D., & Salamon, E. (2014). Barriers and coping strategies of women with gestational diabetes to follow dietary advice. *Women and Birth*, 27(4), 292-297.

- Jirojwong, S., Brownhill, S., Dahlen, H. G., Johnson, M., & Schmied, V. (2017). Going up, going down: The experience, control and management of gestational diabetes mellitus among southeast Asian migrant women living in urban Australia. *Health Promotion Journal of Australia*, 28(2), 123-131.
- Kaptein, S., Evans, M., McTavish, S., Banerjee, A. T., Feig, D. S., Lowe, J., et al. (2015). The subjective impact of a diagnosis of gestational diabetes among ethnically diverse pregnant women: A qualitative study. *Canadian Journal of Diabetes*, 39(2), 117-122.
- Kmet, L. M., Cook, L. S., & Lee, R. C. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*. Edmonton: Alberta Heritage Foundation for Medical Research (AHFMR).
- Lee, S. J. (2014). So much insulin, so much hypoglycemia. *JAMA Internal Medicine*, 174(5), 686-688.
- Martis, R., Brown, J., McAra-Couper, J., & Crowther, C. A. (2018). Enablers and barriers for women with gestational diabetes mellitus to achieve optimal glycaemic control—a qualitative study using the theoretical domains framework. *BMC Pregnancy and Childbirth*, 18(1), 91.
- Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *British Medical Journal*, 320(7226), 50-52.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*, 151(4), 264-269.

National Institute for Health and Care Excellence [NICE] (2015). Diabetes in pregnancy: management from preconception to the postnatal period NG3 (NICE, London). Retrieved 27 Oct 2018 from: <https://www.nice.org.uk/guidance/ng3>

Nielsen, J. H., Olesen, C. R., Kristiansen, T. M., Bak, C. K., & Overgaard, C. (2015). Reasons for women's non-participation in follow-up screening after gestational diabetes. *Women and Birth*, 28(4), e157-e163.

Office for National Statistics (2011) Ethnicity and National Identity in England and Wales: 2011. Retrieved 02 Jan 2019 from: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11>

Oza-Frank, R., Conrey, E., Bouchard, J., Shellhaas, C., & Weber, M. B. (2018). Healthcare experiences of low-income women with prior gestational diabetes. *Maternal and Child Health Journal*, 22(7), 1059-1066.

Parsons, J., Ismail, K., Amiel, S., & Forbes, A. (2014). Perceptions among women with gestational diabetes. *Qualitative Health Research*, 24(4), 575-585.

Parsons, J., Sparrow, K., Ismail, K., Hunt, K., Rogers, H., & Forbes, A. (2018a). A qualitative study exploring women's health behaviours after a pregnancy with gestational diabetes to inform the development of a diabetes prevention strategy. *Diabetic Medicine*, 36(2), 203-213.

- Parsons, J., Sparrow, K., Ismail, K., Hunt, K., Rogers, H., & Forbes, A. (2018b). Experiences of gestational diabetes and gestational diabetes care: A focus group and interview study. *BMC Pregnancy and Childbirth*, 18(1), 25.
- Persson, M., Winkvist, A., & Mogren, I. (2010). 'From stun to gradual balance'—women's experiences of living with gestational diabetes mellitus. *Scandinavian Journal of Caring Sciences*, 24(3), 454-462.
- Purnell, L. (2002). The Purnell model for cultural competence. *Journal of Transcultural Nursing*, 13(3), 193-196.
- Richards, T., Coulter, A., & Wicks, P. (2015). Time to deliver patient-centred care. *BMJ (Clinical Research Ed.)*, 350, h530.
- Ruggiero, L., Spirito, A., Bond, A., Coustan, D., & McGarvey, S. (1990). Impact of social support and stress on compliance in women with gestational diabetes. *Diabetes Care*, 13(4), 441-443.
- Smith, J. A. (2015). *Qualitative psychology: A practical guide to research methods*. Sage.
- The Kings Fund (2018) Shared responsibility for health: the cultural change we need. Retrieved on 02 Feb 2019 from: <https://www.kingsfund.org.uk/publications/shared-responsibility-health>
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45.

- Van Ryswyk, E., Middleton, P., Shute, E., Hague, W., & Crowther, C. (2015). Women's views and knowledge regarding healthcare seeking for gestational diabetes in the postpartum period: A systematic review of qualitative/survey studies. *Diabetes Research and Clinical Practice*, 110(2), 109-122.
- Wah, Y. Y. E., McGill, M., Wong, J., Ross, G. P., Harding, A. J., & Krass, I. (2019). Self-management of gestational diabetes among Chinese migrants: A qualitative study. *Women and Birth: Journal of the Australian College of Midwives*, 32(1), e17-e23.

Chapter 2: Empirical paper

The lived experience of males with complications of Type-2 Diabetes
and symptoms of low mood: An Interpretative Phenomenological
Analysis

Written in preparation for submission to: *Qualitative Health Research*

(see Appendix E for author guidelines)

*Overall word count at time of submission (excluding tables, figures, footnotes and
references): 7953*

2.0 Abstract

Aim: The current study aimed to provide an in-depth understanding of the experiences of men with Type-2 Diabetes Mellitus (T2DM), low mood and diabetic complications. Evidence suggests low mood accelerates the development of diabetic complications and reduces adherence to positive health behaviour. Men with T2DM have been found particularly susceptible to low mood, yet are underrepresented in psychological services. Currently there is limited understanding about men's lived experiences of T2DM, low mood and diabetic complications.

Method: Six men, aged 48 to 70 took part in semi-structured interviews. Methods and analysis were informed by Interpretative Phenomenological Analysis.

Results: Following analysis, two superordinate themes were identified: "*My needs are not important*" and "*I know but I don't want to know*". Results suggested a complexity in the men's experiences, with many conceptualising early life experiences as influencing diabetes self-care and help seeking.

Conclusion: Participants' lived experiences are discussed in relation to the current evidence base and implications for clinical practice. Future research directions are suggested.

Keywords: Diabetes Mellitus; Men; Depression; IPA

2.1 Introduction

2.1.1 Background

In the UK, diabetes affects approximately 3.8 million people (Diabetes-UK, 2018). There are different forms of diabetes, but all share the same central feature of hyperglycaemia (raised blood glucose levels). Type 2 Diabetes Mellitus (T2DM) accounts for 90% of cases in the UK (NCCCC, 2008). It can lead to physical complications including kidney failure, eye disease, amputation, neuropathy and early mortality (Diabetes-UK, 2015). Over 100 diabetic-related amputations are carried out per week. Four out of five of these are reported to be preventable, as they are often preceded by a treatable foot ulcer (Khanolkar, Bain & Stephens, 2008). Self-monitoring and timely presentation in seeking treatment is essential to reduce the risk of such complications.

The NHS spends £9.8 billion pounds per year on diabetes and around 80% of this relates to treating diabetic complications (Diabetes-UK, 2015). Good glycaemic control is associated with reduced incidence of diabetic complications (Stratton et al., 2000). Clinical trials have demonstrated that glycaemic control can be achieved by lifestyle practices of eating a healthy diet, exercising, regular self-monitoring of blood glucose levels (BGLs) and for some, using medication (UKPDS, 1998). Weller, Baer, Nash and Perez (2017) however reported that over time, adherence to self-management practices diminishes. Common risk factors for diabetic complications include obesity, smoking, lower socio-economic status and depression (Diabetes UK, 2015).

2.1.2 Clinical Implications of Depression

The prevalence of depression in people with T2DM is estimated to be twice that of the general population (Mezuk, Eaton, Albrecht & Golden, 2008). Low mood may accelerate development of diabetic complications and reduce adherence to self-management practices (Gonzales et al., 2007; Lustman et al., 2000; Musselman, Betan, Larsen & Phillips, 2003). Previous research postulates that people with low mood are less able to sustain positive health behaviours including dietary management and exercise, increasing their risk of diabetes and diabetic complications (Gavard, Lustman & Clouse, 1993; Wing, Marcus, Blair, Epstein & Burton, 1990). Low mood is also more prevalent among people managing diabetes with medication (Golden et al., 2008; Sankar et al., 2018).

A study exploring patients' attitudes, wishes and needs with diabetes (DAWN) indicated depression coincided with feelings of hopelessness, anxieties about hypoglycaemia, public misunderstanding about diabetes and experiences of discrimination at work (Stuckey et al., 2014). This study collected personal accounts from 7,228 people with T2DM using open-ended questionnaires. Although the data provided increased insight into the psychosocial perspectives of having diabetes, the questionnaires limited data collection to short-written answers. This compromised the richness of the information collected and flexibility for probing of participants' responses.

In an epidemiologic study of 3474 adults with T2DM, clinical depression was associated with a 2-fold higher risk of incident diabetic foot ulcers (Williams et al., 2010). Other studies have demonstrated increased incidence of microvascular and macrovascular complications in people with T2DM and low mood (Pan et al., 2011).

Even symptoms of low mood at a subclinical level in T2DM have been found to reduce adherence to important aspects of diabetes self-management, increasing the risk of morbidity and mortality (Gonzalez et al., 2007; Gonzalez & Esbitt, 2010; Katon et al., 2008). Although the prevalence of depression in the general population is higher in women, the ratio for depression in patients with T2DM is higher in men (Ali, Stone, Peters, Davies & Khunti, 2006). Further, depression and poor medication adherence has also been shown to be more strongly associated in men (Nau, Aikens, & Pacholski, 2007). This is concerning in light of evidence that suggests men deter help-seeking, and are underrepresented in psychological services (Seidler, Dawes, Rice, Oliffe & Dhillon, 2016).

2.1.3 Unmet psychological need

With emerging research, the importance of psychological care in diabetic health is gaining recognition. For example, specialist primary mental health services for people with long-term conditions like diabetes have been set up in response to the UK government's policy "No Health without Mental Health" (Department of Health, 2011). The Improving Access to Psychological Therapy (IAPT) programme is a service delivered by the National Health Service (NHS), offering a stepped-care approach of psychological therapies to people with depression and long-term conditions (NHS England, 2016). There is concern however that this approach may not be fully meeting the needs of people with diabetes. The most commonly available intervention offered by IAPT, Cognitive Behavioural Therapy (CBT) has been found by a systematic review of randomised control trials to have little effect on improving self-care behaviour, weight management or glycaemic control (Ismail, Winkley & Rabe-Hesketh, 2004). This finding was echoed in a study by Delgadillo, Dawson,

Gilbody and Böhnke (2017) who found challenges in delivering stepped-care psychological therapies in isolation from physical healthcare specialists. These findings suggest that co-occurring physical health and psychological difficulties may be a complex experience which would benefit from further consideration.

2.1.4 Rationale

As outlined above, the issue of T2DM is a rapidly growing public health concern, with significant costs both personally to the individual and financially to the economy and healthcare system. To date, research findings denote that socioeconomic status, lifestyle and psychological factors such as depression complicate self-management and increase risks of physical complications (Diabetes UK, 2015). The prevalence of depression in people with diabetes is twice that of the general population (Mezuk et al., 2008). Psychological services have attempted to improve access to therapies for people with diabetes, but their effectiveness has been questioned (Ismail et al., 2004; Delgadillo et al., 2017).

Stuckey et al. (2014) highlighted that people with T2DM may be experiencing a variety of intrapersonal and interpersonal difficulties that complicates their management. However, paucity of qualitative research grounded in interpretative phenomenology has limited our understanding about how these difficulties are experienced. Opportunity to hear the experiences of men with T2DM is particularly pertinent considering evidence that suggests men are more susceptible to depression and underrepresented in psychological services (Ali et al., 2006; Seidler et al., 2016). Gaining further understanding about how men experience living with T2DM, complications and symptoms of low mood could help increase clinicians' knowledge about potential unmet need. Using an interpretivist approach has potential to unearth

potentially complex phenomena which previous research has not yet been able to address. These findings may further inform the direction of future research.

2.1.5 Aims

The primary aim of this study is to understand: what are the lived experiences of men receiving treatment for T2DM in the UK who share the common experience of T2DM, low mood and diabetic complications?

2.2 Method

2.2.1 Research Design

The researcher's constructivist epistemological position assumes reality as we know it is constructed subjectively through the meanings and understandings developed socially and experientially (Cohen & Crabtree, 2006). Therefore, a qualitative phenomenological approach was chosen to meet the study aims of gaining a rich, subjective understanding of how men with complications of T2DM and low mood make sense of this life experience.

2.2.1.1 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a well-established framework that takes an idiographic focus on gaining detailed understanding of human lived experiences. IPA's epistemological position assumes that the only way to develop a true understanding of T2DM and depression in men with diabetic complications would be to explore how they make meaning of their lived experience. The researcher therefore adopts an interpretative and reflective position within their own framework

of experience to analyse the narratives of participants' self-directed stories (Smith, Flowers & Larkin, 2009). Consequently, IPA is more suitably positioned to understand how people make sense of their experiences over other qualitative methods, which aim to develop explanatory theories (e.g. grounded theory) or focus on functional aspects of dialogue (e.g. discourse analysis) (Starks & Brown-Trinidad, 2007). Further, IPA is a well-established approach in areas concerned with complexity, process or novelty, as it seeks to understand both similarities and differences in experiences of a shared phenomenon (Smith & Osborn, 2003). For that reason, IPA has built a strong standing in the area of health psychology, where the complexity of experiences of illness are recognised (Arroll & Senior, 2008; Marriott & Thompson, 2008; Reynolds & Lim, 2007)

2.2.2 Participants

Given the complexity of human phenomena, a small sample size of six men were recruited to the study consistent with recommendations set out within the IPA framework (Smith et al., 2009).

2.2.2.1 Inclusion/exclusion criteria

IPA is concerned with homogeneity and interpretation of perspectives from people who share similar characteristics and experiences, rather than a population. Participants were therefore recruited based on the inclusion and exclusion criteria set out in Table 2.1.

Table 2.1: Inclusion and exclusion criteria

Criteria	Detail
Inclusion criteria	i. Identified with being male gender
	ii. A confirmed diagnosis of Type 2 Diabetes Mellitus (T2DM)
	iii. Low mood ⁹
	iv. At least one form of physical complication of T2DM ¹⁰
	v. Aged 45 years or older ¹¹
	vi. Residing and receiving health care within the UK
Exclusion criteria	i. Other long-term conditions unrelated to T2DM including Type 1 Diabetes ¹²
	ii. Non-English speaking ¹³

The demographic characteristics of the six participants are displayed in Table 2.2. Pseudonyms were created to protect their identities.

⁹ Based on previous research, at a subclinical or clinical level

¹⁰ Indicates prolonged periods of hyperglycaemia/poor control

¹¹ Ensures generational homogeneity and denotes most common age of T2DM onset

¹² May be experienced differently to T2DM

¹³ Interpretative Phenomenological Analysis is focussed on a person's dialogue which may be lost through the use of an interpreter

Table 2.2: Participant characteristics

Name ¹⁴	Age	Ethnicity	Highest Level of Academic Attainment	Type 2 Diabetes related complications	Marital Status
Alan	68	White British	GCSE equivalent	Micro-vascular	Married
John	61	Black British	GCSE equivalent	Neuropathy; Micro-vascular	Married
Francis	65	White British	Some secondary school	Neuropathy	Widowed
Mike	48	White British	GCSE equivalent	Neuropathy	Single
Donald	69	White British	Some secondary school	Macro-vascular (amputation)	Married
Ian	70	White British	A-Level Equivalent	Neuropathy; Cardiovascular disease; Macro-vascular (amputation)	Married

2.2.3 Procedure

2.2.3.1 Ethical procedures

This study adhered to ethical guidelines set out by the British Psychological Society (BPS, 2014) concerning participant confidentiality, informed consent, right to withdraw, minimising risk and offering appropriate debrief. Ethical approval was granted by Coventry University Ethics Committee (Appendix F) and Solihull and West Midlands NHS Research Ethics Committee (Appendix G). The study was subsequently registered with Health Research Authority (HRA) NHS England

¹⁴ Pseudonym

(Appendix H). Permission to recruit was consequently granted by the host NHS Trust's Research and Innovation team (Appendix I).

2.2.3.2 Materials

A semi-structured interview guide was developed with guidance from the IPA framework (Smith et al., 2009) alongside academic and clinical supervisors with health psychology research experience (Appendix J). The guide, which contained open-ended questions was designed to be unobtrusive, flexible and brief, to allow participant-led exploration of concepts that emerged as part of their disclosures. The main function of the interview guide was to facilitate open-ended prompts if necessary and allow for deeper probing of participant responses (Opdenakker, 2006; Smith et al., 2009). Questions were designed to be sufficiently open to allow participants to share perceptions that were of importance to them and limit researcher bias. Other materials included a demographic questionnaire (self-completed by participants) to obtain participant characteristics (Appendix K); a poster that was displayed in clinical areas to advertise the study (Appendix L); and a recruitment referral form containing information about inclusion/exclusion criteria (disseminated to health care professionals (HCPs) involved in recruitment) (Appendix M).

2.2.3.3 Recruitment Procedure

Participants were recruited by a purposive sampling method set out by inclusion/exclusion criteria. This method was necessary to ensure a homogeneous sample. Clinicians working within a community diabetes service provided a letter (Appendix N), participant information sheet (Appendix O) and consent to contact form (Appendix P) to individuals who were potentially eligible to participate. Of the sixteen people who received this information, seven individuals responded, all of whom met

the criteria. One individual decided not to participate due to personal circumstances. Family general practitioners (GPs) of the remaining six participants were notified of their participation in the study (Appendix Q). Due to slow recruitment and limitations to staff capacity, interviews were conducted between November 2017 and February 2019. To ensure continuity of the researcher's experience, notes were made in a reflective journal concerning thoughts, processes and emerging themes that were notable at the time of interview. Transcription was conducted immediately prior to analysis to further aid continuity.

2.2.3.4 Interview Procedures

All six interviews were held in private consulting rooms within NHS clinical departments familiar to participants. Interviews, which were one-to-one between the participant and researcher were audio recorded and ranged in duration from 82 minutes to 104 minutes ($M = 94$ minutes, $SD = 6$). Prior to interview participants were refreshed on the details within the information sheet, given opportunity to ask questions, and their wish to participate was re-confirmed. Participants checked and signed the consent form (Appendix R) and then completed the demographic questionnaire. Following the interview, details contained within a debrief sheet were discussed with the participant and further time was offered for questions. Participants were supplied with a copy of the debrief form to keep (Appendix S).

2.2.4 Analysis

Interviews were transcribed verbatim with personal information replaced with pseudonyms or omitted. Data was analysed using the IPA framework as described by Smith et al. (2009) consisting of eight separate stages (Appendix T). This included the researcher becoming immersed in the participants' experiences by closely reading and

re-reading the transcripts to identify with their thoughts, motivations and feelings. Initial coding of disclosed experiences contained descriptive, conceptual and linguistic constructs. Following initial coding (see an excerpt of coding in Appendix U), the researcher produced interpretations leading to the development of themes. This process was mapped out visually to represent the emergence of themes (Appendix V). To ensure credibility, once the initial overarching thematic structure emerged, transcripts were re-read to clarify the accuracy of the evolving themes. In addition, several quotes from the data were extracted and compared to the developing themes. To confirm the researcher's interpretations were aligned with participant disclosures, one transcript was selected at random and co-coded by another researcher; codes were compared and discussed. Finally, data verification was completed with members of the wider research team. This allowed insightful interpretations of nuances, ambiguity or complexity in the participants' disclosures.

2.2.4.1. Reflexivity

The researcher approached the study with professional experience as a trainee clinical psychologist working therapeutically with patients in a diabetes psychology service. Although total objectivity is undesirable in qualitative research (Ahern, 1999), and the researcher is embraced as an inherent part of the process, the researcher's preconceptions must not divert the participants from delivering the accounts of their own personal experiences. Therefore, the researcher must possess awareness of their own subjectivities and be open to hearing something unexpected in order to allow the participants' experiences to dominate. To facilitate this process the main researcher took part in a bracketing interview prior to interviewing participants. Subsequently the researcher kept a reflective journal to assist with observing their personal responses to

the phenomena being studied during both interviews and analysis, in addition to regular supervision.

2.3 Results

Two superordinate themes emerged from the data. The first theme, “*my needs are not important*” encompasses men’s accounts in which they question their importance to others and whether their needs can even be met. Narratives relating to early life experiences are conceptualised as relating to these difficulties. The second theme, “*I know but I don’t want to know*” represents a complex conflict centred on what the men recognise as denial, knowing what they need to do to look after themselves, but not having capacity to relinquish the lifestyles they know. Superordinate and subordinate themes are summarised in Table 2.3.

Table 2.3: Superordinate and subordinate themes

Superordinate theme	Subordinate theme
<i>Theme 1: “My needs are not important”</i>	“I don’t think I can get any help with it” “It’s a childhood thing...”
<i>Theme 2: “I know but I don’t want to know”</i>	“Behaving like I don’t have it but knowing that I have” “It’s easy to sweep under the carpet”

2.3.1 Theme 1: “My needs are not important”

All the men repeatedly disclosed experiences which indicated they questioned their worth and importance to others. Diabetes put the men into an uncomfortable position of needing support from others; but with doubts about whether they were important enough for care to really be there. The men often described feeling down about themselves, and were quite isolated with these experiences, preferring to manage by themselves rather than rely on other people. Within this theme two subordinate themes emerged and are titled using men’s direct quotes; *“I don’t think I can get any help with it”* and *“It’s a childhood thing”*.

2.3.1.1 *“I don’t think I can get any help with it”*

The men regularly expressed doubt about HCPs and healthcare systems being able to meet their needs. This seemed to be underpinned by an uncertainty in trusting others to consider them as important, or to trust that they would be able to provide what they needed. Linguistic tones of wanting to avoid feelings of shame and embarrassment were also weaved through the men’s narratives. Subsequently, the men disclosed tendencies to withhold information, avoid seeking help altogether and a preference for isolating themselves. Further, many of the men’s diagnoses were a result of their partners’ prompts to get checked. Some men attributed not seeking help to being related to masculinity. For example, Francis said:

She [wife] rang the surgery up to see if the doctor would also see me. I wouldn’t have gone but I thought it was still an appointment for the wife and it wasn’t until we got called in that I realised she had changed the appointment

to be me. I suppose it's one of those things...it's a man thing.

(Francis, lines 186-189)

Although, later in the interview he described an underlying worry about not being listened to:

I get worried about how my responses would be received. Not being listened to. Coming across stupid....I don't...I suppose I hold it in and try and manage it all by myself you know. Like I said it's nobody else's problem.

(Francis, lines 216-218)

In fact, many of the men, in the first instance, seemed to frame their lack of help seeking as being related to masculinity. John perceived a female dominance in healthcare and discussed reluctance to speak to female clinicians or engage in all-female groups as he didn't trust they would relate to him being a man. However, like Francis, many of the men appeared to later consider internal insecurities and uncertainties about trust. Alan described finding it “*hard to trust*” how HCPs might respond, leading him to withhold his problems. He felt that seeing different HCPs did not help his confidence:

I don't like to make a fuss. It's hard to trust, you don't see the same doctor. You don't know how they are going to respond.

(Alan, lines 188-189)

Alan disclosed that due to “*embarrassment*” he had not discussed symptoms of impotence which were having a significant impact on his mood and relationship with his wife. This experience was shared by John:

This is a serious problem for me [impotence] and it does play a massive part with how I am feeling...I found it very difficult to talk about it and I am still having an ongoing conversation with myself

(John, lines 298-300)

Two of the men's expectations of their needs not being important to HCPs appeared linked to perceived discrimination relating to their age. Their language portrayed concern that they had lost their strength and power in society, which led them to question their worthiness to others. Donald stated, "*Because if you get to 65 in this country you are worth nothing*". This also seemed linked with the men feeling as though they had lost respect, as discussed by Alan:

It's quite a shock getting old how much respect you lose. I don't feel valued anymore. It reduces your confidence. You hear from older people when you get to 65 the NHS stop caring less because you haven't got much life to lose. I hear that a lot...it is a worry and if that is the case then what is the point

(Alan, lines 252-257)

Many of the other men felt unimportant to HCPs and experienced them as "*too busy to listen*" or "*not bothered*". When the men perceived the HCPs in this way it led some of them to feel less motivated about their diabetes. For example, Ian disclosed:

We've [practice nurse] got a strange relationship as far as the diabetes is concerned because she didn't seem bothered one way or the other.

(Ian, lines 161-164)

I do mine twice a day [test BGLs]. Not that it really matters because I've done it religiously for ages and nobody's ever looked at them....doesn't give you much motivation.

(Ian, lines 569-572)

Three men discussed wanting franker discussions with their clinicians, in order to startle them into action. Mike disclosed about a recent encounter where a doctor was forthright about the reality of his diabetes and the risk to his health:

Nobody's ever said to me, Mike you've got to stop. The chocolate bars, the drinking. You have got to stop this or else it's going to kill you. Nobody's ever said that to me until I went to a medical last week that made a difference.

(Mike, lines 105-108)

It was unclear from these men's disclosures why they felt franker discussions might be more meaningful for them. Further, there was divergence in opinions about the response style of clinicians, with other men preferring a less authoritarian approach. This highlighted individuality in ways the men wished to receive care. Alan had a unique experience where he felt his HCP spoke to him too gravely:

...she [practice nurse] gave me the feeling that I needed to sit down and this was like announcing I had six months to live, or something like that. She treated it very gravely...I thought that was a bit over the top...

(Alan, lines 3-7)

When men experienced distress or uncertainty, they all described preferences to isolate themselves, rather than connecting with others. Four men spoke about escapism,

immersing themselves into activities such as carpentry, model train building, online videos and stamp collecting. There was difference in how the men made sense of this withdrawal. Alan disclosed difficulties relating to people and a desire for his own company, describing life with no friends. He spoke about being “*forced*” into socialising due to his wife having many friends, and the uncomfortable feelings he experienced in their company trying to be “*nice and uncontroversial*”, despite feeling frustrated and low in mood. He made sense of his withdrawal as being due to depression, something he considered people would not want to see:

Look at me I'm depressed. People don't want to see that. I don't see the point in going somewhere if I couldn't avoid being like that [depressed] and I would avoid situations if I could.

(Alan, lines 58-59)

Mike discussed withdrawal from socialising with friends due to perceiving diabetes being a weakness, and something that would make people look at him differently. This seemed to circulate around trust, not trusting others to respond to him as just Mike:

I would hide away because I just felt you know it was a weakness or somebody would perhaps look at me differently because I've got diabetes. Not a normal person. Baggage.

(Mike, 153-155)

2.3.1.2 “It’s a childhood thing”

Five men made sense of their uncertainties about seeking help for their diabetes as stemming from difficult childhood experiences. Four of them described emotionally unavailable parents who, for various reasons, put their own needs first. There was a real sense of disadvantage and deprivation in their lives, with limited opportunity to experience attuned and nurturing caregivers. These occurrences limited opportunities for the men to experience being prioritised, and therefore appeared to lead to the underlying beliefs of “*my needs are not important*”. Many experienced corporal punishments. Alan, who used to be physically hit and “*shoved*” under the stairs by his “*cold*” father gave examples of suppressing and neglecting his needs from an early age:

I don't reach out to people. It is a childhood thing. My family were like that. If something unpleasant happened at school I wouldn't come home and tell my parents. If I told my father, he would probably say hit them back or something like that. There wouldn't be any point. I remember the first day at school not having a chair and squatting, pretending I did have a chair because I didn't like saying anything... It's trying to manage things by myself again, feeling embarrassed asking for help.

(Alan, lines 88-102)

I suppose if your own parents can't be interested in you why should anyone else be?

(Alan, line 162)

Alan made sense of his reluctance to ask for help as linked to embarrassment. He discussed familiar feelings of inadequacy from childhood, where needing help would lead to humiliation or shame. This was mirrored in the accounts of Dave, Francis and Mike who experienced diabetes as something they were “*getting wrong*” and connected them also to feelings of inadequacy. Mike expressed:

This is why I've struggled with diabetes. I can't face anything that I am not good at...it's always been there since being belittled in childhood... it makes me feel bad about myself...

(Mike, lines 170-172)

Two men normalised their experiences as being “*of that era*”, referring to the generation they were raised. John identified that through childhood he had “*learnt*” to become self-reliant and described it as “*very Victorian*”. He connected that not having opportunities to “*learn how to seek help*” or be responded to as a child limited his capabilities to do so as an adult. Francis shared those sentiments in explaining his difficulties in talking to others and expressing himself:

The old saying was children should be seen and not heard. Especially at meal times. You eat it you don't say a word. I think that's where it all stems from generationally... Even without the grandparents and people around. You never spoke to them [people] only if they spoke to you...Even now. When I go out for a meal, I sit and eat my meal. Won't say a word half of the time. It has really stuck with me.

(Francis, lines 303-309)

Aside from difficult parental relationships, some found school a chastising experience, which appeared to have a long-term impact on how the men viewed their capabilities and importance. Francis spoke about “*embarrassment*” reading in class and the teacher having a “*good go at him*” if he got anything wrong. This experience led him to question his abilities and he described long-lasting anxieties in adulthood about making mistakes. Mike described being “*penalised and banished*” at school which undermined his self-esteem and sense of capability:

I don't think the school should have allowed that to happen. It really made me feel bad about myself. There was one teacher...I was reading, trying to read a book you know and it wasn't going through and she actually pierced her nail straight through my ear and made it bleed everything...As far as schooling went I was penalised and banished (...) I just got on with it in silence I suppose.

(Mike, lines 473-483)

Beyond doubts about getting help, these experiences seemed to limit the men in prioritising their diabetes, due to questioning of their capability and fears about getting it wrong.

2.3.2 Theme 2: “I know but I don’t want to know”

The verbatim quote “*I know but I don't want to know*” presents the second superordinate theme. It reflects a purposeful denial of diabetes, of which most of the men were aware. As a response to internal feelings of vulnerability, the men described building lives aligned with notions of strength, power and capability. Denial coalesced around the men’s ideas of diabetes being a weakness and a threat to the lives they had built. The desire for strength and capability seemed to be driven by normative beliefs

about 'being a man'. The men experienced masculinity as a way to separate from their internal world. In a similar way, the men were reluctant to relinquish ways they emotionally coped (e.g. comfort eating), which conflicted the dietary changes diabetes demanded. This superordinate theme, consisting of two subordinate themes, highlights the men's conscious difficulties to prioritise T2DM, depicting incompatibility with the ways they have learned to live and cope.

2.3.2.1 “Behaving like I don’t have it but knowing that I have”

From early experiences that relate to isolation, physical punishment and emotional unavailability, the men offer unique narratives that reflect adaptive journeys towards self-reliance and emotional security. Each journey is underpinned by a motivation for emotional self-preservation. The drive for self-preservation is a stark contrast to their neglect of T2DM which paradoxically could result in premature self-demise. It perhaps indicates the men are prioritising their psychological wellbeing over physical needs. Herein lies the conflict described by the men as “*I know but I don’t want to know*”, an internal battle which centralises around the men's experiences of knowing what they need to do to look after themselves, but not wanting to relinquish the lifestyles they know. Aspects of lifestyle discussed as most difficult to change appear related to mechanisms of externalised ways of coping. This includes ways of emotionally self-soothing and lifestyles that align them with a position of power and masculinity. This paradox is recognised in linguistic undertones portraying an unrelenting “*war*” or “*battle*”, with the men knowing what they need to do but feeling unable. This was illustrated in Mike's disclosure:

It's a constant war, it is a constant battle with it because you just you don't want to feel like that [low] so you carry on and be as normal as you can. Have

a good life. If you don't you get low in mood, so you dismiss it all, it's easier not to think about it.

(Mike, lines 447-450)

Ian emphasised that for him, it was not a case of not knowing what to do:

I mean I am not stupid I know about diet. It's about one's own willpower

(Ian, line 476)

Similarly, other men echoed the 'knowing what they needed to do' but described resistance about changing their lifestyle. One obstacle appeared related to the high importance the men placed on working, often working long hours by choice. These long hours were often blamed for erratic eating patterns and missing medications. Even though many were now retired, they still had found ways to keep busy which interfered with their self-management. Some men described the function of working as distracting from difficulties and internal insecurities. Donald illustrated this:

If I'm not busy I get bored very quickly. I get easily bored very quickly and if it goes on...I have been known to. There's a danger...to go in the direction of...[referred to suicidal thoughts]

(Donald, lines 217-219)

Mike experienced work as providing achievement and a sense of capability. This was quite a strong contrast to linguistic repetitions of "weak" and "feeble" when describing how he experienced diabetes. He explained that with working for himself he could reduce his hours if he wanted to, to facilitate a more diabetes friendly lifestyle. He fully recognised how the regime of regular meals and insulin did not fit

with his current lifestyle. Like with the other men, the “good-feeling” from work appeared be prioritised over his physical needs. He discussed work as the traditional thing to do, again aligning his position with ‘the strength’ of being a man:

When I’m out working. It’s the only time I feel I am achieving something. It makes me happy because I’m out doing something.

(Mike, lines 358-360).

You know I worked hard to support the four step-children. That’s how I see things (...) where I’ve grown up from it was the man that was expected to go to do the work you know.

(Mike, lines 515-520)

Ian also discussed how working to provide was an important aspect of being a man. He expressed how he thought some men probably did not see the doctor due to consequences of “going into hospital” or “packing up work”.

Working was not the only mechanism that led participants to neglect their diabetes. In addition, they all had intimate relationships with food. The function of food, like working, was connected to “good-feeling” and appeared to help the men emotionally self-regulate. Being unable to relinquish temptation of food often led to feelings of “guilt”. Three men discussed over-using insulin to carry on eating as they always had. This resulted in them using the maximum dosage per treatment, which they recognised to be associated with weight gain. When considering their relationship with food, five men experienced it as emotionally nourishing. Donald disclosed that even though he knew it was unhelpful for his diabetes, he just could not help himself:

My higher readings are because I do a lot of comfort eating. That's it. There is no other reason. I am the one that sits at the fridge and the missus says oh you're not having any more and I'll go yeah, I am just a couple more squares of Aero or whatever. And when I'm finished, I think you're mad.

(Donald, lines 511-516)

John initially normalised his unhealthy eating as part of “*societal makeup and convenience*” but later acknowledged it as emotionally soothing:

My eating is mood-driven, I know most of the time I am eating the wrong things, but I eat it anyway. I know I have got to try to correct that behaviour because my mood is all to do with weight and how I look. Even though I know if I eat what I want to eat shouldn't happen, the urge is so great because I am angry. It is so great just to get some kind of comfort....then it effects my blood sugars and it is a vicious circle.

(John, lines 279-287).

For a few men, eating and drinking was complicated by peer pressure and fear of social disapproval. Ian described how he accepted and enjoyed “*too much lovely Italian food and wine*” his friend would bring for him for fear of offending him. Similarly, he struggled to refrain from participating in office rituals like going to the pub after work, with no healthy options but “*fish and chips*”. Mike also disclosed occasions where he had felt unable to turn food down for fear of upsetting others:

I'd be on 8 or 9 curries every night. That's what started it off. Because I don't want to say no without a reason because I feel that they are offended if I say no, certainly in the Turkish and they see you having food is it is a complement to them.

(Mike, lines 263-266)

Putting the needs of others first was something the men related to masculinity. All identified with the position of needing to be the provider and the pillar of the family. Francis was concerned about supporting problems within his family, so consequently he considered his own needs last:

I've got too much else cooking in the pot. Bigger fish to fry as my mum would have said. It isn't possible to try and deal with it all.

(Francis, lines 410-412)

2.3.2.2 “It’s easy to sweep under the carpet”

Five men spoke about the invisibility of diabetes as facilitating their ability to “*behave like they don’t have it*” and continue with the lifestyles of their choosing. Lack of symptomology appeared to incite disbelief in the men’s responses to their diagnosis, depicted by phrases like “*how the hell have I got that*” and “*this can’t be happening to me*”. There also seemed to be a disconnect between diabetes and physical complications, as all of the men were referred to the study having complications of diabetes but some spoke about being “*symptomless*”. Two men pondered what would happen if they just stopped their medication altogether. Ian who had required a toe amputation and had cardiovascular disease said:

There was nothing obvious that this was actually happening to me. It's easy to sweep under the carpet.

(Ian, lines 171-172)

I mean there's a few times when I thought well I wonder if I just stopped taking everything if I'd get away with it what would happen...

(Ian, lines 245-237)

Even directly witnessing the potential severity of diabetes did not help Mike relate to having the condition. He discussed how visiting his uncle in hospital with severe physical complications of diabetes did not motivate him to change as he still “*couldn't register*” this as happening to him. Francis connected the lack of symptomology as something that facilitated his denial:

I know I've got it but I don't pay any attention to knowing I've got it if you know what I mean. Like I said...I'm not showing any ill effects. So that's all we need to know isn't it. I suppose it is denial in a way. I know I've got it but I don't believe it's going to do anything to me

(Francis, lines 353-356)

When the men did adhere to the T2DM management regime it appeared risk-reactive. For example, when problematic symptoms occurred (e.g. the diabetes became visible) the men described better adherence to the recommended self-management practices. Mike spoke about a dichotomy between having no symptoms and being able to live like he does not have it, but then living like he does not have it, which leads to symptoms. This experienced was shared by Alan:

When I am feeling alright it is something I don't worry about so much...I can cast it aside...I can't see it. There is no thoughts about monitoring it. It is other people like [wife] that make me feel guilty like...hey don't eat those chips you have diabetes...I just feel overwhelmed by the changes I have to make, I can't stick to the changes, I eat crisps, I feel it is ruining my life, and then I notice I am not even ill yet and I wonder why...so I ignore it and I carry on. I suppose it doesn't really ever go away though does it

(Alan, lines 219-221)

None of the men tested their BGLs as regularly as recommended and some avoided it altogether. Three men discussed how BGLs were sometimes their only indicator of their illness, and therefore knowing their BGLs increased their awareness and led to feelings of “*frustration*” and preferences to avoid it. John reported high readings as making him feel “*guilty*” as it increased his awareness that he was failing with his diabetes. Ian disclosed complete apathy towards testing his BGLs, admitting his twice a day testing (prompted by his wife) was only to ensure he could legally drive to “*avoid getting into trouble*”.

2.4 Discussion

2.4.1 Summary of main findings

This study revealed the experiences of six men living in the UK with T2DM, physical complications and low mood. Two superordinate themes emerged, embodied by phenomena relating to men's conflicts in seeking help and sustaining positive health behaviours. The first theme, “*My needs are not important*” encompasses men's narratives which are questioning of their importance to others and if their needs can

even be met. The second theme, *“I know but I don’t want to know”* represents a complex conflict centred on the men knowing what they need to do to look after themselves but not having capacity to relinquish the lifestyles they know

2.4.1.1 Theme 1: “My needs are not important”

A mosaic of narratives in the theme *“My needs are not important”* offer a deep understanding about the men’s experiences of seeking support and self-care. The men initially made sense of deterring help-seeking as a *“man thing”*, however subsequently disclosed doubts about their importance to others and whether their needs could be met. These insecurities preceded patterns of withholding, isolation and difficulties sustaining T2DM self-care. These findings support research that denotes adherence to T2DM self-management practices may wane over time (Weller et al., 2017). It also supports previous findings that signify men as underrepresented in psychological services (Seidler et al., 2016). When the men conceptualised doubts about their importance, they immediately drew links to their childhoods. They made sense of the perceptions of themselves and availability of others as being influenced by early childhood experiences. The men experienced this as negatively impacting their diabetes self-care, drawing parallels with difficulties in help-seeking both as a child and adult. Some men placed importance on the emotional unavailability of parents and teachers, with few childhood opportunities to learn that others were dependable or described feeling chastened and inadequate when they did. These findings support research which has found attachment insecurities to adult caregivers has potential to impair physical health throughout the lifespan (Maunder & Hunter, 2008). Such complexities in the men’s experiences may explain why brief psychological interventions (that are goal-focussed around presenting symptoms and less focussed

on relational issues) have been found ineffective at improving self-care behaviour or glycaemic control (Ismail et al., 2004).

2.4.1.2 Theme 2: “*I know but I don’t want to know*”

From early experiences that related to isolation, physical punishment and emotional unavailability, the men offered unique narratives which reflected adaptive ways of developing lifestyles that aligned them with “*strength*” and “*capability*”, enabling emotional self-preservation. Herein lies the second significant theme, a complex conflict described by the men as “*I know but I don’t want to know*”. This signified an internal battle, interpreted by the men as “*denial*”; knowing what they needed to do, but not being able to relinquish aspects of their lifestyle to embrace the changes. The men described the importance of their lifestyles as a way of avoiding low mood, however this resistance led to poor patterns of self-care, contributing to premature morbidity. This supports findings that demonstrate low mood can accelerate the development of diabetic complications and reduce adherence to its management (Gonzales et al., 2007; Lustman et al., 2000; Musselman et al., 2003).

Adhering to healthier dietary practices was particularly problematic; with all the men identifying an intimate relationship with food, centred around emotional nourishment. Even with recognition that the effects were short-lived, subsequent guilt and weight gain were not enough for them to relinquish this behaviour. Of concern, three men recognised they were overusing their insulin to sustain their comfort eating. These findings may reflect hypotheses set out in the psychosomatic theory of obesity, where certain food types (usually with high carbohydrate and fat content) are associated with regulated affect due to synthesis of brain neurotransmitters, particularly serotonin (Kaplan & Kaplan, 1957).

In addition to dietary balance, self-monitoring and treating consistently with medication are important aspects of care (UKPDS, 1998). These self-management practices were described by the men as incompatible with their occupations. Further, despite being aware of potential consequences, the men resisted making changes to their work schedules, valuing work as a method of keeping busy; citing the importance of providing and feeling a sense of achievement. These functions were also allied with their perceptions of gender-appropriate norms. Even those in retirement elected to partake in community projects, local events and personal projects. For most, experiencing a sense of achievement was important in reducing low mood and increasing self-esteem. This concurs with previous research that identifies achievement being a central factor for male self-esteem (Josephs, Markus & Tafarodi, 1992). These findings additionally support previous research in T2DM that has identified patient resistance to changing well-established lifestyle choices (Booth, Lowis, Dean, Hunter & McKinley, 2013; Lidegaard, Willaing & Færch, 2016). Extending upon these findings, this study offers further insight of potential psychological complexity when expecting some patients to make lifestyle changes.

A further finding of this study indicates that men experience the hidden nature of diabetes as a further barrier to self-management. Even with diabetes complications and insulin regimes, many of the men still perceived an ‘invisibility’ of symptoms that enabled them to regard T2DM with less importance and live as though it did not exist. This has been previously discussed as an issue for non-insulin dependent patients (Whittemore, Melkus & Grey, 2004), however this research highlights this experience in insulin-dependent patients. Finally, the men placed importance on the roles of their partners in ameliorating this resistance and promoting positive health behaviours. This

finding supports a previous systematic review highlighting the mediating impact of family support (Pamungkas, Chamroonsawasdi & Vatanasomboon, 2017).

2.4.2 Methodological Limitations

This study has limitations. Interpretative Phenomenology Analysis (IPA) aims to deepen understanding about lived experiences in a given context, from a homogenous sample of participants with similar characteristics. A small homogenous sample size allows for the researcher to engage in in-depth analysis of the participants narratives. Although the purpose of qualitative research is not to generalise, the small sample size has reduced diversity in this study. The study was widely publicised in clinics within a city with a diverse multi-cultural population. However, all six men were British born, from similar socio-economic backgrounds; five being of Caucasian heritage and one of African-Caribbean heritage. As rates of diabetes complications are equally prevalent across all ethnic groups (Karter et al., 2002; Riste, Khan & Cruickshank, 2001), this study may be missing experiences unique to men from ethnic-minority groups.

This study recruited men who “*identified with low mood*”, in light of previous research which has associated low mood as a risk for diabetic complications. This inclusion criteria however assumes that the men can self-identify with their emotions and recognise low mood. This assumption may have unintentionally excluded men who could have made a valuable contribution to the research. This may also explain the absence of ethnic-minority men who may not immediately identify with a mental health issue, nor elect to seek help due to stigma (Gary, 2005).

2.4.3 Clinical Implications and future research

While this study should be considered within the context of its small sample size, it offers important considerations for clinical practice and policy. A complex interplay of intrapersonal conflict and interpersonal factors led men to predict or fear negative responses from HCPs and services. Further, the men considered their needs as unimportant, which complicated their relationships with HCPs. Increased insight of these complex experiences may help HCPs to know where to direct questioning during initial consultations. Service limitations, for example, irregular appointments and HCPs' availability being reduced by competing work demands, may have compounded men's beliefs of being unimportant and reduced their motivation further. Further, men described unique preferences in the style HCPs delivered advice and information. Practical steps taken by clinicians to avoid irregular care or inconsistencies where possible, in conjunction with psychologically informed patient-centred assessments to understand men's individual preferences could help improve the patient-provider experience. Further, opportunities to engage men's partners in their care may encourage the men's involvement and further improve engagement.

In light of the complexities men face relating to their health behaviours and psychological wellbeing, research should consider the apparent insufficiencies of brief psychological stepped approaches that do not fully resolve issues with self-care behaviour, weight management or glycaemic control (Ismail et al., 2004). Further, this study highlights a link to insulin misuse, with men using maximum doses to enable eating behaviour functioned around emotional regulation. Overusing insulin is linked with weight gain and the life-threatening condition of hypoglycaemia. This concerning behaviour highlights the complexities that may arise during the provision of

psychological assessment and support. In order to confidently identify such issues, psychological therapists supporting men with T2DM would benefit from training and access to diabetes specialists. This would ensure competency to raise awareness about such situations. These observations concur with recent calls for integration of psychological services for long term conditions into physical health care settings (Delgadillo et al., 2017).

It is recommended in keeping with the limitations of this study that future research attempts to explore the experiences of men from ethnically diverse backgrounds. This would improve our knowledge about how T2DM and diabetes complications are experienced in minority groups within the UK and help gain insight into possible cultural nuances connected to their experiences.

This study identified a connection of using insulin in replacement of making dietary changes, and this relationship appeared complicated by the strong emotional relationship the men had with food. Due to the present study's methodology, it is not possible however to ascertain whether this behaviour has high prevalence among the population. Further research should ascertain the prevalence and relationship between insulin misuse and emotional eating, particularly in light of the potential life-threatening consequences of overusing insulin.

A final consideration of future research may be to explore how HCPs experience providing care for this client group. This may help to better understand their part in how they interpret and respond to the men, particularly in situations where the men withhold or disengage from their care.

2.5 Conclusion

Empirical evidence suggests low mood is more prevalent in men with T2DM and reduces their adherence to self-management practices, increasing the risk of physical complications. Prior to this study, the lived experiences of the men with these difficulties were relatively unknown. The findings of this in-depth qualitative study suggest that men's experiences are complex, with men conceptualising early life experiences as influencing diabetes self-care and help seeking. The men recognise patterns of denial that helps separate them from their diabetes and internal vulnerabilities. Aligning themselves with societal ideologies of masculinity, pertaining to concepts of strength, respect and capability, is important to the men, but not always compatible with self-care. The findings reveal conflict where men disclose having little emotional capacity to make the changes T2DM demands.

2.6 References

- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, 9(3), 407-411.
- Ali, S., Stone, M., Peters, J., Davies, M., & Khunti, K. (2006). The prevalence of co-morbid depression in adults with type 2 diabetes: A systematic review and meta-analysis. *Diabetic Medicine*, 23(11), 1165-1173.
- Arroll, M. A., & Senior, V. (2008). Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis. *Psychology and Health*, 23(4), 443-458.
- Booth, A. O., Lowis, C., Dean, M., Hunter, S. J., & McKinley, M. C. (2013). Diet and physical activity in the self-management of type 2 diabetes: barriers and facilitators identified by patients and health professionals. *Primary health care research & development*, 14(3), 293-306.
- British Psychological Society, BPS (2014). Code of human research ethics. *Retrieved online on 08/05/17 from:* <https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%20Human%20Research%20Ethics.pdf>
- Cohen, D., & Crabtree, B. (2006). Qualitative research guidelines project. *Retrieved online on 01/02/19 from:* <http://www.qualres.org/>
- Delgadillo, J., Dawson, A., Gilbody, S., & Böhnke, J. R. (2017). Impact of long-term medical conditions on the outcomes of psychological therapy for depression and anxiety. *The British Journal of Psychiatry*, 210(1), 47-53.

Department of Health (2011). No Health Without Mental Health: a cross-government outcomes strategy. Retrieved online on 07/08/16 from: <https://www.gov.uk/government/publications/no-health-without-mental-health-a-cross-government-outcomes-strategy>

Diabetes UK (2015). Early identification of people with, and at high risk of Type 2 diabetes and interventions for those at high risk. Retrieved online on 28/09/17 from: <https://www.diabetes.org.uk/professionals/position-statements-reports>

Diabetes UK (2018). Diabetes prevalence 2018. Retrieved online on 14/05/19 from: <https://www.diabetes.org.uk/professionals/position-statementsreports/statistics/diabetes-prevalence-2018>

Gavard, J. A., Lustman, P. J., & Clouse, R. E. (1993). Prevalence of depression in adults with diabetes. an epidemiological evaluation. *Diabetes Care*, 16(8), 1167-1178.

Golden, S. H., Lazo, M., Carnethon, M., Bertoni, A. G., Schreiner, P. J., Roux, A. V. D., et al. (2008). Examining a bidirectional association between depressive symptoms and diabetes. *Jama*, 299(23), 2751-2759.

Gonzalez, J. S., & Esbitt, S. A. (2010). Depression and treatment nonadherence in type 2 diabetes: Assessment issues and an integrative treatment approach. *Epidemiology and Psychiatric Sciences*, 19(2), 110-115.

Gonzalez, J. S., Safren, S. A., Cagliero, E., Wexler, D. J., Delahanty, L., Wittenberg, E., et al. (2007). Depression, self-care, and medication adherence in type 2

diabetes: Relationships across the full range of symptom severity. *Diabetes Care*, 30(9), 2222-2227.

Gary, F. A. (2005). Stigma: Barrier to mental health care among ethnic minorities. *Issues in mental health nursing*, 26(10), 979-999.

Ismail, K., Winkley, K., & Rabe-Hesketh, S. (2004). Systematic review and meta-analysis of randomised controlled trials of psychological interventions to improve glycaemic control in patients with type 2 diabetes. *The Lancet*, 363(9421), 1589-1597.

Josephs, R. A., Markus, H. R., & Tafarodi, R. W. (1992). Gender and self-esteem. *Journal of personality and social psychology*, 63(3), 391.

Kaplan, H. I., & Kaplan, H. S. (1957). The psychosomatic concept of obesity. *Journal of Nervous and Mental Disease*, 125, 181-201.

Karter, A. J., Ferrara, A., Liu, J. Y., Moffet, H. H., Ackerson, L. M., & Selby, J. V. (2002). Ethnic disparities in diabetic complications in an insured population. *Jama*, 287(19), 2519-2527.

Katon, W., Fan, M., Unützer, J., Taylor, J., Pincus, H., & Schoenbaum, M. (2008). Depression and diabetes: A potentially lethal combination. *Journal of General Internal Medicine*, 23(10), 1571-1575.

Khanolkar, M. P., Bain, S. C., & Stephens, J. W. (2008). The diabetic foot. *QJM: An International Journal of Medicine*, 101(9), 685-695.

- Lidegaard, L. P., Schwennesen, N., Willaing, I., & Færch, K. (2016). Barriers to and motivators for physical activity among people with Type 2 diabetes: patients' perspectives. *Diabetic Medicine*, 33(12), 1677-1685.
- Lustman, P. J., Anderson, R. J., Freedland, K. E., de Groot, M., Carney, R. M., & Clouse, R. E. (2000). Depression and poor glycemic control: A meta-analytic review of the literature. *Diabetes Care*, 23(7), 934-942.
- Marriott, C., & Thompson, A. R. (2008). Managing threats to femininity: Personal and interpersonal experience of living with vulval pain. *Psychology and Health*, 23(2), 243-258.
- Maunder, R. G., & Hunter, J. J. (2008). Attachment relationships as determinants of physical health. *Journal of the American Academy of Psychoanalysis and Dynamic Psychiatry*, 36(1), 11-32.
- Mezuk, B., Eaton, W. W., Albrecht, S., & Golden, S. H. (2008). Depression and type 2 diabetes over the lifespan: A meta-analysis. *Diabetes Care*, 31(12), 2383-2390.
- Musselman, D. L., Betan, E., Larsen, H., & Phillips, L. S. (2003). Relationship of depression to diabetes types 1 and 2: Epidemiology, biology, and treatment. *Biological Psychiatry*, 54(3), 317-329.
- Nau, D. P., Aikens, J. E., & Pacholski, A. M. (2007). Effects of gender and depression on oral medication adherence in persons with type 2 diabetes mellitus. *Gender Medicine*, 4(3), 205-213.

- National Collaborating Centre for Chronic Conditions. (2008) Type 2 Diabetes: National Clinical Guideline for Management in Primary and Secondary Care (Update). Royal College of Physicians, London.
- NHS England (2016). The five year forward view for mental health. *Retrieved online on 17/04/18 from:* <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>
- Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 7. (4)
- Pamungkas, R., Chamroonsawasdi, K., & Vatanasomboon, P. (2017). A systematic review: family support integrated with diabetes self-management among uncontrolled type II diabetes mellitus patients. *Behavioral sciences*, 7(3), 62.
- Pan, A., Lucas, M., Sun, Q., van Dam, R. M., Franco, O. H., Willett, W. C., et al. (2011). Increased mortality risk in women with depression and diabetes mellitus. *Archives of General Psychiatry*, 68(1), 42-50.
- Reynolds, F., & Lim, K. H. (2007). Contribution of visual art-making to the subjective well-being of women living with cancer: A qualitative study. *The Arts in Psychotherapy*, 34(1), 1-10.
- Riste, L., Khan, F., & Cruickshank, K. (2001). High prevalence of type 2 diabetes in all ethnic groups, including Europeans, in a British inner city: relative poverty, history, inactivity, or 21st century Europe?. *Diabetes care*, 24(8), 1377-1383.

- Sankar, V., Justin, A., Payman, H. M., Swathy, P., KUMAR, N. S. C., & KUMAR, R. S. (2018). Medication adherence and clinical outcomes in type 2 diabetes mellitus patients with depression: A prospective interventional study. *Age*, 30(35), 1.
- Seidler, Z. E., Dawes, A. J., Rice, S. M., Oliffe, J. L., & Dhillon, H. M. (2016). The role of masculinity in men's help-seeking for depression: A systematic review. *Clinical Psychology Review*, 49, 106-118.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage London.
- Smith, J. A., & Osborn, M. (2003). Interpretative Phenomenological Analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods* (pp. 53-80). London: Sage.
- Starks, H., & Brown Trinidad, S. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17(10), 1372-1380.
- Stratton, I. M., Adler, A. I., Neil, H. A., Matthews, D. R., Manley, S. E., Cull, C. A., et al. (2000). Association of glycaemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): Prospective observational study. *BMJ (Clinical Research Ed.)*, 321(7258), 405-412.
- Stuckey, H. L., Mullan-Jensen, C. B., Reach, G., Kovacs Burns, K., Piana, N., Vallis, M., et al. (2014). Personal accounts of the negative and adaptive psychosocial experiences of people with diabetes in the second diabetes attitudes, wishes and needs (DAWN2) study. *Diabetes Care*, 37(9), 2466-2474.

- UK Prospective Diabetes Study (UKPDS) Group. (1998). Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). *The lancet*, 352(9131), 837-853.
- Weller, S. C., Baer, R., Nash, A., & Perez, N. (2017). Discovering successful strategies for diabetic self-management: A qualitative comparative study. *BMJ Open Diabetes Research and Care*, 5(1), e000349.
- Whittemore, R., Melkus, G. D. E., & Grey, M. (2004). Applying the social ecological theory to type 2 diabetes prevention and management. *Journal of Community Health Nursing*, 21(2), 87-99.
- Williams, L. H., Rutter, C. M., Katon, W. J., Reiber, G. E., Ciechanowski, P., Heckbert, S. R., et al. (2010). Depression and incident diabetic foot ulcers: A prospective cohort study. *The American Journal of Medicine*, 123(8), 748-754. e3.
- Wing, R. R., Marcus, M. D., Blair, E. H., Epstein, L. H., & Burton, L. R. (1990). Depressive symptomatology in obese adults with type II diabetes. *Diabetes Care*, 13(2), 170-172.
- Wing, R. R., Marcus, M. D., Blair, E. H., Epstein, L. H., & Burton, L. R. (1990). Depressive symptomatology in obese adults with type II diabetes. *Diabetes Care*, 13(2), 170-172.

Chapter 3: Reflective paper

Reflections on my lived research experience:

Lessons learned

Overall word count (excluding references): 2650

3.0 Introduction

This chapter presents my own reflective account of conducting doctoral research within the context of professional training in clinical psychology. To facilitate this process, over the past 4 years I have kept a personal research journal. This activity was prompted by recommendations within the Interpretative Phenomenological Analysis (IPA) framework (Smith, Flowers & Larkin, 2009) in order enhance transparency in the research process and reduce bias. Little did I know when commencing the journal how many unexpected thoughts, feelings, highs and lows would be captured, in addition to parallels between the research and personal events in my life. This chapter therefore reflects my most significant learning curves in my emergence as a researcher and (like the participants in my research) the challenges I personally experienced to achieve that ‘healthy balance’.

3.1 Reflexivity in research

The double hermeneutic process in IPA methodology requires 1) participants to disclose how they experience and make sense of a shared phenomenon, and 2) the researcher to further interpret their disclosures (Smith et al., 2009). Both stages of this process can be obscured by subjectivity due to the proximity of the researcher (who will have their own suppositions) within the methodology of IPA and subsequent analysis. Berger (2015) states that:

Researchers need to increasingly focus on self-knowledge and sensitivity; better understand the role of the self in the creation of knowledge; carefully self-monitor the impact of their biases, beliefs, and personal experiences on

their research; and maintain the balance between the personal and the universal (p. 220).

The process of reflexive activities ensures the researcher can continually evaluate their personal position and, in IPA, bracketing personal experiences during interviews is particularly important (Smith et al., 2009). Prior to embarking on this research, I hadn't considered the value of reflexivity in my development as a researcher and in ensuring credibility of findings. Upon reflection, this seems paradoxical, as in my clinical work as a trainee psychologist I highly value opportunities to reflect upon practice and it as crucial for development. I believe this was linked to initial underestimation about how much personal experience I could 'bring to the table' of research.

This realisation was first identified in a bracketing interview I undertook with my supervisors. Bracketing interviews are recommended in qualitative research to help 'suspend beliefs' and 'maintain curiosity' about phenomena for which researchers' may already possess theory (Ahern, 1999). The interview helped me to intercept my own assumptions, which might have otherwise led to premature conclusion upon issues, without fully hearing the participants' experiences. I identified pre-conceived ideas about men's reduced help seeking as being related to masculinity, viewing illness as a weakness and thus not wanting to admit illness or seek support. I considered these ideas to have stemmed from experiences of the men in my life, combined with societal expectations of being a male. When conducting interviews with the participants I noted the process of reflexivity had indeed aided awareness, and I allowed myself to hear the unexpected. Deeper probing led to issues beyond masculinity, including self-doubt, embarrassment and uncertainty about the reliability of others. I am convinced that the depth of the men's revelations may not have emerged had I concluded at the

point they were discussing masculinity. Instead, this undoubtedly shifted the power dynamic towards the participant in a positive way, allowing space for their deeper experiences and interpretations to emerge. This recognition had a positive impact on my research, but also my clinical work, opening my eyes to even my most inconspicuous assumptions. I felt surprised as I realised, as a clinician, the power dynamic with my clients might not have been as balanced as I had previously thought. This process has helped me maintain a position of curiosity during psychological assessment, even when hypothesising on my clients' experiences. Further, during research interviews I became conscious of even the most subtle, involuntary gestures such as nodding my head when I heard content that enthused me, or I was familiar with. This made me consider reflexivity more deeply, which I concluded was essential in ensuring the participants' experiences were heard. It has increased my awareness however that even the most inconspicuous subtleties in human connection could assert my position within the room.

3.2 Research design

3.2.1 Personal motivation

My interest in researching in the area of diabetes stemmed from prior clinical experiences in this area of health. Notably, I worked for a year in the Improving Access to Psychological Therapies (IAPT) services (which is discussed in Chapter 2 as not fully meeting the psychological needs of people with diabetes). At the time, I was unaware of the literature that postulated needs were not being fully met (Ismail, Winkley & Rabe-Hesketh, 2004), but I witnessed it nearly every day. Although, I believe services are delivered with the best of intentions in attempting to improve

access to therapy in a resource-stretched National Health Service, for people with long-term conditions, the short length of sessions and brief nature of the work inhibited engagement. In my personal experience, I felt practically limited by time, resources and a lack of training to fully understand the complexities of difficulties that underpinned clients' low mood. Many of the patients referred into the service still benefited from support, however those with more complex needs experienced a disservice. Further, I had awareness from nursing colleagues of a number of patients who were avoiding psychological support altogether. My awareness of the links between psychological distress and the development of physical complications furthered my concern. When I embarked upon clinical training, I therefore explored further into this field as a research topic of interest. For me, I wanted to give voice to a sample of participants from an underserved and underrepresented population, to inform clinicians, services and policy-makers of their needs.

3.2.2 Development of epistemological position

When I was an undergraduate student in 2005, quantitative methodology appeared the dominant approach and I chose this as my dissertation design. From recollection, my research lectures were mostly quantitative in content, with emphasis on ensuring significance, objectivity, replicability, power and generalisability. Upon reflection, naively I did not particularly question that credible research could be carried out in any other way. I do however recall a debate about psychology being called a 'soft science' due to apparent clashing dichotomies in psychological research that attempted to understand complexities of the human experience (Mazur & Watzlawik, 2016). I wondered therefore whether the perceived stronghold position to quantitative methods related to ensuring psychology's scientific integrity, although I have no evidence to

substantiate this. By discussing this, I am not attempting to discredit quantitative research. I value it as a gold-standard to ensuring evidence-based practice. However, dichotomies in empirical research ignited my interest to want to understand more, and as a clinician this became even more true when having the opportunity hear the patient voice, narrative and experiences.

My very first teaching in research methods on the clinical doctorate course (almost 10 years later) was a breath of fresh air. I recall the lecturer discussing epistemological positions, of which ‘interpretivism’ and ‘humanistic’ qualitative methods were very enthusiastically described. Working in a medical setting that placed importance on randomised controlled trials had limited my understanding on how research had transformed, particularly in life sciences. For me, I felt natural alliance to these humanistic methods, as my orientation to hearing the human experience is one reason for choosing to become a psychologist. Further, as discussed in Chapter 1, the importance of listening to the voices of service-users is gaining increased recognition and importance in policy making and service provision (The Kings Fund, 2018). Like all other methods, I recognise qualitative research has its limitations, however, from my experience so far, I value it as complementing rather than competing with other methodologies. This has been emphasised further to me through the findings yielded from this research.

3.3 My lived experience

The intense process of living through real world research does not always translate in academic literature. The beginning of the process felt straight forward and exciting with developing ideas and identifying gaps in knowledge. However, as the process

continued, I experienced several barriers, which raised my anxieties and reduced the positivity of my experience. My first significant hurdle related to gaining NHS ethical approval. I had been prewarned that recruiting patients would also be challenging. Although gaining ethical approval was important and necessary, at times I found the process difficult, which resulted in some frustrations. As a novice, it took some time to comprehend acronyms, navigate systems and protocols and make sense of expectations. I recall a peer relating the process being similar to *‘reading a foreign language.’* Not being in the expert position felt disempowering and support was vital to overcome these challenges. As I reflected on this, I could not help wondering if this experience of disempowerment might have been how it felt for the ethnic-minority women trying to gather information about Gestational Diabetes Mellitus as discussed in Chapter 1. Their access to information was also blocked by absence of a common language or understanding. I had the opportunity of support from supervisors and colleagues who bridged the gap and helped me to regain power. It made me consider who could offer a similar role to empower these women within healthcare services.

Having competing demands of clinical placements and academic teaching also felt challenging. This increased my awareness of the trials and tribulations clinicians face, applying research alongside busy schedules. Nevertheless, I was determined to collaborate with men who had diabetes, and experienced relief when the research project was approved. It was also a significant boost of confidence to know my proposed methodology had passed such stringent assessment. From this point on however, my reflective journal continued to illustrate tones in my narrative which seem tinged with deflation. This predominately related to the challenges of recruitment. One entry in my journal, which epitomised my feelings at the time, said: *“I am trying to conduct research to give power to a voice not commonly heard, but in*

turn this process is disempowering me.” It wasn’t until my first interview that things fully transformed. I felt a resurgence of excitement, hearing the participants’ experiences and knowing I had the opportunity to take this forward for all to hear. Upon reflection, for me, my difficult experiences initiating the research temporarily separated me from my passion and the participants were pivotal to its return.

Another significant learning curve related to parallels that emerged between my personal life and research. Within the introduction of this chapter I discussed achieving a ‘healthy balance’ and inferred a challenge in reaching that. One of the most happy, personal events during my training and research was pregnancy and subsequent motherhood. However, with pregnancy came an unexpected and coincidental event. Gestational Diabetes Mellitus (GDM). Suddenly I had been catapulted to the other side. I was not only hearing experiences of injecting with insulin; I was doing it. The anxieties described by women for their unborn babies in Chapter 1 were now also my own. Unpredictably, I was viewing my research through a very different lens and I needed to step back and evaluate this unexpected ‘insider’ position. When reviewing literature about parallels between the researcher-participant experience, I came across discussion relating to ‘insider’ and ‘outsider’ positioning and its potential to change through the process of research (Ross, 2017). I realised I had never completely held an ‘outsider’ position, and my clinical experience in diabetes was a significant part of that. However, I also reflected that my personal experiences of diabetes, were uniquely my own. This was particularly important to acknowledge when interviewing men with T2DM participating in my empirical research discussed in Chapter 2. Bracketing my personal experiences helped prevent me from assuming I knew how they felt.

In terms of the systematic literature review discussed in Chapter 1, my supervisor encouraged me to consider the potential emotional impact it might have to review literature about a condition I had personally experienced. As both of my children had been born, were healthy and I was no longer submersed in the experience I felt as though it would not be an issue. My decision to continue was two-fold. In one way I felt living through the experience helped me to connect with the content of the academic articles on an even greater level. However, conversely, I couldn't help but attend to feelings that arose in me as I read content that led me to revisit my own experiences. I do feel upon reflection that this resulted in an emotionally exhausting experience and I was grateful for the support offered by my supervisors. One surprise related to learning information about GDM that I had not been made aware of as a patient. For example, I wasn't aware of how high the risk was for T2DM in the future, nor did I realise GDM could affect the health of my children in later life. This signified my own unmet need as a previous patient with GDM.

Time to pause, re-evaluate and engage in self-care gave me the capacity to continue. Due to their poignancy, I decided to start a separate log about my experiences of GDM, devoted to assisting the process of the systematic literature review. This was particularly helpful in alerting me to any 'unconscious' editing that may have occurred being closer to the 'insider' position as described by Valentine (2007). This assisted me to note my own sensitivities and engage more fully, objectively and comprehensively with the review. Once it was completed, I connected to a sense of pride and liberation which I attribute to giving testament to women's experiences that I also had witnessed on the frontline.

3.4 A future within an inequitable system

A palpable theme that has been present throughout my research and reflections appears to coalesce around inequitable access to health services paradoxically designed to meet the needs of all. This has been threaded through my entire research journey, from my initial motivations to embark on this research (propelled by frontline experiences of unmet need), to the narratives of both men and women that reflect varying positions of power to access support. The theory of intersectionality (Crenshaw, 1989) emphasises the disempowerment and marginalisation of individuals, based on the power of the characteristics they possess (e.g. race, gender, socioeconomic status) and differences in personal experience. Even my personal limitations and lack of shared language required to successfully navigate NHS research procedures demonstrated experientially, that intersectionality and disempowerment can exist across all parts of the system. As a future clinical psychologist, the systems and services discussed in this thesis will most likely continue to be my place of work. This research has acutely raised my awareness of inequalities of power, privileges and oppression, that I did not previously consider. My future role may offer me a privileged opportunity to lead attention towards inequitable services and bring about change by raising attention to the needs of those most suppressed.

3.5 Conclusion

Embarking on this journey of research has increased my awareness of the power of research, not just for the phenomena it studies, but also for those involved with its process. The experiences that formed this journey have undoubtedly granted opportunity to develop as a researcher and clinician. Self-awareness of my own

position, theories and motivations have been important learning curves and I highly value the reflexive component to the research approach. Opportunities to navigate processes such as gaining ethical approval, managing recruitment and engaging with my supervisory team has allowed me to gain practical skills to take forward into the future. The most influential experience overall however related to having privilege to hear the voices of people with diabetes, who are unrepresented in services and often unheard. This has emphasised the power of conducting qualitative research to translate their experiences and convey their unmet needs. I hope further opportunities will allow me this privilege again in my future professional role.

3.6 References

- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, 9(3), 407-411.
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, 15(2), 219-234.
- Crenshaw, K. W. (1989). "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics." *University of Chicago Legal Forum*, (1), 139-68.
- Ismail, K., Winkley, K., & Rabe-Hesketh, S. (2004). Systematic review and meta-analysis of randomised controlled trials of psychological interventions to improve glycaemic control in patients with type 2 diabetes. *The Lancet*, 363(9421), 1589-1597.
- Mazur, L. B., & Watzlawik, M. (2016). Debates about the scientific status of psychology: Looking at the bright side. *Integrative Psychological and Behavioral Science*, 50(4), 555-567.
- Ross, L. E. (2017). An account from the inside: Examining the emotional impact of qualitative research through the lens of "insider" research. *Qualitative Psychology*, 4(3), 326.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage London.

The Kings Fund (2018) Shared responsibility for health: the cultural change we need. *Retrieved on 02 Feb 2019 from:*

<https://www.kingsfund.org.uk/publications/shared-responsibility-health>

Valentine, C. (2007). Methodological reflections: Attending and tending to the role of the researcher in the construction of bereavement narratives. *Qualitative Social Work*, 6(2), 159-176.

Appendices

Appendix A: Author guidelines: BMC Pregnancy and Childbirth

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

present a title that includes, if appropriate, the study design e.g.:

"A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"

or for non-clinical or non-research studies a description of what the article reports

list the full names and institutional addresses for all authors

if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below

indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract.

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

the characteristics of participants or description of materials

a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses

the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Competing interests

All financial and non-financial competing interests must be declared in this section.

See our editorial policies for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

Please use the authors initials to refer to each authors' competing interests in this section.

If you do not have any competing interests, please state "The authors declare that they have no competing interests" in this section.

Acknowledgements

Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials. Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

Endnotes

Endnotes should be designated within the text using a superscript and all notes (along with their corresponding letter) should be included in the Endnotes section.

Word Limit

As an online publisher, we do not have restraints on the size of manuscripts submitted to most BioMed Central journals. Manuscripts can include an unlimited number of figures, tables and additional files but the abstract of the manuscript should not exceed 350 words. However, please remember that for the benefit of peer-reviewers and readers articles should be as concise as possible.

Appendix B: Systematic Literature Review Ethical Approval, University



Certificate of Ethical Approval

Applicant:

Laura Onens

Project Title:

Systematic Literature Review

Extending our knowledge of women's experiences of gestational diabetes and self-management in the context of maternity care: A qualitative systematic review.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

08 March 2019

Project Reference Number:

P88879

Appendix C: Qualyst Quality Assessment Tool

<i>Checklist for assessing the quality of qualitative research as proposed using Qualsyst (Kmet, Lee & Cook, 2004).</i>	Yes (2)	Partial (1)	No (0)
Criteria			
1. Question/ objective sufficiently described?			
2. Study design evident and appropriate?			
3. Context for the study clear?			
4. Connection to a theoretical framework/ wider body of knowledge?			
5. Sampling strategy described, relevant and justified?			
6. Data collection methods clearly described and systematic?			
7. Data analysis clearly described and systematic?			
8. Use of verification procedure(s) to establish credibility?			
9. Conclusions supported by the results?			
10. Reflexivity of the account?			

Appendix D: Qualsyst Scores and Kappa Coefficient Calculations

Study	Carolán 2013	Dayyani et al. 2019	Draffin et al. 2016	Gray et al. 2017	Harrison et al. 2019	Hjelm et al. 2012	Hjelm et al. 2018	Hui et al. 2014	Jirojwong et al. 2017	Kaptein et al. 2017	Martis et al. 2018	Nielsen et al. 2018	Oza-Frank et al. 2018	Parsons et al. 2018a	Parsons et al. 2018b	Wah et al. 2018
Quality Criteria																
Objective described	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Study design evident and appropriate	2	2	2	2	2	2	2	2	2	2	2	2	1	2	2	2
Context for study clear	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Connection to theoretical framework/body of knowledge	2	2	2	1	2	2	2	1	0	0	2	0	0	0	2	0
Sampling strategy relevant and justified	2	1	1	2	1	2	2	2	1	2	2	2	2	2	2	2
Data collection methods described & systematic	1	2	1	2	2	2	2	2	2	2	2	2	2	2	2	2
Data analysis described & systematic	2	2	2	2	2	2	2	2	2	2	1	2	2	2	2	2
Verification procedures to establish credibility ¹⁵	2	0	2	2	2	2	2	2	0	2	2	0	0	2	0	2
Conclusions supported by results	1	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Reflexivity of account	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Total score	16	15	16	17	17	18	18	17	13	16	17	14	13	16	16	16

¹⁵ Can only score 0 or 2

Kappa Coefficients

Carolan (2013)

		Symmetric Measures		Approximate T ^b	Approximate Significance
		Value	Asymptotic Standard Error ^a		
Measure of Agreement	Kappa	.630	.321	2.799	.005
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Dayyani et al. (2019)

		Symmetric Measures		Approximate T ^b	Approximate Significance
		Value	Asymptotic Standard Error ^a		
Measure of Agreement	Kappa	.750	.222	2.942	.003
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Draffin et al. (2016)

		Symmetric Measures		Approximate T ^b	Approximate Significance
		Value	Asymptotic Standard Error ^a		
Measure of Agreement	Kappa	.804	.186	3.324	.001
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Gray et al. (2017)

		Symmetric Measures		Approximate T ^b	Approximate Significance
		Value	Asymptotic Standard Error ^a		
Measure of Agreement	Kappa	1.000	.000	4.135	.000
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Harrison et al. (2019)

		Symmetric Measures		Approximate T ^b	Approximate Significance
		Value	Asymptotic Standard Error ^a		
Measure of Agreement	Kappa	.630	.321	2.799	.005
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Hjelm et al. (2012)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	3.162	.002
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Hjelm et al. (2018)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	3.162	.002
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Hui et al. (2014)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	4.135	.000
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Jirojwong et al. (2017)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.821	.154	3.575	.000
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Kaptein et al. (2017)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.706	.198	2.963	.003
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Martis et al. (2018)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.630	.321	2.799	.005
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Nielsen et al. (2018)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.778	.173	2.996	.003
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Oza-Frank et al. (2018)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.796	.180	2.990	.003
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Parsons et al. (2018a)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	3.162	.002
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Parsons et al. (2018b)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	3.162	.002
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Wah et al. (2018)

Symmetric Measures

		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.706	.198	2.963	.003
N of Valid Cases		10			


a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Appendix E: Qualitative Health Research Author Guidelines

Preparing your manuscript

Article Format (see previously published articles in QHR for style):

Title page: Title should be succinct; list all authors and their affiliation; keywords. Please upload the title page separately from the main document.  Blinding: Do not include any author identifying information in your manuscript, including author's own citations. Do not include acknowledgements until your article is accepted and unblinded.

Abstract: Unstructured, 150 words. This should be the first page of the main manuscript, and it should be on its own page.

Length: QHR does not have a word or page count limit. Manuscripts should be as tight as possible, preferably less than 30 pages including references. Longer manuscripts, if exceptional, will be considered.

Methods: QHR readership is sophisticated; excessive details not required.

Ethics: Include a statement of IRB approval and participant consent.

Results: Rich and descriptive; theoretical; linked to practice if possible.

Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.

References: APA format. Use pertinent references only. References should be on a separate page.

Additional Editor's Preferences:

Please do not refer to your manuscript as a "paper;" you are submitting an "article."

The word "data" is plural.

Word processing formats Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text should be double-spaced throughout with standard 1 inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12 point.

Artwork, figures and other graphics

Figures: Should clarify text.

Include figures, charts, and tables created in MS Word in the main text rather than at the end of the document.

Figures, tables, and other files created outside of Word should be submitted separately. Indicate where table should be inserted within manuscript (i.e. INSERT TABLE 1 HERE).

Photographs: Should have permission to reprint and faces should be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be forwarded to QHR's Managing Editor. o TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS. o Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi. o

Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.

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.

Appendix F: Ethical approval: Coventry University



Certificate of Ethical Approval

Applicant:

Laura Onens

Project Title:

The lived experience of men with complications of Type-2 Diabetes and low mood:
An Interpretative Phenomenological Analysis

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

Date of approval:

28 April 2017

Project Reference Number:

P50376

Appendix G: National Health Service Research Ethics Committee Approval



West Midlands - Solihull Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

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

18 July 2017

Mrs Laura Onens
Trainee Clinical Psychologist
Coventry and Warwickshire NHS partnership trust
Universities of Coventry and Warwick Clinical Psychology Doctorate Programme,
Coventry University, James Starley Building
Priory Street, Coventry
CV1 5FB

Dear Mrs Onens

Study title:	The lived experience of males with complications of Type-2 Diabetes and symptoms of low mood: An Interpretative Phenomenological Analysis
REC reference:	17/WM/0220
IRAS project ID:	227051

Thank you for your letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants	1.1	10 July 2017
Covering letter on headed paper [COVER LETTER]	1.0	18 May 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
GP/consultant information sheets or letters [GP LETTER]	1.0	10 July 2017
Interview schedules or topic guides for participants	1.0	18 May 2017
IRAS Application Form [IRAS_Form_24052017]		24 May 2017
IRAS Application Form XML file [IRAS_Form_24052017]		24 May 2017
Letter from funder	1.0	18 May 2017
Letter from sponsor [SPONSOR ETHICAL APPROVAL]		
Letters of invitation to participant	1.1	18 May 2017
Non-validated questionnaire [DEMOGRAPHIC QUESTIONNAIRE]	1.0	18 May 2017
Other [HRA SCHEDULE OF EVENTS]		18 May 2017
Other [HRA STATEMENT OF ACTIVITIES]	1.0	18 May 2017
Other [CERTIFICATE OF APPROVAL]		
Other [RESPONSE LETTER RE AMENDMENTS]	1.0	10 July 2017
Participant consent form [CONSENT TO CONTACT FORM]	1.0	18 May 2017
Participant consent form	1.1	10 July 2017
Participant information sheet (PIS)	1.2	10 July 2017
Participant information sheet (PIS) [DEBRIEF SHEET]	1.1	10 July 2017
Referee's report or other scientific critique report	1.0	18 May 2017
Research protocol or project proposal [RESEARCH PROTOCOL FULL]	3.2	10 July 2017
Summary CV for Chief Investigator (CI)	1.0	18 May 2017
Summary CV for student	1.0	18 May 2017
Summary CV for supervisor (student research) [CV JO KUCHARSKA]	1.0	18 May 2017
Summary CV for supervisor (student research) [CV_CAROLYN GORDON]		18 May 2017
Summary CV for supervisor (student research) [CV JESS TWYFORD]	1.0	18 May 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language	1.0	18 May 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

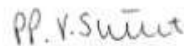
<http://www.hra.nhs.uk/hra-training/>

17/WM/0220

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



**Dr Rex J Polson
Chair**

Email: NRESCCommittee.WestMidlands-Solihull@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Professor Ian Marshall
Ms Sue Palmer Hill, Research and Innovation Manager,
Northamptonshire NHS Foundation Trust*

Appendix H: Health Research Authority Approval



Health Research Authority

Mrs Laura Onens
Trainee Clinical Psychologist
Coventry and Warwickshire NHS partnership trust
Universities of Coventry and Warwick Clinical Psychology
Doctorate Programme,
Coventry University, James Starley Building
Priory Street, Coventry
CV1 5FB

Email: hra_approval@nhs.net

01 August 2017

Dear Mrs Laura Onens

Letter of HRA Approval

Study title:	The lived experience of males with complications of Type-2 Diabetes and symptoms of low mood: An Interpretative Phenomenological Analysis
IRAS project ID:	227051
REC reference:	17/WM/0220
Sponsor	Coventry University

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

Participation of NHS Organisations in England

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

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

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

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

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

IRAS project ID	227051
-----------------	--------

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **227051**. Please quote this on all correspondence.

Yours sincerely

Nabeela Iqbal

Assessor

Email: hra.approval@nhs.net

*Copy to: Professor Ian Marshall, Coventry University, Sponsor contact
Ms Sue Palmer Hill, Research and Innovation Manager, Northamptonshire NHS
Foundation Trust, Lead NHS R&D contact*

Appendix I: Host NHS Trust Approval – Letter of Access

(Identifiable information omitted to protect participant anonymity)

End Date: 16/08/2020
Approval Date: 29/08/2017

Dear Laura,

Re: Experiences of Males with Type Two Diabetes (Non-Portfolio Student Study)

This letter confirms your right of access to conduct research through Research & Innovations Service (R&I Service) for the purpose and on the terms and conditions set out below.

This right of access commences on **29/08/2017** and ends on **16/08/2020**, unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at R&I Service has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

The documents reviewed for this letter of access assurance were:

Title	Version	Date
Signed & Date CV	N/A	14/08/2017
Research Passport	N/A	17/08/2017
Evidence of Substantive Employment	N/A	17/08/2017
DBS	N/A	11/09/2017
Occupational Health	N/A	16/08/2017

You are considered to be a legal visitor to R&I Service premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS

organisation, in particular that of an employee; Nor does this grant permission for you or your research team to access any patient data at practice level. The responsibility for this rests entirely with the practice, as the data controller for all patients registered with that practice.

While undertaking research through R&I Service, you will remain accountable to your employer, **University of Coventry** but you are required to follow the reasonable instructions of in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with R&I Service policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with R&I Service in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

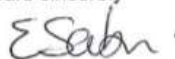
We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. As from 26 July 2010, your HEI employer may initiate your Independent Safeguarding Authority (ISA) registration (where applicable), and thereafter, will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity. You **MUST** stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

R&I Service will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



Head of Research and Innovation

Appendix J: Interview Guide

Qualitative Interview schedule

Introduction

This interview is rather like a one-sided conversation. I am interested in your experiences of having diabetes, diabetic complications and symptoms of depression. There are no right or wrong answers. I am interested in as much detail as you care to give.

1) Can you tell me a little about yourself?

2) Tell me about your health now (physical and emotional)?

Prompts:

- Managing diabetes? “What is that like for you” “Can you tell me more about that” “What does that mean to you” “What sense do you make of that”
- Developing complications. How do they conceptualise the condition?
- What is your mood like? How are you in yourself?
- How do they conceptualise their psychological wellbeing?

3) What do the bad/good days look like?

Prompts:

- What is daily life like?
- What is daily life like with diabetes?

4) What were things like when your health changed?

Prompts:

- Getting the diagnosis
- How complications became apparent?
- When mood started to deteriorate?
- What seeking help felt like?
- What is there experience of support then and now?

Ending the interview

Depending on what direction the interview has taken, the last section about discussing the experience of seeking help, may result in the participant to actively try to seek further help/support. The researcher will offer to raise this with their clinician with their consent.

General Prompts:

- Could you please tell me more?
- Could you give a specific/recent example?
- Can give me an example of a positive/challenging time?
- In what way was that helpful/unhelpful?

-

Appendix K: Demographic Questionnaire



Participant number:

DEMOGRAPHIC INFORMATION

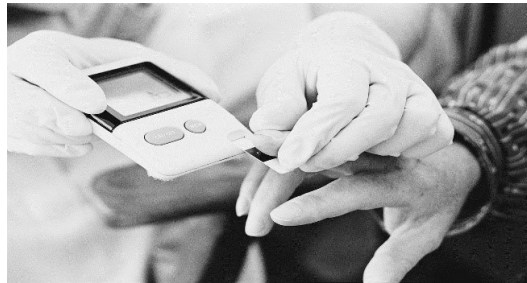
1. What is your age?

2. What is your ethnic group? (e.g. White British, Black African, Indian, Chinese)

3. What is your marital status?

4. What is your occupation?

5. What is your highest level of education achieved?



Are you a man with Type 2 Diabetes?

Do you also suffer with physical problems of diabetes?

Do you often feel low in mood?

If so...we would like to hear your story.

We are looking for men aged approximately **45+** to meet for a one-to-one appointment with a researcher who is interested in hearing about your experience.

If you are interested to participate please contact Coventry University researcher Laura Onens

Either by email: onensl@uni.coventry.ac.uk

Or telephone: 024 7765 8328



Appendix M: Health Care Professional guidance and recruitment material

Date:

Referring Clinician:

Department of work:

Quick Reference Inclusion Criteria:

The lived experience of men with complications of Type-2 Diabetes and low mood

- Male
- Approximately 45+ years
- Type 2 diabetes mellitus
- Comorbid complications of diabetes e.g. foot/vascular problems, neuropathy, eye problems etc.
- Self identifies with low mood

Patient Name: _____

NHS Number:

Patient D.O.B.

Patient Address

Please send referrals to: [Dr Jess Twyford – host recruitment lead] by the same method as your usual clinical referrals.

Appendix N: Recruitment letter

[Host NHS Trust Logo]

[Patient name, address]

Dear

Re: Information about a research study to explore the experiences of men with physical health complications of type 2 diabetes and low mood.

We are sending you this information to let you know about a research study running in the Diabetes Services that you may be interested to take part in.

Laura Onens, a Clinical Psychologist in training at the University of Warwick and Coventry, is working in collaboration with the Diabetes Service at XXXXXXXX NHS Trust to understand more about the lived experiences of males with type 2 diabetes. The research involves interviewing men who have physical complications of type 2 diabetes and who have experienced low mood. You are receiving this information as you are registered under the diabetes services and may be eligible to take part.

In order to collect the views of men experiencing these issues, Laura is conducting one-off interviews that will last approximately 1 to 1.5 hours. Interviews will be organised to take place in clinical areas within local NHS services. We are happy to discuss other arrangements (e.g. a home visit) in the case of transport or mobility problems.

A Participant Information Sheet about the study is included for you to learn more about the research and eligibility criteria. If you have any questions that are not answered by the information sheet, then please do not hesitate to contact Laura on the details above or emailing onensl@coventry.ac.uk

If you are interested in participating in this study you can do the following:

- 1) Complete and return the attached “consent to contact” slip in the enclosed stamped addressed envelope by *date*. On receipt of your slip, Laura will contact you via telephone or email to discuss this further.
- 2) Contact Laura directly by emailing onensl@coventry.ac.uk. You can also telephone the department of Clinical Psychology at Coventry University on 024 7765 8328 to express your interest in taking part.

Laura will then arrange to have an initial discussion with you about the criteria to take part and allow the opportunity for you to ask her any questions.

Please remember that participation is voluntary, and it is entirely your choice. If you chose not to respond to this information, it will not affect your medical care in any way. All information will be treated confidentially.

Thank you for taking time to read this information.

[INSERT CLINICIAN NAME]

[INSERT SERVICE]

Enc: Consent to contact form, flyer, Participant information sheet, Self-addressed envelope

Appendix O: Participant Information Sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7765 7688

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



Study title:

**“The lived experience of men with complications of
Type-2 Diabetes and low mood”**

What is the purpose of the study?

The study is being conducted by chief investigator Laura Onens, a Clinical Psychologist in training, in conjunction with Coventry and Warwick Universities. The purpose of the study is to explore men’s experiences of living with type 2 diabetes. The aim of the research is to increase knowledge about the lived experience of having diabetes and complications from a male perspective. It is hoped that the findings may inform services/clinical care. Laura is particularly interested in men’s experiences as previous research has shown that men may not as readily access services in comparison to females. Participants will be asked to take part in a one-to-one interview.

Who is eligible to take part?

The study is looking to recruit participants who meet the following criteria:

- Male gender
- Approximate Age 45+
- Have Type 2 Diabetes
- Have experienced a physical complication of diabetes, for example: neuropathy, retinopathy, vascular/circulatory problems, foot/limb problems, reoccurring ketoacidosis (this list is not exhaustive).
- Self-identify as having experienced feelings of low mood

Why have I been invited to take part?

Your diabetes team have sent you information about this research as your clinical records indicate that you have Type 2 Diabetes may meet the above criteria. Should you decide you would like to take part, the researcher will contact you for an initial discussion to ensure you are eligible to take part. She will also allow the opportunity for you to ask any further questions about the research.

What will happen to me if I take part?

In order to take part you will need to get in touch with the researcher (details in the invitation letter) and express your interest to take part. The researcher will contact you for an initial discussion. If you meet the criteria to take part and wish to proceed then you will be invited for a one-off interview with the researcher. Interviews will be organised to take place in clinical areas within local NHS services however if you have physical difficulties travelling to a clinic, a home visit may be considered. Before the interview commences you will be offered further opportunity to ask questions and if satisfied, be required to give written consent to participate. You will also be asked to complete a brief demographic questionnaire. The interview will involve the researcher asking you questions about your experiences of diabetes and diabetic complications. All interviews will be confidentially recorded using an audio digital recorder. The audio recording will be transcribed and will contribute towards the analysis and future publication. Your anonymity will be guaranteed in all resulting publications.

You will be asked questions about your health including experiences of diabetes and low mood. Please consider how talking about your personal experiences might make you feel. You have the choice to only disclose what you feel comfortable, and you can take a break and/or withdraw from the interview at any point. If you would like emotional support following the interview then the researcher will be able to signpost you to an appropriate service.

On a personal level, you may find that the interview helps you to reflect on your experiences of diabetes, helping you to make sense of these experiences. By participating you will also be contributing to new research, which will increase our understanding of patients' experiences. This may inform services and the development of treatment programmes.

How will my information be treated?

Your information will be treated as strictly confidentiality and will be protected before and after the study by the following methods:

- Recorded interviews will be typed up word for word (transcribed) removing all identifying information and removing participant name, replacing with a fictitious one (pseudonym). Your transcribed interview will be assigned a participant number. This will be given to you as a point of reference should you wish to contact the researcher with any queries.
- The researcher will request some demographic information including your gender, age, marital status, employment status etc.
- Audio data will be stored on a password protected encrypted USB stick and once anonymously transcribed, the recordings will be immediately destroyed.
- Anonymised transcripts and information on coded pseudonyms will be kept separately in locked cabinets and archived at Coventry University for 5 years after the research has finished in accordance with university policy.
- Only NHS employees from the research team will have full access to your identifiable data, however this information may be confidentially shared with NHS research auditors (responsible for ensuring research standards). In some circumstances (e.g. the researcher interviews you at your home) a member of the research team from Coventry University will be given your details in a sealed envelope which will contain the time/date of your interview, your name and address. This will only be opened if there are any concerns for the researcher's safety. This is to comply with the University and NHS lone working policy. This will be immediately destroyed by the researcher following the interview.
- Findings will be written up into a research report. Quotations of interviews may be included but will be anonymised to protect confidentiality.
- The research report will form part of the researcher's thesis for a Doctorate in Clinical Psychology. A copy of the thesis will be held at Coventry University and The University of Warwick libraries and online. It is the researcher's intention to submit the report to a peer reviewed journal for publication and present the findings at relevant conferences.

Will my GP be aware of my participation?

With your permission, it is best practice to inform GP's about participation in research, particularly should you have any additional need for support once the research project has ended. Your GP will therefore receive a letter including the study title, brief summary about the aims of the research and date of your participation. If you would like to opt out of this, please let the researcher know when they take your consent to participate.

Are there any limitations to confidentiality?

Your confidentiality is extremely important to us, however should you disclose information that raises serious concerns about the risk of harming yourself or others; or there are concerns for the neglect or abuse of children, then the researcher will have to share this information with agencies, and this may be without your permission. If this happens the researcher will try to discuss this with you first.

Do I have to take part?

No. Taking part in any of this research is completely voluntary. Furthermore, if you initially agree to participate but then change your mind then you can choose to withdraw. Due to the nature of the research, once your participation has concluded you can only request to withdraw the information provided within two weeks of your interview. You can do this by informing the researcher by email at onensl@coventry.ac.uk and will only need to email your participant reference number. All of your data will be destroyed. Withdrawing yourself or your data from the study will not affect your care from your health care professionals in any way.

Who is organising and funding the research?

This research is being sponsored by Coventry and Warwick Universities as part of the researcher's doctoral academic programme of study. The research is being funded under the researcher's employment contract with the NHS.

Who has approved this study?

This has been reviewed and approved by Coventry University Ethics Committee, West Midlands -Solihull Research Ethics Committee (REC), Health Research Authority (HRA) and the Research and Development (R&D) department for the NHS.

What if there is a problem?

In the unlikely event that a problem arises during the course of your participation in this study, or if you have concerns about the conduct of the research or a complaint to make, please contact Professor Olivier Sparagano in writing at the following address: AB124, Alan Berry Building, Vice Chancellor's Office, Coventry University, Priory Street, Coventry, CV1 5FB. Professor Sparagano is independent of the research team and is responsible for overseeing research reviewed by the Coventry University Ethics Committee.

You can also seek free confidential advice and support from the NHS Patient Advice Liaison Service (PALS). This service aims to ensure that the NHS listens to patients, their relatives, carers and friends, and resolve their concerns as quickly as possible. PALS also helps the NHS to improve services by listening to what matters to patients and their loved ones and making changes, when appropriate. For Northampton, the local PALS office telephone number is 01536 493305. Alternatively, please ring the NHS advisory line 111 in order to obtain contact details for your nearest PALS service.

Contact for further information?

For further information or queries, or if you would like your data removed from the study, then please do not hesitate to contact;

Researcher: Laura Onens

Email: onensl@uni.coventry.ac.uk

Coventry University contact:

You can also contact the academic supervisors Dr Carolyn Gordon and Ms Jo Kucharska concerning questions about the research.

Email: carolyn.gordon@coventry.ac.uk and jo.kucharska@coventry.ac.uk

NHS contact:

You can contact Dr Jess Twyford about any clinical related issues.

Email: [REDACTED]

Appendix P: Consent to contact form

[Host NHS organisation logo]

CONSENT TO CONTACT FORM

I am interested in participating in the research study “The lived experience of men with complications of Type-2 Diabetes and low mood”. I give my consent for the principal researcher Laura Onens (Trainee Clinical Psychologist) to contact me by telephone or email to discuss this further.

Please circle: YES / NO

(If **YES** then please enter your contact details below)

Name _____

Address:

Telephone number _____

Email _____

Please return your form to us in the stamped addressed envelope enclosed. Please allow up to two weeks to be contacted by the researcher.

Thank you.

Appendix Q: GP letter



[GP Name ,Practice Address]

[Date]

Dear

RE: Patient Name, DOB, NHS Number, Address

For the purpose of your records, I am writing to inform you that the above-named patient has participated the research study titled:

The lived experience of males who have complications of Type-2 Diabetes and symptoms of low mood: An Interpretative Phenomenological Analysis.

[Insert patient's name] participation involved attendance to a one-off, one-to-one interview with researcher, Laura Onens, held on [insert date].

Laura Onens is chief investigator of the study and a Clinical Psychologist in training for the NHS. The study is being conducted in conjunction with Coventry and Warwick Universities and [REDACTED] NHS Trust. The aim of the research is to understand the lived experiences of men who have physical complications of type 2 diabetes and report symptoms of low mood. The research has been ethically approved by Coventry University Ethics Committee, the West Midlands – Solihull Research Ethics Committee, the NHS Health Research Authority and relevant local Research and Development departments.

For further information, please find enclosed a Participant Information Sheet, routinely given to participants at the start of the study. If you have any further questions please contact me directly by emailing onensl@coventry.ac.uk. You can also telephone the department of Clinical Psychology at Coventry University on 024 7765 8328.

Appendix R: Consent form

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7765 7088

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



Consent Form

Title of Project:

"The lived experience of males who have complications of Type-2 Diabetes and symptoms of low mood"

Name of Researcher: **Laura Onens**

Participant number: _____

Please initial box

1. I confirm that I have read and understand the Participant Information sheet for this study.	<input type="checkbox"/>
2. I can confirm that I have had enough time to consider the information and have had the opportunity to ask questions and had these answered satisfactorily.	<input type="checkbox"/>
3. I understand that my participation is voluntary and that I am free to withdraw without giving a reason, and this will not affect my medical care	<input type="checkbox"/>
4. I understand that I have the right to withdraw the information I have provided after the study has concluded (within 2 weeks after interview)	<input type="checkbox"/>
5. I consent to my interview being audiotaped and transcribed.	<input type="checkbox"/>
6. I understand that the information I give will be treated in confidence in the ways detailed in the Participant Information Sheet	<input type="checkbox"/>
7. I understand that the researcher may use word-for-word quotes from my interview, which will be anonymised and could be included in any publications that result from this project	<input type="checkbox"/>
8. If I disclose information that raises serious concerns about the risk of harming myself or others; or there are concerns for the neglect or abuse of children, then I understand that the researcher will have to share my information with agencies, and that this may be without my permission. If this happens I understand the researcher will try to contact me first.	<input type="checkbox"/>
9. I agree to my GP being informed that I have participated in this research.	<input type="checkbox"/>

I consent to taking part:

Name of Participant

Signature

Date

Name of Person taking consent

Signature

Date

The lived experience of males with type two diabetes & low mood V0.1

18.05.17

Appendix S: Debrief

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7765 7688

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol



Debrief Sheet: “The lived experience of men with complications of Type-2 Diabetes and low mood”

Researcher: Laura Onens

Participant Reference:

Thank you for taking part in the research concerning the lived experiences of men who have complications of type 2 diabetes and low mood.

If you have any questions regarding this study, please feel free to ask the researcher (email: onensl@uni.coventry.ac.uk). Please quote your participant reference number.

In the event that you require emotional support following your participation in this study, we would recommend the following:

- 1) Contact the researcher Laura Onens on [contact details] who will be happy to discuss your concerns and direct you to appropriate services.
- 2) Alternatively, you may prefer to discuss your concerns with your diabetes health care professional or GP.
- 3) If you are experiencing thoughts of suicide or self-harm and need urgent advice then please ring the NHS helpline by dialling 111.
- 4) ‘The Samaritans’ additionally have a free 24hr confidential helpline for people experiencing thoughts of self-harm or suicide. Dial 116 123.
- 5) You can obtain general advice and information of local support groups in your area by contacting the charity Diabetes UK on 0345 123 2399 or by visiting their website www.diabetes.org.uk
- 6) If you have any concerns or complaints following participation with the research you can also seek free confidential advice and support from the NHS Patient Advice Liaison Service (PALS). This service aims to ensure that the NHS listens to patients, their relatives, carers and friends, and resolve their concerns as quickly as possible. PALS also helps the NHS to improve services by listening to what matters to patients and their loved ones and making changes, when appropriate. For [REDACTED], the local PALS office telephone number is [REDACTED]. Alternatively, please ring the NHS advisory line 111 in order to obtain contact details for your nearest PALS service.

If you would like to receive a copy of your anonymised transcribed interview, or in time, a copy of the written research project then please return the slip enclosed.

Appendix T: Interpretative Phenomenological Analysis Framework *(from Smith, Larkin & Flowers, 2009)*

Stage of Analysis	Strategy
Stage 1 Line by Line Analysis	A close, line-by line analysis of the experiential claims, concerns, and understandings of each of the participants by making first order notes to summarise the experiences of diabetes and depression as discussed by the participant. This will provide rich, meaningful scripts of language used by the participant to describe their lived experiences of T2DM, depression and physical complications and how they make sense of these. This is directly appropriate to the first research question of this study: How do people with clinical depression, T2DM and physical complications make sense of their lived experience of these phenomena?
Stage 2 Identification of Emergent Patterns	The subsequent identification through second order notes by identifying emergent patterns within this experiential material emphasizing both convergence and divergence, commonality and nuance, first for single cases, then across multiple cases. This will help to answer the second research question: Are there any meaningful themes e.g. similarities or differences in the lived experiences of this homogenous sample?
Stage 3 Interpretative Account	The development of a 'dialogue' between the researchers, their coded data, and their psychological knowledge, about what it might mean for participants to have these concerns, in this context, leading in turn to the development of a more interpretative account.
Stage 4 Development of structure	The development of a structure, frame or gestalt, which illustrates the relationships between themes.
Stage 5 Organisation of findings	The organisation of all of this material in a format that allows for analysed data to be traced right through the process, from initial comments on the transcript, through initial clustering and thematic development, into the final structure of themes. As recommended by Smith et al. (2009) the results section will first present the emergent master themes that are relevant in answering the study's research questions. A table will present the master themes and superordinate themes. A narrative account will follow of each of the master themes, supported by a detailed commentary on data extracts to reflect the interpretation. Depending on the complexity of the themes, thematic maps or diagrams may assist the organisation of the data.
Stage 6 Plausibility	Using supervision with Dr Carolyn Gordon, Ms Jo Kucharska and Dr Jess Twyford to help test and develop the coherence and plausibility of the interpretation.
Stage 7 Diagrammatic representation of the full narrative.	The development of a full narrative, evidenced by a detailed commentary on data extracts, which takes the reader through this interpretation, usually theme-by-theme, supported by a visual guide (e.g. diagram or table).
Stage 8 Self awareness and reflection	Reflection of one's own perceptions, conceptions and processes. As the doctoral student has worked in a diabetes services recently and has directly experienced diabetes, a reflective diary will be kept to increase the researcher's self-awareness of her own assumptions and biases.

Appendix U: Initial coding example

Excerpt example of coding from John's transcript

123 people, I try to deal with it on my own, and my way of coping is food. I didn't reach out and
 124 say I need help blah blah blah... I don't do that often. It would be an exception to the rule. *Help seeking - acknowledges he doesn't run his own business. how I manage sickness?*

125 Again, I learned throughout my childhood that you have to be self-reliant, very Victorian but
 126 that is how it is. I was never given the opportunity to ask for help, or be responded to when
 127 I needed it so I don't think I knew how to ask for help or to express myself. *childhood lessons - self-sufficiency/autonomous → but at a cost to him (isolated and alone swallowing emotions). Sad... No framework on how to seek help when naturally experiencing and*

128 R - Has it always been this way or do you think things have changed over your lifetime?
 129 P - It has changed somewhat. When I got diabetes and was diagnosed with the condition, *No one will come when I am distressed. I can't help but think of attachment patterns. No internal model on how to seek or receive help. recognises it took time so becomes avoidant.*

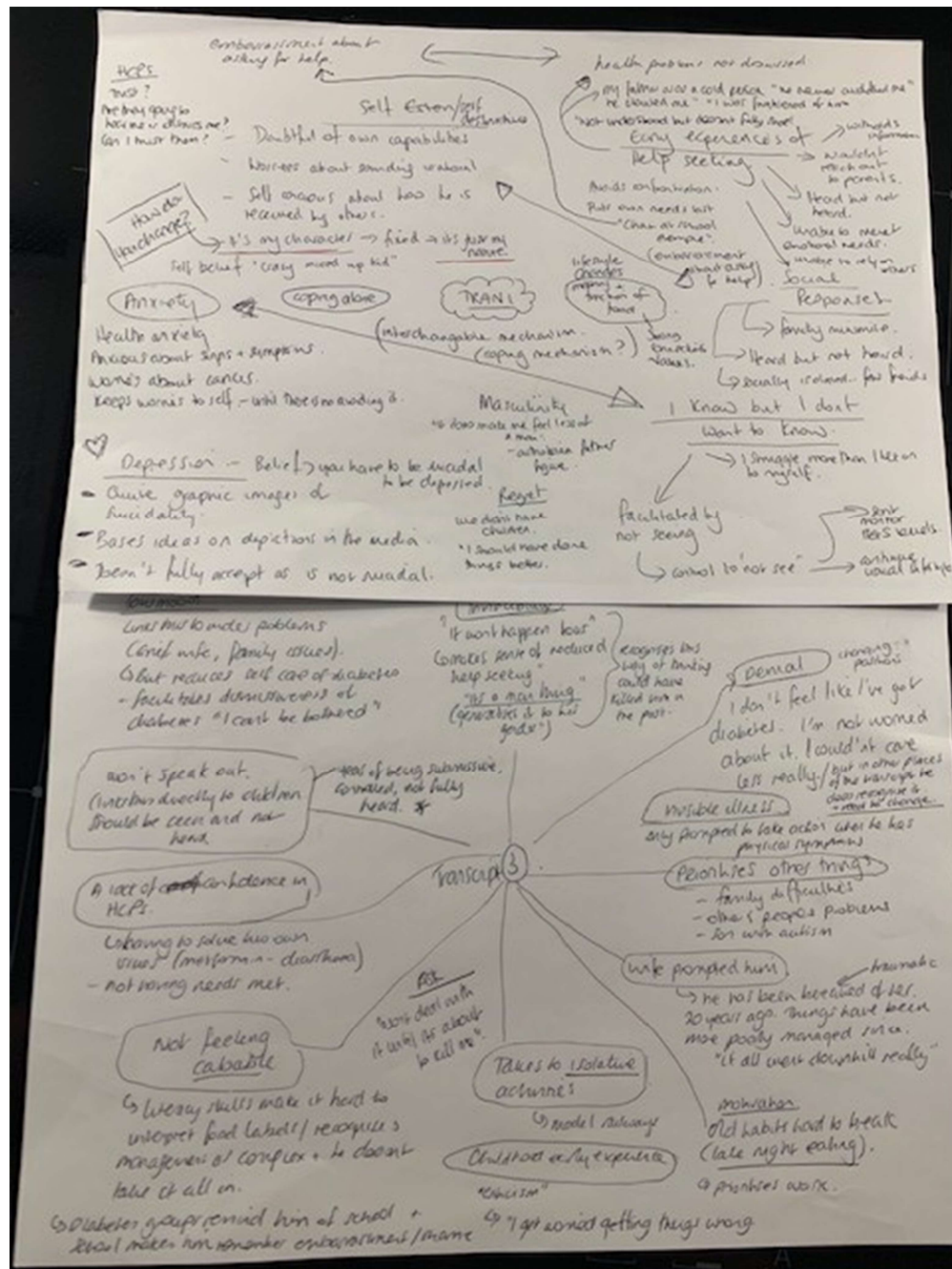
130 apart from the period of denial, I then realised (very slowly albeit) that I had to get some
 131 kind of help. I found myself in danger of alienating my wife and children in the same way his
 132 personality had an effect and I didn't want that to happen. and when saying so, I went out
 133 of my way to spoil the children which is not a good thing, but I did not learn the middle
 134 ground. It was always two extremes. For most of their childhood I was working crazy hours *positive impact of T2DM? repeating historical patterns. Reliance. recognises struggle to self-regulate*

135 anyway. Me and my wife were practically working opposite each other. So I wouldn't see
 136 them as often as I wanted to. So now, they are 24 and 21 and they both go to their mom,
 137 which hurts, but what do I do. It has happened. I wasn't there in the early stages. They had
 138 to grow up pretty fast, because they saw me occasionally during the day. I might pick them
 139 up from school in the afternoon and be off to work at night. The lifestyle we led was bad in *recognises less intimacy + support. desire / value / motivation → ? guilt? identifies a painful feeling → resigned language. is this an accurate perception of biased viewpoint. Robert's childhood. Expect over*

Clinical consideration

Appendix V: Development of themes

Developing themes within interviews



Appendix W: Clustering emerging themes

An example of clustering emerging themes

