THE UNIVERSITY OF HULL

Discussing risk during pregnancy: the experiences of midwives and
women with pre-existing diabetes

being a Thesis submitted in partial fulfilment

of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

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BSc (Hons) Psychology (University of York)

January 2017

Acknowledgements

First and foremost, I would like to thank all the people who gave their time to take part in my study and share their humbling experiences. This thesis is dedicated to those who live and cope with chronic health difficulties. Thanks also go to the diabetes charities who supported recruitment. I am extremely grateful for the knowledge and guidance provided by my research supervisors, Dr Lesley Glover and Professor Julie Jomeen. Your wisdom, compassion and enthusiasm inspired me to 'trust in the process' and remain motivated throughout.

Thank you to my family; you provide a continual source of encouragement. To Mum and Dad, words cannot express how much I appreciate all that you have done, and continue to do for me; practical assistance, emotional support and providing a calm oasis, allowing me to focus on research. Your consistent, loving presence has provided me with space to flourish, follow my ambitions and work with, instead of against, life's obstacles. A special thank you to Charlie, for your unconditional love and patience. You have been a reliable and grounding presence and I couldn't have done it without you.

Thank you to my IBD team, past and present, for working with me to ensure that I remained well enough to complete this research. To Bev M., Dr Nick Hutchinson, Dr Tim Alexander, Dr Emma Lewis, Dr Emma Wolverson and Dr Jemma Jackson, thank you all for your advice and kindness along the way. Eileen, with your warmth and validation, I have nurtured my self-compassion, confidence to trust in myself and ability to express my needs to others - attributes which have been invaluable during the research process.

I'm also grateful to my peers for providing a safe and understanding space to share research related concerns. Specifically, thank you to Jessica for laughing with me all

1

way to the finish line, and to Sarah for being so generous with your time and energy. Lastly, I want to express a huge thank you to everyone still present at the end of the journey, for sticking it out and believing in me, particularly when I couldn't believe in myself. I anticipate a shared sense of achievement and relief!

'Good timber does not grow with ease:

The stronger wind, the stronger trees;

The further sky, the greater length;

The more the storm, the more the strength.

By sun and cold, by rain and snow,

In trees and men good timbers grow.'

Douglas Malloch

Overview

This portfolio thesis contains three separate parts: a systematic literature review, an empirical study and corresponding appendices.

Part one is a systematic literature review, which uses meta-ethnography to synthesise qualitative empirical studies investigating the female experience of living and coping with Type 1 Diabetes mellitus and the impact on identity. A systematic database search identified nine articles which were included. The synthesis of findings resulted in seven subthemes and four super-ordinate themes: 'Identity shaped by the grip of blood glucose levels', 'The influence of others', 'Resistance against a 'diabetic' identity' and 'Creating Stability: integrating diabetes'. The quality of included studies was reviewed and the overall strength of literature considered. Results are discussed in relation to implications for clinical practice in diabetes care and areas for future research.

Part two is an empirical study exploring the experience of discussing risk from the perspective of midwives and pregnant women with Type 1 diabetes mellitus. Five midwives and eight women with Type 1 diabetes were interviewed. Data was analysed using Interpretative Phenomenological Analysis. Twelve subthemes and four super-ordinate themes were identified: 'Understanding and responding to risk', 'Talking about risk', 'Negotiating choice and control' and 'The relationship buffer'. Results are discussed in relation to relevant theory, implications for clinical practice in maternity care and suggestions for future research.

Part three includes appendices which support the meta-ethnography and empirical study. This contains an epistemological statement and a reflective statement detailing the research processes and underpinnings.

Overall word count (excluding appendices and references): 19,928

Table of contents

Part 2: Discussing risk during pregnancy: the experiences of midwives and women with pre-existing diabetes

Part 3: Appendices

List of tables and figures

Part 1: Women with type 1 diabetes and the impact on identity: A meta-ethnography

Part 2: Discussing risk during pregnancy: the experiences of midwives and women with pre-existing diabetes

Part One: Systematic Literature Review

This paper is written in the format ready for submission to the journal

Qualitative Health Research

Please see Appendix A. for Guidelines for Authors.

Word count* (excluding title page, abstract, references, figures and tables): 7977

*for information only - there is no suggested word limit for Qualitative Health Research

Experiences of women with type 1 diabetes and the impact on identity:

A meta-ethnography

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Abstract

Despite awareness of gender specific issues in Type 1 Diabetes, relatively little is understood about how women experience living with and managing this condition. This meta-ethnography synthesised qualitative research exploring the experiences of women with Type 1 Diabetes to gain a thorough understanding of how they make sense of diabetes, cope with difficulties and the impact of diabetes on identity. Four electronic databases (MEDLINE, CINAHL Complete, PsycINFO and Web of Science) were systematically searched to identify qualitative studies related to the experience of diabetes in women. Nine studies were included for review and subjected to data extraction and evaluation of quality. Meta-ethnography produced seven subthemes with four super-ordinate themes: *'Identity shaped by the grip of BGLs', 'Influence of others', 'Resistance against a 'diabetic' identity'* and *'Creating Stability: integrating diabetes'*. Findings are discussed in relation to the gendered impact of illness and implications for female specific diabetes interventions in healthcare settings.

Introduction

Type 1 Diabetes Mellitus (T1DM), previously known as Insulin Dependent Diabetes Mellitus (IDDM), is an auto-immune condition whereby the body is unable to produce insulin, the hormone involved in converting blood glucose into energy (Diabetes UK, 2010). T1DM usually develops in childhood or adolescence; around 542,000 children worldwide live with the condition, increasing approximately 3% each year (International Diabetes Federation (IDF), 2015). This will inevitably result in a growing number of adults living with T1DM. Fluctuating blood glucose levels (BGLs) is a common consequence of diabetes and over time can cause physical damage resulting in blindness, kidney failure, heart attacks, stroke and lower limb amputation (World Health Organization, 2016).

Approximately 199.5 million women worldwide have diabetes (IDF, 2015), around 47% of the total diabetes population. Several gender differences appear to exist in relation to management and outcome. Females are more likely than males to experience difficulties with self-management (Hanna & Guthrie, 2001), display higher BGLs indicating poorer metabolic control (Bryden et al., 2001) and experience more diabetes-related hospitalisations (Cohn, Cirillo, Wingard, Austin & Roffers, 1997). Women with diabetes (WWD) have been found to experience a higher prevalence of anxiety and depression symptoms (La Greca, Swales, Klemp, Madigan & Skyler, 1995; Peyrot & Rubin, 1997) and eating disturbances or eating disorders (Colton, Olmsted, Daneman, Rydall, & Rodin, 2004).

Most literature pertaining to the experience of diabetes involves quantitative methodology surrounding concepts of self-management and compliance with the medical approach. However, there is an emerging body of qualitative literature exploring the lived experience of living with chronic health conditions, such as T1DM

11

(Rasmussen, Ward, Jenkins, King & Dunning, 2011; Watts, O'Hara & Trigg, 2010). An ongoing process of adjustment is required when integrating diabetes into the sense of self and identity (Ironside, Scheckel, Wessels, Bailey, & Seeley, 2003; Youngkhill & McCormick, 2002) which has implications for the effectiveness of treatment and ability to cope. Identity refers to the composition of an individual's attributes, self-beliefs, self-efficacy, roles in interpersonal relationships, values and future possibilities, and is constructed out of symbolic, social and linguistic meaning (Baumeister, 1999; Christiansen, 1999). Self-concept represents aspects of perceived identity, such as social acceptance, behaviour, physical ability, appearance and self-esteem (Harter, 1986).

Long-term conditions, particularly those diagnosed in childhood, can result in rapid identity change (Charmaz, 1995; 2002). Initial sense of 'difference' to others can be reinforced over time, leading to a negative self-concept in people with T1DM (Dovey-Pearce, Doherty & May, 2007). One way to cope with the difficulties evoked by diabetes is through an evolving 'transformational' process (Paterson, Thorne, Crawford & Tarko, 1999). When diabetes challenges are embraced a process of differentiating between 'self' and 'illness' occurs allowing diabetes to be viewed as an external object, detached from the sense of self. This increases mastery and reduces self-blame, particularly when self-management is difficult.

Due to the limited qualitative literature focussing on the lived experience of WWD, experiential processes which may help to interpret gender differences in management or psychological difficulties remain unclear. The female experience of T1DM involves several potential life transitions or issues which are not experienced by men. Diabetes in women can adversely affect puberty, pregnancy and childbirth, with increased risk of complications (Jovanovic, 2004). Qualitative research highlights how pregnant WWD experience loss of control and awareness of having an unwell, 'risky

body', alongside worry, pressure and self-blame associated with responsibility for their baby's health (Berg & Honkasalo, 2000; Richmond, 2009).

This meta-ethnography aimed to synthesise qualitative literature related to women's experience of living with T1DM. It was hoped that this would facilitate an exploration into how diabetes shapes women's self-concept and how WWD experience the process of integration. It was felt that a thorough understanding of the impact of diabetes on sense of self would allow for consideration of how WWD might then cope with female specific transitions i.e. how their relationship with diabetes and the sense of self influences their attitude to and experience of subsequent events such as pregnancy. This would inform how healthcare practitioners (HCPs) individualise treatment, promote effective self-management and best support women, particularly during puberty and pregnancy transitions which may further influence emotional well-being and sense of self. The synthesis aimed to answer the following questions:

- What meaning do women ascribe to having diabetes?

- How does living with diabetes impact on women's self-concept or identity?

- How do women cope with physical and psychological difficulties involved in managing diabetes?

Method

Data Synthesis

A meta-ethnographic approach was utilised to synthesise findings. This a well-developed method for synthesising qualitative data, particularly in health research (Britton et al., 2002). An interpretive stance was deemed important due to the paucity

and diversity of research directly related to the review aims. Seven phases suggested by Noblitt and Hare (1998) guided analysis:

1. Identifying a question to be informed by qualitative research.

2. Deciding what is relevant, developing inclusion/exclusion criteria and obtaining studies.

3. Repeated reading of studies and noting down themes (primary participant perceptions and secondary author interpretations).

4. Determining how studies are related by identifying key concepts through thematic analysis.

5. Reciprocal translation: translating studies into one another through comparison of concepts to identify common or contrasting ideas.

6. Synthesising translations into a whole interpretation.

7. Expressing the synthesis through writing.

Data was extracted using a standardised form to summarise methodology, quality and findings (Appendix C). During reciprocal translation, an index study (study 1 – Williams, 1999) was identified and relevant themes extracted (Atkins et al., 2008). Themes were compared to concepts in the next study (study 2). Subsequent combined synthesis was used to contrast to study 3. This process continued until all articles had been read and synthesised. Refutational synthesis, used to explain why themes do not relate well between studies, was not necessary as the studies translated into each other. Analysis was focused by holding the aims of the review in mind. Themes were contextualised by continually referring to original papers.

A systematic literature search was completed in February 2016 using Medline, PsycINFO, CINAHL Complete and Web of Science; repeating this search in December 2016 yielded no new articles. These databases were chosen to provide a broad review of literature relating to many disciplines involved in diabetes research i.e. medical and psychological. A hand search of literature and scanning the reference lists of included papers was utilised. Search terms were defined by reviewing previous literature around diabetes and qualitative research (Li, Drury & Taylor, 2013; Rasmussen et al., 2013). Initial literature searches revealed further terms, included in the final search strategy. The terms *"type 1 diabet*" OR "type i diabet*" OR T1DM OR IDDM* identified literature related specifically to Type 1 diabetes. The terms *qualitative* OR interview* OR subjective* OR experience* OR narrative* OR phenomenolog* OR "focus group" OR perspective* OR "well-being" OR meaning** focussed the review around qualitative articles exploring lived experience literature. Finally, the terms *wom#n OR female* OR girl** identified female samples. Limiters were applied to include peer reviewed studies published in English.

The following inclusion and exclusion criteria were utilised when reviewing titles, abstracts and full texts to identify relevant literature:

Inclusion criteria

- Articles exploring women's experience of living and coping with T1DM.
- Articles utilising female only samples. Mixed samples with analysis separated by gender were included.
- Articles involving participants aged 13-60, enabling examination of female age-specific issues such as puberty, childbearing and identity development.

- Qualitative methodology.

- Autobiographical research to obtain the perspective of those living with
  diabetes.

- Empirical articles; not literature reviews, dissertations, commentary papers.

- No limiters were applied to year of publication, country or origin to preserve
  relevant literature.

- Written in English language; translation facilities were inaccessible.

- Peer reviewed.

Exclusion criteria

- Type 2 diabetes due to differing cause and effect and to ensure a manageable
  number of articles.

- Male only sample, or mixed gender samples not analysed separately.

- Research exploring interventions (unless they included discussion around the
  impact of diabetes).

- Articles addressing the impact of dual diabetes and eating disorder diagnoses,
  due to the complicating nature of an eating disorder.

- Research with pregnant women/new mothers. Pregnancy and motherhood
  involve a unique transition during which concepts of the self are subject to rapid
  change (Smith, 1999). This is not the focus of the current review.

Quality Assessment

Reviewing quality of qualitative research is widely debated, with little
agreement on how to apply criteria and numerous checklists available (Atkins et al.,
2008). It was decided that this meta-ethnography would subject articles to quality

assessment to provide detail for the synthesis, ascertain limitations in the reporting of findings and inform future research. Quality is discussed to allow for reflection of the strength of findings based on combined literature. Lack of consensus and validation around which criteria to use, and subjectivity involved in interpreting qualitative research also informed this decision. Assessment of quality assessment was conducted for all studies by the first author (KS) using the quality appraisal checklist for qualitative research (National Institute for Health and Clinical Excellence (NICE), 2012).

Each study was graded according to checklist guidelines and the total number of fulfilled criteria (Appendix D & E). Studies obtained the highest quality rating (++), when all or most checklist criteria were fulfilled (cut off = 9-12), and where they had not been this was very unlikely to alter conclusions. Studies obtained the middle quality rating (+), where some checklist criteria were fulfilled (cut off = 5-8), and where they had not been this was unlikely to alter conclusions. No studies obtained the poorest quality rating (–), appropriate if few or no checklist criteria were fulfilled (cut off = 0-4), making it likely that conclusions would be altered.

This checklist was chosen as it combines elements from previous tools and can be used to assess different qualitative methodologies. Four papers were independently evaluated by a peer researcher and inter-rater reliability was high; 90% agreement. Disagreements related primarily to the trustworthiness of analysis such as richness of data and how convincing findings were. Discrepant ratings and rationales were discussed and relevant sections re-read to inform final quality rating decisions; no ratings were altered. No studies were excluded for poor quality due to the limited articles appropriate for inclusion and concerns around rejection of valuable information.
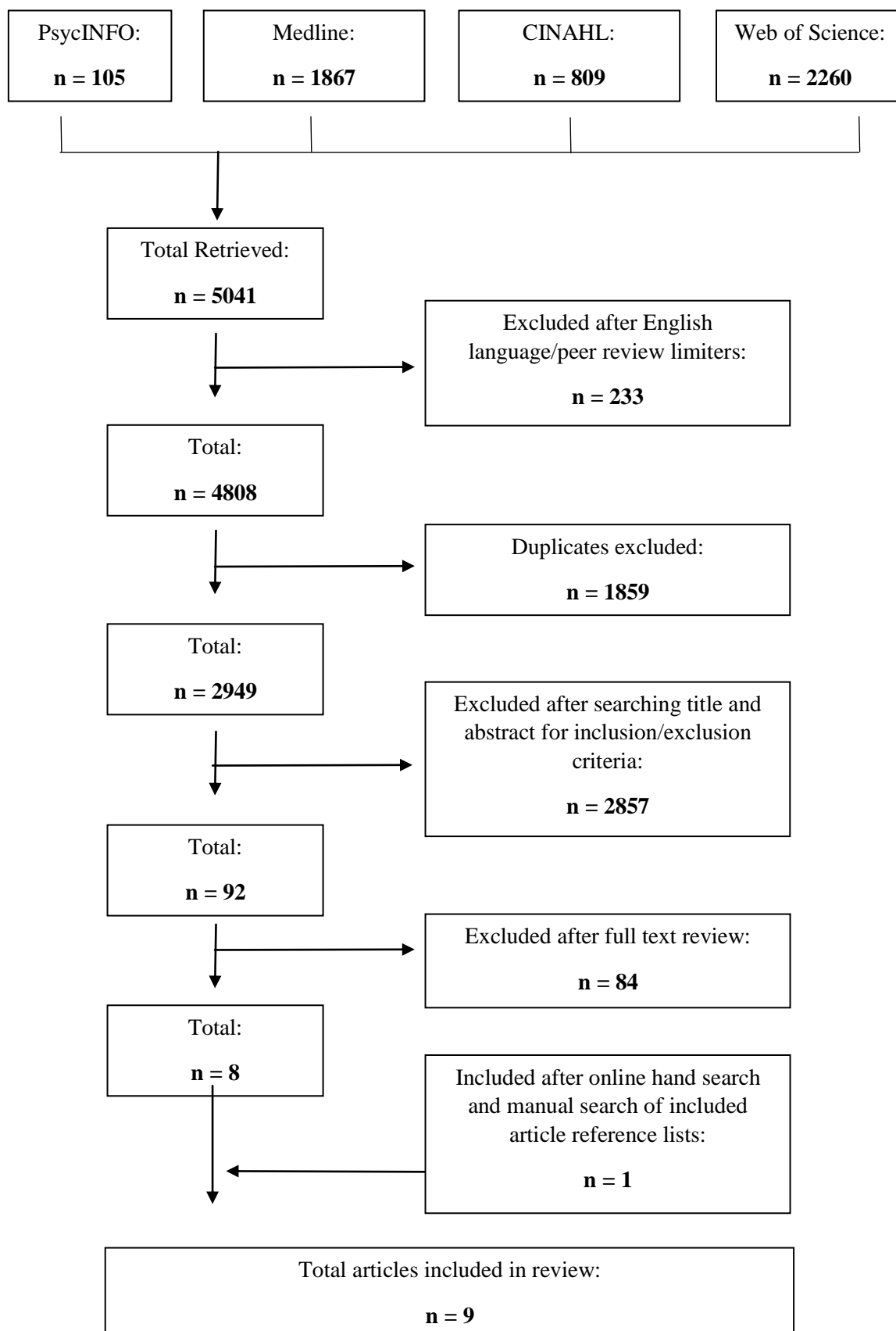
Figure 1. *Article selection process.*

Results

Included study characteristics

Nine papers were identified during the selection process (Figure 1) and included in the meta-ethnography; main characteristics are found in Table 1. Studies were predominantly conducted in Western countries (USA, UK, Canada, and Australia) with one study from Iran. All studies collected data via individual or focus group interviews, sample sizes ranged between 8-24, and a total of 133 participants were included across studies. Articles explored women's experience of living with T1DM including the meaning of diabetes and self-management, impact on development or quality of life, and coping strategies. Participant's ages ranged from 13-57. Three articles explored adolescent perspectives (Dickinson & O'Reilly, 2004; Maslakpak, Anoosheh, Fazlollah & Ebrahim, 2010; Williams, 1999) and seven articles explored adult perceptions (Kay, Davies, Gamsu & Jarman, 2009; Kelly, Lawrence & Dodds, 2005; Rasmussen, Dunning, O'Connell & Cox, 2007; Rasmussen, Dunning & O'Connell, 2007; Stuckey & Tisdell, 2010; Visekruna, Edge & Keeping-Burke, 2015). Studies adopted various analysis methods including phenomenology, content analysis, narrative analysis and grounded theory.

Table 1   *Description and characteristics of included studies*

Author, Year and Country	Aims	Sampling	*n*	Participant Characteristics	Data Collection	Analytic Approach	Quality rating
Dickinson & O'Reilly (2004) *USA*	To explore the meaning of living with diabetes for adolescent females and highlight what motivates them to learn and take care of themselves	Voluntary Purposive Recruited from diabetes camp	10	Aged 16-17 Caucasian Length of diagnosis 5-12 years	Unstructured, individual interviews Lasting 15-35 minutes	Qualitative Van Manen's Phenomenological Framework	+
Kay, Davies, Gamsu & Jarman (2009) *UK*	To explore young women's experience of living with Type 1 diabetes	Voluntary Purposive From specialist diabetes clinic	9	Aged 18-24 White British Length of diagnosis for 4-19 years	Semi-structured, individual interviews Lasting 30-80 minutes	Qualitative Interpretative Phenomenological Analysis	++

Kelly, Lawrence & Dodds (2005) *Australia*	To explore the impact of Type 1 diabetes on women's adult development	Voluntary Identified from diabetes clinic and other support services	24	Aged 23- 55 (mean = 37.5) Ethnicity not specified Length of diagnosis 1.5-50 years Varied experience of diabetes & medication	Semi-structured, individual interviews Lasting around 60 minutes	Qualitative Content Analysis using Riegel's developmental model (quantitative data collected, not analysed as part of this study)	+
Maspaklak, Anoosheh, Fazlollah & Ebrahim (2010) *Iran*	To explore perspectives on barriers to Quality of Life in adolescent, Iranian females	Voluntary Purposive From diabetes educational organisation	20	Aged 13-18 Iranian Length of diagnosis >1 year	Semi-structured, individual interviews Lasting 30-80 minutes Two focus groups (n=5)	Qualitative Content Analysis	+

Rasmussen, Dunning, O'Connell & Cox (2007) *Australia*	To develop a theory based around how women with Type 1 diabetes manage life transitions	Voluntary Purposive & theoretical Recruited via advertisement in diabetes organisation newsletter	20	Aged 20-36 (mean = 28) Indian, Italian, Greek Age at diagnosis 5-11 Length of diagnosis 4-28 years (mean = 17)	Semi-structured, individual interviews Two focus groups (n=5) Lasting 30-140 minutes Newspapers, non-verbal communication & relevant documents	Qualitative Grounded Theory	+
Rasmussen, Dunning & O'Connell (2007) *Australia*	To explore the strategies used to manage life transitions by young women with Type 1 diabetes	Voluntary Purposive & theoretical Recruited via advertisement in diabetes organisation newsletter	20	Aged 20-36 (m=27.6) 'various cultures' Length of diagnosis 4-28 years (mean = 17)	Semi-structured, individual, face-to-face interviews	Qualitative Grounded Theory	+

Stuckey & Tisdell (2010) *USA*	To explore how adults make meaning of Type 1 diabetes and how the role of creative expression could facilitate further meaning making and learning involved in coping with diabetes	Voluntary Recruited through nurse given pamphlets at hospital endocrinology clinic	8	Aged 27-57 Age at diagnosis 4-25 years Length of diagnosis 12-42 years 7 white, 1 bi-racial	Narrative interviews (initial and final) Descriptions of creative images/artwork made in 3 sessions	Qualitative Narrative & Content/Thematic	++
Visekruna, Edge & Keeping-Burke (2015) *Canada*	To describe the meaning of self-management for young women living with T1 diabetes, highlight self-management priorities and describe self-management during the menstrual cycle	Purposive Recruited from a university clinic, diabetes clinic, online networks and diabetes organisation	9	Aged 22-30 (mean = 26) Caucasian Age of diagnosis mean = 12 Length of diagnosis mean = 14 Multiple Daily Injections or insulin pump Students & professionals	Semi-structured, individual interviews Lasting 40-90 minutes	Qualitative Van Manen's Phenomenological framework	++

Williams (1999) *UK*	To explore the way in which gender impacts on the meanings and management of diabetes during adolescence	Recruited by nurses in hospitals, advertisement in diabetes magazine, GP, 'snowballing'	13	Aged 15 - early 20s 75% White, 25% various ethnic minorities Length of diagnosis >1 year	Semi-structured, individual interviews	Qualitative Grounded Theory	++

Methodological quality of included studies

Four studies obtained the highest quality rating (++), five studies obtained the middle quality rating (+) and no studies obtained the poorest quality rating (–). The theoretical approach used, design, and data collection were considered appropriate, defensible and clearly discussed in all but one study which lacked rationale detail (Maslakpak et al., 2010). Most studies were considered valid but some only collected data by one method or lacked consideration of context bias or participant characteristics. Quality of analysis and reporting of findings was regarded as being one of the most important aspects in judging methodological quality, as the rigour and validity of original findings would subsequently impact on synthesised themes. Several papers lacked detailed analysis and were often more descriptive, limiting insight into participant experiences. Trustworthiness of analysis was questioned in many studies e.g. data being coded by one researcher, lack of discussion around how differences were resolved and limited consideration of discrepant results implying that all participants shared similar views. Several papers did not adequately reference quotes making presented findings less convincing. Conclusions were generally adequate, although some studies lacked discussion of limitations or implications.

All but one paper (Kelly et al., 2005) reported ethics committee approval. Reflexivity, an essential feature of qualitative research (Finlay, 2002), was lacking from most studies, making it challenging to judge the extent to which researcher values and assumptions may have influenced synthesised themes or conclusions. Only two papers (Kay et al., 2009; Stuckey & Tisdell, 2010) transparently discussed researcher status, position, relationship with participants, and potential influence. However, absence of reporting due to strict journal guidelines may explain limited reflexivity. Despite these

issues, overall quality ratings of all studies imply that unfulfilled criteria are unlikely to modify study conclusions (NICE, 2012). For a full overview of quality see Appendix E.

Synthesis of findings

Reciprocal translation identified four super-ordinate themes and seven subthemes (Table 2). Additional data can be found in Appendix F.

Table 2. Emergent themes and subthemes.

Super-ordinate Themes	Subthemes
Identity shaped by the grip of BGLs	*Fluctuating BGLs and loss of normality* *Distressing emotions and an uncertain future*
Influence of others	*Standing out and being monitored* *Feeling misunderstood*
Resistance against a 'diabetic' identity	
Creating Stability: integrating diabetes	*Becoming an 'expert': being attentive to BGLs* *Cultivating acceptance and perspective* *Forming meaningful relationships*

Identity shaped by the grip of BGLs

Fluctuating BGLs and loss of normality

'There's no part of any day that I can forget that I have diabetes. I have to be aware of it every part of every day. I have to consciously think of what I'm eating, what my blood sugar might be, how much energy I've used ... I couldn't just have an argument and run out of the house. I'd have to run out of the house with my insulin and some spare glucose. So it affects every facet of my life.'

(Kelly et al., 2005, p4)

Diabetes was described as a pervasive, unrelenting and demanding presence, consistently occupying thoughts (Kelly et al., 2005; Stuckey & Tisdell, 2010; Williams, 1999). WWD submitted to management tasks including monitoring BGLs, attending clinic appointments, controlling diet and injecting insulin, resulting in frustration (Dickinson & O'Reilly, 2004; Kelly et al., 2005; Maslakpak et al., 2010), pressure to make choices and having to demonstrate responsibility (Dickinson & O'Reilly, 2004; Rasmussen, O'Connell et al., 2007; Williams, 1999).

'I think it made me more responsible at least, like earlier.... It just made me grow up, mature sooner so that I could deal with it and take care of it by myself.'

(Dickinson & O'Reilly, 2004, p102)

Loss of normality and spontaneity undermined autonomy and control. Diabetes affected women's professional persona and restricted their careers, particularly when trying to maintain necessary routine alongside unpredictable work patterns (Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015). WWD described limited educational potential, lost good health and freedom, relationship breakdown, difficulties

27

participating in social interactions, limited food choices and inability to engage in physical activities due to concerns about hypoglycaemia (Dickinson & O'Reilly, 2004; Kay et al., 2009; Kelly et al., 2005; Maslakpak et al., 2010).

"I wanted to… go and work on a cruise ship, but you can't do that when you're diabetic." (Kay et al., 2009, p245)

Being unable to perform everyday activities or needing extensive preparation resulted in women feeling '*different*' and disadvantaged (Kay et al., 2009; Kelly et al., 2005).

'It sounds really dumb but the worst thing is that I can't drive. It's just the loss of independence I find most frustrating. I can't socialize as much as I used to. I can't go to pubs that are dark. I can't go to places I haven't been before, can't go out by myself at night.' (Kelly et al., 2005, p5)

Diabetes negatively affected body image and appearance due to weight fluctuations, injection marks or viewing the pancreas as '*broken*' or '*shrivelled*' (Kay et al., 2009; Maslakpak et al., 2010; Visekruna et al., 2015). Those who used an insulin pump felt objectified by being '*attached to a machine*' and highlighted the challenge to integrate the pump into appearance or clothing (Visekruna et al., 2015). Others experienced miscarriages (Kelly et al., 2005), menstrual cycle BGL fluctuations (Visekruna et al., 2015) or menstrual cycle irregularities which were highlighted as difficult for women from Iran to discuss (Maslakpak et al., 2010).

'I inject insulin in my abdomen or arm skin, so my body has always black and blue spots.'

(Maslakpak et al., 2010, p467)

Fluctuating BGLs required '*relentless attention*', caused women to '*feel like a diabetic*', interrupted daily activities and resulted in a focus on '*numbers*' (Visekruna et al., 2015). Women attempted to gain control over diabetes by attaining stable BGLs (Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015; Williams, 1999) which enhanced self-achievement and self-esteem.

'I get really excited when my sensor [CGM sensor] has come in and it's sort of flat lined at 5.5 or something because 5.5 to me is the perfect blood sugar…It's a big deal if you can get it and keep it at that level for 24 hours.'

(Visekruna et al., 2015, p1378)

Distressing emotions and an uncertain future

WWD experienced fear, sadness and anger, associated with restrictions and pressure to achieve stable BGLs (Stuckey & Tisdell, 2010; Kay et al., 2009; Kelly et al., 2005). Perceived lack of control and diabetes instability resulted in uncertainty, guilt, vulnerability and a sense of failure; most apparent during life transitions, when women perceived they had been unsuccessful in controlling BGLs, when the body reacted differently to insulin on different days or when severe hypoglycaemia resulted in hospitalisation (Kay et al., 2009, Kelly et al., 2005; Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015).

'One day, you can mould the clay, and everything works out perfectly. The next time, it could all fall apart.'

(Stuckey & Tisdell, 2010, p42)

Perceived locus of control (LOC) oscillated between external (no personal control) and internal (complete personal control) (Kay et al., 2009). For some, hypoglycaemia resulted in altered mood states (Stuckey & Tisdell, 2010). Others described the difficulty of managing anger and the potential for this to become internalised or a barrier to self-care.

'You can get mad at yourself, but you still have to take care of yourself. It is a constant reminder. You can't get rid of the anger, because there's nothing to put the anger on. It's part of me, and it's easy to be stubborn and angry and to say, "I'm not going to take care of it anymore," but that would be more hurtful than helping.'

(Stuckey & Tisdell, 2010, p48)

Diabetes was perceived as a threat to physical and emotional well-being, particularly at initial diagnosis (Kay et al., 2009; Stuckey & Tisdell, 2010). Women were anxious about complications (hypoglycaemia, blindness, heart failure, renal problems, neuropathy, death), losing independence and their ability to cope, especially if they were unsupported or living alone (Maslakpak, et al., 2010; Kay et al., 2009; Kelly et al., 2005; Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015). Younger women were concerned about the impact of diabetes on future identity i.e. career or relationships (Kay et al., 2009; Maslakpak et al., 2010).

'Now I feel like I have more control over it than it does of me but I still feel that it can at any time, totally destroy whatever it is I've achieved or got.'

(Kay et al., 2009, p246)

Many WWD reported apprehension around pregnancy and perceived that fluctuating BGLs could result in complications or harm to their baby, meaning they needed to work harder to control BGLs (Kay et al., 2009; Maslakpak et al., 2010;

30

Rasmussen, O'Connell et al., 2007). Some were worried about passing diabetes to their child and previous miscarriage caused concerns about this happening again (Kay et al., 2009; Kelly et al., 2005). Often WWD were concerned that previous knowledge did not equip them to cope with the stringent self-management required during pregnancy (Dickinson & O'Reilly, 2004; Kelly et al., 2005).

'If you're going to have a kid, you have to plan everything out before you even start trying because you know, you have to make sure your blood sugars are perfect, like absolutely perfect, and I'm like, "That's not me."'

(Dickinson & O'Reilly, 2004, p104)

Threat and fear reduced women's confidence, and impacted on perceived options. Some responded by self-restricting activities to feel safer or seeking assistance from others, resulting in loss of independence and a sense of self as '*cautious*' (Kelly et al., 2005; Maslakpak et al., 2010).

'You start to lose confidence in yourself ... I don't think I was a tentative person before I was diagnosed with diabetes but I'm definitely a more tentative person now.'

(Kelly et al., 2005, p13)

Influence of others

Standing out and being monitored

Young WWD questioned whether others viewed them as having a disability, which they contrasted with being '*normal*' (Kay et al., 2009). Others perceived themselves as a '*burden*' (Rasmussen, O'Connell et al., 2007) and cultural influences left some identifying as less valued than male siblings (Maslakpak et al., 2010). Women

31

received unwanted attention, focussed on diabetes, rather than them as a person, enforcing '*a diabetic*' illness identity (Dickinson & O'Reilly, 2004; Kay et al., 2009; Maslakpak et al., 2010; Stuckey & Tisdell, 2010).

'Some people just see that as me, you're diabetic and not you're someone with diabetes ... I hate that.'

(Kay et al., 2009, p246)

A hyper-vigilant, protective system (parents, teachers and HCPs) responded to diabetes threat and associated anxiety by imposing rules or constraints, increasing pressure on women to conform to a '*good diabetic*' identity (Kay et al., 2009; Maslakpak et al., Rasmussen, O'Connell et al., 2007; 2010; Stuckey & Tisdell, 2010).

'There is definitely a good-bad girl association, you know, if your blood glucoses are good you are good, and if your glucoses are bad, you are bad. There is kind of stigma attached to people [with diabetes].'

(Rasmussen, O'Connell et al., 2007, p304)

Higher expectations placed on adolescent females and less parental support than males, resulted in reluctance to seek support (Williams, 1999). WWD struggled to maintain control and autonomy, sometimes they were given responsibility, at other times this was taken away (Dickinson & O'Reilly, 2004; Maslakpak et al., 2010).

'In house, I'm under pressure; my family has an excessive stress about my health. They have always a long list about what I must do and what I must not do.'

(Maslakpak et al., 2010, p466)

Interactions with HCPs centred around BGLs, with little consideration of the individual person, their concerns, emotional well-being, preferences or diabetes

expertise (Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010; Visekruna et al., 2015). 'Parental' responses resulted in WWD feeling judged, criticised, guilty and ashamed if they were unable to achieve stable BGLs or maintain regimes (Dickinson et al., 2010; Rasmussen, O'Connell et al., 2007; Williams, 1999). Inadequate encouragement or explanation around restrictions resulted in confusion, ignoring advice or disengagement (Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010).

'They [endocrinologists] know nothing about you. All they look at is your A1c. In their minds, why can't you get it to six? Why can't you get it to seven? Why are you always hovering at the eight mark? So you feel like, you feel like crap…They barely know your last name yet they're telling you to change everything you do.'

(Visekruna et al., 2015, p1385)

Transitioning from paediatric to adult service was challenging; systems became less integrated with increased time pressures (Visekruna et al., 2015). At a time when autonomy and identity were important goals, adolescents were not routinely included in discussions, with HCPs choosing to interact with parents (Dickinson & O'Reilly, 2004).

Feeling misunderstood

Women reported that others did not understand the impact of diabetes, resulting in them feeling misunderstood, alone and isolated (Kay et al., 2009; Maslakpak et al., 2010). Support for family or partners was also perceived as lacking (Rasmussen, O'Connell et al., 2007).

'I get angry because I'm like, you don't understand what it does feel like.'

(Kay et al., 2009, p246)

33

Some women felt frustrated at the lack of awareness, particularly the difference between Type 1 and Type 2 diabetes (Masklakpak et al., 2010; Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015). Despite HCPs holding knowledge, WWD believed they did not necessarily understand the lived experience (Kay et al., 2009). Compassionate care was limited and concerns about diabetes dismissed due to HCP perception that women would not require support or information after managing diabetes for many years (Stuckey & Tisdell, 2010; Visekruna et al., 2015).

'Unfortunately, they're [HCP] really in tune with T2 diabetes and seem to have this disconnect when it comes to their T1 adult patients. They don't seem to understand why someone who's managing diabetes for the past [number] years would have any questions, and it's frustrating'

(Visekruna et al., 2015, p1385)

Feeling misunderstood resulted in women avoiding interaction with people they perceived as misinformed, increasing isolation (Rasmussen, O'Connell et al., 2007). The decision to disclose their diagnosis was difficult and women, particularly from Iran, feared discrimination (Dickinson et al., 2010; Kelly et al., 2005; Maslakpak et al., 2010; Rasmussen, Dunning & O'Connell, 2007).

'Sometimes when I have to leave the same class before lunch some of classmates say that I am only doing it to skip class… Some of classmate mock me or make difficulties for me. I would not tell classmate I'm diabetic'.

(Maslakpak et al., 2010, p467)

WWD wanted to maintain anonymity and protect privacy, particularly when gathering information online (Rasmussen, Dunning & O'Connell, 2007). Diagnosis

disclosure resulted from fear of hypoglycaemia and desire for safety and support (Maslakpak et al., 2010; Rasmussen at al., 2007a; Williams, 1999).

Resistance against a 'diabetic' identity

In most studies, women did not want to be defined by diabetes and resisted control to remain '*normal*' (Dickinson & O'Reilly, 2004; Kay et al., 2009; Kelly et al., 2005; Stuckey & Tisdell, 2010). They did not consistently prioritise self-management, particularly during transitions, stressful periods, or when trying to fit in with peers, despite awareness of potential consequences (Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015).

'I felt scared, because I normally have good control, but during the first year of University, I just wanted to have fun. I'm not saying it is right to live badly with that sort of behaviours, but I think that has to be factored in'

(Rasmussen, O'Connell et al., 2007, p303)

Resistance manifested itself as risk-taking behaviours such as eating excessive sugar, withholding insulin, avoiding monitoring BGLs or lying to HCPs to convince them that they were '*fine*' (Kay et al., 2009; Kelly et al., 2005; Maslakpak et al., 2010; Stuckey & Tisdell, 2010; Williams, 1999). Some women discussed a desire to lose weight (Kay et al., 2009; Visekruna et al., 2015) and disclosed weight loss practices through withholding insulin, despite negative consequences (Kay et al., 2009; Visekruna et al., 2015).

'I went from three injections a day down to one injection a day and that one injection was probably about half of what it should have been; just enough to stop you from

feeling like you wanted to throw up every two seconds but enough that the weight was

coming off and then I did that for about six months and I got quite sick.'

(Visekruna et al., 2015, p1383)

Several explanations were proposed to account for unhelpful management behaviours or minimising the impact of diabetes. Some suggested these strategies reduced perceived threat, normalised diabetes and helped women to cope with overwhelming responsibility, stress, fear or guilt (Kay et al., 2009; Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010; Williams, 1999). They could be considered an 'act of rebellion' to regain control, in response to oppressive, criticising interactions. It was also hypothesised that poor management and physical difficulties might be an expression of distress through the body, with illness as a distraction from emotional difficulties.

'There was a few stages where I ended up in a hospital and, and things like that so I

suppose I sort of showed how I felt through what I was doing to myself really, rather

than saying to everybody, oh, I hate this.'

(Kay et al., 2009, p245)

Others discussed that although preservation, avoidance and disengagement prevent effective self-care (Dickinson et al., 2004; Kelly et al., 2005) perhaps fighting to retain a 'normal' sense of self is adaptive.

Creating Stability: integrating diabetes

Becoming an 'expert': being attentive to BGLs

WWD employed practical strategies to take control including seeking accessible information and reassurance from HCPs or peers (Kay et al., 2009; Kelly et al., 2005; Rasmussen, Dunning & O'Connell, 2007). Internet sources offered accessible, flexible information which adapted to women's changing needs. Planning and routine helped women to counteract uncertainty and manage activities without restriction (Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010; Visekruna et al., 2015).

'The Reality Check website. That is what I use a lot. People post notes for everything and a lot of it is about facing discrimination or 'I fear, I panic, what do I do?' or 'What can I do in this situation? And in that situation?' And gives me reassurance.'

(Rasmussen, Dunning & O'Connell, 2007, p21)

WWD reported getting to know their body and its reaction to activities or insulin, allowing them to remain attentive to BGLs, respond rapidly to fluctuations and feel confident to deviate from regimes while accepting potential consequences (Rasmussen, O'Connell et al., 2007; Williams, 1999).

'If I know we're going to be going out for a meal, then when I do my injection before that meal, I'll put in extra because I know that I'm going to eat more than I should, or eat a pudding that I probably shouldn't eat.'

(Williams, 1999, p1164)

Utilising technology (insulin pumps, Continuous Glucose Monitors) promoted freedom and improved quality of life (Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015), although it was important that management strategies matched lifestyle

(Stuckey & Tisdell, 2010). Improved well-being facilitated women's motivation, confidence and assertiveness.

Moving from a 'healthy person' to a 'person with diabetes' could be a complicated process, involving ambivalence, and evolving with time and age (Kelly et al., 2005; Rasmussen, O'Connell et al., 2007; Visekruna et al., 2015). Some found adaptation difficult and felt '*stuck*' or '*resigned*', despite awareness of how they could alter behaviours (Kelly et al., 2005; Rasmussen, O'Connell et al., 2007). Others located responsibility for change externally and described competing demands, contextual factors such as family, and reluctance to '*depend on others*' as barriers to self-care.

'I'm still not great with my diet. It hasn't been enough to say well get yourself together and be good now. [A]s I said before I just can't manage my life like that. it has to be in stages. [B]ut something always happens and I fall in a heap and I start eating again. I suppose the fact that I had three children has made me a lot more stressed and busy ... I've got three children; my husband works very long hours.'

(Kelly et al., 2005, p11)

Cultivating acceptance and perspective

Women appeared more successful at integrating diabetes within identity when they accepted factors within their control (i.e. can't control having diabetes but can influence attitude and behaviours) and nurtured self-compassion and a non-judgemental attitude towards self-management or fluctuating BGLs (Kelly et al., 2005; Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010; Visekruna et al., 2015).

'Just do not let things stress you out too much. Try to keep it in perspective and try to maintain balance. You might be having a real bad day with your diabetes, but you sort of learn to keep it in perspective. It is only a day and the next day will be a different day.'

(Rasmussen, O'Connell et al., 2007, p305)

With time and experience women reframed challenges, hoped for future treatments, and valued positive aspects of diabetes including increased empathy, assertiveness, resilience and improved relationships (Dickinson & O'Reilly, 2004; Kay et al., 2009; Kelly et al., 2005; Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010; Visekruna et al., 2015). Self-reflection promoted a sense of accomplishment, confidence to cope and enhanced self-efficacy.

'Roberta took a photo of a kite because it reminded her of "flight" and "strength", which were necessary to remain positive about having a chronic illness. The keyhole meant that there was "a key to being whole with diabetes." The key for her was to be positive.'

(Stuckey & Tisdell, 2010, p49)

Attending to BGLs allowed for exploration of future possibilities and identity beyond diabetes (Visekruna et al., 2015). By considering identity as a 'whole person', rather than positioned around diabetes, women could regain control and enhance well-being (Kay et al., 2009; Kelly et al., 2005; Stuckey & Tisdell, 2010; Visekruna et al., 2015). Creative expression helped WWD to develop a '*creative identity*' which was more meaningful than resisting illness (Stuckey & Tisdell, 2010).

'And I got my piano and I started playing piano, and just focused on the things that I could do and focused on me as not being my eyes. Or my diabetes. That I'm still a functional person and I can do things.'

(Kelly et al., 2005, p9)

Forming meaningful relationships

WWD appreciated consistent, positive support from family and friends which motivated them to maintain self-management (Dickinson & O'Reilly, 2004; Kay et al., 2009; Rasmussen, Dunning & O'Connell, 2007). Connecting with others who experience diabetes, through internet forums, peer support groups and diabetes camps, reduced isolation, enhanced sense of belonging and facilitated knowledge sharing (Kay et al., 2009; Rasmussen, O'Connell et al., 2007; Rasmussen, Dunning & O'Connell, 2007). Role models (famous people, camp leaders with diabetes) provided inspiration and reduced women's sense of being different (Kay et al., 2009; Rasmussen, O'Connell et al., 2007). Conversing online provided relief as women could anonymously disclose diabetes or discuss sensitive issues without worrying family.

'I feel much more a part of it now. It is especially doing stuff with the support group where lots of things are going on. I didn't know about all the other people who also had diabetes.'

(Rasmussen, Dunning & O'Connell, 2007, p20)

WWD wanted HCPs to utilise transparent, compassionate, non-judgemental and personalised approaches, rather than '*finger pointing'* (Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010; Visekruna et al., 2015). When HCPs offered time,

valued women's expertise or preferences and included them in decisions, WWD developed skills and were less likely to internalise negative emotions (Dickinson & O'Reilly, 2004; Kay et al., 2009; Rasmussen, O'Connell et al., 2007; Stuckey & Tisdell, 2010; Visekruna et al., 2015). Inquisitive HCPs who showed genuine interest supported WWD to acknowledge emotions.

'You end up thinking more about what you really feel like, because she [the educator] goes to that point in her questioning. I think about it. I like that. I think she… makes me feel less guilty… than many doctors in my past experience… Many of them just kind of yell at you almost, but she gives you the tools rather than just getting on you.'

(Stucky & Tisdell, 2010, p51)

For some, teams were active in self-management, while others relied heavily on themselves. A combination of individualised responsibility and support from others, enabled optimal self-management (Visekruna et al., 2015).

Discussion

This meta-ethnography aimed to synthesise qualitative literature exploring women's experience of living with T1DM to understand the meaning ascribed to diabetes, how it impacts identity and how WWD cope. Unpredictable, fluctuating BGLs required relentless attention and women experienced associated loss, restriction, fear, anger and sadness. The response of others, fuelled by fear, resulted in unwanted focus on diabetes, reinforcing a 'diabetic' identity. WWD lost control and autonomy and felt judged due to constraints placed upon them. Resistance against a 'diabetic' identity, through avoidance or risk-taking behaviours, occurred when WWD wanted to maintain

41

'normality'. They balanced self-management and resistance while integrating diabetes into identity through behavioural strategies, acceptance and supportive relationships.

The synthesis demonstrates that women's emotional and physical well-being is strongly allied to their sense of control over diabetes; achievement of stable BGLs increased confidence and self-efficacy. However, fluctuating BGLs and potential complications threatened women's sense of self, making it difficult to consider future identities i.e. becoming a 'mother'. WWD highlighted increased fluctuations during their menstrual cycle, indicating why it may be harder for women to maintain stability. They responded to vulnerability by self-restricting or looking to others to manage risk and anxiety, undermining autonomy and reinforcing the 'diabetic' identity or self-beliefs about being 'cautious'. LOC over diabetes and self-management oscillated; when women have an external LOC, they may feel unable to influence diabetes, leading to vulnerability and fear. Conversely, extreme internal LOC may place women at risk of becoming overwhelmed by responsibility and developing 'learned helplessness' if they cannot maintain stable BGLs (Skinner, Channon, Howells, & McEvilly, 2000).

Women experienced fear, sadness and anger associated with diabetes management, concurrent with previous quantitative research (La Greca et al., 1995; Peyrot & Rubin, 1997). The synthesis highlights the potential for negative emotions to become internalised. Negative body perception and withholding insulin as a weight loss strategy account for increased co-existence of eating disturbances in females (Colton et al. 2004). Self-concept can be strongly influenced by diabetes, particularly when an initial sense of difference is reinforced over time (Dovey-Pearce, Doherty & May, 2007), emphasised by WWD in this review who felt disadvantaged. Others' lack of knowledge and perceived stigma resulted in isolation, feeling misunderstood and wanting to preserve anonymity by choosing if, and when, to disclose their diagnosis.

The co-construction of identity through relationships, interaction and others' expectations (Harter, 1990) was evident from this synthesis; women felt controlled by negative social responses. Excessive attention and rules imposed to prevent harm reinforced the 'diabetic' identity, undermining autonomy and adding pressure to attain 'perfect' BGLs. HCPs comments and focus on BGLs contributed to women's perception of themselves as being a 'bad' or 'good' girl. If HCPs judged women's efforts or BGLs to be 'bad' women interpreted this as meaning they 'were bad girls', particularly if they ignored suggested diabetes regimes. Some WWD alluded to being treated differently to male siblings, experiencing higher expectations. These issues may be compounded by Western expectations i.e. 'good' women are calm, tolerant, submissive, in control, responsible and resilient (Ussher 1997, 2002). Failure to achieve expectations of femininity caused distress and guilt. It remains less acceptable to be a 'bad' woman compared to a 'bad' man, resulting in women accepting responsibility, managing competing demands and neglecting their healthcare (Hannan, 2009).

Research into pre-menstrual stress highlights how women feel blamed for 'losing control' of their bodies and subsequently repress emotions or subjugate their needs, putting others first (Ussher, 2003; 2004). This 'self-silencing' leads to depression, diminished self-care and a poorly defined sense of self (Jack, 1991). Perhaps women can only legitimise avoidance of responsibility through a discourse of illness. The synthesis highlights a conflation of gender identity with 'diabetic' identity, resulting in the 'diabetic' identity becoming more powerful. This might explain why women are more likely to experience diabetes management difficulties (Bryden et al., 2001; Cohn et al. 1997; Hanna & Guthrie, 2000).

Despite the developing 'expert patient' concept (Department of Health, 2001), WWD did not always feel their expertise was valued by HCPs. Directing care through

traditional compliance models does not promote self-efficacy (Thorne & Paterson, 2001). When women perceived HCPs lacked genuine concern for their well-being they were more likely to dismiss advice or disengage. Interestingly, although women wanted expertise recognition, they reported that HCPs made assumptions that living with diabetes for many years meant they would not have concerns and so information was not provided. This experience of either neglect or oppression demonstrates HCPs limited understanding of women's fluctuating confidence and desire for support.

Desire for control and focus on the 'diseased' negatively perceived part of identity created resistance against the 'diabetic' identity through avoidance, minimisation, not monitoring BGLs, withholding insulin or ingesting sugar. Although this could be a barrier to self-care, resistance protected WWD from overwhelming emotions while allowing covert communication of distress. Portraying an impression of being 'fine' prevented control and facilitated acceptance by others. Fighting to preserve 'normality' and not surrendering control to external forces may be adaptive, demonstrating the individuality in personal development (Baltes & Baltes, 1990).

An evolving 'transformational' process during which WWD discover and learn new capabilities (Paterson et al., 1999) was apparent. Women adopted various strategies to integrate diabetes into identity, while preserving sense of self beyond illness. Practical changes and self-empowerment, including information seeking, knowing the body, utilising technology and structured routines, counteracted uncertainty and promoted control and confidence. However, some WWD felt objectified by insulin pumps and experienced difficulties integrating technology into appearance, an important expression of identity. Cultivating acceptance and self-compassion and attending to personal growth, characteristics known to facilitate integration (Charmaz, 1995; Commissariat, Kenowitz, Trast, Heptuall & Gonzalez, 2016; Hernandez, 1996),

enhanced women's self-belief and assertiveness. By attributing poor BGL control to 'diabetes' unpredictability, women separated the 'diabetic' self and the 'non-diabetic' self, maintaining a sense of being a 'good' woman.

Improved well-being and exploring holistic identity was facilitated by attending to the 'diabetic' identity and stabilising BGLs. However, effective self-management requires well-being through stability in BGLs, showing a reciprocal relationship. As social and personal context changes, people with diabetes can concentrate on healthy living, locating illness in the background. 'Shifting perspectives' is a continuing process during which individuals experience a complex interaction between themselves and their situation, containing components of illness and wellness (Paterson, 2001; 2003). Diabetes 'transformation' can be a double-edged sword - liberation alongside sole responsibility (Paterson et al., 1999).

Despite restrictive interactions, women negotiated supportive relationships to reduce isolation. They demonstrated desire to nurture the 'diabetic' identity though connecting with those who have shared experiences, admiring role models and using internet forums. Meaningful relationships encouraged WWD to utilise their resources and express, rather than internalise, negative emotions. They sought HCPs who showed compassion, empathy, recognition, curiosity about emotional well-being and viewed WWD as individuals. Patient-provider relationship satisfaction is associated with better regime adherence for girls (Taylor, Greca, Valenzuela, Hsin & Delmater, 2016).

Clinical Implications

It is vital that HCPs understand specific gender issues and review their attitudes and the impact on WWD, particularly when supporting them through transitions such as

45

puberty or pregnancy. Effective communication is important during life transitions which result in vulnerability; satisfaction with HCP relationships might encourage women to seek social support and discuss emotional and physical concerns (Commissariat et al., 2016). HCPs can affirm women's needs, values and priorities by acknowledging preferences and diabetes expertise, alongside exploration of concerns and provision of information (Paterson & Thorne, 2000; Thorne, Nyhlin, & Paterson, 2000). This seems especially important during women's first experience of pregnancy or childbirth when new situations may result in uncertainty, compounded by neglectful interactions. Women would benefit from thorough guidance and support pre-pregnancy to manage anxieties associated with potential complications. Equally, increased intervention necessary to manage pregnancy complicated by diabetes might result in women feeling constrained, reinforcing the 'diabetic identity' and potentially leading to resistance. Obstetricians and midwives would benefit from being mindful of this process when discussing options.

Many polarised views were expressed in the synthesis, i.e. responsibility vs. dependence, and influenced how much support or information HCPs perceived WWD required. Promoting 'both/and' rather than dichotomies would assist women to position themselves as both active and acted upon so that they can take credit while reducing self-blame. HCPs would benefit from exploring how WWD assess risks to health, understand previous experiences or fluctuating BGLs, and make management decisions. During pregnancy HCPs are more likely to focus on BGLs due to the impact of these on a developing foetus. By considering individual experiences and emotional well-being, rather than focusing on 'numbers' or using judgemental language, HCPs can prevent women from identifying with a '*bad girl or good girl dichotomy*' (Rasmussen, O'Connell et al., 2007). Focusing on internal resources, successes and personal control

and including women in decision-making, is likely to enhance confidence, assertiveness and self-management, reducing negative effects of fluctuating BGLs.

To prevent women from feeling overwhelmed or disengaging, responsibility for managing diabetes is best viewed as shared between the individual, family and HCPs, without excessive restriction, demands or unrealistic expectations. Facilitating acceptance of inherent variability and unpredictability in diabetes is likely to facilitate women's ability to ask for support without fearing judgement. This remains particularly important during puberty and adjusting to menstruation, events highlighted as causing increased BGL fluctuations.

Enhanced support for family, partners or teachers, such as conflict resolution skills or diabetes education, might help WWD feel understood and supported with their responsibilities, without oppression. Women would benefit from being encouraged to recognise and explore the emotional impact of diabetes i.e. through narrative or creative expression. Enabling women's expression of ambivalence or contextual barriers surrounding self-management would support engagement in adaptive behaviours. Internet services or facilitating the opportunity to talk to others with diabetes could be incorporated into routine service provision and may be useful at times of transition. Such interventions need to be imbedded in child and adolescent care to assist WWD to manage transitions without becoming trapped in oppressive relational dynamics which are enforced during repeated interactions with health care services.

Strengths and Limitations

Due to the limited number of articles and small sample sizes findings cannot be generalised to all WWD. The focus of this synthesis on the experience of women

resulted in exclusion of studies which did not report separate gender analysis, perhaps overlooking significant findings. Wide participant age ranges were included, possibly influencing findings due to life stage issues i.e. resisting a 'diabetic' identity and fitting in with peers being prominent in adolescence (Dickinson & O'Reilly, 2004). Most studies occurred in Western countries; impact of diabetes, gender roles or healthcare provision may be different in Eastern societies influenced by distinctive beliefs or collectivist culture. However, many findings from Maslakpak *et al.* (2010) were consistent with other studies. Most participants were recruited via diabetes clinics or camps, resulting in bias towards those who are committed to attending appointments or interact with people with diabetes. Due to the wide variety of issues explored within articles some, particularly Rasmussen et al. (2007b) which was part of a larger study, only contributed to specific subthemes.

Most articles lacked reflexivity, making it difficult to ascertain the influence of researcher experience or assumptions. The qualitative nature of the synthesis, high level of interpretation, and subjectivity inherent in assessing quality is likely to have shaped findings. However, transparent discussion of methods and researcher assumptions permits consideration of the influence of these factors on validity of identified themes. It remains unclear whether different epistemologies, underlying principles, and philosophical viewpoints influencing the studies prevent a meaningful comparison. However, the translation of concepts into a 'line of argument' allows findings in different studies to be considered as a whole. Combining studies and the additional analysis of findings already interpreted within the original studies, means that the synthesis may not accurately represent primary participant experiences. Continually returning to the original articles during analysis and emergence of initial themes is likely to have reduced this potential discrepancy.

48

<u>Future Research</u>

Future studies need to separate data to explore differences in how men and women experience diabetes and the response of others, gain support or communicate emotional distress. Women highlighted the importance of relationships and impact of interactions in shaping self-beliefs. It would be useful to understand communication between WWD and family or HCPs in more detail. Gaining the perspective of HCPs on discussing diabetes and how they manage interactions focussed around BGLs or restricted choice would help to explain why valuing expertise, shared decision making and a non-judgemental approach are not always utilised, despite previous recommendation. Future research would benefit from exploring the experience of diabetes in samples from varied socioeconomic and cultural backgrounds to ascertain how diversity in resources, practices or beliefs shapes women's self-perception. It remains pertinent to ensure that further research transparently discusses reflexivity and analysis processes to improve validity and allow for thorough critique of methods.

Declaration of Conflicting Interests

No conflict of interest.

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Part Two: Empirical Paper

This paper is written in the format ready for submission to the journal Women and Birth.

Please see Appendix G. for the Guideline for Authors.

Word count* (excluding title page, abstract, references, figures and tables): 9703

*for information only - there is no suggested word limit for Women and Birth

Discussing risk in pregnancy: the experience of midwives and pregnant women with pre-existing diabetes

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Abstract

Problem/Background: Existing literature suggests that women with pre-existing diabetes, experience challenges during pregnancy leading to psychological distress. Communicating risk appears important in determining satisfaction with pregnancy. However, there has been limited research into the intention and impact of risk discussion in midwife-mother interactions for women with pre-existing diabetes, particularly from a midwifery perspective.

Aim: To understand the experience of discussing risk from the perspective of midwives and women with pre-existing diabetes to identify what is helpful or unhelpful, improve pregnancy care and enhance midwifery knowledge.

Methods: A qualitative, interpretative study involved Interpretative Phenomenological Analysis of semi-structured interviews with pregnant women with pre-existing diabetes aged 27-35 (n=8) and midwives aged 34-54 (n=5).

Findings: Four super-ordinate themes were identified including: '*Understanding and responding to risk*', '*Talking about risk*', '*Negotiating choice and control*' and '*The relationship buffer*'. Subthemes were also discussed.

Conclusions: Midwives and pregnant women with diabetes faced shared uncertainty, discomfort and constraint when discussing risk and choices. Their understanding of risk differed and the structure of maternity care often hindered pregnant women's experiences. Acknowledging both uncertainty and what is known is likely to result in more successful interactions and reduce psychological distress. Healthcare professionals can help women to weigh up choices, informed by evidence and guided by women-centred philosophy. Midwifery plays a vital role in supporting women at risk but requires support from clinical teams and institutional systems to manage the challenges of balancing risk alongside women-centred care.

Keywords: *Pregnancy, Risk, Midwifery, Decision-making, Communication, Diabetes*

Statement of Significance

Problem	There has been limited research into the intention and impact of risk communication in midwife-mother interactions for women with pre-existing diabetes.
What is Already Known	Women with pre-existing diabetes experience challenges during pregnancy leading to psychological distress and awareness of a 'risky' body. Perceived negative interactions with professionals can result in these women feeling judged, controlled and highly responsible.
What this Paper Adds	Women and midwives understood terms such as 'high risk pregnancy' differently. Perception of risk influenced information provided. Discussing risk was emotionally challenging and midwives felt conflicted between advocating women's choices and working with the clinical team.

Introduction

Diabetes Mellitus (DM) is a common health condition in which the amount of glucose in the blood is too high.[1] Approximately 2-5% of pregnancies in England and Wales involve women with diabetes (WWD) [2]; it is the most common pre-existing condition complicating pregnancy in the UK.[3] Diabetes in pregnancy is associated with a range of risks to the mother including miscarriage, pre-eclampsia, preterm labour and risks to the foetus including, stillbirth, congenital malformations, macrosomia, birth injury and perinatal mortality.[1,2] Pregnant women with health conditions, including Type 1 diabetes (T1DM) or Type 2 diabetes (T2DM), often experience anxiety, depression, guilt and anger[4-6] associated with pregnancy outcome uncertainty.[7] They perceive risk of adverse outcomes as higher than in women without diabetes and can experience disempowerment or fear of being a 'burden'[7]. Qualitative research highlights that pregnant WWD experience loss of control and awareness of having an unwell, 'risky body', alongside worry and self-blame associated with responsibility for their baby's health.[8,9]

Experience of diabetes in pregnancy is influenced by interactions with Health-Care Professionals (HCPs). WWD report negative encounters with maternity services, feeling judged or frustrated when they perceive professionals do not value their expertise.[10,11] Perceived unsupportive interactions exacerbate worries about jeopardising their baby's health [12.] Conflicting states of 'mastery vs. enslavement' emerge.[13,14] 'Enslavement' is experienced when WWD feel controlled by HCPs who dictate decisions, resulting in feelings of inadequacy. Constant monitoring of Blood Glucose Levels (BGLs) leads to a focus on diabetes rather than pregnancy, creating frustration.[15-17] WWD prioritise identity as a mother and the task of achieving target BGLs, compromising their self-identity.[9] Medical monitoring motivates many to comply with regimes but added pressure can be a barrier to achieving metabolic control.[9] When HCPs establish supportive, caring relationships and provide individualised information, 'mastery' is promoted and women feel empowered to integrate diabetes within pregnancy.[13,14]

Risa et al.[17,18] explored antenatal consultations between pregnant WWD and midwives, revealing two communicative patterns. Consultations were predominantly medically focussed, using an 'expert' frame which limited women's opportunities to express concerns. Employing a 'shared expert' frame, by using active listening and ambiguous talking, facilitated WWD to share their perspectives and worries.

The midwife-mother relationship is an important factor in positive pregnancy and childbirth experience,[19,20] particularly for those with additional complications.[21,22] Midwives caring for pregnant women at risk experience increased anxiety, especially if they are insufficiently supported.[23] Limited research exploring the impact of supporting women with complex pregnancies on midwives highlights helplessness and frustration alongside a struggle to balance natural and medical viewpoints.[24,25] At a time when midwives are working within increasingly stressed health services and feel undervalued, limited time, workload pressures and a focus on efficiency, outcomes and accountability are likely to impact upon quality of care and risk discussions.[26] However, perception and discussion of risk in diabetes has not been studied in midwives.

Risk, 'the probability that something unpleasant will happen',[27] is used by HCPs to decide suitability for a model of care and ensure a positive outcome.[28] The term 'high-risk pregnancy' describes women with chronic health conditions, although research around maternal and midwifery perceptions of this term is lacking. Social theories suggest risk is appraised individually and influenced by social, cultural and political context, philosophy and previous experience.[29-31] Risk has been shown to be contextualised and embedded in pregnant women's lives,[32,33] who demonstrate a lower perceived likelihood of adverse outcomes compared with HCPs.[28] Increased awareness of risk can intensify negative feelings[34] and poor risk communication is associated with increased anxiety.[35]

Alongside emphasis on risk and fear of adverse outcomes is an increased demand for choice creating conflict for HCPs when managing complex pregnancies while providing options, particularly when choice diminishes as risk category increases.[36] Midwifery-led care

places women at the centre, promoting normality of birth, and empowering women to give birth as naturally as possible.[13] Despite evidence demonstrating clinical effectiveness of midwifery-led care for women at increased risk,[37] these pregnancies are predominantly managed within a medical model by specialists including obstetricians, neonatologists and specialist nurses.[38] Obstetric management can undermine women's confidence to give birth naturally and cause difficulty for women who make decisions that fall outside the trajectory mapped out for them.[36] Midwives face a challenge to integrate individualised care while maintaining safety and reducing risk. However, experience of balancing risk and choice, and the impact of this has not previously been explored.

<u>Aims and Rationale</u>

Existing literature emphasises challenges faced by WWD in pregnancy and the importance of supportive HCP relationships. However, no empirical research has explored how midwives communicate risk and choice to WWD, what is significant during discussions, what makes interactions positive and how midwives communicate when outcomes are uncertain. This study aimed to explore the phenomenon of risk discussion and highlight key issues, from the perspective of WWD and midwives. It hoped to highlight positive midwifery practice while identifying where midwives might benefit from additional support. This would have constructive healthcare implications, reducing distress in pregnant WWD, promoting well-being and effective self-management and reducing risks associated with poor diabetes management.

Due to the emphasis on understanding the experience and meaning of risk discussion from the perspective of midwives and pregnant WWD, Interpretative Phenomenological Analysis was used.[39] IPA takes an interpretive and phenomenological stance and aims to understand the meaning of partially disclosed unique experiences. IPA was chosen over other methodologies such as thematic analysis due to this study's focus on idiographic development of themes for each participant, before identifying patterns across the data-set. Along with the interpretive nature, this allowed the researcher to stay close to original data, while understanding shared concepts for midwives and WWD, contextualised within joint interactions

(see Appendix R for full epistemological statement). A multi-perspective design was employed to develop a detailed account of phenomena.[40] Specifically, the study aimed to explore:

- How do pregnant WWD and midwives understand risk?

- How are discussions around risk experienced by midwives and WWD?

- How do midwives manage communicating risk and providing choice?

- Which aspects of risk communication are perceived as helpful or unhelpful and why?

Methods, Participants and Ethics

Design

An exploratory, qualitative design was utilised to investigate the lived experience of risk communication between midwives and pregnant WWD, through semi-structured interviews.

Inclusion criteria and recruitment

Participants were eligible if they were:

- 18 years or over
- Fluent in English

And either:

- Had a diagnosis of T1DM or T2DM and were currently experiencing their first pregnancy or had given birth to their first child within the last 9 months. Nulliparous women were chosen as their experience of discussing risk was not influenced by previous encounters.
- *Or* were qualified midwives, working in the UK, with experience of supporting WWD.

Participants were excluded if:

- WWD had experienced previous pregnancies e.g. miscarriages or had other children.

- Women had gestational diabetes rather than pre-existing diabetes due to differing care pathways and issues involved.[41]

- Midwives had a diagnosis of diabetes to limit bias.

Two recruitment pathways were achieved via purposive sampling. An advertisement for WWD was placed in the Diabetes UK '*Balance*' magazine, on diabetes charity websites, social media and flyers in public places. All women were recruited via '*Balance*' (n=6) or social media (n=2). Midwives were recruited via the midwifery research Joint Information Systems Committee (JISC) mail, a midwifery and reproductive health research online forum. Participants who self-identified by responding to adverts were assessed for eligibility and given further information. Participants were recruited from October 2015-April 2016.

Participant Demographics

Eight women with T1DM and five midwives were interviewed. Twelve participants were female and one midwife was male. Twelve participants identified as White British and one midwife identified as White Eastern European.

WWD ranged in age from 27-35 years (mean = 33; SD = 2.62), had been living with diabetes for 8.5-30 years (mean = 22.20; SD = 7.61) and their age at diabetes diagnosis ranged from 4-23 years (mean = 9.50; SD = 6.32). Two were pregnant at the time of interview and six had given birth. Three identified co-morbid health conditions including Hypothyroidism, Multiple Sclerosis, Asthma and Anaemia. They were not excluded as they reported that these conditions had minimal impact on pregnancy and management. Women utilised various diabetes management strategies including insulin injections, insulin pumps, continuous glucose monitors and carbohydrate counting.

Midwives ranged in age from 34-54 (mean = 47.80; SD = 8.32), had been qualified for 4-26 years (mean = 12.20; SD = 9.26) and worked with WWD for 4-21 years (mean = 7.9; SD =

7.59). Midwives reported working in a range of primary environments including community, antenatal clinics and inpatient units. Two were working as specialist diabetes midwives. Participant details are provided in Tables 1 and 2.

Table 1. *Midwife demographics.*

Participant Pseudonym	Gender	Age (years)	Number of years qualified as midwife	Number of Years working with diabetes in pregnancy
Susan	F	50-59	21-30	21-30
Lorna	F	40-49	0-10	0-10
Fran	F	50-59	0-10	0-10
Alex	M	30-39	0-10	0-10
Christine	F	50-59	11-20	0-10

Table 2. *Women with diabetes demographics.*

Participant Pseudonym	Age	Age at diagnosis (years)	Length of Diabetes (years)	Trimester	Age of baby (months)
Josie	27	11-18	11-15	Third Trimester	-
Hannah	34	Under 11	26-30	-	1-4
Laura	34	11-18	21-25	-	5-8
Abby	34	Under 11	26-30	-	5-8
Kim	32	Over 18	6-10	-	9-12
Rose	33	Under 11	26-30	-	5-8
Helen	35	Under 11	16-20	-	9-12
Lisa	35	Under 11	26-30	Third Trimester	-

<u>Procedure and data collection</u>

Ethical approval was attained from the local University Research Ethics Committee and permission sought from diabetes charities and the Midwifery Research JISC mail administrator to advertise. Written consent was acquired from participants prior to interview. They were notified of their right to withdraw at any point prior to data analysis. To maintain anonymity participants were given a unique identification code and pseudonym. Due to the potentially emotive nature of discussions, participants were offered contact details of relevant support services post-interview.

Single time point, individual, semi-structured interviews were used to explore relevant areas, while allowing flexibility to pursue avenues important to participants.[39] Participants were asked open-ended questions pertaining to experience of risk discussions, what was helpful, unhelpful etc. about these interactions e.g. '*Can you tell me about your experience of discussing risks with midwives?*' (Appendices P & Q). The interview schedule was developed by the researcher after reviewing relevant literature and highlighting key issues or gaps in understanding. Feedback was gained from midwives and pregnant women around the language used and amendments made as necessary. The same interview schedule was used with both participant groups, with minor language alterations to reflect differing perspectives, encouraging participants to cover similar areas, allowing for analysis synthesis. Participants were encouraged to talk openly about experiences. Responses were followed with summaries, reflections or prompts to explore thoughts, feelings and meanings.[39] Two interviews were conducted face-to-face, the rest via telephone due to geographic location. Interviews were audio recorded and transcribed verbatim and ranged from 42 to 83 minutes.

<u>Data analysis</u>

Qualitative interview data obtained from transcripts was analysed using IPA.[42] Transcripts were subject to line by line analysis of content, language and understandings. The researcher noted exploratory comments, significant issues and initial reactions. Each transcript was read several times using an idiographic approach, allowing for the identification of

convergent and divergent themes across participants. The researcher identified relationships between themes organising them into super-ordinate and subthemes, using language taken directly from participants where possible to express experiences. Transcripts for the two participant groups were initially analysed separately. Commonalities and differences across the groups were then integrated and reported as overarching themes, providing a shared overview of what it means to discuss risk. An example of the analysis process is included in Appendix S.

<u>Quality</u>

Pilot interviews were conducted to check suitability of consent and information forms, recruitment procedures, interview schedules and the research procedure. The researcher was a 25-year-old white, female who did not have experience of diabetes or pregnancy. The researcher was aware of issues related to this topic due to reviewing previous literature before constructing the interview schedule and through personal experience of chronic illness. A reflective journal was kept to identify and reflect on personal experiences, concepts and assumptions which may have biased analysis (Appendix T).

To increase credibility and validity of interpretations, data analysis was discussed with research supervisors and members of an IPA group who were familiar with the analysis process. This transparent process promoted rigor and quality[43] and allowed for discussion of transcripts and identifying and modifying themes, particularly when questions around the validity of a theme arose. Quotations are utilised throughout to maintain transparency and reflect the link between original transcripts and subsequent themes. The researcher held no relationship with participants except for research.

Results

Analysis resulted in four super-ordinate themes and eleven subthemes; although some overlap was unavoidable, they appeared appropriately distinct (Table 3). All subthemes include quotes from WWD and midwives. Additional quotes can be found in Appendix U. WWD

referred to various HCPs involved including obstetricians, specialist consultants, midwives (MWs), community midwives (CMWs), specialist diabetes midwives (DMWs) and nurses.

Table 3. *Super-ordinate themes and corresponding subthemes.*

Super-ordinate Themes	Subthemes
Understanding and responding to risk	*'It's a possibility' vs. 'a danger word'* *'You know it's not just you'* *'Meeting risk head on'*
Talking about risk	*'Missing out a little bit'* *'Some kind of disconnect'* *'Feeling like an executioner'*
Negotiating choice and control	*'Outside the norm'* *'Balancing the choices is very difficult'* *'A whole world of new things'*
The relationship buffer	*'Knowing somebody, knowing your midwife'* *'A visitor in their story'*

<u>Understanding and responding to risk</u>

'It's a possibility' vs. 'a danger word'

This subtheme demonstrated how understanding and communication of risk oscillated between something that might occur and a dangerous threat that was highly likely.

WWD used tangible, visual, numerical cues to understand level of risk i.e. scans or measurements. Most WWD and midwives understood risk to mean primarily complications for

the baby including congenital abnormalities or increased weight and described risk in relation to the importance of stable BGLs.

'The main risks are the increased risk of foetal anomaly and stillbirth, and that is why they get so closely monitored. I don't think I could quantify it but I know there is a significant increase in the risks' (Lorna, MW)

WWD and midwives conceptualised risk as fluid and tentative and wanted to avoid blaming diabetes for problems that might occur regardless.

'You can't say your baby will die if...because that isn't true. We don't know that that's going to happen' (Fran, MW)

WWD made sense of risk in relation to everyday examples, comparing their situation to others or the likelihood of complications occurring in pregnancies without diabetes.

'It's just that potential isn't it really, and you know you could be potentially doing everything against all advice and still come up with a perfectly fine baby but it is about increased, increased risk. There is always risk in anything and pregnant ladies without diabetes they have lots of risk too' (Abby)

Risk communicated as fact created distress for WWD and they described HCPs as '*on edge*' or demonstrating limited diabetes knowledge, resulting in women being responsible for providing reassurance.

'You were sort of treated like a bomb, like you are a bomb about to go off, it was all terribly, it just felt as though if I said yes to any of the questions about, have you got any swelling, or have you got this, it would be like action stations, get the baby out, she is about to go off' (Rose)

Risk which was normalised and contextualised as a possibility helped to reduce self-blame and distress.

69

'She [MW] said she had seen other diabetics and things were okay and risks are there if you're diabetic or not. The way she would talk and she was a little bit more, erm, not kinder, just a bit softer' (Josie)

WWD were aware of being categorised as 'high-risk' due to responses from others, being closely monitored and frequent appointments. 'High-risk' labels emphasised importance of sugar control and lack of choice and made some women feel uncomfortable. Focus on risk appeared most intense during early pregnancy and resulted in many WWD feeling worried; facing an overwhelming, unpredictable threat which they wanted to avoid or '*attack*'.

'It was just a big, it was just scary that's the main thing, especially when the say 'risk' or 'high risk' (Josie)

Midwives acknowledged the fear associated with increased risk and '*high-risk pregnancy*' terms. However, they understood these terms as a way of denoting management e.g. specialist care vs. midwifery-led care.

'It is not scary for clinicians because most of the time you understand why we categorise them into a low risk and high risk group to differentiate their management'

(Alex, MW)

'You know it's not just you'

This was a WWD driven subtheme focussing on the balance between women's needs and the responsibility they felt for their baby.

WWD described responsibility to protect the foetus and expressed concerns that they might harm their child through unstable BGLs.

'You feel very guilty if your blood sugar goes up or down because it is not just about you anymore' (Hannah)

Many reported a sense of being '*told off*' or judged by HCPs if they were unable to achieve *'perfect'* BGLs, reinforcing guilt, blame and disappointment.

'You kind of get "you shouldn't be doing this, what about this, what about that" …. I just, straight away I just switch off' (Lisa)

WWD who disagreed with HCP decisions or struggled to maintain stable BGLs questioned their identity as a mother, highlighted by Hannah's interaction with her obstetrician.

'I just felt quite bad about everything because I was trying hard and it is very difficult dealing with it and trying to live an everyday life at the same time. So to be told you are not trying hard enough, you kind of feel like you are a bad mother' (Hannah)

Although challenging, women aimed to cultivate acceptance towards occasional highs or lows and discussed doing their best to manage diabetes which is demanding, unpredictable and '*doesn't play the game'*.

Discussions initiated by HCPs focussed heavily on risks and choices which might impact the baby.

'Our top priority is to look after the baby that potentially is in a dangerous situation' (Lorna, MW)

Women also prioritised their baby's needs, sacrificing their own wishes, leading to a sense that the mother was neglected by herself and others.

'If I did end up with a stillbirth would it be my fault. I spent a lot of time when pregnant thinking about what was more important, my needs or my baby's and what was right for both of us' (Rose)

'Meeting risk head on'

This subtheme was concerned with women's changing behaviours in response to risk and was primarily driven by WWD.

Risk was understood as something to be aware of and minimise. Change in meaning of BGLs during pregnancy, as something which now affected another, signified for WWD an increased importance to prevent fluctuations. They planned for pregnancy by attending pre-pregnancy counselling or gaining information from peers, HCPs, diabetes charities or the internet, assisting them to cope with risk and uncertainty.

> *'I did a lot of self-education but I had also sought the advice with my [diabetes clinic] team to make them aware that I wanted to get pregnant' (Rose)*

Getting to know the body and its response to diabetes was valued by many WWD, enhancing recognition of patterns and preparing for changes. Self-management strategies were altered and WWD described striving towards control of diabetes and BGLs, encouraged by HCPs. This 'doing mode' resulted in new strategies, often continuing after pregnancy, including thorough BGL testing, carbohydrate counting or insulin pump use.

> *'Before I was pregnant I never used to really test my blood sugars because I have quite good warning signs in my body but obviously since I have been doing it three or four times a day, keeping a record, monitoring it and trying to keep it within the 4 to 7 recommended limit' (Lisa)*

Midwives recognised this increased motivation and believed that most WWD, particularly T1DM, were hard-working and keen to engage, making it easier to discuss risk. They perceived that WWD are usually aware of increased risk and restricted choice due to lived experience of managing diabetes.

> *'I think they are aware that, you know, that their pregnancy potentially could be more complicated, that they'll need more appointments, that you know, we, for want of a better description, may have to interfere more' (Susan, MW)*

Talking about risk

'Missing out a little bit'

This subtheme captured the limited time and continuity provided and the associated focus of interactions around diabetes rather than pregnancy.

Many WWD did not have regular midwifery appointments. Midwives and WWD highlighted inadequate time or contact with HCPs and focus around risk management or diabetes, resulting in frustration, limited opportunity for women to express concerns and missing out on '*normal baby stuff*'.

> *'There's that sense of, 'If only I had a bit longer, could I have found another way around that?' And that's a real sense of frustration' (Fran, MW)*

> *'Women miss the continuity with their community midwives. They do get continuity from the diabetic midwife but her focus is on diabetes not on the whole pregnancy' (Lorna, MW)*

WWD who experienced limited midwife contact or continuity, particularly with DMWs, expressed a sense of missing out on extra care, the opportunity to build a relationship, and reassurance from someone who knows about both diabetes and pregnancy.

> *'For my first pregnancy, I just expected a bit more of a relationship (pause) between the midwife and me, just be a bit more caring and but because I saw a different one each time, I never got to build up a good relationship' (Hannah)*

One DMW reported that she lacks the capacity to see all WWD and will only meet regularly with those who struggle with diabetes management or have a specific problem. Some WWD did not want to be '*a burden*' and believed that accessing support required a specific reason.

'If I felt the need to want to go and see the diabetic midwife or the midwives in general, I think I'd feel I would need a reason to be going and I don't feel like I have a big enough reason' (Josie)

WWD who were not offered CMW support or had infrequent midwifery contact desired more one-to-one midwifery interaction to balance out the focus on illness and risk.

'I would have liked to have had a bit more midwife contact to be honest… midwifery and obstetricians and gynaecology are sort of different viewpoints and I think it would have been nicer to get the more midwife perspective on pregnancy and everything as well. Just a bit of a balance. I think it would have been a bit more caring or considered? Just less clinical' (Abby)

Some WWD understood lack of contact or risk discussion as meaning that they had sufficient knowledge of diabetes and risks and HCPs did not deem it necessary to offer additional support. If they envisaged receiving more contact or risk discussion, due to expectations enforced by HCPs, the public, or historical experiences, but this did not occur, they experienced disappointment, frustration or confusion.

'I don't have to worry and I can go home and carry on as a normal person, but when you have been told you are going to get all this care or what have you, it is a bit surprising because I think well where is the care?' (Josie)

Language and cultural differences and reliance on translators were also highlighted by midwives as barriers to discussing risk.

'Some kind of disconnect'

This subtheme referred to confusion for WWD and midwives around who was responsible for leading care or talking about risk, resulting in limited risk discussion.

74

WWD emphasised ambiguity around navigating the healthcare system i.e. what to expect, who they will see, when and why. Many felt that integration and communication between diabetes and pregnancy specialities was poor.

'Now that my pregnancy is involved, I feel like there is no total coverage over the whole thing. It's a case of it being one or the other' (Josie)

WWD expressed confusion around the roles and responsibilities of different HCPs, particularly CMWs and DMWs. They dismissed '*contrasting*', unclear advice that didn't fit with previous knowledge.

Most WWD experienced consultant-led care and a hierarchical effect ensued whereby women perceived consultants as leading diabetes and risk management. Midwives were often experienced as part of a wider team, with a sense of their role being absent or undervalued.

'The community midwife deferred to the diabetic midwife, but the diabetic midwife was bound up in this whole other system, so it wasn't like I had this one on one with the diabetic midwife and then when I went into labour it was a whole other set of midwives.' (Helen)

Many WWD described midwifery contact as a '*mechanical*' process, involving a succession of basic procedures or checklists, resulting in feeling like a '*patient*'. Most risk discussions occurred with consultants and WWD described how midwives, particularly CMWs, appeared '*disinterested*' or avoided detailed discussion around diabetes, risk and choice. When WWD approached midwives with diabetes or risk questions they often perceived that information was withheld and felt dismissed or referred elsewhere i.e. to the DMW or consultant, making it difficult to know who to go to.

'They said to me, "well we won't be discussing anything about your diabetes because you will be discussing that at the hospital with them". So they actually they didn't really discuss the risks with me at all, all they did was sort of give me general antenatal advice and sort of listened to the baby's heartbeat and checked my urine' (Helen)

75

Midwives felt confident about discussing practical and procedural information to prepare WWD for interventions i.e. induction. They discussed the challenge in keeping up-to-date with ever-changing diabetes research and guidance but wanted more knowledge and acknowledged their responsibility to attend training. Many, particularly those without specialist diabetes training, reported limited diabetes knowledge which adversely impacted on confidence and ability to build therapeutic relationships.

'If I have a good knowledge on something and experience then it is easy to show the person you are with you are confident but if it is not the case then everyone senses it. You know much about it but you don't know the whole thing so they don't trust you'

(Alex, MW)

Lack of self-perceived knowledge caused reluctance to discuss risk issues, with many midwives preferring to be non-specific. They believed that they '*shouldn't be discussing obstetric things*' but rather their role involved deferring WWD to specialists or consultants.

'I wouldn't want to have detailed discussions about quantifiable risks unless I was a hundred per cent sure about my facts and I think like I say a diabetic woman just gets referred to a diabetic clinic and that conversation happens in there' (Lorna, MW)

These difficulties resulted in WWD feeling neglected and questioning who was responsible for their care. In response to uncertainty they either withdrew or took on autonomy and responsibility to seek out information and self-care.

'Even though I see someone every two weeks, I do feel fairly abandoned by the midwives if I am perfectly honest! You just kind of feel like you have got to find out yourself or just say sod it I am not going to find it out' (Lisa)

'Feeling like an executioner'

This subtheme was primarily driven by midwives and portrayed the discomfort associated with discussing risk alongside the emotional impact.

WWD desired information about risk to facilitate preparation but wanted to avoid anxiety and discomfort associated with talking about risk, creating tension. They coped by focusing on the present, '*switching off*' or using avoidance, protecting them from difficult emotions.

> *'Not knowing those risks and not knowing the kind of things that may happen, yes it prevents you from thinking the worst-case scenario but it doesn't actually prepare you for the reality of what you may need to practically arrange' (Helen)*

Midwives discussed difficulty finding the '*right time*' to introduce risk information. They acknowledged that WWD don't always want to consider risk and are often bombarded with the importance of stable BGLs. Discussing risk was also uncomfortable for midwives; they sought to avoid causing distress or focussing on negatives of a complicated pregnancy. Fran described risk discussion as something which midwives '*skim over*'. She held concerns that because HCPs focus on stabilising BGLs they don't provide sufficient encouragement or explanation around why management is important.

> *'We're so concerned, we don't want to upset people, we don't want to frighten them that I think often, we don't say enough' (Fran, MW)*

Despite discomfort, midwives believed that transparency about risk and BGLs was an important part of their role to promote effective self-management. Positive changes in pregnancy were hoped to continue influencing mother and baby's health after birth.

> *'You don't want to put a negative on, on a, planning what should be happy event. But we wouldn't be doing our jobs properly if we didn't help women, erm, take on board that information' (Susan, MW)*

Midwives emphasised the emotionally demanding '*invisible bits of midwifery*' including perceiving increased risk to mother or baby, managing distress and supporting women with poor diabetes control or engagement difficulties.

> *'It does take it out of you, you know, their stresses can lie heavily on you and you think right take a step back and where do we start with this'* (Christine, MW)

One midwife highlighted the lack of emotional support received in supervision which centres around professional practice and competence. Most coped with limited diabetes knowledge or emotional challenges by gaining support from colleagues.

> *'It can be very lonely when you feel so responsible and you're trying really hard and you think you're doing your very best but you know you're not getting there. And the reality check of sharing it with a colleague who goes, "Mm. I know what you mean"'*
> *(Fran, MW)*

Negotiating choice and control

'*Outside the norm*'

This subtheme summarised the sense of difference experienced by WWD due to medical management, balanced against the desire for normality.

WWD described hard work and pressure involved in managing diabetes and monitoring BGLs alongside pregnancy, and associated emotions such as fear, sadness, frustration and anger. Risk focus and medical management prevented enjoyment of what should have been an exciting transition.

> *'I felt a bit angry about it, and a bit sad, in general it is nice to be pregnant and it was a very exciting time but I did feel sort of sad that I had this extra load of stuff to worry about'* (Kim)

WWD emphasised the commitment required to attend regular appointments and the negative impact of this on employment, including '*forced*' early pregnancy disclosure to managers. WWD and midwives acknowledged that this disruption was not always considered by HCPs.

'Someone who has got a really demanding job and all of a sudden they need to be at the hospital for two hours every couple of weeks so it is really disruptive to their lives isn't it and I don't think we take that into account quite enough' (Lorna, MW)

Diabetes resulted in feeling '*different*', exacerbated during pregnancy by dominant medicalised management strategies or '*clinical*' environments. WWD identified as part of a group of people with diabetes but also expressed individual diabetes presentation.

'It felt as though the care was not very much individualised, it felt very much as though I was part of a group when the proof was in front of them that I wasn't panning out as a dangerous pregnancy' (Rose)

WWD were aware of risk and potentially requiring different care. However, many did not identify themselves or their pregnancy as 'high-risk' and perceived they were effectively managing diabetes. They desired to trust their bodies and achieve 'normal' pregnancies without medical intervention.

'I don't feel like I am massively unwell, I am not sick as such, I don't really feel like I need to be at the hospital all the time but at the same time you are kind of reassured that they are there and that you are being monitored so closely' (Abby)

Satisfaction with the balance between medicalised management or 'normality' depended on personal preference. Midwives described the challenge of providing '*normal*' midwifery-led care alongside managing '*additional complexity*' through consultant-led care. They believed that diabetes doesn't necessarily require management alterations and advocated promoting 'normality'.

'You've got a pre-existing medical condition so there are certain things we have to do

because of that, but that doesn't mean you can't do x, y and z like any other women'

(Susan, MW)

'Balancing the choices is very difficult'

This subtheme described a shared sense of constraint experienced by midwives and WWD and highlighted the importance of control and explanation when balancing choice.

WWD felt controlled by HCPs who enforced parental, rigid rules, mirroring their perception of diabetes dictating their path through pregnancy. WWD and midwives discussed restricted choice, resulting in WWD feeling stuck, penalised and disappointed.

'I was in a race to the end between my body and the clinical team, who were kind of

under any opportunity trying to convince me to have a caesarean' (Rose)

'Something we do come across a lot is people querying the need for induction. They are

feeling confused, aren't they, because they seem to be between a rock and a hard place,

the risk of diabetes versus the risk of induction' (Lorna, MW)

Many WWD felt risks and choices were '*implicit*', communicated by HCPs in an ambiguous manner i.e. no explanation around why they needed to avoid BGL fluctuations or have an induction. Evidence for intervention choices was questioned by many WWD who wanted HCPs to assist them to weigh up advantages or consequences.

'That was the first time I really felt like a patient and had been told to do this and it

hadn't been really fully explained to you the reason why and that, that was really

upsetting' (Abby)

Interestingly, midwives reported explaining the reasoning behind decisions to help WWD understand limited choices or what they are being asked to do. When thorough,

transparent explanation was provided this was valued highly by WWD, allowing them to discuss issues with partners.

> *'They know sometimes how they are and what their glucose is without testing so much, so sometimes it's sort of I suppose taking back and recapping over knowledge that they, that they do have, erm, but giving or re-emphasising the reason why it's important, to do the tests and what they are going to get out of it'* (Susan, MW)

> *'It was quite nice to be there and it was like I was part of the process without just being told what to do (laughs). When they discussed things if I had a point I could butt in'* (Laura)

Midwives balanced safe clinical decisions and limited options by trying to enhance women's control through consensual choice. Involvement in decision-making and being offered options where possible even if these were '*silly little things*' enhanced control: e.g. labour date, induction vs. C-section or pain relief.

> *'It might be that your choice is limited around this particular issue but that other one, you know, there's this option or there's that option or some women choose that option so you've got more flexibility you know in certain areas'* (Susan, MW)

Occasionally overt expression of frustration was necessary to fight for control and assert confidence in self-management.

> *'I got so irate that they allowed me to take control of one, of my fast-acting insulin'* (Helen)

However, midwives were constrained by guidelines and procedures detailing BGL and labour management. On rare occasions, they worked outside guidelines, causing discomfort. They sought support from team members and negotiated different perspectives around risk and choice. This could be challenging if other HCPs disagreed with suggested decisions.

'You start to get them [WWD] on side, and think I'm getting somewhere and then

you've got to start and have a lot of difficult conversations with colleagues. So you just

shift one lot of difficulty for another' (Christine, MW)

Midwives did not want to display friction between HCPs. Alex highlighted the balance between advocating for women and working with colleagues, resulting in anxiety, fear of judgement and doubting clinical competence.

'Is it what am I supposed to do? Am I making the right decision? Am I supporting the

woman? Am I acting OK? And so on. So there is a lot to be scared about' (Alex, MW)

'A whole world of new things'

This subtheme related to the vulnerability of first-time pregnancy meaning WWD needed to relinquish some control and accept intervention.

Despite existing diabetes knowledge and expertise, pregnancy caused unpredictable physical changes (different response to insulin, deterioration in eyesight, low BGLs) which WWD had not anticipated, resulting in mistrust of their body.

'As well as you thought you were handling your blood sugars level and everything

before, it is a complete turnaround falling pregnant, and trying to, it's a whole different

learning curve and it is constantly changing' (Abby)

Midwives highlighted these changes as an explanation for increased medical intervention and limited choice.

'In labour, I think there is more to do for me as a midwife because the labour care for

diabetic women are very unique (laughs) because we know that the blood sugar, even if

it is a very well controlled diabetes during the pregnancy, it can misbehave' (Alex, MW)

The newness of a first-time pregnancy resulted in vulnerability. To manage uncertainty and protect their baby, WWD handed control and responsibility, particularly during labour, to HCPs who they perceived had more experience and knowledge.

'They have done it however many hundreds of times before, this is our first time, so (pause) we were quite, quite happy to go with whatever they thought was the safest'

(Laura)

Relinquishing control was not always negotiated successfully and some felt resigned to sacrifice wishes and comply with what had been asked of them, compounded by wanting to avoid putting their child at risk and being a 'bad parent'. Tension ensued, particularly for those used to coping with diabetes independently. WWD found it challenging to negotiate control or choice if they lacked knowledge or confidence.

'I am still on edge about it until she is born so I feel I will just do whatever they tell me that I need to do and not question it as such because they know what they are talking about, whereas I feel with diabetes if they told me to take something then I would be asking why do I need to take it and be questioning things' (Josie)

The relationship buffer

'Knowing somebody, knowing your midwife'

This subtheme highlighted the importance of consistent relationships to enhance midwifery confidence, and provide emotional containment, security and reassurance to WWD.

Despite limited midwifery continuity, most WWD described a consistent clinical diabetes team or consultant, nurse or midwife, who helped them to cope and acted as an ally. Continuity when it did occur allowed WWD and midwives to get to know each other. Frequent appointments meant midwives, particularly DMW's, could build trusting relationships with women 'at risk'. When WWD were remembered, this prevented frustration associated with

repeating personal or management information. Being familiar with HCPs style of working resulted in WWD feeling comfortable to voice concerns related to diabetes or risk. Rose valued the '*community midwife atmosphere*' created by her midwife who took time to understand her preferences and style of interacting.

> *'Even though it was a very big busy clinic you still felt they knew who you were, rather than… I had the same lady every time, I always got to see the same person every time, it is not like I had been passed from one person to another' (Rose)*

Midwives aimed to alter communication depending on who they were supporting. This was difficult and relied heavily on time and continuity to discover whether women prefer directive or collegiate support. Knowing each other improved midwives' confidence when communicating information, managing distress or engaging in uncomfortable discussions around risk, restricted choice or medical interventions.

> *'Once you have this trust kind of thing established you are, very easily you can introduce things that probably she is not 100% happy with; being on the monitor for twelve hours, checking the blood sugar every hour, you know all the things which are really not very nice. She will be more able to digest and more happy to, to work together' (Alex, MW)*

A relaxed approach to HCP consultations and basic communication skills such as eye contact and open body language put WWD at ease; often valued more highly than diabetes knowledge. As a midwife, Lorna felt well-placed to build rapport and assist WWD to be honest without fearing judgement.

> *'We maybe bridge the gap between highly intelligent, high skilled, trained consultant obstetrician and they [women] know that we are qualified and trained and experienced and maybe they see us as a bit more approachable' (Lorna, MW)*

Midwives and WWD believed that a humanising, individualised approach was important when supporting women who experience increased medical intervention. This allowed Hannah to feel cared for and prioritised alongside her baby.

'With a lot of midwives' appointments, I just felt they wanted to do the NHS tick list of urine, blood, heartbeat and things and that was it, whereas she [CMW] seemed more interested or as interested in how I was feeling and how I was getting on' (Hannah)

Midwives acknowledged the impact of life events on women's ability to commit to diabetes and risk management. They believed that they could offer woman-centred support to counteract medical intervention and manage distress involved in discussing risk.

'Having a chat to someone about how they are, how's life going? how's the family? - the bigger picture and not, not just they, you know how are your blood glucose readings? Diabetes is just a part of their life, it's a big part that they have to live with every day that they can't switch off from. But they've got a lot more going on apart from that and all those other things can affect, if it affects them, it can affect their diabetes' (Susan, MW)

Contact with a consistent midwife, often CMWs, facilitated development of an intimate relationship centred around pregnancy and 'normality', rather than focussed on risk.

'It has been kind of nice because I am talking about my pregnancy rather than the thing [diabetes] that rules most of my life' (Josie)

Midwives encouraged WWD to use telephone helplines, text messages or emails to promote engagement and reassurance. WWD reported that this flexible midwifery contact reduced isolation and made it easier to discuss issues.

'I felt like I had support twenty-four seven pretty much because of being able to email even if I woke up in the middle of the night and thought oh I need to ask that, I could email and the midwife would respond that day for me' (Laura)

'A visitor in their story'

This subtheme captured the need for shared expertise. Midwives were conflicted between emphasising women's responsibility while reducing blame.

WWD felt confident about their diabetes knowledge and intuition; recognition of their efforts encouraged continued self-management. However, they perceived that expertise and commitment in maintaining stable BGLs was not always acknowledged or valued by HCPs and risks, choices and interventions were not contextualised alongside daily demands or absence of other complications.

> *'There is no kind of credit given that you have lived with it for so long and you are okay, you have no other complications. The only person who values me like that is my diabetic consultant.' (Lisa)*

Midwives acknowledged their '*small part*' in women's stories and wanted to emphasise expertise. However, due to the ever-changing nature of pregnancy and diabetes, they highlighted the importance of working together with shared knowledge to help WWD '*fine tune*' BGLs and make appropriate management decisions.

> *'We've got to explain to them that we acknowledge that they know a lot of stuff about their situation but also acknowledge that things can change, they change quite quickly when you're pregnant' (Fran, MW)*

WWD valued collaborative relationships with HCPs who used tentative, encouraging language and coached them in self-management while respecting autonomy and individuality in diabetes presentation.

> *'I think she [CMW] did a very good job of recognising that I was managing it well and she was not patronising me basically and not overly coming across as kind of interfering or unnecessarily worried' (Kim)*

Specialist knowledge and working with HCPs who had experience of diabetes meant WWD felt understood and confident to trust professionals. Laura highlighted the essential role midwives play in providing a link to consultants, resulting in shared responsibility for decisions and additional expertise.

'If she didn't know the answer she would ask the consultant, so it was quite nice to have the extra support' (Laura)

Midwives reported a process of ascertaining what WWD already know about their condition and the risks, their intervention expectations and how confident they feel about management. They attempt to build on this base level of understanding by providing additional information, reassurance or reinforcing prior knowledge.

'They do know part of the story and it's just filling in the gaps. It depends on the woman, some women are really clued up and know it all before they get there and some women don't or they have not retained that information, so it is just ensuring they know what is going to happen' (Lorna, MW)

Midwives wanted to empower WWD to self-manage through making suggestions, problem solving and helping women to set goals, rather than '*dictating*' change. A conflict developed between reducing blame and emphasising positive changes while assisting WWD to take responsibility for self-management and stabilising BGLs. Fran's example demonstrates an awareness of power dynamics and being drawn into parental judgement of women's efforts or taking on responsibility.

'Either basically pat them on their head and give them a gold star or whatever or we tell them off. And that's all about the power politics. And so, what I need to try in doing that is to shift that round and say, "This isn't about me taking control of you. I'm not more powerful, you are the one who's got the power" (Fran, MW)

Discussion

This study explored the phenomenon of risk discussion and provides a unique insight by highlighting issues from the perspective of both midwives and WWD.

<u>Meaning of risk</u>

For midwives and WWD, 'risk' meant fluctuating BGLs resulting in negative consequences to the foetus. WWD experienced responsibility to prevent harm to their foetus and associated guilt if they were unable to achieve 'perfect' BGLs, exacerbated by perceived judgement from HCPs, consistent with previous literature.[8,12] This change in the meaning of BGLs resulted in women striving to eliminate risk through proactive management strategies, providing control and counteracting the unpredictability of diabetes.

Discussions focussing around the foetus made it difficult for WWD to consider their own needs or make decisions. Pursuing 'zero risk' to the foetus can result in neglect or sacrifice of pregnant women's well-being and values.[9,44] Integrating another being during the motherhood transition may create tension for women with existing medical conditions who are familiar with self-focussed care. Cultural and societal discourse around risk in pregnancy and what makes a 'good mother' i.e. high expectation of self-sacrifice and responsibility[44,45] could explain why some WWD identified as a 'bad mother', particularly if they struggled to maintain stable BGLs or considered choices which were not endorsed by HCPs.

WWD were aware of being categorised as 'high-risk' but this term created some discomfort and fear, supporting previous research.[6,46] In contrast, midwives used 'high-risk' to denote a particular management strategy, highlighting divergence in the way language is understood. WWD attempted to make sense of risk, perceived as possibility, in relation to everyday examples or comparison with risk involved in pregnancies uncomplicated by diabetes.[32,33] Differing risk perception can result in conflict [47] and some women in this study felt frustrated that HCP concern appeared unnecessarily extreme.

<u>Talking about risk</u>

Many WWD did not have experience of discussing risk with midwives. Limited midwifery contact or continuity resulted in inadequate time to discuss questions, loss of normal pregnancy conversations, focus on medicalisation and inability to form supportive relationships which facilitate expression of preferences. Regardless of whether a pregnancy was deemed to be progressing successfully or not, limited midwifery contact caused confusion, frustration, disappointment and tension for women who had expected frequent face-to-face support. There was a sense that HCPs used their perception of risk and risk categories to decide whether to provide additional information or not i.e. if risk perspective was low they offered less information and support.

Integration between diabetes and pregnancy care was limited and WWD discussed confusion about HCP roles and responsibilities, supporting previous findings about disconnected care.[12] WWD experienced conflict between valuing information on risk but wanting to avoid associated fear and sadness. Midwifery contact was experienced by some as a mechanical process involving procedural tasks. Midwives avoided discussion of risk or diabetes, re-directing women to other HCPs, enhancing women's sense of being stuck or lost between HCPs. WWD felt that risk and choices were often communicated in an ambiguous way, without explanation or balanced discussion. Information may be used by women with complex pregnancies capriciously if they sense inconsistency or withholding, resulting in rejection of suggested treatment.[47] Interestingly, midwives described explaining reasons for management strategies, showing divergence between what WWD want, what midwives say they offer, and the lived experience. When HCPs provided explanation, and used transparent discussions, WWD felt included.

Midwives perceived that WWD, particularly T1DM, are aware of risk and restricted choice pre-pregnancy and CMWs believed that women would discuss diabetes or risk with a DMW. However, many WWD did not have regular or one-to-one DMW contact, despite the recognised importance of this role in reducing fragmentation and improving advocacy within

MDT environments.[48] This highlights a gap in provision and could result in ineffective and miscommunicated risk discussion, disengagement or WWD seeking information elsewhere.[12] Multiple HCP involvement and limited continuity threatens midwives' ability to be 'genuine' and provide restorative support.[14,49] Consistent, containing relationships supported WWD at a time of vulnerability. They benefited from telephone and email midwifery contact. With sufficient time and continuity WWD and midwives got to know each other, encouraging WWD to voice concerns. Midwives felt more confident in communicating and individualising risk information, managing distress and broadening the focus of appointments to address pregnancy and risk.

Limited diabetes knowledge or training recognised by many midwives could explain the lack of confidence in discussing risk. Development of the DMW role has perhaps resulted in other midwives losing confidence or not considering diabetes and risk within their remit. Although particular issues may be more appropriately discussed by specialists, WWD may be missing out on the opportunity to discuss risks and choices with midwives. They offer an alternate perspective to the dominant medical discourse and can provide emotional support to reduce isolation.[50] Midwives believed it was important to discuss risk and encourage women to adhere to suggested regimes. However, many held concerns about causing distress, resulting in 'skimming over' risk issues and focussing on procedural management. This might account for lack of risk discussion and explain why midwives have been found to avoid emotional issues.[17]

Some midwives highlighted perceived responsibility to prevent adverse outcomes and limited opportunity to reflect on emotional demands of caring for WWD. The NHS 'blame-culture'[51] and increased accountability may amplify anxiety for HCPs who fear litigation.[52,53] Efficiency and outcome targets also result in frustration, acting as a barrier to relationship building.[54,55] Language and culture differences were an additional challenge for this sample of midwives, a potentially salient issue considering people from South Asian and Black communities are more likely to develop T2DM.[56]

<u>Negotiating choice</u>

WWD emphasised the pressure and commitment required to manage diabetes and pregnancy alongside contextual factors and described associated loss, frustration and sadness. Lack of choice was highlighted; women felt controlled and disappointed, consistent with previous literature.[10,13,14] Despite awareness that pregnancy would involve restriction, medical management emphasised women's differences. They resisted difference and restriction, wanting to achieve pregnancies without intervention, particularly if they did not feel 'unwell'. Satisfaction with the balance between a medicalised or natural approach depended on personal preference. Changing the discourse from 'normal birth' to 'optimal birth', achieving the best possible pregnancy given circumstances, is suggested as one way to reduce women's sense of loss.[57]

Despite dominant medical discourse, midwives advocated holistic, 'natural', humanising care, supporting women to remain in control where possible and recognising expertise and effort. Positive midwifery practice included coaching women and using encouragement to promote change, while respecting autonomy. Despite this, WWD felt expertise and individual context was not always acknowledged by HCPs, highlighting a recurring conflict between the promise and reality of diabetes care.[11,58,59] Facilitating empowerment can fail if HCPs create distance by remaining an 'expert' or dismissing tension in the patient-provider relationship.[60] Dyadic interaction, effective in facilitating change, involves acknowledging and exploring differing points of view and challenging emotions.

Midwives reported conflicting demands around balancing positive encouragement while ensuring women adopt shared responsibility for diabetes and risk management. They were aware of challenging power dynamics and the potential for women to feel criticised. However, they felt constrained by guidelines which undermine autonomy.[53,61] Decisions to work outside guidelines created discomfort. Midwifery responsibilities can result in midwives dominating consultations, potentially explaining women's experience of mechanical care.[17] Midwives described the challenge of advocating on women's behalf while negotiating choices with their

clinical team, a conflict resulting in anxiety, fear of judgement and self-doubt. Complex

pregnancy can be disempowering for all. If obstetricians hold responsibility it may be difficult

to challenge decisions.

Unpredictable physical changes and vulnerability inherent in first-time pregnancy were

highlighted as reasons for increased intervention. Midwives believed it was central to work

together with shared expertise. Uncertainty and concern for their child resulted in many WWD

surrendering responsibility and control to HCPs who they perceived as 'experts',[62]

demonstrating shifting self-efficacy and locus of control (LOC). Some WWD sacrificed

'normality' and conformed with expectation to avoid a 'bad mother' identity. Relinquishing

control and responsibility may be particularly difficult for women with chronic health

conditions. They have years of experience, are familiar with autonomous self-management and

are usually encouraged by HCPs to maintain personal agency and internalised LOC. The

transformation of pregnancy may be unsettling for women who are used to being an 'expert' [63]

and face a conflict between desiring control whilst also craving reassurance. Preference towards

involvement of HCPs may relate to early diabetes experiences and the responses of others as

either paternalistic or collaborative.[64,65]

Strengths and Limitations

The dual perspective design of this study is a significant strength allowing the

experience of risk discussion to be explored from alternative perspectives. Limited previous

research from a UK midwifery viewpoint makes this a valuable contribution. It highlights

barriers faced when midwives try to promote 'mastery'. Inclusion of nulliparous women

minimised the effect of previous pregnancy experience on risk perception.

However, due to the small sample, results are not representative of all midwives or

WWD. Limited time, researcher experience and the subjective nature of IPA may have

influenced interpretation of findings. Retrospective accounts, from women interviewed after

birth, may be more likely to reflect positively on risk discussion. The recruitment and

92

advertisement procedure may have resulted in a sampling bias towards recruitment of older women, with a higher level of education. The age of WWD included was higher than the national average for first time pregnancies,[66] perhaps influencing results. WWD may have been more likely to come forward for inclusion if they had been unhappy with their clinical experience.

The varied environments or systems experienced by midwives and WWD reduced homogeneity, but allowed for a deeper understanding of issues faced across the country, rather than one service. Midwives enthusiasm in advocating individualised care might have been affected by sampling bias and socially desirable responses. However, the interviewers' status as a psychologist, rather than midwife, hopefully promoted honesty. While maintaining homogeneity, the lack of cultural diversity or women with T2DM precludes investigation of cultural or diagnosis specific issues. Finally, engaging in telephone interviews may have impacted on discussions as bodily and facial cues were unavailable.

Clinical Implications

HCPs face a dilemma when supporting two patients whose requirements may be different. They should remain aware of considering the mother's needs and wishes alongside risk to the foetus. A balanced focus would encourage women to feel valued and look after their well-being while considering best intentions for their baby. The negative impact of medicalised pregnancy and the benefits of midwifery continuity are well evidenced in 'normal' populations[37,67,68] but may be particularly important for women with existing medical conditions who experience additional appointments, uncertainty and neglected needs. Encouraging WWD to maintain an accepting, compassionate view towards BGL fluctuations and providing them with sufficient opportunity to discuss emotions associated with diabetes, risk, pressure, restriction and loss remains important. It is vital that midwives respond to maternal understandings of risk and assist women to make sense of information. It is imperative that HCPs discuss the meaning of terms such as 'high-risk' with pregnant women to alleviate

misconceptions or fear. Utilising a positive risk-taking stance[69] through gathering information, discussing options and normalising risk while providing context can reduce distress and promote positive coping strategies.

Employing a collaborative, individualised approach whereby diabetes expertise is utilised would allow women to feel empowered and included in risk management and decision-making.[54,70] Discussing women's values and perspectives can promote their control and increase successful behavioural change. However, this needs to be balanced alongside encouraging women to recognise where they lack knowledge and coaching them to improve confidence when managing a first-time pregnancy. Desire for active or passive involvement can fluctuate depending on the task and HCPs need to respond with fluidity. Through ascertaining women's initial expectations, level of self-efficacy, previous experiences with HCPs and preferred model of care, HCPs can tailor risk discussions, address misconceptions, and reduce ambiguity by providing information i.e. who they are likely to see, when and how often. Receiving timely, relevant, and understandable information is central to satisfaction and involvement in decisions, even if that involves acknowledging uncertainty or unknown outcomes.[55]

HCPs should be provided with support to make risk decisions.[71] Midwives would benefit from additional supervision and reflective practice, with peers or other HCPs. This would allow them to consider the emotional impact of caring for pregnant women with complex problems, and the effect of this on interactions and the barriers faced.[54,60] Enhanced awareness of power dynamics and the desire for HCPs and women to seek control to counteract uncertainty and vulnerability is necessary. Additional diabetes and risk communication training could increase midwifery confidence. Midwives should be supported to work with other HCPs and institutional systems, develop guidelines and define their roles and responsibilities. Their input can shape services for WWD by considering how midwives are utilised, incorporating the benefits of both CMWs vs. DMWs without disconnection, facilitating alternative perspectives in MDT settings and ensuring WWD have regular midwifery support if desired.

Future Research

Future research should address sampling bias through exploration of these issues in younger women, those with type 2 or poorly managed diabetes and parous mothers who have previously experienced pregnancy. It remains unclear from this sample how WWD from other ethnicities or cultural backgrounds experience risk discussion and manage language barriers, perhaps warranting further research. Observing midwife-mother dyads could address socially acceptable response bias and allow for detailed exploration of communication to explain discrepancies between midwives and women's accounts. Investigating obstetricians understanding and communication of risk and their perception of roles and responsibilities or how they work alongside midwives would also be beneficial.

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Part three: Appendices

Appendix A.   Qualitative Health Research (QHR) - Guidelines for authors

1. Article types

Each issue of QHR provides readers with a wealth of information — book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods.

1.1 What types of articles will QHR accept?

QHR asks authors to make their own decision regarding the fit of their article to the journal. Do not send query letters regarding article fit.

• Read the Mission Statement on main QHR webpage.

• Search the QHR journal for articles that address your topic. Do we publish in your area of expertise?

• Ask these questions: Does it make a meaningful and strong contribution to qualitative health research literature? Is it original? Relevant? In depth? Insightful? Significant? Is it useful to reader and/or practitioner?

• Note the sections: General articles, critical reviews, articles addressing qualitative methods, commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

• QHR accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta-analyses, and articles addressing all qualitative methods.

• QHR is a multi-disciplinary journal and accepts articles written from a variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

• Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Book Review Section: *Qualitative Health Research* includes a book review section helping readers determine which publications will be most useful to them in practice, teaching and research.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Qualitative inquiry that has used qualitative methods in an innovative way.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

2. Editorial policies

2.1 Peer review policy

QHR strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are initially reviewed by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Ensure your manuscript does not contain any author identifying information. Please refer to the editorial on blinding found in the Nov 2014 issue: http://qhr.sagepub.com/content/24/11/1467.full.

QHR maintains a transparent review system, meaning that all reviews, once received, are then forwarded to the author(s) as well as to ALL reviewers.

Peer review takes an average of 6–8 weeks, depending on reviewer response.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all authors who:

(i) Made a substantial contribution to the concept and design, acquisition of data or analysis and interpretation of data,

(ii) Drafted the article or revised it critically for important intellectual content, (iii) Approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

When a large, multicenter group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section.

Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

2.3.1 Writing assistance

Individuals who provided writing assistance, e.g., from a specialist communications company, do not qualify as authors and should only be included in the Acknowledgements section.

Authors must disclose any writing assistance — including the individual's name, company and level of input — and identify the entity that paid for this assistance.

It is not necessary to disclose use of language polishing services.

Please supply any personal acknowledgements separately from the main text to facilitate anonymous peer review.

2.4 Funding

QHR requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page to confirm the format of the acknowledgement text in the event of funding. Otherwise, state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of QHR to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a "'Declaration of Conflicting Interests" statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that "The Author(s) declare(s) that there is no conflict of interest."

For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you

have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

In terms of patient privacy, authors are required to follow the ICMJE Recommendations for the Protection of Research Participants. Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published. Participant descriptors should not be listed individually. Because qualitative research is descriptive, it is recommended that participant quotations not be linked to identifiers in the manuscript.

2.7 Clinical trials

QHR conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed Consolidated Standards of Reporting Trials (CONSORT) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

2.9 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

QHR requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or provide detailed information in their articles on how the data can be obtained. This information should include links to third-party data repositories or detailed contact information for third-party data sources. Data available only on an author-maintained website will need to be loaded onto either the journal's platform or a third-party platform to ensure continuing accessibility. Examples of data types include but are not limited to statistical data files, replication code, text files, audio files, images, videos, appendices, and additional charts and graphs necessary to understand the original research. [The editor(s) may consider limited embargoes on proprietary data.] The editor(s) [can/will] also grant exceptions for data that cannot legally or ethically be released. All

data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office at vshannonqhr@gmail.com.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

QHR and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarized other work, or included third-party copyright material without permission, or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

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4. Preparing your manuscript

4.1 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. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.

☐ *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.

4.2 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.

4.3 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.

☐ ☐TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.

☐ ☐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**.

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In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association ["APA"], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at http://www.apa.org/, or search the Internet for "APA format."

4.6 Reference style

QHR adheres to the APA reference style. Click here to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.7 English language editing services

Articles must be professionally edited; this is the responsibility of the author. Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE's Language Services.

5. Submitting your manuscript

5.1 How to submit your manuscript

QHR is hosted on SAGE Track, a web-based online submission and peer review system powered by ScholarOne Manuscripts.™ Visit http://mc.manuscriptcentral.com/qhr to login and submit your article online. Each component of the manuscript is uploaded separately: Title page, main document, tables, figures, supplemental material.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne.

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on How to Help Readers Find Your Article in the SAGE Journal Author Gateway on how best to title your article, write your abstract and select your keywords.

5.3 Corresponding author contact details

Provide full contact details of the corresponding author including email, mailing address and phone number. Academic affiliations are required for all co-authors. Present these details on the title page, separate from the article main text, to facilitate anonymous peer review.

6. On acceptance and publication

6.1 Fees

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6.5 Open Access and SAGE Choice

Articles accepted in QHR have the option to be published as open access after payment of an article processing charge (APC) paid by either the funder or author. Authors wishing to publish open access should contact openaccess@sagepub.com to make the request. Read SAGE Choice FAQs here.

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the QHR editorial office as follows.

Appendix B.   Excluded references following full article review

Babler, E., & Strickland, C. J. (2015). Normalizing: Adolescent experiences living with type 1 diabetes. *Diabetes Educator, 41*(3), 351-360.

Balfe, M. (2007). Diets and discipline: The narratives of practice of university students with type 1 diabetes. *Sociology of Health & Illness, 29*(1), 136-153.

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Appendix C.   Data extraction Form

Study Title:
Authors:
Year of Publication:
Reference and Country of Origin:
Study Characteristics:
- Research question/aims:
- Quality Score:

Concept Deconstruction: Is exploration of the meaning of living with Type 1 diabetes in females a research aim?

Study design: Qualitative?

Participant Characteristics:
- Number of women:
- Age of women:
- Length of diagnosis:
- Ethnicity:
- Geographical Region:
- Other significant demographic variables:

Participant Recruitment:
- Recruitment methods:
- Inclusion criteria:
- Exclusion criteria:

Procedure:

Details of Data Collected:

Results and Analysis:
- Analysis method:
- Theoretical perspective:
- Main findings:

Conclusions
- Interpretation of results:
- Key links to theory/literature:
- Limitations:
- Implications:
- Further research:

Appendix D.   Quality Appraisal Checklist (NICE, 2012)

Study identification: Include author, title, reference, year of publication	
Guidance topic:	**Key research question/aim:**
Checklist completed by:	

Theoretical approach		
1.1 Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
1.2 Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:

Study design		
2.1 How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the	Defensible Indefensible Not sure	Comments:

rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?		
Data collection		
3.1 How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/ inadequately reported	Comments:
Validity (trustworthiness)		
4.1 Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
4.2 Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:
Analysis		
5.1 Is the data 'rich'? For example:	Rich Poor	Comments:

• How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	Not sure/not reported	
5.2 Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
5.3 Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:
5.4 Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined?	Adequate Inadequate Not sure	Comments:

Is there adequate discussion of any limitations encountered?		
Ethics		
6.1 How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
6.2 Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++, +, −	Comments:

Appendix E.   Quality ratings for included studies based on NICE (2012)

	Theoretical Approach		Study Design	Data Collection	Validity			Analysis			Ethics		Overall
	1.1	1.2	2.1	3.1	4.1	4.2	5.1	5.2	5.3	5.4	6.1	6.2	
* Dickinson & O'Reilly (2004)	✓ Appropriate	✓ Clear	✓ Appropriate & defensible	✓ Appropriate	✓ Clear	? Reliability somewhat questionable	✓ Rich	? Reliability questionable	? Findings somewhat questionable	✓ Adequate	✓ Yes	? Reflexivity lacking	8+
* Kay et al. (2009)	✓ Appropriate	✓ Clear	✓ Appropriate & Defensible	✓ Appropriate	✓ Clear	✓ Reliable	✓ Rich	? Reliability questionable	✓ Convincing	✓ Adequate	✓ Yes	✓ Clear	11++
*Rasmussen et al. (2007a)	✓ Appropriate	✓ Clear	✓ Appropriate & Defensible	✓ Appropriate	✓ Clear	✓ Reliable	? Detail lacking	? Reliability questionable	? Findings somewhat questionable	? Adequate, Limitations lacking	✓ Yes	? Reflexivity lacking	7+
Rasmussen et al. (2007b)	✓ Appropriate	✓ Clear	✓ Appropriate & Defensible	✓ Appropriate	✓ Clear	✓ Reliable	? Detail lacking	? Reliability questionable	? Findings somewhat questionable	? Adequate, Limitations lacking	✓ Yes	? Reflexivity lacking	7+
Maslakpak et al. (2010)	✓ Appropriate	✓ Clear	? Rationale unclear	✓ Appropriate	✓ Clear	? Reliability somewhat questionable	? Detail lacking	✓ Reliable	? Findings somewhat questionable	✓ Adequate	✓ Yes	? Reflexivity lacking	7+
Visekruna et al. (2015)	✓ Appropriate	✓ Clear	✓ Appropriate & Defensible	✓ Appropriate	✓ Clear	✓ Reliable	✓ Rich	✓ Reliable	✓ Convincing	✓ Adequate	✓ Yes	? Reflexivity lacking	11++
Stuckey & Tisdell (2010)	✓ Appropriate	✓ Clear	✓ Appropriate & Defensible	✓ Appropriate	✓ Clear	✓ Reliable	✓ Rich	✓ Reliable	✓ Convincing	? Adequate, Limitations lacking	✓ Yes	✓ Clear	10++

* Kelly et al. (2005)	✓ Appropriate	✓ Clear	✓ Appropriate & Defensible	✓ Appropriate	? Validity somewhat questionable	✓ Reliable	✓ Rich	✓ Reliable	✓ Convincing	? Adequate, Implications lacking	? No	? Reflexivity lacking	8+
Williams (1999)	✓ Appropriate	✓ Clear	✓ Appropriate & Defensible	✓ Appropriate	✓ Clear	✓ Reliable	✓ Rich	? Reliability questionable	✓ Convincing	? Adequate, Limitations lacking	✓ Yes	? Reflexivity lacking	9++

* Denotes study where two researchers completed quality assessment　　　　Cut offs:　　0-4 (-)　　5-8 (+)　　9-12 (++)

Appendix F.   Themes and example data

Super-ordinate theme	Subthemes	Concepts	Articles	Example Data
Identity shaped by being in the grip of BGLs	Fluctuating BGLs and loss of normality	• Pervasive nature of diabetes, extra tasks • Striving for control of BGLs vs. failure • Tight grip of BGLs during pregnancy • Fluctuating nature leads to vulnerability • Loss of freedom, careers, educational potential, activities, relationships, ability to choose food • Undermined autonomy, feeling disadvantaged • Negative impact on	Dickinson & O'Reilly, 2004 Kelly et al., 2005 Kay et al., 2009; Maslakpak et al., 2010 Rasmussen, O'Connell et al., 2007 Stuckey & Tisdell, 2010 Visekruna et al., 2015 Williams, 1999	*'It's the weeds that you keep pulling out, and they keep coming back.' (Stuckey & Tisdell, 2010)* *'When I was high [blood glucose] I felt really tired and I just didn't feel like doing anything... It's a pain to have to think about food all the time: what is being served and when, how much is ok to eat and how it will affect the blood glucose level, how much insulin to take.' (Dickinson & O'Reilly, 2004)* *'If I've been woken up with a low sugar…you're just off for the day. You're groggy. You're tired. Your sugar is high and then you're overcorrecting so you're going low again and it's really those days…you really feel like you're diabetic.' (Visekruna et al., 2015)* *'My menstrual cycle is often irregular. I experienced sometimes stop of menstrual cycle... Sometimes three month I experience amenorrhea but I don't say anybody … I am shamefaced.' (Maslakpak et al., 2010)* *'Everything has to be timed... I can't go like a normal person to the pub and say, "Hey lets go and get drunk," or I can't just go to a friend's house and*

128

		physical health and body image e.g. weight fluctuations, objectified		*say, "Hey I don't feel like going home I think I'll stay here the night." If I leave home I have to take a whole medical box with me ...' (Kelly et al., 2005)*
				'It's also a machine that's attached to you and as a girl actually that's a huge difference because it sucks. Where do you put it? It's in my bra most of the time on the side. It's very superficial, but dresses, where do you put it with dresses?' (Visekruna et al., 2015)
	Distressing emotions and an uncertain future	- Negative emotions: fear, sadness, anger - Unpredictable threat - Anxiety about future i.e. complications, ability to cope, pregnancy - Respond to anxiety via self-restriction or looking to others	Dickinson & O'Reilly, 2004 Kelly et al., 2005 Kay et al., 2009 Maslakpak et al., 2010 Rasmussen, O'Connell et al., 2007 Stuckey & Tisdell, 2010 Visekruna et al., 2015 Williams, 1999	*'I think about it quite a lot, sort of being on that desert island, my blood sugar just getting higher and higher and higher, and there's nothing I can do about it' (Kay et al., 2009)* *'You often hear the bad stories everyone is really good at that—"Oh no you can't this and that," and that's really negative. It's really hard because you might be a little bit high but surely they'll still come proper babies?' (Kelly et al., 2005)* *'Everyone should know because then they can help if something happens. It's not a question of minding or not, it's my health, you know. People, everyone should know so that in case something happens, even if they don't know what to do they can tell someone.' (Williams, 1999)*

Influence of others	Standing out and being monitored	• Being a 'burden', viewed by other as having a disability • Unwanted attention and focus on diabetes rather than person. Reinforces 'diabetic' identity, being 'different' • Others impose rules • Loss of control and independence, conformity, feeling judged	Dickinson & O'Reilly, 2004 Kay et al., 2009 Maslakpak et al., 2010 Rasmussen, O'Connell et al., 2007 Stuckey & Tisdell, 2010 Visekruna et al., 2015 Williams, 1999	*'I like to be very active but I can't … I feel my blood pressure goes down and may I faint … I like to dance several hours, but my mom forbids me. She thinks this is very heavy for me.' (Maslakpak et al., 2010)* *'You know, you deal with how to take insulin, how to count carbohydrates, how to test your blood sugar and everything, but no one ever says, "How do you feel?" (Stuckey & Tisdell, 2010)* *'Because of the expectations girls felt others placed upon them to be self-caring, they were often reluctant to ask for support, and this could lead to `secret' non-adherence. Girls also knew that the flexible ways in which they adapted their medication regimens would not generally be seen as them doing their best to achieve good control by either health professionals.' (Williams, 1999)*
	Feeling misunderstood	• Others lack knowledge or understanding • Negative family environments • Isolated and frustrated • HCPs don't understand lived experience	Dickinson & O'Reilly, 2004 Kelly et al., 2005 Kay et al., 2009 Maslakpak et al., 2010 Rasmussen, O'Connell et al., 2007	*'Sometimes … you just want to … sleep and I think people don't understand that sometimes.' (Kay et al., 2009)* *'The decision whether to disclose their diabetes was difficult for all of the women. The underlying factor that influenced disclosure was fear of unpredictable hypoglycemia, which often triggered the decision to disclose diabetes to help them feel safe at work.' (Rasmussen, O'Connell et al., 2007)*

	• Questioning when to disclose diagnosis, anonymity	Rasmussen, Dunning & O'Connell, 2007 Stuckey & Tisdell, 2010 Visekruna et al., 2015	*'They don't think it's a big deal, because it can be something that is physically managed. They figure if you can live with diabetes, then it's not that big of a deal.' (Stuckey & Tisdell, 2010)*
Resistance against a 'diabetic' identity	• Not wanting to be defined by diabetes • Resisting control: avoidance, minimisation, not monitoring BGLs, risk taking • 'Acts of rebellion', fit in with peers, Communication of distress through body, Distance from distressing emotions	Dickinson & O'Reilly, 2004 Kelly et al., 2005 Kay et al., 2009 Maslakpak et al., 2010 Rasmussen, O'Connell et al., 2007 Stuckey & Tisdell, 2010 Visekruna et al., 2015 Williams, 1999	*'Two participants mentioned that when they do not do their diabetes management tasks, they feel as if they do not have diabetes. They both realized, however, the potential consequences of this behavior.' (Dickinson & O'Reilly, 2004)* *'it wasn't the greatest when I was in university and college. Umm cus because being away from home, and the stresses of school and everything, you know kind of put it on the backburner' (Visekruna et al., 2015)* *'The reason I stopped taking my injections … I didn't have to think about other things that were going on. And I didn't have to think about what other people thought of me because I was … feeling ill' (Kay et al., 2009)*

| Creating Stability: integrating diabetes | Becoming an 'expert': enhancing attentiveness to BGLs | • Practical strategies: information seeking, peer support, knowing your body, use of technology, planning

• Hard to adapt due to circumstances, locating responsibly externally

• Complex process, ambivalence, change over time age, stuck | Kelly et al., 2005
Kay et al., 2009
Rasmussen, O'Connell et al., 2007
Rasmussen, Dunning & O'Connell, 2007
Stuckey & Tisdell, 2010
Visekruna et al., 2015
Williams, 1999 | *'Now I know that the web sites are there, I would check that every day. There might not be anything on it, but just the fact, I don't know, it is almost like a bit of a release and quite often I put some questions up on the forum they have got back straight away.' (Rasmussen, Dunning & O'Connell, 2007)*

'I find that with the insulin pump I have more freedom to eat on my own schedule.' (Visekruna et al., 2015)

'You have got to know your own body and how different things affect it and how, you know, what to do to prevent the high sugar levels.' (Rasmussen, O'Connell et al., 2007) |
| | Cultivating acceptance and perspective | • Nurturing self-compassion, holding non-judgemental attitude, being 'good enough'

• Reframing, positive aspects

• Identity as whole person | Kelly et al., 2005
Kay et al., 2009
Rasmussen, O'Connell et al., 2007
Stuckey & Tisdell, 2010
Visekruna et al., 2015
Williams, 1999 | *'I do my best to control it so you just have to realize that it's not going to be perfect.' (Hayley) (Visekruna et al., 2015)*

'Major accomplishment . . . more than people can understand . . . and when it does work, it's very rewarding. Extra rewarding.' (Stuckey & Tisdell, 2010)

'It helped me ... to look for ways that I can achieve a sense of control in my life. I can acknowledge that I can't control the fact that I have diabetes. but I can control the way that I deal with my diabetes and the way that I think about dealing with diabetes.' (Kelly et al., 2005) |

Forming meaningful relationships	• Positive interactions • Connecting with others reduces isolation • Sharing knowledge • Inspired by role models • Desire for compassionate, personalised support	Dickinson & O'Reilly, 2004 Kay et al., 2009 Kelly et al., 2005 Rasmussen, O'Connell et al., 2007 Rasmussen, Dunning & O'Connell, 2007 Stuckey & Tisdell, 2010 Visekruna et al., 2015 Williams, 1999	*'Because my family is a long way away I have to call them regularly to touch base. Fortunately, both my Mum and my sister are on the e-mails now, so that is good.' (Rasmussen, Dunning & O'Connell, 2007)* *'I participated in camps as a child, which was a great way of growing up with peers and knowing that I wasn't all alone.' (Rasmussen, O'Connell et al., 2007)* *'I download my pump data and my sensor data and email it to her [nurse] um as often as I do it. So I'm in contact with her via email at least twice a month, and if I have questions in between then I'm constantly in contact with her.' (Visekruna et al., 2015)*

Appendix G.   Women and Birth - Guidelines for authors

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:

• E-mail address

• Full postal address

All necessary files have been uploaded:

Manuscript:

• Include keywords

• All figures (include relevant captions)

• All tables (including titles, description, footnotes)

• Ensure all figure and table citations in the text match the files provided

• Indicate clearly if color should be used for any figures in print

Graphical Abstracts / Highlights files (where applicable)

Supplemental files (where applicable)

Further considerations

• Manuscript has been 'spell checked' and 'grammar checked'

• All references mentioned in the Reference List are cited in the text, and vice versa

• Permission has been obtained for use of copyrighted material from other sources (including the Internet)

• Relevant declarations of interest have been made

• Journal policies detailed in this guide have been reviewed

• Referee suggestions and contact details provided, based on journal requirements

For further information, visit our Support Center.

BEFORE YOU BEGIN

First time authors are strongly advised to co-author with an academic supervisor or senior colleague who has been successful in writing for publication. Articles submitted for review must be original works, and may not be submitted for review elsewhere whilst under review for the Journal. If a related article, based on the same work, has been submitted or published elsewhere, it must be acknowledged in the cover letter to the editor, added to the end of the cover letter, and referenced in the manuscript.

Considerations specific to types of research designs

Manuscripts must adhere to recognised reporting guidelines relevant to the research design.

Please upload the appropriate and completed Reporting Guideline Checklist during your manuscript submission process.

Observational cohort, case control and cross sectional studies - STROBE - Strengthening the Reporting of Observational Studies in Epidemiology http://www.equator-network.org/reporting-guidelines/strobe/

Quasi-experimental/non-randomised evaluations - TREND - Transparent Reporting of Evaluations with Non-randomized Designs http://www.equator-network.org/reporting-guidelines/trend/

Randomised (and quasi-randomised) controlled trial - CONSORT - Consolidated Standards of Reporting Trials http://www.equator-network.org/reporting-guidelines/consort/

Study of Diagnostic accuracy/assessment scale - STARD - Standards for the Reporting of Diagnostic Accuracy Studies http://www.equator-network.org/reporting-guidelines/stard/

Systematic Review of Controlled Trials - PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses http://www.equator-network.org/reporting-guidelines/prisma/

Systematic Review of Observational Studies - MOOSE - Meta-analysis of Observational Studies in Epidemiology http://www.equator-network.org/reporting-guidelines/moose/

Qualitative researchers are encouraged to consult the guideline listed below:

Qualitative studies - COREQ - Consolidated criteria for reporting qualitative research. Tong, A., Sainsbury, P., Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19 (6), 349-357. COREQ checklist for completion

Human and animal rights

Ethics in Research – Note that research studies that do not have ethical approval prior to being conducted will not normally be published. We will consider publication, however, if the relevant Institutional Ethics Committee provides you with a letter saying that they do not normally provide ethical approval for studies such as the one you conducted. See Cope Guidelines at: http://publicationethics.org/resources/guidelines

For Human Research please consult the National Health and Medical Research Council's (NHMRC) research ethics guidelines: https://www.nhmrc.gov.au/research/responsible-conduct-research/summary-national-statement-content

For research involving humans, please address the ethical aspects of the research in the Methods section. State clearly that the subject gave freely informed consent and, if in dependent relationships with members of the research team, issues of perceived coercion must be addressed. To clarify, women and their families, and students are in dependent relationship with researchers and must not be directly approached by the research team to give consent on-the-spot. Participating or not participating in the research must not disadvantage participants in a dependent relationship. Any benefit for participating must not constitute a financial inducement.

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It is ethically questionable to break up or segment data from a single study to create different papers for publication – a practice called 'salami slicing'. If the authors have legitimate reasons for reporting separately on different parts of the same study, or the same data set, they should justify that to the editor at the time of submission. Equally, readers need to be aware that different aspects of the same study are being reported, thus the methods section of the submitted manuscript must clearly explain why the submitted paper is justified.

Authorship

We have adopted the guidelines of the International Committee of Medical Journal Editors (ICMJE) http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html which have also been adopted by the Australian NHMRC Guidelines for the Responsible Conduct of Research available at:

http://www.nhmrc.gov.au/guidelines-publications/r39, legitimate authors are those that made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted. All potential authors are those that meet requirement (1) above and these people should not be excluded from contributing to the writing and approval of the article. No author should be added who does not meet the first requirement; for more details please read "How to handle authorship disputes: a guide for new researchers" (2003) by Tim Albert and Liz Wage available at the COPE website: http://publicationethics.org/resources/guidelines. During the online submission

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After peer-review, the Editor-in-Chief will notify the corresponding author on whether the paper has been accepted, rejected, or needs revision.

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Once a manuscript is accepted for publication, authors can expect web publication of the article in final version on ScienceDirect in 4 weeks.

 Preparation

Double-Blind Peer Review Process

Editors review all abstracts and using a triage-type checklist will make a rapid decision about whether the article is suitable for peer review in this journal. The overall rejection rate at this stage is approximately 60% and the majority of these happen at the rapid decision stage. This rapid decision is of benefit for authors because if the paper is rejected reasons will be given and the author can consider whether to submit elsewhere without undue delay. The most common reasons for initial rejection are: 1) not having prior institutional ethical approval for research and/or not demonstrating fully informed and fully free consent by participants; 2) not situating the research in the existing literature; 3) poor English and; 4) not following this guide for authors.

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Each paper that the editor/s assess as suitable for peer review is allocated to two reviewers who are asked to assess the paper against one of the Journal's three sets of reviewing criteria i.e. 1) Quantitative Research; 2) Qualitative Research; 3) Scholarly Paper Review Criteria.

View the Review criteria here.

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When submitting a revised manuscript, a Detailed Response to Reviewers must accompany the revision. This document must not contain any of the Author(s) details. The most common error is uploading this document on an organisation's letterhead, or the Author signing off with their name and contact details.

The easiest way to format this document is to either (a) respond underneath each point raised by the reviewer, or (b) create a 2-column table and copy each point raised by the reviewer into the first column, and respond against each point in the second column

Highlight any changes made on the revised manuscript – to make it easy for the peer-reviewers to see where these have occurred. Also, remember to include page and line numbers to the manuscript as this makes the peer-review process easier.

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This journal operates a double blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is

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Article structure

Types of articles:

• Research articles; quantitative and qualitative

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• Theoretical papers

• Opinion / discussion papers

• Case study which is linked to the literature

For standard articles, the maximum length is now 35 double-spaced pages, with standard margins of 2.5 cm (1 inch) all around, and 11 point font size. This page allowance is inclusive of all Tables, Figures, and References, but excluding the Structured Abstract.

Any author who has a very good reason to increase the page number beyond 35, e.g. a qualitative research paper, will need to make a clear case to the Editor-in-Chief. Please email the Editor for approval, including the Structured Abstract, prior to submitting. (Email: kathleen.fahy@scu.edu.au).

Tables must not exceed six typeset pages.

Supplementary material may be added without specific page limits. The readability of the article, however, must not depend upon access to supplementary materials.

Page numbers and line numbers should be included for the convenience of the peer-reviewers.

Language should be standard UK English and woman-centred, e.g. use "childbearing woman" instead of "gravid patient", "birth" instead of "delivery".

Please have the following items ready before you log-on to the system. Every submission, regardless of category, must include the following:

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- The approval number

- The date of approval

• - Note: If the manuscript is based on a quality assurance or practice improvement project this must be made clear in the text of the paper and address ethical issues concerning informed and free consent and confidentiality, as relevant.

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The abstract must be structured and under 250 words.

The structure of most abstracts should be:

• Problem

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- Question, Hypothesis or Aim
- Methods
- Findings
- Discussion
- Conclusion

The Abstract must not include references. Avoid abbreviations and acronyms. Ensure the name of the hospital or health service is not mentioned.

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Provide at least four and up to six keywords, at least three of which should be selected from those recommended by the *Index Medicus* Medical Subject Headings (MeSH) browser list (http://www.nlm.nih.gov/meshhome.html)

Statement of Significance

In the introduction, create a table using the following headings to summaries (in 100 words or less) the contribution of your paper to the existing literature:

Problem or Issue

What is Already Known

What this Paper Adds

Example of Statement of Significance

Problem

Poor assessment and clinical reasoning are major contributors to adverse birth outcomes.

What is Already Known

Midwifery decision-making during birth is mediated by hierarchies of surveillance and control. Midwives are often unable to implement their preferred decision. The international and national professional decision-making frameworks are not sufficiently detailed to guide midwives' clinical reasoning.

What this Paper Adds

Evidence that half of the midwives interviewed did not use clinical reasoning to make decisions. A new and detailed model of midwifery clinical reasoning which incorporates a role for intuition.

Headings

For Original Research Articles references should not be more than 30, except with specific permission from the editor prior to submission), **text** should be organised as follows:

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- Participants, Ethics and Methods (described in detail).

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- Discussion (clear and concise interpretation of results in the context of existing literature)

- Conclusion (summarise key points and make recommendations)

- Acknowledgments and Disclosures

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Minimise abbreviations to no more than four. Do not use abbreviations in the title. Use only abbreviations well known to midwives in the abstract. Define abbreviations at first appearance in the text.

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Acknowledgements

This section is compulsory. Grants, financial support and technical or other assistance are acknowledged at the end of the text before the references. *All financial support for the project must be acknowledged. If there has been no financial assistance with the project, this must be clearly stated.*

The role(s) of the funding organisation, if any, in the collection of data, its analysis and interpretation, and in the right to approve or disapprove publication of the finished manuscript must be described in the Methods section of the text.

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Please submit tables as editable text and not as images.

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Do not use vertical lines. Each table should be numbered (Arabic) and have a title above.

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Tables should be self-explanatory, and the data should not be duplicated in the text or illustrations. Tables must be submitted as part of the text file and not as illustrations.

References

The journal follows the International Council of Medical Journal Editors' (ICMJE's) Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals available at: http://www.icmje.org/recommendations/. Referencing requirements for *Women and Birth* are the same as for other major medical/health journal. Examples of citation and referencing for each type (e.g. article, book chapter, thesis) are at: http://www.nlm.nih.gov/bsd/uniform_requirements.html.

The full details of the National Library of Medicine (NLM) referencing requirements are found at http://www.ncbi.nlm.nih.gov/books/NBK7256/; where the e-book can be accessed.

For users of bibliographic management systems like Mendelay or Endnote please use the most up to date version and select the Lancet Output Style because it complies with the ICMJE referencing standards.

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Supplementary material

Supplementary material can support and enhance your scientific research. Supplementary files offer the author additional possibilities to publish supporting applications, high-resolution images, background datasets, sound clips and more. Please note that such items are published online exactly as they are submitted; there is no typesetting involved (supplementary data supplied as an Excel file or as a PowerPoint slide will appear as such online). Please submit the material together with the article and supply a concise and descriptive caption for each file. If you wish to make any changes to supplementary data during any stage of the process, then please make sure to provide an updated file, and do not annotate any corrections on a previous version. Please also make sure to switch off the 'Track Changes' option in any Microsoft Office files as these will appear in the published supplementary file(s). For more detailed instructions please visit our artwork instruction pages.

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The journal encourages authors to create an AudioSlides presentation with their published article. AudioSlides are brief, webinar-style presentations that are shown next to the online article on ScienceDirect. This gives authors the opportunity to summarize their research in their own words and to help readers understand what the paper is about. More information and examples are available. Authors of this journal will automatically receive an invitation e-mail to create an AudioSlides presentation after acceptance of their paper.

Appendix H. Confirmation of ethical approval

REMOVED FOR HARD BINDING

Date of issue: **06/06/15**

UNIVERSITY OF Hull

Version number: **1.2 (women with diabetes)**

Participant Information Sheet

Title of the study: Understanding the experience of risk communication between midwives and women with pre-gestational diabetes

We would like to invite you to take part in our research study which is looking at the experience of risk communication between midwives and women with Type 1 or Type 2 diabetes. Before you decide if you want to participate we would like you to understand why this research is being done and what it will involve for you if you decide to participate. You can talk to others before you decide if you want to take part. ***The researcher will answer any questions you have.***

What is the purpose of the study?

Research suggests that women with Type 1 or Type 2 diabetes in pregnancy are more likely to experience increased physical risks and psychological difficulties during their pregnancy. However, we know very little about what it is like for these women to talk about risk with midwives. This study is interested in exploring the experience of talking about risks and pregnancy options from the perspective of both pregnant women with diabetes and midwives who care for this group of women. The purpose is to find out how choice and pregnancy options are discussed while balancing the risks associated with diabetes.

Why have I been invited?

You have been invited to take part in this study as you have contacted the researcher and expressed an interest in finding out more about the study and taking part. This study involves women aged 18 or over with Type 1 or Type 2 diabetes who are currently pregnant with their first child or have given birth to their first child in the last year.

Do I have to take part?

No, participation is voluntary. You will be asked to sign a consent form indicating that you agree to take part.

What will happen if I decide to take part?

If you agree to take part you will be contacted by the researcher to arrange an interview either face-to-face or via Skype/telephone at a convenient place and time. You will have to answer some short questions about yourself e.g. age, ethnicity, number of weeks pregnant. Then you will have a conversation with the researcher which will usually last around 45-90 minutes but may take longer depending on what you want to talk about. The researcher is a Trainee Clinical Psychologist who will ask you questions about your experience of diabetes in pregnancy and will audiotape the discussion. There are no right or wrong answers and we are interested in your opinions, beliefs and experience of risk communication with midwives.

What are the possible disadvantages and risks of taking part?

Participating in the study will require 45-90 minutes of your time which may be inconvenient for you. Talking about the experience of diabetes in pregnancy may be upsetting if this brings to mind difficult issues and you can stop the interview at any time. The researcher will offer support and explain how you can access further information if you would like it.

What are the possible benefits of taking part?

While it is unlikely that you will have any direct benefits from taking part in the study, it will provide you with an opportunity to share your views with the researcher. It is hoped that the information you share will help us to understand how risk is discussed between midwives and women with diabetes in pregnancy. It could help identify areas where midwives may benefit from further support or training to improve how risk and choice are communicated. It could also help to identify examples of good practice which can then be included within training, with an overall aim to increase pregnancy satisfaction, improve self-management of diabetes in pregnancy and reduce psychological distress for women with pre-gestational diabetes.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study without giving a reason up to the point of data analysis.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will try to answer your questions. If you remain unhappy and wish to complain formally, you can do this through Professor Kate Galvin, the Associate Dean

for Research in the Faculty of Health and Social Care, University of Hull, on 01482 463336.

Will my taking part in this study be kept confidential?

Yes, all personal information that you provide will be kept strictly confidential. Any information that could be used to identify you will not be used in the research. People who decide to take part will be given a code to protect their anonymity. After the research is completed all the audio recordings will be destroyed. The only time that information cannot be kept confidential is if you disclose something that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact appropriate authorities to ensure that you and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you.

What will happen to the results of the study?

After the study is completed if you wish you will be given written feedback about the results. The results will be written-up and submitted for publication in an academic journal. Direct quotes from your interview may be used in the write-up. Your personal details and any identifiable data **will not** be included in the write-up.

Who is organising and funding the research?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some data collected during the study may be looked at by responsible individuals from the University of Hull to ensure that appropriate guidance was followed by the researcher.

Who has reviewed the study?

The study has been reviewed by the Faculty of Health and Social Care Research Ethics Committee, an independent organisation which protects the interest of people who participate in research. This study has received a favourable opinion.

Further information and contact details

If you have any further questions, comments or queries, please don't hesitate to contact Kathryn Strachan. Thank you for taking the time to read this information.

Yours Sincerely,

Kathryn Strachan

Trainee Clinical Psychologist

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Email address: l.f.glover@hull.ac.uk

UNIVERSITY OF **Hull**

Participant Information Sheet

Title of the study: Understanding the experience of risk communication between midwives and women with pre-gestational diabetes

We would like to invite you to take part in our research study which is looking at the experience of risk communication between midwives and women with pre-gestational diabetes. Before you decide if you want to participate we would like you to understand why this research is being done and what it will involve for you if you decide to participate. You can talk to others before you decide if you want to take part. ***The researcher will answer any questions you have.***

What is the purpose of the study?

Research suggests that women with pre-gestational diabetes in pregnancy are often more likely to experience increased physical risks and psychological difficulties during their pregnancy. However, we know very little about what it is like for these women to talk about risk with midwives. This study is interested in exploring the experience of talking about risks and pregnancy options from the perspective of both pregnant women with pre-gestational diabetes and midwives who care for this group of women. The purpose is to find out how midwives discuss choice while balancing the risks associated with pre-gestational diabetes.

Why have I been invited?

You have been invited to take part in this study as you have contacted the researcher and expressed an interest in finding out more about the study and taking part. This study involves qualified midwives who have experience in supporting women with pre-gestational diabetes in pregnancy (in antenatal clinics, specialist teams, the community or inpatient settings).

Do I have to take part?

No, participation is voluntary. You will be asked to sign a consent form indicating that you agree to take part.

What will happen if I decide to take part?

If you agree to take part you will be contacted by the researcher to arrange an interview either face-to-face or via Skype/telephone at a convenient place and time. You will have to answer some short questions about yourself e.g. age, number of years working as a midwife. Then you will have a conversation with the researcher which will usually last around 45-90 minutes but may take longer depending on what you want to talk about. The researcher is a Trainee Clinical Psychologist who will ask you questions about your experience of communicating with women with pre-gestational diabetes and will audiotape the discussion. There are no right or wrong answers and we are interested in your opinions, beliefs and experience of discussing risks and choice with this group of women.

What are the possible disadvantages and risks of taking part?

Participating in the study will require 45-90 minutes of your time which may be inconvenient for you. Talking about the experience of caring for women with pre-gestational diabetes in pregnancy may be upsetting if this brings to mind difficult issues and you can stop the interview at any time. The researcher will offer support and explain how you can access further information if you would like it.

What are the possible benefits of taking part?

While it is unlikely that you will have any direct benefits from taking part in the study, it will provide you with an opportunity to share your views with the researcher. It is hoped that the information you share will help us to understand how risk is discussed between midwives and women with pre-gestational diabetes in pregnancy. It could help identify areas where midwives may benefit from further support or training to improve how risk and choice are communicated when providing woman centred care. It could also help to identify examples of good practice which can then be included within training, with an overall aim to increase pregnancy satisfaction, improve self-management of diabetes in pregnancy and reduce psychological distress for women with pre-gestational diabetes.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study without giving a reason up to the point of data analysis.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will try to answer your questions. If you remain unhappy and wish to complain formally, you can do this through Professor Kate Galvin, the Associate Dean for Research in the Faculty of Health and Social Care, University of Hull, on 01482 463336.

<u>Will my taking part in this study be kept confidential?</u>

Yes, all personal information that you provide will be kept strictly confidential. Any information that could be used to identify you will not be used in the research. People who decide to take part will be given a code to protect their anonymity. After the research is completed all the audio recordings will be destroyed. The only time that information cannot be kept confidential is if you disclose something that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact appropriate authorities to ensure that you and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you.

<u>What will happen to the results of the study?</u>

After the study is completed if you wish you will be given written feedback about the results. The results will be written-up and submitted for publication in an academic journal. Direct quotes from your interview may be used in the write-up. Your personal details and any identifiable data **will not** be included in the write-up.

<u>Who is organising and funding the research?</u>

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull. Some data collected during the study may be looked at by responsible individuals from the University of Hull to ensure that appropriate guidance was followed by the researcher.

<u>Who has reviewed the study?</u>

The study has been reviewed by the Faculty of Health and Social Care Research Ethics Committee, an independent organisation which protects the interest of people who participate in research. This study has received a favourable opinion.

<u>Further information and contact details</u>

If you have any further questions, comments or queries, please don't hesitate to contact Kathryn Strachan. Thank you for taking the time to read this information.

Yours Sincerely,

Kathryn Strachan

Trainee Clinical Psychologist

The Department Psychological health and Wellbeing

The University of Hull

Cottingham Road

Hull

HU6 7RX

Tel: (work phone no. TBC)

Email: k.a.strachan@2013.hull.ac.uk

Supervised by, **Dr Lesley Glover**

Clinical Psychologist

The Department Psychological health and Wellbeing

The University of Hull

Cottingham Road

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Email address: l.f.glover@hull.ac.uk

Appendix K.   Consent form - women with diabetes

Date of issue: **06/06/15**
Version number: **1.2 (women with diabetes)**

UNIVERSITY OF Hull

CONSENT FORM

Title of Project: Understanding the experience of risk communication between midwives and women with pre-gestational diabetes

Name of Researcher: Kathryn Strachan

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 19/04/2015 (Version 1.2) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis and transcription.

3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.

4. I understand that data collected during the study may be viewed by responsible individuals from the University of Hull e.g. the researcher's supervisors.

5. I agree to take part in the interview and understand that this will be audio taped.

Name of participant	Date	Signature
_____	_____	_____

Name of person taking consent	Date	Signature
_____	_____	_____

156

Appendix L. **Consent form - Midwives**

🜂 ⚙ ♛ ⚜ 🦅 **UNIVERSITY OF Hull**

CONSENT FORM

Title of Project: Understanding the experience of risk communication between midwives and women with pre-gestational diabetes

Name of Researcher: Kathryn Strachan

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 06/06/2015 (Version 1.3) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis and transcription.

3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.

4. I understand that data collected during the study may be viewed by responsible individuals from the University of Hull e.g. the researcher's supervisors.

5. I agree to take part in the interview and understand that this will be audio taped.

Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature
_____	_____	_____

Appendix M.   Initial Screening Questions

<u>Initial Screening Questions</u>

Screening questions asked over the phone when initial contact is made with participants who have expressed an interest in taking part in the study and have contacted that researcher. The answers required for suitability to take part in the study are included in brackets. Contact details for arranging an interview will also be taken.

Women with diabetes

Do you have Type 1 or Type 2 diabetes?	(Yes)
Do you have gestational diabetes?	(No)
Are you aged 18 or over?	(Yes)
Are you currently pregnant?	
Or have you given birth within the last 9 months/1 year?	(Yes)
Is this your first pregnancy/child?	(Yes)
Are you or have you been a Nurse or Midwife?	(No)
Do you have any co-morbid health conditions?	
Is yes, what condition(s) do you have?	(Case by case)

Midwives

Are you a registered Midwife?	(Yes)
Are you currently practicing?	(Yes)
Do you have experience of supporting women with Type 1 or Type 2 diabetes?	(Yes)
Do you yourself have diabetes?	(No)

INFORMATION ABOUT YOU

Please answer the following questions:

Participant number: ....

1. **What is your age in years?** ....

2. **Ethnicity:**

   ☐ White   ☐ Asian   please tick ☑

   ☐ Black   ☐ Chinese

   ☐ Other (please state): ....

3. **What type of diabetes do you have?**   Type 1 ☐   Type 2 ☐

4. **How long have you had diabetes in years/months?** ....

5. **How many weeks pregnant are you?** ....
   (if they have already given birth go to question 6.)

6. **How old is your child in weeks/months?** ....

7. **Do you have any co-morbid health conditions?** (Please
   state) ....

Appendix O.   Demographic information form - Midwives

Date of issue: **06/06/15**
Version number: **1.1 (midwives)**

INFORMATION ABOUT YOU

Please answer the following questions:

Participant number: ....

1. What is your age in years? ....

2. What is your gender?   Male ☐   Female ☐   please tick ☑

3. Ethnicity:

☐ White   ☐ Asian

☐ Black   ☐ Chinese

☐ Other (please state): ....

4. How many years have you been a midwife? ....

5. How many years experience have you had working with women with diabetes?

....

6. What is your primary working environment?

☐ Antenatal Clinic

☐ Community

☐ Inpatient

☐ Other (please state): ....

Appendix P.   Interview schedule - Women with diabetes

<u>Pre-interview information:</u>

- Thank you for agreeing to take part in this study.
- I'll start by asking you some brief demographic questions and then we'll go on to talk in more depth about your experience of discussing risk throughout pregnancy. I am interested in your experiences of talking to midwives so it would be useful if we could keep focussed on this, although of course you are welcome to discuss other issues which you feel are relevant and important.
- The interview will probably last around an hour but may take longer, this will be guided by you. Please ask me if you don't understand a question.
- N.b. Remind participants of right to withdraw, confidentiality, anonymised date, recording on Dictaphone etc.
- Before we start, do you have any questions about the study, consent, information sheet etc.?

<u>Interview questions:</u>

1. How do you manage your diabetes?

   (Medication, diet etc.)

2. How well controlled is your diabetes?

3. What is your understanding of the risks involved during pregnancy and labour due to diabetes?

   (Can you tell me how you are thinking about risk?)

4. What are your thoughts around the term 'high risk' pregnancy?

5. Can you tell me about your experience of discussing risks with midwives?

   (Please think of a particular occasion and talk in detail about that)

6. Can you tell me about your experience of discussing choices and pregnancy options with midwives?

   (Please think of a particular occasion and talk in detail about that)

7. Can you tell me about the balance between risks and choice when talking to midwives?

    (Think of a particular occasion and talk in detail about that)

8. How do you feel about the way the midwife communicated? What is it like for you having these conversations?

    (What was helpful/unhelpful and why?)

9. What, if anything, makes discussing risks or choices difficult? In an ideal world how would you like these conversations go?

    (What gets in the way? How do you feel about doing it?)

N.b. Use probes to explore feelings, impacts, beliefs, explanations etc. And to clarify issues

Post-interview questions:

-   Is there anything you'd like to add?
-   Are there any questions you would like to ask about the study before we finish?
-   How did you find the interview?

N.b. discuss support sheet

Appendix Q.   Interview schedule - Midwives

<u>Pre-interview information:</u>
- Thank you for agreeing to take part in this study.
- I'll start by asking you some brief demographic questions and then we'll go on to talk in more depth about your experience of discussing risk throughout pregnancy. I am interested in your experiences of talking to women with pre-existing diabetes so it would be useful if we could keep focussed on this, although of course you are welcome to discuss other issues which you feel are relevant and important.
- The interview will probably last around an hour but may take longer, this will be guided by you. Please ask me if you don't understand a question.
- N.b. Remind participants of right to withdraw, confidentiality, anonymised date, recording on Dictaphone etc.
- Before we start, do you have any questions about the study, consent, information sheet etc.?

<u>Interview questions:</u>

1. What is your understanding of the risks involved during pregnancy and labour due to diabetes?

   (Can you tell me how you are thinking about risk?)

2. What are your thoughts around the term 'high risk' pregnancy?

3. Can you tell me about your experience of discussing risks with pregnant women with diabetes?

   (Can you think of a particular occasion and talk in detail about that)

4. Can you tell me about your experience of discussing choices and pregnancy options with pregnant women with diabetes?

   (Can you think of a particular occasion and talk in detail about that)

5. Can you tell me about the balance between risks and choice when talking to women?

(Think of a particular occasion and talk in detail about that)

6. What is it like for you having these conversations? How do you feel about the way you communicate with women?

    (What is helpful/unhelpful and why?)

7. What, if anything, makes discussing risks or choices difficult? In an ideal world how would you like these conversations go?

    (i.e. what gets in the way, how do you feel about doing it?)

N.b. Use probes to explore feelings, impacts, beliefs, explanations etc. And to clarify issues

Post-interview questions:

- Is there anything you'd like to add?
- Are there any questions you would like to ask about the study before we finish?
- How did you find the interview?

N.b. discuss support sheet

Appendix R.   Epistemological statement

This statement aims to transparently outline ontological and epistemological assumptions underpinning the research and methodology utilised within this portfolio thesis. Epistemology, the 'theory of knowledge', explores how we come to know things and believe them to be true (Barker, Pistrang & Elliot, 2002). Ontology concerns the study of existence and attempts to answer questions about whether entities are real or unreal (Doucet, Letourneau & Stoppard, 2010). Assumptions about reality and the way in which the world is experienced will inevitably have influenced the approach and methodology used for this research (Carter & Little, 2007). Initially, research questions were considered and the limited literature around the experience of risk discussion resulted in objectives developed from a position of curiosity.

A positivist epistemological stance suggests that objective 'truths' exist, independent of whether they are understood or who might be observing (Bhaskar, 1975). Such an approach implies that these truths can be identified and measured through controlled research (Ponterotto, 2005) i.e. one 'true' experience of risk discussion can be discovered. This position is promoted in quantitative studies which systematically observe and describe phenomena within the constraints of models or theories, test hypotheses, and interpret statistical results (Ponterotto, 2005). The researcher and participants are assumed to exist independently, meaning the researcher can explore a phenomenon without influencing results. This realist ontology rejects the value of subjective experiences (Gill & Johnson, 2002), is reductionist in nature and may not capture the diverse range of ways in which risk discussion in pregnancy is experienced. For these reasons, such a stance was rejected.

In contrast, social constructionist approaches assume that there is no objective reality or 'truth' and encourage the study of idiosyncratic, subjective experiences. Meanings and interpretations are constructed within our minds, influenced by culture, relationships and language, implying that many forms of reality can exist (Burr, 1995; Ormston, Spencer, Barnard, & Snape, 2013; Ponterotto, 2005). This was considered particularly relevant as pregnant women's experiences cannot exist without the presence of midwives or other health care

professionals, and vice versa. In this position, researchers cannot be situated as detached observers, but play a significant part in collecting and making sense of data.

The researcher considers herself positioned between extreme positivist and constructionist stances, utilising a critical realism perspective (Blaike, 2007). This stance assumes the existence of some realities, but these cannot be measured objectively or known with certainty (Cook & Campbell, 1979), suggesting that they can only be reached though exploration of human perceptions i.e. pregnancy and birth are assumed to exist, but are intertwined with individual, subjective interpretations. While some similarities may exist in how individual midwives and women with diabetes comprehend risk, understanding will ultimately be shaped by social and contextual factors, resulting in unique realities. Through exploring the issue from many perspectives (Elliot, Fischer & Rennie, 1999) the research hoped to uncover a shared reality surrounding the phenomenon of risk discussion, facilitating improvements in care.

Due to the above assumptions, qualitative methodology was utilised, an approach increasingly valued within clinical and health psychology (Smith, 2008), to illuminate how illness and treatment experiences are constructed, shaped and reflected upon. In deciding which qualitative approach to use, the researcher explored various methodologies. Content or thematic approaches, which group themes to develop categories, were considered reductionist rather than exploratory (Anderson, 2007). This study wanted to understand risk discussion from a detailed perspective rather than describe phenomena. The lack of interpretation involved resulted in these approaches being rejected. Grounded theory uses qualitative data to generate theory by developing abstract theoretical concepts to capture the essence of a phenomenon (Strauss, & Corbin, 1994). This process, based upon both positivist and interpretative assumptions, requires extensive interviewing and the ability to develop themes from various sources of data, beyond the scale of this research. The current study was not aiming to create theory or make universal claims so this approach was deemed unsuitable (McMullen, 2011).

Discourse analysis methods involve examining text to identify how meaning is constructed through language and context (Willig, 2001) which can be useful when exploring how people use cultural resources. However, these approaches fail to consider communication

which is beyond words i.e. discussion of risk is likely to involve non-verbal processes. Although content and linguistic aspects were explored in the analysis, the research aimed to understand risk discussion through lived experiences, not just language. For these reasons this approach was rejected. Finally, narrative analysis, which explores the content or structure of people's stories and the relationship between stories, was considered (Gilbert, 2002; Crossley, 2002). However, the present research was interested in experiences of risk discussion, not just the way participants 'story' these experiences, thus rendering this approach inappropriate.

Interpretative Phenomenological Analysis (IPA) was considered the most appropriate method due to the emphasis of this empirical research on understanding the experience of risk discussion from the perspective of midwives and women with diabetes (Smith, Flower & Larkin, 2009). IPA aims to understand the meaning attributed to experiences through a practical and interpretative approach to analysing phenomenological data (Smith, Jarman & Osborn, 1999). This approach attempts to get as close to individual perceptions as possible, without claiming generalisable conclusions, generating theory or enforcing pre-defined categories preventing subjective expression.

IPA is informed by three key theoretical assumptions which were considered valuable for the current research; phenomenology, hermeneutics and idiography (Smith et al., 2009). Phenomenology is the study of lived human experience (Barker et al., 2002). Perceived meaning is viewed as more important than objective reality and multiple valid perspectives are possible. This was important in relation to the empirical research which aimed to explore the experience of risk discussion from many perspectives, including two distinctive participant groups: midwives and pregnant women with diabetes.

Hermeneutics considers how researchers discover original participant meaning through interpretation in present day context and how meaning emerges through interaction between participants and researcher (i.e. during the interview and analysis processes). In IPA, the researcher is engaged in a double hermeneutic process and attempts to make sense of how participants made sense of the original phenomena. The researcher's own understandings and experiences are acknowledged and integral to this interpretative process (Smith et al., 2009). For

example, the researcher's own experience of chronic illness and health care interactions may have resulted in bias throughout the research process. However, attempts were made to reduce subjective bias through continual reflection, a balanced interview schedule with open questioning, and the use of participant's own language.

Finally, an idiographic approach allows for deeper understanding of concepts by situating participants in context and examining individual's unique experiences, rather than developing generalised claims. This appeared pertinent in relation to the empirical research as idiosyncratic perceptions are likely to be influenced by individualised health care settings, roles and responsibilities, and experiences of diabetes or pregnancy. It was felt that construction of risk would be influenced by many factors including culture, age, ethnicity, socio-economic status and historical experiences.

A phenomenological approach was also taken for the meta-ethnography as this aimed to explore the subjective experiences associated with type 1 diabetes. Within the meta-ethnography, three levels of interpretation were present: participant understandings, original authors and the researcher. Although this may have limited the focus on original participant realities, it enabled the development of further meaning. Utilising phenomenology was deemed to be particularly important for both sections to allow for exploration of illness and risk beyond historical reductionist biomedical approaches (Brocki & Wearden, 2006).

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I: Interviewer

P: Participant

Descriptive & exploratory comments	Transcript	Emerging Themes
	Interviewer: My next question is for you to talk in a bit more detail about your experience of discussing some of these risks with the midwives. It might help if you pick out one or two particular occasions and kind of talk in detail about those?	
Different midwives	Participant: Yeah I think, I don't know how diabetes care is organised in other places but, erm, so I had different midwives, I don't know if this is the same for everyone across the UK. So I had a clinic where I went and at the clinic there	*Lack of continuity* *Missing out*
MDT clinic approach	was a diabetic midwife, a diabetic nurse, a dietician, er, a diabetes consultant and a consultant gynaecologist. So you I went into this	
Many people in the room - interacting with professionals as overwhelming, intimidating?	room and there were <u>five people</u> in there at a minimum, and they would also have students, they would have other various people sitting in (laughs). You would go into this room, it was	*Outside the norm* *needing extra care*
Laughter indicates discomfort	like a panel (laughs) so my experience of talking to the midwife was in a diabetes specific sense,	
Midwife focused on diabetes	was bound up very much being among all these other medical professionals. That's one thing to	*Focus on diabetes rather than pregnancy*

Bound up in system of other HCPs	say. Then when I went into the hospital it was very different again (pause) because it was normal midwives, in the community, community midwives. So what happened was I found that	*Lack of 1 to 1 midwifery contact (Missing out)*
Community midwife referred to diabetes midwife	when I would go to the community midwife they would kind of refer to the diabetes midwife. So I	*Disconnect responsibly*
Who is responsible?	would say my sugar levels are whatever and I think I might need to go in for steroids and those kind of discussions were not the kind of	
Community midwife told her they wouldn't discuss risk or diabetes	discussions I ever had with the community midwife. They just said, in fact, they said to me, well we won't be discussing anything about your diabetes because you will be discussing that at the hospital with <u>them</u>. So they actually they didn't really discuss the risks with me at all, all	*Avoidance of risk*
Basic procedural checks, 'limited', sense of neglect?	they did was sort of give me general ante natal advice and sort of listened to the baby's heartbeat and checked my urine. That was, that was kind of limited when I went to the doctor's surgery to see the midwife. So all of the diabetes care was sort	*Missing out (on emotional care etc.)*
Diabetes care & responsibility 'shunted', passed around?	of shunted over to the clinic at the hospital. So that was one thing and they, they were kind of like, well their standard line was like, oh well you will be induced anyway. So, so we will just	*Disconnected services*
fragmented	see how you go because you are under <u>their</u>	*Balancing choice is difficult*
Implies lack of choice	supervision. So you know questions you have should go over there. So that was the first thing, when I came to be in hospital whether for	*Feeling controlled*

172

Being monitored	monitoring or particularly, oh <u>particularly </u>when I had steroids, I have never been quite so angry both at the <u>lack</u> of knowledge among midwives,	
Anger at lack of diabetes knowledge and sliding scale	doctors and consultants about diabetes <u>in general</u> not just diabetic pregnancy. I was put on a drip, a sliding scale, so they basically <u>remove control</u>	*Risk = control of sugar*
'they': sense of them vs. her dynamic *Removed control of insulin from her*	of your insulin from you (pause) and take over the control of sugar levels through insulin and ratios and so on. So you tell them your ratios and the insulin that you are on and they give you a big pump and they hook you up to it and they	*Balancing control is difficult*
Attached to machine, objectified	control it because the steroids make you very insulin resistant so, and they don't want anything to happen to the baby, so they think the control of that is best placed in<u> their</u> hands rather than	*Outside the norm*
Tone suggests she feels control best placed with her	<u>yours</u>, because they can respond to it better. What I found, and this was midwives because it was midwives who were <u>checking</u> me, midwives and	*Controlled, expertise not valued*
Midwives and nurses	nurses, a combination of two groups of people	

Appendix T.   Reflective Statement

Throughout the research journey I recorded my decisions, thoughts and reactions in a reflective journal. The following statement transparently summarises key issues encountered.

<u>Choosing the research area</u>

From a young age, I've been interested in the psychological impact of health conditions and at the start of Clinical Psychology training this was at the forefront of my mind. It is likely that such interest originates in my own experience of chronic illness (Inflammatory Bowel Disease), alongside my parents' occupations within the healthcare system. With this in mind, I went to the research fair with a view to pursue research in this area. I also thought long and hard about the choice of research supervisors; I was keen to find someone who was the 'right fit' for my way of working and interacting. I knew that I would be best supported by someone who could provide practical support and structure alongside flexibility, compassion and the ability to nurture my curiosity. I spent a lot of time deliberating between topics and supervisors but this careful consideration has resulted in me feeling well supported and able to gain enjoyment from research.

Being female, I was also drawn to women's issues and pregnancy has always interested me. My experience of midwifery practice was essentially non-existent - naively centred around TV shows such as 'One Born Every Minute'! In hindsight, I wonder if my interest in complex pregnancy also stemmed from my experience of chronic illness and curiosity around how 'high-risk' pregnancy might be constructed. Having attended many hospital appointments and undergone various medical procedures I was familiar with Healthcare Professional (HCP) interactions and my perception of 'helpful' or 'unhelpful' communication fuelled my enthusiasm to explore this area in more depth. However, I was also aware of wanting to choose a topic that wasn't too close to my own experiences, to reduce the impact of bias and for my own well-being in case I should experience strong emotional reactions.

After reviewing the literature and considering where gaps existed, it was decided that exploring diabetes would be valuable. It was also felt that the increasing prevalence of diabetes

would improve my chances of finding and recruiting participants. The limited literature from the perspective of midwives interested me and I was keen to provide midwives with a 'voice'. As a psychologist, I feel strongly about our role in supporting HCPs and promoting self-care and reflection, factors which also shaped my desire to pursue research in this area.

<u>Method and design</u>

Qualitative methodology seemed appropriate considering my interest in lived experiences and different perspectives. However, I had reservations about using a qualitative design due to my unfamiliarity with such methods. I felt more comfortable with quantitative approaches which had been promoted as part of my undergraduate degree and had previously found certainty in statistical studies and there being an 'answer'. Despite these reservations, I was keen to develop my skills as a researcher and felt that interviewing participants would keep me engaged and motivated in the process.

I had wanted to investigate midwife-mother dyads, perhaps in the labour room or antenatal consultations, record these and get participants to listen back and discuss. I also thought about using focus groups. However, feasibility issues and not wanting the study to become a 'service evaluation' or include participants from only one area meant that my design ideas changed. As discussed in my epistemological statement, I investigated several different qualitative methodologies before deciding on Interpretative Phenomenological Analysis (IPA). I was keen to employ a multi-perspective design to capture more than one perspective but I distinctly remember being met by blank faces or suggestions that this would be too ambitious. I have now developed a better understanding of the process and can appreciate this response. At times I have also questioned whether I took on too much, particularly when my health required significant attention. However, I'm also proud that I challenged myself and think that the study design will add something different to the literature.

I recall attending a midwifery and diabetes conference and speaking to an obstetrician about my research. She expressed views that midwives 'shouldn't be discussing risk – this was an obstetrician's role' – and that I would be unlikely to find anything interesting from

interviewing midwives. I felt deflated and I remember my initial disappointment and panic. Was she right? What was the point of my research? I also spoke to some midwives who shared contrasting viewpoints and provided reassurance. My research supervisors helped me to consider the context surrounding these responses and we thought about how differing perspectives provoked even more curiosity; surely there was something interesting to be found here? This experience had a profound impact on my relationship with research and has continued to influence my clinical practice. I'm more aware of pausing before responding in a reactive nature and if I'm met with a response that I wasn't expecting, I'm more likely to remain curious.

Recruitment

I'd heard many 'horror stories' about the challenge of recruitment and trainees needing to re-design their project due to recruitment difficulties. This uncertainty created a lot of anxiety and I clearly remember the sense of trepidation when I pressed 'send' on the first email advertisement for midwives. Would anyone respond? Would they think it was interesting? What if it became oversubscribed? Concerns had been voiced that midwives would be unwilling or unable to converse due to heavy work demands. Despite initial enthusiasm from several midwives, the time between first email contact and final interview was often lengthy. Not hearing back from potential participants caused frustration and I regularly needed to remain compassionate, reminding myself of midwives' work demands, and learning to communicate assertively, without bombarding people. Despite these issues, I was impressed by midwives' commitment to give up personal time at evenings or weekends to talk to me and I believe this demonstrates the need for HCPs to have a space to share their views.

Recruitment of women with diabetes (WWD) was initially slow, with no response to poster or twitter advertisements. However, anxiety over recruitment resulted in considering several strategies within my ethics application. This allowed me to pursue other avenues and I was pleased with my perseverance at this stage. Initially I wondered if trying to recruit nationally was unwise. Targeting recruitment at a select audience proved most valuable and support from Diabetes UK and other online charities was highly significant in managing to

recruit enough participants. I recall the surge of excitement after a flurry of email responses to an advertisement in 'Balance' magazine! I ended up recruiting more WWD than I had originally envisaged and I recall finding it difficult to turn suitable participants away. In future I think I would consider more carefully whether additional data was manageable or necessary.

Interviews

Interviewing excited me most about qualitative research, similar to the enjoyment I gain from one-to-one client interaction in my clinical practice. However, I also experienced anticipation and anxiety, particularly with regards to the first interview and the practicalities involved; pilot interviews had highlighted the challenges of adhering to an interview schedule. In light of conducting interviews with people from all over the country, it was necessary to utilise the telephone which involved several feasibility issues i.e. how to record, the use of speaker phone, the quality requirements of recordings, and not being able to pick up on facial or bodily cues to manage turn taking or judge emotional distress. Not having face-to-face contact is likely to have influenced the interview experience, but I hope that this facilitated openness.

My first interview was conducted in the evening and I remember thinking afterwards that it had been 'horrendous'. The conversation felt stilted and employing open questioning had been difficult; the participant appeared to find it difficult to provide detail. I felt deflated and proceeded to judge my ability, thinking that I hadn't found out 'anything interesting'. On reflection, I can see how anxiety, uncertainty and expectation fuelled these judgments. Ironically when I came to analyse this transcript I found the content to be rich and engaging! The second interview also ended in self-criticism. This participant described a lack of midwifery input and I became concerned about the relevance of my study – how could I find out about the experiences of risk discussion if no one had contact with midwives? Interestingly lack of contact or continuity was a significant finding; once again I'd been hasty in deeming my research uninteresting and unhelpful. These experiences highlight my tendency to feel inadequate or 'not good enough' and to set myself high expectations to counteract these feelings. The research process has been highly valuable in forcing me to 'pause' and consider where my assumptions come from and how reactive thoughts and feelings shape my reality.

Once I settled into the interviewing process, became familiar with procedures and was able to 'shake off' judgements, I began to relax and embrace the experience. I used the interview scheduled flexibly and intuitively to cover necessary areas while remaining interested in what participants had to say. Perhaps knowing that I had already conducted some interviews and trusting that important aspects would 'shine through' also reduced the pressure to obtain 'good' data. I would often come away from interviews feeling exhilarated, empowered and passionate about voicing my participant's views. I was fascinated to learn more about midwifery and the challenges midwives face and believe that being from another profession facilitated honesty. This interest in other professionals and their roles has positively impacted on my clinical consultations skills, something which I have often found challenging and anxiety provoking.

The nature of research interviews vs. clinical interviews was initially difficult to manage. I was inclined to use summarising or reflecting techniques I would use in clinical interviews. It was necessary to be aware of my use of language to avoid 'putting words in people's mouths'. I was aware of wanting to remain a professional researcher but also sharing more of myself than perhaps I would usually do in my clinical work. I was careful not to disclose my own experiences before the interview to reduce the potential influence on participants' expressed views. However, at the end of some interviews, in response to questions, I did share my experience with chronic illness which I feel helped WWD to feel understood.

Analysis and findings

For me, the transcribing process was arduous and the level of continuous concentration required was difficult to manage combined with other demands and my own health. Therefore, I had to accept that I could not manage to transcribe in parallel with analysis and instead conducted these processes one after another. In future I think I would be more confident to start analysis earlier by making initial comments etc. Once transcribing was complete, I could focus on becoming absorbed within the data. Initially this step appeared daunting and having never been through the IPA process I was tentative and unsure. Discussing concerns in supervision allowed me to 'dive in' and explore my initial reactions and comments. Once I got into a flow I

really enjoyed this stage of the research and I felt reunited my with participants, accompanied this time by less anxiety and self-criticism which allowed me to connect with the data.

I analysed WWD first and found that when it came to midwives, I was quicker and more comfortable with the process. I initially analysed the groups separately to get a sense of whether the data felt distinct or if similar issues were highlighted. Initial midwifery themes might have been influenced by having become familiar with WWD concepts. After this stage, I felt stuck and unsure about how to progress and whether it was appropriate to keep the group analyses separate or to combine these when writing the articles. Consulting with supervisors helped me to consider the similarity or divergence of themes. I used the Birkbeck IPA online forum to explore how other researchers had approached this issue. In particular, two papers influenced my decision to integrate analysis (Borg Xuereb, Shaw & Lane, 2015; Rostill, Toms & Churchman, 2011). I perceived that the two groups were highlighting similar issues and encompassing their experiences within the same theme headings would allow a conversation to unfold conveying both perspectives within the whole phenomenon. The process of integrating felt 'right' for the data and facilitated interpretation, while reducing the word count. This was an important issue considering I had two participant groups and found it challenging to decide how to structure and write the article. I wanted to capture important findings but also remain concise and format the report in a way that would be acceptable to submit for publication. I re-drafted my results sections many times and in the process had to let go of quotes to which I had become attached.

Systematic Literature Review (SLR)

I really struggled with the SLR component of the thesis and found it difficult to settle on one topic. Looking back at my journal emphasised how often I referred to the SLR as 'taking a back seat'. Many of my original ideas around the experience of diabetes in pregnancy had already been explored in published reviews. On reflection, I wonder whether this reluctance was associated with uncertainty and concerns that my question would not be 'useful enough' – again a projection of my own inadequacy. I was also concerned that pursuing an idea that turned out to be inappropriate would 'waste time and effort'. Ironically, taking this view probably delayed

the process. I've come to realise how exploring and rejecting avenues of interest is an important and valuable part of progress.

Reading literature around women's experience of diabetes in pregnancy and the impact of this on self-concept got me thinking about what these women brought with them before embarking on the motherhood journey. At the same time, I was also developing a clinical interest in theory related to the construction of the self and the influence of social interactions. I considered many other ideas before returning to the concept of identity. Looking back I think this process has helped me to develop the confidence to trust in my intuition. During analysis, it became apparent that I could relate on a personal level to many of the experiences shared by WWD and I wonder if I had been drawn to this topic for this reason. Engaging with meta-ethnography and a qualitative synthesis was another new experience but choosing this methodology allowed me to develop a deeper understanding of the concepts. By the end, my relationship with the SLR had changed significantly and this is something that I will hold in mind when I am apprehensive about future undertakings.

My relationship with the research

My feelings towards research have fluctuated throughout the journey. I experienced significant health challenges half-way through the process and was forced to put research 'on hold' and prioritise my own self-care, which was a real frustration. I think this helped me to empathise with my participants' experience of constraint or feeling disadvantaged. These challenges, and the need to stop and start research, juggle demands, set boundaries and look after myself, have been invaluable for my personal and professional development. I have been able to explore my own assertive skills when negotiating deadline flexibility which ultimately facilitated my ability to complete this research. Although being on a different time path to my peers was initially frustrating, I believe that in doing this I could step away from comparing myself to others and develop confidence in managing demands in the way which best suited me. At times, I felt a sense of guilt at being given additional time to complete research and I'm aware that I coped with this by withdrawing from others and working independently. With support from personal therapy I've been able to accept my limits and understand that decisions

I've made are about managing the best I can. I've also considered when I need 'space', when to seek support and the importance of nurturing positive relationships rather than trying to cope alone.

Due to fatigue from illness and clinical work, I've often had to complete research in smaller 'chunks' which has sometimes made it difficult to get into a 'flow' and resulted in a sense of 'dread' when returning to research after a longer break. I often lost sight of the rationale and usefulness and lacked motivation. However, returning after a break and reminding myself of what I had previously achieved or where I was up to enriched the depth of my understanding of the concepts involved. Pacing and setting small achievable goals helped me to remain motivated while choosing how and when to approach tasks. I was motivated to return to research by a desire to do my participants justice and a sense of not wanting to let my supervisor down. I hold a great respect for them and could not have coped without their consistent and containing presence. In the past, I've preferred to complete one task before moving onto the next but the research process has allowed me to become more comfortable with juggling demands and tolerating uncertainty. Sometimes I berated myself for not having worked 'harder' earlier on, but over time I have learnt to acknowledge the difficulties I've faced related to living alone, becoming unwell away from family and managing appointments.

There were several occasions when I experienced an emotional reaction to research, particularly during analysis; many themes resonated with my own experiences. During interviews, pressure had been a barrier to experiencing emotional content but during analysis I felt able to express this. It was important for me to remain aware of my emotional reactions and consider the influence of my experiences or bias on the emergence of themes. When feelings became overwhelming, I took a step back, returning to analysis when I felt more able to focus. I was careful to ask myself whether themes appropriately expressed the participant experiences rather than my own.

Final thoughts

What began as a research project has, for me, developed into something with great significance and meaning. Completing this portfolio is a huge personal achievement and symbolises years of planning, medical management, choices, sacrifices and looking after myself. With the support of others, I've been able to let go of expectation, grow in confidence, trust in my decisions and reframe problems as challenges not barriers. I hope that I can continue to develop as an autonomous researcher and anticipate returning to academia as my career progresses bringing with me these new skills and a renewed sense of enthusiasm.

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Appendix U.   Supporting Quotes

Super-ordinate Themes	Subthemes	Quotes
Understanding and responding to risk	It's a possibility vs. a danger word	*'I know that you tend to get a larger baby because of the diabetes and that not necessarily their organs develop on the inside as quick as the outside' (Lisa)* *'I knew that (pause) I had to have good sugar control, that was the paramount thing' (Helen)* *'I used to have to calm them down! As they always looked a bit panicked about how high my blood sugars were about an hour after lunch' (Abby)* *'Being labelled high risk makes you feel more patienty in a way, which I felt was quite unusual, for me' (Abby)* *'It is a danger word isn't it. It is sort of like a thing that doesn't mean that it necessarily is going to happen' (Christine, MW)* *'It is felt that women don't like it, it frightens women to be in either high risk or low risk so we tend to say that they are midwifery-led care or they have a "complex" pregnancy' (Lorna, MW)*
	You know it's not just you	*'Diabetes is just its own thing and sometimes whatever you do it doesn't play the game' (Abby)* *'You are led to believe that you are taking risks with your own baby's life, which no pregnant mother, no normal pregnant mother, wants to think about' (Rose)* *'Sometimes that you do have a high or a low number however hard you try and I know that logically but it is still very difficult emotionally, if I did have a high number I would think oh my goodness I hope the baby is all right, am I destroying my baby?' (Kim)* *'I wanted to manage those risks and make sure I had a healthy baby at the end of the day. I also felt like (pause), like I wanted her to come on her own terms as much as possible and obviously going into induction, you know, is not the baby being ready to be born. I didn't want to induce her any earlier than we absolutely had to. It was quite a difficult line to walk' (Kim)*

	Meeting risk head on	*'Whatever you do or the care that you have is to minimise that risk, minimise the thing that we don't want to happen' (Christine, MW)*
		'Before I even had my pre-counselling, I had already read up as much as I felt I could read up on, on things, so I had a rough idea, so when I went in and I liked to be told everything, the worst of the worst so that I am prepared' (Josie)
		'I tried to make sure my blood sugars were really good before we even started trying, erm, and then tried, really tried to be very on top of things throughout my pregnancy' (Abby)
		'I started using an insulin pump six years ago with a view to wanting to be pregnant and knowing that that was likely to give me the best possible control' (Rose)
Talking about risk	Missing out a little bit	*'I would go and get a scan and then I would go and have my vitals done with the midwife and then I would go and see the consultant so all of those things were all happening, so there wasn't really lots of opportunities to ask for things, they would do a sort of quick five minutes in out' (Rose)*
		'Continuity is important because I felt like I had to explain diabetes all the time to every midwife and every doctor' (Helen)
		'Because I have no (pause) problems with my pregnancy, then that is kind of oh okay then, we'll take the heartbeat and that is fine and then we will see you in so many weeks, (pause) but as I say there has been no consistency' (Lisa)
		'If we've already got somebody in then, erm, you know some ladies if they've been there a long time, if there's nothing burning, they'll go' (Susan, MW)
		'We do get a lot of ladies who perhaps don't understand and need a translator and rely heavily on their husband, that can be a bit difficult.' (Christine, MW)
	Some kind of disconnect	*'They don't touch on that, they don't look at it, they don't ask me how my diabetes is. It is purely kind of go in, "how are you in general, any problems, lets listen to the heartbeat", or they take my urine sample and there is a bit of glucose but that is normal because I am diabetic, but they don't look at further than that' (Lisa)*

'I have one for the baby, my obstetrician and one for my diabetes and the other day I went to see one after the other and it was totally contrasting stories. It was like why are you not liaising in between'(Lisa)

'They would often just tell me, there are more risks, or that current research shows something but I was never really able to be pointed in direction of any research or told exactly what risks were' (Rose)

'I felt like I was chasing them to say look, I haven't had my eyes photographed. I felt I had to chase and be really pushy about, and they also had to be pushy about. There was also some kind of disconnect in the system' (Helen)

'Nobody said to me you are going on this day and you are going to learn everything from it. With the NHS unfortunately, that is the way things are. Your training is often just at the desk' (Christine, MW)

'I shouldn't be discussing obstetric things like that with the women so I would just facilitate it happening I would just try not to get caught up in a really discussions because I am not confident my information would be spot on, as it is not my area of speciality is it?' (Lorna, MW)

	Feeling like an executioner	*'It is not a nice thing to hear that if this doesn't go right your baby could die, that is horrible having to say that, (pause) it is difficult, we don't like to say that.' (Christine, MW)*
		'I think part of the reason to talk to women about the risk is to try and get them to do the best job they can during pregnancy to keep themselves safe' (Lorna, MW)
		'That makes you feel (pause) quite sad because midwives are supposed to be quite positive, jolly sort of people I think really, I think that is what the perception would be' (Christine, MW)
		'It's very, very emotionally demanding. That there is no formal system...for me getting any emotional support' (Fran, MW)
		'I would hope that we can give them that support but sometimes it, it is really hard and it is not the nice part of the job to tell somebody that they really have to work a bit harder to sort of make it right' (Christine, MW)
Negotiating	Outside the	*'...explaining the birth centre and how you could have a water birth and things like that, but we sat there thinking that's a shame*

choice and control	norm	*because we aren't going to be able to do any of that which… You kind of sat there feeling a bit sad and you are like I am going to miss out' (Abby)* *'They started making me go for, erm, monitoring of the baby's heartbeat every day and the impact of that on work was very difficult' (Helen)* *'I lost the idea that despite my diabetes I could still have as natural a pregnancy and birth as possible. So being at clinic having blood tests every couple of weeks and sort of being treated like I was a ticking bomb took away from that special time' (Rose)* *'Checking blood sugar, on a sliding scale, foetal monitoring, these are very traditional and not much to do with normality or nice birthing experience' (Alex, MW)* *'There's an additional level of complexity during pregnancy which we're there to help out with. And on top of that we've got normal midwifery care to provide' (Fran, MW)*
	Balancing the choices is very difficult	*'They said you need to have your baby at 37 weeks, OK so it feels like I don't have a choice in that but I can choose whether I want to have an induction or a C-section and I chose to have the C-section' (Abby)* *'We are constrained by the guidelines under which we work, so I think you just have to be really sympathetic and sympathise with her that it is not what she wanted to do but it is in the best interest of the baby' (Lorna)* *'it is always scary if you are balancing the choices because then the babies… it is scary first because it often takes time and being a midwife it is really difficult, even being an advocate' (Alex, MW)* *'It was like against this backdrop of risk and obviously, you know we want to avoid spiking the sugars but we want to avoid too many hypos, and we kind of didn't really talk specifically about, why we were doing that or what would happen if it doesn't go so well and we were just kind of getting on with how we manage it' (Kim)* *'It has to be a weighing up pros and cons conversation, rather than just going in all guns blazing, this is worst case scenario and it is likely to happen and it is your fault if you don't do what we tell you to do' (Rose)*

		'I would always try to emphasize that the reason we are doing these things or having these rules is to keep mum and baby as safe as we can. It is all about a reduction of risk' (Lorna, MW)
		'Sharing information by being clear with people what it is, what's the knowledge that we're drawing on that's leading us to make certain bits of advice. If we give them that information, then they've got it and they can use next time' (Fran, MW)
		'Talking about that woman in front of her and she can join in, that again is helping her with her choices. And then when doctors are coming in to see her they are discussing her case and I think that is important, so she knows what is going on' (Christine, MW)
		'We worked outside the hospital guideline for that, in the interest of that particular woman with her taking very clear responsibility. This isn't how we would like to do this. We don't feel particularly comfortable doing this but we appreciate that you don't feel comfortable doing our way' (Christine, MW)
	A whole world of new things	*'A lot of being pregnant with it [diabetes] is a new challenge' (Abby)*
		'I had not had a baby before, so it is a whole world of new things'
		'During pregnancy your eyesight changes, that was the one thing that I found really unnerving' (Helen)
		'Giving up that control during the, during labour, I knew I would have to and I was fine with that as labour is something different and you have so many other things going on' (Helen)
		'We do have concerns about women who have diabetes in pregnancy because it's hard on your body. And there's a lot of adaptations that happen and that can mean that, you know, things change for you.' (Fran)
		'As they start talking about risks, you start feeling like, well actually I don't want to be a bad parent and put my child at risk so I better just go along with what they are saying' (Rose)
The relationship buffer	Knowing somebody, knowing	*'What you want most during your pregnancy, and especially with diabetes, you want to feel safe and secure and you want to feel able to ask questions and have some consistency' (Abby)*
		'If you see the same woman week after week after week and provide the sort of core services for her, you build on that

your midwife		*relationship. And of course, you don't have to get back at the beginning in the communication building each time. So, each time it gets, hopefully, marginally easier' (Fran, MW)*
		'Some people do need us to be very directive. Some people want us to be collegiate. And some people actually want us to be next to invisible but there's that whole range. And we've got to find out which women want which style' (Fran, MW)
		'Although the clinic itself is always quite busy and stressful, I would also go and say hello to her and it would always make me feel a bit calmer to see her and she was excited to her of any developments with the baby' (Abby)
		'She was very young, very, really engaged, really caring and she made the process a lot better but she didn't know anything specific about diabetes at all' (Helen)
		'I found it a lot easier to email than talk and I am better at discussing things when they are written down' (Hannah)
A visitor in their story		*'Although I have type I diabetes I know what I am doing with it and I have the skill set and knowledge to be able to cope with most of what that throws at me' (Abby)*
		'Majority of time, people with diabetes are looking after themselves aren't they, ninety odd percent of the time. You know it's, it's very few times that they're seen by somebody medical through a year, so most are pretty good at doing what they do' (Susan, MW)
		'She was thinking about something besides just my blood pressure but also about me as a person and how I manage things' (Kim)
		'It was just really reassuring that they had all this knowledge and were letting me know that basically' (Abby)
		'I'm not gunna tell you off because what good's that going to do, you know, is there a reason (pause) why you haven't done them, is there something you are struggling with, is there something we can help with, is it that you're not getting on with that meter or is it that you just had a bit of a blip?' (Susan, MW)