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Beyond the numbers- understanding women's journey's to clinic for abnormal uterine bleeding (AUB): a qualitative study.

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31 Abstract

32 Objective: To gain a deeper understanding of women's experiences with accessing care for abnormal
33 uterine bleeding (AUB), in order to inform future strategies in early detection of endometrial cancer.

34 Design: We conducted semi-structured interviews with 15 women who attended their first
35 gynaecological specialist consultation for abnormal uterine bleeding at Wellington Regional Hospital
36 between October-December 2019. Inductive thematic analysis was used to decipher facilitators and
37 barriers to care. Results: Thirty women were invited to participate in the study. The medium age of the
38 final participant cohort was 45 years, with women self-identifying as New Zealand European (9/15),
39 Māori (2/15) and Pasifika (4/15). All women had sought investigation for their AUB in primary care,
40 for some women this was over a timeframe of many years. For all women, AUB had a significant and
41 traumatic impact on their quality of life including their relationships and their work or education.
42 Women described how they felt they often received inadequate care for AUB, and negative experiences
43 with their general practitioner. Timely access was further compounded by feelings of embarrassment
44 and that AUB was taboo subject and being able to discuss it with family, friends and their general
45 practitioners. Conclusion: Women in our cohort experienced a multitude of compounding influences
46 that acted as barriers to them having access to appropriate and timely care. Information campaigns that
47 create awareness around 'abnormal periods' alongside better health provider practice guidelines for
48 AUB investigation need to be a priority.

50 Strength and limitations of this study

- 51 - Women with AUB were given the space to discuss their journey to clinic; for most a clearly
52 distressing experience.
- 53 - Inductive thematic analysis was used to draw key barriers to accessing care.
- 54 - The study needs to be extended to the community to include women with AUB who do not
55 reach clinical investigation.

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60 Competing interests

61 The authors have no competing interests to declare.

62

63 Introduction

64 Abnormal uterine bleeding (AUB), including the sub-term heavy menstrual bleeding (HMB), can be
65 excessive, erratic or prolonged blood loss that interferes with a woman's physical, mental, social and
66 quality of life(1). In the United States, it is estimated that 1.4 million cases of AUB are reported each
67 year (2). The International Federation of Gynaecology and Obstetrics (FIGO) defines normal uterine
68 bleeding as approximately 40mls of blood loss over a 5-7 day menstrual period cycle, and heavy
69 bleeding as 100mls of blood loss throughout a whole cycle (3, 4). Although the recent reframing of
70 FIGO terms (5) may go some way to improving a medically defined definition of AUB, such
71 descriptions are still unlikely to be meaningful to women, which may impede the required engagement
72 and discussion with their primary health care providers.

73 AUB is usually a symptom of benign issues however it is also the most common symptom of
74 endometrial cancer (EC) or hyperplasia (pre-cancer) and therefore warrants specialist investigation as
75 early as possible. EC is the most common gynaecological cancer, increasing in incidence, with around
76 400 women diagnosed in New Zealand (NZ) each year. There is a concerning and substantial growth
77 of EC incidence in young, Pacific Island women, with almost half being diagnosed at pre-menopausal
78 ages (<50 years) (6). EC incidence, morbidity and mortality rates in women who identify as Māori and
79 Pasifika are much greater than those who identify as European/Other (7, 8).

80 Although AUB can have serious medical consequences and significantly impact women's daily life, it
81 isn't a condition that women seek timely care for – and this is seen in many countries world-wide;
82 around half of women with HMB believe there are no treatment options available for them (9), even if
83 they experienced symptoms of anaemia (10).

84 Studies which report on EC prevalence in NZ often link the cause of advanced stage diagnosis to 'late
85 presentation (11, 12), placing women at fault for not having sought more timely medical intervention.
86 We aimed to reframe these deficit narratives by looking beyond the numbers, to learn from lived in
87 experiences of women with AUB in NZ. By doing so, it is our goal to improve local support for timely
88 access to EC investigation and provide new perspectives to transform the care pathway for women
89 seeking care.

90

91 Methods

92 Patient and public involvement

93 The development of the research question and outcome measures were informed by researchers and
94 clinicians in the field, based on anecdotal observations and interest. The study design underwent Māori
95 consultation through the Ngāi Tahu research committee, and Research Advisory Board Māori (RAGM,

1
2
3 96 Wellington Regional Hospital). The study design underwent peer review and amendments from an
4
5 97 institutional ethics board (University of Otago approval #H19-072). Patients were recruited to the study
6
7 98 and were directly involved through interviews as follows.

8 9 99 **Setting and participants**

10
11 100 The population sample was recruited from the Women's Clinic at Wellington Regional Hospital, New
12
13 101 Zealand (CCDHB) from October-December 2019. Women were invited to the study to tell their story
14
15 102 about their journey to the clinic for AUB at their first specialist appointment for AUB (including HMB
16
17 103 or post-menopausal bleeding). Women were identified from clinic notes on the day of their
18
19 104 appointment, and given a study brochure which described what was involved in the study. If they
20
21 105 accepted the study invitation, written consent was received before conducting the interview after their
22
23 106 appointed clinic consultation. Women were provided with a grocery voucher for their participation.
24
25 107 Interviews were conducted by CH, a female research fellow. Participants were given the opportunity to
26
27 108 indicate if they would like to know the results of the study- those who did will be emailed the final
28
29 109 publication.

30
31 110
32
33 111 Women were given the opportunity to bring their partner, whānau or support into the interview with
34
35 112 them. Participants were asked to begin recounting their first experiences with AUB. The format of the
36
37 113 interviews was semi structured, with key prompt points to facilitate discussion that included:

38 114- When did you first notice your AUB? Have you sought treatment before?

39 115- Did you discuss with friends or family?

40 116- Did you see a GP, how was your experience?

41 117- What has helped you book and attend your appointment today?

42 118

43 119 **Data collection and analysis**

44
45 120 All interviews were audio-taped and transcribed by a professional and confidential third party
46
47 121 transcription service. Detailed and semi-inductive thematic analysis (13, 14) using *NVivo* software was
48
49 122 used to code themes in each transcript. This was a cyclical process of reflection and analysis. First,
50
51 123 authors read and became immersed in all the transcript data, including preliminarily identifying codes
52
53 124 and drafting of the codebook. Secondly, each transcript was re-read in detail and coded line-by-line.
54
55 125 Thirdly, clustering of the codes from each interview into higher level themes were developed
56
57 126 inductively. Coding was completed independently by CH and RJ and themes were developed from
58
59 127 combined coding of both authors, with the aid of SF.

60 128

129 Results

130 A total of 30 women were identified as appropriate candidates for the study. Of these, 5 women declined
 131 the invitation, 5 women did not attend their appointment, and 5 women were missed (needed an
 132 interpreter or left clinic whilst other interviews were being conducted). Table 1 shows sample
 133 characteristics of the total number of women included in study. The median age of women included in
 134 the final cohort was 45 (\pm 8 years). Self-identified ethnicity was recorded, nine of the fifteen women
 135 identified as NZ European, two identified as NZ Māori, and four identified as Pacific Islander (Cook
 136 Islander, Samoan, Tongan).

137
 138 **Table 1:** Participant characteristics

<i>Participant</i>	<i>Age</i>	<i>Ethnicity</i>
1		NZ European/other
2		Samoan
3		NZ European/other
4		NZ European/other
5		NZ European/other
6		Māori
7		NZ European/other
8		Cook Island
9		NZ European/other
10		NZ European/other
11		Tongan
12		NZ European/other
13		Samoan
14		NZ European/other
15		Māori

139

140

141

142 For all women, AUB had a significant and traumatic impact on their quality of life including their
 143 relationships and their work or education. Most women experienced symptoms such as passing large
 144 blood clots, pain, poor sleep, mood changes and bowel changes, which affected their mental health and
 145 family relationships. At the point of these interviews being undertaken, and after many investigations,
 146 no one had a formal diagnosis, or explanation why they had developed AUB. Women faced a multitude
 147 of barriers at each step of the care pathway, which varied for each individual, from systematic to

1
2
3 148 personal complexities. However, four overarching themes were developed from the interviews that had
4
5 149 an effect on women's decision making around AUB care: health care provider experience, health
6
7 150 literacy, commitments and taboo (figure 1).

8 151

9
10 152 It became obvious at the beginning of the interview process that this was a distressing journey for
11
12 153 women in their search for diagnosis and treatment. Many women cried during the interview session or
13
14 154 used strong language to describe their feelings.

15 155 *"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*
16 156 *options again 'cause I just got so upset, like it kinda' just all scrambled. And I was really nervous with*
17 157 *this appointment too".* Participant 5.

18
19 158 *It was bleeding bleeding and then I cried sometimes... [crying] I went to see the family doctor, that's*
20
21 159 *when he told me all sort of things"* Participant 8.

22
23 160

24 161 Negative experiences with health care providers

25 162 Women in our cohort described negative experiences with their care providers, in particular their GP.
26
27 163 The negative experiences related to the symptoms and lived experience of AUB (and associated impact
28
29 164 that had on their lives) being diminished, lack of diagnosis and resolution.

30
31 165

32 166 Diminished symptoms

33
34 167 Many women felt that AUB was not taken seriously, and GPs were often dismissive of their symptoms,
35
36 168 as this quote exemplifies:

37
38 169 *"I feel like with women's health I go in and I say ((I am bleeding) and they're like doesn't everyone,*
39
40 170 *real dismissive. I definitely find that if I talk to any kind of person about it they're like oh it happens or*
41
42 171 *it's your weight. And I'm like I understand it could be- I can understand it could be estrogen or*
43
44 172 *something but I feel like that's still super dismissive."* Participant 10.

45
46 173 It is also evident from this woman's shared experience that she had spoken to several GPs (and other
47
48 174 non-healthcare practitioners) and also felt that the severity, and impact of, AUB was diminished by
49
50 175 them. Furthermore, AUB was also attributed to her weight, with the inference that she carried a
51
52 176 responsibility for having AUB. It would appear from the above quote that communication between both
53
54 177 parties was not optimal, and that the GP did not understand the severity of her AUB. The feeling of that
55
56 178 AUB was diminished by the GPs was further compounded by feelings that the GP did not care, as
57
58 179 experienced by another woman:

59 180 *"The bleeding was still continuing and I was just getting nowhere, and in the end I was anaemic, I*
60 181 *collapsed and my GP still wasn't really bothered."* Participant 14.

1
2
3 182 All of the women who shared their experiences of AUB had been seeking treatment/resolution, often
4 183 over many years (Table 2, quote 1), and of significance, women predominantly received only
5 184 symptomatic treatment (Table 2, quote 2).

6
7
8 185 It is likely that the suggestion to use hot water bottles (hottie) to help alleviate pain was well-meaning
9 186 (albeit likely ineffective), and the use of ‘just’ conveys a sense of how they felt dismissed. All women
10 187 received pain medication, which further added to the feeling and experience that AUB was being
11 188 diminished (Table 2, quote 3), and any treatment of AUB was not successful for the women in our
12 189 cohort.

13
14
15
16
17 190 *“I’ve been asking for help all the way through and they just keep giving me painkillers and trying the*
18 191 *pill”* Participant 1.

19
20 192 One patient even described how she received treatment that she did not want, but felt that she had no
21 193 choice.

22
23
24 194 *“And my last appointment with him was very traumatic ‘cause I went in thinking I don’t want the*
25 195 *mirena. And then the mirena was put in...I felt like I was a little bit threatened.”* Participant 10.

26
27
28 196 This experience indicates that the communication was not optimal and a trusted relationship had not
29 197 been established with the consequence that her right to make an informed choice to receive this
30 198 treatment was not upheld. The experience that AUB was not being taken seriously, and being given
31 199 medications for symptomatic relief, was further exacerbated for some women as they didn’t understand
32 200 the prescriptions they had been given, but took them anyway (Table 2, quote 4). This suggests that
33 201 women were not enabled to make an informed choice about the course of treatment. A number of
34 202 women were also prescribed iron tablets and felt that whilst this may have helped their fatigue, it did
35 203 not help their AUB and in some cases made their bleeding heavier (Table 2, quote 5).

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42 205 **Relationships**

43 206 Building a sense of trust and connection with primary health care providers made a significant
44 207 difference to the way AUB was managed, and women’s experiences with seeking treatment. For
45 208 example, feeling comfortable to explain all symptoms, feeling listened too, and discussing a treatment
46 209 plan together had a positive impact on participants.

47
48
49
50 210 *“being able to have that rapport with the doctor does make a difference and then they can talk to you*
51 211 *and explain stuff rather than just feeling unsure that you were checked out properly”* Participant 14.

52
53 212 Most women commented on the gender of their GP, and those who did not explicitly state that they
54 213 would have preferred to see a female GP, when women talked of negative experience they mentioned
55 214 that the GP was male. Many women disclosed that they needed to see a female doctor as they felt more
56 215 comfortable and listened to.

1
2
3 216 *"I trust her she can do the gynae in the office, so she's done all my cervical smears and other tasks-*
4 217 *Yeah, she knows my history, my squeamishness."* Participant 4.

6
7 218 Some felt that they would have received a better explanation if the GP was a woman, or a more
8 219 experienced GP. A number of women described seeking care from multiple doctors, in a helpless
9 220 attempt to resolve their chronic and debilitating condition (Table 2, quote 6). In some cases, women
11 221 would see the next available GP, which added an element of chance to whether women would could
13 222 choose a female GP. It was therefore only by chance that women felt comfortable enough to share their
14 223 experiences of AUB:

16 224 *"So I call the doctor, lucky that's the female doctor so I can ((open up)) to talk and then to examine*
17 225 *me"*. Participant 2.

20 226

22 227 Low expectations

24 228 Women experienced low expectations on two levels, one of the care that they were going receive and
26 229 of themselves.

28 230 **Of the care available**

30 231 Women were unsure of what to expect at the specialist clinic and had low expectations in regards to a
32 232 resolution for AUB (Table 2, quote 7).

34 233 *"I kind of didn't really believe that the women's clinic would know more and so I thought I'd just come*
35 234 *up here."* Participant 1.

37 235 It was clear that women did not know what treatment options were available, and one woman was
39 236 thrilled upon learning that the Mirena could help her condition;

41 237 *"I didn't know ((nothing)) 'bout these 'cause like me I'm old school, I don't keep up updates. Until my*
42 238 *lovely doctor just told me about this [The Mirena], put that there for five years"*
44 239 *"I'm really glad I've come today to find out my life what I can do, I'm rapt."* Participant 15.

46 240 Low expectations stemmed from experiences with long wait times, including being put on the waiting
48 241 list for often more than 4 months for their specialist appointment. This compounded women's feeling
49 242 of low expectations that their AUB would be resolved (Table 2, quote 8).

51 243 *"She was like you need to keep on to it. Just stay on the list and just go and see them. It's not your fault*
53 244 *the waiting list is long."* Participant 10.

55 245

57 246 **Of themselves**

1
2
3 247 Compounded by their negative experiences and inability to achieve a resolution, women were left
4
5 248 experiencing self-doubt that AUB was not a condition worthy of warranting further investigation, and
6
7 249 for some women, it was evident that they felt a sense of anguish, which for one woman led to her
8
9 250 cancelling her appointment:

10 251 *“I’d heard in the media about how there are long waits, there are very few specialists for the public*
11
12 252 *health care system, I felt really terrible that I’d like clogged up the system with my unnecessary problem*
13
14 253 *then I panicked and cancelled.”*

15 254 Even though this woman’s intention was founded in believing that by her not attending her appointment
16
17 255 would enable someone else access to healthcare, this exemplifies how women did not think that AUB
18
19 256 was a condition worthy of investigation, or did not want to “waste anyone’s time” (Participant 4). For
20
21 257 some women this prevented them seeking care again (Table 2, quote 9).

22 258 One participant had been experiencing heavy bouts of AUB her whole life and had doubted the severity
23
24 259 of the condition. The only reason she finally had medical investigation was because she was admitted
25
26 260 to emergency and given a blood transfusion due to AUB induced anemia (Table 2, quote 10). Another
27
28 261 woman recalled her experience of bleeding through her clothes and passing out at work, and
29
30 262 immediately went onto put her own story down.

31 263 *“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*
32
33 264 *ongoing... So I’m probably not a dire case or I’m- this may not be useful for your study I don’t know”.*
34
35 265 Participant 9.

36 266 Her experience represents what all these women have become used to – that AUB is (now) their normal,
37
38 267 and speaks to the severity of their AUB.

39
40 268

41 42 269 Health Literacy

43
44 270 Health literacy, and a general understanding around what constitutes normal gynaecological health
45
46 271 influenced women’s decisions to seek earlier investigation for AUB. Many women identified stress as
47
48 272 the cause of their change in bleeding. Nine of the fifteen women interviewed delayed seeking care up
49
50 273 to as long as 3 years as they attributed their symptoms to other causes (Table 2, quote 11).

51 274 For others, simply figuring out that their bleeding was abnormal was difficult to work out:

52 275 *“And it’s only recently looking at- after ((googling)) around I realised I’ve actually had abnormal*
53
54 276 *bleeding for a really long time I just didn’t realise it wasn’t supposed to be that bad...I just wish I knew*
55
56 277 *like the boundaries of normal for what periods were. ‘Cause I have another friend right now she’s going*
57
58 278 *through a real shit time and she’s also had painful periods for a really long time and now it’s like she*

1
2
3 279 *may have uterine cancer and she didn't know...So like I just wish there was more education*” Participant
4 280 5.

6 281 That women were seeking more information indicates that while they were keen to better understand
7 282 AUB and suggests that they may not have had appropriate/accessible information or discussion with
8 283 their GPs.
9
10
11 284

13 285 **Commitments**

14 286 Commitments such as looking after family and employment significantly impacted women's ability to
15 287 attended appointments. For many, juggling an extra day's annual leave to attend clinical appointments
16 288 picking up children from school, and generally finding time for one's self. It was evident that women
17 289 justified not prioritising clinical appointments (primary or secondary) which appeared to be related to
18 290 previous negative experiences or a sense that a resolution wouldn't be achieved (Table 2, quote 12-13).
19 291 This shows the level of, and tolerance, of pain and bleeding and their incredible ability to continue their
20 292 work, family and social life with the condition.
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28 294 **Taboo**

29 295 Embarrassment, shame or shyness around menstruation meant that women were reluctant to talk to
30 296 others about their AUB experiences with friends or family. This extended to work situations, for
31 297 example, needing to take sick days (Table 2, quote 14-15).

32 298 One husband, who was present during the interview, interjected - *“she can't even say period most of*
33 299 *the time to me”*.

34 300 Some women believed they did talk to friends about menstrual experiences, however on reflection their
35 301 AUB problems were not discussed in depth (Table 2, quote 16-17). These examples of menstrual taboo
36 302 can be isolating and perpetuates a cycle of secrecy and limited discussion with others.
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309 **Table 2:** Supporting quotes

Negative experiences with health care providers	Quote
Diminished symptoms	<p>“They couldn’t find anything or couldn’t work out why it was so bad, and yeah just gone through life with it.” Participant 1</p> <p>“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.</p> <p>“He was just like hmm ok I can prescribe you some meds, oh here you go. It was just that’s it” Participant 5.</p>
Relationships	<p>“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.</p> <p>“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.</p> <p>“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 we’ve had a look through your belly button-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.</p>
Low expectations	Quote
Of the care available	<p>“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.</p>
Of themselves	<p>“That was probably six 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.</p> <p>“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.</p> <p>“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 tra- blood transfusion.” Participant 15.</p>
Health literacy	Quote
	<p>“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.</p>
Commitments	Quote
	<p>“I felt when I couldn’t get a 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.</p> <p>And I just like- looking into it it’s just like everyone- 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.</p>
Taboo	Quote
	<p>“But at work I wouldn’t feel comfortable being like I have extremely horrible periods” Participant 5</p> <p>“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.</p> <p>“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.</p> <p>“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.</p>

310

311 Discussion

312 Main Findings

313 With this qualitative study we aimed to explore the barriers and facilitators to seeking care for AUB in
314 a NZ setting. It is clear that women do not experience a linear trajectory to a specialist gynaecological
315 appointment. Rather, they face compounded systemic and personal barriers caused by the poor
316 management of the complex and individual nature of AUB conditions.

317 The overall poor management of AUB and lack of informative discussion around the symptoms and
318 treatments has lead women to form ‘learned hopelessness’, a theory of psychological behaviour
319 exhibited by a person after enduring repeated aversive events, causing them to accept their condition
320 (15). In this case, the chronic and complex nature of AUB, poorly managed by GPs, alongside family
321 and work commitments, can lead to learned hopelessness, preventing women from care-seeking
322 behaviour and normalisation of symptoms as seen here. This can be detrimental to their mental
323 wellbeing (16). As with other conditions such as arthritis (17), learned hopelessness may lead to a worse
324 outcome for women with AUB.

325 Strengths and Limitations

326 The major limitation with this study is biased towards women who attended their specialist appointment
327 – we do not know the barriers women faced who were not able to attend. This study needs to be extended
328 using a community based approach to hear more from those in need. In particular there were a number
329 of women did not attend their specialist appoint and therefore were not included in this study, who had
330 a history of non-attendance, and who were also scheduled for an ultrasound scan and had reported
331 anaemia. It would be imperative to hear their story in order to identify why they did not attend, what
332 areas of support they need. Perhaps, we may find that the compounded effected of all four described
333 themes, heightened by emotional distress and traditional/cultural attitudes will impede the journey to a
334 clinical specialist. Health care providers should aim to improve cultural competency to ensure they are
335 addressing the needs of New Zealand people. In particular, a focus group study with Pacific people
336 from Canterbury highlighted GP availability and flexibility, pacific presence, language/communication
337 and rushed consultation to be the major barriers to accessing primary care (18).

338 Interpretation

339 Two recent studies specifically look at the experiences of women diagnosed with endometrial cancer.
340 Both used a similar cohort size and used interpretive and descriptive coding to deduce common themes
341 amongst participants. The first, also placed in New Zealand, reported similar stories of self-doubt and
342 confusion around their symptoms (19). The second, placed in Canada, investigated morbidly obese
343 women diagnosed with low grade endometrial cancer (20) and focused on barriers to surgery for this
344 group of women. This study found that women with endometrial cancer were subject to stigma and poor
345 provider communication and that many of the participants learnt about the link between endometrial
346 cancer and obesity through their own reading (20). Participants also noted their reluctance to seek care

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2
3 347 due to prior stigmatisation experiences (20). These issues were similarly reported by a number of
4
5 348 participants in our study.

6
7 349 It was clear from our interviews that GPs had difficulty in managing AUB. Many participants described
8
9 350 dismissive nature of treatment including medication of symptoms rather than a thorough investigation
10
11 351 of the underlying condition. This may be because AUB is a complex combination of conditions,
12
13 352 experienced differently, classified by the PALM (structural)-COEIN (non-structural) acronym - polyp,
14
15 353 adenomyosis, leiomyoma, malignancy and hyperplasia, coagulopathy, ovulatory dysfunction,
16
17 354 endometrial, iatrogenic, and not yet classified. Unfortunately within the AUB classification, there are
18
19 355 still underlying causes that are unknown, which occurs in approximately 12% of women (21). The Best
20
21 356 Practice Advocacy Centre NZ (BPAC), which aims to disseminate and communicate practice guidelines
22
23 357 to GPs, has an updated (2019) outline for AUB investigation. Whilst comprehensive, this guideline does
24
25 358 not follow the NICE guidelines, that highlight the need for the recognition of AUB on women's quality
26
27 359 of life (section 1.1), and emphasise treatment addressing this rather than quantity of blood loss. The
28
29 360 BPAC NZ guidelines do not include any such assessment. In our study, we found that women were
30
31 361 treated with iron tablets or pain killers until symptoms worsen, patients return for another consultation,
32
33 362 or change health care provider. A follow up study to gain a deeper understanding of the management
34
35 363 of AUB from the GP's experience, and implementation of GP workshops would be important to change
36
37 364 these practices.

38
39 365 The 2018 audit of gynaecological cancer treatment pathway guidelines indicate a less than 14 day
40
41 366 waiting period for a specialist appointment on the suspicion of malignancy (22). This target was met
42
43 367 for 85% of women in this audit (22). This is possible when risk of endometrial cancer is obvious (post-
44
45 368 menopausal and/or high BMI). However, given the complex nature of AUB in pre-menopausal women,
46
47 369 this guideline may be overlooked. Furthermore there are no time standards for the pathway to a
48
49 370 specialist for AUB. Most women in our study waiting equal to or greater than 4 months for their referral
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51 371 appointment. In cases where AUB is a sign of endometrial cancer in pre-menopausal women, this is of
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53 372 concern.

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55 373 From our investigation and others (19, 20, 23) it is clear that there is a lack of evidence based
56
57 374 information easily available to woman around AUB. Whilst there are successful cancer screening
58
59 375 awareness campaigns for cervical, breast and colorectal (24, 25), there are none for endometrial cancer.
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376 From our study, women were confused about normality, and didn't realise there were treatment options
377 available, such as the Levonorgestrel Intra Uterine System (LNG-IUS, Mirena). Now that it has come
378 under government subsidised funding in New Zealand, the Mirena is free for women, whether that be
379 for contraceptive use or management of periods. The Mirena has also been shown to protect against
380 and/or treat hyperplasia and early stage endometrial cancer (26, 27). We encourage our findings to be
381 seen as a call to action for health care providers to ask about quality of life during AUB investigation,

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2
3 382 help women recognise AUB symptoms, discuss treatment options and arrive at a treatment decision
4 383 together as outlined in the NICE guidelines. It would be particularly useful for information material to
5 384 be based on, and include women's experiences, as we have seen here, to help break down taboos
6 385 associated with menstruation. Furthermore, we urge the use of digital and social platforms to equip
7 386 women with the information they need to support care seeking activity.
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388 **Conclusion**

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16 389 As cases of endometrial cancer are being diagnosed at younger, pre-menopausal ages, these issues are
17 390 critical yet often overlooked. Unfortunately, and unsurprisingly, we have heard from women whose
18 391 stories are seldom a linear trajectory to a clinical specialist and have faced a multitude of compounding
19 392 barriers. Information campaigns that create awareness around 'abnormal periods' alongside better
20 393 health provider practice guidelines for AUB investigation need to be a priority. These results require
21 394 action into tangible outcomes to ensure women are treated at the earliest utmost stage of their symptoms.
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396 **Acknowledgements**

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29 397 We are thankful to the women who participated in this study and shared their stories.
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398

399 **Authors Contribution:**

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36
37 400 All authors were involved in conception and final editing of manuscript. CH was responsible for
38 401 conception, planning, carrying out (interviews), analysis and writing up for this study. RJ was involved
39 402 in analysis and writing of this study. AE was involved in conception and planning of this study. SF was
40 403 involved in conception, planning and writing and overall supervision of this study.
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42
43

404 **Ethics Approval**

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46 405 We received full ethics approval from the University of Otago (H19/072, 24/06/2019) and through the
47 406 women's research committee of CCDHB. We also engaged in Māori consultation through the Otago
48 407 Ngai Tahu Research Committee (19/06/2019), and the CCDHB Research Advisory Group Māori (#670,
49 408 20/06/2019).
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56 410 **Data sharing**

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57 411 De identified interview transcript data can be made available upon request.
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45 413 **References**

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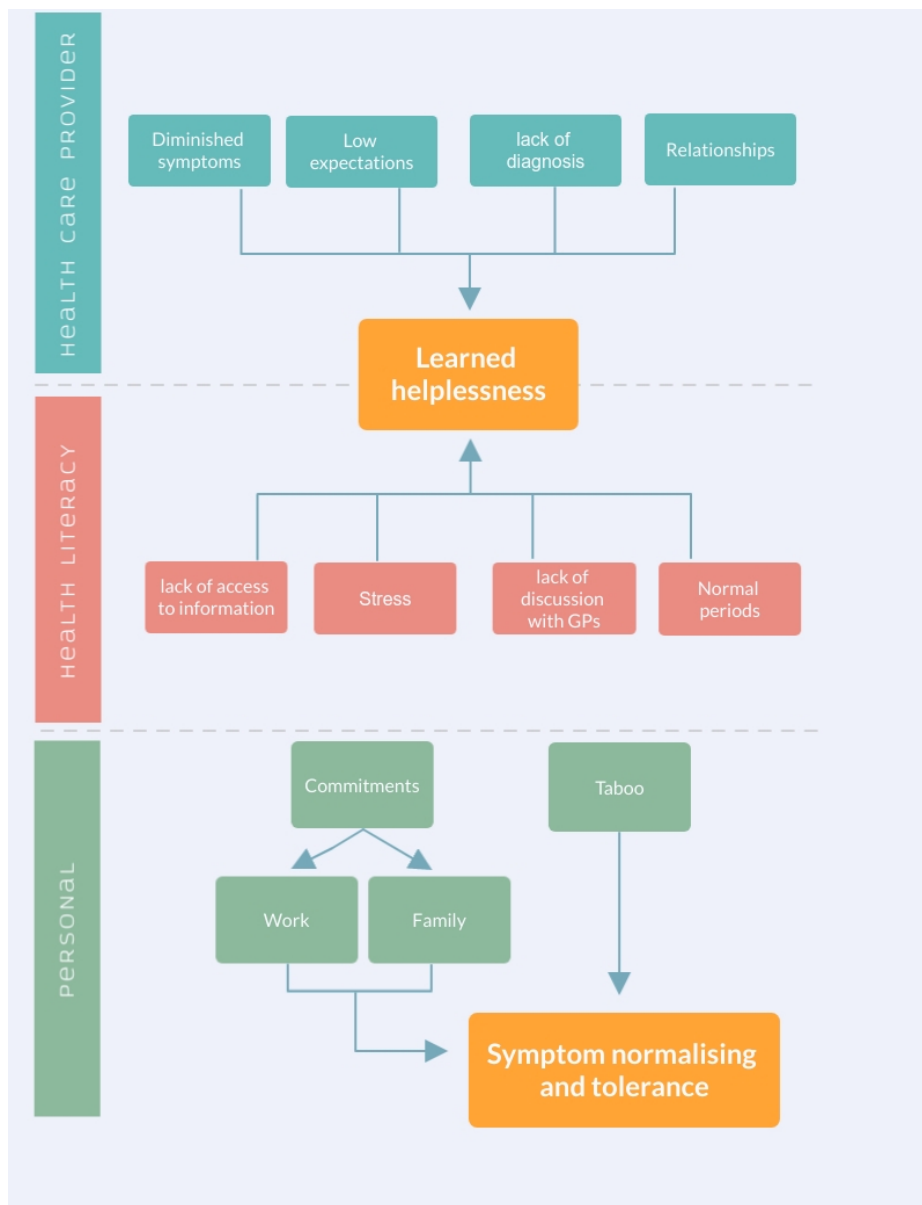
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32 484 Figure legend

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34 485 **Figure 1:** Key themes that lead to women's AUB experience and create a barrier to seeking timely
35 486 specialist investigation.

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38 487 **Table 1:** Participant characteristics.

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40 488 **Table 2:** Supporting quotes.

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Key themes that lead to women’s AUB experience and create a barrier to seeking timely specialist investigation.

211x273mm (96 x 96 DPI)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Beyond the numbers- understanding women's experiences of accessing care for abnormal uterine bleeding (AUB): a qualitative study.

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Keywords:	GYNAECOLOGY, PRIMARY CARE, QUALITATIVE RESEARCH

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3 1 **Title:** Beyond the numbers- understanding women's experiences of accessing care for abnormal
4 2 uterine bleeding (AUB): a qualitative study.
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11 5 **Author Information**
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43 22 **Running title:** Women's journey to clinic for AUB
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48 24 **Key words:** Abnormal uterine bleeding, primary care, experience
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52 26 **Word count:** 4772
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31 Abstract

32 Objective: To gain a deeper understanding of women's experiences with accessing care for abnormal
33 uterine bleeding (AUB) in order to inform future strategies in early detection of endometrial cancer.

34 Design: We conducted semi-structured interviews with 15 women who attended their first
35 gynaecological specialist consultation for AUB at Wellington Regional Hospital between October-
36 December 2019. Inductive thematic analysis was used to explore experiences and barriers to seeking
37 care. Results: The median age of the participant cohort was 45 years, with women self-identifying as
38 New Zealand European (9/15), Māori (2/15) and Pasifika (4/15). All women had sought investigation
39 for their AUB in primary care, for some women this was over a timeframe of many years. For all
40 women, AUB had a significant and traumatic impact on their quality of life including their relationships
41 and their work or education. Women described how they felt they often received inadequate care for
42 AUB, and negative experiences with their general practitioner. Timely access was further compounded
43 by feelings of embarrassment and that AUB was a taboo subject and being able to discuss it with family,
44 friends and their general practitioners was difficult. Conclusion: Women in our cohort experienced a
45 multitude of compounding influences that acted as barriers to them having access to appropriate and
46 timely care. Information campaigns that create awareness around 'abnormal periods' alongside better
47 health provider practice guidelines for AUB investigation need to be a priority.

48

49 Strength and limitations of this study

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

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Introduction

Abnormal uterine bleeding (AUB), including the sub-term heavy menstrual bleeding (HMB), is excessive, erratic or prolonged blood loss that interferes with a woman's physical, mental, social and quality of life (1). In the United States, it is estimated that 1.4 million cases of AUB are reported each year (2). The International Federation of Gynaecology and Obstetrics (FIGO) defines normal uterine bleeding as approximately 40mls of blood loss over a 5-7 day menstrual period cycle, and heavy bleeding as 100mls of blood loss throughout a whole cycle (3, 4). Although the recent reframing in 2017 of FIGO terms (5) 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 health care 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 pre-menopausal ages (<50 years) (6). EC incidence, morbidity and mortality rates in women who identify as Māori and Pasifika are much greater than those who identify as European/Other (7, 8).

Although AUB can have serious medical consequences and significantly impact women's daily life, it isn't a condition that women seek timely care for – and this is seen in many countries world-wide; around half of women with HMB believe there are no treatment options available for them (9), even if they experienced symptoms of anaemia (10).

Studies which report on EC prevalence in NZ often link the cause of advanced stage diagnosis to 'late presentation (11, 12), 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 in 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.

89 Methods

90 Patient and public involvement

91 The development of the research question and outcome measures were informed by researchers and
92 clinicians in the field, based on anecdotal observations and interest. The study design underwent Māori
93 consultation through the Ngāi Tahu research committee, and Research Advisory Board Māori (RAGM,
94 Wellington Regional Hospital).

95 Setting and participants

96 The aim of this study was to explore women's experiences in accessing care for AUB to identify barriers
97 to seeking consultation. The study design underwent peer review and amendments from an institutional
98 ethics board (University of Otago approval #H19-072). The population sample was recruited from
99 Wellington Regional Hospital, New Zealand (Capital and Coast District Health Board) from October-
100 December 2019. We undertook a purposive sampling approach (13) and on the basis of previous NZ
101 based studies (14-16), we aimed to recruit between 15-20 women. Women (over 18 years of age) were
102 invited to the study to share their experiences of seeking care for AUB at their first specialist
103 appointment (including HMB or post-menopausal bleeding). Women were identified from clinic notes
104 on the day of their appointment, and given a study brochure which described what was involved in the
105 study. If they accepted the study invitation, written consent was received before conducting the
106 interview after their appointed clinic consultation. Women were provided with a grocery voucher for
107 their participation. Interviews were conducted by CH, a female research fellow who was not involved
108 in the any facet of the patient care pathway. Participants were given the opportunity to indicate if they
109 would like to know the results of the study- those who did will be emailed the final publication.

110
111 Women were given the opportunity to bring their partner, whānau (family) or support person to the
112 interview. Participants were asked to begin by recounting their first experiences with AUB. The format
113 of the interviews was semi structured, with key prompt points to facilitate discussion that included:

114- When did you first notice your AUB? Have you sought treatment before?

115- Did you discuss with friends or family?

116- Did you see a GP, how was your experience?

117- What has helped you book and attend your appointment today?

118

119 Data collection and analysis

120 All interviews were audio-taped and transcribed by a professional and confidential third-party
121 transcription service. A semi-inductive saturation analytical approach was undertaken (17-19). *NVivo*
122 (QSR International) software was used to code themes in each transcript. This was an iterative process
123 of reflection and analysis. First, authors read and became immersed in all the transcript data, including

124 preliminarily identifying codes and drafting of the codebook. Secondly, each transcript was re-read in
 125 detail and coded line-by-line. Thirdly, clustering of the codes from each interview into higher level
 126 themes were developed inductively. Coding was completed independently by CH and RJ and themes
 127 were developed from combined coding of both authors, with the aid of SF. Any discrepancies in coding
 128 were discussed (CH, RJ and SF) to achieve consensus. Any overall themes were discussed to add weight
 129 to the validation process. Thematic saturation was deemed achieved when no further themes were
 130 revealed.

131 Results

132 A total of 30 women were identified as potential participants for the study. Of these, 5 women declined
 133 the invitation, 5 women did not attend their specialist appointment (therefore not invited), and 5 women
 134 were missed (needed an interpreter or left clinic whilst other interviews were being conducted). A total
 135 of 15 women participated in the study (Table 1). The median age of women included in the final cohort
 136 was 45 (\pm 8 years). Self-identified ethnicity was recorded, nine of the fifteen women identified as NZ
 137 European, two identified as NZ Māori, and four identified as Pacific Islander (Cook Islander, Samoan,
 138 Tongan) (Table 1). The average length of the interviews was 20 minutes, and ranged between 13-34
 139 minutes.

140
 141 **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)

1
2
3 143 The time from symptom onset to first specialist appointment was variable (table 1). All of the women
4 who shared their experiences of AUB had been seeking treatment/resolution, often over many years.
5 144
6 145 Women faced a multitude of barriers at each step of the care pathway, which varied for each individual,
7
8 146 from systematic to personal complexities. However, four overarching themes were developed (table 2)
9
10 147 from the interviews that had an effect on women's decision making around AUB care: health care
11
12 148 provider experience, AUB as a legitimate health concern, health literacy and taboo. For all women,
13
14 149 AUB had a significant and traumatic impact on their quality of life including their relationships and
15
16 150 their work or education (table 3, quotes 1-6). Most women experienced symptoms such as passing large
17
18 151 blood clots, pain, poor sleep, mood changes and bowel changes, which affected their mental health and
19
20 152 family relationships. At the point of these interviews being undertaken, and after many investigations,
21
22 153 no one had a formal diagnosis, or explanation why they had developed AUB.

21 154 It became obvious at the beginning of the interview process that this was a distressing journey for
22
23 155 women in their search for diagnosis and treatment. Many women cried during the interview session or
24
25 156 used strong language to describe their feelings.

26 157 *"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*
27
28 158 *options again 'cause I just got so upset, like it kinda' just all scrambled. And I was really nervous with*
29
30 159 *this appointment too".* Participant 5.

31 160 *" [crying] I went to see the family doctor, that's when he told me all sort of things"* Participant 8.

32
33 161

34
35 162 **Table 2:** Thematic structure

Inductive codes	Preliminary/sub themes	Final themes
Not understanding procedures or prescriptions	Dismiss symptoms Relationships Communication	Health care provider
Never formally diagnosed		
Variability in doctor treatment		
Prescribing pain killers		
Comfort with female doctors		
Seeing family/usual GP		
Seeing different GPs		
Trust in care		
Doubting symptoms	Self doubt Normalisation Prioritising others	AUB as a legitimate health concern
Unable to relate to friends experiences		
Lived with AUB throughout life, dealt with it		
Expectations of hospital visit		
Looking after family/children		
Work deadlines		

Ability to take time off work		
Ability to make it to appointments		
Knowledge of causes of AUB	Gynaecological knowledge around normal/abnormal Knowledge of treatments	Health literacy
Knowledge of treatments available		
Knowledge that AUB is something to be checked – ignoring/normalising symptoms		
What is normal bleeding?		
Emotion (heightened)	Fear Impact on life Embarrassment	Taboo
Scared of pain (IUD)		
Scared of doctors		
Impact on quality of life		
Embarrassed about bleeding through clothes		
Embarrassed about talking about bleeding (friends or colleagues)		
Relationships with partners		
Isolation		

163

164 Negative experiences with health care providers

165 Nine out of fifteen women in our cohort described negative experiences with their care providers, in
 166 particular with their GP. Two other women described being listened to, but also described how they had
 167 to undergo a number of tests for AUB before they received a referral to specialist consultation. The
 168 negative experiences related to dismissal of symptoms and the experiences of living with AUB (and the
 169 associated impact that this had on their lives) being diminished, lack of diagnosis and resolution.

170

171 Dismissed symptoms

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

173 *“I’ve been asking for help all the way through and they just keep giving me painkillers and trying the*
 174 *pill”* Participant 1.

175

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

179 *“I feel like with women’s health I go in and I say (I am bleeding) and they’re like doesn’t everyone,*
 180 *real dismissive. I definitely find that if I talk to any kind of person about it they’re like oh it happens or*

1
2
3 181 *it's your weight. And I'm like I understand it could be- I can understand it could be estrogen or*
4
5 182 *something but I feel like that's still super dismissive."* Participant 10.

6
7 183 Furthermore, AUB was attributed to her weight, with the inference that she carried a responsibility for
8
9 184 having AUB; this was also experienced by Participant 8 (table 3, quote 7). It would appear from the
10
11 185 above quote that communication between both parties was not optimal, and that the GP did not
12 186 understand the severity of her AUB as exemplified by Participant 14:

13
14 187 *"The bleeding was still continuing and I was just getting nowhere, and in the end I was anaemic, I*
15 188 *collapsed and my GP still wasn't really bothered."* Participant 14.

16
17 189 Of concern, communication deficits led to some women receiving treatment that they did not want, with
18
19 190 the consequence that the right to make an informed choice to receive this treatment was not upheld. As
20
21 191 exemplified by the experience of Participant 10:

22
23 192 *"And my last appointment with him was very traumatic 'cause I went in thinking I don't want the*
24 193 *mirrena. And then the mirrena was put in...I felt like I was a little bit threatened."* Participant 10.

25
26 194 Communication deficits also played out in the experience of AUB symptoms being dismissed in the
27
28 195 course of treatment that women were given, as they often received treatment for symptomatic relief
29
30 196 with eleven out of fifteen women predominantly received only symptomatic treatment (Table 3, quote
31 197 8-9). Three women were also prescribed iron tablets and felt that whilst this may have helped their
32 198 fatigue, it did not help their AUB and in some cases made their bleeding heavier (Table 3, quote 10).
33
34 199 Furthermore, it is likely that the suggestion by primary health providers to use hot water bottles (hottie)
35 200 to help alleviate pain was well-meaning (albeit likely ineffective), and the use of 'just' conveys a sense
36 201 of how women felt dismissed.

37
38
39 202

40
41 203 Not all women had negative experiences with their GP. Two participants found that their health care
42
43 204 provider quickly organised an ultrasound (scan) to investigate the issue further, which affirmed their
44
45 205 decision to seek help, and acknowledged their symptoms as a problem to be investigated and treated
46 206 properly rather than managing symptoms.

47
48
49 207 *"She's very matter of fact and said well let's have a look, see what's going on there...she's great"*
50 208 Participant 7

51 209 *"She's a great doctor we've been going to her for years. But then she thought it was pre menopause-*
52 210 *but sent me to have a scan just to find out what was going on."* Participant 6.

53
54 211

55 212 **Relationships**

56
57 213 Building a sense of trust and connection with primary health care providers made a significant
58
59 214 difference to the way AUB was managed, and women's experiences with seeking treatment. For

60

215 example, feeling comfortable to explain all symptoms, feeling listened too, and discussing a treatment
216 plan together had a positive impact on participants.

217 *“being able to have that rapport with the doctor does make a difference and then they can talk to you
218 and explain stuff rather than just feeling unsure that you were checked out properly”* Participant 14.

219 Ten of fifteen women commented on the gender of their GP, and when women talked of negative
220 experience they mentioned that the GP was male. Many women disclosed that they needed to see a
221 female doctor as they felt more comfortable and listened to.

222 *“I trust her she can do the gynae in the office, so she’s done all my cervical smears and other tasks-
223 Yeah, she knows my history, my squeamishness.”* Participant 4.

224 Some felt that they would have received a better explanation if the GP was a woman, or a more
225 experienced GP. A number of women described seeking care from multiple doctors, in a helpless
226 attempt to resolve their chronic and debilitating condition. In particular, one participant noted that she
227 actively sought a female doctor expecting better support, but did not receive it;

228 *“I switched to a female doctor thinking it would be better for a better understanding but they just looked
229 at you as if you’re kind of a like drug seeker type thing- ‘Cause that’s just kind of how I feel, ‘cause
230 they went like they did all these tests -Can’t find anything. I said well I’m really bad, and she wasn’t
231 much help really and then I changed doctors again and he’s quite a really good doctor, he’s done like
232 what he can, I guess he’s sent me for a scans and he’s referred me back up here [women’s clinic]”*
233 Participant 1.

234
235 In some cases, in the general practice clinics that were busy, women would see the next available doctor,
236 which added an element of chance to whether women would could choose a female GP. It was therefore
237 only by chance that women felt comfortable enough to share their experiences of AUB:

238 *“So I call the doctor, lucky that’s the female doctor so I can ((open up)) to talk and then to examine
239 me”.* Participant 2.

240

241 **Gynaecological health literacy**

242 Health literacy, and a general understanding around what constitutes normal gynaecological health
243 influenced women’s decisions to seek earlier investigation for AUB. Nine of the fifteen women
244 interviewed had delayed seeking care up to as long as 3 years as they attributed their symptoms to other
245 causes or as a non-issue; four women linked it to stress (Table 3, quote 11) and one linked to periods
246 ‘syncing’.

247 For others, figuring out that their bleeding was abnormal was difficult to work out:

1
2
3 248 *“And it’s only recently looking at- after ((googling)) around I realised I’ve actually had abnormal*
4 249 *bleeding for a really long time I just didn’t realise it wasn’t supposed to be that bad...I just wish I knew*
5 250 *like the boundaries of normal for what periods were. ‘Cause I have another friend right now she’s going*
6 251 *through a real shit time and she’s also had painful periods for a really long time and now it’s like she*
7 252 *may have uterine cancer and she didn’t know...So like I just wish there was more education”* Participant
8 253 5.

9
10
11
12 254 That women were seeking more information indicates that while they were keen to better understand
13 255 AUB, they may not have had appropriate/accessible information or discussion with their GPs.
14 256 This communication deficit was further exemplified in four of fifteen women who were unsure of what
15 257 to anticipate at the specialist clinic and had low expectations in regards to a resolution for AUB (Table
16 258 3, quote 12).

17
18
19
20
21 259 *“I kind of didn’t really believe that the women’s clinic would know more and so I thought I’d just come*
22 260 *up here.”* Participant 1.

23
24
25 261 Low expectations of healthcare stemmed from experiences with long wait times, including being put
26 262 on the waiting list for often more than 4 months for their specialist appointment. This compounded
27 263 women’s feeling of low expectations that their AUB would be resolved (Table 3, quote 13).

28
29
30 264 Compounding the negative health care provider experience of being dismissed further, some women
31 265 didn’t understand the prescriptions they had been given, but took them anyway (Table 3, quote 14).
32 266 This suggests that women were not enabled to make an informed choice about the course of treatment,
33 267 and reflects on poor communication between GP and patient. Furthermore, it was clear that women did
34 268 not know what treatment options were available for AUB, and one woman was thrilled upon learning
35 269 that the Mirena could help her condition;

36
37
38
39
40 270 *“I didn’t know ((nothing)) ‘bout these ‘cause like me I’m old school, I don’t keep up updates. Until my*
41 271 *lovely doctor just told me about this [The Mirena], put that there for five years”*
42 272 *“I’m really glad I’ve come today to find out my life what I can do, I’m rapt.”* Participant 15.

43
44
45 273

46 47 274 **AUB as a legitimate health concern**

48 275 Compounded by their negative experiences, eleven out of fifteen women were left experiencing self-
49 276 doubt that AUB was not a condition worthy of further investigation, and for some women, it was evident
50 277 that they felt a sense of anguish, which for one woman led to her cancelling her appointment:

51
52
53
54 278 *“I’d heard in the media about how there are long waits, there are very few specialists for the public*
55 279 *health care system, I felt really terrible that I’d like clogged up the system with my unnecessary problem*
56 280 *then I panicked and cancelled.”*

1
2
3 281 Even though this woman's intention was founded in believing that by her not attending her appointment
4 282 would enable someone else access to healthcare, this exemplifies how women did not think that AUB
5 283 was a condition worthy of investigation, or did not want to "waste anyone's time" (Participant 4). For
6 284 some women this prevented them seeking care again (Table 3, quote 15).

7
8
9
10 285 However, another participant described that soon after noticing her symptoms, she consulted her GP to
11 286 find out what was wrong, as she had always been someone to check up on her own health. This may be
12 287 because she worked in a health care setting and was familiar with the clinical environment and
13 288 recognised the potential implication of changes in her symptoms (Table 3, quote 16).

14
15
16
17 289 One participant had been experiencing heavy bouts of AUB her whole life and had doubted the severity
18 290 of the condition. The only reason she finally had medical investigation was because she was admitted
19 291 to emergency and given a blood transfusion due to AUB induced anemia (Table 3, quote 17). Another
20 292 woman recalled her experience of bleeding through her clothes and passing out at work, then
21 293 immediately went onto put her own story down.

22
23
24
25
26 294 "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
27 295 ongoing... So I'm probably not a dire case or this may not be useful for your study I don't know".
28
29 296 Participant 9.

30
31 297 Her experience represents what many of these women have become used to – that AUB is (now) their
32 298 normal.

33
34
35 299 Commitments such as looking after family and employment significantly impacted twelve out of fifteen
36 300 women in their ability to attend appointments. It was evident that women justified not prioritising
37 301 clinical appointments (primary or secondary) which appeared to be related to previous negative
38 302 experiences or a sense that a resolution wouldn't be achieved, or that it was not a concern that was
39 303 worth the hassle.

40
41
42
43
44 304 "I felt when I couldn't get a park and I couldn't get anyone to look after the kids at first, I thought oh
45 305 it's not worth getting my husband home from work" Participant 10.

46
47
48 306 The responsibility of taking care of family was reiterated a number of times for these women (table 3,
49 307 quote 18) and that timing of the appointments were critical to fit in with their lives (table 3, quote 19).

50
51 308 This shows the level of tolerance for pain and bleeding and their incredible ability to continue their
52 309 work, family and social life with the condition, as described;

53
54
55
56 310 "it's always painful you just kinda' deal with it you just kinda' suck it up, like you can't take time off
57 311 work every month usually." Participant 5.

58
59
60 312

313 Taboo

314 Twelve of the fifteen participants had put off seeking help for such a long time that they had experienced
315 traumatic accounts where their bleeding had been so heavy that they had to cover themselves or call a
316 friend to help, as described;

317 *“ I remember feeling so embarrassed, but I was like bleeding through really quickly and bleeding on*
318 *my clothes and just feeling like I couldn't go anywhere or do anything sort of normal”*
319 Participant 9

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

322 Embarrassment, shame or shyness because of these experiences with menstruation meant that women
323 were reluctant to talk to others about their AUB experiences with friends or family; one woman felt she
324 couldn't even talk to her daughter about menstruation (Table 3, quote 20). This extended to work
325 situations, for example, needing to take sick leave (Table 3, quote 21).

326 One participant's husband, who was present during the interview, interjected - *“she can't even say*
327 *period most of the time to me”*. Participant 8.

328 However, participant 10 found that reaching out and discussing openly her problems with others was
329 important in her journey to seeking help;

330 *“I think [taboo] is harmful 'cause it can make you feel alone and I've found out I'm not.”*

331 Some women believed they did talk to friends about menstrual experiences, however on reflection their
332 AUB problems were not discussed in depth (Table 3, quote 22-23).

333

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335

336

Table 3: Supporting quotes

		Quote
Impact on quality of life	1	“That was a three year 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 two 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
Health care 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.
Health Literacy	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
	12	“That was probably six 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.
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	“In my life I always try to go for my appointment. Because my smear test is up to date, my breast screen is up to date, yearly examine you check is always done”. Participant 2
	17	“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 tra- blood transfusion.” Participant 15.
	18	“I’ve got no time to go doctors and stuff, ‘cause I’m at home with four grandchildren.” Participant 15.
	19	“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	20	“At work I wouldn’t feel comfortable being like I have extremely horrible periods” Participant 5
	21	“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.
	22	“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.
	23	“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.

339 Discussion

340 Main Findings

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

347 Interpretation

348 Two recent studies specifically look at the experiences of women diagnosed with endometrial cancer.
349 Both used a similar cohort size and used interpretive and descriptive coding to deduce common themes
350 amongst participants. The first, also placed in New Zealand, reported similar stories of self-doubt and
351 confusion around their symptoms (20). The second, placed in Canada, investigated morbidly obese
352 women diagnosed with low grade endometrial cancer (21) and focused on barriers to surgery for this
353 group of women. This study found that women with endometrial cancer were subject to stigma and poor
354 provider communication and that many of the participants learnt about the link between endometrial
355 cancer and obesity through their own reading (21). Participants also noted their reluctance to seek care
356 due to prior stigmatisation experiences (21). These issues were similarly reported by a number of
357 participants in our study.

358 Overall, participants in this study experienced similar journeys to women with other gynaecological
359 challenges such as endometriosis, which has been investigated in more depth than AUB. In particular,
360 women often experienced poor communication from doctors, and personally normalised their menstrual
361 pain from an early age (22-25). Health care provider dismissal of gynaecological symptoms has been a
362 long standing issue. Like those with endometriosis, women with AUB seem to endure long and ongoing
363 struggle for diagnosis and treatment. Some of the participants with AUB experienced what has
364 previously been described as 'the doctor trail' (26); trying to find someone to support, listen and treat
365 the cause of the symptoms. Women with endometriosis spoke about difficulty in having an undiagnosed
366 problem, and the relief that comes with have a 'medical label'. Unfortunately for some of the
367 participants in this study with AUB, there was often no definitive diagnosis. This may be because AUB
368 is a complex combination of conditions, experienced differently, classified by the PALM (structural)-
369 COEIN (non-structural) acronym - polyp, adenomyosis, leiomyoma, malignancy and hyperplasia,
370 coagulopathy, ovulatory dysfunction, endometrial, iatrogenic, and not yet classified. Unfortunately
371 within the AUB classification, there are still underlying causes that are unknown, which occurs in
372 approximately 12% of women (27).

373 The Best Practice Advocacy Centre NZ (BPAC), which aims to disseminate and communicate practice
374 guidelines to GPs, has an updated (2019) outline for AUB investigation. Whilst comprehensive, this

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2
3 375 guideline does not follow the NICE guidelines, that highlight the need for the recognition of AUB on
4 376 women's quality of life (section 1.1), and emphasise treatment addressing this rather than quantity of
5 377 blood loss. The BPAC NZ guidelines do not include any such assessment. In our study, we found that
6 378 women were treated with iron tablets or pain killers until symptoms worsen, patients return for another
7 379 consultation, or change health care provider. A follow up study to gain a deeper understanding of the
8 380 management of AUB from the GP's experience, and implementation of GP workshops would be
9 381 important to change these practices.

14
15 382 The 2018 audit of gynaecological cancer treatment pathway guidelines indicate a less than 14 day
16 383 waiting period for a specialist appointment on the suspicion of malignancy (28). This target was met
17 384 for 85% of women in this audit (28). This is possible when risk of endometrial cancer is obvious (post-
18 385 menopausal and/or high BMI). However, given the complex nature of AUB in pre-menopausal women,
19 386 this guideline may be overlooked. Furthermore there are no time standards for the pathway to a
20 387 specialist for AUB. Most women in our study waiting equal to or greater than 4 months for their referral
21 388 appointment. In cases where AUB is a sign of endometrial cancer in pre-menopausal women, this is of
22 389 concern.

27
28 390 From our investigation and others (20, 21, 29) it is clear that there is a lack of evidence based
29 391 information easily available to woman around AUB. Whilst there are successful cancer screening
30 392 awareness campaigns for cervical, breast and colorectal (30, 31), there are none for endometrial cancer.
31 393 From our study, women were confused about normality, and didn't realise there were treatment options
32 394 available, such as the Levonorgestrel Intra Uterine System (LNG-IUS, Mirena). Now that it has come
33 395 under government subsidised funding in New Zealand, the Mirena is free for women, whether that be
34 396 for contraceptive use or management of periods. The Mirena has also been shown to protect against
35 397 and/or treat hyperplasia and early stage endometrial cancer (32, 33). We encourage our findings to be
36 398 seen as a call to action for health care providers to ask about quality of life during AUB investigation,
37 399 help women recognise AUB symptoms, discuss treatment options and arrive at a treatment decision
38 400 together as outlined in the NICE guidelines. It would be particularly useful for information material to
39 401 be based on, and include women's experiences, as we have seen here, to help break down taboos
40 402 associated with menstruation. Furthermore, we urge the use of digital and social platforms to equip
41 403 women with the information they need to support care seeking activity.

42 404 **Strengths and Limitations**

43 405 This study was based on the experiences of women who had a referral to a specialist appointment.
44 406 Community-based research is needed in order to better understand women's experience of seeking care
45 407 for AUB. That patient cohort was Euro-centric, and not reflective of the ethnic population of New
46 408 Zealand; however, we did not analyse women's experiences by their ethnicity and additional studies
47 409 with more purposive inclusion of non-European women would be warranted.
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1
2
3 410 The major limitation with this study is the inclusion of women who attended their specialist appointment
4 411 – we do not know the barriers women faced who were not able to attend. In particular there were 5
5 412 women who did not attend their specialist appointment and therefore were not able to be invited to this
6 413 study; these women had a history of non-attendance, and who were also scheduled for an ultrasound
7 414 scan and had reported anaemia. This warrants further investigation, including from a community-based
8 415 recruitment approach. Another 5 women who did attend their appointment and were invited to the study
9 416 were missed, due to needing an interpreter who was not available at the time, or the interviewee busy
10 417 with other participants. These interviews were conducted in a metropolitan area of NZ (Wellington),
11 418 and may not reflect those experiences of women in more rural areas or communities, and therefore
12 419 requires ongoing investigations.

420

421 **Conclusion**

422 As cases of endometrial cancer are being diagnosed at younger, pre-menopausal ages, menstrual
423 symptoms are critical yet often overlooked. Unfortunately, and unsurprisingly, we have heard from
424 women whose stories are seldom a linear trajectory to a clinical specialist and have faced a multitude
425 of compounding barriers. Information campaigns that create awareness around ‘abnormal periods’
426 alongside better health provider practice guidelines for AUB investigation need to be a priority. These
427 results require action into tangible outcomes to ensure women are treated at the earliest utmost stage of
428 their symptoms.

429

430 **Acknowledgements**

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432 **Authors Contribution:**

433 All authors were involved in conception and final editing of manuscript. CH was responsible for
434 conception, planning, carrying out (interviews), analysis and writing up for this study. RJ was involved
435 in thematic analysis and writing of this study. AE was involved in conception and planning of this study.
436 SF was involved in conception, planning, final analysis, writing and overall supervision of this study.

437 **Ethics Approval**

438 We received full ethics approval from the University of Otago (H19/072, 24/06/2019) and through the
439 women’s research committee of CCDHB. We also engaged in Māori consultation through the Otago
440 Ngai Tahu Research Committee (19/06/2019), and the CCDHB Research Advisory Group Māori (#670,
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442 **Data sharing**

443 De identified data can be made available upon reasonable request.

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446 **Competing interests**

447 The authors have no competing interests to declare.

448

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7 537 Figure legend

9 538 **Table 1:** Participant characteristics.

11 539 **Table 2:** Thematic structure.

14 540 **Table 3:** Supporting quotes.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Beyond the numbers- understanding women's experiences of accessing care for abnormal uterine bleeding (AUB): a qualitative study.

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Keywords:	GYNAECOLOGY, PRIMARY CARE, QUALITATIVE RESEARCH

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43 22 **Running title:** Women's journey to clinic for AUB
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30 **Abstract**

31 Objective: To gain a deeper understanding of women's experiences of accessing care for abnormal
32 uterine bleeding (AUB) in order to inform future strategies to improve care pathways, including the
33 early detection of endometrial cancer. Design: We conducted semi-structured interviews with 15
34 women who attended their first gynaecological specialist consultation for AUB at Wellington Regional
35 Hospital between October-December 2019. Inductive thematic analysis was used to explore experiences
36 and barriers to seeking care. Results: The median age of the participant cohort was 45 years, with
37 women self-identifying as New Zealand European (9/15), Māori (2/15) and Pasifika (4/15). All women
38 had sought investigation for their AUB in primary care, for some women this was over a timeframe of
39 many years. For all women, AUB had a significant and traumatic impact on their quality of life
40 including their relationships and their work or education. Women described how they felt they often
41 received inadequate care for AUB, and reported negative experiences with their general practitioner.
42 Timely access was further compounded by feelings of embarrassment and that AUB was a taboo subject
43 and being able to discuss it with family, friends and their general practitioners was difficult. Conclusion:
44 Women in our cohort experienced a multitude of compounding influences that acted as barriers to them
45 having access to appropriate and timely care. Information campaigns that create awareness around
46 'abnormal periods' alongside better health provider practice guidelines for AUB investigation need to
47 be a priority.

49 **Strength and limitations of this study**

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

63 Introduction

64 Abnormal uterine bleeding (AUB), including the sub-term heavy menstrual bleeding (HMB), is
65 excessive, erratic or prolonged blood loss that interferes with a woman's physical, mental, social and
66 quality of life (1). In the United States, it is estimated that 1.4 million cases of AUB are reported each
67 year (2). The International Federation of Gynaecology and Obstetrics (FIGO) defines normal uterine
68 bleeding as approximately 40mls of blood loss over a 5-7 day menstrual period cycle, and heavy
69 bleeding as 100mls of blood loss throughout a whole cycle (3, 4). Although the recent reframing in
70 2017 of older FIGO terms such as menorrhagia, oligomenorrhea, metrorrhagia and dysfunctional
71 uterine bleeding (5) may go some way to improving a medically defined definition of AUB, such
72 descriptions are still unlikely to be meaningful to women, which may impede the required engagement
73 and discussion with their primary health care providers.

74 AUB is usually a symptom of benign issues however it is also the most common symptom of
75 endometrial cancer (EC) or hyperplasia (pre-cancer) and therefore warrants specialist investigation as
76 early as possible. EC is the most common gynaecological cancer, increasing in incidence, with around
77 400 women diagnosed in New Zealand (NZ) each year. There is a concerning and substantial growth
78 of EC incidence in young, Pacific Island women, with almost half being diagnosed at pre-menopausal
79 ages (<50 years) (6). EC incidence, morbidity and mortality rates in women who identify as Māori and
80 Pasifika are much greater than those who identify as European/Other (7, 8).

81 Although AUB can have serious medical consequences and significantly impact women's daily life (9)
82 , it isn't a condition that women seek timely care for – and this is seen in many countries world-wide;
83 around half of women with HMB believe there are no treatment options available for them (10), even
84 if they experienced symptoms of anaemia (11).

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

90

91 Methods

92 Patient and public involvement

93 The development of the research question and outcome measures were informed by researchers and
94 clinicians in the field, based on anecdotal observations and interest (no patient involvement). The study
95 design underwent Māori consultation through the Ngāi Tahu research committee, and Research
96 Advisory Board Māori (RAGM, Wellington Regional Hospital). The interview questions were

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3 97 developed and piloted on university community members. Participants were given the opportunity to
4 98 indicate if they would like to know the results of the study- those who did will be emailed the final
5 99 publication.
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8 100 **Setting and participants**

9
10 101 The aim of this study was to explore women's experiences in accessing care for AUB to identify barriers
11 102 to seeking consultation. The study design underwent peer review and amendments from an institutional
12 103 ethics board (University of Otago approval #H19-072). The population sample was recruited from
13 104 Wellington Regional Hospital, New Zealand (Capital and Coast District Health Board) from October-
14 105 December 2019. We undertook a purposive sampling approach (14) and on the basis of previous NZ
15 106 based studies (15-17), we aimed to recruit between 15-20 women. Women (over 18 years of age) were
16 107 invited to the study to share their experiences of seeking care for AUB at their first specialist
17 108 appointment (including HMB or post-menopausal bleeding). Women were identified from clinic notes
18 109 on the day of their appointment, and given a study brochure which described what was involved in the
19 110 study. If they accepted the study invitation, written consent was received before conducting the
20 111 interview after their appointed clinic consultation. Women were provided with a grocery voucher for
21 112 their participation. Interviews were conducted by CH, a female research fellow who was not involved
22 113 in the any facet of the patient care pathway.
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33 115 Women were given the opportunity to bring their partner, whānau (family) or support person to the
34 116 interview. Participants were asked to begin by recounting their first experiences with AUB. The format
35 117 of the interviews was semi structured, with key prompt points to facilitate discussion that included:

36 118- When did you first notice your AUB? Have you sought treatment before?

37 119- Did you discuss with friends or family?

38 120- Did you see a GP, how was your experience?

39 121- What has helped you book and attend your appointment today?
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46 123 **Data collection and analysis**

47 124 All interviews were audio-taped and transcribed by a professional and confidential third-party
48 125 transcription service. A semi-inductive saturation analytical approach was undertaken (18-20). *NVivo*
49 126 (QSR International) software was used to code themes in each transcript. This was an iterative process
50 127 of reflection and analysis. First, authors read and became immersed in all the transcript data, including
51 128 preliminarily identifying codes and drafting of the codebook. Secondly, each transcript was re-read in
52 129 detail and coded line-by-line. Thirdly, clustering of the codes from each interview into higher level
53 130 themes were developed inductively. Coding was completed independently by CH and RJ and themes
54 131 were developed from combined coding of both authors, with the aid of SF. Any discrepancies in coding
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3 132 were discussed (CH, RJ and SF) to achieve consensus. Any overall themes were discussed to add weight
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5 133 to the validation process. Thematic saturation was deemed achieved when no further themes were
6
7 134 revealed.

8 135

10 136 Results

11 137 A total of 30 women were identified as potential participants for the study. Of these, 5 women declined
12
13 138 the invitation, 5 women did not attend their specialist appointment (therefore not invited), and 5 women
14
15 139 were not interviewed because they either needed an interpreter who was unavailable at the time (two)
16
17 140 or because they left the clinic while other interviews were being conducted (three). A total of 15 women
18
19 141 participated in the study (Table 1). The median age of women included in the final cohort was 45 (\pm 8
20
21 142 years). Self-identified ethnicity was recorded: nine of the fifteen women identified as NZ European,
22
23 143 two identified as NZ Māori, and four identified as Pacific Islander (Cook Islander, Samoan, Tongan)
24
25 144 (Table 1). The average length of the interviews was 20 minutes, and ranged between 13-34 minutes.

26 145

26 146 The time from symptom onset to first specialist appointment was variable (table 1). All of the women
27
28 147 who shared their experiences of AUB had been seeking treatment/resolution, often over many years.
29
30 148 Women faced a multitude of barriers at each step of the care pathway, which varied for each individual,
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32 149 from systematic to personal complexities (table 2). For all women, AUB had a significant and traumatic
33
34 150 impact on their quality of life including their relationships and their work or education (table 3, quotes
35
36 151 1-6). Most women experienced symptoms such as passing large blood clots, pain, poor sleep, mood
37
38 152 changes and bowel changes, which affected their mental health and family relationships. At the point
39
40 153 of these interviews being undertaken, and after many investigations, no one had a formal diagnosis, or
41
42 154 explanation why they had developed AUB. It became obvious at the beginning of the interview process
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44 155 that this was a distressing journey for women in their search for diagnosis and treatment. Many women
45
46 156 cried during the interview session or used strong language to describe their feelings.

43 157 *"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*
44
45 158 *options again' 'cause I just got so upset, like it kinda' just all scrambled. And I was really nervous with*
46
47 159 *this appointment too."* Participant 5.

48 160 *"[crying] I went to see the family doctor, that's when he told me all sort of things."* Participant 8.

50 161

52 162 Four overarching themes were developed (table 2) from the interviews that had an effect on women's
53
54 163 decision making around AUB care: health care provider experience, AUB as a legitimate health
55
56 164 concern, gynaecological health literacy and taboo.

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167 **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)

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182 **Table 2:** Thematic structure

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

183

184 Negative experiences with health care provider

185 Nine out of fifteen women in our cohort described negative experiences with their care providers, in
186 particular with their GP. Two other women described being listened to, but also described how they had
187 to undergo a number of tests for AUB before they received a referral to specialist consultation. The
188 negative experiences related to dismissal of symptoms and the experiences of living with AUB (and the
189 associated impact that this had on their lives) being diminished, and lack of diagnosis and resolution.

190

191 Dismissed symptoms

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

193 *“I’ve been asking for help all the way through and they just keep giving me painkillers and trying the*
194 *pill.”* Participant 1.

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

197 This was described by another participant:

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

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

206 *“The bleeding was still continuing and I was just getting nowhere, and in the end I was anaemic, I*
207 *collapsed and my GP still wasn’t really bothered.”* Participant 14.

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

211 *“My last appointment with him was very traumatic ‘cause I went in thinking ‘I don’t want the mirena’.*
212 *And then the mirena was put in...I felt like I was a little bit threatened.”* Participant 10.

213 Symptom treatment rather than identifying the cause of the problem also played out in the experience
214 of AUB symptoms being dismissed. Eleven out of fifteen women predominantly received only
215 symptomatic treatment (Table 3, quote 8-9). Three women were also prescribed iron tablets and felt

216 that whilst this may have helped their fatigue, it did not help their AUB and in some cases made their
217 bleeding heavier (Table 3, quote 10). It is likely that the suggestion by primary health providers to use
218 hot water bottles (hottie) to help alleviate pain was well-meaning (albeit likely ineffective), and the use
219 of ‘just’ conveys a sense of how women felt dismissed.

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

224 *“She’s very matter of fact and said ‘well let’s have a look, see what’s going on there’...she’s great.”*
225 Participant 7

226 *“She’s a great doctor we’ve been going to her for years. But then she thought it was pre menopause-*
227 *but sent me to have a scan just to find out what was going on.”* Participant 6.

228

229 Relationships

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

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

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

239 *“I trust her she can do the gynae in the office, so she’s done all my cervical smears and other tasks-*
240 *Yeah, she knows my history, my squeamishness.”* Participant 4.

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

245 *“I switched to a female doctor thinking it would be better for a better understanding but they just looked*
246 *at you as if you’re kind of a like drug seeker type thing- ‘Cause that’s just kind of how I feel, ‘cause*
247 *they went like they did all these tests -Can’t find anything. I said ‘well I’m really bad’, and she wasn’t*
248 *much help really and then I changed doctors again and he’s quite a really good doctor, he’s done like*
249 *what he can, I guess he’s sent me for a scans and he’s referred me back up here [women’s clinic].”*

250 Participant 1.

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5 252 In some cases, in the general practice clinics that were busy, women would see the next available doctor,
6 253 which added an element of chance to whether women could choose a female GP. It was therefore only
7
8 254 by chance that women felt comfortable enough to share their experiences of AUB:
9 255 *“So I call the doctor, lucky that’s the female doctor so I can ((open up)) to talk and then to examine*
10 256 *me.”* Participant 2.

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15 258 **Gynaecological health literacy**

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18 259 Health literacy is a term used to describe the skills required to ‘obtain, process and understand
19 260 information in order to make informed health decisions in a complex and multidimensional healthcare
20 261 environment’ (21). Health literacy plays an important role in women’s health (22) however is not always
22 262 recognized by primary health care providers.

24 263 **Normal menstruation**

25
26
27 264 A general understanding around what constitutes normal gynaecological health (normal periods)
28 265 seemed to influence women’s decisions to seek investigation for AUB. Six of the fifteen women
29 266 interviewed had delayed seeking care up to as long as 3 years as they attributed their symptoms to other
30 267 causes or as a non-issue; four women linked it to stress (Table 3, quote 11) and one linked to periods
31 268 ‘syncing’.

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34
35 269 For others, figuring out that their bleeding was abnormal was difficult to work out, and there was a clear
36 270 need for more accessible and trustworthy information around what normal periods are and when to be
37 271 seeking help, as Participant 5 described:

38
39 272 *“It’s only recently looking at- after ((googling)) around I realised I’ve actually had abnormal bleeding*
40 273 *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*
41 274 *boundaries of normal for what periods were. ‘Cause I have another friend right now she’s going*
42 275 *through a real shit time and she’s also had painful periods for a really long time and now it’s like she*
43 276 *may have uterine cancer and she didn’t know...So like I just wish there was more education.”*
44 277 Participant 5.

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50 279 **Knowledge of treatments**

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52 280 The women we spoke to were keen to better understand AUB, but did not appear to have had
53 281 appropriate/accessible information or discussion with or from their GPs. As one woman’s experience
54 282 highlighted that she didn’t think the women’s clinic would ‘know more’:

55
56 283 *“I kind of didn’t really believe that the women’s clinic would know more and so I thought I’d just come*
57 284 *up here.”* Participant 1.

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3 285 This issue is linked with the theme of health care provider experience. This communication deficit was
4
5 286 further exemplified in four of fifteen women who were unsure of what to anticipate at the specialist
6
7 287 clinic and had low expectations in regards to a resolution for AUB (Table 3, quote 12).

8 288 Low expectations of healthcare also stemmed from experiences with long wait times, including being
9
10 289 put on the waiting list for often more than 4 months for their specialist appointment. This compounded
11
12 290 women's feeling of low expectations that their AUB would be resolved (Table 3, quote 13).

13 291 Compounding the negative health care provider experience of being dismissed further, some women
14
15 292 didn't understand the prescriptions they had been given, but took them anyway (Table 3, quote 14).

16 293 This suggests that women were not enabled to make an informed choice about the course of treatment,
17
18 294 and highlights that communication between women and their GP was not optimal. Furthermore, it was
19
20 295 also clear that women did not know what treatment options were available for AUB, and one woman
21
22 296 was thrilled upon learning that the Mirena could help her condition:

23 297 *"I didn't know ((nothing)) 'bout these 'cause like me I'm old school, I don't keep up updates. Until my*
24
25 298 *lovely doctor just told me about this [The Mirena], put that there for five years...I'm really glad I've*
26
27 299 *come today to find out my life what I can do, I'm rapt."* Participant 15.

28 300

301 **AUB as a legitimate health concern**

302 **Self-doubt**

303 Compounded by their negative experiences, eleven out of fifteen women were left experiencing self-
34
35 304 doubt that AUB was not a condition worthy of further investigation, and for some women, it was evident
36
37 305 that they felt a sense of anguish, which for one woman led to her cancelling her appointment:

38
39 306 *"I'd heard in the media about how there are long waits, there are very few specialists for the public*
40
41 307 *health care system, I felt really terrible that I'd like clogged up the system with my unnecessary problem*
42
43 308 *then I panicked and cancelled."* Participant 4.

44
45 309 This woman's intention was founded in believing that by not attending the appointment she would
46
47 310 enable someone else access to healthcare; this exemplifies that women did not think that AUB was a
48
49 311 condition worthy of investigation, or did not want to *"waste anyone's time"* (Participant 4). For some
50
51 312 women this prevented them seeking care again (Table 3, quote 15).

52 313 One participant had been experiencing heavy bouts of AUB her whole life and had doubted the severity
53
54 314 of the condition. The only reason she finally had medical investigation was because she was admitted
55
56 315 to the emergency department and given a blood transfusion due to AUB induced anemia (Table 3, quote
57
58 316 16). Another woman recalled her experience of bleeding through her clothes and passing out at work,
59
60 317 then immediately went onto put her own story down.

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3 318 *“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*
4 319 *ongoing... So I’m probably not a dire case or this may not be useful for your study I don’t know”.*
5
6 320 Participant 9.

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9 321 Her experience represents what many of these women have become used to – that AUB is (now) their
10 322 normal.

11 323 **Prioritising others**

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14 324 It was evident that women justified the needs of others over being able to attend their clinical
15 325 appointments. Many women described how they tolerated AUB symptoms in order to keep family,
16 326 work or social commitments:

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19
20 327 *“It’s always painful you just kinda’ deal with it you just kinda’ suck it up, like you can’t take time off*
21 328 *work every month usually.”* Participant 5.

22
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24 329 Previous negative experiences, a sense that a resolution wouldn’t be achieved, or that it was not a
25 330 concern that was worth the hassle contributed to their justifications. For example, one participant’s
26 331 immediate reaction to parking issues was that seeking care for AUB was not worth the trouble:

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28
29
30 332 *“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*
31 333 *oh it’s not worth getting my husband home from work.”* Participant 10.

32
33
34 334 Commitments such as looking after family and employment significantly impacted twelve out of fifteen
35 335 women in their ability to attend appointments. The responsibility of taking care of family was
36 336 reiterated a number of times for these women (table 3, quote 17) and that timing of the appointments
37 337 were critical to fit in with their lives (table 3, quote 18).

38 39 40 41 42 43 339 **Taboo**

44
45 340 Fear, embarrassment and the impact that AUB has on quality of life instils taboo around the topic of
46 341 menstruation for women. Embarrassment, shame or shyness because of these experiences with
47 342 menstruation meant that women were reluctant to talk to others about their AUB experiences with
48 343 friends or family; one woman felt she couldn’t even talk to her daughter about menstruation (Table 3,
49 344 quote 19). This extended to work situations, for example, needing to take sick leave (Table 3, quote 20).

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53 345 Twelve of the fifteen participants had experienced traumatic accounts where their bleeding had been so
54 346 heavy that they had to cover themselves or call a friend to help, as described:

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56
57 347 *“I remember feeling so embarrassed, but I was like bleeding through really quickly and bleeding on*
58 348 *my clothes and just feeling like I couldn’t go anywhere or do anything sort of normal.”* Participant 9.

1
2
3 349 “She wrapped a tarpaulin around me, that’s how bad it was, so that I could walk out of the main
4
5 350 ((central)) ...So embarrassing.” Participant 10.

6
7 351 One participant’s husband, who was present during the interview, interjected - “She can’t even say
8
9 352 period most of the time to me.” Participant 8.

10
11 353 This fear of menstrual symptoms meant that women felt isolated and were reluctant to discuss the
12
13 354 issues with friends or family. Participant 10 found that reaching out and discussing openly her
14
15 355 problems with others was vital in her journey to seeking help, and explained that taboo can lead to
16
17 356 feelings of loneliness:

17 357 “I think [taboo] is harmful ‘cause it can make you feel alone and I’ve found out I’m not.” Participant
18
19 358 10.

20
21 359 Some women believed they did talk to friends about menstrual experiences, however on reflection their
22
23 360 AUB problems were not discussed in depth (Table 3, quote 21-22).

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Table 3: Supporting quotes

		Quote
Impact on quality of life	1	“That was a three year 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 two 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 health care 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 Literacy	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.
	12	“That was probably six 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.

367 Discussion

368 Main Findings

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

375 Interpretation

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

386 Overall, the women we spoke to experienced similar journeys to women with other gynaecological
387 challenges such as endometriosis, which has been investigated in more depth than AUB. In particular,
388 women often experienced poor communication from doctors, and personally normalised their menstrual
389 pain from an early age (25-28). Health care provider dismissal of gynaecological symptoms has been a
390 long standing issue. Like those with endometriosis, women with AUB seem to endure long and ongoing
391 struggle for diagnosis and treatment. Some of the participants with AUB experienced what has
392 previously been described as 'the doctor trail' (29); trying to find someone to support, listen and treat
393 the cause of the symptoms. Women with endometriosis spoke about difficulty in having an undiagnosed
394 problem, and the relief that comes with have a 'medical label'. Unfortunately for some of the
395 participants in this study with AUB, there was often no definitive diagnosis. This may be because AUB
396 is a complex combination of conditions, experienced differently, classified by the PALM (structural)-
397 COEIN (non-structural) acronym - polyp, adenomyosis, leiomyoma, malignancy and hyperplasia,
398 coagulopathy, ovulatory dysfunction, endometrial, iatrogenic, and not yet classified. Unfortunately
399 within the AUB classification, there are still underlying causes that are unknown, which occurs in
400 approximately 12% of women (30).

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3 401 The Best Practice Advocacy Centre NZ (BPAC), which aims to disseminate and communicate practice
4 402 guidelines to GPs, has an updated (2019) outline for AUB investigation. Whilst comprehensive, this
5 403 guideline does not follow the NICE guidelines, that highlight the need for the recognition of AUB on
6 404 women's quality of life (section 1.1), and emphasise treatment addressing this rather than quantity of
7 405 blood loss. The BPAC NZ guidelines do not include any such assessment. In our study, we found that
8 406 women were treated with iron tablets or pain killers until symptoms worsen, patients return for another
9 407 consultation, or change health care provider. A follow up study to gain a deeper understanding of the
10 408 management of AUB from the GP's experience, and implementation of GP workshops would be
11 409 important to change these practices.

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14 410 The 2018 audit of gynaecological cancer treatment pathway guidelines indicate a less than 14 day
15 411 waiting period for a specialist appointment on the suspicion of malignancy (31). This target was met
16 412 for 85% of women in this audit (31). This is possible when risk of endometrial cancer is obvious (post-
17 413 menopausal and/or high BMI). However, given the complex nature of AUB in pre-menopausal women,
18 414 this guideline may be overlooked. Furthermore there are no time standards for the pathway to a
19 415 specialist for AUB. Most women in our study reported waiting equal to or greater than 4 months for
20 416 their referral appointment. In cases where AUB is a sign of endometrial cancer in pre-menopausal
21 417 women, this is of concern.

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24 418 From our investigation and others (23, 24, 32) it is clear that there is a lack of evidence based
25 419 information easily available to woman around AUB. Whilst there are successful cancer screening
26 420 awareness campaigns for cervical, breast and colorectal (33, 34), there are none for endometrial cancer.
27 421 From our study, women were confused about normality, and didn't realise there were treatment options
28 422 available, such as the Levornorgestrel Intra Uterine System (LNG-IUS, Mirena). Now that it has come
29 423 under government subsidised funding in New Zealand, the Mirena is free for women, whether that be
30 424 for contraceptive use or management of periods. The Mirena has also been shown to protect against
31 425 and/or treat hyperplasia and early stage endometrial cancer (35, 36). We encourage our findings to be
32 426 seen as a call to action for health care providers to ask about quality of life during AUB investigation,
33 427 help women recognise AUB symptoms, discuss treatment options and arrive at a treatment decision
34 428 together as outlined in the NICE guidelines. It would be particularly useful for information material to
35 429 be based on, and include women's experiences, as we have seen here, to help break down taboos
36 430 associated with menstruation. Furthermore, we urge the use of digital and social platforms to equip
37 431 women with the information they need to support care seeking activity.

432 **Strengths and Limitations**

433 This study was based on the experiences of women who had a referral to a specialist appointment.
434 Community-based research is needed in order to better understand women's experience of seeking care
435 for AUB, including reaching out to those who have never sought investigation from any health care
436 provider. The patient cohort was Euro-centric, and not reflective of the ethnic population of New

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3 437 Zealand; however, we did not analyse women's experiences by their ethnicity and additional studies
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5 438 with more purposive inclusion of non-European women would be warranted.

6
7 439 The major limitation with this study is the inclusion of women who attended their specialist appointment
8
9 440 – we do not know the barriers women faced who were not able to attend. In particular there were 5
10 441 women who did not attend their specialist appointment and therefore were not able to be invited to this
11 442 study; these women had a history of non-attendance, and who were also scheduled for an ultrasound
12 443 scan and had reported anaemia. This warrants further investigation, including from a community-based
13 444 recruitment approach. Another 5 women who did attend their appointment and were invited to the study
14 445 were not able to be interviewed due to needing an interpreter who was not available at the time, or the
15 446 interviewee busy with other participants. This may have resulted some groups of women whose
16 447 experiences were not recorded. Furthermore these interviews were conducted in a metropolitan area of
17 448 NZ (Wellington), and may not reflect those experiences of women in more rural areas or communities,
18 449 and therefore requires ongoing investigations.

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26 27 451 **Conclusion**

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29 452 As cases of endometrial cancer are being diagnosed at younger, pre-menopausal ages, timely access
30 453 and appropriate care for AUB is critical yet often overlooked. Unfortunately, we have heard from
31 454 women with AUB whose stories are seldom described straightforward experiences of care to a clinical
32 455 specialist. Information campaigns that create awareness around 'abnormal periods' alongside better
33 456 health provider practice guidelines for AUB investigation need to be a priority. These results require
34 457 action into tangible outcomes to ensure women are treated at the earliest utmost stage of their symptoms.

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43
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45 46 461 **Authors Contribution:**

47
48 462 All authors were involved in conception and final editing of manuscript. CH was responsible for
49 463 conception, planning, carrying out (interviews), analysis and writing up for this study. RJ was involved
50 464 in thematic analysis and writing of this study. AE was involved in conception and planning of this study.
51 465 SF was involved in conception, planning, final analysis, writing and overall supervision of this study.

52 53 466 **Ethics Approval**

54
55 467 We received full ethics approval from the University of Otago (H19/072, 24/06/2019) and through the
56 468 women's research committee of CCDHB. We also engaged in Māori consultation through the Otago

1
2
3 469 Ngai Tahu Research Committee (19/06/2019), and the CCDHB Research Advisory Group Māori (#670,
4 470 20/06/2019).

6
7 471 **Data sharing**

8
9 472 De identified data can be made available upon reasonable request.

10
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12
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14
15 475 **Competing interests**

16
17 476 The authors have no competing interests to declare.

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21 478 **References**

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17 573 Figure legend

19 574 **Table 1:** Participant characteristics.

21 575 **Table 2:** Thematic structure.

23 576 **Table 3:** Supporting quotes.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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