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Gestational diabetes mellitus follow-up in Norwegian primary health care: a qualitative study

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Short title: Gestational diabetes mellitus follow-up

Abstract

Background: Women with gestational diabetes mellitus (GDM) have a tenfold increased risk of developing diabetes, and a high risk of recurrent GDM. Endorsing the life-course approach aiming to prevent disease and promote health across generations, the Norwegian GDM guideline recommends follow-up in primary care after delivery, with information on the increased risks, lifestyle counselling and annual diabetes screening. Few reports exist on Norwegian women's experience of GDM follow-up.

Aim: To elucidate women's experiences with follow-up of GDM in pregnancy and after delivery, and to explore their attitudes to diabetes risk and motivation for lifestyle changes.

Design and setting: Qualitative study in primary care in the region of Stavanger, Norway.

Method: Semi-structured in-depth interviews were conducted 24–30 months after delivery with 14 women aged 28–44 years, with a history of GDM. Data were analysed thematically.

Results: Most women were satisfied with the follow-up during pregnancy, however, only two women were followed-up according to the guideline after delivery. In most encounters with general practitioners after delivery, GDM was not mentioned. To proceed the healthy lifestyle adopted in pregnancy, awareness of future risk was a motivational factor, but the women ask for tailored information on individual risk and improved support. *Uncertainty, stigma and shame, gaining control and finding balance and a need for support to sustain change* were the main themes emerging from the analysis.

Conclusion Women experienced scarce support for GDM in Norwegian primary care after delivery. To maintain the healthy lifestyle, women suggest tailored information and improved support.

Keywords gestational diabetes, qualitative research, primary health care, health promotion

How this fits in

Despite being at high risk, most women with GDM experience scarce follow-up after delivery. In Norway, a continuity of care is ensured by the GPs being responsible for follow-up before, during and after pregnancy, as implemented in a new national guideline. However, in our study, most women experienced a lack of follow-up until 30 months after delivery. Uncertainty, stigma and shame were among the feelings associated with GDM, and the mothers ask for improved support to sustain change and maintain the healthy lifestyle adopted in pregnancy.

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Introduction

Hyperglycemia, affecting one in six live births worldwide, is a common medical complication in pregnancy and should be classified as either diabetes mellitus in pregnancy (DIP) or gestational diabetes mellitus (GDM) (1). In Norway, the prevalence of GDM is now around 6%, after a threefold increase over the last decade (2). Among immigrant women, the prevalence of GDM is higher than in Norwegian women, and the risk of GDM increases with years of residence (3).

GDM is associated with adverse maternal-fetal outcome in the short and long term (4). Women with prior GDM have a tenfold increased risk of being diagnosed with type 2 diabetes mellitus (T2DM) later on (5), and within 15 years postpartum, a third of women with GDM have been diagnosed with T2DM (6). Moreover, the recurrence rate of GDM is high. In a recent Scandinavian study, the overall recurrence risk of GDM in the second pregnancy was 39% (7). As lifestyle intervention reduces the risk of both recurrent GDM and future T2DM, the interconception period is considered as a window of opportunity to improve current and future health of mothers and children (8).

International guidelines seem to agree on recommending long-term follow-up of women with prior GDM, although the specific tests and schedules vary between countries (9). In 2017, a Norwegian GDM guideline was implemented (10), implying that follow-up of women with GDM should be done by general practitioners (GPs) in primary care whereas women with poor glycemic control should be referred to specialist health care. The guideline recommends measurement of HbA1c at 4 months after birth, then annually. Moreover, the GPs should give tailored information about future diabetes risk and offer lifestyle counselling. Most Norwegian citizens are registered with an individual GP, and maternity care is free of charge.

In Norway, introduction of the guideline led to a long lasting debate about cost-benefit, medicalization and in particular, the lack of evidence supporting widespread GDM screening (11).

Despite diverse guidelines and evidence supporting the effectiveness of early detection of T2DM, long time follow-up of women with a history of GDM appears challenging worldwide (12, 13). In England, annual rates of long-term follow-up stayed consistently around 20% (14), whereas in the US, rates up to 54% are reported (15). Although having a national gestational diabetes mellitus register sending reminders to both mothers and GPs, the Australian screening rates at six week postpartum ranged from 43% to 58%, and the annual screening rates were even lower (16). In a recent Danish study, women experienced limited initiative from their health care providers in supporting them to engage in a healthy lifestyle postpartum (17).

The life-course approach aiming to prevent non-communicable diseases (NCD) as diabetes and promote health across generations, emphasizes pregnancy as an important transition period where there might be unique opportunities to make a positive shift in the trajectory of a generation (18, 19). Recently, the urgent need to focus on maternal health to prevent NCDs, was outlined in a global statement by the International Federation of Gynecology and Obstetrics (FIGO). The importance of preconception counselling, antenatal and postpartum care was underlined (20).

To our knowledge, no studies has explored how Norwegian women experience the short and long-term follow-up of GDM following implementation of the Norwegian guideline. Hence, the aims of this study were to elucidate women's experiences of GDM follow-up, both in pregnancy and until 30 months after childbirth, and to explore thoughts of future diabetes risk and motivation for lifestyle changes.

Method

Study setting

In 2017–2018, 147 nulliparous women >25 years with singleton pregnancies participated in a cross-sectional study at Stavanger University Hospital, Norway. The women had a 75 gram oral glucose tolerance test (OGTT) in pregnancy week 24–28, diagnosing 21 (14%) of them with GDM. They were informed about the diagnosis, and advised to contact their GP for further follow-up. All women diagnosed with GDM attended a 3-hour workshop, and were offered an ultrasound examination in pregnancy week 36. According to the Norwegian guideline, women were followed-up in primary care and were referred to secondary health care if glycemic control was not achieved.

The current qualitative study was conducted in 2020 and included 14 of the 21 women diagnosed with GDM in the cross-sectional study.

Sampling and recruitment

Into the qualitative study, we included all the Norwegian-speaking women, resulting in an eligible study population of 18 women with a history of GDM. To achieve a maximum variety sampling, we invited all 18 women. Information letters describing the aims and method of the study, as well as an informed consent form, were sent in September and October 2020. Women who did not reply within a couple of weeks got a reminder on SMS. Those consenting to participate signed the informed consent and an appointment for interview was made within two weeks. Participants could choose between telephone- and face-to-face interviews, and they could choose time and place. Probably due to the Covid-19 pandemic, they all preferred telephone-interviews. A flow-chart of the study population is presented in Figure 1.

Data collection

Data were collected using a semi-structured interview guide to explore women's experiences of the GDM follow-up in pregnancy and after delivery. The interview guide (supplementary

data, S1) consisted of open-ended questions about follow-up, understanding of, and attitude to future diabetes risk and motivation for lifestyle changes. All interviews were conducted, digitally audio-recorded and transcribed verbatim by the first author in October 2020, resulting in 99 pages (50 059 words). Each transcript was anonymized and compared with the complete original audio-recording to ensure reliability. The interviews lasted between 19 and 41 minutes with an average of 30 minutes. All participants received a 50 EUR gift card to acknowledge our gratitude.

Data analysis

A thematic analysis inspired by Braun and Clarke was conducted on the entire data set (21). An inductive approach was used, where two authors individually read all transcripts several times to gain deeper insight of the material (22). Meaningful text relevant to the research questions were highlighted and discussed. Transcripts were then coded line-by-line by the first author. Accordingly, 205 codes were consecutively sorted into the following four categories which had been settled in the interview topic guide: experience of being diagnosed with GDM, follow-up, motivation and future diabetes risk. Next, we collated the codes into broader overarching themes representing repeated patterns across the data set. Through thorough team discussions, a common understanding of the themes was developed. Then a revision and refining of the themes checking their relation to the coded extracts were performed by the first author. Finally, after agreement among all authors, an overall interpretation was developed.

Data saturation was achieved during the last two interviews, indicating that no new knowledge relevant to the research questions was obtained. Examples of the analysis from transcript to themes are provided in Table 1. This study is reported in accordance with the Standards for Reporting Qualitative Research (SRQR) (23), a standard highlighted by the EQUATOR network (24).

Results

Demographics

In total, 14 women were included. The majority had Scandinavian background and almost half had a family history of diabetes. Five women had given birth again, one of these had been diagnosed with recurrent GDM, whereas three women were pregnant. None of the participants had been diagnosed with T2DM. Characteristics of the study population are presented in Table 2.

Main themes

Following the thematic analysis, four main themes emerged: 'stigma and shame', 'uncertainty', 'gaining control and finding balance' and 'a need for support to sustain change'. The themes are elaborated in more detail below.

Stigma and shame

The majority reported that the GDM diagnosis was surprising, as they did not consider themselves to be at risk. Many described initial feelings of shock, embarrassment and shame. Some women with obesity and/or family history of diabetes stated that getting GDM was somewhat expected, although it felt tough. Most of the participants associated the diagnosis with unhealthy dietary habits, leading to self-blame for putting the fetus at risk.

I felt it was hard, what to say, am I that unhealthy? I did not think so. I actually felt ashamed. Are my eating habits so bad? I felt as a bad mother. (participant 9)

Several of the participants described situations where they got hurtful comments from others regarding what they ate. The diabetic management made the diagnosis visible to others, and women measured blood glucose in discrete to avoid questions. One of the participants on insulin therapy stated that the feeling of shame increased when she 'could not control' her blood

glucose without insulin, and the multiple injections throughout the day made the diagnosis even more visible to colleagues.

The majority reported a lack of knowledge about GDM. Together with concern for the fetus, this led to anxiety and a call for updated knowledge. Several participants reported difficulties finding reliable information and appreciated the counselling they got from health personnel. Some of them stated that getting GDM would have been less stigmatic if they had been told about various risk factors for developing GDM, such as family history. Among the participants with non-Scandinavian background, a common finding was that the feeling of stigma associated with GDM predominantly was related to their ethnicity, resulting in less self-blame at the individual level. Additionally, for some of these immigrant women, this impaired their motivation for lifestyle changes after birth, as they thought they would develop T2DM anyhow. In contrast, the Scandinavian women associated the diagnosis with unhealthy lifestyle, causing more self-blame at the personal level.

I know I will get diabetes in the future anyway. All in my family do. (participant 3)

Despite the emotional distress following the diagnosis, concerns for the fetus and wishing to avoid a macrosomic baby seemed to be main motivational factors for lifestyle changes during pregnancy. Other motives were a desire to avoid insulin therapy or induction of labour, or being allowed to stay at the hospital's low-risk unit.

A combination of pressure and fear gave me my motivation. I did it for my own health, but of course, also for my baby's health. (participant 5)

Uncertainty

The initial response to the diagnosis was anxiety, partly due to lack of knowledge and unpredictable implications for the pregnancy. Others became more conscious throughout the pregnancy and after delivery as they learned more about the increased risks. However,

uncertainty affected women's reactions to the diagnosis, expectations of follow-up, and influenced their thoughts of maternal-fetal risk.

During pregnancy I had control because I measured my blood sugar, I knew everything about what to eat and how different food would affect my values. But after pregnancy, I have no idea, how much will it take to develop diabetes in the future? (participant 6)

Whether they actually had GDM was another aspect of uncertainty raised by several participants, as their self-glucose monitorings were within target range, or because of threshold glucose value on the OGTT. Others had become aware of the discussion in the media about the guideline, as well the lack of consensus in GDM-diagnostic criteria among countries. For women experiencing scarce informational and emotional support, the sense of uncertainty became more manifest.

Overall, women's glycemic control was very good with most values within target range. Nevertheless, induction of labor was decided for one woman because of macrosomia, whereas others were frequently checked due to fetal growth restriction, perturbing their understanding of strict glycemic control as the most important factor to avoid complications. One woman could not understand why she needed insulin 'to avoid a macrosomic baby' as her child were small for gestational age.

At least, I did not get any explanation why these insulin injections would do anything good for my baby being too small. How insulin would help her, I never got an answer.

It was very frustrating taking these injections. (participant 3)

Although most women presumed being diagnosed with GDM in their next pregnancy, a few stated that not getting the diagnosis again, felt illogical as they now had a less healthy diet and were more inactive. Moreover, they had not regained pre-pregnancy weight before the second pregnancy.

Gaining control and finding balance

Gaining control was a dominant and ongoing theme, involving dietary planning, meals, blood glucose measurements and clinical follow-ups including ultrasound examinations. Most women reported that self-management such as incorporating blood glucose measurements in daily life, planning diet and activity were most challenging; though achieving glycemic control also gave mastery and stress relief. However, for several women the burdens of treatment were overwhelming, and two participants described the feeling of having an eating disorder. Others felt obsessed with having a well-controlled diet, with the 'numbers' and their blood glucose management took all their time:

I got very upset with the blood sugar measurements. Exercise, eat and measure. I was obsessed, the measurements should all be good. I talked to my GP about it, and I understood that it could be a big problem for those being too obsessed with this.

(participant 12)

Some weeks after the GDM-diagnosis, many participants realized that finding the right balance in measurements and diet, became most important. Others emphasized the emotional support from health personnel to be reassuring.

I suddenly realized my life was all about nutrition and table of contents. I got very cautious and strict. I had to remind myself of common sense. (participant 14)

A need for support to sustain change

Overall, most women contrasted their scarce follow-up after birth with the health care they received for GDM during pregnancy. Most of them stated that the GP did not address the topic of GDM in the encounters after pregnancy. The sense of lack of interest felt like an abandonment, as several requested a need to discuss tailored information regarding their personal risk. Only two women experienced that their GP encouraged them to maintain a

healthy lifestyle after pregnancy and had received information about diabetes risk and/or the importance of controlling weight.

It has been no talk about GDM. I think when the diagnosis caused all that stress during pregnancy, I was surprised that it has not been mentioned nor followed-up after delivery. I could of course have done more myself, but you know, everyday life continues. (participant 14)

Although to a varying degree, most women were aware of the increased diabetes risk and reported that this continuously influenced their lifestyle. The majority were concerned, and thought of this as a motivator to regain pre-pregnancy weight and maintain a healthy lifestyle for themselves and their family. However, more than half of the participants had gained weight.

When I got the diagnosis, I read about the increased diabetes risk, but I am not that worried because I think my food habits are OK and I do exercise, however; by all means, I do think about it and I am aware. (participant 17)

Several participants continued to measure blood glucose sporadically after delivery and in the next pregnancy, just to be aware. A few ignored the risks, or thought that their individual risk was low due to good glycemetic control, a healthy diet and/or a normal BMI.

Nine out of 14 women had measured HbA1c one or more times after their first pregnancy, and all but one stated that this was self-initiated, mostly done when visiting their GP for other reasons. Some reported they were not aware of the recommendation to measure HbA1c, others had forgotten.

There were different opinions among the participants about the preferred time to receive information about diabetes risk; some wanted all information during pregnancy, whereas others stated that the burden of disease and treatment was enough. Moreover, they assumed they would be more receptive after delivery, and several women suggested a GP consultation including HbA1c as part of their maternity care 4–6 months postpartum.

A comprehensive understanding of the four main themes described, could be included in two broader overarching themes. The first is women's internal emotions relating to the GDM diagnosis, and the second is the experiences of contrasting follow-up (during and after pregnancy) affecting women's health seeking behavior to mitigate future risk. The relation between the overarching themes and the main themes along the time course, is illustrated in Figure 2, whereas findings of women's experiences of GDM follow-up and attitudes to future diabetes risk are summarized in Table 3.

Discussion

Summary

This study explored women's experience of GDM follow-up and attitudes to future risk in Western Norway. Our findings indicated that the majority had a positive experience of health care during pregnancy, while most participants stated that they received scarce or no support for GDM after delivery. Women's worries about her own and the baby's health were the major motivational factors for lifestyle changes in pregnancy, and all but one woman, noted that their GDM experience would promote a healthy lifestyle in future pregnancies. The majority were aware of being at risk of diabetes and considered this as a motivation to proceed the healthy lifestyle promoting weight loss after delivery. However, more than half had gained weight. Uncertainty, stigma and shame were among the feelings associated with GDM, and the women ask for improved support to sustain change and maintain the healthy lifestyle.

Strengths and limitations

This qualitative study has several strengths. First, our participants represents the pregnant population with different ages, various pre-pregnancy BMI, living in both rural and urban parts

of our region having their follow-up from different GPs. Although, the majority were ethnic Norwegians, four women had other ethnic background. Second, all participants spoke Norwegian fluently, they spoke freely and gave vivid descriptions of their experiences during the interviews. Third, all interviews were conducted by an experienced resident working at a university hospital's outpatient clinic for women with complicated pregnancies, who also performed the cross-sectional study from which the participants were recruited. This background likely improved the quality of the data. Finally, trustworthiness was ensured by involving all authors in the data analysis, a team experienced with qualitative studies and thematic analysis (25, 26).

One limitation is that the participants were interviewed 24–30 months after delivery. This might have caused recall bias on participants' experiences. On the other side, eight of the women were pregnant or had given birth again, giving an opportunity to elucidate their follow-up in the second pregnancy. A semi-structured interview approach was chosen to get a comprehensive understanding of our research questions. This approach is suitable when addressing sensitive topics. All the interviews were conducted by phone as preferred by the participants. A limitation with telephone-interviews is the miss of facial expressions; however, this does not necessarily influence findings (27). Due to participation in our previous study, we had detailed information on their first pregnancy, including background, blood test results and maternal-fetal outcome. However, as with other qualitative studies, our present findings rely on self-report, and social desirability bias may have influenced the answers. Finally, the majority of the participants had a master's or bachelor's degree, thus, the findings may not be applicable to other socio-economic groups.

Comparison with existing literature

Although the well-documented elevated diabetes risk among women with a history of GDM (5) and the growing evidence that lifestyle intervention and metformin effectively reduce the long-term risk (28), still, follow-up after delivery appears challenging worldwide (13, 14, 29-31). In our study, most participants reported that GDM had not been a topic in the encounters with their GPs after delivery, contrary to the recommendations (10). As we did not investigate the GPs experiences of GDM care, our findings rely on women's reports only. In a recent review, women being lost to follow-up and lack of communication between health care personnel are barriers mentioned by the providers (12). The Norwegian model of care with the GPs being responsible for follow-up before, during and after pregnancy could facilitate a continuity of care for these high-risk women. However, to improve perceived care, women suggest a consultation 4–6 months after birth including HbA1c, lifestyle counselling and individualized risk assessment, which is according to the current guideline (10).

The women in our study got the GDM-diagnosis 9-15 months after publication of the guideline. It is well known that guideline implementation and adherence, might take several years to fulfill (32). However, we observed no difference between women's satisfaction of follow-up between the start and the end of the study period.

A gap in the quality between recommended and actual care is well-documented, also for patients diagnosed with T2DM (33). In Norwegian general practice, major gaps in complication screening among diabetes patients are shown (34), and a recent study found large variations in GPs performance of care with patient reminders being one factor associated with better performance (35).

The Norwegian GDM guideline seems to align with international guidelines in taking the life-course approach. However, regarding GDM, our findings may indicate that some GPs still work within the acute-care paradigm (36). To succeed with the life-course perspective, a shift in priorities is required. The health care systems have traditionally focused on short-term

fixes and acute health care. Thus, involvement of policymakers and stakeholders is necessary (37). Unfortunately, as observed in other developed countries, Norwegian general practice faces several challenges including growing workload and pressures on funding (38).

The burden of treatment is described as the workload of health care and its effect on patient functioning and wellbeing (39). In accordance with others (40), also most participants in our study reported that the burden of GDM was high and medicalization of pregnancy was apparent. Data analysis revealed ‘uncertainty’ as one of the main themes affecting women’s reactions to the diagnosis, expectations of follow-up, and their attitudes to the increased risk. A recent review evaluating factors affecting uncertainty in high-risk pregnancies concluded that personal, pregnancy-related, demographic and health care related factors were involved (41). Uncertainty was associated with less support and lack of information, and closely tied to appraisal of maternal-fetal risk, as also found in our study. Others have reported that uncertainty also affects coping strategies in high risk pregnant women, and that high levels of uncertainty are associated with emotion-focused rather than problem-focused coping (42).

The theme ‘gaining control and finding balance’ resonates with others describing the process of being diagnosed and living with GDM, as a process from stunned to gradual balance (43). In a British study, the initial concerns after being diagnosed, eased as the women learned how they could control and manage GDM (44).

A finding contributing to the burden of disease observed in our study was women’s awareness of risk and then the following experience of scarce follow-up and that they had to request the HbA1c tests themselves. Maybe the motivation for maintaining a healthy lifestyle disappear as the window of opportunity closes? In a recent Scottish study, a lack of aftercare and the need to arrange postnatal testing themselves led some women to question how serious the increased diabetes risk was (44).

Implications for research and practice

To reduce the risk of T2DM among women with previous GDM, effective behavioral change interventions are crucial to make these women sustain change and maintain the healthy lifestyle (45). A key to successful behavioral change, is patient empowerment where ongoing support help patients being responsible for their own health (46). In patient empowerment, health professionals' role is to encourage patients to make informed decisions in order to achieve their goals, and providers need practice in ways to support patients to become effective self-managers.

In England, brief, low-cost healthy conversation skills training of midwives and nurses in a primary care setting was appreciated and made many women set goals for behavioral change (47). This is in line with FIGO's vision 'making the best of every contact' with women in the reproductive age group. The FIGO nutrition checklist is another tool for clinicians (48). It is approved to be acceptable in routine care, helping to flag up nutritional at-risk-women. Future studies should explore how this could be implemented in a Scandinavian health care setting.

Additional information

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Ethical Approval

The Regional Committees for Medical and Health Research Ethics (REC) South-Eastern Norway approved the study; reference number 2017/771, date of approval 31 may 2017. An approval for a project amendment including the qualitative study was given by The Regional Committees for Medical and Health Research Ethics (REC) South-Eastern Norway 25 may 2020, reference number 8402. The cross-sectional study, from which the participants in the current qualitative study were recruited, was registered in Clinical Trials with identifier NCT03372824.

Competing interests

We declare no competing interests.

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Figure legends

Figure 1. Flow chart of the study population

Figure 2. Relation between overarching themes and main themes along the time course.

Supplementary data

Interview-guide (S1) is uploaded as a separate file

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Table 1. Example from the data analysis of transforming transcripts to codes and themes.

Transcript	Code	Theme
After the initial shock, my stress level decreased. I had to do what was possible, no panic of missing one measurement.	Shock getting GDM, stress level decreased gradually.	Gaining control and finding balance
Suddenly, gestational diabetes was very serious. Had my GP and I been too laid-back?	Adequate self-management and follow-up?	Uncertainty
I was frightened, how could gestational diabetes affect my baby's health?	Frightened, worried about the baby.	Uncertainty

GDM; gestational diabetes mellitus, GP; general practitioner

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Table 3. Study participants experiences of GDM follow-up, weight development and attitudes to future diabetes risk (n=14)

	Count (%)
Follow-up in pregnancy	
Good	8 (57%)
Middle	3 (21%)
Not good	3 (21%)
Follow-up after pregnancy	
Good	2 (14%)
Middle	2 (14%)
Not good	10 (71%)
HbA1c measurement after pregnancy	
Participant's initiative	8 (57%)
General practitioner's initiative	1 (7%)
Not measured	5 (36%)
Weight development after pregnancy	
Weight gain ^a	8 (57%)
Weight loss ^a	6 (43%)
The experience with GDM will affect lifestyle and diet in next pregnancy	
Yes	13 (93%)
No	1 (7%)
Aware of/thinking about future diabetes risk	
Yes	12 (86%)
No	2 (14%)

GDM; gestational diabetes mellitus, ^acompared with pre-pregnancy weight in first pregnancy

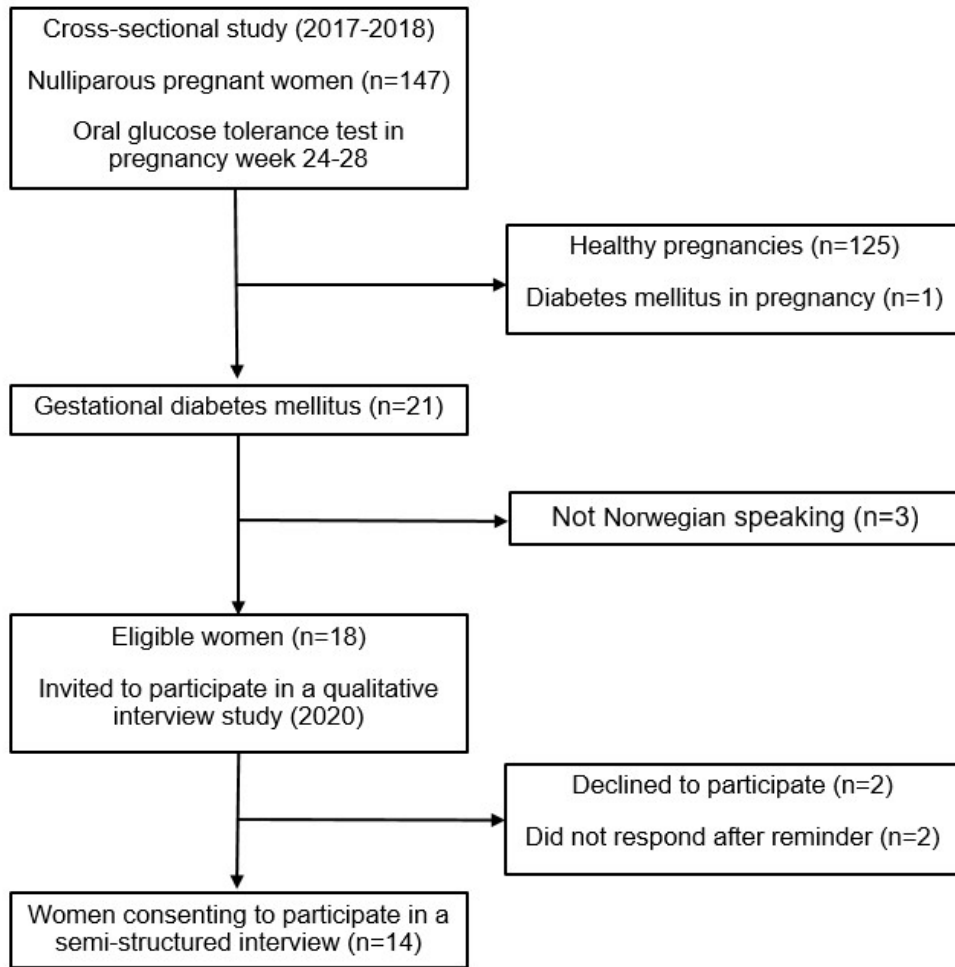


Figure 1. Flow chart of the study population

173x171mm (96 x 96 DPI)

Table 2. Characteristics of the study population (n=14)

	Mean (range)	Count (%)
Age (years)	33.7 (28-44)	
Ethnic background		
Scandinavian		11 (79%)
Mediterranean/Middle Eastern		3 (21%)
Educational level		
Master's degree		7 (50%)
Bachelor's degree		4 (29%)
Student		3 (21%)
First-degree relative with diabetes mellitus		6 (43%)
Pre-pregnancy BMI (kg/m ²) ^a	25.4 (20-36)	
Weight-gain in pregnancy until OGTT (kg) ^a	10.0 (3-18)	
Insulin-use in pregnancy ^a		2 (14%)
Interview time-point ^b	27.4 (24-30)	

BMI: body mass index, OGTT: oral glucose tolerance test; ^ain first pregnancy,

^bmonths after birth

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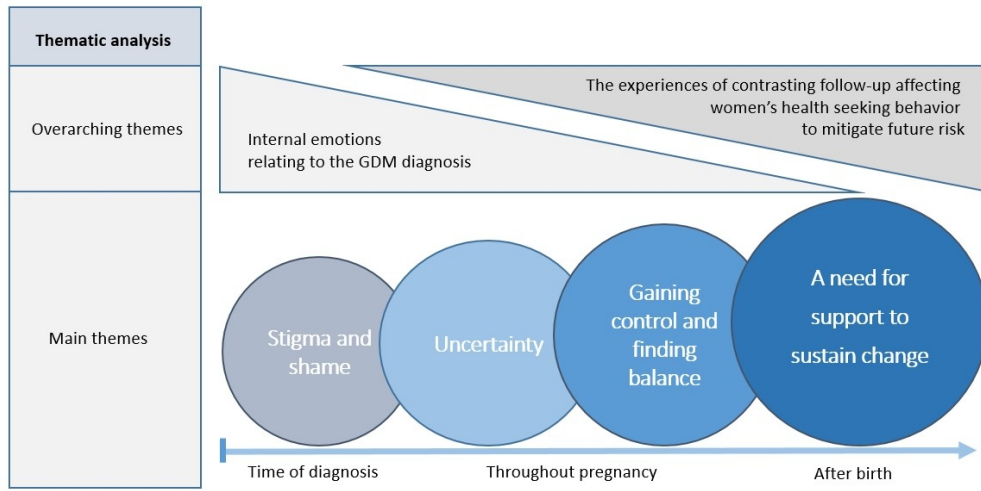


Figure 2. Relation between overarching themes and main themes along the time course.

306x154mm (96 x 96 DPI)