


BMJ Open Barriers and facilitators to self-management of chronic conditions reported by women: a systematic review of qualitative studies

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ABSTRACT

Objectives This systematic review aims to identify, appraise and synthesise the findings of published qualitative research exploring the barriers and facilitators to self-management of chronic conditions reported by women.

Design A systematic literature review and thematic synthesis of qualitative studies.

Data sources A search of MEDLINE, CINAHL, Embase and PsycInfo was undertaken using the search terms 'Women', 'Woman', 'Female', 'Chronic', 'Long-term', 'Disease', 'Illness', 'Condition', 'Health', 'Self-management', 'Qualitative', 'Barrier' and 'Facilitator'. A hand search for literature was also performed.

Eligibility criteria Studies published before 2005 and those not in English were excluded.

Data extraction and synthesis Extracted data were analysed thematically and emerging and recurring themes identified. Themes were mapped to the six components of the COM-B model. Critical appraisal of included publications was undertaken using the CASP (Critical Appraisal Skills Programme) qualitative checklist and finding weighted on quality.

Results Eighty-four publications were identified and eligible for inclusion within the review. Studies were conducted in five continents, with a focus on 20 different chronic conditions and included a total of 1788 women. Barriers and facilitators to physical capability, psychological capability, physical opportunity, social opportunity, autonomic motivation and reflective motivation were identified with a number of recurring themes found. Self-prioritisation, support and culture all had a significant impact on whether women followed self-management recommendations. Certain groups of women such as those living remotely, those with financial difficulties, migrants and those who do not speak the predominant language appear to face additional barriers to self-management.

Conclusions This review highlights that to self-manage chronic conditions women have to overcome various cultural, financial and social barriers. Self-management programmes should be designed taking into account these factors in order to ensure women are better supported and enabled to improve their health outcomes.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The review was conducted using a rigorous and transparent methodology.
- ⇒ 84 qualitative studies from 24 countries were identified and included within the synthesis.
- ⇒ Half of the included studies were in women with diabetes, which may limit the generalisability of the review findings to other chronic conditions.
- ⇒ Only a subsample of abstracts and manuscripts were second reviewed.

INTRODUCTION

A scoping review undertaken by the authors, as well as data published from a multicentre randomised controlled trial of pessary self-management, suggests self-management of pessaries for pelvic organ prolapse offers benefits to women with no increased risk.^{1,2} Despite this, many women are unwilling to self-manage their pessary.^{1,3} At present, there is a lack of understanding about what affects willingness to self-manage a pessary. However, there may be relevant, transferable findings from other literature about barriers to the self-management of other chronic conditions. Therefore, this systematic review aims to identify, appraise and synthesise the findings of published qualitative research exploring the barriers and facilitators to self-management of chronic conditions reported by women. POP is a condition that only affects women, and while many barriers and facilitators to self-managing chronic conditions may be relevant to both men and women, biosocial differences between the sexes may mean findings of mixed sex studies cannot be reliably applied to the female population.⁴

The impact of a chronic disease diagnosis on an individual's psychology and, therefore, behaviour has been well documented since Bury's groundbreaking work with men and women diagnosed with rheumatoid

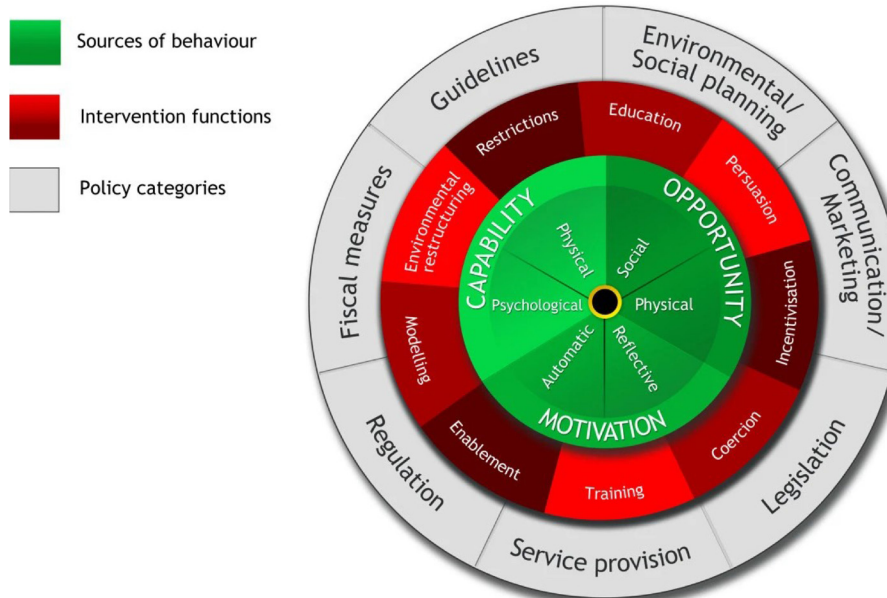


Figure 1 Behaviour change wheel. Reproduced with permission of Michie *et al.*⁸

arthritis.⁵ Using a behaviour change theory enables the application of cumulative knowledge about what motivates or prevents a change in behaviour.^{6,7} The COM-B model, developed based on the findings of a systematic review of 19 behaviour change frameworks, suggests that in order for behaviour to change, an individual needs to be capable, motivated and have opportunity.⁸ Furthermore, the authors highlight there is both physical and psychological capability, reflective and autonomic motivation and physical and social opportunity.⁸ Each of these six components interact and influence the likelihood of someone behaving in a certain way.⁸ The COM-B model is at the core of the behaviour change wheel, surrounded by nine potential interventions to address barriers to capability, opportunity and motivation (figure 1).⁸ The COM-B model and behaviour change wheel have been frequently used to inform intervention design, but more recently, COM-B has also successfully informed the synthesis of systematic review findings related to behaviour change.⁹ Therefore, the COM-B model will be used to structure the findings of the review with the aim of identifying facilitators and barriers to self-management reported by women which should be prioritised for future intervention development, with the long-term goal of better supporting women to self-manage their chronic condition.

METHODS

As detailed in the published protocol,¹⁰ the systematic review was conducted and reported in accordance with both PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ)

guidelines and a guide for the systematic review of qualitative data^{11,12} (online supplemental materials 1 and 2).

The review was registered with The Open Science Framework (OSF) (10.17605/OSF.IO/CTHSF) and PROSPERO (CRD42022327643). On 15 August 2022 and 16 August 2022, a search of MEDLINE, CINAHL, EMBASE and PsycInfo was undertaken to identify relevant articles that met the eligibility criteria (figure 2) using the search terms ‘Women’, ‘Woman’, ‘Female’, ‘Chronic’, ‘Long-term’, ‘Disease’, ‘Illness’, ‘Condition’, ‘Health’, ‘Self-management’, ‘Qualitative’, ‘Barrier’ and ‘Facilitator’ (figure 3 and online supplemental materials 3–6). A hand search for additional eligible publications was undertaken by screening each review article identified during the search. The same searches were run again on 15 March 2024 to ensure the review findings were current. Additional publications identified were screened and included as appropriate within the synthesis. Twenty per cent of articles identified were screened by an independent reviewer to ensure concordance with decisions about eligibility.

Data were extracted using a data extraction tool developed on Microsoft Excel by the reviewers based on qualitative systematic review guidance.^{13,14} Extracted data were recorded in two separate columns to differentiate between first order constructs, extracted from raw data in the review such as direct quotations from participants and second order constructs, extracted from interpretations and observations the researcher had made while writing up their findings.¹³ A second reviewer performed data extraction on a subset of 10% of included articles to ensure a standardised, reproducible approach. No discrepancies in the data extraction processes were identified; therefore, it was not necessary to make any changes to the data extraction tool.

Critical appraisal of all included publications was undertaken using the Critical Appraisal Skills

Eligibility Criteria
Studies where participants are women
Studies where participants are aged 18 or over
Studies exploring a self-management intervention
Studies exploring a self-management intervention for a chronic condition
Studies which are qualitative research
Studies which have findings related to the barriers or facilitators to a self-management intervention
Studies with finding directly reported by the target population of women
Published in the English Language
Original research
Published between 2005 and date of the search

Figure 2 Eligibility criteria.

Programme (CASP) qualitative checklist.¹⁵ Although CASP do not recommend the use of a scoring system for appraising qualitative studies,¹⁵ this review used a scoring system developed to determine the level of quality of each individual study. This facilitated a hierarchical approach to thematic analysis, whereby the quality of a study determined whether or not new codes identified within that paper should be included.⁸ For this review, new codes were created for high and medium quality studies. However, for low and very low quality studies, no new codes were

created but findings used to support themes identified from codes created through thematic analysis of higher quality studies. This ensures findings are weighted appropriately based on the methodological quality of the studies.¹³ A second reviewer performed critical appraisal using the same checklist on a subset of 10% of included articles to ensure a standardised, reproducible approach. Despite minimal variation in checklist completion between both reviewers, this did not affect the overall score for any study; therefore, it was not necessary to have a second review of the quality appraisal of additional studies.

The extracted data were analysed using a thematic approach. Findings were coded line by line to identify emerging and recurring descriptive themes among the studies.¹⁶ Once all extracted data was coded, the themes were separated based on whether they were a barrier or facilitator to self-management and analysed for broader analytical themes.¹⁶ The themes identified within the literature were then mapped to the six components of the COM-B model.⁸

Patient and public involvement

Members of the public and pessary users have not directly been involved with development of the review protocol or process. However, the need for research exploring pessary self-management was highlighted by The James Lind Alliance (JLA) Priority Setting Partnership for pessary and prolapse.¹⁷ Several women with experience of pessaries participated in this partnership either as members of the steering group, by attending the consensus workshop or completing questionnaires. Understanding more about self-management was ranked third out of 20 priorities by the JLA Priority Setting Partnership.¹⁷ The topic of the systematic review has therefore previously been identified and prioritised by patients and members of the public.

Systematic Review Search Strategy

1. women.mp. or Women/
2. woman.mp. or Women/
3. Female/
4. 1 or 2 or 3
5. self-management.mp. or Self-Management/
6. 4 and 5
7. qualitative.mp.
8. 6 and 7
9. chronic.mp.
10. long-term.mp.
11. condition.mp.
12. illness.mp.
13. condition.mp.
14. Health/ or health.mp.
15. 9 or 10 or 11 or 12 or 13 or 14
16. 8 and 15
17. barrier*.mp.
18. facilitator*.mp.
19. 17 or 18
20. 16 and 19
21. limit 20 to english language
22. limit 21 to yr="2005 -Current"

Figure 3 Search strategy.

RESULTS

As demonstrated in [figure 4](#), the database search identified 2100 publications. After duplicates were removed, there were 1228 remaining publications. After reviewing the identified articles in accordance with the inclusion and exclusion criteria ([figure 2](#)), there were 49 eligible articles. A hand search, including searching the reference lists from excluded non-original research papers, revealed a further 35 articles, resulting in a total of 84 publications ([figure 4](#) and online supplemental material 7). In total, 1788 women participated in the included studies. Four of the publications included were solely available as an abstract, which prevented thorough understanding and appraisal of both the findings and methodology, this resulted in a low CASP score. As demonstrated in [table 1](#), the studies included in the review were conducted across five of the six populated continents, with no studies included from South America. Eleven (13%) of the included studies took place in the UK. Over a third (n=30) of eligible studies took place in the USA.

Sixty-three per cent (n=53) of studies did not state the philosophical orientation of their research. The most frequently cited philosophical approach was grounded theory (n=8 11%), with six studies (7%) using phenomenology, three (4%) narrative enquiry and three (4%) ethnography. Despite many of the studies focusing on women, only one study had a feminist orientation. In an additional four studies (5%), the methods were informed by behaviour and health psychology theories.

As detailed in the table of included studies (online supplemental material 7), the majority of studies (n=53 63%) used interviews to collect data. Focus groups were conducted in 22 (26%) of included studies. Questionnaires were analysed thematically in three (4%) studies. In another study, a visual data collection method, the Mmogo method was used,¹⁸ which required participants in a group to respond to questions posed using indigenous materials to create a visual construction.¹⁹ The five (6%) remaining studies used a combination of qualitative methods including interviews, focus groups, questionnaires, analysis of text message communications and participatory observation.

As detailed in [table 2](#), the populations of women studied in the included studies had various chronic conditions; however, half of included studies (n=42) were conducted among women with diabetes.

Critical appraisal of the evidence reveals a number of recurring methodological limitations across the evidence base as demonstrated in the CASP score (online supplemental material 8). The mean score for included publications was 7.5, which denotes moderate quality using the grading detailed in the review protocol.¹⁰ Methodological weaknesses across the evidence base were related to the study recruitment strategy, a failure to critically appraise the potential for researcher influence introducing bias and the presentation of study findings. Methodological strengths of the evidence base were found in the validity of the findings, with most studies having a clear aim which

was appropriately addressed by a qualitative approach. Data collection and discussion of ethical considerations also scored highly throughout the literature.

The six COM-B factors that impact on behaviour are physical capability—the capacity to engage in the physical requirements of a behaviour; psychological capability—the capacity to engage in the psychological requirements of a behaviour such as having understanding, cognitive and executive functioning; physical opportunity provided by the individual's environment; social opportunity as a result of an individual's cultural environment; reflective motivation-intentional thought processes such as evaluating and planning; and autonomic motivation, resulting from emotions and impulses.⁸ The themes identified within the review have been mapped to these six categories.

Physical capability

Symptoms and comorbidities

Physical capability to perform self-management behaviours was limited for some women due to symptoms of the chronic condition, additional comorbidities or discomfort caused by self-management activities.^{14 16 20–34}

This meant women either made a conscious decision not to follow self-management advice, or felt unable to.^{14 16 20–34}

Women also highlighted the challenge of following self-management recommendations while simultaneously dealing with the psychological impact of having a chronic condition and practical issues such as managing finances, adverse family circumstances or unexpected crises.^{14 26 35}

When I wore the bandage in the evening, I felt a pain in my arm, all my fingers were numb and my skin was itchy. It was uncomfortable, so I seldom wore it.²⁰

and

I had several other physical problems that were consuming my attention, so my impatience prevented me from focusing even more on myself.³³

Psychological capability

Knowledge and understanding

In a number of publications, women reported that a lack of, or outdated, knowledge was a barrier to their self-management^{20–22 24 31 32 36–43} and that having existing or new knowledge about the condition, the evidence base supporting self-management or how to self-manage was beneficial.^{16 19 20 43–49}

We need help to be healthy ... We need more health information and support for being healthy.²⁴

Ongoing self-management education was also reported to be necessary.^{21 22} In one study, women reported their behaviour changed and therefore self-management of their condition improved after repeated educational messages over time about dietary control of their diabetes.¹⁹

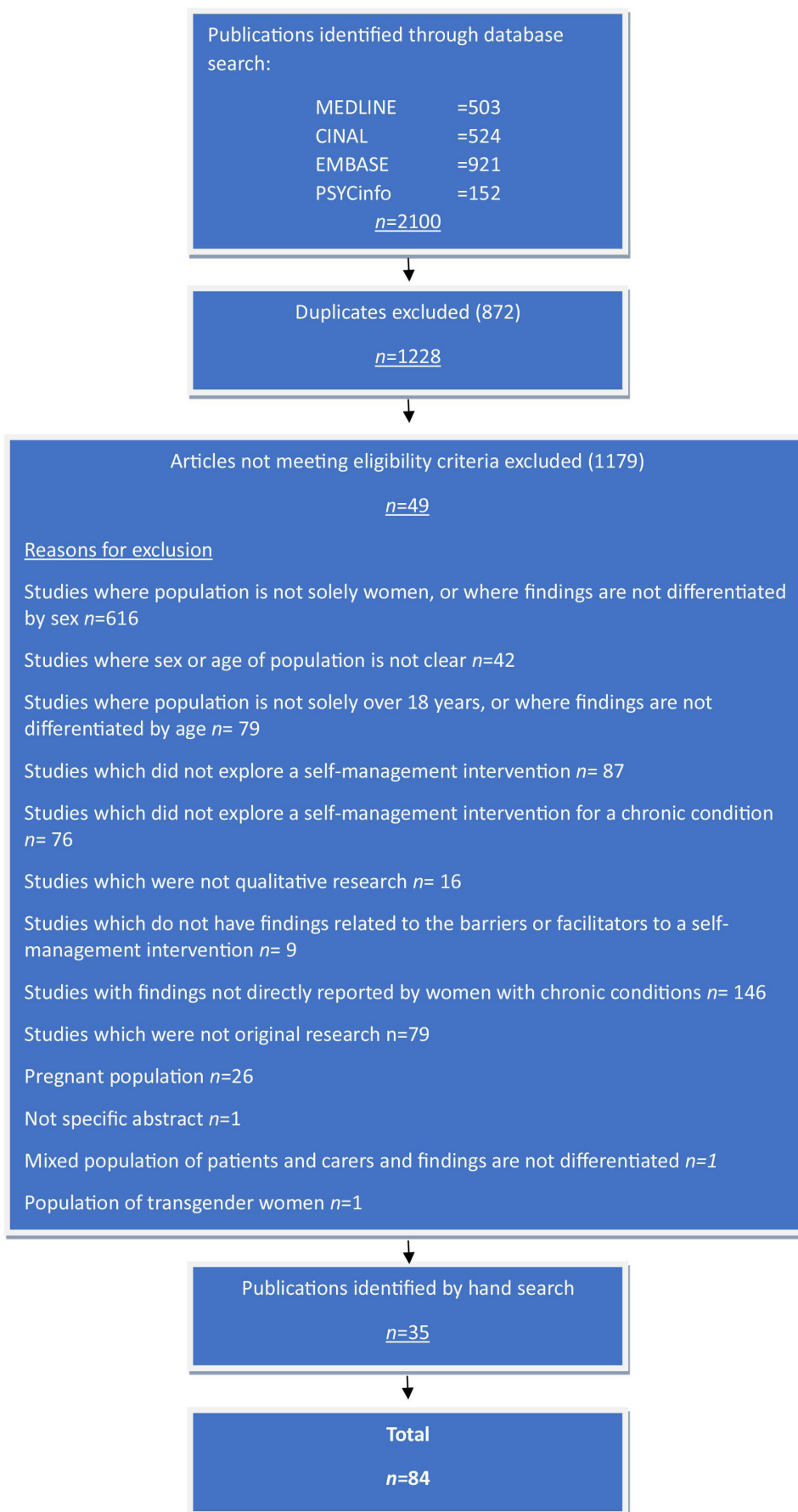


Figure 4 Systematic review flow chart.

Table 1 Summary of included studies

Total publications	84
Full text	80
Abstract only	4
Range of publication years	2005–2024
Mean publication year	2015
Countries research conducted in	
USA	30
Australia	5
Canada	5
China	4
Dominican Republic	1
Ghana	1
India	4
Ireland	1
Iran	1
Israel	1
Korea	2
Lebanon	1
Netherlands	3
Nigeria	1
Pakistan	2
Saudi Arabia	1
South Africa	2
Spain	2
Sweden	1
Taiwan	1
Thailand	1
UK	11
USA and UK	2
Mexico and Costa Rica	1

I would like to express my gratitude. I would say, all these things I never take them serious, until I attended the sessions every time and I learn the importance of them. I see now that they work.¹⁹

At times, women reported a lack of understanding of the need for change or believing change deterred them from following self-management recommendations.²¹ One example of this is the perception held by a number of women in different studies that caring responsibilities or housework was physical activity and therefore it was not necessary to undertake additional exercise as recommended.^{23 39 50}

I do a lot of exercise in my domestic time ... I don't sit 1 min. So, that's my exercise really and I don't think I will take up fully exercise. I think I do enough domestic one.⁵⁰

Table 2 Summary of chronic conditions explored in included studies

Chronic condition	
Adenomyosis	1
Arthritis	2
Breast cancer–related lymphoedema	6
Chronic heart failure	1
Cardiovascular disease	2
Diabetes	42
Diabetes and depression	1
Diabetes and/or hypertension	2
Eating disorder	1
Endometriosis	2
Glaucoma	1
Heart disease, diabetes or osteoporosis	1
Heart failure	1
HIV/AIDS	8
Interstitial cystitis/bladder pain syndrome	1
Lupus	1
Mental health	1
Pain	1
Prolapse	1
Urinary incontinence	6
Various chronic conditions	2

Information

Access to clear and concise information about self-management was deemed important by women.^{32 33 47 51–53} Some felt education provision via E-health technologies was convenient and accessible,^{16 46} whereas other preferred face-to-face contact or struggled with technology.^{16 33 52–54} Women highlighted that educational videos,^{33 52} written information to reinforce verbal communication,²² having images accompanying written information,^{16 33} and group educational sessions⁵⁵ helped them develop their knowledge and understanding. However, in one study, despite attending a diabetes education class, many women did not retain important information about the severity of their conditions and potential complications.²¹ Varying the level of information provided is also an important consideration with information overload being reported in one study as a reason for disengagement with a self-management programme.^{16 47}

Even when I manage to go see the doctor, he just tells me everything he wants me to know by mouth, which got in through one ear and goes out through the other even before I get home; he does not give me any printed material.²²

Adaptability

Women who reported incorporating self-management behaviours into their daily routine were most likely to continue following recommendations over the long term.^{43 47 54 56}

It takes some time. But I think once you get used to it, it just becomes part of your routine. Once you do things so many times, it just becomes a habit.⁴⁷

However, some women were not aware how to incorporate recommendations into their everyday life despite receiving information on recommended behaviours.^{21 57} Women felt healthcare professionals did not always take the context of their patients' lives in to consideration when providing self-management recommendations.^{32 41 42 48 53} When this did not happen, and advice conflicted with cultural behaviours, or dietary recommendations were impractical, women immediately felt disengaged from the recommendations and at worst disrespected by the healthcare professional.^{22 29 32 42 58 59}

There are some people who get angry because I don't eat at all. In those situations, I just eat ... I know that's the polite thing to do ... it would be nice if people just accepted the fact that I have diabetes but they just constantly offer food. They offer apples and sweet potatoes. It is not culturally polite to refuse the offer and if I don't eat, the host family feels very badly.⁶⁰

and

Some of their recommendations would have been great for the general (older male) patient population at the VA (Veteran's Health Administration), but they were just lousy for someone who has to take care of young children.²⁹

This demonstrates that simply providing information is unlikely to result in sustained self-management, women desired practical strategies that would enable them to incorporate self-management behaviour into their everyday life.⁴⁷ Moreover, ensuring women received individualised guidance regarding how to self-manage their condition meant it felt personalised to them and they were more likely to follow the recommendations.^{16 21 48}

Physical opportunity

Cost

Financial considerations women reported associated with the cost of self-management were direct healthcare costs such as medication, equipment and healthcare, and indirect costs such as travelling to attend appointments, following a specific diet and costs associated with exercise.^{20-22 26 27 30 34 39 44 61} This was particularly impactful for those without health insurance in healthcare systems dependent on insurance, living in poverty or on limited resources.^{22 24 38 61 62}

It's eating right is the problem now cause they tell you, eat a lot of fruits and vegetables, and it's expensive.²¹

and

It (the costs of compression hosiery) was so expensive for me and it was not covered by health insurance. I don't want to use it anymore.²⁰

Women who did not have to worry about the cost of healthcare, either due to having health insurance or healthcare being free of charge, reported this to be beneficial to their self-management.^{51 61 63} It is important to recognise that all but one of the studies where cost was acknowledged to be a factor which affects self-management were among ethnic minority or immigrant women.

ACCESS

Problems accessing transport to attend healthcare appointments for self-management support was identified in a number of studies.^{22 24 32 62 64 65} This was particularly problematic for women who were unwilling or unable to drive,¹⁴ and those who lived remotely or did not have local access to services required.^{14 22 29 34}

Not having a hospital or functioning health clinic in the community is a major barrier and challenge for my accessing health care services and medication for my Type 2 diabetes because I do not have any relation that have a vehicle to take me to the doctor; and I live very far from the place where the community members usually go to get transportation for traveling outside the community.²²

Some women highlighted that self-management was more convenient than hospital-based care as it reduced face-to-face clinical appointments and was therefore less time-consuming, which was particularly beneficial if they were still working or had childcare responsibilities.^{16 54 66}

Sometimes it can be tough to have a contact, get to the contact, sit face to face, and go there every week. It feels demanding and it takes too much time, so that was really positive.⁵⁴

Problems accessing medication,^{22 24} technical equipment^{16 67 68} or a healthcare professional were also reported by women as being detrimental to their self-management.^{20 21}

Time

The time-consuming nature of self-management was reported by women in a number of studies as a barrier to self-management.^{20 21 25 26 28 29 38 44 50 53 56 59 69-72} It is known that nationally and internationally, women undertake the majority of unpaid work required to keep society functioning in terms of caring, housework and cooking.^{73 74} Therefore, it is unsurprising these responsibilities detrimentally impact on their own chronic conditions, as they have less time. In 16 studies, women reported that caring responsibilities prevented them from following self-management recommendations or attending appointments related to self-management.^{23 24 29 33 35 39 53 56 57 62 70 75-79}

After finishing up with my children and other household work, I often don't have time to take care of own health and forget to check my blood sugar level before going to sleep, or when eating something sweet.⁸⁰

In addition to caring responsibilities, women explained the role strain of being primarily responsible for household work and also, often paid work, prevented them from self-managing their condition optimally as they simply did not have the time to devote to self-management behaviours.^{16 21 29 32 56 60 71 79 81–83} However, women also acknowledge they did not always prioritise self-management in the free time they did have.^{70 71}

It is very hard to have my own time to do anything except at the weekend. And I often have other chores to do in the weekend, such as getting my hair cut, attending a wedding, and so on.⁷¹

Women stated that help with time management, either by support managing competing priorities or taking responsibilities away from them would address this issue.^{47 56 81 84}

Social support

Emotional and practical support from spouses, family members and friends was identified as important to women's self-management in a number of studies.^{14 22 24 26 27 34–36 41 43 45–47 49 70 79 84–87} Where women reported a lack of support, this was demonstrated by negativity about or refusal to participate in self-management behaviours, a perceived lack of care for the woman's health or even denial that the woman had a chronic condition.^{20–22 34 39 42 45 65 67 71 72 82 88–90}

I felt like they were sabotaging me. If we were starting a diet of me trying to eat better, it just seemed like nobody wanted to help me. I've asked [my husband] numerous times to please not have any sodas in the house. Because if it's there, you want to drink it.

At times, women recognised the lack of support resulted from poor understanding of the chronic condition and the need for recommended behaviours.^{14 28}

The oldest one [daughter] doesn't understand that you have to eat at a regular time.... I went to visit and [dinner] was like 9:00 p.m. one night, but that was too late.... I had to eat me a snack about 5:00 p.m., ... but it [sugar] was up, you know, because I ate two dinners just about.¹⁴

A novel suggestion to address these issues suggested by women with diabetes was that their support person *also* receive an educational intervention to address knowledge gaps and also enable them to improve their lifestyle alongside the woman.⁹¹

A general feeling of lacking support either due to living alone,⁶⁴ being single²⁷ or apathy from those around them^{21 22 44} or society in general^{57 60} were also cited as

barriers to self-management. Some women were aware that they intentionally isolated themselves as a result of their condition.³⁵ In a number of studies, women felt isolated due to their migrant status, language barriers or a lack of familiarisation to the local area.^{32 44 69 79} In one study of Pakistani women, this prevented them from following self-management advice regarding exercise as they were concerned that they might get lost or injure themselves and be unable to ask for help.⁶⁹

What if I fell or collapsed again, I speak little, little English.⁶⁹

and

I don't have anybody around, because they're all Americans. I can't talk to them. There are no Russians living here.⁴⁴

Women believed they were less supported than men who have chronic conditions, due to the fact that it was culturally expected of women who were more accepting and experienced in undertaking a caring, supportive role.^{39 79 87 88 92} Wallace *et al* quantified the number of male and female participants who felt they received support from friends or neighbours and identified that while three quarters of men felt supported, only one quarter of women did.⁸⁷ Moreover, in a study of Latino women with diabetes, a perceived lack of support was only mentioned by female participants.³⁹ In one study, women reported their belief that self-management of their diabetes was solely their responsibility despite supporting other family members with their health conditions.⁷² Interestingly, women with heart failure reported a higher level of emotional support than men, yet they lacked tangible support with activities they felt unable to undertake leaving them feeling generally unsupported.³¹

[looking toward male participants], you are lucky to be a man. Because your wife would help you with your diabetes care. When I am not feeling well, nobody [in my family] wants to hear it.⁸²

and

So my experience is that um men they don't care for you but you have to care for them.⁷⁹

Peer support from individuals with the same condition, provided via various different formats whether virtually or face to face, was reported to be beneficial or desired by women,^{16 19 20 24 35 36 44 47 53 55 57 93 94} who perceived that the lived experience of peers with the same condition enabled them to offer practical advice which enhanced healthcare professional more formal recommendations.⁴⁷

Uh ... it is better ... to establish a Wechat Group comprised of many other BCRL (breast cancer-related lymphedema) patients. In this way, we can communicate with each other online, and I can learn self-care experience from other peers.²⁰

Furthermore, in one study, women with HIV reported that providing peer support and being an advocate for others with the condition was in fact beneficial to their own self-management,⁴⁹ suggesting that peer support may be beneficial to those providing and receiving it.

I feel encouraged and endowed to help and to share with other women ... It will help your self-esteem and it will help you to encourage others.⁴⁹

Healthcare professional support

The importance of consistent and supportive healthcare was also identified as an important to ensure effective self-management.^{43 46 48 51 53 54 95} Women who did not feel supported by their healthcare professional felt this was detrimental to their self-management efforts.^{16 22 28 43 95} Women with osteoarthritis in one study reported their belief that some healthcare professionals were not supportive of promoting self-management, instead preferring to offer a quick fix of analgesia which was less time consuming for them.⁵³

Doctor never give me any advice ... just give me pain-killers. If I got what kind of exercise, a diet plan, how to live day-by-day with pain, then it would be better and easier for me to live with arthritis.⁵³

Women reported a number of practical and emotional ways in which they felt cared for supported by their healthcare professional. These included acknowledging efforts made by the woman, whether or not they had achieved the target outcome^{54 81}; maintaining the woman's motivation throughout their self-management journey^{46 54}; giving them adequate opportunity to ask questions^{19 32 51}; ensuring the woman was able to contact the healthcare professional or had regular follow-up with them in place^{46 51 53 95}; conveying a genuine interest in the woman^{48 54}; providing self-management support guided by a health psychology theory such as motivational interviewing¹⁹ or cognitive behavioural therapy⁵⁴ and ensuring the woman was enabled, encouraged and trusted to be a partner in their care.^{28 45 46 51}

She doesn't sit around and just say something to make you feel better. She actually finds a solution and I like her because of that, because a lot of times I didn't have any.⁵¹

In a study to develop a text message-based platform, even though women acknowledged they were talking with a 'chatbot', it still reduced feelings of social isolation while they self-managed.⁴⁶

I know I'm talking to a chatbot, really. But even that was comforting compared with what I was getting before, which is no communication.⁴⁶

Conversely, in one study, a woman reported that negative comments from a healthcare professional motivated her to improve her self-management.⁶⁴

Prompts

Receiving positive feedback,⁵² regular reminders about self-management or appointments,^{16 33 34 52 70} being set and held accountable to realistic goals^{43 45 47 48 70} and regular monitoring and reassurance from a healthcare professional^{45 54} were also all reported by women as facilitators to their self-management.

It is in my own interest to do this, but it still feels like I need to have someone to keep an eye on me so that I do the training.⁵⁴

Conversely, in one study, some women perceived weekly email reminders negatively as they caused feelings of guilt and filled up their inbox.^{16 54} Tools designed to support self-management detailed in the included studies included a web-based intervention¹⁶ and application.⁵² Women reported that because these tools did not require face-to-face contact, they maintained privacy and were more convenient as they could be used around other responsibilities the women had which increased engagement with self-management.^{16 52} A web-based intervention to support self-management of urinary incontinence was designed using a stepped approach with the difficulty of pelvic floor muscle exercises increasing gradually.¹⁶ This appealed to their curiosity about what the next stage might be and therefore increased compliance with the intervention.¹⁶

Social opportunity

Culture

Women reported that cultural beliefs impacted on their ability to follow self-management advice, highlighting cultural attitudes towards women, food and exercise. It was reported by some that they were expected to fulfil traditional female roles within that culture. This included not verbalising any physical or psychological issues they were experiencing,⁶⁰ sacrificing their needs to meet the needs and preferences of their spouse and family,^{24 65 82} maintaining a curvaceous physique deemed desirable in that culture despite being advised to lose weight,^{19 50} staying at home to housekeep and look after other family members⁶⁹ and being unable to attend appointments due to the lack of an escort to accompany them as culturally expected for women.⁷⁶ In a number of studies, physical activity was recommended as part of self-management behaviour for women with type 2 diabetes. However, cultural attitudes towards exercise, in this review, particularly noted in South Asian, Middle Eastern, Latino, African and Caribbean cultures, prevented women from feeling comfortable and confident undertaking exercise.^{32 39-41 50 69 96-98}

Going to the gym is not in my culture. It's not in my culture at all.⁵⁰

Many foods have particular significance for certain cultures, whether as part of traditions, due to the social event surrounding them, or the positive

connotations associated with that food being a treat, which means many of us have complex and emotional relationships with food rather than solely eating for nutritional purposes.⁹⁹ Cultural influences related to food were acknowledged in a number of studies as conflicting with nutritional self-management advice,^{32 36 41 60 62 68} causing women to either disengage from recommended behaviour as it did not feel feasible for them to follow, or resulting in them feeling disconnected from community support.^{41 44 58}

Most of the food suggested by the media are mostly western food and hard to translate to our local cultural food.²²

Lack of self-prioritisation

A further cultural issue repeatedly found in the literature was the difficulty women had in prioritising themselves and their needs.^{21 23–25 32 36 43 52 56 57 60 65 70 72 75 79 82 83 86 89 90 100}

It's like a mum thing, a mother thing, a woman thing ... it's very hard for me to turn and just say 'Right, okay, I feel lousy, I'm just going to sit where I am.' And I don't think I'll be the only woman that does that ... trying to make life as normal as possible.¹⁰⁰

One example of this was identified in a study of Indian women with HIV and AIDS whereby the women reported eating last to ensure their family were sufficiently nourished.²⁴ At times when women had not eaten sufficiently, they chose not to follow their prescribed antiretroviral therapy to avoid side effects.²⁴

I receive ... less food because I eat at the end ... if we do not have food, we miss our pills because if I take ART without food, I feel giddy and sick. So, whenever I am not eating enough food, I miss my pills.²⁴

It is unclear why women do not prioritise their health. However, in one study, a number of Iranian women, with type 2 diabetes, reported they were persuaded by family members not to follow dietary advice given, following their diagnosis of gestational diabetes, in case it harmed their pregnancy or lactation.⁹⁰ As well as being incorrect, this advice conveys to the woman her health is less of a priority than her unborn child.

Another frequently identified challenge for women's self-management due to lack of self-prioritisation was failure to follow recommended dietary advice because family members would not eat the advised food, often meaning women would choose to eat food they knew conflicted with the self-management advice they had been given.^{21 23 25 32 36 60 65 75 79 82 83 89} Conversely, Cha *et al* found that the wives of males, in the same study, prepared food in accordance with self-management recommendations despite the conflict with family preferences.⁶⁵

They want me to cook separate foods for them, and because it is hard to cook two kinds of food, I am obliged to eat with them.⁹⁰

While women reported feelings of guilt if family members did not like healthy adaptations to their meals, the same emotion was not expressed by men.⁶⁵

It would be easier for me to control my diabetes if I were a man.⁸²

As well as lack of prioritisation of dietary needs, women recognised they were not protecting time to meet their chronic health needs due to family or work responsibilities, but continued to do so.^{32 43 52 56 57 70 72 86 100}

Right now I work 16-hour days—6 days a week ... I have the energy. I just don't have the discipline to stick to a routine. Working always seems more important.⁵⁶

On the other hand, in a study of women with HIV, recognising that they needed to prioritise their health for the benefit of their family motivated them to optimise self-management.⁴⁹ The phenomenon of women failing to prioritise their chronic health self-management was identified in studies from different continents and different groups of women, suggesting this issue does not solely affect those with specific conditions nor certain cultures.

Faith

In a number of studies, women reported that faith in God or spirituality, as well as the use of prayer, was beneficial to self-management of their condition.^{34 35 42 49 64 85} It is unclear whether faith or spirituality are either a barrier or facilitator to self-management because health fatalism reduced motivation to self-manage.⁵⁸

Whatever happens to me, I committed it to the hands of the one above. I am not feeling scared or nervous anymore. I am taking sugar medicine and other medicines as well, but it depends on the will of the one above.⁴²

However, other women who were extremely engaged in self-management of their HIV reported their faith was a source of comfort to them after HIV diagnosis and that their religious beliefs facilitated their acceptance of having HIV because 'God meant her to be' (HIV positive).⁴⁹

Stigma

In a number of studies, women reported experiencing stigma due to their condition (diabetes, depression, HIV, AIDS or urinary incontinence).^{24 32 35 51 52 54 57} Women reported that stigma detrimentally affected their self-management as it either caused them to intentionally isolate themselves when experiencing poor health,³⁵ to feel isolated from friends, family and society^{24 28 51 52 54} which impacted negatively on their mental health and reduced their support network, or to choose not to disclose their condition or to follow self-management behaviours or advice so those around them did not realise they had a chronic condition.^{101 102}

In our culture, if a girl has diabetes, she may not get married because she may then have children with diabetes.³²

For women who experienced discrimination, consciously excluding those with stigmatising beliefs enabled them to regain control over their condition and was therefore beneficial to continued engagement with self-management.⁴⁹

Autonomic motivation

Emotions

Self-management can evoke negative emotions such as feelings of sadness, hopelessness and stress.^{20 22 31 35 45 58 62} The time-consuming nature of self-management,²⁰ feeling overwhelmed by the recommended regime⁵⁸ and need for additional planning²¹ resulted in some women feeling burdened by self-management.⁶⁷

You know, having HIV and all, it's enough to get you down; you get depressed, and stressed over everything.²⁶

Women were better able to self-manage their condition after receiving support for their mental health,^{20 24 49 95} reassurance and counselling. On the other hand, women who had a positive attitude regarding their diagnosis and understood their condition did not define them as a person and could be effectively managed long-term were better able to self-manage their condition.^{47 49}

I had to grieve the person I was before my diagnosis and allow myself the chance to do that and understand that I am a different person. And not just because of that, but I was going to be a different person anyway.⁴⁹

Reflective motivation

Acceptance of diagnosis

Acceptance of being diagnosed with a long-term condition and the resulting need to care for oneself in view of the diagnosis was highlighted in a number of studies as beneficial to optimal self-management.^{20 27 30 47 49 57 64}

It's just something that I had to deal with and learn to deal with it. We have to educate ourselves and look after ourselves. We can't expect somebody else to do it for us.⁴⁷

Conversely, being in denial of one's diagnosis hindered self-management behaviours in a study of women with diabetes.³⁵ Furthermore, in a study of breast cancer-related lymphoedema, women desired definitive and permanent treatment and therefore felt burdened and demotivated by the need to perform daily self-management.²⁰

I do not always want to think about having diabetes. I do not at any time want to say that I am diabetic; I always say that my sugar is a little elevated because this makes me helpless.²²

Perceived self-efficacy

Another aspect of motivation necessary for behaviour change is for the individual to believe they are capable

of performing the desired behaviour known as self-efficacy.¹⁰³ Women highlighted that having a sense of self-value,^{20 57} a belief that self-management of their condition was a feasible challenge^{16 43 47 51 52} and perceived themselves as able to problem-solve challenges⁵¹ facilitated their self-management. Conversely, if they perceived self-management to be too difficult, they were less motivated to self-manage.^{33 43}

Here are many persons like us [who are] less confident and live in fear. We need someone to assure us that everything will be alright. We need home counselling. Our confidence levels have to be boosted up.²⁴

Self-management motivation

Women reported that experiencing severe symptoms,⁵⁴ symptoms impacting on their everyday life,⁴⁷ fear of their condition worsening,^{16 20 22 43 44 47 64} and a desire to avoid future healthcare¹⁶ motivated them to continue self-managing their chronic condition. This is due to 'outcome expectancy' the belief that an action will result in the desired outcome.¹⁰⁴

Of course, in the future, I believe it can go back to how it was before. That way, I know I have to stay committed to it.⁴³

Outcome expectancy as a facilitator to self-management was identified in a number of studies.^{43–45 47} Women who observed an improvement in their symptoms either were motivated to continue self-management,^{19 33 47 52 56} or became less motivated due to their symptoms impacting less on their everyday life causing them to forget self-management advice.^{33 54}

You feel much better if you don't have to think about wearing an incontinence pad, or needing to go to the toilet right now, or stuff like that. So that's what really motivated me, and to be honest I had not expected things to improve this much. So that motivated me to do it.¹⁶

Conversely, if a woman's symptoms failed to improve after following self-management recommendations, the severity of their symptoms fluctuated, they had unrealistic expectations about symptom improvement or low outcome expectancy, they lacked motivation to continue.^{16 33 43 47}

Honestly, I feel sceptical about the idea that simply wearing a bandage without medication or anything else would make it go away.⁴³

Additional facilitators to self-management included having a desire to self-manage,¹⁶ experiencing positive emotions after undertaking self-management,³⁴ and recognising the flexibility and autonomy that could be achieved through self-management.⁹⁵ Women who failed to take responsibility for their health,^{22 58} or perceived self-management advice negatively, as dictated deprivation,

rather than feeling empowered by new knowledge about healthy living were less motivated to self-manage their condition.^{21 34} Women reported a lack of motivation to modify or restrict their desired behaviour or diet which meant they did not follow recommended self-management advice.^{21 32 36 44 59 62 102} It is interesting to note this was found primarily in studies of participants with diabetes,^{21 36 44 62 68 102} and once in a group of women with endometriosis.⁵⁹

Sometimes, I felt like I lack control over food because I craved some type of food and sugary beverages but I am trying very hard to cut the craving for I do not want any complication from this disorder.²²

Some women reported their need to care for their family^{26 27 49 60 84} or desire to meet a future partner,²⁷ motivated them to self-manage their condition.

DISCUSSION

Implications of findings

This systematic review aimed to explore the barriers and facilitators to self-management of chronic conditions in women. While the barriers and facilitators to self-management of chronic conditions have been the focus of previous work, we believe our review is novel because it is specific to females and qualitative research findings, which enables us to identify and understand recurring patterns in the barriers and facilitators reported by women, despite living in different countries and cultures. Synthesis and mapping of the study findings to the COM-B model revealed the practical, sociocultural and personal influences which impacted on capability, opportunity, motivation and therefore behaviour across study settings and conditions. There are a number of important findings of the review for policy makers and clinicians. First, certain groups of women including those living in deprivation, those who have logistical difficulties attending clinical appointments, those who are single or live alone and women with migrant status or language barriers find self-management of chronic conditions particularly difficult. This is particularly concerning as women within these groups are known to be socially vulnerable and at greater risk of poor health¹⁰⁵; therefore, barriers to self-management may exacerbate this further. Second, in several studies, women reported that practical concerns such as finance and accessing resources required to self-manage were problematic. While clinicians are unlikely to be able to address this on an individual basis, having an awareness of these challenges and how they impact on ability to self-manage is extremely important. Third, the impact of cultural beliefs and attitudes to women on self-management and therefore women's health was a recurring theme throughout the literature. A frequently identified theme in the literature was that women prioritised everyone else's needs and desires above their own health. In only one study, women recognised that it was necessary to prioritise their health, for the benefit of

their wider family.⁴⁹ Emphasising this as an important outcome of optimal self-management, by using the analogy of putting one's own oxygen mask on first, as used within other contexts of female self-prioritisation,¹⁰⁶ may increase women's motivation. It is not clear why women do not prioritise their health, but the literature within this review suggests it is linked with the role of being a wife and mother. Tackling this, is a monumental, but necessary, task. As a first step, increasing healthcare professionals' understanding of different cultures and how they may impact on health behaviours is crucial. Furthermore, ensuring self-management guidance is not ethnocentric may lessen disengagement from women who are unable to apply self-recommendations to their own way of life. Fourth, the findings of the review highlight the importance of individualised self-management support. While some may find reminders helpful, others find them stressful. While faith demotivates some from being accountable for their health, it motivates others. As with all healthcare, one size does not fit all, therefore self-management support must be personalised to each woman. Finally, the review has highlighted recurring barriers and facilitators that women face while attempting to self-manage their chronic condition.

Methodological strengths and limitations

The review was conducted using a rigorous and transparent methodology and a large number of qualitative studies were identified and included within the synthesis. Publications covered a wide range of countries and different populations of women offering insight into the challenges and enablers that women around the world face when attempting to self-manage their chronic condition. Critical appraisal of the included publications was performed using the CASP guidelines¹⁵ and a hierarchical approach to results inclusion based on evidence quality was used, strengthening the credibility of our work.¹³ There are a number of limitations to our review which may affect the validity, generalisability and rigour of our findings. First, the team did not contact authors to clarify areas of uncertainty regarding reported methods, therefore it is possible that assessments of the quality of studies may be misinterpreted. Second, the eligibility criteria required publications to be written in English which may limit the generalisability of the review. However, articles were included from 24 countries, suggesting a good representation of the available literature and different populations. While societal and healthcare system differences between countries means some findings are not applicable to other populations, many common themes were identified and are likely to affect women regardless of the country where they live, although potentially to different extents. However, because half of identified studies were conducted among women with diabetes, the review is heavily influenced by themes related to diabetes self-management. This may limit the generalisability of findings to other chronic conditions. A second member of the team only reviewed 20% of identified abstracts

and performed data extraction and critical appraisal on 10% of included studies. This decision was made for practical reasons, and the very high degree of agreement between both reviewers on the sample of abstracts and publications which were double reviewed. Due to the high level of concordance between both reviewers, this is unlikely to have adversely affected the review findings. Initially the authors intended to undertake CONQUAL assessment of each included paper to establish dependability, credibility and therefore confidence in the study findings.¹⁰ However, after undertaking training on use of the CASP qualitative checklist, it became apparent that each of these components are considered as part of the CASP checklist. Therefore, the decision was made not to provide an additional CONQUAL score for each study, and instead rely solely on the CASP assessment.

Women's health

This systematic review had a sole focus of women because previous research highlighted the differing needs and challenges of self-managing men and women, and subsequently suggested gender-sensitive healthcare may be beneficial.^{25 36 39} Therefore, in order to develop an optimal pessary self-management programme, it is essential to understand the facilitators and barriers to self-management of this female condition. While comparison of barriers and facilitators between men and women was not performed as part of this review, many of the themes identified were either specific to women, such as cultural attitudes towards women or plausibly more likely to affect women, for example, the recognised burden of unpaid work which affects women and therefore reduces their time to self-manage.

Clinical significance

Due to the increasing prevalence of chronic conditions and a globally ageing population, there is growing support for the concept of self-management.¹⁰⁷ In the UK, the NHS long-term plan, launched in 2019, refers to supported self-management as a means to meet healthcare delivery goals and improve patient care,¹⁰⁸ demonstrating that self-management is a key aspect of national healthcare policy. The findings of this systematic review enable those developing self-management support programmes for women to take account of factors which are likely to enable or prevent optimal self-management of chronic conditions. The findings also suggest that to better support women to self-manage, consideration of identified female specific factors such as an increased dependence on others, burden of responsibilities, reduced social support and sociocultural attitudes towards women should take place and steps taken to mitigate their impact on women's ability to undertake and optimise self-management. It is of note that in 2003 Lorig and Holman published the tasks and skills they believed necessary to self-manage a condition.¹⁰⁹ These are medical management; role management and emotional management and problem-solving; decision-making; resource utilisation;

formation of patient-provider partnership role; action planning and self-tailoring.¹⁰⁹ Despite the included publications being published since 2003, many of the barriers reported by women in this review could be addressed by self-management programmes designed following these principles.

Conclusion

The findings of this novel review highlight that in order to self-manage chronic conditions, women have to overcome various cultural, financial and social barriers. This may explain why women experience worse health than men despite longer life expectancy.¹¹⁰ Using these findings, self-management programmes could be designed to better meet the needs of women and ultimately improve concordance with self-management recommendations. The recently published results of the 'Women's Health – Let's talk about it' survey recommend that evaluating models of health service delivery that better listen to and serve women's health needs is a research priority.¹¹¹ Therefore, further research exploring the outcomes of self-management programmes specifically designed to meet the needs of women with chronic conditions identified here, is indicated to determine whether this would be clinically and cost effective. The authorship team conducted this review as part of a series of work to understand what affects self-management in women by listening to women's voices and experiences. This work will inform the co-creation of self-management programmes by pessary practitioner and women who use pessaries with the aim of improving access to pessary self-management.

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