

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

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June 10, 2020

Abstract

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

Funding

Capstone Editing Research Grant for Women 2019 to CH

Key words

Abnormal uterine bleeding, experience, women, primary care

Introduction

Abnormal uterine bleeding (AUB), including the sub-term heavy menstrual bleeding (HMB), can be 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 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 lived in experiences of women with AUB in NZ. By doing so, it is our goal to improve local support for timely access to EC investigation and provide new perspectives to transform the care pathway for women seeking care.

Methods

The population sample was recruited from the Women's Clinic at Wellington Regional Hospital, New Zealand (CCDHB) from October-December 2019. We obtained local institutional board ethics approval for the study (#H19-072). Women were invited to the study to tell their story about their journey to the clinic for AUB at their first specialist appointment for AUB (including HMB or post-menopausal bleeding). Women were identified from clinic notes on the day of their appointment, and given a study brochure which described what was involved in the study. If they accepted the study invitation, written consent was received before conducting the interview after their appointed clinic consultation. Women were provided with a grocery voucher for their participation.

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

Women were given the opportunity to bring their partner, whānau or support into the interview with them. Participants were asked to begin recounting their first experiences with AUB. The format of the interviews was semi structured with key prompt points to facilitate discussion that included:

- When did you first notice your AUB? Have you sought treatment before?
- Did you discuss with friends or family?
- Did you see a GP, how was your experience?
- What has helped you book and attend your appointment today?
-

All interviews were audio-taped and transcribed by a professional and confidential third party transcription service. Detailed and semi-inductive thematic analysis (13, 14) using *NVivo* software was used to code themes in each transcript. This was a cyclical process of reflection and analysis. First, authors read and became immersed in all the transcript data, including preliminarily identifying codes and drafting of the codebook. Secondly, each transcript was re-read in detail and coded line-by-line. Thirdly, clustering of

the codes from each interview into higher level themes were developed inductively. Coding was completed independently by CH and RJ and themes were developed from combined coding of both authors, with the aid of SF.

Results

For all women, AUB had a significant and traumatic impact on their quality of life including their relationships and their work or education. Most women experienced symptoms such as passing large blood clots, pain, poor sleep, mood changes and bowel changes, which affected their mental health and family relationships. At the point of these interviews being undertaken, and after many investigations, no one had a formal diagnosis, or explanation why they had developed AUB. Women faced a multitude of barriers at each step of the care pathway, which varied for each individual, from systematic to personal complexities. However, four overarching themes were developed from the interviews that had an effect on women's decision making around AUB care: health care provider experience, health literacy, commitments and taboo (figure 1).

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

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

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

Negative experiences with health care providers

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

Diminished symptoms

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

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

It is also evident from this woman's shared experience that she had spoken to several GPs (and other non-healthcare practitioners) and also felt that the severity, and impact of, AUB was diminished by them. Furthermore, AUB was also attributed to her weight, with the inference that she carried a responsibility for having AUB. It would appear from the above quote that communication between both parties was not optimal, and that the GP did not understand the severity of her AUB. The feeling of that AUB was diminished by the GPs was further compounded by feelings that the GP did not care, as experienced by another woman:

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

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

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

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

One patient even described how she received treatment that she did not want, but felt that she had no choice.

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

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

Relationships

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

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

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

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

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

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

Low expectations

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

Of the care available

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

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

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

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

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

"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 the waiting list is long." Participant 10.

Of themselves

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

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

Even though this woman's intention was founded in believing that by her not attending her appointment would enable someone else access to healthcare, this exemplifies how women did not think that AUB was a condition worthy of investigation, or did not want to *"waste anyone's time"* (Participant 4). For some women this prevented them seeking care again (Table 2, quote 9).

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

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

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

Health Literacy

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

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

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

That women were seeking more information indicates that while they were keen to better understand AUB and suggests that they may not have had appropriate/accessible information or discussion with their GPs.

Commitments

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

Taboo

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

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

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

Discussion

Main Findings

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

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

Strengths and Limitations

The major limitation with this study is biased towards women who attended their specialist appointment – we do not know the barriers women faced who were not able to attend. This study needs to be extended using a community based approach to hear more from those in need. In particular there were a number of women did not attend their specialist appoint and therefore were not included in this study, who had a

history of non-attendance, and who were also scheduled for an ultrasound scan and had reported anaemia. It would be imperative to hear their story in order to identify why they did not attend, what areas of support they need. Perhaps, we may find that the compounded effect of all four described themes, heightened by emotional distress and traditional/cultural attitudes will impede the journey to a clinical specialist. Health care providers should aim to improve cultural competency to ensure they are addressing the needs of New Zealand people. In particular, a focus group study with Pacific people from Canterbury highlighted GP availability and flexibility, Pacific presence, language/communication and rushed consultation to be the major barriers to accessing primary care (18).

Interpretation

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

It was clear from our interviews that GPs had difficulty in managing AUB. Many participants described dismissive nature of treatment including medication of symptoms rather than a thorough investigation of the underlying condition. This may be because AUB is a complex combination of conditions, experienced differently, classified by the PALM (structural)-COEIN (non-structural) acronym - polyp, adenomyosis, leiomyoma, malignancy and hyperplasia, coagulopathy, ovulatory dysfunction, endometrial, iatrogenic, and not yet classified. Unfortunately within the AUB classification, there are still underlying causes that are unknown, which occurs in approximately 12% of women (21). The Best Practice Advocacy Centre NZ (BPAC), which aims to disseminate and communicate practice guidelines to GPs, has an updated (2019) outline for AUB investigation. Whilst comprehensive, this guideline does not follow the NICE guidelines, that highlight the need for the recognition of AUB on women's quality of life (section 1.1), and emphasise treatment addressing this rather than quantity of blood loss. The BPAC NZ guidelines do not include any such assessment. In our study, we found that women were treated with iron tablets or pain killers until symptoms worsen, patients return for another consultation, or change health care provider. A follow up study to gain a deeper understanding of the management of AUB from the GP's experience, and implementation of GP workshops would be important to change these practices.

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

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

to ask about quality of life during AUB investigation, help women recognise AUB symptoms, discuss treatment options and arrive at a treatment decision together as outlined in the NICE guidelines. It would be particularly useful for information material to be based on, and include women's experiences, as we have seen here, to help break down taboos associated with menstruation. Furthermore, we urge the use of digital and social platforms to equip women with the information they need to support care seeking activity.

Conclusion

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

Acknowledgements

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

Conflicts of Interest

None.

Authors Contribution:

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

Ethics Approval

We received full ethics approval from the University of Otago (H19/072, 24/06/2019) and through the women's research committee of CCDHB. We also engaged in Māori consultation through the Otago Ngai Tahu Research Committee (19/06/2019), and the CCDHB Research Advisory Group Māori (#670, 20/06/2019).

Funding

This study was funded by the Capstone Editing Research Grant for Women, awarded to CH.

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Figure legend

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

Table 1: Participant characteristics.

Table 2: Supporting quotes.

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Figure 1.docx available at <https://authorea.com/users/331876/articles/458375-beyond-the-numbers-understanding-women-s-journey-s-to-clinic-for-abnormal-uterine-bleeding-aub-a-qualitative-study>

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