The Perspectives of Māori and Pasifika Mate Kirikōpū (Endometriosis) Patients in Aotearoa New Zealand

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Abstract: Experiences with endometriosis have been understudied in indigenous and people of colour populations. This study aimed to investigate the experiences of Māori and Pasifika endometriosis patients in Aotearoa New Zealand. Twenty-seven Māori endometriosis participants from 21 iwi (tribes), and 10 Pasifika participants from 8 different island nations participated in online, asynchronous, anonymous text-based discussions about their endometriosis journeys. Their explanations were analysed qualitatively with an inductive thematic approach. The average delay from symptom onset to a confirmed or suspected endometriosis diagnosis was 11.6 ± 7.8 years in the Māori cohort and 12.4 ± 6.2 years in the Pasifika cohort. There were high levels of dissatisfaction with the availability of treatment, with 66.7% of Māori participants and 60.0% of Pasifika participants feeling that endometriosis treatment was not readily available to them. Poor experiences with the medical profession might dissuade Māori and Pasifika patients from seeking care, exacerbating a culture of distrust and perpetuating healthcare inequities. This could potentially be improved by increasing the capacity to take time for relationship building within general practice or through the incorporation of cultural advisors to support relationship establishment that emphasises holistic consideration of patient well-being and culturally safe care.

Keywords: Māori; Pasifika; endometriosis; perspectives; experiences; inequities; diagnostic delay; chronic pain; bias; qualitative

1. Introduction

Endometriosis is a common condition characterised by the presence of endometrial-like tissue in extra-uterine locations. It has a suspected prevalence of up to 11.4% amongst Australian women (and people assigned female at birth) [1]. Endometriosis manifests with a range of symptoms, including pain with menstruation, sex, ovulation, urination, and defecation, as well as a propensity for constipation, diarrhea, and fatigue [2–4]. Although endometriosis is a prevalent disease with substantial personal and economic costs [5–7], the pathogenesis of the disease remains unconfirmed [8].

A 2022 study researched the experiences of 50 endometriosis patients in New Zealand, but Māori and Pasifika experiences were not specifically assessed. That study identified an average delay from symptom onset to surgically confirmed diagnosis of 8.6 years [2], consistent with a prior New Zealand report [7]. It was also identified that experiences of dismissal or doubt contributed significantly to the diagnostic delay (reports of dismissal increased the average delay from 4.6 ± 3.4 years to 9.0 ± 5.2 years (*p* = 0.0017)) [9]. Of available treatment methods, those most commonly prescribed by clinicians, such as hormone-based medications, were rarely viewed as effective by users [2]. Patients in the

study identified their priorities for changes in endometriosis care as follows: a higher provision of accessible, subsidised endometriosis care; increased research funding; better availability of public education to combat the long delay in diagnosis; and the perceived lack of effective treatment methods [9].

1.1. Endometriosis and Ethnicity

There remains minimal evidence about the prevalence of endometriosis amongst Black, Brown, and Indigenous people, and people of colour (BIPOC) [10]. In the mid-twentieth century, endometriosis was considered a disease of white women of higher economic status [11], with an assumption that it was due to delays in childbearing and excessive stress [12], a claim with racist undertones [13]. Assessments of the influence of race concluded that endometriosis was more common amongst Caucasians, but it is unclear whether this had a biological or social basis [13].

In a systematic review, Black and Hispanic patients were found to be less likely to receive an endometriosis diagnosis than non-BIPOC patients [14]. It remains unclear whether this relates to actual disease prevalence or factors that influence access to healthcare, such as financial access to private practices or cultural attitudes towards gynaecological health [15]. These reports imply that perceived lower rates of endometriosis incidence amongst Black patients may relate to factors that limit and restrict access to surgical confirmation of endometriosis. This includes clinician bias, access to referrals, and the cost of surgical procedures, as opposed to an actual lower incidence.

In a recent US study involving 5639 patients, Black patients (n = 528) were 1.1–2.45 times more likely than patients of any other race to experience major surgical complications [16]. In a 1998 review study in the US, endometriosis surgical admissions were more expensive for Hispanic and Black patients than for Caucasian patients (by USD 900–USD 1300 and USD 800–USD 1500, respectively). Black patients had longer hospital stays than their Caucasian counterparts by 0.8–1.1 days, which could indicate more extensive operations were required [6]. It is established in the literature that there needs to be an emphasis on including non-Caucasian patients in endometriosis research [13,17,18] to understand the influence of ethnicity on endometriosis patient priorities [19]. US-based research has also observed a trend of longer diagnostic delays for ethnic minorities [20], but there has been no research to characterise whether this increased delay is also specifically present in New Zealand for Māori and Pasifika patients.

1.2. Endometriosis and Māori

Māori people are *tangata whenua* (people of the land) of *Aotearoa* (New Zealand). They arrived in *Aotearoa* (Land of the Long White Cloud) from *Hawaiki* (unconfirmed location) around 1300 BCE [21], over 500 years prior to becoming a British colony in 1840 with the signing of *Te Tiriti o Waitangi*. It is estimated that 892,200 people identify as Māori in New Zealand, accounting for 17.4% of the national population [22].

When compared with non-Māori, Māori patients face delayed treatments [23], lower life expectancies [24] and worse health outcomes [25–28] in the New Zealand health system. Racial discrimination, whether intentional or unconscious, against Māori people is associated with poorer health outcomes, reduced access to healthcare, negative impacts on mental health, and poorer life satisfaction [29,30]. Currently, there are no published studies that assess the prevalence, perceptions, or experiences of diagnosis and care of Māori cohorts experiencing endometriosis (*mate kirikōpū*). In a 2022 New Zealand-based study, 12.1% of the 620 endometriosis patients self-identified as Māori [7], but the data have not been separated from the overall cohort to draw any conclusions.

1.3. Endometriosis and Pasifika

Tagata Pasifika (People of Pacific descent) account for 8.1% of the Aotearoa New Zealand population [31], and among these, people born in the Cook Islands, Niue, and Tokelau have New Zealand citizenship [32]. In the 1960s and 1970s, people of Pacific descent

mass-immigrated to New Zealand in search of employment [33,34]. This wave of immigration was initially welcomed to fill labour shortages, but a subsequent deterioration of the country's economic situation resulted in a rise in racist attitudes towards Pasifika, resulting in the 1970's "Dawn Raids". The Dawn Raids were an unacceptable and inhumane crackdown by the police on overstayers—events that predominantly targeted Pasifika despite there being larger groups of European overstayers [35]. In August 2021, the New Zealand government officially apologised for the long-term hurt caused to Pacific communities by the Dawn Raids [36].

As with Māori people in New Zealand, Pasifika people experience worse health outcomes than New Zealand Europeans, with higher rates of advanced cervical cancers [37], higher blood pressure and body mass index (BMI) [38], and inequitable health actions taken by general practitioners (GPs) [39]. In a 2022 American study of 11,936 endometriosis patients, there were elevated surgical complication rates for Hispanic, Black or African American, Native Hawaiian or Pacific Islander, and American Indian or Alaska Native patients [40]. Pasifika patients were included in other studies in Canada, New Zealand, and the USA [7,41,42], but the data of Pasifika patients were not separated to draw comparisons. In the 2022 New Zealand EndoCost study, only 9 of the 620 (1.1%) endometriosis patients self-identified as Pasifika [7], and like the Māori cohort, cultural differences were not explored.

The significant lack of data available concerning Māori and Pasifika endometriosis patients means that research to fill these gaps is vital. The purpose of this research is to begin to address this gap and highlight the potential improvements required in the care of endometriosis patients in Aotearoa New Zealand.

2. Materials and Methods

2.1. Discussion Board Design

In this study, participants took part in anonymous, asynchronous online text-based discussions on boards hosted on VisionsLive Ltd., (London, United Kingdom). The questionnaire from a 2022 qualitative study conducted with endometriosis patients in New Zealand [2,9] was adapted and streamlined for a cohort comprised of Māori and Pasifika patients to ensure that both cultural appropriateness and experiences unique to these cohorts would be addressed. The redesigned questionnaire was assessed by two Māori researchers (one of which is a person with endometriosis) and two Pasifika medical practitioners to ensure question wording and intent were valid for this context. The final questionnaire was comprised of 45 questions, 25 of which were open-text, and 20 were quantitative polls (Supplementary Materials).

The online discussion boards were set up with the 45 questions split into 6 sections: Whakawhanaungatanga | About You, Experience with Endometriosis, Cultural Influences, Experience with Diagnosis, Experience with Treatment, and Future Focus. While the questions had an intended order, the participants could choose to answer them in any order that suited them—for example, skipping a question and coming back to it later if they wanted to think more about their answer.

2.2. Recruitment

Recruitment was predominantly conducted on social media with members of the research team sharing the study information, allowing for snowball recruitment as members of the public could further share and distribute the invite. The invite was also shared by the networks of the patient organisations Endometriosis New Zealand and Endo Warriors Aotearoa and by the following organisations: Etu Pasifika, Trailblazer Research, the Pacific Women's Network, Pacific Women Lead, and Fale Pasifika Te Taitokerau. Interested individuals then contacted the first author via email or interest forms on social media and were sent the information sheet about the study and a consent form. Participants were either invited to a Māori or Pasifika board and if they identified with both cohorts, they selected which board they preferred to participate in.

2.3. Pseudonyms

Once consent forms were returned, individual participants were sent unique URL links to a platform designed for the study hosted on the VisionsLive Ltd bulletin board software. The unique URL link was preloaded with their pseudonym. Māori participants used a list of Te Reo Māori pseudonyms (e.g., Puawai, Kākāriki, Hapaira) that had been checked for validity and appropriateness of the translation by the second author. Pasifika participants' pseudonyms were the names of bird species of the Pacific Islands (e.g., Koel, Bird of Paradise, Starling). Participants were informed that they were welcome to change their pseudonyms, but no participants opted to do so. The use of pseudonyms allowed participants to share their stories anonymously within the group discussions.

2.4. Data Collection

The online discussion board was open for six days, during which time participants could log on at whatever times worked for their schedule, as many times as they wanted, to answer questions, read the responses of others, and respond to take part in discussion topics. When participants first opened the discussion, they were welcomed with a screen that reiterated the intention of the research, the dates during which the discussion platform would be available, and a *mihi* (introduction) from each author explaining their background, and their reasons for taking part in the research. For the Pasifika board, the welcome screen also incorporated the welcoming greeting from each language of the islands each participant indicated they identified with.

Prior to answering each question, participants were blinded to the answers that prior participants had given. Once they submitted their answer, they could see all the answers that other participants had given (with their pseudonyms attached) and respond to generate further discussion. While focus groups are often limited to very small sample sizes, the online text-based platform allows for greater accessibility for participants, overcoming limitations of geography, and the collection of more data [43]. This method also lacks frequent limitations of focus group-based research, such as groupthink, overrepresentation of the viewpoints of dominant individuals [44], and difficulty in isolating the views of individuals from the views of the group [45].

This approach allowed for the simultaneous collection of high volumes of personal stories in the absence of the groupthink phenomena, as well as the data from the discussion aspects of traditional focus groups. The first author acting as a moderator could also ask additional questions within the discussion. Any additional questions were validated by Māori and Pasifika representatives to ensure the wording was appropriate.

2.5. Participants

In total, 40 individuals returned consent forms, and 33 individuals with a surgically confirmed or clinically suspected diagnosis of endometriosis participated in the study. These participants were split into two cohorts, including 27 individuals who identified as Māori and 10 who identified as Pasifika. Māori participants were associated with a range of different *iwi* (the largest social units in Māori society, often translated as "tribe"), including Kaitahu/Ngāi Tahu, Kāti Māmoe/Ngāti Māmoe, Waitaha, Ngāti Kahungunu, Ngāti Kahungunu ki Heretaunga, Ngāti Maniapoto, Te Whānau-ā-Apanui, Te Āti Awa, Ngāti Ruanui, Te Āti Haunui-a-Pāpārangi, Ngāti Porou, Ngāti Raukawa, Ngāti Raukawa ki te Tonga, Ngāti Hako, Ngāriki Kaipūtahi, Ngāi Tūhoe, Ngā Ruahine, Ngā Puhi, Ngāti Hauiti, Ngāti Ruapani, Rongowhakāta, Ngāti Porou, Ngāti Whātua Ōrākei, and Ngāti Wai. Pasifika participants associated with Tahiti, the Cook Islands, Fiji, Hawaii, Niue, Tokelau, Tonga, and Samoa.

All participant quotes in the manuscript are defined by whether the participant has a confirmed or working diagnosis of endometriosis, their age range, their parity, and their iwi or islands they associate themselves with.

2.6. Data Analysis

Quantitative answers were collated and statistical analysis was completed in GraphPad (version 9). In all figures, (*) indicates $p < 0.05$. The null hypothesis in all cases was that means were equal. Shapiro–Wilk tests were conducted to determine whether data were normally distributed. Data were subsequently found to be non-normally distributed, so unpaired Mann–Whitney *t*-tests were used.

The qualitative data from open-text questions were analysed with a thematic approach [46] by the first author, with the transcripts inductively and iteratively coded in NVivo (Version 1.6.1) and transformed into the main themes identified. First, the first author familiarised themselves with the data set, with all quotations connected to the participants' demographic data. Semantic codes were developed based on the responses of participants within the study, with the codes centred around the explicit explanations and meanings of participants (such as shame). The identified themes were then presented to the other authors with associated quantitative poll answers and quotes for discussion in the construction of the final manuscript. The iterative transformation of codes, themes, and sub-themes resulted in the final theme map summarised in Figure 1.
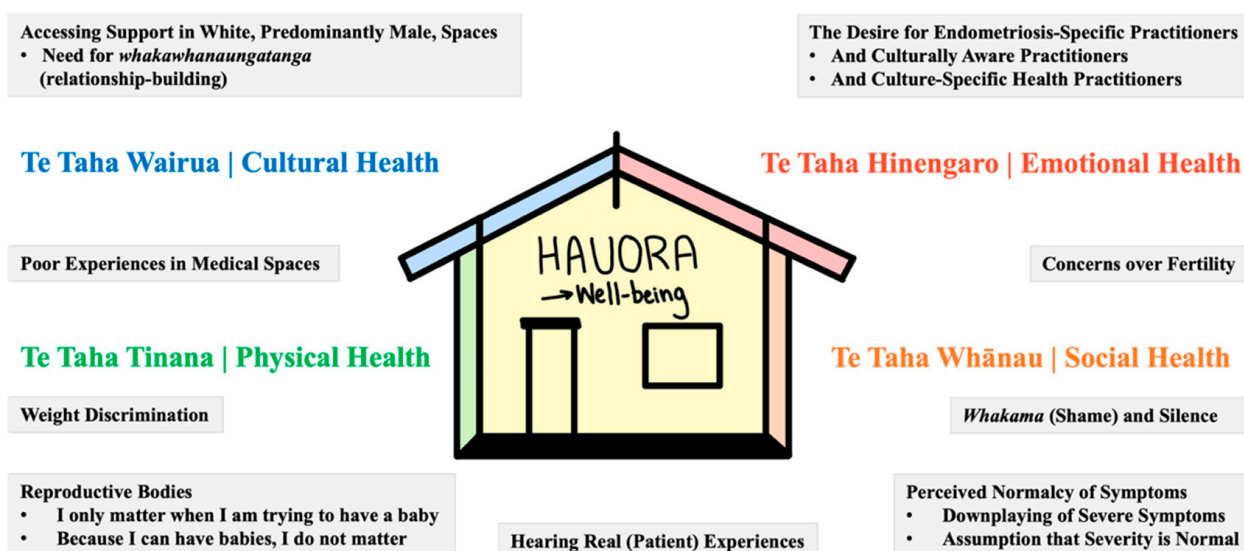
Figure 1. Map of key themes from this study (in black text) and their associations with *Hauora* (coloured text), a Māori concept of the intersecting need for physical, cultural, social, mental, and emotional health for well-being.

Comparison of Priorities Calculation

Participants in this study selected and ranked their top three choices for changes they wanted in the future for endometriosis care out of six options:

a. More social/*whanau* (family) acceptance
b. More research funding
c. More social awareness
d. More education and information
e. More subsidised care
f. More support groups

Choices were assigned points (three points for their first choice, two for their second, and one for their third), which were totalled for each change and then expressed as a percentage of the total points available.

2.7. Ethics Approval

The research was approved by the University of Canterbury Human Research Ethics Committee (Ref: HREC 2022/152). Attention by the Ethics Committee included a focus

on the co-design of the questionnaire and engagement with Māori and Pasifika medical practitioners who work with endometriosis patients. The committee also focused on the approach taken to protect data, an effort to avoid cross-cultural risks between participants and researchers of different backgrounds, as well as the data encryption and security policies of the software used to protect participant data.

3. Results

3.1. Participant Cohort

The average age in the Māori patient cohort was 36.2 ± 9.5 years, with participants spanning in age from 20 to 55 (Table 1). In the Pasifika patient cohort, the average age was 38.1 ± 9.7 years, with ages ranging from 20 to 51. The age at which symptoms first presented was similar, with an average onset age of 16.2 ± 6.4 years in the Māori cohort and an average of 18.9 ± 5.0 years in the Pasifika cohort, which was not significantly different from the authors' 2022 study cohort (15.3 ± 4.2 years) [2].

Table 1. Patient demographics.

	Māori Patient Cohort (n = 27)	Pasifika Patient Cohort (n = 10)
Diagnosis Type		
Confirmed diagnosis (symptoms +/lesions +)	85.2%	80.0%
Working diagnosis (symptoms +/lesions ?)	14.8%	20.0%
Age		
18–24	11.1%	10.0%
25–30	18.5%	10.0%
31–35	11.1%	10.0%
36+	59.3%	70.0%
Parity		
Nulliparous	48.1%	30.0%
Primi/Multiparous	51.9%	70.0%
Working Situation		
Full-time	55.5%	50.0%
Part-time	3.7%	30.0%
Student	18.5%	10.0%
Stay-at-home parent	7.4%	
Not working	3.7%	
Not working due to health	11.1%	10.0%
Disease Stage	**n = 24**	**n = 8**
Stage I	0.0%	0.0%
Stage II	25.0%	0.0%
Stage III	12.5%	0.0%
Stage IV	33.3%	75.0%
I do not know	29.2%	25.0%

Delays in diagnosis were similar across both cohorts, with an average delay from symptom onset to confirmed or working diagnosis of 11.6 ± 7.8 years in the Māori cohort and 12.4 ± 6.2 years in the Pasifika cohort. These delays in diagnosis were significantly longer than those reported in the 2022 New Zealand study (where ethnicity data were not collected) of 7.9 ± 5.1 years ($p = 0.039$ and $p = 0.031$, respectively) [2].

3.2. Knowledge and Diagnosis

3.2.1. Knowledge at Symptom Onset

There was a lack of knowledge amongst the two participant cohorts of what endometriosis was when they began to experience symptoms. In the Māori patient cohort, 63.0% had never heard of endometriosis at symptom onset, while the remaining 37.0% knew "very little" (29.6%) or "a bit" (7.4%), with no patients feeling they were "well in-

formed" or "very knowledgeable". In the Pasifika patient cohort, 90.0% indicated that they had never heard of endometriosis at symptom onset, with 10.0% knowing "a bit".

The primary source that both cohorts of patients first learnt of endometriosis was their doctors, with 51.9% of the Māori and 50.0% of Pasifika patients learning of endometriosis this way. In the 2022 study, only 22.0% of the cohort (n = 50) first heard of endometriosis through this source [9]. Only 7.4% of Māori patients and 10.0% of Pasifika patients learnt of endometriosis through online research about their symptoms in contrast to the prior study where 30% utilised this method. This may be an added difficulty for awareness about the condition as in New Zealand, Māori may be more likely to under-utilise primary care [47]. If this is the key source of information about endometriosis for this population, this may result in a lower overall awareness than in other populations.

3.2.2. Perceived Normalcy

There was a strong sentiment amongst the Māori and Pasifika cohorts that their symptoms were "normal", with two main ways in which this belief took hold. Participants were either (1) aware of the mild experiences of others around them with normal menstrual cramping and pain, and the participants assumed that they were weak or hypochondriacs for having severe reactions to the "same" experiences, or (2) others around them had similarly severe pain and symptoms, and as a result, severe symptomology became normalised to the patient. Both processes were associated with descriptions of a delay in seeking support or medical help.

Downplaying of Severe Symptoms

One participant (Confirmed, 31–35, Nulliparous, Ngāti Kahungunu) explained: "I think I had symptoms for over 15 years before I even knew what endometriosis was, so I definitely thought my symptoms were normal and every wahine (woman) just suffered in silence". This perceived normalcy was a frequent experience with patients explaining that the vacuum of knowledge about endometriosis at symptom onset led them to believe that there was nothing medically wrong with them that required discussion with a medical practitioner. In addition to this internal normalisation, others, particularly medical practitioners, normalising their experiences was sometimes associated with delays in seeking further medical help, a process that was identified in the 2022 cohort to significantly delay diagnosis [9]. Further experiences with the downplaying of severe symptoms included the following:

> "I just got on with it, thinking that this was the norm that came with puberty and being a woman . . . I thought I was just never around when it was their turn or that [my friends] have mamae (hurt) but were just pushing through with a braver face than mine . . . I thought that what I was experiencing was normal. Had I known what I do now . . . I would have connected the dots a little earlier as well because I feel that it relates to other abnormalities going on in my tinana (body). I often felt (and at times was made to feel) like a hypochondriac, by medical professionals and socially as well." (Confirmed, 31–35, Parous, Ngāti Ruapani, Rongowhakāta, Ngāti Porou)

> "I would like to see more women being able to be heard and understood. The belief for so long has been that a period is normal if it is painful and heavy, if I had known it was not when I was younger, I would have dealt with endometriosis so differently." (Confirmed, 25–30, Nulliparous, Ngāti Raukawa ki te Tonga)

> "For me this meant that I kept a lot of my pain to myself and felt I had to "toughen up" as I thought what I was experiencing was normal due to lack of information." (Confirmed, 31–35, Parous, Tonga, Samoa)

In the Māori cohort, 40.7% of participants emphasised that accusations of "drug seeking" were part of their experience with attempting to access endometriosis care and that they were made to feel that they were not trustworthy reporters of their own experiences. One participant (Confirmed, 18–24, Nulliparous, Ngāi Tahu) raised the poignant point

that: "it takes effort and money to see a GP so people do not just go for fun, it can take a lot of courage to present, especially when it is about something so intimate. A lot of people would give up after being dismissed ..." The dismissal of these patients as drug seekers harmed their capacity to access care for their condition. Some participants felt their ethnicity was why they were accused of drug seeking, as articulated by one participant (Confirmed, 25–30, Nulliparous, Ngāti Kahungunu, Ngāti Hauiti, Cook Islands): "I think because I am of Pacific and Māori decent, the doctors thought I was a drug seeker always trying different pain medications. None of it helped and so when they ran out of options it all got flipped onto me."

Assuming Severe Pain Is Normal

In addition to the perception that severe pain was on par with non-pathogenic, menstrual-related discomfort, patients could also be led to believe that being in a severe state of pain was part of the standard experience of people who menstruate. One patient (Confirmed, 25–30, Nulliparous, Ngāti Raukawa ki te Tonga) remembered: "Everyone told me it was normal to have a heavy and painful period". Another (Confirmed, 36+, Parous, Ngāi Tahu) elaborated that the total normalisation of severe pain within their family caused their cisgender male brother to delay informing his family of his appendicitis-related abdominal pain because he thought, after watching his female family members suffer, that severe abdominal pain was a normal part of puberty. Other experiences of this phenomenon are as follows:

> "In my family culture, women tended to share the horror stories [as a] badge of honour when it came to their periods and I just normalized the symptoms." (Confirmed, 36+, Parous, Ngā Puhi, Ngāi Tahu)

> "Mum had always suffered from period pain and very heavy bleeding. Most of her sisters have had a hysterectomy, so we thought pain was normal and heavy bleeding was just part of the package for some women." (Confirmed, 36+, Parous, Ngāti Porou)

> "I had heavy periods which I also thought was normal. My mum had told me stories about having to miss school to stay home and sit on a towel because her period was so heavy. That is just what I thought was normal." (Working, 31–35, Nulliparous, Ngāriki Kaipūtahi, Ngāti Kahungunu ki Heretaunga, Ngāi Tūhoe)

3.2.3. Whakama (Shame) and Silence

Within both the Māori and Pasifika cohorts, there were reports that they were made to feel shame about their symptoms and that this stopped them from discussing their experiences. As one participant (Working, 36+, Parous, Tahiti, Cook Islands) highlighted, "there was a lot of shame I felt, which was a barrier in itself to access support". It was highlighted that this shame, or shyness around their bodies, could prevent them from feeling comfortable in discussing their condition not only with medical professionals but also with family and friends. Many participants shared that their own diagnosis had driven them to be more open about menstruation, menstrual-related pain, and disorders and to create a space where these types of conversations could be normalised. In particular, there was praise for the younger generation for leading the *mahi* (work) in de-stigmatising these conversations. This work was viewed by participants as important because when this shame around female reproductive health prevented discussions about menstruation and menstrual-related health, this could also prevent patients from becoming aware of the pathogenicity of their symptoms:

> "In my culture, we are taught to not show pain. Complaining to my mother, a Pacific woman, and a nurse, was met with little support. She advised that you cannot show people you are in pain and that pain is a weakness that brings shame." (Confirmed, 36+, Parous, Tokelau, Samoa)

> "From a whakama (shame) perspective, yes. In my family at least, periods are not talked about. Although I think this is probably heavily influenced by colonization because I think

traditionally Māori were not ashamed of it." (Confirmed, 31–35, Nulliparous, Ngāti Kahungunu)

3.3. Patterns of Support

All participants were asked about who they relied on for support at symptom onset and ongoing management of their endometriosis. In the 2022 study, when participants compared the individuals who support them on an ongoing basis, to those at symptom onset, there was a drop (−22.0%) in participants consulting with their GPs and an increased proportion (+36.0%) relying on specialists [9]. Amongst the Māori endometriosis patients, 70.4% relied on GPs for initial support when they first developed endometriosis symptoms, which declined to 55.6% for ongoing support. A similar decline (from 70.0% to 60.0%) was observed amongst Pasifika patients. There was a higher ongoing reliance on specialists by Māori endometriosis patients (63.0%) compared with initial support (11.1%), while in the Pasifika cohort, there was no change (20.0%).

3.3.1. Accessing Support in White, and Frequently Male Spaces

Access to, and lack of comfort in, healthcare spaces was also mentioned by these cohorts. One participant (Confirmed, 25–30, Nulliparous, Te Āti Haunui-a-Pāpārangi, Ngāi Tahu) raised the point: "From my experience, I have never once walked into a doctor's office or hospital and felt like it was a Brown space. All I see and feel is tokenism. The health system is built for a Western world, and you feel that when you walk into a healthcare facility. Why would I want to be vulnerable in a place built like this?" In response, other participants highlighted that the lack of time for *whakawhanaungatanga* (relationship building) in healthcare settings made them feel uneasy, reduced their level of comfort, and made it far more difficult to be open and vulnerable to share their experiences.

They felt that within healthcare settings, there was too much of a "focus on the disease, and not on the patient as a whole" (Confirmed, 18–24, Nulliparous, Ngāi Tahu), which researchers have noted directly conflicts with the holistic concepts of health within Pacific cultures [48]. It was highlighted that (Confirmed, 36+, Parous, Ngāti Hako) "Western spaces have never been designed in policy, or practice, with consideration for Māori . . . The perpetuation of discriminatory or biased racial views, that see Māori as failures—in education, in health, in society in general . . . Unless [medical professionals] take this very seriously and apply it in practice as an individual, they just become part of the wider issues . . . Sometimes enduring [these] white spaces requires too much energy in a time when I was already struggling".

Another participant (Confirmed, 36+, Parous) highlighted it was not simply a result of spaces feeling white and exclusionary to brown people but also the maleness of these spaces: "Not just white space but also male space. One of the first doctor appointments specifically just for heavy painful and unpredictable periods was a young male doctor. [It] was slightly *whakama* (shame) but [I] knew [I] had to talk about it to try to get something done . . . [it felt like] the patriarchy standing outside of my body prodding at my abdomen saying, well I cannot feel anything that would cause you pain".

To ensure that patients can access endometriosis health care, doctors must work to earn their patients' trust to allow them to feel comfortable sharing about their bodies and experiences. To have these vulnerable conversations, there needs to be time for *whakawhanaungatanga*, either with longer sessions to allow for relationship building or the capacity for patients to attend multiple sessions over time without the creation of a financial barrier. As one participant (Confirmed, 31–35, Nulliparous, Ngāti Kahungunu) explained: "If there was time for *whakawhanaungatanga* in a doctor's office, I think I would have been more comfortable to be open and vulnerable many years earlier. Meeting a stranger for 15 min when there is no time for that does not exactly set the scene for those vulnerable conversations".

3.3.2. Reproductive Bodies

It was raised by multiple participants in both cohorts that either their endometriosis symptoms were not taken seriously until they tried to conceive or that they were not taken seriously by family or medical personnel about their symptoms if they had previously been able to conceive. There was a sense amongst some that their experiences were often reduced to only the presence, or absence, of the symptom of infertility, in a way that reduced their sense of importance and autonomy to the medical profession and *whanau* (family). Experiences with the sense that fertility was all that mattered included the following:

> *"I feel like Western Medicine places so much emphasis on [endometriosis] having an impact on fertility that they miss all the OTHER signs." (Confirmed, 36+, Nulliparous, Ngā Ruahine, Ngāti Ruanui, Te Āti Haunui-a-Pāpārangi, Taranaki)*

> *"Accepting women's autonomy over their bodies and [understanding] we are not just a biological function. Not every woman wants a baby." (Confirmed, 36+, Parous, Ngāti Hako)*

> *"[Endometriosis] is not just about having babies—it is debilitating and [a] loss of quality of life." (Confirmed, 36+, Parous, Tokelau, Samoa)*

For one participant (Confirmed, 25–30, Parous, Ngāti Kahungunu), this first case of not being taken seriously until trying to conceive was expressed as: "I struggled to be taken seriously by my GP . . . until I tried to get pregnant. When I was not getting pregnant, suddenly help was available to me—as if this non-existent baby was already more important than my own health . . . It was like the 10+ years of my own suffering did not matter." Other experiences included the following:

> *"I can remember being as young as 13 or 14 and experiencing some of those symptoms . . . these became increasingly debilitating over time. When I first saw my GP in my early 20s, it was not until around 10 years later that I received a formal diagnosis but this was only achieved as a result of trying for a baby. Otherwise, I would probably still be living with endometriosis pain." (Confirmed, 31–35, Parous, Tonga, Samoa)*

> *"I have been told that I need to have sex in order to see if there are other symptoms which first of all 'no' and secondly when I asked to put up the priority list because I am literally failing classes due to fainting in pain, I was told 'if you get a partner and are trying to conceive we will help,' that is just stupid." (Working, 18–24, Nulliparous, Fiji)*

Another participant (Confirmed, 36+, Parous) explained their experiences of being dismissed because of their ability to have children: "[My] whole whanau has sympathy for [their family member with endometriosis] and consider her case worse than mine as she was told earlier and told she could never have kids. Nobody thought all the same symptoms that I have could be the same thing because I have children, [so] they do not even think it is a real diagnosis . . . even when I would pass out from the pain. [I] could have children so nothing could be wrong".

3.3.3. Hearing Real Experiences

Participants highlighted a key source of support they found—hearing the stories of other endometriosis patients, whether in person, online, through social media posts, or in medical literature. Engaging with this experiential data was viewed as beneficial not only for increasing awareness and understanding for themselves but also a way they could help other patients, educate people in their own lives, and feel less isolated and alone. This was articulated by both cohorts:

> *"Over time, I have found that YouTube, Zoom Webinars, and social media platforms such as Facebook, Instagram, and TikTok, particularly prior to being diagnosed . . . became the most useful to me as I was about to hear of others' experiences, their symptoms, treatment, etc." (Confirmed, 31–35, Parous, Tonga, Samoa)*

"[What I found useful was] medical literature from previous patients diagnosed with endometriosis. I was able to find medical literature to help my husband understand one case does not fit all." (Confirmed, 36+, Parous, Ngāti Maniapoto, Te Whānau-ā-Apanui, Hawaiian)

"I know it sounds so stupid, but people are so honest in sharing their experiences these days and I get so much comfort knowing I am not alone and hearing their lived experiences. I find it relatable, easy to understand, and I can access it in the doses and amounts I am capable of." (Working, 31–35, Nulliparous, Ngāriki Kaipūtahi, Ngāti Kahungunu ki Heretaunga, Ngāi Tūhoe)

3.4. Patient-Perceived Efficacy of Treatments

In both cohorts, the treatment the most participants wished they had accessed at the start of their journey was laparoscopic surgery (50.0% of Pasifika patients, 37.0% of Māori patients), while 30.0% of Pasifika patients and 25.9% of Māori patients said that the treatment they wished they had skipped was hormone-based medications. This result predominantly stemmed from a sense that hormonal treatments "fix nothing" (Confirmed, 18–24, Nulliparous, Ngāi Tahu), are a "band-aid [that does] not do much" (Confirmed, 31–35, Parous, Ngāti Ruapani, Rongowhakāta, Ngāti Porou). There was an overall sense that despite hormone-based medications being a well-accepted frontline treatment for endometriosis pain [49] and prioritised as first-line in the New Zealand endometriosis guidelines [50], patients found them ineffective in alleviating their symptoms. This is consistent with the authors' previous findings [2].

Fertility Concerns

Amongst the Māori participants, 33.3% had experienced infertility they believed was related to their endometriosis, along with 40.0% of Pasifika participants. Additionally, participants felt dread over their future because of their diagnosis and stated they were "overwhelmed at having this condition and not knowing what the future would hold (further surgeries, recurrence, infertility, etc)" (Confirmed, 18–24, Nulliparous, Ngāi Tahu). This anticipatory dread of endometriosis-related infertility could also have financial implications for some participants. For example, one participant (Confirmed, 25–30, Nulliparous, Te Āti Haunui-a-Pāpārangi, Ngāi Tahu) was informed by their specialist that if they wanted to have children, they would need to freeze their eggs. They explained: "I . . . had a breakdown because I realised there was no public funding for people with [endometriosis] to just freeze eggs. This is because some people [with endometriosis] still get pregnant. This brought me to the realisation [I am] going to need around $30,000 to make having a family a possibility for me. I [already] felt robbed of my late teens/early-mid 20s and now my future".

Endometriosis-related infertility, which impacts approximately half of endometriosis patients [51], felt to some patients as yet another aspect of their lives that was harmed by having endometriosis. One participant (Confirmed, 36+, Parous, Kāi Tahu, Kāti Māmoe, Waitaha) articulated that when they were told they had endometriosis, they were relieved because there was now a reason given for their symptoms after "being told there was nothing wrong for so many years", but they then became angry with the realisation endometriosis "contributed to not being able to have another child, and the struggle and hurt that comes with that is heartbreaking." While endometriosis is not a condition defined only by infertility, the emotional harm to patients who want to have children and face difficulty, as well as emotional and spiritual pain because of endometriosis-related infertility, makes it an important aspect of ongoing consideration and support. As highlighted by one participant (Confirmed, 36+, Parous, Ngāi Tahu), "If people with endometriosis do want [their] fertility kept where possible, that needs [to be] honoured too".

3.5. Availability and Financial Barriers

In the Māori patient cohort, 66.7% of participants disagreed (48.1% strongly) that endometriosis treatment was readily available to them and only 18.5% agreed it was readily available. In the Pasifika cohort, 60.0% disagreed (40.0% strongly) that treatment was readily available to them, and the only Pasifika participant (Confirmed, 36+, Parous, Ngāti Whātua Ōrākei, Samoa) who considered treatment readily available explained, "I was very lucky that I have private health insurance so that when I needed surgery, I was able to get this booked within 2 weeks of my second visit with the [gynaecologist]". Further experiences were articulated as follows:

"I am now in the position where I have to keep paying high insurance premiums due to the condition, but I cannot afford to let the insurance lapse in case I need another surgery or tests." (Confirmed, 36+, Parous, Ngāi Tahu)

"If I had the financial ability to go private, I would have been able to get a diagnosis and possibly surgical treatment years ago." (Working, 18–24, Nulliparous, Te Āti Awa)

Overall, this sentiment that treatment was not readily accessible may relate to the higher reliance on publicly funded healthcare and public waitlists in this cohort. While only 31.0% of patients in the prior cohort relied on publicly funded surgical care for endometriosis [9], 62.5% of Māori patients (n = 24) and 50.0% of Pasifika patients (n = 8) utilised public funding for part or all of their payments for surgery. Similarly, while 61.9% of the 2022 cohort used medical insurance to pay for part or all their surgical care, only 41.7% of the Māori patients (n = 24) and 50.0% of Pasifika patients (n = 8) used this method. Experiences of financial barriers included:

"Specialist services and treatment provided through [the] GP and [district health board] [have] been provided for free (which I have a lot of gratitude for), however, the time frames in which we are seen by specialists for consult/treatment/services can be months sometimes. But the cost of travel and parking has sometimes impacted our family's budget, if I do not have money, I do not have a problem calling to reschedule for a more suitable time." (Confirmed, 36+, Parous, Ngāti Maniapoto, Te Whānau-ā-Apanui, Hawaii)

"I have had to take on another role in my organization to be able to afford to keep my health insurance." (Confirmed, 36+, Parous, Ngāti Wai)

"The cost of medication has been an issue hence why I do not take some [medications] . . . I have asked whanau, however, I got told it was 'my own doing' which honestly sucks." (Working, 18–24, Nulliparous, Fiji)

In the 2022 cohort, 32.0% of patients utilised public funding for specialist consults and 70.7% used medical insurance. Amongst the Māori patients (n = 20), 65.0% used public funding and 50.0% used medical insurance. Similarly, 60.0% of the Pasifika patients (n = 10) used public funding and 40.0% used medical insurance. The power of being able to access private specialists and surgical care was evident in the statements of participants. Participants highlighted that the true cost of the condition was not only in specialist appointments and surgery. Additional costs to participants included the need to pay for medications, park at medical facilities, obtain transport, and absorb the pay lost from taking time off work. Furthermore, the condition sometimes caused emotional and social costs to participants as they missed out on family time and cultural commitments:

"While I was trying to get a diagnosis, I ran out of funded appointments in a year and was told the clinic was busy with more important customers. The financial cost of repeat visits alone was enormous. That does not even include all of the pain medications, travel costs, and opportunity costs of not being able to work." (Confirmed, 36+, Nulliparous, Ngāti Raukawa)

"[The cost includes] GP visits—at least 6 per year at $52 each. I work full time so the cost of taking time off work. The mental cost of bleeding through at work during conference meetings. The cost to take time off work for procedures at the hospital . . . As

a parent, both mine and my husband's sick and annual leave has to be spread between 5 people PLUS cultural responsibilities of honouring relationships such as attending tangihanga (traditional Māori funeral rite) and contributing to marae (Māori meeting ground) events. It all adds up." (Confirmed, 36+, Nulliparous, Ngā Ruahine, Ngāti Ruanui, Te Āti Haunui-a-Pāpārangi, Taranaki)

3.6. Changes for the Future

In these cohorts, participants chose and ranked their top three choices for changes they wanted for the future out of a list of six options as stated in Section 2.3. In the 2022 study cohort, the top selections were more subsidised care, more research funding, and more education, in that order [9]. In the Māori cohort, 28.1% of available points went to more subsidised care (the top selection), 27.5% went to more research funding, and 24.8% to more education—the same order as in the prior study. In the Pasifika cohort, 31.5% of points went to research funding, 25.9% to subsidised care, and 22.2% to education.

In the 2022 cohort, when given the binary choice of improved diagnosis or improved treatment of endometriosis, 50.0% of patients chose each option. In the Māori cohort, 59.3% of patients chose improved diagnosis, a selection even more pronounced in the Pasifika cohort where 70.0% chose improved diagnosis. This may relate to the longer delays in diagnosis exhibited amongst the current cohorts compared with the prior cohort.

3.6.1. Weight Discrimination

There is a general trend where endometriosis incidence is inversely correlated with BMI and positively correlated with height [52], but increased BMI can correlate with more severe forms of the disease [53]. Within this study's cohort, multiple participants perceived medical bias and barriers due to their weight and felt their doctors refrained from offering advice about their health beyond recommending they lose weight. Reports have indicated there are higher BMIs amongst Māori and Pasifika populations than New Zealand Europeans [38,54], which indicates discrimination based on BMI will likely be more common amongst this population than a matched New Zealand European population. There was a strong perception amongst participants who reported weight-based discrimination that medical practitioners were unable to consider aspects beyond their weight and took their reports of their symptoms less seriously as a result:

"I was never taken seriously and everything was put down to my weight." (Working, 36+, Parous, Tahiti, Cook Islands)

"I had a surgeon tell me because I was too big, it would be difficult to find [endometriosis] because of my weight." (Confirmed, 36+, Parous, Niue)

"[I had doctors assume] because I am overweight, I must have diabetes and high blood pressure . . . I took horrible drugs that made me incredibly sick for no reason. ALL of my current medical diagnoses are unrelated to my weight." (Confirmed, 36+, Parous, Ngāti Hako)

3.6.2. The Desire for Endometriosis-Specific Practitioners

Amongst the Pasifika cohort of this study, there was a desire to access medical practitioners who specialised not just in female reproductive health but in endometriosis specifically. There was a common sentiment that New Zealand lacked enough medical practitioners specialising in endometriosis care, that there were too many with a narrow perception of endometriosis symptomology, and that GPs, who are the ones with the most direct contact with the community, often lacked the necessary training to effectively support patients. Participants wanted the relationship they had with their medical practitioners to be a partnership where they could work *with* their doctors holistically to improve their lives, and viewed endometriosis-specific clinics or practitioners as a way to achieve this:

"In an ideal world, it would be encouraging if there was a team/ward/unit designated to endometriosis." (Confirmed, 36+, Parous, Ngāti Maniapoto, Te Whānau-ā-Apanui, Hawaiian)

"[It would be beneficial to have] endometriosis clinics similar to the diabetes clinic at [medical practice] . . . There is nothing worse than being placed in a birthing ward [to receive endometriosis treatment] when endometriosis has prevented so many women from conceiving, women who cannot have any more children due to this debilitating disease . . . it is heartbreaking." (Confirmed, 36+, Parous, Niue)

"I feel like the initial consult with a GP should be a constructive and positive experience. I feel like GPs need more education surrounding this topic." (Confirmed, 36+, Nulliparous, Niue)

3.6.3. Poor Medical Experiences

Evident in many participants' stories was that dismissive, negative, or professionally inappropriate behaviour from doctors made their efforts to obtain treatment more difficult. In addition to accusations of drug seeking and perceived discrimination over their weight, participants felt subjected to abuses of power, medical gaslighting (where patients' symptoms were dismissed or downplayed by medical personnel), and discrimination (Table 2). These behaviours remain key barriers towards accessing effective and timely diagnosis and treatment of endometriosis.

Table 2. Quotes concerning the theme of "Poor Experiences in Medical Spaces".

Sub-Theme	Participant Quotes
Abuse of Power	"I think I was 33 when they found a growth growing outside my cervix, this went unknown to me for about a year. The only reason why it came out was because I had gone to a sexual health clinic for a check-up and told them I was bleeding every time men used fingers inside me . . . He performed a total hysterectomy with bilateral salpingo-oophorectomy. When I read his surgical notes he noted [endometriosis] on my bowel but did not remove." (Confirmed, 36+, Parous, Niue) "I had a uterine ablation that made everything 100 times worse. The pain and bleeding were unbelievable leaving me bedridden. I was furious that the specialist would not believe me when I said that it had not worked and I was sicker and suffering more since. He ended up screaming at me that I would never have a hysterectomy because he believed that his ablation had worked and I needed to get over it . . . One of my doctors was religious and believed that IUDs aborted living babies and would only prescribe me contraception pills." (Confirmed, 36+, Parous, Ngāti Hako)
Medical Gaslighting	"My mother was concerned about the amount of pain I was in and started taking me to the GP regularly asking for help. It went nowhere though and I was told regularly I was just being attention seeking. My mother was told I likely needed a psychiatrist not a GP." (Confirmed, 36+, Nulliparous, Ngāti Raukawa) "In one of my specialist appointments I had an anesthetist tell me it might be helpful to see a psychologist because I told them my [endometriosis] was back. She even said she had not read my file." (Confirmed, 36+, Parous, Niue) "[I was] verbally abused by hospital nurses for 'faking pain' . . . [I was] held down and forced to allow a nurse to give a fast push of antibiotics that caused my veins to reject it and spray it back." (Confirmed, 36+, Parous) "Especially when I had to have multiple initial GP visits for her to take me seriously. The cost alone made reaching out for support and advocating for myself really stressful." (Working, 18–24, Nulliparous, Te Āti Awa) "I have genuinely never had such a bad experience than the pain clinic. I would cry and cry and cry every time because they made me feel like it was not real. This pushed me back a bit. I then saw another specialist (public), she was the first woman specialist I have seen. Again she did nothing but make me cry and made it [feel] like everything I was going through was not real." (Confirmed, 25–30, Nulliparous, Ngā Ruahine)

Table 2. *Cont.*

Sub-Theme	Participant Quotes
Discrimination	"Being Māori has hindered a lot of treatment options because [medical practitioners] believe I am only there to get pain relief and I am a drug user." (Confirmed, 25–30, Nulliparous, Ngāti Raukawa ki te Tonga) "[I] woke up 13 h later to a very apologetic surgical team and nurses who could not believe they [had] thought I was a liar looking for attention and drugs." (Confirmed, 36+, Parous) "I feel being Māori made it more difficult. Cause I wasn't taken seriously. No one took me aside and said let's figure this out. Doctors started putting me on different contraception thinking that would help. Chemists treated me like I was addicted to pain killers and made me feel like a criminal when I purchased Nurofen+." (Confirmed, 36+, Parous, Ngā Puhi)

Not all experiences with doctors were negative. Many of the participants mentioned that when they found a doctor with whom they had a supportive relationship and who acted as an advocate for them, the rate at which they obtained effective diagnostic and treatment tools was elevated, and they felt more supported in their endometriosis journey. As one participant (Confirmed, 18–24, Nulliparous, Te Āti Awa) highlighted: "One of my favourite GPs sent me to hospital and I started crying, he felt super bad, but I knew that it was the best place for me to go. While I was still in the hospital on a Saturday, during his spare time [he] rang me to check how I was doing. He did not need to call me, but he took time out of his weekend to call me".

3.6.4. Future Communications

Participants were asked about the best way to communicate endometriosis information back to their communities. This study's participants felt the best ways to spread better information about endometriosis are through social media and television advertising campaigns, ensuring there are pamphlets in GP clinics that can be shared with patients and their whanau, as well as running education programs in intermediate and high schools (such as in health and physical education classes), universities, and workplaces.

4. Discussion

4.1. Moving Forwards

This article highlights that Māori and Pasifika participants report low levels of knowledge about endometriosis at symptom onset and a longer delay from symptom onset to diagnosis than is common in New Zealand. There is also a perception that common frontline treatments for endometriosis are ineffective for the relief of their symptoms and the sense that the health system is not built for them or accepting of them and their experiences.

4.1.1. Addressing Knowledge

Communication for Māori and Pasifika communities regarding endometriosis was identified as having the most promise when carried out through advertising campaigns and pamphlets at GP clinics. This could allow patients and their support networks to become aware of endometriosis symptoms and identify individuals and services who may be in a position to provide support in accessing endometriosis care. If there is lower overall awareness of endometriosis amongst Māori and Pasifika in New Zealand due to a reliance on doctors for this information, as was identified in this study's cohorts, then designing targeted awareness campaigns that empower these endometriosis patients to seek support from primary care may be important in improving patient awareness of the disease.

4.1.2. Addressing Treatment

The perceived ineffectiveness of common frontline treatments, particularly hormonal treatments, is much more difficult to address. Both cohorts highlighted that more research funding for endometriosis is a priority for them and that more research funding for novel treatment methods would improve the likelihood that new, effective non-hormonal treat-

ment methods could become available. Both cohorts in this study, as in the authors' prior work [2], highlighted the treatment methods they personally found effective for treating their endometriosis symptoms were surgical.

In New Zealand, there is a public health system that provides government-funded healthcare for all citizens; however, the authors' previous work highlighted that the capacity to pay privately or use medical insurance to cover surgical treatments is considered by many patients to be an unofficial requirement for timely treatment [9]. To best treat all endometriosis patients, the capacity to access laparoscopic endometriosis treatments, which are recommended by many endometriosis guidelines [49], should be increased in New Zealand. Ways to achieve this include allotting more funding to training specialists, creating more surgical space for this patient population, and allotting research funding to identify effective, nonsurgical treatment options.

4.1.3. Addressing Cultural Safety in Endometriosis Care

Endometriosis patients of ethnic minorities can get "the double whammy of cultural and gender inequities" (Confirmed, 36+, Nulliparous, Ngā Ruahine, Ngāti Ruanui, Te Āti Haunui-a-Pāpārangi, Taranaki) and "endometriosis has no care in the world whom it grows in, not their size, the colour of [their] skin, age, ethnic group, diet, religion..." (Confirmed, 36+, Parous, Niue), and regardless of any of these characteristics, patients need to feel heard, believed, and supported through the entire journey of endometriosis diagnosis, treatment, and management. This includes an ongoing consideration for culture, as a participant (Confirmed, 36+, Parous, Ngāti Wai) explained, "Did I feel my cultural needs were met? No. Sure, there is a tick box on the pre-surgery checklist, but it goes deeper than a tick box".

There was a strong sense amongst these cohorts that the medical system was inhospitable to them and their cultural needs. There is a need to create better cultural safety within the healthcare system in New Zealand. Cultural safety refers to directly addressing the effects of colonisation within the dominant health system. There is a responsibility of the healthcare provider to ensure that the cultural identity of the patient is recognised and protected [55]. A key part of providing culturally safe healthcare lies in the healthcare provider being able to understand the impact of their own culture on their clinical interactions. Examining their own biases and assumptions can allow for a higher quality of care for their patients [56]. Cultural safety training has been compulsory for nurses in New Zealand since 1992 [57] and for GPs since 2006 [58]. The difficulty arises with culturally safe care due to indicators or outcomes being unable to be measured to confirm the guidelines and policies are working [59]. From this study, it can be seen that there have been many instances of racist and culturally unsafe care (actions that diminish, demean, or disempower the cultural identity and well-being of an individual [60]); therefore; there remains a significant amount of work that needs to be done to ensure all patients receive culturally safe care.

When culturally unsafe care exists, this creates a barrier that discourages patients from seeking care. This barrier becomes particularly significant when that lack of safety is experienced with the first medical professional they engage with [61] (for endometriosis this is usually a GP). The effects of racism in the healthcare system create highly negative experiences that result in the healthcare system being an unwelcoming environment [62], which is further exacerbated when the health issue is difficult to talk about. When socioeconomic status is reviewed alongside culturally unsafe care, this creates an almost insurmountable barrier to overcome.

An approach that may allow these patients to be more open about their bodily experiences could be through consultation with support workers or health coaches from their cultures. Further measures for consideration are the provision of ongoing, targeted cultural training for clinicians to support establishing positive relationships with their patients, which holistically consider all dimensions of the patient's health, workforce equity initiatives, and further research with larger cohorts to define and prioritise cultural

needs in medical environments of diverse groups of endometriosis patients. Previously, the focus was on cultural competence, which does not address the power imbalance that occurs in a healthcare setting and how that influences the actions of both the clinician and patient [60]. Cultural safety in the female reproductive health space also requires clinicians to be aware of the particular spiritual importance some Māori *wahine* place on their *whare tangata* (uterus/womb) when considering treatments that impact this organ. Also, accommodations to honour the sacredness of this organ to cultural and spiritual health must be understood:

> *"When I became eligible for a hysterectomy, I made plans to honour my whare tangata. We had a ceremony on our whānau whenua (familial land) and buried my whare tangata on top of the whenua (family) of all my tamariki (children)." (Confirmed, 36+, Nulliparous, Ngā Ruahine, Ngāti Ruanui, Te Āti Haunui-a-Pāpārangi, Taranaki)*

> *"The cultural belief that the whare tangata is sacred and tapu (sacred) is big for me . . . I faced issues talking to medical staff, GPs about it in this way." (Confirmed, 36+, Parous, Ngā Puhi, Ngāi Tahu)*

4.1.4. Female Patients in Pain

When this study is examined alongside the 2022 study, there is a pattern of women in pain (and people presumed female at birth) not having the severity of their symptoms believed and having their pain downplayed by health professionals, friends, and family [7]. This experience is not exclusive to endometriosis. It has been shown through multiple studies that female patients have different experiences in accessing healthcare and experience differences in treatment compared with their male-presenting counterparts. When colour is added, these differences become heightened, and these issues desperately need addressing. Female patients reporting to American emergency departments with chest pain have been found to wait significantly longer than their male counterparts for triaging and ECGs and are less likely to be hospitalised, while people of colour wait significantly longer for a physical examination [63]. A study by Cleeland et al. found that female and people of colour patients were more likely to receive inadequate pain relief following cancer surgery [64], and female patients presenting to the emergency department with abdominal pain waited an average of 16 min longer than their male counterparts [65].

Including female participants in clinical trials only became a legal requirement by the USA National Institutes of Health in 1993 [66], and females are still underrepresented in trials today [67]. In addition to this, not all trials report outcomes by sex or ethnicity [68]. An analysis carried out in pivotal randomised clinical trials for cardiometabolic drugs found that over ten years, around 4% of patients were Black and 36% were female [69]. Participants from this study have shown that there are still issues surrounding healthcare for females and people of colour, with patients not being believed, having their experiences dismissed, and experiencing racism in the healthcare system. Until significant systematic changes are made, it can be expected that this unacceptable level of care will continue.

4.1.5. Patients as Reproductive Vessels

A theme that came through in this research is the higher focus placed on care when fertility is a concern and the lack of resources that are available when the participant does not want to conceive. The participants in this study were made to feel that a 'hypothetical baby' was worth more than their own health and well-being and that if they were able to conceive then there was no need for further medical attention. This is a significant concern as it undermines the UN's human rights for women, which states women have the right to access without discrimination (among other things) autonomy and sexual and reproductive health [70]. There is a wealth of literature surrounding women's autonomy in developing countries; however, this does not exist at the same level in developed countries [71]. There is, therefore, a need for further research in this area in developed countries in order to fully define the extent of the problem and create workable solutions for equitable care.

4.2. Limitations

4.2.1. Sample Size

As a qualitative study, the sample size of this study was limited to allow for an in-depth analysis of the qualitative data. Larger sample size quantitative studies should be conducted to gain a fuller picture of possible Māori and Pasifika endometriosis patient delays in diagnosis. In both this study and the prior large-scale quantitative study concerning New Zealand endometriosis patients [7], Pasifika patients were underrepresented, and further engagement with this community should be emphasised in future work.

4.2.2. Opt-In Participation

In this study, all individuals interested in participating had to contact the first author to register their interest. It has been shown that opt-in patient survey studies can overrepresent positive healthcare experiences [72], which may prevent this study from representing the full range of negative healthcare experiences these patients may face.

4.2.3. Participant Age Profile

Despite utilising the same social media recruitment method as the authors' prior study [2,9], the age profile of these cohorts was significantly older, with the average age in the Māori patient cohort being 36.2 ± 9.5 years and 38.1 ± 9.7 years in the Pasifika cohort, exceeding the 27.7 ± 6.5 years of the prior cohort ($p < 0.0001$ and $p = 0.0008$, respectively). This may have resulted from the longer delays to diagnosis exhibited within the present study cohorts compared with the prior study, leading to patients being older when they obtained their diagnosis, a requirement for participation. This limits the comparability of the two studies.

5. Conclusions

Throughout this study, it was evident that many of the participants had negative experiences within their journey with trying to access care for endometriosis and that many felt ostracised and unsafe within New Zealand's medical system. The experiences of both Māori and Pasifika endometriosis participants must be incorporated into New Zealand healthcare plans to reduce the delay in diagnosis and improve the provision of treatment. These transformations must be performed in a manner that appreciates the holistic nature of health and centres the person and their wants and needs in the approach to care. Without this person-centred and culture-centred approach, existing inequities will only be further perpetuated.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/soc14040046/s1, The questionnaire utilised in this study is available as "Supplementary Materials—Discussion Board Questions—Māori|Pasifika".

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