Women's experience of diabetes and diabetes management in pregnancy: A systematic review of qualitative literature

A thesis submitted as fulfilment for the award of Master of Clinical Science (Evidence-based Health Care)

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Executive summary

Background

Pre-existing medical conditions, or medical conditions developing during pregnancy, may have an effect on pregnancy outcome or conversely may be affected by the pregnancy. Pre-existing or gestational diabetes mellitus are such conditions. Generally, convention suggests that good control can assist to mitigate the negative effects of these conditions.

Qualitative research is necessary to better inform health care workers and to help them understand the experience of the pregnant woman with diabetes and how the experience may influence her attitudes to treatment. Some issues identified in the literature include shock at the time of diagnosis (both of gestational diabetes and pregnancy in the woman with pre-existing diabetes), fear for the unborn child and the importance of timely and appropriate professional and personal support. There is a worthwhile qualitative literature base focusing on the patient experience of diabetes in pregnancy. As there is no current qualitative synthesis of the literature it is timely and worthwhile to produce a systematic review to identify and summarise the existing qualitative literature exploring women's experience of diabetes and diabetes management in pregnancy.

Objectives

To identify and describe from the available qualitative literature the experience of pregnant women with pre-existing or gestational diabetes and their experiences of adhering (or not) to prescribed treatment regimes.

Inclusion criteria

Studies that were qualitative in design that included currently pregnant women who had preexisting diabetes mellitus or gestational diabetes mellitus.

Search strategy

The search strategy aimed to find both published and unpublished studies and was conducted on 22 and 23 October 2012. No time limits were imposed in this search strategy. A three-step search strategy was utilised in this review.

Methodological quality

All studies that met the inclusion criteria were selected for retrieval. They were subsequently assessed by two independent reviewers for methodological rigor prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument.

Data extraction

Data was extracted from the papers included in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument.

Data synthesis

Research findings were pooled using the Joanna Briggs Institute Qualitative Assessment and Review Instrument.

Results

Following the search and critical appraisal process, 22 studies were identified that were assessed as being of suitable quality to be included in the review, From these 22 studies a total of 172 study findings were included in the categories. A total of six categories were created on the basis of similarities of meaning, and from these, two synthesised findings (meta-synthesis) were produced. These were synthesised finding 1 - Health professionals should be aware that their attitudes and practices in the care of women with diabetes during pregnancy needs to be empathetic and based upon a collaborative model of care and synthesised finding 2 - Women with perceived low adherence need time to adjust and education; these are major factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy.

Conclusions

The findings of this review highlight the need for health professionals to recognise that pregnant women's experiences of their medical conditions and treatments can affect their adherence to treatment regimes and therefore their continued health and perinatal outcomes. Health professionals also need to acknowledge that both the medical condition and pregnancy are only part of women's complex lives and that treatment regimes should accommodate this as far as possible. Treatment of the pregnant diabetic involves a number of different health professionals and it is important that these professions work in synchrony and appointments made in a timely and appropriate time frame.

Keywords

qualitative, experience, pregnancy, maternal, maternity, antenatal, prenatal, diabetes, adherence

Thesis Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Chapter 1

Introduction

Pre-existing medical conditions, or medical conditions developing during pregnancy, may have an effect on pregnancy outcome or conversely may be affected by the pregnancy. Generally, convention suggests that good control can assist to mitigate the negative effects. Type 1 and Type 2 diabetes (pre-existing medical conditions) and gestational diabetes (a pregnancy related medical condition) are conditions where these negative effects may occur. ^{1, 2}

Diabetes

There are many different classifications of types of diabetes. The American Diabetes Association³ identifies Type 1 and Type 2 diabetes and gestational diabetes mellitus as well as 'other specific types of diabetes' including genetic defects of beta-cell function, including Maturity Onset Diabetes of the Young (MODY, also termed monogenic diabetes), genetic defects in insulin action, diseases of the exocrine pancreas, endocrinopathies, drug or chemically induced (e.g. with glucocorticoids), genetic syndromes sometimes associated with diabetes (e.g. Down syndrome, Klinefelter syndrome, Turner syndrome and others), infections (e.g. congenital rubella) and uncommon forms of immunemediated diabetes (e.g. "Stiff-man" syndrome). Monogenic diabetes is particularly interesting in the context of pregnancy as optimal treatment may include the use of glibenclamide (also known as glyburide) and is also dependent on the foetal phenotype.⁴ However, these 'other specific types of diabetes' are rare and in the context of this review diabetes mellitus is referred to as Type 1, Type 2 or gestational diabetes mellitus.

Pre-existing diabetes mellitus can be divided into Type 1 (insulin-dependent diabetes mellitus) and Type 2 (non-insulin-dependent diabetes mellitus). Type 1 diabetes mellitus usually presents in childhood or early adulthood and is not associated with increased age or being overweight. Type 1 diabetes was previously referred to as insulin dependent diabetes or juvenile-onset diabetes, and results from a cellular-mediated autoimmune destruction of the beta-cells of the pancreas, usually

leading to absolute insulin deficiency. Also included in Type 1 diabetes is an idiopathic diabetes with no evidence of autoimmunity. Idiopathic Type 1 diabetes is strongly genetically determined and shows no evidence of beta-cell autoimmunity.³

Type 2 diabetes mellitus is associated with increased age and weight and is more common in various ethnic groups. Type 2 diabetes mellitus was previously referred to as non-insulin-dependent diabetes, or adult onset diabetes, and encompasses individuals who have insulin resistance and who usually have relative (rather than absolute) insulin deficiency.

Gestational diabetes (GDM) is defined as carbohydrate intolerance of variable severity with onset or first recognition during the present pregnancy and therefore can include a subset of women with pre-existing but previously undiagnosed diabetes mellitus.⁵

Diabetes in Pregnancy

In the UK, Type 2 diabetes is more common in Asian, Afro-Caribbean and Middle Eastern immigrants.⁵ In the USA, Hispanic mothers were more likely to have had diabetes than non-Hispanic Whites and non-Hispanic Blacks, with women aged 40–54 years being at highest risk of diabetes during pregnancy while women under 20 years of age were least likely to have diabetes during pregnancy.⁶ In Australia, Aboriginal and Torres Strait Islanders and mothers born in high-diabetes-risk regions, such as Polynesia, Asia and the Middle East are shown to have increased rates of both preexisting diabetes and GDM.⁷ A similar age related trend to the USA has been observed in Australia where women who gave birth with Type 2 diabetes and those with GDM tended to be older than other women who gave birth.⁷

An Australian study of women attending obstetric outpatient services in a major obstetric hospital⁸ reported that 39.3% of women reported at least one ongoing health condition. Diabetes mellitus (including GDM) was reported in 8.7%, with 5.2% of all patients taking anti-diabetic medications.⁸ These figures are consistent with an Australian government report where it was reported that pre-

existing diabetes in pregnancy affected less than 1% of pregnancies, and GDM affected about 5%.7

Pre-existing maternal diabetes with poor blood glucose control is associated with increased rates of congenital malformation. 9 Sacral agenesis, neural tube defects, cardiac defects and skeletal defects are increased compared to the background rate of abnormalities if glycaemic control is poor in the first seven weeks post conception.9 The generally accepted background rate of congenital abnormalities in western countries is 2 to 3% at birth. The increased level of risk of birth defects is directly related to glycated haemoglobin levels (HbA1C). Where HbA1C levels are less than 8% the congenital malformation rate is about 5%; if HbA1C is over 10% that rate increases to about 25%. Gestational diabetes mellitus usually presents after the first trimester, so apart from those women with pre-existing diabetes, the children of women with GDM do not have an increase in the rate of congenital abnormalities. Poor glycaemic control in both pre-existing and gestational diabetes is associated with pregnancy complications including preeclampsia, polyhydramnios, preterm birth, macrosomia or growth restriction, intrauterine foetal death, shoulder dystocia and operative delivery. Neonatal complications include neonatal hypoglycaemia, jaundice and respiratory distress. Children of women with either pre-existing or gestational diabetes are at increased risk of obesity and of developing diabetes themselves. Tight control of glucose levels in late pregnancy has been shown to improve perinatal and obstetric complications. Women with pre-existing diabetes are at increased risk of deterioration of retinopathy during pregnancy and increased risk of pre-eclampsia, especially those with nephropathy and hypertension.⁵

Treatment for diabetes mellitus consists of a multifaceted approach including diet, exercise and often medications. All Type 1 diabetics require insulin. Some pregnant women with Type 2 Diabetes Mellitus and GDM will require either insulin or oral hypoglycaemics. Frequent blood glucose testing and adjustment of therapy is required. In the management of Type 2 diabetes in pregnancy, oral hypoglycaemics were traditionally discontinued and insulin therapy substituted, but there is increasing acceptance of the use of metformin and glibenclamide for both pre-existing Type 2 diabetes in pregnancy and GDM where clinically appropriate.⁵

Sources of information regarding drugs and conditions in pregnancy

A number of countries have developed categorisation systems for the risks of drugs in pregnancy. Concerns have been raised regarding the lack of understanding of these systems by health practitioners and both the FDA and the Australian health authorities have flagged proposed changes to these systems.^{10, 11} While these categorisation systems from different countries have similarities, there are distinct differences required in their interpretation, and it is not always apparent which system is being used (especially where information is obtained from the internet).

Nordeng et al. reported an overestimation of teratogenic risk of medications by Norwegian women in an internet based survey and nearly 70% of women in this study reported that they had chosen not to use a drug because they feared it was not safe, suggesting that non-adherence to medications in pregnancy may be more common than previously documented.¹²

It is thought that between a third and a half of all medicines prescribed for long-term conditions are not taken as recommended.¹³ Swedish studies of the experiences of obstetricians and midwives in treating women with GDM revealed uncertainty regarding roles and resigned frustration with those women who were nonadherent with advice given.^{14, 15} An Australian study⁸ found that nearly 60% of women attending a major Australian maternity outpatient service were non-adherent with their medications.

Adherence to treatment regimens

In 1919, Franz Kafka wrote in his essay 'A Country Doctor' "it's easy to write prescriptions, but difficult to come to an understanding with people." In 1975, Becker commented "patient noncompliance has become the best documented, but least understood, health-related behaviour." In the same paper Becker references a 1966 article by Kasl and Cobb who noted that, in general, studies of reactions to

illness have dealt mostly with "... superficial demographic and background variables rather than with fundamental, theoretically derived attitudes and subjective perceptions. This has an advantage in the area of measurement, but the disadvantage that one does not always understand well the meaning of such associations" suggesting the need for in-depth qualitative inquiry to the issue of compliance or adherence.

Women obtain advice regarding their pregnancies and treatments from a variety of sources and this impacts on their experience and behaviours. The internet is increasingly an important source of information. In Lagan et al.'s study (where participants were recruited from pregnancy related internet sites) almost 94% of women used the Internet to supplement information already provided by health professionals and 83% used it to influence their pregnancy decision-making. Nearly half of the respondents reported dissatisfaction with information given by health professionals (48.6%) and lack of time to ask health professionals questions (46.5%) as key factors influencing them to access the Internet.

Compliance, adherence, concordance and persistence are all terms that are used to describe whether a patient takes their medication or adheres to a treatment regime. ¹⁹ The terms concordance and adherence are sometimes used interchangeably, and imply that some discussion and agreement of the treatment course has been reached between prescriber and patient. Persistence is the continued adherence over time to the prescribed treatment regime. ¹⁹ A consensus document of standardised terminology and taxonomy concerning adherence to medication was produced and published in 2012 by the ABC (Ascertaining Barriers to Compliance) project, which is an international collaboration of European research groups in the field of adherence to medications funded by the European Commission. ²⁰ This group assert that while the term 'patient compliance' is synonymous with medication adherence, use of the term should be discouraged as there are negative connotations of '(non-) compliance', and the term can be ambiguous in that it has multiple unrelated uses (e.g. compliance with drug regulations, compliance with good clinical practice, compliance with good manufacturing practice). ²⁰

Three elements were identified, being Adherence to medications, Management of adherence and Adherence-related sciences.

'Adherence to medications' is the process by which patients take medications as prescribed for them.

Adherence has three components: initiation, implementation, and discontinuation.

- 'Initiation' is when the patient takes the first dose of a prescribed medication.
- 'Implementation' is defined as the extent to which a patient's actual dosing corresponds to the prescribed dosing regimen, from initiation until the last dose is taken.
- 'Discontinuation' marks the end of therapy, when the next dose to be taken is omitted and no more doses are taken thereafter.

Non-adherence to medications can occur in a number of situations including late or non-initiation of the prescribed treatment, sub-optimal implementation of the dosing regimen or early discontinuation of the treatment.

Management of adherence is the process of monitoring and supporting patients' adherence to medications by health care systems, providers, patients, and their social networks (i.e. interventions to improve or monitor adherence).

Adherence-related sciences include the disciplines that study the causes or consequences of differences between the prescribed (i.e. intended) and actual exposures to medicines. This field attracts attention from many disciplines including medicine, pharmacy, nursing, psychology, health economics and biostatistics.²⁰

There are many causes of non-adherence but they fall into two broad categories: intentional and unintentional. Unintentional non-adherence occurs when the patient wants to follow the agreed treatment but is prevented from doing so by barriers that are beyond their control. Examples include poor recall or difficulties in understanding the instructions, problems with using the treatment, inability to pay for the treatment, or simply forgetting to take it.¹⁹ Intentional non-adherence occurs when the patient decides not to follow the treatment recommendations. The patient's beliefs and preferences influence their perceptions of the treatment and their motivation to start and continue with it.^{19, 21} It

follows that to promote adherence to treatment consideration needs to be given to beliefs and preferences that influence motivation to start and continue with treatment, as well as the practical factors that influence patients' ability to adhere to the agreed treatment.¹⁹ Patients who have few concerns about their treatment and are accepting of its necessity are more likely to be adherent to treatment regimes than those who have high concerns about the safety of the treatment and are perhaps sceptical of its necessity.¹⁹

Non-adherence may limit the benefits of medicines or other treatment regimes, resulting in lack of improvement, or deterioration, in health. In the case of pregnant women non-adherence could result in a deterioration of their own long-term health or perinatal complications, with consequences to their unborn child.²² Women's experiences and attitudes to their condition and its treatment may affect their adherence to treatment regimes and affect their long-term and perinatal outcomes.

Research Methods and Methodologies

Qualitative methods seek to take a holistic view which takes into account the complexities of human behaviour, and as such are relevant to the study of adherence to treatment regimes. 23, 24

Qualitative research seeks answers to questions that emphasise how social experience is created and given meaning in the context of the human experience. Qualitative data is generally collected through interviews, focus groups, textual analysis or direct observations of activities or behaviour. The delivery of effective healthcare is informed from a variety of both qualitative and quantitative research methods. Quantitative research methods such as randomised controlled trials, clinical trials and cohort studies provide essential knowledge on the effectiveness of interventions and qualitative research methods such as phenomenology and ethnography can help us understand how the care is being contextualised and/or experienced by the health care recipient. Evidence gained from qualitative research is invaluable in understanding how individuals and communities perceive health, manage their own health and make decisions related to health service usage. The knowledge obtained from qualitative studies can play a major role in increasing our understanding of the culture of communities and health units in relation to implementing change and overcoming barriers to the

use of new knowledge and techniques. This information of how service users experience health, illness and the health system can be used to evaluate components and activities of health services that cannot be measured in quantitative outcomes.²⁵

All research is based on some underlying assumptions about what constitutes 'valid' research and reality, and research follows three different philosophical perspectives or paradigms, being positivist, interpretive and critical.

Positivism suggests that all knowledge is grounded in empirical data and controlled experiments are used to discover and establish causal relationships. Positivist philosophy most closely informs quantitative research and scientific method. Positivists generally assume that reality can be described by measurable properties, which are independent of the observer and positivist research values observation and measurement, whether of scientific measurements or of attitudes, behaviours and opinions through surveys and questionnaires. Positivist research tests a hypothesis generated at the beginning of the research and analysis of the data is generally achieved through the use of mathematical or statistical techniques.²⁶

Interpretive research methodologies explore 'lived experience'. Interpretive research attempts to understand phenomena through the meanings that people assign to them. The interpretive paradigm suggests that reality is socially constructed, subjective and unique to each individual human being. Interpretive research suggests that individuals access reality through social constructions such as language. Interpretive research is philosophically based in phenomenology and hermeneutics and does not predefine variables, but looks for historically situated and culturally derived interpretations of the social-life world. Phenomenology is a research methodology that fits within the interpretive paradigm. Phenomenology suggests that that by revisiting the immediate experience of a phenomenon, while ignoring, as much as possible, prevailing understandings and rationalisations of that phenomenon, that new meaning or greater understanding of that experience may emerge. Phenomenology is uncritical of its subject's responses and attempts to identify, describe, understand and maintain the subjective experiences of respondents. Interpretive research also incorporates

hermeneutic theory. Hermeneutics is the notion that humans are "languaged" beings and that language is central to situations and experiences and the understandings that humans attach to those experiences. Hermeneutics is grounded in the interpretation of meanings from texts. It has its traditions in early Greek, Rabbinical and Judeo-Christian interpretations of literature and religious writings, uncovering deeper meanings to narratives. Modern hermeneutics includes written, verbal, and nonverbal communication.²⁶

Critical methodologies address issues of power and oppression and critique prevailing social conditions and systems of social constraints. They consider the relationships between human interests, knowledge, power and forms of social control. Critical theorists suggest that reality is historically constituted and that some groups in society are more privileged than other groups and that oppression occurs when the less privileged group accept their lower social status as natural, necessary or inevitable. Critical theorists contend that an individual's ability to change social and economic circumstances is constrained by culture; as such they call current ideology into question, and initiate action, in the cause of social justice and emancipation. Critical research is action focused. Critical theorists contend that the culture they explore and the accounts it informs may be founded on a cultural tradition of exploitation, domination and oppression, and that culture should be brought into question. This can be contrasted with interpretivism, which is content to adopt an uncritical view of the culture it explores.²⁶

The methodology of research, that is the strategy or design behind the choice of particular research methods (the procedure used to gather or analyse data related to a research question) is informed by the research paradigm and provides a context for the process.²⁶

Methodologies associated with interpretive research include phenomenology, ethnography and grounded theory. As such, phenomenology seeks to understand people's individual real-life experiences and interpretations of the world and data is collected by undertaking interviews; ethnography seeks to understand the social meanings of activities, rituals and events within a particular culture or sub-culture and data may be collected by focus groups and observations by the researcher; and grounded theory seeks to generate theory that is grounded in the real world. The

data itself defines the boundaries and directs development of theory. Data is collected by observations, purposeful interviews and textual analysis.²⁵

Methodologies associated with critical theory include action research, feminist research, critical theory and discourse analysis. More specifically, action research involves researchers participating with subjects being researched to effect change. Data can be collected by group work and reflective journaling. Quantitative methods may also be used. Feminist research seeks to address inequities for women and effect social change. Focus groups and in-depth interviewing are usually utilised to collect data for this type of research. Quantitative methods may also be used. Critical Theory is concerned with issues of power and justice and is often centred on issues of race, gender, class and economic equality. Data can be collected by in-depth interviews and reflective dialogue. Discourse Analysis assumes that language socially and historically constructs how we think about and experience ourselves, and our relationships with others and data is collected by the study of written texts and other communications.²⁵

Qualitative Synthesis

With the proliferation of research studies the systematic review including meta-analysis is considered the gold standard for analysis of quantitative data from two or more papers. Meta-analysis is a systematic method that uses statistical techniques for combining results from different studies to obtain a quantitative estimate of the overall effect of a particular intervention or variable on a defined outcome and produces a stronger conclusion than can be provided by any individual study. Quantitative meta-analysis aims to increase certainty in cause and effect conclusions, whereas qualitative meta-synthesis seeks to understand and explain phenomena. ^{25, 27, 28} Meta-synthesis of qualitative research is a parallel technique to meta-analysis of quantitative data.

Meta-aggregation or meta-synthesis involves assembling the findings of studies (variously reported as themes, metaphors, categories or concepts) and pooling the findings through further aggregation based on similarity in meaning. The aim is to summarise findings from studies where concepts are

assumed to be largely secure and well specified. Aggregation produces theories of causality, in addition to claims about generalisability.^{25, 27, 28}

Chapter 2

Basis for the Review

After a search of the Joanna Briggs Institute library of systematic reviews, the Cochrane Database of systematic reviews, Medline and CINAHL, no systematic reviews of qualitative literature were identified that addressed the issue of women's experience of diabetes and diabetes management in pregnancy. Therefore, it was the aim of this systematic review to establish the experience of diabetes and diabetes management among pregnant women, and how these experiences relate to their understanding of their condition and adherence to treatment regimes.

Review purpose

The purpose of this review was to collate, critically appraise, synthesise and present the best available evidence exploring the experience of diabetes and diabetes management among pregnant women.

Review Question

The objective of this review was to identify and describe from the available qualitative literature the experience of pregnant women with pre-existing or gestational diabetes and their experiences of adhering (or not) to prescribed treatment regimes.

Inclusion criteria

Types of participants

This review considered studies that include pregnant women who have pre-existing diabetes mellitus or GDM.

This review only included studies where the investigation was conducted whilst the participant was currently pregnant, to minimise recall bias.²⁹

Types of studies

This review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, qualitative description, ethnography, action research and feminist research.

The search was limited to English language studies and there was no date restriction.

In the absence of research studies, other text such as opinion papers and reports were to be considered in a narrative summary, however this was unnecessary as sufficient research studies were identified.

Phenomena of interest

This review considered studies that investigated the experience of pregnant women with pre-existing or GDM and factors that they identified as enablers or barriers to adhering (or not) to prescribed treatment regimes.

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilised in this review. An initial limited search of MEDLINE and CINAHL was undertaken

followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference list of all identified reports and articles was searched for additional studies. Studies published in the English language were considered for inclusion in this review. Studies published in any year where there was access to the full paper were considered for inclusion in this review.

The databases searched included:

PubMed, Embase, Biosis Previews, Academic Search Premier, CINAHL, PsycINFO

The search for unpublished studies included:

EThOS, Index to Theses, Proquest Dissertations & Theses, Mednar

Initial keywords used were:

qualitative, experience, perception, understand, understanding, belief

pregnancy, maternal, maternity, antenatal, prenatal

diabetes

A full detailed list of search strategies for individual databases is detailed in Appendix I.

Databases were searched on the 22nd and 23rd of October 2012.

Method of the review

Prior to critical appraisal articles were read to ensure that inclusion criteria were met. Papers selected for retrieval were assessed by two independent reviewers for methodological rigor prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II). No disagreements arose between the reviewers and therefore involvement of a third reviewer was not required.

The purpose of appraisal was to examine the quality of papers under analysis, and provide an objective critique of the internal validity of papers prior to considering their inclusions in the review.

The JBI-QARI appraisal tool comprises 10 questions that address congruency between the philosophical basis of the study, study methodology and methods, how the data is represented and the interpretation of the results. Also scrutinised are the influences or biases of the researcher and the relationship between what the participants said and conclusions drawn by the researcher.

The JBI-QARI appraisal tool requires the reviewer to allocate findings of 'yes', 'no', 'unclear' or 'not applicable". Papers were included in the review if half of the appraisal questions were answered 'yes' and there was agreement between the reviewers.

The Final Assessment Table presented in Appendix IIa represents the agreed allocation of findings of the appraisal questions according to the JBI-QARI appraisal tool.

Data extraction

Data was extracted from papers included in the review using the standardised data extraction tool from JBI-QARI (Appendix III). The data extracted included specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Qualitative research findings were pooled using JBI-QARI. This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorising these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings that can be used as a basis for evidence-based practice.

Findings, as reported by the individual paper's author, were extracted as were supporting illustrations

(quotes) that best illustrated that finding. These were entered into the QARI module. The finding, illustration and reference was printed and cut up, so that each finding could be separately perused and assigned to groups with other findings (from all included papers) based on similarity of meaning. These groups were read and reread and findings reallocated if necessary. Some findings were allocated to multiple groups. These groups were then further refined to form the final six categories.

Each finding was assigned a level of credibility according to the QARI module. The levels of credibility are as follows:

Unequivocal – evidence beyond reasonable doubt that may include findings that are matter of fact, directly reported/observed and not open to challenge.

Credible - albeit an interpretation, plausible in light of the data and theoretical framework. The interpretations can be logically inferred from the data, but because the findings are essentially interpretive, can be challenged.

Unsupported – findings are not supported by the data, or data is lacking. Unsupported findings were not included in the subsequent synthesis as the findings could not be verified by the data or illustrations provided in the respective papers.

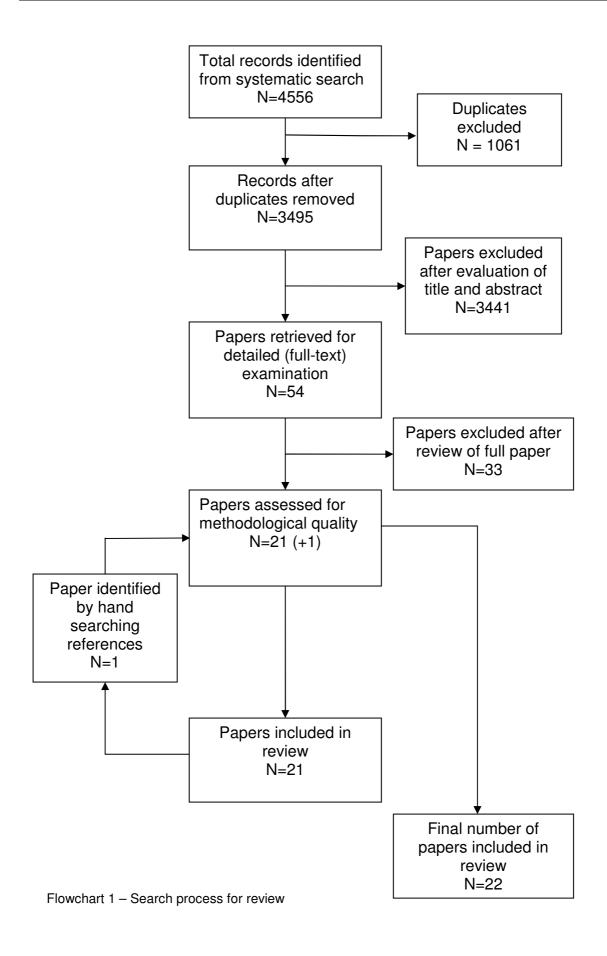
Chapter 3

Results

Search Results

Following the comprehensive search conducted on the 22nd and 23rd of October 2012, 4556 titles were identified (PubMed – 1178, Embase -705, Cinahl – 140, PsychInfo -220, Proquest dissertations and Thesis – 223, Ethos – one, Index to Thesis – six, Mednar – 1309, Biosis Previews – 749, through Academic Premier – 25). There were 1061 duplicates identified by the automated duplicate finding function on Endnote x4 (1988-2010 Thomson Reuters) and hand searching, leaving 3495 titles (where both a thesis and published paper were identified of the same work the published paper only was included and the thesis excluded as a duplicate). These titles were screened by title and abstract for relevance with 54 being identified for full-text retrieval. After reading the full-text, 21 papers were deemed to meet the inclusion criteria and were selected for critical appraisal. Further, the references of these 21 articles were hand-searched for papers not previously identified and one extra paper was selected for critical appraisal (in press at time of search). In total 22 papers were subject to the critical appraisal process. All 22 papers were independently appraised by both reviewers and it was agreed that all 22 of these papers should be included in the review.

The search process for the review is depicted in Flowchart 1.



Description of included studies

All 22 studies included in this review were of qualitative design, and although they were of varying study methodologies and quality, they were all were deemed to be of sufficient methodological quality according to the QARI appraisal tool for inclusion in the review. Prior to appraisal it was determined that studies scoring five or more out of ten on the QARI appraisal tool would be included in the review. The 22 studies were comprised of nine various descriptive qualitative approaches with no explicitly stated methodology, ³⁰ ³¹ ³² ³³ ³⁴ ³⁵ ³⁶ ³⁷ ³⁸ eight phenomenological studies, ³⁹ ⁴⁰ ⁴¹ ⁴² ⁴³ ⁴⁴ ⁴⁵ ⁴⁶ four grounded theory studies ⁴⁷ ⁴⁸ ⁴⁹ ⁵⁰ and one ethnographic study. ⁵¹ Five of the studies were theses and 17 were published papers.

The majority of studies scored well in critical appraisal criteria relating to congruity between the research question and methodology, methods used to collect data, representation and analysis of data and interpretation of results. They were also strong in questions addressing adequate representation of participant's voices; approval by ethics committees and that conclusions are drawn from the analysis or interpretation of the data. Few studies located the researcher culturally or theoretically or addressed the influence of the researcher on the research. Only about half of the studies included stated a philosophical framework to the study.

Disagreements between the independent reviewers of critical appraisal criteria were resolved by discussion. The questions that addressed the location of the researcher culturally or theoretically and the influence of the researcher on the research were the main sources of incongruence between the reviewers.

The final assessment table for critical appraisal is presented in Appendix IIa

Refer to table 1 for a summary of the included studies.

Table 1: summary of the included studies

Study	Methodology	у	Methods		Partic	ipants	Phenomena	of
							interest	
Bandyopadh	Qualitative	(no	Face-to-face	in-	17	immigrant	Experiences	and

yay et al	specific mention	depth interview at	women from	understandings of
2011 ³⁰	of philosophical	two time points: in	South Asia	South Asian
	framework)	pregnancy,	diagnosed with	women in
		following GDM	GDM.	Melbourne,
		diagnosis, and at six		Australia, after
		weeks post-partum		diagnosis with
				GDM.
Berg 2005 ³⁹	Husserlian	Open interviews	18 pregnant	Experience of
	phenomenology		women (10	women with Type 1
			primiparous and	diabetes and how
			eight multiparous)	they handle their
			aged between 25	challenges during
			and 38 years.	pregnancy.
Berg &	Hermeneutic	Open interview	14 pregnant	Women's
Honkasalo	phenomenology		women with pre-	experiences of
2000 ⁴⁰			existing insulin	being pregnant and
			dependent	having insulin-
			diabetes aged 25-	dependent
			38 years.	diabetes mellitus
				(IDDM), particularly
				regarding what the
				crucial elements of
				the experience are
				during pregnancy.
Bieda 2009 ³¹	Qualitative –	Face-to-face, semi-	25 African-	African-American
	theory of	structured interview.	American mothers	mothers'
	planned		diagnosed with	knowledge of Type
	behaviour used		GDM at two high-	2 diabetes risk as

			risk prenatal	well as their
			clinics in Detroit,	intentions to
			MI.	participate in
				preventive
				behaviours after a
				pregnancy
				complicated by
				GDM.
Brooks	Qualitative (no	Open-ended	32 African	Aspects of the
2002 ³²	specific mention	interview and	American women	diabetes treatment
	of philosophical	questionnaires	aged 18 to 49	regimen that are
	framework)		with pregnancies	most difficult to
			complicated by	adhere to among
			Type 2 or GDM	pregnant African-
				American women
				with diabetes.
Carolan	Interpretive	Semi-structured	15 women with a	Women's
2013 ⁴¹	phenomenology	interviews and one	diagnosis of GDM	experiences of self-
		focus group	who had	managing their
			experienced self-	GDM.
			management of	
			their condition.	
Carolan et al	Interpretative	Semi-structured	15 pregnant	To explore the
2012 ⁴²	phenomenology	interviews and a	women, with a	factors that
		focus group	diagnosis of	facilitated or
			GDM, at 28-38	inhibited GDM self-
			weeks gestation.	management
				among women in a

				socially deprived
				area.
Evans &	Heideggerian-	Conversational	12 pregnant	What are the
O'Brien,	Gadamerian	interviews	women who were	meanings that
2005 ⁴³	hermeneutic		diagnosed with	pregnant women
	phenomenology		and being treated	attach to their
			for diabetes	experience of a
				pregnancy that is
				judged at risk as a
				consequence of
				GDM?
Hamel	Grounded	Open-ended, semi-	Seven	The experience of
2003 ⁴⁷	theory	structured	participants	being a woman
		interviews	residing in	diagnosed with
			Northern New	GDM.
			England having a	
			diagnosis of GDM	
Hirst et al	Qualitative (no	Focus groups	Four focus groups	Attitudes and
2012 ³³	specific mention		involving 34	health behaviours
	of philosophical		pregnant women	of pregnant women
	framework)		aged over 18	with GDM in
			years, with GDM	Vietnam.
Hjelm K	Qualitative (no	Semi-structured	Consecutive	Beliefs about
2012 ³⁴	specific mention	interviews.	sample of women	health and illness
	of philosophical		diagnosed with	in women with
	framework)		GDM, 13 born in	GDM born in
			Sweden and ten	Sweden and Africa
			born in Africa,	living in Sweden

			from a diabetes	and the influence of
			clinic in Sweden.	beliefs on self-care
				and care seeking
Hjelm et al	Qualitative (no	Semi-structured	Consecutive	To compare beliefs
2005 ³⁵	specific mention	interviews	sample of women	about health and
	of philosophical		with GD; 13 born	illness between
	framework)		in Sweden and 14	women born in
			born in the Middle	Sweden and the
			East	Middle East who
				developed GDM.
Hjelm et al	Qualitative (no	Semi-structured	Females with	Patients evaluation
2007 ³⁶	specific mention	interview	GDM, 13 born in	of a specialised
	of philosophical		Sweden and 14	diabetes clinic for
	framework)		born in the Middle	management of
			East.	women with GDM
				born in Sweden
				and the Middle
				East and its
				contribution to a
				decreased level of
				stress and
				improved coping
				capability to
				promote health in
				patients receiving
				care
Hjelm et al	Qualitative (no	An explorative	A consecutive	Beliefs about
2008 ³⁷	specific mention	qualitative study	sample of	health, illness and

	of philosophical	using semi-	Swedish women	health care in
	framework)	structured	diagnosed with	women with GDM
		interviews.	GDM; 13	managed in two
			managed in clinic	different
			A and ten	organisations
			managed in clinic	based on
			В.	diabetology or
				obstetrics.
Horrocks	Grounded	Semi-structured	Nine white British	The psychological
2009 ⁴⁸	theory	interviews	women who were	and emotional
			first-time mothers	impact of
			and currently	pregnancy in the
			pregnant and	context of Type 1
			receiving	diabetes for first
			specialist support	time mothers.
			from a diabetes	
			antenatal clinic	
Lavender et	Hermeneutic	Focus groups and	22 women with	To explore the
al 2010 ⁴⁴	phenomenologic	one-to-one	Type 1 or Type 2	experiences of
	al approach	interviews	diabetes of	White British and
	based on		different parity	South East Asian
	Heidegger		and ethnicity	women with Type 1
			(Note only 14	and Type 2
			pregnant at	diabetes, and the
			interview - only	perceived impact of
			these included)	diabetes on their
				reproductive
				health.

Lawson &	Ethnography	Semi-structured	17 women	The meaning
Rajaram		interviews	between the ages	women attach to
1994 ⁵¹			of 24 and 36, with	GDM
			no previous	
			history of GDM	
Neufeld	Qualitative (no	Semi-structured	29 self-declared	How Aboriginal
2011 ³⁸	specific mention	explanatory model	Aboriginal women	women in an urban
	of philosophical	interviews	who had received	setting perceive
	framework)		a diagnosis of	dietary treatment
			GDM within the	recommendations
			last five years - 16	associated with
			pregnant at time	GDM.
			of interview (two	
			of these without	
			current	
			diagnosis). Of the	
			14 pregnant and	
			diagnosed with	
			diabetes four with	
			Type 2 diabetes	
			and ten with	
			current diagnosis	
			of GDM	
Persson et al	Grounded	Semi-structured	Ten women - all	The experiences of
2010 ⁴⁹	Theory	interviews	except one of	pregnant women
			Swedish origin -	being diagnosed
			one immigrant	with GDM and its
			who had lived in	impact on their

			Sweden since her	daily life
			teens, was well	
			established within	
			Swedish society	
			and was fluent in	
			Swedish	
Richmond	A qualitative	Interviews	11 women with	How identity was
2009 ⁴⁵	phenomenologic		Type 1 diabetes	linked to the
	al methodology		attending the joint	improvement, and
	following		obstetric/diabetic	deterioration, of
	Husserl's		clinic in a district	blood glucose
	philosophy		general hospital	control in pregnant
			between October	women with Type 1
			2001 and April	diabetes.
			2004	
Sheffer	Interpretive	Audio taped semi-	Eight participants,	The lived
2000 ⁴⁶	phenomenology	focused one-on-one	who had lived	experience of
		interviews	with IDDM from	pregnancy for
			four to twenty	women with pre-
			years	existing insulin
				dependent
				diabetes mellitus
				(IDDM)
Stenhouse	Grounded	In-depth interviews	12 pregnant	The experience of
et al 2012 ⁵⁰	theory	utilising one-to-one,	women with Type	maternity care
		dyad and group	1 diabetes and	services used by
		interviews	Type 2 diabetes	women whose
			and eight of their	pregnancy is

	significant others	complicated by pre-
		existing diabetes

Findings

From the 22 included studies 153 (four unsupported) findings were extracted. These findings and studies they were extracted from are detailed below.

<u>Paper 1</u>: Lived experience of gestational diabetes mellitus among immigrant South Asian women in Australia.³⁰

This paper by Bandyopadhyay et al. 2011³⁰ aimed to investigate the experiences and understandings of South Asian women in Melbourne, Australia, after diagnosis with GDM. The information was gathered by face-to-face in-depth interview at two time points, following GDM diagnosis, and at six weeks post-partum and analysed by thematic analysis. This paper scored five out of ten in the QARI critical appraisal tool. Participants were 17 immigrant women from South Asia diagnosed with GDM attending a tertiary maternity hospital in Melbourne, Australia.

Finding 1	Response to GDM diagnosis (Credibility – Credible)
Illustration	"upset" - gdm- p362
Finding 2	Difficulties experienced with dietary advice (Credibility –Unequivocal)
Illustration	'your diet is restricted, and the quantity is reduced, and you have limited choice, then the baby does not get proper nutrition to grow' - gdm- p362
Finding 3	Weight issues and exercise (Credibility – Credible)

Illustration	Women described feeling weak after exercising, their muscles "pained" and
	that "can't be good for the baby or the mother" gdm- p363
Finding 4	Concern for the baby (Credibility –Unequivocal)
Illustration	"your only thought is for the baby and for a favourable pregnancy outcome -
	gdm"p363
Finding 5	Achieving a "good reading" and response to insulin (Credibility – Unsupported)
	Their preoccupation with testing and maintaining good sugar levels was
Illustration	because of their fear about injecting insulin. The worst part of being diagnosed
machanon	with GDM for women was that they required insulin to control their blood
	glucose levels gdm - p363
F: " 0	Positive effects on well-being and women's views on care and information
Finding 6	provision (Credibility – Unsupported)
Illustration	Although they were happy with the care they received, they nevertheless felt
Illustration	overwhelmed by frequent visits - gdm- p363
Finding 7	Maintaining changes (Credibility – Unsupported)
Illustration	Women were unsure about maintaining their current diet and lifestyle pattern
	postnatally, as they felt that lifetime control and management was challenging.
	- gdm- p 363

Paper 2: Pregnancy and diabetes: how women handle the challenges.³⁹

This paper based on Husserlian phenomenology by Berg 2005³⁹ aimed to investigate the experience of women with Type 1 diabetes and how they handle their challenges during pregnancy. This paper

scored nine out of ten in the QARI critical appraisal tool. Information was gathered through open interview and analysed with thematic analysis. Theme and subtheme were used as the finding as this was considered more illustrative than the theme by itself. Participants were 18 pregnant women (ten primiparous and eight multiparous) with Type 1 diabetes aged between 25 and 38 years at a University hospital in the Western region of Sweden

Finding 1	Meaningfulness/meaninglessness: Acceptance (Credibility - Unequivocal)
Illustration	As soon as one sees a poor value, you know that there is another person being affected. That is what probably results in anxiety, but at the same time it is a challenge I know that I must do what I can for it to be healthy. (Paula - Type 1 diabetic) p26
Finding 2	Meaningfulness/meaninglessness: Ambivalence (Credibility - Unequivocal)
Illustration	She explained what happens in my body, et cetera, but very little about me as a person, what happens in my head. Very little about what I actually think about being pregnant and whether it was planned. How I felt about it One can still be ambivalent - did I really want this to happen? (Fanny - Type 1 diabetic) p26
Finding 3	Meaningfulness/meaninglessness: Hope (Credibility - Unequivocal)
Illustration	I know now that I can have healthy children despite having diabetes I know that I can influence it (Sara - Type 1 diabetic) p26
Finding 4	Meaningfulness/meaninglessness: Hopelessness (Credibility - Unequivocal)
Illustration	Something could go wrong for somebody and that somebody will probably be me. This is confirmed by the statistics (Paula - Type 1 diabetic) p26
Finding 5	Meaningfulness/meaninglessness: Confirmed normality (Credibility -

Unequivocal)

Illustration

For me, it is magical to be pregnant and to go through a delivery...Being a mother is so fantastic ...being pregnant fills every second of my consciousness, both when asleep and when awakeBeing pregnant is evidence that I am normal. (Lena - Type 1 diabetic) p26

Finding 6

Meaningfulness/meaninglessness: Fortified malaise (Credibility - Unequivocal)

The negative aspect was that of being special-special. It had the opposite effect on me. The feeling of being sick came back. So far, everything had gone so well and now it was just waiting for the big disappointment, because something had to happen. The delivery feels like one big complication and the baby is probably huge. (Gabriella - Type 1 diabetic) p26

You live with the disease as part of the fullness of life. . . . I have diabetes

Illustration

Finding 7

Reconciliation/Conflict: Acceptance (Credibility - Unequivocal)

Illustration because it is part of my life. And now I am pregnant. (Rosa - Type 1 diabetic) p27

Finding 8

Illustration

Reconciliation/Conflict: opposition (Credibility - Unequivocal)

Blood sugar lives its own life. . ., it doesn't matter what I do - I hardly dare move. . . . I haven't tried to find a solution because I don't think there is one. (Ingrid - Type 1 diabetic) p27

Finding 9

Illustration

Reconciliation/Conflict: self-understanding (Credibility - Unequivocal)

When I became pregnant for the first time, I didn't realise the implications. So, before my second child, I understood that it required a certain mental awareness before starting this once again. . . . It largely concerns knowing

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	one's own limits and weaknesses. (Olivia - Type 1 diabetic) p27
Finding 10	Reconciliation/Conflict: Lack of self-understanding (Credibility - Unequivocal)
Illustration	It makes no difference what one changes because the blood glucose seems to have a life of its own anyway (Ingrid - Type 1 diabetic) p27
Finding 11	Reconciliation/Conflict: Rejoice in the present (Credibility - Unequivocal)
Illustration	We must not build up a lot around it in case something should go wrong, but should try to be happy about the situation as it is. To try to push the diabetes aside and just be pregnant. I feel an inner security. Oh! It feels great throughout my whole body. (Nancy - Type 1 diabetic) p28
Finding 12	Reconciliation/Conflict: suppressed joy (Credibility - Unequivocal)
Illustration	One doesn't dare to be too happy in advance, not before everything is seen to be okay, when the baby is born and you can see that it is a healthy child (Sara - Type 1 diabetic) p28
Finding 13	Shared control/unwillingly controlled: responsibility/surrendered responsibility (Credibility - Unequivocal)
Illustration	It is me who is steering the diabetes and not the diabetes steering me It's me who is in control. It is me who has responsibility for this I don't feel like a slave. Being able to measure blood sugar is a benefit. It gives me control. What would it have been otherwise? (Nancy - Type 1 diabetic) p28
Finding 14	Shared control/unwillingly controlled: health-care staff as a supportive resource or as a controlling factor (Credibility - Unequivocal)
Illustration	You have to demonstrate how you have looked after yourself and how you live. Sometimes one may feel that, no, I don't want to go there and take a lot of

samples - I just want to skip the lot. If it's working well, you can be proud to show your blood sugar book. But if it's not so good, then you would prefer to have left it at home. You need to have help to realise that you are pregnant and what is happening and that one can get this thing about samples out of one's head. (Maria - Type 1 diabetic) p28

Finding 15

Shared control/unwillingly controlled: Relatives and employers who provide support or increase the pressure (Credibility - Unequivocal)

Illustration

Support is being there. When, for example, I am worried, then he says that everything is okay, it will be okay.(Rosa - Type 1 diabetic) p29

<u>Paper 3:</u> Pregnancy and diabetes--a hermeneutic phenomenological study of women's experiences.⁴⁰

This paper based on hermeneutic phenomenology by Berg and Honkasalo⁴⁰ aimed to investigate women's experiences of being pregnant and having insulin-dependent diabetes mellitus (IDDM), particularly regarding what the crucial elements of the experience are during pregnancy. The information was gathered by open interview and analysed with thematic analysis partially informed by van Manen. Participants were 14 pregnant women with pre-existing insulin dependent diabetes aged 25-38 years having treatment in the antenatal care unit of a district hospital in Sweden. This article scored eight out of ten in the QARI critical appraisal tool.

Finding 1	Objectification: an unwell body - a risk (Credibility - Unequivocal)
Illustration	You're told about the risks at once (interviewee 1 - Type 1 diabetic) p41
Finding 2	Objectification: almost like getting diabetes again (Credibility – Unequivocal)
Illustration	the hard thing was that, when I got pregnant, I suddenly had to think about my

diabetes a lot, how to spend my days, what to choose to eat and when to eat it...it felt a bit like when I first got diabetes....It became a crisis...It's like mourning...I haven't finished crying yet...almost like a burden (Interviewee 7 - Type 1 diabetic) p41

Finding 3 Objectification: you'll get hit sooner or later (Credibility – Unequivocal)

Illustration

Finding 4

Illustration

Finding 5

Illustration

Finding 6

Illustration

Finding 7

It can't run smooth all the way, something will happen, you'll get hit sooner or later (Interviewee 7 - Type 1 diabetic) p42

Loss of control: wishing for a normal life with control (Credibility – Unequivocal)

What I mostly wish, is that I carry the baby to full term and that I have a normal delivery...It would be so exciting if the diabetes is one thing on its own and now I'm going to give birth, not that I give birth because of the diabetes (Interviewee 12 - Type 1 diabetic) p42

Loss of control: Not knowing my own body (Credibility – Unequivocal)

I like to be in control of my body, and in a way you can't when you have another life inside of you making a mess...like with the blood sugars and such...and it makes me a bit...well, insufficient, hysterical...and very frustrated (interviewee 11 - Type 1 diabetic) p42

Loss of control: controlled and dependent (Credibility – Unequivocal)

the blood sugar controls everything...I always have to take a blood sample before I do anything...It is because I am pregnant, it is on my mind all the time, asleep as well as awake (Interviewee 12 - Type 1 diabetic) p43

Exaggerated responsibility: Constant worry (Credibility – Unequivocal)

Page 35

I'm so scared and frightened that the ultrasound will show something's wrong with the child or a child with two heads, such are the nightmares I have...I'm so Illustration scared my blood glucose levels have caused problems and abnormalities. (Interviewee 11 - Type 1 diabetic) p44 Exaggerated responsibility: Constantly under pressure (Credibility -Finding 8 Unequivocal) I do feel insufficient. If you add it all up, I think that's a general feeling I've had all along...to feel you're inadequate. I think it's linked together with a diabetic's Illustration bad conscience. You can make it up to a point....under some pressure, you may slightly improve a bit more, but somewhere along the line you've reached your limit. I think I found that the hardest (Interviewee 6 - Type 1 diabetic) p44 Finding 9 Exaggerated responsibility: constant self-blame (Credibility – Unequivocal) You constantly have a slice of bad conscience. You may always improve. You easily feel guilty when you have got diabetes. If anything's wrong with the child Illustration or if something had shown up at the ultrasound, you would easily have blamed yourself a lot (Interviewee 7 - Type 1 diabetic) p44

<u>Paper 4</u>: Perceptions of risk for the development of Type 2 diabetes in African-American women with gestational diabetes.³¹

This qualitative thesis by Bieda 2009³¹ aimed to investigate African-American mothers' knowledge of Type 2 diabetes risk as well as their intentions to participate in preventive behaviours after a pregnancy complicated by GDM. The information was gathered through face-to-face, semi-structured interview and analysed with thematic analysis. The emphasis of this study is regarding subsequent development of Type 2 diabetes, but there are useful findings regarding emotional response to

diagnosis and treatment, barriers/enablers to treatment and preventative behaviours. Participants were 25 African- American mothers diagnosed with GDM at two high-risk prenatal clinics in Detroit, MI. The themes developed by the study authors were broader than diabetes, therefore only those themes specific to GDM were extracted. This paper scored eight out of ten in the QARI critical appraisal tool.

Finding 1	Emotional Responses to the Diagnosis of GDM (Credibility – Unequivocal)
Illustration	I was nervous because I didn't understand, like what is gestational diabetes- It was something I had never heard of (#25 - gdm).p106
Finding 2	Causes of GDM (Credibility – Unequivocal)
Illustration	The lack of exercise and you know, putting on weight, eating, being pregnant in general, and not having that, that activity and kind of function to fall back on may have contributed to it. Because you, you're not burning off the calories, your body is storing a lot more fat. (#14 - gdm) p107-8
Finding 3	Sources of GDM Knowledge (Credibility – Unequivocal)
Illustration	The dietician, she really taught me a lot you know. I talked to her - she told me how to break down everything and all that. So, they really do a good job (#3 - gdm).p109
Finding 4	Effects of GDM later in life (Credibility – Unequivocal)
Illustration	I will be used to it - all that stuff they make me do. I'll probably do that for the rest of my life - watching my weight and doing more exercising. Cuz there's a chance that it will come back (#3 - gdm). p111

<u>Paper 5</u>: Perceived barriers to treatment adherence among pregnant African American women with diabetes.³²

This thesis by Brooks 2002³² aimed to investigate aspects of the diabetes treatment regimen that are most difficult to adhere to among pregnant African-American women with diabetes. The information was gathered by questionnaires and qualitative open ended questioning with no specific philosophy mentioned and analysed by content analysis utilising NUD*IST 4.0 software. Participants were 32 African American women aged 18 to 49 with pregnancies complicated by Type 2 or GDM. Only data from direct questioning has been included in this review. This paper scored seven out of ten in the QARI critical appraisal tool.

Finding 1	Exercise: Difficulty with exercise therapy (Credibility – Unequivocal)
Illustration	The hardest thing for me is exercising because most of the time I'm tired - Type 2 diabetes or GDM using insulin p73
Finding 2	Negative feelings: depression, anxiety, anger or fear of diabetes or taking insulin (Credibility – Unequivocal)
	It's a depressing thing, it is very depressing to me 'cause they tell you all the
Illustration	things that could happen if you don't take the insulin and you be worried
	already, stressed out its not fun. Make you want to hurry up and have the baby
	- Type 2 diabetes or GDM using insulin - p73
Finding 3	Side effects: Negative side effects associated with pregnancy and insulin
	(Credibility – Unequivocal)
Illustration	I don't know if it's because of the diabetes that I'm so tired. I just know I don't
	even feel like moving to even check my numbers or anything - Type 2 diabetes
	or GDM using insulin - p72

Finding 4	Glucose monitoring: Difficulty with finger pricks to monitor glucose level (Credibility – Unequivocal)
Illustration	I don't like pricking my finger either. The excessive holes in my fingers, not having a chance to let them heal, trying to let them and stuff and don't have time to - Type 2 diabetes or GDM using insulin - p72
Finding 5	Diet: Difficulty with diet therapy (Credibility – Unequivocal)
Illustration	What I find most difficult is the diet because you are on such a small amount of carbohydrates and then after you finish eating them you are still hungry. Then you can't eat anything until your snackand when your snack is only like two carbohydrates so you only get two crackers or something like that you're still hungry until lunch - Type 2 diabetes or GDM using insulin - p70
Finding 6	Insulin injections: Difficulty with giving self insulin injections (Credibility – Unequivocal)
Illustration	The amount of insulin, how many shots I take is tiresome over a long period of time. It gets real tiresome. They are always increasing it no matter what you eat it's more and more, more - Type 2 diabetes or GDM using insulin - p70

Paper 6 - Women's experiences of gestational diabetes self-management: A qualitative study. 41

This paper by Carolan 2013⁴¹ aimed to investigate women's experiences of self-managing their GDM. The information was gathered through semi-structured interviews and one focus group and analysed with content analysis informed by van Manen. This is article scored ten out of ten in the QARI critical appraisal tool. Participants were 15 women being treated at a diabetes clinic in a metropolitan maternity unit in Australia and representative of population demographics in the area and included

women from Caucasian, Asian, South-Asian, Indian and Arabic backgrounds, with a diagnosis of GDM and who had experienced self-management of their condition.

Finding 1 The shock of diagnosis (Credibility – Unequivocal)

I was very surprised and very upset to be diagnosed. I felt a little bit of a

Illustration failure. I knew that I had brought it on myself because of being overweight ...

(Lili - gdm) p3

Illustration

Illustration

Illustration

Finding 2 Coming to terms with GDM (Credibility – Unequivocal)

(I just thought), this is what I've got to do and it's for the baby and whatever.

So just do it ... so just get on with it and just do it ... (Leanne - gdm) p4

Finding 3 Working it out and learning new strategies (Credibility – Unequivocal)

As the pregnancy went on I would have to eat less and less carbs to get the same results, and also in the day at different times I would get different results for the same meals. So it wasn't exactly just stick to your diet and then you're fine. By measuring your blood you could see exactly what was going on, if something was going wrong and then change it. So it was a good system ... you were in control. Also... like, I could have two slices of bread for breakfast if I wanted, but I could definitely not have two slices of bread in the evening (that) would send my blood sugar over the limit. (Lili - gdm) p5

Finding 4 Feeling better: looking to a healthier future (Credibility – Unequivocal)

And it's just, health-wise you're definitely, you get your own diet working a little bit better because I never thought that I was in the category for getting adult diabetes, never occurred to me. So the information that that's something that I

need to be careful about I think is very helpful. (Lili - gdm) p6

Finding 5 Having a supportive environment (Credibility – Unequivocal)

Now actually my husband comes for a walk with me as well -...he's kind of like me: he doesn't eat vegetables and ...he still doesn't eat vegetables but he's now cooking more for me and he's healthier because he doesn't, because if he's going to eat junk food that's just going to make me jealous. So he's kind

of trying to eat healthy as well for me. (Flora - gdm) p6

<u>Paper 7</u>: Women's experiences of factors that facilitate or inhibit gestational diabetes selfmanagement.⁴²

This paper by Carolan et al. 2012⁴² aimed to investigate the factors that facilitated or inhibited GDM self-management among women in a socially deprived area. An Interpretative phenomenology design was used and information gathered through semi-structured interviews and a focus group and analysed with thematic analysis. Participants were 15 pregnant women, with a diagnosis of GDM, at 28-38 weeks gestation from an Australian multi-ethnic population in the Western region of Melbourne, Australia.

This article scored nine out of ten in the QARI critical appraisal tool.

Illustration

Barriers to GDM self-management: Social constraints: Festivities and social Finding 1 functions (Credibility – Unequivocal)

I'm myself Indian and we have lot of Indian sweets and that sort of thing.

When I didn't know that I was diabetic I was eating sweets as well, like Indian proper sweets. And just the religious festivals and eating certain foods, but now I've stopped that as well. Actually it's not compulsory. It's up to you if you want to get it or not. You just feel a bit out of things. Loni (CDM), po

want to eat it or not. You just feel a bit out of things - Leni (GDM) - p9

Barriers to GDM self-management: Social constraints: Finding the balance Finding 2 (Credibility – Unequivocal) I don't cook the food - it is bad to say I won't eat (the food that her mother-in-Illustration law cooks) - rice - she says it is healthy for the baby - Suji (GDM) - p8 Barriers to GDM self-management: Social constraints: Disruption to the family Finding 3 (Credibility - Unequivocal) We had three different dinners every night- I could have eaten the same thing without the carbs - but so boring - made the choice - and you may not have Illustration the budget to buy crazy expensive things - but you have to expect a little bit more - maybe buying organic, interesting vegetables. Do something nice with it, you know, just make mealtimes feel nice - Lili (GDM) - p8 Barriers to GDM self-management: Time pressures: Finding time for Finding 4 everything (Credibility – Unequivocal) The doctor said to walk for an hour after meals. I mean, I start (work) at seven and finish at three and then I've got to pick my daughter up from school. Trying Illustration to fit that in, it's just - I think, well, God, I'll be dead by the time I get back, you Leanne (GDM) - p7 know Barriers to GDM self-management: Physical constraints (Credibility -Finding 5 Unequivocal) Because I have had pelvic pain, I haven't been able to move a lot. And I have Illustration been quite ill - Tran (GDM) - p8 Barriers to GDM self-management: Time pressures: The urgency of immediate Finding 6 change (Credibility – Unequivocal)

First week, I mean they told me which foods to avoid and so forth, but again that was very limited. I wasn't eating very much anyway during my pregnancy quite a few scores [BGL values] were over what they suggested. I hadn't really looked after what I had been eating -I really wasn't trying that first week I guess - I didn't think it would affect the sugar levels so much. She (diabetes educator) thought it was very bad - They suggested insulin after that first week and I didn't want that at all. I did try to explain, ... I understand why they are high. I need another chance - Tran (GDM) - p6

Barriers to GDM self-management: Limited comprehension: Limited understanding of GDM (Credibility – Unequivocal)

They didn't tell me what's the side effects for the baby. They just told me, You've got diabetes, you'd better control with this and that. But they didn't tell

Finding 8

Illustration

Finding 7

Illustration

Barriers to GDM self-management: Limited comprehension: Limited understanding of GDM self-management requirements (Credibility – Unequivocal)

me, like, what are the side effects for having sugar levels up like why it's really

important to monitor your sugar levels - Prani (GDM) - p9

Illustration

I did get appointments where I got some information. But I found it more outside of those appointments. I mean it was helpful, but it wasn't really in depth. Well like the food for instance, it wasn't a very extensive list of what you could eat, it was very limited and most of the food I eat wasn't on it - Tran (GDM) - p10

Finding 9

Barriers to GDM self-management: Insulin as an easier option (Credibility – Unequivocal)

Illustration

Yeah, it's painful, I have to say, but it really works. I have to say that is a good

	thing. Because it's easier to help me manage my diet and control my sugar
	level Yeah, the drugs (insulin) can help my condition it was so hard to deal
	with cravings - Xioquan (GDM) - p10
Finding 10	Facilitators for GDM self-management - the baby (Credibility – Unequivocal)
	I was very determined to make sure I could do absolutely anything within my
Illustration	power to not allow any, something to happen to the baby. I knew I had brought
	it on myself by being overweightI felt very responsible Lili (GDM) - p11
Finding 11	Facilitators for GDM self-management – support (Credibility – Unequivocal)
	Well I think I could, I probably could do it on my own but having that support
Illustration	base, having someone kind of do it with you makes you feel you're not
	alone doing it Margaret (GDM) - p11
Finalia e 10	Facilitators for GDM self-management: realisation: Realising I had to do it
Finding 12	myself (Credibility – Unequivocal)
W	I realised it was up to me - no one else - there was no point in cheating - I
Illustration	would be just cheating myself - Lili (GDM) - p12
F' ' 10	Facilitators for GDM self-management: realisation: An opportunity to prevent
Finding 13	Type 2 diabetes (Credibility – Unequivocal)
	It's good to learn about it, otherwise the way I was going; definitely I would
Illustration	have diabetes 2. I didn't know about it but now I can control myself andYeah,
	because the way I'm not having anything, I was having heaps of sugars every
	day - Leanne (GDM) - p13

<u>Paper 8:</u> Gestational Diabetes: The Meaning of an At-Risk Pregnancy.⁴³

This Heideggerian-Gadamerian hermeneutic phenomenological paper by Evans & O'Brien 2005⁴³ aimed to investigate are the meanings that pregnant women attach to their experience of a pregnancy that is judged at risk as a consequence of GDM. The information was gathered through conversational interviews and analysed by a reflective process, consistent with the guidelines of thematic analysis. Participants were 12 pregnant Canadian women from varying cultural, social, and educational backgrounds who were diagnosed with and being treated for diabetes at an outpatient diabetic clinic in a large urban teaching hospital. One woman had Type 1 diabetes - others with GDM, and distinction between them was not made. This study scored eight out of ten in the QARI critical appraisal tool.

Finding 1	Balancing (Credibility – Unequivocal)
Illustration	I found that in the beginning it was hard, but once you get used to it it's not hard anymore. It's really routine - Francine - GDM - p72
Finding 2	Being a Responsible Mother (Credibility – Unequivocal)
Illustration	It's not just yourself. I might be feeling fine and it is affecting the baby. It's not just yourself you're thinking about. You have one that is totally dependent on you to keep it safe - Audrey - GDM - p73
Finding 3	Living a Controlled Pregnancy (Credibility – Unequivocal)
Illustration	Everything changes when you become diabetic because if you are not in control, you can't go on that hike. You can't do things spontaneously. You can't go for wings after work because you've got to think, Well, what'd you eat for lunch? - Lynne - GDM - p72
Finding 4	Being Transformed (Credibility – Unequivocal)

Illustration

Illustration

I feel empowered and stuff after this. Like in the past few years I haven't looked after my body as well as I should. I've always struggled with my weight. So I feel like after the baby is born I will get straightened out. So it's been positive. - Helen - GDM - p74

<u>Paper 9</u>: Planning for a healthier birth and beyond: Strategies women use to manage gestational diabetes.⁴⁷

This grounded theory thesis by Hamel 2003⁴⁷ aimed to investigate the experience of being a woman diagnosed with GDM. The information was gathered by open-ended, semi-structured interviews and analysed by constant comparative analysis developed by Glaser and Strauss. There were seven participants residing in Northern New England having a diagnosis of GDM. This thesis scored ten out of ten in the QARI critical appraisal tool.

Finding 1 Getting diagnosed with Gestational Diabetes (Credibility – Unequivocal)

I have not had any friends or family that have been diagnosed, so I think that I

freaked out a little bit more than a lot of people . . . I was pretty panic-stricken. Illustration

Omigosh! What does this mean for the baby? What does this mean for me?

Will the baby be healthy, or be okay? - Emily - GDM - p81

Finding 2 Regaining a sense of control – Stress (Credibility – Unequivocal)

These are all fears of the unknown, particularly if you are like me and did not know someone who had had it before . . . I didn't know how my baby would be, I didn't know if I would be okay, and I didn't know what I would need to do to cope . . . That's where the emotion came out with the whole gestational diabetes diagnosis and treatment, because I could potentially be jeopardising

my new baby. My own body might not be the safest place for my child. - Emily - GDM - p89

Finding 3

Regaining a sense of control: health of both (Credibility – Unequivocal)

Illustration

At least it's something to work towards, that if I do this, and I work hard, then I might be able to get this, too, but at the same time not set myself up. Even if I work very hard and it doesn't end up that way, it's not my fault, at least I was working towards it, you know. That's my ultimate goal. - Emily - GDM - p96

Finding 4

Regaining a sense of control: Perceived threat (Credibility – Unequivocal)

Illustration

My body frustrates me when I can do the exact same thing for diet, get my walk in, and, after, my blood sugar is down - and then it all of a sudden is up again; - Sara - GDM - p97

Finding 5

Regaining a sense of control: Need for information (Credibility – Unequivocal)

I was looking back at my original interview, and, you know, at first it's the fear of the absolute unknown, because I had no idea what to expect with this. Then it was fear: ...Omigosh! So many things I need to be aware of...; I don't think that people are aware that testing your blood sugars is one piece and testing your ketone levels and your urine are another piece, because the decreased ketones can lead to indications of brain development abnormalities in the fetus if your ketones are too high. And so it was scary, even though I still had information, but not having the education to know what levels would still be acceptable, and that the fetus's - the baby's -chances would still be okay . . . [getting that information] was what was the most helpful for me. - Emily - GDM - p100

Illustration

Finding 6

Regaining a sense of control: Need for Social Support (Credibility -

Unequivocal)

GDM - p99

snacks and to make sure I am eating, and he also supports [me] to make sure I am getting out for some exercise. We have a treadmill at home . . . I have someone who will come and will sit with me and talk about different things . . . She is just another support person, actually . . . If there was some kind of a support group available, too [it would be helpful]. I mean, gestational diabetes would be very interesting. Either people that have had it or people that are going through it would be great. I know that was one thing that I would have really appreciated. Having somebody to talk to . . . or to phone . . . Now that I've experienced it, if somebody had a question for different snack ideas, I ate a lot of cheese and crackers. Or - you know what I mean. Just something to let

them know how I did. What I did to manage it, would be [helpful]. - Sarah -

My husband is available and is very supportive. He reminds me to have my

Illustration

Finding 7

Planning for a Healthier Birth and Beyond (Credibility – Unequivocal)

Illustration

For me I think it is . . . the pregnancy. I am hoping - I mean, I know there is always a chance that after I have the baby I will have to continue this, but I think now that I have been though it I will be eating different anyway. I think it really made me take a look at what a serving is. I was heavy before I got pregnant, and I haven't gone back to my prepregnancy weight yet, so in the 9 months that I have been pregnant I haven't gained anything, which has kind of freaked me out. But with the gestational diabetes I am eating differently than I would have before I was pregnant anyway. - Sara - GDM -p114

Finding 8

Planning for a Healthier Birth and Beyond: Commitment to the Fetus's Well-Being (Credibility – Unequivocal)

Illustration

I test my blood four times a day. I check for ketones each morning and then I do my fasting blood, and then 2 hours after breakfast, lunch and dinner. I administer . . . the insulin . . . This isn't about me, it's about the baby, and that makes a load of difference. - Emily - GDM - p115

Finding 9

Planning for a Healthier Birth and Beyond: Concern for Health of Self (Credibility – Unequivocal)

Illustration

I think it is definitely a fair warning for me, to watch what I do. I've always had a weight problem growing up, so it's one of those deals where I know it's all related, what you're eating, what you're not eating, whether you're exercising or you're not . . . It's been a learning experience. - Sarah - GDM - p127

Finding 10

Planning for a Healthier Birth and Beyond: Support and Information (Credibility – Unequivocal)

Illustration

[The members of the health care team need to] reinforce each other, definitely I've asked the same questions of three different people at three different times, none of them sitting in the room together, and received the same answer, and I cannot even tell you how much that's meant to me . . . I have so many doctors' appointments in a week, you know, I usually have about three appointments in a week, one with the nurse, one with the nutritionist, and one with my OB-GYN. - Emily - GDM - p133

<u>Paper 10:</u> Women with gestational diabetes in Vietnam: a qualitative study to determine attitudes and health behaviours.³³

This study by Hirst et al. 2012³³ aimed to investigate attitudes and health behaviours of pregnant women with GDM in Vietnam. The information was gathered by focus group interviews and analysed

with thematic analysis. Participants were 34 pregnant women with GDM aged over 18 years and treated at Hung Vuong Hospital, Ho Chi Minh City, Vietnam. There were four focus groups. This study scored eight out of ten in the QARI critical appraisal tool.

Finding 1	Confusion and concern about the diagnosis of GDM (Credibility – Unequivocal)
Illustration	My doctor did not explain much about this condition. She only noted this condition was resulted partly from gene and partly the food we consume nowadays. Our food contains many kinds of chemicals that may cause diabetes. I could not understand the disease - GDM - p3
Finding 2	Fear of adverse effects from GDM (Credibility – Unequivocal)
Illustration	It may slow baby's growth, sudden deathbabies easily have low blood sugar levels or more likely be born with abnormalities - GDM - p4
Finding 3	Dietary changes - I think it's so tough for us (Credibility – Unequivocal)
Illustration	No sugar milk seems not to make me full. Rice makes me full, but starch is prohibited. It's really hard for us GDM - p5
Finding 4	Blood glucose monitoring: access and understanding barriers (Credibility – Unequivocal)
Illustration	I guess I would be fatigued because of blood loss if I keep getting blood for checking every day until delivery - GDM - p5
Finding 5	Breast-feeding: balancing conflicting information about benefits for baby (Credibility – Unequivocal)
Illustration	I'm concerned about that (transmission of diabetes to the infant) of course. However to my understanding breast milk has antibodies which might be good

for my baby because they would protect it from infection - GDM - p5

Finding 6 The desire for more information about GDM (Credibility – Unequivocal)

There is just a small sheet concerning the risk of GDM distributed by the

Illustration hospital staff at the antenatal care department. No other information on GDM

is available - GDM - p6

<u>Paper 11</u>: Beliefs about health and illness is Swedish and African-born women with gestational diabetes living in Sweden.³⁴

This paper by Hjelm K et al. 2012³⁴ aimed to investigate beliefs about health and illness in women with GDM born in Sweden and Africa living in Sweden and the influence of beliefs on self-care and care seeking. The information was gathered through semi-structured interviews and analysed with qualitative content analysis. Participants were a consecutive sample of women diagnosed with GDM, 13 born in Sweden and 10 born in Africa, from a diabetes clinic in Sweden.

This study scored eight out of ten in the QARI critical appraisal tool.

Finding 1 Illness (Credibility – Unequivocal)

Worried for the child - that the child will be too big - if you get type 2 diabetes -

Illustration followed by coronary heart disease, stroke- that worries me. (Swedish woman

- gdm) p1379

Finding 2 Health (Credibility – Unequivocal)

I need to follow all the rules, all this advice I have got from the doctor and

Illustration health care - I need to take my insulin at the right time, I need to eat at the

right time, I need to rest at the right time...(African woman - gdm) p1379

Finding 3 Self-care and care seeking (Credibility – Unsupported)

Most respondents practised only self-care and measures related to the individual ... when health care was needed, it was mainly sought from midwives or physicians in the professional sector

Paper 12: Swedish and Middle-Eastern-born women's beliefs about gestational diabetes.³⁵

This paper by Hjelm et al 2005³⁵ aimed to compare beliefs about health and illness between women born in Sweden and the Middle East who developed GDM. The information was gathered by semi-structured interviews and analysed by thematic analysis. The participants were a consecutive sample of women attending an in-hospital specialist diabetes clinic in Sweden with GDM; 13 born in Sweden and 14 born in the Middle East.

This study scored six out of ten in the QARI critical appraisal tool

Finding 1	Beliefs about illness (Credibility – Unequivocal)
III. saturation	I panicked, and she said yes you have diabetes and you have to live
	like this and the baby can become too big and complications at birth was
Illustration	the only thing I heardI was terribly frightened (Respondent 9 - GDM) -
	p48
Finding 2	Beliefs about health (Credibility – Unequivocal)
Illustration	Health is everythingIt is good to keep in health for one's work, for one's
	home, for one's husbandthe whole responsibility we [women] have for our
	children. (Respondent 17 - middle eastern woman - GDM) - p52
Finding 3	Self-care and care-seeking pattern (Credibility – Unequivocal)

Fear of the delivery is something natural which I think all women have... but for this I am more worried about how diabetes can affect the baby.... (Respondent 7 - GDM) p53

<u>Paper 13:</u> Management of gestational diabetes from the patient's perspective - a comparison of Swedish and Middle-Eastern born women.³⁶

This paper by Hjelm et al 2007³⁶ aimed to investigate and compare Swedish and Middle-Eastern born women's evaluation of a Swedish specialised diabetes clinic for management of women with GDM and its contribution to a decreased level of stress and improved coping capability to promote health in patients receiving care. Participants were women with GDM, 13 born in Sweden and 14 born in the Middle East. The information was gathered by semi-structured interview and analysed by content analysis.

This study scored five out of ten in the QARI critical appraisal tool.

Finding 1	Patients' perspectives on the process or content of care competence (Credibility – Unequivocal)
Illustration	The midwife does not know all about diabetes and those who work with diabetes don't know all about the baby (GDM) p172
Finding 2	Patients' perspectives on the organisation or structure of care (Credibility – Unequivocal)
Illustration	It would have been good if the midwife had been able to tell me more when I was there - you should not need to wait for two weeks before you can meet a dietician - I don't understand why I met a dietician first and then the physician - (GDM) p173

Finding 3

Patients' emotions and attitudes to the clinic (Credibility – Unequivocal)

at the clinic I was informed about having gestational diabetes but not about the glucose tolerance test - there were further check-ups at the diabetes clinic - a lot of questions arose and that information is not focused on patients but on physicians - and then you ask even more questions - and when you are told that you have to ask your doctor - I think this is very bad - here are no information leaflets about gestational diabetes...First I met the diabetes specialist nurse [at the diabetes clinic] and she couldn't answer the questions. She was very good on diabetes but not on gestational diabetes...I had to wait until two weeks later when I met the doctor with questions that I wondered about rather general and basic questions. It took nearly four weeks, yes it did and X [the diabetologist] explained to me and since then there has been

Illustration

<u>Paper 14:</u> Beliefs about health and illness in women managed for gestational diabetes in two organisations.³⁷

This paper by Hjelm et al 2008³⁷ aimed to explore the beliefs about health, illness and health care in women with GDM managed in two different organisations based on diabetology or obstetrics. Information was gathered by semi-structured interviews and analysed by content analysis. Participants were a consecutive sample of Swedish women diagnosed with GDM; 13 managed in a Swedish university hospital specialist diabetes clinic with regular contact with a diabetologist and antenatal care provided by a midwife and 10 managed in a Swedish university hospital specialist maternity clinic providing regular contact with a midwife, a structured programme for self-monitoring of blood glucose and insulin treatment, and a 1-day diabetes class by an obstetrician, a diabetologist, a midwife and a dietician.

This study scored seven out of ten in the QARI critical appraisal tool.

nothing. (GDM) - p173

Finding 1	Beliefs about health (Credibility – Unequivocal)
Illustration	For me health is feeling well mentally and physicallyI would say being free from any disease. (10 - GDM)p172
Finding 2	Beliefs about illness (Credibility – Unequivocal)
	I was informed about it after the glucose tolerance test in week 28and then I
	didn't react so much but then when I was on my way homestarted to cry
Illustration	violentlyI was horribly sad because I was afraid I had done something
	wrong to my child, that I had not looked after myselfI got a reminder, so I
	was horribly sad. (2 - GDM) p175
Finding 3	Beliefs about health care (Credibility – Unequivocal)
Illustration	that both the pregnancy and diabetes are in focus, so that it isn't just
	diabetes when you come here and not only the pregnancy at the midwifeI
	felt it like thatit could be combined morethat it feels like co-operation. (4 -
	GDM) p178

<u>Paper 15:</u> A qualitative analysis of the psychological impact of pregnancy for first time mothers with Type 1 diabetes.⁴⁸

This grounded theory thesis by Horrocks 2009⁴⁸ aimed to assess the psychological and emotional impact of pregnancy in the context of Type 1 diabetes for first time mothers. Information was obtained from semi-structured interviews and analysed by content analysis, based on a social constructionist form of grounded theory. Participants were nine white British women who were first-time mothers and currently pregnant and receiving specialist support from a diabetes antenatal clinic in East Anglia, England.

This study scored ten out of ten in the QARI critical appraisal tool.

Finding 1	Understanding the Experiences of Pregnancy for First Time Mothers with Type 1 Diabetes - Striving for the Sake of the Baby (Credibility – Unequivocal)
Illustration	If most people realised some of the anguishI am a very rigid person with my diabetes anyway, but I have given everything to this (Laura Type 1 diabetes - line 53).p79
Finding 2	Understanding the Experiences of Pregnancy for First Time Mothers with Type 1 Diabetes - Striving for the Sake of the Baby - Process of Acceptance and Adjustment (Credibility – Unequivocal)
Illustration	It's like reprogramming yourself but you do adapt to it (Layla - Type 1 diabetic, line 92). p81
Finding 3	Understanding the Experiences of Pregnancy for First Time Mothers with Type 1 Diabetes - Striving for the Sake of the Baby -Process of Acceptance and Adjustment - Factors promoting acceptance and adjustment: engagement (Credibility – Unequivocal)
Illustration	I look forward to it now she's on her way now she's become a lot realer [sic] (Cathy, Type 1 diabetic line 220).p83
Finding 4	Understanding the Experiences of Pregnancy for First Time Mothers with Type 1 Diabetes - Striving for the Sake of the Baby -Process of Acceptance and Adjustment - Factors promoting acceptance and adjustment: responsibility (Credibility – Unequivocal)
Illustration	It's not just me now, what I am doing, I am affecting baby as well (Eileen - Type 1 diabetic, line 64-65).p84
Finding 5	Understanding the Experiences of Pregnancy for First Time Mothers with Type

	1 Diabetes - Striving for the Sake of the Baby -Process of Acceptance and
	Adjustment - Factors inhibiting acceptance and adjustment: fear (Credibility -
	Unequivocal)
	Have I looked after myself well enough for it to be alright? (Diana - Type 1
Illustration	diabetic, line 18). p86
	Understanding the Experiences of Pregnancy for First Time Mothers with Type
Finding 6	1 Diabetes - Striving for the Sake of the Baby -Process of Acceptance and
i manig o	Adjustment - Factors inhibiting acceptance and adjustment: negative beliefs
	about diabetes (Credibility – Unequivocal)
	I never actually thought I was going to fall pregnant because of this un-luck
Illustration	thing (Laura - Type 1 diabetes, line 72). p88
Finding 7	Balancing: Issues of Control (Credibility – Unequivocal)
	The pregnancy wasn't planned, so my levels before that were quite terrible,
	my HbA1c was 10.4, it's now 8.1 so it has come down. My sugar levels have
Illustration	always been uncontrollable; trying to find a balance has been quite hard
	(Cathy,- Type 1 diabetic - line 47-50).p89
Finding 8	Balancing: Issues of Control - Losing control. (Credibility – Unequivocal)
	It is constant changing; things can be different every two to three days (Eileen
Illustration	- Type 1 diabetic, line 55). p90
Finding 9	Balancing: Issues of Control - Gaining control (Credibility – Unequivocal)
Illustration	It is just constant testing and checking and not really knowing how you are
	feeling because you don't really have all the obvious signs that you used to
	(Eileen - Type 1 diabetic, line 47). p91

Finding 10	Getting On With It vs. One Step At a Time - Getting On With It (Credibility – Unequivocal)
Illustration	I haven't really sat back and thought about it, I have just got on with it more. I think that I will probably sit back when the baby is here and think, "Well how did that happen"; You know it all came together somehow (Layla - Type 1 diabetic, line 238-240).p 94
Finding 11	Getting on with it vs. One Step At a Time - One Step At a Time (Credibility – Unequivocal)
Illustration	It's like just taking one step at a time, you can't do everything in big massive leaps, you have just got to, excuse the pun, but take baby steps (Jenny - Type 1 diabetic, line 400).p94
Finding 12	Learning / relearning (Credibility - Unequivocal)
Illustration	I've never been pregnant before and I've never taken much notice of my diabetes before so it's all new to me really (Cathy - Type 1 diabetic, line 254). p95
Finding 13	Coping with negative emotion (Credibility – Unequivocal) s
Illustration	I really, really doubted myself (Sophie - Type 1 diabetic, from line 119). p98
Finding 14	How Do Women With Type 1 Diabetes View Themselves During Pregnancy - Risky vs. Nurturing Body (Credibility – Unequivocal)
Illustration	Babies don't like ketones (Diana - Type 1 diabetic, line 47). p100
Finding 15	How Do Women With Type 1 Diabetes View Themselves During Pregnancy - Risky vs. Nurturing Body – empowered (Credibility – Unequivocal)

Illustration	I am proud of myself because I was so frightened of it (Laura - Type 1 diabetic, line 49). p103
Finding 16	How Do Women With Type 1 Diabetes View Themselves During Pregnancy - Risky vs. Nurturing Body - Different From Normal (Credibility – Unequivocal)
Illustration	You are just constantly worried; obviously the doctors have to tell you all the effects that your high blood sugars have, and when you've constantly got it in your mind, you just think well, why can't I be normal, and have a normal baby? (Diana - Type 1 diabetic, line 48-51). p105
Finding 17	How Do Women With Type 1 Diabetes View Themselves During Pregnancy - Risky vs. Nurturing Body – Objectified (Credibility – Unequivocal)
Illustration	We're human and it is not just a case of numbers on a page (Jenny - Type 1 diabetic, line 176). p106
Finding 18	What Are the Participants Views on the Support They Receive From Others - Supportive Network (Credibility – Unequivocal)
Illustration	We know we can't do this on our own (Cathy - Type 1 diabetic, line 341).p109
Finding 19	What Are the Participants Views on the Support They Receive From Others - Supportive Networks -Professional Support How to Promote Self Care? - Specialist care (Credibility – Unequivocal)
Illustration	There is always someone you can ring up if you are really worried and talk it over, sort it out (Eileen - Type 1 diabetic, line 75). p109
Finding 20	What Are the Participants Views on the Support They Receive From Others - Supportive Networks -Professional Support How to Promote Self Care? - Holistic care (Credibility – Unequivocal)

Illustration	[Specialist diabetes midwife], she is always there for me, I just phone her up, even if it's like silly little things, she don't care, she's always there (Diana - Type 1 diabetic, line 173-174). p111
Finding 21	What Are the Participants Views on the Support They Receive From Others - Supportive Networks -Professional Support How to Promote Self Care? - Collaborative care (Credibility – Unequivocal)
Illustration	You need help with your own care, it's not people looking after you, it's you looking after yourself as well, that's what I need, I need to have input in it as well (Cathy - Type 1 diabetes, line 265-267). p113
Finding 22	What Are the Participants Views on the Support They Receive From Others - Supportive Networks - Family and Friends: Do They Understand? (Credibility – Unequivocal)
Illustration	Everyone's been really supportive, it's difficult because most people don't really understand diabetes, they kind of understand it to a point but then don't really understand it past that point (Jenny - Type 1 diabetes, line 223-225) p114
Finding 23	What Are the Participants Views on the Support They Receive From Others - Supportive Networks - Partners: A Shared Responsibility? (Credibility - Unequivocal)
Illustration	I have a very supportive partner who knows all about it so we have sort of done it together. (Eileen - Type 1 diabetes, line 92-93) p115

Paper 16: Women's perceptions of being pregnant and having pregestational diabetes.⁴⁴

This study by Lavender et al. 2010⁴⁴ followed a hermeneutic phenomenological approach based on Heidegger and aimed to explore the experiences of White British and South East Asian women with Type 1 and Type 2 diabetes, and the perceived impact of diabetes on their reproductive health. Information was gathered by focus groups and one-to-one interviews and analysed by content analysis described by van Manen. Participants were 22 women with Type 1 or Type 2 diabetes of different parity and ethnicity managed at obstetric and diabetes clinics in three hospital sites in the North West of England; only 14 participants were pregnant at interview and information from these women only was included in this review.

This article scored nine out of ten in the QARI critical appraisal tool.

Finding 1

Relinquishing personal control - Disruption to everyday lives (Credibility – Unequivocal)

I would say it's more stressful because you're more in hospital. You're coming at least twice a week ...it's another head-ache ...And it's so hard to squash everything in. Like this morning I had to drop my kids at eight o'clock in school - they have breakfast club, so I'm lucky that way, so I could drop them off early to get here for nine o'clock....It's too much. And then I think, - Oh, my God, is this all necessary.... and the waiting times are just a laugh. (Fatima - pre-existing diabetes) - p591

Finding 2

Illustration

Relinquishing Personal control - surrendering control to others (Credibility – Unequivocal)

Illustration

I suppose the only thing with coming in so often, like now with the pregnancy, you know its right for the baby and yourself but you do feel quite vulnerable as well - cause you think suddenly something that you can control is something that you can't control really. And always having to accept that other people will want to know what the blood is doing ...so I've got to come in after 23 years of

managing this to have someone else tell me, you know what to do with it.....(Heather - pre-existing diabetes) - p592

Finding 3 Pregnancy overshadowed by diabetes (Credibility – Unequivocal)

I've had nobody to speak to because it's just so medical which is absolutely understandable because you want your sugars to be absolutely perfect and that's the main objective. But you've gotta remember I'm having a baby and it's my first baby, I don't know what's going on with my body... .(Rachael - pre-

existing diabetes) - p593

Illustration

Finding 4 Haphazard preconception care (Credibility – Unequivocal)

When I came, we just had vague chats about it to be honest...(Lisa - pre-Illustration

existing diabetes) - p593

<u>Paper 17</u>: A transformed pregnancy: the psychosocial consequences of gestational diabetes.⁵¹

This ethnographic paper by Lawson & Rajaram 1994⁵¹ aimed to assess the meaning pregnant women attach to GDM. Information was gathered by semi-structured interviews and analysed by content analysis (using method developed by Glaser and Strauss). Participants were 17 pregnant women between the ages of 24 and 36, with no previous history of GDM being treated at a high-risk maternity clinic at a large university medical centre located in Kentucky, USA.

This article scored six out of ten in the QARI critical appraisal tool.

Finding 1 Reactions to the diagnosis (Credibility – Unequivocal)

I felt like it was the end of the world for me and I just thought of the worse.

Even though they told me that nothing was wrong with baby, I had an

ultrasound and was relieved that the baby was ok. But, I was really depressed 'cause I knew that the diabetes could affect the baby. With sugar [diabetes], they said the baby will be large and then they will take it. I worry about the effects of a C-section on the baby. So, the main concern right now is the baby. (Kathy - GDM diet controlled, family history of diabetes) - p543

Finding 2

Coping with the diagnosis (Credibility - Unequivocal)

Illustration

'I believe in not giving in to diabetes. I will take care of myself and control the diabetes. I know that I will have to lose this weight after I have the baby'. - (Susan GDM - diet controlled) p549

Finding 3

Experiencing a transformed pregnancy - dietary management (Credibility – Unequivocal)

I have always been a sweet addict. I love sugar. It is really hard for me not to eat ice cream. Friends come in and have ice cream and eat it in front of me, but I know I can't have it. . . . I cried when I saw my husband eat ice cream. I really knew that my pregnancy was different when I could not eat ice cream. It is really hard to suddenly change my eating and cooking patterns... If it had happened earlier in my pregnancy, then I would have been more prepared than I am now. But to suddenly change how I eat and cook is hard. (Robin - DGM - diet controlled) – p549-50

Finding 4

Illustration

Experiencing a transformed pregnancy - Insulin injections (Credibility - Unequivocal)

Illustration

I give myself two shots everyday. Even though I had two other pregnancies, this is the worst pregnancy I had. With the insulin, I cry a lot, I feel lonely and have severe mood swings. I watch news stories or commercials on TV and cry. I wake-up at night and wonder if I will die and if I will live to see my

children grow-up, or if I will see my grandchildren. - (Beth - GDM - insulin dependent) - p552

Finding 5

Illustration

Finding 6

Experiencing a transformed pregnancy - Blood glucose monitoring (Credibility – Unequivocal)

I took my blood at Lamaze classes, and it was interesting because I wanted to hide it, even though other gestational diabetics could have been in the class. I have never known anybody who had gestational diabetes 'cause they never talked about it. I could not reveal to others that I was having an abnormal pregnancy by testing my blood. I tested my blood in a bath room stall where no one could see what I was doing. In concealing my testing, I was perpetuating the myth that all pregnancies are normal. I was trying to conform

to the myth of a 'perfect' pregnancy - (Michele - GDM - diet controlled) - $\mathsf{p551}$

Experiencing a transformed pregnancy - patient-provider interactions (Credibility – Unequivocal)

'Most gestational diabetics do not get enough information about nutrition, such as the importance of reading food labels and meal planning.' - (Sharon - diet

Illustration as the importance of reading food labels and meal planning.' - (Sharon - die controlled) - p555

<u>Paper 18:</u> Food Perceptions and Concerns of Aboriginal Women Coping with Gestational Diabetes in Winnipeg, Manitoba.³⁸

This paper by Neufeld 2011³⁸ aimed to assess how Aboriginal women in an urban setting perceive dietary treatment recommendations associated with GDM. Data was collected by semi-structured explanatory model interviews and analysed by thematic analysis. Participants were 29 self-declared Aboriginal women from an urban centre of Winnipeg, Manitoba who had received a diagnosis of GDM

within the last five years - 16 were pregnant at time of interview (two of these without current diagnosis of diabetes). For this review data was collected only from those pregnant at the time of interview. Of the 14 pregnant and diagnosed with diabetes four were diagnosed with Type 2 diabetes and ten with a current diagnosis of GDM.

This article scored seven out of ten in the QARI critical appraisal tool.

Finding 1	Food and Gestational Diabetes – instability (Credibility – Unequivocal)
	It's such a struggle to sit here and have to eat, (She would also tend to eat a
	meal only once a day, consuming larger serving sizes than recommended)
Illustration	I'm not a big eater but I eat more than 1 cup. I meanhello, that's my only
	meal I eat a day! Diane - GDM with current and last pregnancy, 3 y ago;
	second trimester - p485-6
Finding 2	Treatment Experiences (Credibility – Unequivocal)
	Trying to keep it under control, it's getting aggravating sometimes because it
Illustration	doesn't always workPretty much a lot of things bring it (blood glucose) up. I
illustration	found you pretty much got to eat like a mouse to keep it down Terri - GDM
	with previous pregnancies and currently; second trimester - p485
Finding 3	Food and Gestational Diabetes - Food, Fear and Anxiety (Credibility -
	Unequivocal)
Illustration	Somebody says something or things aren't going right, you go eat! - Doris -
	GDM currently; third trimester - p486
Finding 4	Food and Gestational Diabetes - Misinterpretation and Frustration (Credibility
	- Unequivocal)
Illustration	When you think of healthy, you think of fruit and vegetables, but tomatoes and

apples and oranges and whatever aren't good for you, they're high in sugar... At the same time, she explained that for women with GDM, chocolate bars aren't bad for you, because chocolate doesn't release its sugars all at once like Pepsi. - Diane - GDM with current and last pregnancy, 3 y ago; second trimester - p487

<u>Paper 19</u>: 'From stun to gradual balance'--women's experiences of living with gestational diabetes mellitus.⁴⁹

This grounded theory article by Persson et al 2010⁴⁹ aimed to assess the experiences of pregnant women being diagnosed with GDM and its impact on their daily life. Information was gathered by semi-structured interviews and analysed by content analysis. Participants included ten women - all except one of Swedish origin – with one immigrant who had lived in Sweden since her teens, was well established within Swedish society and was fluent in Swedish attending antenatal clinics in a county in Northern Sweden.

This study scored nine out of ten in the QARI critical appraisal tool.

Finding 1	From stun to gradual balance - Struck by lightning (Credibility – Unequivocal)
Illustration	To initially have felt so good and well, not had any nausea and the baby was kicking and everything was so fine, the checkups at the midwife and so on, and then this slap in the face? UGH!? - gdm p457
Finding 2	From stun to gradual balance - having a personal responsibility (Credibility – Unequivocal)
Illustration	You would do anything for the wellbeing of the baby, to have a healthy baby - gdm p457

Finding 3	From stun to gradual balance - Being under surveillance (Credibility - Unequivocal)
Illustration	He [the spouse] becomes a little like this - Are you really going to eat that? Then it rather gives you an even more guilty conscience gdm p457
Finding 4	From stun to gradual balance - Feeling socially apart (Credibility - Unequivocal)
Illustration	You have to say all the time, No thank you, I can't. I'm diabetic - to have to acknowledge this disease all the time. It [the disease] is hidden in one sense, but still gets very obvious in some situations - gdm p458
Finding 5	From stun to gradual balance - Being sufficiently supported (Credibility - Unequivocal)
Illustration	My dad's wife bakes bread and she's very eager to make sure that there is whole grain and no sugar so she is almost more into this than I am.? - gdm p458
Finding 6	From stun to gradual balance - Struggling for protection (Credibility - Unequivocal)
Illustration	Well, a bit of a guilty conscience, I think Not so much for my own sake, but for the baby Oh, poor thing, now he's lying there in a bath of sugar and feels bad gdm p457
Finding 7	From stun to gradual balance - Changing the self-image (Credibility - Unequivocal)
Illustration	Unless there is a miracle somehow I will probably be struck with diabetes mellitus, type 2, and that is so sad because diabetes mellitus brings so many

	other diseases if you don' take care of yourself properly gdm p458
Finding 8	From stun to gradual balance - Adapting to a new situation (Credibility - Unequivocal)
Illustration	It takes time to find your routines, to get all these pieces of the puzzle to fit into your life. My God, it does! You do not change from one day to the next. It is not possible gdm p458
Finding 9	From stun to gradual balance - Waiting for the 'Moment of truth' (Credibility – Unequivocal)
Illustration	When the birth approaches and you're so awfully worried that the baby will be affected gdm p459

Paper 20: Coping with diabetes through pregnancy. 45

This study by Richmond 2009⁴⁵ was designed with a qualitative phenomenological methodology following Husserl's philosophy and aimed to investigate how identity was linked to the improvement, and deterioration, of blood glucose control in pregnant women with Type 1 diabetes. Information was gathered by interviews and analysed by qualitative thematic analysis. Participants included 11 women with Type 1 diabetes attending the joint obstetric/diabetic clinic in a district general hospital between October 2001 and April 2004 in Stockport, UK.

This article scored seven out of ten in the QARI critical appraisal tool.

Finding 1	Hypoglycaemia (Credibility – Unequivocal)
	Owen (four-year-old son) went to tell a neighbourI must have flaked out on
Illustration	the kitchen table and Owen went to tell a neighbour and just as I people
	came in. I then kind of came to when I mention it to people they say Oh my

God how dangerous is that?? But I mean it could have been much worse. (D) pre-existing Type 1 diabetes p90 Finding 2 Concern for their unborn child (Credibility – Unequivocal) I know because I'm pregnant I've got to look after myself more because I don't Illustration want anything to happen to the baby because of it ... because of me not looking after meself ... (K) - pre-existing Type 1 diabetes p89 Finding 3 Concerns for existing children (Credibility – Unequivocal) If I turn away from my child (two-year-old daughter) while it's stood next to you at the side of the road, anything could happen you know, but you might not Illustration recognise that you're having a hypo or you might not have anything in the house for a hypo. It's just too much of a risk for me. (E) - pre-existing Type 1 diabetes p90

<u>Paper 21</u>: The lived experience of pregnancy for women with pre-existing insulin-dependent diabetes.⁴⁶

This interpretive phenomenology thesis by Sheffer 2000⁴⁶ aimed to explore the lived experience of pregnancy for women with pre-existing IDDM. Information was gathered by audio-taped semi-focused one-on-one interviews and analysed by thematic analysis following a framework of interpretive phenomenology outlined by Benner. There were eight participants, who had lived with pre-existing insulin dependent diabetes mellitus from four to twenty years and had treatment in a clinic in a tertiary level health care centre in Dalhousie, Canada.

This thesis scored eight out of ten in the QARI critical appraisal tool.

Finding 1

Uncertainty About Having a Healthy Baby (Credibility – Unequivocal)

Illustration

Like it, it, I'm sticking to it basically for the sake of my baby ...So, everything, everything for this little baby, that's how we're looking at it. Yeah. (Anne - Pre-existing Type 1 diabetes) p54

Finding 2

Yes. I am a Diabetic - Diabetes as a background (Credibility – Unequivocal)

...[But] I don't think about it too much now and it seems to go along pretty well

and I'm very comfortable regulating my insulin myself. I don't mind doing that at all. So, I guess I don't, only way if it's bad and getting a little high, I guess I might think about it then. I mean I'm just thinking about what I've got to do, but nothing that upsets me by any stretch of the means. Just whatever measures I

have to take to make it good again. (Gloria - pre-existing Type 1 diabetic) p57-

8

Illustration

Finding 3

Yes. I am a Diabetic - The meaning of high risk as a diabetic woman (Credibility - Unequivocal)

Illustration

Like once you get used to it, it's not bad And you don 't think anything of it, and ah, what really annoyed me when I first was pregnant, I was, everybody told me I was at such high risk and I thought, you idiot, I'm not at high risk. But you know, seeing the information, well, yes, I guess I am at that high risk, but you know, I don't feel I'm at high risk, I'm just normal. I could see if my blood sugars were really high, yes, but they're not. (Debbie - Type 1 diabetic) p61

Finding 4

Yes. I am a Diabetic - Diabetes as background and foreground (Credibility – Unequivocal)

Illustration

Because you have to, you've got no choice. You have to have that good extra bit of excellent control. The sugars have to be tested four times a day. I started

that as soon as I took the pregnancy test and it came back positive. My sugars are four times a day. I really started watching what I ate and making sure that there was no extra sugars here or little treats here and there that shouldn't have been there and it's paid off. I switched to low-fat everything and I've only put on ten pounds, but the baby's growing good, so, as a matter of fact, I'm measuring bigger than what I should be right now, but I was big to start with. (Betty - Type 1 diabetic) p63

Finding 5

My Baby Comes First (Credibility – Unequivocal)

I thought, okay, I'm not doing this for me anymore, I'm doing this for somebody else and, I was diagnosed with diabetes and I was on my own for a few years. I had no educator. I didn't have anybody to tell me the rights and the wrongs about it. My family doctor had recommended somebody, but that was as far as it had gone. I had never got a referral. I hadn't had anything like that so, up until I got pregnant and went back to my doctor and he says, "Okay, I'm sending you straight to the [hospital";. That's when it hit me like, this is reality. And ah, we took {the] reins and here we are. It was a wake up call. (Elaine - Type 1 diabetic) p66-7

Illustration

Finding 6

Illustration

This is Hard Work (Credibility – Unequivocal)

woman who doesn't have Type 1 diabetes would do to take of herself during pregnancy, I have to do twice as good. I have to, I, you know what I mean, I have to be twice as careful with, with what I eat and my exercise and my rest and everything -I just have to be better than, than the average woman, really.

I think being pregnant and having Type 1 diabetes just means that whatever a

(Anne - Type 1 diabetic) p68

Finding 7

But, Do You Know ME? (Credibility – Unequivocal)

The other doctors were sort of residents and they weren't, I have given up and so I just go along with whatever they say and I go home and I do what I know. I take in what they tell me and then I'll go home and I'll do what I think is going to work and it usually does. I mean I always take into consideration what they say and I'll try what they say, but I still tend to do what I want to do. And, but today, [the nurse] actually heard me and [the nurse] agreed with me. That was actually a big sense of relief....I'm sure sometimes they've got to think well, she's just being resistant or she's just, she's not listening to us, she's doing this wrong. She's probably doing that. She's probably not telling us or whatever. I know this must be going through their heads, but, and so then, I'm sure they're exasperated and I'm exasperated and so then they just sort of humour me and when I go home and do whatever. But today was a good day. (Gloria - Type 1 diabetic) p71

Illustration

Finding 8

Feeling Afraid (Credibility – Unequivocal)

Illustration

I'm more petrified with this one than I was before. I'm anxious all the time about it. I can't wait for it to get here. With [my daughter] I wanted it to stay in; I always knew it would be protected. This one I want completely out, so I know that it's okay. I just don't know what's happening to it inside, you know, I want it out now, I want to make sure that its okay. (Elaine - Type 1 diabetic) p73

Finding 9

Feeling Guilty: The Weight of Responsibility (Credibility – Unequivocal)

Illustration

This is our first child and, like, probably our, our only child so ...we're not planning any more ...it's not engraved in stone or anything like that, but at the present time, under the circumstances as far as, it's been very stressful, as far as the diabetes. As far as the diabetes, like the strict control, like the, food and, uh, like, you know, the complications that could arise, now mind you, I've been very fortunate and I haven't had any problems, but just, uh, like, the

problems that could- a bigger baby, a deformed baby, like, it, it's very stressful to even think, well, oh my soul, my baby could be deformed because of me and my blood sugars, so, it, uh, it's been kind of stressful that way. (Debbie - Type 1 diabetic) p75

Finding 10

Integrating Past Experience (Credibility – Unequivocal)

I, um, had a miscarriage when I was nineteen and my sugars were way out of control at that time and I kind of always think that that you know that probably was the reason why. So when I found I was pregnant this time, I was so strict with myself in the first three months. I kind of eased up a little but not really usual like after that but I was like really strict the first three months because I just didn't want a repeat of that or anything like that ...but that was like totally unplanned and I wanted it that time too so in a way you know I guess that was probably the best thing that could've happened at the time but I always kind of kept in the back of my mind just knowing that I wasn't taking care of myself at all and that's probably why I ended up miscarrying. (Anne - Type 1 diabetes)

Illustration

Paper 22: Women with pre-existing diabetes and their experiences of maternity care services.⁵⁰

This grounded theory paper by Stenhouse et al. 2012⁵⁰ aimed to explore the experience of maternity care services used by women whose pregnancy is complicated by pre-existing diabetes. Information was gathered via in-depth interviews utilising one-to-one, dyad and group interviews with 12 pregnant women with Type 1 and Type 2 diabetes mellitus and eight of their significant others attending an antenatal clinic of a large district general hospital in South West England. Thematic analysis was undertaken.

This study scored eight out of ten in the QARI critical appraisal tool.

p77

Finding 1

Empathetic care (Credibility – Unequivocal)

Illustration

I don't think they really understand how hard it is, or they certainly don't demonstrate that they understand how hard it is, when all these things happen to a person all in one go..... (Oral medication changed to insulin)... it is a big; to me it is a huge thing. The shock of being pregnant so quickly, the shock of having to inject myself, the shock of living with having to inject and having hypos and understanding diabetes – Soebia - Type 2 diabetes - p3

Finding 2

Feeling judged by health-care professionals (Credibility – Unequivocal)

Illustration

Um...it's been quite...I have found the going into the room with lots of people in there is quite difficult to err ...to handle. It's almost like, I find like ,you're being judged really rather than going into see a panel.- Regina - Type 1 diabetes - p4

Finding 3

The notion of Expertise (Credibility – Unequivocal)

Illustration

I can see why we have to go [to hospital]; obviously because if it was uncontrolled then they'd catch it and then make sure there was nothing to harm the baby.... I think we're not stupid we know what we're doing but, yah obviously you go to make sure the baby is okay, but it can be frustrating.Emily- Type 1 diabetes - p4

Categorisation and synthesis of qualitative research findings

Of the 153 reported findings, four findings were not supported by the data and were not included in the categorisation and synthesis of findings. The remaining 149 findings were extracted from the included studies and were collated to form categories based on identified similarities. Some findings were included in several categories, so a total of 174 study findings were included in the categories. This moves from a focus on individual studies to consideration of all findings for all the studies included in the review. A total of six categories were created on the basis of similarities of meaning, and from these, two synthesised findings (meta-synthesis) were produced as is illustrated in Appendix IV - QARI graph.

Meta-synthesis

Synthesised finding 1 - Health professionals should be aware that their attitudes and practices in the care of women with diabetes during pregnancy needs to be empathetic and based upon a collaborative model of care.

Figure 1 is a diagrammatic representation of Synthesised finding 1

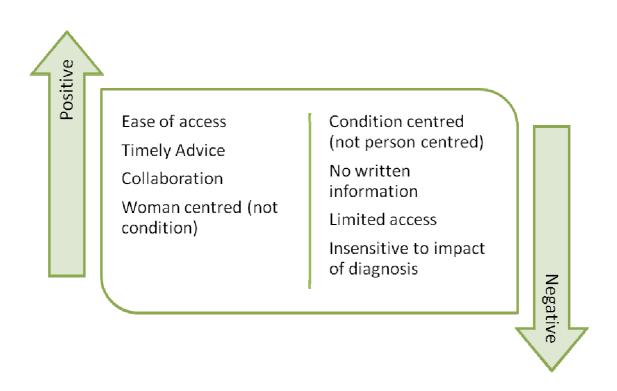


Figure 1 Synthesised finding 1

Health professionals were seen to be supportive and accessible or unsupportive for a variety of reasons: being judgmental, not having relevant information, time-wasting, not acknowledging women's knowledge of diabetes.

Health professionals concentrated on their individual area of expertise rather than treating the woman as a complete individual i.e. diabetes nurse concentrated on diabetes only and midwife on pregnancy only, which was seen to be negative. Health professionals did not always provide enough information in a timely or appropriate fashion to address women's concerns.

This metasynthesis was created from two categories with 29 findings.

Category 1 – Positive effect of health professionals

This category was informed by ten findings from seven studies. The findings all focused on particular positive effects of health professional interactions on pregnant women with diabetes, including knowing the person not just a diagnosis, positive advice for the future, health professional recognising women's knowledge and expertise in managing their condition and working in a collaborative manner and health professionals being easily accessible (e.g. by phone) and supportive. The category

conveys that health professionals can have a positive effect on each woman.

Category 2 – Negative effect of health professionals

This category was informed by 19 findings from 11 studies. The findings all focused on particular negative effects of health professional interactions on pregnant women with diabetes, including lack of relevant information being provided to women regarding the effects of GDM on the child. Culturally appropriate dietary advice was not provided and health professionals concentrated on their own areas of expertise rather than holistic care. Multiple appointments with different health professionals were seen as inconvenient and waiting times both for appointments and referral to specialists were seen as an annoyance and disrespectful to the woman. Health professionals did not provide appropriate written information and were not sensitive to the impact of the diagnosis and required lifestyle modification and treatment to the women. The category conveys that health professionals can have a negative effect on each woman.

Synthesised finding 2 - Women with perceived low adherence need time to adjust and education, these are major factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy.

Figure 2 is a diagrammatic representation of synthesised finding 2

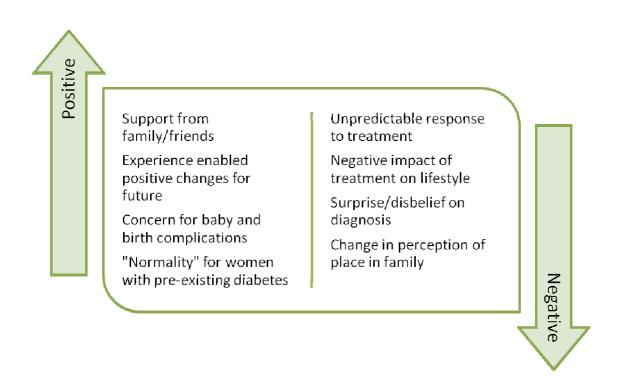


Figure 2 Synthesised finding 2

Women worked out routines and strategies to control their blood glucose with time. They expressed concern and anxiety for the wellbeing of their unborn baby and this often motivated them to control their blood glucose levels. Women with GDM expressed various emotions at the diagnosis including surprise and disbelief and women with pre-existing diabetes were concerned about their loss of diabetic control with pregnancy, their ability to care for existing children and their perception of their place in the family was challenged.

Barriers to adherence to treatment regimes included: the time spent managing their condition, frustration that blood glucose levels seemed unpredictable even though they complied to treatment regimes, concerns with blood glucose monitoring including concerns about blood loss, social isolation and pain associated with finger pricking, concern with the restrictive nature of the prescribed diet and exercise with difficulty with competing priorities with family and social obligations, difficulties with insulin. Some acknowledged however that it made control of their diabetes easier.

Enablers to good adherence to treatment regimes included support by family members and friends, concern about the wellbeing of their unborn child and the effect of their diabetes on the child and delivery of the child. Women with pre-existing diabetes felt that pregnancy conferred 'normality' on them. Women were informed of the causes of diabetes and concerned about their future with diabetes.

This metasynthesis was created from four categories with 145 findings.

Category 3 - Adherence to treatment improves with time, experience and support

This category was informed by 38 findings from 13 studies. The findings all focused on aspects of women's adherence to treatment regimes and the improvement of their adherence with time, experience and support. Factors included women placing more importance of preconception advice depending on their previous pregnancy experiences and being concerned about their future with diabetes. Some women felt that the experience of treatment and monitoring of diabetes in pregnancy meant that they could make lifestyle changes to benefit both themselves and their families in the future and felt empowered to make positive steps toward this goal. With time women gained the skills and knowledge to manage their condition and realised that it was up to them to control their diabetes and worked out strategies to do this. Women were more likely to make positive changes when family members and friends supported them in adhering to their treatment regimes. The category conveys that adherence to treatment regimes improves with time, experience and support.

Category 4 - The restrictions of diabetes impact a woman's lived experience

This category was informed by 35 findings from 13 studies. The findings all focused on aspects of the diagnosis and treatment of pregnant women with diabetes that were perceived to the women as being restrictive in their daily lives. Women felt that diabetes impacted on their social and religious lives due to having to be concerned about the effects of fasting, different foods and exercise regimes on blood glucose levels and having to frequently monitor blood glucose levels made them conspicuous and feel socially isolated. Some women felt that frequent blood glucose monitoring might lead to blood loss and had concerns about the pain associated with frequent finger pricking. Some women had difficulties with insulin including pain with injections and some felt it was associated with mood swings

and that blood glucose levels seemed unpredictable even with good adherence to treatment regimes. Exercise regimes were seen as problematic because of time constraints, tiredness and other physical concerns. The prescribed diet was seen to be restrictive and difficult to fit around competing priorities with family and social obligations and the change from previous eating patterns. The time spent managing their condition was seen as restrictive and of concern to many pregnant women with diabetes. The category conveys that diabetes and its treatment negatively impact the lived experience of pregnant women with diabetes.

Category 5 - Being informed of the risks and causes of diabetes in pregnancy increases both anxiety and motivation

This category was informed by 51 findings from 18 studies. The findings all focused on the anxiety-inducing and motivating effects when pregnant women with diabetes were informed of the risks and causes of diabetes in pregnancy. Women were informed and concerned that their diabetes put their unborn child at greater risk of abnormality or birth complications than the general population and that caesarean section was a likely delivery option. This motivated them to control their blood glucose levels. Women with pre-existing diabetes were motivated to work harder to control their diabetes than before pregnancy to minimise these risks. Women were aware of the association with genes and obesity but some were misinformed and anxious about a perceived infectious nature of transmission of diabetes through breast milk. The category conveys that pregnant women with diabetes being informed of the risk and causes of their diabetes can increase their anxiety but also motivation for good treatment outcomes.

Category 6 - Diabetes causes a change in women's perception of self and their place in the family and of control of self

This category was informed by 21 findings from 12 studies. The findings all focused on the change in the woman's perception of self: her perception of herself within the family unit and her perception of

being in control of herself, brought about by being pregnant with diabetes. Women expressed various emotions, such as surprise and disbelief, with the diagnosis of GDM and also of pregnancy for some women with pre-existing diabetes. Women's underlying health beliefs suggested that they felt that the health of the mother was important for family functioning and that diabetes compromised that role. Women with pre-existing diabetes expressed concern for their existing children and their ability to care for them in the event of hypoglycaemia. Women with pre-existing diabetes felt that pregnancy provided them with a sense of proof of normality. Many women conveyed a sense that they were inherently unlucky. The category conveys that the diagnosis of pregnancy in a diabetic woman or the diagnosis of gestational diabetes in a pregnant woman can have an effect on her self-perception and of her role in her family and society.

Chapter 4

Discussion

This systematic review of the qualitative evidence was undertaken to gain insight and understanding of women's experience of diabetes and diabetes management in pregnancy with the objective of ascertaining how these experiences relate to their understanding of their condition and adherence to treatment regimes.

The 22 papers included in the meta-synthesis resulted in 174 findings, which were developed into 6 categories and two synthesised findings. These were:

- "Health professionals should be aware that their attitudes and practices in the care of women
 with diabetes during pregnancy needs to be empathetic and based upon a collaborative
 model of care" and
- "Women with perceived low adherence need time to adjust and education; these are major factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy"

These synthesized findings provide insight into factors affecting pregnant women's adherence to treatment regimes for diabetes.

A 2008 Cochrane review¹³ was conducted to ascertain the evidence for interventions to enhance adherence to medication regimes. For short-term drug treatments, counselling, written information and personal phone calls were beneficial. For long-term treatments, no simple intervention led to improvements in health outcomes. More complex interventions including combinations of more convenient care, information, counselling, reminders, self-monitoring, reinforcement, family therapy, psychological therapy, mailed communications, crisis intervention, manual telephone follow-up, and

other forms of additional supervision or attention were beneficial. However, even with the most effective methods for long-term treatments, improvements in drug usage or health were small.

The first synthesised finding - Health professionals should be aware that their attitudes and practices in the care of women with diabetes during pregnancy needs to be empathetic and based upon a collaborative model of care – identified that women perceived health professionals to be both positive and negative influences on the management of their diabetes in pregnancy.

Health professionals were seen to be a positive influence when they provided timely, appropriate advice that encompassed both the diabetes and the pregnancy, and when different health professionals reinforced each other. The research indicated that health care settings should facilitate patient-centred practice where appropriate healthcare professionals are easily accessible to patients in a timely fashion and health care professionals should work collaboratively to reinforce each other within their respective specialties, and provide information to women in a timely and culturally appropriate manner.

Health professionals were seen to be a negative influence where there was little cooperation between specialties and where women perceived their condition was being managed rather than them being treated as a whole person. Central to this was being given accurate, appropriate information about their condition and treatment in a timely and culturally appropriate fashion. A recurring theme was that insufficient or culturally inappropriate information was provided about diet and lifestyle factors related to treatment, and that consultations with various specialist health professionals often took some time to arrange and this created both anxiety and frustration. The disjointed nature of many of these appointments also frustrated women who found difficulty with the additional time demand in their already busy lives. Some health professionals were seen to be judgmental and dismissive of women's prior knowledge of diabetes. A number of women identified a lack of appropriate written information and several identified that peer support would be valuable. These findings are consistent with findings from Kardas' recent review of systematic reviews of determinants of patient adherence, where healthcare team and system-related factors affecting adherence having a negative effect on adherence included lack of providers/caregiver availability and poor access to a healthcare facility

(e.g. long waiting times, queues, lack of privacy, inconvenient appointment times, inconvenient opening hours, seeing a different language speaking therapist, difficulty in obtaining sick leave for treatment, and having no time to refill prescriptions, or other pharmacy-related problems). Drug related matters having a negative effect on adherence include unclear information about proper drug administration, greater number of prescribing physicians, conflicting messages between GPs and specialists on medication, discrepancies between treatment guidelines and common clinical practice (as patients try to ask several specialists) and use of multiple pharmacies. Health care provider-client communication and relationship issues having a negative effect on adherence included poor healthcare provider-patient relationship, poor patient-physician communication, lack of trust in doctors and healthcare, lack of patient satisfaction with their healthcare and limited caregiver adherence strategies. Positive effects on adherence included quality, duration and frequency of interaction between the patient and doctor, offering enough time to the patient, leaving space to talk about problems concerning medication or side effects, patient involvement in decision making, encouraging self-management, Doctor responsiveness, Doctor's ability to demonstrate empathy, Doctor's ability to elicit and respect the patient's concerns, and perceived healthcare provider support. Drug related matters having a positive effect on adherence included Doctor's ability to provide appropriate information as to the drug administration and being given information about the action of the drugs and prescription by a specialist.⁵² There is increasing emphasis on 'teaching' empathy in medical and other health professional undergraduate programs.⁵³ The findings of this review suggest that continued development and promotion of such programs would benefit patient's adherence to treatment regimes.

The second synthesised finding - Women with perceived low adherence need time to adjust and education; these are major factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy – identified a number of factors that positively and negatively affected women's attitudes to diabetes and their adherence to treatment regimes.

Women were generally informed that there were risks to the foetus, delivery and their future health risks. These were major motivating factors to adhere to medical advice, although they also produced some angst and self-blame. Some women expressed gratitude for the advice given and felt

empowered to alter lifestyle and diet to positively influence the future health of themselves and their families. Other enablers of adherence to treatment recommendations included support from partners and family.

Barriers to adherence to treatment included difficulties with advice given and the treatment itself. Some women found dietary advice difficult to adhere to, as the foods recommended were not culturally familiar to them, time consuming to prepare and often seen to be expensive. Some women had concerns with customs around various religious festivals. The acts of finger pricking for blood glucose measurements and administration of insulin were said to be painful and time-consuming. Exercise was mentioned as being time consuming and difficult due to the physical constraints of pregnancy. For those women using insulin, hypoglycaemia was seen as a major difficulty, especially if they had responsibility for other children. Again these concerns are similar to those in Kardas' review⁵² – where therapy related factors affecting negative adherence included complexity of the regimen (e.g. complex/frequent dosing schedule/number of tablets), number of prescribed medications (polymedication), doses during the day (particularly the middle-of-day or early-morning doses), instability of the regimen, need to adjust dietary habits for taking medication, and disliking aspects of the medication. Positive factors included simple regimen, fewer drugs prescribed, long acting formulation, unit-of-use packaging, and flexibility/patient choice in treatment regular medication schedule (vs. irregular dose interval).

For some women with Type 2 or GDM, treatment with oral hypoglycaemics may be a clinically suitable alternative to insulin if diet and exercise therapy is insufficient and this would address concerns with the frequent blood glucose monitoring associated with insulin, the insulin itself and in part, the concern some women had with hypoglycaemia. Additionally it has been shown that complex medication regimes are more likely to result in poor adherence to medication,⁵² so simpler oral regimes may be preferable to injectable, where they are clinically appropriate.

There was little mention of the use of oral hypoglycaemics in this review. Metformin particularly is increasingly being used for diabetes in pregnancy, although many guidelines used for diabetes in

pregnancy imply that insulin should be instituted when diet and exercise are not sufficient. With its lesser propensity to cause hypoglycaemia (which was a concern of women using insulin), consideration should be given to using metformin or glibenclamide, which have not been shown to be teratogenic, where clinically appropriate.

This was highlighted in some of the findings of the review, for example: "I don't think they really understand how hard it is, or they certainly don't demonstrate that they understand how hard it is, when all these things happen to a person all in one go..... (oral medication changed to insulin)... it is a big; to me it is a huge thing. The shock of being pregnant so quickly, the shock of having to inject myself, the shock of living with having to inject and having hypos and understanding diabetes" -Soebia - Pre-existing Type 2 diabetes - p 3 - Stenhouse et al 2012.⁵⁰ This statement encompasses a number of concerns that women expressed. Hypoglycaemia is one of these concerns. For women with Type 1 diabetes and Type 2 diabetes treated with insulin the loss of the normal hormonal responses to hypoglycaemia results in loss of the ability to recover spontaneously from insulininduced hypoglycaemia. Also there is a syndrome of 'hypoglycaemia unawareness', or the lack of recognisable autonomic responses to hypoglycaemia (palpitations, tremor, sweating) due to defective adrenaline secretion in response to hypoglycaemia in these women.⁵⁴ For women with pre-existing Type 2 diabetes or GDM hypoglycaemia is more common with insulin therapy than oral hypoglycaemics^{55, 56} and consideration should be made to continue their use where clinically appropriate. Safety of both glibenclamide and metformin in pregnancy has been established. 56-58 although it is acknowledged that no long term neonatal follow-up studies have been performed. An Australian study - Metformin in Gestational diabetes - MiG⁵⁹ - gathered information on the acceptability to women of metformin treatment in GDM via questionnaire. They showed that 76.6% of women treated with metformin would choose metformin in a subsequent pregnancy whereas only 27.2% of women treated with insulin would choose insulin again. Also more women treated with metformin than insulin said that taking medication was the easiest part of treatment and fewer women taking metformin than insulin said that taking medication was the hardest part of treatment.

Separately from pregnancy the risk of hypoglycaemia in patients with Type 2 diabetes is particularly elevated in those receiving insulin therapy. Patients with type 2 diabetes mellitus treated with sulfonylureas such as glibenclamide are also at increased risk of experiencing hypoglycaemic symptoms. Metformin monotherapy is not associated with hypoglycaemia.^{60, 61} It has been demonstrated that hypoglycaemia is inversely related to quality of life and well-being in patients with T2DM.⁶⁰.Guidelines in few countries include metformin or glibenclamide for antenatal management of GDM with a survey study of GDM health workers reporting 17% of countries surveyed reporting use of metformin and 10.6% glibenclamide.⁶² Additional attractions for using these drugs are decreased cost and easier administration than insulin if diet therapy is insufficient.

Limitations of the review

There are a number of potential limitations with this review. While a systematic search was carried out and every effort made to identify relevant studies it is possible that some studies may have been missed. Qualitative studies can be hard to find and indexing is poorer than for quantitative studies, as they are often not referenced in the usually indexed search engines. Also studies that have been conducted and indexed since the search have not been included in this review, and it may be necessary to perform and update as other studies are conducted. Only English language studies were included and this presents another limitation.

This review pooled the data from participants with pre-existing and GDM and also women from ethnic minority groups, at-risk groups and from across socioeconomic groups where subgroup analysis may reveal different findings.

Conclusion

This review identified a number of studies addressing the pregnant women's experience of adherence to treatment for diabetes during the course of pregnancy. Findings were extracted from these studies and then synthesised. These synthesised findings stressed that health professionals should recognise

that pregnant women's experiences of their medical conditions and treatments can affect their adherence to treatment regimes and therefore their continued health and benefit perinatal outcomes. Health professionals also need to acknowledge that both the medical condition and pregnancy are only part of women's complex lives and that treatment regimes should accommodate this as far as possible. Treatment of the pregnant diabetic involves a number of different health professionals and it is important that these professions works in synchrony and appointments are made in a timely and appropriate time frame. The 2008 Cochrane review¹³ conducted to ascertain the evidence for interventions to enhance adherence to medication regimes showed that for short-term drug treatments, counselling, written information and personal phone calls were beneficial. This is particularly relevant for the treatment of GDM as the condition is likely to be relatively short-term (albeit with longer-term consequences and risks), and indeed many of the women in this review cited the need for timely delivery of information, both written and verbal, to be advantageous to improving their understanding of and adherence to treatment regimes.

The findings of this review suggest that the simplest clinically appropriate treatment should be offered to women with diabetes in pregnancy and that education needs to be offered, both orally and written, to support them to adjust to their condition, which for many of them was a life-changing circumstance.

Implications for practice

Health professionals should be aware of the implications of the two synthesised findings of this review, namely that:

- Health professionals should be aware that their attitudes and practices in the care of women
 with diabetes during pregnancy needs to be empathetic and based upon a collaborative
 model of care
- Continued development and promotion of educational programs with an emphasis on 'teaching' empathy in medical and other health professional undergraduate programs would benefit patient's adherence to treatment regimes.
- Women with perceived low adherence need time to adjust and education. These are major

factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy.

Implications for research

Metformin is increasingly being used for the treatment of diabetes in pregnancy. There is also evidence that glibenclamide is used in pregnancy and both show no indication of teratogenic effects. ⁵⁶⁻⁵⁸ There is some information that women with GDM prefer to use metformin rather than insulin where it is clinically appropriate, ⁵⁹ but little other information regarding women's experience or perceptions of taking these medications whilst pregnant. It would be interesting to ascertain women's experience and attitudes to taking these medications via qualitative enquiry, and to determine if interventions for improvement of adherence differ between women who are pregnant and the general population as detailed in the Cochrane review¹³, although evidence provided from this review suggests, that at least for short-term treatment successful interventions for pregnant women with diabetes might be similar as for the general population.

Conflict of Interest

None noted

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Appendix I: Search strategy

Pubmed - search conducted 22 October 2012

#4 Add Search ((#3) AND #2) AND #1

#3 Add Search Experience[tw] OR interviews as topic[mh] OR interview*[tw] OR focus group*[tw] OR anecdotes as topics[mh] OR anecdot*[tw] OR qualitative research[mh] OR qualitative[tw] OR grounded theor*[tw]

#2 Add Search Diabet*[tw] OR glucose metabolism disorders[mh] OR prediabet*[tw] OR blood glucose[mh] OR blood glucose self-monitoring[mh] OR blood glucose[tw] OR blood sugar*[tw] OR glucose tolerance test[mh] OR glucose tolerance[tw] OR hypoglycem*[tw] OR hypoglycem*[tw]

#1 Add Search Pregnan*[tw] OR pregnancy[mh:noexp] OR prenatal care[mh] OR prenatal[tw] OR pregnancy in diabetes[mh] OR matern*[tw] OR maternal behaviour[mh] OR mother*[tw] OR mothers[mh] OR pregnancy trimesters[mh] OR trimester*[tw]

Embase - search conducted 22 October 2012

#4#1 AND #2 AND #3

#3'pregnancy'/exp OR pregnan*:ab,ti OR 'prenatal care'/exp OR prenatal:ab,ti OR 'maternal behaviour'/exp OR matern*:ab,ti OR 'mother'/exp OR mother*:ab,ti OR trimester*:ab,ti

#2'disorders of carbohydrate metabolism'/exp OR diabetes:ab,ti OR diabetic:ab,ti OR 'glucose blood level'/exp OR 'blood glucose monitoring'/exp OR 'blood glucose':ab,ti OR 'blood sugar':ab,ti OR hypoglycem*:ab,ti OR hyp

#1'qualitative research'/exp OR 'qualitative analysis'/exp OR qualitative:ab,ti OR 'interview'/exp OR interview:ab,ti OR interviews:ab,ti OR 'focus group':ab,ti OR 'focus groups':ab,ti OR 'grounded theory'/exp OR 'grounded theory':ab,ti OR 'content analysis'/exp OR 'content analysis':ab,ti OR 'thematic analysis':ab,ti OR 'thematic analysis'/exp OR 'nursing research'/exp

Cinahl - search conducted 22 October 2012

S4 S1 and S2 and S3

S3 (MH "Mothers") OR (MH "expectant mothers") OR mother\$ OR (MH "Pregnancy Trimesters") OR (MH "Pregnancy") OR (MH "Postnatal Period") OR (MH "Periconceptual Period") OR trimester OR Pregnan\$ OR Matern\$

S2 (MH "Blood Glucose") OR (MH "Blood Glucose Monitoring") OR (MH "Blood Glucose Self-Monitoring") OR "diabetes and pregnancy" OR (MH "Diabetes Mellitus, Gestational") OR (MH "Diabetes Mellitus") OR (MH "Pregnancy in Diabetes") OR (MH "Prediabetic State") OR "gestational diabetes" OR "gestational diabetic" OR diabetic

S1 (MH "Qualitative Studies+") or "Action Research" or "Ethnographic Research" or "Ethnological Research" or "Ethnonursing Research" or "Grounded Theory" or "Naturalistic Inquiry" or "Phenomenological Research" or phenomenology or "focus group" or (MH Interviews+) or "qualitative research" or (MH "Discourse Analysis") OR (MH "Thematic Analysis") OR (MH "Content Analysis") OR (MH "Focus group")

PsychINFO - search conducted 22 October 2012

S1 and S2 and S3

S3 DE "Qualitative Research" OR DE "Empirical Methods" OR DE "Grounded Theory" OR DE "Interviews" OR DE "Observation Methods" OR DE "Grounded Theory" OR DE "Interviews" OR DE "Hermeneutics" OR DE "Phenomenology" OR qualitative OR experience OR perception OR understand OR understanding OR belief

S2 DE "Diabetes" OR DE "Diabetes Mellitus" OR DE "Diabetes" OR DE "Diabetes Mellitus" OR DE "Glucose" OR DE "Sugars" OR DE "Blood Sugar" OR diabetes OR diabetic OR diabetics OR "gestational diabetes" OR "gestational diabetics" or "pregnancy in diabetics" OR "gestational diabetic" S1 (DE "Pregnancy") OR (DE "Obstetrical Complications") OR (DE "Pregnancy Outcomes") OR (DE "Expectant Mothers") OR (DE "Mothers") OR pregnancy OR maternal OR maternity OR prenatal OR gestational OR pregnant

Academic Search Premier - search conducted 22 October 2012

S1 and S2 and S3

S3 (MH "Qualitative Studies+") or "Action Research" or "Ethnographic Research" or "Ethnological Research" or "Ethnonursing Research" or "Grounded Theory" or "Naturalistic Inquiry" or "Phenomenological Research" or phenomenology or "focus group" or (MH Interviews+) or "qualitative research" or (MH "Discourse Analysis") OR (MH "Thematic Analysis") OR (MH "Content Analysis") OR (MH "Focus group")

S2 (MH "Blood Glucose") OR (MH "Blood Glucose Monitoring") OR (MH "Blood Glucose Self-Monitoring") OR "diabetes and pregnancy" OR (MH "Diabetes Mellitus, Gestational") OR (MH "Diabetes Mellitus") OR (MH "Pregnancy in Diabetes") OR (MH "Prediabetic State") OR "gestational diabetes" OR "gestational diabetic" OR diabetic

S1 (MH "Mothers") OR (MH "expectant mothers") OR mother\$ OR (MH "Pregnancy Trimesters") OR (MH "Pregnancy") OR (MH "Postnatal Period") OR (MH "Periconceptual Period") OR trimester OR Pregnan\$ OR Matern\$

Biosis Previews - search conducted 23 October 2012

4 #3 AND #2 AND #1

3 TS=Diabet* OR TS=(glucose metabolism disorders) OR TS=prediabet* OR TS=(blood glucose)
OR TS=(blood glucose self-monitoring) OR TS=(blood glucose) OR TS=(blood sugar*) OR
TS=(glucose tolerance test) OR TS=(glucose tolerance) OR TS=hypoglycem* OR TS=hypoglycem*
OR TS=(gestational diabet*)

2 TS=Pregnan* OR TS=pregnancy OR TS=(prenatal care) OR TS=prenatal OR TS=(pregnancy in diabetes) OR TS=matern* OR TS=(maternal behaviour) OR TS=mother* OR TS=mothers OR TS=(pregnancy trimesters) OR TS=trimester*

1 TS=Experience OR TS=interview* OR TS=(focus group*) OR TS=anecdot* OR TS=(qualitative research) OR TS=qualitative OR TS=(grounded theor*)

Ethos - search conducted 23 October 2012

Experience or Qualitative AND Diabetes or Diabetic AND Pregnancy or Pregnant

Index to Thesis - Search conducted 23 October 2012

(experience) OR (qualitative) AND (diabetes) AND (pregnancy)

Mednar - search conducted 23 October 2012

pregnan* and diabet* and (qualitative or experienc*)

Proquest dissertations and theses - search conducted 23 October 2012

(TI,AB(pregnan*) OR TI,AB(prenatal) OR TI,AB(mater*) OR TI,AB(mother*) OR TI,AB(trimester*))

AND (TI,AB(disorders of carbohydrate metabolism) OR TI,AB(diabet*) OR TI,AB(glucose blood level*)

OR TI,AB(blood glucose monitoring) OR TI,AB(blood glucose) OR TI,AB(blood sugar) OR

TI,AB(hypoglycaemia*) OR TI,AB(hyperglycemia*) OR TI,AB(glucose tolerance)) AND

(TI,AB(qualitative) OR TI,AB(interview*) OR TI,AB(focus group*) OR TI,AB(grounded theory) OR

TI,AB(content analysis) OR TI,AB(thematic analysis) OR TI,AB(nursing research) OR

TI,AB(experience*))

Appendix II: Appraisal instrument

QARI Appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer	Date			
Author	Year	Rec	ord Numbe	er
	Yes	No	Unclear	Not Applicable
Is there congruity between the stated philosophical perspective and the research methodology?	П	□	Unclear □	Not Applicable
Is there congruity between the research methodology and the research question or objectives?	. 🗆			
3. Is there congruity between the research methodology and the methods used to co data?	llect			
4. Is there congruity between the research methodology and the representation and analysis of data?				
Is there congruity between the research methodology and the interpretation of res	ults?			
6. Is there a statement locating the researche culturally or theoretically?	er 🗆			
7. Is the influence of the researcher on the research, and vice- versa, addressed?				
8. Are participants, and their voices, adequat represented?	ely 🗆			
9. Is the research ethical according to curren criteria or, for recent studies, and is there evidence of ethical approval by an approp body?				
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?				
Overall appraisal: Include	Exclude		Seek fu	rther info.
Comments (Including reason for exclusion)				

Appendix IIa – Final Assessment Table

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Brooks 2002 ³²	U	Υ	Υ	Υ	Υ	N	N	Υ	Υ	Υ
Sheffer 2000 ⁴⁶	Υ	Υ	Υ	Υ	Υ	N	N	Υ	Υ	Υ
Berg 2005 ³⁹	Y	Y	Υ	Υ	Υ	Υ	U	Υ	Υ	Υ
Berg & Honkasalo 2000 ⁴⁰	Y	Y	Υ	Y	Υ	Υ	U	Υ	U	Υ
Carolan et al, 2012 ⁴²	Y	Y	Υ	Υ	Υ	Υ	N	Υ	Y	Υ
Evans & O'Brien, 2005 ⁴³	Y	Y	Υ	Y	Υ	N	N	Υ	Y	Υ
Hamel 2003 ⁴⁷	Y	Y	Υ	Υ	Υ	Υ	Υ	Υ	Y	Υ
Hirst et al 2012 ³³	U	Y	Υ	Υ	Υ	Υ	N	Υ	Y	Υ
Hjelm et al 2005 ³⁵	U	Y	Υ	Y	Υ	U	N	Υ	Y	U
Hjelm et al 2007 ³⁶	U	U	Υ	Y	Υ	N	U	Υ	Y	U
Hjelm et al 2008 ³⁷	U	Y	Υ	Y	Υ	U	U	Υ	Y	Υ
Horrocks 2009 ⁴⁸	Y	Y	Υ	Υ	Υ	Υ	Υ	Υ	Y	Υ
Lavender et al 2010 ⁴⁴	Y	Y	Υ	Y	Υ	Υ	U	Υ	Y	Υ
Persson et al 2010 ⁴⁹	Y	Y	Υ	Y	Υ	U	Υ	Υ	Y	Υ
Neufeld 2011 ³⁸	U	Y	Υ	Y	Υ	U	U	Υ	Y	Υ
Richmond 2009 ⁴⁵	Y	Y	Υ	Y	Υ	U	U	Υ	U	Υ
Stenhouse et al 2012 ⁵⁰	U	Y	Y	Y	Υ	Υ	U	Υ	Υ	Υ

Hjelm K et al 2012 ³⁴	U	Y	Y	Υ	Y	U	U	Y	Y	Υ
Lawson & Rajaram 1994 ⁵¹	U	Y	Y	Υ	Υ	N	N	Y	U	Υ
Bandyopadhyay et al 2011 ³⁰	U	Υ	Y	Υ	U	U	N	N	Y	Υ
Carolan 2013 ⁴¹	Y	Y	Y	Υ	Υ	Υ	Υ	Y	Y	Υ
Bieda 2009 ³¹	Y	Υ	Y	Υ	Υ	U	U	Υ	Y	Υ
%	54.55	95.45	100.0	100.0	95.45	40.91	18.18	95.45	86.36	90.91

Appendix III: Data extraction instruments

QARI data extraction instrument

JBI QARI Data E & Critical Resea	xtraction Form	n for Interpretive	
Reviewer		Date	
Author		_ Year	
Journal		_ Record Number	
Study Description			
Methodology			
Method			
Phenomena of interest			
Setting			
Geographical			
Cultural			
Participants			
Data analysis			
Authors Conclusions			
Comments			
Complete	Yes 🗌	No 🗆	

	Illustration from		Evidence	
Findings	Publication (page number)	Unequivocal	Credible	Unsupported
	1		1	
Extraction of findings cor	nplete Yes		No 🗆	

Appendix IV: Qari graph - Alternative presentation of synthesised findings and metasynthesis

Synthesised finding 1 - Health professionals should be aware that their attitudes and practices in the care of women with diabetes during pregnancy needs to be empathetic and based upon a collaborative model of care.

Health professionals were seen to be either supportive and accessible or unsupportive for a variety of reasons. These included being judgmental of the woman, not providing relevant information, timewasting, and not acknowledging women's knowledge of diabetes.

Health professionals concentrated on their individual area of expertise rather than treating the woman as a complete individual. For example, diabetes nurse concentrated on diabetes only and the midwife on pregnancy only, which was seen to be negative. Health professionals did not always provide enough information in a timely or appropriate fashion to address women's concerns.

This metasynthesis was created from 2 categories, being "positive effects of health professionals" and "negative effects of health professionals", with a total of 29 Findings. Levels of credibility (as detailed for use with JBI-QARI) are also included for each finding.

Synthesised finding 2 - Women with perceived low adherence need time to adjust and education; these are major factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy.

With time women worked out routines and strategies to control their blood glucose. They expressed concern and anxiety for the wellbeing of their unborn baby and this often motivated them to control

their blood glucose levels. Women with gestational diabetes expressed various emotions at the diagnosis including surprise and disbelief and women with pre-existing diabetes were concerned about their loss of diabetic control with pregnancy, their ability to care for existing children and their perception of their place in the family was challenged.

Barriers to adherence to treatment regimes included: the time spent managing their condition, frustration that blood glucose levels seemed unpredictable even though they complied to treatment regimes, concerns with blood glucose monitoring including concerns about blood loss, social isolation and pain associated with finger pricking, concern with the restrictive nature of the prescribed diet and exercise with difficulty with competing priorities with family and social obligations, and difficulties with insulin. Some acknowledged however that using insulin made control of their diabetes easier.

Enablers to good adherence to treatment regimes included support by family members and friends, concern about the wellbeing of their unborn child and the effect of their diabetes on the child and delivery of the child. Women with pre-existing diabetes felt that pregnancy conferred 'normality' on them. Women were informed of the causes of diabetes and concerned about their future with diabetes.

This metasynthesis was created from 4 categories, being "the restriction of diabetes impact a woman's lived experience", "diabetes caused a change in women's perception of self and their place in the family and of control of self", "being informed of the risks and causes of diabetes in pregnancy increases both anxiety and motivation" and "adherence to treatment improves with time, experience and support" with a total of 145 Findings. Levels of credibility (as detailed for use with JBI-QARI) are also included for each finding as illustrated in the QARI view graph below.

Synthesised Findings

Meta-Synthesis 1:

Finding	Category	Synthesised Finding
Barriers to GDM self-management: Limited comprehension: Limited understanding of GDM (U) ⁴² Barriers to GDM self-management: Limited comprehension: Limited understanding of GDM self-management requirements (U) ⁴² Barriers to GDM self-management: Time pressures: The urgency of immediate change (U) ⁴² Beliefs about health care (U) ³⁷	Negative effects of Health Professionals	Health professionals should be aware that, their attitudes and practices in the care of women with diabetes during pregnancy needs to be empathetic and based upon a collaborative model of care. Health professionals were seen to be supportive and accessible or unsupportive for a variety of reasons: being judgemental, not having relevant information, time- wasting, not acknowledging women's knowledge of diabetes. Health professionals concentrated on their individual area of expertise rather than treating the woman as a complete individual

But, Do You Know ME? (U)46

Confusion and concern about the diagnosis of GDM (U)33

Empathetic care (U)50

Experiencing a transformed pregnancy - patient-provider interactions (U)⁵¹

Feeling judged by health-care professionals (U)50

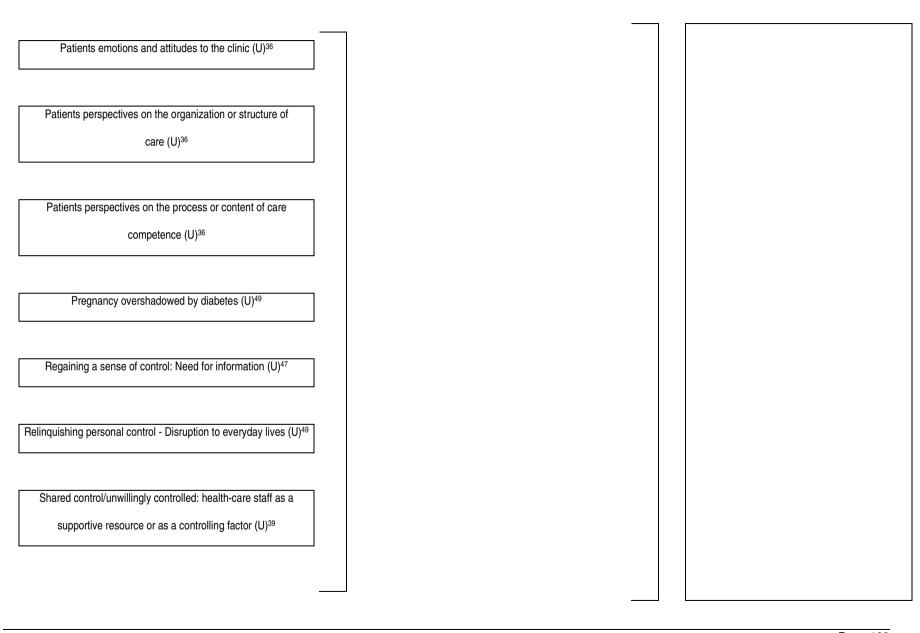
How Do Women With Type 1 Diabetes View Themselves During

Pregnancy - Risky vs. Nurturing Body - Objectified

(U)⁴⁸

Meaningfulness/meaninglessness: Ambivalence (U)³⁹

i.e. diabetes nurse concentrated on diabetes
only and midwife on pregnancy only, which
was seen to be negative. Health
professionals did not always provide enough
information in a timely or appropriate fashion
to address women's concerns.



The desire for more information about GDM (U) ³³ But, Do You Know ME? (U) ⁴⁶ Health (U) ³⁴		
Planning for a Healthier Birth and Beyond: Support and Information (U) ⁴⁷ Relinquishing Personal control - surrendering control to others	Positive effect of health professionals	Health professionals should be aware that, their attitudes and practices in the care of women with diabetes during pregnancy
(U) ⁴⁹ Sources of Gestational Diabetes Knowledge (U) ³¹	Fositive effect of fleatiff professionals	 needs to be empathetic and based upon a collaborative model of care. (cont.)
The notion of Expertise (U) ⁵⁰		
What Are the Participants Views on the Support They Receive		

From Others - Supportive Networks (U)⁴⁸ What Are the Participants Views on the Support They Receive From Others - Supportive Networks - Professional Support How to Promote Self Care - Collaborative care (U) 48 What Are the Participants Views on the Support They Receive From Others - Supportive Networks - Professional Support How to Promote Self Care - Holistic care (U) 48 What Are the Participants Views on the Support They Receive From Others - Supportive Networks - Professional Support How to Promote Self Care - Specialist care (U) 48

Meta-Synthesis 2:

Balancing: Issues of Control - Gaining control

(U) 48

Balancing: Issues of Control - Losing control.

(U) 48

Barriers to GDM self-management: Insulin as an easier option (U)

42

Barriers to GDM self-management: Limited comprehension:

Limited understanding of GDM self-management requirements (U)

42

Barriers to GDM self-management: Physical constraints (U) 42

Barriers to GDM self-management: Social constraints: Disruption to the family (U) 42

......The restrictions of diabetes impact a woman's lived experience

Women with perceived low adherence need time to adjust and education, these are major factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy.

With time women worked out routines and

strategies to control their blood glucose.

They expressed concern and anxiety for the wellbeing of their unborn baby and this often motivated them to control their blood glucose levels. Women with GDM expressed various emotions at the diagnosis including surprise and disbelief and women with pre-existing diabetes were concerned about their loss of diabetic control with pregnancy and their ability to care for existing children and their

Barriers to adherence to treatment regimens

perception of their place in the family was

challenged.

Barriers to GDM self-management: Social constraints: Festivities and social functions (U) 42

Barriers to GDM self-management: Social constraints: Finding the balance (U)⁴²

Barriers to GDM self-management: Time pressures: Finding time for everything (U)⁴²

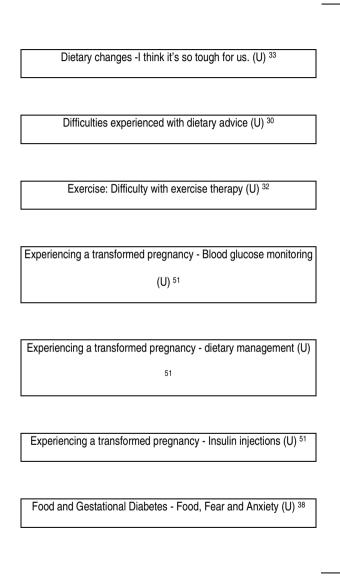
Barriers to GDM self-management: Time pressures: The urgency of immediate change (U) 42

Blood glucose monitoring: access and understanding barriers (U) 33

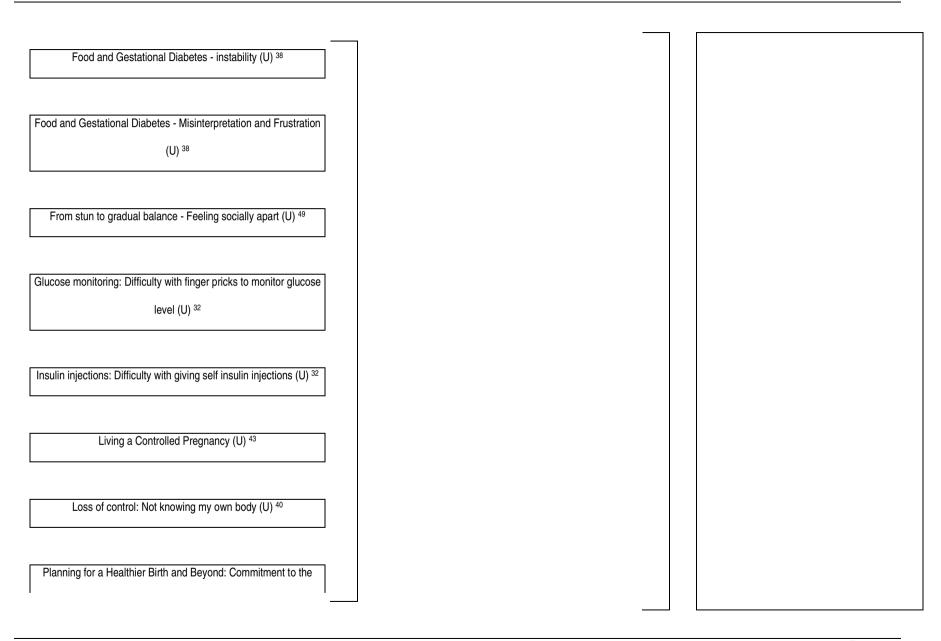
Diet: Difficulty with diet therapy (U) 32

included: the time spent managing their condition, frustration that blood glucose levels seemed unpredictable even though they complied to treatment regimes, concerns with blood glucose monitoring including concerns about blood loss, social isolation and pain associated with finger pricking, concern with the restrictive nature of the prescribed diet and exercise with difficulty with competing priorities with family and social obligations, difficulties with insulin. Some acknowledged however that it made control of their diabetes easier. Enablers to good adherence to treatment regimens included support by family members and friends, concern about the wellbeing of their unborn child and the effect of their diabetes on the child and delivery of

the child, women with pre-existing diabetes



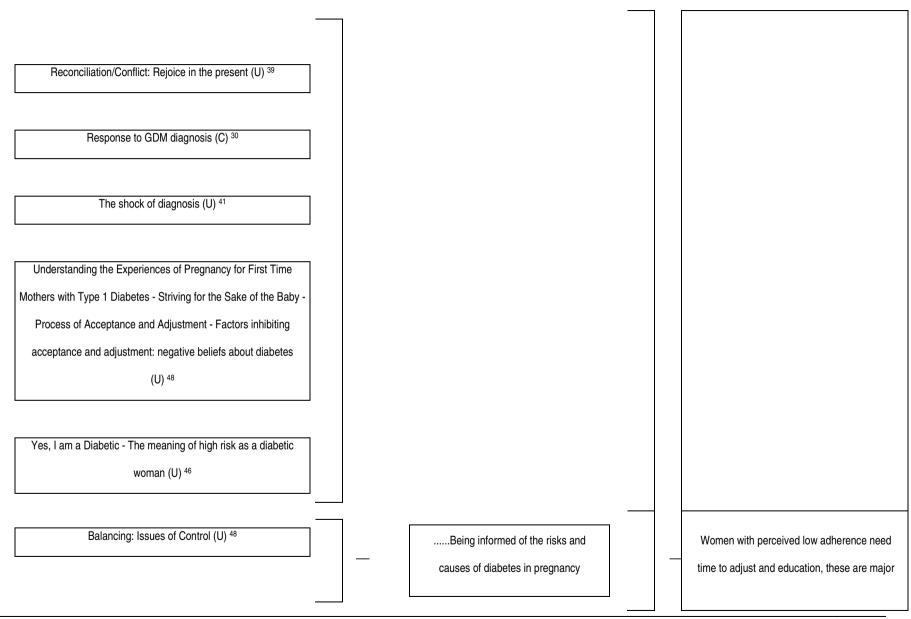
felt that pregnancy conferred 'normality' on them. Women were informed of the causes of diabetes and concerned about their future with diabetes.



	 _	
Fetus's Well-Being (U) 47		
Planning for a Healthier Birth and Beyond: Support and Information (U) 47		
.,		
Reconciliation/Conflict: Lack of self-understanding (U) 39		
Reconciliation/Conflict: opposition (U) 39		
Regaining a sense of control: Perceived threat (U) 47		
Relinquishing personal control - Disruption to everyday lives (U) 44		
Side effects: Negative side effects associated with pregnancy and insulin (U) 32		
. ,		
Treatment Experiences (U) 38		
-		

Weight issues and exercise (C) 30		
Beliefs about health (U) 35,37		
Beliefs about illness (U) 35		
Concerns for existing children (U) ⁴⁵		Women with perceived low adherence need
Coping with negative emotions (U) 48	Diabetes caused a change in women's perception of self and their place in the family and of control of self	time to adjust and education, these are major factors positively affecting women's motivation for adherence to treatment for
Emotional Responses to the Diagnosis of Gestational Diabetes (U)		diabetes in pregnancy. (cont.)
From stun to gradual balance - Changing the self-image (U) ⁴⁹		

	<u> </u>	1	
From stun to gradual balance - Struck by lightning (U) 49			
Getting diagnosed with Gestational Diabetes (U) 47			
hypoglycaemia (U) ⁴⁵			
Loss of control: wishing for a normal life with control (U) 40			
Meaningfulness/meaninglessness: Confirmed normality (U) 39			
Meaningfulness/meaninglessness: Fortified malaise (U) 39			
Meaningfulness/meaninglessness: Hopelessness (U) 39			
Objectification: you'll get hit sooner or later (U) 40			
Reconciliation/Conflict: Acceptance (U) 39			

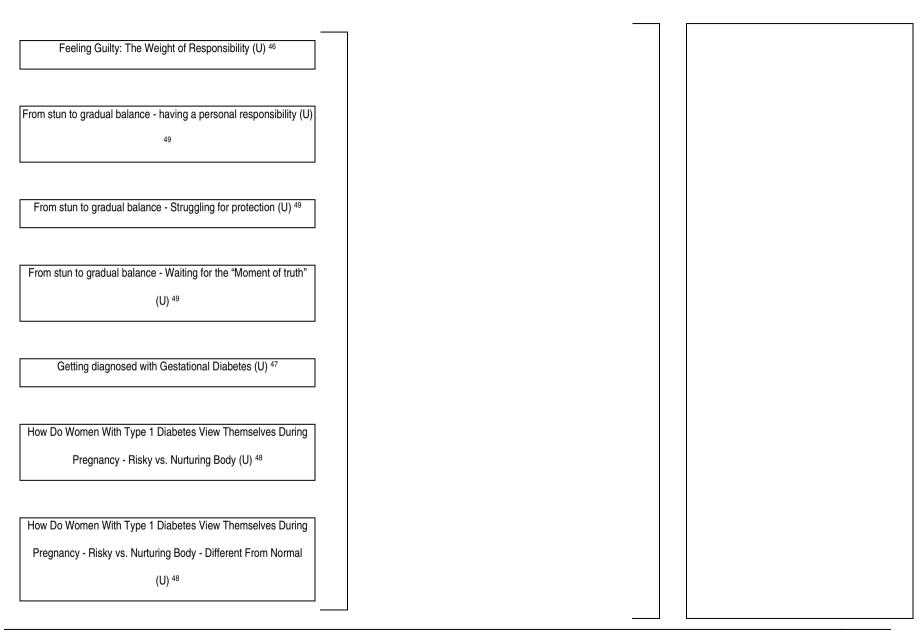


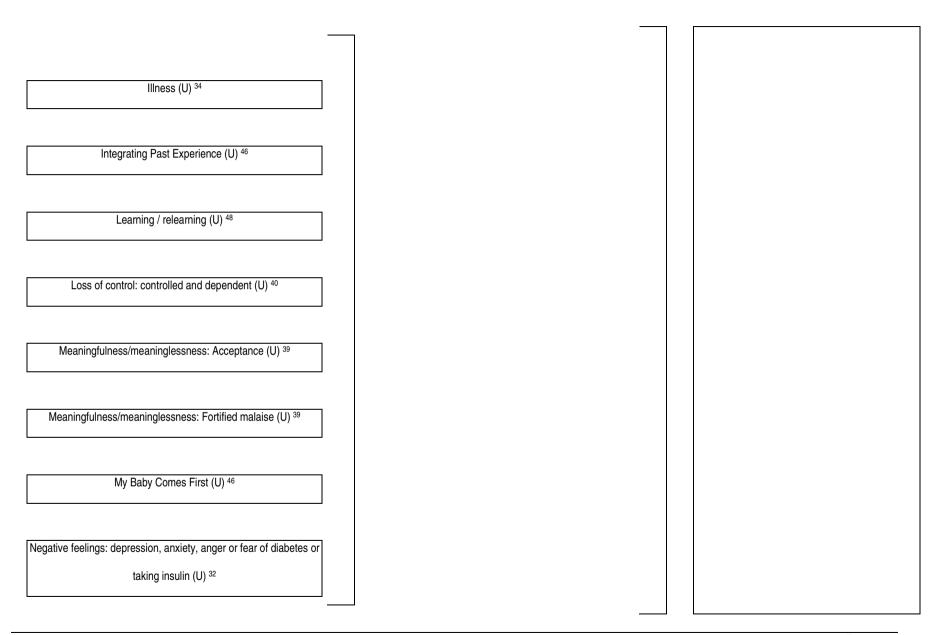
Being a Responsible Mother (U) 43	increase
Being Transformed (U) ⁴³	
Beliefs about illness (U) 35,37	
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benefits for baby (U) 33	
Causes of Gestational Diabetes (U) 31	
Concern for the baby (U) 30	
concern for their unborn child (U) ⁴⁵	
Confusion and concern about the diagnosis of GDM (U) 33	

ncreases both anxiety and motivation

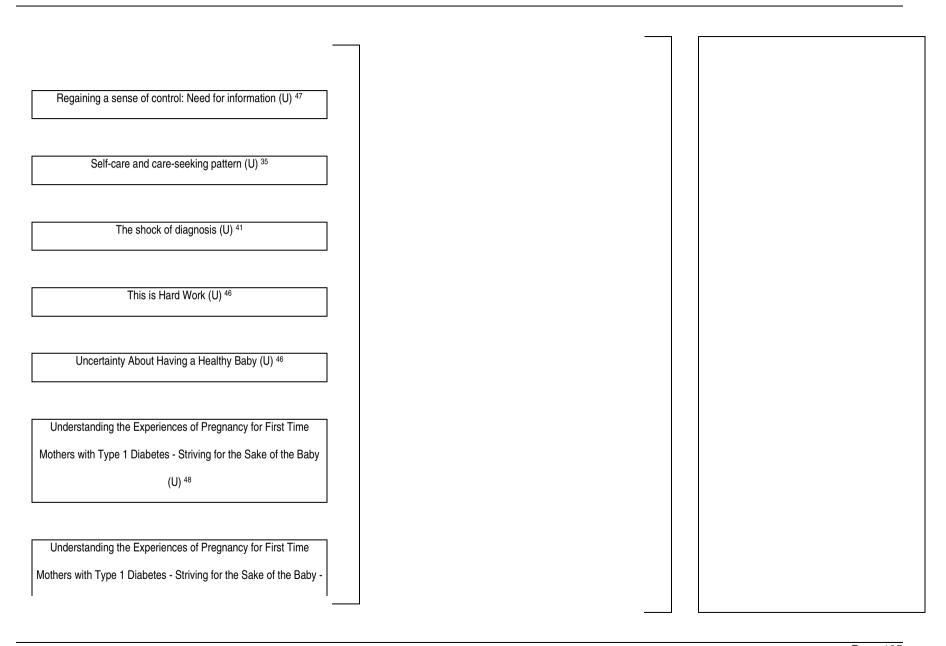
factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy. (cont.)

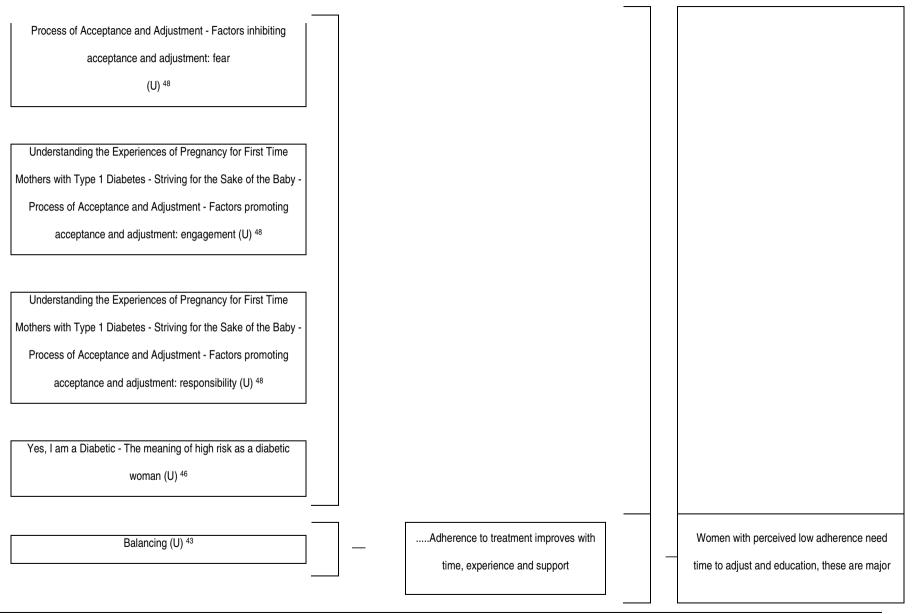
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Effects of Gestational Diabetes later in life (U) 31		
Exaggerated responsibility: constant self-blame (U) 40		
Exaggerated responsibility: Constant worry (U) 40		
Exaggerated responsibility: Constantly under pressure (U) 40		
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Facilitators for GDM self-management: realization: An opportunity to prevent type 2 diabetes (U) 42		
Fear of adverse effects from GDM (U) 33		
Feeling Afraid (U) ⁴⁶		

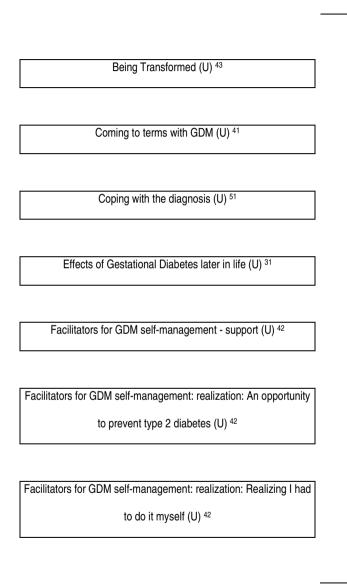




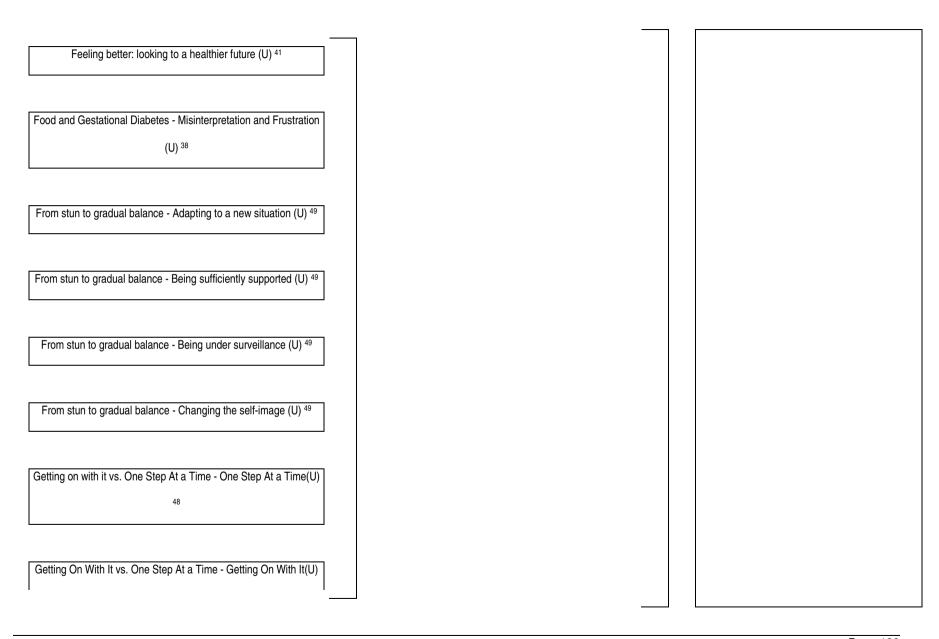
	-
ost like getting diabetes again (U) 40	
: an unwell body - a risk (U) 40	
. all uniwell body - a lisk (o)	
ealthier Birth and Beyond (U) ⁴⁷	
r Birth and Beyond: Commitment to the	
s's Well-Being (U) ⁴⁷	
ss well-being (o) "	
is to the diagnosis (U) 51	
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onso of control offices (O)	
se of control: health of both (U) ⁴⁷	
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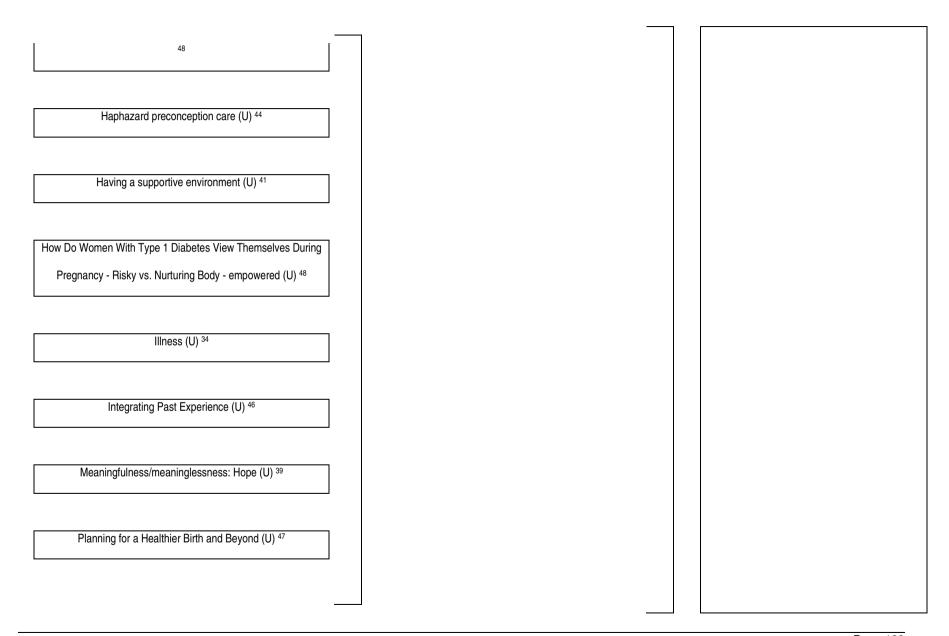


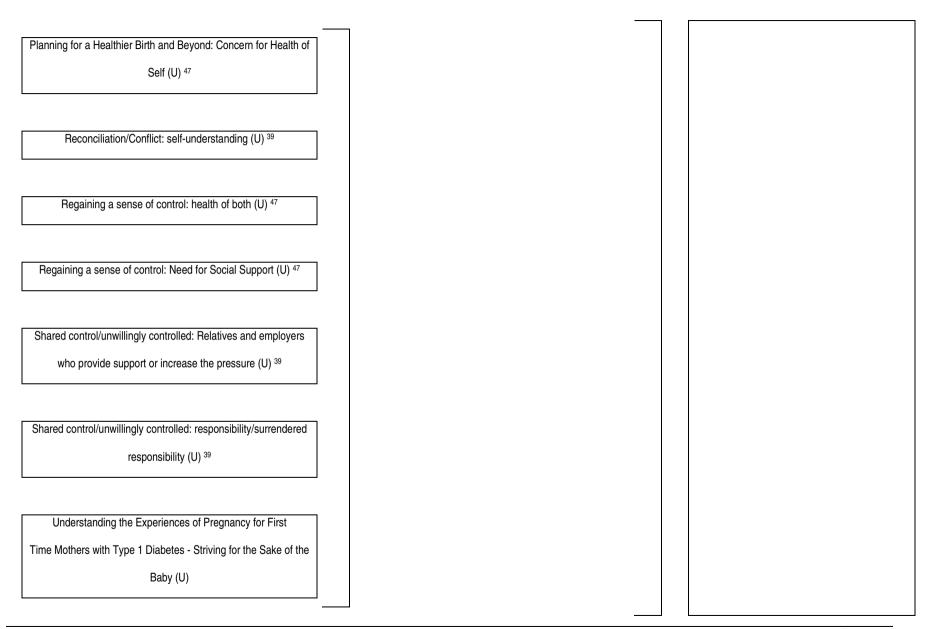




factors positively affecting women's motivation for adherence to treatment for diabetes in pregnancy. (cont.)







Understanding the Experiences of Pregnancy for First Time

Mothers with Type 1 Diabetes - Striving for the Sake of the Baby
Process of Acceptance and Adjustment (U) 48

What Are the Participants Views on the Support They Receive

From Others - Supportive Networks (U) 48

What Are the Participants Views on the Support They Receive
From Others - Supportive Networks - Family and Friends: Do They
Understand? (U) 48

What Are the Participants Views on the Support They Receive
From Others - Supportive Networks - Partners: A Shared
Responsibility?

(U) 48

What Are the Participants Views on the Support They Receive

