



# BMJ Open Beyond the numbers – understanding women's experiences of accessing care for abnormal uterine bleeding (AUB): a qualitative study

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## ABSTRACT

**Objective** To gain a deeper understanding of women's experiences of accessing care for abnormal uterine bleeding (AUB) in order to inform future strategies to improve care pathways, including the early detection of endometrial cancer.

**Design** We conducted semistructured interviews with 15 women who attended their first gynaecological specialist consultation for AUB at Wellington Regional Hospital between October and December 2019. Inductive thematic analysis was used to explore experiences and barriers to seeking care.

**Results** The median age of the participant cohort was 45 years, with women self-identifying as New Zealand European (9/15), Māori (2/15) and Pasifika (4/15). All women had sought investigation for their AUB in primary care, for some women this was over a timeframe of many years. For all women, AUB had a significant and traumatic impact on their quality of life including their relationships and their work or education. Women described how they felt they often received inadequate care for AUB, and reported negative experiences with their general practitioner. Timely access was further compounded by feelings of embarrassment and that AUB was a taboo subject, and being able to discuss it with family, friends and their general practitioners was difficult.

**Conclusion** Women in our cohort experienced a multitude of compounding influences that acted as barriers to them having access to appropriate and timely care. Information campaigns that create awareness around 'abnormal periods' alongside better health provider practice guidelines for AUB investigation need to be a priority.

## INTRODUCTION

Abnormal uterine bleeding (AUB), including the subterm heavy menstrual bleeding (HMB), is excessive, erratic or prolonged blood loss that interferes with a woman's physical, mental, social and quality of life.<sup>1</sup> In the USA, it is estimated that 1.4 million cases of AUB are reported each year.<sup>2</sup> The International Federation of Gynaecology and Obstetrics (FIGO) defines normal uterine bleeding as approximately 40 mL of blood loss over a menstrual period cycle of 5–7 days, and heavy

## Strengths and limitations of this study

- Women with abnormal uterine bleeding (AUB) were given an opportunity to share their experience of care, the findings from which could help inform practice.
- Contemporary and purposeful sample of women.
- Inductive thematic analysis was used to draw key barriers to accessing care.
- The study needs to be extended to the community to include women with AUB who do not reach clinical investigation.

bleeding as 100 mL of blood loss throughout a whole cycle.<sup>3 4</sup> Although the recent reframing in 2017 of older FIGO terms such as menorrhagia, oligomenorrhoea, metrorrhagia and dysfunctional uterine bleeding<sup>5</sup> may go some way to improving a medically defined definition of AUB, such descriptions are still unlikely to be meaningful to women, which may impede the required engagement and discussion with their primary healthcare providers.

AUB is usually a symptom of benign issues; however, it is also the most common symptom of endometrial cancer (EC) or hyperplasia (pre-cancer) and therefore warrants specialist investigation as early as possible. EC is the most common gynaecological cancer, increasing in incidence, with around 400 women diagnosed in New Zealand (NZ) each year. There is a concerning and substantial growth of EC incidence in young, Pacific Island women, with almost half being diagnosed at premenopausal ages (<50 years).<sup>6</sup> EC incidence, morbidity and mortality rates in women who identify as Māori and Pasifika are much greater than those who identify as European/other.<sup>7 8</sup>

Although AUB can have serious medical consequences and significantly impact women's daily life,<sup>9</sup> it is not a condition that

women seek timely care for—and this is seen in many countries worldwide; around half of women with HMB believe there are no treatment options available for them,<sup>10</sup> even if they experienced symptoms of anaemia.<sup>11</sup>

Studies which report on EC prevalence in NZ often link the cause of advanced stage diagnosis to ‘late presentation’,<sup>12–13</sup> placing women at fault for not having sought more timely medical intervention. We aimed to reframe these deficit narratives by looking beyond the numbers, to learn from the lived experiences of NZ women with AUB. By doing so, it is our goal to improve local support for timely access for the investigation of EC.

## METHODS

### Patient and public involvement

The development of the research question and outcome measures was informed by researchers and clinicians in the field, based on anecdotal observations and interest (no patient involvement). The study design underwent Māori consultation through the Ngāi Tahu research committee and Research Advisory Board Māori (Wellington Regional Hospital). The interview questions were developed and piloted on university community members. Participants were given the opportunity to indicate if they would like to know the results of the study; those who did will be emailed the final publication.

### Setting and participants

The aim of this study was to explore women’s experiences in accessing care for AUB to identify barriers to seeking consultation. The population sample was recruited from Wellington Regional Hospital, NZ (Capital and Coast District Health Board) from October to December 2019. We undertook a purposive sampling approach<sup>14</sup> and on the basis of previous NZ-based studies,<sup>15–17</sup> we aimed to recruit between 15 and 20 women. Women (over 18 years of age) were invited to the study to share their experiences of seeking care for AUB at their first specialist appointment (including HMB or postmenopausal bleeding). Women were identified from clinic notes on the day of their appointment and given a study brochure which described what was involved in the study. If they accepted the study invitation, written consent was received before conducting the interview after their appointed clinic consultation. Women were provided with a grocery voucher for their participation. Interviews were conducted by CH, a female research fellow who was not involved in any facet of the patient care pathway.

Women were given the opportunity to bring their partner, whānau (family) or support person to the interview. Participants were asked to begin by recounting their first experiences with AUB. The format of the interviews was semistructured, with key prompt points to facilitate discussion that included:

- ▶ When did you first notice your AUB? Have you sought treatment before?
- ▶ Did you discuss it with friends or family?

- ▶ Did you see a general practitioner (GP), how was your experience?
- ▶ What has helped you book and attend your appointment today?

### Data collection and analysis

All interviews were audio-taped and transcribed by a professional and confidential third-party transcription service. A semi-inductive saturation analytical approach was undertaken.<sup>18–20</sup> NVivo (QSR International) software was used to code themes in each transcript. This was an iterative process of reflection and analysis. First, authors read and became immersed in all the transcript data, including preliminarily identifying codes and drafting of the codebook. Second, each transcript was reread in detail and coded line-by-line. Third, clustering of the codes from each interview into higher level themes was developed inductively. Coding was completed independently by CH and RJ, and themes were developed from combined coding of both authors, with the aid of SF. Any discrepancies in coding were discussed (CH, RJ and SF) to achieve consensus. Any overall themes were discussed to add weight to the validation process. Thematic saturation was deemed achieved when no further themes were revealed.

## RESULTS

A total of 30 women were identified as potential participants for the study. Of these, five women declined the invitation, five women did not attend their specialist appointment (therefore not invited), and five women were not interviewed because they either needed an interpreter who was unavailable at the time (two) or because they left the clinic while other interviews were being conducted (three). A total of 15 women participated in the study (table 1). The median age of women included in the final cohort was 45 (±8 years). Self-identified ethnicity was recorded: 9 of the 15 women identified as NZ European, 2 identified as NZ Māori and 4 identified as Pacific Islander (Cook Islander, Samoan, Tongan) (table 1). The average length of the interviews was 20 min, and ranged between 13 and 34 min.

The time from symptom onset to first specialist appointment was variable (table 1). All of the women who shared their experiences of AUB had been seeking treatment/resolution, often over many years. Women faced a multitude of barriers at each step of the care pathway, which varied for each individual, from systematic to personal complexities (table 2). For all women, AUB had a significant and traumatic impact on their quality of life including their relationships and their work or education (table 3, quotes 1–6). Most women experienced symptoms such as passing large blood clots, pain, poor sleep, mood changes and bowel changes, which affected their mental health and family relationships. At the point of these interviews being undertaken, and after many investigations, no one had a formal diagnosis or explanation why they had

**Table 1** Participant characteristics

Participant	Age range	Ethnicity	Time from symptom to first specialist appointment
1	40–50	NZ European/ other	AUB from a young age (teenager)
2	>50	Samoan	1.5 years
3	>50	NZ European/ other	10 months
4	40–50	NZ European/ other	1 year
5	<40	NZ European/ other	AUB for years, worsening symptoms 5 months
6	40–50	Māori	1.5 years
7	40–50	NZ European/ other	3 months
8	>50	Cook Island	AUB for years, unsure
9	<40	NZ European/ other	5 years
10	<40	NZ European/ other	6 years
11	<40	Tongan	1 year
12	<40	NZ European/ other	6 years
13	>50	Samoan	1 year
14	>50	NZ European/ other	3 months
15	>50	Māori	AUB from a young age (teenager)

AUB, abnormal uterine bleeding; NZ, New Zealand.

developed AUB. It became obvious at the beginning of the interview process that this was a distressing journey for women in their search for diagnosis and treatment. Many women cried during the interview session or used strong language to describe their feelings.

I started crying in the intern and I didn't really expect it....I was like 'I'm sorry can you just do all the options again' 'cause I just got so upset, like it kinda' just all scrambled. And I was really nervous with this appointment too. (Participant 5)

[crying] I went to see the family doctor, that's when he told me all sort of things. (Participant 8)

Four overarching themes were developed (table 2) from the interviews that had an effect on women's decision making around AUB care: healthcare provider experience, AUB as a legitimate health concern, gynaecological health literacy and taboo.

### Negative experiences with healthcare provider

Nine out of 15 women in our cohort described negative experiences with their care providers, in particular with their GP. Two other women described being listened to, but also described how they had to undergo a number

of tests for AUB before they received a referral to specialist consultation. The negative experiences related to dismissal of symptoms and the experiences of living with AUB (and the associated impact that this had on their lives) being diminished, and lack of diagnosis and resolution.

### Dismissed symptoms

Many women felt that AUB was not taken seriously, and GPs were often dismissive of their symptoms:

I've been asking for help all the way through and they just keep giving me painkillers and trying the pill. (Participant 1)

It is also evident from this woman's experience that she had spoken to several GPs (and other non-healthcare practitioners), and also felt that the severity and impact of AUB was diminished by them. This was described by another participant:

I feel like with women's health I go in and I say '(I am bleeding)' and they're like 'doesn't everyone', real dismissive. I definitely find that if I talk to any kind of person about it they're like 'oh it happens' or 'it's your weight'. And I'm like I understand it could be—I can understand it could be estrogen or something but I feel like that's still super dismissive. (Participant 10)

Furthermore, AUB was attributed to her weight, with the inference that she carried a responsibility for having AUB; this was also experienced by Participant 8 (table 3, quote 7). It would appear from the above quote that communication between both parties was not optimal, and that the GP did not understand the severity of her AUB as exemplified by Participant 14:

The bleeding was still continuing and I was just getting nowhere, and in the end I was anaemic, I collapsed and my GP still wasn't really bothered. (Participant 14)

Of concern, communication deficits led to some women receiving treatment that they did not want, with the consequence that the right to make an informed choice to receive this treatment was not upheld. As exemplified by the experience of Participant 10:

My last appointment with him was very traumatic 'cause I went in thinking 'I don't want the mirena'. And then the mirena was put in...I felt like I was a little bit threatened. (Participant 10)

Symptom treatment rather than identifying the cause of the problem also played out in the experience of AUB symptoms being dismissed. Eleven out of 15 women predominantly received only symptomatic treatment (table 3, quote 8–9). Three women were also prescribed iron tablets and felt that while this may have helped their fatigue, it did not help their AUB and in some cases made their bleeding heavier (table 3, quote 10). It is

**Table 2** Thematic structure

Inductive codes	Preliminary/subthemes	Final themes
Not understanding procedures or prescriptions	Dismiss symptoms	Negative experiences with healthcare provider
Never formally diagnosed	Relationships	
Variability in doctor treatment	Communication	
Prescribing painkillers		
Comfort with female doctors		
Seeing family/usual GP		
Seeing different GPs		
Trust in care		
Knowledge of causes of AUB	Normal menstruation	Gynaecological health literacy
Knowledge of treatments available	Knowledge of treatments	
Knowledge that AUB is something to be checked—ignoring/normalising symptoms		
What is normal bleeding?		
Unable to relate to friends experiences	Self-doubt	AUB as a legitimate health concern
Doubting symptoms	Normalisation	
Lived with AUB throughout life, dealt with it	Prioritising others	
Expectations of hospital visit		
Looking after family/children		
Work deadlines		
Ability to take time off work		
Ability to make it to appointments		
Emotion (heightened)	Fear	Taboo
Scared of pain (IUD)	Impact on life	
Scared of doctors	Embarrassment	
Impact on quality of life		
Embarrassed about bleeding through clothes		
Embarrassed about talking about bleeding (friends or colleagues)		
Relationships with partners		
Isolation		

AUB, abnormal uterine bleeding; GP, general practitioner; IUD, intrauterine device.

likely that the suggestion by primary health providers to use hot water bottles (hottie) to help alleviate pain was well meaning (although likely ineffective), and the use of 'just' conveys a sense of how women felt dismissed.

Not all women had negative experiences with their GP. Two participants found that their healthcare provider quickly organised an ultrasound (scan) to investigate the issue further, which affirmed their decision to seek help, and acknowledged their symptoms as a problem to be investigated and treated properly rather than managing symptoms:

She's very matter of fact and said 'well let's have a look, see what's going on there'...she's great. (Participant 7)

She's a great doctor we've been going to her for years. But then she thought it was pre menopause-but sent me to have a scan just to find out what was going on. (Participant 6)

### Relationships

Building a sense of trust and connection with primary healthcare providers made a significant difference to the way AUB was managed and women's experiences with seeking treatment. For example, feeling comfortable to explain all symptoms, feeling listened to and discussing a treatment plan together had a positive impact on participants:

Being able to have that rapport with the doctor does make a difference and then they can talk to you and explain stuff rather than just feeling unsure that you were checked out properly. (Participant 14)

Ten of 15 women commented on the gender of their GP, and when women talked of negative experience they often mentioned that the GP was a man. Many women disclosed that they needed to see a female doctor as they felt more comfortable and listened to:

**Table 3** Supporting quotes

	Quote
Impact on quality of life	1 "That was a 3year course and in the last year you had to have 100% attendance, and I just couldn't do it." (Participant 1)
	2 "We tried to go to <DESTINATION> for a day, 'cause it was summer with the kids, and we couldn't even go 'cause I was like getting the clots out." (Participant 10)
	3 "So sometimes for the few months I have when I have my bleeding - very bad menstruation and cramp. I can't really go, I don't want to go and mix with my friends, I just don't want to go to class, I just want to stay in house." (Participant 11)
	4 "I don't wanna' bleed every 2 weeks, and as a student you can't afford tampax." (Participant 3)
	5 "Every time when it gets to my period, now that it's happened a few times I get quite anxious, I'm like oh I've got this thing I was gonna' do or I've got this work event or- yeah I just have to kind of be prepared to change my plans if it does go downhill." (Participant 9)
	6 "My husband went and got me a bigger one which he found and that's helps me ((right through)). It was bleeding bleeding and then I cried sometimes." (Participant 8)
Negative experience with healthcare provider	7 "He said and another one is because I'm overweight, I need to do something about myself." (Participant 8)
	8 "I can't even remember what they (GP) did, god it was a few years ago. Anyway it didn't really result in much, like didn't refer me anywhere or look at anything, just made a few suggestions and said oh you can take ibuprofen that can slow down bleeding if you're- or just put a hottie on your tummy." (Participant 9)
	9 "He was just like 'hmm ok I can prescribe you some meds, oh here you go'. It was just that's it." (Participant 5)
	10 "So when I took the iron tablet it really helps. It helps with my iron level to go up, but the menstruation bleeding was still like, I was still having the same problem." (Participant 11)
Gynaecological health	11 "I think must be something with my body if it just the level of stress that I'm in and it'll go back to normal." (Participant 11)
Literacy	12 "That was probably 6 months ago, and so I finally have my appointment today. But I don't know how much or what it's gonna' do... if there was gonna' be an examination or a scan or if we were gonna' talk." (Participant 9)
	13 "I don't know if it's a bad thing but my expectations, they're not- They're not high. But that's not...reflective of the quality of treatment, that's just reflective of the wait times, because everything that the hospital does has been fine." (Participant 7)
	14 "I don't really understand what that tablet was but he said it was a blood pressure one and I brought it in to help with period pain, so that kind of helped." (Participant 1)
AUB as a legitimate health concern	15 "Six months later something similar happened and I didn't go to hospital, 'cause I was like 'I'm not going to hospital for having a heavy period again that's just stupid'. I remember feeling so embarrassed." (Participant 9)
	16 "I started feeling dizzy and started waving and started seeing black...So I quickly had to ring the ambulance... I was losing a lot of red cells out of my body. So they had to blood transfusion." (Participant 15)
	17 "I've got no time to go doctors and stuff, 'cause I'm at home with four grandchildren." (Participant 15)
	18 "And it (the appointment) was in the middle of the day so our son was at school so it was real good." (Participant 9)
Taboo	19 "At work I wouldn't feel comfortable being like 'I have extremely horrible periods'." (Participant 5)
	20 "My daughter's really free in talking about it which I love, and I'm trying not to project awkwardness onto her, I feel awkward...she's very open talking about it, in a way that I'm not." (Participant 7)
	21 "Some of my friends I just talk to them about me being uncomfortable in my fibroid and stuff. But they don't have the bleeding menstruation." (Participant 2)
	22 "Obviously there's a few friends I'm really blunt with and we talk about like period poops all the time, but I guess we weren't extremely detailed." (Participant 5)

AUB, abnormal uterine bleeding; GP, general practitioner.

I trust her she can do the gynae in the office, so she's done all my cervical smears and other tasks-Yeah, she knows my history, my squeamishness. (Participant 4)

A number of women described seeking care from multiple doctors. Some felt that they would have received a better explanation if the GP was a woman, or a more experienced GP. Although as one woman experienced, this did not always eventuate, and even though she actively sought a female doctor expecting better support, she did not receive it:

I switched to a female doctor thinking it would be better for a better understanding but they just looked at you as if you're kind of a like drug seeker type

thing- 'Cause that's just kind of how I feel, 'cause they went like they did all these tests -Can't find anything. I said 'well I'm really bad', and she wasn't much help really and then I changed doctors again and he's quite a really good doctor, he's done like what he can, I guess he's sent me for a scans and he's referred me back up here [women's clinic]. (Participant 1)

In some cases, in the general practice clinics that were busy, women would see the next available doctor, which added an element of chance to whether women could choose a female GP. It was therefore only by chance that women felt comfortable enough to share their experiences of AUB:

So I call the doctor, lucky that's the female doctor so I can ((open up)) to talk and then to examine me. (Participant 2)

### Gynaecological health literacy

Health literacy is a term used to describe the skills required to 'obtain, process and understand information in order to make informed health decisions in a complex and multidimensional healthcare environment'.<sup>21</sup> Health literacy plays an important role in women's health<sup>22</sup> however is not always recognised by primary healthcare providers.

### Normal menstruation

A general understanding around what constitutes normal gynaecological health (normal periods) seemed to influence women's decisions to seek investigation for AUB. Six of the 15 women interviewed had delayed seeking care up to as long as 3 years as they attributed their symptoms to other causes or as a non-issue; 4 women linked it to stress (table 3, quote 11) and 1 linked to periods 'syncing'.

For others, figuring out that their bleeding was abnormal was difficult to work out, and there was a clear need for more accessible and trustworthy information around what normal periods are and when to be seeking help, as Participant 5 described:

It's only recently looking at- after ((googling)) around I realised I've actually had abnormal bleeding for a really long time I just didn't realise it wasn't supposed to be that bad...I just wish I knew like the boundaries of normal for what periods were. 'Cause I have another friend right now she's going through a real shit time and she's also had painful periods for a really long time and now it's like she may have uterine cancer and she didn't know...So like I just wish there was more education. (Participant 5)

### Knowledge of treatments

The women we spoke to were keen to better understand AUB, but did not appear to have had appropriate/accessible information or discussion with or from their GPs. As one woman's experience highlighted that she did not think the women's clinic would 'know more':

I kind of didn't really believe that the women's clinic would know more and so I thought I'd just come up here. (Participant 1)

This issue is linked with the theme of healthcare provider experience. This communication deficit was further exemplified in 4 of 15 women who were unsure of what to anticipate at the specialist clinic and had low expectations in regards to a resolution for AUB (table 3, quote 12).

Low expectations of healthcare also stemmed from experiences with long wait times, including being put on the waiting list for often more than 4 months for their specialist appointment. This compounded women's

feeling of low expectations that their AUB would be resolved (table 3, quote 13).

Compounding the negative healthcare provider experience of being dismissed further, some women did not understand the prescriptions they had been given, but took them anyway (table 3, quote 14). This suggests that women were not able to make an informed choice about the course of treatment, and highlights that communication between women and their GP was not optimal. Furthermore, it was also clear that women did not know what treatment options were available for AUB, and one woman was thrilled on learning that the Mirena could help her condition:

I didn't know ((nothing)) 'bout these 'cause like me I'm old school, I don't keep up updates. Until my lovely doctor just told me about this [The Mirena], put that there for five years...I'm really glad I've come today to find out my life what I can do, I'm rapt. (Participant 15)

### AUB as a legitimate health concern

#### Self-doubt

Compounded by their negative experiences, 11 out of 15 women were left experiencing self-doubt that AUB was not a condition worthy of further investigation, and for some women, it was evident that they felt a sense of anguish, which for one woman led to her cancelling her appointment:

I'd heard in the media about how there are long waits, there are very few specialists for the public health care system, I felt really terrible that I'd like clogged up the system with my unnecessary problem then I panicked and cancelled. (Participant 4)

This woman's intention was founded in believing that by not attending the appointment she would enable someone else access to healthcare; this exemplifies that women did not think that AUB was a condition worthy of investigation or did not want to 'waste anyone's time' (Participant 4). For some women this prevented them seeking care again (table 3, quote 15).

One participant had been experiencing heavy bouts of AUB her whole life and had doubted the severity of the condition. The only reason she finally had medical investigation was because she was admitted to the emergency department and given a blood transfusion due to AUB-induced anaemia (table 3, quote 16). Another woman recalled her experience of bleeding through her clothes and passing out at work, then immediately went onto put her own story down.

I'm sure for other people they get it all the time and it's probably a lot worse and it's a lot more ongoing... So I'm probably not a dire case or this may not be useful for your study I don't know. (Participant 9)

Her experience represents what many of these women have become used to—that AUB is (now) their normal.

### Prioritising others

It was evident that women justified the needs of others over being able to attend their clinical appointments. Many women described how they tolerated AUB symptoms in order to keep family, work or social commitments:

It's always painful you just kinda' deal with it you just kinda' suck it up, like you can't take time off work every month usually. (Participant 5)

Previous negative experiences, a sense that a resolution would not be achieved or that it was not a concern that was worth the hassle contributed to their justifications. For example, one participant's immediate reaction to parking issues was that seeking care for AUB was not worth the trouble:

I felt when I couldn't get a [car] park and I couldn't get anyone to look after the kids at first, I thought oh it's not worth getting my husband home from work. (Participant 10)

Commitments such as looking after family and employment significantly impacted 12 out of 15 women in their ability to attend appointments. The responsibility of taking care of family was reiterated a number of times for these women (table 3, quote 17) and that timing of the appointments was critical to fit in with their lives (table 3, quote 18).

### Taboo

Fear, embarrassment and the impact that AUB has on quality of life instil taboo around the topic of menstruation for women. Embarrassment, shame or shyness because of these experiences with menstruation meant that women were reluctant to talk to others about their AUB experiences with friends or family; one woman felt she could not even talk to her daughter about menstruation (table 3, quote 19). This extended to work situations, for example, needing to take sick leave (table 3, quote 20).

Twelve of the 15 participants had experienced traumatic accounts where their bleeding had been so heavy that they had to cover themselves or call a friend to help, as described:

I remember feeling so embarrassed, but I was like bleeding through really quickly and bleeding on my clothes and just feeling like I couldn't go anywhere or do anything sort of normal. (Participant 9)

She wrapped a tarpaulin around me, that's how bad it was, so that I could walk out of the main ((central)) ...So embarrassing. (Participant 10)

One participant's husband, who was present during the interview, interjected: "She can't even say period most of the time to me." (Participant 8)

This fear of menstrual symptoms meant that women felt isolated and were reluctant to discuss the issues with friends or family. Participant 10 found that reaching out and discussing openly her problems with others was vital

in her journey to seeking help, and explained that taboo can lead to feelings of loneliness:

I think [taboo] is harmful 'cause it can make you feel alone and I've found out I'm not. (Participant 10)

Some women believed they did talk to friends about menstrual experiences, however on reflection their AUB problems were not discussed in depth (table 3, quote 21–22).

## DISCUSSION

### Main findings

With this qualitative study we aimed to explore women's experiences of accessing care for AUB in order to elucidate the barriers in a NZ setting. The key themes that emerged from this study were healthcare provider experience, gynaecological health literacy, AUB as a legitimate health concern and taboo. It is clear that women do not experience a linear trajectory to a specialist gynaecological appointment. Rather, they face compounded systemic and personal barriers often compounded by the complex nature of AUB and poor management.

### Interpretation

Two recent studies specifically look at the experiences of women diagnosed with endometrial cancer. Both used a similar cohort size and used interpretive and descriptive coding to deduce common themes among participants. The first, also placed in NZ, reported similar stories of self-doubt and confusion around their symptoms.<sup>23</sup> The second, placed in Canada, investigated morbidly obese women diagnosed with low-grade endometrial cancer<sup>24</sup> and focused on barriers to surgery for this group of women. This study found that women with endometrial cancer were subject to stigma and poor provider communication, and that many of the participants learnt about the link between endometrial cancer and obesity through their own reading.<sup>24</sup> Participants also noted their reluctance to seek care due to prior stigmatisation experiences.<sup>24</sup> These issues were similarly reported by a number of participants in our study.

Overall, the women we spoke to experienced similar journeys to women with other gynaecological challenges such as endometriosis, which has been investigated in more depth than AUB. In particular, women often experienced poor communication from doctors and personally normalised their menstrual pain from an early age.<sup>25–28</sup> Healthcare provider dismissal of gynaecological symptoms has been a long-standing issue. Like those with endometriosis, women with AUB seem to endure long and ongoing struggle for diagnosis and treatment. Some of the participants with AUB experienced what has previously been described as 'the doctor trail'<sup>29</sup>: trying to find someone to support, listen and treat the cause of the symptoms. Women with endometriosis spoke about difficulty in having an undiagnosed problem and the relief that comes with having a 'medical label'. Unfortunately

for some of the participants in this study with AUB, there was often no definitive diagnosis. This may be because AUB is a complex combination of conditions, experienced differently, classified by the PALM (structural)-COEIN (non-structural) acronym—polyp, adenomyosis, leiomyoma, malignancy and hyperplasia, coagulopathy, ovulatory dysfunction, endometrial, iatrogenic and not yet classified. Unfortunately within the AUB classification, there are still underlying causes that are unknown, which occurs in approximately 12% of women.<sup>30</sup>

The Best Practice Advocacy Centre NZ (BPAC), which aims to disseminate and communicate practice guidelines to GPs, has an updated (2019) outline for AUB investigation. While comprehensive, this guideline does not follow the National Institute for Health and Care Excellence (NICE) guidelines, that highlight the need for the recognition of AUB on women's quality of life (section 1.1), and emphasise treatment addressing this rather than quantity of blood loss. The BPAC NZ guidelines do not include any such assessment. In our study, we found that women were treated with iron tablets or painkillers until symptoms worsen, patients return for another consultation or change healthcare provider. A follow-up study to gain a deeper understanding of the management of AUB from the GP's experience, and implementation of GP workshops would be important to change these practices.

The 2018 audit of gynaecological cancer treatment pathway guidelines indicate a less than 14-day waiting period for a specialist appointment on the suspicion of malignancy.<sup>31</sup> This target was met for 85% of women in this audit.<sup>31</sup> This is possible when risk of endometrial cancer is obvious (postmenopausal and/or high body mass index). However, given the complex nature of AUB in premenopausal women, this guideline may be overlooked. Furthermore, there are no time standards for the pathway to a specialist for AUB. Most women in our study reported waiting equal to or greater than 4 months for their referral appointment. In cases where AUB is a sign of endometrial cancer in premenopausal women, this is of concern.

From our investigation and others<sup>23 24 32</sup> it is clear that there is a lack of evidence-based information easily available to woman around AUB. While there are successful cancer screening awareness campaigns for cervical, breast and colorectal,<sup>33 34</sup> there are none for endometrial cancer. From our study, women were confused about normality, and did not realise there were treatment options available, such as the Levonorgestrel Intra Uterine System (Mirena). Now that it has come under government-subsidised funding in NZ, the Mirena is free for women, whether that be for contraceptive use or management of periods. The Mirena has also been shown to protect against and/or treat hyperplasia and early stage endometrial cancer.<sup>35 36</sup> We encourage our findings to be seen as a call to action for healthcare providers to ask about quality of life during AUB investigation, help women recognise AUB symptoms, discuss treatment options and arrive at a treatment decision together as outlined in the NICE guidelines. It would be particularly useful for information material to be based on, and include women's experiences, as we

have seen here, to help break down taboos associated with menstruation. Furthermore, we urge the use of digital and social platforms to equip women with the information they need to support care-seeking activity.

### Strengths and limitations

This study was based on the experiences of women who had a referral to a specialist appointment. Community-based research is needed in order to better understand women's experience of seeking care for AUB, including reaching out to those who have never sought investigation from any healthcare provider. The patient cohort was Euro-centric and not reflective of the ethnic population of NZ; however, we did not analyse women's experiences by their ethnicity and additional studies with more purposive inclusion of non-European women would be warranted.

The major limitation with this study is the inclusion of women who attended their specialist appointment—we do not know the barriers women faced who were not able to attend. In particular there were five women who did not attend their specialist appointment and therefore were not able to be invited to this study; these women had a history of non-attendance, and who were also scheduled for an ultrasound scan and had reported anaemia. This warrants further investigation, including from a community-based recruitment approach. Another five women who did attend their appointment and were invited to the study were not able to be interviewed due to needing an interpreter who was not available at the time, or the interviewee busy with other participants. This may have resulted some groups of women whose experiences were not recorded. Furthermore, these interviews were conducted in a metropolitan area of NZ (Wellington) and may not reflect those experiences of women in more rural areas or communities, and therefore requires ongoing investigations.

### CONCLUSION

As cases of endometrial cancer are being diagnosed at younger, premenopausal ages, timely access and appropriate care for AUB is critical yet often overlooked. Unfortunately, we have heard from women with AUB whose stories are seldom described straightforward experiences of care to a clinical specialist. Information campaigns that create awareness around 'abnormal periods' alongside better health provider practice guidelines for AUB investigation need to be a priority. These results require action into tangible outcomes to ensure women are treated at the earliest utmost stage of their symptoms.

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**Patient consent for publication** Not required.

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