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Type 1 diabetes and menopause, what women would like to know: a public and patient involvement exercise

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Abstract

***Introduction*:** Managing the impacts of the menopause can be a tedious experience for many women, and when coupled with diabetes, the challenges are multiplied. Literature searches confirm a dearth of information and support to help women with these dual conditions.
***Methods*:** A Patient Public Involvement exercise involving an online survey disseminated electronically via social media amongst the Type 1 diabetes online community. It comprised five closed questions and one open question to elicit priority needs. The survey was supplemented with a subsequent Twitter chat. The paper conforms to the guidance for reporting of patient and public involvement in health and social care research (GRIPP).
***Results*:** Of the 184 women who completed the survey across the United Kingdom, most were aged between 40 and 59 years (n = 167, 90.8%). Although 137 (72.8%) women reported that menopause had impacted on their diabetes, only a minority (n = 50, 27.2%) indicated that it had ever been discussed with them. The overarching theme from the open question was of an overall Lack of awareness about the impacts of menopause, with the following subthemes: 1) Need for information about menopause, 2) An additional burden, 3) Symptoms of diabetes or menopause? and 4) Communication – expectations of care.
***Conclusions*:** Women need information, support and guidance during this phase of life. This oft overlooked aspect of care is engendering frustration and suboptimal diabetes management and will be a topic raised with increasing frequency in general practice and diabetes specialities. The management of diabetes and menopause deserves more attention across the diabetes community.

Keywords: *menopause*; *type 1 diabetes*; *patient involvement*; *survey*; *women's health*

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A 'blank wall' – the description ascribed to both the lack of information available to and awareness of menopausal transition amongst women living with Type 1 diabetes.[1] General discussions about menopause have been depicted as being 'somewhere between a taboo and a joke'.[2] In the UK, management strategies for menopause care for women with diabetes are neglected, for example in the National Institute for Health and Care Excellence (NICE) diabetes guidance[3,4], and in the NICE menopause clinical guidance, only the needs of women with Type 2 diabetes in relation to hormone-replacement-therapy (HRT) are addressed, with no reference to women with Type 1 diabetes.[5] At the same time, recent estimates suggest that there are 50,000 women with Type 1 diabetes and almost 600,000 women living with Type 2 diabetes, aged between 40 and 65 years in the UK.[6] So why does menopause remain invisible in diabetes care?

Menopause, a significant part of a woman's reproductive life, signals a major change in hormonal regulation with multiple physiological effects. This can be a very challenging time with potentially negative impacts on physical health and quality-of-life.[1,7,8] Transition to menopause is not well defined and occurs as oestrogen production gradually reduces,[9] with disruptions and eventually cessation of the menstrual cycle.[10,11] Menopause is the 12-month period after the last menstrual cycle, after which the woman is considered post-menopausal.[5] Perimenopause is the time of transition leading up to the menopause and can start several years beforehand.[5]

Not all woman experience menopause and perimenopause in the same way; nevertheless, there are several common effects of relevance in relation to diabetes and metabolic function,[9,12] such as weight gain, impaired glucose tolerance (IGT), hypertension and

hypercholestrolaemia.[13] The physical and emotional symptoms women endure include vasomotor symptoms (hot flushes and night sweats), sleep disturbances, mood swings and increased risk of depressive symptoms, and sexual dysfunction. Longer term, women may experience genitourinary problems and osteoporosis.[13,14] Whilst many of these problems will affect women with Type 1 diabetes or Type 2 diabetes, the menopause presents some additional challenges for women with Type 1 diabetes with disruption to their insulin sensitivity and glucose regulation.[13] This can be particularly frustrating and distressing for women with Type 1 diabetes as they navigate a 'juggling game' between the unpredictability of fluctuating glycaemia and the symptoms of perimenopause or menopause.[1] To date, only one study that explicitly explored the experiences of how women manage living with Type 1 diabetes (n = 10) during menopause[1] was identified in a review of current literature. This qualitative study identified seven categories perpetuating the concept of a 'blank wall' due to a lack of information relative to their Type 1 diabetes, including the 'juggling game' of managing glycaemia, anxiety and fear; the 'haywire' impact of the unpredictability of glucose fluctuations; the challenge of 'treating menopausal symptoms'; depression and low mood; and an awareness of their mortality with a sense that 'I'm old'.[1] There is a dearth of guidance on the care and support for women with Type 1 diabetes transitioning through to menopause and limited empirical evidence of impact of this stage of life for this group. Therefore, we sought direction from women living with Type 1 diabetes as Patient Public Involvement (PPI) in research can improve the relevance and overall quality of research, by ensuring that it focuses on the issues of importance to the specific group.[15]

Method

To gain an understanding about what is important to women with Type 1 diabetes in relation to menopause and perimenopause, we undertook a PPI exercise involving an online open discussion via Twitter hosted at #GBDOC and facilitated by our lay collaborator (AC), and the survey disseminated electronically via social media amongst the Type 1 diabetes online community for 5 weeks during the summer of 2020.

The survey, designed with PPI guidance comprised of six questions, was concise with the aim to elicit broad demographic data, along with women's experience of discussions about menopause during diabetes reviews and their awareness of menopause, and how it might impact their diabetes. Finally, there was an open text question asking the respondents to identify what three things they would like to know or have known about the menopause when living with Type 1 diabetes.

The survey was developed using Jisc Online Surveys software circulated through a range of diabetes social media influencers including our co-author AC who has a substantial social media following. It was also shared via two Facebook groups for people with Type 1 diabetes across the UK.

As this was a PPI exercise, ethical approval was not required. However, we have applied robust analytic methods to interpret the data and used international guidance for reporting of patient and public involvement in health and social care research (GRIPP).[15]

Data analysis

The categorical data captured by the survey were exported into SPSS (V26) for analysis and are presented descriptively. The open text question was analysed thematically using Microsoft Excel for data management. Codes were initially generated on a sample of the responses by three researchers individually and then discussed until consensus reached. The remainder of the dataset was then coded accordingly. Whilst not in-keeping with most qualitative methods, as this was a large sample, it was possible to capture the frequency of each code and, therefore, show the relative prevalence and importance of the (sub)themes. The coded data were then grouped into categories from which subthemes and themes were identified. To promote rigour in the analysis, the initial grouping of categories into subthemes was conducted separately by two groups within the research team and then discussed until agreement was reached amongst the whole research team; this was conducted iteratively.

Findings

There were 184 responses with representation from each region across the United Kingdom (UK) and over 20% (n = 39) from outside of the UK (Table 1). Most of the

Table 1. Regions of participants

Regions – United Kingdom	%	N
Scotland	7.6	14
Northern Ireland	3.3	6
Wales	3.8	7
Northeast England	2.2	4
Northwest England	7.6	14
Yorkshire and the Humber	8.2	15
West Midlands England	6.5	12
East Midlands England	3.8	7
Southwest England	10.3	19
Southeast England	15.2	28
East of England	3.8	7
Greater London	7.1	13
Outside of the United Kingdom	21.2	39

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respondents were aged between 40 and 59 years (n = 167, 90.8%) with 6.5% (n = 12) aged 60 years or older and the remainder less than 39 years (n = 5, 2.7%). Most women considered themselves to be either peri-menopausal (n = 79, 42.9%) or menopausal (n = 60, 32.6%); however, 10% (n = 19) of women were unsure how to describe themselves in relation to the menopausal trajectory.

During their diabetes consultations, participants reported that menopause was not often attended to with less than a third of the women (n = 50, 27.2%), indicating that it had been discussed with them. Despite this, most women (n = 137, 72.8%) reported that menopause had impacted on their diabetes at some point.

Lack of awareness

Considering what was most important to them as women living with Type 1 diabetes, the respondents provided their personal accounts of what they would like to know or have known about menopause. Figure 1 illustrates the themes and subthemes identified through the analysis of the data.

The overarching theme generated from these data illustrates that women want greater awareness about both the general and diabetes specific impacts of menopause for women living with diabetes. Similarly, the data show that women perceived healthcare professionals also lacked awareness and understanding about menopause.

Three subthemes have been identified, which emphasise that woman seek information, support and guidance 1) in relation to both the physical and psychological effects of menopause in general, 2) relative to their diabetes and 3) specifically how to differentiate diabetes and menopausal symptoms. Importantly, these data highlight the current lack of communication about menopause, such that women do not know where, when or from whom to access help. These are presented in the following sections with data excerpts, which are labelled with a unique identifier of each respondent, such as R30.

Need for information about menopause

Overall, women had limited awareness of what to expect in relation to the menopause (89.2%, n = 164). Participants indicating that 'Any info would have been great' R75, and they would like to know about 'The symptoms and how they start' R148. Participants indicated that they would like information about the general menopausal symptoms, such as sleep disturbance, 'fatigue' R44, 'brain fog' R48 and 'the mood swings and the emotional upheaval of menopause' R49, including how to deal with 'the anxiety and depression' R140 that is associated with this time of life. Women shared their concern about weight gain and changing body shape and would like to know 'effective methods to prevent this' R28.

Women were concerned about genitourinary symptoms and the potential for 'loss of libido' R96 and questioned how they could better understand the changes and symptoms they were experiencing as illustrated by one participant 'For me I had a healthy sex drive and it's gone; I find

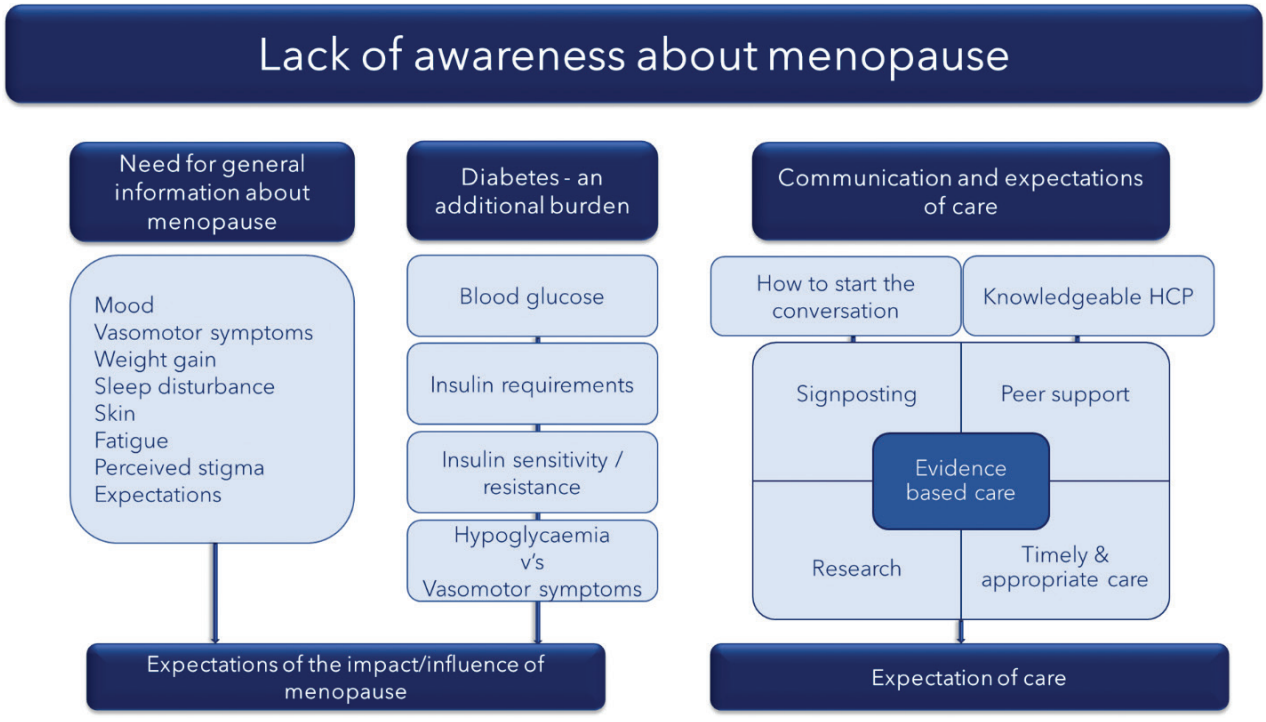

Figure 1. The experiences of menopause.

this extremely upsetting. I wish there was support… for me it seems everyone else is managing it better than myself.' There was also uncertainty about if and when menopausal symptoms would stop, as a woman who had transitioned through menopause described, it would have been good to know that there is 'light at the end of the tunnel and I wasn't on the trash heap' R86.

An additional burden

Living with diabetes whilst transitioning through to menopause presented some distinct challenges, and over two-thirds (77.2%, n = 142) of women were concerned about how menopause would impact their diabetes and vice versa. There was an overall sense that 'menopause generally added to the "burden" of diabetes' R39, and women shared their concerns about how they would know about the influence of menopause on their diabetes rather than 'it is not just me – not managing my diabetes' R53.

Women shared that their diabetes self-care became more problematic, and there was no recognition or awareness raising about the impact of menopause, as one explained 'My blood sugars were all over the place during menopause. Nobody ever linked it to that' R60. Others outlined their sense of failure with not being able to 'control' their diabetes as they previously had with little support offered to alleviate their feeling of self-blame. Women described that these feelings were perpetuated by a lack of awareness about menopause and indicated their desire for more information about the relationship between diabetes and menopause, as one woman stated, 'I would have liked to know that my blood glucose was affected by hormones and that loss of control was not always down to my fault' R14, whilst others described the 'fluctuating unpredictable impact menopause has on glucose' R55 and the challenges of 'The crazy blood sugars' R35.

Women also shared their frustrations with trying to attend to their altering insulin requirements, stating that they would have welcomed advice on 'adjusting insulin for the menopause' R146 and how to deal with their 'increasing insulin resistance' R16, whilst another highlighted 'the challenge hormonal fluctuations cause in the daily dosing of insulin'.

Symptoms of diabetes or menopause?

A concern of importance to many women (61.9%, n = 114) was the chaos of trying to differentiate whether 'the hot flushes and palpitations or the night sweats' R129 were symptoms of hypoglycaemia or the vasomotor symptoms associated with menopause. They described that it was 'not always easy to distinguish between a low blood sugar and hot flush' R78, and that treating symptoms as hypoglycaemia led to deteriorating diabetes management. However, several women stated they were also fearful of not treating their symptoms as hypoglycaemia and reported 'increased anxiety levels, due to misinterpreting symptoms' R145.

Communication – expectations of care

Almost a third of the participants (27.2%, n = 50) in the survey described the difficulties they experienced when trying to communicate with healthcare professionals. Starting a conversation was felt to be confronting as women stated that they often struggled to understand, let alone articulate what they were experiencing. Women indicated they needed to have conversations with 'someone who has knowledge and would not brush it off' R86. Importantly, they would like to know 'How to start a conversation' R21 as from their experiences women reported that 'No-one wants you to talk about it' R15 and 'you have to be brave to bring it up' R131. Women suggested that it would be ideal if they could somehow be supported so that they would have an expectation of the possible impacts that menopause and diabetes have on each other with a participant stating she would like to know 'How to have conversations with clinicians about menopause before it actually starts so you can be prepared and know what to expect' R57.

The participants who did have conversations with healthcare professionals reported that they could not always relate to the information provided as it lacked an understanding of living with Type 1 diabetes whilst transitioning through to menopause with several describing 'the constant criticism of loss of diabetes control' R5. Women stated that they wanted 'openness and honesty' R110 from healthcare professionals, and some shared they were given less helpful or supportive advice such as 'once menopausal my blood sugars would settle down and my patterns should become more like those of a man!' R30, whilst another recalled being advised to take additional insulin during the night if her blood glucose was high but that left her feeling fearful stating 'right get up take some more insulin and then lie awake worrying that I'm going to have a … hypo!' R33.

Women described that they wanted timely and appropriate care or signposting to it, if their own healthcare professionals were not able to provide it. For many women, this included peer support especially from 'other type 1's who are going through or have been through the menopause' R80. They want healthcare professionals to talk to them about 'Coping strategies and mechanisms whilst going through various stages of menopause whilst also living with diabetes' R125.

Discussion

This PPI survey highlights challenges and lack of support women with Type 1 diabetes experiences as they transition through to menopause. The need for greater awareness of the impact of menopause on women is gathering momentum,

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with celebrities in the UK such as Davina McCall bravely speaking out.[16] For women with diabetes, menopause is more nuanced and complex due to the combined impact of two hormonal systems, with minimal understanding of the experiences or care needs for this group.

This PPI exercise sends a signal that women need prior warning about the impact of menopause when living with Type 1 diabetes. They need to be able to manage expectations of their care, including disruption to their established diabetes routines. They want understanding and support as they develop self-care strategies when differentiating symptoms of hyperglycaemia from those of the menopause vasomotor symptoms.

This PPI survey has elucidated the dearth of support available about this life stage, with almost three-quarters (73%, n = 134) of women with Type 1 diabetes, indicating that menopause had never been discussed with them. The diabetes community has focused on formerly taboo topics, including depression,[17] emotional health,[18] and erectile dysfunction[19] to the extent that these are now openly explored during clinical reviews, incorporated into patient and healthcare professional education programmes and have appropriate therapeutic interventions available. It is now time to channel resources into research and service development to build up the evidence base for care during this phase of the lifespan. Whilst tentative steps in this direction have started such as Diabetes UK, highlighting this topic as a research priority,[20] menopause needs to be included in routine diabetes care for women at this time of life.

It is acknowledged that the strength of the evidence underpinning this report is limited in that it was not powered to give generalisable results. Whilst we know the views of the respondents, we do not know their ethnicity, education or socioeconomic details. However, this PPI exercise reflects the views of women from across the UK rather than any one region, and these data reveal this is an important issue generating a great strength of feeling for many women, demonstrated by their swift participation and informative responses.

Conclusion

The management of diabetes and menopause is currently an unmet need within the health service in the UK and does not feature in national guidance, patient or healthcare professional education, or routine clinical practice. This aspect of care is relevant to a large section of the population living with diabetes, and it is engendering frustration and suboptimal diabetes management and will be a topic raised with increasing frequency in general practice and diabetes specialities. Given the paucity of literature relating to this subject, this PPI exercise provides signposts to inform future research that will be relevant to many women with Type 1 diabetes.

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