

Exploring Women's Needs and Information Seeking Behaviors on Online Menopause UK Forums: Implications for Health Communication and Support

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Background

- Most perimenopausal women feel uninformed about menopause, and the highly individual nature of experiences adds to the difficulty, ranging from acceptance to distress. Often stigma and knowledge gaps prevent women from seeking help for menopause symptoms¹.
- Many women in the UK feel uncomfortable discussing menopause with their HCPs, and those who do often report poor care². The symptoms are varied, but the majority of women say they affect their mental health.
- Social media helps women share menopause experiences, learn from peers, and bridge information gaps, fostering community, activism, and education to break taboos and support self-advocacy³.

Objective

There is a lack of education about the course and consequences of menopause despite it being a natural life phase for women. This study aims to identify the reasons women post on online menopause forums to explore information gaps and unmet needs.

Methods

Study Design

A predefined search identified menopausematters.co.uk as the largest UK menopause forum. Social media posts were collected between February 1, 2024, and April 30, 2024, using a third-party social listening tool, Brandwatch. An exhaustive list of 1723 posts were downloaded for analysis. From these posts, those not referring to menopause and menopause treatments were excluded, resulting in a final data set of 622 posts.

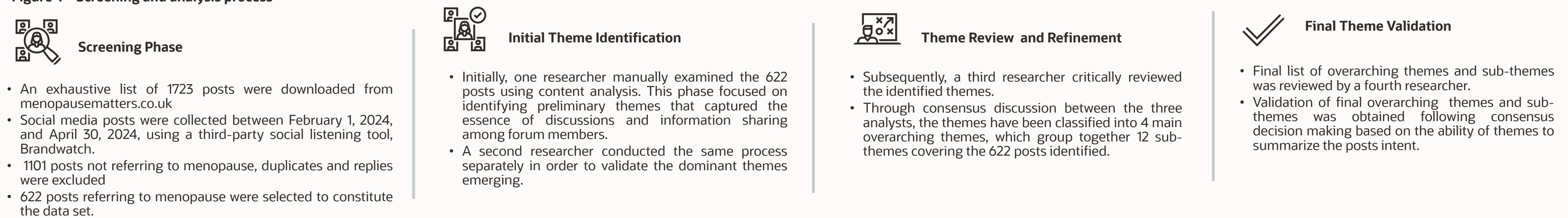
Data Analysis

Content analysis was applied to the 622 original posts, which were then coded using manual thematic analysis. "Original post" is defined as a post which is published on the forum to initiate a thread; replies to these posts are not included (Figure 1).

Process Overview

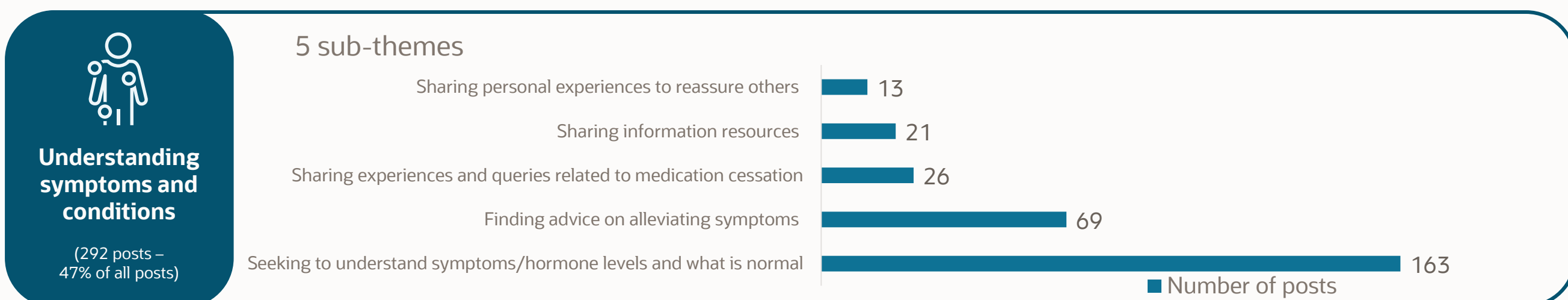
1. Initial Theme Identification	2. Theme Review and Refinement	3. Final Theme Validation
Initially, one researcher manually examined the posts using a content analysis approach. This phase focused on identifying preliminary themes that captured the essence of discussions and information sharing among forum members. A second researcher conducted the same process separately to validate emerging dominant themes.	Subsequently, a third researcher critically reviewed the identified themes. Through detailed discussions, the three researchers refined, validated and expanded these themes to ensure they accurately reflected the content.	Finally, a fourth researcher verified the themes. This step confirmed that themes correctly summarised the intention the post's intent and minimized bias.

Figure 1 – Screening and analysis process



Results

Chart 1 – Overarching theme of understanding symptoms and conditions and associated sub-themes. N=292 posts



Understanding Symptoms and Condition

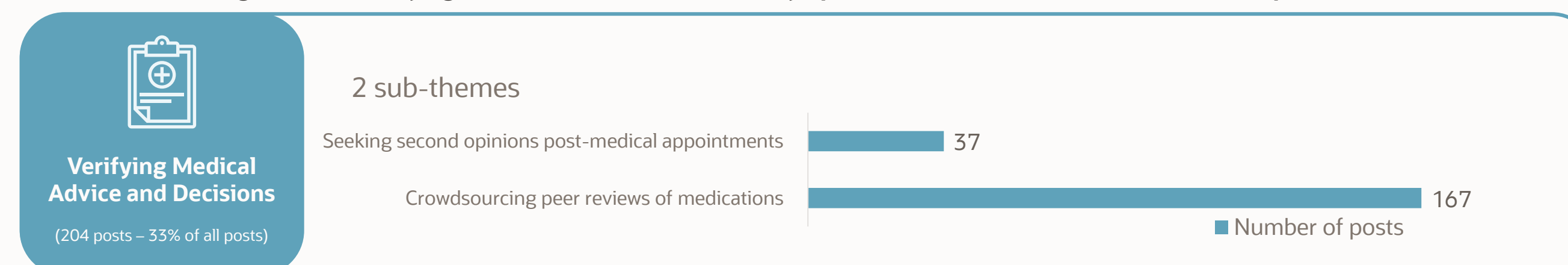
The most common reason members post to the Menopause Matters forum was to better understand their symptoms and conditions (292 posts -47% of all posts) (Chart 1).

- Women trying to understand "what is normal" (163 posts -26% of all posts) is often intersected with sentiments of anxiety as they try to understand what is happening to their bodies.
- This type of advice-seeking occurred not only at the beginning of women's journey into menopause but at all stages as symptoms evolved over time.

I am 61 and have been on HRT for 6 years... This week I have started bleeding, albeit lightly, and last night I had period type pains, which were bad enough to make me take to my bed. Obviously, this has worried me a lot, imagining something terrible going on, so I emailed my menopause clinic.

Has anyone not been able to shake off the physical symptoms of anxiety mainly the chest discomfort? And what the hell is the whooshing about? am going to the GP in the morning but wanted to reach out and see what your experiences are. Everyone is different but I honestly feel like I'm going bonkers and the more I worry the more jittery I get and the more jittery I am the more I worry!

Chart 2 – Overarching theme of verifying medical advice and decisions symptoms and associated sub-themes. N=204 posts



Verifying Medical Advice and Decisions

Verifying medical advice and symptoms was the second largest theme (33%) (Chart 2).

- Within this theme, was the largest sub-theme across all posts; crowdsourcing peer reviews of medications (167 posts - 27% of all posts). After receiving advice or a prescription from an HCP, women sought advice from others who had used specific medications to better understand potential side effects. They also sought advice on which other medication to try after not being satisfied with their current treatment pointing to a "trial and error" approach.

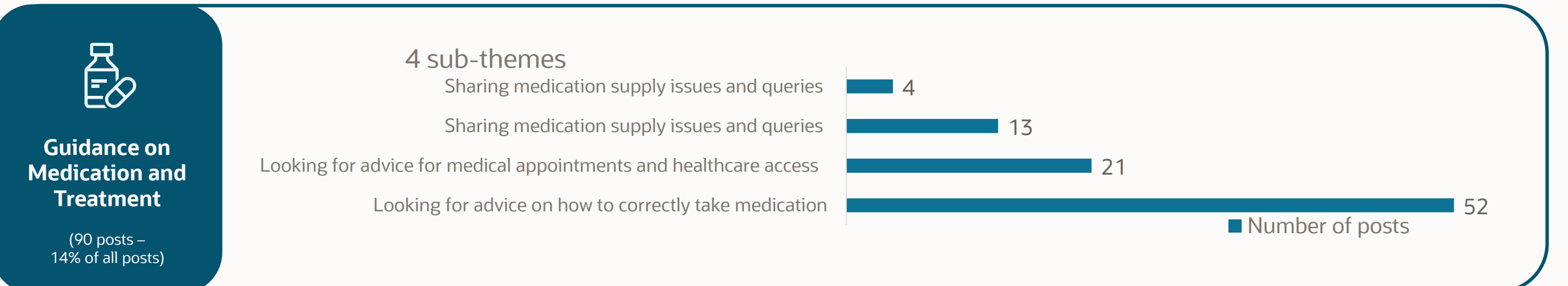
Has anyone else used steroid cream for this and did it work. So sore now but know steroids can be a bit stingy and god knows how long I will have to wait to see a dermatologist.

I am 62 with vaginal atrophy. The pessaries created bladder infections and even more inflammation. So a doctor phoned about prescribing HRT. He scared me half to death, talking about the increased cancer risk for someone my age. I have an excellent BMI and no blood pressure problems although I do have osteoporosis because I've had MS for 20 years which has reduced my mobility although I am still walking and I use an exercise bike. Is it really too much of a risk to take for someone like me?

Conclusion

- Women turn to online forums for community, education, and to express dissatisfaction with healthcare support.
- These unprompted discussions reveal genuine concerns, making social media analysis important for understanding patient needs.
- Many women seek peer advice because they feel medical solutions are inadequate or unclear, which induces anxiety.
- Themes and sub-themes align, suggesting compounding issues that may increase barriers for women seeking effective treatment
- Forums also provide a space to discuss taboo or stigmatizing topics.
- Women desire to be empowered with information to actively participate in treatment decisions.
- Acknowledging these aspects and addressing this need may help improve communication between physicians, patients, leading to better management and outcomes of menopause.

Chart 3 – Overarching theme of guidance on medication and treatment and associated sub-themes. N=90 posts



Guidance on Medication and Treatment

Guidance on medication and treatment (14%) included women seeking practical advice and experiences (Chart 3).

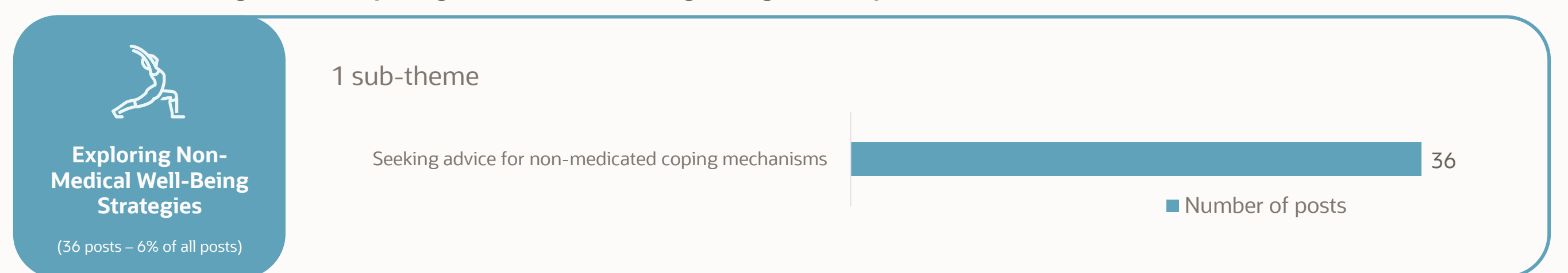
- This theme included women looking for advice on how to correctly take medication (52 posts -8% of all analysed posts). Examples included uncertainty over when to take medication, seeking advice to ensure life activities do not impact on treatment administration, and advice on altering dosage.

I was planning on taking up until day 25 then taking a 3-day break to trigger a bleed then restart. Any ideas please? Not sure what to do now going forward.

This is so embarrassing but I started Blissel estriol gel last night and could'nt get the applicator inside me despite putting lubrication on it. It only went in about half an inch and then all the gel came back out.....Is there anyone who has had this problem and have managed to overcome it some way or another.

I'm 49 and have been getting the entire remit of symptoms EXCEPT for flushes. I have a review appointment with my GP as I've just started month 4 on HRT (Evorel Sequi patches). Due to past missed-diagnoses with something else, I like to get my ducks in a row before I go so I can pre-empt what they might say/do.

Chart 3 – Overarching theme of exploring non-medical well-being strategies. N=36 posts



Exploring Non-Medical Well-Being Strategies

The smallest overarching theme is Exploring Non-Medical Well-Being Strategies which centered on women seeking and sharing advice on non-medicated coping mechanisms (36 posts - 6% of all analysed posts) (Chart 4). This included treatments for specific symptoms.

Can anyone recommend anything they use for thinning hair. It's so fine and also very thin that you can see my scalp. I've been using the Plantur 39 range but not seen much difference. Thank you for any suggestions.

References

1. Barber, K., & Charles, A. (2023). Barriers to Accessing Effective Treatment and Support for Menopausal Symptoms: A Qualitative Study Capturing the Behaviours, Beliefs and Experiences of Key Stakeholders. *Patient Preference and Adherence*, 17, 2971–2980. <https://doi.org/10.2147/PPA.S430203>
2. Martin-Key, N.A., Funnell, E.L., Spadaro, B. et al. (2023) Perceptions of healthcare provision throughout the menopause in the UK: a mixed-methods study. *npj Womens Health* 1, 2. <https://doi.org/10.1038/s44294-023-00002-y>
3. Rachel Weiss. (2023) Menopause and social media: Pros and cons for the general public. *Maturitas*, Volume 174, Pages 67–68, ISSN 0378-5122, <https://doi.org/10.1016/j.maturitas.2023.02.006>.

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