

A grounded theory approach to explore how women with Type 1 diabetes manage their diabetes during the menopausal transition.

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## Abstract

### Aim

To explore the experiences of women with Type 1 diabetes during the menopausal transition using a grounded theory approach and, from the data, develop a substantive theory that will have potential implications for service users and service providers.

### Methods

A qualitative exploratory research framework was employed using grounded theory as an approach. Data were collected from 10 participants using transcribed audio-taped semi-structured interviews and field notes. The transcripts, audio recordings and field notes were reviewed and a coding process facilitated data analysis.

### Results

A wide range of conceptions was revealed. Data are presented in seven categories that reflect the experience of the menopausal transition for women with Type 1 diabetes: '*Blank wall*' (relates to the lack of information regarding menopause and diabetes), '*Juggling game*' (relates to glycaemic control), *Anxiety and fear*, *Self-management*, '*Haywire*' (relates to the signs and symptoms of menopausal transition), *Treating symptoms*, *Depression and mood*, '*I'm old*' (relates to aging and mortality).

### Conclusion

What emerged from the study is a substantive theory in which absence of information regarding the menopause and its impact on Type 1 diabetes (blank wall) was identified as the main problem facing women with Type 1 diabetes during their menopausal transition. The findings may enable practitioners to identify the types of information, advice and support that should be made available to these women and contributes to the limited knowledge base currently available. The findings indicate also that further research into this under-studied but important area of diabetes care is required.

<u>CONTENTS</u>	<u>PAGE</u>
➤ Acknowledgements.....	1
➤ Abstract.....	2
➤ Contents.....	3
 <u>Chapter 1 Introduction</u>	
➤ 1.1 Introduction.....	6
➤ 1.2 Background.....	7
➤ 1.3 Justification for study.....	9
➤ 1.4 Summary.....	10
➤ 1.5 Aim of study and research questions.....	11
➤ 1.6 Overview of thesis.....	11
 <u>Chapter 2 Literature Review</u>	
➤ 2.1 Introduction.....	13
➤ 2.2 Aims and objective of literature review.....	13
➤ 2.3 Method.....	14
➤ 2.4 Results.....	15
➤ 2.5 Discussion of literature search findings.....	17
➤ 2.6 Summary.....	26
➤ 2.7 Conclusion.....	27
 <u>Chapter 3 Methodological Issues</u>	
➤ 3.1 Introduction.....	28
➤ 3.2 Research framework.....	28
➤ 3.3 Methodology.....	29
➤ 3.4 Reflexivity.....	30
➤ 3.5 Grounded Theory.....	32
➤ 3.6 Sample.....	34
➤ 3.7 Recruitment.....	37
➤ 3.8 Data collection.....	38
➤ 3.9 Data analysis.....	40
➤ 3.10 Ethical considerations.....	44
➤ 3.11 Credibility of research.....	46
➤ 3.12 Summary.....	47
 <u>Chapter 4 Findings</u>	
➤ 4.1 Introduction.....	48

➤ 4.2 Organisation of findings.....	48
➤ 4.3 Categories.....	49
➤ 4.4 Core category ‘ <i>blank wall</i> ’ .....	50
➤ 4.5 Category: ‘ <i>Juggling game</i> ’.....	53
➤ 4.6 Category: Anxiety and fear.....	56
➤ 4.7 Category: ‘ <i>Haywire</i> ’.....	59
➤ 4.8 Category: Treating menopausal symptoms.....	59
➤ 4.9 Category: Depression and low mood.....	61
➤ 4.10 Category: ‘ <i>I’m old</i> ’ .....	62
➤ 4.11 Core category rationale.....	62
➤ 4.12 Summary.....	64

### Chapter 5 Discussion

➤ 5.1 Introduction.....	65
➤ 5.2 Impact of ‘Blank wall’.....	66
➤ 5.3 Identifying the menopausal transition.....	68
➤ 5.4 Complications of Type 1 diabetes.....	70
➤ 5.5 Issues concerning menopause.....	72
➤ 5.6 Glycaemic control.....	74
➤ 5.7 Hypoglycaemia.....	75
➤ 5.8 Confusing symptoms.....	76
➤ 5.9 Hyperglycaemia.....	77
➤ 5.10 Symptoms of menopause.....	78
➤ 5.11 Treating menopause symptoms.....	80
➤ 5.12 Impact of the menopausal transition on mood.....	81
➤ 5.13 Conclusion.....	83
➤ 5.14 Limitations/strengths of study.....	83
➤ 5.15 Summary.....	84

### Chapter 6 Conclusion

➤ 6.1 Introduction.....	86
➤ 6.2 Review of chapters.....	86
➤ 6.3 Implications for practice.....	87
➤ 6.4 Further research questions.....	88
➤ 6.5 Personal and professional experience.....	89
➤ 6.6 Summary.....	90

- References.....92
- Appendix 1.....101
- Appendix 2.....105
- Appendix 3.....112
- Appendix 4.....113
- Appendix 5.....126
- Appendix 6.....130

List of Tables and Figures

- Table 2.1 Search strategy.....14
- Table 2.2 Results from electronic database search.....16
- Table 2.3 Papers selected for review.....17
- Table 3.1 Characteristics of participants.....38
- Figure 4.1 Categories.....49
- Poster for presentation.....132

## Chapter 1

### **1.1 Introduction**

It is acknowledged that there are increasing numbers of people who suffer from diabetes mellitus (Diabetes UK 2006). Currently 2.6 million people with diabetes live in the United Kingdom. It is estimated that 15% of these people have Type 1 diabetes (Diabetes UK 2009). The Scottish Diabetic Survey (2006) reported 26 294 people with Type 1 diabetes in Scotland. The burden of this chronic condition has significant clinical and service implications, not to mention expense to the National Health Service (NHS) and the suffering experienced by individuals with this chronic disease. People with diabetes occupy around 10% of hospital beds, costing the NHS approximately £465 million per year (Bull & Veall 2009). Type 1 diabetes is an extremely demanding condition for an individual to manage successfully, and it can have a significant impact on a person's quality of life.

Treatment of Type 1 diabetes involves lifelong medication with insulin and adaptation of lifestyle. To a certain extent the lives of people with Type 1 diabetes revolve around self-monitoring of blood glucose and insulin dose adjustment by considering issues such as carbohydrate intake, exercise, stress, menstrual cycle and other lifestyle factors that they may encounter. This precise day to day management is necessary to avoid hypoglycaemia and hyperglycaemia, acute complications of Type 1 diabetes. Managing glycaemic control in this way is crucial if the person with diabetes is to maintain good quality of life and minimize or prevent long term microvascular and macrovascular complications. (Siguroardottir 2005, Everett *et al.* 2010). The Diabetes Control and Complications Trial (DCCT 1993) was a major, multicenter, randomized control study conducted over a period of ten years that involved 1 441 participants aged 13–39 years with Type 1 diabetes. This is now dated, but as the literature review will demonstrate, there have been no further studies on such a large scale. Intensive glycaemic control was compared to standard glycaemic control. The study demonstrated conclusively that maintaining tight blood glucose control (HbA1c of around 7%) compared to less tight control (HbA1c of 9%) delays onset and progression of microvascular complications such as retinopathy, nephropathy and neuropathy. It also provides a longer term decrease in macrovascular complications such as coronary artery, cerebrovascular and peripheral vascular disease, consequently resulting in improved physical and psychological well-being of people with Type 1 diabetes (DCCT 1993). Furthermore, the

provision of information, education and psychological support to facilitate self-management is an essential component of diabetes care (Winkley *et al.* 2006). Health care teams involved in caring for individuals with diabetes strive to provide this by implementing current evidence-based care.

Menopause is a stage in the female reproductive cycle that occurs as the ovaries reduce and eventually stop producing oestrogen, causing the reproductive system to cease functioning (Freeman *et al.* 2007). Ayers *et al.* (2011) provide a brief synopsis of the changing sociocultural history of menopause. Included in this report is a quote from Robert Wilson (1966) suggesting that a menopausal woman is:

‘...an unstable oestrogen starved’ woman who is responsible for ‘untold misery of alcoholism, drug addiction, divorce and broken homes.’ (Ayers *et al.* 2011:348)

Ayers *et al.* (2011) argue that while the above statement is extreme, Western societies continue to associate menopause with poor emotional and physical health. As the body adapts to changing levels of natural hormones various symptoms may be experienced. These include: hot flushes, palpitations, night sweats, mood swings, lack of concentration, vaginal dryness, decreased libido and weight changes. Additionally Szmuiłowicz and Seely (2009) include sleep disturbance and urinary incontinence as symptoms of menopause. The menopausal transition is defined as a time of irregularities in menstrual cycle and variations in hormone levels, concluding with the final menstrual period (Szmuiłowicz & Seely 2009, Harrison 2007). As a consequence the day to day management of Type 1 diabetes may be more problematic and potentially dangerous for women during this time. Twelve months of amenorrhoea defines the end of the menopausal transition (Harrison & Becker 2007).

## **1.2 Background**

I am a diabetes specialist nurse working in a large teaching hospital, where approximately 4 000 adult patients with diabetes are registered, 800 of whom have Type 1 diabetes. Women with Type 1 diabetes frequently allude to the difficulties in controlling their blood glucose levels during the menopausal phase of their lives. Anecdotally they complain of a variety of issues such as high blood glucose levels, hypoglycaemia unawareness, erratic blood glucose levels, unpredictable hypoglycaemia, deterioration of glycaemic control as demonstrated by an increase in HbA1c and increased insulin requirement. They frequently enquire if this is



'normal' and ask if I have any suggestions to assist them in dealing with the difficulties they experience. Interestingly, several diabetes specialist nursing colleagues have similar observations to mine. However, we are unable to provide any evidence-based information and have no patient information literature regarding this topic to assist these individuals with their diabetes management during this phase in their lives. Women attending the diabetes outpatient department often complain that when they question their GP on the subject of menopause in relation to their diabetes they are advised to consult with their diabetologist. However, the diabetologist will often refer women back to their GPs, claiming that they are best placed to advice on menopausal issues. This situation is clearly unsatisfactory for women with Type 1 diabetes.

The physiological changes seen in pregnancy, weight gain, puberty and in the event of psychological stressors such as anxiety states and depression are known to affect glycaemic control adversely (Russell *et al.* 2001, Weinger & Jacobson 2001). This can result in the acute complications of diabetes and contribute to longer term deterioration in glycaemic control. Dahlgren (2006) recognizes that changes in sex hormones as a result of pregnancy caused by the high levels of placental growth hormone, placental lactogen, and circulating insulin-like growth factor, result in insulin resistance and an increased production of background hepatic glucose. Insulin resistance is defined as a state where more insulin than normal is required to maintain normal blood glucose levels (Dahlgren 2006). Codner (2008) discusses the difficulties experienced by adolescents with Type 1 diabetes during puberty, and in particular, females. This deterioration in glycaemic control may be attributed to a number of reasons, but specifically hormonal changes affecting insulin sensitivity. Certainly in clinical practice I have seen women's insulin dose treble by the third trimester of pregnancy. Immediately after placenta delivery insulin requirements return to pre-pregnancy levels. Currently there is no evidence supporting insulin resistance, or possibly increased insulin sensitivity, during the menopausal transition in women with Type 1 diabetes, when this is also a time of flux of sex hormones. There is significant reduction in sex hormones produced by the ovaries during menopause. Commonly women will experience symptoms of hot flushes and night sweats around the time of menopause (Maclennan *et al.* 2004).

The menopause is described as a complex time for women, resulting in physical and emotional challenges (Price *et al.* 2007). It is well recognized that women with Type 1

diabetes have a greater incidence of menstrual disorders and an earlier menopause compared to non-diabetic women, but very little is actually known about the effects on, and experience of, the menopausal transition in this population (Dorman *et al.* 2001, Zarzycki & Zieniewicz 2005, Strotmeyer *et al.* 2003). The fact that many symptoms experienced during the menopausal transition, such as sweating, palpitations, mood changes and short term memory problems, are similar to those suffered during hypoglycaemic episodes is of concern, as crucial warning signs of this acute complication may be masked (Roberts 2006).

Anecdotal evidence suggests that women may confuse these menopausal symptoms with hypoglycaemia and respond in a way that is counter-productive, potentially causing them some harm, such as consuming refined sugar to treat hypoglycaemia when blood glucose level is in fact *not* low, resulting in hyperglycaemia; presuming symptoms are menopausal and not treating hypoglycaemia, increasing the risk of severe hypoglycaemia. If hypoglycaemia is left untreated blood glucose levels will continue to drop, possibly preventing the person with diabetes from being able to treat the hypoglycaemia independently. If no one else is able to assist in treating the hypoglycaemia such an occurrence might cause loss of consciousness, permanent brain damage and even death (Heller 2011). Other features of the menopause that may be of concern to women in this group include problems sleeping due to night sweats, which may be confused with hypoglycaemic symptoms, weight gain that requires increased insulin doses due to insulin resistance associated with weight gain, fatigue that is also a symptom of hyperglycaemia, vaginal dryness associated with diabetes, exacerbating sexual problems and mood changes (Mayo Clinic 2009).

### **1.3 Justification for study**

#### **Current care**

Currently people with Type 1 diabetes receive a medical review approximately three or four times a year. This review is usually performed in a diabetes clinic in secondary care, where there is access to the multidisciplinary team. In accordance with national guidelines (SIGN 116 2010) care for this population is based on current evidence. This includes

recommendations regarding lifestyle management and psychosocial factors, together with screening for complications of diabetes and management of existing complications. Referral to members of the multidisciplinary team is also instigated at clinic, such as the diabetes specialist nurse, dietitian and podiatrist. This may be for general support or specific education.

Clinics attended by participants in my study are busy with usually at least a two hour wait to be seen by the doctor. The medical staff change frequently, as it is a teaching hospital; rarely do patients see the same doctor at two consecutive appointments. Patients may request to see a particular doctor, but this may incur a longer wait. There is patient information literature in the waiting room in the form of leaflets, posters and flyers. This covers a wide range of topics related to diabetes such as; erectile dysfunction, pregnancy, depression, alcohol, drugs and travel. Anecdotally, patients attending the clinic find it easier to raise a sensitive issue with staff if there is existing literature relating to it. This assures them that their concern or problem is not unique.

The purpose of this study is to explore the perceptions and perspectives of women with Type 1 diabetes experiencing the menopausal transition in order to develop a substantive theory that will have potential implications for service providers and service users. Ultimately it will serve as a means of illustrating the types of information, advice and support which should be made available to this group. The findings from this study will not only have significant practical implications in assisting diabetes self-management for this population, but will also contribute to the limited knowledge base currently available. The motivation driving this study is the current lack of evidence available to patients and health care professionals surrounding the management and complexities of the menopausal transition in women with Type 1 diabetes, with regards to their diabetes management during this time.

#### **1.4 Summary**

Type 1 diabetes is a chronic, progressive disease requiring significant self-management from the individual in order to avoid or minimise the associated acute and chronic complication (Siguroardottir 2005, Everett *et al.* 2010). The influence of hormonal changes may further challenge the ability of self-management in order to achieve optimal glycaemic control. Puberty and pregnancy are two examples of insulin resistance as a consequence of hormonal

changes (Dahlgren 2006, Codner 2008). It is important that people with Type 1 diabetes understand the potential impact hormonal change may present in terms of how they manage their diabetes. Providing evidence-based information, education and advice will better equip the individual to manage their condition (SIGN 116 2010). Currently, little is known concerning the menopausal transition in a woman with Type 1 diabetes. This lack of evidence is highlighted in the next chapter, where related research is discussed.

### **1.5 Aim of study and research questions**

The overall aim of this grounded theory study is to explore the experiences of women with Type 1 diabetes during the menopausal transition with regards to any effect it may have on their diabetes management. The literature review together with my clinical experience has shaped the research questions. Strauss and Corbin acknowledge that:

‘...the researcher brings to the inquiry considerable background in professional and disciplinary literature.’ (Strauss & Corbin 1998:48)

Research questions:

1. Do women with Type 1 diabetes consider that the menopausal transition impacts in any way on their diabetes management?
2. Do women with Type 1 diabetes perceive their glycaemic control to alter during the menopausal transition?
3. What are the perceptions of women with Type 1 diabetes regarding information and support provided by health care professionals during the menopausal transition?

### **1.6 Overview of thesis**

The thesis is presented in six chapters. In this introductory chapter I have provided information regarding Type 1 diabetes and menopause together with justification for the study, the aim of the study and research questions. Chapter 2 focuses on literature search strategies and provides detailed review of existing literature. Chapter 3 discusses the methodological approach employed in the study and implications of using a grounded theory approach in conduction of my study. Recruitment and sampling strategy, together with ethical considerations, are also discussed and justified in this chapter. The research findings of my study are presented in Chapter 4 and discussed in detail in Chapter 5. Chapter 6 is the concluding chapter where implications for practice and further research questions are

presented. Additionally my personal and professional experience regarding the process of conducting my research is discussed. Appendices include: summary of literature reviewed, results from database search, interview guide, tables of codes that form each category and information letters for participants and GP.

## Chapter 2

### Literature Review

#### **2.1 Introduction**

In this chapter I will review literature relevant to the research questions and the rationale of the literature review, highlighting how it differs from reviews performed for other research studies, and describing the search strategy I used.

A search of Diabetes UK's website revealed no information relating to my research topic and nothing has been presented at national diabetes annual conferences within the last ten years. The literature review identified that for both physical and emotional reasons the menopause is a complex time for women (Price *et al.* 2007). While there is a vast resource of research relating to the menopause, much of this is concerned with physical symptoms and use of hormone replacement therapy. I located and reviewed new literature post data collection and analysis as discussed in chapter 5 of my thesis. This literature was relevant in light of my findings. The rationale for placing it in the discussion chapter can be justified as it did not relate directly to my research questions.

#### **2.2 Aims and objectives of literature review**

The review commences with a general overview of Type 1 diabetes and menstrual problems. There is much debate about the purpose of reviewing the literature in qualitative research, particularly in grounded theory approach (Glaser 1992, Bryant & Charmaz 2007). Previously some theorists advised avoiding detailed review of literature due to a risk that it may direct their research and perhaps lead to development of preconceived ideas that may influence the findings from the study (Holloway and Wheeler 2002). Cutliffe (2000) states that the root of this debated subject is not whether a literature review should be performed, as a review of existing literature can provide the rationale for the study and justify the research approach, but the question is when the literature should be reviewed, and to what extent. Cutliffe (2000) suggests that this depends on which version of grounded theory is being used. Strauss and Corbin's (1998) approach to grounded theory will be used for this study, as discussed in the next chapter, and in keeping with that a literature review has been undertaken prior to the study commencing. Furthermore, it has been suggested by Lacey (Gerrish and Lacey 2006)

that repeating research that has previously been adequately addressed is a waste of both time and money. It is also extremely unlikely that funding will be secured for a study unless the researcher has identified the current state of knowledge relating to the topic. In view of that pragmatic rationale, an extensive electronic literature search was conducted prior to the study commencing and continued throughout the study.

### 2.3 Method

A systematic approach was applied to the literature search, critiquing pertinent publications, summarising and synthesising the results. The Scottish Intercollegiate Guidelines Network's (SIGN 2001) recommendations for critiquing research, as adapted by Kennedy *et al.* (2008), were used to include limitations and strengths of literature relevant to the research questions, and results are displayed in Appendix 1.

**Table 2.1 Search strategy**

Database	Time period
CINAHL (Cumulative Index of Nursing and Allied Health Literature)	1996–2010
Ovid Medline	1950–2010 – limited to 2000–2010
EBM Reviews – ACP Journal Club	1991–2010
EMB reviews – Cochrane Systematic Reviews database	2005–2010
British Nursing Index	1994–2010
EMBASE	1996–2010
PsycINFO	1987–2010

The search strategy was extended to Google Scholar and grey literature – this included Diabetes UK charity website. The Joanna Briggs Institute and the Register of Clinic Trials databases were also searched. The dates given in Table 2.1 were the dates available electronically; they were narrowed further in the search strategy. The last search was performed in September 2011; details of the search information are in Appendix 2.

Published literature was chosen from the last 10 years, as prior to that patient self-monitoring of blood glucose was not as readily available as it is now. Additionally the types of insulin available were less sensitive in matching patients' own physiological requirements, resulting in more erratic blood glucose profiles and a greater risk of hypoglycaemia. A strategy consisting of Medical Subject Headings (MeSH) and common words relating to diabetes, as detailed in Table 2.2, was used. Reference lists from relevant studies were also checked to identify further relevant studies. However, no literature that was not currently on the searched databases was identified.

*Inclusion and exclusion criteria for this review:*

The initial inclusion criteria were:

- studies published in the English language within the last decade
- participants with Type 1 diabetes who were either post-menopause, peri-menopause or experiencing the menopausal transition
- qualitative and quantitative studies
- systematic reviews and published literature

The first search, with the inclusion criteria as stated, yielded so little that I expanded my search to include criteria detailed in Table 2.2, despite this, little literature was identified. While some grounded theorists would advocate not expanding the literature search I decided to do so due to the lack of literature concerning my research topic (Glaser & Strauss 1967, Glaser 1978). As a result of expanding the search relevant literature was identified as discussed in the literature review. These comprised:

- Type 2 diabetes and hormone replacement therapy (HRT)
- Existing risk factors for women with established Type 1 diabetes concerning their diabetes pre-menopause and post-menopause
- The impact of menopause in people who have long term physical conditions.

The exclusion criteria consisted of published articles that scrutiny revealed as irrelevant to the research topic, and those not in the English language. The latter was due to time constraints and expense of translation.

## **2.4 Results**

Results from the electronic database searches are shown in Table 2.2. The literature search identified 71 publications with 'diabetes' and 'menopause' in the title. However, these were



mainly relating to the risk of women developing Type 2 diabetes post menopause. Many authors did not stipulate in the title whether their publication referred to Type 1 diabetes or Type 2 diabetes; this necessitated review of several irrelevant abstracts.

**Table 2.2 Results from electronic database search**

<b>Search Term</b>	<b>No. of Results</b>	<b>Included</b>	<b>Excluded</b>
Diabetes OR insulin dependent diabetes mellitus OR non-insulin dependent diabetes mellitus OR Type 1 diabetes AND menopause OR peri-menopause OR post-menopause OR pre-menopause OR menopausal transition	106	8	98
menopause OR peri-menopause OR post-menopause OR pre-menopause OR menopausal transition AND blood glucose OR glycaemic control OR HbA1c OR Haemoglobin A glycosolated	34	0	34
menopause OR peri-menopause OR post-menopause OR pre-menopause OR menopausal transition AND diabetes mellitus, non-insulin dependent OR Type 2 diabetes	23	0	23
menopause OR peri-menopause OR post-menopause OR pre-menopause OR menopausal transition AND chronic disease AND self-management	39	2	37
menopause OR peri-menopause OR post-menopause OR pre-menopause OR menopausal transition AND hyperglycaemia AND diabetes OR insulin dependent diabetes mellitus OR non-insulin dependent diabetes mellitus OR Type 1 diabetes	1	0	1
menopause OR peri-menopause OR post-menopause OR pre-menopause OR menopausal transition AND diabetes OR insulin dependent diabetes mellitus OR non-insulin dependent diabetes mellitus OR Type 1 diabetes and hypoglycaemia	6	0	6

The literature search revealed 209 articles, all of which were reviewed to establish if they fitted the inclusion criteria. Of the 209 articles 10 were included and 199 excluded, as they

did not meet the inclusion criteria. A further four relevant articles were identified from Google scholar. All 14 articles that met the inclusion criteria were retrieved and reviewed.

**Table 2.3** Papers selected for review:

Author	Year	Title
Bertero, C	2003	What do women think about menopause? A qualitative study of women's expectations, apprehensions and knowledge about the climacteric period
Dorman J., <i>et al.</i>	2001	Menopause in Type 1 Diabetic Women: Is it Premature?
Doruk, H., <i>et al.</i>	2005	Effect of diabetes mellitus on female sexual function and risk factors
Harrison, T., <i>et al.</i>	2007	A qualitative study of menopause among women with disabilities
Im, E., <i>et al.</i>	2008	Menopausal symptom experience: an online forum study
Kernohan, A., <i>et al.</i>	2007	Effects of low-dose continuous combined hormone replacement therapy on glucose homeostasis and markers of cardiovascular risk in women with type 2 diabetes.
Morrow, M.	2002	Challenges of change: Midlife, menopause and disability
Price, S., <i>et al.</i>	2007	Menopause experiences of women in rural areas
Rachoń, D., <i>et al.</i>	2003	Serum interleukin-6 levels and bone mineral density at the femoral neck in post-menopausal women with type 1
Smith, R.	1992	A pilot study of the effect upon multiple sclerosis of the menopause, hormone replacement therapy and the menstrual cycle
Soriguer, F.	2009	Type 2 diabetes mellitus and other cardiovascular risk factors are no more common during menopause: Longitudinal study.
Strotmeyer, E., <i>et al.</i>	2003	Menstrual cycle differences between women with Type 1 diabetes and women without diabetes
Strotmeyer, E., <i>et al.</i>	2006	Middle-aged pre-menopausal women with type 1 diabetes have lower bone mineral density and calcaneal quantitative ultrasound than non-diabetic women.
Wedisinghe, L., & Perera, M.	2009	Diabetes and the menopause.

## 2.5 Discussion of literature search findings

### *Type 1 diabetes*

First I will discuss studies relating to Type 1 diabetes. Dorman *et al.* (2001) state that there is evidence to suggest that individuals with Type 1 diabetes experience accelerated biological

aging; numerous physiological reasons are given to substantiate this statement. Following from this, Dorman *et al.* (2001) suggest it would be expected that other indicators of biological age such as menopause will be premature in women with Type 1 diabetes (Dorman *et al.* 2001). This hypothesis was suggested only nine years ago, and at this time Dorman *et al.* (2001) stated that to their knowledge there was no evidence available to support their hypotheses.

This publication is lengthy and detailed; it discusses the Familial Autoimmune Study (FAD), conducted in America, which is the basis of the study conducted by Dorman *et al.* (2001). There is a lot of detail in this discussion, and clarity regarding the current analysis is rather unclear. Essentially in 1981, 656 men and women with Type 1 diabetes and their family members were recruited for the FAD study. In 1993, 143 women from the FAD registry were recruited to participate in the comparative analysis by Dorman *et al.* (2001) together with 186 non-diabetic sisters and 160 unrelated controls. Controls were recruited by mass mailing to individuals living in the same geographical area. All participants were evaluated clinically; assessment of autoimmune diseases, blood pressure, BMI and various blood tests were performed. Thorough questioning via questionnaires gave details regarding complications of diabetes, life style factors such as smoking status, physical activity, socioeconomic status and reproductive histories. Validated tools based on those used by the Healthy Women Study were used for self-reporting of menstrual and menopausal events.

The results demonstrated, as expected according to Dorman *et al.* (2001), the mean age of menarche was significantly older for women with Type 1 diabetes compared to non-diabetic women. An irregular menstrual cycle before the age of 30 was significantly more common in women with Type 1 diabetes. Interestingly, despite the risk of complications of pregnancy, women with Type 1 diabetes were less likely to use oral contraceptives than non-diabetic women. It may be speculated that this finding was because at least some of these women were unaware of the risks regarding complications of pregnancy and diabetes or had concerns regarding the impact of oral contraception on their diabetes. Alternatively, it may have been reluctance of their health care provider to prescribe oral contraception in view of their diabetes. Dorman *et al.* (2001) do not discuss this, however, anecdotally this is noted in my current clinical practice. The age of menopause was younger for women with Type 1 diabetes = 41.6 years than for non-diabetic sisters = 49.9 years and control = 48.0 years (P=0.05). Of note is that approximately 98% of the participants were Caucasian. This has limited the study

to one ethnic group and reduces generalizability beyond this specific group. The authors conclude by highlighting that for women with Type 1 diabetes their reproductive years are reduced by 17% and describe the early menopause as a major complication of Type 1 diabetes. The study is quite small scale, although statistically significant, for such confident claims by the authors, bearing in mind the participants were mainly from one ethnic group. Of particular relevance to my study is the risk of early menopause and the fact that this is not routinely discussed with these women. In my clinical experience most women with Type 1 diabetes are completely unaware of their early menopause risk. Informing this population of such important information may impact on family planning for these individuals.

A further publication using the same participants and methods as Dorman *et al.* (2001) is from Strotmeyer *et al.* (2003). The aim of this study was to determine whether women with Type 1 diabetes are more likely to have menstrual irregularities compared to women without diabetes. There is some repetition in this publication from Dorman *et al.* It is essentially the same study (different data are extracted but the method and participants used are the same) however Strotmeyer *et al.* (2003) reports in more detail menstrual cycle issues. Self-reported menstrual and reproductive histories were obtained from 143 women with Type 1 diabetes, 186 sisters without diabetes and 158 unrelated control subjects. There is some concern regarding bias in self-reported data; the authors allude to this, but state that their data were valid and reliable. They do not demonstrate why this is the case. Data were obtained via questionnaires and all participants were a cohort from the Familial Autoimmune and Diabetes study. Strotmeyer *et al.* (2003) state this is the first study to examine the natural history of menstrual characteristics in all ages, particularly women in the 30–40 year age range. Results demonstrate conclusively that women with Type 1 diabetes are more likely to experience menstrual problems compared to controls and to their non-diabetic sisters. Strotmeyer *et al.* (2003) discuss findings from Dorman *et al.*'s (2001) publication demonstrating that women with Type 1 diabetes will have an earlier menopause compared to those without Type 1 diabetes. Of relevance to my study is the prospective study that Strotmeyer and Dorman *et al.* are currently conducting to validate previous findings from their own studies stating the onset of early menopause in this population. They postulate that this may be caused by a similar underlying aetiology that is responsible for menstrual irregularities amongst diabetic women. By using hormonal measures and menstrual cycle records they hope to determine whether this is the case. Of importance is the possibility that menstrual characteristics in women with type 1 diabetes in their 30s and 40s may in fact be peri-menopausal symptoms, since the

reported mean age of menopause in the population is 42 years. The systematic literature review carried out by Strotmeyer *et al.* (2003) has demonstrated conclusively those women with Type 1 diabetes experience more menstrual disorders than women without diabetes (Yeshaya *et al.* 1995, Adcock *et al.* 1994, Schroeder *et al.* 2000). I located these studies, and Strotmeyer's claims are justified. It is demonstrated clinically that women with Type 1 diabetes have difficulty controlling their blood glucose levels around the time of menstruation. The limitations of the study undertaken by Dorman *et al.* (2001) apply to Strotmeyer *et al.*'s (2003) study; mainly one ethnic group and a relatively small number of participants.

The literature review identified studies that demonstrate significant existing risk factors for women with Type 1 diabetes pre-menopause in relation to having Type 1 diabetes. Strotmeyer *et al.* (2006) conducted a prospective quantitative study to determine if middle-aged pre-menopausal women with Type 1 diabetes experienced more self-reported fractures and had lower bone mineral density (BMD) compared with non-diabetic women. The study was conducted in America using clinical measurements that are compatible with the UK. Clinical measurements were obtained from 67 pre-menopausal women with Type 1 diabetes and 237 non-diabetic controls to achieve the study objective. Results demonstrated that women with Type 1 diabetes have a lower BMD pre-menopausal, therefore may be at a significantly increased risk of developing osteoporosis post-menopause. Strotmeyer *et al.* (2006) recommend that these women should be screened for osteoporosis and fracture prevention during the menopausal transition. Strotmeyer *et al.* (2006) highlight the study limitations that include the data being cross-sectional therefore only allowing the suggestion of a causal relationship. To demonstrate conclusively that woman with Type 1 diabetes are at greater risk of bone loss and fracture post menopause longitudinal studies are required. Of note is that all subjects included in the study had optimal glycaemic control and had no diabetic complications. Rachon *et al.* (2003) provide further evidence for reduced BMD in women with Type 1 diabetes. Their prospective comparison study of 20 post-menopausal women with Type 1 diabetes and 20 non-diabetic matched controls measured serum bioactive IL-6 levels (a regulator of bone resorption, and plays an important role in the pathogenesis of osteoporosis) and BMD at the femoral neck. Despite the small sample size it was found that BMD was lower in the subjects with Type 1 diabetes; this finding was statistically significant. Ethnicity of the participants and the controls were not stated in the paper. Despite the limitations of both these studies there does appear to be good evidence to suggest that

women with Type 1 diabetes should have screening to detect a low BMD. Currently this does not happen in clinical practice. The risk of osteoporosis and cardiovascular disease in menopausal women without diabetes is well documented as discussed in a review conducted by Khoo and Perera (2005). Of concern is the additional risk associated with Type 1 diabetes. If information was available for this population perhaps these women would implement lifestyle measures to help minimise their risk, such as dietary changes and increased physical activity.

An evaluation study investigating the effect of diabetes mellitus on sexual function was undertaken by Doruk *et al.* (2005) in Turkey using questionnaires. The responders consisted of 127 married women: 21 women with Type 1 diabetes, 50 with Type 2 diabetes and 56 healthy control participants. Appropriate inclusion/exclusion criteria were applied. The intention of the questionnaires was to evaluate various aspects of sexual health. A glaring limitation in this study is the omission of reporting HbA1c levels of the participants, as this would have indicated glycaemic control in these individuals, which is known to have an impact on sexual function, particularly if it is suboptimal. The results demonstrated 71% of women with Type 1 diabetes experienced sexual dysfunction, higher than the 42% of women with Type 2 diabetes and 37% of control subjects. The study did not identify any risk factors that may predict sexual dysfunction in the women with Type 1 diabetes in terms of diabetic complications. Of note, is that 31% of the Type 1 women experiencing sexual dysfunction were classed as in the menopausal state, compared with only 23% of the control women. I have included this study to highlight further the impact of Type 1 diabetes on women prior to the menopause and the possibility of additional complications caused by menopause in these individuals.

### ***Type 2 diabetes***

As discussed in the introduction to this chapter, due to the limited publications relating to Type 1 diabetes and the menopause the inclusion criteria were extended to include Type 2 diabetes and the menopause. Wedisinghes and Perera (2009) reviewed current evidence relating to oestrogen correction in post-menopausal women with Type 2 diabetes. In the review it is acknowledged that Type 2 diabetes is the most common chronic disease in post-menopausal women, and it is a significant risk factor for the predisposition of cardiovascular disease. Wedisinghe and Perera (2009) clarify that the review concentrates on Type 2 diabetes and acknowledges that in fact most published data concentrate on this population.

This has been demonstrated in the literature search for my study. The Wedisinghe and Perera (2009) review aims to discuss the pros and cons of correcting the oestrogen deficiency that signifies menopause and associated symptoms of menopause. Wedisinghe and Perera (2009) suggest that for some women these symptoms are ‘devastating’ and that they can significantly reduce quality of life. The focus is on HRT and a number of issues such as: new onset Type 2 diabetes, lipid, carbohydrate and bone metabolism as well as cardiovascular disease. The authors conclude by stating that the incidence of Type 2 diabetes is rising, and that it is a major risk factor for cardiovascular disease. Wedisinghe and Perera (2009) acknowledge the clinical challenge of managing Type 2 diabetes in menopausal women and the necessity for each woman to be assessed individually with regards to the beneficial factors associated with HRT.

Recommendations from this review suggest that HRT can be used in low risk diabetic women, in high risk women non-oestrogen based HRT should be offered. ‘Risk’ refers to cardiovascular, osteoporotic and cancer risk factors in these individuals. This review does not discuss how different treatment options for Type 2 diabetes, such as oral hypoglycaemic agents or insulin therapy, may impact on the existing risk factors. I acknowledge that this review is not directly related to my research questions. However, the potential reduction in quality of life caused by menopausal symptoms is something that must be considered for women with Type 1 diabetes. Their quality of life may already be affected negatively by their diabetes.

Soriguer (2009) conducted a longitudinal cohort study to determine certain risk factors for cardiovascular disease occurring during menopause. Four hundred and seventy five non-diabetic Spanish women were followed up prospectively for six years. Soriguer *et al.* (2009) discuss the issue of the menopause being considered as a cardiovascular risk factor, but state that the reason is unclear. Highlighted is the evidence base demonstrating that reduced oestrogen may cause weight gain, reduced glucose tolerance, abnormal plasma lipids and an increase in blood pressure, amongst other physiological changes. Specific clinical measurements relating to cardiovascular risk were obtained from each subject, as well as menopausal status. Menopause was defined as six months of amenorrhoea, which differs from other published definitions of menopause as 12 months of amenorrhoea. This implies that some participants may not actually be post-menopause, and therefore the findings may not be entirely accurate. Despite findings from other studies (Wedisinghe & Perera). 2009 and Khoo

& Perera 2005) this study demonstrated that none of the risk factors for cardiovascular disease changed during the transition from pre-menopause to post-menopause. The authors conclude by criticising recent attempts to medicalise the menopause. If unaccompanied by other cardiovascular risk factors there is no justification for medical intervention. Other medical conditions are not discussed in relation to increased cardiovascular risk and menopause, such as diabetes. Once more this study is not directly related to my own research questions; however, it demonstrates that weight gain and reduced glucose tolerance may occur as a result of oestrogen deficiency caused by the menopause. In women with Type 1 diabetes this may impact on their blood glucose levels and insulin requirement, as they may be more insulin resistant due to the oestrogen deficiency.

More than 12% of women over the age of 50 will have Type 2 diabetes (Kernohan *et al.* 2007). It is not stated if this is worldwide or pertaining only to Scotland. Type 2 diabetes is described as a 'potent cardiovascular risk' due to elevated plasma glucose, dyslipidaemia and impaired coagulation and inflammation. Kernohan *et al.* (2007) discuss the interest around low-dose hormonal replacement therapy for the treatment of post-menopausal symptoms in women with Type 2 diabetes as an alternative option to conventional HRT. There are concerns regarding increased risk of coronary heart disease and stroke with conventional HRT. A double-blinded randomised control trial, consisting of a small sample (n=28), was the method employed to assess the effects on glucose homeostasis and cardiovascular risk in post-menopausal women with Type 2 diabetes. The study was conducted in Scotland, subjects were randomized to low dose HRT or placebo, and specific clinical investigations were performed. The results demonstrated that low-dose HRT improved menopausal symptoms, decreased fasting glucose and total cholesterol, and is therefore a safer treatment option. Type 1 diabetes is not mentioned in this article. These findings could have potential implications for my own participant group if it is demonstrated that menopausal symptoms affect women's blood glucose control, in particular the menopausal symptoms that are confused with hypoglycaemia. It may be that HRT could be offered more readily if this is demonstrated. Kernohan *et al.* (2007) urge for further randomised control trials of adequate power to establish the effect of low-dose HRT on cardiovascular endpoints in women with and without diabetes.



### *Menopause in people who have long term physical conditions*

As discussed in the introduction to this chapter, due to the limited publications relating to Type 1 diabetes and the menopause the inclusion criteria were extended to menopause in specific groups such as individuals with disability and/or enduring medical conditions. Although this inclusion could be criticised in a grounded theory approach it was considered important for the purpose of my study that all literature should be searched which could have more implications for the research aims and methods. This was to identify possible similarities/differences amongst other groups of women with enduring medical conditions experiencing menopausal transition and those with Type 1 diabetes. Smith (1992) conducted a pilot study to enquire, via questionnaires, about the changes in symptom severity of multiple sclerosis (MS) sufferers during: menstrual cycle, menopause and use of hormone replacement therapy. Eleven pre-menopausal and 19 post-menopausal women who attended lectures at the annual general meeting of Action Research in Multiple Sclerosis in London responded. Of interest is that 54% of post-menopausal women reported their multiple sclerosis symptoms worsened with the menopause. It is not stated if this is a permanent worsening of symptoms or transient. Furthermore, 75% reported an improvement in symptoms during hormone replacement treatment. The ethnicity of the participants is not stated. The author concludes that this pilot study highlighted the need for further research to clarify these findings in more detail. As it was a pilot study the numbers are small and the questionnaire very basic. I chose to review this paper, as multiple sclerosis, like Type 1 diabetes, is a chronic progressive condition. Of interest is the improvement in MS symptoms with hormone replacement therapy. There is the potential to benefit people with diabetes who suffer from painful neuropathy, a complication of the disease.

Morrow (2002) compiled an interesting narrative account of presentations from the 10<sup>th</sup> Annual Meeting, North American Menopause Society. She discusses menopause and disability. She refers to lack of research and health information as ‘troubling’ given the number of women who have some form of disability. Morrow defines disability as a term used to describe ‘a loss of physical and/or mental functioning capacity or activity and the particular social discrimination that people face as a result of impairment’ (page 3). In addition she states that a certain proportion of people with chronic illness consider themselves as disabled, as their illness is a disability. The author highlights the perception of one woman’s disability in relation to menopausal symptoms:

‘I think it makes some of the symptoms of the menopause scarier or worse than what I understand the average population experiences. I guess when I have menopausal symptoms I have a scarier reaction to them than I should have because I think maybe they are signs of something else.’ (Morrow 2002: P3)

I considered this possibility in my study and was aware of this issue when analyzing the data. Findings from my study, discussed in chapter 4, identify that participants in my study shared this perception.

A qualitative study (Bertero 2003) conducted in Sweden aimed to identify expectations, apprehensions and knowledge regarding the menopausal transition. Semi-structured interviews were employed to collect data from 39 participants, thereafter data were analyzed using content analysis. The author does not clarify if participants were pre-menopausal or post-menopausal, merely describing the purposive sample as 47 years old. However, the familiar theme of a lack of knowledge and self-care issues on the part of the women was apparent. The importance of discussion with health care professionals regarding the menopause was highlighted as a significant aspect of health care promotion for this population. It was not stated if this discussion should be 1:1 or group format. Bertero (2003) does not state the ethnicity of participants or if they had any medical or physical conditions.

Price *et al.* (2007) explored experiences of a specific group of women in rural areas of Canada (n=25) during the menopause. This qualitative, naturalistic and constructivist inquiry employed interviews and focus groups to collect data. Findings suggested these women wanted to fully understand their symptoms but were hampered by the quality of available information, which was described as conflicting and inadequate. Particularly inadequate and causing concern was the absence of medical information and support given regarding symptoms they experienced. They described the impact of the menopause as significant, particularly in relation to personal relationships. ‘Social support and humour’ were identified as the main coping strategies that they relied on during the menopausal transition. Price *et al.* (2007) acknowledged limitations of the study, in particular the fact that all participants were White and English speaking; it was not stated if any of them had any medical or physical conditions.

Another group of women living in America (n=19), with mobility disabilities, participated in a qualitative descriptive study (Harrison & Becker 2007) regarding their views of the

menopausal transition. The study included 19 English speaking women with various degrees of mobility impairment. In the main the women maintained that of particular importance was accurate information that may shape their future health and quality of life. Despite the small numbers in the study Harrison *et al.* (2007) concludes by stating that:

‘...the voice of all women, including those with disabling conditions, is needed in our current knowledge base surrounding the menopausal transition’. (Harrison 2007:P9)

Finally, Im *et al.* (2008) echo Price *et al.*'s (2007) findings from an online study forum exploring menopausal symptoms experienced by 23 White midlife women in respect of participants being dissatisfied with information relating to assistance with their symptoms. The author concludes by highlighting the need for nurses to be able to offer support and listen to women's concerns during this period in their lives. Again, it is suggested that further studies are required to determine what advice can be offered regarding symptom management and lifestyle changes. Im *et al.* (2008) acknowledge the limitations of their study. In particular, internet settings using a convenient sampling method were used to recruit White midlife women, who tended to be a select group.

## **2.6 Summary**

The literature search and review demonstrated a lack of literature related to my study aim and research questions. During my search, whilst several articles had diabetes and menopause in the title, the majority concerned Type 2 diabetes. Despite checking all authors' reference lists, no further articles were identified as relevant to my topic of interest.

There is evidence demonstrating the increased risk of menstrual disturbances, sexual dysfunction, early menopause, increased risk of cardiovascular disease in women with Type 1 and Type 2 diabetes, reduced BMD in women with Type 1 diabetes and benefits of HRT in women with Type 2 diabetes. Type 1 diabetes is a chronic, irreversible and progressive condition and its management is extremely complex for patients and health care professionals alike. Health care professionals spend a significant amount of time monitoring and educating patients about diet, activity and glycaemic control as well as detection and prevention of complications caused by the disease. Subsequently individuals spend a significant amount of time accommodating the disease and its management into their lives (Charlton & Mackay 2010). The menopausal transition may further challenge accommodating this disease.

Based on current literature, there is evidence of some academic work exploring and describing women's experiences during the menopausal transition in specific populations, but not in women with Type 1 diabetes. The literature clearly demonstrated the importance of relevant information and health promotion strategies desired by women during this phase of their lives. This may not only provide them with pertinent information but also enable them to develop coping strategies. However, despite the multiple influences that accompany the menopausal transition with regards to physiological and psychological health, no literature was identified concerning the impact this may potentially have on women's glycaemic control and their ability to manage their Type 1 diabetes.

## **2.7 Conclusion**

With regard to my research questions, the robust literature search and review identified a gap in the evidence base. There is no information for health care professionals regarding how women with Type 1 diabetes manage their diabetes during the menopausal transition. Studies discussed in this review have demonstrated the complexities of the menopause. As discussed in the introduction, Type 1 diabetes is a complex disease for the individual to manage. For women to manage diabetes and menopause concurrently may be extremely demanding. It is therefore crucial that health care professionals have evidence-based information to provide support and guidance to women dealing with these issues. The next chapter will discuss the methodological issues within my study.

## Chapter 3

### Methodological Issues

#### **3.1 Introduction**

In this chapter the rationale for choosing a grounded theory approach and its application in this study will be discussed.

When conducting research there should be no ideological adherence to a particular approach or method; different questions require different methods, and it is the research questions that should drive the method employed (Holloway & Wheeler 2002, Starks 2007). The research questions driving this study arise from the research aim, that is: *to explore the experiences of women with Type 1 diabetes during the menopausal transition with regards to the effect, if any, it has on their diabetes management and glycaemic control.* A strong professional interest, coupled with literature reviewed to date, led to formulation of three specific research questions to guide the current study. According to Campbell *et al.* (2004) clarity of questions is essential to ensure quality in the answers to the questions.

The research questions are:

1. Do women with Type 1 diabetes consider that the menopausal transition impacts in any way on their diabetes management?
2. Do women with Type 1 diabetes perceive their glycaemic control to alter during the menopausal transition?
3. What are the perceptions of women with Type 1 diabetes regarding information and support provided by health care professionals during the menopausal transition?

#### **3.2 Research framework**

The type of research questions, the limited research available on the subject to date, and the aim of the research supported an investigation through a qualitative exploratory research framework. Strauss & Corbin identify this as:

‘any kind of research that produces findings not arrived at by a means of statistical procedures or other means of quantification.’ (Strauss & Corbin 1990:17)

This research approach was selected to explore the emic perceptions of the study participants; allowing them to describe in their own words their experiences, beliefs and attitudes relating

to the menopausal transition and its effect, if any, on their diabetes management. Utilizing this approach enabled me to understand the social world through assessing and interpreting what was said by participants (Bryman 2008, Charmaz 2006, Holloway & Wheeler 2002) and relied on the spontaneous sharing of that social world, most often through the spoken word. The aim of the study was to achieve deep understanding of whether the menopausal transition had an effect on a woman's management of her Type 1 diabetes. I focused on gaining insight by exploring the women's experiences of a given phenomenon, about which little was known (Strauss & Corbin 1990). The research paradigm was interpretive and the ontological orientation constructivist (Bryman 2008, Weaver & Olson 2006). Williams (1998) succinctly describes qualitative design by stating:

'...individuals construct the world, each perceiving their own reality. Therefore to understand the world these realities need to be understood.' (Williams 1998:8)

In my study this was exactly the focus; to understand the realities of the women experiencing the given phenomenon. Qualitative research facilitates participants to provide much 'richer' answers to the questions asked by the researcher in comparison to quantitative research that generates numerical data. In addition, participants may provide important insights that may have been missed by employing another method (Holloway & Wheeler 2002). An interpretive paradigm was the most suitable framework to guide my research study. Coates (2004) succinctly sums up the justification for this research study approach by stating:

'...a detailed, holistic view of a topic is required, rather than an examination of a variable in isolation.' (Coates 2004:3)

### **3.3 Methodology**

The nature of the research questions necessitated a qualitative research approach. The next stage was to select an appropriate methodology of inquiry. I acknowledge that there are various qualitative research approaches with significant differences (Denzin & Lincoln 2005). For example, phenomenology is a qualitative method to examine what meaning people construct of their lived experience. The aim is to understand a particular phenomenon by investigating individuals who have lived it (Starks 2007). Ethnography is a qualitative approach used to study behaviour in social groups, cultures or communities. The researcher is integrated into the study environment, enabling observation of how people in the group interact with each other (Holt 2011). These approaches were not suitable for my study, as I aimed to explore the perceptions of women with Type 1 diabetes in relation to the

menopausal transition. The questions and aims of the research, together with apparent lack of knowledge regarding the topic and examination of all the suitable approaches, substantially influenced the choice of a grounded theory approach (Glaser & Strauss 1967, Holloway & Wheeler 2002, Punch 2005).

The rationale for a grounded theory approach relates to the focus of my research; to explore what actually happened during the menopausal transition in women with Type 1 diabetes with regards to their diabetes management and glycaemic control. This was currently unknown, as demonstrated in the literature review by the ‘gap’ in existing knowledge. Grounded theory is defined as a research approach that facilitates discovery of theory from data; theory is developed from empirical research (Glaser & Strauss 1967). McCann and Clark (2003) discuss the value of grounded theory in studies concerned with interaction and ‘under-exposed’ issues. Furthermore, Coyne and Cowley (2006) state that the intention of grounded theory is:

‘...to develop theory that will explain the dominant process in the social area being investigated.’ (Coyne & Cowley 2006:501)

A grounded theory approach may ultimately lead to development of a theoretical framework for future research. Strauss and Corbin (2008) suggest that a grounded theory approach may provide a guide for selection of concepts to be further explored and recommendations for future research questions. My study identified significant and pertinent areas for future research, together with relevant health issues highlighted for this population (Sinclair 2007). These are discussed at the end of this thesis.

### **3.4 Reflexivity**

I was reflexive during the research process. Critical reflection of my own preconceived thoughts and ideas enhanced the rigor of the study. (Holloway & Wheeler 2002). It is stated by Bryant and Charmaz that reflexivity is:

‘...the researcher’s scrutiny of his or her research experiences, decisions, and interpretations in ways that bring the researcher into the process and allows readers to assess how and to what extent his or her interests, positions, and assumptions influence the research.’ (Bryant and Charmaz 2007:609)

Bolt (2010) highlights the importance of self-reflexivity in the research process. Neill (2006) discusses how fundamental it is in grounded theory for the researcher to reflect on the actual researcher–participant relationship as an interactive experience and in grounded theory, the

main concern is the nature of human interaction. I constantly assessed my actions and my role in the research process, and like other data applied the same critical analysis to it (Mason 1998). An example of this was carefully exploring participants' knowledge regarding complications of diabetes and the increased risk of these complications post-menopause. At this time it became apparent to me that most participants were unaware of the increased risk of osteoporosis and cardiovascular disease in women with Type 1 diabetes compared to their non-diabetic peers. I ensured I did not cause distress or alarm by careful wording of the subject. Charmaz (2006) suggests that reflexivity relates to the researcher's crucial reflection on his/her own perceptions and background knowledge and the reflection of the researcher on his/her own biases. Malterud (2001) highlights that while the researcher may have preconceptions, they can only be considered as bias if the researcher fails to mention them and/or allows them to colour the analysis. I do not consider myself to have had any biases regarding the research topic. However, I had a 'hunch' that menopause might impact on diabetes self-management. This 'hunch' originates from patients alluding to difficulties, as discussed in chapter 1. Finlay (2002) discusses in detail the dynamics of the researcher-participant relationship and the potential power imbalances that may exist. This is of particular relevance in my study, as some participants knew me as 'their' diabetes specialist nurse, as an advisor and educator, therefore potentially more powerful than them. From my own position, with this in mind, I endeavored to reduce the potential power imbalance in a number of ways. I introduced myself and established my intentions as a researcher, and for those participants who knew me, I clarified my new role to them. I emphasized that the interview was not a diabetes nurse consultation. I informed participants that I had very limited knowledge regarding the menopause, emphasizing their expertise in providing that information. Although I do not wear a uniform to work when interviewing, I dressed more casually for interviews than I do for my professional role. I offered participants tea/coffee on arrival; this is different to my usual practice. I acknowledged that critical discussion of the service might make participants feel uncomfortable. I attempted to overcome this by empathizing with them and alluding to areas of the service that I thought could be better in an attempt to encourage them 'opening up' but avoid leading them in any way. An example of this was discussion of the potential benefits of consulting with the same doctor at each clinic visit. This would ensure continuity of care and avoid patients having to repeat the same information at each consultation. I did suggest they could request to see a particular doctor if desired.



### 3.5 Grounded Theory

Grounded Theory was first developed in the 1960s by two sociologists, Barney Glaser and Anselm Strauss (1967) as an approach to data collection and analysis. It was defined as a research methodology or a research approach for which a compatible underpinning theory is symbolic interactionism. The approach enables discovery of theory from data, and in doing so operates almost in reverse from traditional research (Charmaz 1990). Essentially the researcher has no predetermined hypothesis prior to engaging in the research, is open-minded and flexible subsequently, allowing theory to emerge from data (Glaser & Strauss 1967, Strauss and Corbin 1990). A provisional hypothesis can be formulated after initial data collection (Holloway & Wheeler 2002). Ultimately the theory developed from data serves to describe and explain what is occurring in the interaction or the social setting (Rees 2003).

Symbolic interactionism originated from the work of George Mead (1934) (Jeon 2004) and other early 20<sup>th</sup> century pragmatic philosophers. With regards to this, Polit and Beck wrote that symbolic interactionism:

‘...focuses on the manner in which people make sense of social interactions and interpretations they attach to social symbols e.g. language’ (Polit & Beck 2006:222)

Symbolic interactionism proposes that meaning is derived through social interaction and through a person’s interpretation of those interactions. For example, individuals: act towards things/people they encounter in a way that matches the meaning these things hold for them, the meaning that things/people have for individuals is learned and developed from social interactions/encounters that they have and these meanings are processed, interpreted and subject to change by individuals (Blumer 1969, Sundin & Fahy 2008). This implies that individuals have an active role to play in research rather than a passive role, and have an active part to play in constructing their own reality. The research is concerned with the actions and perceptions of the individual in an attempt to address the phenomenon under investigation. In my study this relates to the participants ‘encountering’ their diabetes and also ‘encountering’ the menopause on top of that.

Glaser and Strauss developed grounded theory in an attempt to balance inequalities between quantitative and qualitative ideologies present in social science research (Charmaz 2006; Denzin & Lincoln 2005). Development of grounded theory raised the status of qualitative research within social science research and ensured that research questions were addressed

appropriately, aiming to provide more relevant findings (Bryant & Charmaz 2007). Parahoo (2009) acknowledges Glaser and Strauss' valuable contribution in demonstrating development of substantive theories from data, compared with the presiding knowledge production by testing theories, therefore an inductive rather than deductive approach. There has been much debate, multiple definitions and interpretations of grounded theory methodology (Bryant & Charmaz 2007) and it has evolved in sometimes rather conflicting directions (Denzin & Lincoln 2005). Soon after publication of the text 'Discovery of Grounded Theory' (1967) Glaser and Strauss' paths separated due to disagreement over evolution of the methodology. Following this, Glaser (1978) wrote an influential book, *Theoretical Sensitivity*. Whilst the differences between the two researchers were evident, these were recognized more widely following Strauss' published guidance to the grounded theory process (Strauss 1987, Strauss & Corbin 1990). In response Glaser (1992) defended the classic grounded theory, which he extended to provide further theoretical aspects of the methodology. Furthering the divide between the two researchers Strauss and Corbin (1990) published their book detailing the analytical techniques they suggest are used in grounded theory. Glaser argues that the version of grounded theory proposed by Strauss and Corbin (1990) 'forces' the data into preconceived categories and is in complete contrast to the fundamental idea of the methodology (Bryant & Charmaz 2007). This diversification led to the development of two approaches to grounded theory; the Straussian approach and the Glaserian approach. Annells (1997) cautions that this should not be interpreted that one is necessarily greater than the other, instead a demonstration that grounded theory is evolving; however, I suspect that Glaser would disagree with this (Glaser & Holton 2004).

Despite both approaches originating from Glaser and Strauss' original work (1967) each has epistemological and methodological differences. Ghezeljeh and Emami (2009) summarized fundamental differences and wrote:

'Glaser assumes an objective, external reality and a neutral observer who discovers data in an objective neutral way, thus discovering theory.' (Ghezeljeh & Emami 2009:16)

In contrast, Strauss and Corbins' view:

'...assumes an objective external reality, aiming towards unbiased data collection. They give voice to their respondents, acknowledging their view of reality.' (Ghezeljeh & Emami 2009:16)

McCann and Clark (2003) provide detailed analysis of differences between Glaser's perspective on grounded theory and that of Strauss. These include Glaser's belief that the

researcher role is independent, while Strauss and Corbin view the role of the researcher as dialectic and active. According to Glaser, literature should be used to support emerging theory, while Strauss and Corbin suggest a preliminary review to improve theoretical sensitivity, referring to the researchers' personal qualities, and the main literature review to support emerging theory. In terms of data collection and analysis Strauss and Corbin are more prescriptive with the provision of rules and procedures. In my opinion, Strauss and Corbin's grounded theory appears more pragmatic, and as a novice researcher the clarity regarding data collection and analysis, combined with the dialectic and active role of the researcher, is the reason for selection of the Strauss and Corbin approach. Whilst I acknowledge Glaser's argument, the fact that I have not carried out a qualitative research project previously meant that I found Strauss and Corbin's argument more compelling.

Despite diverging approaches to grounded theory the main features of all are:

- Constant comparative analysis
- Generating codes and categories from data
- Theoretical sampling
- Theoretical development ( Glaser and Straus 1967)

These features will be discussed individually in the remainder of this chapter.

### **3.6 Sample**

#### **Theoretical Sampling**

When using a fully grounded theory approach selection of data sources entails theoretical sampling (Glaser & Strauss 1967, Glaser 1978). This involves determining one's next source of data from the information obtained to date by the joint processes of collection, coding and analysis of data. What are not made explicit however are the criteria which should be used for selection of the *initial* sources of data, a problem highlighted by a number of writers, for example Reed et al (1996). Glaser and Strauss (1967) continue their guidance by saying that,

'The initial decisions for theoretical collection of data are based only on a general sociological perspective and on a general subject or problem areas...The initial decisions are not based on a preconceived theoretical framework' (Glaser & Strauss 1967 p45)

### **Purposive Sampling**

Morse (1991) suggests that purposive sampling involves obtaining data in the initial stages from those who have a broad general knowledge of the topic, or who have undergone experience(s) thought to be typical. Mason (1998) defines purposive sampling as,

‘...selecting groups or categories to study on the basis of their relevance to your research question.’ (pp 93-94)

In my study this comprised women who had Type 1 diabetes and who were experiencing the menopausal transition, thus ensuring that I obtained data from participants well-placed to provide data relevant to my research questions (Silverman 2000).

My overall rationale was that a purposive sample would allow me to start building concepts (categories) and identify a core category to which all other categories were linked. This core category may be seen as a theory, and in order to develop my theory I would at a future date approach new participants to test this out, i.e. theoretical sampling (McCann & Clark 2003). This was not possible within my own study due to limitations of time.

Whilst I acknowledge that theoretical sampling until saturation of all concepts is advocated in grounded theory, the 20 month time frame allocated for data collection and analysis in this small project rendered theoretical sampling unrealistic. Dissimilar to other sampling methods that are planned in advance, theoretical sampling in grounded theory continues throughout the research due to its continuous nature and unpredictability of time scale (Holloway & Wheeler 2002). Of note is the possibility that one can never be sure if saturation has in fact been achieved (Charmaz 2006). Charmaz justifies this by stating:

‘Thus, like other qualitative approaches, the grounded theory approach shares the hazard of assuming that categories are saturated when they may not be.’ (Charmaz 2006:14)

### **Limitations of purposive sampling**

Purposive sampling by nature focuses on potential participants’ ability to address the research question(s) but omits biographical and socio-cultural factors which may impact on individuals’ experiences of a given situation. For example, the women in my study were all white and from a similar socio-economic class. Theoretical sampling, had time permitted, would have expanded my recruitment of potential participants to include, specifically, women of different ethnic groups and different socio-economic classes.

Constant comparison of data within and across all the interviews yielded one core category, which was summed up in the concept ‘blank wall’. It is acknowledged however that I cannot state, with such a small sample, that saturation has *definitely* been achieved. Had time permitted, theoretical sampling would have had the potential to enhance my study and to state, with some confidence, that saturation of data had been achieved.

The purposive sample for my research consisted of women with Type 1 diabetes currently experiencing the menopausal transition and who met the following inclusion criteria:

- Female
- Diagnosed with Type 1 diabetes for a minimum of 2 years
- Aged 40–55 years
- Have not experienced a menstrual period for a minimum of 3 months and/or previously regular menstrual cycle that is now irregular – for at least 3 months
- No cognitive impairment
- English speaking

The exclusion criteria were:

- Women who have had a surgically induced menopause, for example, oophorectomy

#### *Rationale for criteria*

Participants would have a diagnosis of Type 1 diabetes for a minimum of two years, as this ensures that the initial period following diagnosis, often referred to as ‘the honeymoon period’ or the ‘remission phase’ where endogenous insulin production may occur, is over. During this stage, when blood glucose levels are returning to normal due to exogenous insulin injections, the beta cells are ‘rested’ and usually start to secrete insulin again. After a period of two to four years it is very unusual for any endogenous insulin to be produced (Ragnar 2007). For the purpose of this study it was important to ascertain that the insulin injected was the participant’s sole insulin supply, and therefore determine the significance of changes to insulin requirement.

While I acknowledge that literature suggests women with Type 1 diabetes will have an earlier menopause, this is not commonly known or discussed in clinical practice. Although I acknowledge that omitting to discuss this information is unsatisfactory, if I included women of a younger age I could have caused them some distress by informing them of this finding. Interestingly, a few of the younger women in the inclusion age range who were contacted

during the recruitment process expressed their surprise that they were included. Harrison and Becker (2007) define the menopausal transition as a time of menstrual irregularities; the inclusion criteria reflect this.

Women with cognitive impairment were excluded, as they might have required assistance in understanding and answering some of the questions included in the interview guide. Due to the sensitive nature of the research it was considered that interpretation via a third party was not desirable, hence the exclusion of non-English speaking women (in addition there would have been a cost element when employing an interpreter).

### **3.7 Recruitment**

Participants were identified from SCI-DC, a local diabetes database containing the details of patients who have previously given consent to be approached to participate in research concerning diabetes. These patients all attended the large teaching hospital where I work as a diabetes specialist nurse (DSN). I knew some participants from my DSN role. Whilst a pre-established relationship may be of benefit given the relatively sensitive nature of the study, ethically this caused concern, as potentially participants may have been in a difficult position, such as feeling obliged to take part in the study (Mason 1998). Whilst the NHS Research Ethics Committee did not view this as problematic, I was acutely aware of this issue and openly discussed with women who know me to feel absolutely no obligation to participate in my study.

Recruitment commenced in September 2010 with a search of SCI-DC data base using the following fields; date of birth between 01011955 and 01011970, date of diagnosis of Type 1 diabetes before 01012008, female, currently attending the hospital Diabetes Clinic. A total of 85 patients were identified. A further search was conducted to establish that these patients had in fact given consent to be approached for research purposes. Seventy-seven patients were identified and contacted, as detailed in the Ethics section, **3.10**. Twenty one patients contacted me regarding the study. Ten patients fitted the inclusion/exclusion criteria. Notably, women who did not meet the criteria expressed an interest in the study and wished to be informed of any outcomes that might be of relevance to them.

Whilst there is little published guidance on sample size in qualitative research, Holloway and Wheeler (2002) suggest that adequate data can be obtained from a homogeneous group of 6–

8, although they acknowledge that a sample can consist of 4–40 informants. Therefore in my study a sample size of 10 should be sufficient to obtain rich data. This was realistic given the time frame for my study (Bryman 2008). Qualitative researchers may use a version of purposive or theoretical sampling that fits with the timeframe of the student, and not always follow the precise strategies advised in a grounded theory approach (Mason 1998).

All participants were Caucasian women living in Edinburgh. Their ages ranged from 49 to 55 years with a median age of 51.5 years. The duration of their diabetes ranged from 7 to 49 years with a median duration of diabetes of 38.5 years. Nine (90%) participants were married, nine (90%) were in employment. Six (60%) had children, number of children ranging from one to three. A summary of participants’ characteristics is detailed in table 3.1.

Table 3.1 Characteristics of participants

Participant No.	Pseudonym	Single/married/divorce	Duration of diabetes years	Employed	Age	No. Of children
1	Rachel	married	11	yes	51	3
2	Mary	married	40	yes	49	0
3	Susan	single	7	yes	50	0
4	Viviane	married	37	yes	55	1
5	Margaret	married	47	no	53	1
6	Barbara	married	35	yes	52	2
7	Ella	married	32	yes	51	2
8	Nuri	married	31	yes	52	0
9	Suzanne	married	20	yes	51	2
10	Mini	married	49	yes	53	0

### 3.8 Data collection

Within my study, face-to-face semi-structured interviews were used as the primary method of data collection. I decided to interview participants individually as opposed to a focus group interview. Whilst participants in focus groups can answer the facilitators’ questions individually the aim of the group is to explore a set of specific issues through interaction with each other. Given the relatively sensitive nature of the research topic, and the unknown ‘set

of specific issues,' I decided individual interviews were a more appropriate method of data collection. Charmaz (2006) suggests that interviewing is the most appropriate and commonly used method of data collection in grounded theory research, and flexibility in the data collection process is one of the main features of qualitative interviewing. It enables the researcher to understand the thoughts and feelings of the participant, and both parties are engaged in the process (Darlington & Scott 2002). Holloway and Wheeler (2002) suggest that by using interviews as a method of data collection the researcher is able to confirm and clarify what exactly is said by participants at the time it is said. In research where phenomena cannot be easily observed, interviewing facilitates exploration of the phenomena as a means of understanding it (Charmaz 2006). However, it is acknowledged that collection and analysis of data obtained from interviewing as a method of data collection can be extremely time-consuming (Holloway & Wheeler 2002).

I interviewed 10 participants using face to face, semi-structured, audio taped interviews and field notes. Field notes allowed me to record any observation or comments from the interview to avoid forgetting significant details, such as a display of emotion or distress, non-verbal communications such as shrugging the shoulders in response to a question. Interestingly, with the exception of one participant, Barbara, I recorded very little in the way of field notes, as most participants appeared to be at ease during the interview. Whether this was because they knew me from my diabetes specialist nurse role is unknown. Barbara was the only participant to become visibly upset during the course of the interview. This was related to her fear of developing complications of her diabetes, in particular, amputation of her leg, as she was currently receiving treatment for a foot ulcer. She expressed a great deal of anxiety and fear at the thought of losing her leg and her inability to cope with such a disability. I reassured her it was normal to feel anxious, and encouraged her regarding the attention she was paying to her diabetes control and attending podiatry appointments to ensure healing. All participants expressed gratitude to me for the opportunity to discuss the research topic, which was of great importance to them.

An interview guide was employed to ensure focus on information relating to the research aim (Appendix 3); this is commonly recommended (Creswell 1998). It also avoided me asking leading questions or putting words into participants' mouths. This guide was originally formulated by considering the literature to date and my own relevant observations as a specialist nurse in clinical practice. This gave a degree of structure and direction to the



interviews. It also prompted me to ask specific questions relating to my area of interest. Whilst the open-ended questions provided a framework for questioning, it was of paramount importance that I ensured there was an opportunity to explore emerging concerns of participants (Bryman 2008). For this reason, prior to interviews commencing I informed all participants that there would be time to discuss any specific questions or concerns they might have regarding their diabetes after the interview. The interview guide was used flexibly, ensuring that I focused on the research questions. However, I was responsive to participants' comments and pursued 'leads' rather than sticking rigidly to the schedule of questions. This ensured that data reflected participants' perspectives. Following the first four interviews two additional questions were added to the interview guide, as detailed in Appendix 3.

Participants were informed regarding the length of time anticipated for the interview to enable them to plan their day. I had anticipated any time between one to two hours would be required. However, interviews did not exceed 30 minutes, as after this period of time no new issues arose that required further exploration. This may reflect that I am a novice researcher; however, I think that the researcher-participant relationship is a more likely explanation; the fact that they knew me, I knew some background history regarding them as individuals, and my level of diabetes knowledge negated the need for participants to explain the terms they used regarding diabetes. Whilst the interview did not exceed 30 minutes all participants discussed several issues with me once the tape was switched off. I did not include this information in my data since I adhered to the protocol in the information sheet.

All audiotapes were transcribed verbatim. Recording and studying transcribed interviews facilitated detailed examination of what participants actually said, and were reviewed repeatedly. Ideally I would have preferred to type the transcriptions myself, but this was not possible due to time constraints. Audiotapes were transcribed by an agency with a code of confidentiality. Participants' identities have been protected, as they chose a pseudonym. Fellow researchers can also examine these data transcripts to assess whether my analysis has been robust and compatible with the data (Holloway & Wheeler 2002). In addition, my supervision team read examples and agreed with my analysis.

### **3.9 Data analysis**

#### *Constant comparative analysis*

Transcription of interviews and field notes of observations during data collection and recordings of interviews were reviewed, and a coding process employed. Strauss and Corbin (1998) discuss the need for collection of data and analysis to be linked from the beginning of the research, proceeding in a parallel fashion and continuously interacting. This is referred to as ‘constant comparative analysis’ and involves examining data for commonalities, constants and variations throughout the research process (Glaser & Strauss 1967). This was achieved by analyzing data from the first interview before I did the second interview, then analyzing data from the second interview and comparing it with data from the first interview, and this process was operated throughout the whole data analysis stage. Where full analysis from the transcript was not possible, I listened to the recording of the interview in advance of the next interview. Analyzing data using this method is designed to generate:

‘...a theory that is integrated, consistent, plausible, close to the data – and at the same time is in a form clear enough to be readily available for testing in quantitative research.’ Strauss & Corbin 1998:103)

I explored the option of using NVIVO, a computer program used to assist with the management and organization of data during the analysis process. However, I decided not to use it, as the number of participants in my study was small and I considered the time spent in familiarizing myself with the software would have been excessive.

#### *Generating codes and categories from data*

Constant comparison analysis employs the three procedures of open coding, axial coding and selective coding (Strauss & Corbin 1998). Coding is an integral aspect of grounded theory. It is the process by which I questioned and analyzed all data, establishing what was actually occurring and what the data revealed (Roberts 2008). This process, where concepts are categorized and compared against each other to detect similarities, is known as open coding. Strauss and Corbin define this as:

‘...part of the analysis that pertains specifically to the naming and categorizing of phenomena through close examination of the data’ (Strauss & Corbin 1990:62)

Open coding is the first stage in the data analysis where concepts are identified and developed. I read each transcript, identifying codes as they became apparent. I chose not to use word by word or line by line coding. As suggested by Moghadden (2006) this can be extremely time-consuming, and due to the volume of data may be confusing for the researcher. I engaged closely with the raw data, assigning labels, referred to as codes, to

segments of data. An example of this process is detailed in Appendix 4 together with tables that feature the number of sub codes attributed to the codes that were collated then reduced into different categories. The purpose of this coding was to conceptualize data by analyzing and recognizing patterns. It is during this process that theories start to develop tentatively (Bryant & Charmaz 2007). These codes occasionally contain words or phrases that participants have themselves used; these are referred to as *in vivo* codes (Strauss 1987). Examples of *in vivo* codes include; ‘*the menopause is like a visitor*’, ‘*what the hell is going on here?*’ and ‘*There’s nothing out there.*’ *In vivo* codes preserve the participant’s views in the coding and can enhance the study, making it more animated. It also avoided me imposing my own preconceived opinion (Holloway and Wheeler 2002). Due to my lack of experience, the process of open coding was challenging. Following coding of the first two interviews I sought feedback from my Director of Studies and Supervisor. They read the transcripts individually prior to reading the codes I had allocated and they agreed with my analysis.

While open coding was in progress I began the process of axial coding. Axial coding is a technique introduced by Strauss and Corbin (1990). It is used to interconnect categories with one another. After the initial or open coding, data are then reconstructed in a different way by forming connections between categories (Strauss and Corbin 1990). Bryant and Charmaz (2007) describe this as a multifaceted process where the researcher thinks in an inductive and deductive fashion. I analyzed the list of initial codes and identified categories on the basis of these codes, as detailed in Appendix 4. Where a code fitted more than one category it was placed in both, with particular attention and identification of its origin. For example, hyperglycaemia fitted the category ‘*Anxiety and fear*’ and also ‘*Juggling game*’. Through this coding the core category was identified. The core category is described by Holloway and Wheeler as:

‘A group of concepts and ideas with similar characteristics that form a unit of analysis’  
(Holloway & Wheeler 2002:284).

Following completion of this process on all 10 transcripts I had a total of 533 codes. I commenced the process of determining emerging categories by collapsing codes after 262 were identified following open coding on five transcripts (Strauss & Corbin 1998). At this stage I felt I needed to organize and make sense of existing data, as I was concerned it might become unmanageable. I was acutely aware of not forcing the data into emerging categories, as cautioned in the literature (Glaser & Strauss 1967, Strauss & Corbin 1990). Completion of

this process resulted in the identification of seven categories. During the process some of the categories were renamed and merged, as they appeared to be subcategories of other categories.

Selective coding was employed to further link all categories to the core category. It is through this process that theoretical ideas were generated (Strauss & Corbin 1990). I detailed each step in the data analysis process to show that my personal opinion did not influence emerging theories, and I critically reflected on my own feelings, ideas and perceptions. It is highlighted that theoretical sensitivity is closely bound to coding of data in grounded theory methodology (Strauss & Corbin 1990) and refers to the personal qualities of the researcher. My professional experience has enhanced the theoretical sensitivity aspect throughout the research process. As a diabetes specialist nurse, I am acutely aware of the subtleties in concepts arising from data, which allowed me to explore participants' responses by asking clarifying questions when required.

### *Memos*

Strauss and Corbin define memos as:

‘...written records of analysis related to the formation of theory’ (Strauss & Corbin 1990:197)

I produced memos during the research process; the intention of this was to assist with formulation and development of theory in conjunction with analysis of data. In theoretical memos I dated and detailed thoughts, I tentatively noted ideas, questions and potential categories. It was particularly useful to jot down my thoughts on the data to avoid forgetting ideas. Memo writing represented my first attempt to articulate ideas and relationships concerning the data, subsequently reflecting my own thoughts (Strauss & Corbin 1990).

Charmaz posits:

‘Memo-writing is a crucial method in grounded theory because it prompts researchers to analyse their data and to develop codes into categories early in the research process’.  
(Charmaz 2006:118)

Memos are written in narrative form and allow the researcher to explain and expand upon the emergent themes, and at the time form linkages between concepts (Charmaz 2006). An example of a memo from my study is located in Appendix 4.

### *Theoretical development*

McCann and Clark (2003) emphasize that grounded theory studies generally produce substantive theories rather than formal theories. Glaser and Strauss (1967) differentiate a substantive theory from a formal theory. Substantive theory is grounded in data on a specific empirical area under study, dealing with a particular limited field of inquiry. A substantive theory is close to reality. In contrast, a formal theory deals with the general sphere of social science, such as formal organizations. Kearney (1998) wrote that a substantive theory aims to uncover:

‘...the basic social-psychological or social structural processes that are used by persons or social groups in response to specific social problems,’ (Kearney1998:118)

In contrast, Kearney (1998) states that a formal theory:

‘...is a broader based more generalized process that occurs in a variety of distinct, yet theoretically similar, social situations.’ (Kearney1998:118)

The higher prevalence of depression in people living with chronic medical conditions is an example of a formal theory. It is therefore logical that grounded theories would be categorized as substantive rather than formal, as they typically focus on the perceptions of a specific group of people in relation to a phenomenon. In my study the focus is how women with Type 1 diabetes manage their diabetes during the menopausal transition, and it is substantive.

### **3.10 Ethical considerations**

Approval to conduct the research was granted by Edinburgh Napier University, Faculty of Health, Life & Social Sciences Research Ethics and Governance Committee and National Health Service Research Ethics Committee. The Royal College of Nursing guidance for research ethics cite Long and Johnson by stating that:

‘...all research can be potentially harmful to participant and researcher...’ (RCN 2004:4)

Bryman (2008) discusses the key ethical principles underpinning all research, which are:

- informed consent
- confidentiality
- data protection
- right to withdraw
- potential benefits
- potential harm.

I ensured that participants fully understood what their participation in the study involved. To this effect a patient information letter outlining the details of the research was provided (Appendix 5). Further verbal information could have been sought by the participant for clarification prior to signing the informed consent document (Appendix 6). This information could have been obtained face to face, via telephone or by email, and not necessarily from me but from a medical colleague, who was not involved in the proposed research and acted as independent advisor. This was to avoid any pressure for the participant to consent to the study because she knew me in my Diabetes Specialist Nurse role.

I acknowledged the sensitive nature of the research questions; if participants had displayed any sign of emotional distress during the interview I would have terminated the interview. When Barbara became upset during the interview in relation to her fear of leg amputation, I offered to switch off the tape; however, she declined. I reiterated to each participant that she could ask for the interview to cease at any time; she could refuse to answer any question and would not be required to explain why she did not wish to respond. Participants were reassured that if any of the above scenarios arose their future care would not be affected in any way. Discussing personal issues concerning the study may have exposed the participant's vulnerability or distress; this in turn could negatively affect their mood. My own clinical experience was valuable in this instance, and I did not witness any distress during the interviews that gave me cause for concern. If counselling was required I would have referred the woman via the appropriate channels, however this was not necessary. Furthermore, if the participant disclosed any information to suggest the current diabetes care received was inadequate or inappropriate, with her permission, I would have informed the participants' diabetes consultant and/or their General Practitioner, but this was not an issue. If the participant had issues relating to the management of her diabetes to the extent that a medical or nursing review was required, I would have referred her to the appropriate health care professional; this was not necessary.

Initially interviews were to be conducted in a small sitting/waiting room located in the Metabolic Unit in the hospital. However, prior to the first interview I reflected on the suitability of this location. Due to several reasons, such as potential interruptions by other members of staff, feeling anxious that I would be called on for DSN duties (despite being off duty) and patients entering the room in error, I decided it was not a suitable venue. I approached the Wellcome Trust and it was confirmed that I could use their facilities free of

charge. During the interviews privacy and confidentiality were respected and an 'engaged' sign was displayed on the door to ensure no interruptions. Participants were all attendees at the Diabetes Clinic of the hospital where interviews were conducted, therefore lived locally with easy access to the hospital and were familiar with the environment. The risk of hypoglycaemia is always present for a person with Type 1 diabetes. If during the interview the participant experienced a hypoglycaemic episode the interview would have been stopped. Blood glucose monitoring equipment and treatment for hypoglycaemia were available during the interview, but were not required.

Participants were assured that all data would be anonymous, as much as possible. They might, however, be identifiable from audio tape recordings of their voice, although with the exception of the transcriber I would be the only person listening to the recorded interview. Participants have been identified by a pseudonym of their choice, and it would not be possible for them to be identified in any reporting of data gathered. All information concerning participants, such as audio tape recordings, NHS encrypted USB stick and field notes, was stored in a locked cupboard in the Metabolic Unit of the hospital and accessed only by me. In complying with NHS Lothian guidelines, data will be destroyed after five years by shredding of paper, and data on the encrypted memory sticks would be removed and saved to NHS Lothian's hard drive and subsequently deleted.

### **3.11 Credibility of research**

Evaluation of grounded theory research is subject to fulfillment of several criteria (Corbin & Strauss 2008, Charmaz 2006). These are credibility, originality, resonance and usefulness (Charmaz 2006). Essentially, credibility relates to the accuracy and trustworthiness of the data. The audit trail detailed in Appendix 4 helped ensure this. A meaningful gauge of credibility is if health care professionals working in the field of diabetes consider the findings of this study meaningful to their own practice. The literature search and review demonstrates the originality of this study. On completion of my thesis, participants and colleagues will be given an opportunity to evaluate the resonance of the research by reading the thesis. In terms of usefulness, the findings demonstrate several practical steps that may be implemented in clinical practice to assist women with Type 1 diabetes during the menopausal transition. It may also be useful in informing further research; this will be discussed at the end of my thesis.

### **3.12 Summary**

In this chapter I have explained the rationale for my chosen research approach, including strengths and limitations. I have discussed the importance of reflexivity that I endeavored to use, employed throughout the research process. A brief history has been presented regarding the development and evolution of grounded theory as a research approach. The justification for using a purposive sample has been provided in this chapter, together with details of the recruitment process and characteristics of participants. Data collection and analysis have been described in detail, and ethical considerations addressed. In the next chapter I shall discuss the findings from my research.



## Chapter 4

### Findings

#### **4.1 Introduction**

In this chapter I will provide an overview of how I managed the findings from the study. On the whole, categories are based on conceptions from most participants with the exception of *aging and mortality*. Although this category was developed from data provided from only three participants, it remains important in terms of richness of data expanding understanding of the ‘whole’, and reflects adherence to the chosen methodology. Information is provided to illustrate the context of the theory that emerged as I discuss each of the seven categories. Examples from the data are included to highlight information regarding challenges faced by participants. These *in vivo* codes are in italics and the participants’ pseudonyms in brackets.

#### **4.2 Organization of findings**

Codes from each paper copy of the transcripts were colour coded and the page number was noted to identify where the code originated. I immersed myself in the raw data during the analytical process, reading the transcripts several times and then listening to a CD of all participants’ interviews. Since I did not transcribe interviews myself, as discussed in chapter 3, this was extremely beneficial. I changed original codes if I considered that they did not reflect the true meaning in the transcript after listening to the CD.

I scrutinized categories for their ‘power, purpose and pattern’ (Charmaz 2006:158) and organized them succinctly. On three occasions this involved merging sub-categories to form one category. For example, it became apparent that the category *‘impact and effect of menopause’* and *‘anxiety and fear’* fitted one category; *‘anxiety and fear’*. All codes and categories are detailed in Appendix 4.

As a novice researcher, accommodating this study within full time employment was extremely challenging. The lack of ‘protected’ time was frustrating. However, the benefit of the theoretical sensitivity of my experience as a Diabetes Specialist Nurse (DSN) became very apparent during analysis of data.

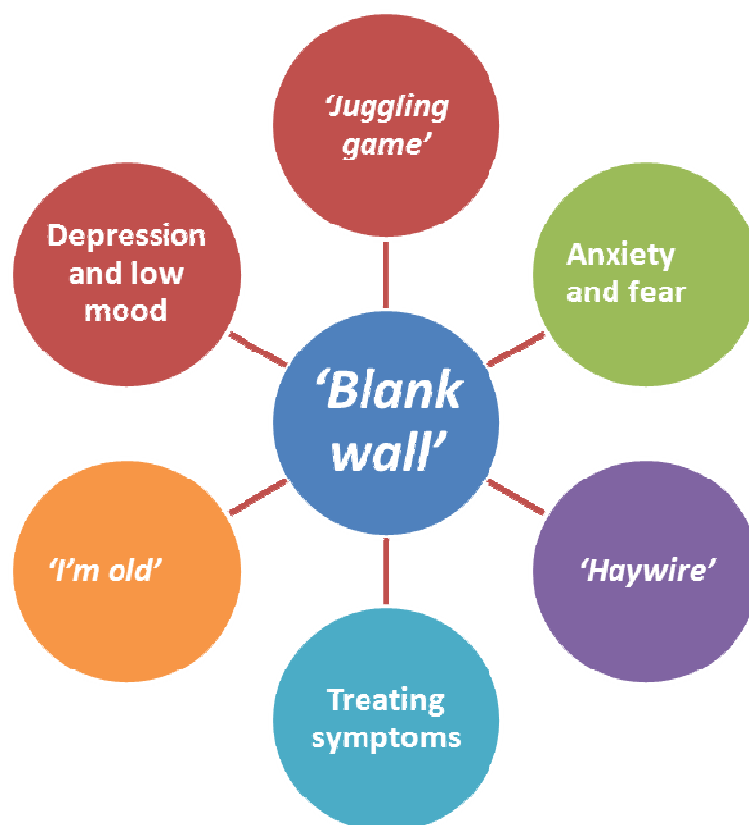
### 4.3 Categories

Data are presented in seven categories that reflect the conceptions of the menopausal transition for women with Type 1 diabetes:

- *'Blank wall'*: relates to the lack of information regarding menopause and diabetes. It is central to all other categories, as demonstrated in Figure 4.1, and is the core category;
- *'Juggling game'*: relates to glycaemic control
- *Anxiety and fear*
- *'Haywire'*: relates to Symptoms of the menopausal transition
- *Treating symptoms*
- *Depression and low mood*
- *'I'm old'*: relates to aging and mortality.

Although some of the themes overlapped, for the purpose of clarity I have treated themes as though they were independent.

Figure 4.1 Categories



#### **4.4 ‘Blank wall’: lack of information regarding menopause and diabetes.**

All participants expressed frustration at the current lack of information available. There was a desire and requirement to have information about the menopausal transition and any effect it might have on their diabetes, and many participants described the importance of getting available information prior to the menopausal transition. They felt if they had known what to expect they might have been better prepared and would not have felt the deterioration in their glycaemic control was their fault. The exemplar quotes from participants in this category:

*‘.. and if somebody, I mean somebody said to me, well you know, it’s because of the menopause that you’re having these highs and, I’m not, I know there’s no guarantee about it disappearing, I’m under no illusions about that. But at least I’d know it wasn’t me.’ (Suzanne),*

*‘Just being prepared I think for it, you know. Um, I just didn’t really think it would have affected me so much because everybody gets it. I don’t see myself as different from anybody else but I am, we are different, you know, but I’ve always looked at it as I’m the same but I’ve got this condition.’ (Barbara),*

*‘I’ve always been conscious of it, and it caught me a bit by surprise.’ (Vivienne),*

*‘If you have more information ahead of time it won’t come as a surprise.’ (Nuri),*

*‘I’ve asked what to expect and I’m told they don’t know, there’s no evidence. There is no concrete evidence, so you’re always just left, you always feel...I had to be aware that my blood sugars would rise when I menstruated, not that it would always rise, that it might rise and that would explain why you have to take more insulin...I cannot believe that there isn’t something similar going to happen, it’s your whole hormonal system that’s changing.’ (Ella).*

There was uncertainty expressed amongst participants with regards to where they should obtain the information they desired. Participants said that menopause had rarely been discussed during a diabetes clinic consultation. Other women felt inhibited to ask at the clinic because the topic had not previously been discussed and they weren’t sure if it was a problem specific to them or general; one woman was worried that she would be treated as if stupid;

*‘I did not know whether to ask, I did not know what to ask.’ (Mary).*

Another perceived the doctor as trivializing the issue when asked;

*‘The hormone thing, you know, I’ve always found difficult but I don’t think that I’ve ever had any doctor that I’ve ever consulted with take it awfully seriously.’ (Margaret).*

Most women felt it would be easier if the doctor was female and if there was information available at the clinic highlighting the topic as it would emphasize its importance;

*'I often see more male doctors when I come to clinic; it is not always the thing I will discuss with them.'* (Mary). One participant perceived that information in the waiting room would be valuable;

*'...perhaps a notice in the waiting room...I read notices at the clinic like if you are pregnant...people become pregnant and at some stage will go through the menopause, um, and I suppose then they can maybe feel that they can ask questions if it's somebody like myself.'* (Susan).

Participants described vagueness from medical staff regarding menopause;

*'Well, we don't really know, it could, it might and I'm not criticizing anybody, but they don't know.'* (Suzanne).

They also felt that medical staff minimized the hormonal effect on their diabetes when asked directly, and that Health Care Professionals (HCP) ignored the impact of menopause on their diabetes;

*'But I think I've more unexplained high blood sugars but when you raise it, it's like your control is not good, you're getting older, you maybe have to do something different but you're always dismissed when you say is it anything to do with menopause.'* (Ella), another participant expressed concern as to why their diabetes control had deteriorated;

*'I've been doing this for years, why is it not working?'* (Mini).

Another woman described HCPs as not volunteering information even when asked, but appreciated that there might not be any information. A minority of participants described feelings relating to the impersonal nature of the diabetes clinic and that care focused on clinical results only. Some women felt that they were blamed for not 'looking after' their diabetes, as demonstrated by the deterioration in glycaemic control evident in the biochemistry results at clinic. They felt it was solely their responsibility to improve their glycaemic control;

*'Medical clinics are about looking at numbers and you know, you go in and come out again.'* (Mary), another participant perceived that she was to blame for the deterioration of her glycaemic control;

*'You've had diabetes for 20/30 years and you always feel it's your fault, you're not taking care.'* (Ella), similarly;

*'If I hadn't had the seventeen years before [relating to managing diabetes for seventeen years prior to menopausal transition] it's like nobody believes you.'* (Suzanne).

Data reflected that participants desired a holistic approach to their care and discussion of health promotion strategies they might implement. Examples were more blood glucose testing to identify a blood glucose profile and facilitate adjusting and increasing insulin doses and to ascertain that symptoms were that of hypoglycaemia rather than menopausal symptoms;

*'...guidelines of what to expect, you know, the fact your blood sugars could increase... and you should be doing X,Y and Z and the importance of exercise and, you know, keep it up and good diet.'* (Nuri).

Most women wanted reassurance that they were managing their diabetes satisfactorily during the menopausal transition and that changing hormone levels associated with menopause might affect their blood glucose levels. Women acknowledged the limited time available during a consultation at the diabetes clinic, depending how busy the clinic was. They did not state a particular length of time. Most participants perceived it would be beneficial to discuss their experiences regarding their glycaemic control and management difficulties with their peers;

*'I think even knowing what happened to other people and how it affected them would be useful, and also knowing that with a change in your hormones and anything else.'* (Mary), likewise;

*'I always think it's good to sort of, you know, hear other people's stories because, you know, what's happening with me, you know, might be happening with other people and you can sort of talk to each other about it, it makes it easier.'* (Nuri).

This was not to be a 'moaning session', rather an opportunity to hear how other women coped.

There was a general feeling of frustration, anger and despondency regarding the lack of information available;

*'I wasn't doing anything different but my blood sugars were higher, and I was looking for a reason to find out why they were higher. And there was just, it was, it was a bit of a blank wall actually.'* (Suzanne), similarly according to another participant;

*'There's nothing out there, there is just nothing at al.'* (Nuri).

This was described as unacceptable by participants. There was a desire for factual information,

*'...there's so much gossip and old wives tale and theories.'* (Susan).

Participants felt that menopause should be routinely discussed at the diabetes clinic. Most participants sourced their own information via the internet. They acknowledged that there was information concerning menopause, but there was nothing regarding both Type 1 diabetes and menopause. Participants expressed uncertainty and anxiety about the duration of the menopausal transition and the effect post-menopause might have on their diabetes;

*'I don't know what to expect as a woman, I certainly don't know what to expect as a diabetic.'* (Ella),

*'having diabetes makes you worry but when this menopause thing kicks in...a huge worry.'* (Barbara), likewise according to another woman;

*'It's not knowing what stage you're at and how much longer you have to go and whether...I mean that's what I talked to the doctor about, it's whether it's worth changing routines that did work in the past.'* (Mini).

Data demonstrated difficulties associated with lack of information for participants.

*'I think it has been more difficult because I had less information about it, there needs to more information and people definitely need to talk about it more.'* (Mini).

Participants felt confused regarding what to expect and desired clarification. Some women described it as being their own responsibility to deal with, another blamed herself for not asking about the issue;

*'My understanding is that everyone is slightly different, and therefore I feel, I've got to work this out for myself.'* (Vivienne), another participant admits;

*'I've actually never consulted anyone about either never consulted anyone, that's bad isn't it?'* (Susan)

The findings in this category, *'blank wall'*, demonstrate the lack of information available to women with Type 1 diabetes during the menopausal transition. It also highlights the lack of evidence-based information available to HCP.

#### **4.5 *'Juggling game'*: glycaemic control**

This category was formed by combining *'juggling game'* with a sub-category called *'self-management'*.

All participants described, in various ways, that the unpredictability of their blood glucose levels was the most noticeable and difficult thing to manage during the menopausal transition;

*'The unpredictability definitely makes it harder, because I was so regular, and I was in a system. So it's...can be unexpected, unpredictable to me is the biggest challenge.'* (Vivienne),  
*'It goes on a day to day basis, practically by blood sugar by blood sugar basis really, it's that difficult to control.'* (Margaret).

For all women the menopausal transition resulted in hyperglycaemia, erratic blood glucose levels, increase and adjustments of insulin doses,

*'...compared to what I've been taking my insulin requirements have changed quite dramatically, I'm still exercising, I'm still the same weight.'* (Suzanne).

Some women described difficulty in managing their diabetes at this time, exemplar quotes;

*'I think I've struggled to control it.'* (Rachael).

*'Unfortunately it's a juggling game which, if you can say, right, you know, I've got this piece of food here and I can jag for that, and that's fine, but there's other things that come into the equation that I can't explain.'* (Suzanne),

*'You are testing 'cause you're high, you take more insulin and you're testing again, you're not sure how quickly it's going to drop ...I cannot believe my age and menopause is not having an impact, but what is it? Is it my lack of control or is it menopause?'* (Ella),

*'But you don't really know what's happening with the menopause...then are you taking actually taking insulin for food or for the menopause?'* (Nuri),

*'Looking for help with hyperglycaemia.'* (Vivienne).

Most participants were self-blood glucose monitoring more frequently than previously and described difficulty managing the swings in their blood glucose levels, in particular unpredictable blood glucose levels and inexplicably high levels;

*'Constantly checking blood sugar, 'cause I wasn't sure I wasn't going hypo.'* (Mary), in the same way;

*'I've got my meter with me all the time.'* (Suzanne),

*'You get highs and lows, I call it the ghost'* (Mini).

All women expressed concern and anxiety regarding the impact of hyperglycaemia on their health;

*'You're worried that your blood sugars have gone up and other things will start to happen to your body.'* (Suzanne),

*'...but I feel at this moment in time that I've lost a lot of protection, more vulnerable, less strong.'* (Nuri).

One woman described dreading the results at the clinic because of her high blood glucose levels;

*'I dread coming here, it's so disappointing.'* (Suzanne).

Others felt that they experienced less hypoglycaemia due to the hyperglycaemia. While this was perceived as a positive, the negative was the anxiety associated with hyperglycaemia potentially increasing the development of chronic diabetic complications. The importance of good glycaemic control was acknowledged. Participants described detrimental effect on blood glucose levels since reducing their exercise because of tiredness thought to be attributable to hormonal changes. Participants described, in various ways, how managing their diabetes became more difficult during the menopausal transition, exemplar quotes from participants;

*'Fifty times harder!'* (Suzanne),

*'I think it probably started as you hit you're early 50's but I feel I've struggled to control it...and I was sort of asked to inject for every snack. That's highly intrusive, I feel it's more intrusive than when I was pregnant.'* (Ella).

*'So I'm doing a lot more testing than I would normally do. A bit more strict with regime and checking all the time.'* (Mini).

Some checked routinely overnight, one woman described difficulties in blood testing in public, as it attracted unwanted attention.

All participants felt it important to be proactive in their own diabetes management. This included trying to identify patterns in blood glucose readings, adjusting their insulin doses more frequently to try and improve glycaemic control. Most women felt that blood glucose management was more difficult because of menopause;

*'Because my blood sugar was definitely slightly higher than average, and I find control more difficult than usual.'* (Rachael).

One woman specifically blamed the lack of oestrogen for the deterioration in glycaemic control;

*'Because you don't have a normal monthly cycle your body doesn't have what it should have to keep the control.'* (Margaret).

Participants felt that they had a pragmatic, proactive approach to their diabetes management, although for some their previous experience concerning diabetes management was worth nothing during the menopausal transition.



Most participants described managing their diabetes at this time as stressful; *'...loss of control, I just think, oh my God when will this end?'* (Mini), equally; *'I think my blood sugars have increased but I think it's because different systems in the body are in overdrive...it's an uphill struggle.'* (Nuri), *'So I've hit 50 and since I think well, it's hit me hard because I've always been level and steady.'* (Barbara).

One woman felt that there was a presumption from others that she should cope. Others described the frustration of not knowing what to expect regarding their blood glucose levels; *'The unpredictability makes it harder because I was so regular and in a system'* (Vivienne). The majority of participants described the impact of the menopausal transition as a trigger to improve self-care strategies; *'It's been a bit of a wake-up call'* (Mary).

One woman described requesting help from a DSN, and most expressed relief at having the ability to manage their diabetes in terms of blood glucose testing, taking correction doses of insulin and adjusting insulin doses.

The findings in the above category highlight unpredictable blood glucose levels during the menopausal transition and the anxiety associated with persistent hyperglycaemia. Despite participants being extremely proactive in managing their diabetes, the findings from this study illuminated that this management becomes more problematic during the menopausal transition.

#### **4.6 Anxiety and fear**

This category was formed by combining *'impact and effect of menopause'* with a sub-category called; *'anxiety and fear'*. It was based on numerous conceptions from participants regarding the negative impact the menopausal transition had on their ability to manage their Type 1 diabetes.

Participants acknowledged the influence that hormones had on their diabetes control, based on experiences from puberty, menstrual cycle and, for some, pregnancy. Most participants described feelings of not knowing what was happening physically at the time of the menopausal transition and ignorance that the change in hormones associated with menopause might affect their blood glucose levels;

*'Nobody has ever talked to me about these chemical changes going on in relation to your diabetes.'* (Mini), another participant perceives;

*'...this must be what it is, it must be menopause.'* (Suzanne).

For most women the menopausal transition was a confusing time;

*'I wasn't doing anything different but my blood sugars were higher, um, and I was looking for a reason to find out why they were higher.'* (Suzanne),

*'It's just more difficult to keep self balanced and not knowing why.'* (Nuri).

They described unpredictable menopausal symptoms combined with unpredictable blood glucose levels and hypoglycaemic symptoms. This resulted in a frustrating, frightening time for some. Most participants described diabetes as being familiar in contrast to the unfamiliarity of menopause;

*'...because your diabetes is always with you, the menopause is like a visitor, it's the stranger, while diabetes is something familiar.'* (Rachael),

*'I would probably say for about a year I was thinking...I was probably confused...I thought 'what the hell is going on here?'* (Mini), another participant refers to diabetes versus menopause;

*'It's like diabetes and menopause are arguing against each other.'* (Rachael)

Data from all participants reflected their fear of hypoglycaemia;

*'I know there are other issues about hormones and after the menopause, but they can be dealt with. But the hypoglycaemia is an acute thing that causes great stress.'* (Vivienne).

Participants said that they confused symptoms of hypoglycaemia with menopausal symptoms, particularly overnight;

*'I am a bit anxious, yeah anxious, I'm careful but I'm terrified in case I dip through the night.'* (Barbara),

*'I think certainly at the beginning, when I had flushes, I was worried about whether I would know the difference between a flush and I'm having a hypo.'* (Susan), similarly;

*'If you're having hot sweats during the night, that kind of masks the symptoms because you're not sure if it's, I mean you can be clammy and be hypo and you can be clammy because of menopause.'* (Suzanne), one participant warns;

*'Don't assume you are hypo, test'* (Ella).

Most women felt that they had less hypoglycaemic warning than before the menopausal transition;

*'hypo symptoms very different now, warning less.'* (Ella).

Some women described becoming familiar with the different symptoms over time. Participants described the impact of the change in hypoglycaemia awareness; fear of losing their driving license, unwelcome attention from work colleagues worrying that they might be hypoglycaemic, needing to eat overnight to be 'safe'.

The physical impact of the menopausal transition left most participants feeling tired;

*'I wake up in the morning and feel like I have a hangover.'* (Barbara).

They blamed this on disturbed sleep for several reasons; feeling hot, sweating, concerned about hypoglycaemia, worrying about glycaemic control. There was a feeling of increased vulnerability in a physical sense due to the reduction in oestrogen associated with osteoporosis and cardiovascular disease. Participants referred to reducing their exercise because of tiredness and recognized this as having a negative impact on their glycaemic control. Several women expressed concern and fear regarding the risk of pregnancy due to their unpredictable menstrual cycle;

*'I mean it did cross my mind at 47 when I went 3 months without a period, and your blood sugars are rising, you're thinking oh! If you are mid to late forties it's terrifying.'* (Ella).

Most women described feelings of concern about their health and worried more than usual.

For some the menopausal transition highlighted the fact that they had a chronic disease because its management became more difficult and associated health risks were accentuated

*'I can't really know if I'm high or low, that's a thing in my life that I can't control as much... in the last two years I've been a bit more aware of my condition, whereas before it didn't, I didn't have to think about it, I just got on with it.'* (Barbara).

One participant described this as having a negative impact on quality of life. For others it was difficult differentiating the potential impact of menopause on their glycaemic control compared to other life stressors that might affect it;

*'...menopause is the final straw.'* (Susan).

The current findings from this category reveal the significant anxiety and fear experienced by participants during the menopausal transition. This fear was attributed to the 'unknown', and being unable to control their diabetes resulting in heightened anxiety and fear of acute complications of diabetes, particularly hypoglycaemia and the associated impact on quality of life.

#### **4.7 ‘Haywire’: Symptoms of menopausal transition**

This category was formed by combining two sub categories; ‘*symptoms of menopausal transition*’ and ‘*factors influencing menopausal transition*’.

All participants felt that the only explanation for their high blood glucose levels was the menopausal transition, exemplar quotes from participants in this category;

*‘...blood glucose went haywire.’ (Barbara),*

*‘...but I think I’ve had more unexplainable high blood sugar.’ (Ella),*

*‘Yes I think what’s happened over the last two years, I do feel like it’s been a gradual increase, I have tried really hard to keep my diabetes balance.’ (Nuri),*

*‘It’s like being permanently premenstrual.’ (Margaret)* relating to high blood glucose levels associated prior to menstruation.

Most women experienced hot flushes and sweating and associated this as a sign of menopause, although for some this was confused with signs of hypoglycaemia;

*‘...and the sweats make me think of hypo.’ (Mary), likewise;*

*‘At the beginning I did confuse symptoms of hypo with menopause.’ (Barbara).*

A few women asked to have a blood test to confirm that they were in fact experiencing the menopausal transition. Participants described various symptoms that they perceived as being menopause these included irregular periods, increased blood loss during menstruation, feeling very tense, and hyperglycaemia. Some participants felt that physically they did not know what was going on because of their high blood glucose levels. It took participants a few months to realize that the hyperglycaemia was in fact a symptom of menopause;

*‘Is it my poor of control or is it menopause?’ (Ella),*

*‘The longer you have it the more aware you are of the changes.’ (Margaret),*

*‘I thought it was myself, the menopause has affected me more than I thought.’ (Barbara).*

One woman expressed concern regarding what signified the end of the menopausal transition and another hoped their diabetes would become easier to cope with post-menopause.

These findings indicate that hyperglycaemia may be a symptom of the menopausal transition. If women with Type 1 diabetes are informed of this possibility it might reduce anxiety and alert them to react to hyperglycaemia quicker in terms of increasing insulin doses.

#### **4.8 Treating menopausal symptoms**

Participants compared themselves to their non-diabetic peers who were also experiencing the menopausal transition. Several women emphasized that they felt luckier compared to other

women, as they were coping with the menopausal symptoms, but perceived their diabetes to be more problematic. Some minimized the impact of menopausal symptoms, despite the perceived difficulties they were experiencing managing their diabetes, and compared themselves to their non-diabetic peers;

*'Regarding menopause, I got off with it lightly compared to others.'* (Rachael), equally;

*'I suppose I've got off fairly lightly compared to most people, my menopause symptoms have not been as bad as others had.'* (Mary).

There was a perception amongst participants that if they could manage their diabetes they could easily cope with menopausal symptoms. Their focus was on their diabetes; their non-diabetic peers' focus was on their menopausal symptoms.

Most women had limited knowledge regarding use of hormone replacement therapy (HRT) in a person with Type 1 diabetes together with its potential effect on their diabetes. For the majority of women the option of HRT had not been discussed and they were doubtful regarding any possible benefits it could offer. They also perceived, as a result of their diabetes, HRT was contra-indicated;

*'I have spoken to my own doctor about it, but they're not too keen because of my condition obviously.'* (Barbara).

This perception was a result of the lack of information they had. Some women felt they had been denied expert advice regarding HRT. Others worried about potential contra-indications of using homeopathic therapies in relation to their blood glucose levels. One participant acknowledged the impact of decreasing levels of oestrogen as problematic and the sole cause for deterioration in her glycaemic control and subsequent hyperglycaemia;

*'Your body is different, it's changing...things are just different'* (Mini).

Two participants experienced normalisation of glycaemic control and reduced insulin doses following initiation of HRT;

*'HRT helped immensely, hugely.'* (Margaret). Only one participant was invited to attend a well women clinic. A few participants described initiating discussion regarding HRT at the diabetes clinic and with their GP.

Several women were less concerned about the possible health risks associated with HRT compared to the immediate and long term risk associated with hyperglycaemia;

*'About the hormone replacement and the worry and the possibilities of what could go wrong, you know, but actually, in actual fact the problems with the diabetes much worse than anything HRT could throw at me.'* (Margaret).

However, one woman acknowledged HRT was contra-indicated due to her family history of breast cancer. Two women felt anxious, concerned and not informed about the implication of stopping HRT in relation to their diabetes and their fear of hyperglycaemia.

The above category highlights a lack of evidence-based information regarding the treatment of menopausal symptoms in women with Type 1 diabetes. Preconceived ideas have been identified regarding the perception that HRT is contra-indicated in women with Type 1 diabetes. Furthermore, this category suggests that menopausal symptoms are much less problematic in comparison to managing diabetes during this phase in women's lives.

#### **4.9 Depression and low mood**

Participants described how the menopausal transition negatively affected their mood. Most women acknowledged that changes in hormone levels at this time might be responsible for low mood. For many women their low mood was attributed to the deterioration in their glycaemic control;

*'Much harder...very difficult and quite depressing, you know, because of what, you know you're doing the right thing but it just isn't responding to what you're doing, and the more you try to change it the worse it gets.'* (Margaret), another participant felt unhappy following a consultation with a GP;

*'So then I went to see one of the GPs in the practice who was a homeopathic, she did some homeopathic stuff. But she said to me there was nothing that would help me. And basically, I felt quite despondent after that really.'* (Suzanne).

Some women felt generally low in mood and another expressed a feeling of hopelessness. Participants felt that lack of sleep, mood swings, erratic blood glucose levels and feeling 'fed up' might contribute to their mood;

*'It'll be fine tomorrow, this isn't going to last, so I didn't get any serious depression or anything like that.'* (Mini).

One participant said that she experienced feeling frightened because of the lack of control she perceived she had over her high blood glucose levels. Two women had a previous history of depression that I was aware of, one of these women expressed concern over the stigma associated with depression;

*'I don't think mood is discussed enough, generally'* (Rachael). Both women questioned whether their depression was caused by medication required for their diabetes. One participant felt that there were other factors besides menopause that might negatively affect mood.

#### **4.10 'I'm old': aging and mortality**

Participants described, in a general way, how they felt a negative physical change with aging as signified by menopause;

*'I think what it highlighted for me, and I don't know if anybody else has said that is my increasing age and diabetes.'* (Mary).

This was accompanied with difficulties in accepting they were getting older. Two women said that the menopausal transition was significant as it highlighted the end of their reproductive years and possible pregnancy; this was perceived negatively. All participants expressed awareness of their own mortality and one described the physical change associated with menopause as emphasizing the duration of her diabetes. This contributed to fearing other external influences that might adversely affect diabetes control and management. One woman described herself as being terrified of the long term complications of diabetes. The complication risk became more apparent due to the physical changes of menopause and consequent hyperglycaemia;

*'I've always looked after myself, but since I've hit menopause I'm having problems, um, I feel my toe, just recently my toe is a bit numb, so that's freaking me out.'* (Barbara).

All participants expressed the desire to live as long as possible free from complication of diabetes;

*'Okay, you're not getting any younger here, and how can you stay as well as you are now? But how can I still be active at 70?'* (Mary).

#### **4.11 Core category rationale**

The core category emerged following use of criteria suggested by Strauss and Corbin (1998):

1. It must be abstract; that is, all other major categories can be related to it and placed under it.
2. It must appear frequently in the data. That means that within all, or almost all, cases there are indicators pointing to that concept.
3. It must be logical and consistent with the data. There should be no forcing of data.
4. It should be sufficiently abstract so that it can be used to do research in other substantive areas, leading the development of more general theory.

5. It should grow in depth and explanatory power as each of the other categories is related to it through statement of relationship. (Strauss & Corbin 2008:105)

The core category was conceptualized as *'Blank wall'*, relating to the absence of information regarding menopause and Type 1 diabetes, which represents the way women in my study regarded the lack of advice. The term *'blank wall'* was an *in vivo* code from one of the participants and summed up analysis and themes from all participants. It is evident from the findings from my study that as a consequence of *'blank wall'* participants perceived that managing their glycaemic control became a *'juggling game'* during the menopausal transition. Participants felt *anxiety and fear* as they did not know why their glycaemic control had altered or why their diabetes had become more difficult to manage. When seeking an explanation as to why their glycaemic control was *'haywire'* they were faced with a *'blank wall'*. In seeking treatment options to assist with the perceived menopausal symptoms of hyperglycaemia and of confusing hypoglycaemic symptoms with menopause symptoms, participants felt once again that they were looking at a *'blank wall'*. Consequently women in my study felt despondent; deterioration in glycaemic control, intensification of self-management strategies and lack of information and support from health care professionals negatively affected their mood.

*'Blank wall'* was justified as the core category since it overarched all other categories, could be easily related to other categories, and appeared frequently in the data. This is demonstrated in the category *'juggling game'* when Ella asked *'is it my lack of control or is it menopause?'* Nuri wondered *'Are you taking insulin for food or for menopause?'* and Mary states *'I did not know whether to ask, I did not know what to ask'*. In the category *anxiety and fear* Mini said that *'nobody has ever talked to me about these chemical changes going on in relation to your diabetes'*. The fact she described the changes as chemical instead of hormonal illustrates her lack of knowledge surrounding the physical changes she was experiencing. In the category *'haywire'*, participants experienced *'unexplainable high blood sugar'* (Ella) and confusion: *'At the beginning I did confuse symptoms of hypo with menopause'* (Barbara). Perhaps provision of relevant information to the women might have avoided this confusion. The category *treating menopausal symptoms* highlights the lack of information participants received regarding HRT, as demonstrated by Barbara stating *'they're not keen because of my diabetes'*. Barbara perceives that because of her diabetes HRT must be contra-indicated, despite not discussing this in any detail with HCPs.



The above categories are described by Creswell as:

‘causal conditions, strategies, contextual conditions and consequences’ (Creswell 2002:441).

The above coding paradigm is a way of relating the core category to all other categories (Strauss & Corbin 1990). Strauss and Corbin simplify this as

‘A (conditions) leads to B (phenomenon), which leads to C (context), which leads to D (action/interactions, including strategies), which leads to E (consequences).’ (Strauss & Corbin 1990:124).

In my study (A) managing Type 1 diabetes during the menopausal transition leads to (B) ‘*Juggling game*’, ‘*Haywire*’ and ‘*Treating symptoms*’ which leads to (C) ‘*Blank wall*’ which leads to (D) ‘*Anxiety and fear*’, ‘*Depression and low mood*’ and ‘*I’m old*’ which links back to (E) ‘*Blank wall*’

Study participants provided evidence that women with Type 1 diabetes experiencing the menopausal transition find it problematic for a number of reasons. The one underpinning theme following analysis of data from all participants was that there is lack of evidence-based information, and lack of support from health care professionals and guidance on managing their diabetes. This provides a background against which the substantive theory that emerged from the data is rooted. It is a theory in which absence of information regarding menopause and diabetes emerged as the main problem facing women with Type 1 diabetes during the menopausal transition. This theory over-arches the key implications of the difficulties these women have in managing their diabetes and achieving acceptable glycaemic control. It includes the anxiety and fear they experience during this period in their lives when they are living with an unknown phenomenon, and despite their best efforts they cannot locate information or support to assist them.

#### **4.12 Summary**

In this chapter I have discussed how I organized and managed my findings. I have discussed findings from my research and I have provided rationale for the identification of the core category ‘*blank wall*’ and evidence indicating that the core category over-arches all other categories; ‘*Juggling game*’, ‘*Anxiety and fear*’, ‘*Haywire*’, ‘*Treating symptoms*’, ‘*Depression and low mood*’ and ‘*I’m old*’. Additionally I have provided an explanation for the development of the substantive theory that has emerged from the data. In the next chapter I shall discuss these findings in detail.

## Chapter 5

### Discussion

#### **5.1 Introduction**

In the previous chapter the research findings were presented, all of which were grounded in empirical data. A variety of concepts and issues were identified. They suggest that from the perspective of women with Type 1 diabetes the menopausal transition is a complex phenomenon about which they receive minimal, or no diabetes specific information. In this chapter the findings will be discussed, as will their relationship to the initial research questions:

1. Do women with Type 1 diabetes consider that the menopausal transition impacts in any way on their diabetes management?
2. Do women with Type 1 diabetes perceive their glycaemic control to alter during the menopausal transition?
3. What are the perceptions of women with Type 1 diabetes regarding information and support provided by health care professionals during the menopausal transition?

Findings from my study suggest that women with Type 1 diabetes perceive that glycaemic control is different during the menopausal transition. This in turn is perceived as having a detrimental effect, not only on their ability to manage their diabetes on a day to day basis, but also on their longer term glycaemic control. These difficulties are compounded by the lack of information and support provided by health care professionals (HCPs) during this period. To my knowledge, and as demonstrated by the literature review in Chapter 2, my study appears to be the first study to explore the perceptions of women with Type 1 diabetes during the menopausal transition. Whilst themes identified in the findings overlap, I will treat them as discrete entities for the purpose of the discussion. Due to lack of literature relating directly to my research questions, I identified new literature that is relevant in light of my findings and further substantiates the findings from my study.

Menopause is not routinely discussed with women who have Type 1 diabetes when they attend the diabetes clinic. In my fifteen years' experience as a Diabetes Specialist Nurse (DSN) I have been unaware of any studies, oral or poster presentations, or journal articles relating to this topic either nationally or internationally. On discussion of the preliminary

findings of the current study with medical and nursing colleagues, they were considerably surprised by the impact the menopausal transition had on participants in my study.

Diabetes is a demanding, chronic, progressive disease that can have a major effect on quality of life for the person with diabetes and their families. Adherence to self-care activities can be demanding and difficult for people living with Type 1 diabetes. People with diabetes are required to constantly manage medication adherence and lifestyle factors. Patient education, empowerment, information and psychological support are considered the cornerstone of diabetes care (DH, Diabetes UK 2005). HCPs have a duty to inform and educate people living with diabetes, ensuring they have the appropriate knowledge to manage this chronic disease. Yet the overarching theme from the findings of my study, presented in chapter 4, is lack of information. This was conceptualized as the core category; '*blank wall*' and represents the lack of information concerning the menopausal transition in women with Type 1 diabetes. The consequences of this lack of information are central to the other findings, each of which I will discuss in turn.

## **5.2 Impact of '*blank wall*'**

Findings from my study indicate that participants were not sure with whom to discuss menopause regarding medical issues. It is my observation in clinical practice that Diabetologists expect General Practitioners (GPs) to deal with issues surrounding menopause, including Hormone Replacement Therapy (HRT). General Practitioners assume Diabetologists will look after diabetes related health issues. Nevertheless, findings from my current study suggest that women require a more holistic approach to their care during the menopausal transition.

Despite the study participants being motivated and proactive in their diabetes management, the lack of information regarding menopause and Type 1 diabetes was perceived by all as a major problem. By a process of elimination participants deduced that the difference in their glycaemic control and difficulties in managing their diabetes were related directly to the menopausal transition. For some it took several months of confusion and anxiety to link the changes in blood glucose levels to the menopause. The perception from participants was that this struggle was solely due to menopause; it was the only logical explanation for the difficulties they experienced, as nothing else in their lives had changed significantly; for example; excessive weight change, different diet or extreme stress. They were perplexed as to

why there was no information available regarding the hormonal changes associated with menopause and the potential affect these might have on their diabetes. They alluded to menstrual cycle, puberty and pregnancy as other times when they experienced hormonal influences on their diabetes and described considerable involvement from their diabetes team during these times. In particular, the Diabetes Specialist Nurse (DSN) would assist women to identify patterns in their blood glucose profile during the menstrual cycle. This was achieved by studying diaries of blood glucose results with the women and considering relevant lifestyle issues such as stress or exercise that might also affect the blood glucose level. This identified times during the menstrual cycle where insulin requirements were different and provided evidence to change insulin doses safely.

Six participants in my study had children. Pregnancy in women with Type 1 diabetes is a high risk state for both the mother and the baby (Persson *et al.* 2005). During pregnancy these women would have attended a joint diabetes/antenatal clinic fortnightly until 30 weeks' gestation, weekly until 36 weeks gestation, and twice a week until delivered. Regular telephone contact with a DSN would have been established to provide advice regarding blood glucose levels and insulin dose adjustment. Three participants from my study had Type 1 diabetes during puberty, again a time of considerable involvement from the diabetes team, when individuals experience significant insulin resistance associated with hormonal changes during puberty (Codner 2008). There is a significant evidence base to demonstrate that hormonal influences associated with menstrual cycle, puberty and pregnancy are physiological and may have a detrimental effect on glycaemic control, requiring the individual to intensify their diabetes management (Russell *et al.* 2001, Weinger & Jacobson 2001). There appears to be a physiological process during the menopausal transition that affects blood glucose levels; further investigation is required.

Participants were proactive in seeking information from sources other than HCPs. Findings suggest that the internet did not provide any suitable or appropriate information regarding the menopausal transition and Type 1 diabetes. Although there was general discussion about menopause with friends, family and colleagues, none of the participants had discussed this with anyone else who had Type 1 diabetes. During my contact with participants involved in my study I was surprised by their eagerness to know about the experiences of other women in the study. There was a great deal of interest regarding how these other women coped, what they were experiencing with regards to glycaemic control, if they were taking hormone

replacement therapy and how long they had experienced difficulties with their diabetes management during the menopausal transition. These enquiries were made after the interview was completed and the audio tape was switched off. I have not used this data in my study, as discussed in chapter 3. Findings from my study identified a definite need and desire for peer support and sharing of experiences as a means of obtaining information. Individuals who suffer from a long term condition benefit from sharing experiences with other sufferers; this has been shown to improve disease outcomes, as demonstrated by Broadhead *et al.* (2002) who conducted a six month feasibility study determining the value of peer support for people who were HIV positive. Emotional and psychological support is important for people with diabetes. Despite this, according to Diabetes UK (2008), these individuals frequently feel that their concerns and priorities are not dealt with, and that HCPs are too busy to talk. Consequently it would seem appropriate to facilitate peer support for women with Type 1 diabetes experiencing the menopausal transition. Nonetheless, further studies are required to determine if this would be of value. Perhaps a focus group would be a favorable approach.

### **5.3 Identifying the menopausal transition**

There was a considerable level of frustration expressed by participants concerning their inability to obtain medical confirmation that the menopausal transition was impacting negatively on their glycaemic control. They expressed a desire for evidence to demonstrate that they were experiencing the menopausal transition, and wanted to know if a blood test would provide them with that. Szmuiłowicz and Seely (2009) state that the menopausal transition is identified by a change from regular to irregular menstrual periods. They argue that due to the varying hormone levels, a blood test checking a single measurement of estradiol or follicle stimulating hormone is of little clinical value in determining peri-menopause. On the contrary, however, a proposed study by Strotmeyer and Dorman *et al.* (2003) suggest the use of hormonal measurements and menstrual cycle diaries to determine early menopause in this population. Three participants in my current study had blood tests performed that did in fact indicate hormonal changes signifying menopausal transition. The blood test was performed at the suggestion of these women in an attempt to identify whether changes in the status of their diabetes was due to hormonal influences associated with menopause. Two participants had blood taken at the diabetes clinic and one had the test performed at her GP practice. The results were communicated to them via letter, informing them that the blood test result indicated peri-menopause, in all of the participants. No further information was provided. Whilst this was reassuring regarding the physical changes they

were experiencing, they had no information or support to assist with their diabetes management at this time. They expressed feelings of concern with regards to coping with the menopausal transition and the perceived impact that hormonal changes had on their glycaemic control. Of note is the fact that these blood tests were performed by female doctors. Findings from my study indicate that participants would find it easier to discuss menopause with female medical staff, as detailed in the category '*blank wall*' in Appendix 4. Therefore it is crucial to raise awareness amongst *all* medical staff that menopause is potentially a problematic time for women with Type 1 diabetes.

Participants intensified diabetes self-management strategies during the menopausal transition; this included home blood glucose monitoring several times per day and increasing the number of tests during times of particularly unpredictable blood glucose levels, carbohydrate counting and daily insulin dose adjustment. Additionally strategies were employed to minimize the risk of hypoglycaemia, for example ensuring insulin sensitivity factor was accurate to avoid over correcting hyperglycaemia and ensuring insulin to carbohydrate ratio was correct, avoiding taking too much insulin with food. Furthermore, participants recorded blood glucose levels in a diary in an attempt to identify times of increased risk of hypoglycaemia, particularly if exercising. In addition, blood glucose testing to exclude/identify hypoglycaemia or a low blood glucose level, for example 4–5 mmol/l ensuring they could take corrective action and therefore prevent hypoglycaemia. For some this included setting an alarm clock overnight. Notably, while participants vigilantly recorded data concerning their diabetes, they did not record menopause information. It would be interesting to consider factors such as time and frequency of hot flushes and sweating attributed to vasomotor menopause symptoms in relation to blood glucose level at that time, also menstrual cycle details. It is not known why this information was not recorded by participants; perhaps because it had not been requested by HCPs and/or it may be assumed that they were unaware of any value in collecting this data, as they would not know with whom to discuss it. The value of such information will be discussed in section **6.3**, Implications for Practice, at the end of the thesis.

All women in my study regularly attended the diabetes clinic for medical review. During the menopausal transition, clinic appointments were perceived as a negative experience for some. Participants felt 'blamed' by medical staff for deterioration in glycaemic control, as demonstrated by their HbA1c result at the clinic. The glycaeted haemoglobin test (HbA1c)

provides accurate clinical information regarding glycaemic control in patients with diabetes. Furthermore, they felt frustrated that the impact of the menopausal transition was not considered as a possible factor for the deterioration in HbA1c. Participants perceived their concerns to be dismissed by medical staff when they enquired about this possibility. Consequently, participants felt unsure regarding raising the issue of menopause at clinic. Findings indicated that if there were information leaflets or posters in the clinic area concerning diabetes and menopause, then it would be much easier for women to raise the issue with the doctor during their consultation. The perceived reluctance by HCPs to discuss the issue highlighted the fact that there is no evidence-based information to communicate to patients; however, if patients do not mention the issue, then HCPs would not know about the perceived problems women encounter. This lack of discussion generated a general feeling amongst participants of being 'let down' and isolated by their diabetes team as they struggled to manage their diabetes and desperately wanted information to assist with their diabetes management during this period. Perhaps a focus group with HCPs providing feedback about this might be a way forward, as suggested in section 6.3 in the concluding chapter of this thesis.

#### **5.4 Complications of Type 1 diabetes**

The literature suggests that for women with Type 1 diabetes their reproductive years are reduced by seventeen percent, and Dorman *et al.* (2001) describe this as a major complication of Type 1 diabetes. Despite this, women with Type 1 diabetes are not informed of this significant complication, which is due to late menarche and early menopause (Zarzycki & Zieniewicz 2005). I am unaware of the rationale for omitting this highly relevant information. Currently in clinical practice, women with Type 1 diabetes are advised not to delay starting a family to ensure, as far as possible, that pregnancy is not complicated by long term diabetic complications such as retinopathy and nephropathy. However, as women generally are delaying the age of starting a family (Office for National Statistics 2010) this information should be communicated during routine diabetes consultations, when contraceptive methods should be discussed with all women of child-bearing age. It is suggested that menstrual characteristics, such as irregular menstrual periods and heavy blood loss, in women with Type 1 diabetes in their thirties and forties may in fact be peri-menopause, since the reported mean age of menopause in this population is 42 (Strotmeyer *et al.* 2003). The median age, perhaps a more accurate measurement than the mean, of participants in my study was 51.5

years; however, all had been experiencing the menopausal transition for several years prior to the study.

Previous studies reported that Type 1 diabetes presents an increased risk of osteoporosis (Strotmeyer *et al.* 2006, Rachon *et al.* 2003) and cardiovascular disease (CVD). CVD results in morbidity and mortality two to five times greater in people with diabetes compared to those without diabetes (SIGN 116 2010). Subsequently, stringent monitoring of people who have Type 1 diabetes is performed to identify and modify potential CVD risk factors such as hypertension, hyperglycaemia and dyslipidaemia. Evidence suggests that, due to low bone mineral density, people with Type 1 diabetes are at greater risk of osteoporosis; however, currently there are no evidence-based guidelines available in clinical practice regarding this information. I do not know the rationale regarding the absence of clinical guidelines concerning osteoporosis and diabetes. Whilst participants appeared to be unaware of these additional risks due to their diabetes, they expressed concern regarding the general risk menopause presented in relation to osteoporosis and cardiovascular disease. Their perception was that they were more vulnerable physically because of reduced oestrogen levels associated with menopause. They wanted information regarding how these risks would specifically affect them because of their diabetes. These are not issues routinely discussed at the diabetes clinic and there is no patient information available. Reasons for this might be related to the fact that this is gender specific information, solely concerning females. It is only in the last few years that female sexual dysfunction has been recognised as a complication of diabetes, unlike male sexual dysfunction or erectile dysfunction, which has been recognized for a number of decades (Mills and Unwin 2011). Perhaps, similar to female sexual dysfunction, menopausal risk factors such as CVD and osteoporosis in women with Type 1 diabetes are also neglected by HCPs. Increasing awareness of health promotion strategies such as smoking cessation, calcium supplements, maintaining a healthy weight and participating in exercise should be available. This information should be directed specifically at the unique requirements for this population to differentiate from general health advice regarding these topics.

It is apparent from the findings that the '*blank wall*' caused a great deal of stress and anxiety for participants and impacted greatly on their coping ability during the menopausal transition. The stress of the added burden of trying to manage diabetes at this time may significantly increase the risk of the acute complications, hyperglycaemia and hypoglycaemia.



Consequently, suboptimal glycaemic control will increase the risk of microvascular complications such as retinopathy, nephropathy and neuropathy, and macrovascular complications such as coronary, cerebrovascular and peripheral vascular disease (Lockman *et al.* 2011). The women in my study were all regular attendees at the diabetes clinic. Diabetes is a largely self-managed disease; of concern is the number of patients who do *not* attend the diabetes clinic for review and are not proactive in their diabetes management. Approximately twenty percent of patients who have diabetic clinic appointments in the hospital where I work do not attend their appointment at any given time. This excludes those patients who have cancelled their appointment. These women will not receive essential screening to detect early signs of microvascular disease. In addition, they will not be referred to other HCPs such as the dietitian, podiatrist or diabetes specialist nurse for specific issues. During the menopausal transition these women may be at considerably greater risk of hypoglycaemia and hyperglycaemia, together with an increased risk of developing retinopathy, nephropathy, neuropathy and cardiovascular disease.

## **5.5 Issues concerning menopause**

Women with Type 1 diabetes are no different from the general population, who describe discussion concerning menopause with HCPs as an important aspect of health care (although I acknowledge that there are many women who do not feel the need to discuss menopause at all with HCPs). They want to receive relevant information from a HCP who is knowledgeable regarding menopause and can discuss potential treatment options if necessary. (Im *et al.* 2008, Price *et al.* 2007, Bertero 2003, and Harrison *et al.* 2007). These findings concur with Lindh-Åstrand *et al.* (2007) who explored conceptions of menopausal women seeking advice for menopausal symptoms; the mean age was 52. Using a phenomenological approach, data were collected from 20 women following their first gynaecology clinic visit for discussion of menopausal symptoms and HRT. It is not stated whether participants had any medical conditions. A wide range of conceptions was identified, the two main categories being different physical changes with varying symptoms and both positive and negative psychological changes. Lindh-Åstrand *et al.* (2007) conclude by suggesting that for women the menopausal transition produces individual conceptions, and it is crucial to provide accurate, appropriate information regarding physical and psychological issues that women may encounter.

It could be argued that for women with Type 1 diabetes the provision of such information is even more crucial because of the perceived impact menopause has on glycaemic control and diabetes self-management. Furthermore, a significant finding from my study is that participants perceived that if there was any information available it would be better to receive it prior to the menopausal transition in the hope that they would be better prepared. The difficulty in current practice is the lack of evidence-based information available for HCPs to enable them to counsel this group of women. This is one area in which further research is required, and will be identified in the recommendations at the end of my thesis. The Diabetes Action Plan (2010) suggests that people with diabetes should be fully involved in their care. They should work together with HCPs to shape local services. Furthermore, the RCN (2009) provide guidance on patient involvement and identify that working in this way improves patient satisfaction and outcomes. Currently there is scope for such joint working to assist in provision of information and support for this population.

Findings from my study suggest that the menopausal transition accentuated the fact that participants had a chronic disease. Different chronic conditions affect people in different ways regarding physical and psychological well-being, together with the impact the condition may have on their social life and employment opportunities (Partnerships for Solutions 2002). Whilst diabetes is considered a chronic disease, the person with diabetes may not be disabled; however, if their diabetes is not treated effectively they may become severely disabled. As discussed in chapter 1 blindness, renal failure and lower limb amputations are some of the disabling consequences of poorly controlled diabetes. Unsurprisingly, participants perceived this accentuation of their chronic disease as having a negative impact on quality of life. In my study, factors such as intensification of self-management strategies, change in symptoms of hypoglycaemia, including reduction of awareness of hypoglycaemia, leading to unwelcome attention from a third party such as work colleague or stranger, deterioration in glycaemic control, and anxiety regarding the complications of diabetes were attributed to the menopausal transition, accentuating the fact that participants had a chronic disease.

The risk of pregnancy for some participants heightened anxiety and fear according to the findings from my study. The risk of an unplanned, unwanted pregnancy in older women is obvious. In addition there is the increased risk of congenital malformation of the foetus in women with poorly controlled diabetes due to the teratogenic effect of hyperglycaemia

(Jonasson *et al.* 2007). In clinical practice pre-pregnancy counselling is offered for women of child-bearing years who have diabetes, and contraception is discussed. As contraception needs change with age there should be opportunity for discussion of this at the diabetes clinic, particularly during menopausal transition.

## 5.6 Glycaemic control

Clarity and reassurance were sought by participants regarding the perceived impact of hormonal change on their glycaemic control. For most, unpredictable blood glucose levels were the greatest challenge compounded by not knowing why they were unpredictable. This encompassed both hyperglycaemia and hypoglycaemia, and is conceptualized in the category '*juggling game*' referring to glycaemic control. All participants experienced more hyperglycaemic episodes during this period. The anxiety and fear this provoked is directly related to the increase of diabetic complications associated with hyperglycaemia (DCCT 1993). Notably, no participants expressed anxiety or fear concerning the increased risk of diabetic ketoacidosis (DKA) as a consequence of hyperglycaemia. DKA is an acute, potentially life-threatening complication of Type 1 diabetes. It may be the initial manifestation of Type 1 diabetes, or may develop as a consequence of hyperglycaemia in people with established diabetes (Harris *et al.* 2005). I assume, since the women in my study were so proactive in managing their diabetes and correcting hyperglycaemia that their concern regarding DKA was unnecessary, as they considered DKA unlikely to happen. However, this was not established in the findings, as I did not ask directly. Despite the median duration of diabetes in my participants being 38.5 years, these women admitted feeling at a loss with regards to managing swings in their blood glucose level during the menopausal transition. All participants intensified self-management strategies; one woman reported by as much as '*fifty times*' since the beginning of the menopausal transition, which was approximately 12–18 months. The inexplicable and unpredictable high blood glucose results caused a great deal of stress. In correcting hyperglycaemia the risk of hypoglycaemia increased. The uncertainty of how long the menopausal transition lasted was of concern to participants. They sought information regarding what signified the end of menopause and how post-menopausal status would impact on their glycaemic control. There is nothing in the literature to indicate that twelve months of amenorrhea, indicating post-menopause, differs for women with Type 1 diabetes compared to non-diabetic women (however, it cannot be assumed that there is no difference merely because there is no evidence). This information is

currently available for the general population; however, as my study findings suggest, these women did not discuss such issues with their HCP.

## **5.7 Hypoglycaemia**

Hypoglycaemia is a significant barrier in preventing individuals with diabetes from achieving optimal glycaemic control to prevent diabetic complications. Regrettably, it is an inevitable consequence of insulin therapy (Heller 2011). Hypoglycaemia is the greatest feared complication by people who require insulin to treat their diabetes (Briscoe & Davis 2006). Anderbro *et al.* (2010) conducted a postal questionnaire survey where 764 patients with Type 1 diabetes completed a rather leadingly named questionnaire entitled 'The Hypoglycaemia Fear Survey'. Participants were identified from the local registers of two hospitals in Stockholm, Sweden. Results demonstrated that frequency of severe hypoglycaemia was the most significant factor associated with fear of hypoglycaemia. Furthermore, this was the first study to note gender differences; findings suggest that for females, fear of hypoglycaemia is greater than that of males. In addition, Leckie *et al.* (2005) suggests that one severe episode of hypoglycaemia may have a significant psychological impact on a person with diabetes and subsequently cause a chronic fear of hypoglycaemia. This in turn results in higher than optimal blood glucose levels in an attempt to avoid hypoglycaemia. Awareness of hypoglycaemia can be impaired as the duration of diabetes increases (Campbell 2011). The median duration of diabetes in my study participants was 38.5 years. For some their awareness of hypoglycaemia had changed during the menopausal transition, and others had lost their awareness completely. It is unclear from the current study if these changes in hypoglycaemia awareness were due to menopause or duration of diabetes. Regardless, anxiety and fear of this acute diabetic complication is apparent from the findings, as it has a significant impact on everyday life. Individuals who have two episodes of unrecognized hypoglycaemia within twelve months have a legal obligation to inform the Driver and Vehicle Licensing Agency (Drivers' Medical Group 2010) and relinquish their driver's license, as they are considered unsafe to be in control of their vehicle. In addition, severe hypoglycaemia is also associated with cardiac failure and accidents (Frier 2011).

Findings from my study indicate significant fear surrounding the possibility of hypoglycaemia affecting driving:

'I wondered if, with something like the menopause, whether that might change everything and, you know, perhaps I wouldn't have the warnings, and that would worry me because I'm.... especially because I enjoy driving and do quite a lot of driving...I rely on my car.' (Susan).

It is therefore of paramount importance that this particular issue is highlighted for this group of women. The women in my study were all motivated and proactive in their diabetes management and performed frequent blood glucose testing to identify hypoglycaemia. It is important for HCPs to highlight the dangers associated with hypoglycaemia to all patients. However, it is crucial to emphasize this to those at increased risk of hypoglycaemia, which includes women with Type 1 diabetes during the menopausal transition, where their hypoglycaemia awareness might have changed as findings from my study suggest. Once more this highlights the risk to non-attendees at the clinic who might not receive this information.

## **5.8 Confusing symptoms**

Findings from my study indicate that the menopausal transition caused 'anxiety and fear' for women with Type 1 diabetes, together with intensification of self-management strategies. The menopausal transition constitutes a period of time affected by hormonal, psychological and social changes (McKinley *et al.* 1992). Ayers *et al.* (2011) discuss physiological changes that occur alongside cessation of menstruation. There are several well-documented issues concerning menopause of particular importance for women with Type 1 diabetes; in addition it is important that these women are aware of these issues. Seventy five percent of Western women will experience vasomotor symptoms (hot flushes and sweating) at menopause, according to Lindh-Åstrand *et al.* (2007). Of concern is that these symptoms are similar to symptoms of hypoglycaemia (Szmuilowicz & Seely 2009), yet this is not highlighted as a potential problem for women with Type 1 diabetes by their health care providers. Notably, despite the range of symptoms Western women report at the time of menopause, i.e. headaches, insomnia, weight gain, forgetfulness and anxiety, the only two symptoms that have shown a clear association with menopause are hot flushes and night sweats. For the women in my study, these two symptoms were responsible for heightening anxiety and fear. Previous studies have demonstrated that forty to fifty percent of women experience sleep difficulties during the menopausal transition (Shaver 2002, Soares 2005). Vasomotor symptoms of hot flushes and night sweats have been suggested as the possible cause of sleep difficulties (Kravitz *et al.* 2003, Freeman *et al.* 2006, Nelson 2008). However, it is unknown

if these symptoms are different for women with diabetes (Szmuiłowicz & Seely 2009). Findings from my study identified that overnight is a time of significant concern. The anxiety and fear associated with the potential for nocturnal hypoglycaemia cannot be underestimated. For people with diabetes, self-monitoring blood glucose level overnight is obviously difficult. Frequently it is the partner of someone with diabetes who is alerted to their nocturnal hypoglycaemia due to restless behaviour or excessive sweating. If hypoglycaemia is untreated it can result in seizure, coma, brain damage and death (Briscoe 2006). During the menopausal transition this fear is exacerbated by the presence of hot flushes and night sweats potentially masking the symptoms of hypoglycaemia. Findings suggest that participants checked their blood glucose levels overnight, if they were awake, to exclude hypoglycaemia, as well as eating more before going to bed to reduce the risk of hypoglycaemia. A combination of disrupted sleep due to menopausal symptoms and worry regarding hypoglycaemia resulted in deterioration in quality of sleep; however, for some it did enable blood glucose testing overnight.

Findings from my study suggest that women do confuse symptoms of menopause with symptoms of hypoglycaemia, particularly at the onset of menopause. Worryingly, women may attribute sweating to menopausal symptoms and not treat hypoglycaemia. Alternatively they may attribute sweating and hot flushes to hypoglycaemia and take corrective action by inappropriately eating carbohydrate, potentially resulting in hyperglycaemia, subsequently increasing the risk of long term consequences of inadequate glycaemic control. Therefore it is essential to highlight this issue to HCPs so they can alert this group of women to these potentially confusing symptoms. In addition they should be encouraged to test their blood glucose level to ensure appropriate treatment is instigated.

## **5.9 Hyperglycaemia**

Participants described being 'frightened' by the high blood glucose levels they experienced, and believed this indicated that they were no longer in control of their diabetes. This was exacerbated by lack of information and/or reassurance from HCPs that hormonal changes associated with menopausal transition may be the cause of the high blood glucose levels. In the short term, hyperglycaemia can cause candidiasis infection, lack of energy and increased risk of infection. Hyperglycaemia combined with disturbed sleep left participants feeling fatigued and less inclined to participate in exercise than normal. Participants in my study perceived this to have a detrimental effect on their blood glucose levels, and they described

themselves in a vicious cycle, too tired to participate in exercise, resulting in higher blood glucose levels, in turn resulting in lack of energy and fatigue. As discussed in Chapter 1, treatment of Type 1 diabetes involves lifelong medication with insulin, but also adaptation of lifestyle. Considering issues such as carbohydrate intake, exercise, stress and other lifestyle factors that they may encounter is a daily task. It is a difficult condition to manage, but coupled with the menopausal transition it appears to be more difficult still. Further research, in light of the findings from my study, is needed in order to base guidelines for clinical practice to assist these women to reduce the incidence of hyperglycaemia and hypoglycaemia. It could be argued that for women with Type 1 diabetes experiencing the menopausal transition, continuous subcutaneous insulin infusion (CSII), also known as insulin pump therapy, should be the favoured method of insulin delivery. An insulin pump is a small device (about the size of a mobile phone) usually worn on a belt that delivers a continuous infusion of rapid acting insulin analogue subcutaneously 24 hours per day. This replaces the need for regular metered insulin injections throughout the day. The rate of background insulin administration through the pump is usually a pre-programmed basal rate which can be adjusted manually for different situations where physiological requirements change. In addition boluses of insulin are given to correct high blood glucose levels or during mealtimes (calculated using carbohydrate counting and insulin to carbohydrate ratios with a correction for pre-meal glucose values). Insulin pumps have been recognized to provide a more stable, predictable background insulin delivery with an improvement in glycaemic control and reduction of hypoglycaemia (Garmo *et al.* 2011). However, insulin pumps are expensive and individuals must meet the criteria specified by SIGN 116 (2010). Currently in Lothian there is a three year waiting list for an insulin pump. Each pump costs £2 500 to purchase with approximately £1 400 per year for consumables per person.

### **5.10 Symptoms of menopause**

Codes conceptualized in the category 'haywire', relating to symptoms of menopause, identified that participants experienced hot flushes and sweating. These symptoms were perceived as a result of menopause although, as discussed earlier, they were at times confused with symptoms and signs of hypoglycaemia. Similar to non-diabetic women, other symptoms included irregular periods, greater blood loss than usual, and feeling tense (Ayers *et al.* 2011). Dissimilar to non-diabetic women, participants described hyperglycaemia. Anecdotal evidence suggests that hyperglycaemia is commonly experienced in women who have Type 1 diabetes during the menstrual cycle, usually a few days before the menstrual period. While

participants referred to this in the findings as ‘unpredictable’ the hyperglycaemia they were currently experiencing was not related to their menstrual cycle, as they were not always experiencing a menstrual period. Together with vasomotor symptoms and irregular periods, hyperglycaemia may be a significant symptom of menopause for women with Type 1 diabetes. Previous studies have indicated that women with Type 1 diabetes have an increased incidence of menstrual irregularities (Kjaer *et al.* 1992, Strotmeyer 2003). It is important to note that this may mask symptoms of peri-menopause. If these menstrual irregularities are combined with a persistent deterioration in glycaemic control then HCPs clinical judgment should alert them to the possibility of the menopausal transition. It is essential to provide information regarding specific menopausal symptoms to women with Type 1 diabetes. If hyperglycaemia is associated with menopause, this information should be made available for both women who have Type 1 diabetes and to HCPs. However, this remains to be studied further.

Of particular interest in my study is finding that despite the substantial impact of the menopausal transition on glycaemic control, diabetes self-management and subsequent increase of anxiety and fear, participants minimized the symptoms of menopause. They related their experiences compared to other non-diabetic women that they knew who had ‘suffered’ more symptoms of menopause. Participants’ main perceptions were on difficulties concerning diabetes related issues rather than menopausal symptoms. Earlier studies postulate that women’s perceptions of menopausal transition are directly related to the severity of their symptoms and menopause status. ‘Status’ refers to whether women were pre-, peri- or post-menopausal (Lindh-Åstrad 2007). It is unknown why women in my study minimized menopausal symptoms and believed that compared to other women they had ‘got off lightly’. It may be speculated that in managing a chronic condition for a median of 38.5 years, participants in my study were more able to cope with physical symptoms than their non-diabetic peers. Additionally, because of hypoglycaemia associated with Type 1 diabetes, all participants had experienced unpleasant symptoms of low blood glucose levels that frequently include sweating and other unpleasant symptoms. Alternatively, since menopausal symptoms directly affected participants’ day to day management of their diabetes, the main focus for them was to achieve normoglycaemia. In comparison to the ongoing efforts of glycaemic control, coping with hot flushes may be perceived as trivial. Subsequently participants did not acknowledge menopausal symptoms as troublesome for the reason that



they were preoccupied with their diabetes management. Further research is required to address this question.

### **5.11 Treating menopausal symptoms**

Previous studies have demonstrated that women with Type 1 diabetes are less likely to use hormone replacement therapy (HRT) (Keating *et al.* 1999). It is unknown whether this is due to the reluctance of medical staff to prescribe this treatment as a result of perceived contra-indications associated with diabetes. There are well-recognized risks associated with HRT in the general population, but to date there are no studies addressing the risks associated with women who have Type 1 diabetes. Participants also had preconceived ideas that HRT would be contra-indicated due to their diabetes. Nevertheless, these women were interested in discussing HRT as a treatment option in the hope that it would reverse the difficulties they were experiencing concerning their glycaemic control. To date there are no studies that demonstrate this. However, use of low dose HRT in women with Type 2 diabetes has been associated with improvement in menopausal symptoms, decreased fasting glucose, total cholesterol and HbA1c (Kernohan *et al.* 2007 & Ferrara *et al.* 2001). Stefanick (2005) suggests that HRT with oestrogen is the most effective treatment for vasomotor symptoms of menopause. In addition, HRT has been found to be efficacious in comparison to placebo in reducing frequency and severity of hot flushes in healthy menopausal women (Maclennan *et al.* 2004). It is unknown if the same applies to women with Type 1 diabetes.

Findings from my study suggest that participants had limited knowledge regarding HRT, and for most the option had never been discussed with a clinician. However, if it was thought beneficial with regards to assisting in their diabetes management and glycaemic control, participants in my study stated that they would take it despite any health risks associated with it. Of note are the benefits experienced by two participants from my study who used HRT and described normalization of blood glucose levels almost instantly. Both women expressed great concern regarding the impact on glycaemic control if/when they stopped HRT. Findings from this study suggest that women with Type 1 diabetes are reluctant to explore the use of homeopathic treatments during the menopausal transition. This issue was raised spontaneously by participants in my study during discussion concerning HRT that I enquired about. Fear of these treatments negatively affecting their diabetes control or diabetes being a contra-indication for use were the main reasons for not using them.

This reluctance, together with the preconceived idea that HRT would be contra-indicated because of their diabetes may be attributed to the stigma associated with diabetes in general. People with diabetes often feel stigmatized for having this condition (Diabetes UK 2011, Pyatak 2011). This may be for cultural reasons or because society does not understand the condition. Many people with diabetes feel they are to blame for having it (Pharm *et al.* 2010, Pyatak 2011, Diabetes UK 2008). This stigmatizing nature of diabetes is frequently alluded to by people living with the condition. The media portrayal of diabetes focuses mainly on Type 2 diabetes. There is a suggestion that the cause of diabetes is related to obesity, inactivity and poor diet. Generally the public do not have the knowledge to distinguish in aetiological terms the differences between Type 1 and Type 2 diabetes. Diabetes UK (2011) highlight myths and stigmas surrounding diabetes, such as that people with diabetes cannot eat sugar and must eat 'diabetic foods', eventually people with diabetes will go blind, people with diabetes should not drive, play sport or cut their own toenails. It is perhaps not surprising that the women in my study presumed that treatment options regarding menopause would be contra-indicated because of their diabetes. This perception is supported by Olshansky *et al.* (2008), who conducted a qualitative study using a grounded theory approach to explore perceptions of people with diabetes about their experiences of living and managing their diabetes. Data were collected via focus group interviews that were audio taped and transcribed verbatim. Sixty participants were recruited for the study. Characteristics included gender, age, ethnicity and education. However, it is unknown if participants had Type 1 or Type 2 diabetes, and their treatment was not stated. The central theme that emerged from the data was 'normalizing an identity as a person with diabetes'. Olshansky *et al.* (2008) discuss the struggle for a person with diabetes to view themselves as such; instead the study identified that they view themselves as a 'diabetic person'.

### **5.12 Impact of the menopausal transition on mood**

Findings from my study suggest that the menopausal transition negatively affected participants' mood. Depression is more prevalent in people with Type 1 diabetes compared to the general population (SIGN 116 2010). Depression is frequently associated with inadequate self-care that can result in reduced quality of life, reduction in physical activity, increased non-compliance with treatments and increased unhealthy behaviours (Valerkou 2010 & SIGN 116 2010). Gendelman *et al.* (2009) assessed the prevalence of depression and use of anti-depressant medication amongst adults with Type 1 diabetes. The Beck Depression Inventory II, a self report questionnaire, was completed by 458 participants with Type 1 diabetes and

558 non-diabetic participants. Results of the study demonstrated conclusively that adults with Type 1 diabetes reported more symptoms of depression and were more likely to use anti-depressant medication compared to those without diabetes. Gendelman *et al.* (2009) acknowledge that whilst self report questionnaires are time- and cost-effective the preferred method of diagnosing poor psychological health is a consultation with a clinical psychologist. However, self report questionnaires may identify general depressive symptoms. Freeman *et al.* (2006) conducted an eight year longitudinal study to determine whether menopausal status was associated with new onset of depressive symptoms and new diagnosis of a depressive disorder. Two hundred and thirty one women were included in the study, none of whom had a previous history of depression, and all of whom were pre-menopausal at the start of the study. After eight years almost half the participants had commenced the menopausal transition, while the rest remained pre-menopausal. Findings provide conclusive evidence that there is a significant risk (threefold) of new onset depressive symptoms and new diagnosis of a depressive disorder for women during the menopausal transition compared to pre-menopause. The perception from participants was that changing hormone levels, combined with deterioration in glycaemic control and intensification in self-management strategies were responsible for low mood. Other contributing factors perceived by participants were disturbed sleep, mood swings, erratic blood glucose levels and feeling 'fed up'. Two participants had a previous history of depressive illness. It has been suggested that mood disturbances are related to hormonal changes around menopause (Lindh-Åstrand 2007). Freeman *et al.* (2006) states that the:

‘...transition of menopause and its changing hormonal milieu are strongly associated with onset of depressed mood among women with no history of depression.’ (Freeman *et al.* 2006:1).

In light of the existing evidence it appears that women with Type 1 diabetes might be at greater risk of depressive symptoms and a new diagnosis of a depressive illness during the menopausal transition. Consequently it would be beneficial to screen for depression in women at this time. Currently this does not happen in clinical practice.

SIGN 116 (2010) stipulates that HCPs working with people who have diabetes should have adequate skills to enable them to identify psychological problems in their patient group. Screening may assist in identifying psychological problems. Zigmond and Snaith (1983) were instrumental in development of The Hospital Anxiety and Depression Scale (HADS) that is commonly used today. While there is no robust evidence demonstrating reliability and

validity in the use of HADS for people with diabetes, it is the most broadly used self report screening tool for adults with diabetes in the UK (SIGN 116 2010). HADS screens for both anxiety and depression and consists of fourteen self report items. The Psychological Working Group for the Scottish Diabetes Group (2006) has recommended that for adults with Type 1 diabetes in Scotland, HADS should be used. This is one area in which further research is required, and will be identified in the recommendations at the end of my thesis.

Although the category 'I'm old', relating to aging and mortality, was formed by findings from only three participants, several concepts were identified. Similar to findings by Lindh-Åstrand *et al.* (2007) participants from my study believed that the menopause was associated with aging and the perceived difficulties in accepting 'getting old' and the end of reproductive years. This perception of aging further accentuated the duration of diabetes for these women, and heightened anxiety regarding the development of complications of diabetes, which was described as 'terrifying'. Consequently there was a real drive to try and minimize the risk of complications. This is reflected in the intensification of self-management and reflects the characteristics of the study sample.

### **5.13 Conclusion**

The findings for my study have been discussed in detail in this chapter and provide valuable insight regarding how women with Type 1 diabetes managed their diabetes during the menopausal transition. Participants in my study perceived that the menopausal transition impacted greatly on how they coped with the management of their diabetes, and their efforts to achieve optimal glycaemic control. This caused a great deal of anxiety and concern. However, the overwhelming finding from my study that encompassed all of the above was the lack of support and information available to these women; they were facing a '*blank wall*'.

### **5.14 Limitations/strengths of the study**

One of the aims of using a grounded theory approach is to generate a theoretical explanation for a phenomenon of interest. In the current study, the exploration of women with Type 1 diabetes experiencing the menopausal transition with regards to any effect it might have on their diabetes was the phenomenon of interest. It is acknowledged that my study has limitations that should be taken into account when considering the findings, as should its strengths.

The sample size of ten participants could be viewed as a limitation. In grounded theory studies rich, original data are more important than a large sample size. Given the short time frame within which I conducted the study, the sample provided rich, original data. The sample comprised Caucasian women only. If women from different ethnic backgrounds had been interviewed, a wider range of categories might have emerged. Women who volunteered to participate were proactive in their own diabetes management and attended the diabetes clinic regularly for review. They identified for themselves that the menopausal transition was difficult in terms of glycaemic control, self-management and lack of information.

The study employed a research process that was rigorous, detailed and thorough. The information provided in Appendix 4 adds to the transparency and credibility of the research process that was discussed in Chapter 3. Presentation of the findings in which participants' own words are the data from which categories are derived demonstrates the usefulness of grounded theory as a rigorous qualitative research approach. In addition, to demonstrate credibility further, during my analysis of data a coded transcript was reviewed by my supervision team, who agreed with my interpretation. With regards to originality, this is the only study to engage in depth with women who have Type 1 diabetes and who are experiencing the menopausal transition as demonstrated in the literature review in chapter 2. Considering resonance, participants will be able to access the findings and discussion from my study. Finally, on the topic of usefulness, there is potential for the findings from my study to be shared and implemented in current practice. They also make a valuable contribution for the basis of future research that will be discussed in the concluding chapter.

### **5.15 Summary**

In my study a grounded theory research approach has been employed. The theoretical framework for this approach originated from symbolic interactionism. People are able to construct their own reality but the structures within which they operate may facilitate/constrain the ability to do so. In my study the structures are not so much physical as organizational in that the information that should be available to these women is not. In symbolic interactionism individuals are viewed as active participants in constructing meaning in any situation. The ability of participants to construct meaning in my study would be dependent on them being able to access the necessary information.

This qualitative study provided insight into, and understanding of, what the menopausal transition means to women with Type 1 diabetes. It is the only study that has explored this issue, and it makes a significant contribution to the limited existing knowledge base. It has demonstrated the usefulness of grounded theory as a rigorous research approach by encouraging participants to articulate their own perception of the menopausal transition. In addition it highlights the value of qualitative inquiry for exploring individual perceptions. Concepts and theories that have arisen from this study are grounded in the data rather than being preconceived by the researcher.

## Chapter 6

### Conclusion

#### **6.1 Introduction**

In this final chapter I will reflect on the study overall. This will include a review of the chapters, implications for current practice and further research questions that have arisen from the findings from my study. I will discuss both my professional and personal experience of undertaking this piece of work.

#### **6.2 Review of chapters**

Chapter 1 introduced the study and provided background information concerning Type 1 diabetes and menopause. This also included a description of current care for people with Type 1 diabetes and justification for the study. It also contained the overall aim of the study and the research questions. Chapter 2 focused on the literature search strategies and review. Chapter 3 discussed the methodological issues in detail. This included a brief history regarding the evolution of grounded theory as a research approach and the implications of using this approach in conducting my study. Additionally, the recruitment procedure and sampling strategy were discussed and justified.

In chapters 4 and 5 the findings of the research were presented and discussed. These findings were grounded in raw data using concepts and categories that emerged from analysis of data. These findings relate to the experiences of women with Type 1 diabetes experiencing the menopausal transition. They suggest that women experience difficulties related to diabetes management and glycaemic control during this time, together with little information or support from health care professionals. It is well recognized that effective management of diabetes requires significant input from the individual in terms of self-management, but it also requires discussion with, and advice from, health care professionals.

In light of the findings from my study there is a need to examine the existing knowledge base and attitudes of health care professionals regarding diabetes and menopause, as suggested in recommendation for further research at the end of this chapter. Whilst health care professionals wish to empower their patient group, it can be difficult to do this without the appropriate evidence. If, due to lack of evidence, women with Type 1 diabetes experiencing

the menopausal transition receive inadequate care, resulting in a detrimental effect on their well-being, then HCPs working in the field of diabetes may be ethically and professionally challenged. Evidence-based information and effective strategies are crucial to support these women during this period of their lives.

### **6.3 Implications for practice**

The current study resulted in generation of a substantive theory in which the absence of information regarding menopause and Type 1 diabetes is central. The potential for the findings to make a difference to this population relies on further research to generate evidence-based information. The study indicated that women feel quite isolated and would appreciate advice and support from health care professionals (HCPs) during this challenging time. There are several implications for current practice that should be considered as they may address several issues concerning these women:

- Raising awareness amongst HCPs that menopause may be a potentially problematic time for women with Type 1 diabetes, and highlighting that additional support might be required to assist these women during this phase of their lives.
- Assessing further the benefit of offering blood testing to determine menopausal status in women with Type 1 diabetes in an attempt to provide an explanation for the changes in glycaemic control perceived by women in my study.
- Encouraging the recording of blood glucose levels and menstrual period details in a diary to try and identify any patterns. These patterns may be identified by the woman herself, in discussion with medical staff at the diabetes clinic or with a Diabetes Specialist Nurse (DSN). This may assist in altering insulin doses and the woman's diabetic management strategies.
- Raising awareness of health promotion strategies such as smoking cessation, calcium supplements, maintaining healthy weight and increasing physical activity, in view of potential increased risk of osteoporosis and cardiovascular disease. Referral to the dietitian at the diabetes clinic for a dietary overview might be instigated.
- Offering women the opportunity to wear continuous glucose monitors for a short period. This may assist in the understanding of blood glucose trends. Additionally it may provide reassurance and advice may be given by the DSN regarding the management of erratic blood glucose levels. Continuous glucose monitoring is



achieved by means of a subcutaneous sensor that measures interstitial glucose levels. It should be considered for people with diabetes who experience difficulties in maintaining normal glucose levels.

- Discussion regarding contraception and changing requirements with age at the diabetes clinic, GP or Well Women Clinic should be encouraged and recorded. Participants in my study expressed fear regarding the risk of an unplanned pregnancy during the menopausal transition.
- Opportunity for patients to request a female doctor when attending the diabetes clinic should be advertised. Women in my study perceived that it would be easier to discuss menopause with a female doctor.
- Establishing a peer support group, either face to face or online. The desire for peer support was an important finding from my study.

#### **6.4 Further research questions**

This thesis embodies the findings of a research study in which I explored how a group of women with Type 1 diabetes manage their diabetes during the menopausal transition. Absence of relevant information for these women has been prioritized by participants as problematic. Further research is required to address issues of particular concern as identified by women in my study. This includes:

- Quantitative studies measuring hormone levels to establish the ability to identify menstrual status and any correlation this may have to glycaemic control, measured by HbA1c assay, total daily dose of insulin, weight and episodes of hypoglycaemia unawareness. This may address the concern of women from my study seeking confirmation that the menopausal transition impacted on their glycaemic control and how they managed their diabetes.
- Quantitative and qualitative studies to determine the effect of Hormone Replacement Therapy (HRT) in women with Type 1 diabetes during the menopausal transition in relation to glycaemic control and quality of life. This may address the findings from my study where 2 participants associated improved glycaemic control and diabetes management with initiation of HRT.

- Whether changes in hypoglycaemic signs and symptoms are associated with menopause in women with Type 1 diabetes. Women in my study reported changes in awareness of hypoglycaemia during the menopausal transition.
- To identify if there is an increased risk of depression and anxiety in women with Type 1 diabetes during the menopausal transition by utilizing screening tools such as The Hospital Anxiety and Depression Scale to determine this. In light of the findings from my study together with existing literature women with Type 1 diabetes experiencing the menopausal transition may be at greater risk of depressive symptoms.
- Qualitative study to explore health care professionals' conceptions of the menopausal transition and Type 1 diabetes. This may demonstrate the perception from the women in my study regarding the 'Blank wall' they are faced with when seeking information from HCPs regarding diabetes and menopause.
- Identification of what happens to blood glucose levels during a hot flush by women wearing a continuous glucose monitoring device that records blood glucose every five minutes and can be worn for six days. This may provide information regarding the perceived erratic/ unpredictable blood glucose levels experienced by participants in my study.
- A comparison study of glycaemic control and insulin doses pre-, peri- and post-menopause by recording of HbA1c, total daily insulin dose, weight and recordings of blood glucose levels. This may determine the perceived difficulties in diabetes management suggested by the findings from my study.

## **6.5 Personal and professional experience**

From a personal perspective the process of conducting this research has given me valuable skills as a researcher. I have learned the importance of planning research projects, collecting and analyzing data and presenting findings. As the data collection progressed I felt my interviewing skills improved. The difficulty accommodating this study together with full time employment was challenging. On reflection, securing protected time to facilitate the research would have been beneficial, although slightly unrealistic, given current financial constraints in the NHS.

From a professional perspective I am concerned about the lack of evidence available to women regarding the research topic, and the lack of support participants felt is available to

them during the menopausal transition. It is apparent from the participants' quotes presented in chapter 4 that the process of discussing menopause allowed them the opportunity to express their dissatisfaction with the current care regarding diabetes and menopause.

## **6.6 Summary**

What emerged from the study is a substantive theory in which absence of information regarding the menopause and its impact on Type 1 diabetes has been identified. Findings from my study may enable practitioners to identify the types of information, advice and support that should be made available to these women, and contributes to the limited knowledge base currently available. Findings indicate also that further research into this under-studied but important area of diabetes care is required. The findings from the research will be presented to national and international diabetes conferences. These would include: Diabetes UK and Diabetes in Scotland annual professional conferences, the European Association of the Study of Diabetes and the American Diabetes Association annual conferences. Publications will be submitted to all diabetes and women's health journals as appropriate. An abstract concerning my study has been accepted for poster presentation at Diabetes UK national conference 7<sup>th</sup>-9<sup>th</sup> March 2012. A copy of the poster is on page 117.

This qualitative study explored the perceptions and perspectives of women with Type 1 diabetes experiencing the menopausal transition and has identified vital findings; these are:

1. Women with Type 1 diabetes consider the menopausal transition to impact negatively on their diabetes management.
2. Women with Type 1 diabetes perceive that their glycaemic control deteriorates during the menopausal transition.
3. Women with Type 1 diabetes perceive that they receive minimal or no information or support from health care professionals during the menopausal transition.

The ability for these women to manage the stresses of the menopausal transition might be enhanced through education and support from HCPs. However, in order to provide both women and HCPs with appropriate information regarding menopause, further research is required as detailed in section 6.4. The current lack of awareness and knowledge amongst HCPs caring for these women is unacceptable. Educating HCPs about the challenges faced by

these women is crucial to ensure that they receive the best care possible, allowing them to make informed choices concerning their health.

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## Appendix 1 Summary of literature reviewed

### Original Studies

<p><b>Bertero <i>et al.</i></b> <b>(2003)</b></p>	<p><b>Location of study:</b> Sweden  <b>Type:</b> Qualitative design.  <b>Aim:</b> To identify and describe the expectations, apprehensions and knowledge of 47 year old women regarding the menopausal period and symptoms.  <b>Method:</b> A convenience sample of 39 women all aged 47 years. Data collection by semi structured interviews /discussions. Content analysis was used to analyse data.  <b>Results:</b> A feeling of freedom was expected by these women regarding the menopause. Apprehension was expressed relating to expected symptoms. Women lacked knowledge relating to potential changes and coping strategies.  <b>Strengths:</b> Moderate sample size for a qualitative study.  <b>Limitations:</b> It is not stated if these women were all pre-menopause.  <b>Key messages:</b> Discussion regarding health implication with women prior to menopause to increase their knowledge is advantageous.</p>
<p><b>Dorman <i>et al.</i></b> <b>(2001)</b></p>	<p><b>Location of study:</b> USA  <b>Type:</b> Quantitative Analysis Report.  <b>Aims:</b> To determine if menopause in women with Type 1 diabetes was premature.  <b>Method:</b> 143 women with Type 1 diabetes, 186 non-diabetic sisters and 160 unrelated controls were recruited. All were assessed clinically for autoimmune diseases, blood pressure, BMI and blood tests to evaluate lipids, HbA1c, auto antibodies and thyroid function. Questionnaires regarding complications of diabetes, lifestyle factors and reproductive histories together with self reporting menstrual and menopausal events.  <b>Results:</b> The age of menopause was younger for women with Type 1 diabetes= 41.6 years than for non-diabetic sisters = 49.9 years and control = 48.0 years (P=0.05).  <b>Strengths:</b> First statistically significant report, validated tools used to collect most data and similar numbers in each group.  <b>Limitations:</b> Small numbers, all White participants and possible bias in self reporting of menstrual and menopausal events  <b>Key message:</b> Menopause occurs earlier in women with Type 1 diabetes. As a result of this women with Type 1 diabetes have on average six fewer reproductive years than non-diabetic women.</p>
<p><b>Doruk <i>et al.</i></b> <b>(2005)</b></p>	<p><b>Location of study:</b> Turkey  <b>Type:</b> Quantitative prospective questionnaire.  <b>Aim:</b> To investigate the effect of diabetes upon female sexual function and identify potential risk factors that may predict sexual dysfunction.  <b>Method:</b> 127 women completed a 19-item questionnaire assessing sexual function over the past 4 weeks. 71 women had diabetes – 21 of these had Type 1 diabetes and 50 had Type 2 diabetes. There were 56 non-diabetic healthy women as a control group.  <b>Results:</b> Sexual dysfunction was significantly higher in the women with Type 1 diabetes.  <b>Strengths:</b> It is an under-researched area and this study highlights the need for further research.  <b>Limitations:</b> Diabetes complications were not recorded, nor were HbA1c levels.  <b>Key messages:</b> Sexual dysfunction is potentially another complication of Type 1 diabetes.</p>
<p><b>Harrison <i>et al.</i></b> <b>(2007)</b></p>	<p><b>Location of study:</b> USA  <b>Type:</b> Qualitative descriptive study.  <b>Aim:</b> To examine the way women with disabilities understand and make decisions regarding menopause.  <b>Method:</b> Semi-structured interviews were carried out with 19 women who had disabilities.  <b>Results:</b> Results were poorly presented and quite unclear. The main finding was that most women described menopause as a ‘back burner issue’ but desired accurate information to assist their decisions with regards to the impact they might have on their overall health.  <b>Strengths:</b> On of the few studies that have considered this issue.  <b>Limitations:</b> 19 English speaking women with different disabilities.  <b>Key messages:</b> The current knowledge base surrounding menopause needs to include women with disabilities to ensure that health care providers can support this group of people.</p>

<p><b>Kernohan <i>et al.</i> (2007)</b></p>	<p><b>Location of study:</b> UK  <b>Type:</b> Double-blind, randomized placebo-controlled trial.  <b>Aim:</b> To assess the effect on glucose homeostasis and cardiovascular risk factors of low dose HRT in post-menopausal women with Type 2 diabetes.  <b>Method:</b> 28 subjects completed the study. They were randomly allocated to low dose HRT-oral 17 [beta] oestradiol (1mg) and norethisterone 90[middle dot] 5mg) (Kliovance, Novo Nordisk) or matching placebo tablet. Stratified for the presence or absence of hypertension. Baseline assessments were performed of fasting blood glucose and then insulin clamp assessments to measure hepatic glucose production.  <b>Results:</b> Low dose HRT had a positive effect on fasting glucose and total cholesterol. HRT did not have a negative effect on glucose clearing, triglycerides or c-reactive protein.  <b>Strengths:</b> All subjects were post menopause for at least 12 months. Groups were matched at baseline for blood pressure, BMI, baseline glucose and treatment of diabetes.  <b>Limitations:</b> Small sample size.  <b>Key messages:</b> Type 2 diabetes is a potent cardiovascular risk factor; low dose HRT offers similar benefits to conventional HRT without some of the attributed risks.</p>
<p><b>Price <i>et al.</i> (2007)</b></p>	<p><b>Location of study:</b> Canada  <b>Type:</b> Qualitative naturalistic inquiry.  <b>Aim:</b> To explore experiences of menopause in women living in rural areas.  <b>Method:</b> 25 participants were interviewed in focus groups and individually. All interviews were transcribed and analyzed using thematic analysis.  <b>Results:</b> 4 main themes were identified: 1) intensity of menopause experience, 2) trying to understand what was happening, 3) accepting the change, and 4) being unable to prevent it and the need for support.  <b>Strengths:</b> Principles established by Lincoln and Guba (1985) were followed to ensure rigour of the findings  <b>Limitations:</b> Small sample size, all White participants therefore results cannot be generalised to all women  <b>Key messages:</b> Menopause is a significant life event. In rural areas nurses are important health care educators and providers; evidence-based information should be available to these women.</p>
<p><b>Rachon <i>et al.</i> (2003)</b></p>	<p><b>Location of study:</b> Poland  <b>Type:</b> A prospective quantitative comparison study.  <b>Aims:</b> To evaluate the relationship between serum bioactive IL-6 levels and bone mineral density (BMD) at the femoral neck of post-menopausal women with Type 1 diabetes.  <b>Method:</b> Clinical measurements of BMD indicators were performed in 20 post-menopausal women with Type 1 diabetes and results were compared with 20 matched healthy controls.  <b>Results:</b> Lower BMD in post-menopausal women with Type 1 diabetes and higher bioactive IL-6 levels compared to the control group. Correlation between lower BMD and higher IL-6 levels was not found. Therefore it was not conclusive that higher levels of IL-6 in Type 1 diabetic women could lead to bone loss.  <b>Strengths:</b> Provides further evidence regarding osteoporosis risk in women with Type 1 diabetes.  <b>Limitations:</b> Small sample size.  <b>Key message:</b> Both menopause and duration of Type 1 diabetes may impact negatively on bone mass.</p>
<p><b>Smith <i>et al.</i> (1992)</b></p>	<p><b>Location of study:</b> UK  <b>Type:</b> Quantitative design  <b>Aim:</b> Enquire about changes in severity of multiple sclerosis (MS) symptoms with menstrual cycle, menopause and use of hormone replacement therapy.  <b>Method:</b> Retrospective questionnaire completed by 11 pre-menopausal women and 19 post-menopausal women.  <b>Results:</b> 82% reported an increase in severity of MS symptoms pre-menstrually. 54% reported an increase in severity of symptoms with menopause and 75% reported an improvement in symptoms with HRT.  <b>Strengths:</b> Provides results for basis of a larger study.  <b>Limitations:</b> Pilot study – small numbers.  <b>Key messages:</b> Withdrawal of oestrogen may cause MS symptoms to be worse, HRT may improve these symptoms.</p>

<p><b>Soriguer <i>et al.</i> (2009)</b></p>	<p><b>Location of study:</b> Spain  <b>Type:</b> Longitudinal prospective cohort study.  <b>Aim:</b> To identify changes in certain risk factors for cardiovascular disease during menopause.  <b>Method:</b> 475 women were followed up for 6 years. They were classified into 3 groups; 1) no menopause at either 1<sup>st</sup> or 2<sup>nd</sup> study, 2) no menopause at first study but menopause at 2<sup>nd</sup> study, 3)menopause at 1<sup>st</sup> study. Various clinical measurements were obtained to identify change significant to increase the individual's cardiovascular risk  <b>Results:</b> There was no change in any of the cardiovascular risk factors during the time from pre-menopause to post-menopause.  <b>Strengths:</b> Prospective nature of study and lengthy follow up (6 years).  <b>Limitations:</b> All participants were from Southern Spain, all participants were ethnically and culturally homogenous. Small sample size.  <b>Key messages:</b> Menopause is not a disease and should not be medicalized unless there are any other cardiovascular risk factors.</p>
<p><b>Strotmeyer <i>et al.</i> (2003)</b></p>	<p><b>Location of study:</b> USA  <b>Type:</b> Quantitative questionnaire evaluation.  <b>Aims:</b> To determine whether women with Type 1 diabetes have a greater prevalence of menstrual irregularities.  <b>Method:</b> 143 women with Type 1 diabetes, 186 non diabetic sisters and 160 unrelated controls were recruited. All were assessed clinically for autoimmune diseases, blood pressure, BMI and blood tests to evaluate; lipids, HbA1c, auto antibodies and thyroid function. Questionnaires regarding complications of diabetes, lifestyle factors and reproductive histories together with self reporting menstrual and menopausal events.  <b>Results:</b> Women with Type 1 diabetes had more problems regarding long menstrual cycles, long menstruation and heavy menstruation before age 30 years compared to non-diabetic women- this was statistically significant. Menarche was later for women with Type 1 diabetes, they experienced earlier natural menopause, had fewer pregnancies and more late inter-uterine deaths.  <b>Strengths:</b> Results were statistically significant.  <b>Limitations:</b> Small numbers, all White participants and possible bias in self reporting of menstrual and menopausal events.  <b>Key message:</b> In young women, Type 1 diabetes is a risk factor for menstrual disturbances.</p>
<p><b>Strotmeyer <i>et al.</i> (2006)</b></p>	<p><b>Location of study:</b> USA  <b>Type:</b> A prospective quantitative comparison evaluation  <b>Aims:</b> To determine if middle-aged menopausal women with Type 1 diabetes had lower bone mineral density (BMD) and self-reported fractures compared with non-diabetic women  <b>Method:</b> Measurements of total hip, femoral neck, whole body and spine BMD in 67 women with Type 1 diabetes and 237 non diabetic controls aged 35-55years old. Dual x-ray absorptiometry and calcaneal broadband ultrasound (BUA) was assessed with quantitative ultrasound.  <b>Results:</b> Women with Type 1 diabetes had significantly lower BMD for total hip, femoral neck and whole body calcaneal BUA compared with non-diabetic controls.  <b>Strengths:</b> Adjustments for age, lean mass and fat mass were made.  <b>Limitations:</b> Small number of diabetic participants and none had severe complications of diabetes.  <b>Key message:</b> Osteoporosis screening for fracture prevention efforts may be appropriate for women with Type 1 diabetes as this could potentially be another complication of the disease.</p>

## Review articles

<p><b>Morrow (2002)</b></p>	<p><b>Aim:</b> review literature regarding midlife, menopause and disability.  <b>Method:</b> A very selective review of presentations at the '10<sup>th</sup> Annual Meeting, North American Menopause Society'  <b>Results:</b> A narrative description of the experiences of women with various disabilities describing the impact that the menopause has had on their lives.  <b>Key message:</b> The need for specialized information relating to specific disabilities and how the menopause may impact on these disabilities in particular osteoporosis and cardiovascular disease.</p>
<p><b>Wedisinghe <i>et al.</i> (2009)</b></p>	<p><b>Aims:</b> To briefly discuss the main problems that women with Type 2 diabetes encounter post menopause and the use of HRT for these individuals.</p>



	<p><b>Method:</b> Not stated, no search strategy shown, no dates given, 49 references cited.</p> <p><b>Results:</b> A narrative description of current literature discussing: pathophysiology of oestrogen deficiency and HRT and newly diagnosed diabetes, HRT and carbohydrate metabolism, HRT and lipids, HRT and bone cardiovascular disease and diabetes, and cancer and diabetes.</p> <p><b>Key message:</b> The incidence of Type 2 diabetes is increasing, diabetes is a major risk factor for cardiovascular disease. Managing menopausal women with diabetes is 'clinically challenging' and HRT should be prescribed with caution. Non-oestrogen based alternatives should be considered to reduce menopause symptoms and protect against osteoporosis.</p>
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**Appendix 2** Results from database search include: CINHAL, Ovid Medline, EBM Reviews, British Nursing Index, EMBASE and PsycINFO

<input type="checkbox"/>	# ▲	Searches	Results	Search Type	Action
<input type="checkbox"/>		exp *Diabetes Mellitus, Type 1/	67073	Advanced	
<input type="checkbox"/>		exp *Menopause, Premature/ or	25703	Advanced	
<input type="checkbox"/>		exp *Menopause/			
<input type="checkbox"/>	3	1 and 2	18	Advanced	
<input type="checkbox"/>		exp *Diabetes Mellitus/	354173	Advanced	
<input type="checkbox"/>		exp *Menopause/	25505	Advanced	
<input type="checkbox"/>	6	4 and 5	277	Advanced	
<input type="checkbox"/>		exp *insulin dependent diabetes mellitus/	67073	Advanced	
<input type="checkbox"/>		exp *menopause/ or exp *early menopause/ or exp *menopause related disorder/ or exp *menopause and climacterium"/	42877	Advanced	

- 9 7 and 8 29 Advanced  
 exp Diabetes
- 10 Health 277133 Advanced  
 Promotion/ or  
 exp Diabetes/
- 11 exp 56900 Advanced  
 Menopause/
- 12 from 11 keep 1- 10 Advanced  
 10
- 13 exp 56900 Advanced  
 Menopause/
- 14 from 13 keep 1- 10 Advanced  
 10
- 15 (type 1 90 Advanced  
 diabetes and  
 menopause).af.  
 type 1  
 diabetes.mp.
- 16 [mp=ti, ot, ab, 34720 Advanced  
 nm, hw, ui, sh,  
 tn, dm, mf, tc,  
 id]  
 menopause.mp.
- 17 [mp=ti, ot, ab, 54930 Advanced  
 nm, hw, ui, sh,  
 tn, dm, mf, tc,  
 id]
- 18 16 and 17 37 Advanced  
  
<http://ovidsp.uk.ovid.com/sp-3.2.2b/ovidweb.cgi?&S=FGJLPDKCELHFKFOOFNDLCDGHPNO>
- 19 type 2 89320 Advanced  
 diabetes.mp.  
 [mp=ti, ot, ab,  
 nm, hw, ui, sh,

		tn, dm, mf, tc, id]		
<input type="checkbox"/>	20	17 and 19	260	Advanced
		change of life.mp.		
<input type="checkbox"/>	21	[mp=ti, ot, ab, nm, hw, ui, sh, tn, dm, mf, tc, id]	903	Advanced
		female change of life.mp.		
<input type="checkbox"/>	22	[mp=ti, ot, ab, nm, hw, ui, sh, tn, dm, mf, tc, id]	0	Advanced
<input type="checkbox"/>	23	16 and 21	1	Advanced
		enduring conditions.mp.		
<input type="checkbox"/>	24	[mp=ti, ot, ab, nm, hw, ui, sh, tn, dm, mf, tc, id]	3	Advanced
		chronic disease.mp.		
<input type="checkbox"/>	25	[mp=ti, ot, ab, nm, hw, ui, sh, tn, dm, mf, tc, id]	279378	Advanced
<input type="checkbox"/>	26	16 and 25	509	Advanced
<input type="checkbox"/>	27	21 and 26	0	Advanced
<input type="checkbox"/>	28	19 and 26	69	Advanced
		exp *Diabetes		
<input type="checkbox"/>	29	Mellitus, Type 1/	67073	Advanced
<input type="checkbox"/>	30	exp	25703	Advanced

- \*Menopause,  
Premature/ or  
exp  
\*Menopause/

31 29 and 30      18      Advanced
- 32 exp \*Diabetes  
Mellitus/      354173      Advanced
- 33 exp  
\*Menopause/      25505      Advanced
- 34 32 and 33      277      Advanced

exp \*insulin
- 35 dependent  
diabetes  
mellitus/      67073      Advanced

exp  
\*menopause/ or  
exp \*early  
menopause/ or  
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\*menopause  
related  
disorder/ or  
exp  
\*\*menopause  
and  
climacterium"/
- 36 35 and 36      29      Advanced

exp Diabetes
- 38 Health  
Promotion/ or      277133      Advanced

exp Diabetes/
- 39 exp  
Menopause/      56900      Advanced
- 40 from 39 keep 1-  
10      10      Advanced

- 41 exp  
Menopause/ 56900 Advanced
- 42 from 41 keep 1-  
10 10 Advanced
- 43 (type 1  
diabetes and 90 Advanced  
menopause).af.
- 44 [mp=ti, ot, ab,  
nm, hw, ui, sh,  
tn, dm, mf, tc,  
id] 532 Advanced
- 45 19 and 44 0 Advanced  
(hormone  
replacement  
therapy and  
diabetes).mp.
- 46 [mp=ti, ot, ab,  
nm, hw, ui, sh,  
tn, dm, mf, tc,  
id] 1273 Advanced
- 47 16 and 46 30 Advanced  
remove
- 48 duplicates from 20 Advanced  
47

Results from EBSCO database

Query	Limiters/Expanders	Last Run Via	Results	Action
S7	Type 2 diabetes and	Search modes -	Interface - EBSCOhost	27 <a href="#">Edit</a>

	menopause	Boolean/Phrase	Search Screen - Advanced Search Database - CINAHL with Full Text		S7
S6	type1 diabetes and menopause	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	5	<a href="#">Edit</a> S6
S5	S2 and S3	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	4	<a href="#">Edit</a> S5
S4	(MH "Menopause") OR (MH "Menopause, Premature")	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	3416	<a href="#">Edit</a> S4
S3	(MH "Menopause") OR (MH "Menopause, Premature")	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	3416	<a href="#">Edit</a> S3
S2	(MH "Diabetes Mellitus, Insulin-Dependent")	Search modes - Boolean/Phrase	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	5291	<a href="#">Edit</a> S2
S1	(MH "Diabetes Mellitus, Insulin-Dependent")	Limiters - Published Date from: 20000101- 20100131; English Language; Language: English	Interface - EBSCOhost Search Screen - Advanced Search Database - CINAHL with Full Text	4791	<a href="#">Edit</a> S1

		Search modes - Boolean/Phrase			
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### **Appendix 3** Interview Guide

1. Tell me about your blood glucose levels during the last few months, has there been any change?
2. What are your blood glucose levels normally like? If they are erratic have they always tended to be erratic for no reason that you are aware of? Have they always been this way?
3. How would you describe your ability to manage your diabetes over the past few months?
4. How would you describe any information or advice that you have received from doctors or nurses about the menopause in relation to your diabetes?

Additional questions following the first 4 interviews:

5. Do you have any concerns regarding effect diabetes may have on menopause?
6. Have you enquired, considered or used hormone replacement therapy at some point?

#### **Appendix 4** An example of data analysis through sub coding, coding and categorizing

The example detailed below contains the 7 sub codes from data that form the code ‘Desiring discussion with peers’ as displayed in Table (1) in Appendix 4. ‘Desiring discussion with peers’ is one of the 51 codes that form the core category ‘*Blank wall*’. The further 50 codes detailed in Table (1) comprise of a number of sub codes also displayed in Table (1).

<b>Data</b>	<b>Sub code</b>
I always think it’s good to sort of, you know, hear other peoples stories...because you know what’s happening to with me, you know, might be happening with others...and it makes it easier	Desiring support and information from others
I don’t know if anyone else has been through this, you know, and come out the other end and are now living without the oestrogen side of it, you know. I’d quite like to know if anybody else is and whether they’ve got any tips.	Seeking experiences of others regarding what actually happens during menopausal transition
It would be nice to know if somebody else has a similar problem to me	Sharing problems with others
...maybe it would be a good thing for, you know, to get together, not, not I don’t know like a major, a major, just an informal chat...	Seeking discussion with other women
...all my pals...they’ve had different experiences but they don’t have diabetes, and I would like people who do to tell me their experiences.	Acknowledging different experiences if diabetic
It’s good to discuss you’re diabetes, but Maggie is not old enough to have it, menopause, yet so I’ve not had a major discussion with her. But I think it might be something that would help other people as well as me.	Benefit from discussing diabetes and menopause with peers
...talk to each other about it, it makes it easier...like a buddy system	Seeking support from other peers

As detailed in the table above I allocated labels that I have referred to as sub codes from data that related to the code topic. With the aid of memos and literature to date I conceptualized the core issue, this was achieved by comparing coded data with data I had previously coded thereby constantly comparing my analysis. By collating all 7 sub codes I formed the code ‘desiring discussion with peers’. I categorized this data as lack of information regarding menopause and diabetes, without forcing data this code fitted the core category ‘*Blank wall*’ that is an *invivo* code relating to lack of information regarding menopause and diabetes. I

used the same constant comparative analysis for the further 50 codes that comprised the core category 'Blank wall'. The same procedure of coding and categorising data was utilised for the further 6 categories detailed in this Appendix and the development of the core category that is discussed in chapter 4.

#### Example of memo

During data analysis I used memos as discussed in chapter 3. Below is an example of a memo written during coding data that ultimately formed the core category 'Blank wall':

*I was unaware how isolated these women feel during the menopausal transition and how they are expected to cope with their diabetes with no support from their diabetes team or family. They do not have anyone to talk to who understands what they are going through. They are expected to get on with it as they have always done. It is their condition, their problem. Few people with Type 1 diabetes know anyone else who has Type 1.*

## Tables of codes and sub codes that form each category

**Table (1).** Detailed below are the codes and sub codes that form the core category: *'Blank wall'*: relates to lack of information regarding menopause and diabetes (codes from 10 participants)

Code	Number of sub codes
Needing information	8
Importance of information prior to menopausal transition	8
Difficulty knowing who to ask	2
Seeking holistic approach	2
Seeking advice regarding hypoglycaemia	1
Health promotion strategies	3
Wanting information regarding what to expect	3
Seeking reassurance	3
Lack of information	11
'Blank wall'	1
'There's nothing out there'	1
Recording of specific detail	2
Initiating discussion at diabetes clinic	1
Blaming self for not asking	1
Never discussed menopause at diabetes clinic	6
Easier to discuss if issue highlighted	3
Prefer female doctor	4
Inhibited to ask about the menopause	3
Feeling stupid	1
Desiring discussion with peers	7
Frustrating lack of support	5
Acknowledging limited information is available	3
Own responsibility	3
Useless information on internet	4
Grateful issue is being explored	1
Needing confirmation that menopause can affect blood glucose levels	2

Vagueness from medical staff	3
Feeling 'despondent'	1
Sourcing own information	4
Menopause should be routinely discussed	4
Menopause information available but none concerning diabetes	1
Need for proactive approach	1
Appreciation of individual experiences	2
Medical staff minimize hormonal effect on diabetes	2
Lack of factual information 'there's so much gossip and old wives' tales and theories'	1
'I think it has been more difficult because I had less information about it'	1
Uncertain about post-menopause effect on diabetes	6
Uncertain of duration of menopausal transition	3
Acknowledging limited time at clinic	2
HCP ignoring impact of menopause on diabetes	3
Seeking clarification	1
Well women clinic useful	1
HCP not volunteering information	1
Impersonal approach at clinic	1
Seeking discussion from DSN	1
Care focused on clinical results	1
Blamed for not looking after self	2
Angry at lack of information	1
Not being taken seriously	1
Unacceptable lack of evidence	2
Confused by what to expect	1

**Table (2).** Detailed below are the codes and sub codes that form the category: '*Juggling game*': relates to glycaemic control (codes from 10 participants). This category was formed by combing two subcategories: *blood glucose control* and *hypoglycaemia*.

<b>Code</b>	<b>Number of sub codes</b>
Unpredictable blood glucose levels, 'unpredictable to me is the biggest challenge'	16
Concerned about hypoglycaemia	3
Testing more frequently	5
Hyperglycaemia	9
Difficult to manage, 'I think I've struggled to control it'	4
Change in hypo symptoms	4
Erratic blood glucose levels	3
Experiencing fewer hypos as blood glucose higher	4
Menstrual cycle was predictable	2
Difficulty managing swings in blood glucose levels	3
Increasing and adjusting insulin	6
Impact of hyperglycaemia on health	5
Acknowledging importance of glycaemic control	1
Impact of reduced exercise on blood glucose levels	2
Dreading results at clinic	1
Unexplainable high blood glucose levels	6
Constantly changing doses, 'a juggling game'	1
'Is it my lack of control or is it menopause?'	1
Risk of hypo when correcting high glucose	1
Anxiety in deterioration of glycaemic control	1
Hoping blood glucose levels stable post-menopause	4
Importance of self testing	1
Constantly checking levels, 'You get highs and lows, I call it the ghost'	1
Confusing nocturnal hypos with menopausal sweats	4
Confusing hypo symptoms and menopause symptoms	5
Less hypo awareness	9
Becoming familiar with different symptoms, 'the old car is running out of gas'	3

Eating overnight to prevent or treat hypo	1
Unwelcome attention from colleagues	1
Fear of losing driving license	1
Hormonal influence causing hypos	1
Fear of hypo	9
'the sweats make me think about hypo'	1
Trying to predict/avoid hypo	1
Assessing hypo risk more	2
Recovery from hypo takes longer	1
Good hypo awareness	2
No hypo awareness now	1
'hypoglycaemia is an acute thing, that causes great stress'	1
More blood glucose testing	5
Trying to identify patterns	2
Adjusting insulin to accommodate changes	2
Proactive in reacting to changing levels	2
Dealing with it on a day to day basis	1
Coping with menopause symptoms	1
Pragmatic approach	1
Importance of proactive self-management	11
Harder work, 'times fifty'	4
Blood glucose management difficult, ' your body doesn't have what it should have to help you keep the control'	4
Previous experience worth nothing	2
Presumption from others to cope	1
Stricter with regime	1
Not knowing what to expect	3
Enquired regarding help with menopause	2
'loss of control, I just think, oh God when will this end?'	1
'you're trying to deal with something that you can't control'	1
Sole responsibility to self-manage	1
Trying to stay positive	1

Trigger to improving self-care strategies, ‘ a bit of a wake up call’	7
Considering other factors	1
Requiring help from DSN	1
Wanting to get it right	1
Getting on with it	2
Checking levels overnight	1
Difficulty testing more in public	1
Benefit of hypnosis	1
Relief at ability to manage diabetes	1



**Table (3).** Detailed below are the codes and sub codes that form the category: *Anxiety and fear* (codes from 10 participants)

This category was formed by joining two subcategories; *impact and effect of menopause and anxiety and fear*.

<b>Code</b>	<b>Number of sub codes</b>
'The menopause is like a visitor'	1
Confusing and unpredictable; 'What the hell is going on here?'	11
Difficulty recognizing when blood glucose is low	2
Misconceptions of menopause	1
Unaware of what is physically happening	2
Unaware that menopause could affect diabetes	2
Frightening, being out of control	1
Acknowledging hormonal influence on diabetes	3
Difficulty differentiating menopause impact on health from other life stresses	3
Frustrating time	1
'Arguing against each other, menopause v diabetes'	4
Feeling tired	1
Reduction in exercise	3
Disturbed sleep	8
Feeling more vulnerable	5
Unpredictable menopause symptoms	2
Feeling hot	2
Worried about complications	2
Loss of physical protection	1
Hyperglycaemia	2
Negative impact on quality of life	1
Low mood	1
'Menopause is the final straw'	1
Minimizing impact of menopause	5
Comparing self to others	3
Seeking experience of others with diabetes	1
Feeling isolated	1

Relevance of family history	2
Implications of life's choices	1
Fear of other health problems	1
Not liking physical changes	2
Effect of alcohol more noticeable	1
Impact of many factors	1
Resenting checking blood overnight	1
Scared of higher glucose levels	3
Menopause highlighted risks of diabetes	3
Worrying more than usual about health	4
Worried about pregnancy risk, 'if you're mid to late forties it's terrifying'	3
Impact of menopause greater than expected	2
Fear of gaining weight	2
Concern regarding duration of diabetes	1

**Table (4).** Detailed below are the codes and sub codes that form the category: *'Haywire'*: relates to symptoms of the menopausal transition (codes from 6 participants).

This category was formed by joining two subcategories; signs of menopausal transition and factors influencing menopausal transition.

<b>Code</b>	<b>Number of sub codes</b>
Recognized own menopause	1
Frequent hot flushes	5
Only explanation for high blood glucose levels, 'went haywire'	8
Uncertain to what signals end of menopause	1
Seeking blood test to determine menopause	3
Family history	1
Irregular periods	3
Attention to menstrual cycle impact on levels	1
Unsure of what is physically happening, 'is it my lack of control or is it the menopause?'	2
Concerned was pregnant	2
Embarrassing menopause symptoms	1
Heavy menstrual periods	1
Feeling tense	1
Dealing with other stress plus the menopause	6
Hoping it will get easier	1
Menopause symptoms noticeable	1

**Table (5).** Detailed below are the codes and sub codes that form the category: *Treating menopausal symptoms* (codes from 7 participants)

<b>Code</b>	<b>Number of sub codes</b>
HRT not discussed	2
Doubtful regarding benefits of HRT	4
HRT nor recommended by GP	1
HRT reducing problematic hypos	1
Impact of lack of oestrogen	1
Normality following HRT	2
Risk of HRT less daunting than hyperglycemia	4
Reduction in insulin requirement following HRT	1
HRT improved blood glucose levels	1
Implications when stopping HRT	2
Inaccurate information about HRT	2
Offered HRT by HCP	1
Worried about risks of HRT	1
Implications of family history and HRT	1
Denied expert advice and HRT	3
Worried about contra-indications of homeopathic treatments	3
Well women clinic useful	1
'your body doesn't have what it should have to keep the control'	1
Initiating discussion at clinic regarding HRT	3

**Table (6).** Detailed below are the codes and sub codes that form the category: *Depression and mood* (codes from 8 participants)

<b>Code</b>	<b>Number of sub codes</b>
Feeling down due to deterioration in diabetes control	4
Feeling low in mood generally	2
Feeling hopeless	1
Lack of sleep affecting mood	1
Stigma regarding depression	1
Acknowledging menopause may cause low mood	4
Feeling frightened	1
Feeling 'fed up', 'it'll be different tomorrow, this isn't going to last'	1
Felt very depressed	1
Mood swings	3
Previous depression	2
Wondering if medication causing low mood	2
Other factors may influence mood	1

**Table (7).** Detailed below are the codes and sub codes that form the category: *'I'm old'*: relates to aging and mortality (codes from 3 participants)

<b>Code</b>	<b>Number of sub codes</b>
Negative physical changes with age	2
Aware of own mortality	3
Terrified of long term complications	1
Scared of external influences affecting diabetes	1
Highlights duration of diabetes	1
Signifies end of reproductive years	2
Desire to live as long as possible	2
Difficulty accepting getting older	1
'complications freaking me out'	1



### ***Information Sheet for Potential Participants***

**A qualitative study to explore how women with Type 1 diabetes manage their diabetes during the menopause.**

I would like to invite you to take part in the above study.

#### ***What is the purpose of the research study?***

This study aims to explore the experiences of women with Type 1 diabetes when managing their diabetes during the menopause. During the menopause there are hormonal changes taking place and I would like to find out a little more about this stage in a women's life with regards to the effect it may or may not have on their diabetes. The findings of the project will be useful because currently there is very little information about this subject.

#### ***Who is organising the research?***

I am a Diabetes Specialist Nurse at the Western General Hospital in Edinburgh and I am also a postgraduate student from the School of Nursing, Midwifery & Social Care at Edinburgh Napier University. As part of my degree course, I am undertaking a research project for my Masters by Research dissertation. I am organizing the research project with supervision from Edinburgh Napier University and NHS Lothian.

### ***Who can take part in the study?***

You can take part in the study if:

- you are female
- you are aged 40–55 years
- you have been diagnosed with Type 1 diabetes for at least 2 years
- you have not had a menstrual period for at least three months or you previously had regular periods but for at least 3 months they have been irregular

Unfortunately you cannot take part in the study if

- you do not meet the above five requirements
- you have had surgery that has caused your menstrual periods to stop
- you are pregnant

### ***Why am I being invited to take part?***

You have been invited to take part in the research because you attend the Western General Hospital Diabetes Out Patient Department, you are female aged between 40–55 years old and have had Type 1 diabetes for more than 2 years.

### ***Do I have to take part?***

No. It is up to you whether or not you take part in this study. If you participate you are free to withdraw from the study at any time without giving a reason. This will not in any way affect your future care.

### ***What would be involved?***

If you agree to participate in the study, you will be asked to take part in an interview with myself lasting approximately 60–90 minutes; the interview will be tape recorded. The potentially sensitive nature of the study topic is acknowledged and the interview can be stopped if you find it at all distressing.

If you experience an episode of hypoglycaemia the interview will be stopped, hypo treatment will be available if required, and the interview will be rescheduled.

### ***Will I be identifiable from the tapes or any other information from the study?***

All data will be anonymous, as much as possible, but you may be identifiable from tape recordings of your voice, however, it will only be myself and one or two other colleagues involved in the study that will listen to the recorded interview. The recorded interview will then be transcribed; this means that what you say in the interview will be put in writing. Your name will be replaced with a false name of your choice, and it will not be possible for you to be identified in any reporting of the data gathered. All data collected will be kept in a secure place to which only I will have access. These will be kept for five years to comply with NHS Lothian guidelines.



### ***What happens at the end of the study?***

The findings from this study will provide women with Type 1 diabetes who are experiencing the menopausal transition with information that may assist with their diabetes management during that time. It will also provide Health Care Professionals with information that they can use in discussion with the women if required. If appropriate, resources may be developed to assist with the provision of information. The results may be published in a journal or presented at a conference.

### ***Who can I contact if I want more information about the study?***

If you would like to contact an independent person, who knows about this study but is not directly involved in it, you are welcome to contact Dr Rebecca Reynolds. Her contact details are given below. Alternatively you can contact me, my contact details are also below.

### ***How quickly must I decide if I want to participate?***

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please contact me directly.

### ***Where will the study take place?***

Since your participation will involve you traveling to the diabetes out-patient department in the Western General Hospital you will be reimbursed for travel expenses.

### ***Who has reviewed the research study?***

The research has been reviewed and approved by Edinburgh Napier University's Faculty of Health, Life and Social Sciences' Research Ethics and Governance Committee and the NHS and Lothian Ethics Committee.

Contact details of the researcher

Name of researcher: Liz Mackay

Address: Diabetes Specialist Nurse/ Postgraduate Student  
Metabolic Unit, Anne Ferguson Building  
Western General Hospital  
Edinburgh EH4 2XU

Email / Telephone: [liz.mackay@luht.scot.nhs.uk](mailto:liz.mackay@luht.scot.nhs.uk) / 0131 537 2542

Contact details of the independent adviser

Name of adviser: Dr Rebecca Reynolds

Address: Clinical senior Lecturer  
Endocrinology Group  
Queen's Medical research Institute  
47 little France Crescent  
Edinburgh EH16 4T  
Contact telephone number- 0131 242 6762  
Email address- rreynolds@staffmail.ed.ac.uk



**Napier University**

**Faculty of Health, Life and Social Sciences Research Ethics and Governance  
Committee**

A qualitative study to explore how women with Type 1 diabetes manage their diabetes during the menopausal transition.

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that the interview I participate in will be tape recorded.

I understand that my GP will be informed regarding my participation in this study.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: \_\_\_\_\_

Signature of participant: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Contact details of the researcher

Name of researcher: Liz Mackay

Address: Diabetes Specialist Nurse/ Postgraduate Student  
Metabolic Unit, Anne Ferguson Building  
Western General Hospital  
Edinburgh EH4 2XU

Email / Telephone: [liz.mackay@luht.scot.nhs.uk](mailto:liz.mackay@luht.scot.nhs.uk) / 0131 537 2542

# A qualitative study to explore how women with Type 1 diabetes manage their diabetes during the menopause

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## Introduction

Changes in sex hormones as a result of pregnancy result in insulin resistance. Adolescents with Type 1 diabetes experience difficulties during puberty, particularly females. This deterioration in glycaemic control may be attributed to a number of reasons but specifically hormonal changes affecting insulin sensitivity. Currently there is no evidence supporting insulin resistance, or possibly increased insulin sensitivity, during the menopausal transition in women with Type 1 diabetes when this is also a time of flux of sex hormones.

## Background

Menopause is described as a complex time, resulting in physical and emotional challenges. Women with Type 1 diabetes have a greater incidence of menstrual disorders and an earlier menopause than non diabetic women, but very little is actually known about the effects on, and experience of, the menopausal transition in this population. The fact that many symptoms experienced during the menopausal transition such as sweating, palpitations, mood changes and short term memory problems are similar to those suffered during hypoglycaemic episodes is of concern as crucial warning signs may be masked.

Anecdotally women complain of a variety of issues such as hyperglycaemia, erratic blood glucose levels, unpredictable hypoglycaemia, deterioration of glycaemic control and increased insulin requirement. Anecdotal evidence suggests that women may confuse menopausal symptoms with hypoglycaemia and respond in a way that is counter-productive potentially causing them some harm, such as consuming refined sugar to treat hypoglycaemia when blood glucose levels are in fact not low resulting in hyperglycaemia, or alternatively presuming symptoms are menopausal and not treating hypoglycaemia increasing the risk of severe hypoglycaemia.

### Other features of the menopause that may be of concern to women in this group include:

- problems sleeping due to night sweats which may be confused with hypoglycaemic symptoms
- weight gain that requires increased insulin doses due to insulin resistance associated with weight gain
- fatigue that may also be a symptom of hyperglycaemia
- vaginal dryness associated with diabetes exacerbating sexual problems and mood changes

## Aim of study

To explore the experiences of women with Type 1 diabetes during the menopausal transition with regards to any effect it may have on their diabetes management. The literature review together with my clinical experience as a Diabetes Specialist nurse has shaped the research questions:

1. Do women with Type 1 diabetes consider that the menopausal transition impacts in any way on their diabetes management?
2. Do women with Type 1 diabetes perceive their glycaemic control to alter during the menopausal transition?
3. What are the perceptions of women with Type 1 diabetes regarding information and support provided by health care professionals during the menopausal transition?

## Method

A robust literature search and review was performed that revealed no information relevant to women with Type 1 diabetes during the menopausal transition.

A qualitative exploratory research framework was employed using grounded theory as the research approach. Approval to conduct the study was granted by Edinburgh Napier University's FHLSS Research Ethics and Governance Committee and by NHS Lothian's Research Ethics Committee.

Participants were identified from SCI-DC, a local diabetes database containing the details of patients who have previously given their consent to be approached to participate in research. Women fitting the criteria below were approached:

### Inclusion criteria

- Female
- Diagnosed with Type 1 diabetes for a minimum of 2 years
- Aged 40-55 years
- Have not experienced a menstrual period for a minimum of 3 months and/or previously regular menstrual cycle that is now irregular - for at least 3 months
- No cognitive impairment
- English speaking

### Exclusion criteria

- Women who have had a surgically induced menopause, for example, oophorectomy

Ten participants were recruited, all Caucasian women living in Edinburgh. Ages ranged from 49 to 55 years with a median age of 51.5 years. Duration of participants' diabetes ranged from 7 to 49 years with a median duration of diabetes of 38.5 years. Nine participants (90%) were married, nine (90%) were in employment. Six (60%) had children, number of children ranged from 1-3.

## Data collection

Face-to-face semi-structured interviews, which were audiotaped and transcribed verbatim, were used to collect data. A flexible interview guide ensured that participants' own issues relating to the topic were explored.

### Interview Guide

1. Tell me about your blood glucose levels during the last few months, has there been any change?
2. What are your blood glucose levels normally like? If they are erratic have they always tended to be erratic for no reason that you are aware of? Have they always been this way?
3. How would you describe your ability to manage your diabetes over the past few months?
4. How would you describe any information or advice that you have received from doctors or nurses about the menopause in relation to your diabetes?
5. Do you have any concerns regarding the effect diabetes may have on menopause?
6. Have you enquired, considered or used hormone replacement therapy at any point?

## Data analysis

Transcriptions of interviews and field notes of observations during data collection and recording were reviewed and a coding process employed following which similar codes were placed into categories with one category emerging as core.

## Findings

Data are presented in seven categories that reflect the conceptions of the menopausal transition for women with Type 1 diabetes:

- **'Blank wall'**: relates to the lack of information regarding menopause and diabetes. It is central to all other categories as demonstrated in figure 1 and is the core category
- **'Juggling game'**: relates to glycaemic control,
- **Anxiety and fear**
- **'Haywire'**: relates to Symptoms of the menopausal transition
- **Treating symptoms**
- **Depression and low mood**
- **'I'm old'**: relates to aging and mortality.

Figure 1:



Category	Data
<b>'Blank wall'</b>	"I've asked what to expect and I'm told they don't know, there's no evidence" (Ella) "I did not know whether to ask, I did not know what to ask" (Mary) "I read notices at the clinic like if you are pregnant.....but nothing about menopause" (Susan) "Always dismissed when you say it is anything to do with menopause" (Ella) "I've been doing this for years, why is it not working?" (Mini) "unexplainable high blood sugars but when you raise it it's like your control's not good, you're getting older" (Ella) "You always feel it's your fault, you're not taking care" "if I hadn't had the seventeen years before [relating to managing diabetes for seventeen years prior to menopausal transition] it's like nobody believes you" (Suzanne) "I don't know what to expect as a woman, I certainly don't know what to expect as a diabetic" (Ella)
<b>'Juggling game'</b>	"unpredictable to me is the biggest challenge" (Vivienne), "day to day, blood sugar to blood sugar" (Mini) "a juggling game" (Suzanne) "is it my lack of control or is it menopause?" (Ella), "Are you taking insulin for food or for menopause?" (Nuri), "looking for help with hyperglycaemia" (Vivienne), "you get high and lows, I call it the ghost" (Mini), "Insulin requirements have changed quite dramatically" (Suzanne), "fifty times harder" (Suzanne), "highly intrusive" (Ella), "A bit more strict with regime and checking all the time" (Mini) "loss of control, I just think, oh my God when will this end?" (Mini), "uphill struggle" (Nuri).
<b>Anxiety and fear</b>	"the menopause is like a visitor" (Rachael), "What the hell is going on here?" (Mini), "Arguing against each other" (Rachael) (referring to diabetes versus menopause), "terrified in case I dip through the night" (Barbara), "worried I'd know the difference between flashes and hypo" (Susan), "not sweets during the night mask symptoms" (Suzanne), "don't assume you are hypo, test" (Ella), "hypo symptoms very different now, warning less" (Ella), "menopause is the final straw" (Susan).
<b>'Haywire'</b>	"blood glucose went haywire" (Barbara), "unexplainable high blood sugar" (Ella), "Blood sugars have increased" (Nuri), "permanently premenstrual" (Margaret) "sweats make me think of hypo" (Mary), "At the beginning I did confuse symptoms of hypo with menopause" (Barbara), "is it my lack of control or is it menopause?" (Ella), "the longer you have it the more aware you are of the changes" (Margaret), "I thought it was myself, the menopause has affected me more than I thought" (Barbara).
<b>Treating symptoms</b>	"they're not been because of my condition" (Barbara) (regarding HRT) "HRT helped immensely, hugely" (Margaret), "problems with diabetes much worse than anything HRT could throw at me" (Margaret).
<b>Depression and mood</b>	"quite depressing" (Margaret), "Felt despondent" (Suzanne), "It'll be fine tomorrow, this isn't going to last" (Mini), "I don't think mood is discussed enough, generally" (Rachael).
<b>'I'm old'</b>	"highlighted increasing age and diabetes" (Mary), "complications freaking me out" (Barbara), "How can I stay as well as I am now?" (Mary).

## Discussion

Concerns reported by study participants provide evidence that women with Type 1 diabetes experiencing the menopausal transition find it problematic for a number of reasons. In particular, there is lack of evidence based information, and lack of support from health care professionals and guidance on managing their diabetes. This provides a background against which the substantive theory that emerged from the data is rooted. It is a theory in which absence of information regarding menopause and diabetes emerged as the main problem facing women with Type 1 diabetes during the menopausal transition.

## Conclusion

This study has identified vital findings for women with Type 1 diabetes. Their ability to manage the stresses of the menopausal transition might be enhanced through education and support from Health Care Professionals (HCPs). However in order to provide both women with diabetes and HCPs with information regarding menopause further research is required. The current lack of awareness and knowledge amongst HCPs caring for these women is unacceptable. Educating HCPs about the challenges faced by these women is crucial to ensure that they receive the best care possible, allowing them to make informed choices concerning their health.