How women manage their type 1 diabetes during the menopausal transition: a qualitative study using a grounded theory approach

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Abstract
This study aimed 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 with implications for service users and service providers.

A qualitative exploratory research framework was employed using a grounded theory approach. Data were collected from 10 participants using transcribed audiotaped semi-structured interviews and field notes. The transcripts, audio recordings and field notes were reviewed and a coding process facilitated data analysis. This approach enabled themes to emerge from the data and ultimately a theory.

A wide range of conceptions was revealed. Data are presented in seven categories that reflect the experience of the subjects: ‘Blank wall’ (relates to the lack of information regarding menopause and diabetes); ‘Juggling game’ (relates to glycaemic control); Anxiety and fear; ‘Haywire’ (relates to the signs and symptoms of menopausal transition); Treating symptoms; Depression and mood; and ‘I’m old’ (relates to ageing and mortality).

A substantive theory emerged. 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 could enable practitioners to identify the types of information, advice and support that should be made available to these women, and contribute 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. Copyright © 2014 John Wiley & Sons.

Keywords
type 1 diabetes; menopausal transition; lack of information; hyperglycaemia; hypoglycaemia; erratic glycaemic control

Introduction
Menopause is a stage in the female reproductive cycle that occurs when ovaries reduce and eventually stop producing oestrogen, causing reproductive function to cease. The body’s response to reduced oestrogen levels may cause hot flushes, palpitations, night sweats, mood swings, lack of concentration, vaginal dryness, decreased libido, weight changes, sleep disturbances and urinary incontinence. Daily management of type 1 diabetes may be more problematic and potentially dangerous for women during this time.

The menopausal transition is defined as a time of irregularities in the menstrual cycle and variation in hormone levels, concluding with the final menstrual period. It is recognised that changes in sex hormones due to pregnancy result in insulin resistance and an increased production of background hepatic glucose. Despite this recognised influence of sex hormones during pregnancy, there is currently no evidence to suggest insulin resistance, or increased insulin sensitivity, during the menopausal transition. Due to their similarities, anecdotal evidence suggests that women may confuse menopausal symptoms with those of hypoglycaemia and therefore crucial warning signs of hypoglycaemia may be masked. Specific menopausal symptoms of concern to women with type 1 diabetes include problems sleeping due to night sweats, weight gain, fatigue, vaginal dryness, sexual problems and mood changes which also may be symptoms of hypoglycaemia or hyperglycaemia.

Aim and questions
The study aim and questions were to explore the experiences of women with type 1 diabetes during the...
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Methods
A study using a grounded theory approach was conducted. This approach may guide a selection of concepts to be analysed and provide recommendations for future research.7

Ethics approval
Approval to conduct the research was granted by Edinburgh Napier University’s Ethics and Governance Committee and the National Health Service Ethics Committee.

Recruitment
Recruitment took place over a three-month period. Patients were identified from a hospital database using the following fields:
• Date of birth between 1 January 1955 and 1 January 1970.
• Diagnosis of type 1 diabetes before 1 January 2008.
• Female.
• Currently attending the hospital’s diabetes clinic.

Seventy-seven patients were identified and contacted by the lead researcher. Twenty-one patients responded, 10 of whom fitted the inclusion/exclusion criteria:
• Female.
• Diagnosed with type 1 diabetes for a minimum of two years.
• Aged 40–55 years.
• No menstrual period for a minimum of three months and/or previously regular menstrual cycle that was now irregular – for at least three months (presuming that pregnancy was not a reason for amenorrhea).
• No cognitive impairment.
• English speaking.

The exclusion criterion was women who had a surgically induced menopause.

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<th>Question 1</th>
<th>Tell me about your blood glucose levels during the last few months: has there been any change?</th>
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<td>Question 2</td>
<td>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?</td>
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<td>Question 3</td>
<td>How would you describe your ability to manage your diabetes over the past few months?</td>
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<td>Question 4</td>
<td>How would you describe any information or advice that you have received from doctors or nurses about the menopause in relation to your diabetes?</td>
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<td>Do you have any concerns regarding the effect diabetes may have on the menopause?</td>
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<td>Question 6</td>
<td>Have you enquired about, considered or used hormone replacement therapy at some point?</td>
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Box 1. Summary of the interview guide used to ensure focus on information relating to the research aim and questions

Data collection
Data were collected by the lead researcher via tape recorded, one to one, semi-structured interviews and field notes of observations. An interview guide (Box 1) was employed to ensure focus on information relating to the research aim. While the guide provided a framework for questions it gave participants an opportunity to converse and report their own meaning and understanding. Interviews were transcribed verbatim by an agency with a code of confidentiality.

Analysis
Constant comparative analysis. Transcription of interviews and field notes were reviewed by the lead researcher, and a coding process employed. Constant comparative analysis was carried out throughout the study. This involved examining data for commonalities, constants and variations.8 This was achieved by analysing data from the first interview before embarking on the second interview, then analysing data from the second interview and comparing it with data from the first interview, a process which continued throughout the study.

The option of using NVivo, a computer program used to assist with the management and organisation of data during the analysis process, was explored and rejected as the number of participants in the study was small and manual analysis using paper copies worked well.

Constant comparative analysis employs the three procedures of open coding, axial coding and selective coding.2 Coding is an integral aspect of grounded theory. In open coding, concepts were identified and developed. Axial coding was then used to interconnect categories with one another and identify the core category. Selective coding was subsequently employed to further link all categories to the core category. It was through this process that theoretical ideas were generated.10

In addition, theoretical memos were compiled during the research process to assist with formulation and development of theory in conjunction with analysis of data.
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**Theory development.** Grounded theories are substantive rather than formal, as they typically focus on the perceptions of a specific group of people in relation to a phenomenon. In this study the focus was on how women with type 1 diabetes manage their diabetes during the menopausal transition, and is substantive.

**Data credibility**

 Reflexivity was used during the research process. This critical reflection of the researchers’ own preconceived thoughts and ideas enhanced the rigour of the study. In addition, to ensure compatible and robust data analysis, the supervision team read examples of transcripts and agreed with the analysis.

**Findings**

Constant comparison of data within and across all the interviews yielded one core category, to which all data related, and which was summed up in the concept ‘blank wall’. This study resulted in the generation of a substantive theory in which the absence of information regarding menopause and type 1 diabetes is central.

Data are presented in seven categories that reflect conceptions of the menopausal transition for the women in the study.

- ‘Blank wall’: lack of information regarding menopause and diabetes.

It was central to all other categories, as demonstrated in Figure 1 and is the core category.

- ‘Juggling game’: relates to glycaemic control.
- ‘Blank wall’
- ‘Haywire’: symptoms of menopausal transition and difficulty with glycaemic control.
- ‘Treating symptoms’
- ‘I’m old’: ageing and mortality.

Quotations from participants were selected due to their illustration of key themes.

- ‘Blank wall’: lack of awareness of information regarding menopause and diabetes.

The findings in the core category, ‘blank wall’, highlight lack of awareness of information available to women with type 1 diabetes during the menopausal transition and the lack of evidence-based information available to health professionals.

‘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...’ (Ella).

Most women felt it would be easier if the doctor was female and if information was available at the clinic highlighting the topic to emphasise 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 woman 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 at some stage will go through the menopause, and I suppose then they can maybe feel that they can ask questions if it’s somebody like myself,’ (Susan).

Women felt that medical staff minimised the hormonal effect on diabetes, and ignored the impact of menopause on diabetes:

‘But I think I’ve more explained 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).

Some women felt blamed for the deterioration in glycaemic control evident in their biochemistry results:

‘If I hadn’t had the 17 years before [relating to managing diabetes for 17 years prior to menopausal transition] it’s like nobody believes you,’ (Suzanne).

Women desired a holistic approach to their care and discussion of health promotion strategies they might implement:

‘...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 perceived benefit in peer support:

‘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).

**Figure 1.** The seven categories identified in the study. ‘Blank wall’ is central to all the categories relating to the lack of information regarding menopause and type 1 diabetes.
Peer support could provide opportunities to hear how other women coped:

'T 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).

‘Juggling game’: glycaemic control. Findings in this category highlight unpredictable blood glucose levels during the menopausal transition and anxiety associated with persistent hyperglycaemia:

'The unpredictability definitely makes it harder, because I was so regular, and I was in a system. So if it’s... can be unexpected, unpredictable to me is the biggest challenge,' (Vivienne).

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

‘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 juggle for that, and that’s fine, but there’s other things that come into the equation that I can’t explain,’ (Suzanne).

Most women monitored blood glucose more frequently and described difficulty in managing alterations in blood glucose levels, particularly unpredictable and inexplicably high levels:

‘I’ve got my meter with me all the time,’ (Suzanne).

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).

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

‘I dread coming here, it’s so disappointing,’ (Suzanne).

Others experienced less hypoglycaemia due to the hyperglycaemia. While this was perceived as positive, there was anxiety about development of diabetic complications.

All women felt it important to be proactive in their own diabetes management. For some, their previous experience concerning diabetes management was worth nothing during the menopausal transition. For most, managing their diabetes at this time was stressful:

‘...loss of control, I just think, oh my God when will this end?’ (Mini).

**Anxiety and fear.** Findings from this category revealed significant anxiety and fear experienced by women during the menopausal transition. This was attributed to the ‘unknown’, the inability to control diabetes, heightened anxiety, fear of acute complications of diabetes, particularly hypoglycaemia, and negative impact on quality of life.

Women acknowledged the influence of hormones on glycaemic control, based on experiences from puberty, menstrual cycle and, for some, pregnancy. Most described feelings of not knowing what was happening physically and ignorance as to whether 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).

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).

Most women described diabetes as 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).

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).

Women confused symptoms of hypoglycaemia with menopausal symptoms, particularly overnight; for example:

‘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).

Most women experienced less hypoglycaemia and some described familiarity with different symptoms over time. Participants described the impact of the change in hypoglycaemia awareness: fear of losing their driving licence, unwelcome concern from work colleagues about potential hypoglycaemia, needing to eat overnight to be ‘safe’.

The physical impact of the menopausal transition left most women feeling tired:

‘I wake up in the morning and feel like I have a hangover,’ (Barbara).

They blamed this on disturbed sleep due to feeling hot, sweating and anxiety about glycaemic control. They perceived increased physical vulnerability due to reduction in oestrogen levels which is associated with osteoporosis and cardiovascular disease. Women referred to reducing exercise because of tiredness and recognised this as having a negative impact on 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 three months without a period, and your blood sugars are rising, you’re thinking: oh! If you are mid to late 40s it’s terrifying,’ (Ella).

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

‘...menopause is the final straw,’ (Susan).

‘Haywire’: symptoms of menopausal transition and difficulty with glycaemic control. These findings indicate that unpredictability of blood glucose levels may be a symptom of the menopausal transition. All women referred to their high blood glucose levels and the menopausal transition, for example:

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

Most experienced hot flushes and sweating and associated these as signs of menopause, although for some these were confused with hypoglycaemia:

‘At the beginning I did confuse symptoms of hypo with menopause,’ (Barbara).
Women described symptoms they perceived as being menopausal and for some it took months to realise that the hyperglycaemia was also a symptom of menopause:
‘The longer you have it the more aware you are of the changes,’ (Margaret).

**Treating menopausal symptoms.** This category highlights lack of evidence-based information about treatment of menopausal symptoms in women with type 1 diabetes. Preconceived ideas from the women were evident regarding possible contraindications of hormone replacement therapy (HRT) in women with type 1 diabetes. Furthermore, this category suggests that menopausal symptoms are much less problematic than maintaining normoglycaemia during the menopausal transition.

Women compared themselves to non-diabetic peers experiencing the menopausal transition. Several of them felt luckier than non-diabetic women, as they were coping with menopausal symptoms, but perceived their diabetes to be more problematic:
‘Regarding menopause, I got off with it lightly compared to others,’ (Rachael).

Women perceived that if they could manage diabetes they could easily cope with menopausal symp- toms. Their focus was on diabetes; their non-diabetic peers’ focus was on menopausal symptoms.

Most women expressed limited knowledge regarding use of HRT for women with type 1 diabetes. For the majority of them the option of HRT had not been discussed and they were doubtful regarding any possible benefits. They also perceived, as a result of their diabetes, that HRT was contraindicated:
‘I have spoken to my own doctor about it, but they’re not too keen because of my condition, obviously,’ (Barbara).

Some women felt they had been denied expert advice regarding HRT. One woman 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 women experienced normalisation of glycaemic control and reduced insulin doses following initiation of HRT.

Several women were less concerned about the possible health risks associated with HRT compared to the immediate and long-term risk associated with hyperglycaemia:
‘In actual fact the problems with the diabetes are much worse than anything HRT could throw at me,’ (Margaret).

Two women felt anxious, concerned and un-informed about the implications of stopping HRT in relation to diabetic control.

**Depression and low mood.** Most women acknowledged that changes in hormone levels might be responsible for low mood, but for many this was attributed to deterioration in 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).

‘I’m old’: ageing and mortality.
Women described, in a general way, feeling a negative physical change with ageing 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 by difficulties in accepting they were getting older. Two women said the menopausal transition was significant in highlighting the end of their reproductive years and possible pregnancy; this was perceived negatively.

All women expressed awareness of their own mortality. One woman described herself as terrified of the long-term complications of diabetes. The complication risk became more apparent due to the 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).

**Discussion**
This study has generated 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 indicates that women feel quite isolated and would appreciate advice and support from 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 among 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, may be beneficial. It may also be useful to assess 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, as perceived by women in this study.

It could be beneficial to encourage 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 diabetes management strategies. Women may be offered the opportunity to wear continuous glucose monitors for a short period of time. This may assist in 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.

Perhaps HCPs should be raising the awareness of health promotion strategies such as smoking cessation, calcium supplements, maintaining healthy weight and increasing physical activity, in view of the potential increased risk of osteoporosis and cardiovascular disease in this population.

Participants in the current study expressed fear regarding the risk of
an unplanned pregnancy during the menopausal transition. Discussion regarding contraception and changing requirements with age should be encouraged and recorded at the diabetes clinic, general practice or well woman clinic.

The opportunity for patients to request a female doctor when attending the diabetes clinic should be available. Women in the study perceived that it would be easier to discuss menopause with a female doctor. In addition, the establishment of a peer support group, either face to face or online may be useful. The desire for peer support was an important finding from the study.

Conclusion
Study participants provided evidence that women with type 1 diabetes experiencing the menopausal transition find it problematic for a number of reasons. The underpinning theme was lack of evidence-based information, and lack of support and guidance from HCPs about the impact of the menopausal transition on their glycaemic control. This contributes to the difficulties these women experience in managing their diabetes successfully. It includes the anxiety and fear they experience during this period in their lives when they are living with an unfamiliar phenomenon and, despite their best efforts, cannot locate information or support.

The participants’ ability to manage the stresses of the menopausal transition may have been enhanced through education and support from HCPs. However, to provide both women and HCPs with appropriate information regarding menopause, further research is required. The current lack of awareness and knowledge among some HCPs caring for these women is unacceptable. There is an urgent need to ensure staff possess relevant information to enable them to support and empower women with type 1 diabetes prior to, and during, their menopausal transition.

Limitations of the study
While the purpose of this study was to gain in-depth data from participants, the small sample size means that it is not possible to generalise the findings to all peri-menopausal women with type 1 diabetes. The sample comprised Caucasian women only who 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. It is acknowledged that it cannot be stated, with such a small sample, that saturation of data was definitely achieved.

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. Theoretical sampling, had time permitted, would have expanded recruitment of potential participants to include, specifically, women of different ethnic groups, different socio-economic classes and locations.

Declaration of interests
There are no conflicts of interest declared.

References