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Women's views about online communities for gestational diabetes mellitus: A qualitative interview study

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ABSTRACT

Problem and background: Gestational diabetes mellitus (GDM) is a common medical complication of pregnancy, and the emerging evidence demonstrates how GDM online communities have a positive impact on promoting self-management and improving outcomes. Further analysis of such groups can increase understanding of how peer support in GDM online communities is enabled and enacted.
Aim: To examine women's experiences of GDM online communities on Facebook, their motivations for participation, and perceptions of dynamics within the community.
Methods: Semi-structured phone interviews were conducted with 28 participants, recruited from an online survey posted in two self-organised Australian GDM Facebook groups.
Results: From our thematic analysis of the interview data, four themes were identified from participants' views about GDM online communities: 'A safe community' encapsulated a desire to be connected with others having similar experiences in a non-judgmental space; 'A supportive and informative group' concerned the need for, and giving of, support, and gaining knowledge; 'An adjunct to healthcare' referred to participants' use of GDM online communities to inform their healthcare experiences; and 'A waiting room' reflected participants' continued involvement in GDM online communities, in part due to future uncertainty.
Discussion and Conclusion: Our findings affirm the value of GDM online communities on Facebook for community, support and information. GDM online communities serve as an adjunct to formal healthcare, augmenting clinic-based appointments and clinical management of GDM, encouraging informed decision-making and self-advocacy. We highlight how, in such spaces, women collaboratively navigate self-management and healthcare.

Introduction

Social media has revolutionised the way participation occurs online, enabling users to share their own content and comment on others'. (Gage-Bouchard, LaValley, Mollica, & Beaupin, 2017) For health communication, social media has long been identified as having benefits (Moorhead et al., 2013) and the adoption of smartphones has enabled greater penetration of the internet into everyday life, with social media and other apps accessible for health purposes.(Luxton, McCann, Bush, Mishkind, & Reger, 2011; Peng, Kanthawala, Yuan, & Hussain, 2016) Many use the internet and social media, such as Facebook, for support and information with their pregnancies,(Harpel, 2018) and closed Facebook groups can be spaces where women share lived experiences. (Archer, Johnson, & Williams Veazey, 2021) This includes experiences of conditions like gestational diabetes mellitus (GDM).

GDM is defined as any degree of hyperglycaemia recognised for the first time during pregnancy (Metzger and Coustan, 1998) and is currently the most common medical complication of pregnancy with high prevalence in many parts of the world.(McIntyre et al., 2019) It is associated with adverse maternal and neonatal outcomes, including increased birth weight of babies as well as greater risk of future diabetes. (McIntyre et al., 2019) As an acute condition, there is limited time for most women to acquire optimal knowledge for self-management of GDM.

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The growing body of evidence supports online communities having a positive impact on promoting self-management and improving outcomes for women with GDM.(Cheng, Hao, Tsofliou, Katz, & Zhang, 2023) Our previous research found women in Australia joined GDM online communities on Facebook to seek out peer support, information and practical advice, lived experiences and community.(Pham et al., 2024a) There are also some studies from the United Kingdom and Ireland exploring the phenomenon of GDM online communities; qualitative studies by Edwards et al. and Elton explored women's experiences of online community on Facebook for GDM and found they facilitated communication and mutual support through the difficulties of GDM and into the postpartum period.(Edwards, Bradwell, Jones, Andrade, & Shawe, 2021; Elton, 2022) Another study focused on GDM discussions in an online forum by Eades et al. was more cautious in its conclusions, finding users seemed to derive peer support but there was insufficient consideration of GDM being a serious diagnosis and a signal of future risk of T2DM.(Eades, Clarke, Cameron, Coulson, & Evans, 2020)

These contrasting findings point to an opportunity for further exploration about the dynamics within self-organised GDM online communities, including roles and responsibilities that enable mutual support, as social media is a readily available resource that may be consequential for the sustainability of the healthcare system. In the Australian context, these GDM online communities are particularly under-examined and there is a need for further research, given these groups attract thousands of members and are important hubs for informational and emotional of support.(Pham et al., 2024b) There is also a need for deeper analysis of group discussions, not only as content taken at face value,(Eades et al., 2020) but based on self-reporting from participants in these groups. As it stands, the existing literature includes both content analysis and interview-based qualitative studies, but there remains scope for more nuanced research with enlarged samples. Building on the extant evidence, this exploratory study collects qualitative data directly from within the membership of Facebook groups in Australia, with the aim of examining how women with GDM perceive and utilise online communities for support and self-management, including experiences of GDM online communities on Facebook, and their motivations for participation and perceptions of dynamics within these communities.

Method

Given the research aims, a descriptive qualitative study design using semi-structured interviews was chosen. With the focus of exploring women's experiences of GDM support communities on Facebook, semi-structured interviews were the most suitable method to meet the objectives of the research agenda while also allowing for spontaneous descriptions and narratives from respondents.(Brinkmann, 2008) Analysing the interview data required an appropriate strategy to search for patterns of experience to address the research questions.(Ayres, 2008) Thematic analysis was chosen for this reason, as it focuses on identifying, analysing and reporting patterns within the data.(Braun & Clarke, 2006) The reporting of this study was guided by COnsolidated criteria for REporting Qualitative research (COREQ)(Tong, Sainsbury, & Craig, 2007) (see Appendix 1).

Ethics

Prior to the commencement of data collection, ethics approval was received from Macquarie University's Human Research Ethics Committee (Reference number: 5201827734364). The first author (SP) requested permission from the administrators of both groups to join and conduct research; in her application to join she disclosed having lived experience of GDM. Participants opted-in to an interview and provided voluntary informed consent to participate, understanding their interviews would be recorded and used for research purposes.

Participants

Recruitment occurred via an online survey posted in two GDM Facebook groups,(Pham et al., 2024b) and included questions about demographics and use of the internet for GDM management. The cross-sectional online survey included, where possible, validated and established measures. At the end of the survey, respondents could register their interest in participating in semi-structured interviews. Maximum variation sampling was instituted so that of those who registered, interview participants were prioritised to include administrators as well as maximise coverage across age groups and all Australian states and territories in major cities and regional/remote areas to promote geographical representation. The aim was for a sample size of at least 20-25 participants, when data saturation(Bradshaw et al., 2017; Fusch and Ness, 2015) would presumably be reached based on research on similar topics.(Baron et al., 2017; Draffin et al., 2016; McMillan et al., 2018)

Interviews were conducted by SP (female, PhD candidate) over the phone and audio-recorded. During interviews with participants, SP asked questions around three broad topic areas, which mirrored the questions in the survey: (i) healthcare experience of GDM; (ii) experience of GDM and the internet; and (iii) experience of GDM online communities on Facebook. The interview guide is included in full in Appendix 2, providing more detail about the types of questions asked. Prior to data collection, pilot interviews were conducted with two individuals with lived experience of GDM and use of online communities on Facebook.

Of 340 survey respondents, 107 women registered their interest in being interviewed. From these registrations, 32 women were invited to further participate, and 28 women (aged 22-45 years, median 32.5 years) took part in an interview, which resulted in data saturation. Participants' socio-demographic details are summarised in Table 1. The mean interview duration was 47 minutes (range 17–100 minutes).

Data analysis

Interview recordings were de-identified and transcribed, firstly

Table 1
Participant characteristics.

Description	N=28
Age range (in years)	n (%)
20-25	1
26-30	8
31-35	13
36-45	6
Location	
Major city	22
Regional/remote	6
State	
QLD	4
NSW	9
VIC	4
ACT	2
SA	2
WA	5
TAS	2
Birthplace	20
Australia	8
Other	
Education	
Less than year 12	1
High school	3
Vocational qualification	4
Bachelor's degree	7
Postgraduate degree	12
Current pregnancy status	
Yes	10
No	18

through the use of NVivo Transcription, followed by SP manually validating each transcript by listening closely to each interview then correcting transcripts as required for subsequent analysis in NVivo R1. (Lumivero, 2020) Using an analytical approach both inductive and deductive, data were initially analysed by examining interview transcripts, consulting early analytical notes and reviewing related studies. The six steps of thematic analysis identified by Braun and Clarke (2006) were followed in the present study: 1. familiarising yourself with your data, 2. generating initial codes, 3. searching for themes, 4. reviewing themes, 5. defining and naming themes, and 6. producing the report. (Braun & Clarke, 2006) First, familiarisation occurred by examining transcripts and close listening to interview recordings. The transcripts were then initially analysed by moving back and forth between examining transcripts, consulting analytical notes and reviewing other related studies (e.g. (Elton, 2022)) in order to generate initial codes. After repeated readings while listening to interview recordings, SP developed an early coding framework based on ten transcripts and discussed this with KC who suggested further refinements (e.g. consolidating codes ‘reassurance’ and ‘normalisation’ into one code). In a sample of transcribed interviews, KC checked the validity of early codes and the accuracy and reliability of their application to the transcribed data. The consistency of coding and interpretation leading to potential themes was checked during analysis by revisiting transcripts, including with the research team. Themes were then reviewed through an iterative process, before being defined and named. The final themes generated and reported on captured the range of experiences and views.

Reflexivity

Given her lived experience of GDM, SP was an ‘insider researcher’(Sherry, 2008) and her positionality with respect to data collection required careful consideration to protect the integrity of the research. It is worth noting that SP had not previously been a member of a GDM Facebook group, so had no firsthand experience of using an online support community for self-management of GDM. Taking her positionality into consideration, SP’s personal responses to participants were ultimately not so much a source of bias as they were a source of insight and interpretation in the research.(Scott, 1997)

Results

Four main themes were identified from the analysis of the interview data with respect to participants’ views about GDM online communities and their experiences: ‘a safe community’, ‘a supportive and informative group’, ‘an adjunct to healthcare’, and ‘a waiting room’, which encompassed 11 sub-themes (see Fig. 1).

Theme 1: A safe community

The first theme ‘a safe community’ involved participants’ views that an online community on Facebook alleviated isolation and provided a sense of connection through shared experience. The word ‘community’ was explicitly used by several participants: “People are going through the same thing as you; you’re not feeling alone, and you’re feeling a part of a community and you feel accepted” (P28, 28 years). Being “accepted” meant a non-judgemental and safe place to commune. As participant 22 (28 years) described, the potential for anonymity was one basis for the lack of judgement: “No one on Facebook knows your weight, so they don’t judge you on it”.

Communities are created when people come together for a common purpose; several stated there was a “group for everything” (P1, 26 years) on Facebook, referring to the platform’s ubiquity. An online community for GDM was described as valuable because it meant being in proximity with others going through the same experience: “I liked knowing that I wasn’t alone, that there were other people out there… there was a nice sense of community there” (P5, 31 years). The majority expressed feeling simpatico with other women in the group, as participant 3 (41 years) stated: “You know everyone else is in the same boat. Everyone else is just as frustrated.”

To promote a culture of safety and mutual respect, a community requires active government. Several participants indicated that the group administrators (‘admins’) were a strong and visible presence, as Participant 11 (40 years) described:

> “It feels like it’s quite a good, well-moderated group in terms of the admins [who] seem to do a very good job in not tolerating… if anyone violates the group rules. The admin’s pretty good pulling people up or saying, ‘Hey, you know we shouldn’t offer medical advice,’ or ‘You should check with your endo[crinologist]’. Or ‘Hey,

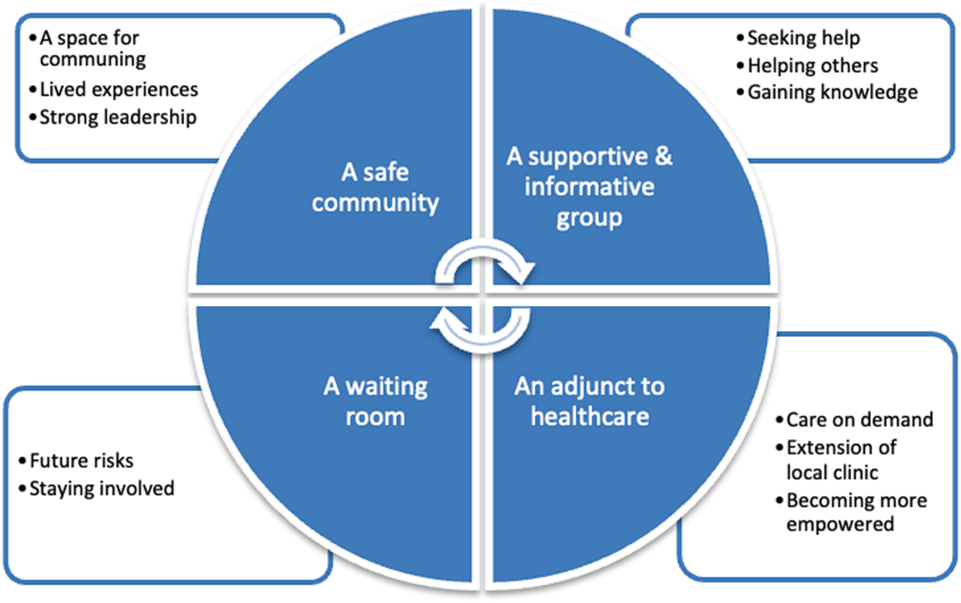

Fig. 1. Themes arising from qualitative data.

> we're not about shaming, or we're not about bragging about what we even got away with.'"

Although most acknowledged group administrators in a positive manner, a number of participants stated they disagreed with some aspects of governance:

> "The admin seemed to be… very pro going on medication if you have to. And they didn't like any talk about misdiagnosis or the possibility of that and people being concerned about taking insulin, they all sort of pushed for that, which is fine. That's the only thing I didn't like about [the group]." (P12, 30 years)

As with most peer-led online support groups, volunteer administrators come from the community. In our sample, four participants were also GDM Facebook group administrators (i.e. P10, P13, P22, P24). Their comments underscored the demands of content management work: "Some days I just want to bang my head against the wall when I see some of the comments that I've had to delete or some of the arguments I've had." (P13, 32 years, admin). Providing leadership as an admin included a serious duty of care aspect:

> "Obviously we're not medical professionals and we certainly don't want to give that impression that we are because we aren't held as accountable as a medical professional is. And the last thing we want to do is give someone the wrong advice at the end of the day." (P13, 32 years, admin)

An online community was especially important for participants who described having insufficient support in 'real life': "I didn't even tell my parents for a long time [about my GDM diagnosis]. I was quite embarrassed that I had failed the baby." (P25, 30 years). This sentiment was reiterated by one of the group administrators who observed she was lucky to have supportive family and friends, but not all women in the group did:

> "It sounds like some women really struggle and there's a real kind of bias, there's a shame to it, or they feel like they caused this or they feel like it's because they're not eating well or whatever it is." (P10, 33 years)

Many participants stated they perceived a high level of agreement within the group: "Most people were on the same page" (P14, 31 years). One participant appreciated the diversity in viewpoints and said it was encouraging to read "what different people have to say", though noted that came with potential problems: "You've got to be careful that you don't get offended or upset by things that certain people are saying" (P23, 33 years).

As the above quote suggests, co-existence online around a topic of mutual interest with people from a mix of backgrounds and experiences was the source of vexation for some. Participant 25 (30 years) described how being in an online community meant having differences to navigate: "It's a… mix of cultures and a mix of socioeconomic everything on there, which can be a bit difficult sometimes". These 'difficulties' emerged in relation to weight stigma, among other concerns. Participant 17 said "there is stigma around diabetes", and furthermore noted weight stigma was a reason why she did not contribute to many discussions in the group:

> "I don't participate that much or respond to things that much because I also sometimes think that they don't want to hear it from me because [they'll say things like], 'I'm actually a fitness fanatic and super thin. How could you lump me into this diabetic category with all those fat, unhealthy people?' So I sometimes feel like they wouldn't want me to respond to them anyway." (P17, 29 years)

Participant 21 stated she did judge what others posted and was sometimes disturbed by what she read, and described the group as full of strong opinions "whether it was educated or not": "I would just read what people were saying and I would get frustrated and I would … message my friend and be like, 'oh my God, can you believe what people were saying?'" (P21, 32 years).

For many women, reading other people's lived experiences was helpful with decision-making. When choosing medication, participant 15 (40 years) described how reading experiences about Metformin versus Protaphane (medications for GDM) helped: "Partly because of their experience and what they'd written, I decided to go with the protaphane at night, which doesn't cross the placenta." More generally, participants reported feeling reassured about birth because of what they read: "I liked hearing that their birth and everything had gone well. It gave me reassurance that even though I had this diagnosis I could still have a normal safe birth." (P20, 35 years)

Theme 2: A supportive and informative group

The second theme identified was 'a supportive and informative group', reflecting participants' desire for support from a GDM online community on Facebook; not only emotional support, but informational support as well. One participant explained the specific value of peer support for GDM:

> "I find that I have more support from them, simply because the people around me aren't going through gestational diabetes. Or only know as much as what someone can know without going through it themselves. The support that someone can give you when they're going through the same situation… feels more valid because they're having the same experiences" (P26, 22 years).

Participants described how the help sought primarily occurred through posting questions, reading answers and receiving reassurances. Participant 26 (22 years) described asking if others had had an early diagnosis and how receiving responses from "a lot of women" diagnosed early "comforted me and made me less concerned and less freaked out." Many described how the practical tips and inspiration around food provided by peers was helpful, as managing GDM on a day-to-day basis was onerous:

> "I was really lost before I found the Facebook page. Because the hospital they just give you this information and they go, 'all right, go deal with it now'. And they only ever want to see you when you have your appointment... Whereas I could open that FB page each morning and see what people are having for breakfast or seeing what people are having for lunch or snacks." (P9, 32 years)

Due to members' accumulated input, these Facebook groups become a repository of knowledge and help could be found by searching the archives rather than posting: "I did a lot of searching… [about] any kind of questions I could think of… and there's usually three or four previous posts that answer what I have been after" (P19, 37 years). A few participants were 'lurkers' but stated they still found the group's content helpful: "I never commented, I never wrote back to people… I just liked hearing the conversation" (P21, 32 years). Providing help to others was described as affirming because it validated their own experiences and knowledge, as one administrator said of her own motivation to volunteer:

> "It's a bit of a 'pay it forward' situation… People need support and advice and I know how hard it was for me and how much I had to grapple with it. If I can make that a little bit easier for someone else, well, I'm happy to do that" (P24, 45 years, admin).

In addition to those with official administrative duties, some described taking on informal roles to help. A participant with scientific training stated, "one of my motivations in the group…is probably to just like try and help correct misinformation or misunderstanding" (P7, 37 years). Another described how there was one specific topic she would comment on as her contribution:

> "When people ask those kinds of questions, I like to chime in on that because I think that it helps to know that not every person with GD has like giant babies and you shouldn't be so scared about the whole thing" (P17, 29 years).

Another administrator (P10, 33 years) stated "medical people" were not let into the group due to their qualifications, only if they had GDM, such was the case with one member she described who occasionally provided informal but informed advice: "we've let her in because it is useful having a diabetes educator in there who can set some facts straight and reassure some people".

Self-management of GDM requires knowledge, something which participation in the group was able to provide members, as participant 10 (33 years) stated: "I probably got most of my knowledge from the Facebook group". Knowledge was gained by being prompted to consider new information: "When I read other people's posts or other people's comments that's made me question things or think about things I've not had to think about before" (P18, 35 years). Participants also stated new ideas made them seek out further information elsewhere: "The girls are talking about this and maybe that's why my numbers are high… it's made me sit back and think, or do a little bit of research into it" (P8, 28 years). In other cases, the group itself *was* the source of research; one participant described how crowdsourcing knowledge made up for her own shortcomings: "I'm not very good at research myself. I think that's why I like the Facebook [support] page because I actually really suck at researching" (P1, 26 years).

GDM was frequently described as an acute experience. Because of the compressed timeframe, there was strong awareness that knowledge was gained against the clock, as participant 6 (30 years) stated: "You learn so much about it in such a short period of time… really, only 10 weeks that you've got to wrap your head around". A GDM online community was how many women learned to tailor their own self-management:

> "I saw a lot of people are finding that their ratings change over time for the same meals that they're having and that's where I found out that as the pregnancy progresses, your resistance changes and you get higher readings. So you just gotta keep working on the insulin until you found the right spot... That I learned on Facebook." (P3, 41 years)

The camaraderie of the group was also expressed through humour, as some found levity in the situation and took it upon themselves to provide comic relief to the group:

> "I took a photo and posted… it seemed like everyone was always so stressed about trying to get meals right, meal ideas, and I spent the evening trying to accurately get this GD meal down pat and then went and dropped it on the floor. It was funny and a lot of people laughed at it." (P6, 30 years)

Theme 3: An adjunct to healthcare

The third theme identified was 'an adjunct to healthcare'. According to the data, healthcare was intrinsic to the experience of GDM, and online communities functioned as 'appendages' to the healthcare system by allowing participants to ask questions, discuss and critique experiences. The ready availability of Facebook augmented clinic-based appointments and clinical management of GDM, with healthcare expressed by many as being limited due to a lack of continuity of care. In contrast, peer support provided through the GDM Facebook group was always available and viewed as "a lot more continuous" (P7, 37 years). Participants ascribed value in having access to a form of out–of-hours care, which they suggested bridged the gap between discussions with their healthcare providers: "When you're feeling down at night time… you've got that support. You don't have the hospital; you can't always speak to someone and ring them at night time so that's mainly why I was on [the Facebook group]" (P3, 41 years).

Some participants stated it was difficult to access formal care due to factors out of their control, and why they turned to an online community: "I got diagnosed towards the end of the year, and they [the clinic] were only open three days a week. And I worked on the days that they were open" (P10, 33 years, admin). Several participants described how the advice and support from the GDM online community was more person-centred than the care received through the healthcare system: "It was more personal. I felt at the hospital I was very much a number" (P12, 30 years).

Participants consistently acknowledged the inconsistent guidelines for GDM diagnosis and care across Australia: "The thing that I found really interesting…was that gestational diabetes was managed quite differently between states. And that was frustrating. It's like, shouldn't there be a standard?" (P21, 32 years). The inconsistent standards for managing GDM was also observed at the local level: "People would say, 'well, it's different doctors, different hospitals.'" (P23, 33 years)

One woman reported how reading other's experiences of healthcare was useful in confirming her healthcare could have been better: "I wasn't happy with aspects of the way I was being managed so I found it really useful to get a gauge on how other people were being managed" (P4, 35 years). While for some, hearing about other's negative experiences confirmed they had a good healthcare situation: "I know that on Facebook some of the women having to wait 2, 3, 4 weeks to get into that clinic, whereas I was in the very next day" (P2, 33 years).

The collaborative processes within GDM online communities on Facebook demonstrated the way self-organisation on social media can occur, as one administrator stated: "I'm not sure that healthcare professionals realise how much people are actually reaching out to one another" (P24, 45 years, admin). Becoming aware of other's experiences empowered many to negotiate with their own healthcare providers. As one stated, "They kind of taught me to push back a little bit…whereas I probably wouldn't have done that if I wasn't on the [Facebook] page" (P9, 32 years).

Theme 4: A waiting room

The fourth theme identified was 'a waiting room', which reflected the somewhat unexpected phenomenon that most participants interviewed already had their baby (n=18) and not currently managing GDM, yet still in the group for reasons largely related to concerns about the future. Some participants viewed GDM as a finite journey – "I'll probably definitely stay in there until birth and then quietly leave the group" (P8, 28 years) – while others described waiting until the postpartum oral glucose tolerance test: "It'd still be good to be on the group till I did my six week check." (P27, 35 years). However, other participants suggested GDM had altered their perception of risk, something to consider with future family planning and their own health. T2DM risk was discussed by several participants, and cited as a reason to stay: "I'm really keen not to get type two diabetes, so I think it would be really good support to check in every now and then and get ideas of healthy things to eat" (P19, 37 years). Remaining in the group was thus an acknowledgement of future risk of T2DM, which some even viewed as an inevitability:

> "I stayed in it for a while afterwards because I was going into that second test. I was wanting to for my own reassurance... a lot of people stay in there afterwards and a lot of people talk about what they got on their level afterwards and if they've got diabetes... I was really anxious about getting diagnosed afterwards especially with my family history" (P4, 35 years).

Related to family planning, participants cited an additional motivation for remaining in the group as being the continued accrual of 'lay expertise' about GDM: "Maybe I'll have another baby one day, or if something about the research pops up because obviously I'm not… looking into it anymore… [but] something might pop up and might spark my interest" (P25, 30 years).

Beyond concerns about recurring GDM and future T2DM, some participants also indicated a desire to gain closure and see the completion of their peers' GDM journeys:

> "'cause there were some people's journeys that I guess I was following… I liked to see the birth announcements at the end and everything turns out okay and I just like to keep up to date with what's going on" (P12, 30 years).

Several participants also remained actively involved in supporting other women because being postpartum made it easier to contribute to the group: "When you've had your baby and you've kind of stepped away from it it's easier to look back and be able to give answers to other people as well" (P28, 28 years). Filling in the survey and being interviewed for the present study was described by some as their way of making a contribution.

Finally, participant 22, who went on to become the administrator of another GDM-related Facebook group, discussed how the community led to connections she wanted to continue beyond the experience of GDM itself:

> "We were all talking on the page and how… when it's time to say goodbye, which obviously is a personal choice. Everyone misses the connection. They've often made friends on the group. In these groups, you get to know everyone in the situation and everyone's stories... So it becomes a mothers' group" (P22, 28 years, admin).

Discussion

The findings of this study affirm how GDM online communities on Facebook offer community, support and information for women. Most participants discussed how being involved validated their struggles with GDM, and bolstered their self-management. Contributing to the community and supporting others was also reported as validating, and administrators played an important role in enabling this. Furthermore, the findings showed how GDM online communities serve as an adjunct to formal healthcare, augmenting clinic-based appointments and clinical management, encouraging informed decision-making and self-advocacy in healthcare encounters.

At the individual level, regardless of the formal healthcare received, a GDM diagnosis places the onus on the individual to work out how to self-manage GDM in a relatively short span of time. Women are taught to monitor their BGLs, adjust their diets and increase physical activity, among other strategies.(Carolan-Olah, Steele, & Krenzin, 2015) The findings of this study accord with a recent systematic review of the effects of online support and social media communities on GDM, which found that online support interventions have a positive impact on promoting self-management and self-care, thus improving healthcare outcomes for women with GDM.(Cheng et al., 2023)

Given the way GDM is an experience that is situated at the nexus of health and motherhood, the phenomenon of online communities for GDM is not dissimilar to a 'mothers' group', which provide opportunities for new parents to build supportive networks, community connectedness and can be vital for mothers who otherwise have a shortfall of social support.(Strange, Fisher, Howat, & Wood, 2014) It is worth noting that social support is not easily definable or measurable from a theoretical point of view, but the findings of the present study underscores how it is a thick concept that can be understood from a variety of perspectives and potentially encompasses both positive and negative aspects.(Hupcey, 1998)

Participants reported the leadership of volunteer administrators promoted a culture of safety and mutual respect; this is important given the group draws together people from a diverse range of backgrounds. Furthermore, a novel finding was the presence of self-appointed informal leadership roles in GDM online communities, with some taken on by those with medical and scientific expertise, while others were taken on by those with lay expertise. With the inclusion of data from four administrators, our study contributes further insights about the formal roles in GDM online communities. In Edwards et al.,(Edwards et al., 2021) the work of administrators was praised but no administrators were interviewed, and in Elton the lack of administrators among interviewees was identified as a shortcoming.(Elton, 2022)

Given the acute nature of GDM, 'A waiting room' was a somewhat unexpected theme, though supported by the fact that 18 out of 28 participants were not pregnant at the time of interview, which indicated a notable level of active participation from women who no longer had GDM. The theme resonated with previous findings from the studies by Edwards et al.(Edwards et al., 2021) and Elton,(Elton, 2022) which found that after the women had been through the experience of GDM, the community 'continued to feature in their lives'. This theme also confirms that Facebook groups do function as virtual communities, which are distinguished by long-term, meaningful conversations among members.(Sundaram, Lin, Choudhury, & Kelliher, 2012) Contrary to the findings of Eades et al,(Eades et al., 2020) several participants in the present study acknowledged the risk of T2DM and had a long-term view of GDM, with the experience leading to feelings of future uncertainty along with a transformed sense of self.

Participants' discussions of feeling stigmatised due to GDM resonate with recent studies exploring GDM stigma, where women reported discrimination from others, including healthcare providers, in addition to internalised stigma.(Davidsen et al., 2022; Davidsen et al., 2023; Sun et al., 2023) In a recent study specifically focused on GDM stigma, Benton et al. found many women discussed how engaging in GDM online communities reduced self-blame, shame and feeling isolated.(Benton, Hotung, Bird, Ismail, & Silverio, 2024) The study findings largely supports the extant literature exploring GDM stigma, and adds a new contribution with exploration of stigma *within* a GDM online community. Although the idea of these groups as safe and supportive spaces was discussed almost universally by participants, there are clearly limits to the safety given the presence of both weight stigma and internalised GDM specific-stigma as well.

As a virtual resource available on demand, needs are met through GDM online communities that are not otherwise possible to address through formal healthcare. It is observable that these online communities reflect the typical lifecycle of GDM experience for most, including successive points of contact with the healthcare system, from diagnosis right through to postpartum testing. As such, one of the unintended consequences of a national membership in an online community was increased visibility of how unstandardised care is for GDM—which participants reported as being inaccessible, inadequate and inconsistent. The broadening of knowledge by consumers has significant implications for the way healthcare is delivered, as greater awareness of shortcomings may have an impact on trust in assigned healthcare providers in local settings.

Implications for policy

Considering the findings discussed in sum, there are significant implications for policy. Online support communities for GDM are invaluable because they are a patient-led innovation and can create a sense of continuity between clinics and the community-at-large. In real terms, they augment the healthcare system and act as a stopgap measure between appointments because of the availability of support at all times. An active national membership is simply not replicable in localised clinical contexts. The patient-led innovation of self-organised online communities for GDM presents an opportunity for healthcare professionals to leverage off patient initiative, by collaborating with existing groups. There are thus compelling reasons for healthcare providers to engage with GDM online support communities on Facebook, but caution is nonetheless required. Policies and procedures need to be regularly updated to keep up with the ever evolving risks involved with being on social media platforms for both individuals and organisations.

Strengths and limitations

The thematic approach used to analyse interview data was a strength of the present study, as the analysis revealed important nuances of women's experiences of GDM in an online community. As a study embedded in a larger mixed methods investigation, codes and themes generated could be cross-checked and reconfirmed with existing data as well as with the research team. Another signficant strength of the study was the use of telephone interviews, which enabled the capture of a data set from across Australia, including women who were either pregnant or caring for newborn babies and other children at home; the shortcomings of telephone interviews, which may come at a cost to the richness of information,(Johnson, Scheitle, & Ecklund, 2019) was balanced against the considerable volume of interviews capturing a wide range of experiences.

A key limitation was that the sample was self-selected. Respondents were more educated than the general population(Australian Bureau of Statistics, 2023) and more than two-thirds were Australian-born. Thus, findings are not necessarily generalisable to other populations, such as more diverse ones within Australia, nor online communities elsewhere though the findings have some resonances with findings from the published studies in the UK. These demographics point to gaps to address in future to ensure a more representative sample. For example, current research suggests a potentially higher at-risk profile for GDM for women who migrate(Kragelund Nielsen, Davidsen, Husted Henriksen, & Andersen, 2023) and from certain ethnicities,(Liu, Lamerato, & Misra, 2020) though the international evidence is inconclusive on these being clear risk factors.

Conclusion

GDM online communities provide community and support, and serve as an adjunct to formal healthcare. In these spaces, women collaboratively navigate the challenges of self-management and healthcare, similar to the way mothers' groups operate. Although such spaces are largely experienced as safe, weight stigma and internalised GDM-specific stigma may be experienced by some. The exchanges in these online communities on Facebook extend beyond the antenatal period into the postpartum phase, as a pregnancy with GDM can lead to a transformed sense of self and heightened awareness of risk, leading to an interest in helping others through the experience.

CRediT authorship contribution statement

Sheila Pham: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Kate Churruca:** Writing – review & editing, Validation, Supervision, Methodology, Formal analysis, Conceptualization. **Louise A. Ellis:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Jeffrey Braithwaite:** Writing – review & editing, Supervision, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix 1

COnsolidated criteria for Reporting Qualitative research (COREQ)

From Tong A, Sainsbury P, Craig J. COnsolidated criteria for Reporting Qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007;19(6):349-57.

COnsolidated criteria for Reporting Qualitative research (COREQ)

No.	Item	Guide questions/descriptions	Reported on page no.
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	p2
2.	Credentials	What were the researcher's credentials?	p2
3.	Occupation	What was their occupation at the time of the study?	p2
P44.	Gender	Was the researcher male or female?	p2
5.	Experience and training	What experience or training did the researcher have?	(Trained in qualitative research in MPH)
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	p2
7.	Participant knowledge of the interviewer	What did the participants know about the researcher?	(Female, lived experience of GDM, PhD candidate)
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	p2
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study?	p2
Participant selection			
10.	Sampling	How were participants selected?	p2
11.	Method of approach	How were participants approached?	p2
12.	Sample size	How many participants were in the study?	p2
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	p2 (Reasons unknown)
Setting			

(*continued on next page*)

(*continued*)

No.	Item	Guide questions/descriptions	Reported on page no.
14.	Setting of data collection	Where was the data collected?	p2
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	p2
16.	Description of sample	What are the important characteristics of the sample?	p2
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	p2
18.	Repeat interviews	Were repeat interviews carried out? If so, how many?	n/a
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	p2
20.	Field notes	Were field notes made during and/or after the interview or focus group?	n/a
21.	Duration	What was the duration of the interviews or focus group?	p2
22.	Data saturation	Was data saturation discussed?	p2
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	n/a
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	p3
25.	Description of the coding tree	Did authors provide a description of the coding tree?	p3
26.	Derivation of themes	Were themes identified in advance or derived from the data?	p3
27.	Software	What software, if applicable, was used to manage the data?	p3
28.	Participant checking	Did participants provide feedback on the findings?	n/a
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified?	p3-6
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	p3-7
31.	Clarity of major themes	Were major themes clearly presented in the findings?	p3-6
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	p3-6

Appendix 2

Interview guide

Healthcare experiences

- When were you diagnosed and how did you feel at the time?
- How did you come to understand what the diagnosis meant for you and the rest of your pregnancy?
- What were some of the challenges for you at the start?
- Did these challenges become easier? If so, how?
- Has having GD changed your perception of yourself and your body?
- What kind of professional healthcare do/did you have?
- What have been the positive aspects of having GD?
- What have been the negative aspects of having GD?

Internet

- What websites do you look at to help you manage GD?
- Does it matter to you what site is giving the advice or who’s giving it?
- How have you found the information provided to you by your healthcare provider(s)?
- Did your healthcare provider(s) discuss GD information on the internet? What did they say? What did you think?

Facebook

- How did you come to join a GD Facebook group?
- Which groups did you end up joining?
- Do you prefer one group over another. If yes, why?
- What do you like about the GD Facebook group? What don’t you like?
- How do you primarily use the GD Facebook group?
- If you post, what do you post? If you don’t post, why not?
- What do you find most helpful about the group?
- What sort of interactions do you have with the other women?
- Do you feel a sense of belonging to the group?
- How does the support you get from the GD Facebook group compare with the support you get from healthcare professionals?
- What have you learned from a GD Facebook group that you would not have known about otherwise?
- Is there anything you have learned from being in a GD Facebook group that you discussed with your healthcare providers?
- Is there anything you could not discuss?
- What’s an example of how a post, yours or someone else’s, ended up having an impact on you?
- How did it change the way you manage GDM?
- Did you talk to a healthcare professional about it? If not, why not?

- ASK IF CURRENTLY PREGNANT: Do you think you'll continue to be part of the group after you've had your baby? Why?
- ASK IF NOT CURRENTLY PREGNANT: Why do you continue to be part of the group now?
- Do you have any concerns for the future now that you've had GD? If so, what are they?

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