Is self-management a burden? What are the experiences of women self-managing chronic conditions during pregnancy? A systematic review

Bethany Ellen Jakubowski, Lisa Hinton, Jaspreet Khaira, Nia Roberts, Richard J McManus, Katherine Louise Tucker

ABSTRACT

Objective This systematic review examines the qualitative literature on women’s experiences of self-managing chronic conditions in pregnancy.

Design Systematic review of qualitative literature. Searches were performed in PubMed and CINAHL from inception to February 2021. Critical interpretive synthesis informed the coding framework and the analysis of the data. The Burden of Treatment theory emerged during the initial analysis as having the most synergy with the included literature, themes were refined to consider key concepts from this theory.

Participants Pregnant women who are self-managing a chronic condition.

Results A total of 2695 articles were screened and 25 were reviewed in detail. All 16 included studies concerned diabetes self-management in pregnancy. Common themes coalesced around motivations for, and barriers to, self-management. Women self-managed primarily for the health of their baby. Barriers identified were anxiety, lack of understanding and a lack of support from families and healthcare professionals.

Conclusions Pregnant women have different motivating factors for self-management than the general population and further research on a range of self-management of chronic conditions in pregnancy is needed.

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INTRODUCTION

Chronic diseases that manifest during pregnancy, or exist pre-pregnancy, can have a lasting impact on the health of the mother. Numerous conditions can affect women during pregnancy, some confined to that time (eg, pre-eclampsia or gestational diabetes) and others that are longer lasting (chronic hypertension and diabetes). These conditions may lead to harm for both the mother and the baby; hypertensive disorders, for example, are one of the leading causes of maternal mortality globally.

SELF-MANAGEMENT

Self-management has been shown to support and improve the management of chronic conditions in the general population and there is a growing body of research to suggest self-management of chronic conditions in the pregnant population is also effective. Self-management interventions in pregnancy tend to focus on self-monitoring (blood pressure, blood glucose, etc) and in some cases titrating medication (insulin). Self-management following a hypertensive pregnancy has been explored post-partum, the evidence to date suggests not only is it feasible, but it may result in better diastolic blood pressure control at 6 months post partum. In the antenatal period, the OPTIMUM-BP (Optimising Titration and and Monitoring of Maternal Blood Pressure) pilot trial suggested that self-monitoring of blood pressure was both feasible and acceptable to women with chronic hypertension. Self-management of diabetes in pregnancy has also been explored. In pregnant women...
with type 1 and type 2 diabetes, self-monitoring of blood glucose is common and self-management programmes in women with gestational diabetes are also becoming more commonplace. In the general population, self-management has been explored in numerous chronic conditions; in particular hypertension and diabetes, where there is a large body of research around understanding the patient experience. Much of this research has demonstrated patient’s confidence and ability to self-manage (sometimes referred to as self-efficacy) and suggests that self-management strategies improve health outcomes for those with chronic conditions. These conditions also affect women during pregnancy, but thus far this population is under-represented in this field of research. Moreover, research on self-management in the general population may not be wholly applicable to the pregnant population. Pregnancy presents an additional set of motivations for self-management, not accounted for in current self-management frameworks which often assume long-term self-management, whereas with pregnancy the period of management is often temporarily bounded even if it continues post partum and considerations are for the mother and baby dyad.

METHODS
This review was influenced by the critical interpretive synthesis (CIS) approach. A CIS approach leaves more space for interpretation than a conventional systematic review and in theory using this approach allowed us more space to consider lived experiences across a range of chronic conditions. This approach also allowed us to iteratively develop the research question and the inclusion criteria as the search progressed and the lack of research on the self-management of chronic conditions in pregnancy became apparent. In light of a lack of data, it was necessary to limit the scope of the review to the following research question: ‘what are the current behaviours and attitudes among pregnant women regarding the self-management and self-monitoring of chronic conditions in pregnancy?’ (see online supplemental appendix 1).

Searches were performed in PubMed and CINAHL (EBSCOHost) (1982–present) from inception to February 2021 (see online supplemental appendix 2).

Potentially eligible studies were screened by two independent reviewers against the following inclusion criteria: 1. Chronic condition: including but not exclusively diabetes (gestational or chronic), hypertension (gestational or chronic), obesity, kidney disease. 2. Pregnancy. 3. Self-management: including but not exclusively self-monitoring, self-weighing, self-care. 4. Qualitative methods.

This review used a broad definition of self-management, ‘the ability of an individual, in conjunction with family, community and healthcare professionals, to manage symptoms, treatments and lifestyle changes.’ We expanded the search criteria retrospectively to include risk factors for chronic conditions, in order to capture as much data as possible. The authors felt that qualitative literature was best placed to explore the lived experiences of people self-managing during pregnancy. Papers were excluded if the reviewers concluded that commonly recognised qualitative methods were not used, that is, interviews, focus groups, or ethnographic observations.

Two reviewers (BEJ and JK) independently reviewed the titles and abstracts of identified articles, a full-text assessment of the relevant papers by both reviewers followed. The reference lists of included studies were screened but found no further articles to include. Disagreements on articles were resolved by consensus or discussion with a third reviewer (KLT). Data extraction was conducted by BEJ and checked by the study team.

Data analysis
CIS also informed the analysis of the data. Analysis began with a detailed examination of the included papers, identifying themes and developing an understanding of the material. Dixon-Woods et al emphasise what distinguishes a systematic review using a CIS approach is ‘the aim of being critical’ and questioning ‘taken-for-granted- assumptions’ meaning that the coding framework for this review was developed to critique the idea that general population self-management research was applicable to pregnancy. During the initial analysis, elements of the Burden of Treatment theory, developed for chronic condition management in the general population, were identified in the included literature. The coding framework was revised considering this theory’s key concepts, such as the effect of patient work (eg, self-monitoring, self-management, lifestyle changes) on self-management efficacy and the role of support networks, allowing for a more nuanced interpretation of the woman’s experience of self-management. Data extraction was conducted by BEJ using NVivo V.12 Pro (QSR International Pty Ltd, released 2018), and a coding framework was developed by BEJ and agreed on by the study team (LH, KLT and RJM).

The burden of treatment
May et al have developed a theory explaining the relationship between ‘sick people’ and their healthcare providers in the context of chronic disease. In the absence of a possible cure, patients must engage in ‘routine work’ to manage the disease. May et al explain that patient work in the context of the Burden of Treatment theory includes symptom monitoring, treatment management and lifestyle changes while ‘maintaining (these tasks) alongside the demands of other aspects of everyday life’. Transferring the burden of treatment to the patient prompts a change in the patient-clinician relationship. Within pregnancy this could theoretically provide women with more agency, as well as more responsibility.

The first interpretation of the data, reviewing the themes that already existed in the included papers, revealed the synergy with the Burden of Treatment theory; therefore,
the coding framework was iteratively mapped to two broad themes reflecting elements of the burden of treatment. These themes were grouped around motivations for self-management and barriers to self-management. As the coding progressed, more elements of the theory were incorporated into the analysis. One element of the theory is ‘the structure and performance of patient work’; a process that May et al call ‘sense making’ where ‘people and members of their social networks are expected to identify, understand and explain the diverse tasks that make up their work’. This idea was reflected in the themes concerning support from healthcare professionals and family, the impact of a lack of support, and women’s anxiety and understanding of their diagnosis.

**RESULTS**

Searches in PubMed and CINAHL identified 2745 articles, which when controlled for duplicates left 2695 for screening (see online supplemental appendix 2 and figure 1 for further details. The majority of articles were excluded as they did not include qualitative research or self-management, or the study population was not pregnant women. 25 articles were identified by the two reviewers for full-text review, of which 16 fulfilled the inclusion criteria (see table 1). Data quality checks using the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were carried out (see online supplemental appendix 3). Fifteen of the included studies were of medium to high quality. One was considered low quality because of the small sample size. Included studies were published between 2011 and 2020 and all focused on diabetes in pregnancy. Six were conducted in the USA, four in Australia and the remaining studies were carried out in Canada, Spain, Thailand, China, Singapore and New Zealand. The studies recruited from a range of settings: gestational diabetes clinics, antenatal clinics supporting low-income women, healthcare provider’s offices, day care centres and hospital based obstetric clinics. Fifteen of the studies used one-to-one interviews and one used focus groups for primary data collection. Two studies supplemented the interviews with focus groups, one supplemented with additional diary entries. One study was a mixed-methods study, including one-to-one interviews alongside survey data. The study population for all included studies was pregnant women, although one study had a mixed population of women who were currently pregnant, women planning on getting pregnant, and women who had previously been pregnant. Only papers concerning diabetes self-management in pregnancy fulfilled the inclusion criteria, leading to the results focusing on the challenges of self-management in this disease.

The two broad themes that emerged from the data were motivations for and, conversely, barriers to self-management during pregnancy (see table 2). Under the former, women express that having a healthy baby, supportive families and supportive healthcare professionals were their primary motivating factors. Barriers to self-management included a lack of knowledge and understanding of the condition lead to feelings of anxiety, as well as a lack of support from families and healthcare professionals. The following sections will address each subtheme in detail.

**Motivations for self-management**

**Desire for a healthy baby**

The most significant motivating factor for self-management was the desire for a healthy baby. Pregnancy comes with specific concerns and anxieties, women felt anxious over the burden of self-management and the health of their baby. It was clear that many women wanted to ‘do the right thing by the baby’ to ensure they had a healthy start in life. Women expressed fear about the potential to pass their ill health onto the baby. Most often, the initial response to their diagnosis was concern for the baby; ‘oh my God…you know is the baby gonna be OK?’. Some women expressed feelings of responsibility for their condition, and their desire to minimise the effect on their baby’s health; ‘I knew I had brought it on myself by being overweight…I felt very responsible’.

**Supportive environment: family**

When the familial support was positive, women were motivated to self-manage for reasons beyond the health of the baby: ‘The biggest thing I can recommend is getting support. If you try to do it on your own, it’s going to seem very confusing and tedious’. When speaking about her partner one woman said ‘he was very supportive in helping

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of study search strategy.
### Table 1  Characteristics of included studies

<table>
<thead>
<tr>
<th>Title</th>
<th>Year</th>
<th>Authors</th>
<th>Chronic condition</th>
<th>Journal</th>
<th>Sample size</th>
<th>Setting</th>
<th>Qualitative method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with gestational diabetes in a rural community</td>
<td>2014</td>
<td>Abraham and Wilk</td>
<td>Diabetes</td>
<td>The American Journal of Maternal and Child Nursing</td>
<td>10</td>
<td>USA</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>Women’s experiences of gestational diabetes self-management: A qualitative study</td>
<td>2013</td>
<td>Carolan¹⁸</td>
<td>Diabetes</td>
<td>Midwifery</td>
<td>15</td>
<td>Australia Diabetes clinic</td>
<td>One on one interviews, focus group</td>
</tr>
<tr>
<td>Women’s experiences of factors that facilitate or inhibit gestational diabetes self-management</td>
<td>2012</td>
<td>Carolan et al²⁰</td>
<td>Diabetes</td>
<td>BMC Pregnancy and Childbirth</td>
<td>15</td>
<td>Australia Diabetes clinic</td>
<td>One on one interviews, focus group</td>
</tr>
<tr>
<td>Experiences, perceptions and self-management of gestational diabetes in a group of overweight multiparous women</td>
<td>2014</td>
<td>Chavez-Courtois et al²⁹</td>
<td>Diabetes</td>
<td>Cien Saude Colet</td>
<td>5</td>
<td>Spain</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>“Is gestational diabetes a severe illness?” exploring beliefs and self-care among women with gestational diabetes living in a rural area of the south east of China</td>
<td>2016</td>
<td>Ge, et al⁶¹</td>
<td>Diabetes</td>
<td>Australian Journal of Rural Health</td>
<td>17</td>
<td>China Obstetric clinics, wards</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>The maternal experience of having diabetes in pregnancy</td>
<td>2011</td>
<td>Nolan et al²³</td>
<td>Diabetes</td>
<td>Journal of the American Academy of Nurse Practitioners</td>
<td>8</td>
<td>USA</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Self-monitoring lifestyle behaviour in overweight and obese pregnant women: qualitative findings</td>
<td>2018</td>
<td>Sheih and Draucker³⁰</td>
<td>Overweight/obese</td>
<td>Journal of Clinical Nursing</td>
<td>13</td>
<td>USA Clinics (community health centre and health network)</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>Socio-cultural aspects of self-management in gestational diabetes</td>
<td>2012</td>
<td>Wazqar and Evans</td>
<td>Diabetes</td>
<td>Diabetes Nursing</td>
<td>12</td>
<td>Canada</td>
<td>Secondary analysis of one on one interviews</td>
</tr>
<tr>
<td>‘I was tired of all the sticking and poking’: Identifying barriers to diabetes self-care among low-income pregnant women</td>
<td>2015</td>
<td>Yee et al³¹</td>
<td>Diabetes</td>
<td>Journal of Healthcare for the Poor and Underserved</td>
<td>10</td>
<td>USA Clinic</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>Factors promoting diabetes self-care among low-income, minority pregnant women</td>
<td>2016</td>
<td>Yee et al³⁶</td>
<td>Diabetes</td>
<td>Journal of Perinatology</td>
<td>10</td>
<td>USA Diabetes clinic</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>Lived experience of blood glucose self-monitoring among pregnant women with gestational diabetes mellitus: a phenomenological research</td>
<td>2017</td>
<td>Youngwanichsetha and Phumdoung¹⁹</td>
<td>Diabetes</td>
<td>Journal of Clinical Nursing</td>
<td>30</td>
<td>Thailand Antenatal clinic, diabetes clinic, obstetric ward</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>Self-management of gestational diabetes among Chinese migrants: A qualitative study</td>
<td>2018</td>
<td>Wah et al²⁴</td>
<td>Diabetes</td>
<td>Women and Birth</td>
<td>18</td>
<td>Australia Antenatal clinic</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>The experience of gestational diabetes for indigenous Māori women living in rural New Zealand: qualitative research informing the development of decolonising interventions</td>
<td>2018</td>
<td>Reid et al³²</td>
<td>Diabetes</td>
<td>BMC Pregnancy and Childbirth</td>
<td>10</td>
<td>New Zealand Primary care clinic</td>
<td>One on one interviews</td>
</tr>
</tbody>
</table>

Continued
me get over things’, similar to her partner’s support she was able to overcome her fear of blood glucose self-testing. Families and partners who got involved in the recommended lifestyle changes and self-management activities, such as following the same diet, was motivational for pregnant women and increased their adherence to self-management and increased adherence to self-management.

Supportive environment: healthcare professionals

Similarly, a supportive and constructive relationship with healthcare professionals proved to be a strong motivator for self-management, often minimising feelings of anxiety and uncertainty. Healthcare professionals who provided self-management advice gave women more autonomy over their pregnancy, ‘the diabetes educator is really friendly…she did a demo in front of me, how to inject yourself’.18 Women who understood their condition better were able to make positive choices about their self-management; ‘I would limit my foods in order to control my blood sugar’.19

<table>
<thead>
<tr>
<th>Title</th>
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<th>Sample size</th>
<th>Setting</th>
<th>Qualitative method</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Diabetes Just Tends To Take Over Everything’: Experiences of Support and Barriers to Diabetes Management in Pregnancy in Women With Type 1 Diabetes</td>
<td>2019</td>
<td>Singh et al.33</td>
<td>Diabetes</td>
<td>Diabetes Spectrum</td>
<td>15</td>
<td>USA Diabetes clinic</td>
<td>One on one interviews</td>
</tr>
<tr>
<td>Barriers to Gestational Diabetes Management and Preferred Interventions for Women With Gestational Diabetes in Singapore: Mixed Methods Study</td>
<td>2020</td>
<td>Hewage et al.34</td>
<td>Diabetes</td>
<td>JMIR Formative Research</td>
<td>15</td>
<td>Singapore Gestational Diabetes clinic</td>
<td>One on one interviews, in a mixed methods study also including a survey</td>
</tr>
</tbody>
</table>

Table 2 Quote table: barriers and motivations for self-management

<table>
<thead>
<tr>
<th>Barriers to self-management</th>
<th>Motivations for self-management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge and understanding</td>
<td>‘Actually, I didn’t know anything about it...So, I...thought that if you were diabetic then you kind of get it. But then I didn’t know something you can just develop during pregnancy as well. So, it was quite new to me.’20</td>
</tr>
<tr>
<td>Feeling anxious and overwhelmed</td>
<td>‘With the fourth pregnancy, I had sort of lost control. I was living in the garage with my three children [and husband], I was huge and six months [along in my pregnancy] when I was diagnosed with depression...I didn’t want to do anything. I’d just wake up [and] went through the motions.’31</td>
</tr>
<tr>
<td>Lack of support: family</td>
<td>‘I need to cook for my husband and I can’t make him eat the same thing...I need to follow him because he needs energy for his work...and I can’t avoid using sauce, you know how on the menu it says you need to avoid sauces and stuff, I can’t do that, my husband wouldn’t want to eat according to that.’32</td>
</tr>
<tr>
<td>Lack of support: HCP</td>
<td>‘You are told that you have this and nobody spends time with you, it’s kind of frustrating because you want to cry. You think that it’s something you did wrong’.33</td>
</tr>
</tbody>
</table>

Table 1 Continued

HCP; healthcare professional.
some evidence that being given ‘too much information (about gestational diabetes)’\textsuperscript{15} also made women feel overwhelmed. Women were negative about self-management when they perceived that it had not gone to plan: ‘When I took the higher dose [of insulin], I felt defeated...this is crazy, I don’t think my body is ever going to be perfect’.\textsuperscript{16}

Lack of knowledge and understanding

A lack of knowledge and understanding often led to a lack of motivation to self-manage. Women who did not understand their condition often underestimated the seriousness of their diagnosis or heard anecdotally from other women that it was not ‘a severe illness’\textsuperscript{21} thus preventing women from committing to self-management. Contrastingly, others felt as though it was ‘the end of the world’\textsuperscript{17} leading to women feeling too overwhelmed to self-manage efficiently. Central to the lack of understanding was a perception of insufficient education from healthcare professionals; one woman said that she was given ‘a list of food but no instructions’ meaning ‘you really have to work it out for yourself’.\textsuperscript{15}

Lack of support: family

This dataset reported traditional forms of support networks: women’s families, friends, and their healthcare professionals. A key theme to emerge from the data was the negative effect of a lack of familial support, which made women feel isolated and alone. Without strong family support networks women either stopped complying with self-management or lost the motivation to self-manage. Concerning dietary self-management women reported their families being unwilling to follow the same dietary restrictions because ‘you can’t expect everybody to change everything’,\textsuperscript{15} or failing to understand the importance of the dietary guidelines. Some women expressed that adhering to the strict diabetes diet made them feel socially isolated.

Lack of support: healthcare professionals

A discordant relationship with healthcare professionals made women feel less motivated to self-manage, ‘I love my OB/GYN, but I feel they are always in a hurry. Like they don’t have time to sit there and talk to you about what to do about it (GDM), but they are always in a hurry’.\textsuperscript{17} One woman described her healthcare professional’s attitude as ‘here, you take the ball, and you run with it’,\textsuperscript{26} but found that when her family were not informed about her self-management needs, it was difficult for her to stay on track. Women who wanted to self-manage reported either not being supported adequately by their healthcare professionals or subject to paternalistic responses: ‘you have no idea what you’re doing, I know best, here’s what we’re going to do’.\textsuperscript{25} Some women had difficulty accessing information and understanding the self-management tasks, particularly when there were language barriers: ‘It’s a bit difficult because my English isn’t very good...I have always been asking for an interpreter, but I have never got one’.\textsuperscript{24} There were also concerns ranging from a lack of information (‘they didn’t tell me what’s the side effects for the baby’)\textsuperscript{15} to accusations of patronising healthcare professionals who ‘talked down to [me]’ and ‘didn’t trust me’.\textsuperscript{17}

DISCUSSION

Principal findings

This review found that women with diabetes predominantly undertake self-management during pregnancy for the health of their baby. Support networks are crucial in alleviating the burden that comes with managing a chronic condition, particularly a new one, such as gestational diabetes. When these networks are less effective, women may feel overwhelmed by the self-management, which is compounded by a lack of knowledge and understanding.

One of the most notable findings from this review was the lack of research dedicated to managing chronic conditions in pregnancy. Diabetes was the only condition represented in the included literature, but with only 16 papers eligible for inclusion, the qualitative evidence base around managing gestational or chronic diabetes in pregnancy is still thin. While the findings of this review are framed by the self-management challenges of diabetes, a number of generic activities are applicable across other chronic conditions. Self-management of diabetes (type 1, type II and gestational) includes self-testing (of blood glucose levels) and diet and exercise management, all of which are applicable more widely in pregnancy. However, it is clear there is a lack of specific research on other chronic conditions in pregnancy, such as hypertension.

It is also worth noting that in the general population chronic conditions are self-managed due to the absence of a ‘cure’, but this is not strictly the case in pregnancy where conditions can be temporarily bounded by the pregnancy; gestational diabetes and hypertension (or pre-eclampsia) can be resolved with delivery, and if they are not resolved, they are recategorised as type 2 diabetes or hypertension\textsuperscript{25}—thus, they are no longer conditions brought about by pregnancy.

While some of the motivations and barriers identified in this review are applicable to chronic conditions in the general population, this review has also demonstrated that the motivating factors for pregnant women to self-manage are different to those motivating the general population; none more so than the desire to improve outcomes for the baby. As far as the authors are aware this paper is the first to use the burden of treatment theory as a theoretical lens to explore experiences of chronic disease management in pregnancy. Although this theory does not fully account for the specific challenges of pregnancy, as demonstrated by this review, it still broadly accounts for the actors and work involved in self-management in this context. Using this theory allowed for a deeper understanding of the burden of self-management and the work involved.
Interpretation

Acting for the baby

May et al argue that the work of self-management in the general population is often done in the context of ‘holding together something larger and more complex’, alluding to everyday life. While this applies in pregnancy, the work of self-management is also done in the context of maintaining the health of the unborn baby. Previous literature has touched on pregnant people acting ‘not for the self but also for the unborn ‘other’ and the burden of pregnant women having to be accountable for the health of their baby alongside their own health cannot be underestimated. Current self-management models are not equipped to consider that particular burden of treatment.

Support networks

Current self-management models emphasise that ‘self-management is manifested as both an individual and family construct’ and underscore the importance and necessity of social networks. The importance of social networks is also realised in the Burden of Treatment literature. May asserts that ‘knowledge and beliefs about health and healthcare are often shared [within social networks]…decisions about what to do, and how to access services, are often distributed amongst multiple participants in a social process’. In pregnancy, the sharing of lay knowledge and expertise is commonplace. Hinton et al demonstrated the nature of information sharing among pregnant people, often now in the form of online communities, in those with pregnancy hypertension or raised blood pressure. Pregnant women with hypertension valued the advice and support of their peers, and in the online space peer advice tended to trump the advice of medical professionals. Support networks are a central part of any self-management model in the general population, often emphasising that ‘self-management is manifested as both an individual and family construct’. As both a barrier and a facilitator of self-management, it is evident family support is an important factor in continued adherence. While current self-management models do not accommodate pregnancy entirely, this review demonstrates that elements of existing models, such as social networks and the need for education around diagnosis, are applicable.

Strengths and limitations

The research question evolved throughout the search as it became apparent that little data on self-management in pregnancy existed, and none outside of diabetes management. This review should act as a call for further work. Lived experiences are often over looked in self-management literature and by using qualitative literature we have been able to address some of these research gaps.

Limitations include that the coding framework is constrained by how the original researchers interpreted the interviews and their interactions with patients. Distinguishing between pre-existing chronic conditions and pregnancy acquired chronic conditions is important, but it was not a distinction that was reflected in the dataset; it is both a limitation of the included studies and this review. While the majority of the included papers were on gestational diabetes, there were two on pre-existing diabetes, and three with a mixed population of gestational and chronic diabetes. The burden of treatment theory does not perfectly map to pregnancy, however, elements of this theory are helpful in understanding how and why patients interact with self-management. Many of the included papers specifically considered barriers to self-management, as opposed to facilitators, thus potentially creating a negative bias towards self-management.

Included studies took place across a variety of international settings, operating within different health systems, ranging from those dominated by private insurance-based systems to those with national healthcare systems aimed at universal healthcare coverage. Individualised medicine is intertwined with self-management; six of the included studies took place in the USA, where they operate within an insurance-based system that lends itself to an individualised approach to medicine. With the exception of Canada, New Zealand and Singapore, none of the other countries included in this review have health systems based on almost near universal healthcare coverage. A patient’s relationship with their healthcare system also affects their relationship with the acceptability of self-management and their efficacy undertaking it. As none of the included studies were conducted in the UK, it raises questions about how pregnancy self-management would operate within the National Health Service.

CONCLUSIONS

Clinical implications

This review suggests there are several ways to improve adherence to self-management interventions in pregnancy, these interventions often involve self-monitoring and titrating medication. Healthcare professionals communicating the importance of self-management in terms that focus on the health of the baby, and educating women on the condition they have been diagnosed with, could have a positive impact on self-management adherence.

Research implications

There is a need for research on the self-management of chronic conditions in pregnancy, particularly in chronic conditions other than diabetes. There are ongoing trials on self-management in pregnancy, predominantly in hypertension, but how self-management will fit into usual care remains to be seen. Remote forms of care are now more commonplace, in light of this, a better, qualitative understanding of the new burden of treatment self-management creates is needed.
Main conclusions

This review shows that the primary motivating factor for women self-managing is the health of their baby. Their support networks and their understanding of the condition contribute to whether they self-manage effectively. The burden of treatment shifting to women requires further research, as patient work increases, feelings of anxiety can also increase. In this dataset, it was clear that some women found this treatment shift to be overwhelming but their anxiety largely stemmed from a lack of knowledge and understanding of the condition with which they had been diagnosed. Evidently, education is a barrier to pregnant women effectively self-managing, as when these issues are addressed women are willing and able to self-manage.

Contributors

BEJ, KLT, LH, RJM and NR contributed to creating the research question and parameters of the review, including the search strategy. BEJ conducted the search with assistance from NR. BEJ and JK reviewed the titles and abstracts of identified articles and carried out the full text assessments. Disagreements on reviewed articles were resolved by consensus with KLT. Data extraction and complete analysis was conducted by BEJ and reviewed by KLT, LH and RJM. The write up was led by BEJ, with edits provided by KLT, LH and RJM. BEJ is the guarantor for this research.

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Competing interests

None declared.

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication

Not applicable.

Ethics approval

This study does not involve human participants.

Provenance and peer review

Not commissioned; externally peer reviewed.

Data availability statement

All data relevant to the study are included in the article or uploaded as online supplemental information.

Supplemental material

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REFERENCES


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**Systematic review**

   Give the title of the review in English
   What are the current behaviours and attitudes among pregnant women regarding the self-management and self-monitoring of chronic conditions in pregnancy?

2. Original language title.
   For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. *Anticipated or actual start date.*
   Give the date the systematic review started or is expected to start.
   01/04/2019

4. *Anticipated completion date.*
   Give the date by which the review is expected to be completed.
   31/12/2019

5. *Stage of review at time of this submission.*
   Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.
   
   Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.

   This field uses answers to initial screening questions. It cannot be edited until after registration.

   The review has not yet started: No
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Review stage

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<th>Completed</th>
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<tr>
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<td>Yes</td>
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<tr>
<td>Formal screening of search results against eligibility criteria</td>
<td>Yes</td>
</tr>
<tr>
<td>Data extraction</td>
<td>No</td>
</tr>
<tr>
<td>Risk of bias (quality) assessment</td>
<td>No</td>
</tr>
<tr>
<td>Data analysis</td>
<td>No</td>
</tr>
</tbody>
</table>

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Beth Jakubowski

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Ms Jakubowski

7. * Named contact email.

Give the electronic email address of the named contact.

bethany.jakubowski@phc.ox.ac.uk

8. Named contact address

Give the full institutional/organisational postal address for the named contact.

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

01865 617961

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Oxford

Organisation web address:

https://www.phc.ox.ac.uk/

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Ms Bethany Jakubowski. University of Oxford
Ms Jaspreet Khaira. University of Oxford
Professor Richard McManus. University of Oxford
Dr Katherine Tucker. University of Oxford
Dr Lisa Hinton. University of Cambridge

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

CLAHRC Oxford

**Grant number(s)**

State the funder, grant or award number and the date of award

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None


Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**


State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

What are the current behaviours and attitudes among pregnant women regarding the self-management and self-monitoring of chronic conditions in pregnancy?


State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

- Pregnancy MeSH
- Pregnant women MeSH
- Pregnancy OR gestational OR maternal
- Decision making MeSH
- Self-care MeSH
- Shared decision making OR self manag* OR self-monitor
The search terms used for CINAHL
- Pregnancy OR Expectant Mothers
- Pregnan* OR gestational OR maternal
- Self-care
- Shared decision making OR self-manag* OR self-monitor

There was also a broad secondary search using the search term ‘pregnancy self-management’ in PubMed

17. URL to search strategy.
Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search results.
https://www.crd.york.ac.uk/PROSPEROPROFILES/136681_STRATEGY_20200916.pdf
Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.
Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.
Give a short description of the disease, condition or healthcare domain being studied in your systematic review.
This review is on the self-management of chronic conditions in pregnancy i.e. hypertension, diabetes, kidney disease. The scope of the review is to look at the feasibility and acceptability of women self-managing, and how they regard this new burden of treatment.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.
The population being studied is pregnant women with a chronic condition, there are no further restrictions on the study population.

Inclusion Criteria
1. Chronic condition: diabetes (gestational or chronic), hypertension (gestational or chronic), obesity, kidney disease, others to be reviewed as they come up
2. Pregnancy
3. Self-management: self-monitoring, self-weighing, self-care, others to be reviewed as they come up
4. Qualitative.

20. * Intervention(s), exposure(s).
Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The
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This review is looking at the self-management of chronic conditions in pregnancy. Self-management can be defined as self-monitoring (i.e. of blood glucose or blood pressure), or as action on the basis of self-monitoring (i.e. diet management, self-care, weight management).

21. Comparator(s)/control.
Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.
Usual care if appropriate.

22. Types of study to be included.
Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.
Qualitative studies are eligible for inclusion, including secondary analysis of previous qualitative research.
Inclusion Criteria
1. Chronic condition: diabetes (gestational or chronic), hypertension (gestational or chronic), obesity, kidney disease, others to be reviewed as they come up
2. Pregnancy
4. Qualitative

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.
Chronic conditions in pregnancy are under researched, so the aim of this review is to examine the current qualitative evidence of the behaviours and attitudes towards the self-management of chronic conditions in pregnancy. It is important to determine what, if any, self-management currently takes place and whether women find it acceptable and feasible to self-manage. Therefore the inclusion criteria for this review is for the participant to have a chronic condition (i.e. hypertension, diabetes) during pregnancy (this can be defined as gestational or chronic), and for some form of self-management to be taking place. This self-management can either be self-monitoring (i.e. of blood glucose or blood pressure), or action on the basis of self-monitoring (i.e. diet management, self-care, weight management).

24. Main outcome(s).
Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.
The study aims to explore whether self-management of chronic conditions in pregnancy is acceptable and
feasible to pregnant women. It also aims to explore current practice and the current evidence base of chronic
disease management in pregnancy.

Measures of effect
Please specify the effect measure(s) for your main outcome(s) e.g. relative risks, odds ratios, risk difference,
and/or 'number needed to treat.
Not applicable.

25. * Additional outcome(s).
List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main
outcomes. Where there are no additional outcomes please state ‘None’ or ‘Not applicable’ as appropriate
to the review
None.

Measures of effect
Please specify the effect measure(s) for your additional outcome(s) e.g. relative risks, odds ratios, risk
difference, and/or 'number needed to treat.
Not applicable.

26. * Data extraction (selection and coding).
Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how
this will be done and recorded.
All of the studies identified in the search were screened independently by two reviewers (title and abstract)
who then came together to agree on which articles should get a full text review. Both reviewers then
independently completed the full text review and met again to agree on which articles should be included in
the final review. Discrepancies were resolved by reviewing the definition of self-management and chronic
condition as these were often the causes of uncertainty. The first author will then use a data extraction
spreadsheet to list the key themes and findings from the papers. 10% of the included articles will be
screened by another member of the study team, measuring the 10% of articles against the inclusion criteria
and the COREQ quality assessment guidelines. The included studies will then be put into NVivo 12 and a
thematic analysis, using the guidelines produced by Braun and Clarke (2006), will be carried out by the first
author. A theoretical lens will be used to reflect the themes that emerge during data analysis.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment
tools that will be used.
Two researchers carried out the screening of articles, and met after the title and abstract screening to feed
back results and decide which articles required a full text review. They met again following this screening to
decide which articles should be included in the final review. To determine the quality of the studies, the
COREQ guidelines will be used, which is a standard set of guidelines to determine the quality of qualitative
work. The quality of the studies will be acknowledged in the write up, in order to be transparent about the
quality of the work in this field to date.

Describe the methods you plan to use to synthesise data. This must not be generic text but should be specific to your review and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

Using NVivo 12, an initial thematic analysis will be conducted by the first author to create a coding framework of themes and sub themes. A theoretical lens will be used to develop the coding framework further. Discrepancies will be discussed with the wider study team and feedback will be incorporated into the framework.

29. * Analysis of subgroups or subsets.
State any planned investigation of ‘subgroups’. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.
Not currently planned

30. * Type and method of review.
Select the type of review, review method and health area from the lists below.

<table>
<thead>
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<th>Type of review</th>
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<td>Intervention</td>
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<td>Methodology</td>
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<td>Narrative synthesis</td>
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<td>Network meta-analysis</td>
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<td>Pre-clinical</td>
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<td>Prevention</td>
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<tr>
<td>Prognostic</td>
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</table>
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No
Prospective meta-analysis (PMA)
No
Review of reviews
No
Service delivery
No
Synthesis of qualitative studies
Yes
Systematic review
Yes
Other
No

Health area of the review
Alcohol/substance misuse/abuse
No
Blood and immune system
No
Cancer
No
Cardiovascular
No
Care of the elderly
No
Child health
No
Complementary therapies
No
COVID-19
No
Crime and justice
No
Dental
No
Digestive system
No
Ear, nose and throat
No
Education
No
Endocrine and metabolic disorders
No
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Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
Yes

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
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No
Surgery
No
Tropical Medicine
No
Urological
No
Wounds, injuries and accidents
No
Violence and abuse
No

31. Language.
Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English
There is not an English language summary

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.
England

33. Other registration details.
Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.
If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)
Add web link to the published protocol.
Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.
No I do not make this file publicly available until the review is complete
Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.
Do you intend to publish the review on completion?

Yes
Give brief details of plans for communicating review findings.
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We will aim to publish the review in a high impact scientific journal.

36. Keywords.
Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Pregnancy; maternal health; chronic conditions; self-management

37. Details of any existing review of the same topic by the same authors.
If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.
Update review status when the review is completed and when it is published. New registrations must be ongoing so this field is not editable for initial submission.
Please provide anticipated publication date
Review_Ongoing

39. Any additional information.
Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.
Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.
Give the link to the published review or preprint.
Appendix 1: Search Strategy

Two databases were searched, CINAHL and Pub Med. The search terms used to find articles in Pub Med (n=107) were MeSH terms ‘pregnancy,’ ‘pregnant women’, ‘decision making’, ‘self-care’, and ‘pregnan* OR gestational OR maternal’, and ‘shared decision making OR self manag* OR self-monitor’. There was also a broad secondary search in Pub Med using the search term ‘pregnancy self-management’ which identified a further 1,931 articles for review. The search terms used for CINAHL (n=707) were ‘pregnancy OR expectant mothers’, ‘pregnan* OR gestational OR maternal’, ‘self-care’, and ‘shared decision making OR self-manag* OR self-monitor’. This identified a total of 2,745 articles, which when controlled for duplicates left 2,695 for review. 25 articles were identified for full text review, of which 16 were selected for the systematic review.
<table>
<thead>
<tr>
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<th>Participants</th>
<th>Methods</th>
<th>Data Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>Recruited from obstetric clinics and health care providers in New York State</td>
<td>Women: 4 African American, 4 Latina, Mean age 28.5,</td>
<td>Focus group in private room in clinic, interviews conducted in participants' homes or health center, audiorecording</td>
<td>Thematic analysis</td>
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**Supplemental material**

**BMJ Open**

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<th>Verification</th>
<th>Derived themes</th>
<th>Analysis software</th>
<th>Descriptions of data analysis and results</th>
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<td>Yes</td>
<td>Yes</td>
<td>ATLAS.ti 6</td>
<td>Analysis was rigorous. Clarity of major findings consistent.</td>
</tr>
</tbody>
</table>

Participants were interviewed about their experiences. The recruitment and analysis processes were transparent. However, the sample size was small. Despite the small sample size, multiple themes were clear and supplemented with quotes. The dataset was rich, allowing for a richer dataset. The exploration of themes was nuanced and rich. The methods, leading to an apparently rich dataset. Paper was clear.

Reasons:

- Small sample size, but an exploratory study.
- Very large sample size, very rich dataset.
- Good sample size, rich dataset and mixed qualitative analysis.
- Good sample size, clear description of recruitment and analysis processes.
- Small sample size, short interviews, but the discussion of findings was clear.
- A good sample size for a secondary analysis.