

Women's experiences of follow-up medical care for preeclampsia in Australia: A qualitative study

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Background and objective

Preeclampsia is associated with increased risk of later-life cardiovascular, metabolic and mental health disorders. Follow-up is key to managing this risk, yet little is known about how women are managed in Australia. The aim of this study was to understand women's experiences of medical follow-up care and support in Australia after preeclampsia.

Methods

Semi-structured interviews were conducted with 12 women with previous preeclampsia residing in Australia. Data were analysed using thematic analysis.

Results

Three themes were generated: ongoing health impact; craving accurate information; and fragmented follow-up care. Participants reported ongoing physical and mental health symptoms, ad hoc information provision and fragmented follow-up. Women valued continuity of care and debriefing.

Discussion

There is a significant gap between recommended medical follow-up and the actual care women receive following preeclampsia. The value of debriefing for women after preeclampsia warrants more research.

OCCURRING IN THE SECOND HALF of pregnancy, preeclampsia is a multisystem disorder that commonly manifests with elevated blood pressure, proteinuria, coagulopathy and liver dysfunction.¹ Severe hypertension, pulmonary oedema, stroke, HELLP (Haemolysis, Elevated Liver enzymes and Low Platelets) syndrome and progression to eclampsia are some of the severe acute maternal complications that can result.¹ Affecting 1 in 20 pregnancies, preeclampsia is the most common serious medical pregnancy complication in Australia and is one of the most common causes of maternal and fetal morbidity and mortality worldwide.^{2,3} A diagnosis of preeclampsia has implications for the future health of the mother, with research showing that a woman who has experienced preeclampsia is at increased risk of later-life cardiovascular, metabolic and renal disease and poorer mental health outcomes.⁴⁻⁶

To improve the diagnosis and management of women with preeclampsia, the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) published a set of guidelines in 2015.⁷ These guidelines recommend women are counselled on lifestyle measures to mitigate the later-life cardiovascular risk, such as weight management, smoking cessation, healthy diet and exercise.⁷ Women are also advised to have an annual blood pressure check and at least five-yearly screening for other cardiovascular risk factors, such as serum lipids and diabetes.⁷ In addition, the SOMANZ guidelines recommend linking

women to patient advocacy groups, such as Australian Action on Preeclampsia (AAPEC), and offering psychological support to manage the potential mental health impacts of the disease.⁷ Despite these recommendations, research indicates that women are unaware of the implications preeclampsia has on their future health.^{2,6}

In Australia, there has been limited research into women's experiences of care and information provision after preeclampsia following the introduction of the SOMANZ guidelines.⁷ In addition, it is unclear to what level Australian women receive emotional and psychological support following preeclampsia. The overall aims of this study were to gain an insight into women's knowledge of their long-term health risks after preeclampsia and to understand their experiences of preeclampsia follow-up and support in Australia.

Methods

Study design

In this study, listening to the voices and perspectives of women who have had experience of follow-up care for preeclampsia was central to understanding the phenomenon of interest. For this reason, a qualitative design underpinned by the constructionist epistemology was the chosen methodology.⁸⁻¹⁰ Constructionism asserts that knowledge is socially constructed and individuals develop new meaning or knowledge by reflecting on what they

already know and integrating this with new experiences they are exposed to.^{9,10} Therefore, rather than revealing a definitive 'truth', this study explored the meaning of the women's experiences of preeclampsia follow-up care as articulated by them.

Data collection

Data were collected via one-to-one interviews using a semi-structured interview guide in June and July of 2023. To ensure the focus was relevant for the aims of the study, the interview questions were developed collaboratively by the authors, who have different levels of experience with qualitative methods. The interview guide consisted of basic demographic questions followed by 11 open-ended questions. The quantitative data were collected to provide a description of the sample population used in the study. Prior to data collection, a pilot interview was conducted and recorded with a participant who had experienced the phenomena. Feedback was obtained from the respondent and fellow researchers for clarity and comprehension. No changes were made to the interview guide after this review.

Interviews were conducted by the primary researcher (DP) using the online platform Microsoft Teams. With consent, the interviews were recorded and transcribed. Interviews took between 25 and 52 minutes to complete, with the mean interview time being 35 minutes.

The concept of 'information power' by Malterud et al was used to determine sample size.¹¹ Central to this idea is that the more information the sample holds relevant to the study aim, the smaller the sample size required.¹¹ Taking this into consideration, a proposed sample size of between 10 and 15 participants was anticipated.

Setting

Women who had a history of preeclampsia and resided in any state or territory of Australia were recruited to the study. Online interviews enabled participants to choose a place that was convenient and comfortable to them and facilitated privacy. The interview setting was commonly the participant's own home.

Participant recruitment and selection

Women were recruited to this study via an advertisement on the AAPEC social

media platforms. Purposeful sampling was used targeting women who had a singleton pregnancy complicated by preeclampsia between 12 months and 10 years prior to selection, thus allowing for sufficient time for the phenomena under study to occur. Additional eligibility criteria required women to have birthed and received follow-up care in Australia and to be aged 18 years or over to consent. Participants were also required to speak English. Women who had experienced stillbirth or a neonatal death, significant postnatal depression or other mental health conditions were excluded from the study due to the potential distress the interview process might cause. Participation was voluntary and women were not remunerated in any way.

Data analysis

Braun and Clarke's⁸ reflexive thematic analysis (RTA) was the method used to organise, interpret and describe the themes identified in the data. RTA involves reading the dataset, in this case the transcripts from semi-structured interviews, and finding patterns in meaning across the data. Information from the data is then organised and labelled to discover relationships and themes. To ensure methodological rigor, reflexivity was used throughout this process.⁸ Reflexivity recognises that the researchers' subjective experiences can have a considerable effect on how the data are collected and interpreted, and encourages researchers to critically examine and understand what their own views, values and perspectives bring to the data.⁸ With this in mind, the process of initial coding was performed manually by the primary researcher (DP), a midwife. The additional members of the research team, an obstetrician (SB) and two nursing/midwifery researchers (HH, KL), experienced with qualitative methods, worked collaboratively to review and refine the codes and develop the themes.

Ethics approval for this project was gained through the Federation University Australia, Human Research Ethics Committee (Approval no. 2023/039).

Results

Using the approach by Malterud et al, 'information power' was reached by the 12th interview.¹¹ The 12 women who participated

in the study were aged between 29 and 42 years and had levels of education ranging from Year 12 to a postgraduate degree. One participant was from a rural area, seven were from regional areas and four lived in metropolitan areas throughout Australia. Participants experienced moderate to severe preeclampsia symptoms, with one woman diagnosed with eclampsia. All were at least one year postpartum, with 10 participants birthing in the past five years and two birthing between five and seven years ago. The key demographic characteristics of the participants are presented in Table 1. Pseudonyms have been used for all participants to protect their identity.

Three themes were identified during the data analysis process: ongoing health impact of preeclampsia; craving accurate information; and fragmented follow-up care. There were a further five subthemes, which are presented in Table 2.

Theme 1: Ongoing health impact of preeclampsia

Some women reported feeling unwell for an extended period following birth with symptoms described in terms of dizziness, fatigue and brain fog. Participants often attributed these symptoms to the medications they were on to manage their ongoing blood pressure (BP) issues. Several women instigated BP monitoring at home of their own volition due to their ongoing symptoms. As Kate explained:

It (blood pressure) stopped being monitored as soon as I was out of hospital, and we ended up buying a machine. I would take my own blood pressure a couple times a day and I honestly felt faint and dizzy up to ... 20 times a day for the better part of a year.

Follow-up healthcare was not commensurate with the degree of ongoing symptoms, and some women reported physical symptoms for up to 12 months after their diagnosis. For example, Anne received one midwifery visit at home and a postnatal check with her general practitioner (GP) at six weeks and had this to say about her experience:

After having blood transfusions and being in (the intensive care unit) and just still being on blood pressure medication, I feel like the

Table 1. Demographic characteristics of the study participants

Age at interview (years)	n	%	Time since last birth complicated by preeclampsia	n	%
18–29	1	8	12–23 months	2	17
30–39	8	67	2–5 years	8	67
≥40	3	25	>5 years, <10 years	2	17
Country of birth			Mode of birth^A		
Australia	10	83	Normal vaginal	2	15
New Zealand	2	17	Assisted vaginal	2	15
Marital status			Elective caesarean section	1	8
Married/de facto	10	83	Emergency caesarean section	8	62
Single	0	0	Parity		
Widowed	0	0	Primipara	7	58
Divorced or separated	2	17	Multipara 2	4	33
Education level			Multipara 3	1	8
<Year 12	0	0	Geographic location of maternity health service		
Year 12	2	17	Urban	7	58
Vocational qualification	2	17	Regional	5	42
Bachelor degree	7	58	Rural	0	0
Postgraduate degree	1	8	Remote	0	0
Geographic location of subject			Model of maternity care^A		
Metropolitan	4	33	Midwifery group practice	3	23
Regional	7	58	Private-based obstetrician	5	38
Rural	1	8	Hospital-based medical	3	23
Remote	0	0	Hospital-based midwifery	1	8
Gestational age at birth^A (weeks)			GP shared/medical/midwifery	1	8
<32	4	31			
32–<36	2	15			
36–<38	3	23			
≥38	4	31			

^ARelates to all pregnancies complicated by preeclampsia (n=13).

GP, general practitioner.

care was probably a little bit lacking because I was not well for ... quite a while after that.

Throughout the interviews, participants commonly referred to the emotional impact their preeclampsia diagnosis had on them. Typically, they described feelings of guilt, anger, anxiety and fear. Participants reported

that the emotional effects of preeclampsia were rarely acknowledged by their treating physicians. In response to being asked how she felt about her preeclampsia in the time since she had had her baby, Gemma described being anxious and frustrated at the lack of recognition for ongoing mental health issue:

It hasn't really affected me physically, but I guess it's just like a background anxiety ... and also ... a pretty big frustration in the health system with how it was handled, not just in terms of physical health, but also like in terms of mental health. There was no ... check in ... on mental health either. It's just kind of, like, left to your own devices.

Women frequently reported that they instigated their own mental health follow-up through their GP and spoke about the insincere nature of mental health screening. At times this served to turn them away from sharing how they were feeling with their healthcare provider and potentially delayed help seeking.

For many women, a diagnosis of preeclampsia served as a motivator for behaviour and lifestyle change. Behaviour change occurred even when cardiovascular risk was not fully understood. As Chloe expressed:

I think I focus a lot on it more now ... especially if I was to have another baby, ... I don't know if you know if it makes a difference, but I'd wanna be really fit, eating really healthily ... I wouldn't work as much. I'd probably take ... a different approach than what I did, but ... I don't know if that would even make a difference.

Although many women intimated that they had or were thinking about instigating lifestyle measures to improve their overall health or outcomes in future pregnancies, none verbalised that they had received this information from a healthcare worker. Information provided from healthcare workers was limited in relation to all aspects of preeclampsia and was the second key theme identified.

Theme 2: Craving accurate information

Another prevailing theme throughout the interviews was participants' desire for information about their preeclampsia diagnosis and what it might mean for their future health. Of the 12 women interviewed, only two were unaware of the future

health risks associated with preeclampsia, but many reported receiving little to no information from their healthcare providers. In the absence of standardised information, participants often resorted to the internet to source information. As Kate described:

I've done a lot of research and sometimes I like seeing it cause I ... wanna get prepared and then sometimes I'm ... distraught afterward ... I'm at higher risk of a million things and ... I'm two or three times more likely to die of heart disease ... but I'm not doing anything different in my life, ... I don't know how to better make sure that I'm in a good position for the future.

The perception that some healthcare providers trivialised or glossed over the risks associated with preeclampsia was also mentioned during the interviews. Eve talked about how she tried to initiate a conversation with her GP after researching online:

I've even mentioned it to my GP even recently about how ... I saw ... recent research about ... being much higher risk for heart attack ... and he just sort of laughed and said ... don't worry about it, there's nothing you can really do, you're already healthy.

The need for standardised information was a key priority for many of the women. For example, when asked if there was anything that could be done to improve her follow-up care, Breanna offered the following:

No one said anything about any increased risk ... I think it would be good if there was a standard kind of, ... like when you go into hospital and you get a little fact sheet about

something ... you get this information sheet and you can have a read.

Theme 3: Fragmented follow-up care

Follow-up care for the women in this study was often unplanned, not standardised and occurred secondary to other appointments. Only one woman interviewed indicated that she had a plan in place as per the recommended 2014 SOMANZ guidelines.⁷ The care was often limited to the six-week check or ended when blood pressure normalised. When asked what follow-up she received after birth, Breanna gave a typical response:

Pretty much nothing other than my blood pressure being tested at my follow-up appointment ... I think its two weeks then six weeks my blood pressure was tested. It was normal and there was nothing else, no other education or ... any discussion around it or ... saying ... come back in 12 months or ... any kind of time frame to do any kind of follow-ups.

Participants also described disjointed and inconsistent healthcare related to the impact of preeclampsia on their mental health. Women found the system difficult to navigate and the need for ongoing referrals off-putting. GPs, who are often the referral point for mental health assistance, were not always fully aware of the services available. Kate described the following:

I actually found the process pretty hard because I had to go to the doctor first to get the recommendation and then after five (sessions) I had to go back and do it again, which was just draining cause I had a newborn and I wasn't coping.

Peer support was spoken of in a positive light, with several women feeling that this form of counselling was beneficial. Hannah was linked into a support group through her GP and commented that she 'was surprised by how good it was'. Informal and formal debriefing was also frequently mentioned in terms of how valuable it was and as a recommendation for improvement to follow-up care in the future. Gemma suggested that a formal debrief might have helped mitigate some of the mental health impact of her diagnosis:

Table 2. Themes and subthemes identified in the study

Theme	Subtheme
1. Ongoing health impact of preeclampsia	Physical health impact
	Mental health impact
	Lifestyle and behaviour change
2. Craving accurate information	
3. Fragmented follow-up care	Ad hoc follow-up
	Desire for continuity of care

I think it did impact my mental health and I think that was also a result of ... things not being explained to me ... I felt like I could have had a proper debrief from the hospital and if things have had been explained ... I could have ... had a better understanding and wouldn't have been ... left very confused about everything.

A clear subtheme identified was the desire for continuity of care. The few women who expressed satisfaction with aspects of their postnatal follow-up care received follow-up with a known healthcare provider who they trusted. Hannah described her GP as the person most valuable in her preeclampsia journey:

I actually had faith that someone had my back ... and she was very particular about making sure that everything was where I should be and how I should be ... so I think I was lucky to have her.

Some women spoke about their desire for continuity of care but were denied midwifery-led models of care because they were considered high risk. For some, paying for private obstetric care was the only option to ensure some level of continuity.

Discussion

Although preeclampsia typically ends soon after birth, for many of the women in this study, the physical and emotional effects of the condition extended well past discharge. Research in countries other than Australia has shown that the effects of preeclampsia can persist into the postpartum period.^{2,12} Our study indicates that women would benefit if healthcare providers were more aware of the long-term physical and emotional consequences of preeclampsia and provided ongoing information and support. As recommended by the SOMANZ guidelines published in 2015,⁷ several women commented on the effectiveness of peer support groups, and this was an intervention that could be of benefit.

There is evidence indicating women prefer information about long-term health implications resulting from hypertensive disorders of pregnancy to come from a healthcare provider supported by

standardised print and online information.¹³ In addition, information provided at time of transition from maternity care providers to the community can assist women in initiating conversations with their care providers and empower them to advocate for themselves.¹³ Although knowledge of cardiac risk among participants was higher than indicated by other research,^{14,15} in most instances, participants reported sourcing their information from the internet, suggesting there is scope for improvement in this area.

Most participants in our study were aware of their increased risk, and many also understood ways to mitigate the risk; however, only one person indicated that they had a plan in place consistent with the SOMANZ guidelines published in 2015.⁷ For participants, follow-up medical care occurred at, and was often limited to, the six-week postnatal appointment with their doctor. While this research project was nearing completion, SOMANZ released updated guidelines that recommend even more frequent blood pressure monitoring and screening for cardiovascular risk as part of the postpartum management plan following preeclampsia.¹⁶ This widening gap between what is happening in practice and what is recommended in the guidelines needs addressing.

Although there was no specific line of questioning in the interviews that introduced the concept of a debrief, several participants reported that such an intervention was beneficial. Debriefing after a traumatic birth is not a new concept, but research is limited in relation to its efficacy with this population. Debriefing has been shown to improve information clarity among recipients and, for this reason, clinicians should consider offering this intervention to women who have had preeclampsia.¹⁷

Many of the participants in our study reported a desire for continuity of care from their healthcare providers. Research has shown that continuity of care models can benefit women with complex pregnancies and improve participation in behaviour management strategies to reduce later-life cardiovascular risk.^{18,19} It is reassuring to know that the implementation of continuity of care models is gaining momentum in Australia driven by consumer demand.¹⁸ Although this will go some way to improving

antenatal and postnatal care, there remains a significant challenge around the transition from maternity services to the community.

Strength and limitations

The strengths of this study included the recruitment of women from across Australia. The semi-structured interview style allowed researchers to explore aspects of the follow-up care that had not yet been identified, such as the importance of debriefing. The participants differing characteristics, such as age, severity of preeclampsia diagnosis, time since preeclampsia, number of pregnancies, geographic area and educational diversity, widened the perspective.

Study limitations include the lack of representation of participants from rural and remote settings. In addition, because women were recruited from an advertisement on the AAPEC website, there was a possibility of selection bias. Women accessing organisations such as AAPEC might have been more engaged in learning about their condition. Given the different times from preeclampsia diagnosis (up to seven years), some women might have experienced recall bias. Recruitment was limited to English-speaking participants, and therefore the participants might not be reflective of Australia's culturally diverse population. Finally, only one participant received GP-led care; exploring the experience of more women in this model of care might have elicited different results. It is also important to note that the interpretation of results is dependent on the demographic, cultural and social context of the participants and although our results are representative of women receiving care in the Australian healthcare system, they might not be transferrable to other populations.

Conclusion

This research provides insights into our understanding of women's experiences of follow-up medical care following a diagnosis of preeclampsia in Australia. Although many women in this study had knowledge of cardiovascular risk, knowledge about recommended follow-up care was limited. Women in this study desired a more standardised approach to information provision and follow-up

care recommendations. Acknowledging the ongoing physical and emotional health impacts of preeclampsia and providing services specific to postpartum women, such as peer support groups, would be of benefit. The value of debriefing was a novel finding from the interviews and, although not well researched, is an area worth further consideration. This study has shown that although guidelines were first published in 2015,⁷ and recently updated in 2023,¹⁶ there remains a dichotomy between what is recommended in the guidelines and the reality of information provision and follow-up care for women following preeclampsia in Australia. Useful resources include the current SOMANZ guidelines¹⁶ and the AAPEC website (www.aapec.org.au).

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