

Research: Educational And Psychological Aspects

Analysis of spontaneous, user-generated data about gestational diabetes on online forums: implications for diabetes prevention

C. E. Eades¹ , K. M. Clarke¹, D. M. Cameron¹, N. Coulson² and J. M. M. Evans¹ 

¹Faculty of Health Sciences and Sport, Pathfoot Building, University of Stirling, Stirling and ²Faculty of Medicine and Health Sciences, University of Nottingham, Nottingham, UK

Accepted 18 June 2020

Abstract

Aims To explore the experiences and perceptions of gestational diabetes mellitus reported by women within online parental-support forums and, specifically, to analyse what women say about a diagnosis of gestational diabetes, their future risk of type 2 diabetes, and lifestyle behaviour for management of gestational diabetes and prevention of type 2 diabetes.

Methods The discussion boards of two parenting websites (Mumsnet and Netmums) were searched using the search term 'gestational diabetes or GD' in February 2019. Relevant posts made by users with gestational diabetes on or after 1 January 2017 were retained for analysis. Framework analysis using pre-existing framework from a previous study was used to organize and analyse the data.

Results A total of 646 posts generated by 282 unique users were included in the analysis. Analysis of the online content identified three important implicit messages that may be being conveyed to readers. The first is that gestational diabetes is not a serious diagnosis that warrants undue concern. Secondly, few users recognized the importance of their own behaviours or lifestyle, with others minimizing personal responsibility or attributing gestational diabetes to non-modifiable factors. Finally, there was a lack of acknowledgment of heightened risk of type 2 diabetes. These three messages will all directly mitigate against the efforts of clinicians (and others) to encourage women with gestational diabetes to improve their lifestyle behaviours in the longer term.

Conclusions These findings highlight messages that are being widely disseminated and that are unlikely to support prevention of type 2 diabetes.

Diabet. Med. 37, 2058–2066 (2020)

Introduction

In Europe, 5.4% of pregnancies are complicated by gestational diabetes mellitus (GDM) [1]. Women who have had GDM have a sevenfold increased risk of developing type 2 diabetes compared to women who have not, with up to 70% of women with GDM eventually being diagnosed with type 2 diabetes [2,3]. Lifestyle interventions targeted at high-risk individuals can prevent or delay the onset of type 2 diabetes [4]. However, the evidence for interventions that target women with prior

GDM is not as convincing as that for other high-risk groups [5,6]. Learning about the experiences of women with GDM may help to identify common beliefs and perceptions that could be a barrier to (or facilitator of) behaviour change, and may help ensure that interventions are appropriately tailored to these.

There is a growing body of research in the UK exploring the perceptions of women with GDM about this condition and their future risk of type 2 diabetes [7–10]. These studies have shown that, although some women have an awareness of their increased risk of type 2 diabetes, their general understanding of type 2 diabetes is poor. Lifestyle changes that are made during pregnancy are primarily motivated by concern for their baby, and women report finding it difficult to maintain these changes in the longer term. They also report feeling a

Correspondence to: Claire Eades. E-mail: c.e.eades@stir.ac.uk

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

What's new?

- Perceptions of gestational diabetes mellitus (GDM) and future risk of type 2 diabetes have previously been explored in traditional research interviews. This study used data from online discussion boards, which may overcome some of the biases present in interviews with volunteer participants.
- The study highlighted messages potentially being widely disseminated which may be unhelpful in promoting type 2 diabetes prevention; for example, that women need not take personal responsibility for GDM and lack of acknowledgement of the heightened risk of type 2 diabetes.
- Clinicians need to be aware of these perceptions and address them where necessary.

sense of abandonment after delivery in relation to diabetes [7–9]. Although this research provides valuable direction for lifestyle intervention in women with GDM, the traditional qualitative methods used expose the findings to possible presentation bias resulting from the presence of the researcher and from the bias inherent in relying on a small self-selected sample of women who are motivated to participate in research and/or may have a particular interest in GDM.

An alternative research approach is to opportunistically use 'found' data that is spontaneously user-generated within online discussion forums [11,12]. As regular access to the internet becomes almost universal, with 87% of adults in the UK using the internet daily or almost daily [13], and women increasingly seeking health-related information online (68% of women, and an even higher proportion of pregnant women, reported doing so [13,14]), such research is becoming increasingly common and offers a number of benefits. Online disinhibition means that people may share things online that they would not in face-to-face interactions. Indeed members of online communities may disclose information or viewpoints that are not widely accepted or that may attract shame or embarrassment in a face-to-face interaction [15]. Therefore, data held in online forums can provide researchers with the means to access large datasets which have been generated in a naturalistic setting and arguably may get closer to people's real lived experiences. Such research reduces the burden on participants and avoids the artificiality that may result from the intervention of researchers [16]. The objective of the present study was to explore what women say about GDM within online parental support forums for parents. Specifically, this study has analysed women's posts on online forums that relate to their diagnosis of GDM, their future risk of type 2 diabetes, and lifestyle behaviour for management of GDM and prevention of type 2 diabetes.

Methods**Sample**

A search was carried out using the Google search engine to identify online discussion forums that could be of relevance to women with GDM in the UK. The search returned 120 results from which we identified 10 potentially relevant forums focusing on either parenting, diabetes generally, or GDM specifically. We screened these 10 forums to identify those containing relevant data that could be considered public (i.e. not a closed or private forum, or a forum that is password-protected or requires permission/authorization to join) and selected the forums Mumsnet and Netmums to be included in the study. The terms and conditions of Mumsnet and Netmums tell users that their data is visible to anyone on the Internet and the discussion on these websites could be considered public. Copyright restrictions on Mumsnet and Netmums prevent reproduction of content from the websites. The present study does not reproduce any content and so does not breach these restrictions. In addition, Mumsnet and Netmums were considered suitable for this study because of the high number of visitors they each attract and because of the differing demographic profiles of visitors to each site. Mumsnet receives 14 million unique visitors [17] and Netmums receives 11 million unique visitors in the UK each month [18]. Users of Mumsnet have a higher household income and are less likely to be 'stay-at-home mums' than users of Netmums [19]. The sample for this study was users of these two websites who posted about GDM on either discussion forum. Only posts about GDM made by women who had themselves had GDM were included in the study. In the majority of cases this was explicitly stated by women, but for 10% of users this had to be ascertained from the content of the message and a judgement made by one of the authors (C.E.)

Data collection

Users of the discussion forums of Mumsnet and Netmums can add messages to these forums known as 'posts', which display their username and the date and time of posting. Posts can either be made in response to other users' posts (in a string of posts known as a 'thread') or a new post can be made (to which other users can respond [6]). The discussion forums of Mumsnet and Netmums were searched in February 2019 using the search term 'gestational diabetes or GD' to identify relevant posts. They could be within threads that were initiated explicitly to discuss topics relating to GDM, or incidentally within threads that originated for discussion of other topics.

The search engines within Mumsnet and Netmums are limited to displaying only 100 and 250 results (i.e. relevant posts), respectively. In order to retrieve the maximum

amount of relevant data given this restriction, the search was run twice on both Mumsnet and Netmums: once with results ordered by the most recent first and once with them ordered by relevance. This meant that approximately 200 results in total were screened on Mumsnet (we cannot be certain that the two searches did not display duplicate results) and approximately 364 results were screened on Netmums (each search on Netmums returned fewer than the maximum 250 results). Because of the volume of relevant data identified in the search, only posts made on or after 1 January 2017 up to the search date (14 February 2019) were retained to ensure the most recent data were identified. Data were organized so that multiple messages from the same person were linked together as a single unit, analogous to a research participant, using an anonymized identifier. All screening of search results was carried out by one author (C.E.).

Ethical considerations

This study was approved by the General University Ethics Panel at the University of Stirling and adhered to the British Psychological Society [20] ethical guidelines for internet-mediated research. There are some potential ethical issues related to the use of data from online discussion forums. Firstly, there is an ethical concern over whether we can consider data posted by users of online discussion forums as public or private. As discussed above, we sampled data from online forums which can be considered public where users could not necessarily expect privacy. Another consideration is that this study was carried out without users' informed consent and they will not be aware of their 'participation'. However, while users may not be explicitly aware that their data are considered to be public, it would not be possible to gain informed consent in this situation [20].

Users of online networks are usually anonymous and use 'usernames'. However, this does not necessarily make them non-identifiable as they may disclose information that makes them identifiable. For this reason, we did not store or report usernames, or any potentially identifying information about users (e.g. location, obstetric history, names of healthcare professionals etc.). Messages were only viewed by those directly involved in analysing the data for the study and anonymized user numbers were used to maintain confidentiality. Shortened and paraphrased segments of original posts were used in place of verbatim supporting quotations to reduce the likelihood that these could be traced via a search engine [20].

Data analysis

The framework analysis method was used to organize and analyse the data [21]. This method is relatively structured and allows pre-set objectives and reasoning to inform data collection while still allowing original contributions from participants. This approach involved the researchers

familiarizing themselves with the data, then re-reading and paraphrasing or labelling any passages they interpreted as important. These labels can be deductive and come from predefined theories or models, or can be inductive or 'open', that is where anything that is relevant from any perspective is labelled. In this study the analysis took both a deductive and inductive approach, with the former informed by previous research findings. Specifically, a framework developed in a previous qualitative study by the authors [8] was used to code and sort the data. This framework was informed by a theoretical approach that combined both the Self-Regulation Model [22] and the Theory of Planned Behaviour [23] (see Eades *et al.* [8] for full details and Table 1 for a copy of the framework). An additional 'other' category was added to the framework for the present study to cover data that did not fit any of the pre-existing headings, thereby allowing inductive analysis as required.

In the present study, one author (C.E.) screened and extracted messages posted to the two websites and coded the content of included messages using the framework outlined in Table 1. A proportion (15 threads from Mumsnet and 15 from Netmums) of the data were also independently coded by another author (K.C.) at the early stages of the analysis, and the two authors compared their coding and resolved any differences before C.E. reviewed the remaining data. When coding was complete, C.E. summarized data collected using a matrix. Separate matrices were developed for each topic theme and each column of the matrices was labelled with a subtheme (except the first column which contained a participant identifier). Each row represented one participant. In each cell of the matrix, relevant data were summarized. Abstraction and interpretation then followed; the matrices were read repeatedly to identify common patterns and disconfirming cases using constant comparison. Comparisons were made between and within participants in the present study, and with the data from those in other studies.

Results

A total of 646 posts in 137 threads from 282 unique users were included in the analysis from Mumsnet and Netmums. Of these, 388 posts in 61 threads were posted by 183 users on Mumsnet and 99 Netmums users contributed 258 posts in 76 threads. The majority of Mumsnet users contributed to one thread [$n = 139$, 76%, mean (SD; range) number of threads 2.12 (1.76; 1-4)] and posted only once [$n = 97$, 53%, mean (SD; range) number of posts 1.3 (0.63; 1-11)]. Only four Mumsnet users posted eight or more times about GDM. Similarly, the majority of Netmums users contributed to one thread [$n = 85$, 86%, mean (SD; range) number of threads 1.29 (1.08; 1-9)] and posted only once [$n = 62$, 62.6%, mean (SD; range) number of posts 2.61 (5.01; 1-45)]. Only six Netmums users posted eight or more times about GDM.

The results are discussed under the five major themes that were identified as being most prominent in the dataset:

Table 1 Framework used to organize the data

Theme	Subtheme	Definition of subtheme
1. Background	1.1 Family history*	Do they have a family history of any type of diabetes?
	1.2 Pregnancy experience*	Any other relevant general information about their pregnancy
	1.3 Previous GDM*	Have they had GDM in previous pregnancies?
	1.4 Postnatal testing*	Attending postnatal blood glucose testing for diabetes
2. Gestational diabetes mellitus	2.1 Identity [†]	The label given to the illness (the medical diagnosis) and the symptoms experienced
	2.2 Timeline [†]	How long the illness will last, acute or chronic
	2.3 Cause [†]	May be biological (e.g. virus) or psychosocial (e.g. stress, health behaviour)
	2.4 Consequences [†]	The possible effects of the illness on their life
	2.5 Control [†]	Whether they believe it can be treated, controlled or cured
	2.6 Emotional representations [†]	How illness affects them emotionally
	2.7 Illness coherence [†]	Understanding of the illness
	2.8 Education about gestational diabetes*	Perception of information provided by healthcare professionals about their condition
3. Type 2 Diabetes	3.1 Identity [†]	See 2.1
	3.2 Timeline [†]	See 2.2
	3.3 Cause [†]	See 2.3
	3.4 Consequences [†]	See 2.4
	3.5 Control [†]	See 2.5
	3.6 Emotional representations [†]	See 2.6
	3.7 Illness coherence [†]	See 2.7
	3.8 Risk perceptions*	Personal perception of whether they are susceptible or at risk of developing type 2 diabetes
4. Diet	3.9 Prevention*	Understanding of whether they can prevent type 2 diabetes and how
	4.1 Attitude [‡]	Attitude toward the behaviour is a person's overall evaluation of the behaviour. Has two components which work together: beliefs about consequences of the behaviour and corresponding positive or negative judgements about each these consequences
	4.2 Subjective norm [‡]	A person's estimate of the social pressure to perform or not perform the target behaviour
	4.3 Perceived behavioural control [‡]	The extent to which a person feels able to enact the behaviour. It has two aspects: how much a person has control over the behaviour and how confident a person feels about being able to perform or not perform the behaviour
	4.4 Intention [‡]	Intention to change diet
5. Exercise	4.5 Behaviour [‡]	Actual dietary behaviour
	5.1 Attitude [‡]	See 4.1
	5.2 Subjective norm [‡]	See 4.2
	5.3 Perceived behavioural control [‡]	See 4.3
	5.4 Intention [‡]	Intention to exercise
7. Other	5.5 Behaviour [‡]	Actual exercise behaviour

GDM, gestational diabetes mellitus.

*Data-derived subthemes.

[†]Subtheme taken directly from illness representations of the Self-Regulation Model.[‡]Subtheme taken directly taken from concepts of the Theory of Planned Behaviour.

emotional response to and understanding of diagnosis; personal responsibility; consequences and impact of GDM; lifestyle change; and type 2 diabetes. Within these themes, we identified salient topics, which are presented in Table 2, with illustrative shortened quotations (to reduce traceability). These are identified by anonymized user number.

Emotional response to, and understanding of diagnosis

On diagnosis of GDM, around one-quarter of users described experiencing a negative emotional response to their diagnosis ($n = 61$). They frequently described an emotional response that was overwhelming ($n = 18$) using terms such as 'gutted' and 'devastated'. Low mood, fear and

feelings of guilt/shame were also frequently experienced in response to diagnosis ($n = 19$, $n = 24$ and $n = 12$, respectively). Some users also described feeling shocked by the diagnosis ($n = 13$) or frustrated ($n = 4$). However, these emotional responses were often relatively short-lived, and users described how they adjusted to the diagnosis and felt better with the passing of time ($n = 8$) or with reassurance from other users ($n = 3$). Two users described using this emotion to motivate lifestyle change.

There was some misunderstanding and doubt about the diagnosis of GDM present on the discussion boards, with some users describing their GDM as mild or borderline ($n = 16$) and others stating that they did not believe they had GDM, despite having tested positive for it ($n = 3$), and thus

Table 2 Summary of themes and topics with illustrative quotations (website names have been anonymized to reduce traceability of paraphrased quotations)

Theme	Topic	Sub-topic	Illustrative quotation	Key messages
Emotional response and understanding	Strong emotional reaction to diagnosis		'I feel so ashamed that I've let this happen and put my baby at risk! So gutted. Feel silly as well because I only said to midwife the other day that I'm surprised how well I feel!' User 207 (Site A)	
	Reaction eases over time		'I cried for days and days when I was diagnosed but now I've got the hang of it it's fine.' User 119 (Site B).	Downplays seriousness of GDM
	Questioning of (possibly mild) diagnosis		'My test was just slightly over the safe level here so I think mine was quite mild.' User 12 (Site B). 'The results were borderline and been testing several times a day and my results never been above the recommended level.' User 216 (Site A).	Downplays seriousness of GDM
Personal responsibility	Personal responsibility recognized		'They say you're more likely to get it if you've had a lot of children (I have), the older you are (I was 40) and if you are overweight (I was).' User 11 (Site B). 'I feel shit for being fat and not taking care of myself while pregnant as I've been eating crap if I'm being honest.' User 13 (Site B).	
	Personal responsibility minimized	GDM attributed to other factors	'You haven't given yourself gestational diabetes. It's a hormonal problem driven by your placenta, there's nothing you could have eaten or not eaten when you were pregnant that would have changed anything.' User 104 (Site B).	Minimizes personal responsibility for GDM
		GDM attributed to bad luck	'I was sick of people telling me that my gestational diabetes was my own fault. I had a BMI of 26, no family history and I never ate sweets and cake etc! It's luck of the draw and you can't prevent it.' User 55 (Site B).	Minimizes personal responsibility for GDM
Consequences and impact	Restrictions/hassle		'Has anyone with gestational diabetes got any ideas for breakfast? I will be fine at the weekend but I need some quick ideas for weekdays when I've got to be at work for 7am.' User 1 (Site B). 'I've gone from finding out I have gestational diabetes last Friday to needing insulin both before bed and before meals.... It's becoming more and more of tricky and I was wondering if anyone else is going through similar?' User 44 (Site B). 'I'm getting so fed up of it now.' User 60 (Site B).	
	Current concerns among pregnant women with GDM	Concerns about delivery	'I've been told that I will definitely be induced at 38 weeks due to gestational diabetes. When I read about induction it scares me how much intervention and interference there is in something that should be as natural as possible. I hate the idea of forcing my body to give birth before it's ready and forcing my baby out before it's ready. I've heard induction pains are worse than normal ones.' User 177 (Site A) 'I wanted a water birth with very little medical intervention and now I'm looking at a very stressful clinical labour requiring a drip and hourly blood tests.' User 113 (Site B). 'I have nightmares about C-sections and having a big baby.' User 16 (Site B).	
		Concerns for baby	'I've just read about the complications of gestational diabetes online and I'm in absolute bits. I feel so bad for having done this to my baby and I'm so scared of things going wrong'. User 103 (Site B).	
		Concerns over future GDM	'I had gestational diabetes before and was told that I would be treated for gestational diabetes from the beginning if I fell pregnant again. I've recently found out I'm pregnant again and I'm keen to keep on top of it this time.' User 22 (Site B)	
	Retrospective reassurance from women post-delivery		'I had gestational diabetes. Don't stress, it's nothing to worry about.' User 163 (Site A). 'Don't panic. I had quite severe gestational diabetes and had to change my diet, take medication and insulin. I was told baby would be huge and there would be complications, but she was absolutely fine. A happy, healthy and very normal 6lb 13 baby.' User 112 (Site B). 'I couldn't get my glucose under control, but my son was fine although he was big, 10lbs at birth. He's now 19 and has no health issues at all.' User 106 (Site B)	Downplays seriousness of GDM

Table 2 (Continued)

Theme	Topic	Sub-topic	Illustrative quotation	Key messages
Lifestyle change	Dietary changes		'I'd recommend joining the Gestational Diabetes UK Facebook group. Because of their advice I managed to stay diet controlled and I would have had to take medication if I had kept following the NHS advice.' User 105 (Site B).	
			'I cut out carbs and sugar from my diet completely.' User 39 (Site B).	
	Physical activity		'I also found that exercise was really helpful. Going out for a 20-minute walk soon after eating can burn off lots of glucose.' User 39 (Site B).	
Type 2 diabetes	Very little reference	Continuation of lifestyle changes post-delivery	'Does anyone have advice about diet and lifestyle from now on as I really want to avoid type 2 or delay it for as long as I can? The diabetes clinic just said to 'be healthy' but not sure for example if I should be trying a low carb high fat diet or what.' User 71 (Site B).	Lack of acknowledgement of risk of type 2 diabetes
			'When I was pregnant I stuck to all the diet guidelines and lost lots of weight but after the baby came I went back to my bad habits and put it all back on oops.' User 253 (Site A).	
			'If you're overweight, have an unhealthy diet or don't do enough exercise take your diagnosis as a warning and make changes now before you develop full-blown diabetes later on. My diagnosis of gestational diabetes kicked me into losing seven stone so it did have a positive effect!' User 7 (Site B).	

GDM, gestational diabetes mellitus.

were concerned that they were 'wasting NHS [National Health Service] time'. Disbelief about the diagnosis stemmed from having self-monitored blood glucose results in the normal range ($n = 1$), thinking that something they had eaten or drunk had affected their oral glucose tolerance test results ($n = 2$), or confusion about different guidelines for diagnosis of GDM ($n = 2$).

Personal responsibility

The possible cause of GDM was a controversial topic that generated strong sentiments among users of the two websites and was discussed by around one-quarter of users ($n = 64$). Users generally fell into one of two groups: those who recognized personal responsibility for their condition and those who denied any personal responsibility.

Among those users who recognized some responsibility for their condition ($n = 22$), some explicitly blamed themselves for their diabetes ($n = 8$), linking in with the feelings of guilt and shame described above, while others described the lifestyle factors that they believed had caused their GDM, such as being overweight and having a poor diet without any self-blame ($n = 14$). Being overweight and having a poor diet were the most commonly cited lifestyle factors, with exercise only mentioned by two users.

There were more users in the second group ($n = 36$), many of whom explicitly denied or downplayed the role of lifestyle in causing GDM and stated that it was not their fault but the result of biological factors such as hormones, their pancreas and placenta, or that it was the result of bad luck ($n = 19$). Other users in the second group described non-modifiable risk factors such as family history or polycystic ovary

syndrome that they believed had caused their GDM ($n = 5$), or stated that they had no known risk factors ($n = 12$), and were therefore 'surprised' at their diagnosis.

Consequences and impact of GDM

The consequences of having GDM on users' day-to-day lives was one of the most discussed topics, with 198 users (70%) making reference to this. The extent to which the consequences impacted on users' lives varied. The majority of users simply stated or listed the consequences, with no indication of the extent to which they had impacted on their life ($n = 116$), while 36 users presented their experience of GDM as negative overall. Twelve users presented it as a positive experience.

On a day-to-day basis, users referred to restrictions to their daily lives, such as various aspects of their diet, taking medication or insulin ($n = 72$) and self-monitoring their blood glucose ($n = 33$). Advice on living with and managing GDM on a day-to-day basis was often sought and offered, mainly by users who currently had GDM. However, the potential longer-term consequences of GDM were discussed by 123 users, most commonly in relation to the impact that GDM might have on their delivery (e.g. having to be induced, have a C-section or other interventions; $n = 92$) and the risk of having a large baby ($n = 45$). The possible consequences of GDM on their unborn baby's health was discussed by 36 users. Some users described the risks for their baby in general terms, while others stated specific risks such as their baby's blood sugars post-delivery and risk of stillbirth. These statements were often accompanied by emotional responses relating to guilt. The risk of having GDM again in

subsequent pregnancies was also explicitly recognized by some users ($n = 19$).

In contrast, a minority of users found that their diagnosis of GDM in fact had some positive consequences, including that they lost or maintained weight during pregnancy ($n = 15$), improved their diet and activity levels ($n = 7$) and generally felt healthier ($n = 4$). These users viewed it as a 'blessing in disguise'.

A common element of these discussions about the consequences of GDM on both websites was that they usually included comments and responses that in some way diminished the seriousness of GDM ($n = 76$), often by women post-delivery who had been through GDM in the past. Sometimes these comments sat contradictorily alongside description of quite serious consequences and complications that the same users had experienced. These comments were often made explicitly to provide reassurance to other concerned users, but were also often inherent in posts without the purpose of providing reassurance.

Lifestyle change

Diet was the lifestyle change that was most commonly made in response to a diagnosis of GDM ($n = 38$), with only 28 users stating that they made changes to both their diet and physical activity levels. The benefits that users saw to making lifestyle changes were predominantly in the short term, for example, to control blood glucose levels ($n = 15$), to avoid medication or insulin ($n = 4$), to feel healthier ($n = 4$), to keep their baby safe ($n = 2$), to reduce the risk of having a big baby ($n = 2$), to avoid induction or C-section, or exercising to allow them to eat treats ($n = 2$). Successful lifestyle changes were among the positive consequences that were reported by a minority of women with a GDM diagnosis. The dietary advice and support provided by the NHS for managing GDM was not found to be helpful by some users ($n = 20$), with some stating that they had sought advice and help from websites or social media (most frequently the Gestational Diabetes UK Facebook page/webpage) and had found this helpful ($n = 24$).

Only eight users described how they had continued the lifestyle changes made during pregnancy after they had their baby. Some explicitly stated that they did so to prevent future development of Type 2 diabetes ($n = 3$), while for others the aim was to prevent a recurrence of GDM ($n = 1$). Two users mentioned that they wished to make permanent lifestyle changes and had struggled to do this before they became pregnant, and another two users described how they had failed to maintain weight lost during pregnancy after their baby was born.

Type 2 diabetes

Only six users in total explicitly referred to type 2 diabetes and their increased risk of developing it, and another five users referred to their risk without explicitly naming type 2

diabetes, for example, by saying that their GDM might remain after they gave birth. Two users stated that they had since developed type 2 diabetes, two had developed prediabetes and one thought they might have prediabetes.

Implications for diabetes prevention

As a result of the present analysis, we identified three important 'messages' arising from the content of users' posts about GDM: downplaying the seriousness of GDM; minimization of personal responsibility for GDM; and lack of acknowledgment of heightened risk of type 2 diabetes (Table 2).

Discussion

In this study we explored what women say in their posts on online forums about their diagnosis of GDM, their future risk of Type 2 diabetes and lifestyle behaviour in relation to these conditions. We analysed the 646 posts of 282 users of Mumsnet and Netmums, deriving from 137 threads. All users either currently had GDM or had been diagnosed with GDM in their last or previous pregnancy. Their online interactions may have been motivated by the seeking of, or the provision of, information, or social or emotional support. Or they may simply have been 'chat'. Some comments were unprompted initial posts; others were responses to posts. Some occurred within GDM-specific threads; others occurred incidentally within threads that originated for discussion of other topics. Some users may have been active or vociferous social media users posting regularly about various topics in general; others may have been less frequent users, but perhaps had a particular interest in, or unusual experience with GDM. While most users probably fell within these two extremes, we cannot generalize our findings to all women with GDM as we do not know how representative the users are of all such women. We do not suggest that we have identified all salient concerns among women with GDM, nor can we comment on the prevalence of particular views or beliefs. However, the study provides an important insight into the public interactions about GDM that occur among women on online parental networks set up to provide social interaction, information and advice.

Our analysis of the online content has identified three implicit messages. The first is that GDM is not a serious diagnosis that warrants undue concern. Although there is often an initial strong emotional response to a diagnosis of GDM that has been noted in other studies, this response tends to ease for many women over time, evolving into a view of GDM as a manageable condition [8,9,24]. Post-delivery, as in the present study, this view is then reinforced when women deliver 'happy, healthy' babies with 'no complications'. While this will be the result of sensitive and effective clinical care for many women, it paradoxically downplays the seriousness of GDM to readers of the online

content. Furthermore, the existence of a minority of women who question their diagnosis, either at the time or retrospectively (also observed in other studies [8,9]), tends to convey a sense that GDM cannot be that serious or even real.

Similar downplaying of the seriousness of GDM was also evident from our analysis of users' comments regarding the consequences of GDM, which was by far the most commonly discussed topic, but although these may have resulted in a worrying pregnancy and a negative experience of GDM for many users, most emphasized, as described above, that everything was 'fine in the end' and that GDM was a manageable condition with limited long-term impact. Given that online networks are often set up explicitly as 'supportive communities' and their importance as a source of positive social and emotional support is widely acknowledged [24], it is unlikely that many women who had experienced complications would respond and cause worry and anxiety to fellow users. Others who did experience complications may have been consciously filtering their comments to be encouraging to others. This may therefore perpetuate the notion that complications are infrequent. However, if women are influenced by messages that talk down the seriousness of GDM, it will be challenging to persuade them of the importance of behaviour change for diabetes prevention in the longer term.

A second implicit message emerging from the online content relates to the causes of GDM, to which 58 users referred. However, fewer than half publicly acknowledged the importance of their own behaviours or lifestyle, with others minimizing their own personal responsibility or attributing GDM to non-modifiable factors. There was a substantial amount of mutual re-inforcement of this viewpoint between users, with some making supportive comments to others ('Don't stress', 'You haven't given yourself gestational diabetes'), ostensibly to reassure them or to alleviate them of guilt. However, it will be challenging to persuade women who do not take any personal responsibility for GDM of the importance of behaviour change for diabetes prevention in the longer term.

The third subliminal message relates to the infrequent explicit reference to risk of type 2 diabetes. Only 16 users in this study mentioned topics relating to type 2 diabetes, five of whom had already developed prediabetes or type 2 diabetes. Another six were aware of their future risk of prediabetes or type 2 diabetes. In a previous study we questioned participants directly about their understanding of future diabetes risk, and while most stated that they were aware of their increased risk, they minimized this for themselves personally, thought diabetes was a mild condition or a long way in the future and were not unduly concerned [8]. Our results reinforce this underlying lack of concern, especially as most users, in the absence of a prompt by a researcher, did not even allude to risk of future type 2 diabetes.

Although we have identified three subliminal messages, we cannot be certain that these were the actual views, experiences and perceptions of the women who posted online; they may simply represent how they chose to construct and present them

in an online environment. However, our concern is whether these messages are being conveyed to readers of the online content. Online networks have huge reach, and are viewed by millions of visitors who do not necessarily post themselves, but are signposted to these sites when they pose questions to global search engines [17,18]. If women are influenced by these messages, they will mitigate against efforts by clinicians to encourage women to change their lifestyles for future diabetes prevention. A study that assessed quality of health information online (including Mumsnet and diabetes as exemplars) suggested that the majority of information was of reasonably good quality [26]. However, we would argue that it is this potential diffusion of underlying implicit views and beliefs that may be of more concern.

In general, despite using a novel methodological approach, our results were not inconsistent with results from other more traditional studies in this area. There was one notable difference in that postpartum abandonment has been an issue that is frequently identified as: eliciting frustration and concern for mothers post-delivery [27]; conveying a sense that the consequences of GDM are not serious enough to warrant follow-up post-delivery [8]; or diminishing the importance of women's own health by seeing them as baby machines [9]. Although some of our users had yet to deliver, it is notable that such abandonment was barely mentioned by any. However, most other studies on this topic in the UK have recruited women within an NHS context purposively for substantive GDM research using focused interviews or focus groups [7–9]. This is likely to have a bearing on the matters brought up by participants of research studies. Future researchers on this topic might also consider using alternative survey methods to seek clarification on how many women do experience post-partum abandonment, and possibly to capture even wider perspectives on GDM.

The strengths of the present study are its novel analysis of the real-life unprompted communications of a group of women who have experienced a diagnosis of GDM, many of whom might not ordinarily be recruited for research. We used a theoretically informed pre-existing framework to code the data, with initial coding of a subsample carried out independently by two researchers, but we allowed unexpected themes and topics to emerge.

The study also has some limitations. As explained above, we could only analyse what women choose to say in an online environment. The data that were analysed were highly contextual and probably influenced by Internet demographics, and also the characteristics, demographics and socially patterned usage styles of the platform in question. The approach also excludes people who do not engage online. The nature of the online forums mean we cannot be certain that the 282 users included in the study were truly 282 different individuals. It is possible that one person could use multiple usernames to post either within websites or across the two websites, and we cannot necessarily be certain that the users were who they presented themselves as being (i.e. a woman diagnosed with GDM).

Despite this, we believe the study has clear implications for future diabetes prevention. The messages that GDM is an easily managed condition and that women need not take personal responsibility for it, and the lack of acknowledgement of the increased future risk of type 2 diabetes, are powerful ones that may inadvertently be being conveyed on online platforms. The involvement of clinically qualified moderators on online health forums may be a partial solution to ensure that inaccurate information is questioned [25]. In terms of intervention development, it may be necessary to ascertain whether women have been influenced by these messages and challenge them where appropriate. Given that women are turning to social media for support and advice about GDM, it may be that social media itself can be harnessed to help address and challenge these messages. Future research should explore interventions delivered via social media to address perception of GDM.

Funding sources

None.

Competing interests

None declared.

References

- Eades C, Cameron D, Evans JMM. Prevalence of gestational diabetes: a meta-analysis. *Diabetes Res Clin Pract* 2016; **139**: 173–181.
- Yogev Y, Visser GHA. Obesity, gestational diabetes and pregnancy outcome. *Semin Fetal Neonat M* 2009; **14**: 77–84.
- Ferrara A. Increasing prevalence of gestational diabetes mellitus: a public health perspective. *Diabetes Care* 2007; **30**: 141–146.
- Gillies CL, Abrams KR, Lambert PC, Cooper NJ, Sutton AJ, Hsu RT et al. Pharmacological and lifestyle interventions to prevent or delay type 2 diabetes in people with impaired glucose tolerance: systematic review and meta-analysis. *Br Med J* 2007; **2007**: 299.
- Gilinsky AS, Kirk AF, Hughes AR, Lindsay RS. Lifestyle interventions for type 2 diabetes prevention in women with prior gestational diabetes: a systematic review and meta-analysis of behavioural, anthropometric and metabolic outcomes. *Prev Med Rep* 2015; **2**: 448–461.
- Cheung NW, Smith BJ, van der Ploeg HP, Cinnadaio N, Bauman A. A pilot structured behavioural intervention trial to increase physical activity among women with recent gestational diabetes. *Diabetes Res Clin Pract* 2011; **92**: e27–29.
- Lie MLS, Hayes L, Lewis-Barned NJ, May C, White M, Bell R. Preventing Type 2 diabetes after gestational diabetes: women's experiences and implications for diabetes prevention interventions. *Diabet Med* 2013; **30**: 986–993.
- Eades C, France E, Evans J. Postnatal experiences, knowledge and perceptions of women with gestational diabetes. *Diabet Med* 2018; **35**: 519–529.
- Parsons J, Sparrow K, Ismail K, Hunt K, Rogers H, Forbes A. A qualitative study exploring women's health behaviours after a pregnancy with gestational diabetes to inform the development of a diabetes prevention strategy. *Diabet Med* 2019; **36**: 203–213.
- Dennison R, Ward RJ, Griffin SJ, Usher-Smith JA. Women's views on lifestyle changes to reduce the risk of developing Type 2 diabetes after gestational diabetes: a systematic review, qualitative synthesis and recommendations for practice. *Diabet Med* 2019; **36**: 702–717.
- Malinen S. Understanding user participation in online communities: A systematic literature review of empirical studies. *Comput Hum Behav* 2015; **46**: 228–238.
- Im E, Chee W. Practical guidelines for qualitative research using online forums. *Comput Inform Nurs* 2012; **30**: 604–611.
- Office for National Statistics. *Internet access - households and individuals, Great Britain Internet access - households and individuals, Great Britain: 2019*. UK: Office for National Statistics. [Cited 2020 Feb 21]. Available at <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2019>
- Sayakhot P, Carolan-Ola M. Internet use by pregnant women seeking pregnancy-related information: a systematic review. *BMC Pregnancy Childbirth* 2016; **16**: 65.
- Suler J. The online disinhibition effect. *Cyberpsychol Behav* 2004; **7**: 321–326.
- Smedley RM, Coulson NS. A practical guide to analysing online support forums. *Qual Res Psychol* 2018; <https://doi.org/10.1080/14780887.2018.1475532>.
- Mumsnet.com. Mumsnet by parents for parents. About us; c2019 [Cited 2019 Jan 16]. Available at <https://www.Mumsnet.com/info/about-us>.
- Netmums.com. Netmums. About us; c2016 [Cited 2019 Jan 16]. Available at <https://www.netmums.com/info/about-us>.
- Pederson S, Smithson J. Mothers with attitude - How the Mumsnet parenting forum offers space for new forms of femininity to emerge online. *Women's Stud Int Forum* 2013; **38**: 97–106.
- British Psychological Society. *Ethics Guidelines for Internet-mediated Research*. INF206/04.2017. Leicester: British Psychological Society. [Cited 2020 Feb 20]. Available at <https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Ethics%20Guidelines%20for%20Internet-mediated%20Research%20%282017%29.pdf>.
- Spencer L, Ritchie J. Analyzing qualitative data. In: Bryman A, Burgess B (eds). *Qualitative data analysis for applied policy research*. London: Routledge, 2002: 187–208.
- Leventhal H, Diefenbach M, Leventhal EA. Illness cognitions: using common sense to understand treatment adherence and affect cognition interactions. *Cognit Ther Res* 1995; **16**: 143–163.
- Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process* 1991; **50**: 179.
- Feighan C, Daniel U, Divine H, Hatunic M, Higgins NF. The emotional journey of gestational diabetes. *Lancet Diabetes Endocrinol* 2017; **5**: 924.
- Zhao Y, Zhang J. Consumer health information seeking in social media: a literature review. *Health Info Libr J* 2017; **34**: 268–283.
- Cole J, Watkins C, Kleine D. Health advice from Internet discussion forums: How bad is dangerous? *J Med Internet Res* 2016; **18**: e4.
- McMillan B, Easton K, Goyder E, Delaney B, Madhuvrata P, Abdelgalil R, Mitchell C. Reducing risk of type 2 diabetes after gestational diabetes: a qualitative study to explore the potential of technology in primary care. *Br J Gen Pract* 2018; **68**: e260–e267.