INTERNATIONAL PELVICPAIN SOCIETY

A Qualitative Study on the Lived Experiences of Women With Persistent Pelvic Pain Including Endometriosis and Pelvic Floor Myalgia.

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Introduction

Persistent pelvic pain (PPP), effects up to 1 in 4 women with significant biopsychosocial and economic impact irrespective of diagnosis.[1-2]

Overlapping conditions, including endometriosis, often involve overlooked muscular contributors to PPP (pelvic floor myalgia), treatable with physiotherapy and Botox.

Qualitative research on PPP, endometriosis and pelvic floor myalgia remain limited.[3]

Such qualitative research can help inform and improve the diagnostic journey and experience of women living with PPP.

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Aim

Objective - to explore the lived experiences of adult women (≥18 years) with PPP (≥6 months) with self-reported endometriosis and/or pelvic floor myalgia, or those without a diagnosis yet.

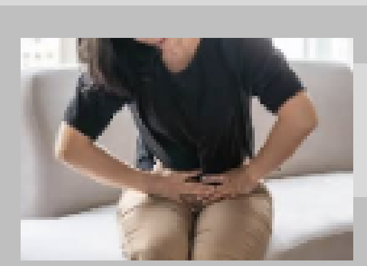
Method

Single-timepoint, cross-sectional, qualitative design using one on one semi structured interviews.

From private and public metropolitan gynaecology and physiotherapy clinics, social media and personal networks.

Reflexive thematic analysis was utilized

Recruitment - snowball sampling



THEME 1 : Psychosocial impact of the condition itself

"I had some kind of knowledge. But then, once I knew it was just like, Wow, okay. Now, I have a clear mind. I know what is going on and now I can get treated for it instead of just living in limbo " (B02, 25yrs, both endometriosis and PFM)

"I think I didn't expect like the mental load of it all, I think people like don't really talk about that a lot and I think that that's a big factor like being in pain all the time is hard and trying treatment that may not work is also very hard" (B02, 25yrs , both endometriosis and PFM).

THEME 2 : Psychosocial impacts of the healthcare journey when they have this condition

"this is what women experience, women experience period pain. You know you can go home and take some Naprogesic, or you can take some Panadol. But this is the joy of being a woman. You know, things like that. Just that real insensitive, not really even listening to what you're saying and actually having empathy and understanding" (B04Karise, 47 yrs , both endometriosis and PFM)

"But everything came back completely normal and then, instead of being like, Hey, maybe this is something else you could try. It was like, there's not a problem here bye" (N02Taylor, 35 yrs , no diagnosis)

THEME 3 : Financial and non Financial cost of this condition and its healthcare

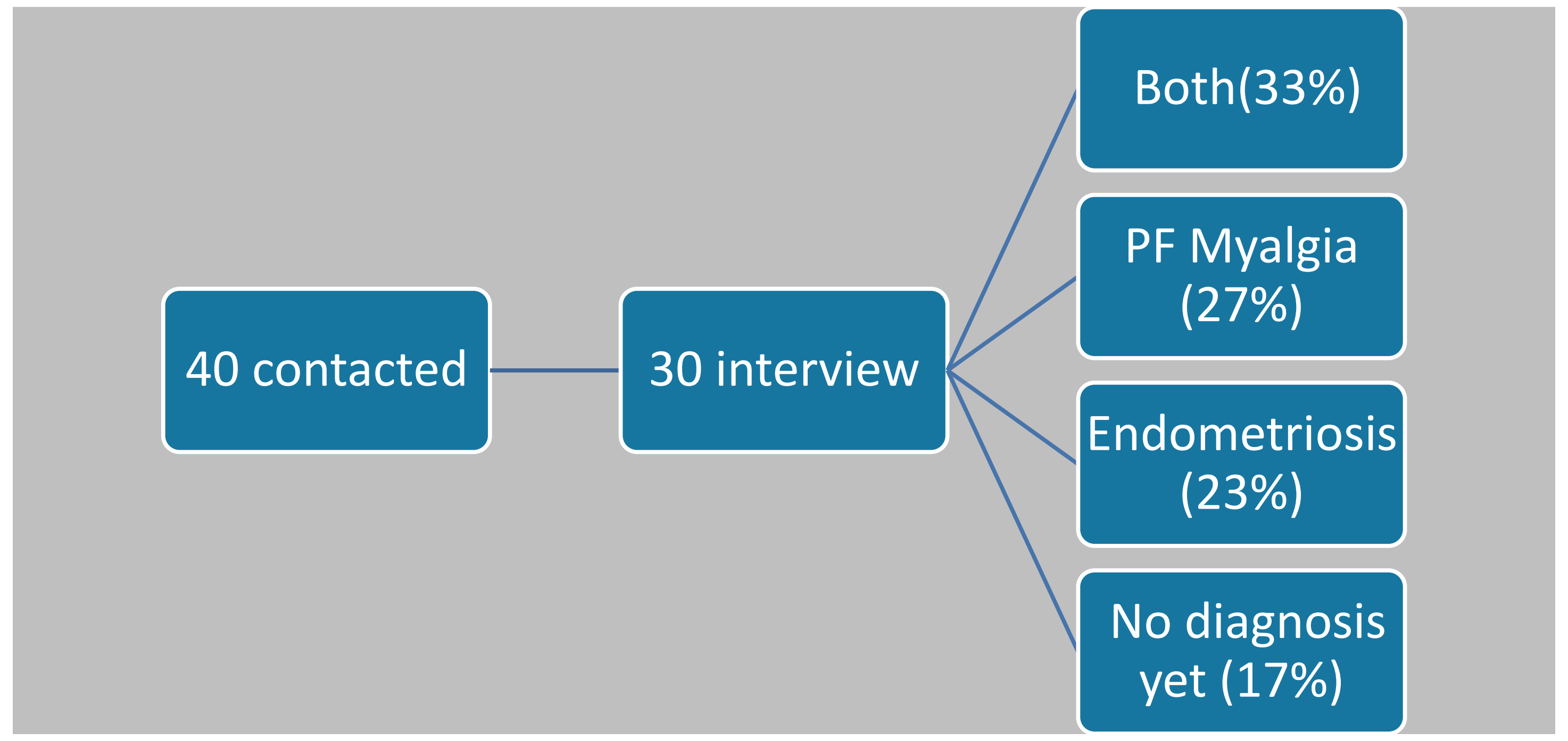
"the frustration of the intersection of being essentially disabled by this condition, which means that you earn less but you've got to pay more to access health care and the frustration and stress that comes from that intersection of issues even if someone understood that, even if they couldn't necessarily change the fees. (E04Leah, 35 yrs, endometriosis).

☐ "It was really hard to be really productive at work, because you've got the brain fog and the fatigue. So I'd say, Yeah, pelvic pain has been just like the biggest blight on my 30s. It was awful really, really awful." (B08Elsie, 35 yrs , both endometriosis and PFM)

(graph or photo).

Participant demographics

- Median age - 32.5 years (21-47)
- Mean duration of PPP of 11.4 years (2-29)
- Undergraduate degree (70%)
- Living in areas (of least disadvantage (63.3%) according to the Index of Relative Socio-economic Disadvantaged (IRSD).



Conclusion

•Our data reveal that women experience wide-ranging psychosocial impacts related to their condition itself (PPP irrespective of diagnosis) and its associated healthcare, often without tailored and streamlined support. Our findings, highlight the need for person-centered care models that prioritize improved diagnostic experience, access, ongoing psychosocial support, enhancing the lived experience and healthcare journey.

References

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