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From Insight into Action: Understanding How Employer Perspectives Shape Endometriosis-Inclusive Workplace Policies

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Abstract: Endometriosis costs Australia $9.7 billion AUD annually, with most of the cost burden due to absenteeism and lost productivity. Previous research has shown how the absence of workplace support(s) for endometriosis symptom management exacerbates these negative effects. Despite this knowledge, little is known about the role of employers and workplace policies in supporting employees with endometriosis, and what institutional barriers prevent the operationalisation of workplace supports. **Background/Objectives:** As part of the Endo@Work project (co-designed Endometriosis workplace guidelines), this study examines the perceptions and experiences of employers (managers, HR, and senior leaders) to understand how the Endo@Work guidelines can be implemented. **Methods**: Seven focus groups with 24 Australian employers were undertaken. Using reflexive thematic analysis, data was interpreted through a post-structural feminist lens with focus group discussions revealing how employers recognise the importance of workplace guidance/policies. **Results/Conclusion**: Problematically, existing policies and practices were often tokenistic and inconsistent. This study identifies practices contributing to equitable workplaces including leadership buy-in, flexible work arrangements and the thoughtful integration of workplace education initiatives. The findings emphasise the need for consistent policy enactment alongside ongoing education/training to foster inclusive workplaces and gender equity outcomes.

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Introduction

The introduction should briefly place the study in a broad context and highlight why it is important. It should define the purpose of the work and its significance. The current state of the research field should be carefully reviewed and key publications cited. Please highlight controversial and diverging hypotheses when necessary. Finally, briefly mention the main aim of the work and highlight the principal conclusions. As far as possible, please keep the introduction comprehensible to scientists outside your particular field of research. References should be numbered in order of appearance and indicated by a numeral or numerals in square brackets—e.g., [1] or [2,3], or [4–6]. See the end of the document for further details on references. As women''s' labour market participation inches closer to parity [1,2], scholars have sought to expand our attention from greater workforce participation to understanding women's work and career experiences. This has led to research into the gender pay gap, sexual harassment and assault in the workplace and women''s' leadership experiences [3–8]. Understanding the experience of women in organisations is critical as the workplace has often been a traditionally male space, and workplace cultures and everyday practices (as we will show) can 'discipline' women's bodies [9–11] and inequitably shape their career trajectories [12–14].

There is a growing recognition of how women''s' working lives are shaped by menstruation, menopause and chronic illnesses including endometriosis and chronic pelvic pain[1] [14,16]. Scholars including Acker's (1990) seminal work illuminates how workplaces value and reproduce the "ideal worker" norm – an unencumbered employee who prioritises work above personal, familial, or social obligations. This ideal continues to shape workplace values, rewards, and promotions that benefit men [12,13,17]. Employees who "fail" to embody this ideal worker include parents, people with chronic illnesses, women, and people presumed female at birth (PFAB) who menstruate, experience menstrual disorders, and transition through menopause – as their bodily functions are often considered productivity disruptions. Relevant to the present research, women/PFAB living and working endometriosis often fail to embody the ideal worker, as the unpredictability and severity of their symptoms can reduce their perceived 'commitment' to work. Overall, the salience of the ideal worker norm prevents lasting, meaningful workplace change by reinforcing narrow definitions of a 'good worker' – one deemed worthy of reward and promotion [12].

To advance workplace gender equity outcomes, increasingly occupational health and safety approaches that value and enable women to manage their gynaecological health at work are prioritised [14,18–20]. For example, endometriosis, a chronic inflammatory condition that affects 10-14% of women and those PFAB [21–23]. The condition can impact many if not all aspects of a person's life including their work and career [24–27]. The cost of illness burden for endometriosis is estimated at 9.7B AUD per year, with the majority of costs (84%) attributed to lost workplace productivity [28].

Endometriosis negatively impacts productivity, absenteeism, career choices and progression, and professional life [24,26,29,30]. Debilitating endometriosis symptoms, combined with limited workplace flexibility and support, contribute to increased presenteeism (i.e., working with reduced productivity) and absenteeism (i.e., missing work) [31]. Accordingly, women diagnosed with endometriosis are more likely to transition out of the labour market when compared with women without the condition [21]. Those who suffer more severe symptoms report lower workability [32] and a higher probability of being unemployed [16]. Consequently, to advance gender equity outcomes, the development and implementation of workplace guidance associated with chronic health conditions such as endometriosis and chronic pelvic pain is essential.

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[1] This paper sometimes uses the term 'women' and 'women's health'. This is to acknowledge the specific experiences and challenges faced by cisgender women at work, often exacerbated by menstruation, menopause and/or chronic illnesses including endometriosis and chronic pelvic pain. Additionally, this represents that most of the research in this area to date has been conducted with cisgender women at work. The authors of this paper acknowledge that trans men, intersex, non-binary and gender diverse people can menstruate, transition through menopause, and/or have chronic illnesses including endometriosis and chronic pelvic pain. By using the term 'women' this paper both accurately reports the cohort represented in existing studies while also illuminating the gaps in our understanding of the specific experiences, challenges and ways to support our gender diverse communities at work. Where possible, this paper uses the term women and those presumed female at birth (PFAB) as guided by the research around inclusive language & accurate reporting (Adler H, Jeffrey S, Ashton LM, Howe D, O'Shea M, Ng CHM, Last L, Wilson-King G, Bush D, Armour M: **The Language of Endometriosis Prevalence: How Can Gender Inclusivity and Accuracy Coexist?** *Women's Reproductive Health* 2024:1-18..)

Research suggests that relatively simple workplace adjustments can improve endometriosis symptom management and work performance as evidenced during the COVID-19 pandemic and associated lockdowns forcing employees to work from home. Adjustments including but not limited to flexible work schedules, adequate breaks, modified physical loads, access to nearby bathrooms, and the ability to rest or use heat packs as needed were reported to greatly assist employees to manage symptoms and improve productivity [33,34]. Despite these gains, there has been little empirical research providing employers with guidance on how best to develop and implement supportive policies and practice post-pandemic for people with endometriosis [35].

This paper explores the perceptions and experiences of employers in various roles, including managers, supervisors, senior leadership, and human resources (HR) representatives, in managing the work of employees with endometriosis or similar health conditions. Accordingly, the present research aims to (a) provide practical guidance for employers seeking to support employees managing endometriosis symptoms at work, and (b) recommends how guidance and supports can be integrated across existing workplace policies and practices. The study is guided by two overarching research questions.

1. What workplace policies and supports currently exist and how do they compare to the proposed Endo@Work guidelines?

2. How have existing workplace interactions and/or supports enabled employees with endometriosis to work productively while managing endometriosis symptoms?

Methods

Participants and Recruitment

This study is the third phase of a wider project (titled: Endo@Work) involving the co-design of a set of evidence-based guidelines for Australian employers. The first two phases included a national online survey and focus group discussions to understand experiences of Australians living and working with endometriosis. This work has informed the third phase, a set of focus group discussions with employers (managers, supervisors, and HR specialists) across Australian workplaces.

After receiving ethics approval from Western Sydney University (H15537), we advertised the study (focus groups) through social media platforms Instagram) via Endometriosis Australia an endometriosis advocacy organisation, and their platforms supporting the endometriosis community (>45,000 combined followers in 2022). The research team also shared the recruitment invitation through their personal and professional networks. The study was open to people living and working in Australia who are over the age of 18 years and who are currently employed in a managerial, supervisory, executive, and/or HR role. Participants self-selected to follow a QR code on the study's advertisement to complete an expression of interest form, via the online survey platform Qualtrics. Contact and demographic information including job title, organisation name, industry/field, and number of employees were collected. The primary author (DH) contacted via email all respondents who met the inclusion criteria and assigned people to focus groups based on their availability.

This project adopts a participatory action research (PAR) approach by emphasising a continuous commitment to understanding participants'' lived experiences [36]. Building on Foucault's "power-knowledge relations" [37] this study approach is firmly rooted in the embodied everyday experiences and understandings of its participants [38].

Between October and November 2023, 24 participants took part in seven focus groups. The majority (92%) identified as women, with the remaining 8% identifying as men. Most participants were employed in medium-sized organizations (25%, with 50-199 employees) or large organizations (50%, with over 200 employees). Approximately one-third worked in national workplaces, while Victoria (42%) and New South Wales (29%) were the most represented locations. Participants came from a diverse range of industries, offering varied perspectives across different workplace types (See Table 1).

Table 1. Demographics, workplace and role related information (N=24).

Gender, n (%)		
Women	22	92%
Men	2	8%
Work in (Australian States & Territories) n, %		
Across all states and territories	8	33%
New South Wales	7	29%
Queensland	2	8%
South Australia	-	-
Tasmania	-	-
Victoria	10	42%
Western Australia	-	-
Australian Capital Territory	-	-
Northern Territory	1	4%
Job Title, n (%)		
Manager/Supervisor	13	54%
Executive Team	2	8%
HR Department	6	25%
Consultant	3	13%
Industry/Field, n (%)		
Healthcare and Social Assistance	4	17%
Education and Training	2	8%
Administrative and support services		
Professional, scientific, and technical services	4	17%
Financial and insurance services	4	17%
Retail Trade	1	4%
Public administration and safety		
Information media & Telecommunications	2	8%
Construction	1	4%
Mining/Manufacturing	2	8%
Other		
Emergency services	2	8%
HR Strategy	1	4%
Utilities	1	4%
Number of Employees, n (%)		
Up to 19	3	13%
20 to 49	2	8%
50 to 199	6	25%
Over 200	12	50%

Procedure

Participants took part in a 60–90-minute online focus group (via Zoom). Focus groups followed a semi-structured discussion in which questions were informed by previous research preliminary findings (phases one and two), and acted as open-ended prompts to explore:

- Experiences managing people with endometriosis (and similar conditions) in the workplace.
- Experiences with workplace accommodations, supports, and policy.
- Perceptions and feedback on the research team's codesigned Endo@Work guidelines. (see next section Reviewing Endo@Work Guidelines)

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Following each focus group, researchers leading the session stayed online to discuss their initial observations and reactions. This also acted as an iterative feedback session, which helped shape and refine open-ended prompts and questions for the following session.

Reviewing Endo@Work Guidelines

Before the focus groups, participants were asked to review a draft set of codesigned endometriosis guidelines (Endo@Work) including policy recommendations, educational factsheets, and processes/promotion recommendations. All guidance/recommendations included key findings and best practices informed by the authors previous research: global scoping review of workplace policies, guidelines and legislation to support menstruation, menstrual disorders and menopause at work [35]; a national survey generating a snapshot of people experience with existing policy and managing endometriosis at work [39]; and focus group data exploring women's experiences managing endometriosis at work [40].

The guidelines reflect three pillars: Policy, Processes, and Promotion. Policy supports included (but were not limited to) recommendations for flexible working arrangements, flexibility to take breaks or access the toilet, access to quiet break rooms, and one-time medical certificates. Processes, the second pillar, included prescriptive steps for an organisation to take to successfully embed policy into ongoing processes. For instance, instructions on embedding reasonable adjustments for staff, roles, and responsibilities for a workplace "EndoChampion". The EndoChampion (discussed as one of the study themes) was introduced in the guidelines to serve as a supportive and approachable workplace advocate and resource. The nominated 'champion' does not need to have a diagnosis of endometriosis but demonstrates empathy, have highly developed communication skills, and a willingness to learn about the condition. EndoChampions help foster inclusivity and direct colleagues to appropriate resources. The third pillar, promotion, included education and factsheets for supervisors, and staff and suggestions for how the nominated 'champion' can promote endometriosis awareness in the workplace. Finally, participants discussed their experiences implementing similar guidelines or supports, experiences and/or perceived challenges.

Data Analyses Approach

Reflexive thematic analysis (RTA) [41] was employed to explore how the subjective experiences of endometriosis symptom management in the workplace and how these experiences intersect with broader societal systems and structures. By drawing on Braun and Clarke's (2006) framework, RTA offers a structured method for identifying, organising, and capturing patterns of meaning within qualitative data. Familiarising oneself with the data, generating initial codes, identifying latent themes by clustering the conceptually similar manifest codes, refining themes and assigning representative labels, and producing a detailed report that highlights the relationship between themes underpins their approach [42]. During the initial analytic phase, primary author (DH) de-identified all transcripts, assigned pseudonyms to participants, and compiled them alongside authors' initial reflections into Word documents. To deepen data familiarity, DH repeatedly reviewed the de-identified transcripts and accompanying notes, documenting observations and reactions. She then engaged with all authors to discuss these initial reflections.

Through the second phase, DH developed preliminary codes by re-reading transcripts and organising the data alongside their corresponding codes in a structured Word document. A table was used to list the initial codes in the left column, while the related line-by-line transcript data was assigned to the appropriate code. In the third phase, DH collaborated with authors (MA and MO) to review and refine the initial codes and related data. Together, they grouped codes based on conceptual similarities and identified latent themes to uncover deeper meanings. Reflexivity was maintained by acknowledging assumptions, resolving disagreements in coding, and collectively reaching consensus on latent themes. Finally, to cross check codes and themes DH used NVivo to systematically recode the transcripts line-by-line under the agreed-upon latent themes.

Positioning Ourselves in Data Analyses Approach

This study adopts a post-structural feminist lens to critically examine the experiences of employers (managers, supervisors, and HR specialists) managing employees with endometriosis. Post-structuralism offers a framework that acknowledges the diversity of knowledge, truth, rationality, and power [43,44]. By extending "problematisation" as a method to 'stand back' from 'objects' and 'subjects' presumed to be objective and unchanging (e.g., workplace structures: policy and processes) to look "at the unfolding, the evolution and the interaction of different practices" [45] we can usefully contribute to alternative ways of workplace organising [46] that enables the involvement and productivity of a diverse workforce.

Findings

In principle, most managers value policy, guidelines, and reasonable adjustments to support employees managing endometriosis symptoms at work. Despite this in principle support there was little knowledge or consensus on how to design inclusive policies – with theme 1 demonstrating employers' perceptions that existing policies were tokenistic, inconsistent and inequitable across all employees. Theme 2 illuminates the every-day practices (via top-down, trust, and advocating) shaping inclusive workplaces.

Table 2. Themes and Subthemes.

Themes		Subthemes
1.0	**"We have policies"**	**1.1** …but are we leaving people behind? **1.2** …but they're inconsistent across managers **1.3** …but they're only beneficial to the ideal worker
2.0	**Workplace culture change is driven by the banal (everyday) practices**	**2.1** Change is driven from the top-down **2.2** Change is driven by managers who trust staff and understands they're not homogenous **2.3** Change is driven by a consistent education (and a role to facilitate it)

1.0. "We Have Policies"

1.1. We Have Policies…"But Are We Leaving People Behind?"

Post-pandemic, most participants stated that their workplace offers a policy relevant to flexible working arrangements and/or flexible practices as outlined through the Endo@Work guidelines. Concerning menstruation (or leaky bodies at work), none of the workplaces represented by the focus groups had a menstrual or menopause policy/guideline. Accordingly, while participants reported that policies existed for flexibility, the unspoken norm that you 'just get on' with the job.

For many employers, they took their cue from existing national standards. Sam, focus group 1 (FG1), remarked:

> "…there's the national employment standards that organisations have to meet in terms of their obligations around offering flex [flexible work practices]"-Sam, FG1

The nature of the work also shaped flexibility outcomes. Jordan (FG2) explains:

> *"In the manufacturing industry…we would have about 80% blue collar workers and then… 20% white collar. The recommendations that you'd put in [Endo@Work], all of those are either already implemented or could easily be implemented. But…when I reflect…at previous workplaces that are probably more predominantly white collar, 100%, they're probably already introduced." -Jordan, FG2*

As Sam outlines (FG1) the business/workforce size also impacted formalised policies:

> *"…most [workplaces] will have a flexible work approach or policy, particularly in the larger organisations, often not in the smaller ones, but they'll be a bit more* ad hoc *in how they approach flex."-Sam, FG1*

However, when the research team asked respondents to discuss *how* staff were accessing the policies, several issues emerged. While policies existed in a formal capacity, they were inconsistently accessed and were often perceived as a mere 'tick-a-box' exercise. *"Looking at our policies… how do we make it consistent? We could be doing better."-Grace (FG4)* Further problematically, policies were either not promoted, or different teams identified challenges accessing the policy:

> *"It tends to be a bit tokenistic...there's a lack of promotion because…it's sometimes easier to just kind of go, yeah, it exists and we're doing the right things as far as we're keeping our noses clean from a legislative and regulatory perspective, but we're not going to encourage our people to use it and we're not going to tell them how they can use it, when…and why they can use it…that sort of process piece is absent"-Olivia, FG6*

Without advocacy of policy and encouragement of uptake from management at all levels, employees may not feel comfortable to take up the supports offered:

> *"We support people, we just don't loudly support them. That doesn't allow for an environment where people who are suffering from endometriosis or any other chronic illness feel safe to come up and say, hey, this is what I'm suffering with. This is my pain management; this is what I might need"-Grace, FG4*

> *"We know that we're a supportive firm and that we would be 100% flexible with any team member, with whatever their needs may be. But how do we make sure that each employee and each team member feels and knows that as well? I'm starting to think now, is anyone being left behind?"-Natalie, FG4*

1.2. We Have Policies…But They're Inconsistent Across Managers

In most workplaces, line managers were positioned as policy gatekeepers who could render policy access easy or difficult. Matt (FG6) remarked how, *"…every individual line manager would deal with it differently*". Other participants discussed how access to support was influenced by the line managers' experience living with endometriosis and management style:

> *"I think biases play a huge part in this, and I know that it shouldn't, but it does. As someone who's experienced endometriosis for a long time, I will do whatever I can to keep [flexibility] 'off the books', to help somebody within the realms of appropriateness...But for other managers, it would just be, 'absolutely not. We're going to go by the letter of the law and we're going to follow due process. So, I think it really comes down to the individual."-Olivia, FG6*

As Sam (FG1) explains, having a manager who is empathetic, understanding, and willing to advocate for you and overcome workplace culture norms can profoundly shape your career trajectory:

> *"One of my staff couldn't figure out for quite a while why she was in a lot of pain. Then she found out that she has endo. I had quite a negative experience with my employer at the time because they were not open to allowing her to work from home. So…I just said, I know she's a hard worker. I know that she's not*

> *taking me for a ride. I told her, you do what you need to do. She does an incredible job. So, it was really hard…the senior management was predominantly male. They don't know anything about endo. There was very little want to know and to understand that it's chronic illness and what it entails. So, there was very little support for me. And at some point when I put her forward for [a promotion], I was told that, well, she needs to be aware that she needs to come into the office and the fact that she wants to work from home is not going to work out…I had… [to] champion for her, but it's not very common and there is no policies and there is very little support to understand that it's a chronic illness and that the work can be done"-Sam, FG1*

1.3. We Have Policies…But They're Only Beneficial to the Ideal Worker

In a post-pandemic work setting, many workplaces have implemented a company-wide or one-size-fits-all 'flexibility' policy. Problematically, this approach is wedded to 'hours worked' rather than work outcomes and/or outputs. Our data demonstrates that this one-size fits all approach may be ineffective in supporting people with endometriosis because, endometriosis is a chronic (non-cyclical) condition which symptoms vary from person to person, and therefore types of support vary. As Matt (FG6) elaborates:

> *"I think you've got to define what flexibility is a little bit. Is flexibility working from home? Is it being able to work from home sometimes? Is it flexibility within an office environment? And what does someone actually see [flexibility] as being? Because I know when we, as an example, we came back from COVID I thought that we needed to be in the office a little bit. So, we went three days in the office, two days out of the office. Then after three months, I asked the team, 'do you think this is working?' And it was, 'no'. So, I suggested, 'why don't we default [everyday] working in the office? And if you've got to work from home, then work from home.'...That was more flexible than when we had certain days in the office"-Matt,* FG6

Workplaces adhering to strict expectations relevant to *when* employees' work flexibility can be enabled – can fail to support staff with chronic illnesses, such as endometriosis, where flare-ups are non-cyclical and can vary:

> *"What people need at different times is very different. You might have someone who's very acutely unwell, having a lot of surgery, and then they might have a period of being well for a year or 18 months. It's really hard to…spell out people's experiences because everyone's [symptoms] are just so different and what support they need, it will differ at different times. Having that flexibility and responsiveness and openness and to reviews these actions…is probably more beneficial."-Georgia, FG6*

The physical office lay-out was also problematic for some staff managing endometriosis:

> *"There's a lack of privacy [hot desking], especially if you cannot keep your personal items at your desk. So, if you need to bring into work your heat packs, with you every single day because you're working at a hot desk, that's not ideal for people with chronic illness…And then just comfortable seating, like leg rests and things. Some of the seating we have is uncomfortable, so being able to bring in a cushion, wearing comfortable clothes to work, we all dress very corporate in my office, which is fine, but when you're having a flare-up, you just want to wear something that's a bit more comfortable. So these are just like really simple examples of: can the workplace be accommodating in small ways"-Mia, FG2*

Relatedly, the physical infrastructure available in some workplaces presented obstacles for employees seeking to manage symptoms while physically present in the workplace:

> *"So, at the moment I think we're in a good space prior to this, though, and a lot of my colleagues, female colleagues are experiencing this, is that we get deployed to sometimes quite different locations where you don't have access to the type of toilet or microwaves, heat packs, all the comfort items. And there is an expectation in my job that we get on with it and you just have to deal with it."-Riley, FG4*

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2.0. Workplace Culture Change Is Driven by the Banal (Everyday) Practises

Our data illuminates that policy socialisation arises through informal everyday practices. While introduction of policy is a key step, positive change to support people with endometriosis is driven by everyday managerial and leadership led practices.

2.1. Change Is Driven from the Top-Down

Most study participants acknowledged that culture (change) is driven from the top-down. For example, Jane (FG1) provides a case where a manager who does not apply strict rules and norms around work can help drive an inclusive and supportive environment:

> *"The people that were managing the centre before…were very stringent. No food at desks, signs everywhere, and just telling people how to be human beings. And it was just not a nice environment...A few people felt uncomfortable. They went to HR. HR…realized there was a fundamental problem with the way that the [workplace] was being managed. So those managers were moved on [and] a new manager was brought in. He was tasked with really shifting the culture...it's just appreciating the people that we have and just trying to make it as inclusive and supportive and comfortable as we can." –Jane, FG1*

During the discussion, another participant, Jen (FG1), elaborated on the importance of senior leadership buy-in enabling a top-down cultural change:

> *"…it is that cultural thing from the top…if the top of your organisation is advocating for flexible work, open and honest conversations, then it flows down to the next level of management, and then it flows down to my level of management, which is middle management, which is the people on the ground who can say, 'yeah, look, I'm happy to accommodate your flexible working request within operational reasons' " -Jen, FG1*

Even in male-dominated workforces (numerical and cultural), where ideal worker norms remain deeply entrenched, Margaret (FG5) presents a case for how senior leadership buy-in can enable culture change:

> *"…if we send an internal communication out* via *email. The way that they think about the information that's in their email is how much money worth of time is it going to take for our entire business to read that? If everyone's average salary is $250,000 a year and we're asking them to dedicate a portion of their time at work to read that email, it better be worth it. So, it is a challenge, but if I can…plant the seed among some of our senior leaders…[and] keeping them mindful that this is a problem, and it is something that people struggle with every single day"-Margaret, FG5*

Implementing policy or cultural change through a top-down approach ensures consistent adoption across the workplace. Lydia (FG5) describes how:

> *"It needs to be modelled…by all of management so then people feel safe to do it. And that's where, in our organisation, it is modelled by our senior leaders that you do work four days a week, that you're not expected to answer your emails when you're not there or your phone."-Lydia, FG5*

2.2. Change Is Driven by Managers Who Trust Staff and Understand They're Not Homogenous

When prompted, participants in the focus groups provided examples of how they have successfully supported their staff with endometriosis (or similar issues). Many participants reported the importance of understanding how *all* staff have different needs and require varying levels of support. They suggested that meaningfully meeting these needs is tied to establishing and maintaining trust. For example, participants interpreted how employees are experts of their own health, are best placed to communicate when they require additional support, and that most employees if supported will be productive at work. Matt (FG6) remarks:

> *"[Managers need to be] willing to say… 'I'm going to be led by you and I'm happy to be led by you as much as possible'. And a lot of that comes down to trust the person that's working for you. If they get it wrong, then deal with that, but go with the view that they want to do a good job and you're just providing an environment and the tools for them to be able to do that rather than coming at it as, 'well, that person's going to need this. So actually, they're just having-me-on'…"-Matt, FG6.*

Natalie (FG4) also reflects on the positive effects of trust:

> *"I've got team members who have endometriosis, and for the firm that I work in, we have quite a large female or assigned a female at birth team, so we're quite female leading…A lot of the things in the [Endo@Work] guidelines are already in practice for us. We have quite a trust-based culture…we are always giving our team the time that they need to manage any of their health or life responsibilities"-Natalie, FG4*

Tied to the discussion of trust Lydia (FG5) interprets how transactional relationships with staff can undermine employee commitment and work outcomes:

> *"So, it's…humanising it, sitting with a person and just going, I don't really understand what you're going through, but I'm here for you. And you've got a real challenge in that because you work in a workforce that is so…transactional, right? Yeah, but I know the power of having that within an organisation...with people feeling acknowledged with their struggles, whether that be physical or mental health. It's trying to find that thing, that point of sameness or something…getting through to somebody somehow."-Lydia, FG5*

2.3. Change Is Driven by Consistent Education and Advocacy

All seven focus groups recognised that normalising endometriosis (and women's health more broadly) was an important factor in creating culture change and promoting policy/guidelines. *"If the conversations are normalised around women's health in general, which is very different to men's health, then…that creates a far better environment"-Matt, FG6.*

Participants perceived that there were two successful approaches to advancing endometriosis (and health promotion): consistent education and advocacy:

> *"I honestly think for most in large organisations, it tends to fall on the outspoken few…it feels like [policy] is more tokenistic than anything else. At an organisational level…we throw some tampons and pads in the women's restrooms and that's it. We've got something visual that says, 'look at us!!' But it really does come down to those people that are willing to kind of be outspoken and…stomp their feet a little bit to lead the way for others, which is a bit of a shame in this day and age, but we're making headway"-Georgia, FG6*

Most participants responded positively to the creation of an EndoChampion role, as proposed in the Endo@Work guidelines. The role intends to foster inclusivity by promoting education and direct colleagues to appropriate policy supports and resources in the workplace's endometriosis guidelines. Through this role, workplaces could embed consistent education (informed by lived experience). Most participants felt this was an easy process to embed in their workplaces; and could be adopted by an existing diversity or inclusion (or similar) role within the workplace.

> *"That would be…[an] easy win. Like…low-hanging fruit, because you've got…mental health first aid, as mental health champions, you've got LGBTQ…I think a lot of organisations would be open to it."-Jordan, FG2*

Olivia (FG6) referenced earlier discussions associated with 'not expecting line managers to know everything'. The EndoChampion would enable consistent education across the organisation without having too great an expectation of line managers:

> *"I honestly think my career has been mainly large-scale organisations, so hundreds, thousands of employees. I think the challenge is always making sure that it's not a discrimination or psychosocial hazard checkbox because that tends to happen. I think the role of the champion is…critical here. We're expanding our policies and leave, and the flexibility that we're providing for employees around mental health, domestic violence, menstruation, menopause, and endometriosis and I think that's wonderful. But you can't expect line managers to have a good understanding of all those things, nor be comfortable having the discussion. Having Champions that are well educated… trained, that understand the difference between providing advice versus support, and the workplace does a really good job of communicating who those champions are" Olivia, FG6*

4. Discussion

Guided by the research questions, this study examined employers' experiences in managing employees with endometriosis or similar conditions. It also assessed existing policies and practices, comparing them to the proposed Endo@Work guidelines. This study presents two key findings. First, post-pandemic (in)flexibility still rewards the ideal worker – an unencumbered employee who prioritises work above personal, familial, or social obligations. This is evident from the workplaces reporting pre-existing policies and practices aimed at supporting employee health and wellbeing, which this study found were often tokenistic, inconsistent, and inequitably applied across employee cohorts. Second, policy alone is not enough and must be accompanied by top-down education, trust and advocacy (often embedded through a support role such as an EndoChampion). Specifically, this approach can contribute to challenging every-day (banal) practices and help to transform workplace cultures responsive to the diverse needs of the workforce towards greater equity and inclusion. Lastly, this study recommends workplaces take a top-down approach to embed tangible flexibility and deliver education and embed advocacy alongside policy, as practical guidance to support employees with endometriosis.

Post-COVID (in)Flexibility Still Rewards the Ideal Worker

The COVID-19 pandemic fundamentally changed how workplaces operate. As illustrated through the study findings, most workplaces have shifted to a 'new normal' and introduced new working from home and flexible working conditions [47]. Despite some moves to mandate that employee's return to the office, a scoping review exploring the impacts of the pandemic on workplace productivity revealed that managers and employees adapted well to remote and flexible working, achieving productivity levels similar to those before COVID-19 [48]. The review findings also agree with participants discussion of how genuinely flexible work practices enabling employees to manage their endometriosis symptoms can contribute to outcomes for individuals and institutions. The fact that hybrid working continues to benefit both employees and employers, proves that deeply entrenched workplace norms (such as the expectation an ideal worker must be in the office for eight hours a day, five days a week) can be challenged and transformed into a mutually beneficial 'new normal' [13,47].

Despite envisaged mutually beneficial outcomes, the findings of this study suggest that changes made so far (post-pandemic) to workplace policies and practices are still enveloped by ideal worker norms that discipline women's bodies at work and shape gendered and other intersecting workplace subjectivities [49]. For instance, employers still set expectations around flexibility; in assigning days that staff must be in the office or can work from home (E.g. assigning Wednesdays as a work from home day). Placing this 'norm' around flexibility does not benefit a person with a chronic and unpredictable condition, such as endometriosis, as they cannot 'schedule' a 'flare-up' or fatigue to coincide with their workplace's assigned work-from-home days. This is also true for menstruation and menopausal bodies more generally. The unpredictable nature of heavy menstrual flow, chronic pelvic pain and menopausal symptoms [50,51] still persistently prevents people from embodying this unencumbered ideal worker whom would benefit from these post-pandemic (in)flexible working norms [12]. This study shows that this only serves to perpetuate a norm that menstruating women/PFAB are to 'just get on with it', compelling them to hide and conceal their menstruating or menopausal bodies in order to reflect a socially acceptable 'professional self' to succeed in the workplace [10,11].

If workplaces wish to be inclusive and truly 'have' flexible policy, then they need to reimagine workplaces – and recognise that regardless of gender, all staff are likely to have *something* which takes precedence over work [12]. Research calls for workplaces to enact tangible flexibility [39,40]. Tangible flexibility refers to concrete, practical measures that allow employees to adjust when, where, or how they work to accommodate their individual needs without compromising organisational goals [52]. Unlike abstract policies or general principles, tangible flexibility focuses on actionable strategies that directly impact employees' work-life balance and productivity. Examples include (but are not limited to) individualised flexible work hours, remote work options, job sharing and adaptable workspaces. Previous research demonstrates that employees with endometriosis who had access to tangible flexibility took significantly fewer sick days and were significantly associated with improved presenteeism [39]. Tangible one-on-one flexibility would enable workplaces to better support people with endometriosis, as well as others who struggle to embody the ideal worker. This includes people who menstruate, transition through menopause, people with caring responsibilities, and people with chronic illnesses and disabilities. In turn, this inclusive flexibility may improve productivity levels establishing a mutually beneficial 'new normal' [48].

Policy Alone Is Not Enough

The findings demonstrate how policy frameworks alone cannot sufficiently challenge inequitable dynamics and form inclusive workplaces. Designing an inclusive policy is an important first step, however it will be ineffective if the organisation does nothing to address the (banal) everyday practices reproducing and strengthening gendered and intersecting power relations [49,53]. For instance, a policy may offer tangible flexibility for people with endometriosis, as recommended above. However, if employees who use the policy face negative treatment, are perceived as 'lazy', or are overlooked for opportunities and promotions, they may avoid using it out of fear of discrimination.

This paper argues that policy as a 'solution' to inclusive workplaces must also disrupt the norms perpetuating inequality regimes [49]. Leading from Foucauldian post-structural feminist ideas, managers enact informal everyday practices which discipline and punish employees' sense of self and their subjectivities [53,54]. Accordingly, we advocate for policies to be accompanied by education for supervisors and managers that provide advice and encouragement about how to "disrupt the relations of power that constitute the 'ideal' worker as masculine" [55]. For instance, our findings provide multiple cases where managers (who understood how endometriosis impacts women at work) were able to create a cultural change through every day (banal) practices that helped women with endometriosis feel supported. Key supports included trusting employees to get their work done (regardless if physically in the office or not), listening to employees and respecting their needs, advocating to prioritise their health needs and being transparent about accessing flexible workplace supports themselves to create an open culture.

Research has demonstrated how a top-down approach with a shared strategy across leadership, can incrementally drive culture change which has shown to enhance economic performance and quality of working life [56]. Additionally, it's advantageous if the education (complementing policy) is informed by lived experience. This approach to education and training (or unlearning) helps to challenge the ideal worker norm and address the mechanisms and day-to-day processes that (re)produce to systemically discriminate against people with endometriosis based on their gender and ability [40]. Different workplaces will require tailored (un)learning resources since the roots of inequality differ across industries (future research focused on specific sectors could help create targeted educational tools) [57]. However, the success of these efforts will depend on commitment among senior leadership. Introducing a workplace advocate role, such as an EndoChampion, who also has a direct line to senior leadership, can ensure that the strategy/education is effectively and consistently supported across leadership and the workforce [58]. This role could be adopted by existing diversity and inclusion offices/officers, human resources, and/or lived experience roles [58,59]. For any solution to be effective, it will require input from a diverse range of stakeholders including occupation health and safety representatives, human resources, senior leadership and operations.

Some key recommendations have come from this work:

- **Tangible flexibility**: Workplace policies that enact tangible flexibility offering individualised support plans (within the agreed to terms in the policy)
- **Create Guidelines which deliver policies alongside education**: While policy is an important step to enacting change, education (informed by lived experience) is instrumental in normalising endometriosis and reducing associated discrimination.
- **Advocacy role**: A workplace advocate, like an EndoChampion, with direct senior leadership access can help ensure consistent support for strategy and education, potentially absorbed within diversity, HR, or lived experience roles.
- **Top-down approach**: Workplaces need to ensure leadership buy-in and advocacy through a stronger educational/training focus for senior leadership, supervisors and managers for a top-down approach.

Limitations

The recruitment strategy relied heavily on social media, which may have introduced sampling bias by excluding individuals not active online. To mitigate this, a partnership with Endometriosis Australia facilitated wider outreach through their networks.

The study sample was predominantly composed of white Australians with higher education levels and middle-class incomes, limiting the findings' applicability to migrants, minority ethnic groups, and Indigenous populations. This lack of diversity highlights gaps in our understanding of how class and race intersect with gender and ability, particularly in relation to workplace policies (Acker, 2006). Further research focusing on underrepresented communities is essential to explore their unique experiences, address systemic inequities, and develop tailored workplace support.

Despite these limitations, the study offers significant insights and expands the existing literature on improving workplace support for people with endometriosis.

Conclusion

Very little literature exists exploring the employers' perspectives of supporting employees with endometriosis at work. We sought to address this gap by understanding (RQ1) existing workplace policies and supports, and attitudes towards proposed Endo@Work guidelines; as well as (RQ2) understanding how existing workplace interactions drive equitable workplace culture and supports staff living and working with endometriosis.

Analysis of focus group discussions reveals that, while most workplaces outwardly value policy, guidelines and reasonable adjustments for employees with endometriosis, these commitments are often tokenistic, inconsistently applied and inequitable. Theme 1 highlights these policy shortcomings, while Theme 2 explores the (banal) every-day practices – such as top-down leadership, trust, and advocacy – that drive cultural change towards equity.

To better support employees with endometriosis, we recommend that employers: (1) implement tangible flexibility; (2) develop guidelines that integrate policy with education; (3) embed a dedicated advocacy role; and (4) adopt a top-down approach to secure leadership buy-in.

Our findings demonstrate that while employers acknowledge the importance of supporting employees with endometriosis, the findings highlight the need for consistent, equitable policies and practices, with recommendations emphasising flexibility, comprehensive guidelines, and leadership engagement to foster workplace equity.

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